

Suffolk County Council

Learning disabilities needs assessment 2021

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Introduction

There are approximately 1.5 million people have a learning disability (LD) in the UK. Approximately 350,000 of them have a severe or profound learning disability¹⁰. Following national trend this number will increase in the coming decades. Thus, it is critical to understand the changing needs of this population. People with learning disabilities face inequalities in health and social outcomes. It is important to understand these inequalities and changing needs to prioritise planning and resources. The definition used in this needs assessment is in Appendix 1.

An LD needs assessment was last undertaken in 2014. The outcome of this work is described by SCC Adult and Community Services as follows:

“The previous NA 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”.

Which population is this needs assessment about?

This report considers the needs of people with LD in Suffolk. This also includes carers and families of this group where applicable. The information sourced from both local authority and General Practice registers. This includes all age people who are receiving some support. Limitations or uncertainties surrounding data are outlined where possible.

Note: The Disabled Children and Young People team are undertaking a review of their services. The Social Care Sufficiency and Special Educational Needs and Disabilities (SEND) Strategy is also being refreshed. Some information from this work is used in this report.

What is the focus of this needs assessment?

This needs assessment takes life-course approach, assessing data for all ages from birth. The report focuses on ‘transition’ stages in the lifespan, from young people to adult services. This corresponds to ages 16-25 and 65 and over. This will help to capture the changing needs during stages of life and required service. Suffolk County Council (SCC) service data on "primary need" has been used for assessment of prevalence and service use of this group. It is important to note some of these users may also have other disabilities.

Autism and autism spectrum disorders (ASD) are included in the LD category. Depending on definition, some individuals with a learning disability will also have autism. Many autistic people do not consider themselves to have a learning disability. Thus, it is not appropriate to include this group in the wider learning disability cohort. The focus of this needs assessment is on people with learning disabilities. Some may also have autism and there is a challenge to separate it based on recording of primary needs. These challenges have been noted where possible.

Health and social needs of people with learning disabilities are also considered, alongside the current provision. This includes health inequalities, social care, housing, employment and other social provision. We also aimed to assess the impact of COVID-19 pandemic and noted the changing needs for service.

Prevalence data has been included for children and young people aged 5-18, with their social needs based on SEND data. This includes moderate, severe, or profound/multiple learning disabilities as a primary need. There are different definitions for LD and SEND. Thus, differences in cohort sizes and data sets have been acknowledged, where possible.

This needs assessment includes SCC data for the period April 2018- March 2021. 2019 and 2020 service data has been compared with pre-pandemic trends. This can help to understand COVID-19 impact.

Main aim and objectives of the needs assessment

This needs assessment is focused on health and social needs of people with learning disabilities. It also assesses the service provision against the national standards. Stakeholders contributed their views on what is working well, challenges and areas for improvement.

Main objectives:

- Estimate the current and future prevalence of people with learning disabilities
- Identify risk factors and population groups at high risk of learning disabilities
- Assess level of inequalities in health and social outcomes
- Assess how service provision is meeting the needs relating to availability, accessibility and acceptability
- Identify areas for improvements and meeting the changing needs of this group
- Understand the impact of COVID-19 on people with learning disabilities
- Provide recommendations for local system to inform the planning and decision-making process

Outline of methods

The following steps were undertaken:

- 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 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 ACE Anglia online health and wellbeing sessions also included. Also included information from Suffolk People First event of May-June 2021. Information from market engagement activities for the Suffolk Supported Housing Redesign has been 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.

Appendix 3 provides the methods used for this work and related explanations. Where applicable, limitations to the methods used are outlined.

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.

Estimated prevalence of learning disabilities among Suffolk residents

This section provides estimated prevalence of people with learning disabilities of all ages. Information available from different sources has been used to inform this section. It is a challenge to define the number of people with learning disabilities. There are different estimates and datasets which are not linked to each other. Therefore, caution is recommended in comparing statistics.

Quality and Outcomes Framework (QOF) data indicates that the prevalence of learning disabilities in Suffolk in 2019/20 was 0.5%. This is statistically significantly similar to both national and regional prevalence. This equates to 4,285 individuals (all ages) in Suffolk⁷². But, it is an underestimate of the true prevalence of learning disabilities. Many people have no diagnoses, and GP record data are often incomplete⁷³.

Further uncertainty in these numbers arises from Public Health England (PHE) Fingertips reporting that in 2020. There were 2,597 children with LD in Suffolk known to schools⁷⁴. Also 2,330 adults receiving long-term support from local authorities for LD⁷⁵. This brings to a total of 4,927 individuals. The data on children with a primary need of LD came from the Department for Education School Census. So, whilst it should include all school-age children (aged 4-16), some of those aged 0-4 or 16-18 are also in this data. PHE estimates the true prevalence of LD in children is approximately 2.5%⁷³. When applied to estimates of 0–19-year-olds in Suffolk this equates to 4,197 children⁷⁶. Also, in 2020/21, two CCGs had

a total of 3,345 people aged 14+ on their learning disabilities register. 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 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)⁷⁷ and Projecting Older People Population Information System (POPPI)⁷⁸. This number is predicted to increase to 14,934 by 2030 and to 15,557 by 2040, with most of this increase coming in the 75-84 age category^{77,78}.

Prevalence of children with learning disabilities

This section focuses on estimated prevalence of learning disabilities among Children and Young People (CYP) in Suffolk. We use different data sources. For example, education data describes moderate to profound learning difficulties. Further detail of methods is provided in the appendix.

The rates for LD are compared with national and Statistical Nearest Neighbours (SNNs). Suffolk's SNNs for children's services include 11 Local authorities. (Cornwall, Devon, Dorset, East Sussex, Gloucestershire, Somerset, Lincolnshire, Norfolk, Shropshire and Worcestershire). The data shows that Suffolk lower rates of school children with LD between 2015 and 2020. This is when compared with both national rates and the average of those of Suffolk's Children's SNNs. This lower rate is statistically significant (Figure 1).

There are three primary categories of learning disability (moderate, severe, and profound & multiple). Suffolk rates were lower than national and Children's SNN for moderate and profound & multiple (Figure 2; Figure 4). This is statistically significant. However, the rates are comparable for children with severe learning difficulties (Figure 3) during this period. Reasons for this difference could be in differences in identification, reporting or categorisation, or children with profound learning difficulties educated out of county. Rates for severe learning difficulties appear to be increasing slightly over recent years. Much of this increase seen in primary school aged children (Figure 3). Improved survival rates for babies born with disabilities may be contributing as well.

Rates of children with autism in schools increased nationally between 2015 and 2020. Suffolk is mirroring this increase year-on-year (Figure 5). However, it is difficult to categorise the primary need for each individual. Some of these children have both LD and autism, some don't. So true numbers or status of autism and LD is not known.

Numbers of children with specific learning difficulties (SPLD) are also increasing in Suffolk. It is also increasing at national level. This can have a knock-on effect on the prevalence of learning disabilities. SPLD is not considered in this needs assessment. But it is in the cognition and learning SEN category.

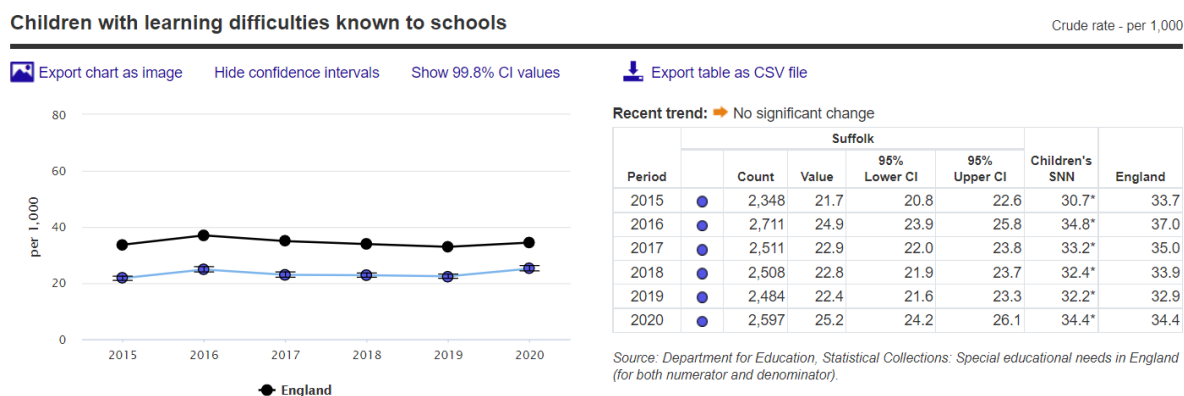
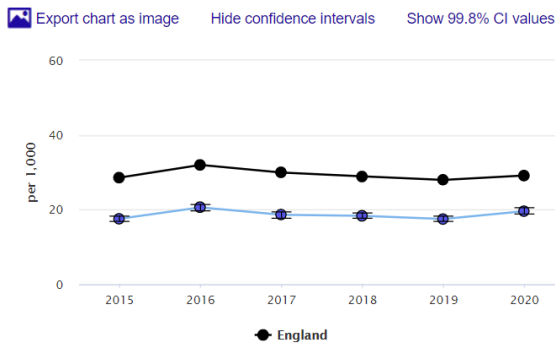


Figure 1: Comparison of rates of children with learning difficulties known to schools (Suffolk versus England). Data from Public Health England Fingertips

Children with Moderate Learning Difficulties known to schools

Crude rate - per 1,000



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Recent trend: No significant change

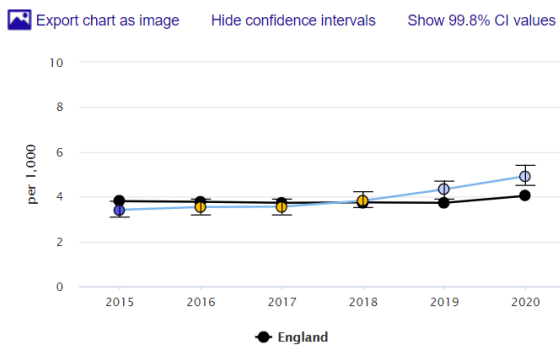
Period	Suffolk				Children's SNN	England
	Count	Value	95% Lower CI	95% Upper CI		
2015	1,897	17.5	16.8	18.3	25.7*	28.6
2016	2,246	20.6	19.8	21.5	29.8*	32.0
2017	2,041	18.6	17.8	19.5	28.1*	30.0
2018	2,016	18.3	17.6	19.2	27.5*	28.9
2019	1,934	17.5	16.7	18.3	27.3*	28.0
2020	2,022	19.6	18.7	20.5	29.1*	29.1

Source: Department for Education, Statistical Collections: Special educational needs in England (for both numerator and denominator).

Figure 2: Comparison of rates of children with Moderate Learning Difficulties known to schools (Suffolk versus England). Data from Public Health England Fingertips

Children with Severe Learning Difficulties known to schools

Crude rate - per 1,000



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Recent trend: Increasing

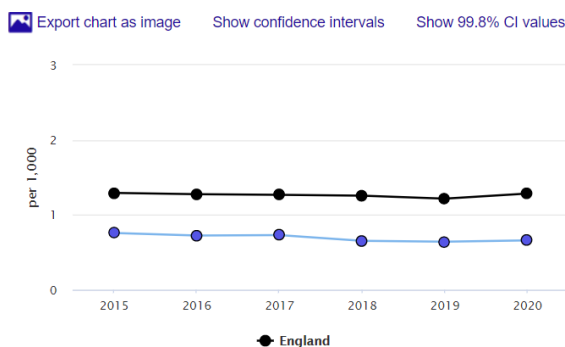
Period	Suffolk				Children's SNN	England
	Count	Value	95% Lower CI	95% Upper CI		
2015	369	3.4	3.1	3.8	3.8*	3.8
2016	386	3.5	3.2	3.9	3.9*	3.8
2017	390	3.6	3.2	3.9	4.0*	3.7
2018	420	3.8	3.5	4.2	3.9*	3.7
2019	479	4.3	3.9	4.7	4.0*	3.7
2020	507	4.9	4.5	5.4	4.3*	4.0

Source: Department for Education, Statistical Collections: Special educational needs in England (for both numerator and denominator).

Figure 3: Comparison of rates of children with Severe Learning Difficulties known to schools (Suffolk versus England). Data from Public Health England Fingertips

Children with Profound & Multiple Learning Difficulty known to schools

Crude rate - per 1,000



Export table as CSV file

Recent trend: No significant change

Period	Suffolk				Children's SNN	England
	Count	Value	95% Lower CI	95% Upper CI		
2015	82	0.76	0.60	0.94	1.14*	1.29
2016	79	0.72	0.57	0.90	1.10*	1.28
2017	80	0.73	0.58	0.91	1.09*	1.27
2018	72	0.66	0.51	0.83	1.03*	1.26
2019	71	0.64	0.50	0.81	0.97*	1.22
2020	68	0.66	0.51	0.84	1.02*	1.29

Source: Department for Education, Statistical Collections: Special educational needs in England (for both numerator and denominator).

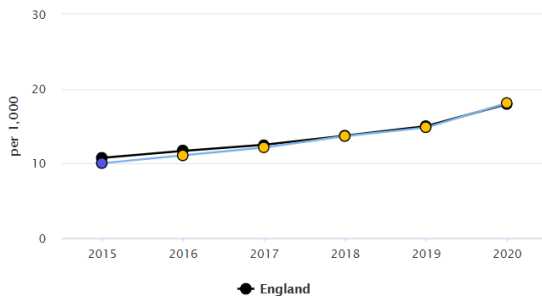
Figure 4: Comparison of rates of children with Profound & Multiple Learning Difficulties known to schools (Suffolk versus England). Data from Public Health England Fingertips

Children with Autism known to schools

Crude rate - per 1,000

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Export table as CSV file



Recent trend: ↑ Increasing

Period	Count	Value	Suffolk		Children's SNN	England
			95% Lower CI	95% Upper CI		
2015	1,085	10.0	9.4	10.6	9.6*	10.8
2016	1,209	11.1	10.5	11.7	10.3*	11.7
2017	1,331	12.2	11.5	12.8	10.7*	12.5
2018	1,503	13.7	13.0	14.4	11.6*	13.7
2019	1,640	14.8	14.1	15.6	12.5*	15.0
2020	1,870	18.1	17.3	19.0	15.2*	18.0

Source: Department for Education, Statistical Collections: Special educational needs in England (for both numerator and denominator).

Figure 5: Comparison of rates of children with Autism known to schools (Suffolk versus England). It is likely that there are individuals that are counted as both living with Autism and with learning difficulties, as these categories are not mutually exclusive. Data from Public Health England Fingertips

School age children with learning disabilities

The data on children with LD came from the Department for Education school census. Therefore, it should include all school-age children (aged 4-16), and some aged 0-4 or 16-18. This also looked at primary and secondary need of moderate, severe or profound and multiple LDs. The national comparison above only looked at primary need.

In 2021, there were a total of 3,314 children in Suffolk schools (National Curriculum Years 1-14; ages 2-18) with LD. They were receiving some form of support in school (Table 1). That equated to 17.5% of all Suffolk pupils with an Education Health and Care (EHC) plan or receiving Special Educational Need (SEN) support. The vast majority of these students had moderate learning difficulties. The overall number remained relatively constant since 2018. But a slight increase reported among those with severe learning difficulties (Figure 6).

Less than 100 pupils received support for profound & multiple LD every year since 2018 (Figure 6). In 2021, additional 438 pupils aged 2-25 educated in independent settings and colleges. The January 2021 school census had a total of 3,804 pupils with an EHCP and 11,853 receiving SEN Support. In May 2021, Suffolk had a total of 5,910 people (0-25), with an EHCP.

