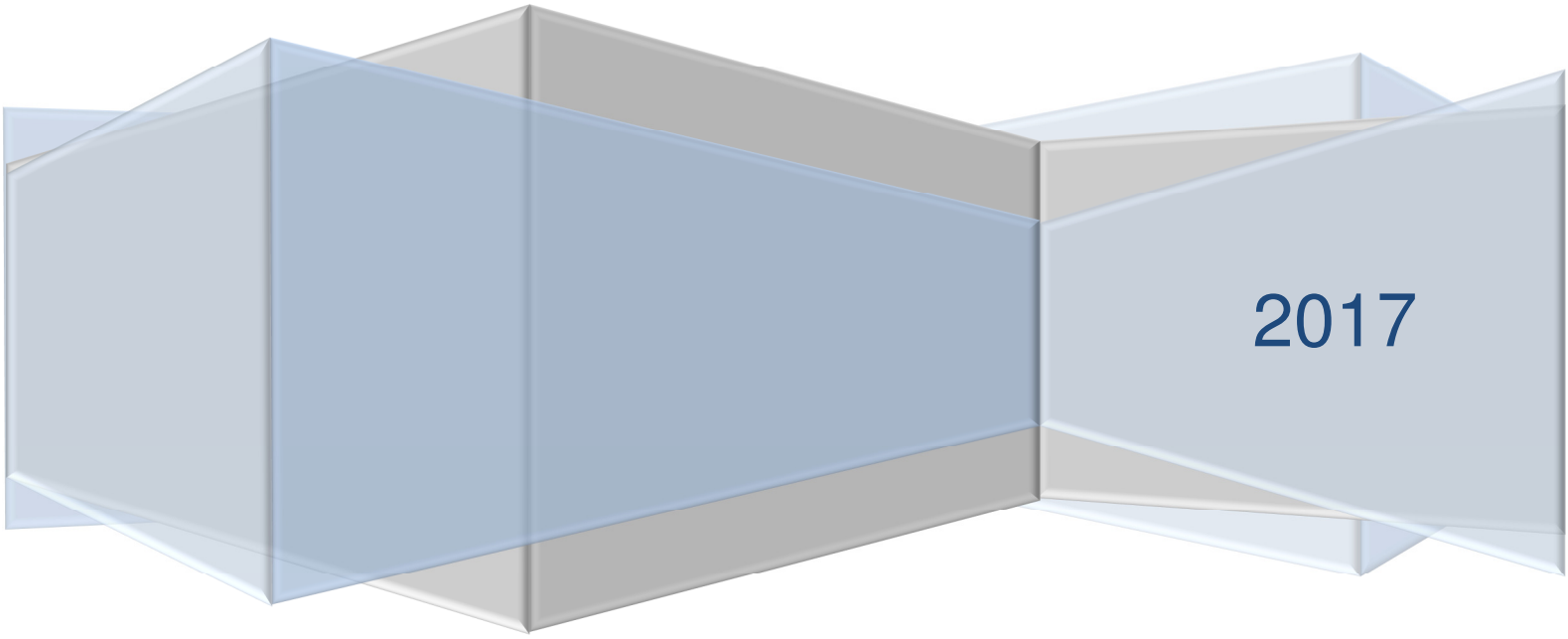
Kent Community Health NHS
NHS Foundation Trust

Data Intelligence Report

Kent Learning Disabilities



Excellent care, healthy communities

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Acknowledgements

We thank our Clinical Support Team colleagues from Kent Community Health NHS Foundation Trust who undertook the role of data collectors, collated evidence for the data intelligence audit and provided local knowledge to assist this project. We would also like to show our gratitude to the Intelligence Network members who offered their knowledge and time to support the deliverance of this project.

Acronyms and Definitions

CCG	Clinical Commissioning Group
CLDT	Community Learning Disability Team
HEF	Health Equalities Framework
IHaL	Improving Health and Lives
KCC	Kent County Council
KCHFT	Kent Community Health NHS Foundation Trust
KMPT	Kent and Medway Partnership Trust
NHS	National Health Service

Executive Summary

This report presents available evidence on people with learning disabilities within Kent, combined with nationally published statistics and research materials. The evidence base looks at current literature and Kent intelligence regarding the prevalence and trends of the health needs of people with a learning disability.

The objective of the collation of this report is to assist in the development of first class leading care for people with learning disabilities. This report presents data intelligence on the demographics, health needs and future requirements of people with learning disabilities. This information will be beneficial in the design and implementation of services to match care to need of people living in Kent with learning disabilities; ensuring the formation of services aimed at addressing the areas of health inequality.

Defining Learning Disability

The term 'learning disability' commonly refers to a group of individuals with a history of developmental delay, a delay in or failure to acquire a level of adaptive behaviour and/or social functioning expected for their age and in whom there is evidence of significant intellectual impairment[1].

One of the most commonly used definitions of learning disability in the UK is contained in the 2001 White Paper, Valuing People: A New Strategy for Learning Disability for the 21st Century. The report defines learning disability as the presence of "a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development[2]"

Objectives

The purpose of the project is to better understand the current and future needs of people with learning disabilities in Kent. Strengthening the demographic intelligence will improve outcomes for service delivery and enhance workforce planning.

The specialist needs of people with a learning disability in Kent continue to increase year on year. Public Health Kent states "the number of adults with moderate and severe learning disabilities (and therefore likely to be in receipt of services) is predicted to increase by 4.1% from 2012 to 2016, resulting in an estimated 5,814 people in Kent with moderate to severe learning disabilities by 2020."[3]

To ensure people who are accessing learning disability health services receive first class leading care, it is essential staff providing that care have the right skills and personal development which is planned and forecast. To enable this to happen first we must understand the nature of the needs presented. Public Health also states, "of the predicted population increase for Kent, 1,304 people are likely to have severe learning disabilities in 2016 (an estimated additional 2.4% people than in 2012 and therefore is likely to make further demands on existing resources."[4]

Background

The Community Learning Disability Team (CLDT) received funding from Health Education Kent, Surrey and Sussex to undertake findings within a 12 month period. Prior to commencing the project a comprehensive plan was established to ensure the time period would not constrain the project outcome.

The CLDT is an integrated service with Kent County Council (KCC) and Kent & Medway Partnership Trust (KMPT). The CLDT provides specialist health advice and support to people with learning disabilities, their carers, families and the wider health and social care community across Kent.

The service is made up of 4 locality teams and provides a multi-agency, professional service to adults who are aged 18 years, or those who are 17 and in transition between young people's services and adult services. The integrated service employs over 300 staff across KCC, KMPT and KCHFT; of which 132 are health employees. The health component of the multi-disciplinary team comprises of Occupational Therapy, Nursing, Speech and Language Therapy, Sensory, and Physiotherapy.

The CLDT in Kent works across 7 Clinical Commissioning Groups (CCGs): Ashford CCG; Canterbury and Coastal CCG; Dartford, Gravesham and Swanley CCG; South Kent Coast CCG; Swale CCG; Thanet CCG and West Kent CCG. A new Section 75 Agreement between the 7 Kent CCGs and the 3 learning disability provider organisations was introduced in April 2017 which has led to alliance commissioning.

