

# Suffolk County Council

## Learning disabilities needs assessment 2021

### Executive summary

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## Executive Summary

There are approximately 1.5 million people have a learning disability (LD) in the UK (definition in Appendix 1). Approximately 350,000 of them have a severe or profound learning disability<sup>1</sup>. Following national trend this number will increase in the coming decades. Therefore, it is critical to understand the changing needs of this population.

People with learning disabilities face inequalities in health and social outcomes. We must understand these inequalities and changing needs to prioritise planning and resources.

A needs assessment was initially undertaken in 2014. The outcome of this work is described by Suffolk County Council (SCC) Adult and Community Services (ACS) as follows:

*“The previous Needs assessment in 2014 was instrumental in informing the co-produced Learning Disabilities Strategy for Suffolk. It has also been used in relation to setting and informing funding bids and service development activity. The assessment is vital for informing Social Care and Health sector organisations on the opportunities and challenges facing individuals with Learning disabilities now and in the future”.*

2021 work assesses the health and social needs of people with learning disabilities. It also assesses the service provision against the national standards. This work was undertaken in Spring/Summer 2021 and consists of the following elements:

- Literature review on prevalence, health and social inequalities and best practice (May 2021).
- Data analysis of prevalence and service use (data between April 2018-March 2021).
- A self-assessment of the service provision against the NICE quality standards. This involved stakeholders from SCC ACS and Children and Young People (CYP) service leads (July 2021).
- Survey with stakeholders with differing responsibilities. Commissioners & contract managers (2), service providers (20) and other professionals (2). Questions included what is working well, challenges, and areas for improvement (July 2021).
- Online engagement with service users. These activities facilitated by ACE Anglia and led by Public Health and Communities. The experiences captured through the ACE Anglia online health and wellbeing sessions also included. Information from the Suffolk People First event of May-June 2021 is also included. Furthermore, information from market engagement activity for the Suffolk Supported Housing Redesign is referenced.

The scope and purpose of this needs assessment agreed by the Steering Group. This consists of representatives from multi-agencies and departments. A list of stakeholders and contributors is in Appendix 2.

The corporate assessment section includes the information provided by colleagues and area experts. This information has been obtained through engagement activities by partner organisations and SCC. Where applicable, this has been referenced and acknowledged, and compared with data gathered via the evidence review and engagement activities.

This needs assessment triangulates all available information from these exercises at the time. The main findings and recommendations presented below.

## Key findings

### Epidemiology of people with learning disabilities in Suffolk

- The Institute of Public Care projects that there were 14,212 people with LD aged 18 and over in 2020.
- This is based on data from Projecting Adult Needs and Service Information (PANSI)<sup>2</sup> and Projecting Older People Population Information System (POPPI)<sup>3</sup>. This number is predicted to increase to 14,934 by 2030 and to 15,557 by 2040 (9.5%), with most of this increase coming in the 75-84 age category<sup>2,3</sup>.
- The number of people known to local health or care services is significantly lower than the Institute of Public Care figure of 14,212. The ACS register shows 2,640 people aged 18 and over identified as having a LD as a primary need in 2020-2021.
- Data for Ipswich and East Suffolk and West Suffolk Clinical Commissioning Groups (CCGs) had a total of 3,345 people aged 14+ on their registers. 2,091 for Ipswich and East Suffolk CCG and 1,254 for West Suffolk CCG. These CCG figures exclude the Waveney area which is part of the Norfolk and Waveney CCG.
- The gaps between estimated and recorded numbers suggests an unidentified and unmet need. A high proportion of people with LD may not be receiving the support they need.
- ACS customer data for the last 3 years shows a higher number of male customers (1,567) than female (1,073).
- The number of people with LD is projected to increase over the coming decades. The increase is in older age groups, meaning services must adapt to meet their needs. National data from 2014 estimated a 30% increase in adult social care services by 2030. This equates to a 164% increase in adults aged 80 and over<sup>4</sup>.
- There are 3,306 children and young people aged 5-17 in Suffolk receiving Special Educational Needs and Disabilities (SEND) support. This support is for a moderate and, severe or profound and multiple LD. The LD rates among children was statistically significantly lower than the national average in 2000-2020. Rates for severe learning difficulties appear to be increasing slightly over recent years. Much of this increase seen in primary school aged children.
- In 2021, 87.5% of students (2285/2601) with a moderate condition were educated in mainstream schools. 84.2% of those (523/621) with a severe and 65.5% (55/84) with profound & multiple conditions were educated in specialist schools.
- The number of pupils with LD has increased as they progress from nursery and primary school. It reached a peak in National Curriculum Year (NCY) 6.
- In 2021, there was a marked increase of more than 50 pupils in both NCY 4 and 5 compared to year before cohort (Year 2020, NCYs 3 and 4). These increases in 2021 were much higher than the previous survey years at this age group. This means more children were identified and recorded with LD as they progress in school.
- A decrease was observed among pupils in secondary schools every year, with a marked decline in NCYs 12, 13 and 14. The school census is not completed by colleges, where many pupils go on to for their post-16 education. This could be a reason for this marked decline in NCYs 12, 13 and 14.
- Children in more deprived areas of Suffolk are statistically significantly more likely to have LD than those in less deprived areas.

