Adults with Learning Disabilities

Introduction

There are several definitions of learning disability used in the UK. Mencap define a learning disability as 'a reduced intellectual ability and difficulty with everyday activities – for example household task, socialising or managing money - which affects someone for their whole life¹. Whilst an older document, Valuing People: White Paper for England about health and social care support for people with a learning disability (2001) explains how an learning disability can effect individuals including:

- a significantly reduced ability to understand new or complex information or to learn new skills;
- a reduced ability to cope independently;
- an impairment that started before adulthood, with a lasting effect on development.

Summary

In 2023 it was estimated that in England there were 1.3 million people with learning disabilities, of these 950,000 are adults. This is the equivalent to 2.16% of the adult population in the UK. In 2019/20 the number of working aged adults known to councils, who were receiving long-term support was 153,145². It is predicted that there are over 17,653 adults in Norfolk that have a learning disability, of which 12,714 are of working age⁵. Of these it is predicted that there are around 2,892 adults that have a moderate to severe learning disability. Approximately 5,000 adults and children with learning disabilities who could require some form of support are known to Norfolk County Council's Social Services department.

Headlines

Compared to the rest of the population, adults with learning disabilities have:

- **Lower life expectancy** evidence shows that adults with learning disabilities have a significantly shorter life expectancy than those of the general population. The latest LeDeR (2021) states the median age at death for people with a learning disability is 62 years. This is significantly less than the median age of death of 82.7 years for the general population³.
- **Different causes of death** the main causes of death in adults with learning disabilities in England are circulatory diseases (16.7%), respiratory diseases (14.5%) and cancer (14.6%)³. This differs to the general population, of which 4.8% of all deaths registered in 2021 were the cause of cancer, 14% circulatory diseases and 10% Dementia and Alzheimer⁴. A possible reason for this difference is that adults with a learning disability have a lower life expectancy than the general population and probability of getting cancer increases with age. Although compared to the general population the life expectancy is lower, within the population group it is actually increasing each year. Estimated population figures show that, over the next 10 years there will be an increase in the number of adults aged 65 and over with a learning disability⁵.
- **Different lifestyle issues** adults with learning disabilities have higher rates of obesity and are more likely to be overweight in comparison to people who do not have a learning disability. Many adults with learning disabilities are less likely to eat a well-balanced healthy diet and have low levels of physical activity⁶.
- **Different levels of severity and impact –** a learning disability is lifelong, however there are different types which can alter the impact a learning disability has on an individual's life. Those

⁶ NHS Health Scotland, People with Learning Abilities in Scotland (2004)



¹ Learning disability – applying All Our health, March 2023 <u>Learning disability - applying All Our Health - GOV.UK</u> (www.gov.uk)

² OHID Public health profiles - OHID (phe.org.uk)

³ LeDeR Annual Report learning from Lives and Deaths: People with a Learning Disability and Autistic People <u>Master LeDeR</u> 2023 (2022 report) (kcl.ac.uk)

⁴ Office for National Statistics, Deaths registered in England and Wales: 2022 <u>Death registration summary statistics, England</u> and Wales - Office for National Statistics

⁵ POPPI, http://www.poppi.org.uk/index.php?&PHPSESSID=n3t75vvafpc9qpe9sp28o9g8i0&sc=1&pageNo=374&loc=8268

with a mild learning disability are often able to mix well with others and cope with most everyday task. They may only require support in small areas of their life, such as filling out forms. Adults with a severe learning disability will need more support in areas such as mobility, personal care and communication. Some people with a moderate learning disability may also need support in these areas, but not definitely.

