

ADULTS WITH A LEARNING DISABILITY JSNA

Warwickshire Joint Strategic Needs Assessment 2025



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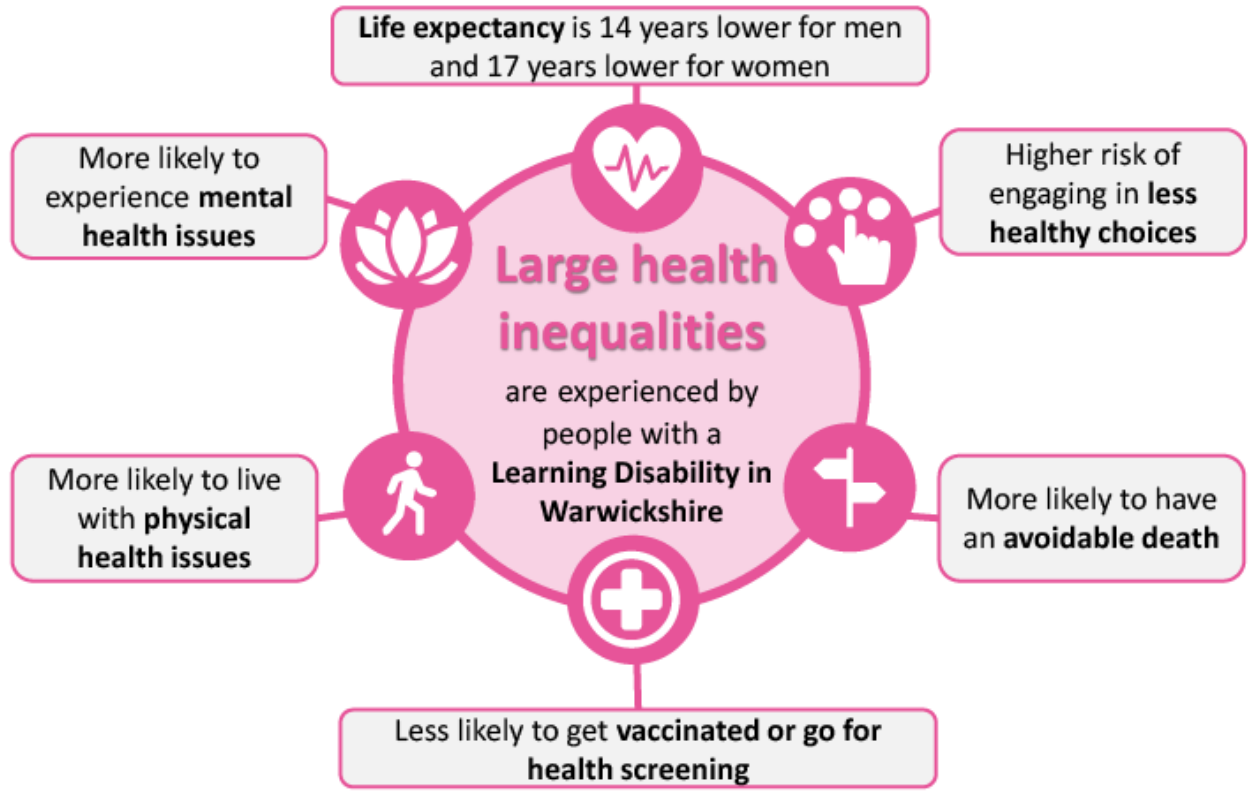
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Adults with a Learning Disability JSNA Summary



Locally, feedback has told us that people with a learning disability want:

 Support for independent living	 Improved transport options	 Access to leisure activities
 Support moving from child to adult services	 Improvements in housing and employment options	



To tackle health inequalities and better meet the needs of people with a learning disability we need to....

- **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.**

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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



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 [4 P's Reasonable Adjustments Model](#) 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 **duties** 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 **Coventry & Warwickshire Lung Health Check programme** which screens people who smoke or have ever smoked for lung cancer.
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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 **The Green Book** 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**.
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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 [Coventry and Warwickshire ICS website](#).

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.

INTRODUCTION

OVERVIEW AND SCOPE

This Joint Strategic Needs Assessment (JSNA) examines the needs of the adult population with a learning disability, aged 16 years or older, looking at the demographics of the adult population with a learning disability, their health outcomes, and how some of the wider determinants of health impact on these outcomes.

All local areas have a statutory responsibility to produce JSNAs and they fulfil a core public health purpose: to understand the current and future health and care needs of the population. This enables services to be planned and delivered in a way that best meets these needs, which ultimately improves our population's health and wellbeing and reduces health inequalities.

Since 2020, Warwickshire has produced several thematic needs assessments on a range of topic areas. More information on Warwickshire JSNAs can be found on the Warwickshire County Council website here - <https://www.warwickshire.gov.uk/joint-strategic-needs-assessments-1>.

This JSNA uses the Mencap definition of a learning disability: *“A learning disability is a reduced intellectual ability and difficult with everyday activities – for example household tasks, socialising, or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.”*¹

In line with the Mencap definition above, this JSNA does not include learning difficulties (such as dyslexia, dyscalculia, and dysgraphia), or neurodevelopmental and neurological conditions (such as attention deficit hyperactivity disorder or ADHD) in the definition of a learning disability.

Whilst there is a notable overlap between the population with a learning disability and those with autism (as demonstrated in Figure 15), it was agreed that this JSNA would focus on people with a learning disability and will not cover needs around autism.

Additionally, whilst this JSNA has a Warwickshire focus, it also includes Coventry in some data, reflecting the cross area working to support people with a learning disability.

¹ Mencap. *What is a learning disability?* <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability> [Accessed 25/11/2024]

THE VOICE OF ADULTS WITH A LEARNING DISABILITY IN WARWICKSHIRE

To ensure the voice of the population with learning disability is reflected within this JSNA an exercise was undertaken to map recent engagement work done in Warwickshire. This mapping exercise captured the following engagement:

- Getting a job and keeping it – feedback from Experts by Experience
- Direct Payments Survey Responses – April 2024
- Independence Focus Group – feedback from Experts by Experience
- Emergency situations feedback – October 2023
- Cancer screenings feedback – April 2023
- LeDeR Focus Group Feedback on ‘Did not Attend’ – February 2023
- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs: Service User and Family/Carer Engagement Update March – April 2021.
- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs: engagement summary October – December 2020
- Respite & Short Breaks Review – February 2019
- Care at Home Lot 2 – Supported Living Review – December 2018
- Complex Needs Service Review – January 2018

Engagement findings have been incorporated where they match the scope of this JSNA, and additionally a “Themes from engagement” section in the wider determinants chapter has been included to further reflect findings related to the wider determinants of health.

OPTUM PHM DATA

As part of this JSNA, we were able to access to a snapshot patient-level dataset called Optum Reporting Suite (RS). This tool forms part of our local Population Health Management (PHM) offer and is a patient-level dataset which combines data from a range of sources including primary care, secondary care, community, mental health and open sources such as the Office for National Statistics (ONS). The data covers a one-year time period from July 2022 to June 2023 and is a representative sample covering 61.5% of the Warwickshire population.

Using this tool, it is possible to draw out local insight and interpretation at a population level to compare those with a learning disability to the population without a learning disability, as well

as differences between ethnic groups and in Core20 areas (those areas that are in the top 20% most deprived areas nationally).

Without this tool, gaining this level of local insight would be significantly more challenging, and this JSNA would be more reliant on national research and evidence. The data produced from Optum RS has been sense checked against national evidence to ensure this representative sample reflects an accurate picture of need.

This JSNA includes a large 'Health of the population' chapter to utilise this new local tool. The Optum RS data used in this JSNA was accessed before October 2024. A subsequent update of the data is now available following a refresh of the tool on 1st November 2024 and therefore the figures in this needs assessment are subject to change, in line with when other data sources are updated. Unfortunately, the timeline associated with this JSNA did not allow the analysis to be updated, however it is expected that the key messages arising from the data will not change.

LEARNING FROM LIVES AND DEATHS – PEOPLE WITH LEARNING DISABILITIES AND AUTISTIC PEOPLE (LEDER)

LeDeR² is a national programme that examines the lives and deaths of people with a learning disability and autistic people. In Coventry and Warwickshire, the programme brings together partners in health and social care, with the aims to improve access, experience, and outcomes of care. Established in 2017, LeDeR works to:

- Improve care for people with a learning disability and autistic people.
- Reduce health inequalities for people with a learning disability and autistic people.
- Prevent people with a learning disability and autistic people from early deaths.

LeDeR undertake a review every time they are notified that a person with a learning disability or autism has died in Coventry and Warwickshire. Learning and best practice from these reviews is then published in an annual report to be shared across the system. Data and findings from these reports has been fed into this JSNA. Notifying that a person with a learning disability or autism has died is not a mandatory process, meaning that the data may be an under-representation of this population.

² NHS Coventry and Warwickshire. *LEDER*. <https://www.happyhealthylives.uk/integrated-care-board/resources-and-services/learning-disability-and-autism/leder/#:~:text=LeDeR%20is%20a%20national%20service,experience%20and%20outcomes%20of%20care>. [Accessed 08/08/2024]

The full LeDeR annual reports are available online on the Coventry and Warwickshire Integrated Care System (ICS) website:

https://www.happyhealthylives.uk/document-library/?keyword_search=annual+report

LOCAL POPULATION

Learning Disability (LD) Warwickshire Population Data							
Age 18+	With a LD on practice registers Source: LD health check scheme	Estimated to have a moderate or severe LD Source: PANSI		Estimated to be living with a LD Source: PANSI & POPPI			
	2,620 (March 2024)	2,289 (2024)	10.7%	2,556 (2040)	11,197 (2024)	13.0%	12,657 (2040)
	% of Population	Age	2024	2040	% Change	While numbers are similar between practice registers and those with moderate or severe LD according to PANSI, those estimated to be living with LD are around 4 times higher.	
	0.8% Nuneaton & Bedworth	18-24	269	313	14.2%		
0.5% Warwick	25-34	404	437	8.7%			
0.5% Stratford-on-Avon	35-44	464	509	7.6%			
0.4% Rugby	45-54	398	477	19.8%			
0.6% North Warwickshire	55-64	400	377	-6.7%			
	65-74	217	266	21.5%			
	75-84	103	124	18.1%			
	85+	34	54	54.3%			
All Age	With a LD (2022/23) Source: Fingertips	Increasing trend 0.5% Warwickshire		Increasing trend 0.6% England			
	With a LD (July 2022 – June 2023) Source: Optum Snapshot	8% of LD Population are from an Ethnic Minority Group					
		14% of non-LD Population are from an Ethnic Minority Group					
Children	School Population (2022/23) Source: Education Team Business Intelligence, WCC			95 pupils			
	In learning difficulty categories (moderate, severe or profound or multiple learning difficulties)			With EHCP	Year 11 (turning age 16) who were identified as having moderate, severe or profound and multiple LD (the most associated categories with LD) and an EHCP to support their needs		
	4.5% Warwickshire Schools	3,925		981			
	4.1% Primary Schools	1,936		359			
5.2% Secondary Schools	1,804		475				
	3.1% Secondary 16+	185		147			
	The proportion of Warwickshire state school pupils (Reception to Year 13) who have an EHCP for moderate, severe or profound and multiple learning difficulties has been 1.1% for the past five years.			With an LD Aged 14-17 on practice registers (March 2024) Source: Learning disabilities health check scheme		226	
Age 18-64	Estimated to have a LD Source: PANSI			Moderate		Severe	
		2024	2040	% change			
	Moderate	1,431	1,556	9.1%			
	Severe	509	557	9.4%			
Age 65+	Estimated to have a moderate or severe learning difficulties Source: PANSI			With LD		% Distribution	
	354						
	Nuneaton & Bedworth	73			20.6%		
	Warwick	79			22.3%		
	Stratford-on-Avon	99			28.0%		
	Rugby	59			16.7%		
	North Warwickshire	44			12.4%		

HOW MANY ADULTS ARE ESTIMATED TO HAVE A LEARNING DISABILITY?

There are several data sources which help provide a picture of the local population with a learning disability. Some apply a rate of learning disability to Warwickshire's population and extrapolate numbers accordingly. Additionally, people with learning disability may be registered with their GP and on the 'learning disability register' and this too provides insight into the size and characteristics of the population. The following is a summary of different sources of information about people with learning disability in Warwickshire and the different aspects of this population they are seeking to capture. It is noted that people with mild learning disability may be less 'visible' in some data sources as they may not be known to health services or adult social care.

Baseline projections published by POPPI³ and PANSI⁴ give a much larger population of people with learning disability than is accounted for in QOF data from GP practice registers. It is likely these baseline figures include people with mild learning disability who may not be known to GPs and/or other service areas and who do not feature in estimates of moderate and severe learning disability.

11,197

The number of people (Aged 18+) estimated to be living in Warwickshire with a learning disability in 2024.

Source: [PANSI](#) and [POPPI](#)

12,657

The number of people (Aged 18+) estimated to be living in Warwickshire with a learning disability in 2040.

Source: [PANSI](#) and [POPPI](#)

The projections presented in this section (sourced from POPPI and PANSI) are based on applying an age specific expected rate of learning disability in the population and applying this to population projections published by the Office for National Statistics.

³ [Projecting Older People Population Information](#) (POPPI), 2024 [accessed 30/07/2024]

⁴ [Projecting Adult Needs and Service Information](#), (PANSI), 2024 [accessed 30/07/2024]

HOW MANY ADULTS ARE REGISTERED ON THE LEARNING DISABILITY PRACTICE REGISTER?

QOF PREVALENCE

Data is available on the number of patients with learning disabilities recorded on the practice register as part of the Learning Disabilities Health Check Scheme aimed at those aged 14+.⁵

2,620

The number of people aged 18+ with a learning disability registered on practice registers in Warwickshire in March 2024

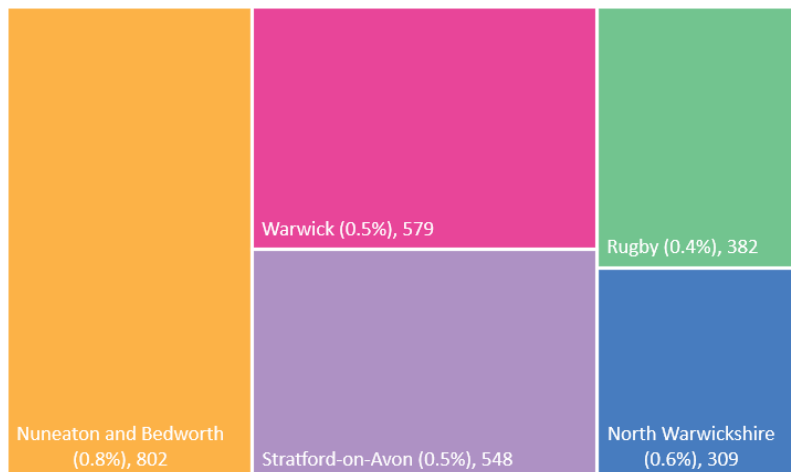
226

The number of people aged 14-17 with a learning disability registered on practice registers in Warwickshire in March 2024

Source: [Learning disabilities health check scheme](#)

Figure 1: The rate of people with a learning disability is slightly higher in Nuneaton and Bedworth.

Distribution of people with a learning disability in Warwickshire, 2024



Source: [Learning disability health check scheme, 2024](#)

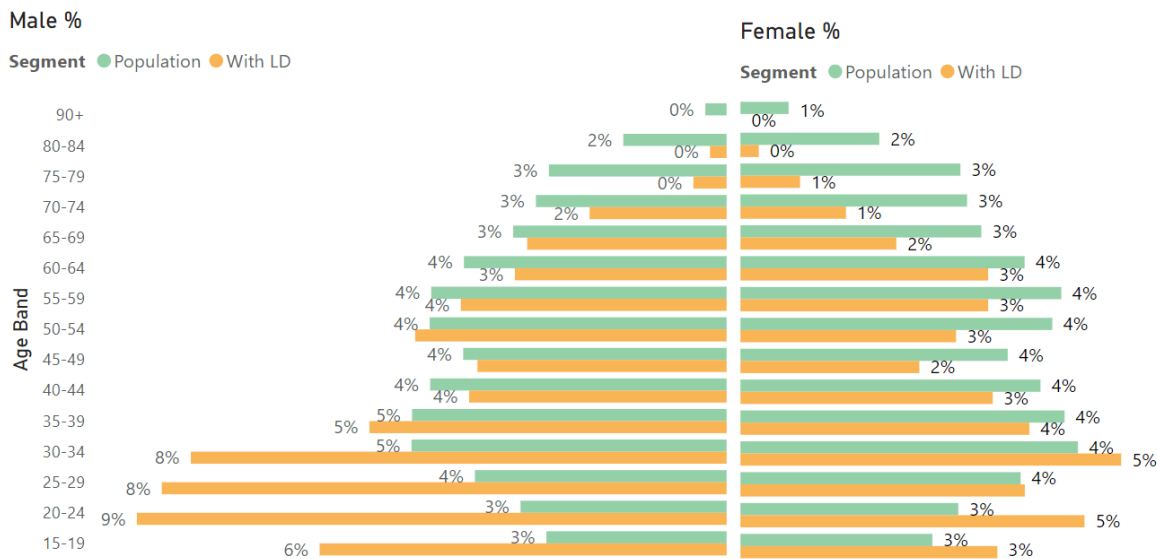
*Values for local authorities were calculated by assigning all patients of the GP to the local authority where the GP practice is located.

⁵ NHS England. *Learning Disabilities Health Check Scheme*. <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme>. [Accessed 30/07/2024]

The distribution of the population who have a learning disability by age and sex is illustrated in Figure 2.

Figure 2: The GP registered population with a learning disability had a younger age profile compared to those not living with learning disability, with males in younger age categories more highly represented.

The distribution of the population who have a learning disability by age and sex.



Source: Optum Dataset July 2022 to June 2023

RECENT TREND

In 2022/23, 0.5% of the all-age practice population in Warwickshire were recorded as having a learning disability. This compares to 0.6% for England.⁶ The recent trend (for the previous 5 years) for both Warwickshire and England is ‘increasing’, with an increase in Warwickshire from 0.4% in 2018/19 and 2019/20 to 0.5% in 2020/21 and subsequent years.

⁶ [Public health profiles, Learning disability: QOF prevalence \(all ages\)](#) [accessed 30/07/2024]

HOW MANY CHILDREN HAVE A LEARNING DISABILITY?

Current numbers of children and young people with learning disability can also give an indication of potential future need. Data from Warwickshire state schools for specific categories of Special Educational Needs or Disability (SEND) is presented in Table 1. It is emphasised that not all children and young people who have SEND needs will have a learning disability. However, several codes within this category provide a proxy or 'best-fit' for the population most likely to include learning disability. These include pupils identified as having 'moderate', 'severe', or 'profound and multiple learning difficulties'.

In 2022/23, approximately 3,925 pupils across Warwickshire primary and secondary schools were identified as having a moderate, severe, or profound and multiple learning difficulty.⁷ This equates to around 4.5% of the primary and secondary school population. Rates were slightly higher in the secondary school population (Year 7-11) at 5.2% compared to 4.1% of primary aged (Year Reception to Year 6) and 3.1% of those in Warwickshire state schools aged 16+.

Pupils in these categories had either an Education Health and Care Plan (EHCP) or received Special Educational Need support (SEN support). Children with EHCPs are likely to have greater need for support or more complex needs than those who get support as part of SEN support. Approximately, 20-25% of pupils identified as having moderate, severe, or profound and multiple learning difficulties had an EHCP in 2022/23 equating to around 980 pupils across primary and secondary year groups. Table 1 presents the estimated number of pupils who are in the SEND categories most likely to be associated with a learning disability.

⁷ Warwickshire state-school SEND data, 2024, Business Intelligence (Education Team)

Table 1: In 2022/23, around 4.5% of the total school population were identified in the SEND categories of moderate, severe, or profound and multiple learning difficulties.

Estimated number of pupils who are in the SEND categories most likely to be associated with a learning disability.

	Total	Primary	Secondary	Secondary 16+
Total in learning difficulty categories*	3,925	1,936	1,804	185
Proportion of total school population in learning difficulty categories*	4.5%	4.1%	5.2%	3.1%
No. in phase with EHCP	981	359	475	147

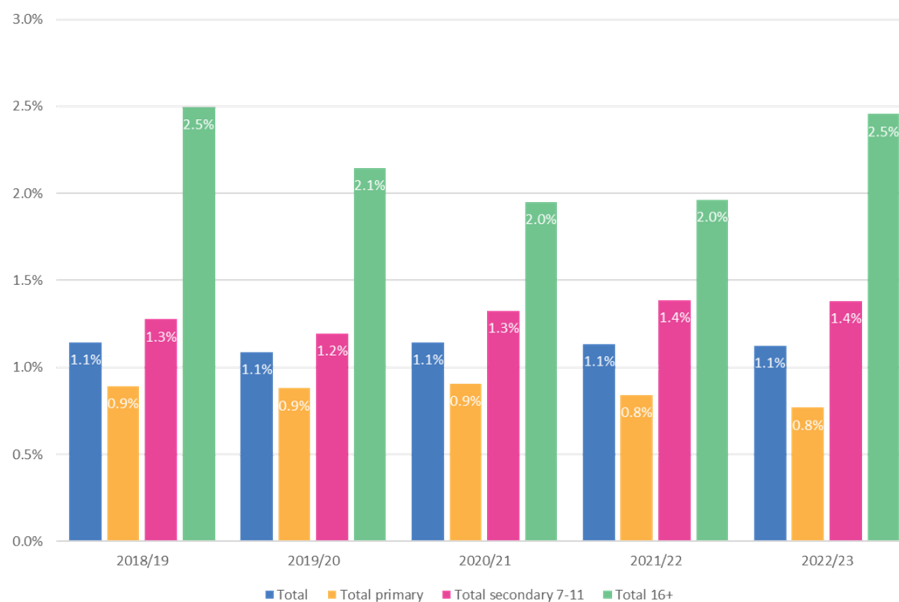
*Includes pupils identified with moderate, severe or profound and multiple learning difficulties

Source: Business Intelligence (Education Team), 2024

The proportion of pupils within these learning difficulty categories who have an EHCP has changed little over the previous five years – see Figure 3 below.

Figure 3: 1.1% of Warwickshire state school pupils have had an EHCP for moderate, severe, or profound and multiple difficulties each year over the past five years.

Proportion of pupils (reception to year 13) who have an EHCP for moderate, severe, or profound and multiple difficulties.

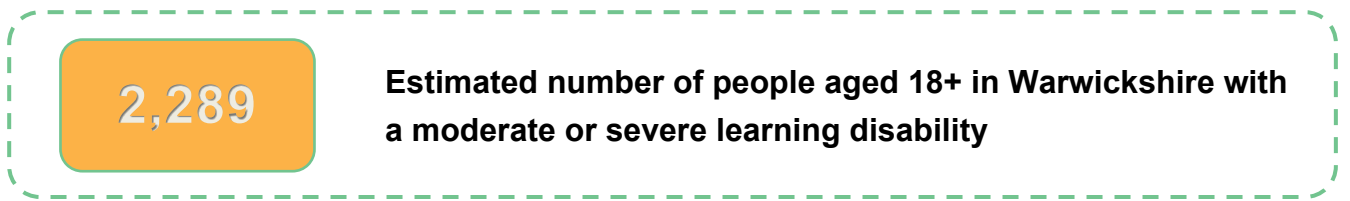


Source: Education Team, Business Intelligence, 2024

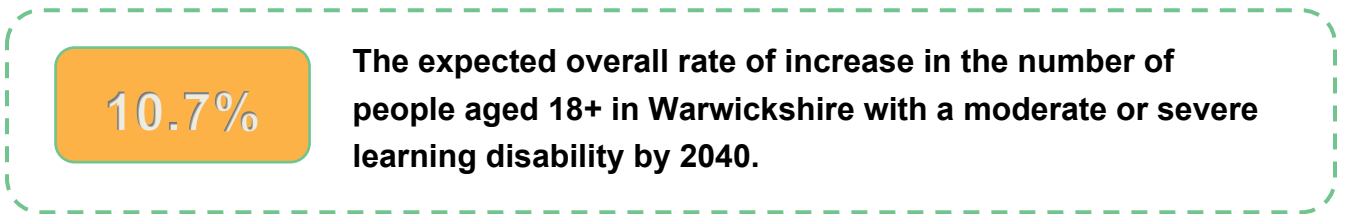
In 2022/23, there were around 95 pupils in year 11 (turning age 16) who were identified as having moderate, severe, or profound and multiple learning difficulties (the most associated categories with learning disability) and an EHCP to support their needs.⁸ This group of young people may be in need of future support as they become young adults.

HOW MANY ADULTS HAVE MODERATE AND SEVERE LEARNING DISABILITIES?

People with a moderate or severe learning disability are the most likely to be in receipt of/need support services. When aggregated, numbers for these estimates and projections are more in line with QOF estimates outlined above which are sourced from GP record data.



Source: PANSI, 2024



Source: PANSI, 2024

Table 2 presents the current and projected estimated number of people with moderate and severe learning disability by age group. In general, there are higher numbers of people with learning disability in age categories between 25 and 54 years and fewer in the age categories above this. By 2040, there is estimated to be 2,556 people with moderate or severe learning disabilities in the county.

⁸ Warwickshire state-school SEND data, Business Intelligence (Education Team)

Table 2: While the rate of increase is higher in the upper age categories, the volume of older people with learning disabilities remains lower.

Current and projected number of people with moderate and severe learning disability.

Age	No. 2024	No. 2040	% Change
18-24	269	313	14.2
25-34	404	437	8.7
35-44	464	509	7.6
45-54	398	477	19.8
55-64	400	377	-6.7
65-74	217	266	21.5
75-84	103	124	18.1
85+	34	54	54.3
Total	2,289	2,556	10.7

Source: PANSI, 2024

The above figures are derived by applying a prevalence rate to the population projections for Warwickshire. The percentage change will reflect expected changes in those age categories in the general population.

