Cambridgeshire County Council

PETERBOROUGH CITY COUNCIL

Cambridgeshire and Peterborough Joint Strategic Needs Assessment

Health of Adults with a Learning Disability, 2023

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Acknowledgements

A very wide range of people have contributed to this needs assessment, including adults with a learning disability, their carers and health professionals. Many thanks to everyone who has contributed their time and ideas to this piece of work.

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Version 1.02 September 2023

1. Executive summary

This health needs assessment describes the health needs of adults with a learning disability living in Cambridgeshire and Peterborough. There are around 17,000 people with a learning disability living in Cambridgeshire and Peterborough, representing just over 2% of the population of Cambridgeshire and Peterborough. Most of these adults are not known to health services and are not on the primary care learning disability register, which is the most complete record of adults with a learning disability. Even fewer are known to specialist learning disability services.

For those adults who are known to have a diagnosis of a learning disability, their physical and mental health needs are significant. National data on mortality of adults with a learning disability reviewed in the national LeDeR programme show that the most common causes of mortality in 2021 (excluding causes given as congenital malformations and cerebral palsy) were: covid-19, cancer, influenza and pneumonia and ischaemic heart disease. An analysis of this data, together with local insights from key stakeholders and engagement with adults with a learning disability, have helped to focus this needs assessment.

National data on mental and physical comorbidities shows that adults with a learning disability are much more likely to have a range of significant long term conditions than the general population, including epilepsy, diabetes and obesity, as well as serious mental illnesses. They are more likely to have sensory impairment and autism.

Despite the complexity of the health needs of adults with a learning disability, the majority of these individuals have their health needs met through mainstream health and preventive services, which have a legal requirement under the Equality Act to make reasonable adjustments. Specialist learning disability services provide additional care for those with the most complex needs, whose needs are unable to be met in mainstream health services.

Key themes

Recommendations are set out at the end of each chapter, and summarised in section 18, according to the organisation for which they have relevance.

Across these recommendations, a number of key themes emerge:

- The importance of ensuring that adults with a learning disability are included in **mainstream health promotion work**;
- The importance of effective processes for **making reasonable adjustments** in mainstream preventive, physical and mental healthcare services, given that the vast majority of adults with a learning disability will receive their care in these services;

- **Inequities in commissioning** of specialist LD health services between Cambridgeshire and Peterborough, with some very significant gaps in services in Peterborough;
- The significant **gaps in the respiratory care pathway** for adults with a learning disability and complex respiratory needs in both Cambridgeshire and Peterborough;
- The importance of the learning disability **Annual Health Check**, which has the strongest evidence base of interventions aimed at reducing health inequalities specifically at adults with a learning disability;
- The need to support **informal carers** with their understanding of the health needs of the individuals they care for;
- The importance of holistic **care planning**, which takes into account the breadth of an individual's needs, in line with the Care Act;
- The breadth of **training needs for health and social care staff**, relating to the health needs of individuals with a learning disability that they provide care for;
- The **difficulty in obtaining good data** on this population in Cambridgeshire and Peterborough.

The presence of a recommendation should not necessarily be taken to mean that no action is being taken already on this area by the relevant organisation(s).

2. Background

This section sets out the definition, common causes and classification of learning disability and national policy context to help contextualise findings.

2.1 Definition, common causes and diagnosis of learning disability

2.1.1 Definition

'Learning disability' (LD) is a term used to describe a range of conditions that cause a reduced intellectual ability and difficulties with everyday living, affecting an individual throughout their life (1). It is important to distinguish LD from a similar term with a different meaning, learning *difficulty*. Definitions for these two terms, adapted from the International Classification of Disease 11 (ICD-11), are presented below. This needs assessment will only deal with learning disability, ***not*** learning difficulty.

Learning disability: A group of aetiologically diverse conditions characterised by:

- An onset during the developmental period
- Significantly below average *intellectual functioning*
    - "Limitations in intellectual functioning across various domains such as perceptual reasoning, working memory, processing speed, and verbal communication" (2)
- Significantly below average *adaptive behaviours*
    - Adaptive behaviours are "the set of *conceptual, social, and practical* skills that have been learned and are performed by people in their everyday lives. *Conceptual skills* are those that involve the application of knowledge (e.g., reading, writing, calculating, solving problems, and making decisions) and communication; *social skills* include managing interpersonal interactions and relationships, social responsibility, following rules and obeying laws, as well as avoiding victimization; and *practical skills* are involved in areas such as self-care, health and safety, occupational skills, recreation, use of money, mobility and transportation, as well as use of home appliances and technological devices" (2)

Wherever possible, these impairments should be measured using individually administered standardised tests, with scores being less than the 2.3rd percentile. Severity of learning disability may be specified as either mild, moderate, severe, or profound/multiple. This classification is detailed in Section 2.1.3.

Learning difficulty: A group of conditions characterised by "significant and persistent difficulties in learning academic skills", typically affecting a single domain of adaptive behaviour, without impairment to intellectual functioning or another underlying health condition or social limitation (2). Examples of common learning difficulties include dyslexia (i.e., difficulty reading), dyscalculia (i.e., difficulty with mathematics), and attention-deficit hyperactivity disorder (i.e., difficulty maintaining attention for prolonged periods with impaired impulse control or hyperactivity). Like LD, learning difficulties begin during the developmental period of childhood and may exist in isolation or in combination with other learning difficulties.

Source: These definitions are adapted from the International Classification of Disease 11 (ICD-11), categories 6A00 'Disorders of intellectual development' and 6A03 'Developmental learning disorder', for learning disability and learning difficulty, respectively (2).

The term “intellectual disability” is also used to refer to people with a learning disability. In the UK, “learning disability” (abbreviated to LD) is the most common term used in the context of health services, so is used in this report.

Many people with a learning disability also have autism, their needs are included in this needs assessment. The needs of people who have autism only are out of scope.

2.1.2 Common causes of learning disability

The onset of LD is during development of the brain and may be caused by one or more factors occurring before, during, or shortly after birth. Causes of LD include congenital diseases (e.g., Down’s syndrome, Fragile X syndrome), perinatal complications (e.g., premature rupture of membranes, poly/oligohydramnios), and post-natal events (e.g., early childhood illnesses, seizures, or injuries) (3). A non-exhaustive list of conditions that either directly cause LD or carry a substantial risk of LD are presented below, in table 2.1.

Table 2.1: Conditions that either cause or carry an increased risk for LD (non-exhaustive)

Genetic conditions	
Down’s syndrome Fragile X syndrome Phenylketonuria Lesch-Nyhan syndrome Niemann-Pick disease Hunter disease Hurler disease Maple syrup urine disease	Hartnup disease Homocystinuria Galactosemia Neurofibromatosis type 1 Rett syndrome DiGeorge syndrome
Pre-natal	
Infections: • Rubella • HIV • CMV • Syphilis • Toxoplasmosis	Uncontrolled pre-natal conditions: • Pregnancy hypertension • Asthma • Urinary tract infection • Obesity • Gestational diabetes
Post-natal	
Infection: • Encephalitis • Meningitis Head trauma Asphyxia Malnutrition	Intracranial tumour, mediated via: • Seizure • Neurosurgery • Chemo/radiotherapy) Exposure to toxic substances (e.g., lead)
Obstetric complications	
Conditions leading to anoxia: • Premature rupture of membranes • Placenta previa • Placenta abruption • Umbilical cord prolapse	

Source: (4)

2.1.3 Diagnosis and classification

Any diagnosis of LD should be age-appropriate and holistic, accounting for intellectual and adaptive impairments as well as history of onset, through administration of standardised testing by appropriately qualified and trained professionals (5). A combination of results from these two components along with the individual's history is used to formally diagnose LD (5). All standardised tests come with a margin of error, so some clinical judgement may be needed for borderline cases (5).

Historically, individuals with a learning disability had their diagnosis sub-categorised by severity, typically mild/moderate/severe/profound, often based on IQ scores. There has been a move away from this sub-categorisation in some professional groups, towards a simpler classification where clinically helpful of disability or severe disability (5). However, much of the research literature still uses these distinctions, so this needs assessment does sometimes make reference to these groups.

2.2 National policy context

2.2.1 Mortality reviews

There have been many national reports over the last 15 years highlighting avoidable and preventable deaths of people with an LD. Examples include Mencap's Death by Indifference and Treat Me Right reports (6,7); the national Confidential Inquiry into Premature Deaths of People with Learning Disabilities (8), and the national LeDeR mortality review programme (9).

All of these reviews have made consistent conclusions and recommendations relating to key themes over many years, including:

- Many people with an LD die prematurely, often as a result of avoidable factors such as poor care;
- There is often a lack of reasonable adjustments for people with an LD within mainstream healthcare services;
- There is often a lack of adherence to the Mental Capacity Act when providing care to people with an LD;
- There can be a lack of coordination of care where individuals were known to more than one service;
- There can be problems with the application of DNACPR processes.

2.2.2 Long stay inpatient unit reviews

There have been a number of very serious incidents in long stay inpatient units for adults with an LD.

The Winterbourne View Review looked at some very serious, sustained abuse of adults with an LD in a long stay inpatient unit in 2006 (10). The Cawston Park review also looked at a number of deaths of on a long stay inpatient unit in 2018-2020 (11).

Despite being 14 years apart, there were many common themes within these two reviews:

- Overreliance on long-stay, out of area placements for adults with an LD who have challenging behaviour, with a lack of scrutiny and challenge to oversight and management of units;
- Closed culture, with overreliance on restraint and poor management of risk;
- Poor quality care provision and lack of personalised care, with basic needs not met.

The NHS Transforming Care Programme, with support from the Association of Directors of Adult Social Care and the Local Government Association, set out a vision of ending long stays on inpatient units for adults with an LD who have challenging behaviour (12). This is set out in more detail in section 9.

2.2.3 NHS Long Term Plan

The NHS Long Term Plan sets out the current priorities for healthcare services for people with a learning disability (13). The relevant actions for adults with a learning disability are summarised below:

Table 2.2: Actions relating to adults with an LD in the NHS Long Term Plan

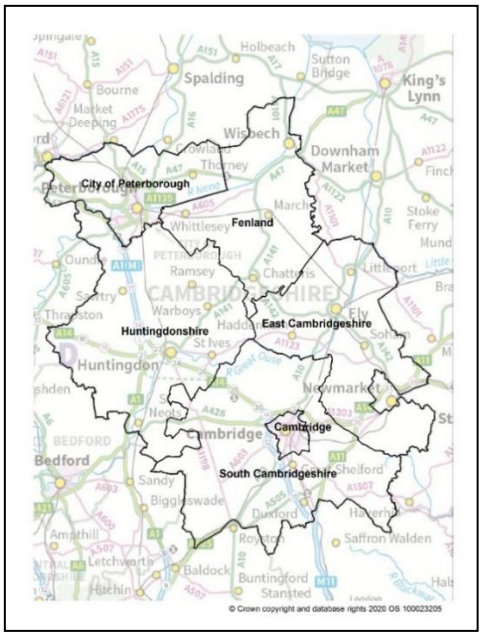
3.31. Reduce avoidable morbidity and mortality	• 75% uptake of Annual Health Checks amongst people aged 14 years and older with a learning disability • Expand STOMP programme (Stopping over-medication of people with a learning disability) • Continue to fund LeDeR (Learning Disabilities Mortality Review programme)
3.32. Improve understanding of needs of people with an LD in mainstream health services	• NHS staff will receive training on supporting people with a learning disability • Integrated Care Systems will have to ensure health providers are making appropriate reasonable adjustments • A digital reasonable adjustments flag will be implemented
3.34 Inpatient care	• The number of long stay inpatients will be reduced by 50% • People with a learning disability will be supported to have a Personal Health Budget where appropriate
3.35 Crisis support	• Each local health system will have a seven-day specialist multidisciplinary service and crisis care
3.36 Quality of inpatient care	• All inpatient care (not just specialist LD services) commissioned by the NHS will meet the Learning Disability Improvement Standards (14)

Source: NHS Long Term Plan (13)

3. Local context

Cambridgeshire and Peterborough are two separate local authorities, covered by Cambridgeshire County Council (CCC) and Peterborough City Council (PCC). CCC is a two-tier local authority, with five districts, whereas Peterborough is a unitary council. The two local authorities are covered by a single Integrated Care System, Cambridgeshire and Peterborough Integrated Care System (C&P ICS). However, there is not an exact match between the local authority and ICS population, as C&P ICS covers patients registered with its constituent GP practices, including some based in neighbouring local authorities, whereas CCC and PCC are responsible for individuals resident in their geographic boundaries.

Figure 3.1: Local authority districts, Cambridgeshire and Peterborough



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Source: Ordnance Survey 2020 (15)

The planned structure of the ICS is complex. Specialist learning disability health services will be covered by the Mental Health, Learning Disability and Autism Accountable Business Unit (MH-LDA ABU), which is hosted by Cambridgeshire and Peterborough NHS Foundation Trust; this covers all of Cambridgeshire and Peterborough. Adult social care services are commissioned by Cambridgeshire County Council and Peterborough City Council.

Primary care and secondary care services will be covered by two Accountable Business Units, the North Place Partnership (led by North West Anglia Foundation NHS Trust and covering Peterborough, Fenland and Huntingdonshire), and South Place Partnership (led by Cambridge University Hospitals NHS Foundation Trust, linked to Cambridge, South Cambridgeshire and East Cambridgeshire). Some specialist health services remain the responsibility of the regional NHS England team.

3.1.1 Cambridgeshire and Peterborough Health and Wellbeing Strategy

The Cambridgeshire and Peterborough Health and Wellbeing Strategy has 3 overarching outcomes and 4 priority areas:

Overarching ambitions

- Have better outcomes for our children
- Reduce inequalities in deaths under 75 years
- Increase the number of years that people live in good health

Priorities

- Ensure our children are ready to enter education and exit, prepared for the next phase of their lives.
- Create an environment to give people the opportunity to be as healthy as they can be.
- Reduce poverty through better employment, skills and housing.
- Promote early intervention and prevention measures to improve mental health and wellbeing.

These ambitions and priorities will underpin the work of C&P ICS on health inequalities until 2030.

4. Methodology

This section describes the methodology used for the needs assessment. Issues with local data availability and quality are outlined and the caveats and metadata associated with national data sources are described.

4.1 Overarching approach

A health needs assessment is defined as:

“a systematic approach to understanding the needs of a population…[which] can be used as part of the commissioning process so that the most effective support for those in the greatest need can be planned and delivered” (16)

There are many different ways to approach needs assessments. The overarching methodology that has been used for this needs assessment is as follows (16):

- Identification of need: through use of mortality information; stakeholder survey of health and care professionals and commissioners; research evidence; local data and engagement with adults with an LD and their carers.
- Identification of assets: through service mapping and stakeholder engagement.
- Determination of priorities: through cross-referencing the analysis of needs and assets with an analysis of gaps against national guidance and the research evidence base.

These analyses have led to the generation of a range of recommendations within each chapter for consideration.

4.2 Data sources

4.2.1 Quantitative data sources

Data has been collected from a range of publicly available national data sources including via NHS Digital reporting and the OHID Fingertips site. Any data used is referenced in the text, with definitions and dates provided.

Alongside these publicly available sources, local data has been provided where available. Sources of non-publicly available local data include:

- Service use data provided directly by services: this has been provided by appropriate service leads or managers, and is referenced accordingly;
- Primary care data: this data is derived from GP records, and was provided by the Cambridgeshire and Peterborough Integrated Care Board primary care data team.

Where there have been difficulties obtaining nationally or locally collected data, or data on a topic is not collected, data from reliable and generalisable research studies has been presented.

4.2.2 Research evidence

Where there are gaps in national guidance on key topic areas, reviews of research evidence have been undertaken for the purposes of this review. A number of topics were the subject of detailed literature reviews and critical appraisal of literature, based on key topics linked to mortality data and prevalence data. These reviews are not contained within this needs assessment due to their length. The specific questions that were the subject of detailed review were:

- What interventions are effective at improving cancer screening uptake amongst people with an LD?
- What interventions are effective at improving routine immunisation uptake amongst people with an LD?
- What interventions relating to healthy eating are effective at helping people with an LD to maintain a healthy weight?
- What interventions are effective at helping people with an LD to increase their levels of physical activity?
- What interventions are effective at reducing dental caries amongst people with an LD?
- What components of care pathways are effective at improving management of epilepsy amongst people with an LD?
- What interventions are effective at increasing the uptake of annual health checks amongst people with an LD?

4.2.3 National guidance

Where available, national guidance from NICE, NHS England or an appropriate national body has been referenced. The historic Public Health England Learning Disabilities team have also produced two series of guidance on topics related to health inequalities which have been very helpful in the production of this needs assessment, and have guided the content of a number of chapters:

- PHE Health Inequalities series, available from Inequality Tools - OHID (phe.org.uk);
- PHE Reasonable Adjustments series, available from Reasonable adjustments for people with a learning disability - GOV.UK (www.gov.uk).

4.2.4 Qualitative data sources

Local qualitative data has been obtained through surveys (professional stakeholders and carers) and through engagement work (people with an LD), as well as analysis of previous engagement and coproduction outputs.

Where appropriate, qualitative research evidence has been presented.

5. Demographics

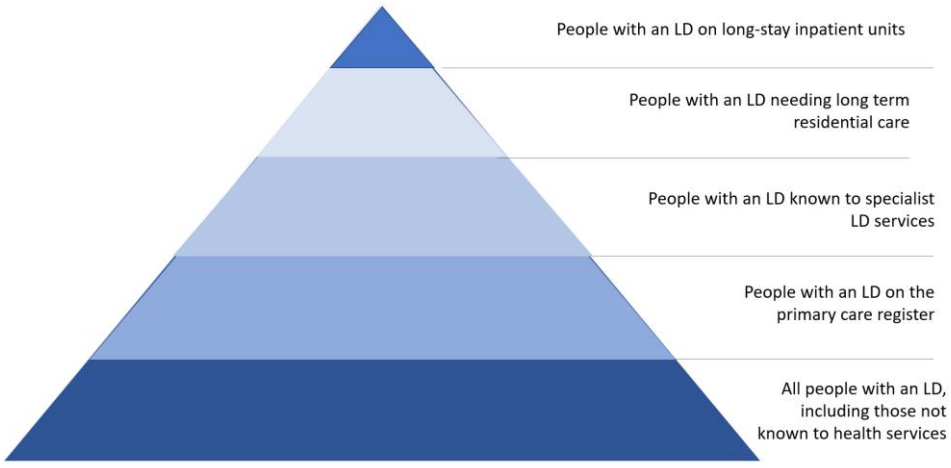
This section sets out demographic data for people with an LD.

5.1 Prevalence of LD

5.1.1 Context of epidemiological data for learning disability

When reviewing any data concerning the epidemiology of LD, it is important to consider data within the framework of the “hidden” population of people with an LD who are not known to health and care services (Figure .1)(17,18). In general, the more severe a person’s level of learning disability, the greater likelihood that they will be known to health and care services and require support.

Figure 5.1: Population pyramid representing cohorts of people with an LD, by engagement with LD services



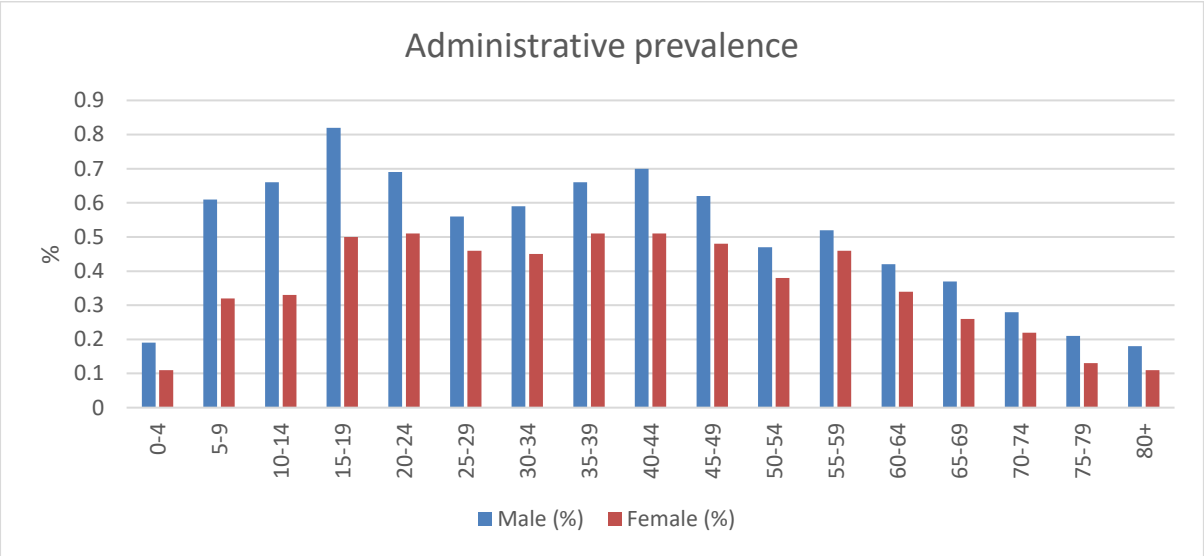
Research commissioned by the Department of Health in 2004 estimated that although 2% of the UK population were thought to have an LD, only 0.46% were known to use specialist LD health and/or care services (19). In a review of LD registers in England, the majority of people known to specialist LD services had moderate, severe, or profound LD, suggesting that the “hidden” population is mostly composed of people with a mild LD (20). This may reflect a lack of formal diagnosis, a lack of perceived need for specialist LD services, that members of this cohort are deemed ineligible to receive social service services, a wish to avoid diagnostic stigmatisation, or a lack of community and/or healthcare professional awareness regarding the diagnosis (17). Regardless of the severity of LD within the “hidden” cohort, this population potentially represents a large group with unmet need.

5.1.2 Estimating the "total" number of people with a learning disability in the general population

As discussed above, patients known to LD specialist services in the UK likely represent only a minority of the "total" population. Although the cohort known to specialist LD services is likely to have more severe LD and greater care needs, the "hidden" population potentially represents a substantial unrecognised group.

In 2004, Emerson and Hatton published research that has since become a cornerstone of the epidemiological understanding of LD in England: *Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England* (21). The authors compiled data from 15,000 people with LD in England who were known to specialist LD services from across 24 local authorities, from a population base of 3.2 million people (7% of the population of England at the time). This data was compared with 2001 national census data to calculate age- and sex-specific prevalence rates for people with LD known to specialist LD services (referred to as the "Administrative" prevalence; figure 5.2).

Figure 5.2: Estimated "Administrative" Prevalence of Learning Disabilities in 2004 in England (those people known to LD specialist services)



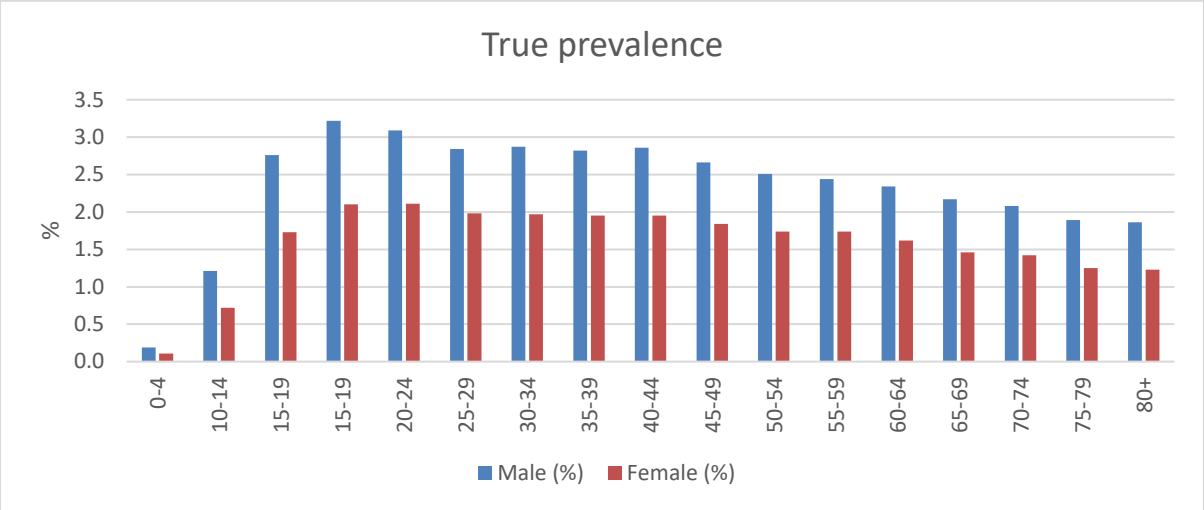
A potential issue with historical primary care LD register data used to inform these administrative projections is discussed in Appendix 1, Section 19.1

Source: Emerson and Hatton (2004) (19,20)

Emerson et al. then made the assumption that this 'administrative' prevalence is an underestimation of the total number of people with LD in England, the 'true' prevalence. Based on a review of historic epidemiologic studies for LD, the authors assume that the overall prevalence of LD is 2.5%. They go on to calculate the number of people with LD, including those not known to services, using an estimated total LD prevalence of 2.5% for 15-24-year-olds and applying a -0.1% decrement with each decade to reflect mortality among people with mild LD ("True" prevalence; figure 5.3). Since publication, these data and associated assumptions have been

propagated throughout academic literature and serve as this basis for much work concerning the epidemiology of LD in England. Potential uncertainty with these data is described in Appendix 2, Section 19.2.

Figure 5.3: Estimated "True" Prevalence of Learning Disabilities in 2004 (those people known to LD specialist services plus those people not known to LD specialist services)



Source: Emerson and Hatton (2004) (19,20)

It is also worth noting that the prevalence of LD is higher in men than women.

5.1.3 Estimating the true number of people with a learning disability in Cambridgeshire and Peterborough

Applying the percentages from Emerson and Hatton (2004)'s work to the Cambridgeshire and Peterborough population (based on 2021 census data) to estimate the "true" number of people with a learning disability gives the following estimates, by age and sex, set out in table 5.1.

Table 5.1: Estimated "total" number of people with an LD in Cambridgeshire and Peterborough, by age and sex

Area name	Peterborough		Cambridgeshire	
	Male (n)	Female (n)	Male (n)	Female (n)
Aged 4 years and under	14	8	34	18
Aged 5 to 9 years	98	55	239	136
Aged 10 to 14 years	224	128	552	325
Aged 15 to 19 years	213	126	631	397
Aged 20 to 24 years	182	120	705	445
Aged 25 to 29 years	213	156	659	453
Aged 30 to 34 years	241	175	677	477
Aged 35 to 39 years	237	172	632	454
Aged 40 to 44 years	217	150	626	433
Aged 45 to 49 years	186	127	585	414
Aged 50 to 54 years	171	120	572	416
Aged 55 to 59 years	146	111	544	393
Aged 60 to 64 years	119	86	440	308
Aged 65 to 69 years	89	67	343	251
Aged 70 to 74 years	81	60	339	254
Aged 75 to 79 years	49	39	229	165
Aged 80+ years	62	59	264	244
Total	2542	1759	8071	5583
	4,301		13,654	

Sources: ONS 2021 (22); Emerson and Hatton (2004) (19,20)

5.1.4 Estimating the number of people with a learning disability in Cambridgeshire and Peterborough who are known to health services

Currently, the main method for population data collection for people aged over 14 years with LD in England is through the primary care LD Register. These registers are typically compiled by each GP surgery through use of clinical diagnostic read codes as well as multidisciplinary input, especially from specialist LD teams and social services. Data from primary care LD registers is centrally collated and analysed by NHS Digital to provide population level insight at local authority, regional, and national levels. NHS Digital analyses this data on LD each year along with a number of other outcomes as part of the Quality and Outcomes Framework (QOF). The NHS Digital publication discussing insights into LD is entitled, *Health and Care of People with Learning Disabilities*. Although there are limitations to the

primary care LD register, it is the most complete register of adults with an LD in England and in Cambridgeshire and Peterborough.

The number of people on the primary care LD register is set out in table 5.2 below, by sex:

Table 5.2: sex-specific prevalence of people registered on primary care LD register in Cambridgeshire and Peterborough, Feb 2023

	Number of males on primary care LD register	Number of females on primary care LD register	Total
Cambridgeshire and Peterborough ICB	2602	1757	4359

Source: primary care LD register, Cambridgeshire and Peterborough ICB (23)

The age profile of people on the LD primary care LD register is set out in table 5.3.

Table 5.3: age profile of people on the primary care LD register in Cambridgeshire and Peterborough, Feb 2023

Age (years)	Actual number of people on the primary care LD register (n)	Estimated "total" number (based on estimated numbers in table 5.1)
14-17 years	436	1066
18-25 years	918	2294
26-60 years	2472	9652
61 years and older	533	3357

Source: primary care LD register, Cambridgeshire and Peterborough ICB (23); ONS 2021 (22); Emerson and Hatton (2004) (19,20)

Table 5.3 shows that completeness of the primary care LD register is better in younger age groups than older age groups, with double the coverage in the 14-17 years age group compared to the 61 years and older age group.

Table 5.4 has the total numbers broken down by Primary Care Network (PCN).

Table 5.4: Sex-specific prevalence of people registered on LD Primary Care Register by PCN, Cambridgeshire and Peterborough, August 2022

PCN Name	Male (%)	Male (n)	Female (%)	Female (n)	Total (n)
A1 Network PCN	0.54	101	0.33	64	165
BMC Paston PCN	0.68	124	0.71	125	249
Bretton, Park and Hampton PCN	0.66	85	0.69	90	175
CAM Medical PCN	0.18	45	0.16	32	77
Cambridge City 4 PCN	0.31	80	0.24	59	139
Cambridge City PCN	0.67	155	0.49	103	258
Cambs Northern Villages PCN	0.64	132	0.33	70	202
Cantab PCN	0.19	53	0.18	41	94
Central Thistlemoor and Thorpe Road PCN	0.45	100	0.31	61	161
Ely North PCN	0.83	136	0.58	99	235
Ely South PCN	0.45	82	0.30	47	129
Fenland PCN	1.03	133	0.81	109	242
Granta PCN	0.45	86	0.29	56	142
Huntingdon PCN	0.90	174	0.56	106	280
Meridian PCN	0.47	98	0.34	71	169
Non-aligned	0.37	17	0.27	13	30
Peterborough and East PCN	0.61	161	0.43	111	273
Peterborough Partnerships PCN	0.75	97	0.61	75	172
South Fenland PCN	0.71	93	0.46	62	155
South Peterborough PCN	0.79	193	0.42	108	301
St Ives PCN	0.57	115	0.31	62	177
St Neots PCN	0.73	104	0.39	56	160
Wisbech PCN	0.76	168	0.51	109	277
Grand Total	**0.58**	**2,532**	**0.41**	**1,729**	**4,262**

Source: Cambridgeshire and Peterborough ICB primary care data (23)

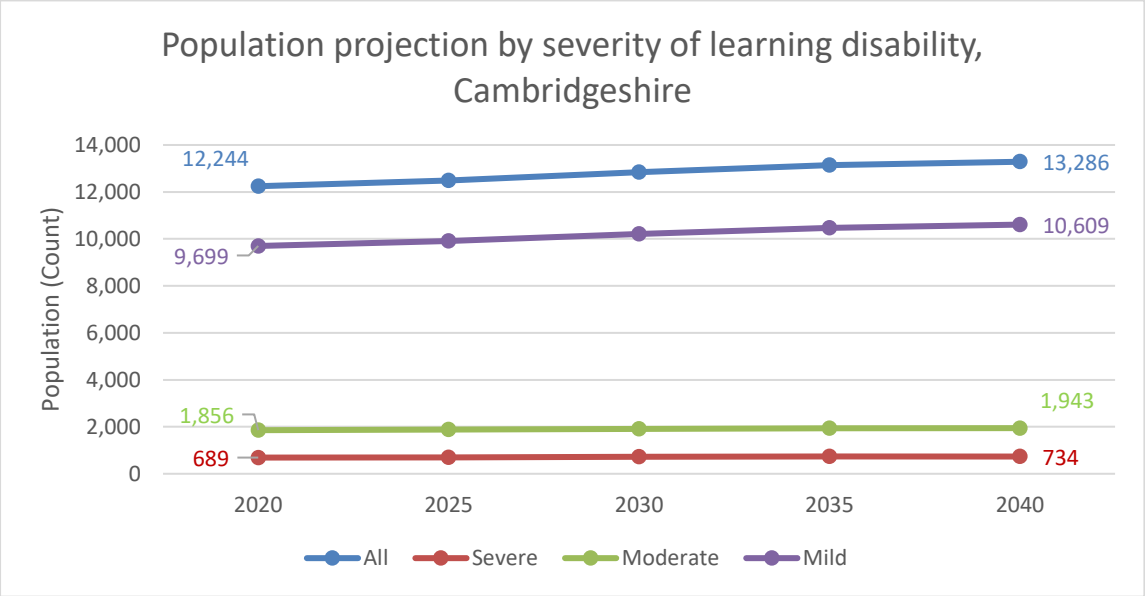
There is significant variation in prevalence of individuals on the primary care LD register between PCNs. There are a number of possible reasons for this: this may reflect the true prevalence of people with an LD registered with those PCNs, it may represent differences in recording or it may be to do with differences in diagnosis rates.

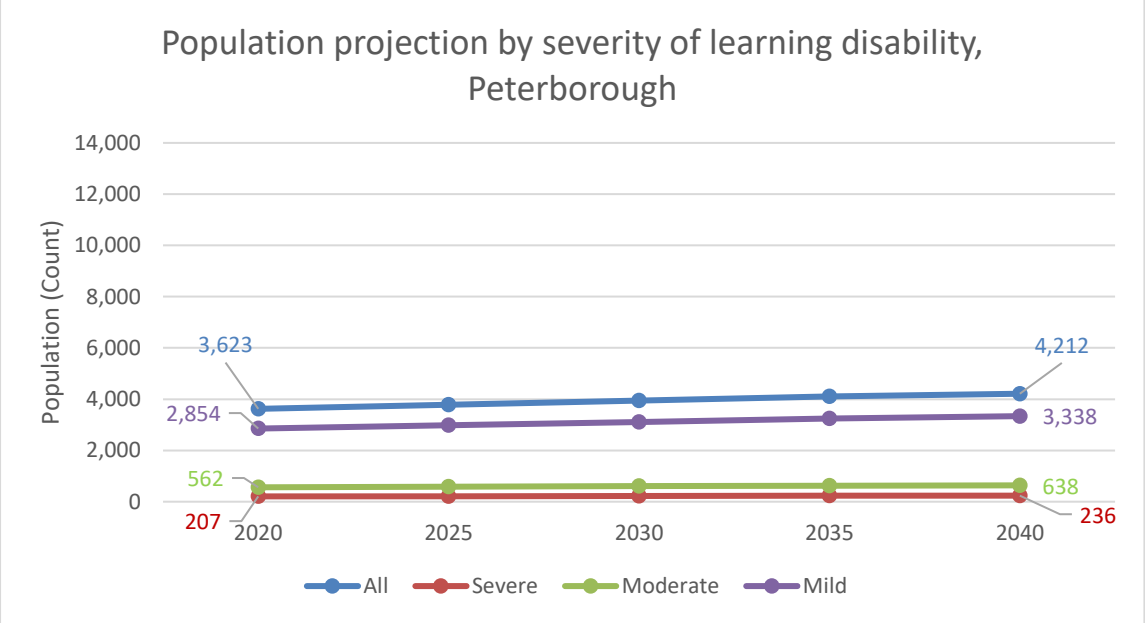
5.1.4 Future growth in numbers of people with an LD in Cambridgeshire ad Peterborough

POPPI and PANSI are two systems originally developed for use by local authority planners and commissioners of social care provision in England. POPPI and PANSI

provide demographic data on populations aged 65 years and older and 18–65 years, respectively. Both POPPI and PANSI provide future projections for the estimated "true" number of people with LD (figure 5.4). During 2020–2040, Peterborough is projected to show twice as much growth in the adult LD population size as Cambridgeshire, with 8% and 16% increases, respectively.

Figure 5.4: Future projections for the "total" number of adults (aged 18+) with LD in Cambridgeshire and Peterborough, 2020-40, by severity of learning disability





These data are derived from POPPI and PANSI future projections. Further data from POPPI and PANSI presenting age-specific prevalence are available in Appendix 1, Section 19.3.

To estimate the proportion of patients with severe LD aged 65+, calculations were performed based on data presented in the Institute of Public Care Working Paper, Estimating the Prevalence of Severe Learning Disability in Adults. Further details of the work performed by the Institute of Public Care can be found in Appendix 1, Section 19.4.

As POPPI and PANSI do not explicitly present data for 'profound' LD, this group are expected to be represented as a minority of the people with severe LD in these projections. Children (aged <18) are not accounted for in these projections.

Source: POPPI (24) and PANSI (25), Institute of Public Care(26)

These estimates adjust the “total” prevalence rates from Emerson and Hatton 2004 (table 5.2), accounting for national changes in ethnicity (i.e., the increased prevalence of learning disabilities in South Asian communities), mortality (i.e., both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities), and population growth (as per ONS linear projections).

POPPI and PANSI estimates do not account for local authority-level variation in population growth (24,25). Furthermore, these projections are noted to over-estimate LD prevalence in communities with a small South Asian community, and under-estimate in communities with a large South Asian community (24,25). As such, POPPI and PANSI may underestimate the prevalence of LD in Cambridgeshire and Peterborough where local demography work has identified population growth beyond that nationally predicted, particularly in Peterborough.

5.2 Ethnicity

5.2.1 National data on ethnicity of people with an LD

Current data on the relationship between LD and ethnicity is sparse, leading to substantial uncertainty in assessing the prevalence of LD within different population groups in the UK.

Department of Health 2001

In 2001, the Centre for Research in Primary Care at the University of Leeds was commissioned by the Department of Health to conduct a scoping study of services for people with learning disabilities from minority ethnic communities (27). The published report noted that the prevalence of LD in people of South Asian ethnicity aged between 5–32 years was up to three times higher than in other communities. Although lower prevalence rates were seen in children under 5, these were attributed to South Asian children failing to be diagnosed until school age. Furthermore, it was observed that families of South Asian ethnicity who had one member with an LD, frequently (19%) had multiple members with LD. This report also noted that outside of this work, little evidence existed for the prevalence of LD within other ethnic groups.

Race Equality Foundation 2021

The Race Equality Foundation is a national charity based in England that aims to address racial inequalities. In 2021, the charity published a briefing paper entitled *Collaboratives on addressing racial inequity in covid recovery*, focusing on the impact of COVID-19 on individuals with LD (28). The authors reference an article by Gill and Badger (2007; British Institute of Learning Disabilities) that estimated there were 60,000 people from BAME backgrounds with LD in the UK (29). However, this original source is unpublished and cannot be scrutinised. Furthermore, it is likely that factors such as population growth and shift, as well as immigration, will have significantly impacted upon this number since 2007. Therefore, 60,000 likely does

not provide a robust estimate for the number of people from BAME backgrounds with LD in the UK.

The Race Equality Foundation's briefing paper goes on to state that according to Lancaster University's Centre for Disability Research, 25% of new entrants to adult social care with an LD were from ethnic minority groups from 2011-2020. This statistic is not referenced, so again is difficult to scrutinise.

5.2.2 Ethnicity of people with an LD in Cambridgeshire and Peterborough

The main data available to estimate ethnicity of adults with an LD in Cambridgeshire and Peterborough is from primary care LD registers. Data on ethnicity is available for 95% of individuals on the LD register in Cambridgeshire and Peterborough. Table 5.8 below shows the proportion of people with an LD by ethnicity and PCN.

Table 5.8: ethnicity of people with an LD on primary care LD registers in Cambridgeshire and Peterborough (%)

PCN Name	White (%)	South Asian (%)	Black (%)	Mixed (%)	Other (%)	Unknown (%)	Grand Total (%)
A1 Network PCN	90.3	0.6	1.2	2.4	0.6	4.9	100.0
BMC Paston PCN	82.3	10.0	4.4	0.8	0.8	1.6	100.0
Bretton, Park and Hampton PCN	82.9	9.1	2.3	3.4	0.0	2.3	100.0
CAM Medical PCN	81.8	9.1	1.3	0.0	3.9	3.9	100.0
Cambridge City 4 PCN	84.2	4.3	1.4	4.3	0.7	5.0	100.0
Cambridge City PCN	84.9	5.0	0.8	2.3	1.2	5.8	100.0
Cambs Northern Villages PCN	92.6	1.0	0.5	0.0	0.5	5.5	100.0
Cantab PCN	79.8	5.3	2.1	0.0	0.0	12.8	100.0
Central Thistlemoor and Thorpe Road PCN	61.5	29.2	1.2	1.2	1.2	5.6	100.0
Ely North PCN	91.9	0.4	0.0	2.6	0.4	4.7	100.0
Ely South PCN	87.6	2.3	0.8	0.0	1.6	7.8	100.0
Fenland PCN	98.4	0.4	0.0	0.8	0.0	0.4	100.0
Granta PCN	81.0	2.8	0.7	1.4	0.7	13.4	100.0
Huntingdon PCN	93.6	3.9	0.4	0.7	0.0	1.4	100.0
Meridian PCN	84.6	1.8	0.0	2.4	1.2	10.1	100.0
Non-aligned	70.0	10.0	6.7	0.0	3.3	10.0	100.0
Peterborough and East PCN	88.3	4.4	2.6	2.2	0.0	2.6	100.0
Peterborough Partnerships PCN	80.8	14.5	1.7	1.2	1.2	0.6	100.0
South Fenland PCN	95.5	0.7	0.7	0.7	0.7	1.9	100.0
South Peterborough PCN	73.1	1.3	1.3	13.0	0.7	10.6	100.0

St Ives PCN	89.8	5.7	0.0	0.6	0.0	4.0	100.0
St Neots PCN	95.0	0.0	0.6	0.0	0.0	4.4	100.0
Wisbech PCN	93.5	0.0	0.4	2.2	0.0	4.0	100.0
Grand Total	**86.5**	**4.7**	**1.2**	**2.3**	**0.6**	**4.8**	**100.0**

Source: C&P ICB, primary care LD register (23)

This shows that the ethnicity of people with an LD on primary care registers varies by PCN.

There is a slightly higher percentage of individuals from a minority ethnic background on the LD register than in the general population in Cambridgeshire and Peterborough.

5.3 Recommendations

Cambridgeshire County Council and Peterborough City Council Business Intelligence team

- Further work is needed to understand whether there is any significant divergence between POPPI and PANSI growth forecasts, which are the most reliable nationally available forecasts, and local actual demand, given overall population growth trajectories.

6. Mortality

6.1 National LeDeR programme

6.1.1 Introduction to national LeDeR programme

Learning from Lives and Deaths – people with a learning disability (LeDeR) is a national initiative to review the death of any person with a learning disability over the age of four years. The intention is that the outcomes of these reviews will be used to improve the lives of people who have a learning disability across three key areas:

- Improving care
- Reducing health inequalities
- Preventing early deaths

The 2021 national report looks at information from referrals in 2021 as well as data from previous years. This report can be used to consider how to improve lives of people with learning disabilities locally as well as nationally. The COVID-19 pandemic makes the 2020 and 2021 data more difficult to compare to previous years but remains pertinent. The following sections relate to the 2021 report (30), unless otherwise specified in the text.

6.1.2 Methodology

The LeDeR programme reviews the deaths of people with a learning disability aged 4 years and over. For people aged 18 years and over, deaths can be referred in through an open portal for consideration; anyone is able to make a referral in. Once a referral is received, it is checked for eligibility. Adults without a clinical diagnosis of a learning disability are excluded. All deaths have an initial review by a LeDeR reviewer, who gathers information about the deceased's life, the circumstances of their death, and confirms the medical cause of death through linkage to their death certificate via ONS. A proportion of deaths have a more focussed review undertaken, where the reviewer feels there may be system learning, or the family requests this, or the person is from an ethnic minority background.

As many people with milder learning disabilities are not known to health and care or may not have a formal diagnosis, the findings from LeDeR may disproportionately represent those with more severe learning disabilities.