Table 1: Learning disability requirements for Suffolk school students in 2021

	Education, Health and Care Plan	Special Educational Need (SEN) Support	Total
Moderate Learning Difficulty	724	1,877	2,601
Severe Learning Difficulty	582	39	621
Profound & Multiple Learning Difficulties	75	9	84
Total	1,381	1,925	3,306

Number of Suffolk students with learning disabilities by level of need and survey year

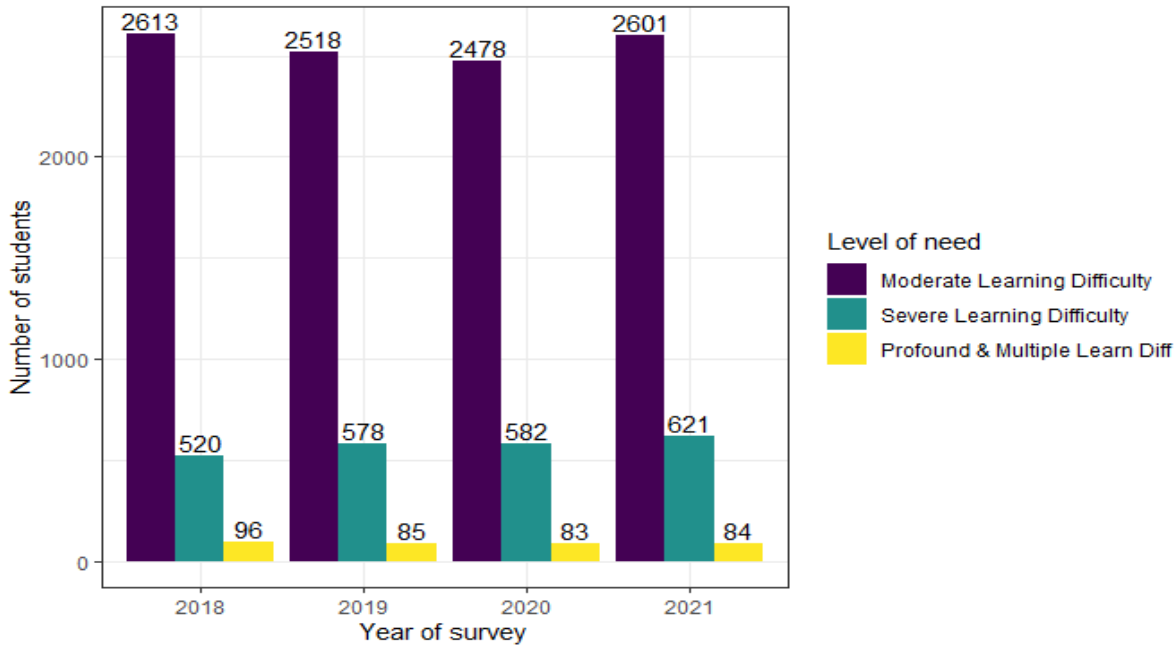


Figure 6: Number of Suffolk students with learning disabilities by level of need and survey year

In 2021, the largest ethnicity group among children with LD was White British (82.56%). This mirrors Suffolk’s ethnic composition. Other White (includes Romanian, Traveller and White Irish) was the second largest (6.19%). Mixed ethnicities was the third largest group (5.43%; Table 2).

Table 2: Ethnicity groups for Suffolk students with known learning disabilities in 2021, and a comparison to the known ethnicity percentages in the Suffolk population aged 18-85+ from the 2011 ONS Census.

Ethnicity group	Total number of Suffolk students with LD	Percentage of total Suffolk students with LD	Percentage of Suffolk population aged 0-17 (2011 census)
Asian (including Bangladeshi, Chinese, Filipino, Indian and Pakistani)	51	1.50%	2.45%
Black (including African and Caribbean)	35	1.06%	0.9%
Mixed ethnicities (including White and Asian, White and Black African, White and Black Caribbean)	181	5.43%	4.27%
Other ethnicities	30	0.91%	0.36%
Other White (including Romanian, Traveller and White Irish)	205	6.19%	3.86%
White British	2729	82.56%	88.15%
Not provided or refused	75	2.26%	NA
Total	3306	-	-

In 2021, 87.5% of students (2285/2601) with a moderate condition educated in mainstream schools. 84.2% of those (523/621) with a severe and 65.5% (55/84) with profound & multiple 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 (Figure 7).

In 2021, a marked increase of more than 50 pupils in both NCY 4 and 5 was observed compared to year before cohort (Year 2020, NCYs 3 and 4) (Figure 7). These increases in 2021 were much higher than the previous survey years at this age group. This means more children identified and recorded with LD as they progress in school.

A decrease among pupils in secondary schools every year, with a marked decline in NCYs 12, 13 and 14 (Figure 7). 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.

Number of Suffolk students with learning disabilities by National Curriculum Year and survey year

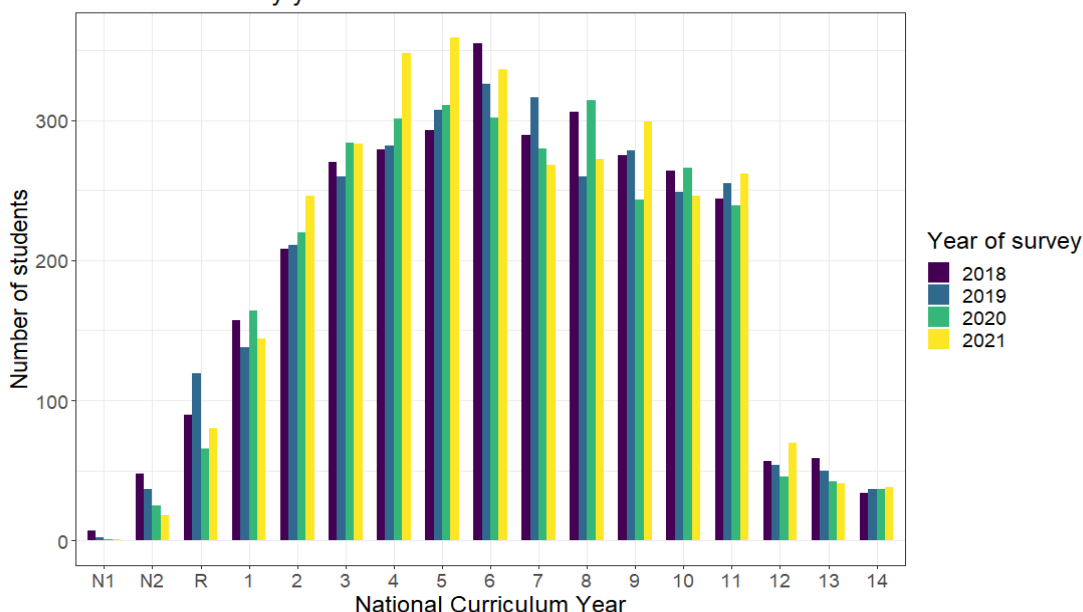


Figure 7: Total number of Suffolk students with known learning disabilities by National Curriculum Year and survey year

Children in care with learning disabilities

As of March 2021, among children in care (CiC) in Suffolk, 51 were recorded as having moderate condition. Also 15 with severe and 2 with profound and multiple learning difficulties. Among these children 21 were aged between 3 and 10, 33 aged 11-15 and 14 aged 16-18.

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. Parental learning disability was a reason for small number of children becoming looked after.

Evidence shows a statistically significant association between deprivation and learning disabilities. Children living in most deprived areas are likely to be identified as having LDs⁷⁹. Data from 2021 shows that this was also the case in Suffolk. Pupils in the most deprived deciles (IMD 1, 3 and 4) are more likely to have LDs than those in least deprived deciles (IMD 8, 9 and 10) (Figure 8). This was statistically significant.

Age standardised rates of learning disabilities by Index of Multiple Deprivation decile for Suffolk LSOAs in 2021

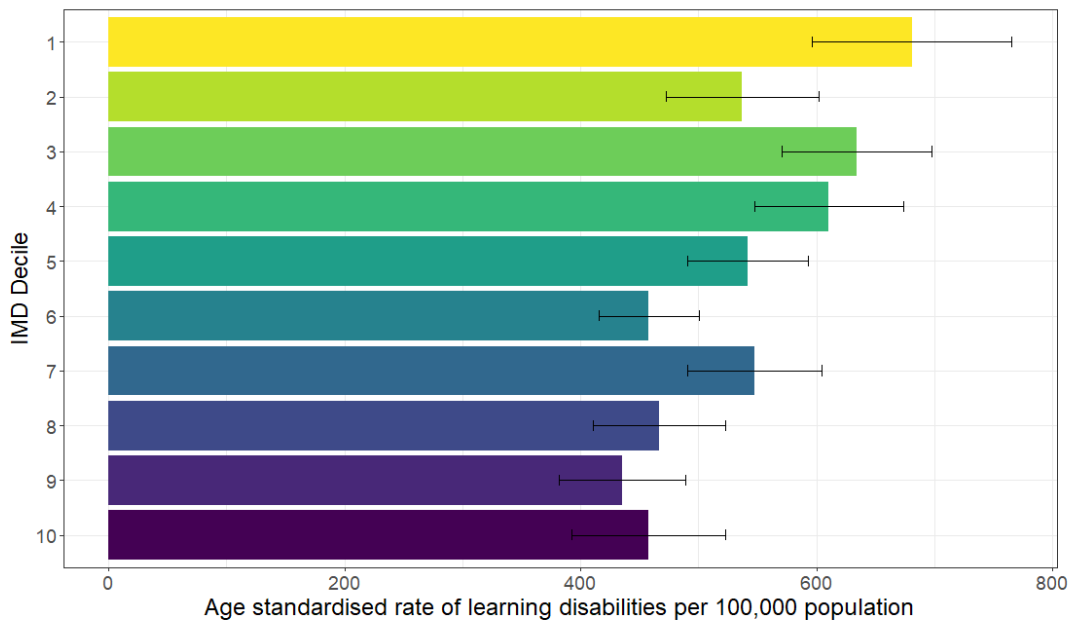


Figure 8: Age standardised rates of learning disabilities in Suffolk children in 2021 by Index of Multiple Deprivation decile

Epidemiology of learning disabilities – What does the evidence say?

Risk factors for learning disabilities

Medical diagnoses associated with learning disabilities include Downs syndrome, Global developmental delay, Fragile X syndrome, Williams Syndrome, SYNGAP, and cerebral palsy. A proportion of people who have autism and Asperger syndrome or display challenging behaviour also have learning disabilities⁵¹.

Risk factors for the development of learning disabilities include illness or infection during pregnancy, oxygen deprivation during birth, an infection such as meningitis or injury in early childhood, and certain genetic disorders¹⁰. With improvements in survival for pre-term babies and among infants with brain injury or illness, the prevalence of cohort with learning disabilities is projected to increase⁵².

Life expectancy

Life expectancy is significantly shorter for people with learning disabilities than for the general population, although estimates vary in the literature. A University of Bristol study as part of the Confidential Inquiry Into Premature Deaths of People with Learning Disabilities (CIPLOID) reported on average adults with a learning disability die 16 years earlier than the general population, with the gap more marked for women at 20 years, compared to 13 years for men⁵³. More recently, the 2020 Learning Disability Mortality Review (LeDeR) reported that women with learning disabilities die on average 27 years before their peers, while for men the difference is 23 years². Differences in the median age of death for people with learning disabilities vary according to the degree of impairment, with 40 being among those with profound and multiple disabilities compared to age 62 among those with mild learning disabilities⁵⁴. The CIPLOID inquiry found a higher proportion of adults with learning disabilities (38%) die from avoidable causes than the general population (9%)⁵³.

For the general UK population in 2019, 85% of people were in the 65 years and over age group at their time of death, however this figure was 38% for people with learning disabilities notified to the LeDeR in 2018-2019 (Figure)².

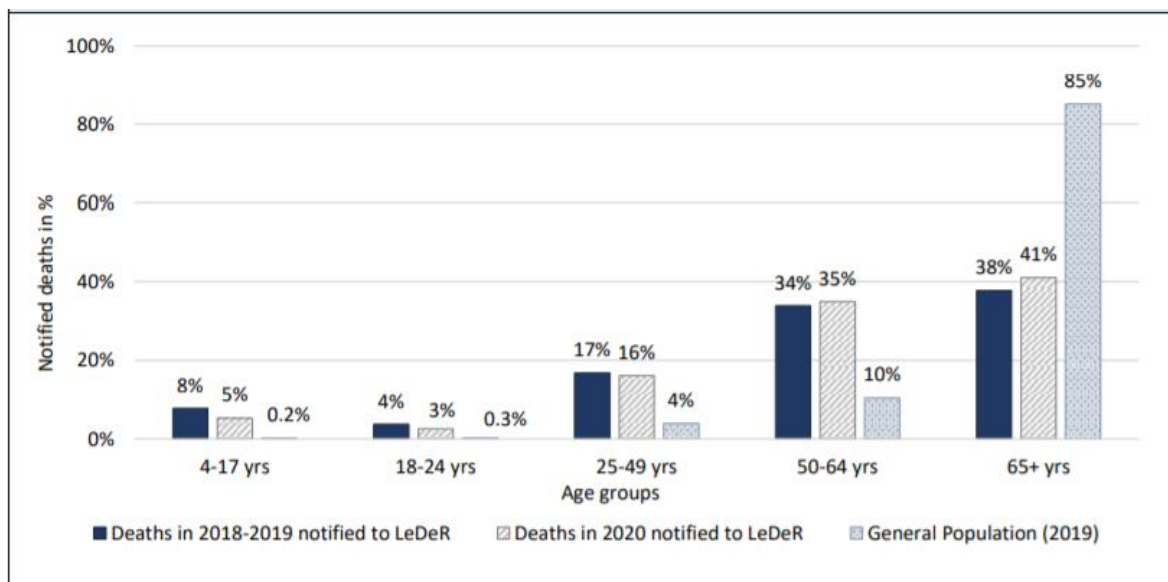


Figure 9: Age group at death for people with learning disabilities and the general population. Figure taken from the Learning Disability Mortality Review 2021

Despite overall and healthy life expectancy being significantly lower for people with learning disabilities, average life expectancy for this group is increasing. Two of the reasons for the global increase in life expectancy have been identified as improvements in neonatal care, and general improvements in health and care provision for this group. This means there will be an increasing number of older people with learning disabilities over the coming decades, and care providers and commissioners must take this increase into account when designing future services and estimating need. The largest increase in demand is expected to be seen in the 80 years and over age category^{3,1}. In 2014 there was projected to be a 164% increase in social care users in this age category by 2030, compared to an overall 30% increase in those aged over 50¹.

The NHS Long Term Plan recognises that despite experiencing worse health outcomes, people with learning disabilities often have poorer access to healthcare than the general population¹¹.

Prevalence of comorbidities and common health issues

A systematic review of studies, the majority of which were based in the UK, identified that adults with learning disabilities are less likely to receive screening and health promotion than the general public, with accounts of experiences of adults revealing a desire to avoid paternalistic care⁸¹. It is known that people with learning disabilities have some specific health needs that are identified in higher prevalence than the general population, including respiratory diseases, gastrointestinal cancers and coronary heart disease⁸²

Autism and Attention Deficit Hyperactivity Disorder (ADHD)

An estimated 20-30% of people with a learning disability also have autism⁵⁵, and it is estimated that around 60-70% of people with an autistic spectrum condition will also have a learning disability⁵⁶. There is some evidence to suggest that the prevalence of ADHD is higher among people with learning disabilities than in the general population (with an association between the condition and fragile X syndrome⁵⁷), but a 2011 review argued that ADHD often goes undiagnosed⁵⁸.

Mental health

The prevalence of mental ill-health is estimated to be substantially higher among people with learning disabilities than the general population⁴. Population based estimates indicate that 40% of adults with learning disabilities may experience mental ill-health at any one time, while this is estimated to be 36% in children and young adults⁴⁵. However, mental ill-health often goes undetected. A 2017 research study concluded that the increased risk of mental ill-health among people with learning disabilities may be attributed to greater exposure to social determinants of mental ill-health such as poorer living conditions or economic disadvantage⁵⁹.

Dementia

The prevalence of dementia is considerably higher among people with LD than the general population, and many conditions causing learning disability are associated with an onset of dementia decades earlier than is seen in the general population⁷.

The number of people with learning disabilities with dementia is expected to increase over the coming decades as life expectancy increases for this population group increases. This means that forward planning to develop and provide appropriate services is needed.

Dental health

People with Learning disabilities often experience poor dental health compared to their peers, including higher rates of tooth decay and loss, and lower compliance with oral health advice⁴⁶. The reasons for this are multifactorial and include lack of understanding about the importance of oral hygiene and the impact of diet on health, inability to follow oral hygiene advice due to limited dexterity, and barriers to accessing dental services.

Digestive health

It is estimated that approximately 50% of people with learning disabilities suffer from constipation⁶⁰. As of 2019, the LeDeR has recorded 12 deaths as a result of complications arising from constipation⁶¹. While this represents a small proportion of deaths reviewed, the numbers highlight the vulnerability of people with LD to complications from a preventable and treatable condition^{2,54}. Malnutrition is more common among people with LD than the general population and being underweight is a concern for some individuals with profound and multiple needs⁶². Malnutrition may arise from difficulties in eating or drinking among those with more severe needs or may be associated with overweight and obesity and lack of ability to follow a healthy diet.

Sensory impairments

Approximately a third of people with learning disabilities are estimated to have a sensory impairment, and some of these impairments may progressively worsen over time. Among many people with mild learning disabilities, sensory impairments may present greater support needs than the learning disability^{63,64}.

Inactivity and obesity

Inactivity levels among people with LD have been found to be significantly lower than the general population, with 45.5% of people with LD being physically inactive compared to 27.1% of the general population⁵. A higher proportion of people with learning disabilities are in the category of obese, compared to those without a learning disability⁴⁷. One recent study reported the prevalence of overweight and obesity is a particular health need among forensic inpatients with learning disabilities⁶⁵.