Different levels of complexity – some people with a learning disability have complex and
multiple need including those with both LD and Autism which brings complex needs and
behaviours that can challenge as well as multiple and profound needs. It is estimated that 1.1%
of the Norfolk population are Autistic, which mirrors the UK average. This means that there are
10,000 people in Norfolk with autism, as stated in the Norfolk Autism Strategy. This figure is
forecast to rise. By 2035 there is expected to be the following number of people autism, if it
remains at 1.1% of the population:

0-19	19-64	65+	Total
2,900	5,200	2,800	10,900

Around 130 young people transfer to Adult Services each year. Of which 15 are autistic without a learning disability or mental health issue, 85 have a learning disability with around 50 young people also recorded as autistic. 20 people have mental health needs and 10 have physical disabilities. ¹⁹

People supported by Norfolk County Council

- Currently in Norfolk there are just over 3,565 adults with learning disabilities that are known to Norfolk County Council's Adult Social Services Department. Of those adults over 95% are receiving some form of long-term package support. Long-term support is described as 'support provided with the intention of maintaining quality of life for an individual on an ongoing basis' and covers services such as residential and nursing care, day services and supported living.
- The vast majority of adults with learning disabilities supported by Norfolk County Council Adult Social Services Department are of working age (18-64), with 37.6% falling within that age category (Figure 1). This is to be expected due to the lower life expectancy of those with learning disabilities, however based on previous estimates we anticipate the number of those in Norfolk aged 65+ with a learning disability to increase over time.
- PfAL Service data shows that in 22/23 in Norfolk we had 163 young people turning 18 and being
 actively assessed under The Care Act to move in to Adult Social Care. This is an increase from
 the previous year and the number is predicted to increase again for 23/24. The PfAL service also
 provides information and advice to additional young people at the point of referral to the service
 but who do not require a Care Act assessment and through 'PfAL Conversations' with young

⁷ NHS Digital, Short and Long Term Data Return 2017-18 Guidance



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Age profile of adults with learning disabilities supported by NCC 40 35 30 25 % 20 15 10 5 0 18 to 64 65 to 74 75 to 84 85 to 94 95 and over

people open to the Service but not old enough yet to be assessed under The Care Act.

Figure 1: Age profile of adults with learning disabilities supported by NCC - Source: Norfolk County Council Active to Adult Social Services Monitor 15/12/2023

Of the service users in Norfolk, 3.7% are in some form of paid employment in 2021/22. This figure is lower than the middle ranked local authority in England, of which 4.8% of working age adults with learning disabilities were in any form of paid employment⁸. In 2022/23, 5.1% of adults with a learning disability were in paid employment in Norfolk. This is higher that the previous year's (3.7%) for Norfolk. Unforunately 2022/23 county level data cannot be compared with regional and national average as this has not become publicly available yet. This is significantly lower than that of the general population. In Norfolk 59.2% of adults in the general population are in some form of paid employment. Norfolk's employement rate is slightly lower than that of England, which is 63.4%⁹.

Adults with learning disabilities who are in paid employement have higher rates of part time working, with 31.8% of those working 16 hours or less a week in England, compared to 21.1% of working age adults without a learning disability¹⁰.

There is substantial evidence showing an association between work and health outcomes¹¹. Being unemployed is detrimental for physical and mental health and wellbeing¹². Long term unemployment is associated with higher risk of early mortality and it has been found that being in work reduces the risk of depression. A study on unemployment and mental health found those who were unemployed said that it affected their mental health, noticing an increase in depression and anxiety¹³. In 2021/22, there was 42% of adults of working age with secondary mental health needs living independently in Norfolk.

Residential care is the biggest category of long-term support expenditure for people who have a learning disability in Adult Social Services in England. In 2023 £1.2 million was spent on residential care for

¹³ Unemployment and metal health, April 2021 <u>Unemployment and mental health - The Health Foundation</u>



⁸ Norfolk Insight, Health Report for Norfolk Health - UTLA | Norfolk | Report Builder for ArcGIS (norfolkinsight.org.uk), Measures from the Adult Social Care Outcomes Framework, England, 2022-23 - NHS Digital

⁹ Norfolk Insight, Economy & Employment <u>Economy and employment - Map explorer - Norfolk Insight</u>

¹⁰ Census 2021 Disability and employment - Office for National Statistics (ons.gov.uk)

¹¹ http://publichealthmatters.blog.gov.uk/2016/09/14/understanding-the-relationship-between-health-work-andworklessness/

¹² Department for Health & Social Care, Work health and disability green paper: Improving lives https://www.gov.uk/government/consultations/work-health-and-disability-improving-lives/work-health-and-disabili green-paper-improving-lives

adults with learning disabilities (figure 2).