ADULTS AGED 18-64 WITH A MODERATE LEARNING DISABILITY

People with a moderate learning disability make up most (almost 75%) of all people aged 18-64 years with a moderate or severe learning disability.⁹

1,431

The estimated number of people aged 18-64 years living with a moderate learning disability in Warwickshire in 2024

Source: PANSI, 2024

⁹ Projecting Adult Needs and Service Information, 2024 [accessed 30/07/2024]

District/borough numbers broadly follow the proportion of the general population for those ages and are illustrated in the chart below.

Figure 4: Warwick District has the largest estimated number of people aged 18-64 with a moderate learning disability.

Estimated number of people aged 18-64 in Warwickshire with a moderate learning disability, 2024 by district and borough.



1,556

The projected number of people aged 18-64 living in Warwickshire with a moderate learning disability in 2040; an increase of 9.1%

Source: PANSI, 2024

ADULTS AGED 18-64 WITH A SEVERE LEARNING DISABILITY

509

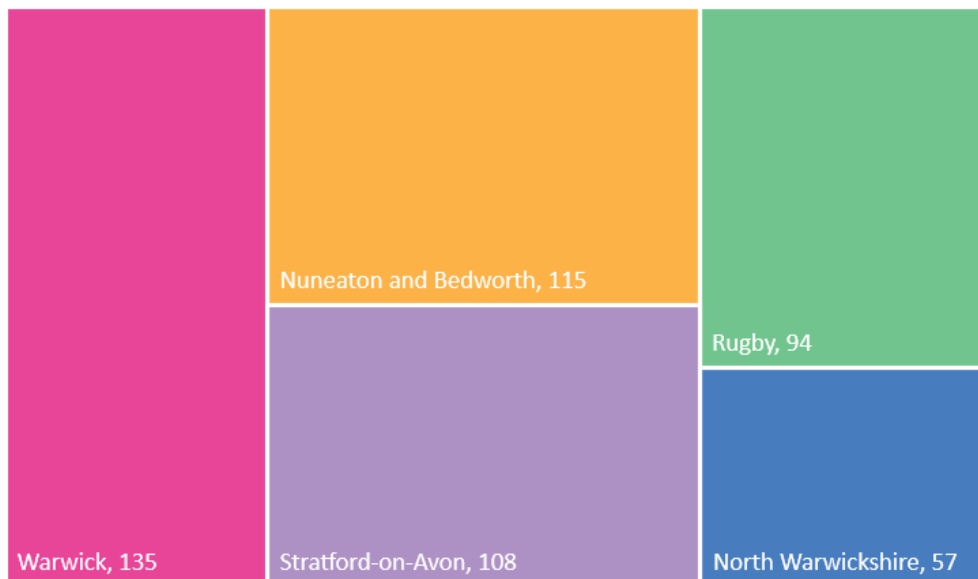
The estimated number of people aged 18-64 living in Warwickshire with a severe learning disability in 2024.

Source: PANSI, 2024

The number of people in Warwickshire aged 18-64 estimated to have a severe learning disability and therefore the most likely to either need or be in receipt of support services in 2024 is expected to rise by 9.4% by 2040 to 557 people. The current estimated distribution within the county is illustrated in Figure 5.

Figure 5: Warwick District has the largest estimated number of people aged 18-64 with a severe learning disability.

The estimated number of people aged 18-64 with a severe learning disability in districts and boroughs in Warwickshire, 2024.



Source: PANSI, 2024

PEOPLE AGED 65+ WITH A MODERATE OR SEVERE LEARNING DISABILITY

Separate figures for moderate or severe learning disability are not available for those aged 65+ but as in younger age categories, it is expected that most people would have moderate difficulties.

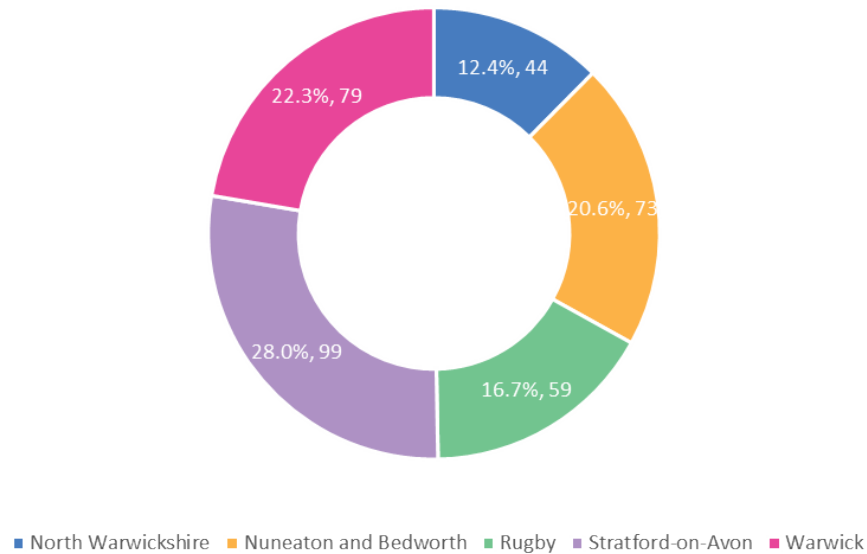
354

The estimated number of people aged 65+ living in Warwickshire with a moderate or severe learning disability in 2024.

Source: POPPI, 2024

Figure 6: Stratford-on-Avon District has the largest estimated number of people aged 65+ with a learning disability.

Estimated distribution of population aged 65+ with learning disability, 2024



Source: PANSI, 2024

HOW MANY PEOPLE FROM DIFFERENT ETHNIC GROUPS HAVE A LEARNING DISABILITY?

Analysis of the Optum dataset indicated 8% of the sample with a learning disability in Warwickshire were from an ethnic minority group. This compares to 14% of the snapshot population without a learning disability; this suggests the population of people with a learning disability registered at GP practices in Warwickshire is less diverse than the general population and that there may be general under-representation of ethnic minority groups on the GP register. A recent report published by MENCAP suggests representation on the GP learning disability register from ethnic minority backgrounds is more limited nationally and can contribute to the discrimination and inequalities in health experienced.

In the most recently published national [LeDeR report \(2022\)](#),¹⁰ it is noted that 8% of reviews to the programme were from ethnic minority backgrounds suggesting under-representation from

¹⁰ [2022 LeDeR report into the avoidable deaths of people with learning disabilities](#), Kings College London, November 2023 [Accessed 30/07/2024]

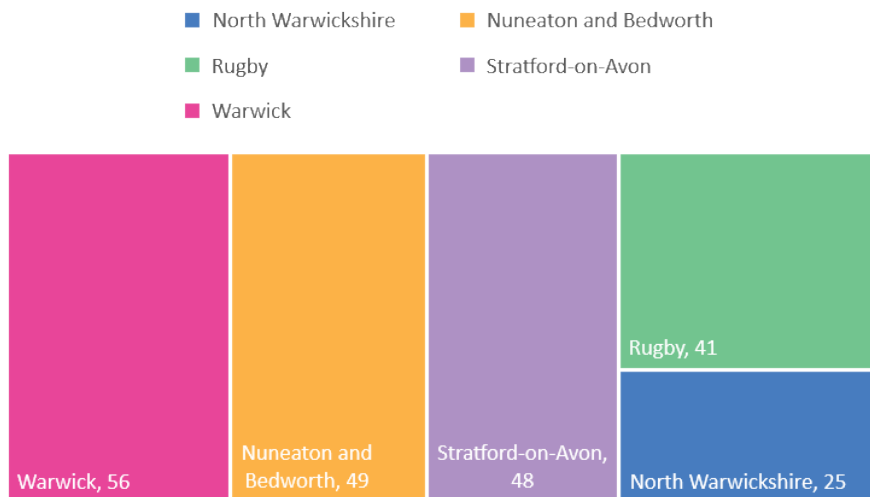
ethnic minority groups with a learning disability as part of this process. This under-representation was acknowledged in the most recent NHS Coventry and Warwickshire LeDeR (2023-24) report and work has been undertaken to promote the programme among ethnic minority groups. Further analysis by the LeDeR programme nationally suggests ethnicity was strongly associated with age at death with those from black, black British, Caribbean or African and Asian British at greater risk of earlier death compared to those who were white.¹¹

HOW MANY PEOPLE HAVE DOWN SYNDROME?

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.¹² In 2024, in Warwickshire the number of people with Down Syndrome aged 18+ was estimated to be 219. By 2040 this is expected to rise to 234 (6.8%).

Figure 7: The distribution of people with Down syndrome reflects the distribution of the general population with smaller numbers in North Warwickshire and a higher number in Warwick District.

Estimated number of people with Down syndrome by District and Boroughs.



Source: PANSI, 2024

¹¹ [Learning from Lives and Deaths](#) – Kings College London, 2023, [Accessed 30/07/2024]

¹² Mencap. *Down syndrome*. <https://www.mencap.org.uk/learning-disability-explained/learning-disability-and-conditions/down-syndrome> [Accessed 20th August 2024]

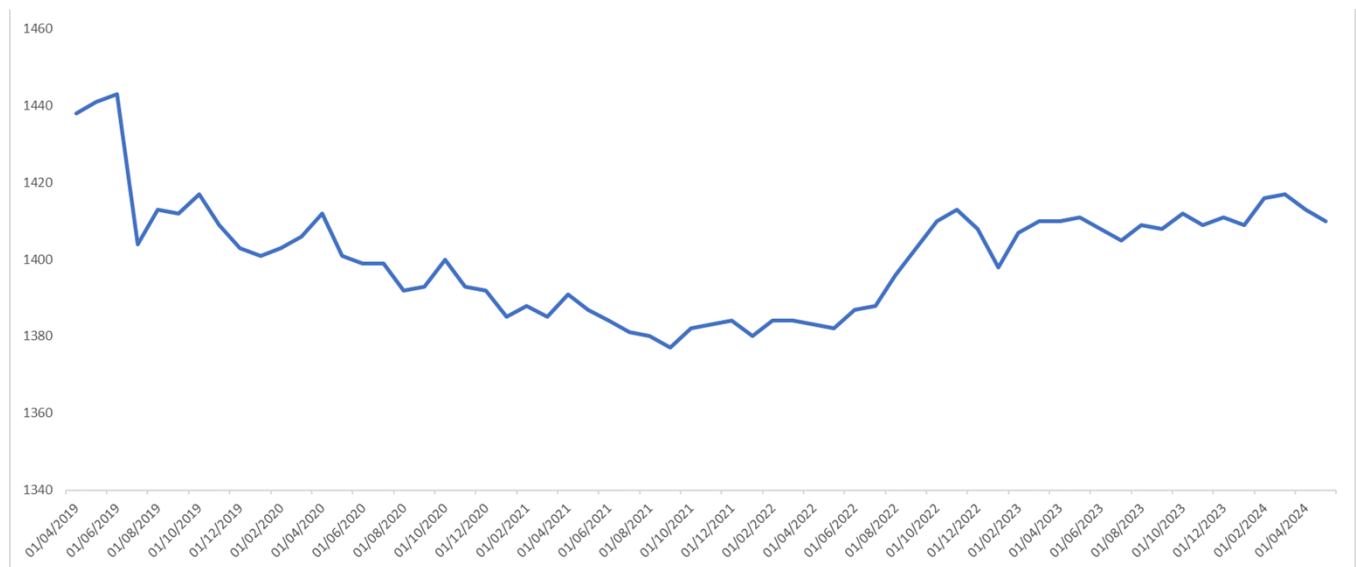
HOW MANY ADULTS WITH A LEARNING DISABILITY ARE OPEN TO SOCIAL CARE?

In April 2024 there were 1,412 adults with a learning disability receiving support from social care. The following information shows people with a primary support reason of 'support for learning disability (LD)' receiving support from Warwickshire County Council commissioned services. It should be noted that the term 'LD Service Users' refers to individuals with a Warwickshire County Council commissioned service who have a primary support reason of 'support for learning disability'. This is not the same as people receiving services from the learning disability budget or receiving services from the learning disability specific providers, which have different definitions.

Figure 8 shows the number of learning disability service users who have been active since April 2019 on a snapshot date. There is a slight decrease in active service users between April 2019 and October 2021, following which there is a slight increase to the latest snapshot in April 2024.

Figure 8: There is a slight decrease in active service users between April 2019 and October 2021, following which there is a slight increase to the latest snapshot in April 2024.

Number of LD Services Users active on snapshot dates since April 2019.

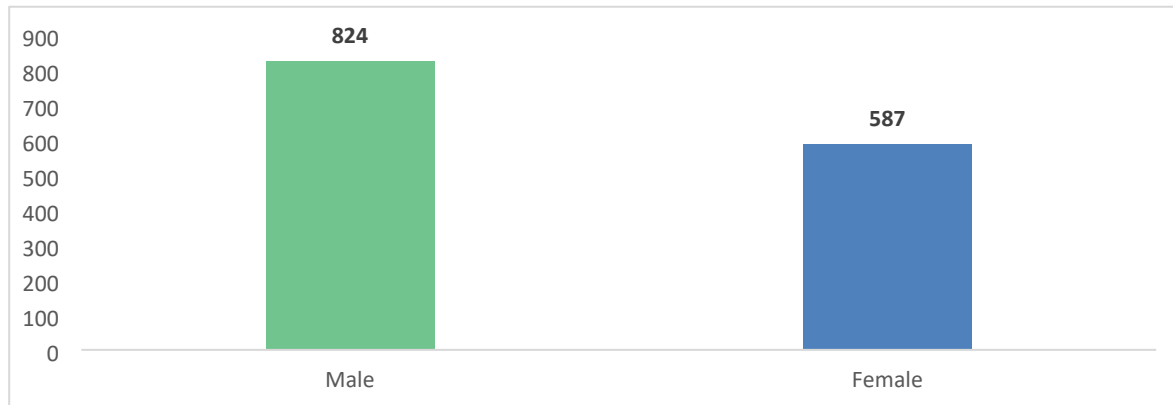


Source: Business Intelligence, Adult Social Care

Figure 9 shows the gender breakdown of learning-disabled service users as of 15th April 2024. 58% of service users were male (824 people) and 42% were female (587 people).

Figure 9: There are more males who are accessing learning-disabled services than females.

Number of learning-disabled service users by gender (15/04/2024)

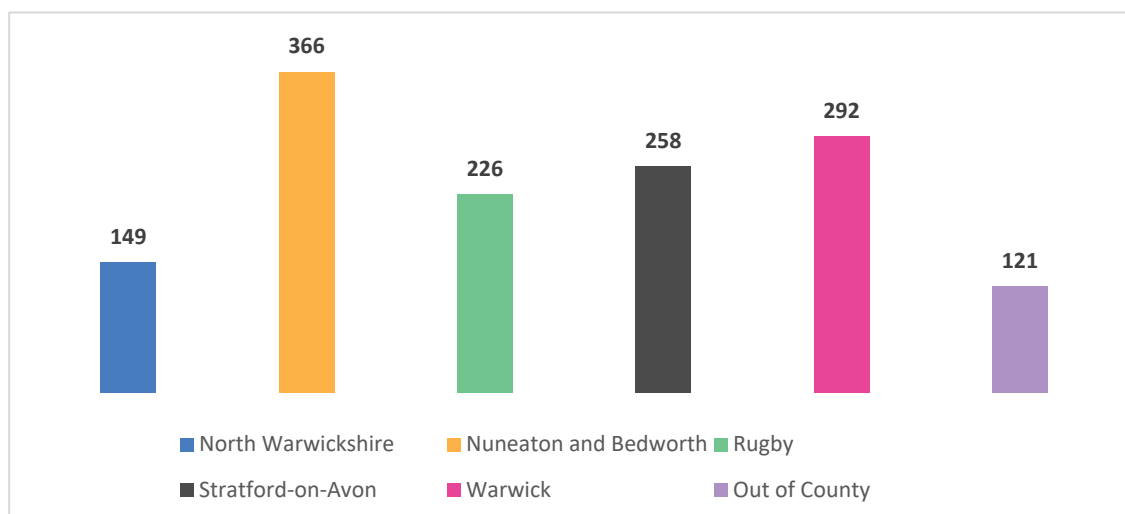


Source: Business Intelligence, Adult Social Care

Figure 10 shows the number of learning-disabled service users by District and Borough. Nuneaton & Bedworth has the highest number of service users.

Figure 10: The number of LD service users varies across district and boroughs, with Nuneaton and Bedworth having the largest number (366) and North Warwickshire having the smallest number (149).

Number of learning-disabled service users by district and borough (15/04/2024)

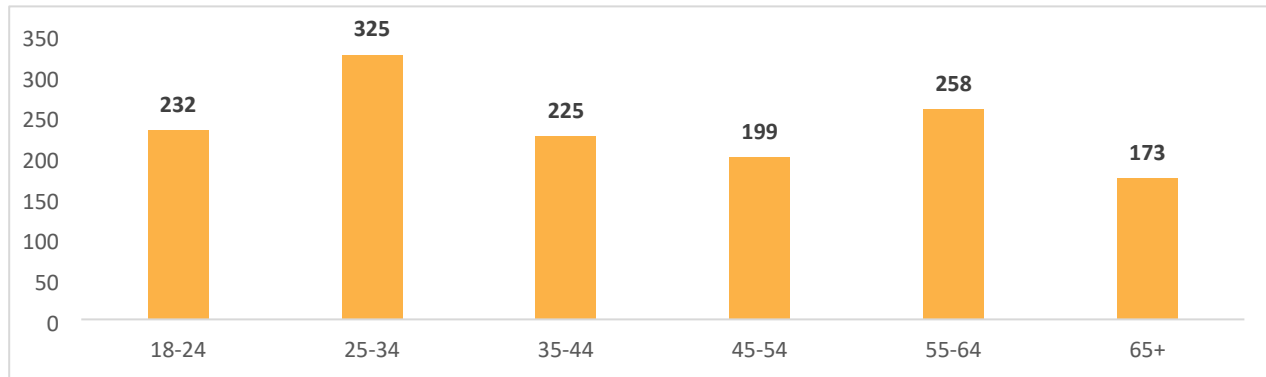


Source: Business Intelligence, Adult Social Care

Figure 11 shows the number of learning-disabled service users by age group. The highest number is in the 25-34 year-old age category, with the lowest in the 65+ age group.

Figure 11: The 25-34 age category has the highest number of service users, with the lowest number in the 65+ age category.

Number of LD Service Users by Age Group

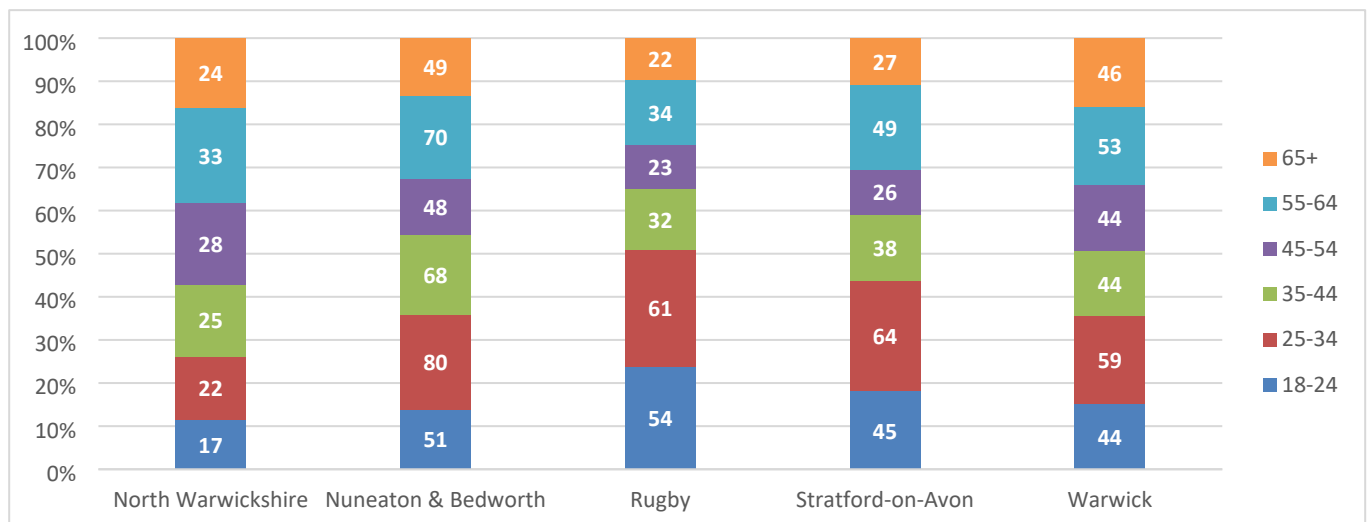


Source: Business Intelligence, Adult Social Care

Figure 12 shows the number of learning-disabled service users by age group and district and borough. Most district and boroughs follow the overall age trend for the county, although North Warwickshire has a smaller proportion in the 25-34 year-old age category.

Figure 12: Most district and boroughs have a similar age trend for LD service users, although North Warwickshire has a smaller proportion of 25-34 year-olds.

Number of LD Service Users by Age Group and District & Borough (15/04/2024)

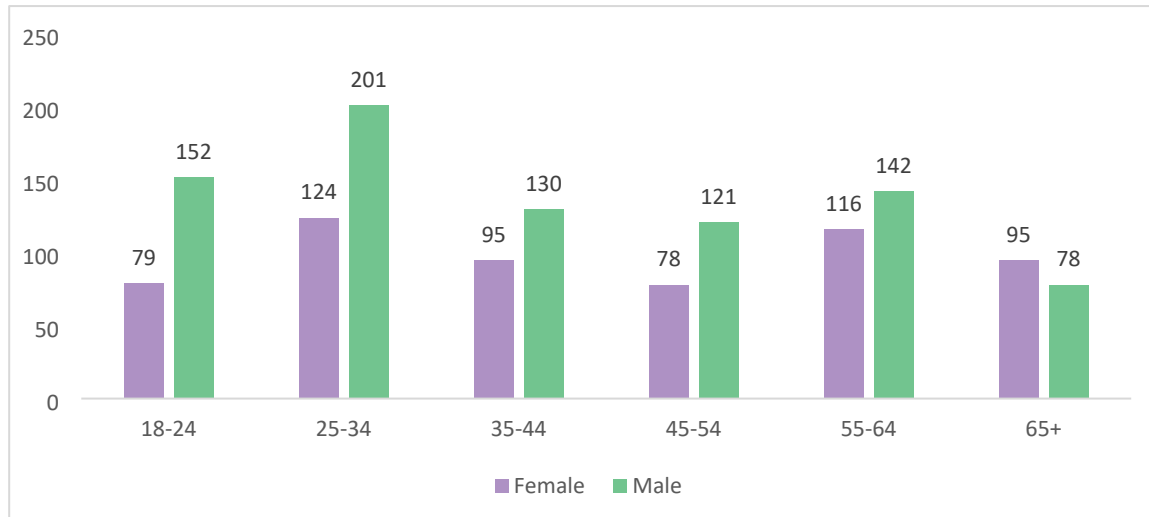


Source: Business Intelligence, Adult Social Care

Figure 13 shows the number of learning-disabled service users by age group and gender. In all age groups there were more males than females, except for the 65+ age group which had more females. This is reflective of Figure 2 which shows a disproportionately high proportion of young males with a learning disability.

Figure 13: There are more males than females in all age groups except those aged 65+.

Number of current LD Service users by age group and gender (15/04/2024)



Source: Business Intelligence, Adult Social Care

Table 3 shows the number of learning-disabled service users by ethnicity. The majority of service users are English/Welsh/Scottish/Northern Irish/British.

Table 3: The majority of service users are English/Welsh/Scottish/Northern Irish/British.

Number of current LD Service users by ethnicity

Ethnicity	Number of current LD service users
English/Welsh/Scottish/Northern Irish/British	1,312
Indian	21
Undeclared/Not known	14
Any other White background	12

Any other Asian background	10
Any other ethnic group	10
White and Asian	*
White and Black Caribbean	*
Any other mixed/multiple ethnic background	*
African	*
Pakistani	*
Any other Black/African/Caribbean background	*
Chinese	*
Irish	*
Caribbean	*
Gypsy or Irish Traveller	*
White and Black African	*
Total	1,412

Source: Business Intelligence, Adult Social Care

*suppressed due to small numbers

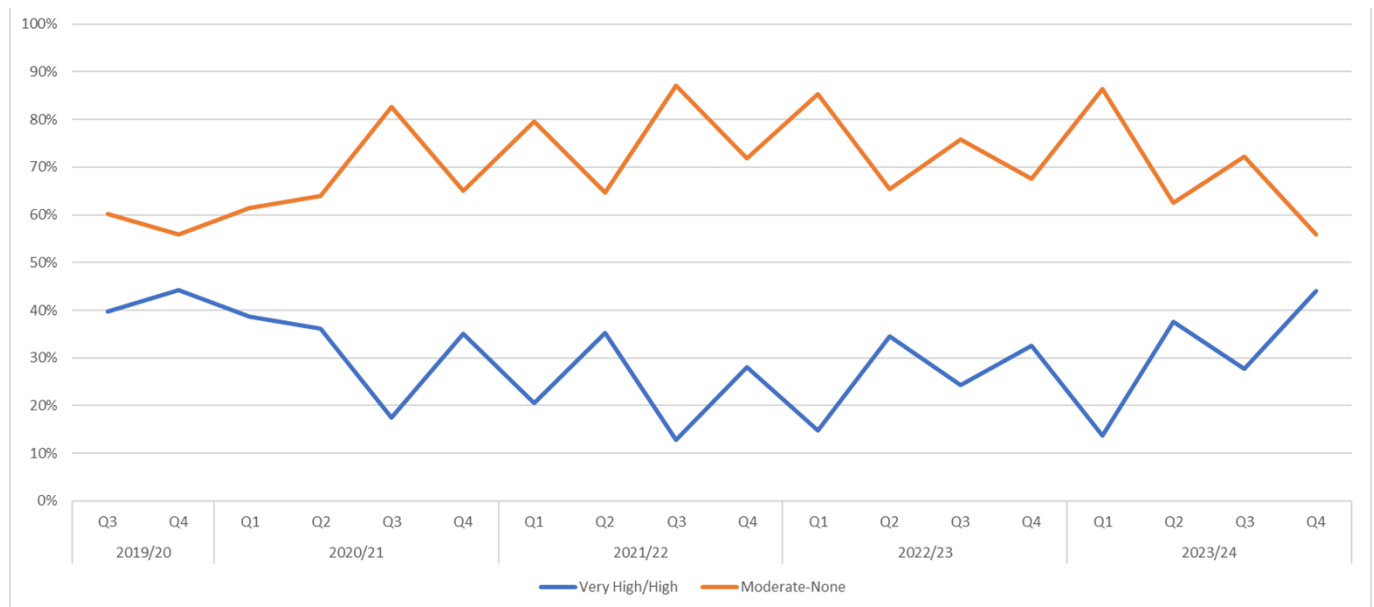
There is no clear trend suggesting that a greater proportion of people with a learning disability accessing social care services have a higher or lower level of need. There is no proxy for complexity of a service user's need on Mosaic. Cost and hours can be used as a rough indication but several other factors (financial assessments, care refused, etc) impact this and affects the reliability as a proxy for need. The current version of the My Assessment form (introduced in September 2019) includes two fields which identify the service user's client group/support reason and their level of need on a scale of A-F, according to practitioner judgement during the assessment:

- A. Very high
- B. High
- C. Moderate
- D. Low
- E. Very low
- F. No support need

Figure 14 shows the percentage of My Assessment Forms for people with a learning disability only who fall into categories A & B (very high or high need) compared to categories C – F (moderate, low, very low, or no support need) over time. Whilst there is fluctuation between each quarter, there is no clear trend suggesting that a greater proportion of these assessments show a higher or lower level of need.