6.1.3 Demographics

Nationally, 12,398 deaths have been reported to LeDeR from 2018-2021, with 3304 deaths reported to LeDeR in 2021. This represents 0.58% of all deaths in England from 2018-2021 and 0.6% of all deaths in England during 2021 (31).

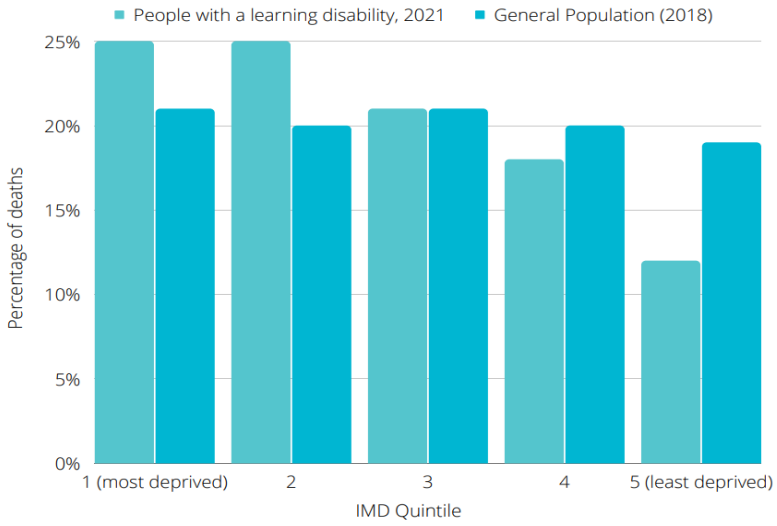
Nationally, 56% of people notified to LeDeR in 2021 were male. 91% of people notified to LeDeR were white, compared to 85% in the general population. This may be due to underreporting of deaths of people from minority ethnic backgrounds, or

possibly due to the population structure (e.g. fewer older people from minority ethnic groups).

In 2021, 60% of people with a learning disability whose deaths were reported to LeDeR died before they were 65, compared to 15% of the general population. Males with learning disabilities died on average 22 years before males from the general population and females 26 years before females from the general population. The median age at death for those notified to LeDeR was 61 years for males and 60 years for females.

50% of people who had their deaths reported to LeDeR died in the two most deprived quintiles in England using the Index of Multiple Deprivation (IMD), which is higher than for the general population (Figure 6.1).

Figure 6.1: % of deaths reported to LeDer by deprivation quintile, 2021



Source: White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Carter, B; Ruane, M; Xiang, X; Chauhan, U; Tuffrey-Wijne, I; Strydom, A; (2022). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2021 (LeDeR 2021). Autism and learning disability partnership, King's College, London, reproduced with permission of authors (30)

Information on severity of learning disability is not included in the 2021 report. The 2020 national report gives some data on this, with data on severity of LD available for 71% of deaths in adults reported from 2018-2020 (9). This suggests that around 33% of deaths reported are in people with a mild LD, 35% are in people with a moderate LD, 25% are in people with a severe LD and 7% in people with a profound LD (9). These proportions have remained relatively stable from 2018-2020. This suggests individuals with severe and profound LD are significantly overrepresented in the LeDeR data, and individuals with a mild LD significantly underrepresented, compared to the overall population of people with an LD.

6.1.4 Causes of death

Causes of death were analysed using the underlying cause of death, which is based on the lowest completed line of part on of a death certificate and assigned an ICD-10 chapter code. This is an internationally recognised method for analysing mortality data, and allows for comparisons with other cohorts.

6.1.5 Causes of death in adults aged 18-64 years

For adults aged 18-64 years, the most common causes of death in 2021, by ICD-10 chapter, were:

- Covid-19 (codes for special purposes);
- Congenital malformations, deformations and abnormalities;
- Diseases of the circulatory system;
- Diseases of the nervous system;
- Cancer;
- Diseases of the respiratory system.

The breakdown is shown in Figure 6.2 below:

Figure 6.2: breakdown of the most frequently reported causes of death, people aged 18-64 years

Appendix 2.3.3: The most frequently reported ICD-10 chapter causes of death, by year of death, 18-64-year-olds.

ICD-10 chapter	2018		2019		2020		2021	
	M	F	M	F	M	F	M	F
Codes for special purposes (COVID-19)	0.00%	0.00%	0.00%	0.00%	20.84%	20.91%	20.52%	20.00%
Diseases of the circulatory system	15.13%	9.57%	12.53%	12.23%	12.92%	9.76%	14.58%	11.45%
Diseases of the respiratory system	16.54%	18.32%	14.20%	17.58%	8.61%	11.03%	9.81%	10.81%
Cancers	11.67%	16.50%	13.84%	14.98%	7.83%	10.90%	10.84%	12.74%
Diseases of the nervous system	14.36%	14.69%	16.71%	13.30%	13.31%	10.90%	14.06%	12.26%
Congenital malformations, deformations and chromosomal abnormalities	17.82%	17.99%	18.14%	19.11%	12.52%	14.32%	14.19%	14.52%

Source: Appendix from: Source: White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Carter, B; Ruane, M; Xiang, X; Chauhan, U; Tuffrey-Wijne, I; Strydom, A; (2022). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2021 (LeDeR 2021). Autism and learning disability partnership, King's College, London, reproduced with permission of authors (30)

For adults aged 65+ years, the most common causes of death in 2021, by ICD-10 chapter, were:

- Covid-19 (codes for special purposes);
- Diseases of the circulatory system;
- Diseases of the respiratory system;
- Cancer;
- Diseases of the nervous system

The breakdown of these is shown in figure 6.3:

Figure 6.3: breakdown of the most frequently reported causes of death in over 65s

Appendix 2.3.4: The most frequently reported ICD-10 chapter causes of death, by year of death, people aged 65+.

ICD-10 chapter	2018		2019		2020		2021	
	M	F	M	F	M	F	M	F
Codes for special purposes (COVID-19)	0.00%	0.00%	0.00%	0.22%	28.62%	20.13%	24.87%	22.25%
Diseases of the circulatory system	19.86%	19.12%	17.37%	21.80%	11.80%	16.11%	16.81%	15.83%
Diseases of the respiratory system	27.57%	24.55%	24.39%	23.82%	17.64%	17.28%	14.41%	16.06%
Cancers	13.01%	13.95%	15.61%	13.03%	10.28%	11.58%	10.98%	11.93%
Diseases of the nervous system	6.34%	5.43%	4.91%	8.09%	5.84%	4.36%	7.03%	6.19%

Source: Appendix from: White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Carter, B; Ruane, M; Xiang, X; Chauhan, U; Tuffrey-Wijne, I; Strydom, A; (2022). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2021 (LeDeR 2021). Autism and learning disability partnership, King's College, London, reproduced with permission of authors (30)

With respect to deaths from respiratory diseases in 2021, the breakdown of causes (all-age) in 2021 was as follows:

- COVID-19 dominated as most common cause of these deaths (64%),
- Pneumonia due to unspecified organism (21%),
- Other chronic obstructive pulmonary disease (4%),
- Pneumonitis due to solids or liquids (3%),
- Unspecified lower respiratory infection (3%),
- Bronchiectasis (1%) and
- Asthma (1%).

With respect to deaths from cancer, the most frequently reported types of cancer for all ages in 2021 were:

- Those of the digestive organs (35%), specifically colon and rectal cancer (14%), oesophagus (7%) and pancreas (5%),
- Lymphoid, haematopoietic and related tissue cancers (11%),
- Respiratory and intrathoracic organ cancers (8%) and
- Breast cancer (8%).

6.1.6 Circumstances of death

A higher proportion of people with learning disabilities (61%) die in hospital than the general population (42%). Of those that had an initial LeDeR review (2,662) 64% had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision in place at the time of death. In 60% of these deaths, reviewers judged that DNACPR documentation and processes were appropriate.

6.1.7 Quality of care

There was evidence of good practice in 7 out of 10 reviews in LeDeR. Reviewers rated overall care as ‘good’ or ‘excellent’ in 58% of reviews (compared to 54% in 2020).

In 30.6% of reviews of deaths in 2021 there was a concern expressed to the reviewer about the death. Key areas of concern related to:

- Lack of preventative healthcare, particularly immunisations and screening
- Problems accessing GP appointments
- Lack of reasonable adjustments in hospitals, including access to specialist equipment, interpreters and accessible information
- Lack of adherence to the Mental Capacity Act
- Missed/late diagnosis of potentially treatable conditions
- In social care, a lack of understanding of physical health
- Individuals not being on the primary care LD register
- Learning disability being recorded as cause of death, which is not in keeping with best practice guidelines

Positive practice highlighted in reviews included comprehensive annual health checks; multidisciplinary working in primary and community care, and learning disability liaison nurses and ‘hospital passports’ in hospital in-patient care.

6.1.8 Factors associated with age at death

Sex and geographical region of death were found to not be significantly associated with age at death for individuals included in LeDeR. However, people of Black, Black British, Caribbean or African, mixed ethnic group and Asian or Asian British ethnicity

died at a younger age than those of white ethnicity. This association remained even when controlling for factors such as long-term health conditions.

With respect to long term conditions, the greatest hazard for early death was associated with having epilepsy compared to not having epilepsy (hazard ratio 1.47; 95% confidence interval 1.28-1.69).

6.1.9 Additional findings from national LeDeR reports 2015-2020

The previous sections summarise the findings from the latest LeDeR report for 2021, however, there are additional relevant findings from previous reports (9).

In addition to ethnicity, variables significantly associated with greater likelihood of dying aged 18-49 years included having a severe or profound and multiple learning disabilities, being subject to mental health or criminal justice restrictions in the five years prior to death and not having an annual health check in the year prior to death (9).

Regarding positive progress, there was an overall reduction in the proportion of avoidable medical causes of death in adults with learning disabilities in the period 2018-2020 (although they remained higher than for people in the general population) (9).

6.2 Cambridgeshire and Peterborough LeDeR programme

Cambridgeshire and Peterborough have a local process for LeDeR reviews. The programme received a total of 162 reports from March 2018- March 2022 (32–35). This represents approximately 0.55% of deaths in Cambridgeshire and Peterborough during this time period (31).

6.2.1 Methodology

The local process for reviewing deaths is similar to the national process. However, the process for reviewing causes of death is different, and is based on reviewing part 1a of the Medical Certificate of Cause of Death. This means that local data on causes of death is not currently comparable to national LeDeR analyses or local analyses of causes of death in the general population.

The following data is taken from the 2022 report, although the date range for the notifications analysed is not always specified.

6.2.2 Demographic information

The local report for 2022 provided the following demographic data, based on 73 cases:

- Average age of death was 61 years;
- More male deaths were reported than female deaths;
- 93% of deaths were in individuals who identified as white British.

In terms of severity of disability, the 2022 local report had data for 83% of reviews undertaken from 2018. Where data on severity of LD was available, this showed that 5% of reviews were in people with a profound LD, 34% in people with a severe LD, 30% in people with a moderate LD and 31% in people with a mild LD. This shows that people with a mild LD are likely to be significantly underrepresented in the LeDeR review process.

6.2.3 Causes of death – people with an LD

The methodology for analysing cause of death is not comparable to other reports and therefore is not included here.

6.2.4 Circumstances of death

65% of deaths occurred in hospital, 13% in a residential home, 12% in their own or a family home and 10% in a supported living setting. This is similar to the national report. 78% of individuals had a DNACPR decision in place, of which 39% were completed following an appropriate process. This is a higher percentage of cases with a DNACPR in place, with a lower proportion following the correct process, than in the national LeDeR data.

6.2.5 Quality of care

73% of cases analysed in the 2022 LeDeR report had care graded as satisfactory, good or excellent. This is slightly higher than the national LeDeR data for 2022. 18% had care that fell short of expected practice that contributed to the cause of death, or had the potential to contribute to the cause of death. This is almost twice as high as the national LeDeR data for 2021. However, the local data is based on very low numbers.

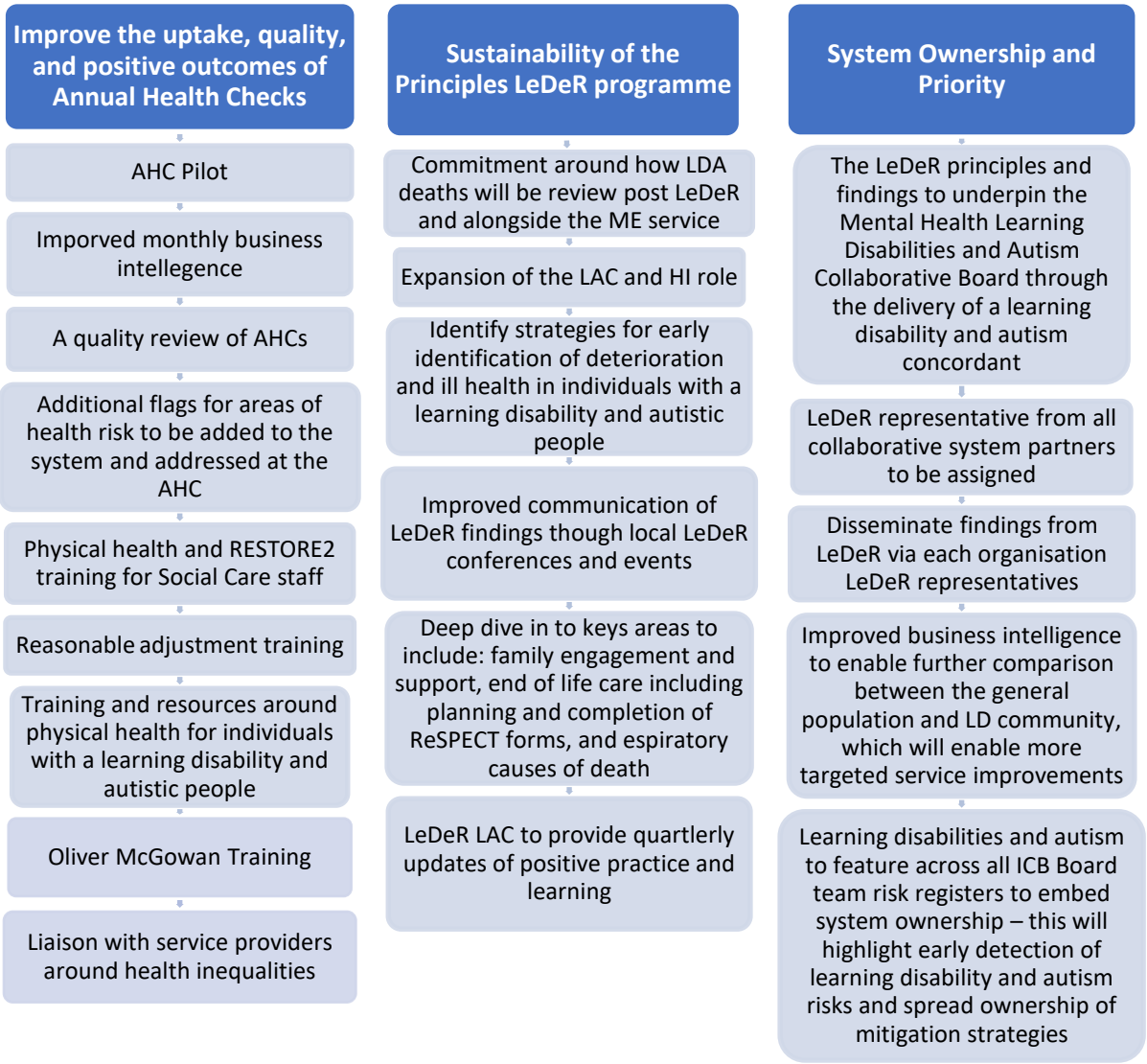
The five commonest themes identified from the reviews in Cambridgeshire and Peterborough were:

- No annual health check
- Missed opportunities for diagnosis and treatment
- Mental Capacity Act not followed or adhered to
- Poor end of life planning and/or provision of care
- Issues surrounding the ReSPECT form and treatment (the ReSPECT form is the local process for making and documenting DNACPR decisions)

6.2.6 Local LeDeR recommendations

Figure 6.4 sets out the 2022 local LeDeR report’s recommendations.

Figure 6.4: recommendations from 2022 Cambridgeshire and Peterborough LeDeR report



Source: (35)

6.2.7 Local mortality data for Cambridgeshire and Peterborough – general population

For reference, an analysis of mortality data for the general population for Cambridgeshire and Peterborough was undertaken.

Table 6.1 shows that the leading ICD-10 chapters for adults aged 18-64 years.

Table 6.1: underlying causes of death by ICD-10 chapter for all adults aged 18-64 years in Cambridgeshire and Peterborough

Cause of Death by ICD10 Chapter	2018		2019		2020		2021		
	No.	%	No.	%	No.	%	No.	Rank	%
Neoplasms	350	35.5%	376	38.6%	370	36.6%	381	1	36.6%
Diseases of the circulatory system	204	20.7%	187	19.2%	197	19.5%	214	2	20.6%
Diseases of the digestive system	63	6.4%	67	6.9%	73	7.2%	108	3	10.4%
Codes for special purposes	9	0.9%	9	0.9%	81	8.0%	104	4	10.0%
Diseases of the respiratory system	62	6.3%	62	6.4%	57	5.6%	52	5	5.0%
External causes of morbidity and mortality	159	16.1%	143	14.7%	129	12.7%	50	6	4.8%
Diseases of the nervous system	49	5.0%	43	4.4%	38	3.8%	45	7	4.3%
Other	45	4.6%	38	3.9%	29	2.9%	41	9	3.9%
Endocrine, nutritional and metabolic diseases	22	2.2%	26	2.7%	20	2.0%	21	9	2.0%
Certain infectious and parasitic diseases	7	0.7%	10	1.0%	11	1.1%	15	10	1.4%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	16	1.6%	14	1.4%	7	0.7%	9	11	0.9%
Total	**986**		**975**		**1,012**		**1,040**		

Source: (36)

The leading ICD-10 chapters for underlying cause of death in adults aged 65+ years are shown in table 6.2.

Table 6.2: underlying causes of death by ICD-10 chapter for all adults aged 65 years and older in Cambridgeshire and Peterborough

Cause of Death by ICD10 Chapter	2018		2019		2020		2021		
	No.	%	No.	%	No.	%	No.	Rank	%
Neoplasms	1,631	27.4%	1,567	26.5%	1,724	25.9%	1,651	1	25.1%
Diseases of the circulatory system	1,504	25.3%	1,617	27.3%	1,540	23.1%	1,571	2	23.9%
Codes for special purposes	1	0.0%	5	0.1%	584	8.8%	660	3	10.0%
Diseases of the respiratory system	828	13.9%	838	14.2%	744	11.2%	641	4	9.7%
Diseases of the nervous system	430	7.2%	430	7.3%	491	7.4%	579	5	8.8%
Mental and behavioural disorders	674	11.3%	659	11.1%	630	9.5%	571	6	8.7%
Diseases of the digestive system	227	3.8%	242	4.1%	295	4.4%	243	7	3.7%
Diseases of the genitourinary system	99	1.7%	87	1.5%	101	1.5%	130	8	2.0%
Endocrine, nutritional and metabolic diseases	106	1.8%	89	1.5%	144	2.2%	124	9	1.9%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	112	1.9%	94	1.6%	109	1.6%	118	10	1.8%
External causes of morbidity and mortality	155	2.6%	152	2.6%	141	2.1%	114	11	1.7%
Certain infectious and parasitic diseases	87	1.5%	67	1.1%	55	0.8%	80	12	1.2%
Diseases of the skin and subcutaneous tissue	34	0.6%	25	0.4%	32	0.5%	34	13	0.5%
Diseases of the musculoskeletal system and connective tissue	38	0.6%	34	0.6%	51	0.8%	32	14	0.5%
Other	30	0.5%	12	0.2%	20	0.3%	27	15	0.4%
Total	**5,956**		**5,918**		**6,661**		**6,575**		

Source: (36)

Table 6.3 shows the breakdown of respiratory causes of disease.

Table 6.3: respiratory causes of death by ICD10 code (all ages), Cambridgeshire and Peterborough

Cause of Death by ICD10 Code	2018		2019		2020		2021		
	No.	%	No.	%	No.	%	No.	Rank	%
COVID-19	0	0.0%	0	0.0%	647	44.7%	754	1	52.1%
Other chronic obstructive pulmonary disease	291	32.7%	303	33.5%	288	19.9%	265	2	18.3%
Pneumonia, organism unspecified	297	33.3%	297	32.9%	220	15.2%	192	3	13.3%
Other interstitial pulmonary diseases	75	8.4%	96	10.6%	88	6.1%	80	4	5.5%
Unspecified acute lower respiratory infection	83	9.3%	55	6.1%	71	4.9%	54	5	3.7%
Bronchiectasis	21	2.4%	32	3.5%	27	1.9%	30	6	2.1%
Pneumonitis due to solids and liquids	44	4.9%	32	3.5%	30	2.1%	24	7	1.7%
Asthma	21	2.4%	19	2.1%	27	1.9%	20	8	1.4%

Source: (36)

Table 6.4 shows the breakdown of the cancers.

Table 6.4: breakdown of causes of death by types of cancer (all ages), Cambridgeshire and Peterborough

Cause of Death by ICD10 sub-chapter	2018		2019		2020		2021		
	No.	%	No.	%	No.	%	No.	Rank	%
Digestive organs (C15-C26)	590	29.7%	586	30.1%	614	29.2%	573	1	28.2%
Respiratory and intrathoracic organs (C30-C39)	333	16.8%	364	18.7%	421	20.0%	370	2	18.2%
Lymphoid, haematopoietic and related tissue	170	8.6%	166	8.5%	165	7.9%	201	3	9.9%
Breast	126	6.3%	134	6.9%	138	6.6%	149	4	7.3%

Source: (36)

6.2.8 Comparison of causes of death in people with LD and the general population

Although there is no local data on deaths in people with an LD that is comparable to the local data on mortality in the general population of Cambridgeshire and Peterborough, a number of observations can be made about the data:

- The top 5 ICD-10 chapter codes for mortality in people with an LD are very similar for adults aged 18-64 years, and identical for adults aged 65 years and over, when compared to the general population, although they are in a different order.

- Covid-19 continues to make a significant contribution to mortality in people with an LD, over and above what is seen in the general population.
- When disaggregating respiratory causes of death, COPD is less common as a cause of death in people with an LD than the general population. Pneumonia is more common.
- The most common types of cancer leading to death were identical in people with an LD and the general population.

6.3 Risk factors for common causes of mortality

In order to inform the topics covered in the needs assessment, further consideration of detailed causes of death for adults with an LD aged 18-64 years and adults aged 65 years and over has been made, and mapped to the relevant chapters in the needs assessment.

Using the data from the national LeDeR report, this section considers the risk factors in adults with a learning disability for the top 5 causes of mortality in people with an LD, excluding deaths due to congenital malformations, deformations and abnormalities and cerebral palsy.

6.3.1 Leading causes of death for adults aged 18-64 years

The leading causes of death for adults aged 18-64 years are listed below in figure 6.5.

Figure 6.5: leading causes of death, adults aged 18-64 years, national LeDeR report

Appendix 2.7.3: The most frequently reported leading causes of death, by year of death (18- to 64-year-olds).

2018			2019			2020			2021		
Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%
Adults (aged 18-64)											
Congenital malformations, deformations and chromosomal abnormalities	248	17.88	Congenital malformations, deformations and chromosomal abnormalities	276	18.49	Covid-19	378	20.85	Covid-19	283	18.93
Cancers	189	13.63	Cancers	215	14.4	Congenital malformations, deformations and chromosomal abnormalities	241	13.29	Congenital malformations, deformations and chromosomal abnormalities	200	13.38
Influenza and pneumonia	146	10.53	Influenza and pneumonia	126	8.44	Cancers	165	9.1	Cancers	163	10.90
Cerebral palsy and other paralytic syndromes	92	6.63	Epilepsy and status epilepticus	90	6.03	Cerebral palsy and other paralytic syndromes	104	5.74	Cerebral palsy and other paralytic syndromes	83	5.55

Epilepsy and status epilepticus	57	4.11	Cerebral palsy and other paralytic syndromes	82	5.49	Influenza and pneumonia	99	5.46	Influenza and pneumonia	80	5.35
Ischaemic heart disease	55	3.97	Ischaemic heart disease	56	3.75	Epilepsy and status epilepticus	61	3.36	Ischaemic heart disease	62	4.15
Cerebrovascular disease	43	3.1	Cerebrovascular disease	54	3.62	Ischaemic heart disease	59	3.25	Epilepsy and status epilepticus	49	3.28

Source: Appendix from: White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Carter, B; Ruane, M; Xiang, X; Chauhan, U; Tuffrey-Wijne, I; Strydom, A; (2022). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2021 (LeDeR 2021). Autism and learning disability partnership, King's College, London, reproduced with permission of authors (30)

6.3.1.1. Covid-19 – risk factors

People with an LD are more likely to die from covid-19 than the general population (37).

Risk factors for mortality from covid-19 in adults with a learning disability include (38):

- Increased severity of learning disability;
- Living in residential care;
- Having Down's syndrome or cerebral palsy.

People with a learning disability may also be more likely to have physical comorbidities that increase their risk of death from covid-19 (38).

The most effective way to prevent death from covid-19 is immunisation; this is covered in section 7.3.

6.3.1.2 Cancers – risk factors

Opportunities to prevent mortality from cancer can be broken down into risk factors for developing cancer, and improvement of prognosis through early detection and treatment of cancer.

People with a learning disability share many risk factors for developing cancer with the general population in the UK. In the general population in UK, the following risk factors were responsible for around one third of all cancers (39):

- Smoking;
- Overweight/obesity;
- Exposure to UV radiation;
- Occupational risk factors;
- Infections;
- Alcohol.

Modifiable risk factors in the general population that are specific to the most common cancers in people with a learning disability are shown in table 6.5.

Table 6.5: modifiable risk factors for cancer in people with an LD

		Modifiable risk factors	**Non-modifiable risk factors**
Digestive organs	Colorectal cancer	• Main risk factors are being overweight/obese, diet (particularly consumption of processed foods and red meat), physical inactivity and alcohol consumption (40)	• Increasing age, male sex and family history (41)
	Oesophageal cancer	• Risk factor profile depends on type of cancer • Squamous cell cancer: main risk factors are smoking and drinking alcohol (42) • Adenocarcinoma: main risk factors are gastro-oesophageal reflux disease and obesity(42)	• Male sex and ethnicity (43)
	Pancreatic cancer	• Key modifiable risk factors are smoking, high BMI and diabetes (44)	• Increasing age, ethnicity (45)
Lymphoid, haematopoietic and related tissue		• The main modifiable risk factors for lymphomas and leukaemias are smoking and exposure to radiation and chemotherapy (46)	• Ethnicity, immunosuppression (46)
Respiratory and related intrathoracic organs	Bronchus	• Smoking is the main modifiable risk factor for lung cancer	• Family history(47)

Key risk factors are considered in the following sections:

- Overweight/obesity – section 7.7;
- Smoking – section 7.5;
- Diabetes – section 7.1;
- Alcohol – section 7.4.

With regards to detection and treatment, cancer screening is considered in section 7.2.

A recent paper has also analysed historical LeDeR data on deaths from cancer in more detail (Heslop, 2022). This analysis showed that:

- Adults with an LD are much more likely to be diagnosed with cancer after presenting as an emergency (35% of diagnoses, compared to 19.8% in the general population) (48);
- Adults with an LD are more likely to be diagnosed with cancer when it has progressed to stage 3 or 4, meaning their prognosis is poorer, than the general population (49).

Reasonable adjustments for mainstream health services are considered in section 15.

6.3.1.3 Influenza and pneumonia – risk factors

Influenza and pneumonia are key causes of death in adults with an LD (see section 6.1).

The British Thoracic Society have released guidelines for prevention and management of community acquired pneumonia in people with an LD (50).

They have identified the main risk factors for people with an LD as described in figure 6.6 (50).

Figure 6.6: risk factors for community acquired pneumonia in people with an LD

Table 1 Risk factors for CAP in people with learning disability	
Risk factor	**Comments**
Sleep-disordered breathing*	Although not specifically studied in people with learning disability, non-interventional retrospective analyses support an association between obstructive sleep apnoea (OSA) and CAP 55 56 Several retrospective cohort studies have demonstrated an increased rate of CAP in patients with NMD and nocturnal hypoventilation with a reduction following appropriate treatment.43 57
Previous history of respiratory infections	Previous episodes of CAP indicate an increased risk of subsequent CAP.213 This risk is of particular note in cerebral palsy (CP) where a respiratory hospital admission is associated with a >50% likelihood of a further hospitalisation for CAP in the subsequent 12 months.214 215
Reduced mobility/impaired motor function*	Reduced mobility and impaired motor function have been identified as a risk factor for pneumonia in many disorders associated with learning disability including CP.214 234 Physical activity and mobility reduce more rapidly in older adults with learning disability compared with the general population.23 235 236
Eating, drinking and swallowing difficulties	People with learning disability are at increased risk of swallowing difficulties. Population studies have found 8.1% to 11.5% of adults known to formal learning disability services present with swallowing difficulties 101 102 although this is likely an underestimation due to diagnostic issues and selection bias.103. Eating, drinking and swallowing difficulties are a recognised risk factor for CAP in people with learning disability.237
Gastro-oesophageal reflux disease (GORD)*	GORD has been identified as a risk factor for CAP,238 most notably in those with neurodisability.214 Clinical features that may indicate GORD include feeding refusal, failure to thrive, heartburn/chest pain and epigastric pain.
Sialorrhoea*	Sialorrhoea is increased saliva in the mouth, which can be either anterior, resulting in drooling, or posterior, where the saliva pools in the oropharynx and posterior pharynx. This can result in aspiration and aspiration pneumonia.23 239
Poorly controlled epilepsy*	Seizures are associated with an increased risk of aspiration, including vomit or saliva.130 Medications used to control or terminate seizures can lead to reduced muscle tone or drowsiness, further increasing the risk of aspiration."7
Bacterial colonisation*	Bacterial colonisation, including with Gram-negative organisms such as Pseudomonas aeruginosa, is associated with more severe CAP, including increased rates of hospitalisation and critical care admission and prolonged hospitalisations, 240 241
Immunodeficiency	Immunodeficiency is a feature of several learning disability-associated syndromes such as Down and Di George. Deficiencies in both humoral and cellular immunity have been identified in Down syndrome, for example, and are felt to at least partially explain the increased risk of CAP that has been described in these patients.242

Tracheostomy	Infection and colonisation are common long-term complications of tracheostomies in both children and adults, with P. aeruginosa colonisation in up to 90% of children with tracheostomies.243 Presence of a tracheostomy has been identified as an independent risk factor for developing P. aeruginosa-associated CAP.241
Oral health*	People with learning disability experience more problems with their oral health than the general population.134 Poor oral care and decaying teeth are risk factors for CAP in the elderly with some evidence in younger age groups." 132 133
Nutritional status*	People with learning disability have a higher incidence of both obesity and being underweight when compared with the general population.144-14% Being underweight is associated with an increased risk of CAP.141 Obesity may lead to reduced mobility and secondary problems such as OSA and GORD which in turn may impact chest health.143
Smoking/environmental tobacco smoke (ETS) exposure*	Smoking is associated with an increased risk of developing CAP.167 ETS exposure in childhood is associated with an increased risk of hospitalisation for CAP and increased severity of disease once hospitalised. 168 244
Presence of comorbid conditions	Comorbid conditions including chronic heart disease, chronic obstructive pulmonary disease, diabetes mellitus, cerebrovascular diseases, dementia, chronic liver disease and chronic renal disease are recognised risk factors for CAP.245
*Modifiable. CAP, community-acquired pneumonia; NMD, neuromuscular disorder.	

Source: (50), reproduced from Thorax, Legg J, Allen J, Andrew M, *et al*, 78:s1-s31, 2023 with permission from BMJ Publishing Group Ltd.

Most of the modifiable risk factors are considered elsewhere in this needs assessment, particularly sections 7.3 (immunisations), 7.5 (smoking), 7.7 (physical activity), 7.8 (annual health checks), 10.4 (dysphagia), 10.5 (postural care), 10.6 (oral health), 10.8 (underweight) and 12.2 (epilepsy). Section 12.11 considers actions in more detail.

6.3.1.4 Ischaemic heart disease – risk factors

Ischaemic heart disease is not well researched in people with an LD (51).

Modifiable risk factors in the general population are (52,53):

- Smoking
- Being overweight
- Physical inactivity
- High blood pressure
- Diabetes
- High cholesterol

Non-modifiable risk factors include increasing age, ethnicity, male gender and family history (52,53).

Cardiovascular disease prevention is covered in section 7.1.

6.3.1.5 Epilepsy

Epilepsy is covered in section 10.2.

6.3.2 Leading causes of death in adults aged over 65 years with an LD

The LeDeR report sets out the leading causes of death in adults aged over 65 years with an LD, shown in figure 6.7.

Figure 6.7: leading causes of death in adults aged over 65 years

Appendix 2.7.3: The most frequently reported leading causes of death, by year of death (18- to 64-year-olds).											
2018			2019			2020			2021		
Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%
Older adults (aged 65+)											
Cancers	130	13.39	Cancers	147	14.48	Covid-19	365	25.14	Covid-19	242	22.87
Influenza and pneumonia	129	13.29	Influenza and pneumonia	132	13.00	Cancers	157	10.81	Cancers	116	10.96
Ischaemic heart disease	74	7.62	Dementia and Alzheimer disease	77	7.59	Influenza and pneumonia	118	8.13	Influenza and pneumonia	94	8.88
Congenital malformations, deformations and chromosomal abnormalities	71	7.31	Congenital malformations, deformations and chromosomal abnormalities	77	7.59	Dementia and Alzheimer disease	80	5.51	Dementia and Alzheimer disease	64	6.05
Dementia and Alzheimer disease	68	7.00	Cerebrovascular disease	72	7.09	Ischaemic heart disease	71	4.89	Cerebrovascular disease	60	5.67

Source: Appendix from: White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Carter, B; Ruane, M; Xiang, X; Chauhan, U; Tuffrey-Wijne, I; Strydom, A; (2022). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2021 (LeDeR 2021). Autism and learning disability partnership, King's College, London, reproduced with permission of authors (30)

Covid-19 is still the leading cause of death, however dementia and Alzheimer disease, and cerebrovascular diseases are both in the top 5 leading causes of death.

6.3.2.1 Dementia and Alzheimer's disease

Modifiable risk factors for dementia are covered in section 9.9.

6.3.2.2 Cerebrovascular disease

The risk factors for cerebrovascular disease are very similar to those for ischaemic heart disease. Cardiovascular disease prevention is covered in section 7.1.

6.3.3 Summary

Reviewing causes of mortality in adults with an LD has given a clear set of priority diseases to focus on, which are driving mortality amongst adults with an LD:

- Covid-19
- Cancer
- Influenza and pneumonia
- Ischaemic heart disease
- Dementia
- Stroke
- Epilepsy

This analysis has informed the content of the needs assessment, with subsequent chapters considering these key causes of mortality and their modifiable risk factors.

6.4 Recommendations

Cambridgeshire and Peterborough ICB

- Cambridgeshire and Peterborough ICB should ensure learning from local and national LeDeR reviews is shared widely amongst health and care partners, with identified actions addressed.

Healthcare providers and commissioners

- All healthcare providers and commissioners should ensure their staff have an understanding of the key causes of mortality in adults with an LD.
- All healthcare providers and commissioners should ensure they consider what systemic actions they need to take to address actions identified by local and national LeDeR work.

Social care providers and commissioners

- All providers and commissioners of care to adults with an LD should ensure their staff have an understanding of the key causes of mortality in adults with an LD.
- All providers and commissioners of care to adults with an LD should ensure they consider what systemic actions they need to take to address actions identified by local and national LeDeR work.

7. Views of adults with an LD

7.1 Local strategy around coproduction

Cambridgeshire and Peterborough ICS have approved a People and Engagement Strategy, to set out the local system's aims around involving local people in making decisions about services (54).

This local strategy is underpinned by the 10 key principles in the NHS's statutory guidance on working with people and communities (55):

Figure 7.1: key principles for working with people and communities

1. Ensure people and communities have an active role in decision-making and governance.	6. Provide clear and accessible public information
2. Involve people and communities at every stage and feed back to them about how it has influenced activities and decisions.	7. empower people and communities, making connections to what works already.
3. Understand your community's needs, experiences, 3 ideas and aspirations for health and care, using engagement to find out if change is working.	8. Use co-production, insight and engagement 8 methods so that people and communities can actively participate in health and care services.
4. Build relationships based on trust, especially 4 with marginalised groups and those affected by inequalities.	9. Tackle system priorities in partnership with people and communities.
5. Work with Healthwatch and the voluntary, community and social enterprise (VCSE) sector as key partners.	10. Learn from what works and build on the assets of all ICS partners - networks, relationships, activity in local places.

Source: (55),

7.2 User participation forums in Cambridgeshire and Peterborough

CCC and PCC commission two VCS organisations to facilitate user participation. In Cambridgeshire, Voiceability support the Speak Out Council. In Peterborough, Enabling Independence support the Network Team. Both of these user participation groups are represented on the health sub-group of the Learning Disability Partnership Board, which is a formal forum for engagement between CCC and PCC adult social care services and service users.

7.3 Coproduction and engagement with people with an LD in Cambridgeshire and Peterborough – health needs

CCC, PCC, Cambridgeshire and Peterborough Healthwatch and Cambridgeshire and Peterborough ICB have all undertaken an extensive programme of coproduction work relating to the health needs of people with an LD in the last 2 years. The learning from this work is summarised here.

7.3.1 CCC and PCC – LD vision work

CCC and PCC adult social care commissioning team have undertaken an extensive programme of engagement and coproduction work with people with an LD, their carers and health professionals, to help develop a strategic vision for LD services commissioned by CCC and PCC.

This work included an online survey, which received 281 responses, and face-to-face engagement and coproduction with people with an LD. The work took place in summer 2021.

The scope of the work was broader than this needs assessment, however it did include health services and factors that contribute to an individual's health.

Key findings from this work are summarised below.

Table 7.1: summary of key findings from CCC and PCC LD vision coproduction work

Priority area	Key findings
Health in the community	• Annual health checks were highlighted as important opportunities to prevent ill health developing • Discrepancies in access to community healthcare between people with an LD and the general population were highlighted • Suggestions for improvement included better provision of EasyRead materials; better training on the needs of people with an LD for health professionals; better communication between health professionals
Health in hospitals	• The role of LD liaison nurses was highlighted as extremely valuable • The value of a carer or someone who knows the person being able to attend with the individual was highlighted as very important • Training for health professionals on the needs of people with an LD was a key point, particularly around the need to ask about reasonable adjustments • Adequate equipment in hospitals for non-ambulatory individuals who need hoists was also raised as an issue

Source: (56)

7.3.2 Cambridgeshire and Peterborough ICB – coproduction work

Cambridgeshire and Peterborough ICB are currently undertaking a planned programme of coproduction work with people with an LD, around a number of key topics. This work is being undertaken with the Speak Out Council (delivered in partnership with VoiceAbility) and the Network Team (delivered in partnership with Enabling Independence).

The priority areas are:

Health in the Community

a) Focusing on Access to Primary Care, Annual Health Checks, Health Action Plans and Vaccination/Health Screening.

Health in Hospitals

a) Focusing on people's experiences within a hospital environment, covering general, emergency and people who may have had an admission to a mental health unit.

This programme of work is ongoing. Recommendations from the work already undertaken by the Speak Out Council are reproduced below (57).

Table 7.2: recommendations from coproduction work undertaken by Speak Out Council

Annual health checks	• "Explain how the health check will work and why we are doing it. • Check if I have understood and if I have any questions for you • Ask if I want extra support • Ask if I want to speak to someone privately • Give me a choice about where, or how my health check takes place. • Give me Easy Read information. • Make annual health check appointments longer. • Give me the choice of a male or female doctor. • Try to make sure I can see a doctor or nurse I have met before."
Health Action Plans	• "More people should be offered a Health Action Plan • Health Action Plans should be Easy Read"
Access to GP appointments	• "It should be easy for everyone who makes their own appointments to do this. • People should be able to make appointments online or over the phone, depending on what they prefer • People should be offered a choice of face to face or phone appointments. • Communication about Annual Health Checks could be better. We are still not sure whether people on the autistic spectrum are entitled to an Annual Health Check • Some health professionals could be better at listening."
People with high support needs	• "Staff need to organise checks and make sure they happen. This may mean arranging for a health professional to attend a care home, or making special arrangements at the GP surgery. • Staff also need to help by: Providing information during the appointment – staff need to have a good knowledge of the individual and their medical and

	health needs. Supporting the person and making them feel safe during tests – for example, a blood pressure check.”
Screening	• “People need clear, Easy Read information about screening checks. • People need time to talk about their worries about going to these checks. • We wondered if health professionals are assuming that people are not sexually active and not offering them cervical screening checks. • Health professionals need to be giving more people information about testicular screening”

Source: (57)

Recommendations from the work already undertaken by The Network Team are reproduced below (58).

Table 7.3: recommendations from coproduction work undertaken by The Network Team

Annual health checks	“What helps? • Easy Read letters to invite us to Health checks. • Reminders – Text or Phone calls • Some of us like Texts. Some of us prefer phone calls. Some of us need help from a carer or family member. • The Mencap Easy Read leaflet is helpful. • Some people might need the person doing the Health check to speak to their family or carer before meeting them. • This would help them to know how to talk to the person in a way that works for them • Parents and carers can have a lot of knowledge and experience. • Asking the person if they want the parent or carer to speak up for them can help some people with a learning disability.”

Source: (58)

7.3.4 Engagement undertaken for the LD needs assessment

Engagement was undertaken to help prioritise issues and recommendations for the LD needs assessment. This was done in two ways:

- Attendance at the Learning Disability Partnership Board Health Sub-group;
- Engagement session with Enabling Independence.

Feedback from the Learning Disability Partnership Board Health Sub-group

Members of the group were asked to give their priority areas for the needs assessment. Issues raised were:

- Access to annual health checks;
- Accessibility of primary care for individuals who are wheelchair users, for example lack of hoists;
- Challenges navigating GP practices and 111;
- Alternative face-to-face options to attending Access and Emergency.

Feedback from the engagement session with Enabling Independence

Attendees were asked to give priorities for 3 questions:

1. **Priorities for preventing ill health**
   Issues raised under this area were:
   - Support with healthy eating was ranked the highest priority
   - Insufficient LD nurses in hospital to meet need
   - Importance of seeing friends face-to-face for wellbeing
   - Importance of employment for self-esteem
2. **Priorities for improving access to mainstream health services**
   Issues raised under this area were:
   - Access to GPs was ranked as the highest priority
   - Challenges using online booking systems and phone booking systems were raised
   - Difficulties getting face-to appointments were raised
   - Difficulties caused by branch closure were raised, particularly because participants couldn't drive, and found it difficult to access alternative practice locations
   - A wish to see GPs of the same sex to discuss sexual health needs or issues to do with prostate/testicular health was expressed
3. **Priorities for increasing levels of physical activity**
   Issues raised under this area were:
   - Cheaper activities was ranked as the highest priority intervention to take
   - Access to safe green space was raised
   - Closure of gyms and other sports opportunities following covid was raised

7.4 Summary

In summary, a number of consistent priorities are present across a range of coproduction and engagement work. These are mapped to the needs assessment as follows:

- AHCs are viewed as a priority (these are covered in section 7.8);

- Consistent challenges in accessibility of routine GP appointments is raised as a concern (reasonable adjustments are covered in section 15);
- Accessibility of health services for profoundly disabled individuals, particularly those with physical disabilities is raised as a persistent challenge (reasonable adjustments are covered in section 15)

7.5 Recommendations

Cambridgeshire and Peterborough ICB

- The current programme of coproduction work should continue, to ensure people with an LD have their views and experiences heard.

Primary care

- Further work is needed to support primary care to make appropriate reasonable adjustments for people with an LD.

8. Stakeholder survey

8.1 Purpose of survey

A survey was undertaken in order to gain views from health and care professionals who regularly work with adults with an LD. The survey was promoted through a range of routes, including CPFT internal communications, ICB GP Gateway communications and the local authority's LD provider communications.