Diabetes

The prevalence of diabetes is estimated to be twice as high among people with learning disabilities than among the general population (10% vs. 5%), with the majority of cases being Type 2 diabetes⁶.

Cancer screening

Nationally, people with learning disabilities are statistically significantly less likely to receive screening tests for cancer than those without learning disabilities⁶⁶. Cervical cancer screening rates in particular are considerably lower among eligible women with learning disabilities, with uptake at 31% for women with learning disabilities compared to 73% for those without^{67,68}.

Flu vaccination uptake

People with learning disabilities and their carers have been eligible for flu vaccinations since 2014, however nationally, uptake of the vaccine among the LD population has been below target⁴⁴, with only 44% among people with LD in 2018⁶⁹. This is despite people with learning disabilities often experiencing complications with respiratory health than the general population with pneumonia being a leading cause of death². Nationally, uptake of the flu vaccination is lower among younger people with LD than their older counterparts⁴⁴.

Annual health check uptake

NHS data from 2016/17 showed that of those people registered as having LD on a GP register, 53% had an annual health check⁷⁰. The NHS Long Term Plan sets a target that by 2023/24 at least 75% of people with learning disabilities aged 14 or over will have had an annual health check¹¹.

The impact of COVID-19 on people with learning disabilities

People with learning disabilities have been particularly clinically vulnerable to COVID-19, with both hospitalisations and mortality recorded as being significantly higher among this group than the general population. Analysis by PHE data from March-June 2020 found that during this period, the death rates from COVID-19 was 4.1 times higher among people registered as having a learning disability than for the general population. Given there is under-registration of these people, the authors estimated the true rate may have been 6.3 times higher.

Among those with learning disabilities who died, the distribution of deaths by age was very different than deaths from COVID-19 in the general population, with the death rate being 30 times higher among those aged 18 to 34 than the rate among the same age group without learning disabilities. The report authors highlighted that the higher prevalence of obesity, diabetes and susceptibility to respiratory infections among people with learning disabilities makes them particularly vulnerable to COVID-19. The authors also found that people with learning disabilities resident in residential care settings were at higher risk of mortality than those living in the community. A population-based cohort study considering data from March 2020-February 2021 found similar results⁷¹. The authors found that adults and children with a learning disability were significantly more likely to be hospitalised with COVID-19 than those without, and the association between hospitalisation and learning disabilities was more pronounced among individuals with more severe and profound learning disabilities.

Health status of people with learning disabilities in Suffolk

Experimental statistics published by NHS Digital⁸³ have been used to report on the prevalence of specific health conditions among people with learning disabilities in Suffolk. There are however several caveats to note around the data included, meaning these figures should be interpreted with caution:

- Data is reported at CCG-level, therefore it is not possible to ascertain an overall prevalence for Suffolk.
- The data is not based on all GP practices in Suffolk. For West Suffolk CCG, 37% of practices are included, however these are not randomly distributed leading to varying coverage across the area. For the Norfolk and Waveney CCG (covering the Waveney area of Suffolk), coverage was 16% of practices, although there was no information available to indicate if these practices were within the Waveney area. For Ipswich and East Suffolk CCG, coverage was much lower at 3% of practices, therefore data reported is unlikely to be representative of the overall learning disability population, therefore it is not included.
- The estimated prevalence of each condition reported for West Suffolk was applied to the overall estimated prevalence of adults aged over 18 with learning disabilities in Suffolk (14,212).

Obesity

In West Suffolk in 2019/2020, prevalence of obesity according to the most recent Body Mass Index (BMI) assessment was significantly higher among people with learning disabilities (26.3%) compared to 10.3% among those without. This difference in prevalence was seen across all age groups, with the most pronounced difference being in the 35-44 age category among whom prevalence was 37% among people with learning disabilities compared to 8.8% among those without. Data for Norfolk and Waveney CCG were similar, with 22.5% overall prevalence among people with LD, compared to 9.6% among those without recorded LD. Applying the obesity prevalence for adults in West Suffolk to the total estimated prevalence of people aged 18 and over with learning disabilities in Suffolk, there are 3737 adults with learning disabilities living with obesity in Suffolk.

Diabetes

For West Suffolk CCG, across all age groups (0-9 to 75 and over), the prevalence of diagnosed non-type 1 diabetes was 7.1% among people with learning disabilities compared to 6.0% for those without. The higher prevalence among people with learning disabilities was present in all adult age groups, with the difference being most pronounced among with 55–65-year-old age group (20.3% among people with learning disabilities compared to 7.5% of people

without). In Norfolk and Waveney CCG, the overall prevalence was similar (5.3% among people with LD vs. 5.1% among people without), and in the aged categories of 35-44, 45-54 and 55-64, the prevalence was higher among people with LD (5.6 vs.1.4, 7.1 vs. 4.1 and 12.1 vs. 8.2 respectively). Using the same methodology described above, this would give an overall estimated 1,009 adults with learning disabilities diagnosed with non-type 1 diabetes living in Suffolk.

Severe mental illness

In West Suffolk CCG, the proportion of patients with a severe mental illness diagnosis in 2019/2020 was 8.3% among people with learning disabilities, and 0.8% among those without. The age group with the highest proportion of people diagnosed was the 45-54 category, where 20% of has a diagnosis of severe mental illness. The overall difference in prevalence was similar in Norfolk and Waveney CCG, with 7.3% of people with LD being diagnosed with a severe mental illness, compared to 0.7% among people without an LD. In this CCG, the 55–64-year-old age category had the highest proportion of people with LD diagnosed, at 22%, compared to 1% of their peer age group without LD. Using the methodology described above, there may be 1179 people in Suffolk with learning disabilities with severe mental health problems.

Epilepsy

In 2019/2020 the all-age prevalence of epilepsy among people with learning disabilities in West Suffolk CCG was 12.3% compared to 0.7% of those without, and this significantly higher proportion was present in every age group. The difference was more pronounced in Norfolk and Waveney CCG, where the prevalence was 22.6%, compared to 0.6% among people without LD. Using the methodology described above, there may be in the region of 1748 adults with learning disabilities with epilepsy in Suffolk.

Cancer screening

Using data from the NHS Health and Care of People with Learning Disabilities dashboard, the lower uptake of cancer screening among people with LD is also seen for Suffolk residents (people registered in the Ipswich and East Suffolk CCG and West Suffolk CCG), particularly for breast and cervical cancer screening (Figure 10; Figure 11). In 2019-2020, breast screening rates were 63% for women with LD compared to 82% for the general population. For cervical screening, uptake among women with LD was 41% compared to 71% in the general population. Although these data are limited for Suffolk (only 16.5% of total Suffolk patients are included in this dataset and geographic coverage is highly varied), they are the best available source of data on cancer screening in people with learning disabilities in Suffolk.

Percentage of patients who are female, aged 50 to 69 and received breast cancer screening in the five years up to and inc 31 March, by year

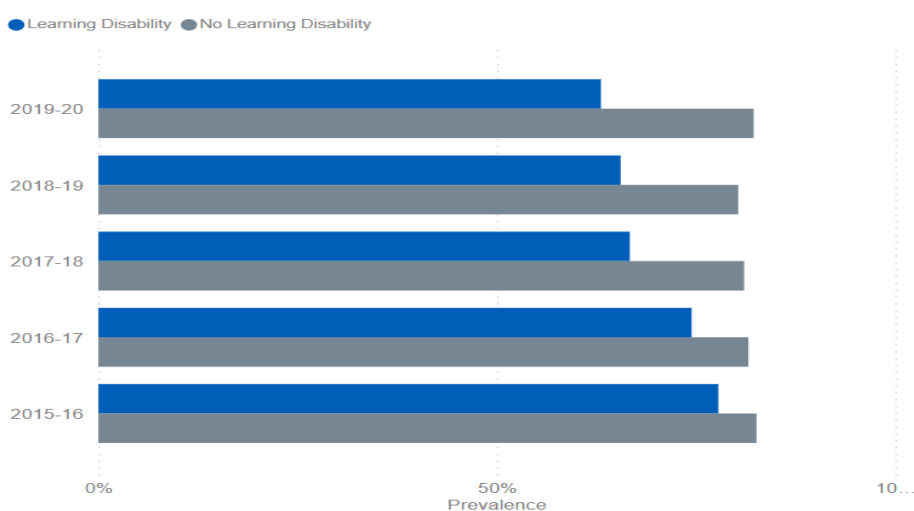


Figure 10: Breast cancer screening uptake rates for Suffolk residents (Ipswich and East Suffolk & West Suffolk CCGs) for people with and without learning disabilities. Data taken from NHS Digital Health and Care of People with Learning Disabilities dashboard

Percentage of patients eligible for cervical cancer screening (female, aged 25 to 64 with no history of hysterectomy), on whom an adequate cervical smear test has been performed in the three years and six months up to and including the 31 March for patients aged 25 to 49 and in the five years and six months up to and including the 31 March for patients aged 50 to 64, by year

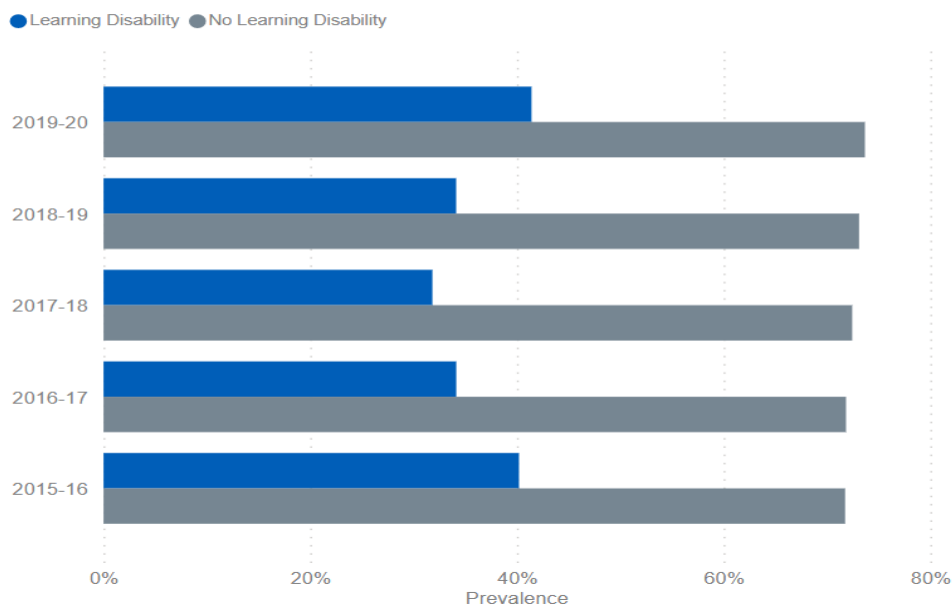


Figure 11: Cervical cancer screening uptake rates for Suffolk residents (Ipswich and East Suffolk & West Suffolk CCGs) for people with and without learning disabilities. Data taken from NHS Digital Health and Care of People with Learning Disabilities dashboard

For breast cancer screening, it appears that the screening rates for people with learning disabilities in Suffolk have decreased over the most recent five years for which there are data, when compared to people without this condition (Figure 10). For cervical cancer screening, people with learning disabilities generally access at approximately half the rate of people without it (Figure 11).

In October 2020, the Suffolk CCGs commissioned a cervical cancer screening service, with an objective to increase uptake in specific groups (including those with a learning disability)⁸⁴. This work is continuing through 2021/22, but early results identified a disproportionate cessation of screening by people with learning disabilities. In contrast, for colorectal cancer, Suffolk residents both with and without learning disabilities access screening at very similar levels (Figure 12).

Percentage of patients who are eligible for colorectal cancer screening (aged 60 to 74) and have a colorectal cancer screening result recorded in the two years and six months up to and inc 31 March, by year

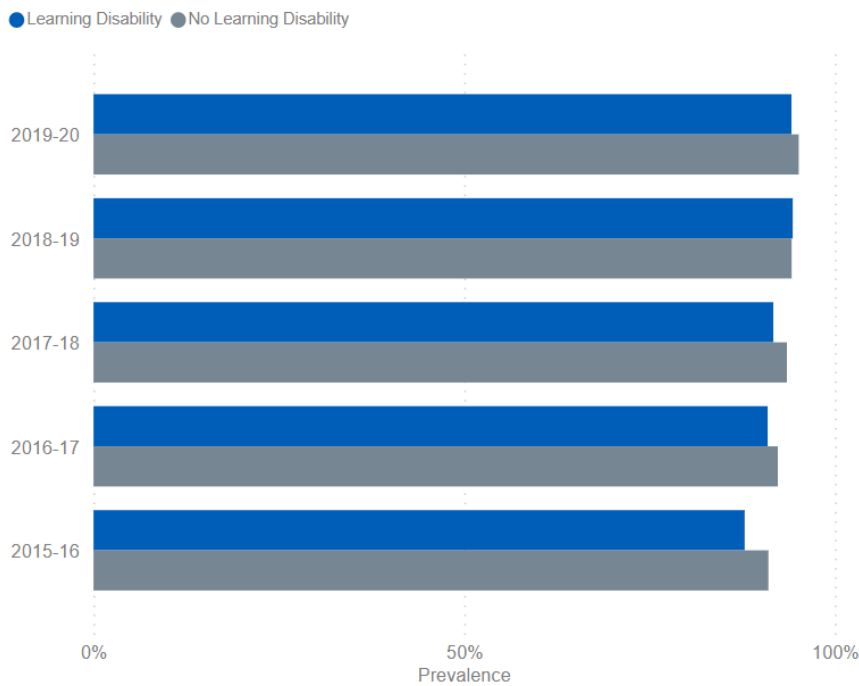


Figure 12: Colorectal cancer screening uptake rates for Suffolk residents (Ipswich and East Suffolk & West Suffolk CCGs) for people with and without learning disabilities. Data taken from NHS Digital Health and Care of People with Learning Disabilities dashboard

In 2020/21, Suffolk LeDeR reported that 17% of cases reviewed consistently took up the offer of cancer screening, and 28% of cases were offered some screening available, but not all, however 34% of people had no evidence of screening being offered in their records⁸⁴. This inconsistency in screening offer and poor uptake was highlighted as an issue in the Suffolk LeDeR 2020/21 findings⁸⁴, and a programme to tackle this has been set up in late 2020 by NHS England and NHS Improvement – East of England.

Annual health checks

Nationally, uptake of annual health checks for people with learning disabilities has increased in recent years, although remains below target.

The COVID-19 pandemic substantially impacted the abilities of Suffolk CCGs to complete annual health checks for people with learning disabilities, with only 1% of checks being completed in quarter one of 2020/21⁸⁴. Targeted work to increase this to 67% completion for the year was undertaken and data provided by NHS Ipswich and East Suffolk CCG indicate that this goal was exceeded overall for Suffolk, but that people registered in Ipswich and East Suffolk CCG had a higher percentage of completed health checks than in West Suffolk CCG (Figure 13).

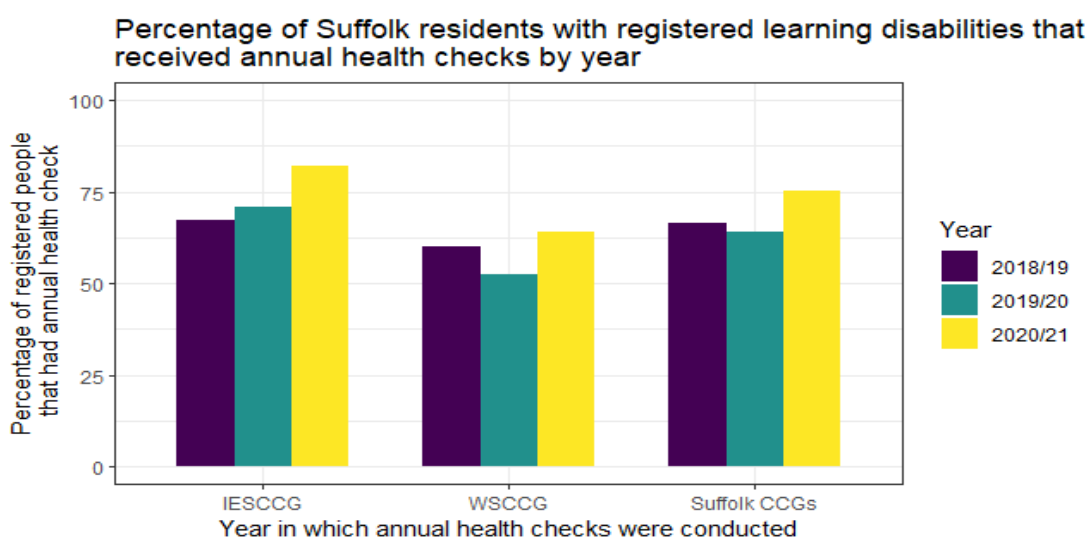


Figure 13: Percentage of Suffolk residents with registered learning disabilities receiving annual health checks per year, broken down by the two Suffolk CCGs (Ipswich and East Suffolk CCG and West Suffolk CCG), as well as the combined Suffolk figures

Flu vaccination

Data available from the NHS Digital Experimental Statistics dashboard for the health and care of people with learning disabilities showed that in 2019/2020, overall uptake of the flu vaccination among this group in West Suffolk was 43.5%, based on coverage of 37% of GP practices. The data shows uptake was highest among the oldest and youngest age groups: 75% for those aged 75 and over, 69.2% among those aged 65 to 74, while among children aged 0-9 uptake was 60%. Among all adult age categories from age 18 to 54, uptake was below 40%. This data suggests that uptake is strongly dependent on known or perceived eligibility by age, rather than the presence of a learning disability determining eligibility at any age. Overall uptake in Norfolk and Waveney CCG was 49.1%, with a similar distribution by age, although these results were based on 16% practice coverage so should be interpreted with caution. Very low practice coverage for IESCCG means that we have not included data for this area.