Figure 14: Whilst there is fluctuation between each quarter, there is no clear trend suggesting that a greater proportion of these assessments show a higher or lower level of need.

Percentage of My Assessment Forms (LD only) by level of need over time (quarters)



Source: Business Intelligence, Adult Social Care

HEALTH OF THE POPULATION

OVERVIEW OF HEALTH CONDITIONS

People with a learning disability have a higher prevalence of health conditions than those without a learning disability and are more likely to experience multiple health conditions.¹³ Table 4 gives an overview of the prevalence of some health conditions in the Warwickshire population with a learning disability, some of which are explored in more detail later in this chapter.

Table 4: People with a learning disability have a higher prevalence of a range of health conditions compared to those without a learning disability.

Prevalence of conditions in people with a Learning Disability across Warwickshire

	Warwickshire population with LD	Warwickshire North population with LD	Rugby population with LD	Warwickshire South population with LD	Warwickshire Population (for comparison)
Anxiety	24%	27%	21%	23%	18%
Asthma	15%	15%	13%	16%	10%
Depression	16%	22%	12%	14%	15%
Diabetes	9%	9%	7%	10%	6%
Heart Failure	2%	2%	1%	2%	1%
Housebound	6%	11%	5%	3%	1%
Hypertension	11%	12%	8%	13%	17%
Obesity	35%	37%	33%	34%	17%
Serious Mental Illness	6%	6%	5%	5%	1%
Smoker	19%	22%	15%	21%	10%
Smoking Cessation	37%	32%	34%	45%	35%
Social Vulnerability*	39%	42%	30%	45%	2%

Source: Optum

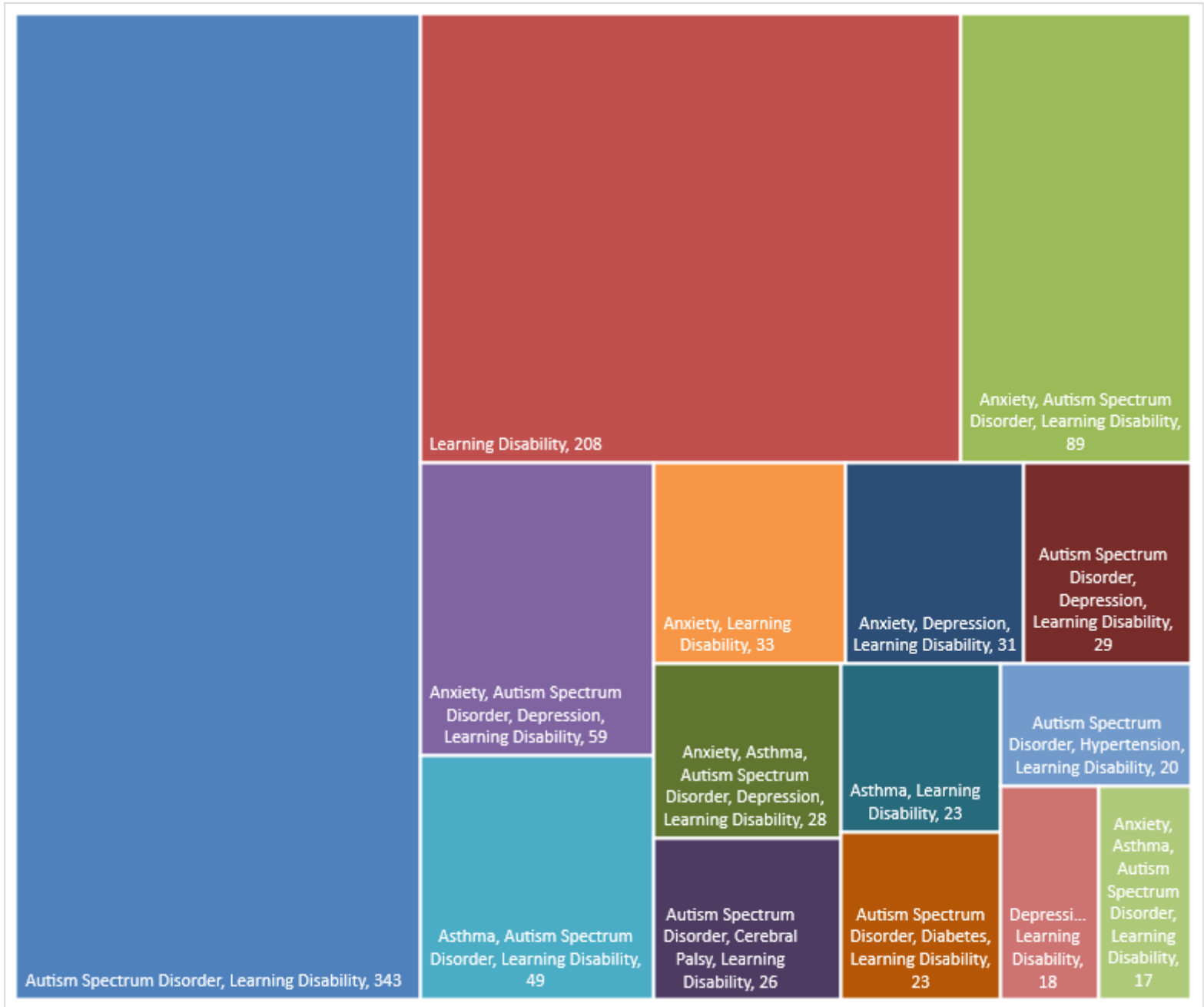
*Social vulnerability is an indicator used by the electronic frailty index to help identify people with frailty. If an individual registers as having one of seven codes they are considered to be socially vulnerable. These codes include being widowed, vulnerable elderly person, housing problems, lives alone (no help available), social isolation, death of partner, and does not speak English. More information on the eFI can be found here - <https://ihub.scot/media/6442/20190705-efi-read-codes-guide-v10.pdf>.

¹³ Optum dataset, July 2022-June 2023

As the population with a learning disability are more likely to experience multiple health conditions, it is probable that there will be people represented multiple times in the table above. Figure 15 shows the most frequent combination of conditions for those with a learning disability in Warwickshire.

Figure 15: There is a significant overlap between those with a learning disability and those with autism spectrum disorder.

Largest combination of conditions for those with a Learning Disability in Warwickshire



Source: Optum dataset

OVERVIEW OF HEALTH CONDITIONS FOR PEOPLE WITH DOWN SYNDROME

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.¹⁴ People with Down syndrome can have poorer health outcomes compared to the learning disability population, as well as the population without these conditions¹⁵. The median life expectancy in the UK for someone with Down syndrome is 58 years¹⁶, however people with Down syndrome can lead active, healthy, and independent lives into their 60s, 70s, and beyond¹⁷.

The “Multiple morbidity across the lifespan in people with Down syndrome or intellectual disabilities: a population-based cohort study using electronic health records” study¹⁸ explored the pattern of morbidities throughout the lifespan of people with Down syndrome, comparing these to people with other intellectual disabilities and the general population. Electronic health-record data from the UK Clinical Practice Research Datalink from 1st January 1990 to 29th June 2020 was used including 10,204 people with Down syndrome, 39,814 people from the general population, and 69,150 people with intellectual disabilities.

Figure 16 shows the incidence rate ratio between people with Down syndrome and the general population. The findings highlight that:

- Some conditions had a higher incidence in people with Down syndrome, most notably dementia which was nearly 95 times as high in the Down syndrome population compared to the general population.

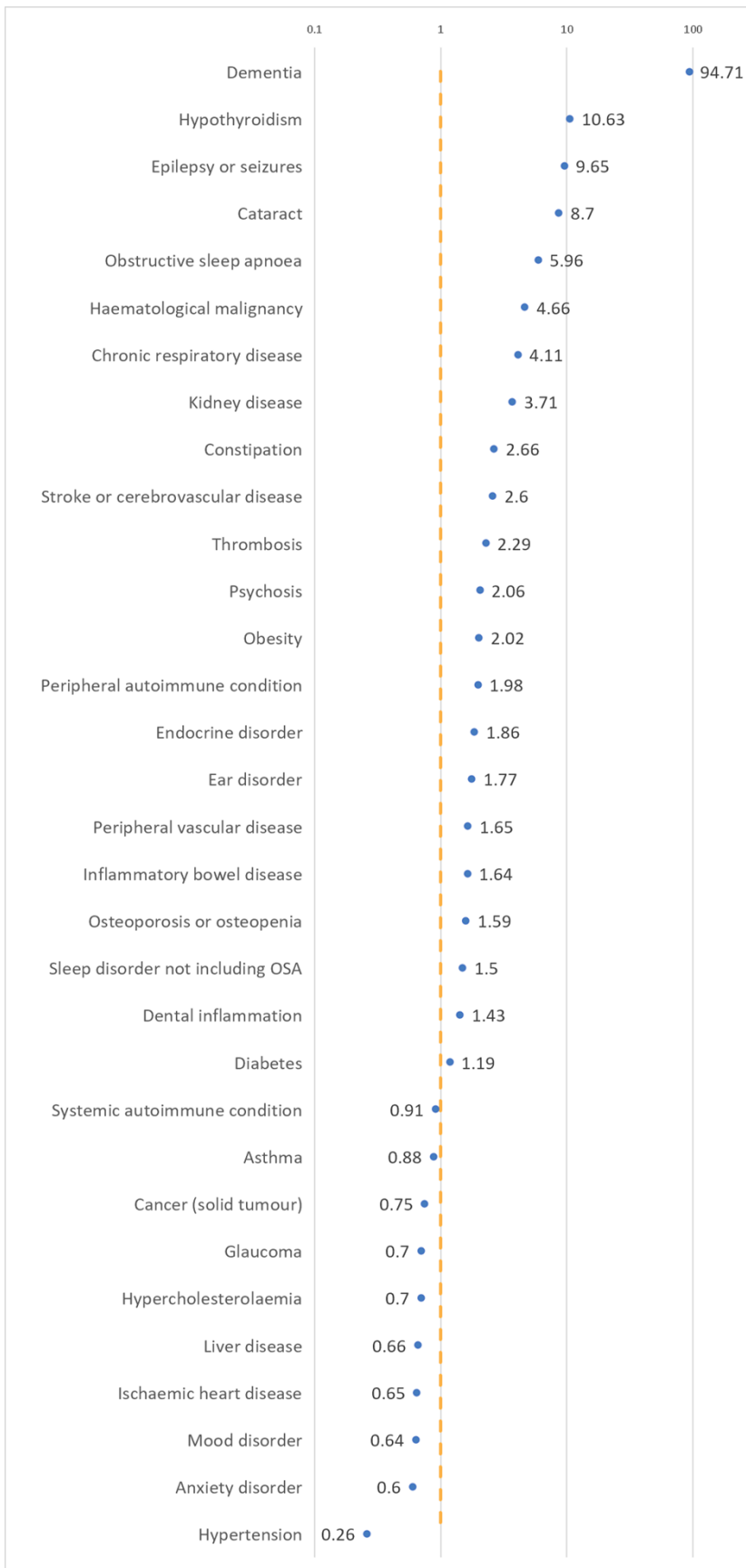
¹⁴ Mencap. *Down syndrome*. <https://www.mencap.org.uk/learning-disability-explained/learning-disability-and-conditions/down-syndrome> [Accessed 20th August 2024]

¹⁵ Department of Health & Social Care. *Down Syndrome Act 2022 guidance: call for evidence*. <https://www.gov.uk/government/calls-for-evidence/down-syndrome-act-2022-guidance-call-for-evidence/down-syndrome-act-2022-guidance-call-for-evidence> [Accessed 20th August 2024]

¹⁶ The Down Syndrome Medical Interest Group. *Demography*. <https://www.dsmig.org.uk/information-resources/by-topic/demography/> [Accessed 21st August 2024]

¹⁷ NHS Inform. *Down's syndrome*. <https://www.nhsinform.scot/illnesses-and-conditions/downs-syndrome/#:~:text=It's%20also%20known%20as%20Trisomy,any%20additional%20help%20and%20support.> [Accessed 21st August 2024]

¹⁸ R Asaad Baksh, Sarah E Pape, Li F Chan, Aisha A Aslam, Martin C Gulliford, Andre Strydom. Multiple morbidity across the lifespan in people with Down syndrome or intellectual disabilities: a population-based cohort study using electronic health records. *The Lancet*. 2023. e453-62. <https://www.thelancet.com/action/showPdf?pii=S2468-2667%2823%2900057-9> (accessed 20th August 2024)



- Some conditions were significantly less common in people with Down syndrome compared to the general population, particularly hypertension. Others that are less common include asthma, cancer, glaucoma, hypercholesterolaemia, liver disease, and mental health disorders (mood disorder and anxiety disorder).

Figure 16: People with Down syndrome experienced a higher incidence of some health conditions compared to the general population, most notably dementia. However, some conditions had a lower incidence, particularly hypertension. Incidence rate ratio* between people with Down syndrome and the general population.

Source: UK Clinical Practice Research Datalink

*An incidence rate ratio (IRR) compares the incidence (rate at which new cases or events occur over a specified time period) of conditions for two populations. When the IRR is 1, that means there is no difference between the populations. If the IRR is greater than 1, that means there is a higher incidence in the specified population.

Figure 17 shows the incidence rate ratio between people with Down

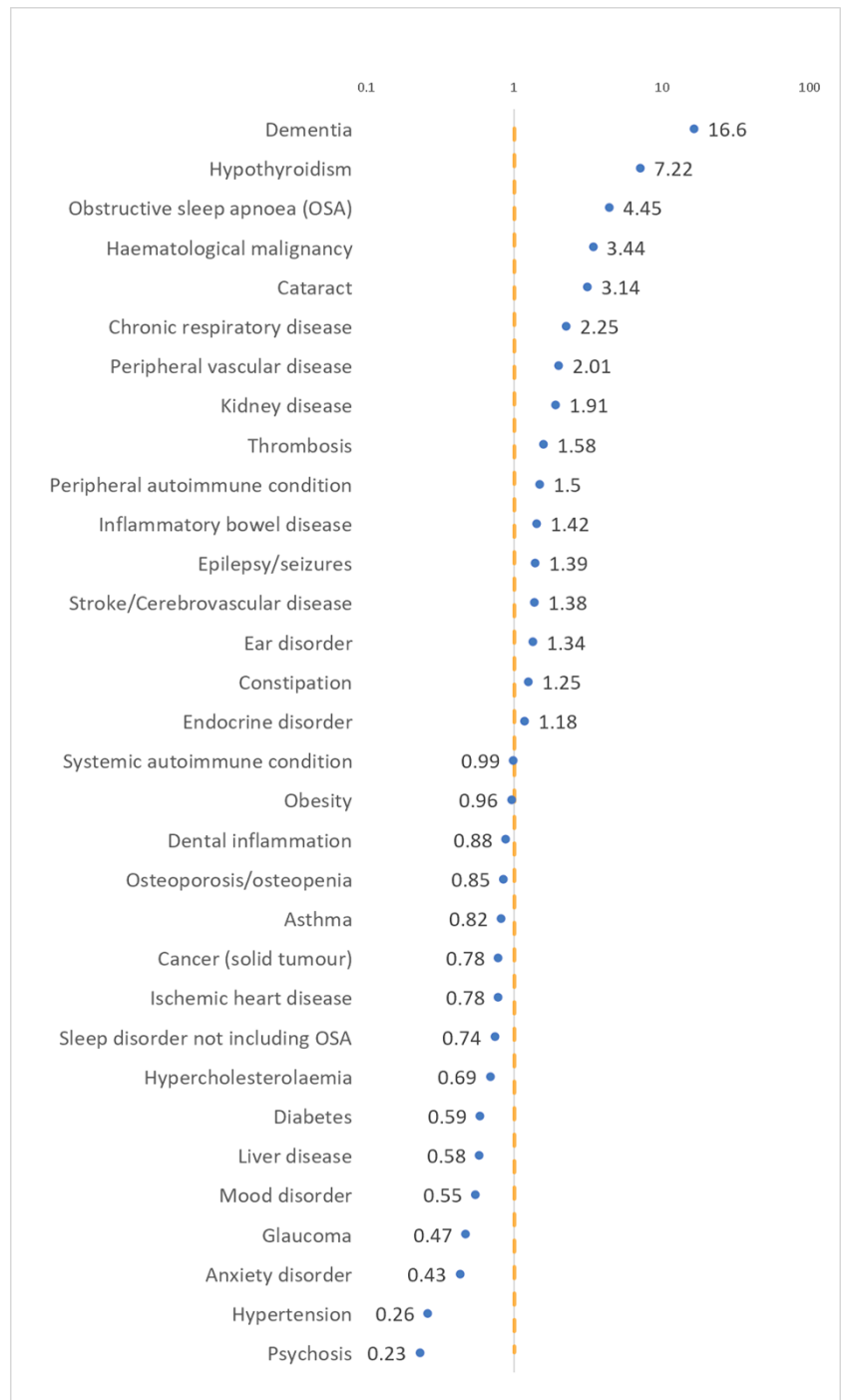
syndrome and people with other intellectual difficulties. The findings highlight that:

- Some conditions had a higher incidence in people with Down syndrome compared to people with an intellectual difficulty, most notably dementia (16.6 times higher) and hypothyroidism (7.22 times higher).
- Some conditions had a lower incidence in people with Down syndrome compared to people with an intellectual difficulty, most notably hypertension and psychosis.

Figure 17: People with Down syndrome experienced a higher incidence of some health conditions compared to people with other intellectual disabilities, most notably dementia and hypothyroidism. Some conditions had a lower incidence, particularly hypertension and psychosis.

Incidence rate ratio between people with Down syndrome and the people with other intellectual disabilities.

Source: UK Clinical Practice Research Datalink



The study also found that the incidence of cataracts, obesity, osteoporosis or osteopenia, kidney disease, and diabetes began to increase at earlier ages than in the intellectual disabilities and the population not living with these.

ANNUAL HEALTH CHECKS (AHCS)

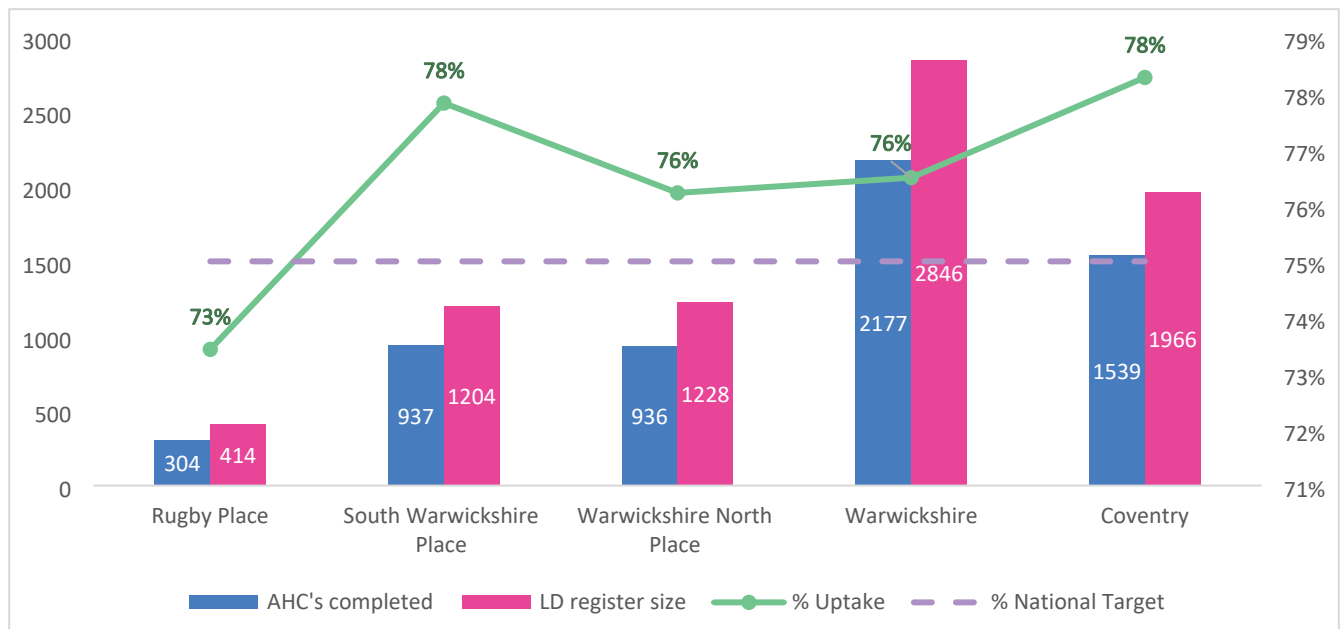
Annual Health Checks (AHCs) are available to people aged 14 and over with a learning disability who are on their GP practice's learning disability register. Annual health checks can help those with a learning disability stay well and help to mitigate against health inequalities experienced by this population.

Annual health checks are conversations with a doctor or a nurse about an individual's health to help find health concerns early. The individual doesn't need to be ill to have a health check, but are an important opportunity to ask about health, share any concerns, and talk about treatment or medication.

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% (Figure 18). This can then be broken down into two age band, 14-17 year-olds (Figure 19) and 18 years and over (Figure 20).

Figure 18: In 2023/24 Warwickshire was in line with the national target of 75%. There is slight variation across Places, with Rugby Place slightly lower than the Warwickshire average at 73% and South Warwickshire Place slightly higher at 78%.

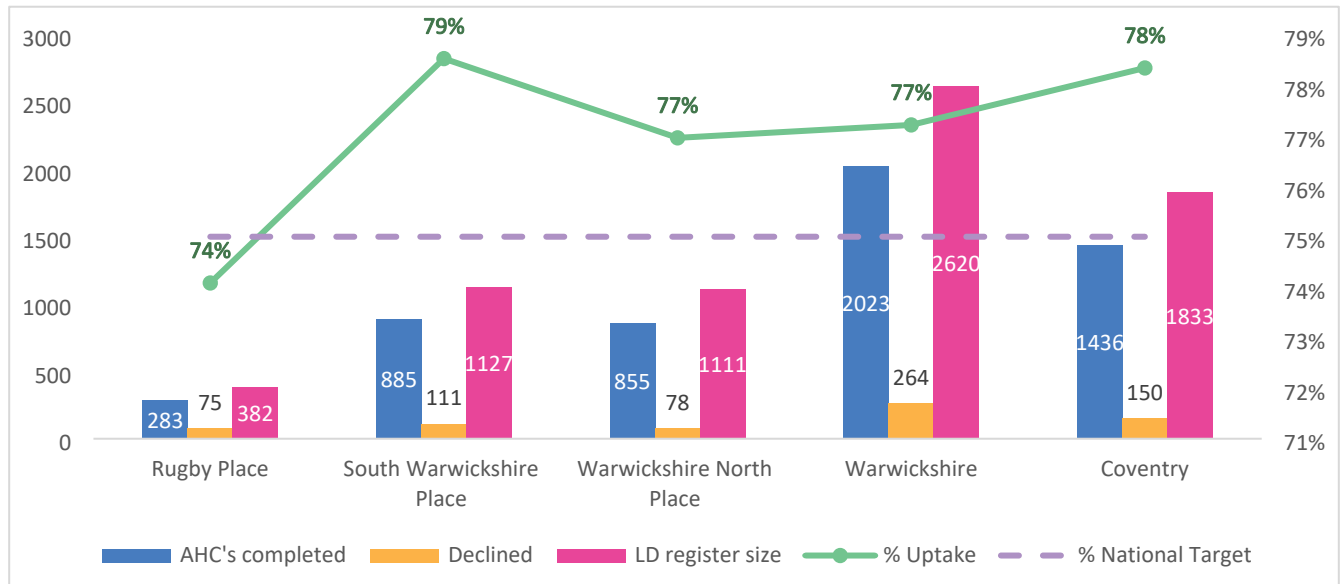
AHC uptake in people with a learning disability aged 14 and over, April 2023 – March 2024



Source: [\[MI\] Learning Disabilities Health Check Scheme, March 2024 - NHS England Digital](#)

Figure 19: The uptake of AHCs in Warwickshire for those aged 18+ was 77%, with some variation across Places.