32 responses were received in total, 25 from health professionals and 7 from care professionals.

8.2 Survey results

87% of respondents had had a patient or service user experience a delay in receiving appropriate health care, investigations or treatment for a physical health need in the last 12 months. The most commonly cited reasons were:

- General waiting list/delays affecting all patients/service users (61%)
- The service user did not recognise the need to seek healthcare advice (43%)
- A health service did not know how to make appropriate reasonable adjustments (39%)

53% of respondents had had an adult patient or service user with a learning disability who experienced a delay in receiving appropriate health care, investigations or treatment for a mental health need. The most commonly cited reasons were:

- General waiting list/delays affecting all patients/service users (71%)
- Transport difficulties (24%)
- A health service knew what reasonable adjustments were necessary, but was not able to make them (24%)

The three areas ranked most highly for work to support access to mainstream healthcare services for adults with an LD were:

- Health checks (53%)
- Routine GP appointments (50%)
- Screening (50%)

Respondents were able to write in free text comments around access to mainstream healthcare services. Common themes were:

- Poor access to dental services – this was highlighted by a very high number of respondents across multiple questions
- Problems in accessing mainstream GP services
- Lack of training around of needs of individuals with an LD in mainstream health services, including how to make reasonable adjustments, assess capacity and make best interest decisions

- Insufficient additional resource within mainstream health services to be able make reasonable adjustments
- Lack of capacity within specialist LD health services to meet demand

Respondents were also able to write in free text comments around gaps in specialist LD health services. For some issues raised, it wasn't clear if the issues were related to Cambridgeshire or Peterborough. Issues raised were:

- Lack of LD physiotherapy;
- Lack of access to dental care;
- Lack of capacity and resilience in many specialist LD services (LD nursing in Peterborough, psychology, access to speech and language therapy for communication needs, access to sensory integration specialists);
- Insufficient crisis beds in Peterborough;
- Insufficient respite beds for individuals with complex health needs;
- Incorrect recording of diagnosis in health records, impacting on service users' ability to access specialist LD services (e.g. because they are recorded as having a learning difficulty, not a learning disability);
- Access to support for challenging behaviour in the community;
- Access to specialist dietician support.

A number of respondents used this question to make further suggestions about improving access to mainstream health services:

- Additional training for primary care around the needs of individuals with an LD;
- Need to improve access to mainstream psychological therapies for individuals with a mild LD.

8.3 Summary

This survey highlights a number of priority areas. Similar to the coproduction work with people with an LD, AHCs and access to routine GP appointments were highlighted as priority issues. AHCs are covered in section 7.8 and reasonable adjustments in section 15.

There were also a range of concerns raised relating to availability and capacity of specialist LD services. These services are considered in section 17.

9. Prevention

9.1 Cardiovascular disease

9.1.1 What is cardiovascular disease?

Cardiovascular disease (CVD) is a term that encompasses a range of conditions that are caused either by atherosclerosis (fatty plaques that build up on the walls of blood vessels) or blood clots (59). This group of diseases includes ischaemic heart disease (which covers heart attacks and angina), stroke and peripheral arterial disease. Cardiovascular disease is the second most common cause of disease in adults with an LD (30).

9.1.2 What are the risk factors?

Risk factors for the development of cardiovascular disease can be divided into modifiable and non-modifiable risk factors (60), as set out in tables 7.1 and 7.2.

Table 9.1: Non modifiable risk factors for cardiovascular disease

Age	Risk increases with increasing age
Sex	Men are at increased risk
Family history	Having a relative who has died at an early age from cardiovascular disease increases risk of developing cardiovascular disease
Ethnicity	Individuals of black and South Asian ethnicity are at greater risk than individuals from a white British background. Individuals of South American or Chinese ethnicity are at lower risk.

Source: (60)

Table 9.2: Modifiable risk factors for cardiovascular disease

Behavioural	Smoking, unhealthy diet, increased alcohol consumption and lack of physical activity increase someone's risk of developing CVD.
Social	Social isolation and lower socioeconomic status increase risk of developing CVD
Comorbidities	Inadequate medical management of a number of comorbidities increases risk of developing CVD, including hypertension, diabetes, high cholesterol, atrial fibrillation and systemic inflammatory disorders such as rheumatoid arthritis.
Overweight/obesity	Being overweight or obese increases risk of developing CVD.

Source: (60)

The pattern of cardiovascular disease risk factors is different in adults with an LD when compared to the general population; for example, adults with an LD have lower levels

of physical activity and higher levels of obesity (PHE, n.d.) (see sections 7.7 and 10.9). Adults with a mild LD are more likely to smoke than the general population (ibid).

9.1.5 What is the prevalence of cardiovascular disease in people with an LD?

Prevalence of cardiovascular disease in adults with an LD compared to the general population is set out in table 7.3 below. The data comes from primary care data.

Table 9.3: prevalence of cardiovascular disease amongst the general population and people with an LD on the LD register in Cambridgeshire and Peterborough

Disease	**Prevalence in general population in C&P** (61)	**Prevalence in people on the LD register in Cambridgeshire and Peterborough (95% CI)** (23)
Ischaemic heart disease	2.8%	1.6% (1.1, 1.9)
Stroke	1.5%	1.7% (1.3, 2)
Heart failure	0.8%	0.4% (0.2, 0.6)

Sources: primary care data, as referenced in the table

This suggests the prevalence of diagnosed stroke is similar in people with an LD, and that the prevalence of diagnosed ischaemic heart disease and heart failure is lower. This data shows some differences to national data on people with an LD, which suggests that heart failure is more common in people with an LD (51).

Prevalence of clinical risk factors is set out in table 7.4 below.

Table 9.4: prevalence of clinical risk factors for cardiovascular disease in the general population and people on the primary care LD register in Cambridgeshire and Peterborough

Clinical risk factor	**Prevalence in general population in C&P** (61)	**Prevalence in people on the LD register in Cambridgeshire and Peterborough (95% CI)** (23)
Hypertension	12.7%	10.3% (9.4, 11.2)
Hypercholesterolaemia	Local data not available	21.6% (20.4, 22.9)
Diabetes	6.3%	9% (8.2, 9.9)
Atrial fibrillation	2%	1.1% (0.8, 1.4)

Sources: primary care data, as referenced in the table

This data fits with patterns in national data when comparing prevalence data in the general population with people with an LD (62). The prevalence of diagnosed diabetes is higher in people with an LD, and the prevalence of diagnosed hypertension and atrial fibrillation is lower.

9.1.6 How is cardiovascular disease prevented?

Prevention of cardiovascular disease requires action across a range of modifiable risk factors, as well as promoting early identification and treatment of clinical risk factors. Recommendations on actions that should be taken around modifiable behaviour risk factors are contained in sections 7.1, 7.4, 7.5 and 7.7.

9.1.7 National strategy for CVD prevention

The national strategy for CVD prevention in England has a number of priorities for the NHS to achieve by 2029 relating to management of modifiable medical risk factors (63):

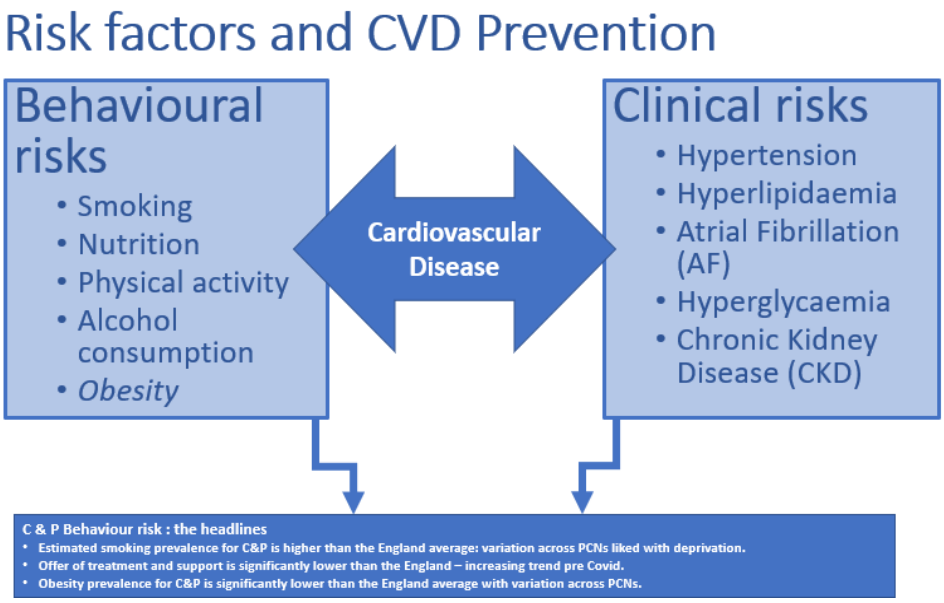
- Atrial fibrillation: 85% of the expected number of people with AF have been diagnosed and if at a high risk of stroke, 90% are anticoagulated;
- High blood pressure: 80% of the expected number of people with high blood pressure are diagnosed and of these, 80% are treated to target blood pressure ranges as per NICE guidance;
- High cholesterol: 75% of people aged 40-74 years have had a CVD risk assessment and cholesterol reading in the last 5 years; if identified as having a 20% or greater risk of developing CVD are treated with statins; 25% of individuals with familial hypercholesterolaemia are treated optimally.

9.1.8 Local strategy for CVD prevention

The local Cambridgeshire and Peterborough ICS have developed a Cardiovascular Prevention Strategic Framework to inform prevention work locally (64).

The local prevention strategy has adopted the national ambitions as well as a number of additional ambitions, linked to the NHS Rightcare CVD prevention in primary care toolkit (65).

Figure 9.1: Cambridgeshire and Peterborough CVD prevention strategy



Source: (64)

Robust identification and medical management of comorbidities that increase risk is a key element of the local CVD prevention strategy. The local strategy prioritises early identification and management of 5 comorbidities (hypertension, atrial fibrillation, diabetes, hyperlipdaemia (which includes hypercholesterolaemia) and chronic kidney disease), particularly through the following priority areas:

- Increased uptake of NHS Health Checks: NHS Health Checks are statutorily commissioned by public health for adults aged 40-74 years who do not already have a diagnosis of certain long term conditions. They offer an opportunity to give advice on behavioural risk factors and also tests for hypertension, hypercholesterolaemia and hyperglycaemia.
- Incentivisation of primary care to diagnose atrial fibrillation, hypertension, diabetes and chronic kidney disease, as well as promotion of opportunistic screening.
- Improved follow-up of actions from NHS Health Checks.
- Improved access to structured diabetes education.

9.1.9 What is the local data on prevention and management?

The table below shows how the management of key clinical risk factors in adults with an LD compares to the general population in Cambridgeshire and Peterborough. Please note, the data for adults with an LD is from a slightly different time period to the data on the general population, however this is the best available current data.

Table 9.5: management of clinical risk factors for cardiovascular disease in the general population and people on the primary care LD register in Cambridgeshire and Peterborough

	Indicator	**General population in C&P** (64)	**People on the LD register in Cambridgeshire and Peterborough* (95% CI)** (23)
Health checks	Proportion of eligible population who have received an NHS Health Check in the last 5 years	28% Cambridgeshire 26% Peterborough (2021/22 Q2)	31%** (28,34)
Atrial Fibrillation	Atrial Fibrillation patients stroke risk assessed	74% (2020/21)	11% (5,24)
Diabetes	% of patients with diabetes who receive all 8 care processes	58% (2019/20)	28% (24,33)
	% of patients with type 2 diabetes who meet all 3 treatment targets	37% (2019/20)	31% (26,36)
	% of patients newly diagnosed with diabetes who are referred to structured education	44% (2020/21)	23%*** (19,28)
Hypertension	% of hypertension patients aged under 80 years where blood pressure is 140/90 or less in last 12 months	50% (2020/21)	79% (74, 82)

*All data is for 2023 except where noted

**There was a very high proportion of individuals classed as ineligible for the NHS Health Check

***This data includes all people with diabetes, regardless of when they were diagnosed

This data shows a mixed picture in the management of risk factors for cardiovascular disease in people with an LD. Management of AF and diabetes are particular areas for improvement. This interpretation should be qualified by the fact that the data from the general population is from different years (as indicated in the table) to the data on the population on the LD register (which is from 2023).

There is specific NHS Rightcare guidance relating to making reasonable adjustments for people with an LD in diabetes care, which contains a range of recommendations,

including increasing uptake of Annual Health Checks and supporting structured education and self management (NHS Rightcare, 2017).

9.1.10 Summary

In summary, cardiovascular disease is a leading cause of death in adults with an LD. Risk factors in this group particularly include obesity, lack of physical activity, diabetes and high smoking prevalence in adults with a mild LD.

There is evidence to show locally that management of diabetes and atrial fibrillation could be improved in adults with an LD.

9.1.11 Recommendations

Primary care

- Further work is needed to understand the high exclusion rate for the NHS Health Check, and to ensure that adults are not inappropriately classed as ineligible for the NHS Health Check.
- Further work is needed to understand the alignment between the Annual Health Check and the NHS Health Check, ensuring that those adults who only receive an Annual Health Check receive appropriate health promotion advice and review on management of long term conditions.
- Further work is needed to understand the very low rates of adults with AF who have been risk assessed for stroke.
- Further work is needed to support adults with diabetes to receive all 8 evidence-based care processes for diabetes. Access to diabetic eye screening is considered in section 7.1.

Self-management and structured education providers and commissioners

- All pathways for prevention and management of cardiovascular disease should ensure that they are making appropriate reasonable adjustments for people with an LD. This includes any commissioned self-management or structured education programmes for people with long-term conditions, which should include carers where appropriate.

Unpaid carers

- Unpaid carers should be supported to access information and education relating to supporting the person they care for with long term clinical risk factors such as diabetes, hypertension, hypercholesterolaemia and atrial fibrillation.

Social care providers and commissioners

- Commissioners of residential and domiciliary social care for adults with an LD should ensure that appropriate training is in place for staff to support adults with

an LD in the management of long term conditions linked to cardiovascular disease where they care for individuals with one of these conditions;

- Providers of residential and domiciliary social care should ensure their staff have appropriate training to support adults with an LD in the management of long term conditions linked to cardiovascular disease where they care for individuals with one of these conditions.

Lifestyle risk factors

- For recommendations relating to smoking, physical activity, alcohol and obesity, see sections 7.4, 7.5, 7.7 and 7.9.

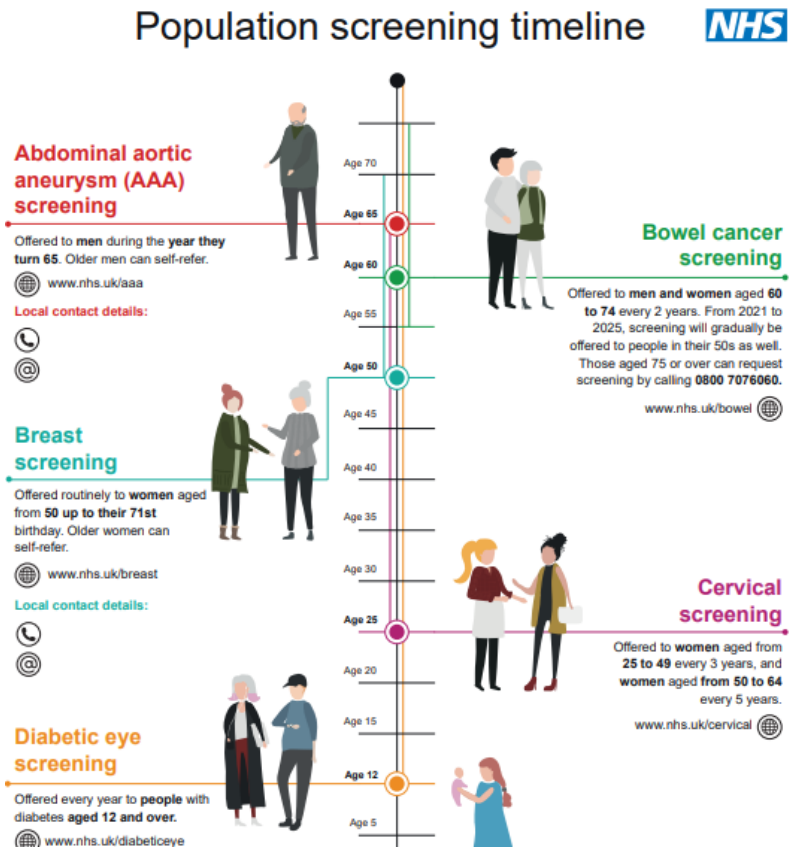
9.2 Screening

9.2.1 What is screening?

Screening programmes look for individuals who do not have symptoms of a disease, but who may be at higher risk of developing it (66). Someone who is identified as being at higher risk will need further follow-up and tests to determine if further treatment is needed (66).

There are a number of national screening programmes, outlined in figure 9.2.

Figure 9.2: population screening programmes for adults in England



Source: (66), reproduced under the terms of the Open Government Licence v3.0

9.2.2 Cancer screening uptake – Cambridgeshire and Peterborough

Local data has been obtained from primary care records to enable comparison in screening uptake between eligible adults on the primary care LD register and the general population. This data should be treated with some caution, as it has not been possible to gain comparator data for the same time periods in the general population; the local primary care data from the LD register defines eligibility by age and sex, and does not take into account those excluded at practice level, for example because participation in screening was not deemed to be in their best interest or because they have chosen not to participate in screening. However, this data does give an indicator of uptake.

Table 9.6: screening uptake for the general population and people on the primary care LD register in Cambridgeshire and Peterborough

	General population	People with an LD on primary care LD register
Breast screening coverage		
	2022	**2023**
Cambridgeshire	63.9%	25% (21,30)
Peterborough	64.2%	
	2022	
England	65.4%	
Bowel screening coverage		
	2021/2	**2023**
Cambridgeshire and Peterborough ICB	72%	51% (47, 56)
	2021/22	
England	70.3%	
Cervical screening coverage - 25-49 year olds		
	Q2 22/23	**2023**
Cambridgeshire and Peterborough ICB	64.9%	30% (27, 34)
	Q2 22/23	
England	67.1%	
Cervical screening coverage - 50-64 year olds		
	Q2 22/23	**2023**
Cambridgeshire and Peterborough ICB	74.8%	26% (22, 31)
	Q2 22/23	
England	75%	

Sources:

All data on the primary care LD register is taken from (23)

Breast screening coverage (local and national data for general population) (67)

Bowel screening coverage (local and national data for general population) (68)

Cervical screening coverage (local and national data for general population) (69)

Despite the caveats in the data comparability, there is a clear signal in the data that uptake of all cancer screening is lower in people with an LD than the general population.

9.2.4 AAA screening and diabetic eye screening

AAA screening and diabetic screening are also important screening pathways, although there is more limited data available on them. AAA screening looks for abdominal aortic aneurysms, which may be reparable surgically. Diabetic eye screening looks for diabetic retinopathy, which can lead to avoidable sight loss.

9.2.5 Barriers and facilitators to screening

A reasonable quality systematic review looked at barriers and facilitators to screening (70). The UK studies included in the review identified that individuals who lack capacity to consent to screening and individuals who are non-verbal are significantly less likely to participate in screening (70). Other identified barriers to screening included fear of the procedure and mobility problems (70). The only identified facilitator in a UK context was the participation of a paid carer (70).

9.2.6 Evidence on improving uptake

An evidence review was undertaken for this needs assessment, to look for evidence of interventions to improve uptake of screening in adults with an LD. No good quality evidence was found to support any particular approach.

9.2.7 Guidance on improving uptake

PHE has produced guidance for screening providers on how to make reasonable adjustments for people with an LD (71).

9.2.8 Local pathways

Discussions were had with local screening providers to understand what pathways were already in place to support people with an LD to access screening. These are summarised in table 7.7.

Table 9.7: screening pathways in Cambridgeshire and Peterborough

AAA screening	• Provider feedback received from CUH • Appointment letters are generated centrally, information is pulled from the NHS Spine, but the primary care LD flag is not part of what is pulled. Therefore, there is no way to know when a letter is sent that a patient may need reasonable adjustments • Service is able to make reasonable adjustments, such as EasyRead information or longer appointment times, if they are aware that they are needed • The screening offer is evergreen, so an eligible individual who has previously not attended can reattend at a later date if they change their mind • Service links in with LD nurses at CUH when required • Service is planning a Health Equity Audit
Breast screening	• Provider feedback was received from both CUH and NWAFT • Both providers are dependent on the GP or the patient making them aware that they have a learning disability and may need reasonable adjustments. The national process for breast screening includes steps to ask GPs to advise of patients with a known LD. • Both providers are able to make reasonable adjustments, such as providing EasyRead information or offering longer appointments, once they are aware that they are needed
Bowel screening	• The first step of the programme is a home testing kit sent to an individual's address. • If the test kit is positive, an individual will be invited for further testing at CUH or NWAFT • Services won't know in advance of screening that an individual needs reasonable adjustments unless they have contacted them in advance • There is currently an extensive ongoing programme of work looking at improving uptake of bowel screening generally and reducing inequalities
Cervical screening	• First two appointment letters are sent out centrally, third letter is sent via GP practice. • Central team is not aware of who may need reasonable adjustments, so reliant on GP to adapt third letter if needed. • Initial appointment held in GP practice, who should be aware of what reasonable adjustments a patient may need • If follow-up for colposcopy is needed, it is unlikely they will know that an individual needs reasonable adjustments in advance as referral will come via lab, who are unlikely to know.

Diabetic eye screening	• Service provider is In Health Intelligence • Appointment letters are pulled from NHS Spine, they do have access to LD flag so know in advance if someone needs reasonable adjustments • They are currently undertaking an extensive Health Equity Audit. This will include reviewing individuals with an LD who have persistently not attended, to understand what barriers they face in attending. It will also include reviewing GP practices that have high exclusion rates, to check that individuals with an LD are not being inappropriately excluded from screening. • They are able to offer a range of reasonable adjustments, including EasyRead information, longer appointments and pre-visits for familiarisation.

Sources: information provided by screening providers

9.2.9 Recommendations

Screening providers and commissioners

- Screening providers and commissioners should be confident that they have a process in place to identify when reasonable adjustments are needed, and to make them. Currently only the diabetic eye screening programme has access to the primary care LD flag. Providers and screening commissioners should work to understand how to support other screening programmes to access the digital LD flag. Once the NHS England reasonable adjustments flag is rolled out (see chapter 15), commissioners and providers should work together to ensure that this information can be accessed by all screening providers.
- Screening providers and commissioners should be confident that they can make appropriate reasonable adjustments where need has been identified.
- Findings from the diabetic eye screening and planned AAA screening Health Equity Audits should be disseminated to other screening programmes, as there is likely to be common learning. Cervical, bowel and breast screening programmes should consider if they would benefit from undertaking a Health Equity Audit.
- Providers and commissioners should be confident that there are clear processes and training for staff in how to apply the Mental Capacity Act with regards to consent for screening.

Primary care

- Take-up of screening should be reviewed at AHCs. If someone has missed a routine screening programme, steps should be taken to understand why and how access might be facilitated if the individual wants to attend or it is in their best interests where they lack capacity to make the decision for themselves. This may involve support from LD nurses.

- GP practices should ensure they are following the Mental Capacity Act when making decisions to exclude people with an LD from screening.

Health promotion

- People with an LD should be actively targeted in health promotion campaigns to increase screening uptake, including with accessible information.

Unpaid carers

- Unpaid carers of people with an LD should be included in health promotion campaigns to increase screening uptake.

Social care providers

- Care providers should ensure that their staff have an awareness of screening programmes that they may need to support their clients to attend.

Social care commissioners

- Commissioners of social care should ensure there is sufficient flexibility and funding within service provision to enable paid carers to accompany individuals to a screening appointment where there is an identified need.

Care planning

- If individuals have a need for a paid carer to accompany them to a screening appointment, this should be included within their care plan.

9.3 Immunisations

9.3.1 Background

Immunisations protect against a range of infectious diseases. They provide a protective effect through triggering an immune response from the body without an individual becoming infected (72).

9.3.2 Immunisation schedule

Adults with a learning disability are eligible for the same routine immunisations as the general population. The current routine immunisation schedule for adults is set out in figure 7.3.

Figure 9.3: routine immunisation schedule for adults in England

65 years old	Pneumococcal (23 serotypes)	Pneumococcal Polysaccharide Vaccine (PPV)
65 years of age and older	Influenza (each year from Sept)	Inactivated influenza vaccine
70 to 79 years of age	Shingles	Shingles

Source: (73)

In addition to routine immunisations, people with learning disabilities are eligible for the following immunisations based on clinical risk:

- Seasonal influenza: the Green Book states that individuals with Down's Syndrome or a severe or profound and multiple learning disability should receive the annual seasonal vaccine (74). In addition, individuals living in long stay residential accommodation, such as a care home or supported living setting, are recommended to have it. The NHS offers flu vaccination to all individuals with an LD (75).
- Covid: the Green Book states that individuals aged 5 years and above with Down's Syndrome, profound and multiple learning disabilities (PMLD), severe learning disabilities or those who are on the learning disability register are eligible due to clinical risk (76).
- Hepatitis B: the Green Book states that individuals with a learning disability who live in residential accommodation should be vaccinated against hepatitis B ((77). Individuals attending day services or schools where there is a risk of exposure from biting should also be risk assessed for vaccination (77).

Unpaid carers and frontline health and social care workers are also eligible for free flu and covid vaccinations (75,78).

9.3.3 Uptake

Table 9.8 shows uptake of routine immunisations amongst those on the LD register in Cambridgeshire and Peterborough. Where available, data on uptake amongst the general population has been shown, although there have been challenges in getting comparable figures.

Table 9.8: uptake of routine immunisations amongst general population and people on the primary care LD register in Cambridgeshire and Peterborough

	People on the LD register, 2023 (95% CI) (Cambridgeshire and Peterborough)	**General population**
Flu	56% (57, 60) [Age 14 years and above]	48.3% (2022/23), C&P ICB [At risk groups (under 65 years)]
Covid-19	67% (65, 68) [Covid vaccine in last 12 months, age 14 years and above]	No directly comparable coverage data available
Pneumococcal	35% (30,40)	70.6% (2020/21), England
Shingles	50% (42, 57) [Age 70-80 years]	62% (2021/22), England

Sources:

Uptake amongst people on the LD register: primary care data from (23)
General population - Flu: (79)
General population - Pneumococcal: (80)

General population – shingles: (81)
There are difficulties in comparing this data with the general population for a number of reasons. Firstly, there are difficulties in getting comparable local or national data for the general population for some immunisations. Secondly, some data is from different years. Thirdly, coverage data for shingles is difficult to interpret due to changes in eligibility.

However, despite the cautions needed for comparison, uptake of all adult vaccines is far from optimal amongst people on the LD register in Cambridgeshire and Peterborough.

9.3.4 Facilitators and barriers to immunisation uptake

A literature search undertaken for this needs assessment was unable to identify any research literature systematically considering facilitators and barriers to immunisation uptake in adults with an LD.

PHE undertook a Health Equity Audit of vaccine uptake in England; this audit also identified evidence gaps relating to immunisation of people with an LD (National Immunisation Programme: Health Equity Audit, 2021).

9.3.5 Evidence for interventions to improve uptake

As part of this needs assessment, a literature review was undertaken to look at evidence for effective interventions to increase uptake of routine immunisations amongst people with a learning disability.

The review identified two good quality systematic reviews, which provided good quality evidence for the effectiveness of health checks in increasing the uptake of routine immunisations in this cohort (83,84). No other interventions were identified.

9.3.6 Local pathways

Learning disability nurses in both Cambridgeshire and Peterborough are able to support with desensitisation work for people with a learning disability.

9.3.7 Recommendations

Primary care

- The best-evidenced intervention to increase immunisation uptake is the annual health check. Work to optimise uptake of AHCs should continue (see section 9.8).
- GP practices should ensure they are able to make reasonable adjustments for vaccination where these are indicated. These may include EasyRead information, longer appointments, desensitisation or home visits. They should make use of support from LD nurses can be obtained if required.

Unpaid carers

- Unpaid carers of people with an LD should be supported to access flu and covid vaccinations.

Health and social care providers

- Frontline health and social care workers should be supported to access flu and covid vaccinations.

Social care providers

- Care providers should ensure that their staff have an awareness of routine immunisations that they may need to support their clients to attend.

Social care commissioners

- Commissioners of social care should ensure there is sufficient flexibility and funding within service provision to enable paid carers to accompany individuals to a immunisation appointment where there is an identified need.

Care planning

- If individuals have a need for a paid carer to accompany them to an immunisation appointment, this should be included within their care plan.

9.4 Substance misuse

9.4.1 Background

Alcohol misuse is associated with many harmful effects, including increased risk of cardiovascular disease, unintentional injury, liver disease, pancreatic disease and mental ill health (85).

Misuse of illegal substances can also lead to health consequences, including mental ill health, transmission of blood borne viruses, lung disease and cardiovascular disease (86).

For people with a learning disability, research shows a range of other health impacts associated with substance misuse, including greater risk of seizures, interactions with medications, increased risk of offending behaviour, increased vulnerability to exploitation as well as deterioration in physical and mental health, and changes in behaviour, that are seen in the general population who misuse substances (87)

Risk factors for substance misuse in people with learning disabilities include having a borderline or mild learning disability, being young and male, having a comorbid mental health problem, living independently, boredom, low self-esteem and impulsivity (88).

9.4.2 Prevalence

It is very difficult to get data on misuse of alcohol and illegal substances by people with learning disabilities. Research suggests that generally, the rate of misuse is lower in people with learning disabilities, and extremely low in people with severe or profound and multiple learning disabilities (87,88), although there is some evidence to suggest that alcohol misuse may be higher in individuals with mild or borderline LD (89).

Snapshot data from the local substance misuse services in March 2023 suggests:

- 42 individuals (2.18%) of service users report having a learning disability in Cambridgeshire;
- 25 individuals (1.31%) of service users report having a learning disability in Peterborough.

9.4.3 Evidence of what treating substance misuse in adults with an LD

There is very limited research evidence around approaches to treating substance misuse in people with an LD (90).

9.4.4 Local services

There are no specific local services or pathways for people with a learning disability and a substance misuse problem. Instead, people with an LD access mainstream substance misuse services, which are currently provided by CGL in Cambridgeshire and Peterborough.

As part of this needs assessment, CGL shared information about their processes for making reasonable adjustments based around the areas in NHS England's Quality Checkers community self-assessment questionnaire (91).

This information is summarised in table 9.9.

Table 9.9: CGL drugs and alcohol service – reasonable adjustments

Standard 1. I am involved in my care at all times.	• Service users are asked at their initial appointment about whether they have a learning disability. • If a service user identifies that they do have a learning disability, they will be asked about preferred methods of communication and any other reasonable adjustments that they might need. • CGL can't access SystmOne, so are unlikely to know in advance if a patient has an LD unless in referral letter. • Initial appointment also involves consideration of mental capacity, and whether an individual is likely to be able to consent to treatment.

	• Service has a user participation group, although not clear if this is well attended by people with an LD. • Unable to separate out feedback from individuals with an LD.
Standard 2. My care, treatment and support is planned to meet my needs.	• Patients are asked if they would like information about their care and treatment plan shared with carers. • Service buildings are all physically accessible for people with wheelchairs or mobility issues. • The service offers physical health checks. • There is a gap in inpatient detox services for patients with an LD, with many providers unable to meet the needs of this cohort.
Standard 3. I get good care and feel safe	• Service has had additional funding over the last 18 months which has allowed them to increase their staffing and is allowing them to offer more flexible appointments, including 1-1s rather than group support. • Service is used to working with service users who display challenging behaviour for a variety of reasons. Staff receive training around managing challenging behaviour and de-escalation techniques. • Best interest meetings are held where appropriate.
Standard 4. I get good care from a service that has trained staff that know how to do their job well and are always looking to improve.	• All staff receive training around mental capacity. • Staff access training around safeguarding via the C&P Safeguarding Board • Staff will be undertaking training in line with the Oliver McGowan mandatory training, as the service is CQC-registered. • The service links in with specialist learning disability services as appropriate.

Source: information provided by CGL

9.4.5 Recommendations

Provider of specialist alcohol and drugs services

- CGL should continue to ensure that they are complying with national legislation around training for staff relating to learning disability.
- CGL should consider monitoring treatment outcomes for patients with an LD, to see how they compare to their broader population of service users. If service users with an LD have poorer treatment outcomes, further work will be needed to understand why.
- As CGL are not an NHS provider, it is not clear whether they will be able to access NHS reasonable adjustment flags when this programme goes live (see

section 15). Commissioners should explore whether the current process of relying on patient self-report at the initial appointment is sufficient, and whether there is value in supporting CGL to have access to SystmOne.
- CGL should continue to develop links with specialist LD services to ensure that they can access specialist guidance where needed around the needs of service users with an LD.

Commissioners of specialist alcohol and drugs services

- Commissioners should understand what options there are for patients with an LD who need inpatient detox, and how this can be supported where it is indicated.

Primary care

- Primary care providers should ask about alcohol and drug misuse as part of the AHC, and offer referral into substance misuse services where appropriate.

Specialist LD services

- Specialist LD services should screen for substance misuse at initial referral, and offer referral into substance misuse services where appropriate.

9.5 Smoking cessation

9.5.1 Background

Smoking is a major risk factor for many preventable diseases, including cancers, cardiovascular disease and COPD (92). Smoking is the biggest cause of avoidable deaths in England (93).

9.5.2 Prevalence of smoking

National data on prevalence of smoking in people with an LD is very difficult to obtain. Research evidence suggests that prevalence of smoking is lower amongst individuals with moderate, severe or profound learning disabilities than the general population, and higher amongst individuals with a mild learning disability (both young people and adults) (88).

Local primary care data suggests that 17% (95% CI 16, 19) of people on the LD register in Cambridgeshire and Peterborough are smokers currently (23). This compares to a smoking rate of 13% in the general population in Cambridgeshire, and 14.4% in Peterborough, as measured through the Annual Population Survey (94). Due to the reliance on GP coding for primary care data, it is likely that the primary care data underestimates smoking prevalence in people with an LD.

9.5.3 Evidence on supporting smoking cessation in adults with an LD

There is very little research evidence to recommend any specific approaches to smoking cessation in adults with an LD (95).

9.5.4 Local services

There are no specific services for people with a learning disability who wish to stop smoking. The mainstream services are provided through GP practices and by Healthy You for Cambridgeshire and Peterborough, and offer evidence-based support to quit.

The Healthy You service is open access, and accepts self-referral or referral from healthcare professionals. They offer a 12-week programme of support, which could be face-to-face, virtual or by phone, depending on service user preference. There is a standardised process of appointments to support someone to set a quit date and then support after quitting. In practice there is some practitioner discretion in length and number of appointments. Individuals can access the service repeatedly if they aren't successful in quitting.

9.5.5 Recommendations

Smoking cessation services

- Commissioners and providers should ensure that smoking cessation practitioners have training appropriate to their role around making reasonable adjustments for adults with an LD.
- Services should ensure that they have appropriate EasyRead materials.
- Commissioners and providers should ensure that flexibilities around making reasonable adjustments to length and number of appointments are clear to practitioners.

Primary care

- Smoking status should be asked as part of the AHC, and support to quit offered as appropriate.

Specialist LD services

- Specialist LD health services should ask service users their smoking status on initial screening and offer support individuals to access smoking cessation services as appropriate.

Social care providers

- Providers of residential care for adults with an LD should ensure their staff are familiar with how to access smoking cessation services, and can support their service users to access them as appropriate.

Unpaid carers

- Given the mortality due to pneumonia in adults with an LD (see section 6), unpaid carers of adults with an LD should be offered support to quit, to reduce exposure to second-hand smoke.

9.6 Sexual health

9.6.1 Background

People with an LD have the same rights to private and family life as those without disabilities (96). These rights are contained in the Human Rights Act 2008; the Care Act 2014 also lists domestic, family and personal relationships as eligible needs.

Evidence suggests that most adults with a mild or moderate LD are sexually active by the age of 20 years (97). However, many adults with an LD face barriers to pursuing healthy relationships and having their sexual health needs met (98). Evidence suggests that significantly fewer adults with an LD are in long term relationships compared to the general population, the number of adults with an LD who are married has declined very significantly in the past decades (96).

Research evidence highlights a number of challenges that can be faced by adults with an LD:

- Lack of formal and informal sex and relationship education: sex and relationship education is not always provided consistently to people with an LD (99). In addition, evidence suggests that adults with an LD often have smaller social networks than people without disabilities, meaning that they have less opportunity for informal discussion and learning about sex and relationships (97).
- Concerns from paid care staff: evidence suggests care staff can be supportive of adults with an LD entering into a relationship, but are often worried about what might happen if something goes wrong in a relationship, and are not confident in their ability to support positive risk-taking by individuals with capacity to make their own decisions about relationships (100)Individuals with an LD can feel restricted by their caregivers (96).
- Concerns from family caregivers: there is mixed evidence from the literature around family caregivers' role in supporting relationships. Although there are often concerns expressed in qualitative work with paid care providers that family members are overly restrictive, there is also evidence that suggests that family members are positive about relationships (101,102).
- Accessibility of sexual health services: there is very limited evidence available around issues with accessing mainstream sexual health services for people with an LD (103). However, given the barriers faced by people with an LD in accessing mainstream healthcare services more generally, it is likely that many

adults with an LD may struggle to access appropriate information and advice from mainstream sexual health services without appropriate reasonable adjustments being made.

9.6.2 Sexual health needs of adults with an LD

Sex and relationship education

There is clear evidence that adults with a learning disability need access to appropriate information about sex and relationships, as well as ongoing opportunities to access sex and relationship education (104).

Contraception

There is limited data on contraceptive need and use amongst women with an LD (105). There is a suggestion that women with an LD may be more likely to be prescribed depot (injectable) contraception than women without an LD, which can increase risk of osteoporosis (106).

There is also evidence to suggest that significantly higher number of women with an LD are prescribed contraception to manage menstrual bleeding than the general population, particularly women with severe or profound learning disabilities (106). This raises questions about the decision making process around prescribing or fitting contraception, and whether best interests processes are always followed (104).

STI testing

There is limited data on rates of STIs amongst adults with an LD. However, any adult who is sexually active will need access to sexual health services for STI screening and testing.

9.6.3 Local data

There is no local data available around sexual health needs of adults with an LD.

9.6.4 Local services

There are no specific sexual health services for people with an LD in Cambridgeshire and Peterborough. Contraception and sexual health services for the whole population can be accessed via a number of routes in Cambridgeshire and Peterborough:

- Primary care: contraceptive services in primary care are commissioned by Cambridgeshire and Peterborough ICB (long-acting reversible contraception used for menorrhagia or other medical reasons is commissioned by Cambridgeshire and Peterborough ICB).
- iCASH: this is the integrated contraception and sexual health service that is provided by Cambridgeshire Community Services (CCS) across Cambridgeshire and Peterborough. This service is commissioned by CCC and

PCC public health. Individuals can access contraception as well as STI and HIV testing.

- Terence Higgins Trust (THT): THT are commissioned by CCC and PCC public health to undertake sexual health promotion and outreach work in Cambridgeshire and Peterborough.

9.6.5 Recommendations

Sexual health services commissioners and providers

- Commissioned sexual health promotion work should include adults with an LD as routine.
- Sexual health services should ensure that they are able to make appropriate reasonable adjustments for adults with an LD.
- CQC-registered services should ensure they are compliant with legislation around staff training relating to the needs of adults with an LD.
- Commissioned clinical sexual health services should consider how they will incorporate the NHS reasonable adjustments flag into their services once this national programme is live.
- There is an upcoming sexual health needs assessment about to be undertaken to inform services in Cambridgeshire and Peterborough. The needs of adults with an LD should be considered in detail as part of this, particularly with regards to ensuring that commissioned services are able to make reasonable adjustments, and that sexual health outreach and promotion work actively includes adults with an LD.

Sex and relationship education

- Specialist LD services and commissioned sexual health services should consider how they can collaborate to ensure that there is a route for adults with an LD to access appropriate sex and relationship education.

Social care providers and commissioners

- All care staff in residential services should undertake training about sexual health and relationships, as well as around capacity and consent, that is appropriate to their role.
- Care provider policies around relationships for individuals in residential care should be reviewed as part of the routine contract monitoring process.

Care planning

- Care plans should include supporting an individual’s needs around domestic, family and personal relationships.

Day services commissioners

- There is a need to ensure that adults with an LD have opportunities to socialise and develop social networks, including both friendships and personal relationships. This should be recognised as an outcome of day services.

Primary care

- Annual health checks should cover need for contraception, STI screening and cervical screening.

9.7 Physical activity

9.7.1 Background

Regular physical activity is important for maintaining physical fitness, cardiovascular health, healthy weight and mental wellbeing. Increased inactivity is associated with a wide range of adverse outcomes, including increased levels of obesity, poorer mental wellbeing, increased risk of falls and increased risk of long term conditions such as arthritis, cardiovascular disease and diabetes (107).

Figure 9.4: health benefits of exercise

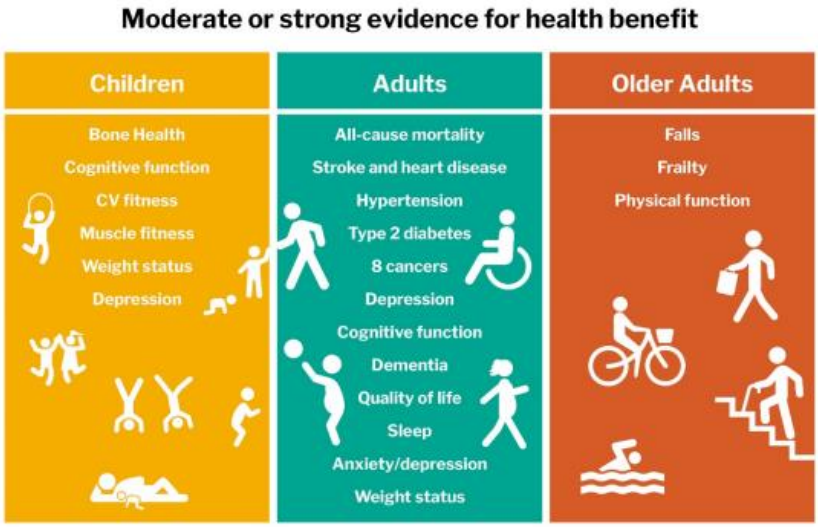


Figure 1: Cumulative health benefits of physical activity across ages. Adapted from (1)

Source: (107), adapted from (108), reproduced under the terms of the Open Government Licence v3.0

People with disabilities have been identified as a priority cohort in the national Sport England 10-year strategy for increasing physical activity (109).

9.7.2 Recommended levels of physical activity for people with a learning disability

There are national recommendations for physical activity for people with disabilities; these recommendations cover all types of disability - there are no specific recommendations for different subtypes of disability.

The national recommendations for physical activity levels for adults with a disability are set out in table 9.10 (107).

Table 9.10: recommendations for physical activity for adults with a disability

Cohort	Recommendation
Adults aged 19 years+	• 2.5 hours of moderate intensity activity or 1.25 hours of vigorous intensity activity per week • Strength work twice a week • Adults should try and be active every day, and break up long periods of sedentary activity.

Source: (107)

9.7.3 Safety of physical activity for people with disabilities

The national guidance for adults is based on an evidence review which found “no evidence exists that suggests appropriate physical activity is a risk for disabled adults and analogous health benefits for disabled adults of engaging in physical activity as for the rest of the adult population” (107). Furthermore, the guidance states “there is little evidence to suggest that physical activity is unsafe for anyone when performed at an intensity and in a manner appropriate to an individual’s current activity level, health status and physical function… Starting at low durations and intensities and building up over time as the body adjusts is the safest way to progress from inactivity to meeting the guidelines.” (107).

9.7.4 Data on participation in physical activity by people with a learning disability

Data on physical activity participation by people with a learning disability is sparse; however, the data that is available consistently indicates that adults and young people with a learning disability have very substantially lower levels of physical activity than people without a learning disability (110).