- Children with LD are more likely to enter care during the adolescent years. Many parents often find it increasingly difficult to meet their child's needs at this age. They feel less confident in their ability to support their child at home. For some children, parental learning disability was a reason coming into care.
- In Suffolk there is currently a cohort of young adult ACS LD customers aged in their 20s and 30s. This group is larger than any other age group. This needs consideration when planning for health and care provision, preference and housing.

## Health and wellbeing issues

- People with LD face considerable health and social inequalities. This impacts on both life expectancy and quality of life. Life expectancy for people with LD is significantly shorter than the general population. It is estimated to be 27 years less than average for women and 23 years male<sup>5</sup>. There is some evidence that life expectancy is increasing among some groups with LD. This is due to improvement in health and care and medical advances<sup>6</sup>.
- Both physical and mental health outcomes are significantly poorer than for the general population. The prevalence of some diseases including diabetes, epilepsy, and respiratory conditions considerably higher.
  - The literature shows 40% of adults and 36% of children with LD experience mental ill-health at any one time<sup>7</sup>. This equates to 5,684 adults with LD who may be experiencing mental ill-health. West Suffolk CCG data shows 8.3% of adults with LD have a severe mental health diagnosis. This can be compared to 0.8% of those without LD in the CCG area.
  - The prevalence of some digestive health issues is significantly higher. Constipation is most common condition at 50%. This means almost half (7,000) adults with LD suffering from constipation in Suffolk in any given time.
  - Inactivity levels among people with LD are estimated to be 45.5% compared to 27.1% in the general population<sup>8</sup>. West Suffolk CCG data indicates 26.3% of adults have obesity compared to 10.3% of those without. This means over 3,700 adults with LD in Suffolk may be living with obesity.
  - The prevalence of diabetes is estimated to be twice as high among people with LD (10%) than among those without (5%)<sup>9</sup>. In Suffolk, this would equate to approximately 1,400 adults with LD living with diabetes.
  - Dental health outcomes are significantly worse among this group than the general population<sup>10</sup>.
  - The prevalence of dementia is significantly higher than the general population. For age-related dementia in the 60-65 year age group, prevalence in the LD population is estimated to be 13%. Whereas this is only 1% in the general population.
  - People with LD and their carers are eligible for flu vaccination. Despite this, rates in younger adults age groups (18-54) in Suffolk are all below 40%.
  - Over the last 3 fiscal years, there has been an increase in safeguarding referrals for adults with LD. In total 867 referrals made since 2018/19. Physical abuse was the most common and frequent followed by psychological and sexual abuse. Data on location is incomplete. But available data noted that 198/867 occurred in hospitals, 170/867 in the person's home and 269 in other places.
- The reasons for these health inequalities are often multifactorial. This includes genetic factors, poor access to services and poorer socio-economic outcomes. Housing, educational attainment, employment and social inclusion determine their health and wellbeing.
- Higher number of working-age adults with LD are living in settled accommodation in Suffolk. This is significantly higher compared with the national average. This has increased in recent years to 81.3% in 2019/20.
- Much lower number of adults with LD are in paid employment in Suffolk. This is significantly lower than the national average (3.6% vs. 5.6%). Employment status is recorded for only 6% of people receiving social care support. There also appears to be a reduction in the proportion in paid employment over recent years.

