SUNDERLAND JOINT STRATEGIC NEEDS ASSESSMENT: LEARNING DISABILITY (2023)

1. INTRODUCTION

The Joint Strategic Needs Assessment focuses on the health and social care needs of adults with a learning disability living in Sunderland. It is a live document which will inform Sunderland's commissioning intentions and support co-production.

This JSNA and any associated work programmes will be overseen and maintained by Sunderland Adult Services and Northeast & North Cumbria Integrated Care Board. The action plans and strategies resulting from this JSNA will ensure that the key issues rising from this report are addressed in a systematic way.

In summary the JSNA:

- Describes the needs of people in the City of Sunderland who have learning disabilities.
- Identifies inequalities experienced by this group compared to the general population.
- Will inform future commissioning strategies, plans and intentions based on a local assessment of need.

2. POPULATION AND PROJECTED ESTIMATES

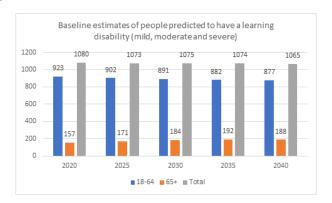
A learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), as well as a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.

Sunderland has a population (mid-2020) of around 277,846. The population has fallen from close to 300,000 in the early 1990s, due in part to outward migration of younger working age people. Recently, this fall has levelled out and the population is predicted to remain stable at around 277,000 by 2031[1] . The recorded prevalence of learning disability in Sunderland is 0.8% compared to a prevalence of 0.5% in England.

Baseline estimates from POPPI[2] predict that the overall number of people with learning disabilities is stable, with a small reduction predicted by 2040, however there are two significant trends that have been identified:

- There is a growth in people with learning disabilities who are over 65 and who will have a high chance of frailty and of early onset dementia.
- There is an increase in complexity of the young people transitioning from children's services, in particular people with multiple disabilities and others whose behaviour presents challenges which can clearly be seen by Commissioning trends over recent years. Due to the

complexity of the young people transitioning from children's services there is significant demand arising from their needs.



[1] oce22413 Sunderland JSNA 2021-220 Oct Review Cover A4.gxp.

[2] www.poppi.co.uk

IDENTIFICATION

While we recognise that not everyone who has a learning disability needs care and support, it is estimated that only 60% of children with learning disabilities are known to state services as they grow up — this is a problem because those who are not known to services until adulthood are more likely to be in secure settings in later life[3].

We know that in January 2023, 2,463 children/young people had an education, health and care plan - 883 were children/young people aged 11-15 years and 569 were aged 16-19 years[4]. However, what we don't know is:

- How many children and young people are living at home who Together for Children do not currently know, but who may require information, advice support in the future.
- How many children at school have special educational needs but do not have an education, health and care plan and there are no statutory duties on schools or services around transition.
- Data and intelligence about our Black and Minority Ethnic communities.

There is a need to ensure that we know and understand who and how many people may need support in the future so that we can plan and develop the right services for people. Sunderland's Transition Management Group provides strategic and operational leadership and manages the transition process for young people into adulthood to ensure that those who will need care support into adulthood are known by Adult Services and can receive the right support at the right time.

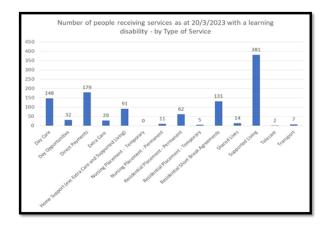
[3] Fair Society Healthy Lives full report (parliament.uk)

[4] Data from Together for Children

4. ADULT SOCIAL CARE SUPPORT

Adult Services data[5] shows that in March 2023:

- In total there were 875 adults receiving support from the Local Authority. This equates to 28% of the estimated 3,096 adults living in Sunderland who have a learning disability diagnosis:
- 766 people were aged under 65 years
- 109 people were 65 years and over
- 375 people were female
- 500 people were male



[5] Data from Sunderland City Council Adult Services

5. HEALTH CARE AND HEALTH INEQUALITIES

People with a learning disability are more likely to experience poorer health outcomes and have shorter life expectancies than the general population. While, they have the same health issues as those without, they are more likely to experience additional health needs including diabetes, sensory impairment, obesity, coronary heart disease, cancer, dental issues, gastrointestinal problems, epilepsy, swallowing and feeding problems, mental health problems, dental issues, and respiratory disease.

5.1 Annual Health Checks

In recent years Primary Care Services in Sunderland have increased the uptake of annual health checks and health action plans for people with learning disability, year on year, as well as increasing the numbers of health checks provided, GP practices are working to ensure the health checks that are carried out are of high quality, purposeful, holistic and that they address the physical, mental health and emotional wellbeing needs.