The impact of COVID-19

During the period April 2020-March 2021 there were 7 confirmed deaths from COVID-19 among people with learning disabilities resident in Suffolk, all of whom has underlying respiratory conditions and were aged from 44-83⁸⁴.

It was identified early in the pandemic that people with learning disabilities often had difficulty adhering to social distancing guidance, which was attributed in part to an initial delay in accessible information being made available nationally. The LeDeR Annual report for the Suffolk CCGs states that in some cases this lack of adherence to social distancing led to Safeguarding referrals being made⁸⁴.

SCC Adult and Community Services customers

SCC ACS customer database shows that in total, 2,640 individual customers with learning disabilities, comprising 1,073 females and 1,567 males, were supported between April 2018 and April 2021 (Table). Due to confidentiality reasons, any numbers under 7 have been suppressed.

Ethnicity

The majority of SCC ACS customers who had received support for learning disabilities were recorded as being White British/British (92.2%; Table 3).

Table 3: Recorded ethnicity groups of Suffolk residents with known learning disabilities that were active customers in the Suffolk County Council Adult and Community Services system between April 2018 and April 2021, and a comparison to the known ethnicity percentages in the Suffolk population aged 18-85+ from the 2011 ONS Census.

Ethnicity group	Total SCC ACS customers	Percentage of total SCC ACS customers with LD	Percentage of Suffolk population aged 18-85+ (2011 census)
Asian (including Bangladeshi, Chinese, Filipino and Indian)	24	0.91%	1.63%
Black (including African and Caribbean)	26	0.98%	0.95%
Mixed ethnicities (including White and Asian, White and Black African, White and Black Caribbean)	43	1.63%	1.04%
Other ethnicities (including other European)	24	0.91%	0.34%
Other White (including Gypsy/Roma and White Irish)	27	1.02%	4.49%
White British/British	2436	92.27%	91.54%
Not provided or refused	60	2.27%	NA
Total	2640	-	-

As the numbers of individuals who are recorded as ethnicities other than White British are relatively small, and the best quality ethnicity denominator data is quite old at the time of this publication (taken from 2011 ONS Census), making inferences about the over- or under-representation of specific ethnicity groups is discouraged.

Table 4: Age and sex distribution and learning disabilities requirements of Suffolk residents that were active customers in the Suffolk County Council Adult and Community Services system between April 2018 and April 2021

Age group	Sex	Latest recorded LD health condition	Total customers
18-64	Female	Asperger's Syndrome / High Functioning Autism	37
		Autism (excluding Asperger's Syndrome / High Functioning Autism)	106
		Learning Disability	707
		None recorded	60
	Male	Asperger's Syndrome / High Functioning Autism	125
		Autism (excluding Asperger's Syndrome / High Functioning Autism)	329
		Learning Disability	897
		None recorded	81
65+	Female	Autism (excluding Asperger's Syndrome / High Functioning Autism)	Suppressed
		Learning Disability	143
		None recorded	17
	Male	Asperger's Syndrome / High Functioning Autism	Suppressed
		Autism (excluding Asperger's Syndrome / High Functioning Autism)	12
		Learning Disability	113
		None recorded	8
	Total		-

Age breakdown

For ACS customers with learning disabilities who accessed services in 2020-21, the age breakdown has been provided in Table 3. When compared to the overall Suffolk population estimates, these customers with LD are generally much younger than the general population, with more than 80% of them being under 60 years old.

Table 3: Age groups of SCC ACS customers with learning disabilities who accessed services in 2020-21

Age group	Total SCC ACS customers with LD in 2020-21	Percentage of SCC ACS customers with LD in 2020-21	Suffolk population estimates (2020)
18-29	639	29.4%	12.1%
30-39	458	21.1%	11.7%
40-49	329	15.1%	11.6%
50-59	391	18.0%	14.3%
60-69	213	9.81%	12.4%
70-79	111	5.11%	11.1%
80+	31	1.43%	6.7%
Total	2172	-	-

Projections of learning disabilities demand

Projections of the future demand for support for people with learning disabilities come from POPPI and PANSI ^{77,78}. These estimates, based on prevalence rates and projected future populations, indicate that by 2040 there would be 15,557 adults in Suffolk will have a learning disability, an increase of 9.5% on levels in 2020 ^{77,78}.

Most of this growth is projected to come in the 65 and over age categories, with 1,470 more adults aged 65 and over having a learning disability in 2040 than in 2020. For those adults with moderate or severe learning disabilities, and therefore likely to be in receipt of services, a slight increase is projected in total number between 2020 and 2040.

However, the age distribution of this population is projected to change with older people making up a higher proportion of those requiring support for learning disabilities (Figure 14).

In 2020, it was estimated that adults aged 65 and over accounted for 17.7% of those with moderate or severe learning disabilities in Suffolk (509/2,871), but this is projected to increase to 22.1% by 2040 (670/3,025). This change in age of the population will inevitably lead to a change for the types of requirements and support to be provided by services.

Projected number of Suffolk adults with moderate or severe learning disabilities by year and age group

Number indicates total number projected adults with moderate or severe LD

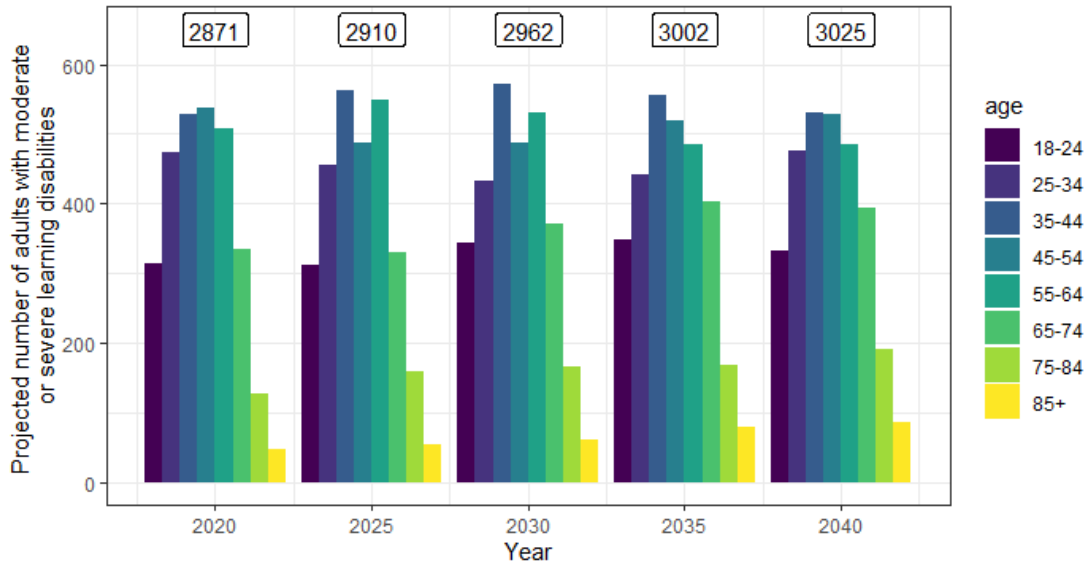


Figure 14: Projected number of Suffolk adults with moderate or severe learning disabilities between 2020 and 2040. Data from POPPI and PANSI.

Recent work conducted in 2021 by Suffolk County Council and the East and West Suffolk Alliances on demand and capacity modelling for learning disability services identified a total of 9,155 yearly contacts with service users, of which 30 were for in-patient care. The demand on services is likely to change as the population age and needs requiring support changes in the future.

Service provision by Adult and Community Services

Types of provision

Day services, supported housing, and home care and support were the three service types that were used by the highest numbers of SCC ACS customers with learning disabilities (figure 15). There are no obvious patterns in the types of services used by them.

Number of Suffolk County Council ACS customers with learning disabilities by service type

Please note: service users can, at times, have multiple service types

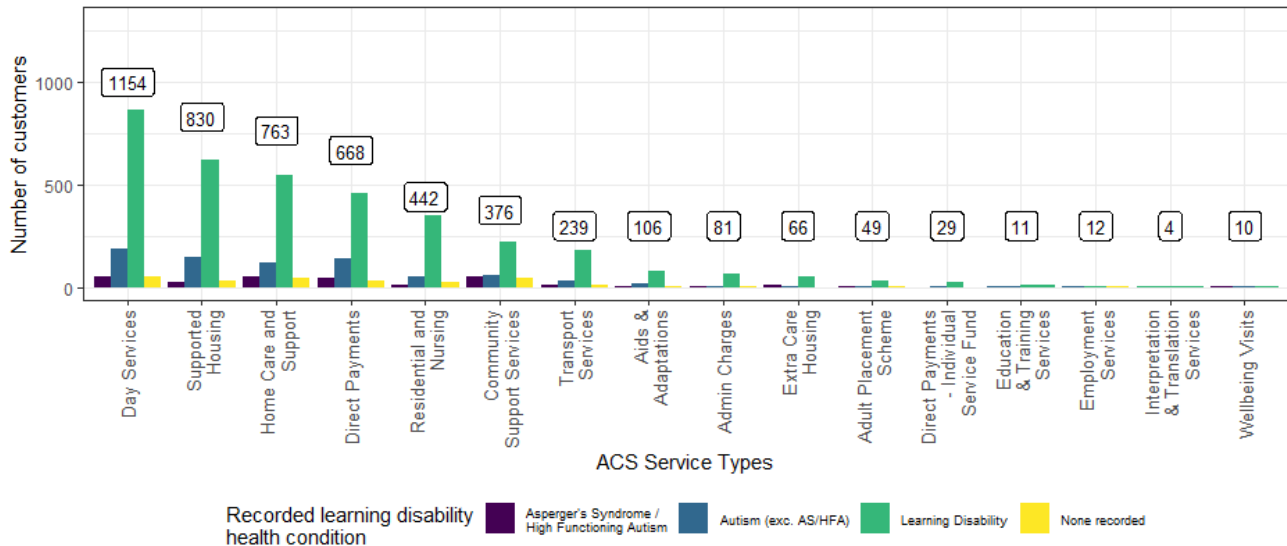


Figure 15: Number of Suffolk County Council Adult and Community Services customers with learning disabilities that were actively supported between April 2018 and April 2021 by contract type

PHE Fingertips (2018/19 and 2019/20) data shows the rate of adults in Suffolk with learning disabilities who received long-term support from local authorities has increased in the most recent two years where data are available through In 2019/20, this rate was statistically significantly higher than the national rate (Figure 16).

Adults (18+ yrs) with learning disability receiving long-term support from local authorities (per 1,000 population)

Crude rate - per 1,000

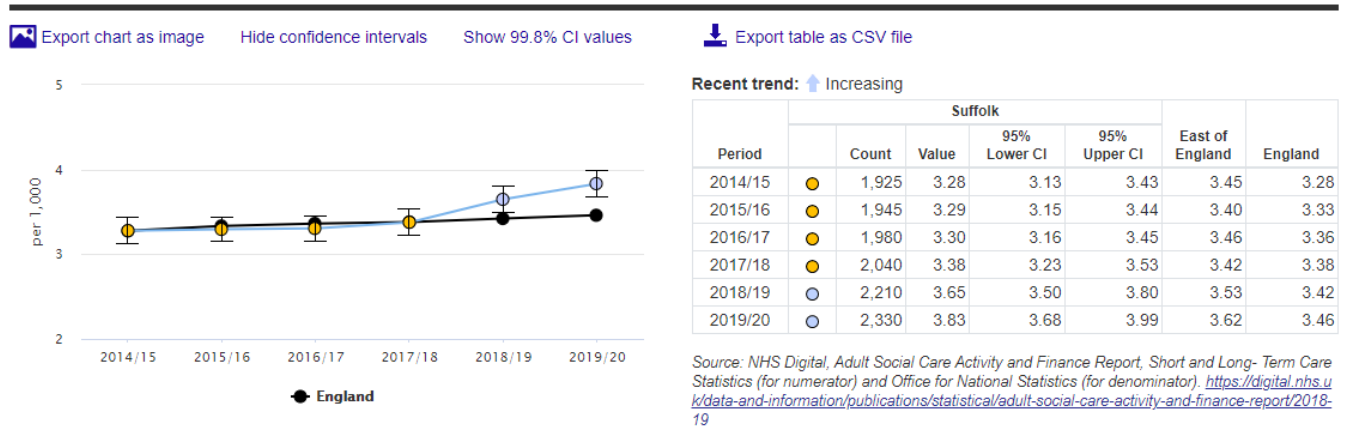


Figure 16: Comparison of rates of working age adults with learning disabilities receiving long-term support from local authorities (Suffolk versus England). Data from Public Health England Fingertips

Location of provision

There was a wide geographic spread of locations that ACS customers with learning disabilities used to connect with services (Figure 17), however approximately a third of the services provided were accessed in Ipswich (IP1-4 postcodes) or Lowestoft. These are the two biggest towns by population in Suffolk⁷⁶, so this is not unexpected. There

do not appear to be any strong geographic trends in customers with different recorded learning disabilities accessing services in certain locations.

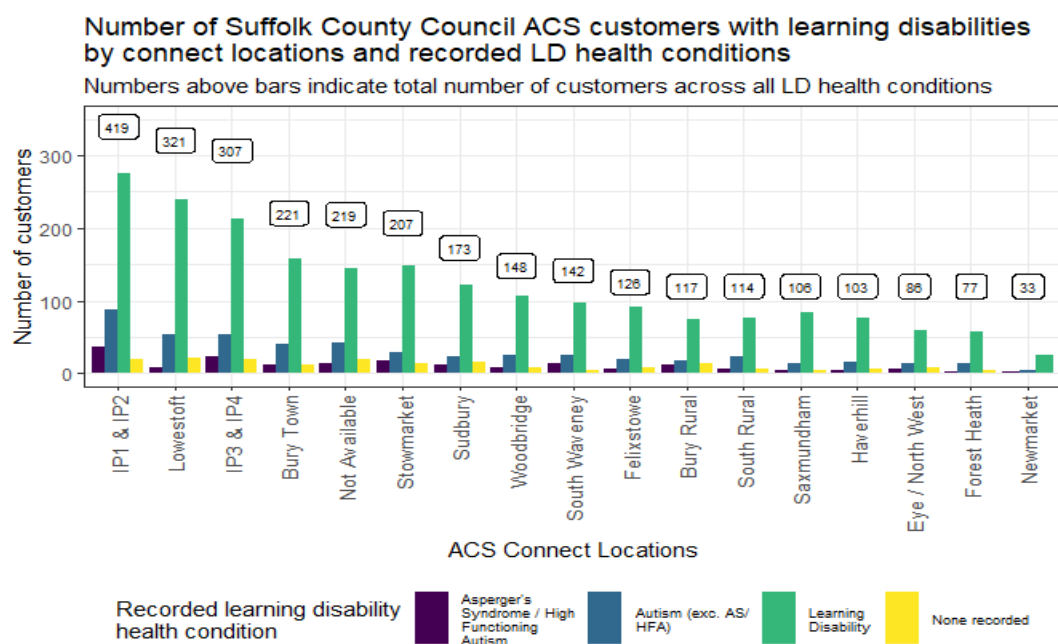


Figure 17: Number of Suffolk County Council Adult and Community Services customers with learning disabilities by their recorded LD health condition and where they connect with their support services. As many customers have connected with services in more than one location during this time frame, the total number is higher than the number of individual customers.

Accommodation

Adults with learning disabilities often live in unsettled or temporary accommodation and that, historically, Suffolk County Council recording of accommodation status for adults with learning disabilities has been poorer than regional and national rates (Figure 18; Figure 19).