There is more data available on activity for people with a disability, covering all types of disability and not solely learning disabilities. A key source of reliable information is the national Active Lives survey, which is undertaken on an annual basis (111). It gives

detailed information on levels of activity amongst the general population aged 16 years and above. It is not possible to get data on activity levels specifically for people with a learning disability; however, the survey does allow analysis of trends in activity for people who have a disability compared to people who do not have a disability.

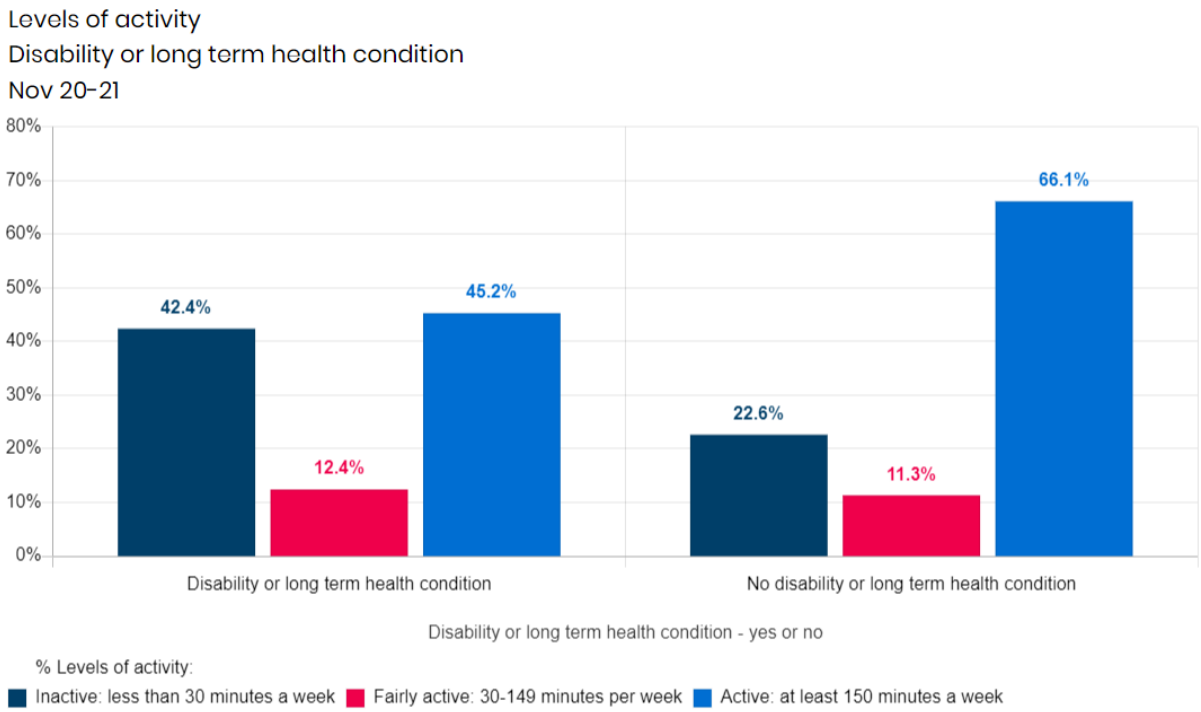
The survey shows that people with a disability are more likely to want to increase their physical activity levels than people who do not have a disability (110).

The survey also gives data on levels of activity amongst adults and children with a disability at local and national level.

9.7.5 Levels of physical activity amongst adults with a disability in Cambridgeshire and Peterborough

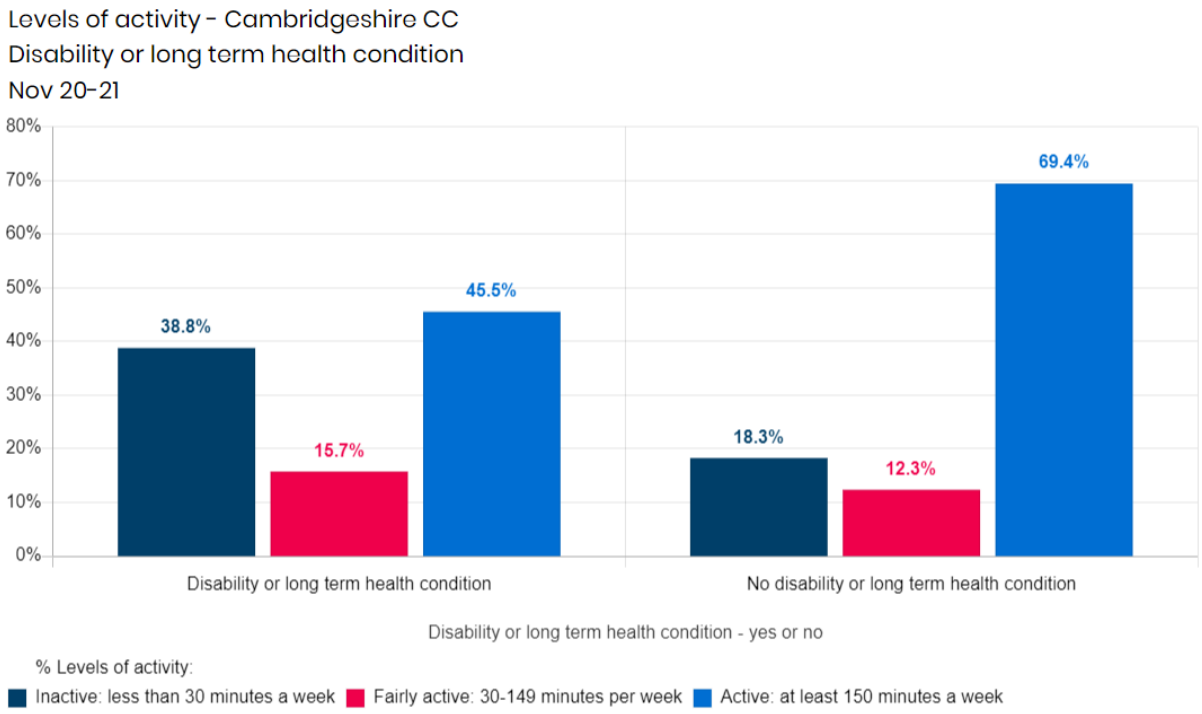
The figures below show the percentage of people with a disability or long term condition in Engand (figure 9.5), Cambridgeshire (figure 9.6) and Peterborough (figure 9.7) who are active, fairly active or inactive on a weekly basis (112).

Figure 9.5: levels of physical activity in the general adult population in England



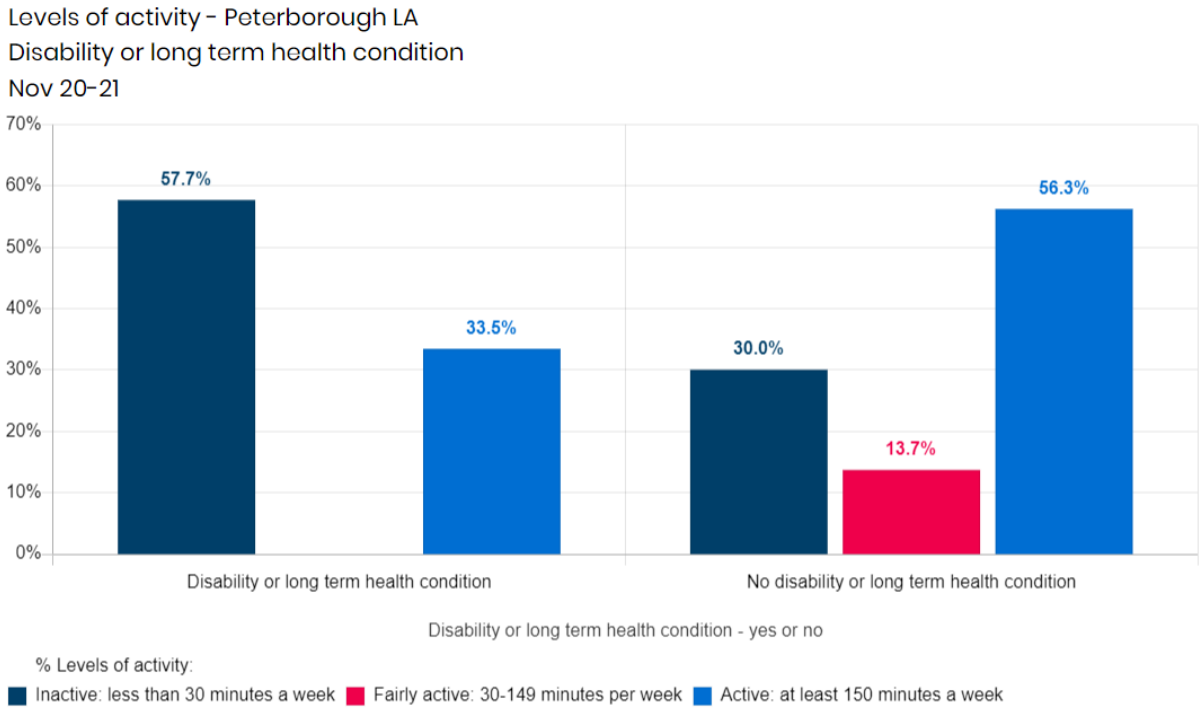
Source:(112), reproduced with permission from Sport England

Figure 9.6: levels of physical activity in the general population in Cambridgeshire



Source: (112), reproduced with permission from Sport England

Figure 9.7: physical activity levels in adults in Peterborough



Source: (112), reproduced with permission from Sport England

This data shows that people with a disability or long term health condition are much more likely to be inactive compared to the general population in England,

Cambridgeshire and Peterborough. Less than half of people with a disability or long term health condition in Cambridgeshire and Peterborough meet the national guidance for physical activity levels. Over half of people with a disability or long term health condition were inactive in Peterborough, a greater proportion than in England as a whole.

9.7.6 What are the facilitators of / barriers to physical activity in people with a learning disability?

A number of systematic reviews have examined research evidence relating to facilitators and barriers to physical activity in people with a learning disability (113–115). Most of the evidence comes from qualitative studies.

- Bodde and Seo (118) found that across the studies in their review, the most commonly cited barriers were transport, cost, carers' fears about health risks of physical activity and lack of support from carers.
- Dairo et al (113) undertook a statistical analysis of factors associated with reduced levels of physical activity amongst adults in the studies included in their review. Increasing age, residence in a care facility such as a care home and increased severity of learning disability were all associated with lower levels of physical activity.
- Bossink et al (114) found that across the studies in their review, the most commonly cited barriers to physical activity were related to health concerns, individual motivation and choice, cost, transport and staffing levels. The most commonly cited facilitators were perception of activities as enjoyable, opportunities for social interaction and being rewarded. These studies predominately covered individuals with mild or moderate LD, few studies looked at people with severe or profound LD.

9.7.7 What works to increase physical activity in people with a learning disability?

An evidence review was undertaken for the purposes of this needs assessment, to look at the evidence for particular programmes in increasing physical activity in adults and/or children with a learning disability. Methods and results are available on request.

This review did not identify any strong evidence for any particular programme or approach to support increasing physical activity in people with a learning disability. In part, this reflects a limited amount of research in this area.

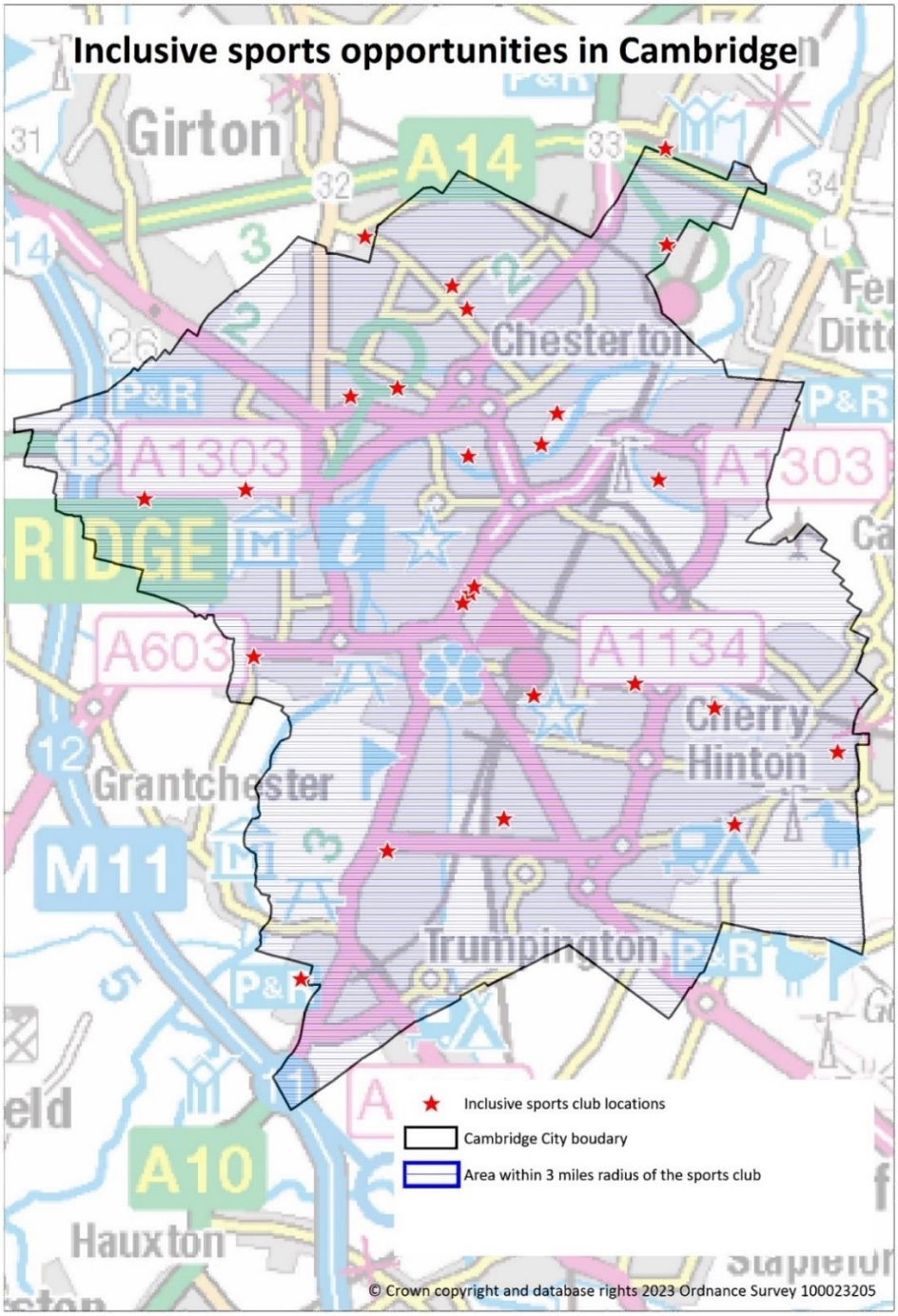
Therefore, there is no single template for increasing physical activity levels amongst people with a learning disability in Cambridgeshire and Peterborough.

9.7.8 Local offers

There is a wide range of sport and activity provision that is specifically designed to be inclusive of people with disabilities in Cambridgeshire and Peterborough.

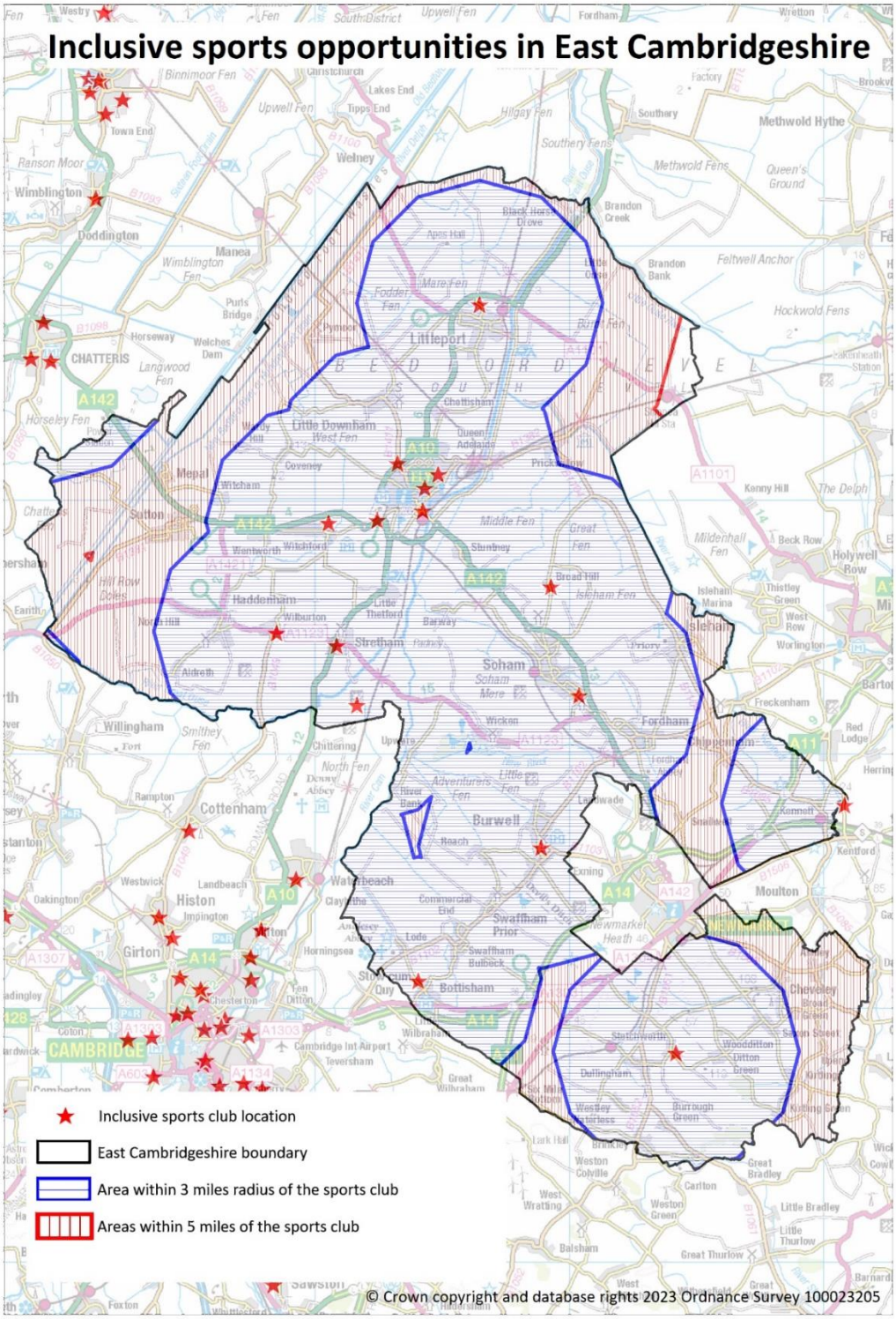
Figures 9.8-9.13 show this provision.

Figure 9.8: inclusive sports in Cambridge



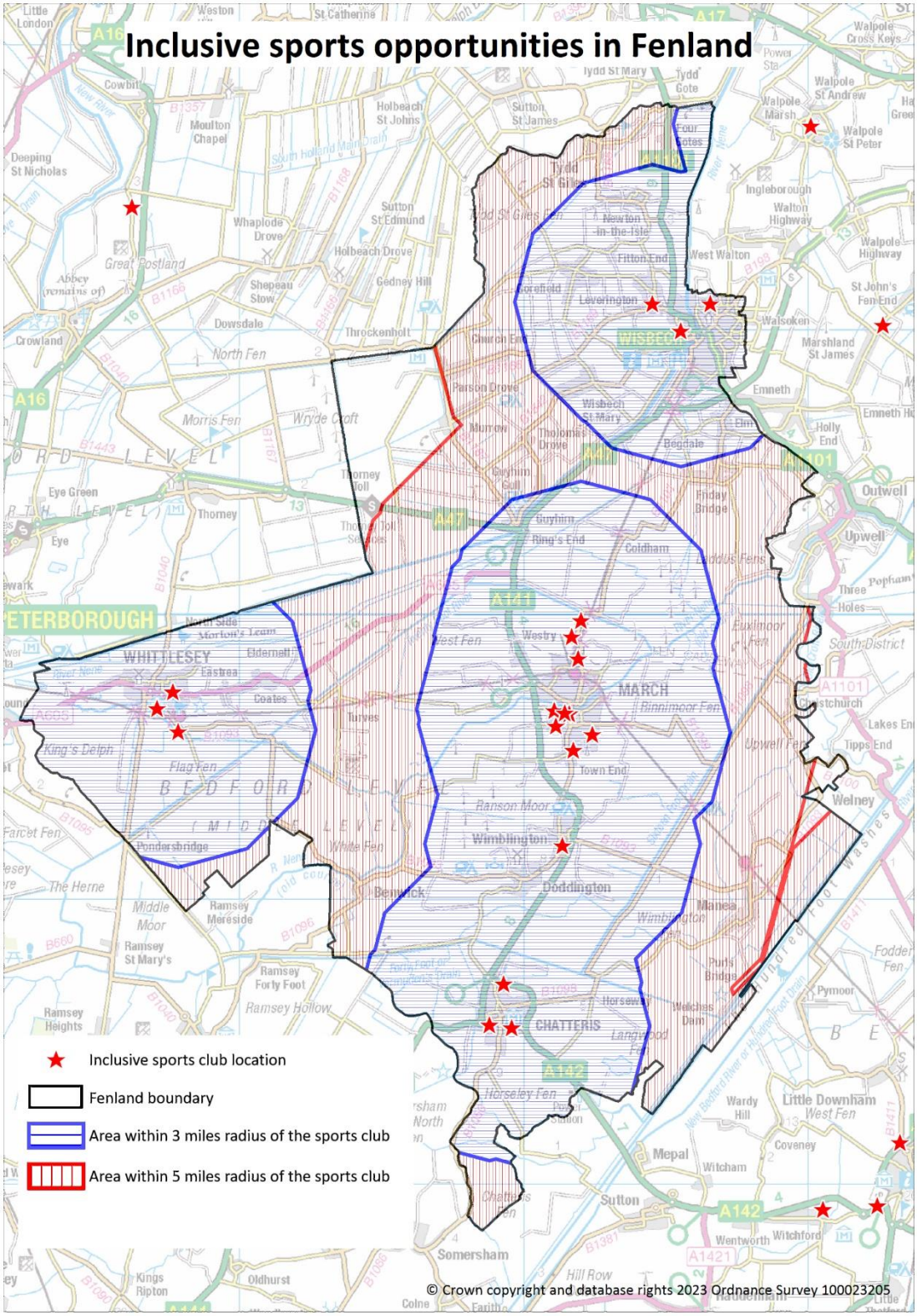
Source: Living Sport Inclusive Activity Map (117)

Figure 9.9: inclusive sports in East Cambridgeshire



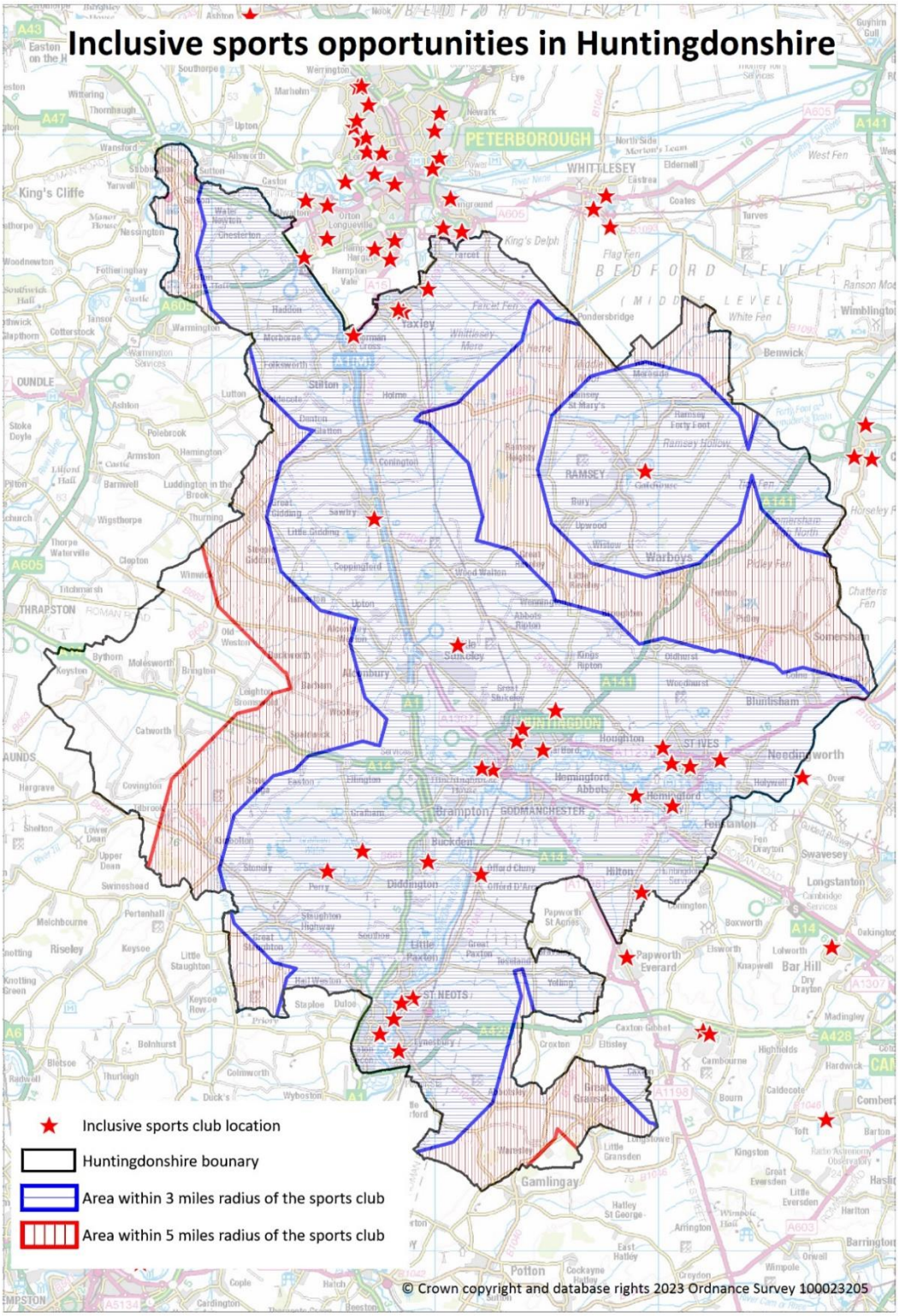
Source: Living Sport Inclusive Activity Map (117)

Figure 9.10: inclusive sports opportunities in Fenland



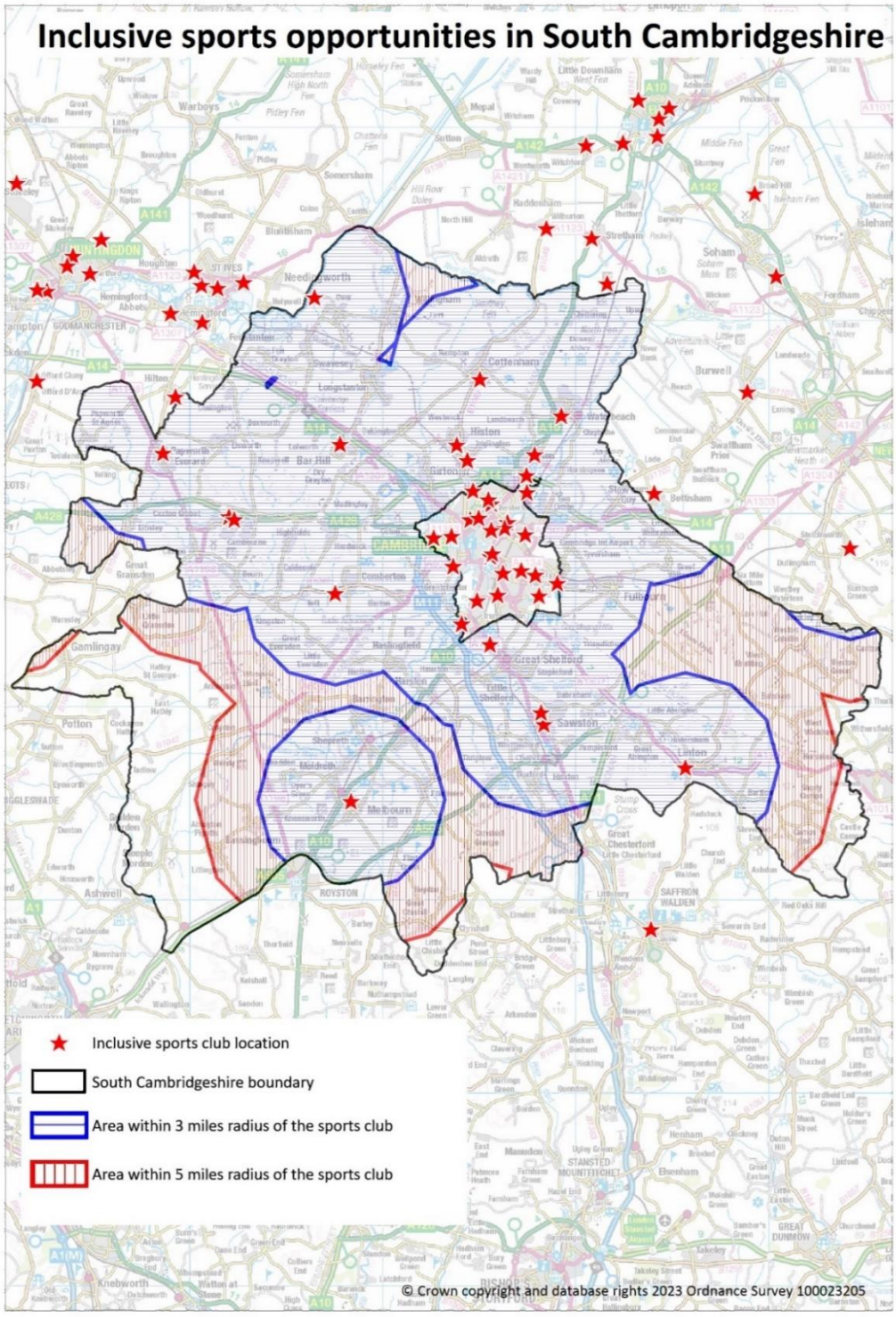
Source: Living Sport Inclusive Activity Map (117)

Figure 9.11: inclusive sports opportunities in Huntingdonshire



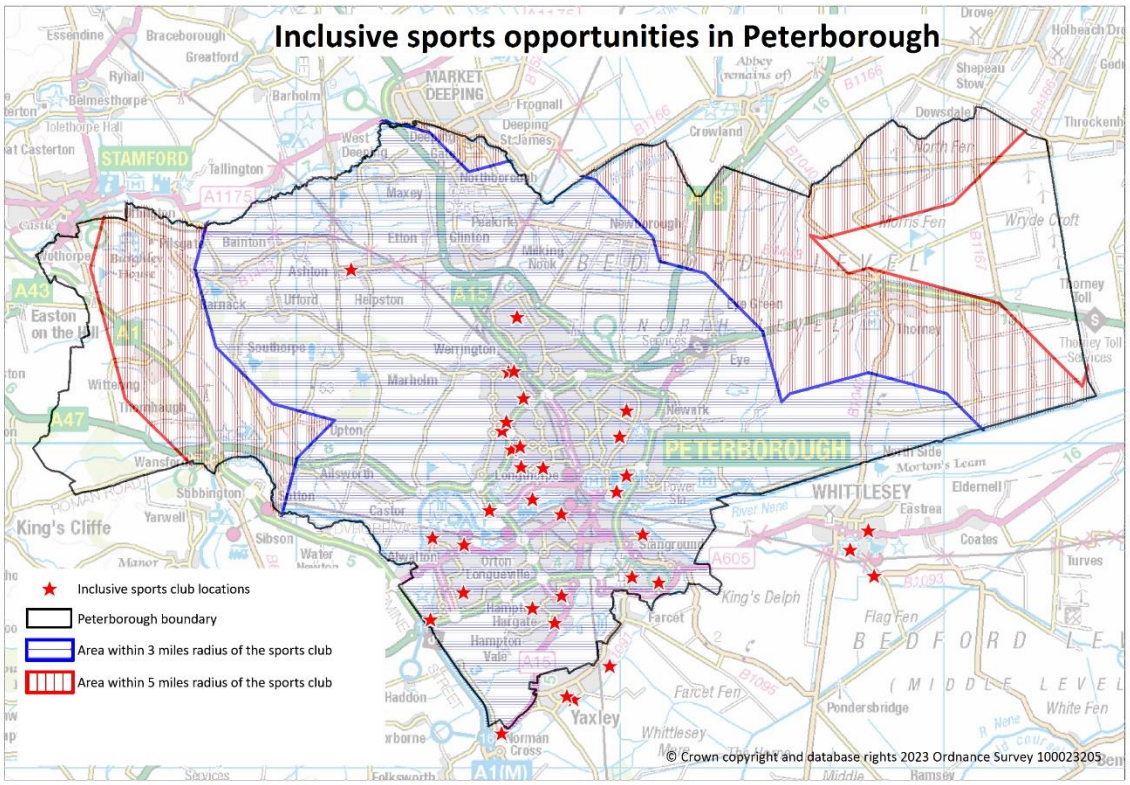
Source: Living Sport Inclusive Activity Map (117)

Figure 9.12: inclusive sports in South Cambridgeshire



Source: Living Sport Inclusive Activity Map (117)

Figure 9.13: inclusive sports in Peterborough



Source: Living Sport Inclusive Activity Map (117)

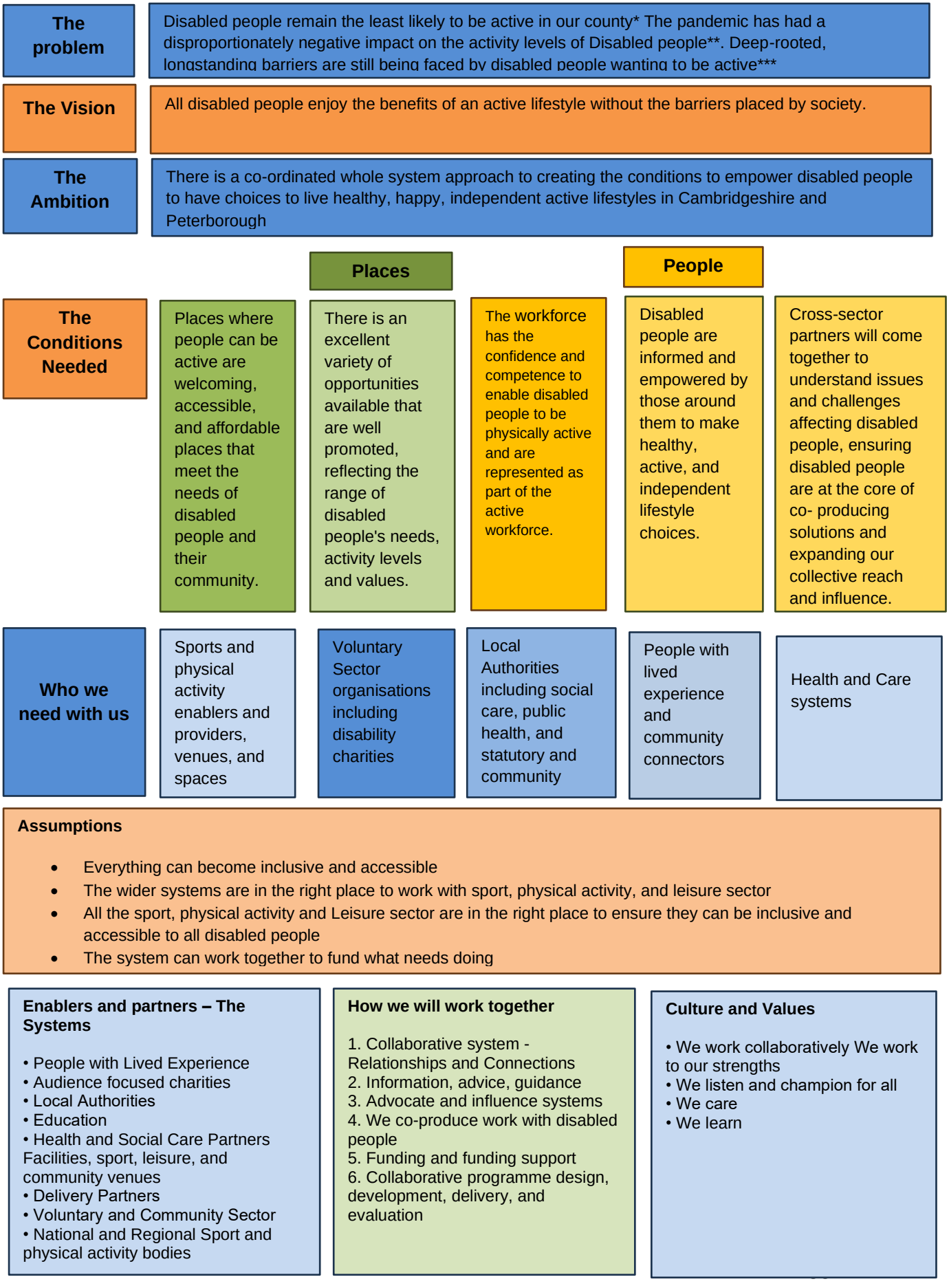
In addition, many people with a learning disability should be able to access mainstream provision with appropriate reasonable adjustments.

9.7.9 Local strategy

Living Sport (a local VCS organisation in Cambridgeshire and Peterborough) is currently leading the development of a Disability Active Lifestyle Framework, to underpin a strategic approach to increasing levels of physical activity amongst people with disabilities in Cambridgeshire and Peterborough (118).

The theory of change is set out below (118).

Figure 9.14: Disability Active Lifestyle Framework – Theory of Change



Source: Living Sport (118)

The domains support the development of accessible places, a skilled workforce and investment in the confidence and skills of people with a disability around physical activity.

9.7.10 Recommendations

Health promotion

- Develop a regular health promotion education offer incorporating physical activity for people with a learning disability and their carers.

Specialist LD services

- Ensure staff in specialist LD services have knowledge of physical activity recommendations and local opportunities.

Social care providers and commissioners

- Consider embedding requirements around supporting service users to access physical activity into care home, supported living and domiciliary care service specifications.
- Consider embedding requirements to offer physical activity to service users attending day opportunities.

Care planning

- If support is necessary to support an individual with care needs to access physical activity, this should be included within their care plans.
- Support social workers, alternatively qualified practitioners and commissioned social care provider staff to undertake training around physical activity, to cover how to embed into care plans (including different components of physical activity), behaviour change and motivational approaches, and supporting service users to access opportunities.

Physical activity providers

- Consider how additional opportunities can be supported in geographical areas where currently there is a limited offer targeted at people with disabilities.
- Work with public health commissioned health trainer and physical activity provision to ensure appropriate pathways are in place.
- Ensure staff within public health-commissioned healthy lifestyles service receive regular training around reasonable adjustments.
- Ensure exercise professionals have appropriate level of training (skills and knowledge) to adapt and tailor delivery of activity for successful inclusion.

Information and guidance

- Include signposting to inclusive sports offer within the local authority's Directory of Services.
- Ensure social prescribers and community navigators are aware of the inclusive sports / exercise / physical activity / active travel opportunities.

Primary care

- Ensure physical activity is included with annual health check discussion.
- Support healthcare staff to undertake brief intervention training around physical activity through the Active Providers charter.

9.8 Annual health checks

9.8.1 What is an annual health check?

The NHS commissions GP practices to undertake annual health checks (AHCs) for individuals aged 14 years and older who are on the practices' registers of patients with an LD. Locally, this means Cambridgeshire and Peterborough ICB commission GP practices through a Direct Enhanced Service (DES) contract.

Undertaking an AHC offers an opportunity to review a patient's overall health and management of long term conditions, as well as develop the relationship between the patient and their GP(119). It also offers an opportunity to explore any unmet health needs.

The NHS Long Term plan sets a target of 75% of patients on the LD register receiving an LD health check (120).

9.8.2 What are GP practices required to deliver?

GP practices are required to undertake a number of activities as part of the C&P DES (121):

- "Ensure that they have an up-to-date register of individuals eligible for AHCs;
- Invite eligible patients annually for an AHC;
- Undertake an AHC, covering the following areas as a minimum:
    i. The provision of relevant health promotion advice, this should include but is not limited to, smoking, cholesterol, alcohol, and substance misuse.
    ii. The use of screening programmes including cervical, breast, diabetic eye, bowel and abdominal aortic aneurysm screening.
    iii. Immunisation status, childhood/school, HPV, flu and pneumococcal.
    iv. Chronic illness and systems enquiry
    v. Physical examination, including any appropriate diagnostic tools.
    vi. A consideration of epilepsy.

vii. A consideration of the patient's behaviour and mental health.
viii. Specific syndrome check.
ix. A check on the accuracy of prescribed medications.
x. A review of coordination arrangements of secondary care.
xi. A review of transition arrangements where appropriate in view of patients attaining the age of 18.
xii. A review of communication needs, including how the patient might communicate pain or distress
xiii. A review of family carer needs
xiv. Support for the patient to manage their own health and make decisions about their health and healthcare.

- Produce a health action plan following the AHC, which is shared with the patient.
- Follow up any patients who do not attend.
- Undertake a check on the appropriateness of prescribed medication."

There is not a single prescribed template, however NHS England has developed templates for each of the main primary care IT systems (122).

9.8.3 What is the evidence for effectiveness of annual health checks?

There has been a range of research into the impact and effectiveness of AHCs for people with an LD.

Evidence shows that:

- Health checks identify significant unmet health needs in people with an LD, for example diagnosing major health conditions (123)
- Health checks lead to increased referrals for health promotion interventions such as screening and immunisations (123–125)
- Health checks lead to reduced emergency hospital admissions and reduced need for primary care resource (126–128)

Further research is needed into whether health checks lead to reduced mortality, as there is mixed evidence on this currently (129–131).

9.8.4 Uptake

Uptake of LD AHCs amongst eligible patients in Cambridgeshire and Peterborough was 67% in 21/22.

Data from the end of Feb 2023 suggested at that point, uptake was 72% in C&P.

9.8.5 Local work to improve uptake

There has been a significant amount of work undertaking in C&P to support and improve the uptake of LD AHCs. Identified issues leading to lower uptake include GP

capacity, high rate of DNAs and lack of knowledge about health needs of people with an LD in primary care ((132).

Actions taken locally to address this include working with primary care staff employed as part of the Additional Roles scheme to undertake elements of the AHC, such as the medications review. Funding has been identified for an LD link nurse to support practices in validating their LD registers, although as yet the post has not been filled. Previously financial incentives have been offered to primary care but these had no impact on uptake.

9.8.6 Evidence on increasing uptake of AHCs

There is limited systematic research on approaches to increasing uptake of AHCs (133). Most evidence that exists comes from quality improvement projects or qualitative interviews.

Suggested actions from the research that does exist include:

- There is some limited evidence that incentivisation may increase uptake (134), although this has not worked locally in Cambridgeshire and Peterborough;
- There is some qualitative evidence that emphasises the importance of having clear system governance around uptake of AHCs, supported by good data (135);
- There is some qualitative evidence that emphasises the importance of building relationships with individual GP practices, for example by supporting them to understand the value of AHCs and also with the practicalities of following up DNAs and providing training to primary care staff (135,136).

9.8.7 Recommendations

Primary care

- Aim for 75% coverage of AHC amongst eligible patients, in line with the Long Term Plan.
- Ensure that there is access to appropriate equipment in primary care to be able to undertake a full AHC for individuals with comorbid physical disabilities, for example hoists to enable physical examination or wheelchair scales to enable a weight to be measured.
- Continue to work with primary care to understand how GP practices can best be supported to deliver good quality AHCs.
- The CVD prevention section (7.1) notes the very high exclusion rate for NHS Health Checks amongst patients on the LD register. This may be entirely appropriate, however the AHC template does not include all elements of the NHS Health Check. GPs should ensure that exclusion from NHS Health Checks does not inadvertently mean that adults with an LD miss out on CVD prevention opportunities.