## Suffolk services for people with learning disabilities

Current provision in Suffolk was assessed to see how it is meeting the needs of this group. A self-assessment exercise was undertaken with SCC ACS and CYP service leads in July 2021. NICE Quality Standards were used as a benchmark for this assessment. Stakeholder views were also gathered through a survey in July 2021. Frontline professionals from provider organisations and SCC Commissioners and Contract managers participated. Service user experiences captured through online engagement sessions. These activities hosted by ACE Anglia and led by Public Health and Communities.

The following themes were explored: what is working well, challenges and areas for improvements. The main findings presented below:

### What is working well?

The following aspects of health provision identified as working well by stakeholders. There are a range of measures in place to improve access to health services for this group. These include:

- Learning disability liaison nurses support easy access to healthcare across CCGs. Access to specialist services including Adult Learning Disability Community Services, Adult Learning Disability Inpatient Services, Integrated Delivery Teams for community mental health services, Under 25s Learning Disabilities Community Team, Primary Learning Disability Liaison Service, Child and Adolescent Mental Health Service Learning Disability Community Service<sup>11</sup>.
- A range of accessible resources and health education sessions provided by advocacy organisation ACE Anglia.
- Annual health checks for people with LD in Suffolk has increased over the last 3 financial years. This is meeting the national target of 75% in 2020/21.
- The following aspects of social provision identified as working well by stakeholders:
  - There are improvements in recording of accommodation status of adults with LD. ACS is providing support to this group, 81.3% are resident in settled accommodation.
  - Large number of agencies providing a range of day services and activities for adults with LD.
  - Provision for children in Suffolk is in line with best practice. There is evidence of good pathways in place for the transition from children's to adult's services. A range of support provided to young people with LD who do not meet the criteria for long-term support from ACS.

### What are the main challenges?

Regarding health provision, the following challenges were identified:

- Currently there is no specific pathway for adult referrals to dietetics services. Some referred to the service after annual health check or some by consultants.
- Pathway to paediatric dietician is different between children with LD and without LD.
- There are gaps in provision of reasonable adjustments in clinics. Some difficulties in making longer appointments, poor access to speech and language therapists. Also lack of resources to support people with LD for whom English is a second language.
- Limited access to dental care is a significant area of need. Community dental services are often no longer available due to funding cuts. It can be very difficult to refer to specialist services. Private dental care is available but often not affordable for this group.
- The annual health check provision is not uniform by geography and age. There is a lower completion rate in West Suffolk and among younger age groups.

Uptake of screening is significantly lower among this group. No data was available on the distribution of uptake according to demographic characteristics.

- Screening invites sent via the national call-recall system. This does not include information on additional needs of individuals. This is a big barrier for people with LD to understand and enrol in it.
- Lack of affordable and flexible travel options hinder attendance in activities and services.

- GP surgeries provide nasal spray vaccine for those with needle anxiety. But this is not offered to adults with LD. Some people reported that they could not access this provision due to older age.
- Suffolk [LeDeR](#) 2020/21 data showed 34% of cases had no evidence of attending cancer screening. NHS Digital reports on cervical screening rate for women with LD. Suffolk screening rates for those with LD are only half of those compared to eligible women without LD. Breast cancer screening rates in this cohort appear to have decreased over the last 5 years.