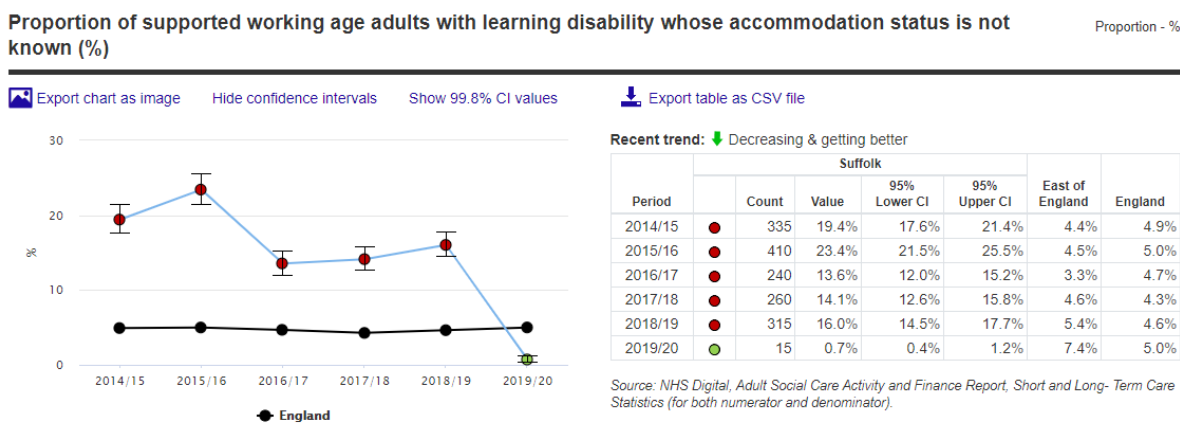


Figure 18: Comparison of percentages of supported working age adults with learning disabilities whose accommodation status is not known (Suffolk versus England). Data from Public Health England Fingertips

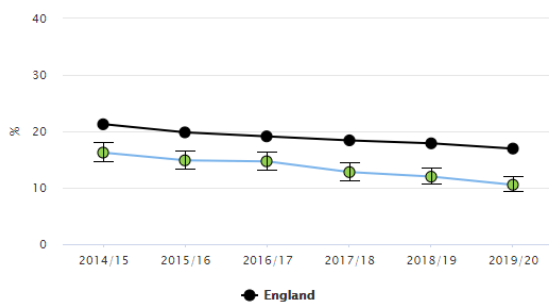
The proportion of supported working age adults with learning disabilities in Suffolk that were living in unsettled accommodation had been consistently statistically significantly lower than the national average, and decreasing, since 2014/15 (Figure 19).

Proportion of supported working age adults with learning disability living in unsettled accommodation (%)

Proportion - %

Export chart as image Hide confidence intervals Show 99.8% CI values

Export table as CSV file



Recent trend: Decreasing & getting better

Period	Count	Value	Suffolk		East of England	England
			95% Lower CI	95% Upper CI		
2014/15	280	16.2%	14.6%	18.0%	23.4%	21.3%
2015/16	260	14.9%	13.3%	16.6%	22.0%	19.8%
2016/17	260	14.7%	13.1%	16.4%	21.1%	19.1%
2017/18	235	12.8%	11.3%	14.4%	20.2%	18.4%
2018/19	235	12.0%	10.6%	13.5%	18.3%	17.9%
2019/20	220	10.5%	9.3%	11.9%	17.6%	16.9%

Source: NHS Digital, Adult Social Care Activity and Finance Report, Short and Long- Term Care Statistics (for both numerator and denominator).

Figure 19: Comparison of percentages of supported working age adults with learning disabilities living in unsettled accommodation (Suffolk versus England). Data from Public Health England Fingertips

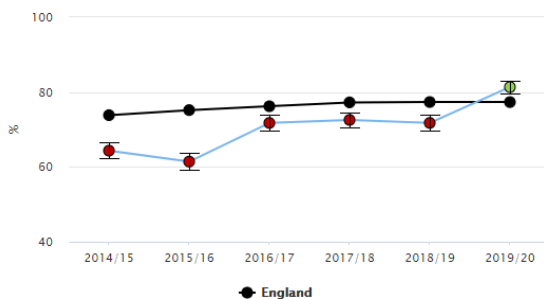
The proportion of supported working age adults with learning disabilities in Suffolk that were living in settled accommodation increased to above the national average for the first time in 2019/20 (Figure 20). After at least five years of being below the national average, this increase coincided with a concerted effort to collect data on the accommodation status of SCC Adult and Community Services (ACS) customers with learning disabilities in 2019 (Figure 20). This is positive.

Proportion of supported working age adults with learning disability living in settled accommodation (%)

Proportion - %

Export chart as image Hide confidence intervals Show 99.8% CI values

Export table as CSV file



Recent trend: Increasing & getting better

Period	Count	Value	Suffolk		East of England	England
			95% Lower CI	95% Upper CI		
2014/15	1,110	64.3%	62.1%	66.6%	72.2%	73.8%
2015/16	1,075	61.4%	59.1%	63.7%	73.5%	75.2%
2016/17	1,270	71.8%	69.6%	73.8%	75.6%	76.2%
2017/18	1,335	72.6%	70.5%	74.5%	75.2%	77.2%
2018/19	1,410	71.8%	69.7%	73.7%	76.3%	77.3%
2019/20	1,700	81.3%	79.6%	83.0%	74.0%	77.3%

Source: NHS Digital, Adult Social Care Activity and Finance Report, Short and Long- Term Care Statistics (for both numerator and denominator).

Figure 20: Comparison of percentages of supported working age adults with learning disabilities living in settled accommodation (Suffolk versus England). Data from Public Health England Fingertips

Following a change in the ACS customer management software in September 2018 and additional work to clean historic data, more recently available SCC data indicates that of the 2,640 customers who received support for learning disabilities between April 2018 and April 2021, 93.3% of them had their accommodation status recorded and that the majority of people lived in settled accommodation (Ta

Table 4).

Table 4: Recorded accommodation status for Suffolk residents with known learning disabilities that were active customers in the Suffolk County Council Adult and Community Services system between April 2018 and April 2021

Latest recorded accommodation status	Total SCC ACS customers	Percentage of total SCC ACS customers
Settled mainstream housing with family/friends	996	37.7%
Supported accommodation/lodgings/group home	646	24.5%
Tenant – local authority/housing association/social landlord	294	11.1%
Registered care home	249	9.4%
Tenant – private landlord	70	2.7%
Owner occupier/shared ownership scheme	66	2.5%
Sheltered housing	46	1.7%
Acute/long stay healthcare facility	42	1.6%
Shared Lives scheme	29	1.1%
Staying with family/friends as short-term guest	8	0.3%
Other temporary accommodation	6	0.2%
Other accommodation category (inc. nursing home/rough sleeper/prison)	11	0.4%
No information provided	177	6.7%
Total	2640	-

Employment

Approximately 6% of adults receiving care for learning disabilities were in paid employment nationally in 2018/19⁸⁰.

There was a reduction in the proportion of supported working age adults with learning disabilities that were in paid employment in 2018/19 and 2019/20, with Suffolk being statistically significantly lower than the national average in this metric (Figure 21). As discussed later in this document, it appears this recent decrease and difference from the national average may be attributed to data quality issues, although further exploration is required.

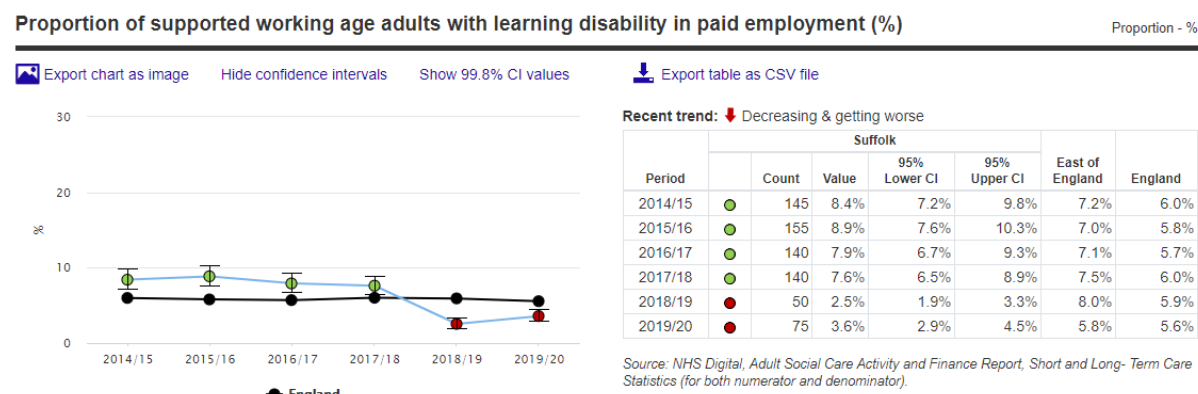


Figure 21: Comparison of percentages of supported working age adults with learning disabilities that are in paid employment (Suffolk versus England). Data from Public Health England Fingertips

Of the 2,640 ACS customers who received support for learning disabilities between April 2018 and April 2021, only 11 were known to be in paid work (0.4%) and 24 were known to be in unpaid voluntary work (0.9%). However, employment status was not known for 2,550 of these customers (96.6%). Work that was due to be undertaken in

2020/21 to collect further data on employment and voluntary work status for ACS customers receiving support for learning disabilities was impacted by the COVID-19 pandemic and had to be put on hold, resulting in limited data collection in 2020/21. This work will be restarted in 2022 as part of a wider employment strategy being initiated by the ACS learning disabilities service.

Safeguarding for adults aged 18-64

Information on safeguarding referrals regarding adults with learning disabilities in Suffolk came from SCC safeguarding datasets, filtered to only include adults that have learning disabilities as their primary support reason. The 2014 learning disability needs assessment identified safeguarding data as a gap and recommended improvement. This recommendation has been acted upon in the intervening years. In the three fiscal years of 2018/19, 2019/20 and 2020/21, a total of 867 safeguarding referrals were made for adults with learning disabilities. Some of these referrals were made with multiple types of risk highlighted (as defined under the NHS Digital Adult Social Care Data Dictionary⁸⁵), though due to historic data incompleteness, some older referrals have limited information on associated risks and locations.

The most frequent type of risk highlighted in safeguarding referrals regarding Suffolk adults with learning disabilities is for physical abuse, which has increased from 90 in 2018/19 to 163 in 2020/21 (Figure 22). Psychological and sexual abuse are the second and third highest types of safeguarding risk that have been referred, both of which have also experienced increases since 2018/19. It is thought that lockdowns caused by the COVID-19 pandemic have led to an increase in the number of safeguarding referrals in 2020/21, however the increase prior to the pandemic has not been examined.

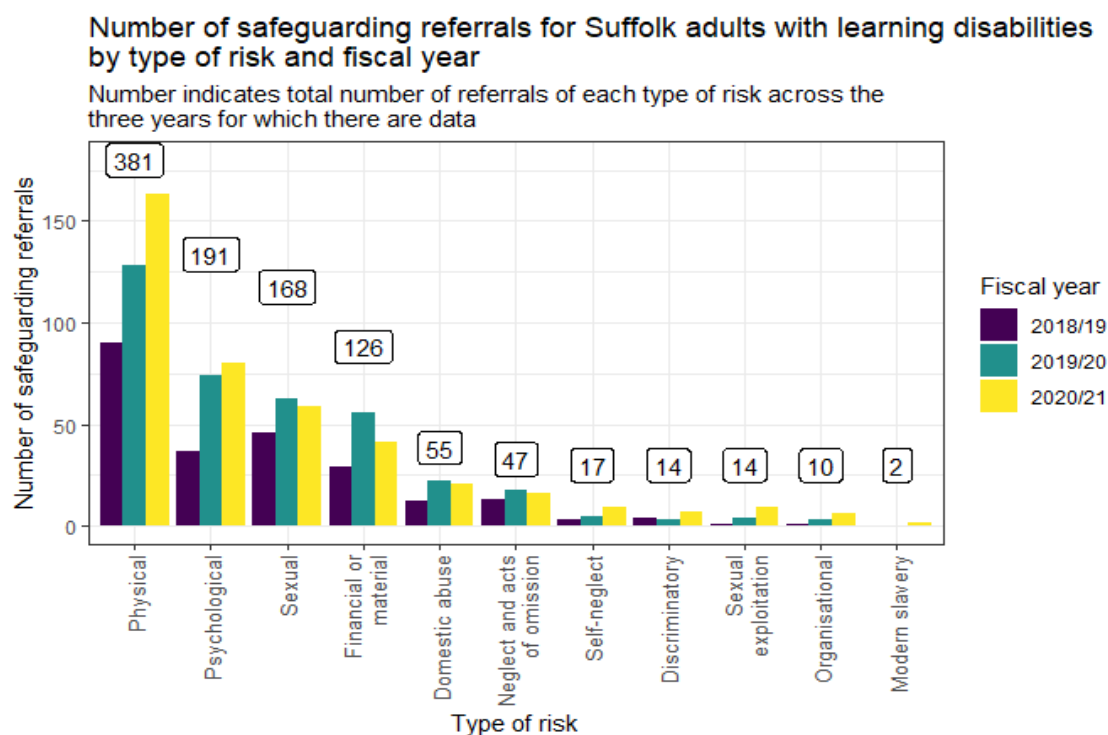


Figure 22: Safeguarding referrals for Suffolk adults with learning disabilities in 2018/19, 2019/20 and 2020/21 by type of risk

Due to historic data incompleteness, for almost 20% of referrals in the dataset (173/867), the location where the safeguarding incident occurred was not recorded. For those where it was recorded, 198 were noted as occurring in hospitals, 170 in the person’s own home and 269 in “other” settings (which includes where the location was not known).

Corporate assessment of provision in Suffolk

The purpose of this assessment was to assess provision of services for people with learning disabilities in Suffolk against the best practice identified in the relevant literature. We have intended to identify examples of good provision, challenges, and gaps in providing appropriate services accordingly.

Information was collected through the following activities:

- Online questionnaire sent to providers, contract managers and commissioners of services for children and adults with learning disabilities in Suffolk.
- Interviews and self-assessment activities with colleagues from SCC ACS and CYP teams (July 2021).
- Online engagement activities with adults with learning disabilities hosted by ACE Anglia. These consisted of 2 sessions hosted solely for the purpose of gathering information for this needs assessment with a group of approximately 15 experts by experience. Additionally, recording of service user experiences was made through attendance by the public health at Suffolk People First and Health and wellbeing sessions hosted by ACE Anglia in May-June 2021.

A full description of the methods used to engage with stakeholders is included in the appendix of this report. Key findings from engagement activities undertaken with stakeholders have been reported below for specific elements of provision, and more detailed information is recorded in the appendices of this document. These areas of provision have been selected given their prominence in NICE Guidance, as recurring themes in the relevant literature, and their inclusion in the Suffolk Joint Learning Disability Strategy 2015-2020.

Informed choices and personalisation of care provision

Examples of good practice in this area is the implementation of the named worker 'annual allocations' model which is being implemented across the ACS Learning Disabilities and Autism (LD&A) teams. This model helps meet customer's needs and it enables delivering good reviews, as workers can build relationships over time. ACS is also enabling providers to contact social work practitioners directly to discuss needs of customers.

ACS have rolled out a project called 'Doing Reviews Differently', providing a platform for practitioners to offer meetings online, virtually. This has involved working closely with ACE Anglia and other co-production partners on delivering a set of tools to improve the experience of reviews and explain the customer journey in ACS. Offering a choice, where appropriate on how a customer's review is carried out ensures that a review is proportionate and flexible to meeting need. Some service users prefer online reviews.

There is a strong programme of practice transformation that encourages person focused, strengths-based practice, using a Customer Journey as a guide. Audits are commonplace and a Practice and Funding Escalation Forum supports good practice.

There can sometimes be challenges in delivering the individualised, personalised choice model in line with best practice while ensuring there is standardisation of practice allowing for effective monitoring.

Accessible information to make informed choices

The ACS LD&A team have co-produced easy-read resources covering a range of issues including 'Preparing for your online review', 'What is a social care review?', a guide to the customer journey and an easy read version of the Care Act. The Suffolk Ordinary lives website contains a range of accessible resources on housing, employment, and money, in addition to signposting to other useful resources.

SCC maintains the Infolink website which contains details on a range of providers for services for people with learning disabilities. Contract managers within ACS and Children and Young People Services (CYPS) stated that the information provided on the Infolink website may not be up to date for some providers, particularly considering how service provision may have changed following COVID-19 restrictions.

It was also recognised that there needs to be greater provision of, and signposting to, accessible information on available services to enable service users and their families to make informed choices. In addition to online services, through the provider Realise Futures, ACS have provided pop-up accessible information advice and guidance services in venues such as libraries. Uptake of these services has been low, potentially due to low awareness, therefore further work is needed to understand the best model of provision.