Health promotion

- Continue to promote AHCs to people with an LD and their carers.

Social care providers

- Ensure that social care staff have adequate awareness of the importance of attending AHCs.
- Ensure that where a staff member is needed to attend with the person to support, this is someone who knows the individual well.

Care planning

- Ensure that supporting attendance at AHCs is included in care plans if necessary.

9.9 Healthy weight

9.9.1 Definition

Body Mass Index (BMI) is used to define boundaries for healthy and unhealthy weight in adults. The ranges are set out in the table below.

Table 9.11: BMI

BMI	Weight Status
Below 18.5	Underweight
18.5 – 24.9	Healthy Weight
25.0 – 29.9	Overweight
30.0 and Above	Obesity

Being overweight or obese increase someone's risk of cardiovascular disease, stroke, type 2 diabetes, osteoarthritis and cancer (particularly breast, ovarian and colon cancer) (137).

9.9.2 Prevalence of obesity

26% of all adults are obese and a further 38% are overweight in England (138).

Risk factors for obesity include:

- Demographic: More men than women are overweight, although levels of obesity are similar in the two sexes (138). The risk of obesity is also increased if someone lives in a deprived area, and in later middle age (138).
- Behavioural: eating too many calories, particularly from sugar or saturated fat; not taking enough exercise; not getting enough sleep (139).
- Biological: some medical conditions may increase someone's risk of being overweight; weight gain is also a side effect of some medications (139).

- Environmental: stress can increase someone's risk of obesity; living in an environment where making health lifestyle choices is difficult also increase risk of obesity, for example if someone lives somewhere where it is difficult to walk and cycle (139).

It is difficult to get good quality data on obesity in adults with a learning disability. Research suggests that the prevalence is higher in this group than the general population (140). A good quality cross-sectional survey undertaken in 2010 suggested that adults with a learning disability are 1.8 times more likely to be obese than the general population (141), with a prevalence of obesity of around 40% in adults with an LD at that time.

9.9.3 Risk factors for being overweight and obese in adults with an LD

There is limited good data on overweight and obesity in adults with an LD. What data is available suggests the following risk factors for overweight and obesity in this group (140):

- Women with an LD are more likely to be obese than men;
- Adults with an LD become obese at a much younger age than the general population;
- Adults with mild or moderate LD are more likely to be obese than adults with severe or profound LD, although there are still significant numbers of obese adults in the latter group;
- Adults living in supported living or with family are more likely to be obese than those living in more restrictive environments.
- Adults with an LD are much less likely to be physically active than the general population;
- A high proportion of adults with an LD are prescribed psychotropic medications, which have weight gain as a side effect;
- Certain genetic syndromes that cause learning disabilities are associated with obesity, for example Prader Willi Syndrome.

9.9.4 Evidence based approaches

There is limited evidence around approaches to weight loss in adults with an LD and no national guidance specific to this cohort.

PHE have set out some recommendations based on the best available evidence (142).

Table 9.12: recommendations around weight management for people with an LD

Raising awareness of excess weight with people with learning disabilities and their family carers	• Some evidence to suggest that people with an LD have less knowledge around the importance of healthy lifestyles • Tailored health promotion work may be of benefit
Annual health checks	• Health checks offer an opportunity to have a conversation about an individual's weight and give advice to individuals and their carers about action to take, or review any medical factors that may be contributing
The role of families and social care staff	• Evidence suggests that involving formal and informal carers in weight loss interventions makes them more effective • Conversely, inadequate support from carers can create barriers to maintaining a healthy weight • Particular issues are lack of carer knowledge and understanding about healthy eating; lack of time to cook; use of food as reward or punishment.
Ensuring mainstream programmes are accessible	• Mainstream programmes should be accessible to people with an LD • Evidence shows that multi-component weight management interventions can be successful with people with an LD • Particular issues that may need addressing include adaptation of written materials
Environmental, social and personal factors	• Adults with an LD may need support navigating barriers to healthy eating and exercise, including transport and financial issues
Capacity and choice around diet and physical activity	• Carers may need support in understanding how to make best interest decisions about physical activity and diet; they may need support in managing risks and benefits and also in making sure that an individual understands the risks and benefits before making an unwise decision

Source: PHE (142)

9.9.5 Local pathway

There are no specialist weight management services for adults with an LD. Weight management services in Cambridgeshire and Peterborough for the general population are delivered through the Healthy You service. The service consists of three tiers:

- Tier 1: support from a health trainer around behaviour change, such as physical activity or diet;
- Tier 2: group programmes, such as WeightWatchers, delivered either face-to-face or online;

- Tier 3: specialist multidisciplinary support lasting 18 months, including input from a physician, psychologist, dietician and physical activity specialist.

Referral routes are listed on the Healthy You website: Adult Weight Management - Healthy You.

9.9.6 Recommendations

Health promotion

- Health promotion work around healthy eating should be targeted at people with an LD and their carers

Weight management commissioners and providers

- Staff in all weight management services should have training on how to make reasonable adjustments for people with a learning disability and on mental capacity.
- Commissioners should consider whether there is a need to add in additional eligibility criteria for tier 3 services that are related to complexity of need, rather than BMI.
- There should be a clear pathway to access dietetic support for individuals whose weight gain is linked to medical reasons rather than behavioural factors.
- Commissioners and providers should be assured that appropriate reasonable adjustments can be made within weight management services.

Specialist LD services

- Ensure that specialist LD services are aware of referral routes into specialist weight management services.

Social care commissioners and providers

- Staff in residential care and domiciliary care providers should have training on healthy eating and mental capacity relating to food choices.

Unpaid carers

- Unpaid carers should be offered access to health promotion and education around healthy diet, alongside the people they care for.

Care planning

- If an individual with care needs requires support around making food choices, this should be incorporated into their care plan.

10. Wider determinants of health

10.1 What are the wider determinants of health?

Health outcomes are impacted by a range of factors, including an individual's genetics, experience of healthcare, behavioural factors and experience of what are often called the wider or social determinants of health, which can include housing, work and education. The Dahlgren and Whitbread model gives a conceptual framework for thinking about the different factors that impact on health.

Figure 10.1: factors that affect health

Source: (143), Dahlgren G, Whitehead M. (1991). Policies and Strategies to Promote Social Equity in Health. Stockholm, Sweden: Institute for Futures Studies, reproduced with permission

Research evidence suggests that 40-50% of population health outcomes are attributable to wider determinants (144).

This section considers how some of these key determinants might impact on the health of adults with learning disabilities.

10.2 Housing

10.2.1 How does housing impact on health?

Housing has a range of direct impacts on physical and mental health. Cold, damp, mould and noise can lead to respiratory and cardiovascular disease (145). Overcrowding can lead to increased spread of infectious diseases (145). Living in insecure or poor quality housing can also lead to mental health problems, such as anxiety and depression (145).

10.2.2 Where do adults with an LD live?

It is challenging to obtain good data on housing quality for adults with an LD.

The most recent 2021 ONS Annual Population Survey groups adults with learning difficulties and adults with a learning disability together. This data suggests that

these groups have a very different pattern of housing to the adults who do not have a disability (146).

Table 10.1: housing type for adults

Housing type	Adults with severe or specific learning difficulties	People without a disability
Owner occupier	8%	53.3%
Social rented housing	15.1%	7.9%
Private rented housing	5.8%	17.4%
Living with parents	65.9%	19.2%
Other	5.1%	2.2%

Source: (146)

Of particular note is the high proportion living with parents, which may have implications as individuals and their parents age. This i0s a very hidden group, but these individuals may well be unknown to statutory services, meaning that they may only come into contact with services in crisis (147). Given the increasing ageing population of adults with an LD, this group may become more prominent (147).

There is also data for adults who receive long-term support for their care needs from the local authority (148):

Table 10.2: housing status of adults supported by a local authority due to their learning disability

	(1G) Proportion of adults with a primary support reason of learning disability support who live in their own home or with their family (2021/22)
Cambridgeshire	87.1%
Peterborough	84.1%
England	78.3%

Source: (148)

In this indicator, the definition of “own home” includes supported living but not care home settings.

Section 13 discusses the residential accommodation with care and support that is commissioned by both local authorities in more detail. However, it is important to note that the quality of this accommodation will also impact on individual’s health, so consideration of housing hazards such as damp, mould and cold should be part of the quality assurance of commissioned providers.

10.3 Employment

10.3.1 How does employment impact on health?

There is a clear correlation between employment and mortality, with being employed increasing life expectancy (149). Employment is a protective factor, as it provides

income (which mediates many other wider determinants of health) as well as an opportunity for social interaction and a sense of identity and purpose (150). Unemployment is a risk factor for poor health, including increasing mental health problems (150).

Quality of work is also important. Low quality work, for example insecure work or work that is low paid, can also negatively impact health compared to secure, well-paid employment (151).

There is evidence to suggest that adults with an LD who are unemployed have poorer health than adults with an LD who are in employment (152).

10.3.2 What is the employment rate of adults with an LD?

Data on employment status of adults with an LD is difficult to obtain. The 2021 Annual Population Survey, which includes adults with learning difficulties and learning disabilities in the same group, suggests the employment rate amongst adults aged 18-64 years is 26%, of whom around half are in full-time employment and half are in part-time employment (146). This compares to 81.6% of the non-disabled population (146).

Other population-based surveys focussing on adults with an LD living in the community or with mild-moderate impairment have found varying employment rates, ranging from 15%-38% (152).

Data on adults with an LD who receive long term support from their local authority (and therefore are likely to have more severe disabilities) shows the following employment rates (148):

Table 10.3: employment status of adults supported by a local authority due to their learning disability

	1E: Proportion of adults with learning disabilities who are in paid employment (2021/22)
Cambridgeshire	3%
Peterborough	1.7%
England	4.8%

Source: (148)

10.4 Crime

10.4.1 How does crime impact on health?

Crime can impact on health in several ways. Firstly, being a victim of crime can impair someone's psychological wellbeing (153). Secondly, fear of crime can impact on an individual's health-promoting activities, for example by reducing their social interaction with others or reducing their levels of physical activity (153).

10.4.2 How does this impact on adults with an LD?

Data from the national Crime Survey for England and Wales (2019/20) shows that adults who report experiencing problems with learning, understanding or concentrating are significantly more likely to have experienced anti-social behaviour or attempted/actual sexual assault in the previous year (154).

Table 10.4: proportion of adults experiencing anti-social behaviour or sexual assault over the last year

Impairment type	% of adults experiencing any anti-social behaviour in the last year (95% CI)	% of people aged 16 to 59 that experienced any sexual assault (including attempts) (95% CI)
Learning or understanding or concentrating (%)	50.5 (45.5, 55.6)	5.6 (3.9, 7.3)
Non-disabled people	39 (38.3, 39.5)	1.9 (1.8, 2)

Source: Crime Survey for England and Wales (154)

10.5 Income

10.5.1 How does income affect health?

Income has a wide range of direct impacts on health. Low income is associated with lower life expectancy, lower disability-free life expectancy and worse self-reported health (153). This is mediated in many ways. For example, people on a low income might not be able to afford healthy and nutritious food, heat their home adequately or afford good quality housing (145).

10.5.2 How does this affect the health of adults with an LD?

Adults with an LD and their families are more likely to live in poverty than the general population (152,155). Experiencing financial hardship is associated with poorer health outcomes in adults with an LD (156).

10.6 Neighbourhood deprivation

10.6.1 How does neighbourhood deprivation impact health?

Living in a deprived neighbourhood can adversely impact the health of people who live there (157). This could be for a range of factors, including poor air quality, poor quality housing, lack of green space and poor transport (158).

10.6.2 How does this affect the health of adults with an LD?

Adults with an LD are more likely to live in deprived areas in England (159). This is also shown in the prevalence data for Cambridgeshire and Peterborough in table

5.6, whereby Primary Care Networks in Fenland and Peterborough have a higher proportion of people with an LD on their patient list.

There is limited evidence to suggest that the relationship between neighbourhood deprivation and mortality between adults with an LD is less strong than in the general population (159). It is not clear why this might be.

10.7 Social isolation

10.7.1 What is the impact of social isolation on health outcomes?

Social isolation has been consistently associated with poor health outcomes, including all-cause mortality and cardiovascular disease (160).

10.7.2 How does this affect the health of adults with an LD?

Data from the national Annual Population Survey suggests that adults with a disability are around 4 times more likely to report feeling lonely often or always, compared to adults without a disability (154). A smaller survey by Mencap suggested these rates were even higher in adults with an LD (161). There is limited evidence around the impact of this on the health of adults with an LD (156).

10.8 Recommendations

Information and advice

- Adults with an LD should be supported by social prescribers in primary care to access services that may support them with any of the areas in this section that may be impacting on their health.

Care planning

- Many of the wider determinants of health intersect with eligible care needs under the Care Act, particularly:

  (e) being able to make use of the adult's home safely;

  (f) maintaining a habitable home environment;

  (g) developing and maintaining family or other personal relationships;

  (h) accessing and engaging in work, training, education or volunteering;

  (i) making use of necessary facilities or services in the local community including public transport, and recreational facilities or services.

  Care planning should consider all of these areas.

Social care providers

- Care providers should ensure that their staff have the knowledge and understanding to support adults with an LD who are eligible to claim benefits to access income maximisation support if needed.
- Care providers should ensure that their staff have the knowledge and skills to help individuals they support to access training, education and employment opportunities.

Social care commissioners

- Commissioners need to ensure they have an understanding of the future housing needs of adults with an LD who live with their parents.
- Commissioners should ensure commissioned housing is of a high quality, without environmental hazards.
- Commissioners should ensure that they have a varied day opportunities offer, that supports with developing employment skills and with developing friendships and social networks.

Unpaid carers

- Unpaid carers of adults with an LD should be able to access support to claim any benefits that they are entitled to.

11. Mental health

11.1 Common and serious mental health disorders

11.1.1 Risk factors for poor mental health in people with a learning disability

People with an LD face often multiple risk factors for poor mental health.

These are summarised in the table below:

Table 11.1: Risk factors for poor mental health in people with an LD.

Biological	• People with an LD have poorer overall physical health than the general population • Genetic & developmental factors (known and unknown ones) (162) • Some causes of learning disability are associated with higher prevalence of specific mental health conditions, such as dementia in Down's syndrome (163) and affective psychosis in Prader-Willi syndrome (164)
Psychological	• Self-stigma around LD is associated with poorer quality of life, and symptoms of anxiety and depression (165) • Low self-esteem is a predictor of depression in people with an LD (166)
Social	• There is an association between socioeconomic deprivation and risk of mental ill health amongst people with an LD (167) • There is a strong link between difficult life events and increased risk of mental health conditions in adults with an LD (168)

Source: Adapted from: (162)

11.1.2 What is the prevalence of common and serious mental health disorders in people with a learning disability?

Finding good quality data around prevalence of mental health disorders in people with a learning disability is challenging. There is evidence to suggest that mental health problems are more common in people with an LD than the general population, and also that they are more enduring (162).

Table 11.2 below describes the prevalence of mental health conditions in people with an LD and the general population as calculated in a good quality research study, based on primary care data:

Table 11.2: Some mental health conditions in people with a learning disability and the general population

Mental health condition	Prevalence in LD population	Prevalence in general population (aged 18+)	Odds Ratio - OR (Effect size 95% confidence interval)
Schizophrenia or bipolar disorder	5.6%	0.9%	OR 7.16 (6.49, 7.89)
Anxiety, neurotic and stress disorders	8.1%	3.9%	OR 2.62 (2.41, 2.84)
Depression	15.8%	10.1%	OR 1.88 (1.76, 2.00)
Anorexia/bulimia	0.5%	0.4%	OR 1.31 (0.95,1.82)

Source: (169)

This data suggests that people with an LD are more likely to have schizophrenia, bipolar disorder, anxiety disorders or depression than the general population. There was no significant difference in rates of anorexia and bulimia.

There is also evidence to suggest that individuals who have an LD and co-occurring autism have an even higher risk of a comorbid diagnosis of a mental illness, with one population-based study in Scotland suggesting that after adjusting for age and sex, adults with both an LD and autism had odds of having a mental health condition of 25.55 times the general population (95% CI 23.93, 27.28), an odds ratio that rose to 130.80 when an adjustment for interaction between age and presence of an LD and autism was made (170).

Disordered eating

Separately to eating disorders such as anorexia and bulimia, people with an LD can also suffer from other types of disordered eating behaviours, particularly pica (ingesting inedible objects) and hyperphagia (overconsuming food). Some of these syndromes are associated with particular diagnoses, for example hyperphagia is associated with Prader Willi Syndrome. Management of these behaviours can be highly complex and require a multi-disciplinary approach.

11.1.3 What is the prevalence of common and serious mental health disorders in Cambridgeshire and Peterborough?

GP Quality Outcomes Framework (QOF data) for Cambridgeshire and Peterborough was used to calculate prevalence of depression and serious mental illness, for the general population, and for the subset of people on the LD register. The prevalence of serious mental illness was calculated using the Mental Health register, which

covers individuals with schizophrenia, bipolar affective disorder and other psychoses.

Table 11.3: prevalence of mental health conditions in Cambridgeshire and Peterborough

	People on the LD register in Cambridgeshire and Peterborough (95% CI) (171)	**QOF register for Cambridgeshire and Peterborough** (172)
Depression	12.1% (11.2, 13.2) (n=506)	10.95%
Serious mental illness (calculated by using number on Mental Health register)	8.6% (7.8, 9.5) (n=357)	0.81%

Source: primary care data, as referenced in table

This suggests that the prevalence of serious mental illness is significantly higher in people on the LD register than the general population, which is similar to the national picture. The prevalence of depression is also slightly higher.

11.1.4 How do adults with an LD access diagnosis and treatment for common and serious mental illness in Cambridgeshire and Peterborough?

There are a number of routes to accessing diagnosis and treatment for mental illness for adults with an LD in Cambridgeshire and Peterborough:

- Some individuals may be managed solely in primary care;
- Some individuals, particularly those with a mild or borderline LD, may access mainstream specialist mental health services, which are primarily delivered by CPFT;
- Some individuals may be seen in specialist LD services, which may be provided by CCC, PCC or CPFT.

Section 17 describes the referral pathway into specialist outpatient LD services in Cambridgeshire, which include specialist LD mental health services, and the current establishment.

Section 17 describes the current referral pathway into specialist outpatient LD mental health services in Peterborough and the current establishment.

11.1.5 What are the service standards for assessing and treating common and serious mental illness in adults with learning disabilities?

NICE sets out extensive guidelines for assessing and treating mental illness in people with learning disabilities (173).

These contain five quality standards for mental health services for people with learning disabilities (174):

Table 9.4: NICE quality statements NG54

	Cambridgeshire	Peterborough
Statement 1 "Young people and adults with a learning disability have an annual health check that includes a review of mental health problems"	The SystmOne AHC template covers mental health. AHCs are covered in more detail in chapter 9.8.	The SystmOne AHC template covers mental health. AHCs are covered in more detail in chapter 9.8.
Statement 2 "People with a learning disability who need a mental health assessment are referred to a professional with expertise in mental health problems in people with learning disabilities"	There is a pathway for people with an LD into specialist LD psychiatry and psychology. Some patients with an LD are seen in mainstream mental health services. It is possible that some patients are managed solely in primary care.	There is a pathway for people with an LD into specialist LD psychiatry and psychology. Some patients with an LD are seen in mainstream mental health services. It is possible that some patients are managed solely in primary care.
Statement 3 "People with a learning disability and a serious mental illness have a key worker to coordinate their care"	Cambridgeshire LDP has care coordinators who are able to fulfil this role. Individuals who are admitted to The Hollies (inpatient unit) have care coordinators.	There is some facility to provide care coordination within some parts of Peterborough services. The LD nurses based in PCC do some care coordination for CHC funded individuals. The Intensive Support Team are able to provide some care coordination. Individuals who are admitted to The Hollies (inpatient unit) have care coordinators.
Statement 4 "People with learning and mental health problems who are receiving psychological interventions have them tailored to their preferences, level of understanding, and strengths and needs"	Cambridgeshire LDP has specialist clinical psychologists. For patients who are referred into mainstream mental health services, there is an expectation that services will make	There is a clinical psychologist in outpatient services Peterborough. For patients who are referred into mainstream mental health services, there is an expectation that services will make

	reasonable adjustments as required, but there is no specific funding or provisions for this currently. There is currently a pilot of reasonably adjusted IAPT being planned for adults with LD and low level mental health needs (step 2 level intervention).	reasonable adjustments as required, but there is no specific funding or provisions for this currently. There is currently a pilot of reasonably adjusted IAPT being planned for adults with LD and low level mental health needs (step 2 level intervention). There is psychology input into the Intensive Support Team.

Source: (174)

The Royal College of Psychiatrists also sets out standards for community learning disability services which cover a number of areas relevant to service provision for mental health disorders (175). Standards specific to community mental health are listed in table 11.5.

Table 11.5: RCPsych service standards for community learning disability services

	Standard	Cambridgeshire	Peterborough
Section 1: Assessment and treatment	"14. People with learning disabilities have a comprehensive evidence-based holistic assessment which includes their: • Mental health; • Medication; • Psychosocial and psychological needs; • Strengths and areas for development. Guidance: Assessments are completed by the most appropriate member of the multi-disciplinary team and in line with NICE guidelines for mental health in learning disability"	This is in place in the LDP.	There is no single route into specialist LD psychiatry and psychology, but these services offer assessments in line with this standard. There is no formal MDT commissioned in Peterborough.
Section 2: Care planning and treatment	"30. The team have developed mental health … pathways that are appropriate to the needs of the population they cover."	30. There are pathways to access specialist LD psychiatry, psychology and art/music therapy. There are some missing pathways, including IST. Patients with dementia are seen, but there is not a defined clinical pathway for all areas of the county.	30. There are pathways to access specialist LD psychiatry and psychology. Missing pathways include art/music therapy. Patients with dementia are seen, but there is not a defined clinical pathway.
	"32. People with learning disabilities (and carers, with consent) are offered accessible information about their mental health, physical health and intervention."	32. This is in place in the LDP	32. This is in place in specialist LD services

Source: (175)

11.2 Challenging behaviour

11.2.1 What is challenging behaviour?

The Royal College of Psychiatrists defines challenging behaviour as “Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion” (176).

Challenging behaviour is not a clinical diagnosis in itself, rather the term is used descriptively to indicate a type of behaviour.

Many of the individuals who feature in the serious case reviews in section 2.2.2 had a diagnosis of challenging behaviour.

11.2.2 How common is it?

It is difficult to gauge how common challenging behaviour is amongst people with a learning disability, for several reasons (177). Firstly, there is no single accepted definition or measure, which makes it difficult to get comparable data between studies (177). Secondly, people with a learning disability who have behaviour that challenges are more likely to be known to specialist services, meaning the prevalence of challenging behaviour in that group is probably higher than in the whole population of people with an LD (177).

A review of prevalence studies has estimated that between 5% and 15% of people with an LD who are known to specialist LD services have challenging behaviour (177). The prevalence amongst people with an LD who are not known to specialist services is not known.

11.2.3 What are the causes of challenging behaviour?

Causes of challenging behaviour can be considered using a bio-psycho-social model (177).

Table 11.6: causes of challenging behaviour

Biological causes	• Challenging behaviour can be a response to physical illness or pain.
Psychological causes	• Challenging behaviour can be linked to an individual's desire to communicate needs or wishes; to respond to or alter the outcome of a situation they are in; or to respond to external stimuli.
Social causes	• Certain environments may lead to challenging behaviour, for example environments that have fewer positive activities for an individual to engage in, poorer social support and more restrictive practices.

Source: (177).

11.2.4 What are the risk factors for challenging behaviour?

There are a number of risk factors for challenging behaviour (177):

- Sex: men are more likely to display types of challenging behaviour that are aggressive, although self-injury is equally common in both sexes;
- Severity of learning disability: challenging behaviour is more common in people with a severe or profound learning disability;
- Communication: poorer communication skills are associated with greater levels of challenging behaviour;
- Sensory impairment: having a sensory impairment is associated with increased prevalence of challenging behaviour;
- Traumatic events: experience of traumatic events can increase the risk of challenging behaviour.

11.2.5 What is the NICE guidance for management?

NICE guidance sets out quality standards for preventing and managing challenging behaviour in people with learning disabilities. The table below sets out the standards relating to adult services.

Table 11.7: NICE quality standards for challenging behaviour

Statement 1 “Local authorities and clinical commissioning groups jointly choose a lead person to oversee strategic commissioning of services for all people with a learning disability.”
Statement 2 “People with a learning disability have an annual health check from their GP. “
Statement 3 “People with a learning disability and behaviour that challenges have an initial assessment to identify possible triggers, environmental factors and function of the behaviour”
Statement 4 “People with a learning disability and behaviour that challenges have a named lead practitioner”
Statement 5 “Families and carers of people with a learning disability and behaviour that challenges are involved by services in developing the person's care and support plan, which includes how to prevent or respond to a crisis”
Statement 7 “People with a learning disability and behaviour that challenges take part in personalised daily activities”
Statement 8 “People with a learning disability and behaviour that challenges have access to specialist behavioural support in the community”
Statement 9 “Adults with a learning disability and behaviour that challenges are supported to choose where and how they live”
Statement 10 “People with a learning disability and behaviour that challenges have a documented review every time a restrictive intervention is used”

Source: (178)

11.2.6 What services are in place in Cambridgeshire and Peterborough?

Many patients with challenging behaviour are managed through the specialist LD community services in Cambridgeshire and Peterborough. Most of these are managed in outpatient services, with support from LD psychiatry, LD psychology and LD nurses or other allied health professionals.

For the most complex cohort of patients, the Transforming Care programme of work underpins service commissioning.

The Transforming Care programme of work was started by NHS England in 2015, and aims to reduce inappropriate long stays for LD patients on mental health inpatient units by improving care and support services in the community.

Table 11.8 sets out what is currently commissioned in Cambridgeshire and Peterborough:

Table 11.8: commissioned Transforming Care services in Cambridgeshire and Peterborough

	Cambridgeshire	Peterborough
Intensive support team	Not commissioned	Provided by CPFT
Community-based forensic support	Provided by CPFT	Planned
Acute LD inpatient admissions	Provided by CPFT at The Hollies	Provided by CPFT at The Hollies

11.3 Intensive Support Team

11.3.1 What is an intensive support team?

Intensive support teams are very specialist services that provide assessment and support (including in crisis) to individuals with very high risk challenging behaviour or severe mental illness who may be at high risk of an inpatient admission (179). They are able to provide advice, guidance and training to other professionals. They also have significant expertise in behavioural support, including in approaches like PBS (Positive Behavioural Support).

11.3.2 What is commissioned in Cambridgeshire and Peterborough?

Cambridgeshire does not have an intensive support team, as it is not commissioned. Behavioural support is provided through the wider LDP team of professionals.

Peterborough has an intensive support team (IST), provided by CPFT. The pathway to access this team is outlined in section 17. The staffing structure is set out in table 9.9.

Table 11.9: Peterborough IST staffing structure

Manager	1 WTE
Psychology	0.2 WTE psychologist 1 WTE assistant psychologist
Learning disability psychiatry	0.2 WTE consultant LD psychiatrist
Learning disability nurses	4 WTE band 6 LD nurses 1 WTE band 5 LD nurse
Occupational therapist	1 WTE
Associate/assistants	1 WTE nurse associate 2 WTE band 4 health care assistants
Admin	0.5 WTE admin

11.4 Inpatient mental health care

Adults with a learning disability may need admission for assessment or treatment of severe mental illness or to manage a crisis situation where there is a serious risk of harm, and where the individual can't be managed safely in the community.

The main specialist LD inpatient unit for Cambridgeshire and Peterborough is The Hollies, which is run by Cambridgeshire and Peterborough NHS Foundation Trust. Occasionally individuals are sent to out of area inpatient beds.

11.4.1 Service structure

The Hollies is described in the extract below (180).

Figure 11.1: description of the Hollies

The Hollies is a specialist ten bed unit providing assessment and treatment for adults with learning disabilities.
It provides a single room with ensuite facilities for each patient, and the unit is divided into male and female accommodation. This inpatient unit provides care for adults with a learning disability who have additional complex needs and are at immediate risk to themselves or others of harm, neglect and/or abuse. Additional complex needs may include:

- Mental health conditions, including personality disorder, not responding to interventions in community settings
- Epilepsy affecting everyday living skills and social inclusion
- Challenging behaviours
- Pervasive developmental disorders including autistic spectrum/ADHD disorders, which may be resistant to treatment and related to other bio-psycho-social needs. May require:
    - Legislation
    - more than one professional and a multi-disciplinary team to meet their needs
    - care programme approach continued support

Source: CPFT (180)

Referrals are taken from GPs, First Response Service, Liaison Psychiatry, community learning disability teams and Peterborough IST.

It has not been possible to obtain a staffing structure for this service.

The service has been operating under capacity for some time due to issues with the layout of the unit, as well as staffing challenges (vacancies are decreasing but stood at 23.9% in April 23). There are planned capital improvements to allow an increased occupancy. The lack of capacity has impacted other parts of the wider system, resulting in patients being accommodated in the local s136 suite or acute hospital Emergency Department.

11.4.2 Number of inpatient admissions in Cambridgeshire and Peterborough

Table 11.10 below shows the total number of inpatient admissions from Cambridgeshire and Peterborough ICB registered patients to any inpatient specialist LD bed in the last 3 years; a snapshot of the number of admissions at the end of Q4 to give an idea of how many inpatient admissions are being managed at any one time, and the number of delayed transfers of care (DTOC):

Table 11.10: number of inpatient admissions to specialist LD inpatient beds in Cambridgeshire and Peterborough ICB

Year	Number of admissions	Snapshot of inpatient numbers in Q4	Number of delayed transfers of care
2019 /20	30	11	2
2020/21	28	15	7
2021/22	29	5	1

Source: Cambridgeshire and Peterborough ICB

11.5 Forensic services

Forensic learning disability services provide support to people with learning disabilities who are in contact with the criminal justice system.

It is difficult to get precise estimates of the number of people with an LD who are in this category; population surveys suggest the proportion of people in prison with an LD is significantly higher than expected, with a prevalence of around 4.7% (181).

11.5.1 What services are commissioned in Cambridgeshire and Peterborough?

Most adults with an LD who have are in contact with the criminal justice system are seen in mainstream mental health services or mainstream LD services. A small number are seen in forensic services:

- Tier 4 adult medium and low secure services are currently provided at a regional level by East of England Adult Secure Provider Collaborative (East of England)**.** The lead provider is Essex Partnership University NHS Trust and Norfolk and Suffolk NHS Trust. There are no beds in Cambridgeshire and Peterborough, but these services can be accessed by Cambridgeshire and Peterborough residents.
- The mental health needs of people with an LD in prison are met through prison healthcare services, which are currently commissioned by NHS England.
- Community forensic LD services can be commissioned by both NHS England and ICBs. Most people with an LD access mainstream community forensic services. C&P ICB has commissioned a specialist community forensic LD team in Cambridgeshire, and is planning to commission a team for Peterborough.

11.6 STOMP

11.6.1 What is STOMP?

Psychotropic medication can have significant side effects, including weight gain and sedation. STOMP (Stopping over medication of people with a learning disability, autism or both) is an NHS England campaign that highlights the inappropriate use of medication for people with an LD to manage challenging behaviour, particularly psychotropic medications such as anti-psychotics, anxiolytics, anti-depressants, hypnotics and anticonvulsants(182). It is a key component of the NHS Long Term Plan (13).

Research has shown that people with a learning disability are more likely to be prescribed psychotropic medication with no recognised indication (183), meaning there is a risk also that the medications will be ineffective in achieving their therapeutic aim.

As a result of concerns about overprescribing of psychotropic medication, NICE has set out clear standards around use of psychotropic medication.

Table 11.11: NICE quality standards relating to psychotropic medication

NICE Quality Standards for managing mental illness in people with learning disabilities QS142	Statement 5 "People with a learning disability who are taking antipsychotic drugs that are not reduced or stopped have annual documentation on reasons for continuing this prescription"
NICE Quality Standards for preventing and managing challenging behaviour in people with learning disabilities QS101	Statement 11 "People with a learning disability and behaviour that challenges only receive antipsychotic medication as part of treatment that includes psychosocial interventions"
	Statement 12 "People with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months"

Source: (184,185)

11.7 Recommendations (11.1-11.6)

Primary care

- Consideration is needed as to what support and training might be needed for GPs who are managing adults with an LD and mental health conditions in primary care, taking into account NICE NG54 Quality Statement 2.

Mainstream mental health services – commissioners and providers

- Commissioners and providers should ensure that mainstream mental health services who provide assessment and treatment to adults with an LD have the

necessary resources, capacity and capability to make appropriate reasonable adjustments.
- Commissioners and providers should be clear about the criteria for stepping patients up from mainstream mental health services into specialist LD services, taking into account NICE NG54 Quality Statement 2.

Specialist LD service commissioners

- Commissioners should consider how to strengthen LD psychiatry and psychology capacity in Peterborough, as the service is not currently resilient (see section 17).
- Commissioners should consider how to provide art and/or music therapy in Peterborough, as there is currently an inequity in provision for non-verbal adults with an LD who would benefit from therapy.
- Commissioners should consider how capacity for care coordination can be provided more consistently in Peterborough.
- Commissioners should assure themselves that the NICE Quality Standards on challenging behaviour are being met in Cambridgeshire and Peterborough.
- Commissioners should consider if there is a need for an IST in Cambridgeshire
- Commissioners should consider what support, education and training is offered to unpaid carers of adults with an LD who have challenging behaviour
- Commissioners should ensure that adults with an LD who have challenging behaviour receive a consistent support offer in line with NICE guidance, regardless of which service supports them. This includes the provision of MDT support.
- Commissioners should ensure that they have embedded lessons from national reviews of inpatient, such as those generated from Winterbourne View and Cawston Park.

Unpaid carers

- Consideration is needed of what support and advice might be needed for unpaid carers of adults with an LD who have a mental illness or challenging behaviour.

Social care commissioners and providers

- Commissioners and social care providers should ensure that social care staff who care for individuals with an LD who have a mental illness have the necessary knowledge and skills to meet their individual needs.
- Commissioners and social care providers who provide care to adults with an LD who have behaviour that challenge in the community should ensure that staff who have appropriate skills and knowledge to support effectively.
- Section 11 considers residential care commissioning for adults with an LD. Some of these adults will have challenging behaviour. In light of the NHS Long

Term Plan ambition to reduce the number of inpatient stays, consideration is needed of whether there is sufficient, appropriate community capacity for individuals being discharged.

Healthcare commissioners and providers

- Commissioners and providers should consider how to support STOMP in Cambridgeshire and Peterborough, in line with the NHS Long Term Plan.

11.8 Autism

11.8.1 What is autism?

Autism is a developmental disorder. It is “characterised by some degree of difficulty with social interaction and communication. Other characteristics are atypical patterns of activities and behaviours, such as difficulty with transition from one activity to another, a focus on details and unusual reactions to sensations” (186).

The health needs of people with autism include (187):

- Other developmental disorders, such as tic disorders and ADHD as well as learning disabilities;
- Sleep disorders;
- Medical comorbidities such as gastrointestinal disorders;
- Mental health disorders, such as anxiety, depression and OCD.

A high proportion (around 45%) of people with autism have a learning disability (187).

11.8.2 How many people with learning disabilities have autism?

Evidence suggests around 10% of individuals on the GP LD register also have autism (188); this compares to a prevalence in the general population of around 1% (187). This cohort have particularly complex needs; a population level study of individuals with an LD and comorbid autism have very significantly higher odds of comorbid mental health conditions, physical disability and sensory disability than the general population, with greater odds than individuals with an LD only (170).

11.8.3 What services are available?

There is a separate Adult Autism Assessment service, provided by CPFT. However, if an adult has a comorbid diagnosis of a learning disability, they are likely to be seen by specialist LD services instead. There are no treatment services for autism.

11.8.4 What is the local strategy?

There is an all-age autism strategy in Cambridgeshire and Peterborough. It has the following aims related to access to healthcare for adults with autism (189):

- Ensure all providers of mental health services apply reasonable adjustments for people with autism to receive the right support including Child & Adolescent Mental Health Services (CAMHS) so that fewer people with autism access in-patient settings for long periods.
- Ensure that autism is recognised in the local Mental Health strategy and future service models which includes reasonable adjustments.
- Ensure that autism awareness and training is provided/encouraged to early intervention practitioners (Child Wellbeing Practitioners (CWP), Education Mental Health Practitioners (EMHP) and Mental Health Support Teams (MHST)).
- Ensure that when commissioning mental health services, these services can make reasonable adjustments and that their quality is monitored.
- Ensure people with autism are supported in a smooth transition between children and young people mental health services to adult mental health services (taking into account children and young people with an EHCP and different pathway age limits).
- Ensure that advice and guidance provided on websites is written in an accessible and reasonably adjusted way.
- Work together with acute services to look at pathways into hospitals for people with autism that ensures areas make reasonable adjustments and adopt a person centred approach with a range of information, such as health passports.

11.8.5 Recommendation

- Many of the recommendations in the local all-age autism strategy fit well with the recommendations in this needs assessment, particularly around reasonable adjustments. Work should continue with its implementation.

11.9 Dementia

11.9.1 What is dementia?

Dementia is a term given to a collection of degenerative diseases that cause an affected individual to have issues with memory and cognitive function (190). There are a number of different causes of dementia; the most common is Alzheimer's disease, which accounts for around 70% of cases of dementia (190). Other causes include vascular disease and Lewy body dementia (190).

Around 40% of cases of dementia in the general population are potentially due to modifiable risk factors (191). These modifiable risk factors are shown in table 9.12.

Table 11.12: modifiable risk factors for dementia

Early life	Less education
Midlife	Hearing loss
	Traumatic brain injury
	High blood pressure
	Excessive alcohol consumption
	Obesity
Later life	Smoking
	Depression
	Social isolation
	Physical inactivity
	Air pollution
	Diabetes

Source: (191)

Obesity, physical inactivity, diabetes, depression and social isolation are risk factors that are more common on adults with an LD than the general population (192).

In addition, adults with Down's syndrome have a markedly higher risk for dementia, which starts at a much earlier age – 30% of adults in their 50s with Down's Syndrome have dementia (193).

11.9.2 What is the prevalence of dementia in people with an LD?

Accurate data on the prevalence of dementia in people with an LD is challenging to obtain. However, the best available evidence suggests that dementia is more common in people with an LD than the general population, and very much more common in people with Down's syndrome (PHE reasonable adjustments).

GP data from Cambridgeshire and Peterborough suggests that 1.7% (95% CI 1.3, 2.2) of people aged 18 years and older on the LD register have dementia (171). This compares to 0.8% in the total general population aged over 18 years.

11.9.3 What is the national guidance?

There are three sets of NICE guidance relevant to the diagnosis and management of dementia in people with an LD:

- NG96 Care and support of people growing older with learning disabilities (194)
- NG97 Dementia: assessment, management and support for people living with dementia and their carers (195)
- NG54 Mental health problems in people with learning disabilities: prevention, assessment and management (196)

Recommendations from the guidance are set out in table 11.13.

Table 11.13: NICE recommendations for management of dementia in people with an LD

NG96	"1.2.8 Mental health commissioners should develop protocols to ensure that Care and support of people growing older with learning disabilities, including people in later old age, have access to mainstream mental health services for older people, including dementia support. 1.5.6 Consider commissioning training for people and their family members and carers in recognising changes and managing age-related conditions such as…dementia 1.5.14 Health checks and screening: Discuss with people the changes that may occur with age. Ask them about and monitor them for symptoms of common age-related conditions or changes in any existing conditions, including…dementia 1.5.36 Explain at an early stage to people with learning disabilities (particularly people with Down's syndrome) and their family members, carers and advocates about the link between learning disabilities and dementia. Explain the signs of dementia, how it usually progresses and what support is available. Give people: • printed information on dementia • opportunities for one-to-one discussion with a professional • advice on communication strategies for people with dementia. 1.5.37 Commissioners should ensure information is provided to family members, carers and advocates of people with learning disabilities who are being assessed for, or have been diagnosed with dementia. Consider also providing training. Information and training might cover: • types of dementia • how dementia might present in people with different learning disabilities • care pathways for different dementias • practical steps to manage daily life • communication skills • how to find further advice and ongoing support, including support groups and respite services (short breaks). 1.7.3 Managers in health and social care services should ensure that all staff working with people with learning disabilities have skills and knowledge in…common health conditions to which people with learning disabilities are predisposed, for example, the earlier onset of dementia"
NG97	"1.3.6 Service providers should design services to be accessible to as many people living with dementia as possible, including…people with learning disabilities, sensory impairment (such as sight or hearing loss) or physical disabilities"
NG54	"1.6.4 During annual health checks with adults with Down's syndrome, ask them and their family members, carers or care workers (as appropriate) about any changes that might suggest the need for an assessment of dementia, such as: • any change in the person's behaviour • any loss of skills (including self-care) • a need for more prompting in the past few months. 1.7.5 Refer people with learning disabilities who have a suspected serious mental illness or suspected dementia to a psychiatrist with

	expertise in assessing and treating mental health problems in people with learning disabilities. 1.8.16 Consider supplementing an assessment of dementia with an adult with learning disabilities with: • measures of symptoms, such as the Dementia Questionnaire for People with Learning Disabilities (DLD), the Down Syndrome Dementia Scale (DSDS) or the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) • measures of cognitive function to monitor changes over time, such as the Test for Severe Impairment (TSI) • measures of adaptive function to monitor changes over time. 1.8.17 Complete a baseline assessment of adaptive behaviour with all adults with Down's syndrome.”

Source: (Overview | Mental Health Problems in People with Learning Disabilities: Prevention, Assessment and Management | Guidance | NICE, n.d.-a), (Overview | Care and Support of People Growing Older with Learning Disabilities | Guidance | NICE, n.d.), (195)

These recommendations highlight the importance of ensuring that people with an LD can access dementia pathways and be assessed by health professionals with knowledge and expertise of how dementia presents in adults with an LD.

They also highlight the importance of giving accessible information about dementia to individuals with an LD and their carers, and the importance of offering training to social care staff on this area.

Finally, dementia is an area that should be covered in annual health checks.

11.9.4 What is the pathway for diagnosis of dementia in people with an LD in Cambridgeshire and Peterborough?

Individuals are seen in outpatient specialist LD services in Cambridgeshire and Peterborough, however there is not a defined pathway for adults with an LD who need to be assessed for dementia in Cambridgeshire and Peterborough.

There is no formally commissioned training for health or social care staff relating to the needs of people with LD who have dementia.

11.9.5 Recommendations

Healthcare commissioners

- Commissioners should ensure there is a clear pathway for diagnosis of adults with an LD who need assessment for dementia.
- Commissioners should assure themselves that the NICE recommendations relevant to the needs of people with an LD who have dementia are being met in Cambridgeshire and Peterborough.

Unpaid carers

- Consider offering education and support for unpaid carers who care for adults with an LD around healthy ageing, including dementia awareness.
- Ensure accessible information is available for individuals with an LD and their carers about dementia.

Social care providers and commissioners

- Commissioners and providers should ensure that care staff who care for adults with an LD have the skills and knowledge to support people with dementia.

Primary care

- Ensure that questions around dementia are included in the AHC.

Care planning

- Planning for later life should be part of care planning for adults with an LD and their carers.

12. Physical health

12.1 Common Physical Health Conditions

This chapter describes the prevalence of common physical health conditions amongst people with a learning disability. People with learning disabilities (LD) are 43 times more likely to have self-rated poor general health outcomes, compared to the general population (198).

Table 12.1 below describes the prevalence of long-term physical health conditions in people on the primary care LD register and the general population. Data is taken from two robust population studies using primary care data:

- Cooper et al, 2015 : this was an analysis of 1.4 million adults (aged 18+ years) and 8014 people with an LD registered at 314 Scottish general practices. Prevalence rates were calculated, standardised for age, sex and neighbourhood deprivation.
- Carey et al, 2016 (199): this was an analysis of 86,221 adults (aged 18 - 85 years) and 14,751 people with an LD registered with 408 English general practices.