Health Inequalities

Responding to the health inequalities faced by people with learning disabilities is a critically important issue for healthcare services in England. It is clear that these health inequalities are, to an extent, avoidable. It is also clear that existing patterns of healthcare provision are insufficient, inequitable and likely to be in contravention of legal requirements under the United Nations Convention on the Rights of Persons with Disabilities.

Department of Health policies and guidance have emphasised the central role that mainstream health services must play in meeting the health needs of people with learning disabilities.

Progress on reducing health inequalities in general will require greater attention to the health inequalities faced by particular 'high risk' groups, including people with learning disabilities.

5 Determinants of Health Inequality

Research studies have investigated five broad classes of determinants of the health inequalities faced by people with learning disabilities that are, in principle, potentially amenable to intervention:

- Increased risk of exposure to well established 'social determinants' of health;
- Increased risk associated with specific genetic and biological causes of learning disabilities;
- Communication difficulties and reduced health 'literacy';
- Personal health risks and behaviours;
- Deficiencies in access to and the quality of healthcare provision.

Reducing Inequality

Measuring the impact of policies, services, programmes and projects on reducing health inequalities is a complex process. It is important that true intelligence is captured on the impact of any proposals to reduce health inequalities in Kent.

The Health Inequalities and People with Learning Disabilities in the UK (2012)[5] identified a number of ways to reduce inequalities among those with learning disabilities:

1. Reduce the exposure of people with learning disabilities to adverse social determinants: poverty, poor housing, unemployment, social disconnectedness and discrimination
2. Improve the early identification of illness through annual health checks and cervical and breast screening
3. Enhance the health literacy of people who play a critical role in promoting healthy lifestyles: e.g. family and carers
4. Enhance healthcare workers' knowledge and skills for working with people with learning disabilities 5 Make 'reasonable adjustments' in all areas of health promotion and healthcare, and act within legal frameworks of the Equality Act 2010 and the Mental Capacity Act 2005 (e.g. more accessible information and longer appointments)
5. Make 'reasonable adjustments' in all areas of health promotion and healthcare, and act within legal frameworks of the Equality Act 2010 and the Mental Capacity Act 2005 (e.g. more accessible information and longer appointments)
6. Build a more robust evidence-base of the determinants of health inequalities among people with learning disabilities, and effectiveness of interventions to reduce them. Monitor progress towards the elimination of these health inequalities

Methodology

The information presented in this report is based upon the data intelligence audit undertaken by the Clinical Support Team in 2016/17, the Health Equality Framework data analysis 2015-2017 and published literature, such as the Kent Learning Disability Needs Assessment as well as evidence from a literature review.

Health Equalities Framework

The Health Equalities Framework (HEF) was developed as an outcome focused measurement framework to enable practitioners to evidence their contribution to improving person centred health outcomes. Unlike many outcome measurement tools, the HEF measures the effectiveness of services in taking actions to reduce the different adverse health outcomes experienced by people with intellectual disabilities; this enables commissioners, providers, people with learning disabilities and their families to understand the impact and value of services. The HEF is endorsed by the National Valuing Families Forum and professional senate. It is referenced in NHS England and Department of Health reports. It is also referenced in the Joint Self-Assessment Framework, can be implemented across health and social care,

and can support local authorities with their duty to promote wellbeing under the Care Act 2014[6].

Data Intelligence

Analysis of 1000 randomly selected closed cases has been undertaken. As the project has followed these cases through their journey of the service, we have omitted 25 cases who refused treatment, relocated or passed away, leaving a sample of 975 cases. This approach was taken following extensive research into other local needs analysis and data reviews, which highlighted the importance of not relying on a single method of entry. "Many qualitative analytic strategies rely on a general approach called "constant comparative analysis"…this strategy involves taking one piece of data (one interview, one statement, one theme) and comparing it with all others that may be similar or different in order to develop conceptualisations of the possible relations between various pieces of data"[7].

These areas were presented to the Intelligence Network, with details around what data the areas could evidence. These data sources included:

- Patient Information Systems
- Local records
- Databases
- Interviews

The data intelligence audit was conducted during a 6 month period undertaken by the Clinical Support Team, which is independent of any clinical care provided. The outcomes following the data intelligence audit are discussed in the main body of this report.

Limitations

This report focuses on people with learning disabilities who are open to the CLDT in Kent. However, there are some people who are not known to the service. This means there is an incidental bias towards addressing the needs of those who are receiving CLDT interventions.

Furthermore, methods of information recording on local data systems have differed due to implementation of a new patient information system.

However, despite these limitations, by pulling all the evidence together we are able to give the most comprehensive picture possible of the needs of people with learning disabilities in Kent, and how these needs might be met in the future.

National Picture

What we know nationally[8]:

Respiratory Disease

Most common cause of death (49% compared to 16% in general population).

Lung problems (from solids or liquids going down the wrong way) account for 14% of all deaths but may be preventable.

Circulatory Disease

As with the general population, coronary heart disease (CHD) is one of the most common causes of death and ill-health (12% of deaths compared to 29% in general population).

Half of those with Down's syndrome have a congenital heart defect

Epilepsy

Epilepsy found to be around 20 times more common than in general population.

Epilepsy & convulsions account for 14% of deaths, many likely to be preventable.

Seizures are often multiple and also resistant to drug treatment

Mental Health

Anxiety and depression higher than general population, particularly among those with Down's syndrome

36% of children with learning disabilities have a psychiatric disorder compared to 8% in general population

Of all children with a psychiatric disorder, 14% have learning disabilities

Challenging Behaviour
Aggression and self-injury is common among 10-15% of learning disabilities population, particularly 20-49 year olds
1 in 4 people with learning disabilities may self-injure
Challenging behaviour is likely to result in poorer health and is associated with abuse, neglect and inappropriate treatment

Dementia
Dementia is more common in the learning disabilities population than the general population (22% compared to 6% for aged 65+).
Those with Down's syndrome develop dementia 30-40 years earlier than general population

Visual Impairment
Evidence suggests that around one in 10 learning disabled adults are likely to be blind or partially sighted, ten times higher than the general population.
Six out of ten people with learning disabilities need glasses

Eating and Swallowing
8-15% of those with learning disabilities have eating difficulties and may need mealtime support
4 out of 10 of those having difficulties have recurrent respiratory tract infections

Oral Health
1 in 3 adults with learning disabilities and over three quarters of those with Down's syndrome have unhealthy teeth and gums
Those living with families have more untreated decay; those in institutional care have more extracted teeth

Estimates for England

Unfortunately there is not a definitive record of the number of people in England who have learning disabilities. "No government department collects comprehensive information on the presence of learning disabilities in the population and learning disabilities are not recorded in the decennial census of the UK population".[9]

However, by combining the few pieces of information which is collected by government departments on the presence of learning disabilities among people using services, overall population predictions for England and the results of epidemiological research, it can be estimated that in England in 2015 there were 1,087,100 people with learning disabilities, including 930,400 adults. The number of people with learning disabilities recorded in health and social care systems is much lower, for example GPs identified 252,446 children and adults as having learning disabilities on their practice-based registers[10].

The numbers of people with learning disabilities in the population is influenced by a range of demographic factors which influence incidence (number of new cases) and prevalence (numbers of people increasing from improved life expectancy). National modelling suggests sustained growth in the need for social care services for adults with learning disabilities between 2011 and 2026, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%)[11].