Based on their greater health needs, it is critical that people with a learning disability have full access to health and care services and full access to preventative services. GP practices have comprehensive learning disability registers that are validated each year, ensuring their learning disability patients are invited to their health checks, working with individuals and their families or carers, practices identify, document, and the review reasonable adjustments that their patients may require to ensure experiences are both positive and helpful.

In 2024, we expect that more individuals will be asked about the reasonable adjustments needed to deliver good health care, this is in line with the Equality Act 2010, as well as a new campaign initiated

by the Northeast and Cumbria Learning disability Network, this new initiative means that where consent is gained, information will be shared with other organisations to further improve patient outcome and experience.

In 2022/2023, 1874 annual health checks were provided, the target was 79% and it was exceeded and 81% of health checks were achieved. In 2023/2024 the target was slightly increased to 80%, this allows for patient choice as not everyone with a learning disability wants a health check. We will know if the target has been met by the end of March 2024[6].

[6] Sunderland ICB

5.2 Lifestyle Factors

Local lifestyle data[7] has identified that adults with a learning disability are:

- More likely to smoke (26.7% compared to 15.9%)[8]
- Less likely to eat the recommended 5 or more portions of fruit and vegetables each day (44.8% compared to 47.6%)[9]
- More likely to be of excess weight (74.8% compared to 58.0%)[10]
- More likely to have lower average mental wellbeing scores (44.3 compared to 52.9)[11]

[7] <u>Living well - Sunderland City Council</u> *and* <u>oce22413 Sunderland JSNA 2021-220 Oct Review Cover</u> <u>A4.qxp</u>;

[8] ALS 2017 Profile - Smoking and Vaping.pdf (sunderland.gov.uk)

[9] ALS 2017 Profile - Healthy Eating.pdf (sunderland.gov.uk)

[10] ALS 2017 Profile - Healthy Weight.pdf (sunderland.gov.uk)

[11] ALS 2017 Profile Mental Wellbeing.pdf (sunderland.gov.uk)

5.3 Access to Health Care Services

People with learning disabilities are less likely to get some of the evidence-based treatments and checks they need, as well as facing barriers when accessing services. While GPs are usually the first point of contact for people accessing health care services, people with a learning disability make far less use of their GP than the general population, which can lead to delays in diagnosis and treatment.

Barriers stopping people with a learning disability from getting good quality healthcare include[12]:

- a lack of accessible transport links
- patients not being identified as having a learning disability
- staff having little understanding about learning disability
- failure to recognise that a person with a learning disability is unwell
- failure to make a correct diagnosis
- anxiety or a lack of confidence for people with a learning disability
- lack of joint working from different care providers
- not enough involvement allowed from carers

• inadequate aftercare or follow-up care.

Led, by the ICB working with partners, Sunderland has a Primary Care Strategy aimed at improving the health, wellbeing, and care outcomes for Sunderland residents with specific outcomes achieved for improving the health of people with learning disabilities.

[12] Learning Disability - Health Inequalities Research | Mencap

5.4 Premature Mortality

Research shows that on average, people with a learning disability die earlier than the general public, and do not receive the same quality of care as people without a learning disability. On average, the life expectancy of women with a learning disability is 18 years shorter than for women in the general population. The life expectancy of men with a learning disability is 14 years shorter than for men in the general population (NHS Digital 2017).[13] LeDeR reviews deaths to see where we can find areas of learning, opportunities to improve, and examples of excellent practice. This information is then used to improve services for people with a learning disability[14].

[13] Learning Disability - Health Inequalities Research | Mencap

[14] LeDeR - Home

5.5 Stopping over medication of people with a learning disability (STOMP)

Public Health England estimates that about 30,000 to 35,000 adults with a learning disability takes psychotropic medication daily, children and young people are also prescribed this medication. If taken for an extended period, or prescribed at a higher dosage, this medication can cause problems and side effects can include putting on weight, feeling tired or 'drugged up', serious problems with physical health.[15]

[15] <u>STOMP Everyone working together to stop the overuse of psychotropic medicines and to improve people's quality of life (england.nhs.uk)</u>

5.6 Building the Right Support and Transforming Care

Historically, too often people with learning disabilities have been routinely placed in institutions away from their homes and communities. The scandal at Winterbourne View in 2011 and subsequent scandals, highlighted the fact that despite the progress made as a society in recent decades, for a small number of people nationally there is still a reliance on hospital care, particularly in some parts of the country[16]. Adult Services along with the ICB commissioners take a leading role in supporting the discharge planning for people who are currently in a long stay hospital, with the aim of enabling people to live in their own homes, with support, in the local community.