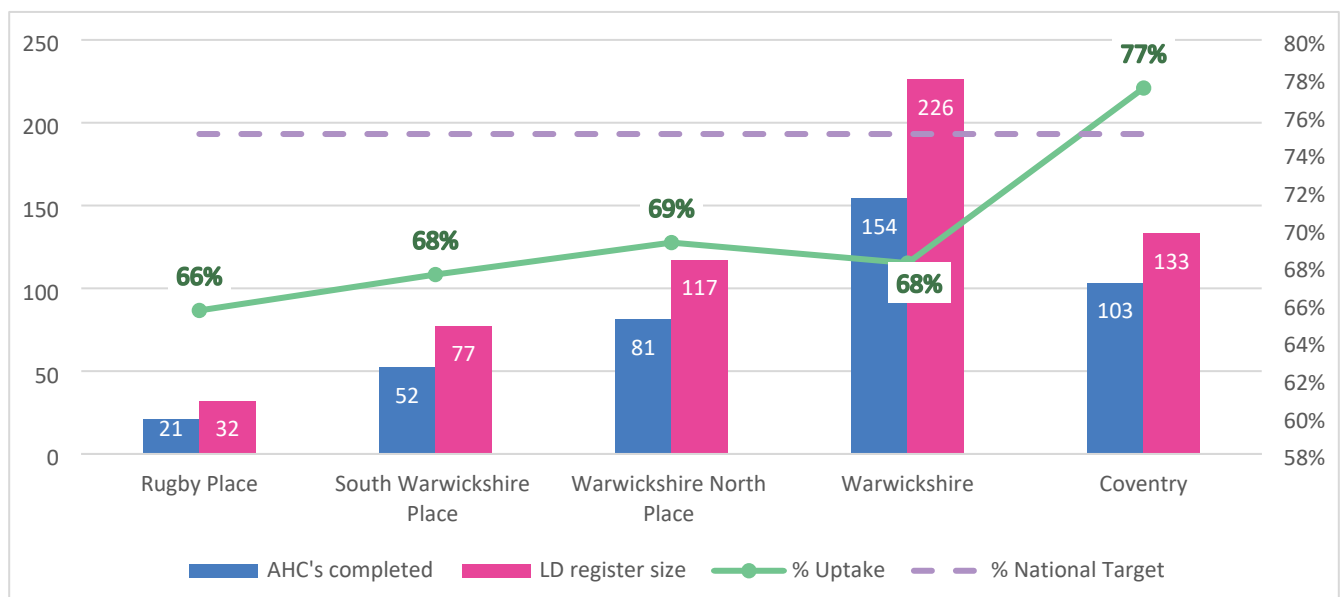
AHC uptake in people with a learning disability aged 18+, April 2023 – March 2024



Source: [\[MI\] Learning Disabilities Health Check Scheme, March 2024 - NHS England Digital](#)

Figure 20: AHC uptake for 14-17 year olds is lower than for the 18+ age group, with Warwickshire achieving a 68% uptake compared to 77% for those aged 18+.

AHC uptake in 14-17 years old's with a learning disability, April 2023 – March 2024

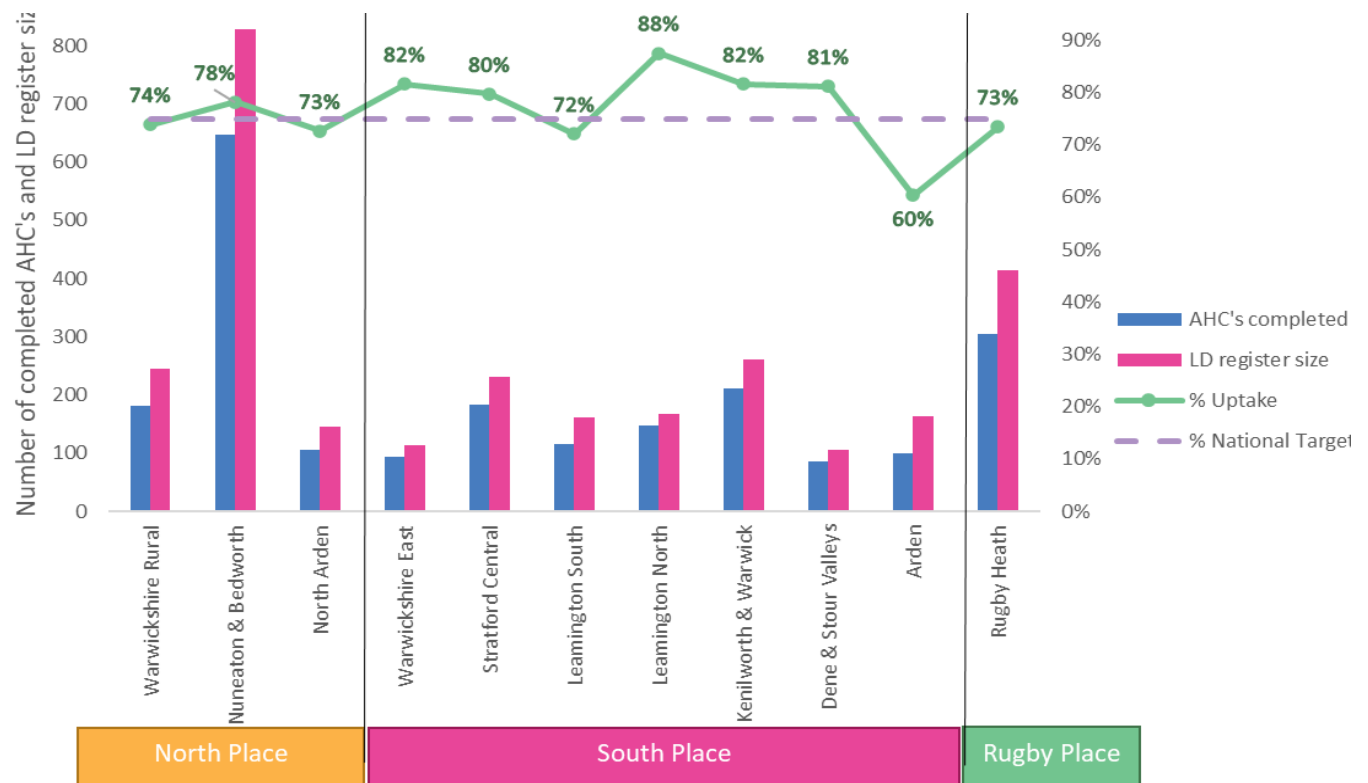


Source: [\[MI\] Learning Disabilities Health Check Scheme, March 2024 - NHS England Digital](#)

Uptake in AHCs can also be seen at PCN level (Figure 21). Some variation can be seen across Places in PCNs, particularly in South Place which has the highest uptake in Leamington North (88%) and the lowest uptake in Arden (60%). It should be noted however, that in 2022-23 Arden PCN had an 82% uptake, and delivered nearly the same number of health checks as in 2023/24 (101 in 2022/23, 99 in 2023/24). This percentage point decrease is therefore likely due to an increase in the number of people on the learning disabilities register in that area.

Figure 21: There is variation within Places in PCN uptake across Warwickshire in 2023/24.

AHC uptake in people with a learning disability by PCN aged 14 and over, April 2023 – March 2024



Source: [\[MI\] Learning Disabilities Health Check Scheme, March 2024 - NHS England Digital](#)

In 2023/24 a learning disability annual health check quality and under-served population project was undertaken in Coventry and Warwickshire. This project reviewed the quality of annual health checks from a sample population and engaged with people who didn't have annual health check to understand why AHCs aren't being taken up.

When looking at the quality of annual health checks from a sample population of 32 the project found that:

- 25% had not received a pre-health check questionnaire.
- In 97% of AHC's there was no discussion about a hospital passport.
- Despite all the AHC's saying that a Health Action Plan (HAP) had been provided, there was only evidence of an HAP in 50% of reviews.

Of the 32 AHCs that were evaluated, feedback was obtained on people's experiences for 22 checks. The feedback was provided either by the person who received the AHC, a family carer, or a care home staff member. This feedback found that:

- 41% said they did not receive a Health Action Plan, with 14% saying they don't remember. This supports the above finding that 50% of reviews had no evidence of an HAP.
- Building trusted relationships was important for the experience, particularly having the same GP and friendly staff.
- Good communication and listening skills were important for the experience, ensuring they feel listened to and supported.
- Reasonable adjustments add value to the AHC.
- When the AHC took place via telephone individuals felt rushed and forgot it took place.
- Lack of explanation and follow-up took away from the experience of the AHC, for example being told they are overweight and then not being given advice on weight management.

Key themes of positive practice and key themes of improvements required, and areas of concern were identified in the review. These are summarised in the table below.

Key themes of positive practice	Key themes of improvements required and areas of concern
Excellent use of reasonable adjustments	AHC delivery method, with patients not recalling that they had received an AHC if it had occurred via telephone.
AHC leading to further investigations being initiated	Incomplete recording, particularly relating to ethnicity and reasonable adjustments.
Reduced need for return appointments, with some medical intervention happening during the AHC such as administering a vaccine.	Missed opportunities, including no discussion or promotion of relevant screening, the

	pneumococcal vaccine, or hospital passports.
Good utilisation of a Health Action Plan	Inappropriate requests such as asking a family member to take an observation which should be conducted by practice staff.
Evidence of STOMP	Further education required to ensure less missed opportunities.
Holistic care	Providing evidence of Health Action Plans.

When engaging with people who are eligible for annual health checks but didn't have them, key themes were identified that act as barriers and enablers to accessing annual health checks.

Key barriers include:

- Duplication of health checks and other support from professionals, with participants saying that they do not feel an AHC is necessary if they are accessing other health checks.
- Personal choice and circumstances meaning they choose not to or find themselves very busy.
- No recollection of being invited to an AHC.
- A lack of support network to help with the AHC, such as supporting with travel or helping to keep track of appointments.
- No reasonable adjustments to support attendance.
- Accuracy of the learning disability register, as they may not identify as having a learning disability.

Key enablers identified include:

- Combined appointments and health checks to reduce duplication.
- Reasonable adjustments supporting attendance, such as a home visit.
- Consistent support to attend the AHC.

LIFE EXPECTANCY

Typically, people with a learning disability die younger than people without a learning disability. Based on 2018-19 data, males with a learning disability had a life expectancy at birth of 66 years; this is 14 years lower than for males in the general population. Females with a learning disability had a life expectancy of 67 years; 17 years lower than for females in the general population. NHS England noted in 2020 that there had been no statistically significant change in life expectancy for people with a learning disability between 2014-15 and 2018-19.¹⁹

Data about life expectancy for people with learning disability has been available in recent years from both national and local 'Learning from the Lives and Deaths of people with a learning disability and autistic people' annual reports (LeDeR). In 2021, NHS noted that people with learning disability were '*dying earlier than they should, many from things which could have been treated or prevented*'.²⁰

In 2023, in Coventry and Warwickshire, of the people for whom notifications to LeDeR were received, the median age of death was 63 years for men and 62 years for women.²¹ These figures were broadly in line with national LeDeR findings where median age of death was 62.9 for males and females in 2022. This compares with 85.5 years for females and 81.8 years for males for the population without a learning disability between 2018-20.²²

¹⁹ NHS England. *Health and Care of People with Learning Disabilities*. <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2018-to-2019/condition-prevalence> [Accessed 30/07/2024]

²⁰ NHS England. *Learning from lives and deaths – People with a learning disability and autistic people (LeDeR)*. <https://www.england.nhs.uk/learning-disabilities/improving-health/learning-from-lives-and-deaths/> [Accessed 30/07/2024]

²¹ Coventry and Warwickshire LeDeR 2023/24, NHS Coventry and Warwickshire, 2024

²² [Mortality in England and Wales: past and projected trends in average lifespan](#), Office for National Statistics, 2022

Table 5: The median age of death for males and females was lower in populations with a learning disability with a ‘gap’ of 19 and 23 years respectively.

Median age of death ‘gap’ learning disability and non-learning disability population, males and females, England, 2018-20 & 2022

Median age of death			
	Learning Disability population (2022)	General population (2018-20)	Gap
Males	63	82	19
Females	63	86	23

Source: England LeDeR Annual report, 2023

The national LeDeR also highlights the greater proportion of deaths among people with a learning disability which occur in younger age groups. Around 85% of deaths in the population without a learning disability happen in the 65+ age group compared to around 40% for those with a learning disability. Approximately 10% of deaths in the population without a learning disability happen in the 50-64 age group compared with around 35% of those in the population with a learning disability.²³

In short, living with a learning disability reduces the number of years they can expect to live.

CAUSES OF DEATH

Data about causes of death among those with a learning disability is available from national and local LeDeR reports.




In Coventry and Warwickshire in 2023-24, the leading causes of death for people with a learning disability whose death had a LeDeR review were respiratory (47%), cancer (16%), and cardiovascular (15%) see Table 6. In 2023-24, pneumonia (a respiratory infection that affects

²³ Kings College London. 2022 LeDeR report into the avoidable deaths of people with learning disabilities. <https://www.kcl.ac.uk/news/2022-leder-report-into-the-avoidable-deaths-of-people-with-learning-disabilities> [Accessed 30/07/2024]

the lungs) was classified as a local priority within the Coventry and Warwickshire LeDeR programme.

Table 6: In Warwickshire in 2023, the leading cause of death among the population with a learning disability whose death was reviewed as part of the LeDeR programme related to respiratory conditions.

Top 3 causes of death in learning disability population whose deaths were reviewed as part of the LeDeR programme, Warwickshire, and England, 2022/2023.

Condition	% of all deaths reviewed - Warwickshire	% of all deaths reviewed England
 Cardiovascular	14.3%	16.7%
 Respiratory	46.9%	14.6%
 Cancer	16.3%	14.5%

Source: NHS Coventry and Warwickshire LeDeR report, 2023 and [Kings College London, LeDeR annual report, 2023](#)

The same top three causes of death were identified albeit in a different order at national and local level. The variation may be related to differences in sample size between the two groups but both datasets highlight key areas where there may be opportunities to improve outcomes for people with learning disabilities.




AVOIDABLE DEATHS

There is an [official definition of avoidable deaths](#) which is used by the Office for National Statistics and the LeDeR programme. An avoidable death does not necessarily mean there was a failure of care but is more about looking at deaths where, if certain possible and reasonable steps were taken, the death may not have occurred. For example, deaths from hypertension may be considered avoidable because the condition can be mitigated by actions to lower risk such as diet and exercise. Data is only available from the national LeDeR programme where a higher number of deaths could be analysed. The 2023 national LeDeR report highlighted that 42% of deaths among the population with a learning disability were

considered avoidable. This compared to 22% among the population without a learning disability.

Table 7: Cardiovascular conditions were the most likely to be linked to avoidable deaths in people with learning disabilities, followed by respiratory and cancer deaths.

Avoidable deaths in learning disability population whose deaths were reviewed as part of the LeDeR programme, England, 2023.

Condition linked to avoidable death	% of all avoidable deaths
 Cardiovascular	26.4%
 Respiratory	23.8%
 Cancer	15.7%

Source: [Kings College London, LeDeR annual report, 2023](#)

Furthermore, according to national figures, males were more likely to die from an avoidable cause of death than women and the most likely age group to experience avoidable death was 25-49 years.²⁴

One issue raised in the context of avoidable deaths relates to weather extremes. A particular concern is the potential increase in periods of very hot weather. These episodes impact on many people especially those with underlying health conditions including people with respiratory or heart conditions; these are more prevalent in people with a learning disability. There will be a need to ensure that health advice during periods of extreme heat are tailored to the needs of those with a learning disability.

²⁴ Kings College London. 2022 LeDeR report into the avoidable deaths of people with learning disabilities. <https://www.kcl.ac.uk/news/2022-leder-report-into-the-avoidable-deaths-of-people-with-learning-disabilities> [Accessed 30/07/2024]

HEALTHY WEIGHT

People with learning disabilities are at increased risk of being overweight or obese compared to those not without a learning disability.²⁵ In turn, this increases the likelihood of a range of associated health and social issues including;

- cardiovascular disease
- diabetes
- some cancers
- stigma and bullying in childhood
- poor mental health in adulthood

²⁵ Public Health England. *Obesity and weight management for people with learning disabilities; guidance*. <https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance> [Accessed 30/07/2024]

Guidance from OHID stress the importance of Annual Health Checks (AHCs) as an opportunity to review a person’s health and lifestyle and provide appropriate support through the post check health action plan which is now a requirement following a health check. Figure 22 shows that locally people with a learning disability had a rate of obesity 18.6 percentage points higher (35.8%) compared those without a learning disability (17.2%). Differences were especially marked in age categories from 10-19 years to 60-69 years.

Figure 22: Rates of obesity in people with a learning disability were considerably higher than those without a learning disability.

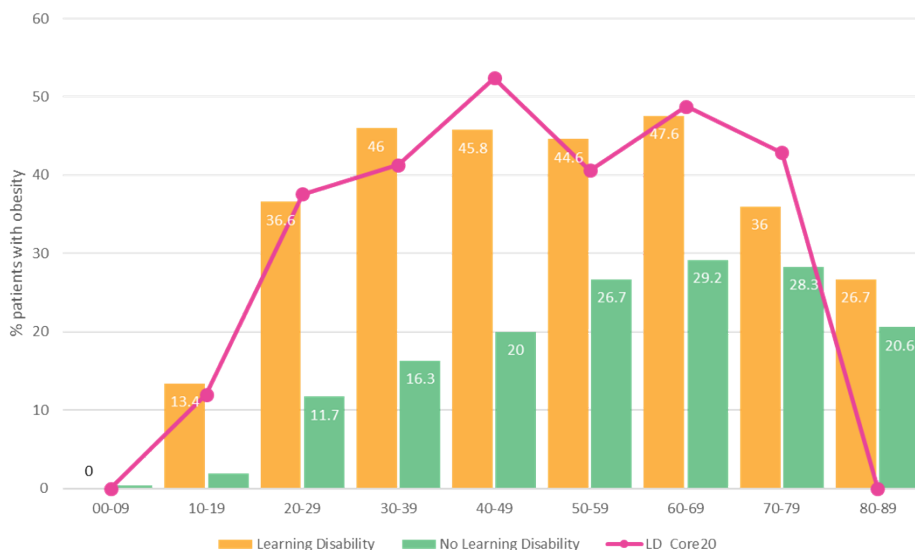
Obesity rates (%) by age among people with a learning disability and those with no learning disability, Warwickshire, 2024

Source: Optum dataset, 2024

SMOKING

Smoking continues to be the leading preventable cause of disability and disease in the UK.

Priority groups have, in the past, been identified (young people, pregnant women, black and ethnic minority groups and those with mental health conditions) and while people with a learning disability could also be part of one of these groups, there appears little focus on people with a learning disability as a group of people who smoke; there appears limited work



around the factors that influence the uptake, continuation or cessation of smoking in people with learning disabilities. Figures from the local GP registered population indicate the following levels of in year smoking prevalence.

Table 8: People with learning disabilities registered with Warwickshire GPs record a slight increase in the likelihood of smoking compared to those without learning disability.

Smoking prevalence in people with a learning disability and non-learning disability population registered with a Warwickshire GP, 2024.

 Smoking prevalence	
Learning disability	Non-learning disability
11.2%	9.8%

Source: Optum, 2024

Figures from the GP registered population indicate that of people with a learning disability who smoke, 37% had been offered smoking cessation options compared with 35% of remaining population who smoke. However, it is likely people with learning disabilities who smoke have specific needs in accessing smoking cessation services; there is a requirement to better understand need in this area and look at ways of supporting someone with a learning disability who wishes to stop smoking.

ALCOHOL MISUSE

Recorded levels of alcohol misuse among people with a learning disability in Warwickshire were similar to people without a learning disability based on data from the GP registered population in Warwickshire. In 2024, based on data for the previous year, 0.5% of people registered with a learning disability were recorded with an alcohol issue compared with 0.3% of the population with no recorded learning disability. Those recorded as ever having an issue with alcohol were also similar at 2.1% and 2.3% respectively. However, as with smoking, it appears that prevalence of alcohol misuse among people with learning disability is relatively little understood with few published papers or reports. There is a suggestion that substance use disorders (including alcohol) are more common in people with milder levels of learning disability who may

not have contact with specific learning disability services.²⁶ Additionally, alcohol is seen to exacerbate physical conditions already experienced at higher rates among those with learning disabilities.

Alcohol issues will impact on people with a learning disability in terms of their health and wider social experiences. Managing alcohol use as well as accessing services relating to alcohol treatment will present a range of issues and there is a need to consider what reasonable adjustments might look like for people who wish to access support services.

HEALTH CONDITIONS

DIABETES

A recent [Kings College London report](#) highlighted the increased prevalence of type 2 diabetes among people with a learning disability. They note “*rates of type two diabetes in people with a learning disability is shifted 10-15 years earlier than in people from the general population*”.²⁷

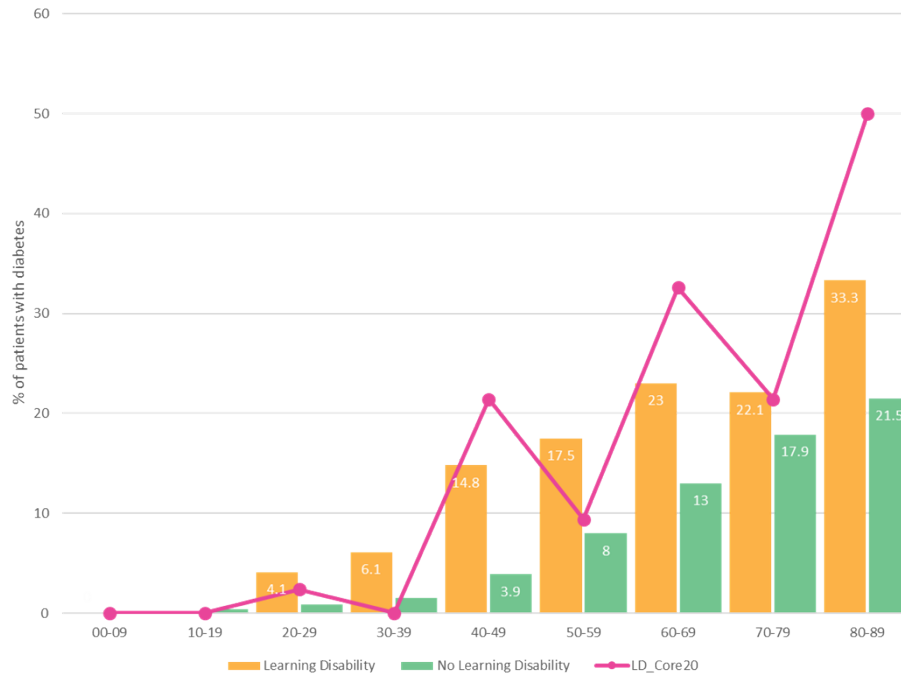
Data for Warwickshire is presented in Figure 23 and shows a higher proportion of those with a learning disability experiencing diabetes when compared to those without a learning disability. Overall, rates among those with a learning disability were 9.3% compared with 6.2% in the population without a learning disability. Differences between the two groups were especially marked in those aged 40-69 suggesting earlier onset for those with a learning disability as noted by the report cited above.

Figure 23: Higher levels of diabetes were seen in all age groups with a learning disability compared to those without; rates in both groups generally increased with age.

Percentage prevalence of diabetes among those with a learning disability and those without, Warwickshire, 2024

²⁶ Cambridge University Press. *Alcohol use disorders in people with intellectual disability*. <https://www.cambridge.org/core/journals/bjpsych-advances/article/alcohol-use-disorders-in-people-with-intellectual-disability/49C8C4541841ABD6F8AABC118C1B06D2> [Accessed 30/07/2023]

²⁷ Baksh, R. A., Gulliford, M., Chauhan, U., Sheehan, R., Strydom, A. *Onset and Care of Type 2 Diabetes Mellitus in People with a Learning Disability*. King's College London. 2022.



Source: Optum dataset, 2024

People with a learning disability living in Core 20 areas had an all-age prevalence rate similar to people with learning disability generally. Diabetes has links with other conditions including obesity, hypertension, and cardiovascular health. Again, the opportunities to monitor/screen for diabetes during health checks and other appointments is proposed by the Kings College London research report.

ASTHMA

A number of studies highlight that people with a learning disability frequently have 'compromised or vulnerable respiratory status'.²⁸ Indeed, respiratory conditions were the main cause of death among people with a learning disability in Warwickshire in 2023.²⁹ Local data suggest rates of asthma among people with a learning disability were higher (14.7%) than those

²⁸ Public Health England. *Health inequalities: Respiratory disease*.

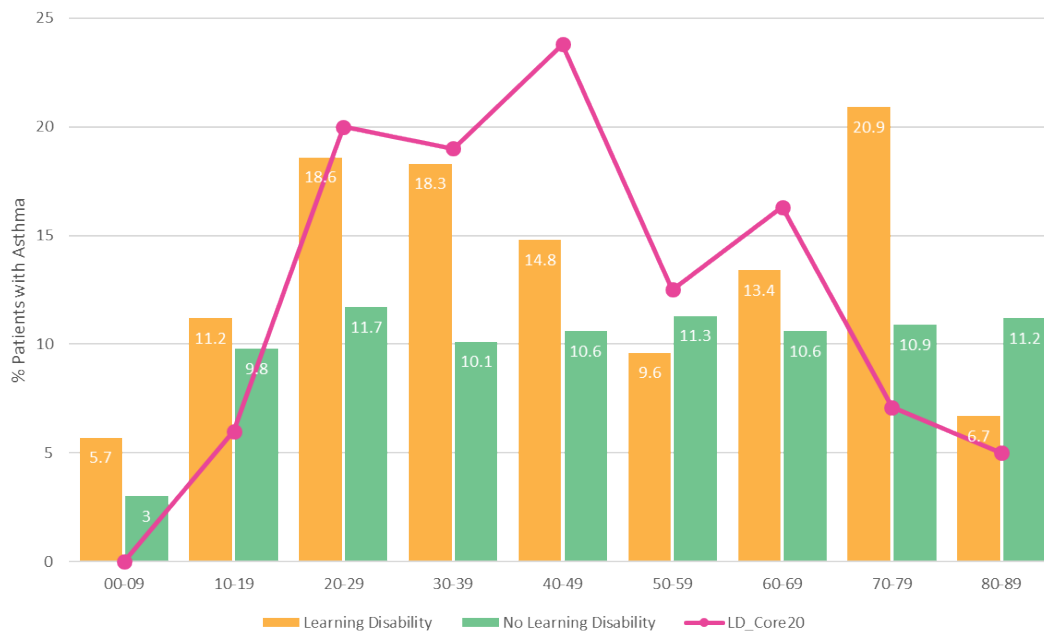
https://fingertips.phe.org.uk/documents/Health_inequalities_Respiratory_diseases.pdf [Accessed 30/07/2024]

²⁹ NHS Coventry and Warwickshire Integrated Care Board. *Learning from the Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR) Annual Report 2023/24*. NHS Coventry and Warwickshire Integrated Care Board. 2024.

in the population without a learning disability (9.9%). The overall rate for people with a learning disability living in the 20% most deprived areas was 15.7%, broadly in line with the overall rate for people with a learning disability, although some age groups appeared to have higher rates.