This differs from the demand for services which is likely to outstrip changes in need due to a variety of factors combining to reduce the capacity of informal support networks to provide care, for example: increases in lone parent families; more women in work; increasing life expectancy of people with learning disabilities and changing expectations of people's right to live independently.

Demand can also be generated by the way in which health and social care systems operate. For example, when issues are not dealt with at an early stage or where systems are complex to navigate, people may be forced into more regular and high demand contact with services than is necessary, and the more reliant on these services people become, the more their demand for them increases.

With the exception of Learning Disability services there is evidence that the numbers of people receiving state support from councils in social care is declining[12]. Current demand for services for

people with learning disabilities is also increasing, and demographic trends suggest that this growth is set to continue over the next 15 years.

The most widely cited estimates of future demand and need for learning disability services are those from a project conducted by the Centre for Disability Research at Lancaster University on behalf of Mencap. Previous estimates have suggested that the extent and pattern of need for social care services for adults with learning disabilities in England is likely to change due to:

- Decreasing mortality among people with learning disabilities, especially in older age ranges and among children with severe and complex needs;
- The impact of changes in fertility over the past two decades in the general population;
- The ageing of the 'baby boomers', among which there appears to be an increased incidence of learning disabilities[13].

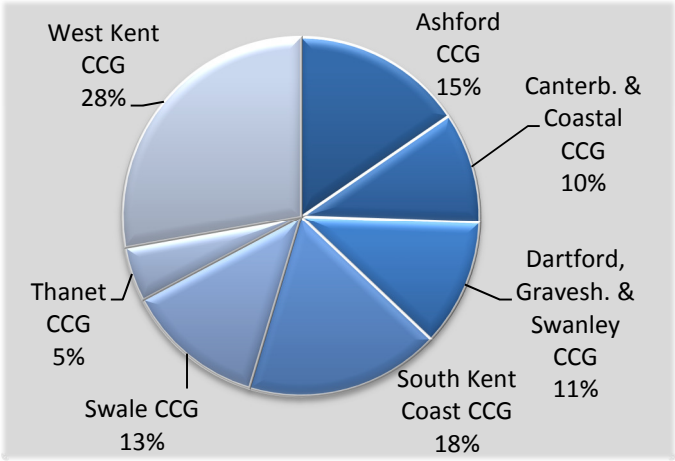
It is predicted that these demographic changes will result in a significant increase in the numbers of older people with learning disabilities and young adults with complex needs and learning disabilities requiring support.

The research estimates that[14]:

- Approximately 25% of new entrants to adult social care with learning disabilities will belong to minority ethnic communities.
- Approximately one in three new entrants to adult social care will come from a home in which the child is eligible for Free School Meals (nationally one in six children in this age range are eligible for Free School Meals)
- By 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double.

Kent Population

The breakdown of the data intelligence audit by CCG area was: Ashford CCG (151), Canterbury & Coastal CCG (98), Dartford, Gravesham & Swanley CCG (112), South Kent Coast CCG (172), Swale CCG (123), Thanet CCG (48) and West Kent CCG (271).



The below table displays the recorded prevalence of learning disabilities in 2014-15 by Kent's CCG's.

	LD Register	CCG Population Size	LD Prevalence
Ashford CCG	521	126,411	0.41%
Canterbury & Coastal CCG	953	215,303	0.44%
Dartford, Gravesham & Swanley CCG	661	257,242	0.26%
South Kent Coast CCG	1,316	198,899	0.66%
Swale CCG	456	108,243	0.42%
Thanet CCG	876	143,193	0.61%
West Kent CCG	1,622	475,717	0.34%
Kent	**6,405**	**1,525,008**	**0.42%**
England	**252,446**	**56,817,654**	**0.44%**

Source: Quality and Outcomes Framework, 2014-15[15]

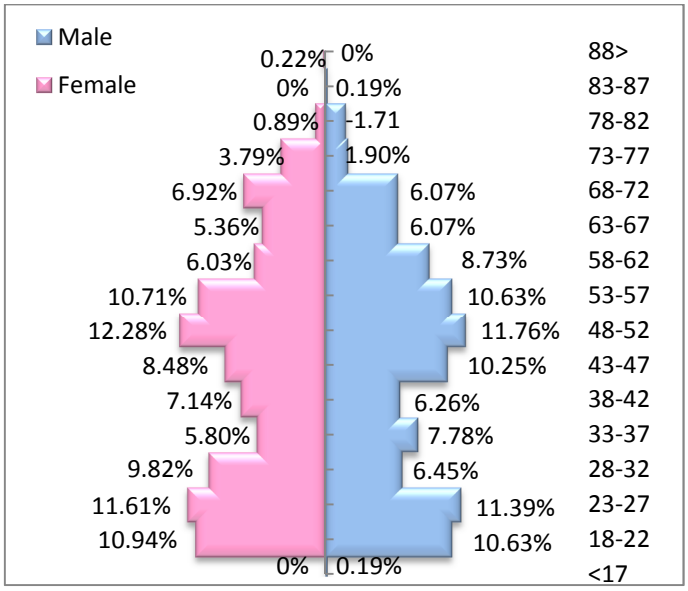
The highest numbers of people with learning disabilities are recorded in West Kent CCG; however this is the largest geographical area. The highest prevalence of learning disabilities is recorded in South Kent Coast CCG. The total prevalence rate in Kent (0.42%) is slightly below the prevalence rate of England (0.44%).

Age

For both male and females there are 2 peaks within the age demographics of people with a learning disability included in the data intelligence audit, 18-27 years and 48-57 years. No one was identified as

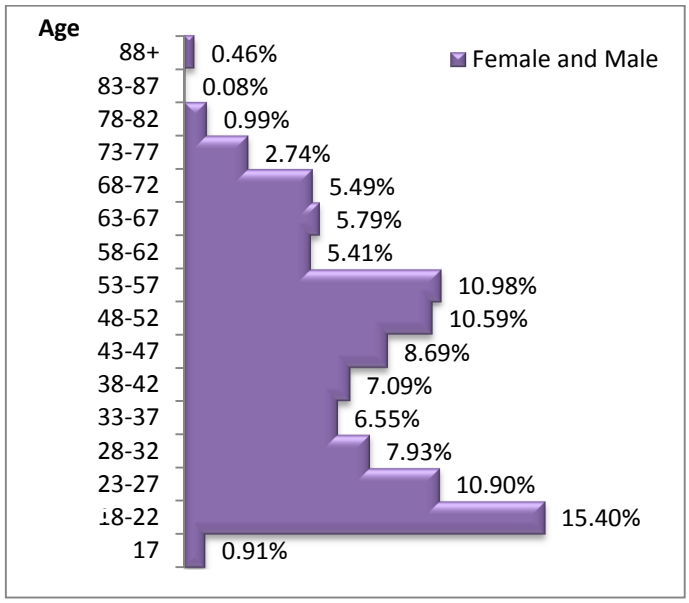
being transgender within the data intelligence audit.