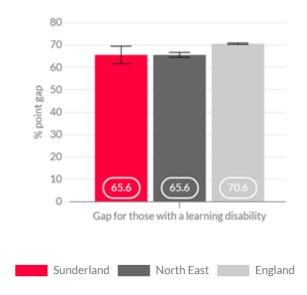
[16] Id-nat-imp-plan-oct15.pdf (england.nhs.uk)

6. EMPLOYMENT

People who are unemployed are more likely die prematurely, have poor mental health or other health problems and be living in poverty. People with learning disabilities are less likely to be in paid employment that people who do not have a learning disability[17].

The 2021-2022 Adult Social Care Outcomes Framework reported that only 3% of adults with a learning disability were in paid employment which is comparable with the North East (4%) and England (5%).[18] The JSNA shows[19] the gap in employment rates was:

Gap in employment rates (2021/22)



There is a need to ensure that people with learning disabilities have opportunities to gain skills and support, to get a job and remain employed.

[17] LD Report Easy Read (instituteofhealthequity.org)

[18] Health - UTLA | Sunderland | Report Builder for ArcGIS

[19] Economy - UTLA | Sunderland | Report Builder for ArcGIS

HOUSING WITH SOCIAL CARE AND SUPPORT

In Sunderland, 94% of adults with a learning disability live in their own home or with their family[20].

In March 2023, there were 381 people with a learning disability living in a supported living service, funded by Sunderland Local Authority. Data held by Adult Services from November 2023, showed that there were a further 64 people with learning disabilities known to adult social care to have a need for accommodation with social care and support, 5 of who were currently in a hospital [21] .

There is a need to ensure that people with learning disabilities have access to the right type of housing with the right care and support so that they can live safe, happy and independent lives in their local communities.

[20] Health - UTLA | Sunderland | Report Builder for ArcGIS

[21] Data from Sunderland City Council Adult Services

8. DISCRIMINATION

People with a learning disability are more likely to suffer discrimination and be bullied than those without a learning disability. This can result in it being harder for them to develop social networks and relationships, gain paid employment and it can lead to people experiencing poor mental health[22].

9. SOCIAL ISOLATION AND LONLINESS

Friendships and socialising are as important to people with learning disabilities as they are to those without, however people with learning disabilities may have fewer chances to take part in leisure activities or socialise with their peers, and so may have fewer friends. Having an active social life can help people with a learning disability to feel happier, included and valued, however some of the barriers preventing people with learning disabilities being able to access their local communities and have an active social life may include [23]:

- Inaccessible venues and facilities
- Lack of inclusive activities
- Lack of support
- Financial constraints
- Lack of accessible information
- Mobility and transport difficulties
- Negative attitudes towards disability

Further Information:		
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People at the Heart of Care - Adult Social Care Reform White Paper:

https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper

NHS Long Term plan 2019:

https://www.longtermplan.nhs.uk/areas-of-work/learning-disability-autism/

Down Syndrome Act 2022: <u>Down Syndrome Act 2022 (legislation.gov.uk)</u>

Down Syndrome Act 2022 guidance: call for evidence - GOV.UK (www.gov.uk)<u>Easy Read Down</u>
<u>Syndrome Act 2022 guidance - call for evidence - Department of Health and Social Care (dhsc.gov.uk)</u>

Equality Act 2010 – Learning Disabilities:

https://www.gov.uk/government/publications/equality-act-guidance/disability-equality-act-2010-guidance-on-matters-to-be-taken-into-account-in-determining-questions-relating-to-the-definition-of-disability-html

Building the Right Support: NHS England » National plan – Building the right support

Mental Health Act 2007: newbook.book (legislation.gov.uk)
https://www.legislation.gov.uk/ukpga/2007/12/contents

Valuing People - A New Strategy for Learning Disability for the 21st Century:

Valuing people now.pdf (iriss.org.uk)

Sunderland City Plan: oce22807 CoS Sunderland City Plan 2023-2035.indd

Sunderland Healthy City Plan: M0103076 HEALTHY CITY PLAN 2021.pdf (sunderland.gov.uk)

Sunderland Living Well and Ageing Well: https://www.sunderland.gov.uk/article/27863/Living-and-Ageing-Well-2022-2024

Sunderland Carers Strategy: https://www.sunderland.gov.uk/Carers-Strategy

Sunderland Adult Social Care Market Position Statement:

https://www.sunderland.gov.uk/media/20135/Adult-Services-Market-Position-Statement-2018/pdf/oce21115 Adult Services Market Position Statement 2018 A4 Web.pdf?m=636577633 663670000

https://www.sunderland.gov.uk/media/20981/Adult-Service-Market-Position-Statement-Update-November-2018/pdf/MPS Update 2018.pdf?m=636809016975370000

[23] Learning Disability - Friendships and Socialising Stats Mencap