Figure 24: In most age groups people with a learning disability experienced higher levels of asthma compared those without a learning disability.

Proportion of patients on GP registers in Warwickshire diagnosed with asthma, 2024.



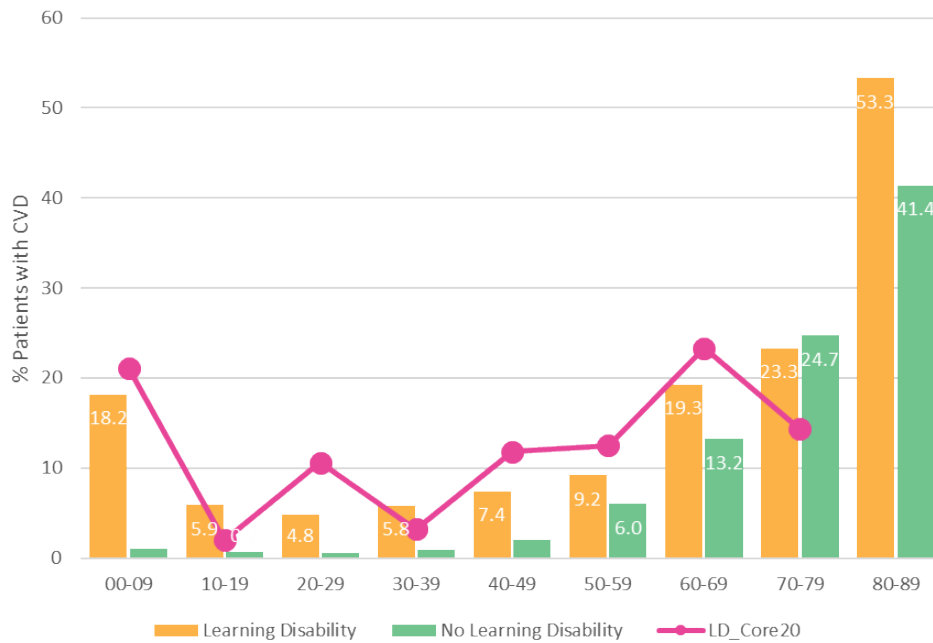
Source: Optum dataset, 2024

CARDIOVASCULAR DISEASE

Data for Warwickshire from the GP registered population indicates that cardiovascular disease was more prevalent in people with a learning disability than those without. The all-age rate of cardiovascular disease for people with a learning disability was 9.3% compared to 7.6% for those without a learning disability. For those with a learning disability and living in the 20% most deprived areas of the county the proportion was 10.6%.

Figure 25: Rates of cardiovascular disease were routinely higher in people with learning disabilities compared to those without a learning disability especially in younger age groups.

Percentage of patients recorded with cardiovascular disease, with a learning disability and without a learning disability by age, Warwickshire, 2024



Source: Optum 2024

Cardiovascular disease is one of the leading causes of death in populations both with and without a learning disability as highlighted in the causes of death section of this document. Cardiovascular diseases can be associated with some genetic causes of learning disability, for example, Down Syndrome.³⁰ However, higher rates may also be explained by other risk factors associated with cardiovascular disease being more likely in populations with a learning disability. This includes higher rates of obesity and diabetes which are linked to cardiovascular disease as well as other lifestyle factors that contribute to a picture of poorer heart health in the learning disability population.

³⁰ Public Health England. *Health inequalities: Cardiovascular disease*.

https://fingertips.phe.org.uk/documents/Health_inequalities_cardiovascular_disease.pdf

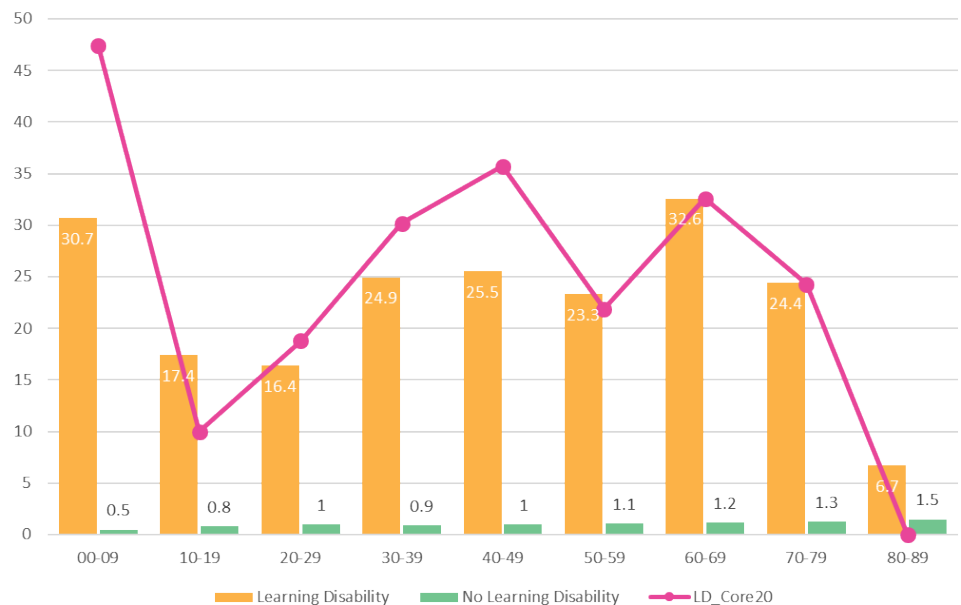
file:///C:/Users/mmad3/Downloads/Health_inequalities_cardiovascular_disease.pdf [Accessed 30/07/2024]

EPILEPSY

Research indicates that rates of epilepsy are generally more common among adults with a learning disability compared to those without a learning disability. Prevalence of epilepsy is also known to increase with the severity of learning disability and is more common among men.³¹ In 2024 in Warwickshire, just over one in five (22.5%) people with a learning disability also had epilepsy. This compared to just one in a hundred (1%) of the population without a learning disability. Rates varied across age groups but the pattern of higher rates for those with a learning disability when compared to those without remained consistent.

Figure 26: People with a learning disability experience higher rates of epilepsy than those without a learning disability.

Prevalence of epilepsy in those with and without a learning disability, Warwickshire 2024



Source: Optum dataset, 2024

People with a learning disability and who live in the 20% most deprived areas experienced the highest levels of epilepsy at 24.9% (all ages) although levels were not consistently higher across all age groups. There is some evidence that socio-economic factors (such as deprivation) are associated with both the development of epilepsy and the health outcomes of people with epilepsy although these are not specific to people with a learning disability.³²

³¹ NHS England. *National bundle of care for children and young people with epilepsy: annex 2.*

<https://www.england.nhs.uk/long-read/national-bundle-of-care-for-children-and-young-people-with-epilepsy-annex-2/#:~:text=Around%201%20in%203%20people,also%20have%20a%20learning%20disability>. [Accessed 30/07/2024]

³² Public Health England. *Health inequalities: Epilepsy.*

https://fingertips.phe.org.uk/documents/Health_inequalities_epilepsy.pdf [Accessed 30/07/2024]

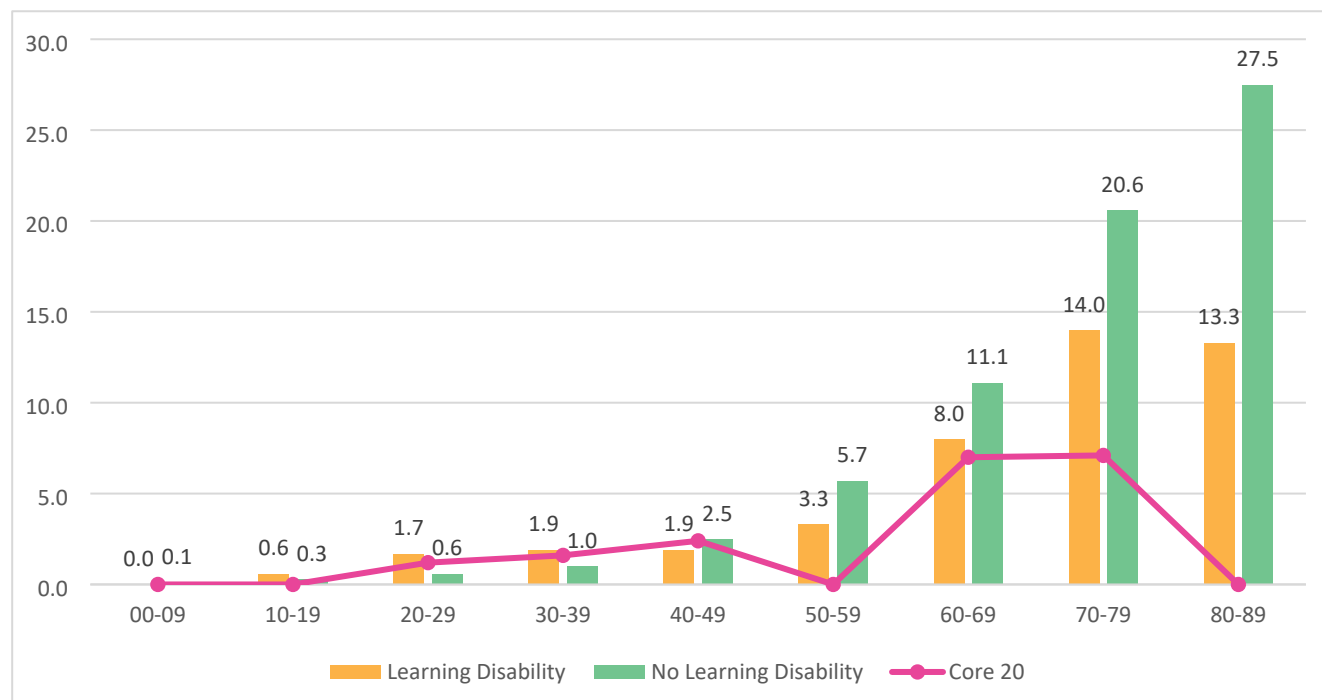
CANCER

Cancer is a leading cause of death for people with a learning disability, with 16.3% of deaths reviewed in the Warwickshire LeDeR programme in 2022/23 being due to cancer. Nationally it is acknowledged that cancer is diagnosed at a later stage in people with a learning disability compared to people without a learning disability³³, which heavily impacts on survival outcomes.

Figure 27 shows that whilst rates of cancer are slightly higher in younger age groups with a learning disability (20-29 and 30-39) compared to the population without a learning disability, in older age groups rates are lower in those with a learning disability. These rates are likely to reflect later diagnoses and lower uptake of cancer screening, rather than being an indication of reduced prevalence for people with a learning disability.

Figure 27: The prevalence of cancer in people with a learning disability is lower in older age groups (50+) compared to the population without a learning disability.

Percentage prevalence of cancer in those with and without a learning disability, Warwickshire, 2024



Source: Optum dataset, 2024

³³ Public Health England. *Health inequalities: cancer*.

https://fingertips.phe.org.uk/documents/Health_inequalities_cancer.pdf [Accessed 10/09/24]

National evidence points to screening inequalities among people with a learning disability.³⁴ These include screening programmes for breast, cervical and bowel cancer. Table 9 compares screening rates in the population with and without a learning disability in Warwickshire and England.

Table 9: Rates of breast and cervical screening for learning disability populations were lower in Warwickshire than England but better for bowel screening. In all screening programmes, rates for the learning disability population were lower than the population without a learning a learning disability.

Cancer screening summary Warwickshire and England, 2022-23

Cancer Screening Summary									
	Breast Screening			Cervical Screening			Bowel Screening		
Population	LD	Non-LD	PPD*	LD	Non-LD	PPD*	LD	Non-LD	PPD*
Warwickshire	38.5%	53.5%	15	28.9%	68.4%	39.5	56.9%	60%	3.1
England	46.8%	61.2%	14.4	31.2%	65.6%	34.4	52.7%	68.7%	16

*Percentage point difference

Source: Optum & Health and Care of People with Learning Disabilities, NHS England, 2022/2023

Source: [Health and Care of People with Learning Disabilities, NHS England, 2024](#)

Breast screening

The rate of uptake among eligible females with a learning disability was lower in Warwickshire than England. The NHS breast screening programme is offered to females aged 50 to 69 registered with a GP every three years. In England in 2022/23, 46.8% of eligible women with a learning disability had received breast cancer screening in the five years up to March 2023

³⁴ Public Health England. *Population screening: reducing inequalities for people with a learning disability, autism or both*. <https://www.gov.uk/government/publications/population-screening-supporting-people-with-learning-disabilities/population-screening-reducing-inequalities-for-people-with-a-learning-disability-autism-or-both#:~:text=Screening%20inequalities%20exist%20among%20people,than%20people%20without%20learning%20disabilities>. [Accessed 30/07/2024]

compared with 61.2% of eligible women who did not have a learning disability – a percentage point difference of 14.6; this has stayed relatively stable over time.³⁵

In Warwickshire, uptake of breast screening among women registered with a GP with a learning disability was 38.5% of the snapshot population while for women without learning disability it was 53.5% showing lower uptake in both learning disability and non-learning disability populations compared to the national picture – it has a similar percentage point difference between the two groups (15.0%).

Additionally, the 2024 Coventry and Warwickshire LeDeR report highlighted that of those deaths that were part a review and who would have been in the eligible group for breast screening, 38% had completed one providing further evidence that local rates of breast screening uptake are lower than the national rate.

Cervical screening

Local levels of cervical screening in women of eligible age (25-64) showed marked differences between the population with and without a learning disability. In 2023, the proportion of eligible women with a learning disability who completed cervical screening was 28.9% compared with 68.4% of the eligible population without a disability, a difference of 39.5 percentage points.³⁶ Additionally, the 2023-24 Coventry and Warwickshire LeDeR report noted that cervical screening was completed for 26% of eligible people whose death had been reviewed as part of the LeDeR programme further reflecting the lower proportion of women who completed cervical screening who live with a learning disability.

These figures reflect a national picture of difference for women with a learning disability and those without; in 2022-23 there was a 34.4 percentage point difference between the two groups completing a cervical smear test. – see Table 9. National figures confirm that this difference has been ongoing and that between 2018-19 and 2022-23, there was consistently a marked difference between the two populations.³⁷

Bowel cancer screening

There was a narrower gap between those with and without a learning disability who had completed bowel screening compared to other screening programmes.

³⁵ [Health and Care of People with Learning Disabilities](#), NHS Digital, 2024 [accessed 30/07/2024]

³⁶ Optum, 2024

³⁷ [Health and Care of People with Learning Disabilities](#), NHS Digital, 2024 [accessed 30/07/2024]

Bowel cancer screening is available to people registered with a GP aged between 50-74 every two years. In 2024 in Warwickshire, 56.9% of the eligible population with a learning disability completed bowel screening compared with 60% of the population without learning disability. Similarly, the 2023-24 Coventry and Warwickshire LeDeR report indicated that 57% of those eligible, whose death was reviewed as part of the LeDeR programme had completed bowel screening previously.

National data is available for bowel screening for those aged 60-74 and suggests a wider gap between the two populations than is apparent in Warwickshire. In 2022-23, NHS England report that 52.7% of the eligible population with a learning disability had been screened for bowel cancer while 68.7% of the population without learning disability who were eligible had been screened, a difference of 16 percentage points.³⁸

Feedback on cancer screenings

Grapevine engaged with people with a learning disability seeking feedback on cervical, bowel, and breast cancer screening. Table 10 provides a summary of barriers to cancer screening, and potential solutions to address them that were identified as part of this engagement.

Table 10: There are a range of barriers experienced by people with a learning disability when accessing cervical, bowel, and breast cancer screening.

Feedback on barriers to cervical, bowel, and breast cancer screening.

Barriers	Potential solutions
Anxiety around attending screening appointment.	<ul style="list-style-type: none"> • Reminder that you can bring someone with you to the appointment. • More information being shared before the appointment about what it will entail in an easy read format. • Trusted services being encouraged to talk about screenings with people. • An option to meet with the doctor before screening appointments to get to know their face.

³⁸ [Health and Care of People with Learning Disabilities](#), NHS Digital, 2024 [accessed 30/07/2024]

<p>Embarrassment about nudity.</p>	<ul style="list-style-type: none"> • Gender-appropriate doctor. • Acknowledgement at the start of the appointment and clear explanation of the process to help this. • More information shared before the appointment about what it will entail in an easy read format. • Talk to people about this in secondary school.
<p>Unable to get to the appointment due to travel complications, independence, and/or getting lost.</p>	<ul style="list-style-type: none"> • Community screenings/mobile units. • More travel support options for getting to appointments. • Home screenings offered. • Maps put in letters so that someone can find their way around the hospital and/or doctors surgery.
<p>Clear communication and explanations.</p>	<ul style="list-style-type: none"> • Explain about what clothes to wear to the appointment beforehand. • Clear instructions for every step, easy read to follow along with during the appointment (step by step). • Staff clearly explaining each step and what is required. • Staff asking if more explanation is needed. • A phone call beforehand to explain the process.
<p>No-one to go with to the appointment.</p>	<ul style="list-style-type: none"> • Offered LD nurse to help with these appointments.
<p>Lack of physical resources.</p>	<ul style="list-style-type: none"> • Information needs to be sent to people's homes in an easy read format. • Digital competency expected to book appointments, reasonable adjustments and support needed to book in appointments.
<p>Having to phone to book the appointment.</p>	<ul style="list-style-type: none"> • Being comfortable on the phone is needed to book appointments. • Alternative methods to booking – text/email.

Forgetting to book appointment.	<ul style="list-style-type: none"> • Follow up phone call needed if someone has not booked after X number of weeks. • Offer times/dates on letter as options.
Being unable to communicate what you need.	<ul style="list-style-type: none"> • Doctors and nurses check in with patient. • Encourage patient to bring someone with them – trusted person who understands them. • Doctors/nurses adapt communication style if needed.
Navigating a hospital environment.	<ul style="list-style-type: none"> • LD nurse offered to help support appointment. • Clearer signs in hospitals. • Easy read hospital maps offered. • Directions included on original letter sent to patients. • More help desks and people to guide you around the hospital.
Lack of understanding about why appointment is important ('I feel fine')	<ul style="list-style-type: none"> • Clear easy read explanation of why appointment is good for them and outline of what could happen if you don't go to the appointment (you could not know and then get ill).

CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

Chronic obstructive pulmonary disease (COPD) is the name for a group of conditions that affect the lungs and cause breathing difficulties, including emphysema and chronic bronchitis. COPD mainly impacts middle-aged or older adults who smoke and can limit normal activities.

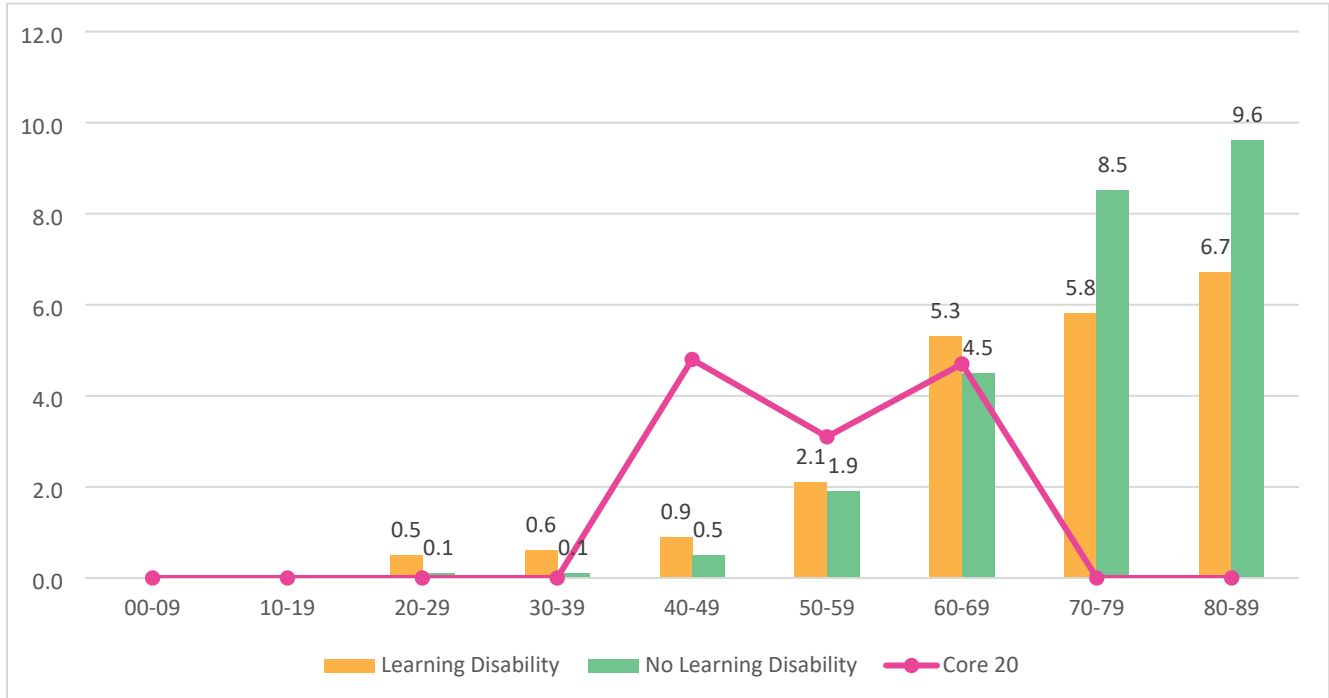
National research shows higher rates of COPD in people with a learning disability.³⁹ Figure 28 shows the percentage of people with and without a learning disability in Warwickshire who have COPD. Rates are slightly higher in those with a learning disability until the age of 70, particularly in the younger age groups (20-29 and 30-39).

³⁹ Public Health England. *Health Inequalities: Respiratory diseases*.

https://fingertips.phe.org.uk/documents/Health_inequalities_Respiratory_diseases.pdf [Accessed 10/09/24]

Figure 28: COPD rates are slightly higher in those with a learning disability until the age of 70, particularly in the younger age groups (20-29 and 30-39).

Percentage prevalence of COPD in those with and without a learning disability, Warwickshire, 2024



Source: Optum Dataset, 2024

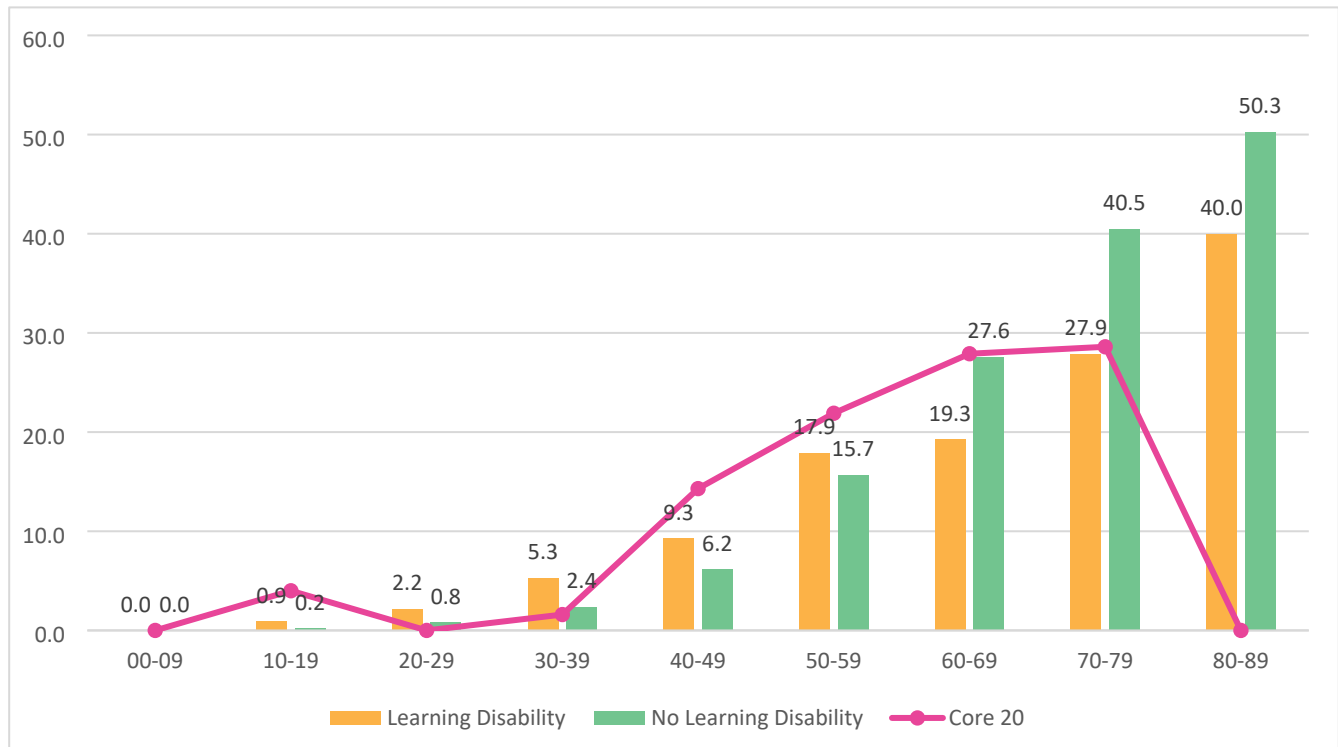
MUSCULOSKELETAL CONDITIONS

Arthritis

Arthritis is a condition that causes pain and inflammation in a joint. There is no cure for arthritis, however there are treatments that can help manage the condition. Figure 29 shows the prevalence of arthritis in those with and without a learning disability in Warwickshire. There is a slightly higher prevalence in younger age groups with a learning disability compared to without a learning disability (10-59), but a lower prevalence in older age groups (60+).