Regarding social provision, the following challenges were identified:

- There is a good range of provision of care and activities for children with LD in Suffolk. However, there are gaps in day and respite provision in some areas of the county. This is for some age groups and categories of need for activities provision. There is a shortage of providers for children with more complex levels of need. This was particularly in the north of Suffolk.
- To enable informed choices, ACS provide pop-up accessible information advice and guidance services. Libraries used as main venues and online services through the provider Realise Futures. Uptake of these services has been low so far. This could be due to low awareness. Thus, it is important to understand the best model of provision.
- There is evidence of good practice in provision of housing for adults. But this provision is not uniform across the county. There is a mismatch of provision, need and preference across some geographical areas. There is a particular shortage of provision in the Waveney area.
- Younger customers prefer a self-contained accommodation. But there is a shortage of such units. There is also a shortage of housing options for people with more complex needs. This includes the Transforming Care cohort and vulnerable young adults with mild condition.
- Across all commissioned supported housing for LD cohorts, 15% of settings currently have a void. 97% of this void in shared accommodation among those aged 40 and over. Often voids present in shared housing settings for older cohorts. This suggests that available accommodation often does not meet the preferences of younger adults. There is a mismatch between the demand for housing and available supply. Customers often live in supported housing for years. This provision of support is suitable when they are younger. But customers often require different provision as their physical needs change with age.
- Some service users felt they did not receive accessible information on their tenancy rights. Some were concerned that allocation of housing based on outdated annual reviews.
- Maintaining a resilient staff workforce for supported housing is a challenge. The pandemic has accentuated it further. Some staff needed to self-isolate. Also, staff leaving due to the increasing clinicalisation of care, “no job, no job” policy. Many seeking employment elsewhere.
- SCC is not facilitating volunteering or work placement options for people with LD. Supported internships provided in Suffolk, but very few posts available. These are often more suitable for people with high functioning autism than with LD.
- Fewer than 1% of adults with LD are known to ACS recorded to be in paid employment. A very low proportion are known to be volunteering in the community. This is a recognised gap in enabling people with LD to lead fulfilled lives. There is also a need for increased provision of activities supporting skill acquisition.

What needs to be done?

Health provision

- Raising awareness about reasonable adjustments among all services. This includes, frontline staff, service providers and commissioners. It is important to develop effective policy adoption and monitoring system. This will help to improve reasonable adjustments across health and care services.
- Adoption of easy read materials in cancer screening and health check promotion. Active engagement of carers and family members in this promotion. Thus, increase awareness of eligibility for screening and annual health checks.
- Improving identification of people with LD among the cohort of eligible patients. There is a need to tailor the screening pathway according to needs.

- Suffolk could consider the use of the Eclipse database in all GPs following Norfolk's example. This could help increase the offer and uptake of cancer screening, by improving identification of people with LD.
- Support younger adults and their carers to have the flu jab.

#### Social provision

- Provide more accessible information on housing options to enable informed choices.
- Increase all types of housing provision in the Waveney area to reflect demand.
- Current provision of social and day opportunities may not fully reflect customer preferences. This potential gap has been accentuated by the pandemic. There are changing preferences and needs emerging because of the pandemic. A review of customer preferences is needed to tailor provision.
- Further understanding of reasons for the increased safeguarding referrals for this group is needed.

#### The impact of COVID-19 on people with learning disabilities

The national evidence shows pandemic has disproportionately affected people with learning disabilities. Death rates estimated to be up to 6 times higher in this group than among the general population<sup>12</sup>.

Stakeholder engagement work in July 2021 revealed significant challenges relating to service provision. In some cases the pandemic has delayed planned work to improve provision.

COVID-19 has significantly affected ACS's ability to undertake annual reviews. Challenges included reduced uptake of some services and maintaining staff resilience. There are concerns around social isolation and the resulting impact on mental health of this group.

Some opportunities for a greater provision of online activities and digital skill acquisition have occurred. There was opportunity for some to re-evaluate their choice of care and activities.

## Conclusions

For people with LD to lead ordinary lives, they require easy access to services. Provision that promotes independence, and meaningful involvement in their community. Informed choices and a person-centred, holistic approach to care and support are important. Greater independence is crucial, alongside choices of where to live and socialise.

Engagement activities undertaken as part of this needs assessment show these remain important issues for this cohort. Previous needs assessment in 2014 estimated the increase of this cohort. The number of residents in Suffolk has increased. It is projected to increase further. Thus, this increase and changing needs should be considered for planning resources.

There are inequalities in life expectancy for this cohort. There is a higher prevalence of certain medical conditions. There are noted difficulties in accessing some health services including screening. Poor access to appropriate housing, social and leisure opportunities hinders health and wellbeing.