Table 12.1: Prevalence of physical health conditions

Health Conditions	Prevalence in LD population	Prevalence in general population (aged 18+)	Measurement* (Effect size 95%CI)	Reference
Conditions with a higher recorded rate in the LD population				
Epilepsy	18.8%	0.8%	OR 31.03 (29.23 - 32.93)	(200)
Constipation	14.0%	2.5%	OR 11.19 (10.97 – 12.68)	
Parkinsonism	0.35%	0.19%	OR - 2.83 (1.95 - 4.13)	
Migraine	0.74%	0.65%	OR - 1.32 (1.02 - 1.71)	
Bronchiectasis	0.3%	0.2%	OR 1.68 (1.08 – 2.61)	
Diabetes	6.9%	4.4%	PR 1.64 (1.53 – 1.75)	(199)
Hypothyroidism	7.9%	3.1%	PR 2.69 (2.52 – 2.87)	
Chronic kidney disease	3.2%	2.1%	PR 1.64 (1.49 – 1.82)	
Heart failure	0.8%	0.4%	PR 2.26 (1.84 – 2.78)	
Osteoporosis	1.7%	1.0%	PR 1.84 (1.60 – 2.12)	
Asthma	8.2%	6.6%	PR 1.25 (1.18 – 1.33)	

Conditions with a lower recorded rate in the LD population				
Hypertension	10.7%	12.1%	PR 0.93 (0.89 – 0.98)	(199)
Ischemic Heart Disease	1.7%	2.7%	PR 0.65 (0.57 – 0.74)	
COPD	2.6%	3.7%	OR 0.84 (0.73 – 0.97)	(199)
Atrial fibrillation	0.9%	1.7%	OR 0.83 (0.61 – 0.98)	
Prostate Disease	0.5%	1.1%	OR 0.60 (0.44 – 0.82)	
Diverticular disease	0.8%	2.4%	OR 0.49 (0.39 – 0.63)	
Inflammatory Arthritis (incl. gout)	1.88%	4.08%	OR 0.57 (0.48 – 0.67)	
Peripheral vascular disease	0.7%	1.6%	OR 0.44 (0.33 – 0.60)	
Chronic sinusitis	0.3%	0.6%	OR 0.44 (0.26 – 0.62)	
Multiple sclerosis	0.11%	0.27%	OR - 0.49 (0.25 - 0.96)	
Conditions with equal recorded rate to the general population				
Inflammatory bowel disease	0.5%	0.7%	OR 0.82 (0.60 – 1.13)	(200)
Irritable bowel syndrome	3.1%	5.7%	OR 0.97 (0.86 – 1.1)	
Glaucoma	0.9%	1.1%	OR 1.17 (0.92 – 1.48)	
Viral hepatitis	0.1%	0.1%	OR 0.82% (0.39 – 1.74)	

*OR: odds ratio; PR: prevalence ratio.

Use of these studies gives an indicator of which physical health conditions are likely to be more common in adults with an LD. Epilepsy and constipation have the highest odds ratios, meaning these are the conditions with the biggest difference in prevalence between adults with an LD and the general population. These conditions are considered in subsequent chapters.

Limitations in the completeness of GP LD registers means that these figures may not be reflective of the whole population of adults with an LD. These figures may also be impacted by underdiagnosis of conditions in people with an LD or inaccurate or incomplete coding.

12.2 Epilepsy

12.2.1 What is epilepsy?

Epilepsy is a neurological condition that can cause individuals to suffer from seizures. There are different types of seizure, which can cause a wide range of symptoms, including absences, uncontrolled movements or loss of consciousness (201). Epilepsy can be managed through medication, or in rare cases surgery or special diet (201). Causes include head trauma, hypoxic brain injury at birth, brain tumours or brain infections; it is not always possible to find a cause for epilepsy (201).

12.2.2 What is the prevalence of epilepsy in people with an LD?

Epilepsy is more common in people with a learning disability than the general population. Its prevalence increases with severity of LD, meaning that it is probably even more common in people known to specialist LD services or living in specialist residential accommodation (202). It is estimated that around 10% of people with a mild LD have epilepsy, compared with 30% of people with a severe or profound LD (203).

In Cambridgeshire and Peterborough, prevalence of epilepsy amongst individuals aged 14 years and over on the primary care LD register is 17% (708 patients), similar to the prevalence found in research studies.

12.2.3 What are the consequences of epilepsy?

Good management of epilepsy is important for a number of reasons (202):

- Poorly controlled epilepsy can have negative impacts on an individual's quality of life (202);
- Epilepsy increases the risk of an individual dying suddenly; this is known as SUDEP (Sudden Death in Epilepsy). Someone with epilepsy is over 20 times more likely to die suddenly than someone without epilepsy (204);
- People with epilepsy also have an overall risk of dying that is higher than people without epilepsy (205). Causes of death associated with epilepsy include SUDEP, death during status epilepticus, accidental death and suicide (206).

12.2.4 What is best practice for epilepsy management in people with an LD?

- NICE guidance sets out best practice for managing epilepsy in the general population (207). This guidance also covers children, young people and adults with a learning disability.
- The NICE guidance for people with a learning disability is broadly the same as for the general population, with the addition that people with a learning disability should be considered for whole genome sequencing, and should have an annual review of their epilepsy management. It emphasises that people with a learning disability should not be excluded from tertiary referrals for surgery or other specialist intervention.

- In practice, epilepsy in people with a learning disability can be managed via neurology or via learning disability psychiatry; there is no clear national consensus on what is the best route.
- An evidence review was undertaken for the purposes of this literature review, to consider if there were any additional interventions that can support people with an LD to self-manage their epilepsy. No interventions were identified.

12.2.4 What are the issues for people with an LD who have epilepsy?

A recent Royal College of Psychiatrists report (2017) highlighted a number of issues that people with an LD who have epilepsy may face:

- People with an LD are less likely to have well controlled epilepsy than people without LD. This may be for a number of reasons, including genetic or chromosomal abnormalities associated with their learning disability (202);
- People with an LD may need additional support in taking medication and managing risks associated with epilepsy;
- People with an LD may wait longer for investigations or tertiary-level treatment than people without an LD.

12.2.5 What is the pathway for management of epilepsy in adults with an LD in Cambridgeshire and Peterborough?

There is not a clearly defined pathway for management of epilepsy in adults with an LD in Cambridgeshire and Peterborough. Some individuals known to LD psychiatry will be managed by LD psychiatrists, others may be managed in neurology. There is no formal pathway in place around shared management of cases.

12.2.6 Recommendations

Healthcare commissioners

- Ensure that people with an LD in Cambridgeshire and Peterborough are offered diagnostic and treatment pathways for epilepsy that are in line with NICE guidance for the diagnosis and management of epilepsy regardless of whether they are managed in specialist epilepsy services or learning disability psychiatry;
- Ensure that specialist epilepsy services in neurology are able to make reasonable adjustments for people with a learning disability.

Unpaid carers

- Consider if there is a need for a specific training offer for unpaid carers of people with epilepsy.

Social care providers and commissioners

- Ensure that care providers of people with a learning disability offer their staff training on epilepsy as standard, reflecting the likely high prevalence of epilepsy amongst their residents.

12.3 Constipation

12.3.1 What causes constipation?

Constipation is defined as when individuals are not opening their bowels frequently or are passing very hard stool (208). There are 3 main causes of constipation (209):

- Idiopathic – no obvious medical cause, but associated with lifestyle factors such as diet and physical activity;
- Medical – linked to a specific medical condition;
- Iatrogenic – caused by medication.

12.3.2 How common is constipation in people with an LD?

It is difficult to get exact data on constipation in people with an LD in England. However, research looking at primary care data from LD registers suggests that it is much more common in people with an LD (210).

The reasons for this higher prevalence are varied. People with an LD are more likely to have an unhealthy diet and be physically inactive; they are more likely to have certain medical conditions linked to constipation, such as hypothyroidism, and they are more likely to be on medication that causes constipation as a side effect, such as antipsychotics (211). Increased severity of learning disability increases the risk of constipation (209).

12.3.3 What are the consequences in people with an LD?

Constipation can be misdiagnosed in people with an LD, who may not be able to communicate their symptoms. Left untreated, constipation can have significant health consequences. These include poor quality of life (with a similar impact to that seen with significant long term conditions such as diabetes, arthritis and inflammatory bowel disease); faecal incontinence; prolapse; faecal impaction leading to bowel obstruction and perforation, and in some cases death (211).

12.3.4 How is it managed?

Constipation can be managed through lifestyle changes, such as increasing fluid and fibre intake as well as increasing levels of physical activity (209). Abdominal massage can also be used, as well as support with toilet training and medication review if indicated (209). If these measures don’t work, then laxatives can be prescribed.

12.3.5 Recommendations

Health promotion

- People with an LD should be supported to be physically active and to eat a balanced diet.

Unpaid carers

- Unpaid carers of people with an LD should be supported to be aware of the symptoms and signs of constipation.

Social care providers

- Social care providers should ensure that their staff are aware of the symptoms and signs of constipation.
- Social care providers should ensure that their staff are supporting the people they care for to be physically active and eat healthily.

Primary care

- Bowel habits should be enquired about at the annual health check.
- Advice should be offered around diet and physical activity.

12.4 Dysphagia

12.4.1 What is dysphagia?

Dysphagia is “difficulty in eating, drinking or swallowing” (212). It can be caused by a wide range of conditions, including neurological conditions such as stroke, dementia, cerebral palsy or multiple sclerosis; gastro-oesophageal reflux disease, or cancer (213).

12.4.2 What are the consequences of dysphagia?

Dysphagia can have significant health and wellbeing consequences for people who are affected, including (214):

- Aspiration pneumonia;
- Choking;
- Inflammation of lungs or oesophagus;
- Malnutrition;
- Dehydration;
- Reduced quality of life due to loss of enjoyment in eating and drinking.

12.4.3 What is the prevalence of dysphagia in people with an LD?

It is difficult to quantify the true prevalence of dysphagia in people with an LD, as it often goes unrecognised (214).

An extensive systematic review found it challenging to find good quality data to estimate prevalence; the best available evidence suggested a prevalence of 8.1%-11.5% of people known to specialist LD services (214), but acknowledged that this is probably an underestimate.

Risk factors for dysphagia in people with an LD include (214–216):

- Increasing age;
- Increasing severity of LD;
- Cerebral palsy;
- Poor oral health.

12.4.4 What is the best practice for management of dysphagia in people with an LD?

Initial investigation of new onset dysphagia depends on the suspected clinical cause. Speech and language therapists will generally be involved in supporting the long-term management of dysphagia, with regards to supporting recommendations regarding texture of food, prompting and behavioural support during meal times, positioning and any additional equipment that may be needed.

There is a lack of research around interventions to support people with LD specifically (214).

12.4.5 What are the issues around management of dysphagia in people with an LD?

However, research and serious incident reviews have identified a number of issues that recur in management of dysphagia in people with an LD ((214,217):

- Paid and informal carer awareness and knowledge around recognition of dysphagia;
- Paid and informal carer awareness and knowledge of the importance of adherence to strategies to manage dysphagia, leading to lack of adherence to care plans;
- Lack of reporting of incidents of choking;
- Lack of carer training in First Aid, including management of choking;
- Intersection between eating behaviours, such as bolting food or eating non-food items, and dysphagia;
- Lack of understanding of care pathways for individuals with dysphagia amongst care staff and health staff.

12.4.6 What is the pathway in Cambridgeshire and Peterborough?

There are specialist LD speech and language therapists who receive dysphagia referrals in both Cambridgeshire and Peterborough. Pathways outlining how to access these services are in section 17.

12.4.7 Recommendations

The recommendations below are based on best practice reviews and summaries of available research evidence (215,217).

Health care commissioners and providers

- All health staff working with people with an LD should be required to have up-to-date Basic Life Support training as a minimum contractual requirement in service specifications.
- Commissioners and providers should ensure that all health staff working with people with a learning disability receive regular training around eating and drinking/dysphagia that is appropriate to their role.

Social care commissioners and providers

- All social care staff working with people with an LD should be required to have up-to-date Basic Life Support training as a minimum contractual requirement in service specifications.
- Commissioners and providers should ensure that all care staff working with people with a learning disability receive regular training around eating and drinking/dysphagia that is appropriate to their role.

Care planning

- Care plans should consider eating and drinking needs as standard.
- Care plans should include regular dental check-ups; attendance should be monitored as part of the annual review.

Primary care

- Annual health checks should include questions around eating and drinking.

Unpaid carers

- There should be consideration of how to offer unpaid carers of people with a learning disability training around eating and drinking/dysphagia.

Specialist LD services commissioners

- Currently there is only one qualified specialist LD speech and language therapist in post covering Peterborough (see section 17). Consideration is needed from commissioners of how to improve the resilience of this service.

12.5 Inability to maintain a natural body shape (postural care)

12.5.1 What is body distortion?

Many individuals with a profound learning disability will have problems maintaining their natural body shape, often due to difficulties in moving or changing position independently (218). Postural care is the term used for care aimed at supporting individuals to maintain their natural body shape (219). Postural care may involve provision of specialist seating, lifting equipment and advice to carers around positioning (219). It is a 24 hour need, not a sporadic need.

12.5.2 What are the consequences of not being able to maintain a natural body shape?

Consequences of body distortion include (218,219):

- Respiratory: chest infections, pneumonia;
- Musculoskeletal and neurological: spasticity, contractures, hip dislocation, osteoporosis;
- Skin integrity: pressure sores;
- Pain;
- Gastrointestinal: difficulty swallowing, aspiration; constipation;
- Quality of life: difficulty in moving and receiving personal care; difficulty in interacting with surrounding environment.

Provision of postural care has been recognised as vitally important for preventing avoidable deaths from respiratory infection in adults with an LD (220).

12.5.3 How many people with a learning disability need postural care?

It is very difficult to estimate how many people need postural care; however, the number of people with profound and multiple learning disabilities can be used as a proxy (219).

12.5.4 What is the pathway for accessing postural care in Cambridgeshire and Peterborough?

Postural care is usually led by specialist LD physiotherapists (221).

The pathway for accessing specialist LD physiotherapy for Cambridgeshire is in section 17. However, currently all posts are vacant. This means there is no clear route to access postural care for adults with a learning disability in Cambridgeshire.

Specialist LD physiotherapy is not commissioned in Peterborough. This means there is no access to postural care for adults with an LD in Peterborough.

12.5.5 Recommendations

Cambridgeshire and Peterborough ICB

- There is an urgent need to re-establish postural care pathways for both Cambridgeshire and Peterborough.

Social care providers

- Where individuals have postural care systems, carers must be adequately trained so that they understand the importance of adhering to them 24 hours/day.

Unpaid carers

- Where individuals have postural care systems, carers must be adequately trained so that they understand the importance of adhering to them 24 hours/day.

Mainstream healthcare service providers

- Consideration is needed as to the best pathway for managing postural care need when an individual is admitted to hospital.

12.6 Oral health

12.6.1 What is the prevalence of oral health problems amongst adults with an LD?

Obtaining good quality data on the prevalence of oral health problems in adults with an LD is very challenging, due to the very fragmented nature of dentistry in England. There is no systematic data available at national or local level on access to NHS or private dentistry by people with an LD, or on levels of oral disease. National surveys have often excluded people with an LD.

Some small surveys have been undertaken in England (222–224). These suggest that adults with an LD have poorer oral health than the general population.

12.6.2 Risk factors for poor oral health

Adults with an LD have a number of risk factors for poor oral health (222,225):

- Poor diet, particularly high sugar intake, which may be due to consumption of sugary foods or sugar added to medication or nutritional supplements;
- Side effects of medications, particularly related to reduced saliva flow;
- Challenges with toothbrushing, for example lack of carer knowledge of the importance of good oral hygiene and adequate skill in toothbrushing; sensory needs that mean an individual finds toothbrushing difficult to tolerate;

- Associated medical comorbidities may increase the risk of oral health problems, for example gastro-oesophageal reflux disease or being a non-oral feeder.

12.6.3 What are the consequences of poor oral health?

Poor oral health has many consequences (226–228):

- Pain due to infections or cavities;
- Tooth loss, which can impact negatively on nutrition;
- Increased risk of pneumonia and coronary heart disease;
- Impaired quality of life.

12.6.4 How should oral health problems be prevented and managed?

National evidence-based advice for prevention of oral health problems in adults is as follows (229):

Table 12.2: Prevention of oral health problems in all adults

Recommendation	**Strength of recommendation**
"Brush teeth at least twice daily: • last thing at night (or before bedtime) and on at least one other occasion • with toothpaste containing 1,350 to 1,500ppm fluoride • spitting out after brushing rather than rinsing with water, to avoid diluting the fluoride concentration"	Strong
"Minimise the amount and frequency of consumption of sugar-containing food and drinks"	Strong
"Avoid sugar-containing foods and drinks at bedtime when saliva flow is reduced and buffering capacity is lost"	Conditional
Professional intervention	
"Assign a recall interval ranging from 3 to 24 months, based on oral health needs and disease risk"	Conditional

Source: (229)

Table 12.3: Oral health prevention in adults giving concern because of dental caries risk

Recommendation	Strength of recommendation
All the above, plus:	
Advice	
"Support toothbrushing where required (for example carer assistance, specialised brush, non-foaming toothpaste)"	Good practice
"Use a fluoride mouth rinse daily (0.05% NaF; 230 ppmF) at a different time to toothbrushing"	Conditional
Professional intervention	
"Apply fluoride varnish to teeth 2 times a year (2.26% NaF)"	Strong
"For those with active coronal or root caries, consider recommending or prescribing daily fluoride rinse (0.05% NaF; 230 ppmF, to be used at a different time from toothbrushing) until dental caries risk is reduced"	Conditional
"For those with obvious active coronal or root caries, consider prescribing 2,800 or 5,000ppm fluoride toothpaste until dental caries is stabilised and risk is reduced"	Conditional
"Where a patient is prescribed medication frequently or long term, liaise with medical practitioner to request that it is sugar free"	Good practice
"Investigate diet and assist adoption of good dietary practice in line with the Eatwell Guide"	Good practice
"Assign a shortened recall interval based on dental caries risk"	Conditional

Source: (229)

Additional recommendations for supporting good oral health in adults with a learning disability include (222):

- Reducing anxiety around visiting the dentist, which may include providing EasyRead information, visiting the practice or desensitisation work;
- Providing training and education to carers around oral health, including around toothbrushing;
- Provision of accessible information to people with an LD about oral health;
- Providing training to dental staff around reasonable adjustments.

An evidence review was undertaken for this needs assessment, to look at whether there are any specific interventions around oral health promotion for this cohort; there was no strong evidence for any particular type of intervention.

12.6.5 NICE guidance

Given the lack of long-term, high-quality evidence to support oral health interventions in people with LD, consideration should be given to evidence and guidelines pertaining to oral health interventions in the general population, assessing applicability for people with LD. Relevant NICE guidelines include (230–232):

- Oral health for adults in care homes [NG48]
- Oral health promotion: general dental practice [NG30]
- Oral health: local authorities and partners [PH55]

These documents provide an overview of national guidance on oral health interventions recommended for application within the general population.

Relevant quality standards are set out in table 12.4.

Table 12.4: NICE quality standards on oral health relevant to people with an LD

Oral health in care homes [QS151]	1. "Adults who move into a care home have their mouth care needs assessed on admission 2. Adults living in care homes have their mouth care needs recorded in their personal care plan 3. Adults living in care homes are supported to clean their teeth twice a day and to carry out daily care for their dentures."
Oral health promotion in the community Quality standard [QS139]	1. "Local authorities carry out oral health needs assessments to identify groups at high risk of poor oral health as part of joint strategic needs assessments. 2. Health and social care services include oral health in care plans of people who are receiving health or social care support and at high risk of poor oral health."

Sources: (233,234)

12.6.6 Fluoridation

Fluoridation is where fluoride is added to drinking water with the aim of reducing dental decay (235). This is a population-level intervention. There is very strong research evidence that fluoridation significantly reduces dental decay without harmful impacts on wider health (235). Because this intervention does not rely on behaviour change, it is very effective at reducing inequalities in oral health for populations who may be less likely to respond to interventions that rely on individual action (ibid).

Currently, water is not fluoridated in Cambridgeshire and Peterborough. Fluoridation of water is likely to significantly improve the oral health of people with learning disabilities.

12.6.7 What are the pathways in C&P?

There are severe national problems with access to NHS dentistry in England. These problems are replicated in Cambridgeshire and Peterborough. Patients who are not already registered with an NHS dentist may find it extremely challenging to find an NHS dentist for routine care.

There is a special care NHS dentistry pathway for Cambridgeshire and Peterborough. This service is called Dental HealthCare, and is provided by Cambridgeshire Community Services. This service will accept referrals for “adults with complex needs who have a proven difficulty in accessing or accepting care in general dental services, including adults with moderate and severe learning and physical disabilities or mental health problems” (236). This service will only accept referrals from registered dental practitioners.

There are no oral health prevention schemes for adults commissioned in Cambridgeshire and Peterborough.

12.6.8 Recommendations

Health promotion

- Given the lack of good quality data and the current issues with accessing NHS dentistry, commissioning an oral health survey for the most vulnerable cohorts (adults in nursing and residential care) of adults with LD would enable an understanding of unmet need.
- Incorporate messaging around toothbrushing and oral health into regular wider health promotion work with adults with learning disabilities.
- Consider initiating discussions around introducing water fluoridation.

Primary care

- Ensure annual health check discussion covers attendance at routine dental check-ups.

Social care providers and commissioners

- Ensure staff who are required to support with toothbrushing are trained on how to do so appropriately.
- Ensure that staff training around health promotion includes elements of oral health promotion.

Care planning

- Ensure that mouth care is explicitly incorporated into care plans.
- Attendance at routine dental appointments should be incorporated into care plans, including any necessary support for attendance.

12.7 Underweight

12.7.1 Definition

The definition of being underweight is having a BMI less than 18.5. Being underweight can have many harmful consequences, including (237–239):

- Increased risk of nutritional deficiencies such as anaemia
- Increased risk of osteoporosis
- Fertility problems
- Weakened immune system
- Reduced energy levels
- Poor wound healing

12.7.2 Prevalence

There is very limited data on the prevalence of being underweight amongst adults with an LD. The data that exists suggest that it is more common than in the general population, particularly for adults with a severe LD or profound and multiple learning disabilities (240).

12.7.3 Risk factors

Adults with profound and multiple disabilities are particularly at risk of being underweight, because they often have difficulties with feeding and swallowing (237).

12.7.4 Interventions

Management of underweight and malnutrition requires specialist dietetics input.

12.7.5 Cambridgeshire and Peterborough pathway

There are no specialist LD dieticians in Cambridgeshire or Peterborough. Instead, individuals are referred to the mainstream dietetics team in CPFT, with reasonable adjustments as appropriate. This pathway has good links to specialist LD services.

12.7.6 Recommendations

These recommendations focus on adults with profound and multiple disabilities, as they are at highest risk of malnutrition.

Primary care

- Measuring weight is a component of the AHC. Commissioners and providers should ensure that there is access to wheelchair-accessible scales in the community, so that individuals who can't weight bear can be weighed.

Social care providers

- Social care staff should receive training on diet and nutrition appropriate for the needs of the residents they are caring for.
- Residential care providers should ensure they have access to scales, including wheelchair-accessible scales, for individuals where weight monitoring is indicated.

Specialist LD health services commissioners

- Health commissioners should consider whether there is sufficient breadth of dietetic support to meet the needs of adults with an LD, as per Royal College of Psychiatrist recommendations in section 17 of this needs assessment.

12.8 Falls prevention

12.8.1 How common are falls in adults with an LD?

Adults with an LD fall more frequently than the general population; it is estimated that 25%-40% of adults with an LD fall each year, which is a similar rate adults aged over 65 years in the general population (241–243).

12.8.2 What are the risk factors?

The increased falls rate partly reflects the fact that adults with an LD become frailer at an earlier age – falls prevention interventions should be targeted at adults with an LD aged 50 years and older (241).

The increased falls rate also reflects the increased prevalence of other risk factors for falls in adults with an LD, including the following (243):

- Epilepsy
- Sight loss
- Medication
- Issues with balance or gait
- Impaired mobility
- Reduced levels of physical activity

12.8.3 What are the consequences of falls?

Falls can cause serious injury, such as a fracture, and in some cases even lead to death (244). Falls can also have negative psychological and social consequences for an individual, including anxiety and loss of confidence (244).

12.8.4 How can falls be prevented?

Although there is not a significant evidence base around falls prevention specifically in people with an LD, the same principles around prevention can be applied (245). Prevention is based around the principles of multifactorial falls risk assessments (MFFRA), which take a holistic view of an individual's risk factors, including gait, physical activity, vision, environmental risks, and medication. Bone health is another key component that should be considered.

Actions that may be taken following an MFFRA include: promotion of strength and balance activities; review of medication; mitigation of environmental hazards, for example by providing aids or adaptations; promotion of bone health.

12.8.5 Recommendations

Physical activity

- Recommendations contained in the physical activity section (7.7) will also support with falls prevention.

Specialist falls prevention services

- Commissioners and providers should ensure that specialist falls prevention services are able to make appropriate reasonable adjustments for adults with an LD.

Specialist LD physiotherapy

- Specialist LD physiotherapists may also be able to support with falls prevention in complex cases. Recommendations on specialist LD physiotherapy provision will also support this area.

Social care providers

- Social care providers should ensure that staff have appropriate training around falls prevention, both in terms of individual and environmental risk factors.

12.9 Hearing impairment

12.9.1 What is the prevalence of hearing impairment in people with a learning disability?

There are a wider range of causes of hearing impairment, including noise, ageing, genetic causes and infections (246). Some causes of learning disability are associated with an increased risk of hearing loss, such as Down's Syndrome (247).

Estimates of hearing loss amongst people with a learning disability vary. Estimates based on primary care records suggest a prevalence of around 8% (248), which is around three times higher than the general population. Studies that have actively tested hearing, rather than solely relying on diagnosed cases, have suggested a much higher prevalence, particularly in people with a severe learning disability, where as many as 40% of individuals have been found to be hearing impaired (249–252).

12.9.2 What are the consequences of hearing impairment?

Hearing loss can lead to missed opportunities to learn, communication problems, isolation and potentially mental ill health or challenging behaviour (253). Untreated, it is a risk factor for dementia (254).

There is evidence to suggest that people with a learning disability struggle to access audiology, for a number of reasons (253,255):

- Symptoms of hearing loss are not identified by carers;
- Diagnostic overshadowing by health professionals;
- Reliance on self-referral to access audiology services.

12.9.3 What is the pathway for managing hearing impairment in C&P?

Managing hearing loss in people with a learning disability is considered to require specialist assessment by audiology in secondary care, not high street audiologists (255). There are specialist audiology services for adults with an LD provided by Cambridgeshire University Hospitals NHS Trust in Cambridgeshire, accessed via GP referral. It has not been possible to identify if there is an equivalent service in Peterborough.

Currently there are no commissioned screening pathways for adults with a learning disability.

12.9.4 Recommendations

Primary care

- Ensure that the annual health check includes questions about hearing loss.
- Ensure that primary care staff understand how to access specialist audiology services for adults with an LD.

Cambridgeshire and Peterborough ICB

- Consider whether there is a need for regular screening in residential settings.

Health promotion

- Ensure awareness that audiology services for people with a learning disability are accessed through specialist audiology, not high street hearing tests.

Social care providers

- Ensure that social care staff have an awareness of signs of hearing loss amongst adults with an LD.

12.10 Sight problems and visual impairment

12.10.1 What causes sight problems and visual impairment?

There are many causes of sight problems and visual impairment. These range from refractive errors, which are corrected with glasses, to developmental problems, squints, issues with eye muscles and diseases such as diabetic retinopathy, macular degeneration and glaucoma, which can cause blindness.

12.10.2 How common is visual impairment in people with an LD?

Research suggests that visual impairment is ten times more common in adults with an LD than the general population (256). Around 60% of adults with an LD are estimated to have refractive errors, meaning that they need glasses, around 5%-10% are estimated to have a visual impairment and around 2% are blind (256).

Risk of visual impairment increases with increased severity of learning disability (257). There are also some specific types of sight problem that are associated with certain syndromes, for example people with Down's syndrome are more likely to develop keratoconus (257).

12.10.3 What are the consequences in people with an LD?

Sight problems can have many negative consequences for people with an LD, including negative impacts on someone's quality of life, ability to interact socially and find employment, and increased risk of falls (257).

12.10.4 How is it managed?

All adults should have an NHS sight test from an optician every two years. These sight tests can be adapted for any severity of disability, including people who are non-verbal (257).

Sight tests will look at visual acuity as well as broader eye health. Individuals can be referred to hospital-based ophthalmology services if needed.

It is difficult to get good data on uptake of sight tests in people with an LD, however surveys of adults known to specialist LD services suggest a high proportion have not had a sight test within the recommended time period (258).

Barriers to accessing sight tests include (258,259): assumptions that they aren't needed for, or can't be accessed by, individuals who can't read; lack of flexibility in pathways to accommodate the need for reasonable adjustments; diagnostic overshadowing, with attribution of problems caused by impaired vision to the individual's learning disability.

12.10.5 Local pathway

NHS sight checks are usually accessed via high street opticians. There is a legal requirement for providers of NHS care to make reasonable adjustments for individuals with an LD, however in practice the funding provided for an NHS sight check can make it challenging for a provider to make those adjustments (257,259).

The national charity SeeAbility, which advocates for people with an LD who have sight loss, keeps a register of opticians that particularly welcome individuals with an LD to attend their optical practice; this register is voluntary and relies on a practice putting themselves forward. There are 4 practices listed for Cambridgeshire and Peterborough on this register (260).

The NHS also commissions domiciliary eye tests, for those who are unable to leave home unaccompanied due to a physical or mental illness, which includes physical disability or cognitive impairment (261). This covers individuals who live in their own home and those who live in supported living or a care home (262).

Some areas commission specialist LD sight test pathways, to provide additional funding to support longer appointment times and to allow staff to develop expertise in managing the needs of individuals with more severe disabilities (259). There is no such pathway commissioned in Cambridgeshire and Peterborough currently.

12.10.6 Recommendations

Primary care

- The AHC should ask about attendance at routine sight tests.

Social care providers and commissioners

- Providers of residential social care should ensure that they support the people they care for to access routine sight tests.

Care planning

- Attendance at routine sight tests should be incorporated into an individual's care plan, with support identified if required.

Optometry commissioners

- Commissioners of NHS sight tests should ensure that their providers have sufficient capacity, training and resource to make reasonable adjustments.

12.11 Pneumonia

12.11.1 What is pneumonia?

Pneumonia is a term for an acute respiratory infection, which may be cause by a virus, bacteria or fungi (263). Pneumonia can be categorised as hospital acquired pneumonia or community acquired pneumonia, depending on where the individual was when they developed their infection; this distinction is made as different organisms are different (263,264). It can range in severity, with the most severe infections having a high risk of mortality (263). Aspiration pneumonia contributes to both community acquired pneumonia and hospital acquired pneumonia (265).

12.11.2 How common is pneumonia?

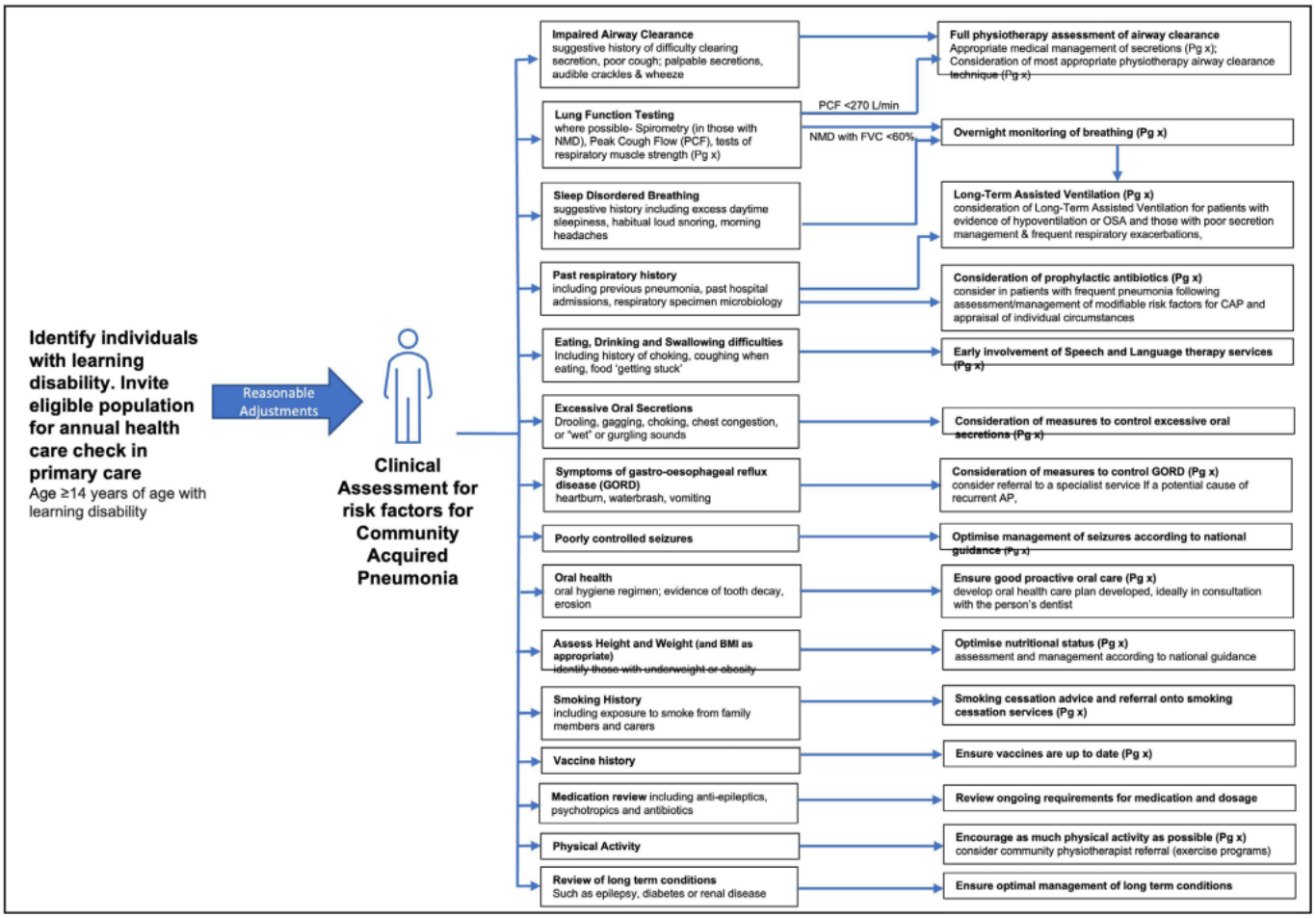
It was not possible to obtain local data on hospital pneumonia admissions for adults on the LD register in Cambridgeshire and Peterborough.

A population-based observational study in England using GP record data linked to hospital admissions data showed that hospital admissions for influenza or pneumonia were almost 4 times as common in people with an LD compared to those without (this study included adults and children) (266).

12.11.3 How can pneumonia be prevented?

The BTS guidance on community acquired pneumonia for people with an LD sets out clear guidance on prevention of community acquired pneumonia in this group.

These recommendations are set out in figure 12.1.



Source:(50) reproduced from Thorax, Legg J, Allen J, Andrew M, *et al,* 78:s1-s31, 2023 with permission from BMJ Publishing Group Ltd

The guidance also recommends support for carers in recognising early signs of clinical deterioration, for example through the use of RESTORE2 (50) (RESTORE2 is a clinical early warning tool for use in the community).

12.11.4 What pathways exist in Cambridgeshire and Peterborough?

There is not a clear pathway for assessment of adults with an LD who need a medical assessment or specialist LD physiotherapy assessment to reduce their risk of community acquired pneumonia in Cambridgeshire and Peterborough. There is a specialist clinic that has just commenced in CUH for individuals transitioning from paediatric respiratory into adult respiratory services, but it has not been possible to determine the capacity or geographical scope of the clinic at the time of completing this needs assessment.

As discussed in section 17, there are significant gaps in specialist LD physiotherapy pathways in both Cambridgeshire and Peterborough currently.

12.11.5 Recommendations

Cambridgeshire and Peterborough ICB

- Further work is needed to clarify the local pathway for medical assessment for individuals at risk of community acquired pneumonia for Cambridgeshire and Peterborough, in line with BTS guidance.
- The LD physiotherapy vacancies in Cambridgeshire and lack of commissioned service in Peterborough represent significant risks, although significant work has been undertaken in Cambridgeshire to try to fill the current vacancies. Further support is needed to address the service gaps across both areas.
- Further work is needed to support local data linkage between primary care and hospital episode statistics datasets, via DSCRO, to enable monitoring of hospital admissions for pneumonia.

Informal carers

- Informal cares need support in recognising signs and symptoms of clinical deterioration, to enable early recognition and treatment.

Social care providers and commissioners

- Residential care providers should ensure that staff have training on recognition of signs and symptoms of clinical deterioration that is appropriate to their role.

Healthcare commissioners

- RESTORE2 training should be offered to learning disability residential settings as well as older people’s settings.

13. Social care

Although the focus of this needs assessment is health needs of adults with an LD, not care needs, in practice the two are often linked. Therefore, this section will consider social care commissioning for adults with an LD, with a focus on the overlap with health needs.

13.1 What social care services are commissioned for individuals with an LD?

Cambridgeshire County Council and Peterborough City Council commission a range of services for adults with an LD, including:

- Nursing homes;
- Residential homes;
- Supported living
- Respite care;
- Crisis care;
- Domiciliary care;
- Shared lives;
- Day opportunities;
- Advocacy services.

13.2 Residential care (nursing homes, residential homes, supported living)

Housing needs assessments have recently been undertaken by the local authority in both Cambridgeshire and Peterborough to understand demand for specialist accommodation. The current commissioned provision and number of service users in LD residential care is set out in table 13.1.

Table 13.1: commissioned residential care for adults aged 18-65 years with an LD in Cambridgeshire and Peterborough

	Cambridgeshire	Peterborough
	Number of service users	Number of service users
Nursing home	5	3
Residential home	193	54
Supported living	430	116
Total	628	173

Source: (267,268)

13.2.2 Demographics of service users in long term residential care

There is some demographic information available for Cambridgeshire residents.

41% are female and 59% are male, which is in keeping with national and local demographics (see section 5).

An age profile is set out in table 13.2.

Table 13.2 Age profile of residents aged 18-65 years in long term care funded by CCC or Cambridgeshire and Peterborough ICB, resident in Cambridgeshire

Age band	Number	%
18-24 years	76	12
25-34 years	141	22
35-44 years	159	25
45-54 years	126	20
55-64 years	126	20

Source: Mosaic data 2023, CCC

The number of individuals aged over 65 years isn't clear.

The ethnicity of residents is described in table 11.3.

Table 13.3: ethnicity of residents in long term care funded by CCC or Cambridgeshire and Peterborough ICB, resident in Cambridgeshire

Ethnicity	Number	%
Asian/Asian British	13	2
Black/African/Caribbean/Black British	<5	<1
Mixed/Multiple ethnic groups	10	1.6
White	598	95
Other	<5	<1
Unknown	<5	<1

Source: Mosaic data 2023, CCC

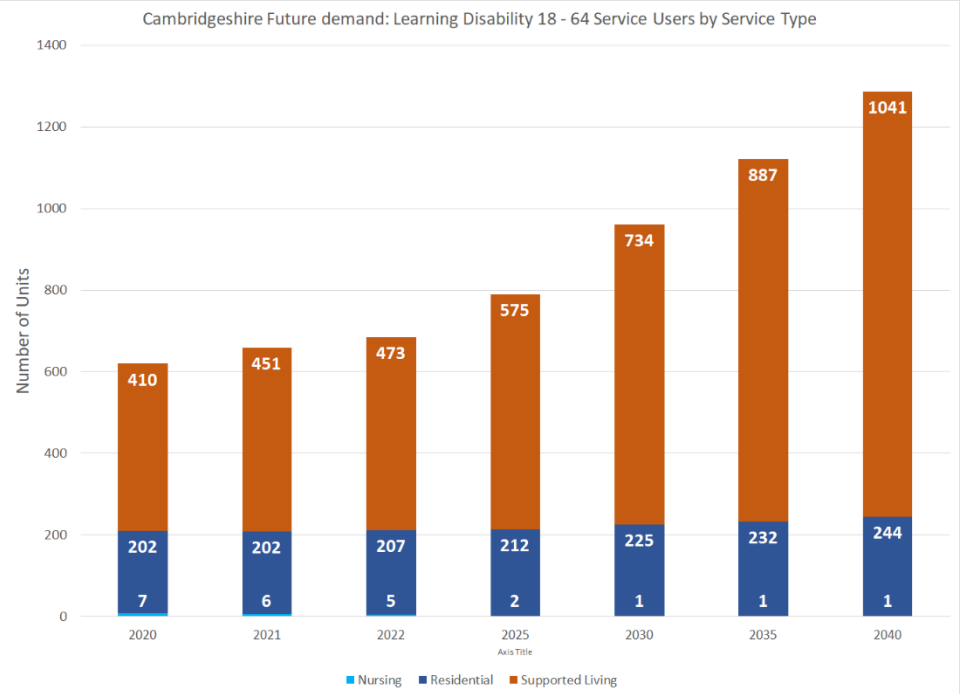
Table 13.3 shows that a higher proportion of individuals with an LD in long term residential care are white than the general population of Cambridgeshire.

Demographic data was not available for Peterborough.

13.2.2 Projected demand for residential care

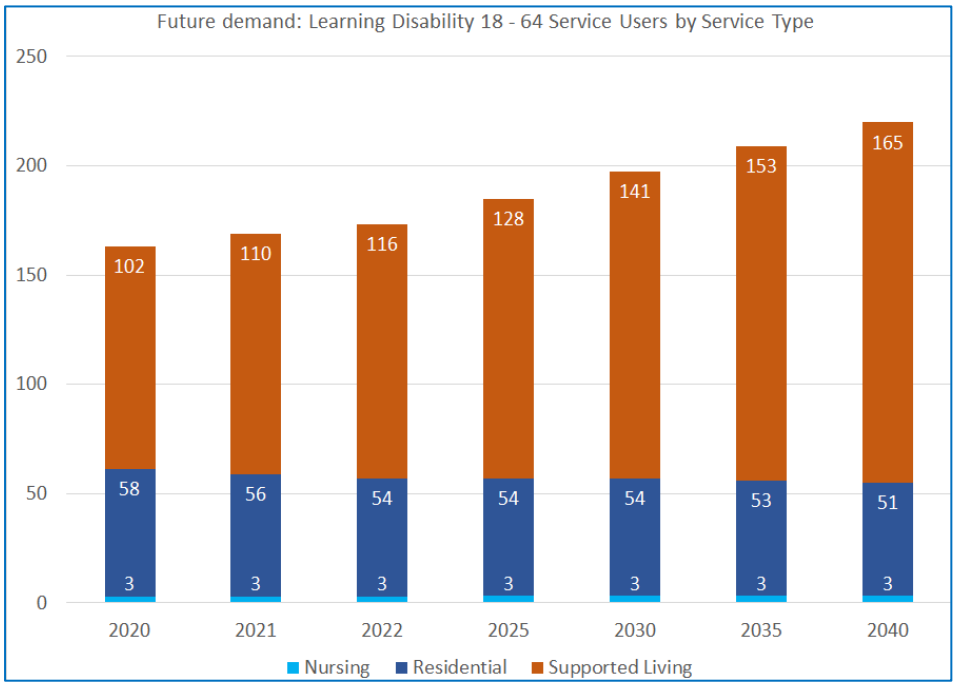
Trends for projected demand for residential beds in Cambridgeshire and Peterborough are shown in figures 13.1 and 13.2.