Figure 29: There is a slightly higher prevalence of arthritis in younger age groups with a learning disability compared to without a learning disability, but a lower prevalence in older age groups.

Percentage prevalence of arthritis in those with and without a learning disability, Warwickshire, 2024



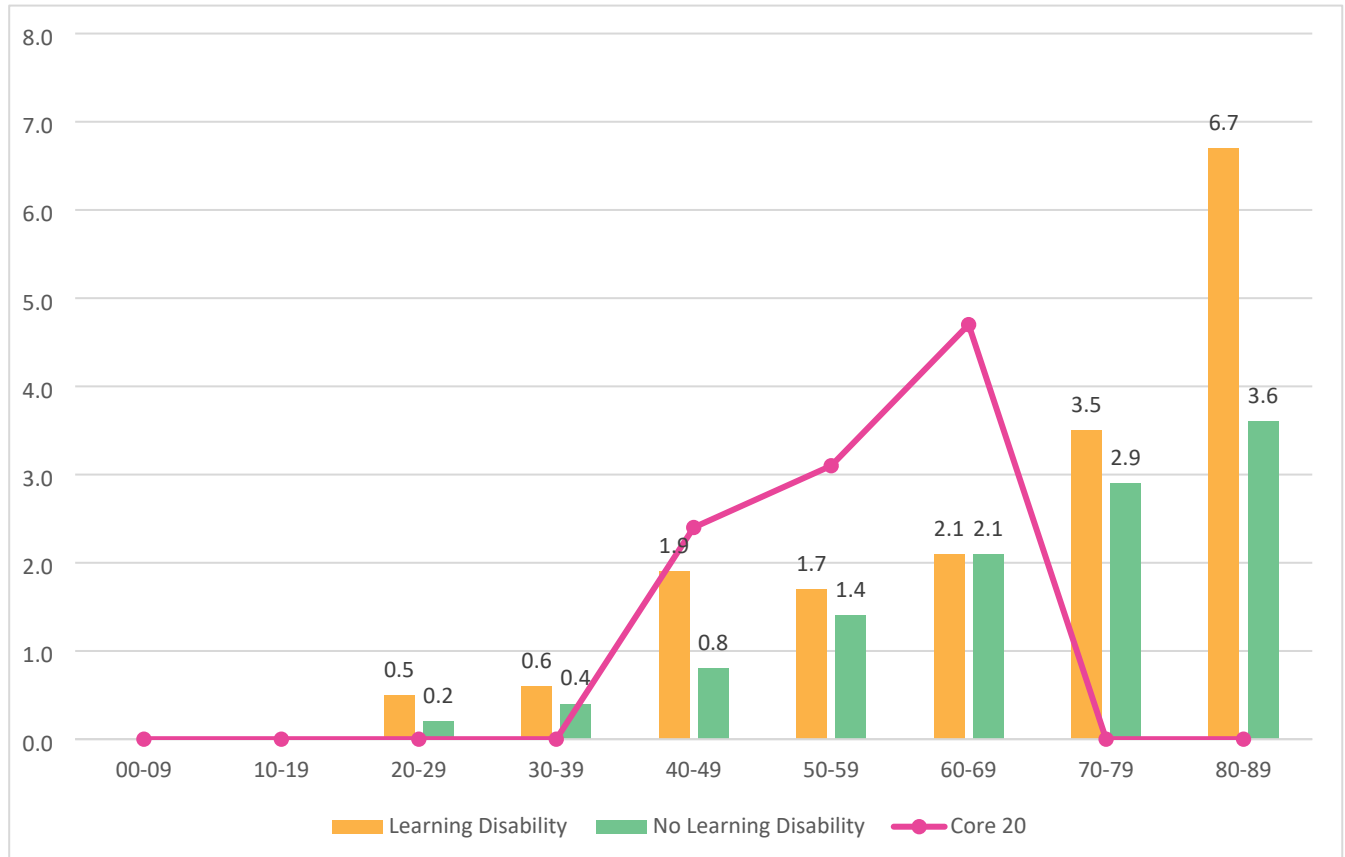
Source: Optum dataset, 2024

Rheumatoid arthritis

Rheumatoid arthritis is a type of arthritis that often starts when a person is between 30 to 50 years old. Figure 30 shows the prevalence of rheumatoid arthritis in those with and without a learning disability in Warwickshire. Prevalence is slightly higher across the age groups in those with a learning disability compared to those without a learning disability.

Figure 30: Prevalence of rheumatoid arthritis is slightly higher in those with a learning disability compared to those without a learning disability.

Percentage prevalence of rheumatoid arthritis in those with and without a learning disability, Warwickshire, 2024



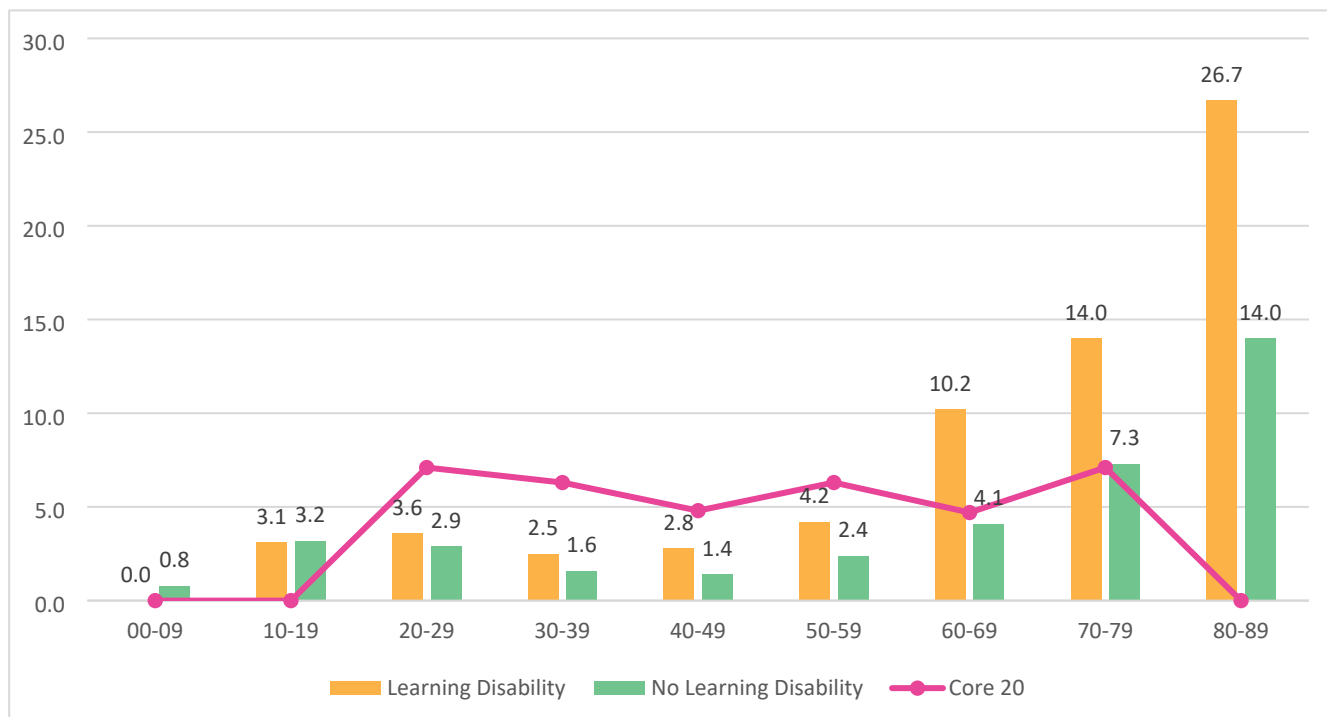
Source: Optum dataset, 2024

Fragility Fracture

A fragility fracture is a broken bone that is caused by a fall from a standing height or less. Figure 31 shows that the prevalence of fragility fractures is higher in those with a learning disability from the age of 20. Prevalence is particularly high over the age of 60 for people with a learning disability.

Figure 31: The prevalence of fragility fractures is higher in those with a learning disability across all age groups over the age of 20.

Percentage prevalence of fragility fractures in those with and without a learning disability, Warwickshire, 2024



Source: Optum dataset, 2024

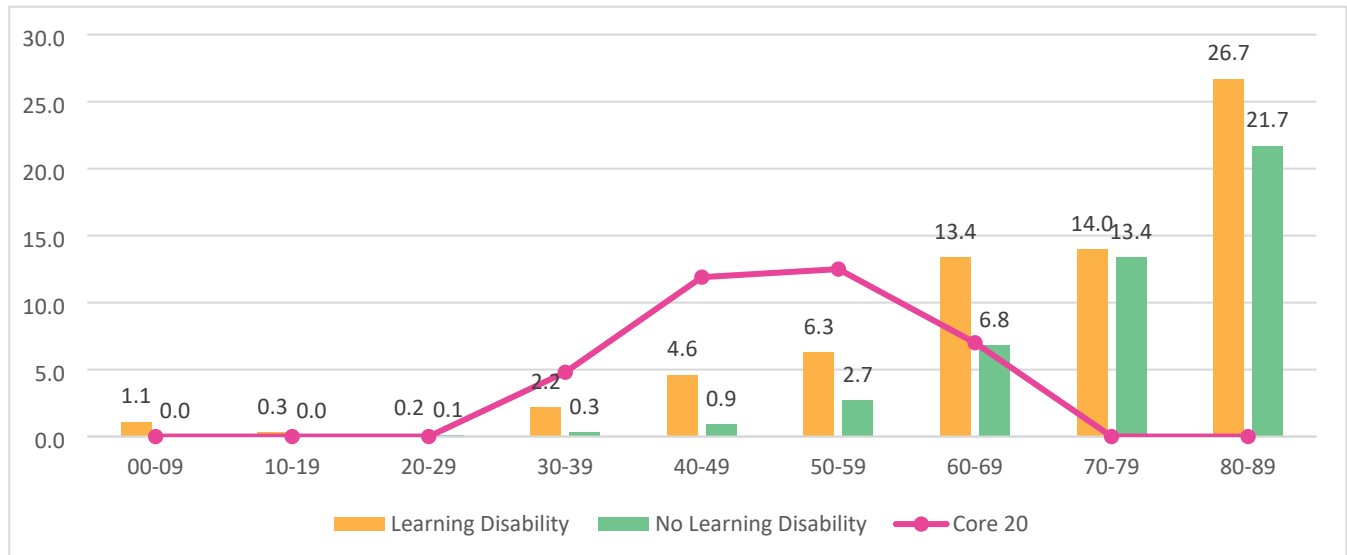
Osteoporosis

Osteoporosis is a health condition that weakens bones, making them fragile and more likely to break. National studies show that people with a learning disability have an increased prevalence of osteoporosis than those without a learning disability.⁴⁰ Figure 32 shows the prevalence of osteoporosis is higher in Warwickshire in those with a learning disability compared to those without a learning disability. There is a higher rate of people with osteoporosis in younger age groups compared to the general population, indicating an earlier onset.

⁴⁰ Public Health England. *Health inequalities: Osteoporosis*.

https://fingertips.phe.org.uk/documents/Health_inequalities_osteoporosis.pdf [Accessed 10/09/24]

Figure 32: The prevalence of osteoporosis is higher in those with a learning disability.
Percentage prevalence of osteoporosis in those with and without a learning disability, Warwickshire, 2024



Source: Optum dataset, 2024

MENTAL HEALTH

Mental health problems can affect anyone at any age. However, there is some evidence that people with a learning disability are more likely to experience poor mental health.⁴¹ Mencap outline four types of risk factors which may contribute to why people with a learning disability experience poor mental health.

- Biology and genetics may increase vulnerability to mental health problems
- A higher incidence of negative life events
- Access to fewer resources and coping skills
- The impact of other people’s attitudes

The above creates implications for the recognition, diagnosis and management of mental health conditions experienced by people with a learning disability. It emphasises the need for awareness among health and social care practitioners, carers, and all those who support

⁴¹ Mencap. *Mental health*. <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/mental-health> [Accessed 20/07/2024]

someone with a learning disability of mental health to ensure appropriate support is available and accessed.

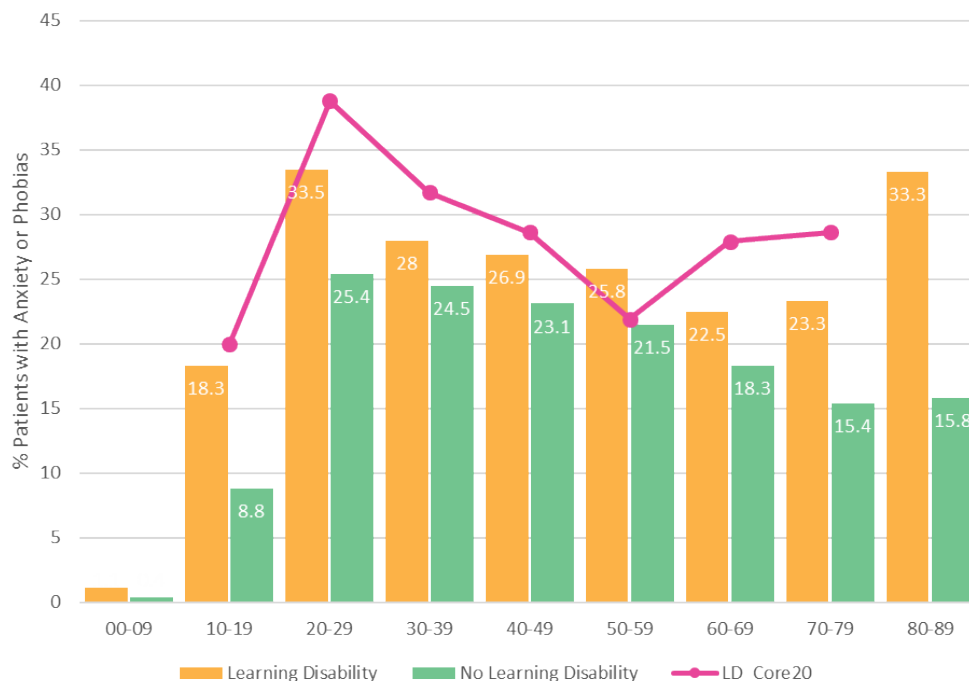
The following sections take a closer look at the topics of anxiety, depression and serious mental illness experienced by the GP patient population in Warwickshire.

ANXIETY

Differences in levels of anxiety/phobias among people with a learning disability compared to the population without a learning disability appeared to be noticeably higher in younger age categories suggesting young people with a learning disability may face challenges with their mental health.

Figure 33: Levels of recorded anxiety among people with a learning disability appeared slightly higher than those without a learning disability and were routinely higher for people with a learning disability also living in the 20% most deprived areas.

Levels of diagnosed anxiety in GP registered practice population, Warwickshire, 2024



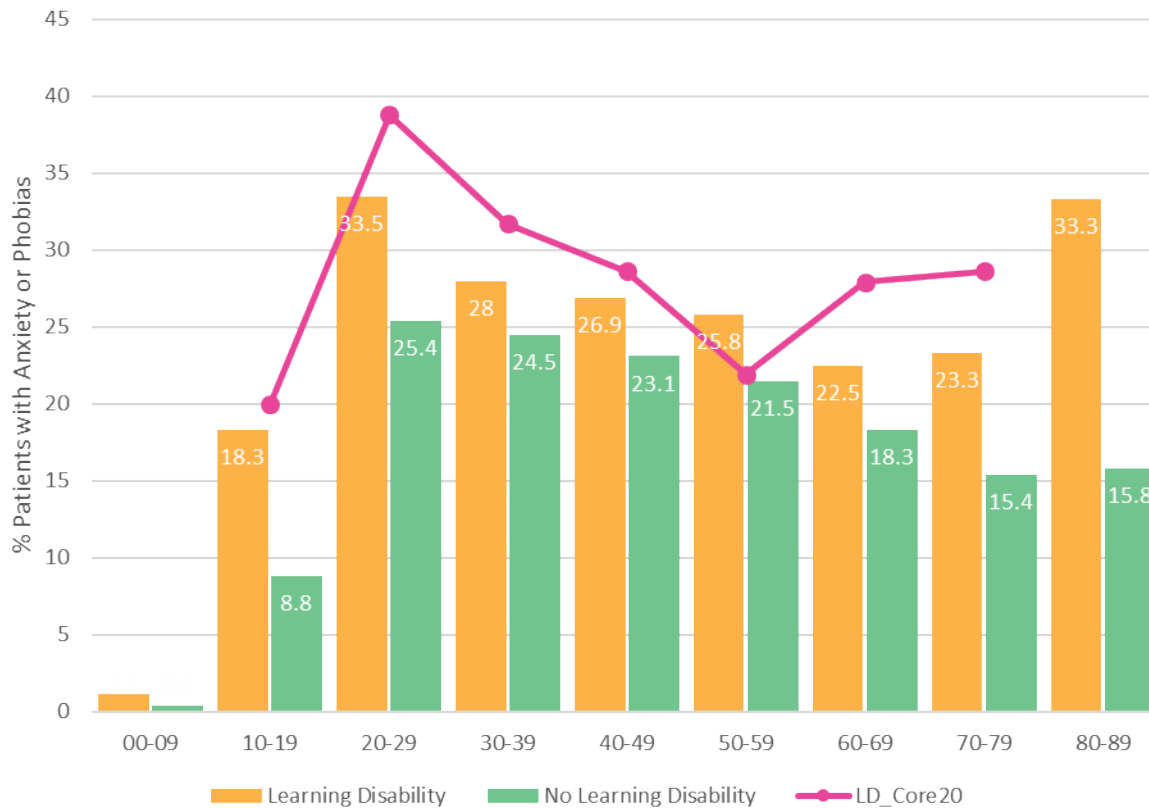
Source: Optum dataset, 2024

DEPRESSION

Local data suggested levels of depression were similar across middle age groups either with or without a learning disability. However, greater disparities were evident in both younger and older age groups. Overall, all-age rates were 4.1 percentage points higher in the population with a learning disability and 11.8 percentage points higher in people with a learning disability and living in the 20% most deprived areas of the county.

Figure 34: Differences in rates of depression between those with a learning disability and those who were not was most noticeable in younger people and older age groups. Rates were considerably higher for those aged 10 years and older with a learning disability who live in the 20% most deprived areas locally.

Depression prevalence GP registered population by age, with and without a learning disability, Warwickshire, 2024



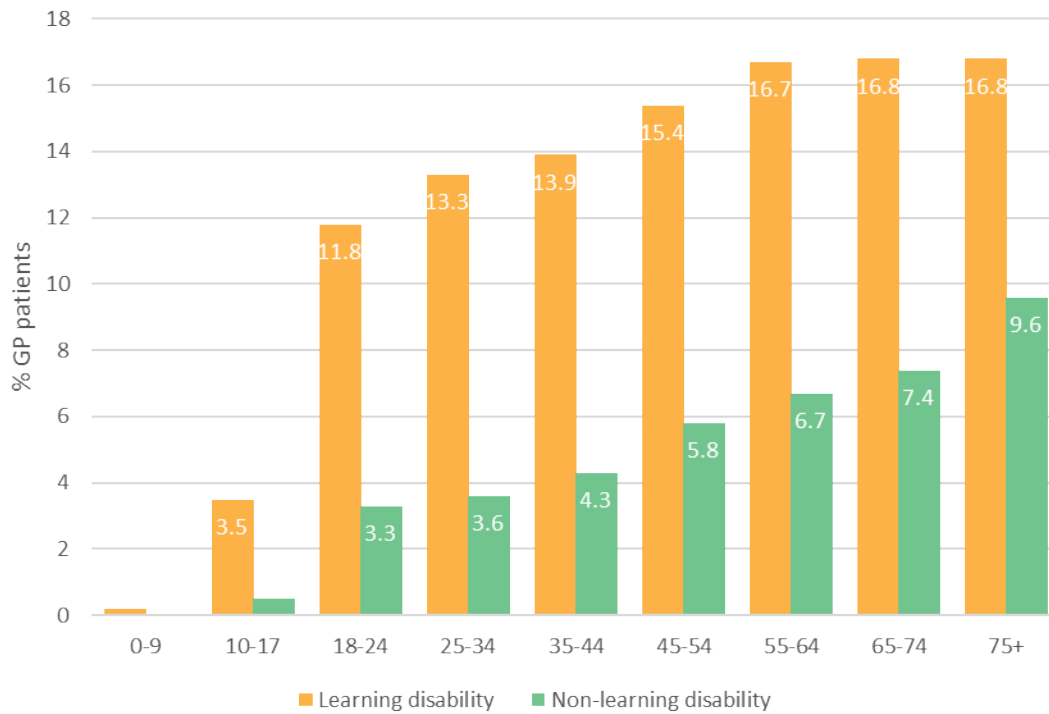
Source: Optum dataset, 2024

Data from NHS Digital suggests that people with a learning disability were more likely to be treated with anti-depressants than people without a learning disability, even accounting for the

higher prevalence of depression in that group.⁴² The chart below highlight data relating to NHS Coventry and Warwickshire which follow the national picture for antidepressant prescribing.

Figure 35: People with a learning disability in every age group were more likely to be prescribed anti-depressants than people without a learning disability.

Percentage of patients without an active depression diagnosis who were treated with antidepressants, Coventry and Warwickshire, March 2023



Source: [NHS Digital, Health and Care of People with Learning Disabilities, 2024](#)

SERIOUS MENTAL ILLNESS

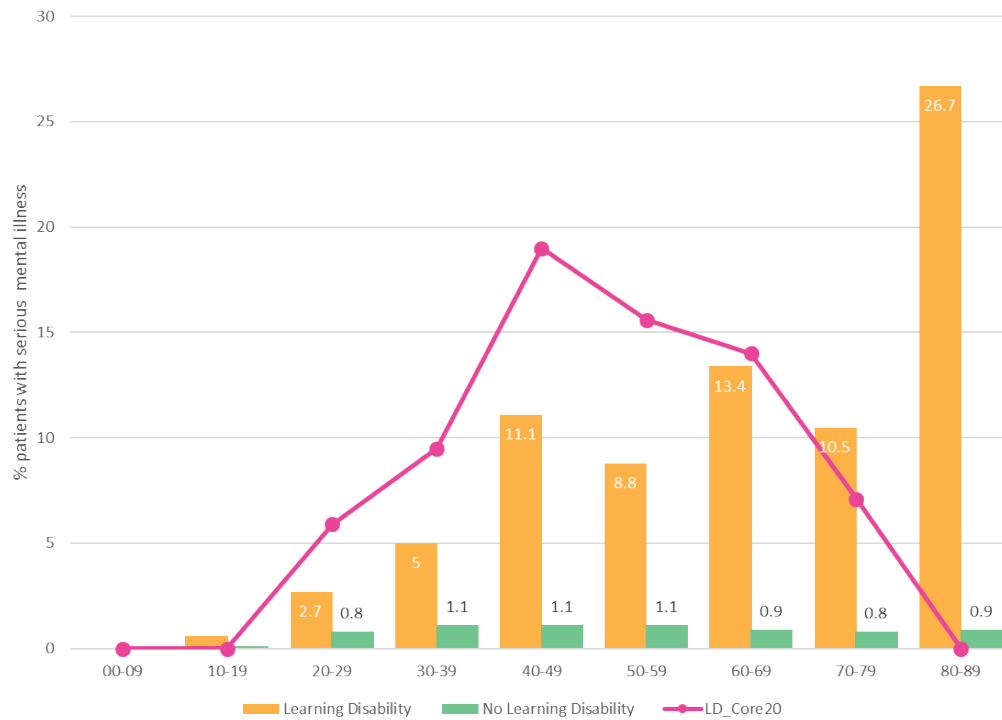
Overall people with a learning disability registered at GP practices in Warwickshire were just over seven times more likely to have a diagnosed serious mental illness compared to the general population; the prevalence rate of mental illness was 6% for people with a learning disability compared with 0.8% for those without. For those with a learning disability living in the

⁴² [Health and Care of People with Learning Disabilities](#), NHS Digital, 2024 [accessed 30/07/2024]

20% most deprived areas of the county the rate was 8.7%; over ten times the rate of the general population. Differences were most marked in older age categories.

Figure 36: People with a learning disability were more likely to have a diagnosis of severe mental illness than the general population in all age groups, especially older categories.

Prevalence of diagnosed severe mental illness among people with learning disability and general population, Warwickshire, 2024.



Source: Optum dataset, 2024

There has previously been work which explored, at a national level, the over-prescribing of psychiatric drugs to people with learning disabilities. This included prescribing to adults who do not have a recorded diagnosis of a condition which the medication is designed to treat.