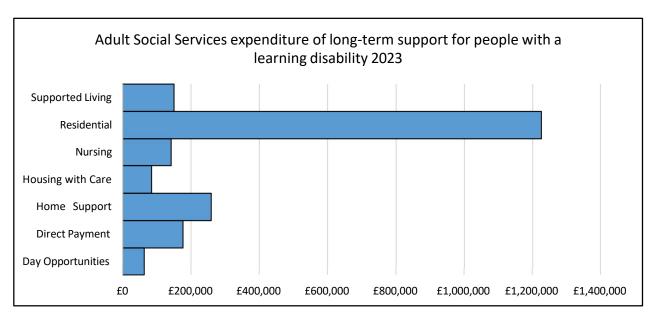
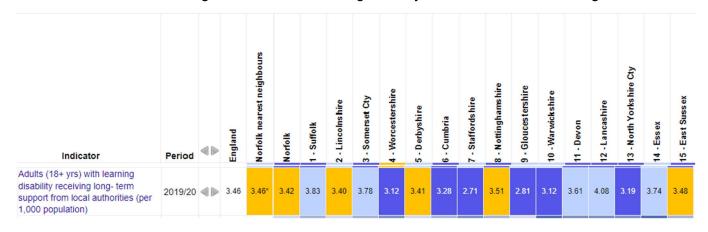


Figure 2: Adult social services expenditure of long-term support 2023.

There has been a slight increase in the number of adults with learning disabilities living in stable and appropriate accommodation in Norfolk, 74.5% in 2016 to 75.6% in 2021. This is still lower than the rate for England, which is 78.8% but is higher than that of the East of England (73.3%)¹⁴.

Over 35.8% of adults with learning disabilities receiving support from Norfolk County Council are in residential care. There were 61 new long term residential admissions to residential care for the financial year 2022/23 (1 Apr 2022 – 31 March 2023) in Norfolk. An admission is a long term admission to residential care without an end date. In 2022/23, long term support needs of working age adults (18-64) met by admission to residential and nursing care homes, was 16.7 per 100,000 population in Norfolk. This is lower than the financial year 2021/22 figure (24.2 per 100,000 population). ¹⁵

Figure 2 is information taken from the Public Health Outcome Framework Learning Disability Profile that shows Norfolk has a higher rate of adults with learning disabilities known to local authorities than England and the East of England region. The rate for Norfolk is also one of the highest among Norfolk's CIPFA (Charted Institute of Public Finance and Accountancy) nearest neighbours. Figure 3 shows that this rate has been decreasing over time and is not significantly different rate to that of England.



¹⁴ Public Health Outcomes Framework, 1.06i Adults with a learning disability who live in stable and appropriate accommodation https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/

¹⁵Measures from the Adult Social Care Outcomes Framework, England, 2022-23 - NHS Digital



Figure 2: Adults (18 to 64) with learning disability known to Local Authorities per 1,000 population Source: Public Health Outcome Framework https://fingertips.phe.org.uk/profile/learning-disabilities/

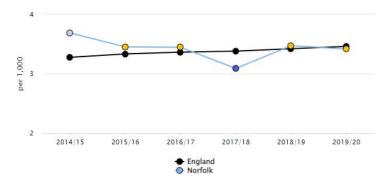


Figure 3: Adults (18 to 64) with learning disability known to Local Authorities per 1,000 population over time Source: Public Health Outcome Framework https://finaertips.phe.org.uk/profile/learning-disabilities/

Influences on Health and Wellbeing

The cost of residential care is not only financial, it can also have a negative effect on the health and wellbeing of the residents if admitted without other options being explored. The loss of independence that can be experienced from a stay in residential care can have a lasting effect and create a reliability on care. This can increase the length of time an individual spends in a residential care home. People can lose contact with neighbours and friends and can end up suffering from loneliness which affects their health and wellbeing.