Figure 13.1: Cambridgeshire future housing demand, adult learning disability services



Source: (268)

Figure 13.2: Peterborough future housing demand, adult learning disability services



Source: (267)

13.2.3 Health needs of individuals in long term care

Currently, this information is not obtainable at population (rather than individual) level without manual audit. However, there are plans as part of the Cambridgeshire and Peterborough ICS population health management work to allow data linkage between local authority social care data and primary care data. This will enable a better understanding of mental and physical health needs, at aggregate level, which will support commissioning of services to support and improve the health of residents.

Both housing needs assessments note the increase in demand for single service user residential accommodation, largely driven by the national direction in the NHS Long Term Plan to significantly reduce the number of individuals on long stay inpatient units (13,267,268). Although this impacts a small number of individuals, their health and care needs are often very high, so ensuring there is an adequate supply of appropriate single service user accommodation, with appropriate support, will be crucial moving forwards.

13.2.4 Delegated health tasks

The majority of individuals in long term residential care are in supported living or residential homes, without registered nurses on site. This means that where individuals have nursing needs, their needs are met either by district nurses or other NHS nurses attending to provide care directly to the patient, or by a registered nurse delegating the task to a carer. It is not possible to understand at population level the number or type of delegations currently being undertaken. There is currently no local guidance for providers to follow around delegations.

There is national work currently being undertaken to produce a framework for delegation, to enable it to be undertaken consistently and safely (269).

13.3 Continuing Healthcare (CHC)

Individuals who have long term care and support needs may have those needs paid for by the NHS (through Continuing Healthcare), the local authority or self-fund, depending on the individual's circumstances. Continuing Healthcare funding criteria are set out nationally, and cover those with the most complex health needs. Individuals who do not meet the criteria for CHC may still have significant health needs.

In Cambridgeshire and Peterborough, arrangements are in place that mean that Cambridgeshire and Peterborough ICB have delegated their responsibility for commissioning CHC placements for adults with an LD to CCC and PCC.

In practice, this means, if an individual is eligible for CHC-funding, their initial assessment is undertaken by Cambridgeshire and Peterborough ICB. Individuals who meet CHC criteria are then passed to the CCC and PCC brokerage teams to

source suitable placements. Case-management and annual reviews are undertaken by the LDP in Cambridgeshire and PCC LD nurses in Peterborough.

13.4 Respite Care

Respite care is commissioned for individuals who live at homes, to provide short-term breaks for their carers. These beds can also be used on a short-term basis as crisis prevention or as step-down from hospital admissions.

Currently, the following provision is commissioned:

- Cambridgeshire: CCC commission 19 beds, of which 15 are provided by in-house services, and 4 by an external provider.
- Peterborough: PCC commission 11 beds for overnight respite, of which 6 beds are ringfenced for crisis prevention or for step-down from hospital. These are all provided externally.

Current issues for commissioners are:

- Need to understand future demand from young people coming through to adult services;
- Need to understand demand for nursing provision;
- Need to ensure there is sufficient single service user provision;
- Risk of long stays if no further long-term accommodation options.

There is no data available currently around service use.

13.5 Crisis Care

There are no crisis beds in the community commissioned in Cambridgeshire or Peterborough currently.

13.6 Shared lives

Shared lives carers offer support to someone in the carer's own home, providing opportunities for short stays and respite.

13.7 Day opportunities

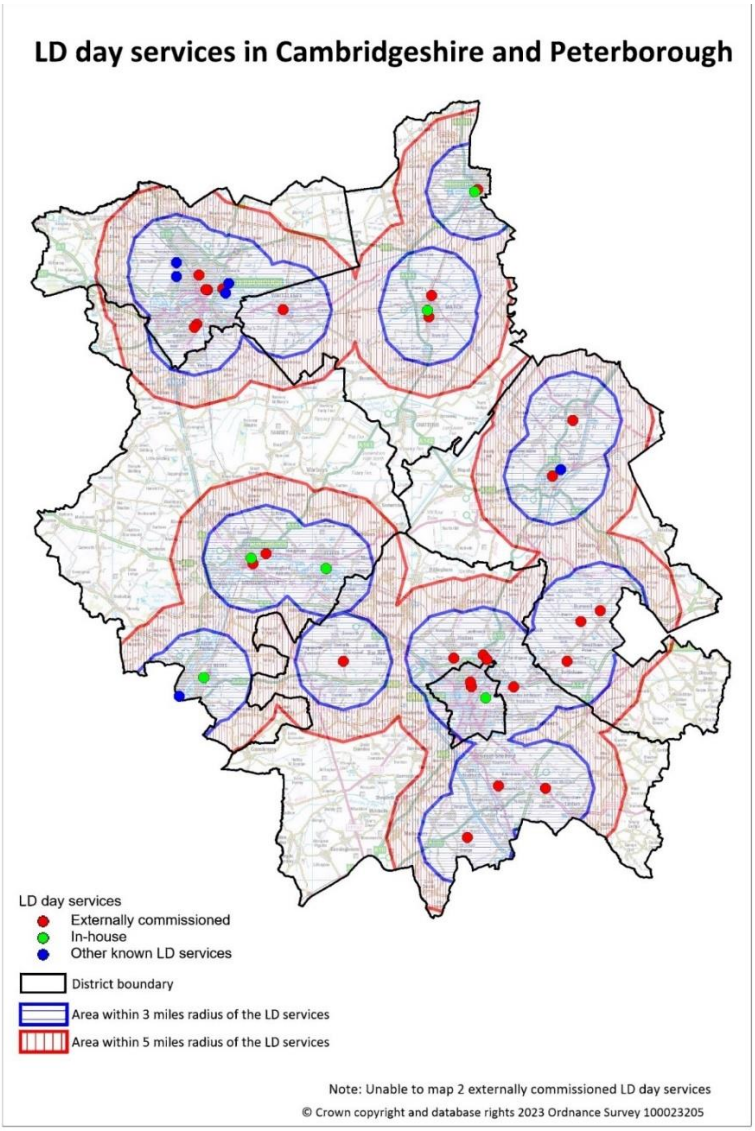
Day opportunities offer a range of opportunities for adults with an LD to make friends and socialise, develop skills and participate in employment opportunities.

Currently the following services are funded by the local authority:

- Cambridgeshire: 32 services are funded by CCC, of which 7 are in-house and 25 are external.
- Peterborough: 8 services are funded by PCC, of which 5 are in-house and 3 are external.

Figure 13.3 shows a map of these services, alongside other independently-run services, with distances to give an indication of accessibility. This mapping shows large areas of the county with no local day opportunities.

Figure 13.3: LD day opportunities in Cambridgeshire and Peterborough



Source: Cambridgeshire County Council and Peterborough City Council commissioning information

Some services are used for individuals whose long-term care and support needs are met by the local authority, some are also open to other service users.

13.8 Advocacy services

CCC and PCC currently commission a single provider to deliver all-age advocacy services across Cambridgeshire and Peterborough. The current provider is Voiceability.

Advocacy services fulfil a number of statutory and non-statutory functions. Statutory functions include:

- Providing access to Independent Mental Capacity Advocates (IMCAs) – this is a legal safeguard to help individuals who lack capacity to make significant health or care decisions and who do not have a friend or family member to help them make that decision.
- Providing access to Independent Mental Health Advocates (IMHAs) – these advocates support individuals who are being detained for more than 72 hours under the Mental Health Act or who have a Community Treatment Order.
- Providing access to Independent Health Complaints Advocacy – this supports individuals to make complaints about their NHS healthcare.
- Providing access to independent advocates to support individuals to make decisions about their care and support if they have autism.

13.9 Recommendations

Understanding need

- CCC and PCC commissioners should work with Cambridgeshire and Peterborough ICB to make use of the new DSCRO data warehouse once appropriate data-sharing agreements are in place, in order to understand the physical and mental health comorbidities of individuals that are in long-term care.
- CCC and PCC commissioners should work with Cambridgeshire and Peterborough ICB to understand the future demand for single service user provision that will derive from individuals who are currently in long stay inpatient units.

Delegated health tasks

- System work will be needed to implement the national framework for delegations once it is released.

Training

- Many other sections of this needs assessment contain recommendations relating to training needs of social care providers that are relevant to social care commissioners.

Care planning

- Many other sections of this needs assessment contain recommendations relating to care planning that are relevant to social care commissioners and providers.

14. Carers

14.1 Local carers' views

As part of this needs assessment, the views of carers of adults with an LD were sought. This was undertaken through two routes:

- Attendance at the Carers Partnership Board
- Survey undertaken with Caring Together

14.2 Feedback from Carers Partnership Board

Themes from the engagement session with the carers partnership board are summarised below:

- Need for holistic care of an individual, taking into account their physical and mental health needs as well as their learning disability;
- Importance of a face-to-face AHC to support the first point;
- Ensuring that carers are involved in the process;
- Importance of services being able to make reasonable adjustments, particularly relating to EasyRead and longer appointments (it was noted that using EasyRead as standard for everyone would also help others with low literacy);
- Better sharing of information between services.

14.3 Feedback from survey

Unfortunately, despite promotion by Caring Together, the response rate to the survey was very low, with only 8 responses received.

A summary of the responses is as follows:

- 38% of respondents reported that the person they care for had experienced challenges in receiving healthcare, investigations or treatment in the last 12 months. The most common reason for this was general delays affecting all patients.
- The three areas ranked highest for prioritisation in work to improve access were health checks, access to mainstream GP services and access to mental health services.

Some carers shared their practical challenges of trying to access healthcare support:

- Issues with trying to get additional hours of paid care to support their adult child who lives in supported living to attend weight management classes and physical activity
- Issues with paid carers not wanting to support with breast self-examination
- Lack of hoists for physical examination of wheelchair users in general practice

- Lack of scales for non-weightbearing wheelchair users in the community
- Lack of access to speech and language therapy input for communication needs
- Lack of care coordination
- Lack of access to dental appointments
- Lack of support for carers' wellbeing
- Residential care providers struggling to navigate multiple services on behalf of service users

14.4 Local carer support

Cambridgeshire County Council and Peterborough City Council commission Caring Together to provide support to all unpaid carers. They provide the following offer:

- Support/peer support groups
- Transition support
- Carers helpline
- Monthly newsletter
- Website
- Workshops and webinars

Topics covered in the workshops are based on carers' requests. Over the last 12 months, the following topics have been covered

Table 14.1: workshop topics delivered through Caring Together for carers

Topic Talks (Caring Together)	Topic Talks (in partnership)	Carer Thrive
Self Care	Mindfulness	First Steps
Sleep	Legal, Wills, POA	My Steps
Navigating Social Care	Benefits	Next Steps
Carer Passports	Social Care transitions (parents)	
Coming Home from Hospital	MCA transitions (parents)	
	Managing Relationships (parents)	
	Dementia Q&A	
	Healthy You	
	Community Resources (eg Care Network)	
	Assisting Someone to Move	
	Back Care & Falls Prevention	
	Medication Management	
	Personal budgets (parents)	
	5 day offer (parents)	
	First Aid	

Cambridgeshire County Council public health team also commission the following for carers:

- Health trainer, within the Everyone Health lifestyle services, to support carers who would like support making lifestyle changes

14.5 Local carers strategy

A local carers strategy for Cambridgeshire and Peterborough is currently in development.

14.6 Summary

Key themes from engagement with carers fit the themes raised by people with an LD and professionals, particularly around the importance of the AHC (covered in section 7.8) and the ability of providers to make reasonable adjustments (covered in section 15). Issues with accessing routine GP appointments were raised again here as well.

14.7 Recommendations

Learning needs

- There are a range of recommendations around supporting unpaid carers with their skills and knowledge throughout this needs assessment. A consideration of how to support informal carers' learning needs should be part of the carers' strategy.

15. Reasonable adjustments

15.1 What are reasonable adjustments?

Organisations that provide services to the public have a legal duty under the Equality Act 2010 to ensure that people with a disability can access their services as well as people who don't have a disability (270). This duty is "anticipatory", which means that organisations have to proactively plan what adjustments might reasonably be needed for people with disabilities, rather than wait to be told (271). The law covers three types of adjustments: adjustments to policies and processes; adjustments to physical barriers to access, and provision of aids to support an individual to access the service (271).

15.2 What do reasonable adjustments look like for people with a learning disability?

Reasonable adjustments can be systemic or based on an individual's needs. However, there are some common reasonable adjustments that are helpful to many people with a learning disability, such as longer appointment times or providing information in EasyRead format (272).

NHS England have summarised common reasonable adjustments for people with an LD (273).

Figure 15.1: common reasonable adjustments

Reasonable adjustment	Primary care	Acute care	Linking services
Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems	√	√	√
Patient-held records for all people with learning disabilities with multiple health conditions	√	√	√
Named healthcare coordinator for people with complex or multiple health needs		√	
Accessible information for people with learning disabilities and carers, universally available	√	√	
Accessible processes for people with learning disabilities to make appointments	√	√	
Appointments: longer appointment times and planned appointments at beginning/end of day to reduce waiting time within the health care setting	√	√	
Working in partnership with families and paid carers: providing information, inclusion in decision-making, adjusted visiting hours, facilities for overnight stay	√	√	
Proactive access to learning disability liaison specialist staff (typically nurses) to remove barriers and facilitate access to effective health services	√	√	√
Comprehensive annual health check	√		
Clear health action plan following from annual health check	√	√	√

Risk assessment and associated linked reasonable adjustments action plan for people with learning disabilities entering acute care		√	
Advocacy for people with learning disabilities	√	√	
Annual audits of scale, type and effectiveness of reasonable adjustments	√	√	
Training for all staff to promote effective reasonable adjustments for people with learning disabilities	√	√	

Source: (273), reproduced under the terms of the Open Government Licence v3.0

There are some specific programmes of work within the NHS that are linked to reasonable adjustments for people with an LD:

- **Annual health check**: the AHC for people with an LD can be seen as a form of reasonable adjustment to support people with an LD to access healthcare (274);
- **Hospital passport**: hospital passports can be used when people with an LD go into hospital, to tell staff about what reasonable adjustments they need.
- **Reasonable adjustments flag** (272): this is a large national programme of work, which is a planned rollout of a reasonable adjustments flag on the Summary Care Record to enable any patients with a disability to record their need for reasonable adjustments on their patient record, to enable health care providers to make anticipatory adjustments;
- **Oliver MacGowan mandatory training** (275)**:** this is mandatory training for all staff working in CQC-registered health and social care providers in England. It focusses on the health needs of people with an LD, and also how to make reasonable adjustments;
- **LD liaison nurses:** LD nurses in acute settings can help healthcare staff to make appropriate reasonable adjustments for their patients;
- **NHS Quality Checker programme:** this is a series of audit tools that support mainstream health services to audit their accessibility for people with learning disabilities (NHS England » NHS Quality Checkers toolkits).

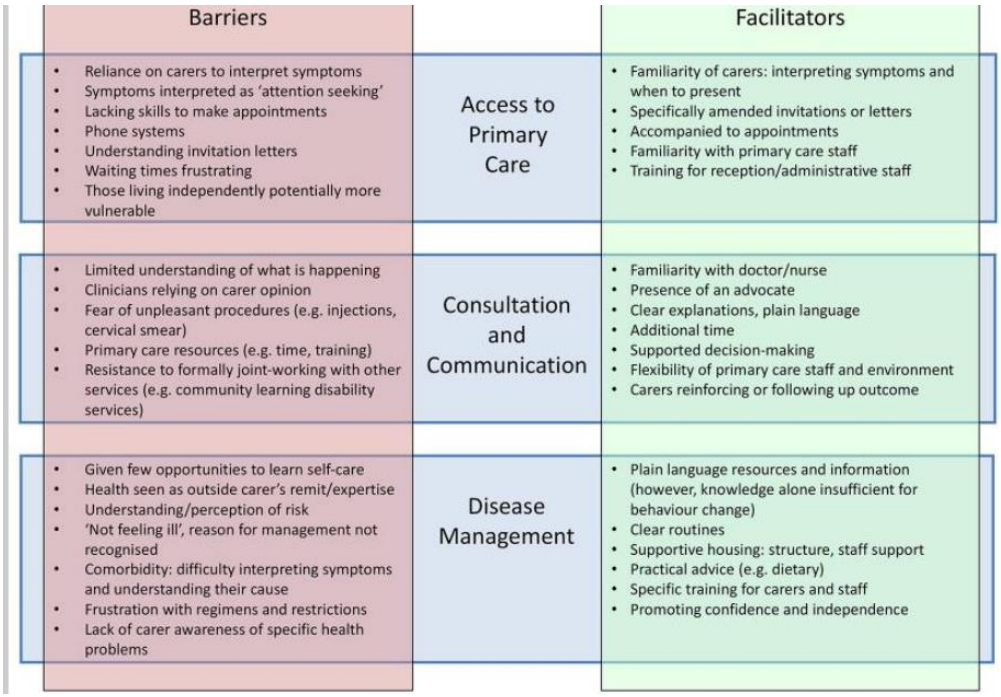
15.3 Evidence for improving provision of reasonable adjustments for people with an LD in health services

There is limited evidence around factors that improve the provision of reasonable adjustments for people with an LD in health services.

15.3.1 Primary care

A systematic review of barriers to primary care people with an LD identified the following barriers and facilitators (276).

Figure 15.2: barriers and facilitators for access to primary care



Source: (276), Peter Hanlon, Sara MacDonald, Karen Wood, Linda Allan, Sally-Ann Cooper BJGP Open 2018; 2 (1): bjgpopen18X101445, reproduced under the terms of Creative Commons Licence CC BY 4.0 Creative Commons — Attribution 4.0 International — CC BY 4.0

15.3.2 Secondary care

An extensive research study looking at reasonable adjustments in NHS hospitals found that the following factors are linked to effective reasonable adjustments (277):

1) "hospital structures, systems and policies that allow for the need for reasonable adjustments to be identified and acted upon;
2) "funding and allocation of adequate resources;
3) "management support for reasonable adjustments, and in particular support from ward managers; and
4) "staff understanding of a wide range of potentially complex adjustments that may be needed."

LD liaison nurses in Cambridgeshire and Peterborough

Cambridge University Hospitals NHS Trust (CUH) and North West Anglia Foundation NHS Trust (NWAFT) both employ LD liaison nurses.

NWAFT employ 2 WTE LD nurses. They fulfil a number of functions:

- Training for staff at NWAFT around the needs of patients with a learning disability;
- Liaison work with patients admitted onto the wards;

- Support to facilitate planned admissions and outpatient appointments, e.g. support with desensitisation, familiarisation visits;
- Support with discharge planning.

It was not possible to obtain information from CUH for this needs assessment.

15.4 Recommendations

Health providers and commissioners

- All health services should be confident in the ability of their services to make reasonable adjustments for people with an LD. Audit tools such as those provided by the NHS England Quality Checkers programme may help give assurance to commissioners
- All health staff in CQC registered organisations need to undertake training appropriate to their role in line with new legislation. Cambridgeshire and Peterborough ICB should liaise with Health Education England and Skills for Care to ensure that the rollout reaches all providers. Commissioners should ensure that they gain assurance from services that the rollout has taken place.

Cambridgeshire and Peterborough ICB

- Commissioners should ensure that health providers have sufficient flexibility in care pathways and sufficient funding to enable appropriate reasonable adjustments to be made, for example to allow longer appointments or more appointments.

Social care providers and commissioners

- All social care staff in CQC registered organisations need to undertake undertake training appropriate to their role in line with new legislation. Cambridgeshire and Peterborough ICB should liaise with Health Education England and Skills for Care to ensure that the rollout reaches all providers. Commissioners should ensure that they gain assurance from services that the rollout has taken place.
- Commissioners of social care should review flexibilities within funding arrangements for enabling paid carers to attend hospital whilst their service user is an inpatient, to facilitate the process of reasonable adjustments.

16. Accessible information standard

16.1 What is the Accessible Information Standard?

Under the Health and Social Care Act 2012, Health and social care organisations that provide publicly funded services are legally required to follow the Accessible Information Standard (AIS) (278).

Organisations are required to undertake the following steps:

1. "**Identification of needs**: a consistent approach to the identification of patients', service users', carers' and parents' information and communication needs, where they relate to a disability, impairment or sensory loss.
2. "**Recording of needs**:
    a) Consistent and routine recording of patients', service users', carers' and parents' information and communication needs, where they relate to a disability, impairment or sensory loss, as part of patient / service user records and clinical management / patient administration systems;
    b) Use of defined clinical terminology, set out in four subsets, to record such needs, where Read v2, CTV3 or SNOMED CT® codes are used in electronic systems;
    c) Use of specified English definitions indicating needs, where systems are not compatible with any of the three clinical terminologies or where paper based systems / records are used;
    d) Recording of needs in such a way that they are 'highly visible'.
3. "**Flagging of needs**: establishment and use of electronic flags or alerts, or paper-based equivalents, to indicate that an individual has a recorded information and / or communication need, and prompt staff to take appropriate action and / or trigger auto-generation of information in an accessible format / other actions such that those needs can be met.
4. "**Sharing of needs**: inclusion of recorded data about individuals' information and / or communication support needs as part of existing data-sharing processes, and as a routine part of referral, discharge and handover processes.
5. "**Meeting of needs**: taking steps to ensure that the individual receives information in an accessible format and any communication support which they need."

16.2 Why is it important?

When it was introduced, it was expected that the Accessible Information Standard would have a range of benefits, including improving the ability of patients impacted to be involved in decisions about their care, to follow instructions about medication and treatment, and improve their patient experience (279).

There is national evidence to suggest that the AIS has not been fully implemented as intended (280,281).

16.3 Recommendations

Health and social care providers

- All health and social care organisations providing publicly funded care should ensure they have the appropriate policies, processes and staff training in place for the AIS to be implemented fully.

Health and social care commissioners

- Commissioners should ensure that the AIS is included within contracts and that there is sufficient funding to enable organisations to meet their legal requirements.

17. Specialist LD services

17.1 Specialist adult community learning disability health services - staffing

The Royal College of Psychiatrists has a set of quality standards for specialist Adult Community Learning Disability Services (175). These cover a range of areas, including staffing.

Sections 17.2 and 17.3 below review commissioned specialist outpatient adult community learning disability services in Cambridgeshire and Peterborough against these standards.

17.2 Cambridgeshire

Specialist adult outpatient learning disability health services in Cambridgeshire are delivered by Cambridgeshire County Council, through the Cambridgeshire Learning Disability Partnership (LDP). Table 17.1 below shows the composition of the commissioned workforce. However, not all commissioned posts are filled.

Table 17.1: staffing establishment of specialist outpatient LD services in Cambridgeshire

Role	Commissioned WTE	Provider
Service lead	1 Head of service 1 lead service manager	CCC
Occupational therapy – LD	1.21 band 7 4.17 band 6	CCC
Learning disability nursing	2.0 band 7 16.06 band 6 4.0 band 4	CCC
Speech and language therapy – LD	1.0 band 8 2.0 band 7 0.8 band 6 1.0 band 5 1.0 band 4	CCC
Outpatient LD psychiatry	2.13 consultants	CPFT
Outpatient psychology – LD	4.95 band 8 1.0 band 5	CCC
Physiotherapy – LD	1.0 band 7 1.0 band 6	CCC
Music therapy	0.69 band 8 0.79 band 7 1.84 band 6	CCC
Art therapy	0.3 band 7 0.6 band 6	CCC

Dietician	No dedicated LD service commissioned – support for malnutrition only accessed via mainstream services	CPFT
Pharmacist	No dedicated service commissioned	-
Admin	3.79 band 3 2.04 band 4	CCC

The current vacancy rate across CCC roles is 4.4%. However, the service reports that the recruitment of staff with the skills and experience to meet the needs of the service a consistent challenge. Maintaining a relatively low vacancy rate is an ongoing challenge.

17.3 Peterborough

Specialist outpatient adult learning disability health services in Peterborough are delivered through Peterborough City Council and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT). Table 17.2 below shows the composition of the commissioned workforce; however not all commissioned posts are currently filled.

Table 17.2: staffing establishment of specialist LD services in Peterborough

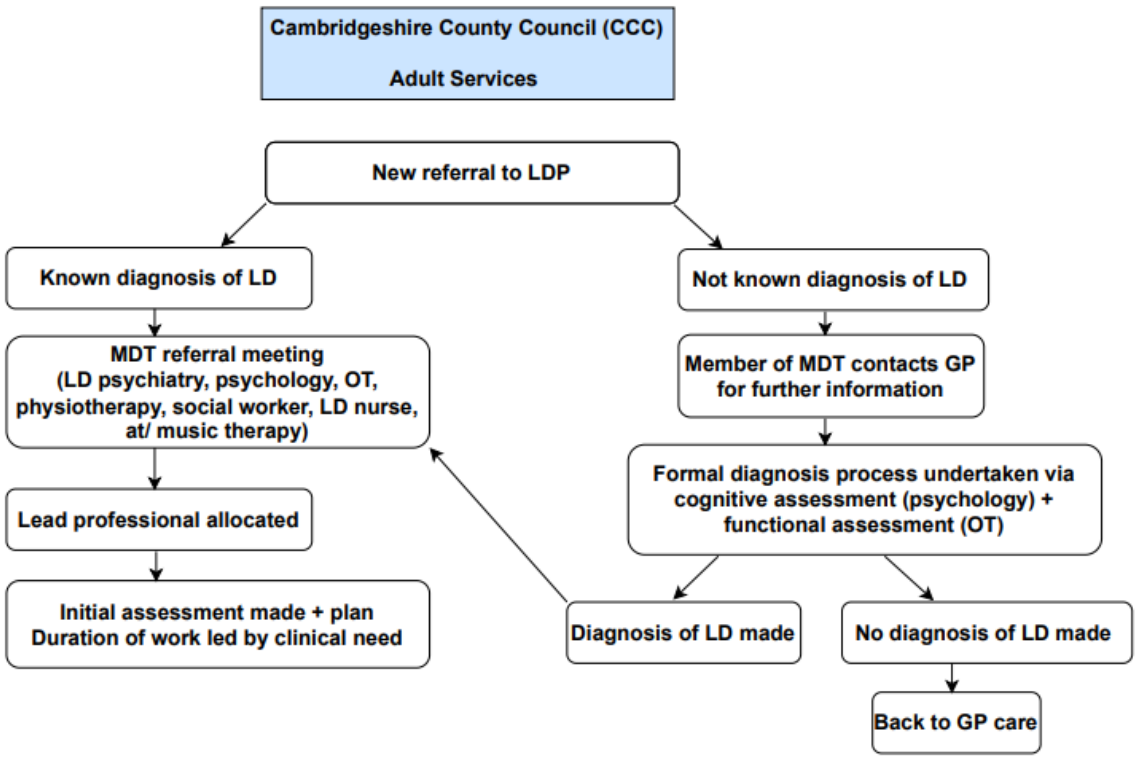
Role	**Commissioned WTE**	**Actual WTE (May 2023)**	**Provider**
Service lead	Not in place, as no single community adult LD service	-	-
Occupational therapy - LD	Unable to ascertain	0.8 band 7 0.5 band 6	Peterborough City Council
Learning disability nursing	1.0 band 7 3.0 band 6 1.0 band 5	3.6 nurses	Peterborough City Council – long term team
Speech and language therapy – LD	1.0 band 7 1.4 band 6 1.0 band 4	0.6 band 7 1 band 4	Peterborough City Council
Outpatient LD psychiatry	There is a consultant in post, but it was not possible to confirm their allocated time for outpatient activity.	There is a consultant in post, but it was not possible to confirm their allocated time	CPFT

		for outpatient activity.	
Outpatient psychology - LD	0.6 band 8a	0.6 band 8a	CPFT
Physiotherapy - LD	Not commissioned	-	-
Music therapy/arts therapy	Not commissioned	-	-
Dietician	No dedicated LD service commissioned – support for malnutrition only accessed via mainstream services	Unable to quantify	CPFT
Pharmacist	No dedicated service commissioned	Unable to quantify	-
Admin	No single community service, so admin support split between many different teams	-	-

17.4 Cambridgeshire specialist LD services referral pathway

Figure 17.1 sets out the referral pathway into the LDP, which is a single service.

Figure 17.1: referral pathway into the LDP



17.5 Peterborough specialist LD services

Figures 17.2-17.7 show the referral routes into specialist LD services in Peterborough.

Figure 17.2: referral route into LD nursing

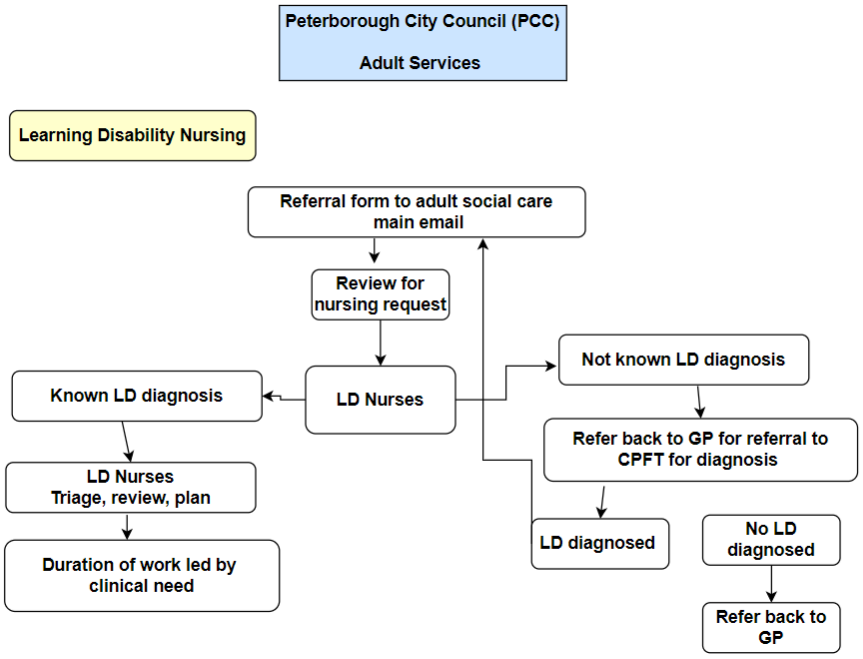


Figure 17.3: referral route into specialist LD SALT

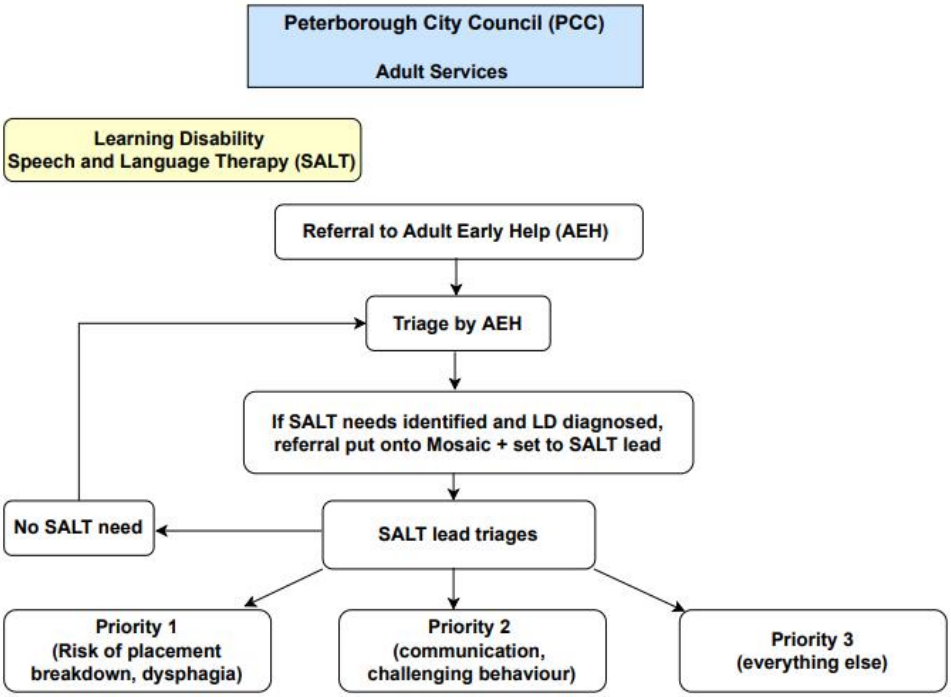


Figure 17.4: referral into specialist LD psychology

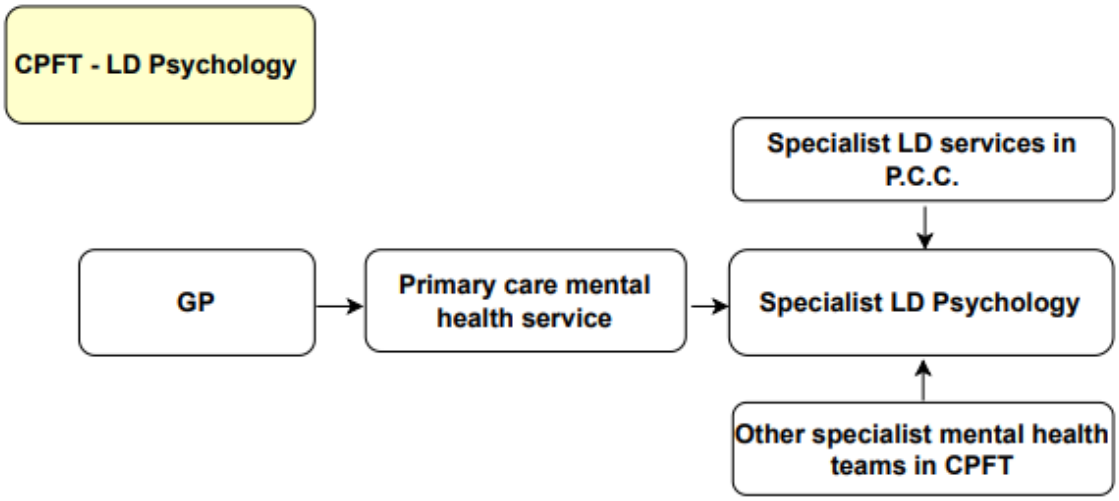


Figure 17.5: referral route into specialist LD psychiatry

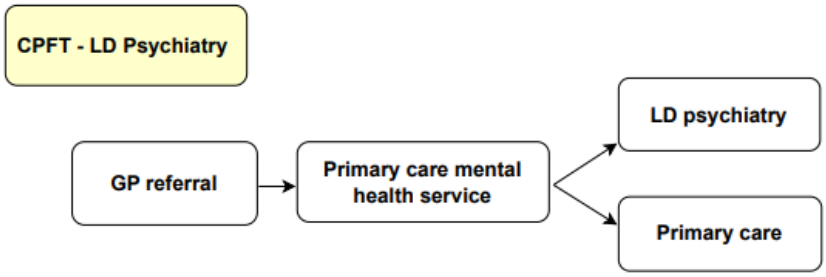


Figure 17.6: referral route into IST (CPFT)

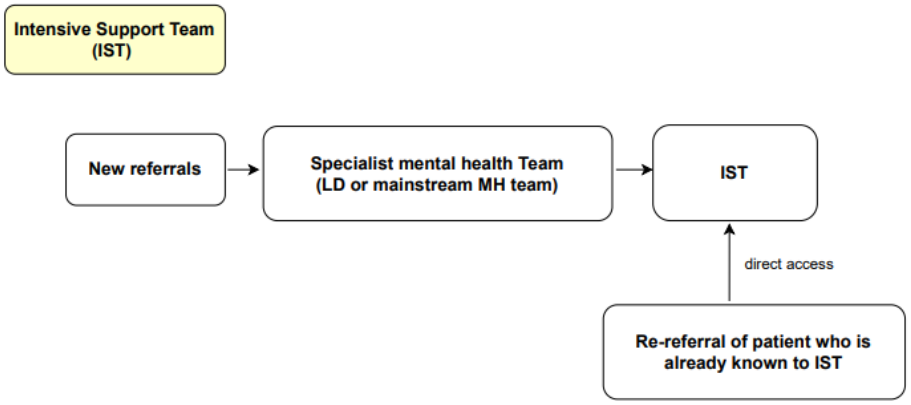
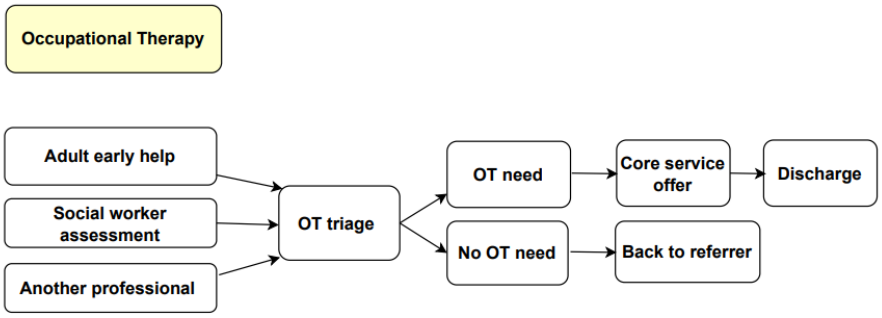


Figure 17.7: referral route into specialist LD Occupational Therapy (PCC)



17.6 Adult learning disability health services – activity

17.6.1 Cambridgeshire

Number of new referrals by speciality are summarised in the table below.

Table 17.3: referrals to specialist LD services

Role	2021
Occupational therapy - LD	104
Learning disability nurse	195
Speech and language therapy – LD	205
Outpatient LD psychiatry	87
Outpatient psychology - LD	75
Music therapy – LD	47
Art therapy - LD	

Source: Cambridgeshire LDP demography work

Open cases over time

It is not possible to breakdown open cases by specialty, only by referral to the overall team (LDP or Young Adult Team). These are summarised in table 17.4.

Table 17.4: overall referrals to Cambridgeshire LDP

Team	2010	2021
Learning Disability Partnership	1590	1602
Young Adult Team	0	320

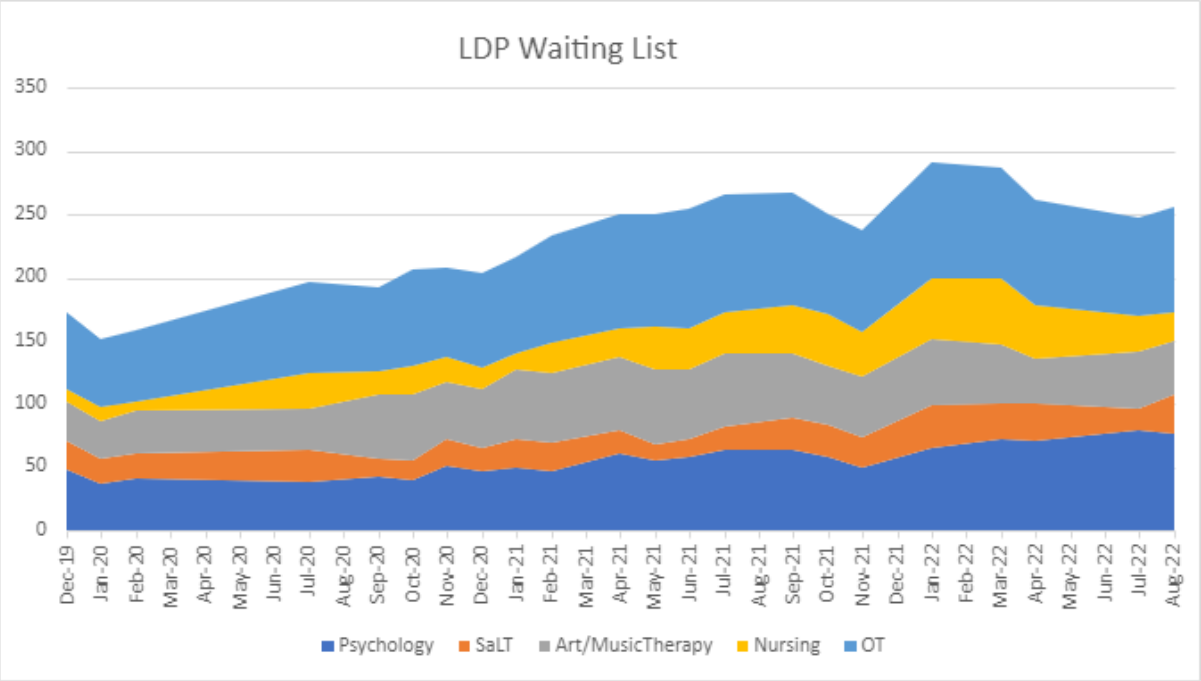
Source: Cambridgeshire LDP demography work

As the Young Adult Team was created after 2010, the numbers aren't completely comparable, as the Young Adult Team takes individuals from age 16 years. However, as the majority of their caseload is likely to be aged 18 years and over, there has been some overall growth in open cases.

Waiting list over time

In order to get a sense of demand, waiting list numbers for each specialty in the LDP are presented in figure 17.7 below. This shows a growth in waiting times, particularly for OT and psychology, over the last 2-3 years.

Figure 17.8: Cambridgeshire LDP waiting list



Source: Cambridgeshire LDP demography work

It was not possible to ascertain waiting lists for LD psychiatry.

17.6.2 Peterborough

Table 17.5 below shows the number of new referrals by service where the information was available from Dec 21-Nov 22.

Table 17.5: referrals to specialist LD services in Peterborough

Role	Dec 21-Nov 22	Source
Outpatient LD psychiatry	51	CPFT data
Outpatient psychology - LD	41	CPFT data

Waiting list

A snapshot of the waiting lists for some services from March 2023 is below:

Table 17.6: waiting lists for specialist LD services in Peterborough

LD nursing	2
LD SALT	40
LD OT	2-3 weeks

It is of concern that LD nursing has such a short waiting list, given the limited size of the service.

17.7 Adult learning disability social work services

17.7.1 Cambridgeshire

Social work support in Cambridgeshire is integrated into the Learning Disability Partnership.

Table 17.6 staffing establishment for social work staff in Cambridgeshire LDP

Role	WTE	Provider
Adult support coordinator	19.21	CCC
Team manager	7	CCC
Senior social worker	11.35	CCC
Social worker	23.35	CCC

The team received 366 referrals in 2021.

17.7.2 Peterborough

Unable to quantify, as there is not a single LD team; rather, service users with an LD are access a range of social work teams based on need (Adult Early Help team, Long Term Team, Reablement, Review Team, 0-25 Team).

17.8 Benchmarking staffing levels

There is no clear guidance relating to minimum levels of staffing or caseloads in community LD health teams. A national NHS England-led benchmarking exercise was undertaken in winter 2022, to get a baseline for specialist LD health staff. However, the results of this have not yet been released, so it is not possible to compare Cambridgeshire and Peterborough with other ICBs.

The Royal College of Psychiatrists' guidance does have standards regarding processes that should be in place to maintain safe staffing levels (175).

Table 17.7: standards for maintaining safe staffing

	Cambridgeshire	**Peterborough**
106. The service has a mechanism for responding to low/unsafe staffing levels, including: • A method for the team to report concerns about staffing levels; • Access to additional staff members; • An agreed contingency plan, such as the minor and temporary reduction of non-essential services	The LDP service leads oversee staffing levels and support with planning to cover low staffing levels. There are issues with recruitment to some roles.	There is not a single process for doing this, it is dependent on each specialty/professional escalating their concerns via their line managers within their own organisation. There are issues with recruitment to some roles.
107 When a staff member is on leave, the team puts a plan in place to provide appropriate cover for the people with learning disabilities who are allocated to that staff member	Long term vacancy cover for health roles, e.g. to cover maternity, does not currently take place in the LDP.	Ad hoc arrangements are made for short-term cover dependent on individual specialties. It has not been possible to find long term cover for the PCC health role vacancies.
There has been a review of the staff members and skill mix of the team within the past 12 months. This is to identify any gaps in the team and to develop a balanced workforce which meets the needs of the service	This has been undertaken within the last 12 months by the LDP for roles that fall under CCC.	This does not appear to have been undertaken in Peterborough for some time.

17.9 Comparison of Cambridgeshire and Peterborough

Specific issues related to specialist outpatient adult community LD services in Cambridgeshire are summarised below:

- Although specialist LD physiotherapy is commissioned in Cambridgeshire, both posts are currently vacant.
- Although the current vacancy rate is relatively low, recruitment of specialist staff is an ongoing challenge for the service.