Engagement activities with service users indicated that while the Ordinary Lives website was a useful resource, there was a need for more standardisation around the types of information available, and where these could be accessed. Several people also expressed a desire for a drop-in hub for advocacy and health information.

Flexibility of choice

Adult customers are able to change provider for day activities if their preferences change via the Customer First Service, however contract managers acknowledged that there may not always be sufficient accessible information on services for service users to make that choice.

COVID-19 has significantly affected ACS's ability to undertake annual reviews. Social work teams have been largely focusing on urgent work as COVID-19 has interrupted the routines of so many customers and a large proportion have seen a dip in their mental health. However, significant efforts were undertaken throughout the pandemic to ensure continuity of provision as far as possible. Customers with an allocated worker were risk assessed and given light touch reviews, and social workers were in regular contact with service development and contracts colleagues, who were in close contact with daytime opportunity providers. To ensure situations remained stable for customers and family carers, changes were made based on risk assessments and need, ensuring wellbeing outcomes were maintained.

Stakeholder engagement suggested customer preferences around annual reviews and social opportunities may be changing considering COVID-19, and work is needed to understand this.

ACS managers also stated that support to carers needs to improve, although there has been progress in this area. Engagement with service users indicated some of the benefits of the pandemic included the flexibility of connecting online and learning new skills, and greater awareness of the need for accessible materials.

There was frustration around the delays in annual reviews, and a desire for more flexibility around provision of reviews. Suggestions included in-person meetings, online options, and the option of conducting meetings outside to meet COVID-secure guidelines.

In summary, while there is good provision of accessible resources across many areas of care provision, there may be a need for better signposting to these resources to ensure people with learning disabilities are able to make informed choices

Housing provision

A summary of housing provision in Suffolk for people with learning disabilities is outlined below against key recommendations from the literature. This assessment has been completed based on information provided by ACS contract managers.

As mentioned early, there is good data on ACS service user housing status (data available for 93.3% of users) and a high proportion of customers (81.3%) are in settled housing. In line with the Care Act, needs and preferences around housing are captured in annual review (if there is no urgent change of need), and the findings are reviewed and fed into housing planning. If there are urgent needs these are considered sooner.

The ACS Housing development board works with providers and developers to meet the housing needs of service users. ACS also works with NHSE in joint bidding to provide services, and work with the CCG to purpose build bespoke accommodation. An example of good practice is provision of bungalows or small dwellings in a defined area

where space and support can be provided. The LD&A supported housing project will look at general needs housing, and ways of working with the district and borough councils to utilise this better, and the learning disability population is included in District and Borough Housing Strategies^{86/87}.

A housing choice

At the time of undertaking this needs assessment SCC was undergoing a recommissioning exercise around housing provision, including a gap analysis of supported housing for people with LD. A market engagement exercise around supported housing provision was undertaken in May 2021. Key information from this work is included below as part of this assessment.

The principles of the redesign of supported housing⁸⁸ reflect the vision of the Suffolk Learning Disability Strategy, and many of these principles reflect the evidence of best practice gathered from the literature:

- A house is my home, not a placement
- People are able to live in and feel part of the community
- Right support that enables and maximises independence including employment opportunities and individuals to take control of living an ordinary life
- Solutions that are flexible and can accommodate people's individual needs that allow them to remain independent for as long as possible
- Reliable and safe care whilst ensuring value for money and good use of technology and digital solutions
- Solutions that offer choice, control and flexibility – type of housing and the ability to move on
- Solutions that are financially sustainable for the Council and our Providers
- Managing expectations of what an ordinary life will mean

Supported housing provision

Currently there are over 200 supported housing settings in Suffolk providing support for service users with learning disabilities, and over 40 providers. This provision comprises a mixture of 'shared setting' housing, self-contained units and a mixture of housing types located in clusters. Each of the shared accommodation types includes houses, flats and bungalows. Most of this supported housing provision is via shared housing, with dwellings typically housing 3 or 4 individuals.

Across all commissioned supported housing in Suffolk, 15% of settings currently hold a void, with 97% of these voids being in shared accommodation, with most of these voids are being among those aged 40 and over. Interviews with service contract managers for the LD cohort in July 2021 confirmed that there are often voids present in shared housing settings for older cohorts, suggesting that available accommodation will often not meet the preferences of younger adult service users. This data suggests that there is a mismatch between the demand for housing and available supply in terms of appropriate for service users. Customers often live in supported housing for years, with this provision of support being suitable when they are younger, but customers often require different provision as their physical needs change with age.

Key results from scoping engagement undertaken Sept 2020-Apr 2021 with service users as part of supported housing redesign included the following findings which are in line with findings from the online engagement activities with adult services users undertaken in July 2021 as part of this needs assessment:

- There is a demand from many service users to live in or close to towns enabling access to good transport links, and access to community and retail services, day services and voluntary and paid employment opportunities.
- Some provision is necessary in rural areas as it is important to have the option of keeping close to families and social networks, while enabling independence.

Results of initial scoping as part of the design indicated that:

- There is an over-supply of supported housing services with 3-4 beds/general needs provision.
- There is a need to understand the implications and impact of increased life expectancy on existing housing models.

- There is a need to pursue alternative models of housing e.g. hub and bespoke.

Engagement with contract managers in July 2021 showed that the main gaps and challenges in housing provision for this cohort included the following:

- There is a shortfall in the supply of all types of housing in the Waveney area of the county, therefore this means that services users in this area do not have the choice of provision that their peers in other areas of the county have, and some people have been housed in residential care that is not appropriate for their needs. Demand is also known to be high in this area of the county, meaning that there is a need to increase provision of both supported housing and independent living options.
- The balance of general needs provision and self-contained units may not reflect demand, and the deficit in self-contained units and larger sites may mean the 'Ordinary lives' vision is not being met.
- It was felt there is insufficient accessible information on available housing options to enable informed choices.
- There is a need to make sure housing provision is age-appropriate and not necessarily of the highest specification. People in their 20s will often want the option to move around rather than being placed in accommodation that on paper meets the highest standards. Need to build in flexibility and meet individual needs.
- There is a lack of general needs provision housing for people with more complex needs, including for the Transforming Care cohort and for Vulnerable Young adults who often have mild learning disabilities.
- There are issues across the county with customers moving into accommodation but not necessarily moving on as their needs change.

Additional challenges reported by contract managers in meeting the housing needs of this cohort included maintaining a resilient staff workforce for supported housing and being able to supply housing across all areas of the county given the strength of the housing market in Suffolk. The LD&A supported housing project will look at general needs housing, and ways of working with the district and borough councils to utilise this better.

The pandemic has accentuated existing challenges in maintaining sufficient staffing levels for supported housing provision. This part has been based around the need for staff to isolate, but also due to staff leaving roles due to the increasing clinicalisation of care, "no jab, no job" policy and seeking of employment elsewhere.

Key Findings from service user engagement activities held online in July 2021 showed that:

- There were some concerns that allocation of housing was based on annual reviews that may be out of date and not reflect current needs
- While it was felt there was a reasonable choice of housing available, some service users felt that there should be more opportunity to see housing options before committing to a choice of property
- There were concerns recipients of housing benefit did not always receive accessible information on their rights as tenants, and that some of the conditions of tenancies did not enable them to live as independently as they would wish

In summary, while Suffolk maintains a range of housing types and provides for service users with a range of needs and preferences there are some known gaps in service provision by geography and changing demographics of the learning disability population in Suffolk will mean that some of the challenges in providing appropriate accommodation that meets the preferences of service users will be accentuated over the coming decades. There is a need for careful planning around the requirements of older individuals, as the proportion of services users within this older cohort increases.

Plans for redesign are in line with the key recommendations from the literature and the ordinary lives vision from the 2015-2020 strategy, in that priorities include enabling a choice of accommodation that promotes independent living, and flexibility of being able to move on when needs and preferences change.

Day, evening and weekend opportunities, enablement care and short breaks

For adult service users, day, weekend, and evening services, planned breaks are included in the Suffolk Learning Disability Framework. There are a wide range of providers who have successfully bid to join this framework. There are around 60-70 day service providers facilitating a range of activities, community support, and two providers for planned breaks respectively. This Framework is dynamic, and providers can join at any time.

Interviews conducted in July/August 2021 with contract managers for adult services indicated that Suffolk is performing well in the following areas:

- There is a good range of day service providers, with a range of services across the county
- There are 17 or 18 care farms situated across Suffolk, which are attended by a large number of service users
- Peer support facilitated socialising has been very successful. This has been provided in response to need for opportunities to form genuine friendships, and replaces some befriending services
- There is good provision for enablement care for this cohort. Short term enablement is a Tier 2 offer, and ongoing support is also provided depending on need. Short term enablement service is based on what customers want, and this provision has been successful in terms of both broad social work practice and safety-net work around crisis intervention.
- ACE Anglia have provided opportunities for informal outdoor socialising since the lifting of pandemic restrictions which have been well-attended

Priorities identified included the need to look at models for facilitating friendships among people with LD to reduce social isolation. A good example is the Teaming up Avenues East Scheme, with small social groups facilitated by a befriender. Disability training with venues is very helpful to ensure success. Need to look at similar, time limited programmes, to help link up people with similar hobbies. Without suitable provision of social activities, independence can mean more isolation.

Gaps and challenges

The following self-assessment is based on information and views gathered from interviews with SCC contract managers

- There needs to be a review of provision for young adults that considers interests and skills, and a need for more skills-based opportunities, particularly for younger customers, including provision of more cafes.
- There is a need to understand the preferences of younger service users in particular to provide age-appropriate services. Performing arts and music opportunities have been popular but there is a need for more providers, particularly in the east of the county.
- There are fewer day services available for those with profound levels of need.
- While there was a view that digital care should be used more by providers, as more social opportunities may move online post-COVID, there is a need to consider accessibility to service users of all ages, including older people and those with more complex needs who may not have tech skills. Online options will suit some individuals due to lower transport costs but not others.
- There are challenges in ensuring uptake of available services, particularly as customer preferences change following the pandemic. Day services are paid according to their use, which can lead to challenges when customers do not access a service they are signed up for. This means provision can be hard to plan, meaning further work is needed to understand changing preferences. This suggests there is a need for more flexible models of provision.
- Ongoing challenges around COVID-secure provision, which limits capacity.
- While there is provision of short breaks, there is need for work for a more flexible model that meets the needs of young customers.
- There is further work needed to understand the best model of provision for drop-in social sessions. While service users have expressed a desire to attend these sessions, provision of 'Open Spaces' drop-in meet and greet sessions have not seen good uptake, so work is needed to understand why.

Service users views

Service users that participated in engagement activities stated that they would like to review the opportunities available to them following the pandemic and have more informal and drop-in activities available to them. They stated that there were not enough social activities in the community and sometimes what was available could be hard to find.

There was some enthusiasm for provision of more occasional evening social opportunities, including those where individuals with LD were able to volunteer to help provide these activities.

There was also enthusiasm for support to undertake hobbies, rather than structured social activities.

In the early stages of the pandemic, service users accessing day services (of which there were approximately 900), were prioritised for reviews in Spring/Summer 2020 to ensure that they were offered alternative support if required. The pandemic has increased demand for services among some groups of users, and costs have gone up around providing services around the easing of restrictions, given the need to operate with reduced capacity. The reopening of day services required extensive work with providers around risk assessments, infection control measures and assessment of where individual service users were attending. This need for infection control has meant that some service users have only been able to return to one service where previously they had attended multiple services on different days of the week, meaning that in some cases attendance was reduced for individuals from 5 days a week to one or two days.

Contract managers recognised that post-COVID there needs to be a review of provision and preferences as demand changes, and efforts to ensure that hard to reach people are included.

Support for CYP with learning disabilities and their families

Provision of day, weekend and evening opportunities

In line with national guidance, the Suffolk SEND Local Offer contains details of a range of providers providing day, weekend and evening opportunities for children and young people and where required reasonable adjustments are considered such as allowing carers to attend with a child or young person.

An extract taken from the SEND Local Offer database in July 2021, a total of 266 providers are listed as providing services for children with additional needs across the following areas:

- 8 Social Care and Early Help services
- 9 services supporting preparation for adulthood and employment
- 84 services offering leisure activities and short breaks
- 6 independent advice and support services
- At time of the extract, 144 Early Years and Childcare providers were listed; however, pressures on services as result of COVID-19 mean an emerging shortage of providers for children with LD in this age group.

These services were recorded as being located across Suffolk, and for the majority of providers, information has been updated during the first half of 2021. Among services providing information on service user input to planning, 42 had included services users in service design.

An interview undertaken with CYP contract managers summarised coverage in Suffolk relating to recommendations in the NICE Guidance.

Access to support services for children and young people and their families

- Early years provision in Suffolk is very inclusive of children with learning disabilities
- All providers of activities through the SEND offer are expected to meet LD needs at some level, although not all will be able to meet complex needs

- Children with complex needs are given support through specialist providers, and providers are supported through Activities Unlimited to meet their needs
- There is provision of regular overnight planned care for children with complex needs, in addition to shared care arrangements and link carers. There is evidence to suggest that shared care is working well for families.
- Provision of independent advice and support via SENDIASS, and information and signposting via the Local Offer and Customer First.

Provision for CYP with learning disabilities & behaviour that challenges

- Via short breaks there is a Behavioural Support Service with a tiered approach, and there is Behaviour Safe Approach which teaches de-escalation skills to families and professionals.
- For children with LD and challenging behaviour, there is a tiered approach for providing support. As part of a universal offer, The School Nurse Alternative Provision (SNAP) team initially pick up referrals and assess them. If a child's needs cannot be met by the service, children are referred to the LD Behaviour support team (a Tier 2 service), and if appropriate they are referred upwards to the specialist learning disability CAMHS service. This tiered approach, and the work undertaken by the SNAP team ensures children are given the right level of support at right time, as opposed to immediate escalation which may not be appropriate for their needs.

Gaps and challenges

- There are gaps in availability of providers for children with complex needs in the north of the county, and work is needed to find more providers.
- It can be hard to find sufficient providers for children under 8 due to the requirement for Ofsted registration; meanwhile there are challenges with the regulation of provision for children aged over 8 due as Ofsted registration is not required; this means further work is needed around supply of providers for young children and quality assurance of some services.
- There is a recognised need for more link carers for children with LD, and this is forming part of the DCYP service review, in addition to more local provision of shared care.
- It can be challenging to provide groups and activities for children and young people with physical disabilities and a mild learning disability, as opportunities provided for their peers with severe learning disabilities will not be appropriate for their needs.
- While there are a range of opportunities provided for young people, including those that develop life skills, work is needed to understand how well accessed some of these opportunities are.

The DCYP team reported that the impact of home schooling for parents of children with learning disabilities has put families under strain. Education is considered a protective factor for all children, and this is magnified for children with disabilities and their families. Inability to access to school education and day activities during lockdowns has meant that the pandemic has had a greater impact on this cohort than others, and the need for short breaks and shared care has been felt by families.

Examples of good practice during the pandemic included support from the Virtual School initiative in supplying laptops and tablets, and all special schools remained open on an alternative timetable to support children with higher levels of need. Over the course of the pandemic, a multi-agency short breaks panel met each week including representatives from schools and health services to ensure that families with the highest levels of need were provided with appropriate support.

Provision for Children in Care

Provision in Suffolk for children in care with learning disabilities and support for families to care for their children at home is being assessed as part of the DCYP service review. This work will include a review of Early Help Provision for children with SEND, a review of whether services are appropriately targeted at the right ages and areas and a review of the support available for parents with learning disabilities and their carers. The Social Care Sufficiency Strategy will also include a gap analysis for provision for the DCYP cohort, which includes children with learning disabilities and their families. Additionally, the SEND Strategy is looking at strategies for providing more accommodation locally for children who can't be looked after at home.

Care service specifications for children in care set minimum standards for activities provided, ensuring children with learning disabilities in care receive the same opportunities as those not in care in terms of educational and social provision.

DCYP data shows that families are being supported in being able to keep their children at home, and further investment for provision of short breaks and shared care will ensure this trend continues. Residential placements are commissioned as close to home as possible, with an aim to be within a 20-mile radius of Suffolk.

Staff training

Information provided by SCC CYPS colleagues indicated good provision in terms of training for SCC social workers, and that staff of commissioned providers working with children with LD receive specialist training. Young people have been involved with some interview panels, and the co-produced work 'The Ideal Keyworker' has included children and young people with learning disabilities.

'I Statements' from young people collected as part of the SEND Strategy highlighted priorities for children and young people:

"I want to be supported to take part in activities and to pursue my hobbies and interests"

"I want to be involved in choosing the right services for children and young people with SEND"

"I want places and activities to be accessible for people using wheelchairs and who have other disabilities"

In summary, while there is overall a good range of provision of care and activities for children with learning disabilities in Suffolk, there are gaps in day and respite provision across some areas of the county, and potentially for some age groups and categories of need for activities provision. The pandemic has accentuated demands on services and families (including but not limited to staffing pressures, operating with reduced capacity to enable social distancing and increased pressures on family carers due to lockdown school closures) but there are examples of good practice during the pandemic and plans to strengthen specific support for families such as link carers.