Age	Female	Male	Total
17	0	1	1
18-22	49	56	105
23-27	52	60	112
28-32	44	34	78
33-37	26	41	67
38-42	32	33	65
43-47	38	54	92
48-52	55	62	117
53-57	48	56	104
58-62	27	46	73
63-67	24	32	56
68-72	31	32	63
73-77	17	10	27
78-82	4	9	13
83-87	0	1	1
88+	1	0	1
TOTAL	**448**	**527**	**975**



The HEF data illustrates that health inequalities experienced by people with a learning disability vary between 23% and 42% based upon aggregate initial scorings. However, an individual may score much higher than this, as demonstrated by the lone person recorded in the 83-87 age bracket who had an initial HEF score of 75%. The analysis of the HEF data confirms the peaks (18-27 and 48-57 years) within the age distribution for both genders combined, as illustrated by the below chart and graph.

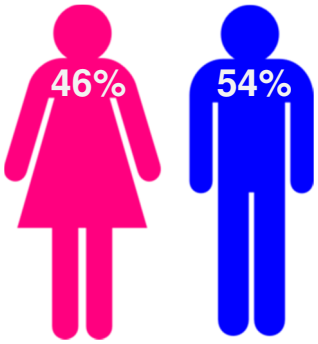
	HEF % Scores		Difference 1st to Final	Number of HEFs Completed	
Age	First	Final		First	Final
<17	23%	22%	-1%	12	2
18-22	37%	24%	-13%	202	73
23-27	39%	19%	-20%	143	60
28-32	42%	23%	-19%	104	43
33-37	38%	24%	-14%	86	23
38-42	39%	26%	-13%	93	35
43-47	39%	24%	-15%	114	41
48-52	39%	22%	-17%	139	64
53-57	40%	24%	-16%	144	50
58-62	38%	25%	-13%	71	29
63-67	42%	27%	-15%	76	29
68-72	39%	25%	-14%	72	34
73-77	37%	31%	-6%	36	12
78-82	36%	27%	-9%	13	8
83-87	75%	N/A	N/A	1	0
88+	35%	26%	-9%	6	3
TOTAL				**1,312**	**506**



The median age at death of people identifiable as having learning disabilities in death certificates has risen steadily from 2008 to 2012 from 54 to 58 years[16]. Although life expectancy is increasing, with people with mild learning disabilities approaching that of the general population, the mortality rates among people with moderate-to-severe learning disabilities are three times higher than in the general population[17].

Gender

Of the 975 people reviewed in the data intelligence audit, 448 were female and 527 were male. Additionally, the HEF data identifies males as being more prevalent than females, with 57% (744) of the 1312 HEFs being male and 43% (568) being female. The initial and final HEF scorings illustrate that health inequalities are not affected by the person's gender as the scorings are the same. However, when compared with the general population, men with learning disabilities die on average 13 years younger and women 20 years younger[18].

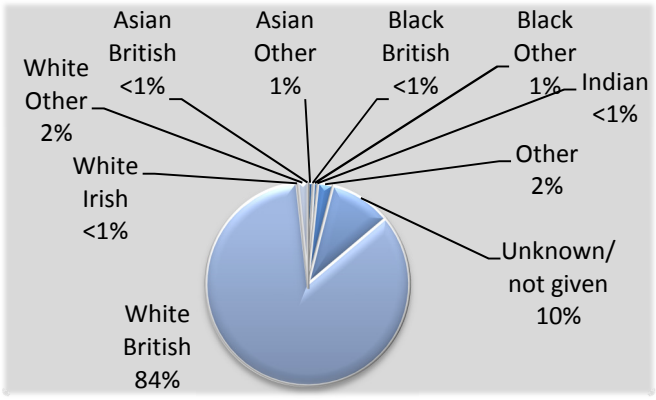


	HEF % Scores		Difference 1st to Final	Number of HEFs Completed	
	First	Final		First	Final
Male	39%	24%	-15%	744	281
Female	39%	24%	-15%	568	225
TOTAL				**1,312**	**506**

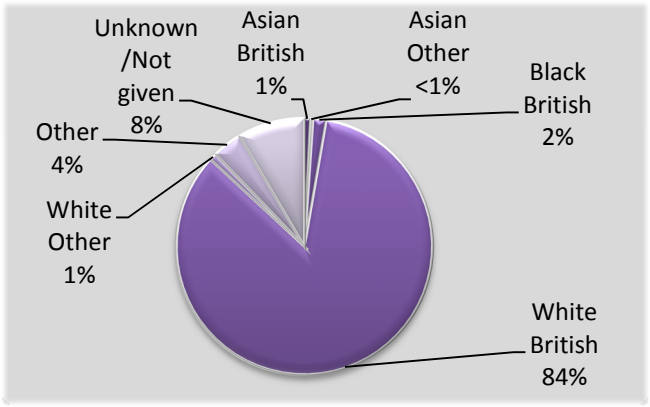
Ethnicity

The ethnicity breakdown of the 975 people with a learning disability was Asian British (1), Asian Other (7), Black British (1), Black Other (6), Indian (1), Other (23), White British (823), White Irish (2) and White Other (15).

According to E.Emerson et al[19], there is an expected increase in the proportion of younger English adults who belong to South Asian minority ethnic communities.



The information extracted from the HEF below, further evidences data available regarding the ethnicity of the people referred to the CLDT.

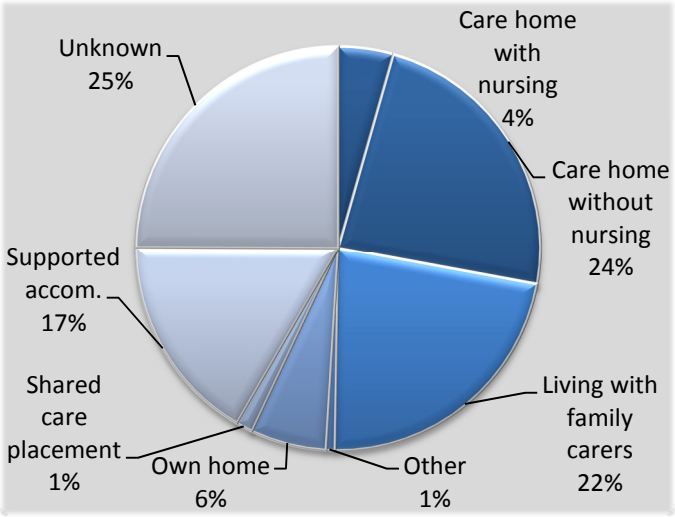


The level of aggregated health inequality varies between ethnicities, ranging from 39% to 53% on initial referral. However, on discharge from the service aggregated final HEF scores range from 22% to 31%.