Suffolk maintains a range of housing for people with differing needs and preferences. But there are some known gaps in accommodation provision by geography. Demographics of the learning disability population in Suffolk is changing. The proportion of services users within the older cohort is increasing. This means their needs and preferences are changing as they age. Thus, there is a challenge to meet this demand in coming decades. So careful planning around the requirements for older individuals is crucial.

This needs assessment found that there is generally good provision of services this group in Suffolk. But this is not always uniform across the county. There are several areas of unmet need. This includes gaps in provision of suitable housing in some areas, as well as support to access employment and acceptable social activities. Many of these gaps are recognised



and there is work planned to improve provision. However, some of this work has been delayed due to the COVID-19 pandemic.

The engagement exercise suggests customer preferences may be changing in light of the pandemic. Uptake of services may not reflect the current provision. This suggests that customer services and preferences may require some review. Also, there is a need for more accessible information on available services. Reasonable adjustment should be promoted further to improve access to services.

## Recommendations

No.	Recommendation	Responsible body
1	Action to improve uptake of cancer screening among this cohort to reduce inequalities. Provide training to carers & family members to recognise and report changes in health of this group. Targeted communications for this cohort and carers around the time of landmark birthdays. Thus, to raise awareness of eligibility for specific screenings.	ICS Board for LD and Autism
2	Improve access to all statutory and non-statutory services through reasonable adjustments principles. Embed these principles into all provision and develop system to track it.	ICS Board for LD and Autism & Health and Wellbeing Board (HWB)
3	Improve access to library services among this cohort, their families and carers to support social and educational engagement	Public Health & ACS
4	System wide action to enhance support for emotional and mental wellbeing of this group and their cares/families and improve access to appropriate provisions in the community. Agencies are encouraged to address these needs through their effective strategy and intervention	ICS Board and LD and Autism and HWB
5	System wide action to improve uptake of flu vaccines and quality of annual health checks and follow up interventions for each individual for prevention of ill-health.	ICS Board for LD and Autism & HWB
6	System wide action to improve opportunities for skills development and good quality employment opportunities through effective employment strategy. This includes appropriate pathways from education to volunteering and apprenticeships and developing a database to monitor it. For example, understanding the gaps between education, skills level and employment opportunities, challenges and preferences and levels of need among young adults in their 20s and 30s and develop kick start programme. The database could include a list of metrics such as hours worked, level of pay to understand quantity and quality of employment, sectors and feedback from employees and employers.	ACS, HWB
7	Undertake an audit of adult safeguarding data to understand recent increases and reasons for referrals to inform the next steps	ACS
8	System wide action to improve accessibility to Ordinary Lives Partnership Portal and the validity of its content. This is to ensure people can get an accurate information about available provisions such as day support, targeted activities and social opportunities. This work may include developing a protocol for providers to frequently update information about their services, and the ways to easily access.	ACS
9	System wide action to improve appropriate housing options for people with learning disabilities meeting the changing needs and preferences of different age groups, including increasing provision in Waveney area. As a part of Housing Options Review to ensure information on available housing choices and tenancy conditions are communicated appropriately to enable informed decision. This will be considered as a part of the Supported Housing Review (Independent Lives Programme).	ACS, Districts and Boroughs
10	System wide action to review current provisions of day, weekend, and evening opportunities for adult service users post-COVID to consider appropriate services in line with the changing needs and preferences of customers with learning disabilities.	ACS