In 2016, NHS England launched STOMP ‘stopping the over-medication of people with a learning disability’ as part of the NHS Long Term Plan.^{43 44} Nationally, prescribing rates have

⁴³ NHS England. *Stopping over medication of people with a learning disability and autistic people (STOMP)*. <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp-stamp/>. [Accessed 30/07/2024]

⁴⁴ Public Health England. *Psychotropic drugs and people with learning disabilities or autism*. <https://www.gov.uk/government/publications/psychotropic-drugs-and-people-with-learning-disabilities-or-autism/psychotropic-drugs-and-people-with-learning-disabilities-or-autism-results>. [Accessed 30/07/2024]

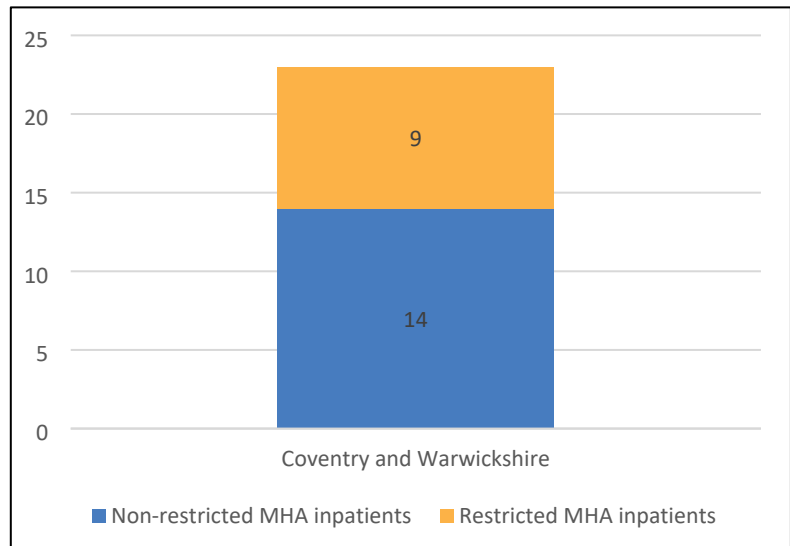
declined from 15.5% of patients with a learning disability who were prescribed antipsychotics in 2017-18 to 14.4% in 2022-23. The percentage of patients without a learning disability who were prescribed antipsychotics has remained stable at 0.9% over the same period. In NHS Coventry and Warwickshire, the percentage of patients with a learning disability and treated with antipsychotics in 2022-23 was 16.3%.⁴⁵ These rates highlight the importance of monitoring the long-term impact of antipsychotic medication in people with a learning disability as well as day-to-day management of their side effects.

ADULT MENTAL HEALTH INPATIENTS

In Coventry and Warwickshire there are 23 people with a learning disability who are mental health inpatients. Inpatients are either classified as restricted or non-restricted. Restricted patients are defined as “mentally disordered offenders who are detained in hospital for treatment and who are subject to special controls by the Justice Secretary due to the level of risk they pose. These controls include permission for community leave, transfer to another hospital, discharge and recall to hospital”⁴⁶. Of the 23 people with a learning disability who are mental health inpatients in Coventry and Warwickshire, 9 are classified as restricted (Figure 37).

Figure 37: In Coventry and Warwickshire, there are 23 people with a learning disability who are mental health inpatients, 9 of which are classified as restricted.

Number of inpatients with a learning disability by level of restriction.



Source: CWPT/Assuring Transformation Dataset

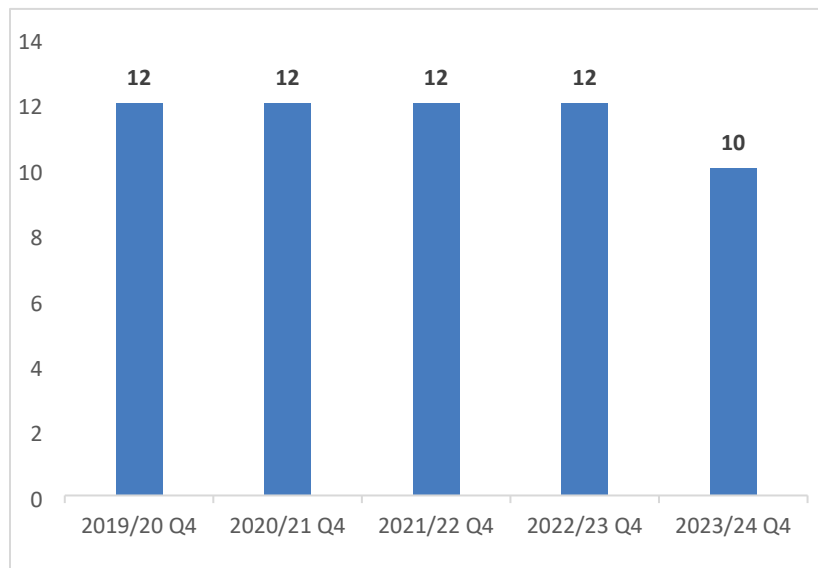
⁴⁵ [Health and care of people with learning disabilities](#), NHS Digital, 2024 [accessed 30/07/2024]

⁴⁶ Gov.UK. *Working with restricted patients*. <https://www.gov.uk/government/collections/working-with-restricted-patients>. [accessed 06/09/24]

Of the 23 people with a learning disability who are mental health inpatients in Coventry and Warwickshire, 10 are considered as a long stay. An adult long stay is classified as 5 or more years in a mental health hospital inpatient setting. The number of long stay inpatients with a learning disability has remained consistent over time (Figure 38).

Figure 38: The number of long stay (5+ years) inpatients with a learning disability has remained consistent over time.

Number of long stay mental health inpatients with a learning disability over time.



Source: CWPT/Assuring Transformation Dataset

DEMENTIA

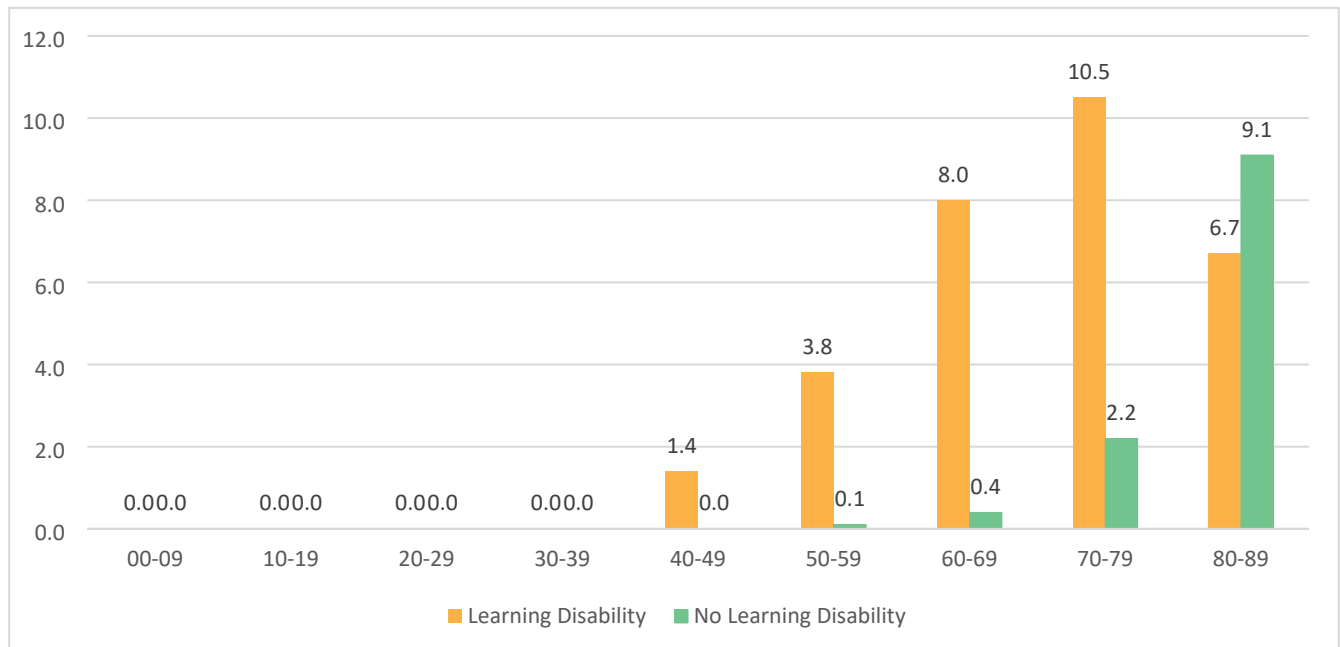
People with a learning disability are more likely to get dementia than people without a learning disability with about 1 in 5 people with a learning disability who are over the age of 65 developing dementia.⁴⁷ People with a learning disability are also more likely to develop dementia at a younger age.

⁴⁷ Alzheimer's Society. *Learning disabilities and dementia*. <https://www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia#:~:text=People%20with%20a%20learning%20disability%20are%20more%20likely%20to%20get,of%2065%20will%20develop%20dementia>. [Accessed 10/09/2024]

Figure 39 shows that until the age of 80, people with a learning disability have higher rates of dementia than those without a learning disability in Warwickshire. There is a higher rate of people with dementia in younger age groups compared to the general population, indicating an earlier onset.

Figure 39: There is a higher rate of people with a learning disability in younger age groups compared to the general population, indicating an earlier onset of dementia.

Percentage prevalence of dementia in those with and without a learning disability, Warwickshire, 2024



Source: Optum Dataset, 2024

Under priority one “reducing the risk of developing dementia” of the Coventry and Warwickshire Living Well with Dementia Strategy 2024-2029 there is a new action targeted towards groups at greater risk of dementia including people with a learning disability: *“In our awareness-raising we will include targeted communications and support for those at greater risk (e.g., those with Mild Cognitive Impairment, individuals with learning disabilities and people from Black and Minority Ethnic backgrounds.”*⁴⁸

⁴⁸ Coventry City Council, NHS Coventry and Warwickshire, Warwickshire County Council. *Coventry and Warwickshire’s Living Well with Dementia Strategy 2024-2029.*

<https://api.warwickshire.gov.uk/documents/WCCC-684757548-759>. [Accessed 28/11/24]

REFLECTING THE NATIONAL PICTURE OF DIFFERENCE

There are marked inequalities in health outcomes experienced by people with a learning disability. These variations were observed in data from the GP registered population in Warwickshire as well as in deaths reviewed by the Coventry and Warwickshire LeDeR programme.

Figure 40 presents a summary of all-age difference between people with a learning disability and those without a learning disability across a range of health conditions as recorded at national level. It confirms that where Warwickshire records differences in prevalence, it largely reflects a national picture.

Figure 40: In all cases the prevalence of the selected health condition was higher in the population with learning disabilities compared to those without learning disabilities.

Variation in condition prevalence all-age with a learning disability and non-learning disability population, England, 2022/23



Source: [NHS Digital, Health and Care of People with Learning Disabilities](#)

VACCINATION RATES

This section considers the uptake of three vaccines in the population with a learning disability, the initial two doses of the COVID-19 vaccine, the flu vaccine, and pneumococcal vaccine (pneumonia). Table 11 shows the uptake of each of these vaccines in 2024 in Warwickshire across different ages.

Table 11: Across all age groups the flu vaccine has a lower uptake than the 75% target coverage.

Uptake of Covid, Flu and Pneumonia vaccines in people with a learning disability, Warwickshire, 2024

Vaccination	Age group			
	0-49 years %	50-64 years %	65+%	All%
Covid*	79.2	94.5	96.2	83.6
Flu	49.6	69.6	73.9	55.5
Pneumonia	0.8	2.3	6.1	1.5

*Initial two doses

Source: Optum dataset, 2024

The Covid vaccine was initially offered to several priority groups based on age and underlying health conditions and then subsequently available to all people aged 5 and over. Uptake of the vaccine among those with a learning disability was higher in older age groups. People with a learning disability registered on the GP register are an eligible population for Covid vaccine boosters.

People with learning disability (and their carers) were identified by NHS England as a clinically 'at risk' group eligible for a flu jab as part of the national flu immunisation programme back in 2019-20.⁴⁹ The World Health Organisation target for those aged 65+ is 75% coverage of the population. Uptake rates for the flu vaccine for those aged 65+ with a learning disability were

⁴⁹ NHS England. *Flu Immunisation Programme 2019-20*. <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2019/10/flu-comms-toolkit-learning-disability-focus-2019-20.pdf> [Accessed 30/07/2024]

slightly under target at 73.9 (and over target at 80.2% of the non-learning disability population⁵⁰) and considerably lower in the younger age groups illustrated in the table above, if the same target were applied. Given the role of respiratory conditions in deaths involving people with a learning disability, measures to improve uptake should be welcomed.

Prior to September 2024, everyone over the age of 65 and those aged 2-64 with certain health conditions were eligible for the pneumococcal vaccine. As of September 2024, guidance on vaccination has been updated to make anyone with a learning disability eligible for a pneumococcal vaccine, although this is yet to be reflected in [The Green Book](#) for health professionals and immunisation practitioners.. This vaccine helps protect against some types of bacterial infections that can cause serious illness including meningitis, sepsis, and pneumonia. One dose of the vaccine is sufficient to offer protection and repeat doses are not required. The results illustrated in the table above refer to uptake rates where the percentage of those with a learning disability in selected age categories received the vaccine in the period July 2022 to June 2023. Nationally, uptake during the period 2022/23 for those aged 65+ was estimated to be 4.5%. Rate of uptake was slightly higher in Warwickshire for people aged 65+ with a learning disability. Again, given the proportion of deaths in which respiratory conditions were implicated for people with learning disabilities, promotion of this vaccine to which people of all ages with learning disability have recently become entitled should be encouraged.

As well as the above key vaccines to prevent infections, people with a learning disability may be entitled to other vaccines because of their age, underlying health condition or lifestyle. Annual health checks for people with a learning disability should provide opportunities to ensure uptake is made available where appropriate.

END OF LIFE CARE

Nationally, the 2016 Care Quality Commission review into end of life care⁵¹ highlighted that people with a learning disability experience inequalities when accessing end of life care. The report recognised several barriers that can contribute, including:

- Recognition of end of life due to being more likely to have unidentified health needs.

⁵⁰ Optum dataset

⁵¹ Care Quality Commission. *A different ending: End of life care review*.

<https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review> [Accessed 29/07/24]

- Communication, with health and care staff sometimes assuming an individual may not be able to cope with discussions on end of life.
- Inequalities in accessing good care, with health and care staff sometimes feeling they must fight to get people with a learning disability the right care.
- Staff awareness, with health and care staff feeling that they lack knowledge around learning disabilities.
- The importance of coordination of care, including getting to know someone to make sure they get the right care.

The review asked a group of people with a learning disability what is important to them with end of life care. Their responses included:

- Having family and friends nearby.
- Having privacy, peace, and quiet.
- Preferring not to be in a hospital.
- Being able to go outside.
- Having the support of a care coordinator when needed.
- Services talking to them to get their views.

Locally, the 2023/24 LeDeR report found that when compared to the 2022/23 report, the national LeDeR report, and the data for the general population, Coventry and Warwickshire have a higher incidence of people with a learning disability and autism dying in a hospital setting. The report included a key theme on end of life and advance care planning:

**End of life and advance care planning key theme
2023/24 Coventry and Warwickshire LeDeR report**

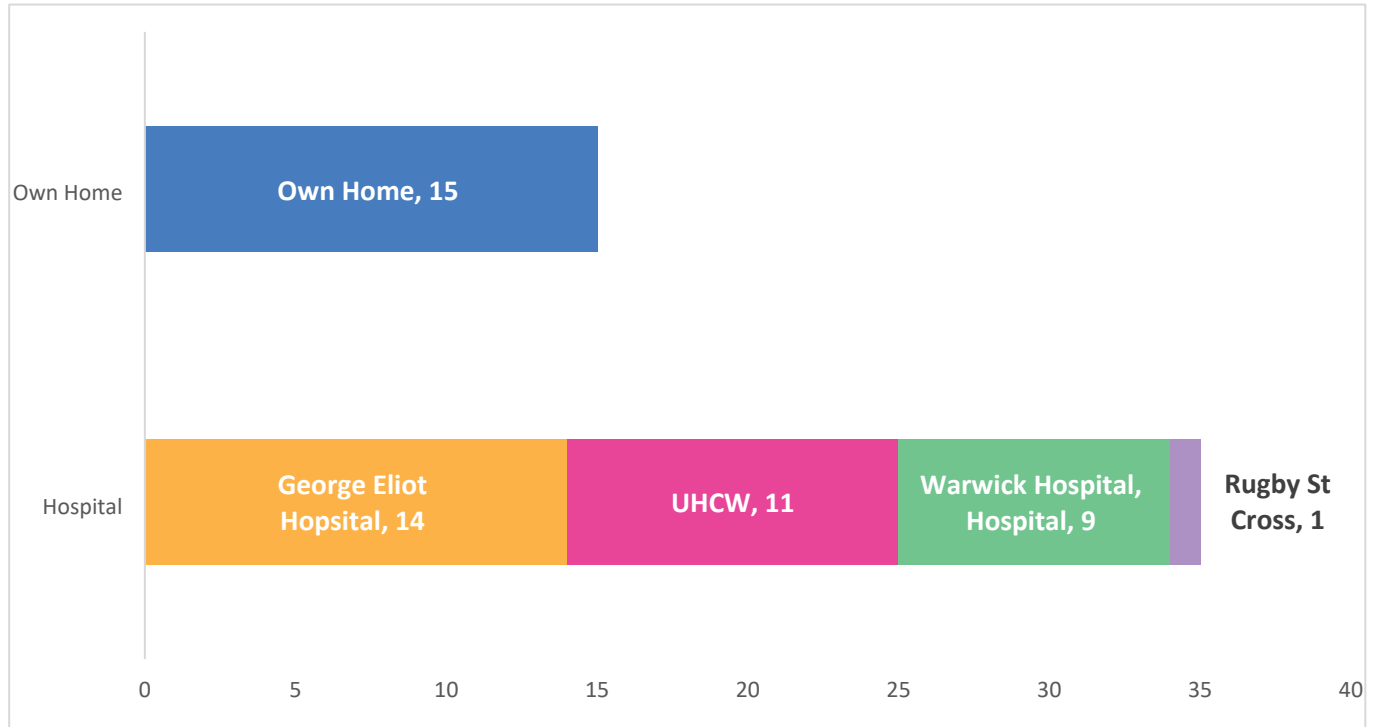
There was minimal evidence of recognition for when individuals were in the last year of their life; this meant a lack of advance care planning and end of life discussions. The impact of this means individuals do not have access to the palliative care teams they require, as well as being able to express their wishes around treatment and death. This learning is being shared with the Palliative and End of Life Programme.

Figure 41 shows the place of death of the 49 adult LeDeR reviews completed during 2023/24. 69% of people died in a hospital setting compared to 67% in 2022/23. Mortality data for Warwickshire in 2022 indicated that typically between 42-46% of the population die in hospital.⁵² No-one died in a hospice setting, compared to 5 people who died in a hospice setting in 2022/23.

⁵² Primary Care Mortality Database, 2020-2022, Business Intelligence (Population health team), [accessed 06/09/2024]

Figure 41: 69% of people with a learning disability died in a hospital setting compared to their own home in Coventry and Warwickshire.

Place of death of initial and focused LeDeR reviews, 2023/24.



Source: LeDeR

The “Delivering high quality end of life care for people who have a learning disability” report from the Palliative Care for People with Learning Disabilities (PCPLD) Network⁵³ highlights six ambitions in delivering end of life care for this population:

1. Each person is seen as an individual.
2. Each person gets fair access to care.
3. Maximising comfort and wellbeing.
4. Care is coordinated.
5. All staff are prepared to care.
6. Each community is prepared to help.

⁵³ NHS England. *Delivering high quality end of life care for people who have a learning disability.*

<https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf> [Accessed 29/07/24]

The PCPLD Network has a range of resources to support palliative care for people with learning disabilities that can be found here - <https://www.pcpld.org/links-and-resources/>.

WIDER DETERMINANTS

The wider determinants of health, how the social, economic, and cultural world around people impacts on them, can have a huge impact on health and wellbeing. This chapter highlights examples of wider determinant inequalities experienced by people with a learning disability, including:

- Being more likely to live in a deprived area.
- Ethnic minorities with a learning disability being under-represented in health services.
- Being less likely to be in paid employment.
- Being less likely to live in settled accommodation.

A UKHSA article⁵⁴ highlighted that when socio-economic factors and opportunities for social participation are accounted for, the increased prevalence of health problems and risk factors amongst people with a learning disability drops dramatically, in some cases to the extent where there is no longer any significant difference between people with learning disabilities and people without a learning disability. This highlights the extent of the impact the wider determinants of health can have on those with a learning disability, and the importance of addressing these to improve health and wellbeing.

THEMES FROM ENGAGEMENT

An engagement mapping exercise was undertaken as part of this JSNA to ensure the voice of the population with a learning disability was reflected in this document, details of which can be found in the introduction. Findings have been fed into the document where they align with the scope, this section captures themes of importance for this population as highlighted by the engagement mapped that do not align with other sections in this JSNA.

INDEPENDENCE

The theme of independence underpins most of the engagement reports and links with many of the below themes. This theme presented itself in a manner of ways, whether services become more community based, knowledge of services, and barriers to building independence.

⁵⁴ UK Health Security Agency. *Health inequalities and the 'hidden majority' of adults with learning disabilities*. <https://ukhsa.blog.gov.uk/2016/10/04/health-inequalities-and-the-hidden-majority-of-adults-with-learning-disabilities/> (Accessed 07/08/24)

In an independence focus group with experts by experience, participants were asked “what does independence mean to us?” which had the following responses:

- Home skills – cooking, cleaning, laundry.
- Doing things for yourself.
- Choice of what to do, where to go, when to do it.
- Having a choice.
- Doing things at a time that suits me.
- Going shopping.
- Make my own decisions without outside interference.
- Holidays on my own.
- Choice of how to spend my money.
- Having a place of your own.
- Budgeting and money skills.
- Choosing where and how to travel.
- Travelling on my own.
- Not being told what to do.
- Choosing where to live.

The focus group identified barriers and enablers to being independent, summarised in the table below.

Barriers	Enablers
Transport issues – unreliable, irregular, expensive	Travel training on routes I choose
Lack of awareness about opportunities	Money management courses
Lack of clear information	Support on learning independent living skills e.g. from day services
Lack of supported living options where I live	Classes for new skills e.g. swimming
Not having the opportunity to learn	Contact with social groups to open up opportunities
Not having enough money	Having the right team to support me
Relying on other people	Accessible information
	A good support worker

ACCESSING ACTIVITIES

Respondents from the engagement mapped for this JSNA said they wanted to access activities in the community and feel safe doing this. Themes on this included:

- Wanting to do more volunteering.
- Wanting a wider variety of activities in more local locations to minimise travel.
- Wanting to take part in sports activities.
- Needing the right support to go out, such as helping to organise the day.
- Knowing in advance when and where they're going to.
- Being concerned about finding places that they've never been to.
- Wanting activities to be age appropriate.
- Having activity options that don't require parents to come along.
- Needing more information to know what activities are on and how they are accessed.

“More variety within the local community, we have to drive to other parts of Warwickshire to take part in some activities... Also look at the age groups available you seem to put us adults all in the same activity from 18-70... Put young people in more appropriate groups”

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant.

“It would be good if they could have something to do in the evening without mum or dad tagging along”

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant. (families/carers, Oct – Dec 2020).

“I think I could do more but I don't know what's happening. Could be more things to do in the evening and weekends.”

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant. (customer, Oct – Dec 2020)

HAVING A BUILDING AS A BASE

Respondents to the mapped engagement said that having a building they know and are comfortable with is important to them. Several respondents said they like having a balance between being in the building and out in the community. Respondents highlight themes on how a building can act as a good base, including that the building is:

- Accessible, such as not having stairs to climb and having accessible bathrooms.
- Has lots of rooms and a garden.
- Familiar and nicely decorated.
- A socialising place with friends.
- Equipped with activity options.
- A calm and peaceful environment.

“It’s the calm peaceful environment that I like. It is also welcoming as you can have a chat and a coffee...same building, it’s somewhere I know and feel comfortable in.”

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant.

TRANSPORT

In the engagement mapped for this JSNA transport was highlighted as an important part of how and when people have services and can access community life. Themes around transport included:

- Transport services being accessible.
- Transport services informing people about who would be picking them up and when.
- Having engaging staff who could enhance the journey experience.
- Needing support about learning a new route.
- Difficulties when there is a lack of transport options and therefore relying on parents.
- Difficulties if transport is only available at certain times meaning that they may miss out on activities/social opportunities, particularly in the evenings or on weekends.

“I can only have transport Monday to Friday day time, not in the evening, so it stops me from doing things if no one is available to take me. It would be better if they could give me transport in the evenings and weekends as I want to get out and see my friends.”

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant.

HAVING A GOOD SUPPORT WORKER

The engagement asked what qualities and skills people felt are important for support workers to have to work with them. Themes included:

- Knowing the individual and having the same staff regularly.
- Making them feel safe and comfortable.
- A good sense of humour and enjoying what they do.
- Good communication.
- Adapting things for the individual.

“My staff know me well and help with communication. Having the same staff regularly is important to me”.

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant.

EXPERIENCE OF TRANSITIONING BETWEEN CHILD AND ADULT SERVICES

Feedback from the engagement mapped for this JSNA highlighted that people found moving from child to adult services was difficult. Themes from the feedback included:

- Finding the change of routine and structure challenging.
- Not wanting to leave friendship groups and support staff.
- Having a plan made about what would happen after college would help.
- Feeling like adjustments weren't made for their disability.

“Leaving school was hard because they put me in a training centre it was hard in the real world for me with my disabilities. They didn't give me help or a plan... they didn't ask me what I wanted to do or what I wanted to try.”

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant.

REASONABLE ADJUSTMENTS

Reasonable adjustments ensure equitable access and achieve positive outcomes for those with a learning disability. Public sector organisations are required to provide reasonable adjustments under the Equality Act 2010⁵⁵ and should do so in an anticipatory manner, as opposed to waiting to react to a need. Reasonable adjustments can include changes to policies, procedures, and staff training, as well as physical alterations such as providing lifts, wide doors, ramps, and tactile signage.