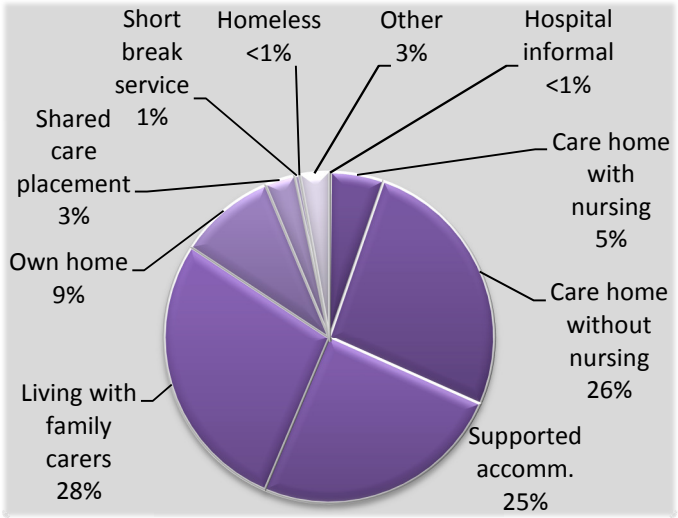
	HEF % Scores		Difference 1st to Final	Number of HEFs Completed	
	First	Final		First	Final
Asian British	43%	27%	-16%	10	5
Asian Other	53%	22%	-31%	4	2
Black British	40%	25%	-15%	22	11
White British	39%	24%	-15%	1104	439
White Other	42%	31%	-11%	12	5
Other	39%	23%	-16%	49	20
Unknown/ Not given	41%	26%	-15%	111	24
TOTAL				**1,312**	**506**

Accommodation Setting

There were 14 categories for accommodation setting included in the data intelligence audit however 5 categories (homeless, hospital detained, hospital informal, hostel and prison) did not have any applicable people with a learning disability. The remaining categorisation was care home with nursing (43), care home without nursing (229), living with family carers (218), other (7), own home (59), shared care placement (13), supported accommodation (163) and unknown (243).



The results of the HEF analysis for 2015-17 showed highly comparable result totals across all accommodation types, with the highest variation being 8% for shared care placement.

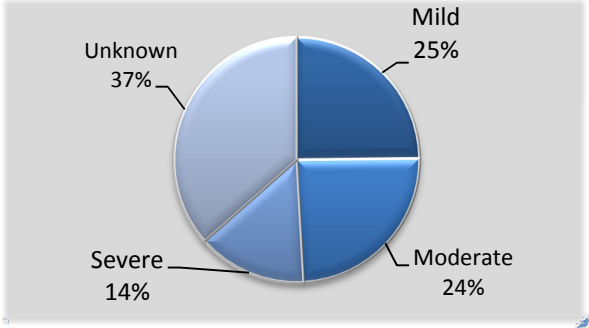


The HEF data also showed variations in health inequality status depending on accommodation type. However, we have to take into consideration the number of HEFs completed, as with hospital detained, hospital informal and homeless there have only been one HEF completed for these accommodation types. It is also worth noting that for hospital informal the first and final HEFs were for different people.

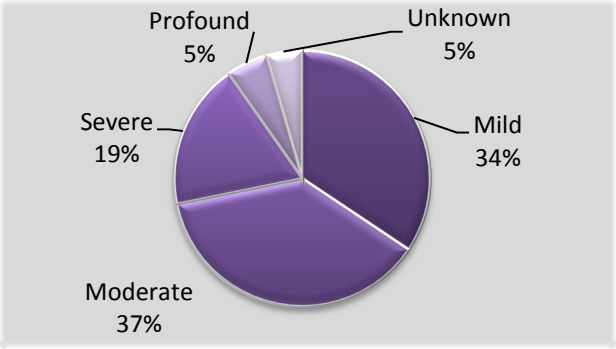
	HEF % Scores		Difference 1st to Final	Number of HEFs Completed	
	First	Final		First	Final
Living with family carers	38%	22%	-16%	365	119
Care home without nursing	42%	27%	-15%	345	151
Supported accommodation	37%	21%	-16%	325	155
Own home	36%	21%	-15%	124	38
Care home with nursing	38%	30%	-8%	68	17
Shared care placement	41%	22%	-19%	39	13
Other	40%	33%	-7%	37	12
Short break service	40%	N/A	N/A	6	0
Hospital detained	44%	N/A	N/A	1	0
Hospital informal	41%	60%	19%	1	1
Homeless	77%	N/A	N/A	1	0
Prison	N/A	N/A	N/A	0	0
Hostel	N/A	N/A	N/A	0	0
TOTAL				**1,312**	**506**

Degree of Learning Disability

The audit collected data on the degree of learning disability with 4 groupings; mild (242), moderate (237), severe (140) and unknown (356). The unknown category would have included people with a learning disability whose client records and information did not detail their level of need.



With the recorded HEF data there is an additional category of profound for the degree of learning disability. "Those diagnosed with profound and multiple learning disabilities (PMLD) have more than one disability, with the main disability being a learning disability. They are likely to have difficulty in communicating, have mental health disorders and need carer support to assist with daily functions such as washing, dressing and eating"[20].



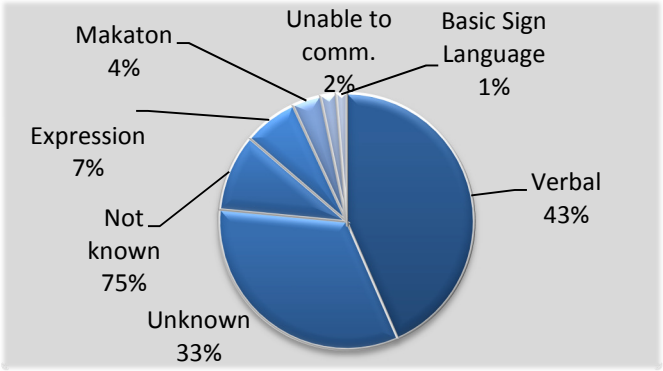
	HEF % Scores		Difference 1st to Final	Number of HEFs Completed	
	First	Final		First	Final
Mild	37%	21%	-16%	451	184
Moderate	40%	25%	-15%	491	199
Severe	44%	29%	-15%	242	75
Profound	41%	30%	-11%	69	19
Unknown	30%	14%	-16%	59	29
TOTAL				**1312**	**506**

Through studying the HEF data we can identify a trend for first and final HEF scores to be higher when the degree of learning disability is more complex. The CIPOLD report also corroborates with this information by reporting the average age of death for different levels of impairment:

- 67.5 for people with a mild learning disability
- 64 for people with a moderate learning disability
- 59 for people with a severe learning disability
- 46 for people with profound and multiple learning disabilities[21]

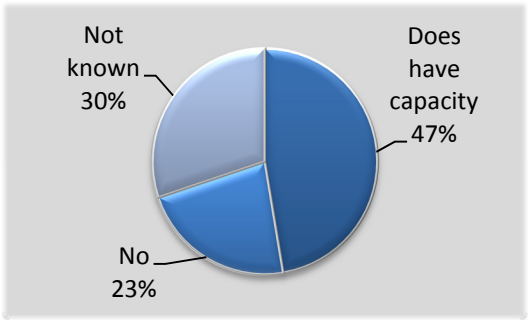
Communication Need

As part of the data intelligence audit, records were analysed to explore the communication level of the people included in the audit. The records for 353 people did not disclose their communication need. However, 464 people could verbally communicate, 104 utilised objects of reference, 73 communicated through expression, 39 people used Makaton, 14 used basic sign language and 21 were unable to communicate. Limited communication skills may reduce a person's ability to convey identified health needs effectively to others (e.g., relatives, carers). As a result, carers (unpaid and paid) play an important role in the identification of health needs for many people with more severe learning disabilities[22]. Research has found that 67% of people with learning disabilities asked about their health reported pain, and 18% said they did not tell people when they were in pain[23].