Transforming care provision

The Transforming care cohort supported by SCC ACS includes 34 customers in the community and 19 in hospital, of which 13 were previously in community settings. Many of these cohort transitioned from DCYP services, and funded jointly with the CCG. Currently there are fewer than 10 providers for this cohort and approximately 200 customers go out of county to receive care. It is recognised this cohort will grow based on the number of service users with complex needs currently supported by DCYP.

Examples of good practice in Suffolk

- Weekly meetings take place between Norfolk and Suffolk Foundation Trust (NSFT), CCGs and ACS so there is good joint working and close monitoring of the transforming care cohort, and work to meet their needs is from a whole system perspective. Admission avoidance is being considered as a whole system issue.
- Services develop transition plans for all customers in hospital, and there is an established pipeline in place to identify who is ready for discharge and will need to be supported in the community. ACS works ahead of time with customers and providers to ensure suitable provision in place.
- For older individuals in the transforming care cohort, provision is based around specific needs rather than age, and this cohort also supported to live outside of hospital by specialist providers.
- Provision of admission avoidance facilities shown to be effective in preventing hospital admission
- Support in the community is based around 1:1, 2:1 or 3:1 support, often with areas provided for sleep-in staff, or clusters of bungalows designed for high-needs residents.

Gaps in provision and ongoing challenges

- There is a shortage of providers with some existing providers in business continuity and others recognised as underperforming.

- There are challenges in maintaining a workforce with the right skill level and with staff recruitment and retention.
- Some of these challenges relate to overall fragility of the care market and providers struggling to get staff and provide appropriate training, which has been accentuated by the pandemic.
- Current challenges include provision of sufficient admission avoidance accommodation and outreach for the transforming care cohort.
- One of the most experienced providers is currently in business continuity, which is putting pressure on the rest of the system.
- Gaps in provision can make the transition period (when customers are coming out of hospitals or from a different provider) harder at a time when it is important to ensure appropriate and timely handover and crossover of care.
- Not always having suitable provision has made it hard to offer choice in some cases, leading people to be placed out of county or in expensive placements.
- There is recognition for the need for longer term planning around the needs of this cohort as some provision tends to be reactionary. In particular, urgent cases are often among the cohort in their 40s-50s when parental support has dropped off, so there is a need to make sure advocacy services can respond according to the needs of this group.

Ongoing and planned work

- There are plans to develop more providers for this cohort, and ACS will be working with Skills for Care to do this.
- There is a recognised need to better utilise existing provision for admission avoidance and work is underway to plan this.
- There is work planned to increase small support provision for this cohort through the national programme working with NDTi and LGA.

In summary, joint systems working and provision of appropriate care options has enabled avoidance of hospital admission for this cohort. While there are challenges around the number of in county providers, work is planned to address these challenges.

Transition between children and adult services

Interviews with ACS and CYP colleagues indicate there is coordinated provision with SCC for supporting users in transition between CYP and adult services.

Examples of good practice in Suffolk relating to joint working to meet the needs of this age group include:

- There is a Bespoke Transitions team within the ACS Independence and Wellbeing Service (IWS). This team offers advice and guidance for those aged 14+; triage, support and Care Act assessment for the 16-25 cohort; and assist planning for the cohort leaving care aged 16-18.
- The team is responsible for triaging and signposting/referring on young adults transitioning from CYP to ACS. This team offers reablement ahead of a warm handover and has improved outcomes for people, in addition to enabling joint working between CYPs and ACS.
- If a young person has a EHC plan, they receive a person-centred 'Moving to Adulthood' review, and a pathway for these reviews has been formed.
- In addition to supporting the transition of children known to SCC CYPs, the Transitions team works with the whole system to proactively identify children and young people who are eligible for support under the Care Act, including those with LD who do not have a diagnosis. The team works with other agencies to ensure they get the right support. Around 70% do not go on to long-term care and support. Instead, the team works with the young person to understand their hopes and wishes and finds resources and solutions in their community. These may include employment, volunteering and informal support networks. Conversations starts with the young person and are supported by provision of easy-read materials including an adapted care act assessment. Families and carers are also part of the conversation, advocacy is provided throughout the process.

- There is good joint working between DCYP and ACS for the Transforming Care cohort, enabling early conversations to understand customers' needs and preferences and smooth transition. ACS have a worker based within the DCYP service, and there is a transition practice lead. The most complex and vulnerable with the DCYP cohort retain the same worker as they progress through transition.
- Learning from the Stella Maris Inquiry⁸⁹ is being used to create a new system pathway for vulnerable young adults including those with mild LD and the social work and service offer.
- There is good support for access to employment and internships for this cohort (via Kickstart, Workwell Suffolk, Supported Internships).
- Successful implementation of person-centred practice, and positive feedback received from customers. Feedback received is due to be audited in Autumn 2021.

Gaps in provision and key areas of need identified for this group include:

- One of the main challenges is commissioning services that reflect preferences, and support people to achieve their goals. Work is required to be able to use the intelligence gathered from reviews with young people around their preferences and aspirations, so that this is reflected in the provision of services and support.
- Service provision for this group is currently weighted towards supported housing and there is little in the way of outreach or preventative space for vulnerable adults with mild LD.
- To better meet the mental health needs of this cohort there needs to be development of a pathway for transitions within Mental Health Services.
- The Employment Offer for this group is identified as needing improvement and is being picked up under the SEND action plan.
- When limited internships have been available, these are not consistently provided for SEND students; there is a need to form appropriate pathways to enable employment for those it is appropriate for, and work on aspirations relating to employment.
- Some colleagues suggested further work to understand the needs of specific groups within the transition cohort. This included a need to understand outcomes over time among the cohort of young people with mild LD who do not meet the criteria for ACS care. While there are resources such as Work Well Suffolk which are available for all those over 18 with additional needs, these services are not necessarily well accessed by individuals beyond the transition years.
- While there is a comprehensive transitions guide for families of young people provided through the SEND Local Offer ([SEND 16+ Transitions Guide | Community Directory \(suffolk.gov.uk\)](#)), and a [Preparing for Adulthood and Employment Guide](#) accessible via the Suffolk InfoLink website, there is a need to increase provision of accessible information for young people with learning disabilities on opportunities post-16. The Transitions team are however currently developing an online & face-to-face course for families to build on the current SEND 16+ guide.

Ongoing and planned areas of work include the following:

- The CYPS team are looking at ways to increase skills and participation among this group and a focus on post-16 opportunities are a priority area in the SEND strategy.
- Co-production is planned with partners including children and young people to get their views on that is needed/how provision can meet needs relating to this age group.

'I Statements' from young people collected as part of the SEND Strategy highlighted priorities for young people relating to skills and employment:

"I want options explained to me and for people to think 'outside the box', focusing on my skills and interests."

"I want help to get a job or to be self-employed, again based on my skills and interests."

Employment and volunteering

As mentioned early there are significant gaps in recording of employment status for people with learning disabilities in Suffolk (employment status is missing for 96.6% of customers), and that very few people with LD are known to be in paid (11, 0.4%) or voluntary (24, 0.9%) employment. COVID-19 has delayed work to increase support for employment; similarly delays with annual reviews have limited options for collecting information on employment.

Interviews with colleagues from SCC ACS and CYPS indicated that there are several gaps in provision relating to employment and volunteering:

- There are currently no volunteering or work placement options facilitated via SCC for people with LD. While supported internships are provided in Suffolk, very few are available, and where internships are available these are often more suitable for people with high functioning autism than people with learning disabilities
- There is a need for SCC to work with partners to provide more apprenticeships and internships below level 2, and ensure that application forms and interviews are accessible.
- There is recognition of the need for supported employment options and a need to work with employers to provide opportunities for supported employment, in addition to working with voluntary sector partners to provide volunteering opportunities.
- Referrals for employment support are often received for older young adults (late 20s) rather than teenagers, so the system is missing the opportunity to give support to those at the age of entering work.
- There is a need to explore digital opportunities and role models to facilitate engagement with employment opportunities.
- There is a recognised need to record better data around employment status in order to plan future provision. In line with best practice recommendations in the literature, there is a need to understand quantity and quality of employment in terms of hours worked and outcomes, not just numbers working.

Despite these challenges it was recognised there was a strong reablement culture within Social Care for people with an LD and this provides an opportunity to refer into employment by default. An example of good practice in Suffolk is First Steps Employment Support, an organisation that supports young adults with LD to get into employment and undertakes a vocational profile and dynamic assessment. Other resources for younger adults include 'Mind the Gap' provided by Lapwing and the Kick Start initiative.

Planned work in this area includes the following:

- Post-16 opportunities including those promoting work-based skills are a Priority area in the SEND strategy
- There are plans to develop an employment strategy

Information collected via the engagement activities with adult service users showed that there is a need for more opportunities and support to enter employment. There was also enthusiasm to have the opportunity to volunteer at social events and activities aimed at people with LD, and this would be an opportunity to acquire skills. There was a feeling however that opportunities for employment should be prioritised over volunteering where these were feasible. Attendees felt that employers needed to engage more with advocates to understand their needs.

In summary, while there are opportunities supporting access to employment offered to the "Transitions" cohort, there do not seem to be the same opportunities for older ACS customers with LD, or customers are not directed to the opportunities available such as Workwell Suffolk. Stakeholder views suggest that annual reviews done by ACS may be an opportunity for more review and conversations around adult learning and skills, and there is a need to understand gaps between aspirations and provision for the transition cohort and young adults relating to skills and employment. Overall, there is a need an employment strategy for people with LD in Suffolk, and improved recording of the metrics around employment.

Information provided by stakeholders suggests that employment is the area of social support with the greatest gap in provision in Suffolk, and this has implications for independence and fulfilment for adults with learning disabilities. There is a need to understand employment levels for people with LD, maintain records and provide opportunities for

adults with LD wanting to enter the workforce. There is also a need to understand more about the voluntary work available for this cohort and provide quality opportunities for volunteering for those who want it.

Meeting the health needs

Key recommendations from the literature in reducing health inequalities are outlined in full in the evidence review. The following section outlines provision in Suffolk against these recommendations and identifies areas in which there are gaps in provision.

Availability of accessible information on health issues

The Suffolk Ordinary lives website provides easy read materials explaining a range of health topics. These include COVID-19 testing and guidance, growing older with learning disabilities, bowel screening and bowel scope screening, cervical cancer screening, physical activity, healthy eating, physical activity, healthy digestion, flu, skin health, keeping warm in winter, surgery, grief and bereavement, suicidal thoughts, mental health and emotional wellbeing, diabetes, prostate cancer, sexual health and stroke prevention. All of these resources have been developed through co-production with the NHS and experts by experience, and a further list of health topics is currently under development.

These easy read resources have been extensively downloaded, and are used by primary care liaison nurses to support patients with learning disabilities. Stakeholders commented there is still a need to raise wider awareness of these resources and the Ordinary Lives website as a 'one-stop shop' for advice. The health section of the resources on the Ordinary Lives website also contains easy read resources on accessing healthcare including specialist services, and easy read versions of recent NHS policy documents and health campaign documents.

Provision of peer education and workshops on health-related topics

ACE Anglia also holds regular online sessions providing advice and information on a range of health issues including gender-specific cancer screening, flu vaccinations and annual health checks. These are well-attended by adults with learning disabilities and professionals. ACE Anglia staff reported anecdotal evidence that people are listening to advice in these workshops and are attending annual health checks and screening appointments as a result.

A key need addressed by these workshops is education around the rights of people with learning disabilities in accessing health and other services and what people can expect and ask for. One of the aims of these sessions to empower people to proactively ask for the adjustments they need rather than suffer a negative experience and later complain about the service.

Annual health checks

ACE Anglia have a peer educator network dedicated to increasing uptake of annual health checks and run regular education sessions as part of their programme of online events <https://www.aceanglia.com/resource/peer-health-educator-network/>.

ACE Anglia reported that health actions plans are not always given out at annual health checks.

Flu immunisations

While GP surgeries in Suffolk can provide nasal spray vaccine for those with needle anxiety, some people reported being unable to make appointments for this provision due to being of adult age. It is therefore necessary that surgeries recognise the needs of service users with needle anxiety at the point of making appointments. Colleagues from ACE Anglia also highlighted the need for GP surgeries to explore why flu vaccine appointments are missed and whether reasonable adjustments such as nasal spray immunisation can be made for those missing appointments who are identified as having learning disabilities.

ACE Anglia provide accessible resources and workshops aims at increasing uptake of the flu vaccine, and regularly updating their flu resources based on information provided by NHS England. They also supported adults with LD to get onto GP surgery LD registers to be flagged as eligible for the flu vaccine.

ACE Anglia described supporting service users with needle anxiety to access flu vaccinations, and the 4 LD liaison nurses working in Suffolk ensure reasonable adjustments are happening. Priority areas for action include working with pharmacies to increase uptake of the flu jab among family member and carers of people with LD.

Diabetes

An assessment made by NHS colleagues indicated that there is good provision of reasonable adjustments for people with LD at diabetes appointments, that health professionals are supported to have conversations about diabetes and that is facilitated involvement of family members and carers at appointments. For children and young people, the school nursing service works in partnership with paediatric diabetic nurse specialists to support involvement of families. Colleagues from ACE Anglia reported that while diabetes workshops had been successfully run, it would be beneficial for these to include specialist diabetes colleagues from the NHS.

The Suffolk and North East Essex Diabetes prevention programme had hosted a small number of clients with learning disabilities on the programme, and at time of completing this needs assessment had expanded their remit to provide tailored programme access to clients with LD, including easy-read materials, small groups and provision for parents and carers to attend sessions.

Increasing physical activity levels and promoting access to leisure facilities

Contract managers from SCC CYPS considered that services provided via the SEND Local Offer included a range of options enabling physical activity for service users, and opportunities were being further expanded through joint working with the organisation "Teaming Up". Activities provided via Activities Unlimited are routinely promoted to families, while there is promotion of physical activity through schools. Due to time constraints in completing this assessment it was not possible to assess provision for physical activity through services commissioned via ACS. There was a recognition among stakeholders that more work needed to be done locally to increase awareness of the importance of physical activity among both people with LD and their carers, and more support to enable them to be physically active. Peer education sessions have been recognised as a valuable method to undertake this work, and work is underway in Suffolk to facilitate these.

During this needs assessment exercise, ACE Anglia were undertaking engagement activities to assess access to leisure centres in Suffolk. This is part of a wider initiative to improve service access to people with disabilities, funded via the Suffolk Health and Wellbeing Fund. Preliminary results of this work showed that:

- People would prefer to use leisure centres alongside mainstream users rather than have segregated sessions
- Staff at leisure centres are often scared to support customers with learning disabilities, suggesting the importance of appropriate training.

Previously, Suffolk Sport had undertaken the iCAN gym questionnaire to understand accessibility of gyms and leisure centres for people with disabilities in Suffolk. This was translated to an easy read version to promote accessibility to those with learning disabilities

Weight management

Examples of good practice in Suffolk include use of care and support plans to plan activities aimed at increasing physical activity, and discussions around weight are included in Annual Health Checks. There are also a range of easy read resources available on the Ordinary Lives website, and for children and young people, health assessments completed by school nursing promote healthy lifestyles.

At the time of completion of this needs assessment, people with LD are able to access mainstream weight management services commissioned through One Life Suffolk, but uptake has been limited.

One Life Suffolk have worked with ACE Anglia to co-design an adapted weight management programme which will be piloted with a small group of individuals.

Digestive health

Dietitians working with children and adults with learning disabilities revealed the following challenges in meeting the needs of these groups in relation to dietary needs and weight management:

- Currently there is no specific pathway for adult referrals to dietetics services, and some patients are referred to the service after annual health checks while some are referred by consultants.
- Special schools for children with learning disabilities have links to paediatric dieticians while children in mainstream schools will attend paediatric outpatient clinics, although there is work underway to develop a children's pathway and referral form.
- Underdiagnosis of LD means that some patients at risk of malnutrition are not given support to prevent this.
- There are gaps in provision of reasonable adjustments in clinics including difficulties in making longer appointments, lack of access to speech and language therapists and a lack of resources to support people with LD for whom English is a second language.

Recognised areas of need included

- The need to provide carers information on healthy diet options, potentially via an app.
- Better access to accessible materials on dietary health for patients, and accessible resources for families on cookery.
- Joint working between allied health professionals, carers and the voluntary sector to understand and support needs of patients with LD.