Mencap's "Treat me well" report⁵⁶ provides a list of their top 10 reasonable adjustments:

1. Speak clearly and use simple words. Don't be patronising but do check understanding. It is really important not to make assumptions that someone has understood information they have been given.
2. Take your time. People with a learning disability may need a bit longer than other patients to be able to understand information they are given and to make themselves understood. Just ten extra minutes can make a big difference to many people.
3. Work with supporters. This could be a support worker or family member. Supporters can be really important, particularly for people with profound and multiple learning disability, but remember to talk to the person directly and support them to make decisions - supporters are there to help you do this!
4. Be flexible with appointment times. Many people with a learning disability will find it easier coming to hospital when it is quieter, so an appointment at the very beginning or very end of the day might make their appointment go more smoothly. They may also need an appointment at a time when their supporter is able to accompany them.
5. Make sure people can get into and around the hospital. This includes ensuring there are no physical barriers for people using wheelchairs or with mobility issues, but also making sure signs in the hospital are as easy to understand as possible.
6. Provide a quiet place to wait. Hospitals are often busy, noisy places and this can be overwhelming for many people with a learning disability. Having a quiet place to wait can

⁵⁵ Government Equalities Office. *Equality Act 2010: guidance*. <https://www.gov.uk/guidance/equality-act-2010-guidance> (Accessed 11/06/24)

⁵⁶ Mencap. *Top 10 reasonable adjustments*. <https://www.mencap.org.uk/sites/default/files/2018-06/Treat%20me%20well%20top%2010%20reasonable%20adjustments.pdf> (Accessed 11/06/24)

prevent people getting anxious and having to leave the hospital. Many people also find waiting a long time very difficult.

7. Listen to your learning disability liaison nurse. Most hospitals have learning disability liaison nurses who know lots about reasonable adjustments and can help you to support your patient. Ask your learning disability nurse if you know you will be seeing a patient with a learning disability.
8. Use hospital passports (now known as health and care passports). These are a patient-held, personalised record of what the person needs, how they communicate, and what they like and don't like. Lots of people with a learning disability have hospital passports and reading them will make your job a lot easier!
9. Provide written information in Easy Read format. This means people are much more likely to read and understand information about their appointments and procedures. This is also a requirement of the NHS's own Accessible Information Standard.
10. Always ask the person what they need. Reasonable adjustments are about what the person in front of you needs and they know that better than anyone. Don't make assumptions, just ask the person - and any family or carers with them – and do your best to provide the support they need.

Useful tools:

[The 4 P's Reasonable Adjustments Model](#): Produced by Coventry and Warwickshire Integrated Care System (ICS), to ensure equitable access and achieve positive outcomes for autistic people, we all have a duty to make reasonable adjustments. To understand what reasonable adjustments are required, the 4 P's model can provide a helpful starting point.

[Equality Impact Assessments](#): Equality Impact Assessments (EqiA) make sure a consistent approach is taken across services. It is an evidence-based assessment tool which helps to identify the potential impact of strategies, policies, services, and functions on customers and staff.

[Workplace adjustments for people with a learning disability – Mencap](#): This factsheet gives advice for workplaces on making adjustments for people with a learning disability including interviews, selection, application forms, advertisements, recruitment days, equal opportunities policy statements, and disability confidence.

[The Reasonable Adjustment Digital Flag action checklist – NHS](#): The Reasonable Adjustment Digital Flag is a national record which indicates that reasonable adjustments are required for an individual. This checklist has been produced to support implementation of the flag, so

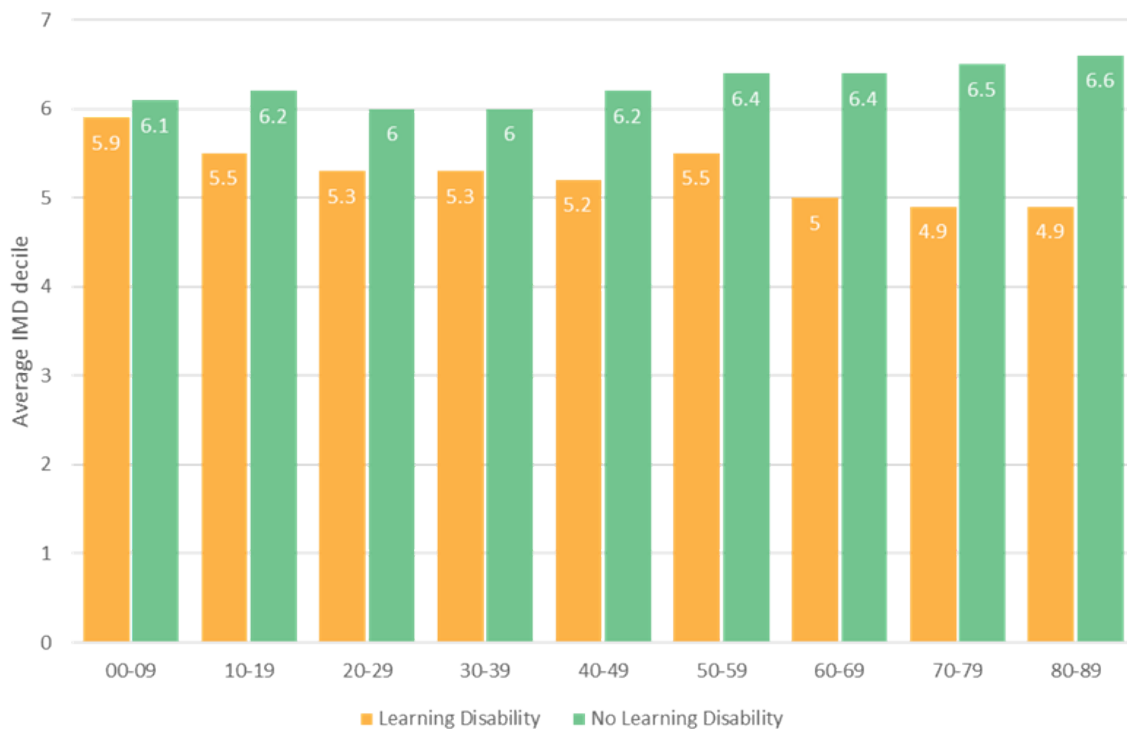
organisations can ensure that processes are in place to identify, record, flag, share, meet, and review and update reasonable adjustment needs on their own systems and records.

DEPRIVATION

In Warwickshire, people with a learning disability are more likely to be living in more deprived areas than people without a learning disability (Figure 42). This difference is more pronounced as people get older, suggesting that whilst the population without a learning disability move towards less deprived areas as they age, the population with a learning disability does the opposite. This could be due to several factors, including the availability of provision to provide support to this population, and the ability to accumulate wealth over their lives linked to lower employment rates.

Figure 42: People with a learning disability were more likely to be living in areas with a lower (more deprived) Index of Multiple Deprivation (IMD) score; this was more marked as people age.

Average IMD decile of place of residence, Warwickshire GP registered population, learning disability and non-learning disability, 2024



Source: Optum dataset & IMD 2019

This pattern was reflected in the national 2022 LeDeR report⁵⁷ which found that 25% of adults who died in 2022 and had a completed review by LeDeR lived in a neighbourhood with one of the two most deprived deciles, compared to 20% for the general population.

The health of the population chapter of this JSNA has highlighted some areas where the learning disability population living in the 20% most deprived areas experience poorer health than the overall population with a learning disability in Warwickshire, including prevalence of:

- Anxiety/phobia
- Depression
- Serious mental illness
- Epilepsy

However, other areas of health such as prevalence of asthma, diabetes, cardiovascular diseases, and obesity, the uptake of flu vaccination, breast screening, and cervical screening have similar rates in the learning disability population living in the 20% most deprived areas as the overall population with a learning disability in Warwickshire. Additionally, the uptake of bowel screening is higher in the learning disability population living in the 20% most deprived areas compared to the overall population with a learning disability in Warwickshire.

ETHNICITY

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 “We deserve better: Ethnic minorities with a learning disability and access to healthcare” report⁵⁸ found that 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.

⁵⁷ Kings College London. *2022 LeDeR report into the avoidable deaths of people with learning disabilities*. <https://www.kcl.ac.uk/news/2022-leder-report-into-the-avoidable-deaths-of-people-with-learning-disabilities> [Accessed 26/09/2024]

⁵⁸ Race Equality Foundation. *We deserve better: Ethnic minorities with a learning disability and access to healthcare*. <https://raceequalityfoundation.org.uk/press-release/we-deserve-better-ethnic-minorities-with-a-learning-disability-and-access-to-healthcare/> [Accessed 30/07/24]

As highlighted in the Local Population chapter of this JSNA, there is an under-representation of those with a learning disability from an ethnic minority group on the GP register. This may result in a higher percentage of the ethnic minority population with a learning disability not getting support they're entitled to such as annual health checks which may then exacerbate health inequalities. This under-representation is also seen in LeDeR reviews, with Table 12 showing the percentage of reviews in the Midlands in 2021 of different ethnic groups compared to the 2021 Census.

Table 12: There is an under-representation of people with a learning disability from ethnic minority backgrounds in LeDeR reviews in the Midlands.

The proportion of notifications to LeDeR in 2021, by region and ethnicity, compared to 2021 Census data.

Source		Ethnicity grouping				
		Asian or Asian British	Black, Black British, Caribbean or African	Mixed	Other	White
Midlands	LeDeR	4.0%	1.7%	3.5%	1.0%	89.9%
	Census	10.7%	3.6%	2.7%	1.7%	81.4%

Source: LeDeR 2021 and Census 2021

When looking at cancer screening rates for the Black and Minority Ethnic (BAME) population across Coventry and Warwickshire, rates of uptake are lower than both the total population with a learning disability and the learning disability population in the Core 20 areas (Table 13).

Table 13: The uptake of both breast screening and cervical screening is lower in the ethnic minority learning disability population compared to the general learning disability population.

Breast screening and cervical screening in Coventry & Warwickshire for the learning disability population, learning disability population in Core 20 areas, and learning disability BAME population.

Population	Breast Screening			Cervical Screening		
	LD	LD Core 20 areas	LD BAME population	LD	LD Core 20 areas	LD BAME population
Coventry & Warwickshire	30.5%	28.3%	13.3%	31.5%	41.5%	29%

Source: Optum, 2024

The “We deserve better: Ethnic minorities with a learning disability and access to healthcare” report undertook a review of published literature to identify factors that impact the access, experience, and outcomes of people from an ethnic minority background with a learning disability.⁵⁹ This review highlighted themes including:

- **Discrimination**, including a lack of culturally appropriate services, language barriers, experiences of racism, and cultural inappropriateness of existing services in terms of diet, activities, religious provision, and staff provision.
- **Community and family networks**, highlighting a difference in living arrangements and main source of support. The report highlighted that people with a learning disability from a minority ethnic background were more likely to live at home (23% of White British reported living in their own or family home compared to 44% of Black/African/Caribbean/Black British ethnicity and 67% of Asian/Asian British background) and more likely to receive their main support from a family member or

⁵⁹ Race Equality Foundation. *We deserve better: Ethnic minorities with a learning disability and access to healthcare*. <https://raceequalityfoundation.org.uk/press-release/we-deserve-better-ethnic-minorities-with-a-learning-disability-and-access-to-healthcare/> [Accessed 30/07/24]

informal carer (14% for White British compared to 49% for Asian or Asian British Background).

- **Increased stress for carers**, including finding stigma around learning disabilities in different communities, and studies suggesting that carers from ethnic minority backgrounds experience higher levels of stress than carers from majority ethnic backgrounds.
- **Abnormal glucose levels**, with screening in Leicester finding that people with a learning disability from an ethnic minority background were four times more likely to have abnormal glucose levels.

The report also makes several recommendations for ICB's to support people with a learning disability from ethnic minorities, including:

- Develop inclusive interventions for carers of people with a learning disability from ethnic minority backgrounds that address the range of challenges faced by carers, including those related to their wellbeing.
- The quality (completeness, validity, and accuracy) of ethnicity coding for people with a learning disability should be validated in health care records by integrated care boards.
- LeDeR reviewers should ensure that they accurately record in the LeDeR review the ethnicity of the person whose death they are reviewing. These data are best collected from the family as part of the review process, where the family can participate in the process.
- Ensure that the number of LeDeR reviews notified within their ICB reflect the demographics of their local population and take action to raise awareness of LeDeR within those communities, especially where notifications are below the anticipated number.

ACCOMMODATION

While there is acknowledgement that accommodation options for people living with learning disability have improved compared to several decades ago, there remain challenges to the provision of appropriate housing or accommodation. Mencap note that these challenges include;

- There is sometimes a lack of choice available to people with a learning disability regarding where they live.

- It can be hard for people to find somewhere good to live, where the right support is provided.
- There is often insufficient safe or suitable housing available.⁶⁰

Engagement mapped as part of this JSNA showed that the right housing is important for people with a learning disability. When asked what is or would be important as part of their housing, participants highlighted:

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

“I have my own flat. I live on my own with support. It’s good. My friends don’t live too far away. That’s very important to me. I visit my friends’ lots. I live near green space which is important for walks. I live near fields so I can see dogs, sheep, cows. I’m really happy where I live.”

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant.

The following provides a breakdown of housing tenure arrangements among people with a learning disability in receipt of a social care package in Warwickshire– see Table 14.

⁶⁰ Mencap. *Housing*. <https://www.mencap.org.uk/advice-and-support/housing> [Accessed 30/07/2024]

Table 14: Just over 1 in 5 people with learning disability and receiving support from adult social care were living in settled mainstream housing with family or friends

Distribution of housing tenure for WCC adult social care service users with learning disability, 2024

Tenure	Number	%
Settled mainstream housing with family/friends	300	21.2%
Unknown	255	18.0%
Supported accommodation/supported lodgings/supported group home	235	16.6%
Tenant (including local authority landlord, arm's length management organisation, registered social landlord, housing association)	195	13.8%
Registered care home	145	10.6%
Tenant private landlord	125	8.8%
Owner occupier or shared ownership scheme	100	7.1%
Sheltered housing/extra care housing/other sheltered housing	20	1.4%
Approved premises for offenders released from prison or under probation supervision	15	1.1%
Registered nursing home	10	0.7%
Shared lives scheme	10	0.7%
Other temporary accommodation	*	*
Placed in temporary accommodation by the council including homelessness re-settlement	*	*
Staying with friends or family short term	*	*

Figures in the above table have followed the guidance on [data suppression](#) issued by NHS digital

Source: Business Intelligence (Adult Social Care), October 2024

Local feedback has highlighted that access to appropriate housing for people with a learning disability can be difficult due to a lack of available stock that meets people's needs. Finding suitable accommodation can be even trickier when trying to provide for complex needs, such as having physical and/or mental health conditions. As highlighted in the health of the population chapter of this JSNA, people with a learning disability have a higher prevalence of a range of health conditions compared to those without a learning disability, meaning they will be more likely to have complex needs that need to be met. Situations where more specialised provision is required sometimes involves that need being met outside of Warwickshire.

LIVING WITH PARENTS

Some people with a learning disability will continue living with parents into adulthood. This may be through choice or because other options are unavailable. We know from Warwickshire County Council data that around 21% of people with a learning disability who have a social care package were recorded as living with family/friends.⁶¹

Estimates suggest that in 2024 in Warwickshire almost 700 people with a learning disability aged 18-64 were living with parents.⁶² This is around a third of people aged 18-64 with a moderate or severe learning disability estimated to be living in Warwickshire. Other sources, however, suggest the proportion is nearer two thirds.⁶³ The age structure of those living with parents is estimated in Figure 43 below.

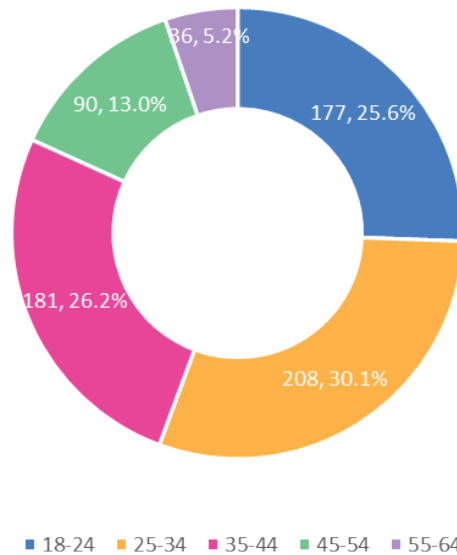
⁶¹ Adult Social Care (Learning disability package), Business Intelligence, 2024

⁶² Projecting Adult Needs and Service Information, PANSI, 2024, [accessed 30/07/2024]

⁶³ NICE. *Care and support of people growing older with learning disabilities*.
<https://www.nice.org.uk/guidance/ng96> [Accessed 30/07/2024]

Figure 43: Just under 20% of adults with a learning disability living with parents estimated to be aged over the age of 45.

Age structure of people aged between 18-64 estimated to be living with parents in Warwickshire, 2024.



Source: PANSI, 2024

This number is expected to grow as the population of adults with a learning disability grows. Pressure of rising costs for either renting or buying a home may also shift accommodation preferences. It is estimated that by 2040 the number of people aged 18-64 with a learning disability living with parents will be around 770 people.⁶⁴

A growing number of people with learning difficulties who live with parents may create implications if there is insufficient support for parents/carers who are happy and willing to care for their loved ones. As the population ages, people with learning disabilities may find themselves living with ageing parents who may be less able to meet their needs. In some instances, people with learning disabilities may find themselves providing care for their parents.

⁶⁴ Projecting Adult Needs and Service Information, PANSI, 2024 [accessed 30/07/2024]

Some of key challenges regarding people with a learning disability and housing is to facilitate access to social housing, ensure housing options are fully explored and supported and seek to integrate the needs of those with a learning disability into wider planning policy.

INFORMAL/UNPAID CARERS

The [Carers' Trust Heart of England](#) currently provides a range of information, support, and training for unpaid carers in Coventry and Warwickshire, including those caring for someone with a learning disability. Data from June 2024 shows the number of individual carers supporting someone with a learning disability in Warwickshire who are known to the Carers' Trust.

Table 15: There are 951 carers supporting someone with a learning disability in Warwickshire known to the Carers' Trust.

Unpaid carers providing support to people with a learning disability in Warwickshire.

Age group	Number of carers
16-64	621
65+	330
TOTAL	951

Source: Carers Trust Heart of England, 2024

In the engagement mapped as part of this JSNA the importance of good respite care to support carers was acknowledged. Respondents with a learning disability wanted respite to work for them, whether this be by continuing their routines or being an opportunity for an enjoyable activity, such as going on holiday on trips out.

“I enjoy it I’m going again for 2 nights in a few weeks. The best bit about respite is seeing other people like staff who are friendly. I have the same staff and they’re very nice. I stay in different rooms, but my favourite room is number 3. I have friends at respite”

- Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant.

EMPLOYMENT

In 2017, a Department of Work and Pensions' report noted that employment rates amongst disabled people reveal a significant inequality in the UK.⁶⁵ The NHS Long Term Plan acknowledges that employment rates for people with learning disability have remained low for many years.⁶⁶ This information sits, however, in the context of widely held acknowledgement that appropriate work can bring a range of health and wellbeing benefits.⁶⁷

One measure of the above is the gap in the employment rate between those who are in receipt of long-term support for a learning disability (aged 18-64) and the overall employment rate. In 2022/23 in Warwickshire, this gap was measured at 76.5 percentage points, significantly worse than the England value of 70.9 percentage points.⁶⁸

A further measure of employment levels among people with a learning disability is the record of the percentage of the population (aged 18-64) who are in receipt of long-term support for a learning disability who are in paid employment. This is shown in Figure 44, which shows that the rate of employment among people with a learning disability in Warwickshire has declined over the past 6 years.

⁶⁵ Department of Work and Pensions, Department of Health and Social Care. *Improving lives: the future of work, health and disability*. <https://www.gov.uk/government/publications/improving-lives-the-future-of-work-health-and-disability> [Accessed 30/07/2024].

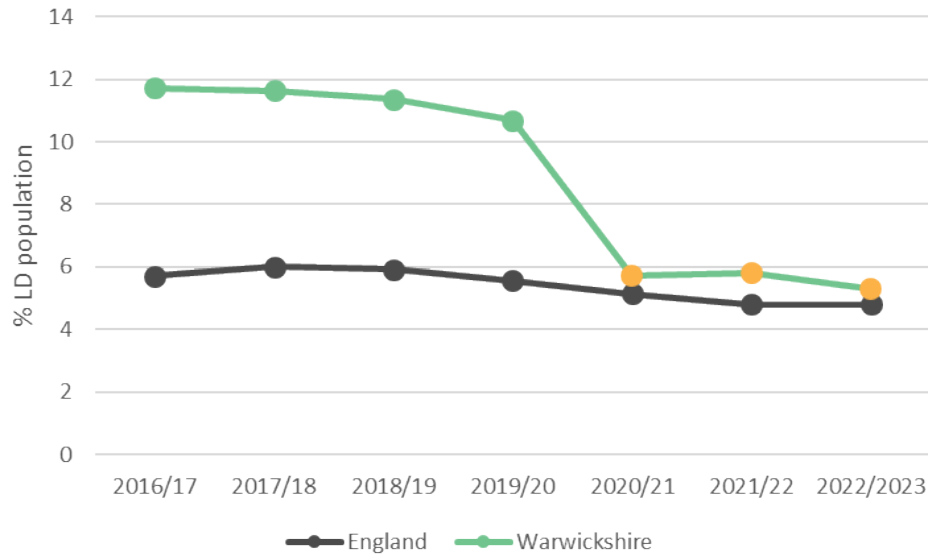
⁶⁶ NHS. *Creating a new 10-Year Health Plan*. <https://www.longtermplan.nhs.uk/> [Accessed 30/07/2024]

⁶⁷ [Supporting Information](#), 2024, Fingertips, Dept of Health and Social Care [accessed 30/07/2024].

⁶⁸ [Gap in Employment rate between those who are in receipt of long-term support for a learning disability and the overall employment rate](#), 2022/23, Fingertips, Dept of Health and Social Care [accessed 30/07/2024]

Figure 44: Over the past 6 years, Warwickshire’s rate of employment among people with a learning disability (aged 18-64) has declined; between 2016/17 and 2019/20 its rate was significantly better than England but in the last two recorded periods it is in line/similar to England.

The percentage of the population (aged 18-64) in Warwickshire who are in receipt of long-term support for a learning disability who were in paid employment, 2016/17 to 2022/23.



Source: Fingertips, 2024

Employment appeared regularly in engagement mapped for this JSNA, including mentions of support with getting paid work, work experience placements, and voluntary roles. Some engagement participants reported being in voluntary roles which they enjoyed but many wanted the opportunity for paid employment. For those looking to gain employment or volunteering roles, participants said they would like to find roles relating to their interests and hobbies.

“I prefer volunteering but wouldn’t mind being paid working in the future. I don’t think there’s enough support to find employment.”
 - Community Provision for Working Age Adults with Disabilities and/or Mental Health Needs engagement participant.

One engagement activity sought feedback from experts by experience on getting a job and keeping it. The engagement highlighted barriers to getting a job, and solutions of how to address this:

Barriers	Potential solutions
Job application forms and processes can be complicated and can take a lot of time.	<ul style="list-style-type: none"> • More support to complete forms. • Pictures on application forms. • Less complicated questions. • Other ways to apply like having a conversation.
Interviews can cause a lot of anxiety.	<ul style="list-style-type: none"> • Support to prepare for interviews. • Opportunities to practice interview skills. • Alternative options for interviews like a job trial.
There isn't always transport to get to work.	<ul style="list-style-type: none"> • Support to apply for Access to Work. • Support to arrange transport.
Some parts of jobs might be difficult. For example, if there's too much reading or computer work.	<ul style="list-style-type: none"> • Encouraging employers to adapt jobs to fit with a person's individual strengths.
Colleagues may not understand my disability(s) or my needs.	<ul style="list-style-type: none"> • Training for employers and staff by people with lived experience. • Making sure there is up-to-date information for employers.
It can be difficult when there are a lot of day-to-day changes at work.	<ul style="list-style-type: none"> • Support and training for colleagues so they tell you about changes in good time.

“I would like people and employers to have patience”
- Getting a job and keeping it engagement participant.

“I would like people to understand my disability and understand what I can and can't do. I don't want to be pushed into what I can't do”
- Getting a job and keeping it engagement participant.

WARWICKSHIRE SUPPORTED EMPLOYMENT SERVICE

Launched in February 2023, [Warwickshire Supported Employment Service](#) (WSES) is a dedicated service aimed at enabling people with learning difficulties and or autism to gain paid or sustain employment. Each customer receives help with a range of pre-employment activities including 1-1 journey guide support, preparation for employment workshops, CV building, industry tours, and access to training and qualifications.

The service can continue to provide in-work support once employment has commenced and accepts referrals from people in employment to support individuals to stay in paid roles. Between the start of the service in February 2023 to May 2024, 70 customers have been supported to gain and sustain paid work, and the sustainability figure shows that 90% of these roles have been retained. In June 2024 WSES had 157 people receiving direct support across Nuneaton, Rugby, Leamington Spa and Stratford-upon-Avon. Of the total customers to date (June 2024) around one third had a learning disability.

WSES sits within the skills hub and works closely with Fair Chance Employment Programme, conducting 'upskill sessions' for fair chance employers, recently training 28 NHS employees in supported employment techniques such as TSI and job design. Currently, 72 businesses are registered with the Fair Chance Employer Programme, which has a flexible support fund that has facilitated the creation of five WSES paid roles. As a result of the growing scheme, 31 of our customers are now employed by a Fair Chance employer.

A key part of the Fair Chance Employment Programme is an easier to use Fair Chance Jobs Portal which aims to break down barriers in traditional recruitment process. The team may also be able to access funding to support people into work – for example for tools or equipment required for a job.

Many people with a learning difficulty will be in receipt of benefits to support them. Some of these are impacted by paid employment and more work needs to be done to assist people to navigate the financial implications of taking up paid employment.