Capacity

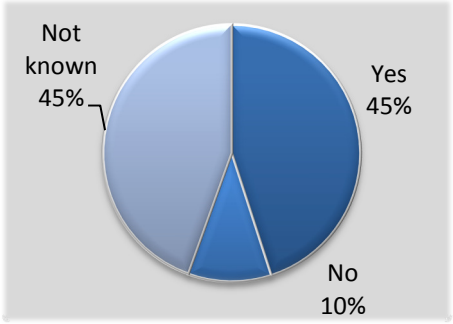
The data intelligence explored whether the people included in the sample had capacity to make their own decisions and choices. 462 people with a learning disability had capacity, 219 did not have capacity and for 294 people it was unidentifiable from the information available whether they had capacity or not. Research studies have highlighted low levels of compliance with the Mental Capacity Act in day-to-day decision making and food choices, with the National Patient Safety Agency, has reported concern about "consent being sought from a carer rather than taking the time to gain consent from the person with the learning disability"[24].



Annual Healthchecks and Check-ups

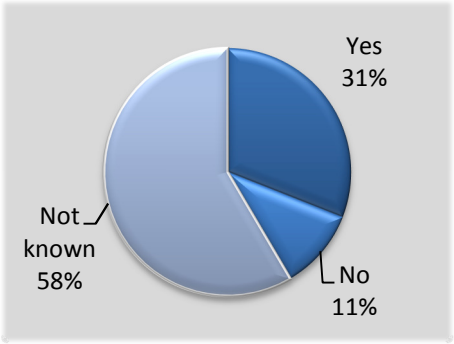
Annual health checks:

Annual Health Checks for people with learning disabilities are designed to promote good health and provide early diagnosis of the onset of disease conditions. They were introduced as part of the Reasonable Adjustments agenda for primary care to reduce the risk of early morbidity for adults with learning disabilities. However, the take up rate of health check is low[25]. In the data intelligence audit 439 people had received an annual healthcheck in the last 12 months, 102 had not received an annual healthcheck and for 434 people it was unknown if they had received a healthcheck or not.



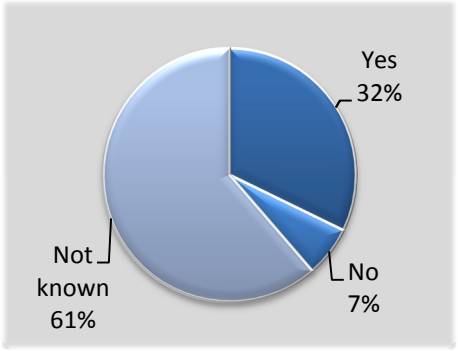
Dental check-up:

From the records available it was unidentifiable for 570 people if they had received a dental check-up in the last 12 months. 302 people had received a check up, but 103 had not. There is very little research on dental care and oral hygiene for people with learning disabilities, but comprehensive studies in Oldham in 2001 conclude that adults living in the community had significantly higher levels of untreated decay than those in residential settings.[26]



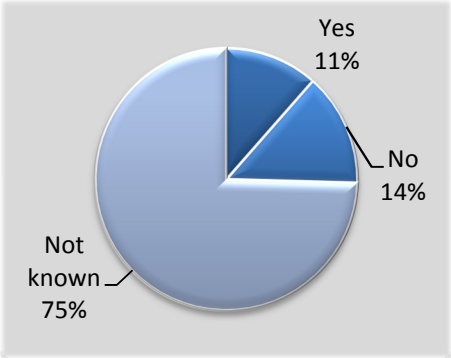
Optician check-up:

Over half of the records did not identify if the person had had an opticians check-up in the last 12 months (598), 314 people had received an opticians check-up and 63 had not. 30% of people with learning disabilities are likely to have some visual impairment and 10% are registered blind or partially sighted[27].



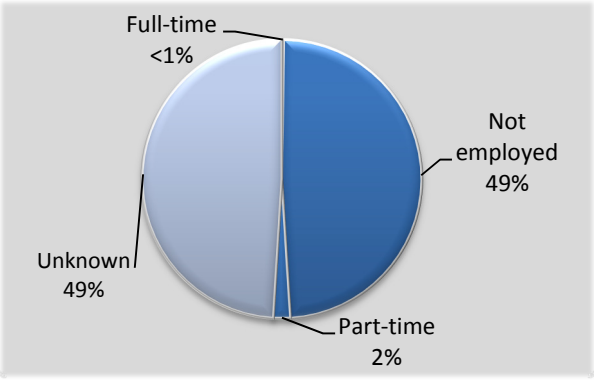
Audiology check-up:

For 727 people with a learning disability it was unidentifiable if they had received an audiology check-up in the last 12 months. 112 people had received a check-up and 136 had not. Recent calculations estimate 9,620 people with learning disabilities in Kent have some form of deafness[28].



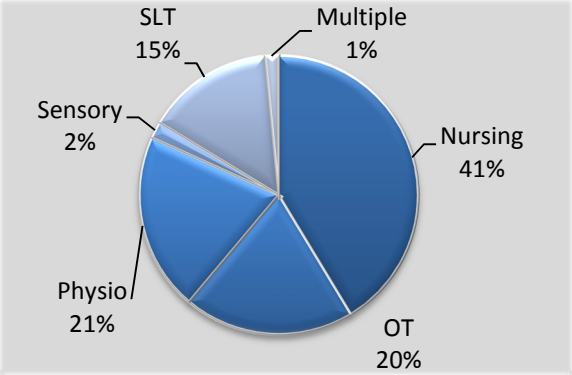
Employment

The data intelligence audit researched the employment rate amongst people with a learning disability. Although the employment was unknown for 478 people with a learning disability, 2 people were in full-time employment, 19 in part-time employment and 476 were not employed. The Public Health England report details how the employment of people with learning disabilities has reduced from 9,905 people in 2011/12 to 7,430 people in 2014/15, which equates to a 6% employment rate[29].



Referral

The profession(s) being referred to were monitored and the resulting number of referrals were: Nursing (403), OT (193), Physiotherapy (201), Sensory (19), SLT (144) and 15 referrals were for multiple professions.



The below table identifies the source of the referrals:

Referred By	Count	%
KCC	359	37%
Care Home	237	24%
CLDT Inter Team Referral	179	18%
General Practitioner	51	5%
Carer	40	4%
Other	26	3%
Other NHS provision e.g.: epilepsy service	18	2%
Psychology / Psychiatry	18	2%
Community Nursing	15	2%
Self-referral	15	2%
Family member	8	1%
Mental Health Service	5	1%
Dietician	2	<1%
Wheelchair services	2	<1%
Audiology	0	0
Ophthalmology	0	0
Orthotics / podiatry	0	0
TOTAL	**975**	

The referrals reasons were as follows:

Referral Reason	Count	%
Behaviour & Emotions	95	10%
Assessment	88	9%
Eating & Drinking	87	9%
Health Screening / Promotion	73	7%
Posture Management	73	7%
Communication	59	6%
Daily Living Activities	55	6%
Equipment Assessment & Support	50	5%
Advice & Support	41	4%
Healthy Lifestyles	41	4%
Support to understand treatment	37	4%
Dementia	36	4%
Sensory assessment	33	3%
Environment Assessment	31	3%
Falls	27	3%
Relationships	25	3%
Desensitisation	18	2%
Sexual Health	17	2%
Hydrotherapy	12	1%
Accommodation	11	1%
Support to visits	11	1%
Medication	8	1%
Personal Care	7	1%
Employment & Meaningful Activities	6	1%
Hospital Admission	6	1%
Adult Protection Raised	5	1%
Continuing Health Care	4	<1%
Diabetes	4	<1%
End of Life Care	4	<1%
Transition	4	<1%
Women's Health	3	<1%
Complex Care Pathway	2	<1%
Mental Capacity Assessment	1	<1%
Sleep Problems	1	<1%
Men's Health	0	0%
Transfer of Care	0	0%
Understanding relative's illness	0	0%