Dental health

Suffolk Special Care Dental Services is provided by Cambridgeshire Community Services (CCS). This service provides reasonable adjustments, and there is good provision on accessible materials both via their website and in clinics. Stakeholders reported however that limited access to dental care was a significant area of need. Community dental services are often no longer available due to funding cuts, and it can be very difficult to be referred to specialist services. Private dental care, while available is often not affordable for people with learning disabilities.

Cancer screening and pathways

In November 2020 the LD Transformation Strategy was launched with 5 main deliverables relating to cancer screening, covering many of these gaps in provision as priority areas of work:

- Identification of people with learning disabilities
- Communication across systems
- Improving follow up of DNAs
- Proper practice around ceasing
- Education events

Examples of good practice in Suffolk in relation to cancer screening for people with learning disabilities include:

- Provision to help support uptake of screening by people with learning disabilities includes a range of accessible information materials developed by ACE Anglia available through the Suffolk Ordinary Lives website. ACE Anglia also hosts regular online health sessions which have included those aimed at providing information on screening, attended by local learning disability liaison nurses. These have included gender specific sessions, and there are plans in place to develop further accessible materials to support this work.

One of the main challenges in providing reasonable adjustments at screening is invites are sent via the national call-recall system which does not include information on additional needs. There is a need to ensure communication between location systems to enable people with LD to receive the support they require when attending screening appointments.

While it is recognised that uptake of screening is significantly lower among people with LD, there is currently no available data on distribution of uptake according to demographic characteristics, therefore further analysis to understand whether there is variation according to age is required.

Recognised areas of need in relation to cancer screening include the following:

- The need for a local case-finding exercise to identify people with LD who are eligible for screening then working with providers to support them to attend.

- There is a need for greater flexibility around appointment booking in terms of times and location, with screening taking place in settings such as care home to be explored.
- There is a need to ensure that all services caring for people with LD have access to accessible resources explaining the importance of screening.

Three areas of work that have been identified as priorities to improve uptake of screening include increasing uptake of LD Health checks as these are an opportunity for signposting to screening, follow-up of missed screening appointments and investigating reasons for ceasing of screening.

Examples of good practice in Suffolk in relation to improving cancer outcomes for people with learning disabilities include:

- There is a primary care nurse liaison team employed by NSFT, and this team will be expanded significantly through the LD Transformation Plan. Members of this team help with desensitisation around attending secondary care for diagnostics.
- Disability liaison nurses provide information and support on reasonable adjustments where treatment is needed, so care provision is individualised.
- Community learning disability nurses act as a liaison with hospitals, and work to support patient treatment pathways including working with support workers in a health facilitation role. This is considered to work well. The nurses can support with taking people to attend appointments and empower people to access services as part of independent living support. Treatment services will make reasonable adjustments when the need is recognised.
- The development of the 'Rosie' end of Life app.

[Recognised areas of need in relation to the wider cancer pathway include the following:](#)

Participants in engagement activities with experts by experience revealed that sometimes the barriers to staying were often about the wider determinants of health such as a lack of affordable and flexible travel options to attend activities and services. There was also a desire for community drop-in sessions to discuss health issues, and a national approach to accessible information on health.

Information provided by colleagues from across the Suffolk system indicates that there is good provision for people with learning disabilities, with many services providing reasonable adjustments to enable uptake by people with learning disabilities. Some of the challenges in provision stem from people with LD not being on Learning Disability registers and therefore not being identified by this system as requiring additional support. Other challenges result from lack of specialist training for staff or lack of awareness of eligibility for services. Many of these challenges have been recognised and are scheduled as priority areas of work over the coming years.

While there is work planned across the Suffolk system to focus on specific aspects of health provision for people with learning disabilities, there are some general themes emerging. These include raising awareness of eligibility for health interventions (e.g. flu vaccination and annual health checks) among people with LD and their carers, and ensuring mainstream services and Public Health campaigns are accessible for people with LD via targeted communications.

[Specialist health care services in Suffolk](#)

The NSFT website details specialist health services for people with learning disabilities in Suffolk.

These services consist of an Adult Inpatient Service, Adult Community Services, Integrated Delivery Teams, the Primary Care Disability liaison service, and the Child and Adolescent Mental Health Service Learning Disability Community Service.

In addition, the West Suffolk CCG website outlines the commitments to implementing the NSFT Community Service model for people with learning disabilities, staff training to improve awareness of learning disabilities and a focus on continuing to improve uptake of annual health checks and data sharing with social care.

Each of the Suffolk CCG websites contains links to accessible information on a range of health topics and provision for people with learning disabilities, although the information and resources provided are not standardised across the three websites.

Conclusion

The available data and information obtained via stakeholder engagement activities indicates that while there is good provision of support in Suffolk for both children and adults with learning disabilities, there are several areas of unmet need and priorities for improving provision.

The health needs for this group include additional support to access mainstream health services through provision of reasonable adjustments, in addition to accessible information and support on health and wellbeing issues. Information and views collected through this needs assessment suggest that while there are some very good examples of reasonable adjustments in addition to planned work, further work is needed, with cancer screening being an example of clear inequalities in access for this group.

Identified social needs for this group include provision of housing, social and employment opportunities that promote independence and personal choice in the 'Ordinary Lives' model described in the literature. While there are a range of housing and social opportunities for this cohort, there are some areas of the county, notably Waveney and the north where provision does not meet demand.

As this cohort is projected to grow, with an increase in people with LD aged over 65, planning of future provision must take into account the additional needs of older people in the cohort such as dementia and frailty.

In particular, there is a need for work aimed at improving outcomes relating to employment for this cohort, through improved data collection and monitoring of employment status of adults with LD, and a review of the opportunities available and how these are accessed by both young people and adults. There is also a need to understand the recent increase in safeguarding referrals for adults with LD, and to what extent these can be contributed to the impact of COVID-19.

In general, there is good provision of accessible information which is crucial in enabling informed choices around care and support provision; however, this provision may not be uniform or appropriately signposted to, in particular in relation to housing provision.

Information from stakeholder engagement activities suggests that in some cases there are mismatches between the demand and supply of specific service types such as self-contained supported housing and social opportunities, and that the COVID-19 pandemic has not only impacted on service provision, but also on customer preferences. Demand for some support services has increased, in particular services for children and young people, while some adult service users reported wishing to re-think their choices and a desire for greater flexibility. These findings suggest the value of a service mapping exercise alongside further engagement with service users to better understand how needs and preferences can be best met post-COVID-19.

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

Glossary

The below list provides definitions and descriptions of terms used in this report. Where definitions from other sources are used, references to these sources are provided.

Day services -services provided by the social services, the NHS and other voluntary organisations and can encompass a range of activities and facilities that serve to benefit the people that attend them. These include day centres providing care and activities and social opportunities.

Direct Payment – an amount of money paid by the local council or NHS Trust to a client or their care carer to meet a client’s needs.

Education, Health and Care (EHC) Plan – An EHC plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social need and set out the additional support to meet those needs⁹⁰.

Learning disability – 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, and an impairment that started before adulthood, with a lasting effect in development.

Learning difficulty- Constitutes a condition which creates an obstacle to a specific form of learning but does not affect the overall IQ of an individual⁹¹.

Personal budget – The amount of money paid by the local council towards social care and support.

Profound and multiple learning disabilities (PMLD) - 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 independent¹⁰.

Special Educational Needs (SEN) - when a child has a learning difficulty or disability which calls for special educational provision to be made for them⁹².

Special Education Needs and Disabilities (SEND)- Defined by the NHS as a learning difficulty and/or disability that means that special health and educational support is required⁹³.

Settled accommodation – secure, medium to long-term accommodation.

Severe learning disabilities – Someone with a severe learning disability will have little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing washing, eating and keeping safe, have difficulties with social skills and need life-long support⁹⁴.

Supported living – a service designed to help people with a wide range of support needs retain their independence by being supported in their own home⁹⁵.

Unsettled accommodation – accommodation where the resident has no or low security of tenure/residence.

Working aged adults – adults aged 18-64.

Acronym list

ACS – Adult and Community Services
ADHD – Attention Deficit Hyperactivity Disorder
ASD – Autism Spectrum Disorder
CAMHS- Child and Adolescent Mental Health Services
CCG- Clinical Commissioning Group
CiC – Children in Care
CYP - Children and Young People
CYPS - Children and Young People Services
DCYP- Disabled Children and Young People
HWB - Health and Wellbeing Board
ICD-10 – International Classification of Diseases, Tenth Revision
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
NDTi – National Development Team for Inclusion
NHSE – National Health Service England
NICE - National Institute for Health and Care Excellence
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 development⁹⁶

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 diagnosis⁹⁷. When addressing the wider needs of people with learning disabilities, it is generally accepted and legislated under the Care Act¹² 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 multiple⁹⁸. 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 support⁹⁰. 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 above⁹⁸.

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

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Appendix 3: Description of methods used in this needs assessment

This appendix chapter outlines the methods and data sources used to gather the information presented in this report. Where applicable, limitations to these methods that impact on the validity of our findings have been described.

Evidence review and national epidemiology data

National policy review: A pragmatic search was undertaken of the Gov.uk and NHS websites for relevant national policy documents, in addition to a review of reports and other publications from national organisations supporting people with learning disabilities.

Evidence review: A list of search terms was devised, designed to retrieve information on learning disabilities and health, housing, education and social care service in use in order to understand inequalities and evidence for best practice. These search terms were based on those used in an evidence review undertaken as part of the Hackney Adult Learning Disability Needs Assessment in 2016 (cite). These search terms were used to search the NHS Evidence database. This database was chosen as it contains content from a range of archives including Cochrane libraries, Social Care Online, GOV.UK, the Royal Colleges and Clinical Knowledge Summaries, therefore content aligns with our objectives to understand both health and social needs of people with learning disabilities.

The search terms used in the evidence review as entered into the NHS Evidence Database are outlined below:

Health search:

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND ("health care*" OR "healthcare" OR "health service*" OR healthservice* OR "health support" OR "health and social care" OR "health protection" OR "health promotion" OR "wellbeing" OR "wellness" OR "medicine" OR "medical" OR "clinic*")

Housing search:

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND (Hous* OR "Social Hous*" OR Rent* OR "Private Rent*" OR "Social* Rent*" OR Home* OR Homeless* OR "Rough sleep*" OR shelter* OR residenc*)

Employment search:

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND (job* OR employ* OR work* OR career* OR unemploy*)

Additionally, a list of simplified search terms were used to gather information on specific health needs. These search terms were entered into both the NHS Evidence database and Google.

- Learning disability dental
- Learning disability mental health
- Learning disability flu vaccine
- Learning disability screening

Given limitations on time and resources, the main focuses of our review were key policy and guidance documents and secondary research papers. Reports and articles from 2014 onwards were reviewed, to reflect the timing of the last needs assessment, although where key references predating 2014 were cited within other papers or by organisations representing those with learning disabilities, information from these references was included. As the term 'learning disability' is often used in North America to refer to what would be termed in the UK as 'learning difficulty', our focus was primarily on literature from the UK.

Limitations: The results of this evidence review were based on a pragmatic search of the available literature with limited resources. It is therefore possible that some recommendations were missed in our search. Similarly, the vast majority of literature available pre-dates the start of the COVID pandemic therefore there is limited evidence and data relating to provision for this cohort during the pandemic.

Prevalence of learning disabilities in Suffolk residents

Demographic data

Demographic data for this report were taken from a number of publicly available sources, primarily Public Health England Fingertips (www.fingertips.phe.org.uk) and POPPI (Projecting Older People Population Information - <https://www.poppi.org.uk/>) and PANSI (Projecting Adult Needs and Service Information - <https://www.pansi.org.uk/>). The quality of Fingertips data are generally considered to be high, as they have been aggregated and cleaned from various sources, however they may not be up-to-date due to reporting and processing delays. Data from POPPI and PANSI are based on recent estimates of prevalence of various conditions that are then extrapolated using Office for National Statistics population projections. These projections are based on the prevalences not changing over time, and therefore are considered to be less accurate as time increases.

Children and young people

Suffolk Children and Young People data on learning disabilities is primarily collected through the Department for Education termly school census, which includes all school-age children (aged 4-16), and some, but not all, individuals aged 0-4 or 16-18 (where they are registered at an education setting that takes part in the school census). A large proportion of 16–18-year-olds will continue their education at settings outside of this census, so individuals with learning disabilities may not be included in this dataset.

Adult service users

Suffolk data on adult service users comes from the SCC Adult and Community Services case management system (LiquidLogic), and includes individuals that currently, or have previously, accessed support services for learning disabilities. Previously, SCC used a different case management system (CareFirst6) and migrated to LiquidLogic in September 2018. As a result, some historic data before this date may have been incomplete or inaccurate, and a data cleansing exercise was undertaken on live cases at the point of the switch-over. More recent data are considered to be more reliable and of higher quality, though some data collection has been impacted by the COVID-19 pandemic, with efforts being undertaken to address this issue.

Health data

Data on the uptake of screening and prevalence of health conditions were obtained from the PowerBI Dashboard containing experimental statistics as part of the publication 'Health and Care of People with Learning Disabilities', published by NHS Digital.

Data on health check completion for people with learning disabilities across Suffolk for the last three financial years was supplied by colleagues at Ipswich and East Suffolk CCG.

Limitations to the health data available for Suffolk are outlined in the relevant report chapter.

Engagement activities to form the corporate assessment of provision in Suffolk

Social care provision

Interviews were undertaken with contract managers from SCC ACS and CYP to record an overview of provision of SCC commissioned services and compare provision to recommendations from the evidence review. This exercise was also used to report on recognised gaps in provision against these key recommendations, challenges in providing services in the context of the COVID-19 pandemic, and priorities and planned work in light of these gaps and challenges. A standard template was used to record responses (included in the appendices of this document). In addition to these interviews, extracts were taken from the SEND Local Offer and ACS Learning Disability Frameworks in order to map service social care provision for people with learning disabilities in Suffolk relating to day weekend and evening activities, housing provision and short breaks.

Survey to gather views on health and social care provision in Suffolk

A survey was distributed among the largest providers of social care for adults with learning disabilities and across providers for day services, weekend services and short breaks for children and young people funding via Activities Unlimited. Contract managers and commissioners within SCC ACS and CYP were also surveyed.

In total this survey was sent to 91 providers for people with learning disabilities and 42 commissioners and contract managers within ACS and CYP Directorates of SCC, with the survey open over a period of 3 weeks from 14/07/2021 to 03/08/21. Responses were received from 22 providers and 2 contract managers/commissioners, giving an overall response rate of 18%. A report extract of this survey is included in Appendix 3.

Due to resource limitations, it was not possible to complete engagement activities with parents and carers of children and young people with learning disabilities, or with young people themselves, but statements from engagement activities undertaken for the Suffolk SEND Strategy were reviewed and quotes relating to the objectives of this needs assessment are included in the assessment.

Health provision mapping exercise

A template was developed detailing health outcomes and areas of health provision where inequalities among people with learning disabilities are well documented. Against each of these areas, a summary of key recommendations from Government Guidance and interventions from the literature were listed. This template was distributed among local stakeholders including colleagues from the NHS, Public Health and local advocacy and provider organisations. Several of these templates were returned via email while other stakeholders provided information via video call. The purpose of this mapping exercise was to identify how provision in Suffolk compared to these recommendations, detail gaps and challenges in provision, and to outline any upcoming work to meet the needs of people with learning disabilities in these priority areas.

A copy of this template including complete responses from NHS and Public Health colleagues is included in Appendix 2 of this document.

Health care provision interviews

Where resources and availability allowed, interviews were completed with NHS colleagues to enable reporting of provision in Suffolk, including gaps, challenges and planned work. An outline of the findings of these interviews are included in this report and will help inform an action plan for ongoing work to reduce health inequalities for people with learning disabilities in Suffolk. These interviews took place in relation to screening provision, cancer pathways, and dietetics services.

Specialist health services

Information on specialist health services for people with learning disabilities was obtained from the NSFT and Suffolk CCG websites.

Engagement session with adult service users

Two 90-minute engagement sessions with adults with learning disabilities were undertaken in July 2021, facilitated by ACE Anglia. The main purpose of these sessions was to gather information on the health and social needs of adult services, and views on the accessibility of social care provision in Suffolk. A set of questions were used to guide discussions, and these are included in Appendix 4 of this document alongside the results of these sessions.

These engagement sessions attended by a relatively small number of people, therefore views gathered may not be representative of people with learning disabilities as a whole. Due to the nature of the sessions, there was a higher degree of engagement from people with a mild to moderate level of need than those with more severe needs, therefore information collected is more likely to reflect needs and preferences of this cohort.

Additional data on the experiences of users by experience was gathered from advocacy sessions run by ACE Anglia in May-June 2021, including the Suffolk People First event held on Friday 21st May. Information gathered is included in this needs assessment with permission from ACE Anglia.

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