People who have learning disabilities have more difficulty in identifying health problems and getting treatment for them compared to those that do not have a learning disability. This can have an effect on the life expectancy of adults with learning disabilities and can result in pressure on the hospital services as conditions that are left will deteriorate and can result in hospitalisation. As a response to this the NHS introduced annual learning disability health checks in 2008.

In Norfolk, of those eligible adults with a learning disability almost 53.4% have had a GP health check. This is in line with East of England (53%) and is not significantly higher than England (52.3%). Within the East of England region Norfolk sits within the middle of the other areas, with the best being 69.6% and the worse 30.7%.

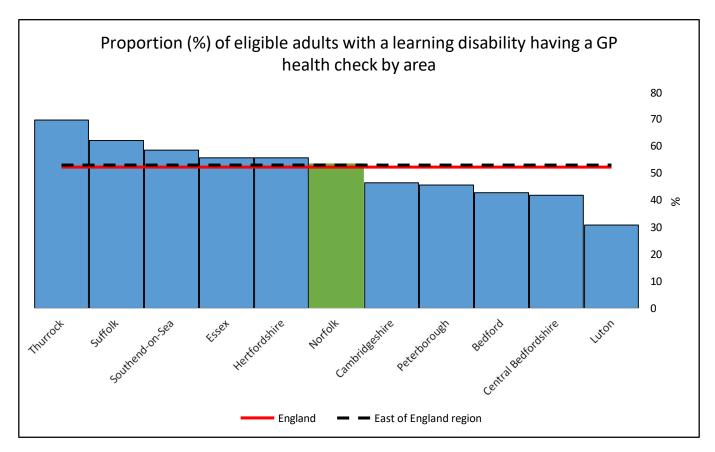


Figure 4: Proportion (%) of eligible adults with a learning disability having a GP health check Source: Public Health Outcome Framework https://fingertips.phe.org.uk/profile/learning-disabilities/

Following an inquiry into premature deaths of people with learning disabilities the Healthcare Quality Improvement Partnership on behalf of NHS England commissioned the Learning Disabilities Mortality Review (LeDeR) Programme. The LeDeR programme aims to make improvements in the quality of health and social care for people with learning disabilities and to reduce premature deaths among this population¹⁶. As part of this programme the ICB LeDeR undertakes a review of each person with learning disabilities that has died.

Current services, local plans and strategies

Norfolk Adults Learning Disability Partnership, which includes Norfolk County Council and Norfolk and Waveney Integrated Care Board and all those providers they work with, have developed a Norfolk Adults Learning Disability Plan (formerly known as 'Strategy'). The development of the plan has included a range of engagement, consultation, co-production and co-design with people with a learning disability, their parents and carers and professionals and providers. The priorities of the strategy have been identified by people with a learning disability and in addition articulates a better joined up consistent approach across with those who are involved in the lives of people with a learning disability. All people with a learning disability should have a good, safe and healthy life. Through the delivery of a more person centred and preventative approach NCC and partners will seek to reduce the number of people receiving residential and hospital provision through recognising needs earlier and preventing them from escalating.