The breakdowns of the top 5 referral reasons per CCG area are:

Ashford CCG	Behaviour & Emotions Health Screening / Promotion Eating & Drinking Daily Living Activities Communication
Canterbury & Coastal CCG	Posture Management Support to understand treatment Dementia Behaviour & Emotions Healthy Lifestyles
Dartford, Gravesham & Swanley CCG	Assessment Behaviour & Emotions Posture Management Falls Communication
South Kent Coast CCG	Health Screening / Promotion Equipment Assessment & Support Eating & Drinking Behaviour & Emotions Healthy Lifestyles
Swale CCG	Posture Management Daily Living Activities Eating & Drinking Equipment Assessment & Support Falls
Thanet CCG	Behaviour & Emotions Eating & Drinking Equipment Assessment & Support Health Screening / Promotion Healthy Lifestyles
West Kent CCG	Assessment Behaviour & Emotions Eating & Drinking Communication Advice & Support (carers, family etc.)

The treatment and support types provided are documented in the table opposite:

Treatment / Support Type	Count	%
Advice / Signposting	115	11%
Behaviour Management Support	88	8%
Daily Living Support	88	8%
Dysphagia Management	81	8%
Mobility Assessment & Treatment	73	7%
Posture Management	67	6%
Healthy Living Advice	66	6%
Communication Management	58	5%
Equipment Prescription & Support	55	5%
Environment Assessment & Support	48	4%
Dementia Support	44	4%
Health Screening	41	4%
Health Action Plan	38	4%
Support to appointments	25	2%
Desensitisation / Familiarisation	23	2%
INP	23	2%
Social Interaction Support	19	2%
Falls Assessment & Support	17	2%
Medication & Support	15	1%
Visual Management	15	1%
Hydrotherapy	13	1%
Access to other services	10	1%
Providing Training	8	1%
Mental Health Support	7	1%
Best Interest meetings	6	1%
Resource Making	6	1%
Transition Advice and Support	6	1%
End of Life Care	5	<1%
Diabetes Support	4	<1%
Respiratory Treatment	4	<1%
Mental Capacity Assessment	3	<1%
Epilepsy Support	2	<1%
Oral Care	2	<1%
Safeguarding Investigation	2	<1%
Reasonable Adjustment Advice	1	<1%
Hearing Management	0	0%
TOTAL	**1,078**	**100%**

Additional Health Criteria

In total there were 1186 additional health criteria recorded for people with a learning disability in the data intelligence audit. 54.26% had 1 or more additional health needs, with 2 people possessing 10 additional health needs.

Additional Health Criteria	Count	%
Physical impairment/reduced mobility	175	18%
Epilepsy	155	16%
Autism	114	12%
Challenging behaviour	85	9%
Mental health issues	77	8%
Continence needs	76	8%
Wheelchair user	73	7%
Visual impairment	62	6%
Dementia	60	6%
Dysphagia	56	6%
Sleep problems	44	5%
Respiratory problems	41	4%
Nutritional problems	33	3%
Diabetes	26	3%
Cancer/other major health problems	25	3%
Hearing impairment	23	2%
Chronic pain	18	2%
Coronary heart disease	15	2%
Oral health problems	15	2%
Endocrine disorder	13	1%
Blood Condition	0	0%
TOTAL	**1,186**	**100%**

People with a learning disability are more likely to have secondary disabilities and other health problems than the rest of the population[30],[31],[32],[33].

The table opposite identifies the count of people included in the data intelligence audit by the number of additional health criteria.

Number of Additional Health Criteria	Count	%
0	446	45.74%
1	226	23.18%
2	140	14.36%
3	79	8.10%
4	39	4.00%
5	15	1.54%
6	12	1.23%
7	10	1.03%
8	4	0.41%
9	2	0.21%
10	2	0.21%
TOTAL	**975**	**100%**

The top 5 additional health criteria varied between each CCG area, the below table identifies the most prevalent additional health needs for each CCG area.

Ashford CCG	Physical impairments / reduced mobility Mental health issues Autism Dysphagia Epilepsy
Canterbury & Coastal CCG	Epilepsy Physical impairments / reduced mobility Autism Wheelchair user Visual impairment
Dartford, Gravesham & Swanley CCG	Physical impairments / reduced mobility Epilepsy Autism Challenging behaviour Mental health issues
South Kent Coast CCG	Physical impairments / reduced mobility Epilepsy Autism Continence needs Endocrine disorder
Swale CCG	Epilepsy Autism Physical impairments / reduced mobility Challenging behaviour Wheelchair user
Thanet CCG	Epilepsy Mental health issues

	Respiratory problems Diabetes Physical impairments / reduced mobility
West Kent CCG	Physical impairments / reduced mobility Challenging behaviour Epilepsy Autism Continence needs

The results of the data intelligence audit can be verified by the results of the HEF analysis. People's additional health criteria between 2015 and 2017 are identified below with the count of referrals that have the additional health conditions and the aggregated score of health inequality:

	HEF % Scores		Difference 1st to Final	Number of HEFs Completed	
	First	Final		First	Final
Challenging behaviour	44%	29%	-15%	402	44
Physical impairment	40%	27%	-13%	346	117
Autism	42%	25%	-17%	332	131
Continence needs	42%	28%	-14%	297	106
Epilepsy	40%	27%	-13%	276	85
Mental Health Issues	45%	27%	-18%	263	106
Visual impairment	40%	27%	-13%	231	84
Wheelchair user	41%	28%	-13%	222	70
Sleep problems	44%	26%	-18%	146	46
Nutritional problems	46%	28%	-18%	143	43
Dysphagia	39%	26%	-13%	125	37
Hearing impairment	39%	26%	-13%	105	33
Respiratory problems	42%	26%	-16%	84	22
Cancer/ other major physical condition	44%	28%	-16%	82	24
Dementia	42%	28%	-14%	81	30
Chronic pain	46%	25%	-21%	79	22
Oral health problems	47%	22%	-25%	63	18
Endocrine disorder	40%	26%	-14%	53	16
Coronary heart disease	42%	33%	-9%	30	5
TOTAL				**1,312**	**506**

Future Need for Kent

Most population figures for Kent have been determined from current and previous service contact, often derived from case registers on information systems. As the future needs are estimated by reviewing previous and current cases and variants in demands, the following information is subject to changes.

It is estimated that in Kent the population of people with learning disabilities is set to increase by approximately 13% between 2015 and 2030.