Specific issues related to Peterborough specialist outpatient LD health services are summarised below:

- Peterborough City Council and CPFT boundaries are not coterminous, which makes it challenging to access support for patients who live in the north part of CPFT's patch but who do not live in Peterborough local authority boundaries. Clarity is needed regarding the population that the specialist LD health services provided by PCC are to be provided to as it is not clear within the s75.
- LD occupational therapy in PCC is not commissioned to undertake sensory assessments, sensory integration therapy or interventions.
- There is a discrepancy in the s75 agreement between PCC and Cambridgeshire and Peterborough ICB, between the scope of delegation of functions from the ICB and the service specifications for the individual clinical specialties with regards support for patients with mental illness. The scope of the delegated functions includes patients experiencing mental illness as well as challenging behaviour, but the service specifications for health services provided by PCC only reference challenging behaviour. This creates a gap in support from LD nursing before service users meet the threshold for the Intensive Support Team.
- The s75 agreement governing eligibility for specialist LD health services in Peterborough City Council requires an individual to have a diagnosis of a learning disability on their GP record or to have a diagnosis from a psychologist, but does not reference a diagnosis made by an LD psychiatrist.
- LD physiotherapy, music therapy and arts therapy are not commissioned in Peterborough.
- There are no dedicated care coordinator roles for specialist LD health services in Peterborough.
- LD psychiatry, clinical psychology and speech and language therapy services have each got only a single registered healthcare practitioner in post. This means these services are not resilient.
- There is no overarching clinical lead for the health roles in PCC, meaning that there is not a clear route of escalation for clinical queries.
- Triage for LD services provided PCC is undertaken by non-clinical staff in PCC Adult Early Help.
- LD health staff employed by PCC are not able to access individual's clinical records to determine eligibility for their service.
- There is no capacity in PCC to undertake non-urgent SALT work.
- The size of the PCC LD nursing waiting list is surprising given the very small size of the service.

Comparing Peterborough with Cambridgeshire, a number of observations can be made:

- Neither Cambridgeshire nor Peterborough currently has LD physiotherapy provision;
- Peterborough is missing a number of key roles and services entirely (LD physiotherapy, care coordinators, art and music therapy);

- Peterborough has proportionally significantly less clinical psychology and LD nursing time;
- There is no single service lead role in Peterborough, reflecting the fragmented nature of the commissioning of specialist LD health services;
- Peterborough is carrying a lot of vacancies;
- A number of key specialties in Peterborough are covered by a single practitioner, which is not resilient and represents significant business continuity risks.

17.10 Recommendations

LD physiotherapy

- The vacancies in Cambridgeshire and lack of commissioned service in Peterborough represent significant risks, although significant work has been undertaken in Cambridgeshire to try to fill the current vacancies. Further support is needed to address the service gaps across both areas.

Peterborough services

- Commissioners should look to at minimum achieve parity of services between Cambridgeshire and Peterborough. This would mean increasing WTE to achieve similar caseload/WTE staff across current Peterborough services. This would also mean looking to commission specialist LD physiotherapy, art and music therapy, and to create a service lead and a care coordination function.
- Inconsistencies in the section 75 agreement for Peterborough should be reviewed, with clinical input from provider services as appropriate.
- Issues identified with Peterborough services should be reviewed by both commissioners and service providers.

Benchmarking

- Once national LD workforce data is available, benchmarking should be attempted.

Cambridgeshire and Peterborough ICS workforce group

- LD health services should be included within the system work on recruitment and retention.

18. Summary

This section summarises the recommendations contained within this needs assessment. Recommendations have been grouped by organisation or category, rather than by chapter. The presence of a recommendation should not necessarily be taken to mean that no action is being taken already on this area by the relevant organisation(s).

18.1 Primary care

- Further work is needed to support primary care to make appropriate reasonable adjustments for people with an LD.
- Further work is needed to understand the high exclusion rate for the NHS Health Check, and to ensure that adults are not inappropriately classed as ineligible for the NHS Health Check.
- Further work is needed to understand the alignment between the Annual Health Check and the NHS Health Check, ensuring that those adults who only receive an Annual Health Check receive appropriate health promotion advice and review on management of long term conditions.
- Further work is needed to understand the very low rates of adults with AF who have been risk assessed for stroke.
- Further work is needed to support adults with diabetes to receive all 8 evidence-based care processes for diabetes.
- Take-up of screening should be reviewed at AHCs. If someone has missed a routine screening programme, steps should be taken to understand why and how access might be facilitated if the individual wants to attend or it is in their best interests where they lack capacity to make the decision for themselves. This may involve support from LD nurses.
- GP practices should ensure they are following the Mental Capacity Act when making decisions to exclude people with an LD from screening.
- The best-evidenced intervention to increase immunisation uptake is the annual health check. Work to optimise uptake of AHCs should continue (see section 9.8).
- GP practices should ensure they are able to make reasonable adjustments for vaccination where these are indicated. These may include EasyRead information, longer appointments, desensitisation or home visits. They should make use of support from LD nurses can be obtained if required.
- Primary care providers should ask about alcohol and drug misuse as part of the AHC, and offer referral into substance misuse services where appropriate.
- Smoking status should be asked as part of the AHC, and support to quit offered as appropriate.
- Annual health checks should cover need for contraception, STI screening and cervical screening.
- Ensure physical activity is included with annual health check discussion.

- Support healthcare staff to undertake brief intervention training around physical activity through the Active Providers charter.
- Aim for 75% coverage of AHC amongst eligible patients, in line with the Long Term Plan.
- Ensure that there is access to appropriate equipment in primary care to be able to undertake a full AHC for individuals with comorbid physical disabilities, for example hoists to enable physical examination or wheelchair scales to enable a weight to be measured.
- Continue to work with primary care to understand how GP practices can best be supported to deliver good quality AHCs.
- The CVD prevention section (7.1) notes the very high exclusion rate for NHS Health Checks amongst patients on the LD register. This may be entirely appropriate, however the AHC template does not include all elements of the NHS Health Check. GPs should ensure that exclusion from NHS Health Checks does not inadvertently mean that adults with an LD miss out on CVD prevention opportunities.
- Consideration is needed as to what support and training might be needed for GPs who are managing adults with an LD and mental health conditions in primary care, taking into account NICE NG54 Quality Statement 2.
- Ensure that questions around dementia are included in the AHC.
- Bowel habits should be enquired about at the annual health check.
- Advice should be offered around diet and physical activity.
- Annual health checks should include questions around eating and drinking.
- Ensure annual health check discussion covers attendance at routine dental check-ups.
- The AHC should ask about attendance at routine sight tests.
- Measuring weight is a component of the AHC. Commissioners and providers should ensure that there is access to wheelchair-accessible scales in the community, so that individuals who can’t weight bear can be weighed.

18.2 Cambridgeshire and Peterborough ICB

- Cambridgeshire and Peterborough ICB should ensure learning from local and national LeDeR reviews is shared widely amongst health and care partners, with identified actions addressed.
- The current programme of coproduction work should continue, to ensure people with an LD have their views and experiences heard.
- There is an urgent need to re-establish postural care pathways for both Cambridgeshire and Peterborough.
- Consider whether there is a need for regular audiology screening in residential settings.
- Commissioners should ensure that health providers have sufficient flexibility in care pathways and sufficient funding to enable appropriate reasonable

adjustments to be made, for example to allow longer appointments or more appointments.

- Further work is needed to clarify the local pathway for medical assessment for individuals at risk of community acquired pneumonia for Cambridgeshire and Peterborough, in line with BTS guidance.
- The LD physiotherapy vacancies in Cambridgeshire and lack of commissioned service in Peterborough represent significant risks, although significant work has been undertaken in Cambridgeshire to try to fill the current vacancies. Further support is needed to address the service gaps across both areas.
- Further work is needed to support local data linkage between primary care and hospital episode statistics datasets, via DSCRO, to enable monitoring of hospital admissions for pneumonia.
- Informal cares need support in recognising signs and symptoms of clinical deterioration, to enable early recognition and treatment.

18.3 Healthcare providers and commissioners

- All healthcare providers and commissioners should ensure their staff have an understanding of the key causes of mortality in adults with an LD
- All healthcare providers and commissioners should ensure they consider what systemic actions they need to take to address actions identified by local and national LeDeR work
- Frontline health and social care workers should be supported to access flu and covid vaccinations.
- Commissioners and providers should consider how to support STOMP in Cambridgeshire and Peterborough, in line with the NHS Long Term Plan.
- Commissioners should ensure there is a clear pathway for diagnosis of adults with an LD who need assessment for dementia.
- Commissioners should assure themselves that the NICE recommendations relevant to the needs of people with an LD who have dementia are being met in Cambridgeshire and Peterborough.
- Ensure that people with an LD in Cambridgeshire and Peterborough are offered diagnostic and treatment pathways for epilepsy that are in line with NICE guidance for the diagnosis and management of epilepsy regardless of whether they are managed in specialist epilepsy services or learning disability psychiatry.
- Ensure that specialist epilepsy services in neurology are able to make reasonable adjustments for people with a learning disability.
- All health staff working with people with an LD should be required to have up-to-date Basic Life Support training as a minimum contractual requirement in service specifications.
- Commissioners and providers should ensure that all health staff working with people with a learning disability receive regular training around eating and drinking/dysphagia that is appropriate to their role.

- Consideration is needed as to the best pathway for managing postural care need when an individual is admitted to hospital.
- Commissioners and providers should ensure that specialist falls prevention services are able to make appropriate reasonable adjustments for adults with an LD.
- RESTORE2 training should be offered to learning disability residential settings as well as older people's settings.
- Commissioners of NHS sight tests should ensure that their providers have sufficient capacity, trainng and resource to make reasonable adjustments.
- All health services should be confident in the ability of their services to make reasonable adjustments for people with an LD. Audit tools such as those provided by the NHS England Quality Checkers programme may help give assurance to commissioners.
- All health staff in CQC registered organisations need to undertake training appropriate to their role in line with new legislation. Cambridgeshire and Peterborough ICB should liaise with Health Education England and Skills for Care to ensure that the rollout reaches all providers. Commissioners should ensure that they gain assurance from services that the rollout has taken place.
- All health and social care organisations providing publicly funded care should ensure they have the appropriate policies, processes and staff training in place for the AIS to be implemented fully.
- Commissioners should ensure that the AIS is included within contracts and that there is sufficient funding to enable organisations to meet their legal requirements.

18.4 Mainstream mental health services – commissioners and providers

- Commissioners and providers should ensure that mainstream mental health services who provide assessment and treatment to adults with an LD have the necessary resources, capacity and capability to make appropriate reasonable adjustments.
- Commissioners and providers should be clear about the criteria for stepping patients up from mainstream mental health services into specialist LD services, taking into account NICE NG54 Quality Statement 2.
- All health and social care organisations providing publicly funded care should ensure they have the appropriate policies, processes and staff training in place for the AIS to be implemented fully.
- Commissioners should ensure that the AIS is included within contracts and that there is sufficient funding to enable organisations to meet their legal requirements.
- All health services should be confident in the ability of their services to make reasonable adjustments for people with an LD. Audit tools such as those provided by the NHS England Quality Checkers programme may help give assurance to commissioners.

18.5 All-age autism strategy

- Many of the recommendations in the local all-age autism strategy fit well with the recommendations in this needs assessment, particularly around reasonable adjustments. Work should continue with its implementation.

18.6 Specialist LD health service commissioners

- Commissioners should consider how to strengthen LD psychiatry and psychology capacity in Peterborough, as the service is not currently resilient (see section 17).
- Commissioners should consider how to provide art and/or music therapy in Peterborough, as there is currently an inequity in provision for non-verbal adults with an LD who would benefit from therapy.
- Commissioners should consider how capacity for care coordination can be provided more consistently in Peterborough.
- Commissioners should assure themselves that the NICE Quality Standards on challenging behaviour are being met in Cambridgeshire and Peterborough.
- Commissioners should consider if there is a need for an IST in Cambridgeshire
- Commissioners should consider what support, education and training is offered to unpaid carers of adults with an LD who have challenging behaviour
- Commissioners should ensure that adults with an LD who have challenging behaviour receive a consistent support offer in line with NICE guidance, regardless of which service supports them. This includes the provision of MDT support.
- Commissioners should ensure that they have embedded lessons from national reviews of inpatient, such as those generated from Winterbourne View and Cawston Park.
- Currently there is only one qualified specialist LD speech and language therapist in post covering Peterborough (see section 17). Consideration is needed from commissioners of how to improve the resilience of this service.
- Health commissioners should consider whether there is sufficient breadth of dietetic support to meet the needs of adults with an LD, as per Royal College of Psychiatrist recommendations in section 17 of this needs assessment.
- The vacancies in LD physiotherapy in Cambridgeshire and lack of commissioned service in Peterborough represent significant risks, although significant work has been undertaken in Cambridgeshire to try to fill the current vacancies. Further support is needed to address the service gaps across both areas.
- Commissioners should look to at minimum achieve parity of services between Cambridgeshire and Peterborough. This would mean increasing WTE to achieve similar caseload/WTE staff across current Peterborough services. This

would also mean looking to commission specialist LD physiotherapy, art and music therapy, and to create a service lead and a care coordination function.
- Inconsistencies in the section 75 agreement for Peterborough should be reviewed, with clinical input from provider services as appropriate.
- Issues identified with Peterborough services should be reviewed by both commissioners and service providers.
- Once national LD workforce data is available, benchmarking should be attempted.

18.7 Specialist LD health services

- Specialist LD services should screen for substance misuse at initial referral, and offer referral into substance misuse services where appropriate.
- Specialist LD health services should ask service users their smoking status on initial screening and offer support individuals to access smoking cessation services as appropriate.
- Ensure staff in specialist LD services have knowledge of physical activity recommendations and local opportunities.
- Ensure that specialist LD services are aware of referral routes into specialist weight management services.

18.8 Social care providers and commissioners

- All providers and commissioners of care to adults with an LD should ensure their staff have an understanding of the key causes of mortality in adults with an LD.
- All providers and commissioners of care to adults with an LD should ensure they consider what systemic actions they need to take to address actions identified by local and national LeDeR work.
- Commissioners of residential and domiciliary social care for adults with an LD should ensure that appropriate training is in place for staff to support adults with an LD in the management of long-term conditions linked to cardiovascular disease where they care for individuals with one of these conditions.
- Providers of residential and domiciliary social care should ensure their staff have appropriate training to support adults with an LD in the management of long-term conditions linked to cardiovascular disease where they care for individuals with one of these conditions.
- Care providers should ensure that their staff have an awareness of screening programmes that they may need to support their clients to attend.
- Commissioners of social care should ensure there is sufficient flexibility and funding within service provision to enable paid carers to accompany individuals to a screening appointment where there is an identified need.
- Frontline health and social care workers should be supported to access flu and covid vaccinations.

- Care providers should ensure that their staff have an awareness of routine immunisations that they may need to support their clients to attend.
- Commissioners of social care should ensure there is sufficient flexibility and funding within service provision to enable paid carers to accompany individuals to an immunisation appointment where there is an identified need.
- Providers of residential care for adults with an LD should ensure their staff are familiar with how to access smoking cessation services, and can support their service users to access them as appropriate.
- All care staff in residential services should undertake training about sexual health and relationships, as well as around capacity and consent, that is appropriate to their role.
- Care provider policies around relationships for individuals in residential care should be reviewed as part of the routine contract monitoring process.
- There is a need to ensure that adults with an LD have opportunities to socialise and develop social networks, including both friendships and personal relationships. This should be recognised as an outcome of day services.
- Consider embedding requirements around supporting service users to access physical activity into care home, supported living and domiciliary care service specifications.
- Consider embedding requirements to offer physical activity to service users attending day opportunities.
- Ensure that social care staff have adequate awareness of the importance of attending AHCs.
- Ensure that where a staff member is needed to attend with the person to support, this is someone who knows the individual well.
- Staff in residential care and domiciliary care providers should have training on healthy eating and mental capacity relating to food choices.
- Commissioners need to ensure they have an understanding of the future housing needs of adults with an LD who live with their parents.
- Commissioners should ensure commissioned housing is of a high quality, without environmental hazards.
- Commissioners should ensure that they have a varied day opportunities offer, that supports with developing employment skills and with developing friendships and social networks.
- Care providers should ensure that their staff have the knowledge and understanding to support adults with an LD who are eligible to claim benefits to access income maximisation support if needed.
- Care providers should ensure that their staff have the knowledge and skills to help individuals they support to access training, education and employment opportunities.
- Commissioners and social care providers should ensure that social care staff who care for individuals with an LD who have a mental illness have the necessary knowledge and skills to meet their needs.

- Commissioners and social care providers who provide care to adults with an LD who have behaviour that challenge in the community should ensure that staff who have appropriate skills and knowledge to support effectively.
- Section 11 considers residential care commissioning for adults with an LD. Some of these adults will have challenging behaviour. In light of the NHS Long Term Plan ambition to reduce the number of inpatient stays, consideration is needed of whether there is sufficient, appropriate community capacity for individuals being discharged.
- Commissioners and providers should ensure that care staff who care for adults with an LD have the skills and knowledge to support people with dementia.
- Ensure that care providers of people with a learning disability offer their staff training on epilepsy as standard, reflecting the likely high prevalence of epilepsy amongst their residents.
- Social care providers should ensure that their staff are aware of the symptoms and signs of constipation.
- Social care providers should ensure that their staff are supporting the people they care for to be physically active and eat healthily.
- All social care staff working with people with an LD should be required to have up-to-date Basic Life Support training as a minimum contractual requirement in service specifications.
- Commissioners and providers should ensure that all care staff working with people with a learning disability receive regular training around eating and drinking/dysphagia that is appropriate to their role.
- Where individuals have postural care systems, carers must be adequately trained so that they understand the importance of adhering to them 24 hours/day.
- Ensure staff who are required to support with toothbrushing are trained on how to do so appropriately.
- Ensure that staff training around health promotion includes elements of oral health promotion.
- Social care providers should ensure that staff have appropriate training around falls prevention, both in terms of individual and environmental risk factors.
- Ensure that social care staff have an awareness of signs of hearing loss amongst adults with an LD.
- Providers of residential social care should ensure that they support the people they care for to access routine sight tests.
- Social care staff should receive training on diet and nutrition appropriate for the needs of the residents they are caring for.
- Residential care providers should ensure that staff have training on recognition of signs and symptoms of clinical deterioration that is appropriate to their role.

- Residential care providers should ensure they have access to scales, including wheelchair-accessible scales, for individuals where weight monitoring is indicated.
- CCC and PCC commissioners should work with Cambridgeshire and Peterborough ICB to make use of the new DSCRO data warehouse once appropriate data-sharing agreements are in place, in order to understand the physical and mental health comorbidities of individuals that are in long-term care.
- CCC and PCC commissioners should work with Cambridgeshire and Peterborough ICB to understand the future demand for single service user provision that will derive from individuals who are currently in long stay inpatient units.
- System work will be needed to implement the national framework for delegations once it is released.
- All social care staff in CQC registered organisations need to undertake undertake training appropriate to their role in line with new legislation. Cambridgeshire and Peterborough ICB should liaise with Health Education England and Skills for Care to ensure that the rollout reaches all providers. Commissioners should ensure that they gain assurance from services that the rollout has taken place.
- Commissioners of social care should review flexibilities within funding arrangements for enabling paid carers to attend hospital whilst their service user is an inpatient, to facilitate the process of reasonable adjustments.
- All health and social care organisations providing publicly funded care should ensure they have the appropriate policies, processes and staff training in place for the AIS to be implemented fully.
- Commissioners should ensure that the AIS is included within contracts and that there is sufficient funding to enable organisations to meet their legal requirements.

18.9 Care planning

- If individuals have a need for a paid carer to accompany them to a screening appointment, this should be included within their care plan.
- If individuals have a need for a paid carer to accompany them to an immunisation appointment, this should be included within their care plan.
- Care plans should include supporting an individual's needs around domestic, family and personal relationships
- If support is necessary to support an individual with care needs to access physical activity, this should be included within their care plans.
- Support social workers, alternatively qualified practitioners and commissioned social care provider staff to undertake training around physical activity, to cover how to embed into care plans (including different components of physical

activity), behaviour change and motivational approaches, and supporting service users to access opportunities.

- Ensure that supporting attendance at AHCs is included in care plans if necessary.
- If an individual with care needs requires support around making food choices, this should be incorporated into their care plan.
- Many of the wider determinants of health intersect with eligible care needs under the Care Act, particularly:

> (e) being able to make use of the adult's home safely;
>
> (f) maintaining a habitable home environment;
>
> (g) developing and maintaining family or other personal relationships;
>
> (h) accessing and engaging in work, training, education or volunteering;
>
> (i) making use of necessary facilities or services in the local community including public transport, and recreational facilities or services.

Care planning should consider all of these areas.

- Planning for later life should be part of care planning for adults with an LD and their carers.
- Care plans should consider eating and drinking needs as standard.
- Care plans should include regular dental check-ups; attendance should be monitored as part of the annual review.
- Ensure that mouth care is explicitly incorporated into care plans.
- Attendance at routine dental appointments should be incorporated into care plans, including any necessary support for attendance.
- Attendance at routine sight tests should be incorporated into an individual's care plan, with support identified if required.

18.10 Unpaid carers

- Unpaid carers should be supported to access information and education relating to supporting the person they care for with long term clinical risk factors such as diabetes, hypertension, hypercholesterolaemia and atrial fibrillation.
- Unpaid carers of people with an LD should be included in health promotion campaigns to increase screening uptake.
- Unpaid carers of people with an LD should be supported to access flu and covid vaccinations.
- Given the mortality due to pneumonia in adults with an LD (see section 6), unpaid carers of adults with an LD should be offered support to quit, to reduce exposure to second-hand smoke.
- Unpaid carers should be offered access to health promotion and education around healthy diet, alongside the people they care for.

- Unpaid carers of adults with an LD should be able to access support to claim any benefits that they are entitled to.
- Consideration is needed of what support and advice might be needed for unpaid carers of adults with an LD who have a mental illness or challenging behaviour.
- Consider offering education and support for unpaid carers who care for adults with an LD around healthy ageing, including dementia awareness.
- Ensure accessible information is available for individuals with an LD and their carers about dementia.
- Consider if there is a need for a specific training offer for unpaid carers of people with epilepsy.
- Unpaid carers of people with an LD should be supported to be aware of the symptoms and signs of constipation.
- There should be consideration of how to offer unpaid carers of people with a learning disability training around eating and drinking/dysphagia.
- Where individuals have postural care systems, carers must be adequately trained so that they understand the importance of adhering to them 24 hours/day.

18.11 Information and guidance

- Include signposting to inclusive sports offer within the local authority's Directory of Services
- Ensure social prescribers and community navigators are aware of the inclusive sports / exercise / physical activity / active travel opportunities
- Adults with an LD should be supported by social prescribers in primary care to access services that may support them with any of the areas in this section that may be impacting on their health.

18.12 Self-management and structured education providers and commissioners

- All pathways for prevention and management of cardiovascular disease should ensure that they are making appropriate reasonable adjustments for people with an LD. This includes any commissioned self-management or structured education programmes for people with long-term conditions, which should include carers where appropriate.

18.13 Health promotion

- People with an LD should be actively targeted in health promotion campaigns to increase screening uptake, including with accessible information.
- Specialist LD services and commissioned sexual health services should consider how they can collaborate to ensure that there is a route for adults with an LD to access appropriate sex and relationship education.

- Develop a regular health promotion education offer incorporating physical activity for people with a learning disability and their carers
- Continue to promote AHCs to people with an LD and their carers.
- Health promotion work around healthy eating should be targeted at people with an LD and their carers.
- People with an LD should be supported to be physically active and to eat a balanced diet.
- Ensure awareness that audiology services for people with a learning disability are accessed through specialist audiology, not high street hearing tests.
- Given the lack of good quality data and the current issues with accessing NHS dentistry, commissioning an oral health survey for the most vulnerable cohorts (adults in nursing and residential care) of adults with LD would enable an understanding of unmet need.
- Incorporate messaging around toothbrushing and oral health into regular wider health promotion work with adults with learning disabilities.
- Consider initiating discussions around introducing water fluoridation.

18.14 Screening providers and commissioners

- Screening providers and commissioners should be confident that they have a process in place to identify when reasonable adjustments are needed, and to make them. Currently only the diabetic eye screening programme has access to the primary care LD flag. Providers and screening commissioners should work to understand how to support other screening programmes to access the digital LD flag. Once the NHS England reasonable adjustments flag is rolled out (see chapter 15), commissioners and providers should work together to ensure that this information can be accessed by all screening providers.
- Screening providers and commissioners should be confident that they can make appropriate reasonable adjustments where need has been identified.
- Findings from the diabetic eye screening and planned AAA screening Health Equity Audits should be disseminated to other screening programmes, as there is likely to be common learning. Cervical, bowel and breast screening programmes should consider if they would benefit from undertaking a Health Equity Audit.
- Providers and commissioners should be confident that there are clear processes and training for staff in how to apply the Mental Capacity Act with regards to consent for screening.

18.15 Provider of specialist alcohol and drugs services

- CGL should continue to ensure that they are complying with national legislation around training for staff relating to learning disability.
- CGL should consider monitoring treatment outcomes for patients with an LD, to see how they compare to their broader population of service users. If service

users with an LD have poorer treatment outcomes, further work will be needed to understand why.

- As CGL are not an NHS provider, it is not clear whether they will be able to access NHS reasonable adjustment flags when this programme goes live (see section 15). Commissioners should explore whether the current process of relying on patient self-report at the initial appointment is sufficient, and whether there is value in supporting CGL to have access to SystmOne.
- CGL should continue to develop links with specialist LD services to ensure that they can access specialist guidance where needed around the needs of service users with an LD.

18.16 Commissioners of specialist alcohol and drugs services

- Commissioners should understand what options there are for patients with an LD who need inpatient detox, and how this can be supported where it is indicated.

18.17 Smoking cessation services

- Commissioners and providers should ensure that smoking cessation practitioners have training appropriate to their role around making reasonable adjustments for adults with an LD.
- Services should ensure that they have appropriate EasyRead materials.
- Commissioners and providers should ensure that flexibilities around making reasonable adjustments to length and number of appointments are clear to practitioners.

18.18 Sexual health services commissioners and providers

- Commissioned sexual health promotion work should include adults with an LD as routine.
- Sexual health services should ensure that they are able to make appropriate reasonable adjustments for adults with an LD.
- CQC-registered services should ensure they are compliant with legislation around staff training relating to the needs of adults with an LD.
- Commissioned clinical sexual health services should consider how they will incorporate the NHS reasonable adjustments flag into their services once this national programme is live.
- There is an upcoming sexual health needs assessment about to be undertaken to inform services in Cambridgeshire and Peterborough. The needs of adults with an LD should be considered in detail as part of this, particularly with regards to ensuring that commissioned services are able to make reasonable adjustments, and that sexual health outreach and promotion work actively includes adults with an LD.

18.19 Physical activity providers

- Consider how additional opportunities can be supported in geographical areas where currently there is a limited offer targeted at people with disabilities
- Work with public health commissioned health trainer and physical activity provision to ensure appropriate pathways are in place
- Ensure staff within public health-commissioned healthy lifestyles service receive regular training around reasonable adjustments
- Ensure exercise professionals have appropriate level of training (skills and knowledge) to adapt and tailor delivery of activity for successful inclusion.

18.20 Weight management commissioners and providers

- Staff in all weight management services should have training on how to make reasonable adjustments for people with a learning disability and on mental capacity.
- Commissioners should consider whether there is a need to add in additional eligibility criteria for tier 3 services that are related to complexity of need, rather than BMI.
- There should be a clear pathway to access dietetic support for individuals whose weight gain is linked to medical reasons rather than behavioural factors.
- Commissioners and providers should be assured that appropriate reasonable adjustments can be made within weight management services.

18.21 Cambridgeshire County Council and Peterborough City Council Business Intelligence team

- Further work is needed to understand whether there is an significant divergence between POPPI and PANSI growth forecasts, which are the most reliable nationally available forecasts, and local actual demand, given overall population growth trajectories.

18.22 Cambridgeshire and Peterborough ICS workforce group

- LD health services should be included within the system work on recruitment and retention.

19. Appendix 1 – Demography

19.1 LD Register Clinical Code Update

As discussed in Section 5, the main source of data collection for LD is through the primary care LD registers. However, this system of identification was subject to issues with both sensitivity (patients with LD not being correctly included) and specificity (patients without LD being incorrectly included) (282). Historically, some coded clinical diagnoses, such as Down's syndrome, did not automatically result in a patient being included on the register. This led to some affected patients not being included within local and national level statistics, as well as potentially missing out on valuable health input, such as the LD annual health check. Furthermore, some clinical codes may have conflated *learning disability* with *learning difficulty*. For example, although 'academic developmental disorder' may have been appropriately used to code a patient with dyslexia, this would have resulted in inappropriate automatic inclusion of this patient on the LD Register (282).

Other issues that lead to heterogeneity between LD registers and impact the robustness of collating data from multiple registers include (283):

- The variety of ways in which people are referred to the registers
- The degree to which health and social care professionals have been made aware of the registers
- The way in which assessments are conducted, i.e., interview versus self-administered questionnaire
- The difference in the definitions of severe or complex learning disability that have been used.

In 2020, NHS England and NHS Improvement undertook work with clinical and coding experts to identify a list of appropriate diagnostic codes that would automatically place a patient on their GP's LD register (282). A second list of codes was created to highlight those patients that should be considered on a case-by-case basis. This update was implemented in early-2020 with the goal of improving both the sensitivity and specificity of LD Registers, leading to improved epidemiological estimates and better targeted provision of health and care services. However, data obtained through the LD Register prior to this improvement are potentially subject to error and should be considered within this context.

19.2 Uncertainty associated with the Emerson et al. (2004) data

Emerson et al. (2004) uses original data collected in England to represent the 'administrative' prevalence rate of LD. The authors then assume that the 'true' prevalence of LD is ~2.5% and that the difference between administrative and true prevalence rates are composed of a "hidden" cohort of cases of LD, mostly mild in severity. The source referenced by Emerson et al. (2004) to support the 2.5% total prevalence of LD is *The Epidemiology of Mental Retardation: Challenges and Opportunities in the New Millennium*, Leonard et al. (2002) (284). This article is an

evidence review that builds upon work published 5 years previously by Roeleveld et al. (1997), *The prevalence of mental retardation: a critical review of recent literature* (285). These two sources summarise a range of epidemiological studies of LD (using the outdated term 'Mental Retardation' under historic nomenclature). Several key limitations of this historic data are noted:

- There has not been a consistent and internationally accepted definition of LD used over time, meaning that diagnostic criteria differ between individual studies, increasing inter-study heterogeneity and reducing comparability (284).
- Historic definitions for LD have consistently required both an impairment to intellectual functioning and to adaptive behaviour. However, the 5th edition guidance published in 1961 by the *American Association of Mental Retardation* (AAMR; now *American Association on Intellectual and Developmental Disabilities*) only required an IQ lower than 85 (15.9% of the overall population). By the 9th edition guidance published in 1992, this criterion had been refined to "an IQ standard score of approximately 70 to 75 or below" (2.5–5.3% of the overall population). Hence, the choice of cut-off for intellectual impairment has a significant impact on the anticipated overall prevalence of LD.
- Likewise, the classification of severity of LD has also varied over time with various IQ thresholds being proposed. In the 9th edition AAMR guidance published in 1992, LD severity shifted away from IQ thresholds and was defined by the level of support required by an individual: intermittent (mild), limited (moderate), extensive (severe), and pervasive (profound). These evolving definitions impacted upon how epidemiological studies over time have reported on LD sub-classification. It is noted that a binary classification of LD by IQ is often used in historic studies, with an IQ <50 being considered as severe and >50 non-severe (or 'mild').
- The prevalence of LD has been shown to depend on if criteria for adaptive behaviour are included alongside IQ in case detection. One historic study found that inclusion of criteria for adaptive behaviour alongside IQ reduced the estimated prevalence of LD from 2% to 1% (284). It has been noted that adaptive behaviour criteria are frequently omitted from epidemiological studies due to a lack of cross-cultural, validated assessment methods.

Roeleveld et al. (1997) summarise reported prevalence of mild (non-severe) and severe LD in in their work (285).

It is noted that the SMR prevalence is broadly similar to the prevalence of severe and profound LD amongst school-age children with SEN in England. However, when considering non-severe LD, there is substantial variability in the prevalence rates between studies. Possible explanations for the anomalous high reported prevalence rates are discussed in their paper (285). However, when calculating the overall average prevalence rate the authors discarded individual administrative rates and

included the anomalous high prevalence results, potentially resulting in an artificially high average prevalence.

Importantly, neither Leonard et al. (2002) nor Roeleveld et al. (1997) explicitly state a calculated overall prevalence of LD of ~2.5%, as referenced by Emerson et al. (2004)(20). Therefore, the estimate of 2.5% total prevalence of LD may have been based upon two key assumptions:

- A diagnosis of LD can be made if a person has an IQ <70, regardless of the adaptive behaviour diagnostic criterion for LD
- IQ is normally distributed around a mean of 100, with standard deviation of 15

Together, these assumptions would equate to ~2.5% of the total population having an IQ of <70, and thus having LD. However, this approach would be a simplification and would likely overestimate the prevalence of LD. As the Emerson et al. (2004) data has been propagated for almost two decades as the most accurate LD prevalence estimate in England, these points of uncertainty should be considered carefully.

19.3 POPPI and PANSI data

Table 19.1: People in Cambridgeshire predicted to have a moderate or severe learning disability, by age

	2020	2025	2030	2035	2040
People aged 18-24 predicted to have a moderate or severe learning disability	369	375	421	432	409
People aged 25-34 predicted to have a moderate or severe learning disability	428	414	396	410	444
People aged 35-44 predicted to have a moderate or severe learning disability	511	515	509	494	473
People aged 45-54 predicted to have a moderate or severe learning disability	478	459	460	471	469
People aged 55-64 predicted to have a moderate or severe learning disability	403	435	429	410	412
People aged 65-74 predicted to have a moderate or severe learning disability	237	234	262	285	283
People aged 75-84 predicted to have a moderate or severe learning disability	87	108	113	115	131
People aged 85 and over predicted to have a moderate or severe learning disability	32	36	43	54	58
Total population aged 18 and over predicted to have a moderate or severe learning disability	**2,545**	**2,576**	**2,633**	**2,671**	**2,679**

Source: POPPI(24)

Table 19.2: People in Peterborough predicted to have a moderate or severe learning disability, by age

	2020	2025	2030	2035	2040
People aged 18-24 predicted to have a moderate or severe learning disability	89	91	107	115	108
People aged 25-34 predicted to have a moderate or severe learning disability	160	153	146	150	164
People aged 35-44 predicted to have a moderate or severe learning disability	184	199	198	190	182
People aged 45-54 predicted to have a moderate or severe learning disability	140	143	154	166	166
People aged 55-64 predicted to have a moderate or severe learning disability	109	120	122	122	130
People aged 65-74 predicted to have a moderate or severe learning disability	59	61	69	76	78
People aged 75-84 predicted to have a moderate or severe learning disability	20	25	27	29	33
People aged 85 and over predicted to have a moderate or severe learning disability	8	8	9	12	13
Total population aged 18 and over predicted to have a moderate or severe learning disability	**769**	**800**	**832**	**860**	**874**

Source: POPPI(24)

Table 19.3: People in Cambridgeshire predicted to have a severe learning disability, by age

	2020	2025	2030	2035	2040
People aged 18-24 predicted to have a severe learning disability	122	124	139	143	135
People aged 25-34 predicted to have a severe learning disability	120	116	111	115	124
People aged 35-44 predicted to have a severe learning disability	138	139	137	133	128
People aged 45-54 predicted to have a severe learning disability	106	102	102	104	104
People aged 55-64 predicted to have a severe learning disability	94	102	102	97	97
Total population aged 18-64 predicted to have a severe learning disability	**580**	**583**	**591**	**592**	**588**

Source: POPPI(24)

Table 29.4: People in Peterborough predicted to have a severe learning disability, by age

	2020	2025	2030	2035	2040
People aged 18-24 predicted to have a severe learning disability	29	30	35	38	36
People aged 25-34 predicted to have a severe learning disability	45	43	41	42	46
People aged 35-44 predicted to have a severe learning disability	50	54	53	51	49
People aged 45-54 predicted to have a severe learning disability	31	32	34	37	37
People aged 55-64 predicted to have a severe learning disability	25	28	29	29	30
Total population aged 18-64 predicted to have a severe learning disability	**180**	**187**	**192**	**197**	**198**

Source: POPPI(24)

Table 3: People in Cambridgeshire predicted to have a learning disability, by age

	2020	2025	2030	2035	2040
People aged 18-24 predicted to have a learning disability	1,588	1,591	1,774	1,812	1,701
People aged 25-34 predicted to have a learning disability	1,992	1,927	1,845	1,907	2,067
People aged 35-44 predicted to have a learning disability	2,030	2,044	2,018	1,957	1,871
People aged 45-54 predicted to have a learning disability	2,125	2,035	2,021	2,065	2,050
People aged 55-64 predicted to have a learning disability	1,851	2,010	1,995	1,908	1,909
People aged 65-74 predicted to have a learning disability	1,475	1,447	1,614	1,764	1,757
People aged 75-84 predicted to have a learning disability	843	1,047	1,108	1,128	1,287
People aged 85 and over predicted to have a learning disability	341	391	468	596	644
Total population aged 18 and over predicted to have a learning disability	**12,245**	**12,492**	**12,843**	**13,137**	**13,286**

Source: POPPI(24)

Table 19.5: People in Peterborough predicted to have a learning disability, by age

	2020	2025	2030	2035	2040
People aged 18-24 predicted to have a learning disability	383	385	448	479	449
People aged 25-34 predicted to have a learning disability	745	710	677	697	764
People aged 35-44 predicted to have a learning disability	732	791	786	753	721
People aged 45-54 predicted to have a learning disability	622	630	675	725	724
People aged 55-64 predicted to have a learning disability	500	555	566	565	600
People aged 65-74 predicted to have a learning disability	364	378	423	470	482
People aged 75-84 predicted to have a learning disability	195	240	268	284	325
People aged 85 and over predicted to have a learning disability	81	90	102	131	146
Total population aged 18 and over predicted to have a learning disability	**3,622**	**3,779**	**3,945**	**4,104**	**4,211**

Source: POPPI(24)

19.4 Institute of Public Care Working Paper: Estimating the Prevalence of Severe Learning Disability in Adults

As discussed in Section 2.1.3, LD can be categorised by severity: mild, moderate, severe, profound/multiple. Ascertaining the prevalence of each severity within the total population of people with LD is important, as a person's health and social care needs are typically greater with more severe LD. A 2009 report published by the Institute of Public Care at Oxford Brooks University sought to estimate the prevalence of severe LD in adults in England (283).

Sheffield and Leicestershire local authorities collected data on severity in different manners. The Sheffield registry recorded Social and Physical Incapacity (SPI) diagnostic ratings, used to identify the nature and severity of disability. These SPIs were broadly aggregated into three categories (Table 4). 'Severe disability' was felt to resemble 'Severe' LD most closely, although this comparison is not formally validated. The Leicestershire registry assessed disability through the Leicestershire Intellectual Disability (LID) tool, a validated research methodology used to establish a person's developmental age, which was used as a proxy for LD severity categorisation.

Table 4.6: Categories of disability use in the Sheffield LD register

SPI Category	Sheffield Category	Description of Disability
1 – 4	Severe Disability	• Severe incontinence • Severe behaviour problems • At least partly mobile with severe incontinence and severe behaviour problems • Non-ambulant
5 – 8	Moderate Disability	• Mild incontinence problem only • Mild behaviour problem only • Ambulant but mild behaviour and incontinence problems • No severe problems but only partly mobile
9	Most able	• Not incapacitated

Taken from: Institute of Public Care OBU. Estimating the Prevalence of Severe Learning Disability in Adults. Available at: https://ipc.brookes.ac.uk/files/publications/Estimating_the_prevalence_of_severe_learning_disability_in_adults.pdf (283)

The report calculated age-adjusted prevalence rates using data collected from the local authority registers alongside ONS population data (Table 19.7). The 'administrate rate' refers to the prevalence rate of LD of any severity requiring input from specialist LD or social care services, including those people only requiring minor levels of support. The 'complex rate' refers to the prevalence rate of severe LD within local authorities, as defined by the metrics described above.

Table 19.7: Comparison of Sheffield and Leicestershire LD Case Register populations, aged 20+ (prevalence rates for 'administrative' and 'complex' populations)

Age band	Leicestershire 'admin' rate (%)	Leicestershire 'complex' rate (%)	Sheffield 'admin' rate (%)	Sheffield 'complex' rate (%)
20-24	6.43	1.84	5.35	2.20
25-29	7.78	1.92	4.67	1.88
30-34	7.39	1.87	5.90	1.79
35-39	5.89	1.64	6.42	1.67
40-44	5.00	1.28	8.82	2.05
45-49	5.16	1.17	7.77	1.93
50-54	5.14	0.93	6.90	1.54
55-59	4.24	0.77	5.66	1.40
60-64	3.28	0.79	4.98	1.49
65-69	2.89	0.48	3.83	1.22
70-74	1.96	0.58	3.21	1.05
75-79	1.32	0.39	1.88	0.85
80-84	0.58	0.18	1.69	0.81
85-89	0.34	0.10	1.26	0.50
All ages	4.77	1.16	5.31	1.64

Taken from: Institute of Public Care OBU. Estimating the Prevalence of Severe Learning Disability in Adults. Available at: https://ipc.brookes.ac.uk/files/publications/Estimating_the_prevalence_of_severe_learning_disability_in_adults.pdf (283)

Notably, both prevalence rates are similar to one another across local authorities throughout most age bands from age 20-89. The difference between administrate rate and complex rate narrows with increasing age likely due to mortality drop-out being higher within the 'complex' cohort and advancing age leading to increasing care requirements amongst people within the 'administrative' population, mitigating the mortality drop-out in the 'complex' cohort but reducing the overall 'administrative' cohort. The report's authors estimate that the prevalence of severe/complex LD within the overall population of people with LD is between 20–33%, varying by age (Table 19.8).

Table 19.8: Percentage of people registered known to social care services with a learning disability that have a complex or severe learning disability

Age range	People with severe/complex LD as a % of people with a registered LD
18 – 24	33%
25 – 29	29%
30 – 34	27%
35 – 39	27%
40 – 44	27%
45 – 49	24%
50 – 54	20%
55 – 59	21%
60 – 65	27%

Source: Institute of Public Care OBU. Estimating the Prevalence of Severe Learning Disability in Adults. Available at: https://ipc.brookes.ac.uk/files/publications/Estimating_the_prevalence_of_severe_learning_disability_in_adults.pdf (283)

20. Abbreviations

AHCs – Annual health check for people with a learning disability

AIS – Accessible Information Standard

BTS – British Thoracic Society

CCC – Cambridgeshire County Council

CGL – Change Grow Live

COPD – chronic obstructive pulmonary disease

C&P – Cambridgeshire and Peterborough

C&P ICB – Cambridgeshire and Peterborough Integrated Care Board

C&P ICS – Cambridgeshire and Peterborough Integrated Care System

CPFT – Cambridgeshire and Peterborough NHS Foundation Trust

CQC – Care Quality Commission

CUH – Cambridge University Hospitals NHS Trust

CVD – cardiovascular disease

DNA – Did Not Attend [an appointment]

DNACPR – Do Not Attempt Cardiopulmonary Resuscitation

IAPT – Improving Access to Psychological Therapies

IHD – ischaemic heart disease

LD – learning disability

LeDeR – Learning from Lives and Deaths Review programme

MDT – Multi-Disciplinary Team

MH-LDA ABU – Mental Health, Learning Disability and Autism Accountable Business Unit

NICE – National Institute for Health and Care Excellence

NWAFT – North West Anglia Foundation NHS Trust

ONS – Office for National Statistics

OT – Occupational Therapist

PCC – Peterborough City Council

RCPsych – Royal College of Psychiatrists

S75 – section 75

SALT – Speech and Language Therapist

STOMP – Stopping over-medication of people with a learning disability

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