The <u>Norfolk Adults Learning Disability Partnership</u> is independently co-ordinated by ASD Helping Hands who took on this role in October 2022. ASD Helping Hands also co-ordinate the Learning Disability Partnership Board who meet four times a year. Membership of the Learning Disability Partnership Board

¹⁶ Adass, https://www.adass.org.uk/the-learning-disability-mortality-review-leder-programme/



includes people with a learning disability, family carers, people who work for NCC, the NHS and other organisations, such as charities. The goal of the Norfolk Adults Learning Disability Partnership Board is to improve the lives of people with disabilities in Norfolk over the age of 18 years and to help those who care for people with a learning disability. The Norfolk Learning Disabilities Partnership Board plays an important role in shaping the priorities for the future and delivering a partnership and co-produced approach. It provides challenge and governance to support the continued improvement of life outcomes, opportunities, quality service development and increasing community inclusion.

The <u>Transforming Care Programme</u> is focussed on supporting people with a learning disability to be able to move into some kind of housing in the community and to have the support to be as independent as possible when in the community and to be able to have help to get out and about; so these areas include all people in Norfolk with a learning disability. ASSD has a TCP team whose role it is to support people with an LD and/or autism move into the community from long-term placements.

Norfolk County Council Specialist Housing Team provides housing options for people with care and support needs in Norfolk. In Supported Living, people are normally of working age and can live in their own home or share a home with others and can choose types of supported living tailored to their needs.

<u>Local Supported Employment Programme</u> is to help autistic adults and adults with learning disabilities to move into and stay in work. Types of employment support includes things such as internships, apprenticeships, or vocational training. Employment Team (Adult Services) & Life Opportunities providers supported by LD Commissioners support people who are currently being supported by Adult Social Services, into paid employment through help from the Norfolk Employment Service or the Life Opportunities – Skills & Employment pathway with Day Services. Adult Services Employment Team also support people with a LD and / or autism into employment through the Local Supported Employment (LSE) Scheme. There are also <u>Adult Learning Courses</u> that develop independent skills.

<u>Carers Matter for Norfolk</u> provide services that are free and available to people aged 18+ caring for another adult who lives in Norfolk. The service provide information, signposting and advice on issues such as local accessing local services and support, carers rights (including employment), accessing health and social care services, social welfare, legal and housing signposting, equipment and adaptations and emergency planning.

The <u>preparing for adult life (PfAL) service</u> is responsible for ensuring young people make a smooth transition into adult social services. The service promotes independence in relation to the four preparing for adult life outcomes from the Children and Families Act 2014: Employment, Independent living, Being as healthy as possible and Being part of the community.

Learning Disability Partnership members, Adult Services, Health teams and Norfolk Safeguarding Adults Board support the commitment to safeguarding principles in helping someone with a Learning Disability to understand about keeping themselves safe. Norfolk County Council (NCC) and Norfolk Safeguarding Adults Board (NSAB) have introduced a keeping safe resource. This is a pack to support people to have conversations with individuals or groups of people with additional needs to understand about safeguarding and how to keep themselves safe.

The <u>National Disability Strategy</u> sets out the actions the government is committed to take to improve the everyday lives of all disabled people. This government strategy is incorporated in the approaches to be taken locally which includes a focus on improvements of the physical and social environments for people with a disability.

The Green Light Toolkit, developed by the National Development Team for Inclusion (NDTi), has been designed to improve the quality of mental health services for adults with learning disabilities and/or autism. The toolkit includes an audit framework to support reviews, an 'easy-read' version of the

framework and a database of examples of adjustments made by services to aid people seeking innovate ideas and shared learning¹⁷.

The NHS Long Term Plan outlining the ambitions of the NHS over the next 10 years and including learning disability as one of its four clinical priorities. This includes improving community-based support, reducing the number of people with a learning disability in hospital settings and reducing health inequalities through a focus on increasing uptake of annual health checks and reducing overmedication of children and young people with a learning disability.

Voice - the perspective from the public, service users, referrers and front line staff

The development of the Learning Disability Plan 2023-2028 focused on co-production and participation with over 360 people completing questionnaires from people with a learning disability, unpaid carers, workers and the wider community.