## Acronym list

**ACS** – Adult and Community Services  
**ASD** – Autism Spectrum Disorder  
**CAMHS**- Child and Adolescent Mental Health Services  
**CCG**- Clinical Commissioning Group  
**CiC** – Children in Care  
**CYP** - Children and Young People  
**DCYP**- Disabled Children and Young People  
**HWB** – Health and Wellbeing Board  
**ICD-10** – International Classification of Diseases, Tenth Revision  
**ICS**- Integrated Care System  
**IESCCG** – Ipswich and East Suffolk CCG  
**IQ** – Intelligence Quotient  
**IWS**- Independence and Wellbeing Service  
**LD**- Learning Disabilities  
**LD&A** – Learning Disabilities and Autism  
**LeDeR** – Learning from deaths of people with a learning disability  
**LGA** – Local Government Association  
**MiA** – Moving into Adulthood  
**NICE** - National Institute for Health and Care Excellence  
**NDTi** – National Development Team for Inclusion  
**NSFT** -Norfolk and Suffolk Foundation Trust  
**PANSI** -Projecting Older People Population Information System  
**POPPI** – Projecting Older People Population Information  
**PHE**- Public Health England  
**PWLD**- People with Learning Disabilities  
**QOF**- Quality Outcome Framework  
**SALT**- Speech and Language Therapy  
**SCC**- Suffolk County Council  
**SNNs**- Statistical Nearest Neighbours  
**SPLD** – Specific Learning Difficulties  
**YP**- Young Person

## Appendix

### Appendix 1: Definitions of learning disability

While the term 'learning disability' can mean different things to different people, and is used differentially across English-speaking countries, in the UK, the term learning 'Learning disability' is generally defined by the presence of:

- 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 in development<sup>13</sup>

Learning disabilities have previously been defined according to ICD-10 classifications and can be defined based on estimation of IQ score and the presence of a medical diagnosis<sup>14</sup>. When addressing the wider needs of people with learning disabilities, it is generally accepted and legislated under the Care Act<sup>15</sup> that provision of support should not be based on a medical diagnosis. It is therefore important to note that individuals recorded as having a learning disability as a support need by local authorities and providers may not have a diagnosis of a learning disability in their medical records.

Learning disabilities are lifelong conditions, and can be classed as mild, moderate, severe, or profound and multiple<sup>16</sup>. Descriptions of these categories of learning disability are outlined below:

- Mild learning disabilities: A person who is said to have a mild learning disability is usually able to hold a conversation and communicate most of their needs and wishes, and are often independent in caring for themselves and doing everyday tasks. They may need some support with understanding complex ideas and with tasks such as budgeting and completing forms. People with mild learning disabilities often go undiagnosed.
- Moderate learning disabilities: People with a moderate learning disability are likely to have some language skills that mean they can communicate about their day to day needs and wishes. People may need some support with caring for themselves, but many will be able to carry out day to day tasks with support.
- Severe learning disabilities: A person with a severe learning disability will have little or no speech, find it very difficult to learn new skills, need support with daily activities, have difficulty with social skills and need life-long support.
- Profound and multiple learning disabilities: A profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent.

The needs of an individual with a mild learning disability will differ significantly from those with a severe or profound learning disability, therefore it is important to understand the differences in need among this cohort and the implications for providing support and services.

It is important to note that in the UK, mild and moderate learning disabilities have different meanings in education services and in health services when describing the needs of children and young people. The term 'Special educational needs and disability' (SEND) is used to refer to the needs of a child or young person if they have a learning difficulty and/or disability that means they need special health and educational support<sup>17</sup>. The categories of 'Severe' and 'Profound' learning difficulty as used in SEND guidance broadly align with the categories of severe and profound learning disabilities outlined above<sup>16</sup>.

The term 'learning disabilities' is distinct from the term 'learning difficulties', which is used in the UK to define a condition which creates an obstacle to a specific form of learning but does not affect the overall IQ of an individual. It is however important to acknowledge that an individual may have both a learning disability and a learning difficulty.

Depending on the definition of learning disabilities used, autism and autism spectrum disorders (ASD) may be included under the category of learning disabilities, and a proportion of individuals with a learning disability will also have autism. It is important to recognise however that the majority of people who have autism do not consider

themselves to have a learning disability, therefore it is not generally appropriate to include individuals with autism/ASD alone in the wider learning disability cohort. The focus of this needs assessment is therefore people with learning disabilities, some of whom may also have autism; where the available data has presented challenges in defining the cohort with learning disabilities as distinct from those with autism based on recording of primary needs, these have been acknowledged.

Given the differential definitions of learning disabilities and consequent challenges in identifying the cohort of people with learning disabilities, where there are differences and uncertainties indicated by datasets used in this needs assessment, these have been highlighted in our results.

## Appendix 2: Steering group and contributors

### **Steering group members**

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