There were 5 main things people reported as important to support people with a learning disability living in Norfolk.

- 1) Choices about where they live.
- 2) Being healthy.
- 3) Help to be as independent as possible.
- 4) Getting out and about.
- 5) Support for unpaid carers.

Quotes taken from the conversations show that there is still room for improvement and a desire to enable opportunities to be more independent by people with a learning disability, with quotes from the day including.

'I want help to stay living in my own home', 'I want help to get to exercise', 'I want help with getting a job', 'I want to know what help is out there to support me as a carer', 'I would like to feel safe when I am out and about'

Considerations for Health and Wellbeing Board and commissioners

Norfolk County Council has in partnership with Health Commissioners a responsibility to support people with a learning disability and their families to enable increasing opportunities to equally access universal and mainstream services, ensuring that services are of good quality and maximise their health and wellbeing.

The statutory requirements of the undertaking of the Care Act should equally apply to people with a learning disability with preventative and responsive services working in partnership at a universal, targeted and specialist thresholds of need which is based upon the individual needs and outcomes delivered via a person centred approach.

Transforming Care and building the right support articulates the importance of reducing the use of institutions with a specific focus on reducing the numbers of children and adults in hospital environments for those people with a learning disabilities and or Autism, increasingly locally there is a greater focus on prevention and developing a sustainable model.

For those people with a learning disabilities and Autism consideration is also given to the Autism Act and Statutory guidance in delivering reasonably adjusted services and a workforce with the knowledge in being able to assess and take into consideration the impact of autism in their lives and needs.

In Norfolk work is underway to map the housing and support requirements across the county, informed by the operational teams. In addition to targeted programmes of work to improve and maximise the

¹⁷ National Development Team for Inclusion, The Green Light Toolkit, <u>Home page - NDTi</u>



opportunities for people to live in appropriate accommodation, access meaningful daytime activity, including accessing employment, raising aspirations into adulthood and enabling people's health and wellbeing, including the importance of relationships. These are included within Norfolk LD Plan and Promoting independence project NCC

Work to promote the opportunities, equality and independence for adults with learning disabilities must remain a priority. Adults with learning disabilities want to live as independently as possible and remain in stable accommodation. Moving away from a risk adverse and reactive culture to one of greater independence will not only improve the lives of those adults with learning disabilities but will also reduce the expenditure impact of the Adult Social Services Department.

The training of professionals in the signs of abuse and adults at risk is important to ensure that the safeguarding responsibilities of Norfolk County Council are fulfilled. There is a responsibility to ensure that those using social services feel safe and protected from any potential abuse and harm.

Evidence¹⁸ shows that those in work have better health and wellbeing than those who are unemployed, so work to get adults with learning disabilities into paid employment has to be continued. Working closely with charities and potentially local business to offer work experience or development courses to build up essential work place skills should be a consideration of the Health and Wellbeing Board. This would allow those with learning disabilities the best possible chance of gaining paid employment.

Cabinet is recommended to: agree the actions for Adult Social Services in the Learning Disability Plan 2023-28, agree the actions for Adult Social Services in response to the joint review of Learning Disability and Autism, agree to transfer the commissioning of Specialist Health Services to the ICB in line with the approach set out in Section 5, delegate the authority for the financial arrangements relating to the transfer of Specialist Health Services to the ICB to the Interim Executive Director Adult Social Services. ¹⁹

References and information

Public Health England (2016) Learning Disabilities Observatory: People with learning disabilities in England 2015: Main report https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england-2015

Public Health Outcomes Framework

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Mencap

https://www.mencap.org.uk

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Send us your query or feedback online using our online feedback form at http://www.norfolkinsight.org.uk/feedback

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¹⁹ Cabinet Report



¹⁸ ¹⁸Department for Health & Social Care, Work health and disability green paper: Improving lives https://www.gov.uk/government/consultations/work-health-and-disability-improving-lives/work-health-and-disability-improving-lives