	2015	2030	% Change
People aged 18-24 predicted to have a learning disability	3,365	3,454	3%
People aged 25-34 predicted to have a learning disability	4,415	4,360	-1%
People aged 34-44 predicted to have a learning disability	4,563	5,227	15%
People aged 45-54 predicted to have a learning disability	5,127	4,759	-7%
People aged 55-64 predicted to have a learning disability	4,052	4,921	21%
People aged 65-74 predicted to have a learning disability	3,538	4,281	21%
People aged 75-84 predicted to have a learning disability	1,902	2,960	56%
People aged 85 and over predicted to have a learning disability	791	1,453	84%
People aged 18 and over predicted to have a learning disability	**27,753**	**31,415**	**13%**

Source: PANSI (figures may not sum due to rounding)

The aged 85 and over category has the highest percentage increase of people due to the aging population of the UK. "Kent, like the rest of England, has an ageing population that will put increasing demands on the system, and will require long-term complex care. This, along with unhealthy lifestyle behaviours and the rising cost of technology means that nationally the NHS faces a £30bn funding gap by 2021, unless the system of health and social care can be transformed"[34].

The below table shows the estimated prevalence of learning disability within the 18-64 population. According to the Office for National Statistics, it has been projected that there could be 22,722 persons with a learning disability within Kent by 2030.

	2015	2020	2025	2030
Ashford	1,745	1,806	1,845	1,864
Canterbury	2,305	2,293	2,308	2,355
Dartford	1,543	1,623	1,677	1,732
Dover	1,551	1,524	1,498	1,478
Gravesham	1,530	1,566	1,605	1,627
Maidstone	2,346	2,439	2,501	2,549
Sevenoaks	1,636	1,663	1,693	1,725
Shepway	1,522	1,534	1,531	1,526
Swale	2,035	2,105	2,162	2,209
Thanet	1,879	1,926	1,957	1,991
Tonbridge & Malling	1,761	1,828	1,866	1,895
Tunbridge Wells	1,668	1,710	1,746	1,757
Kent	**21,522**	**22,017**	**22,403**	**22,722**

Source: PANSI (figures may not sum due to rounding)

"It has been projected that there could be approximately 5,216 persons with a moderate or severe learning disability within the Kent districts in 2030. Of these, 1,380 people will have a severe learning disability and 419 are predicted to display challenging behaviours."[35]

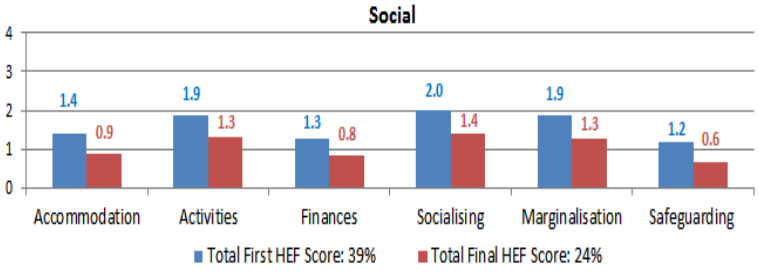
	2015	2020	2025	2030
People aged 18-24 predicted to have a severe learning disability	257	243	244	271
People aged 25-34 predicted to have a severe learning disability	266	279	275	262
People aged 35-44 predicted to have a severe learning disability	310	313	340	356
People aged 45-54 predicted to have a severe learning disability	255	248	232	241
People aged 55-64 predicted to have a severe learning disability	207	234	257	251
Total population aged 18-64 predicted to have a severe learning disability	**1294**	**1317**	**1347**	**1380**

Source: PANSI (figures may not sum due to rounding)

Determinants of Health Inequality in Kent

Social

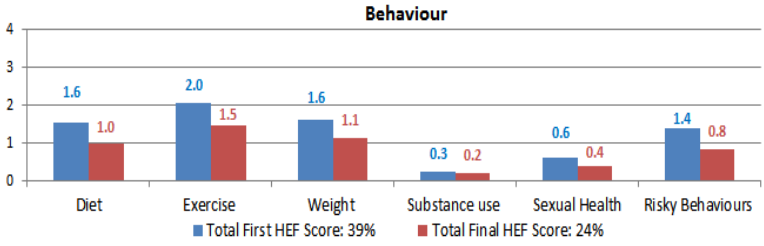
People with learning disabilities, especially people with less severe learning disabilities and those who do not access specialist learning disability services, are more likely to be exposed to common 'social determinants' of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination.



In Kent the top 3 social indicators of health inequality are socialising, activities and marginalisation. The top 3 health inequality reductions are activities, marginalisation and safeguarding.

Behaviour

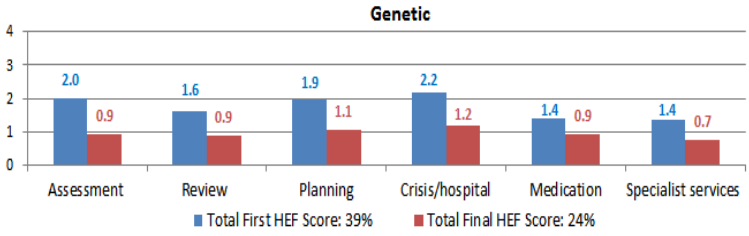
Refers to personal health behaviour (including behaviours that challenge) and lifestyle risks such as diet, sexual health and exercise. People with learning disabilities commonly take poor diets. In some instances, due to reduced health literacy, they have a poor understanding of what a healthy diet is. Other people are dependent on carer knowledge to ensure they receive a balanced and nutritious diet.



In Kent the top 3 behaviour indicators of health inequality are exercise, diet and exercise. The top 3 health inequality reductions are diet, risky behaviours and exercise.

Genetic and biological

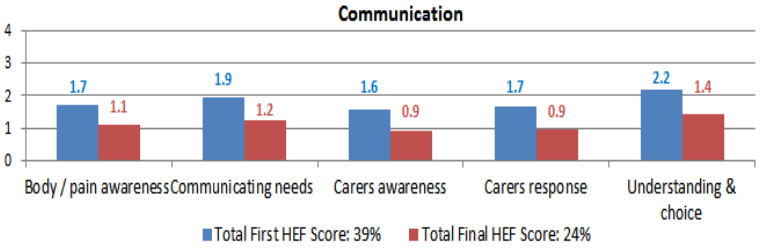
People with learning disabilities are more likely than the general population to die from congenital abnormalities. Many genetic and biological conditions which give rise to learning disabilities are also associated with an increased risk of further physical and mental health conditions. As detailed earlier in the report, many specific health conditions are considerably more prevalent in the learning disability population and there can be difficulties in detecting and recognising conditions and symptoms (often atypical) of specific health conditions.



In Kent the top 3 genetic indicators of health inequality are crisis/hospital, assessment and planning. The top 3 health inequality reductions are assessment, crisis/hospital and planning.

Communication

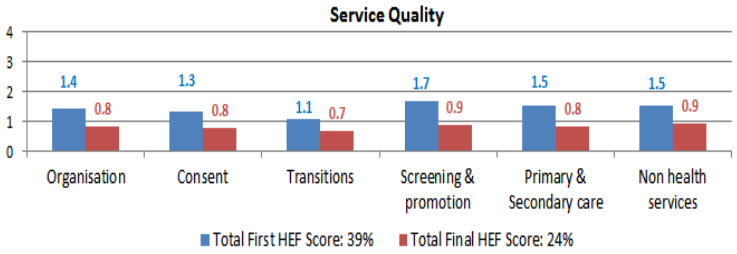
People with learning disabilities may have limited communication skills which may reduce their capacity to convey identified health needs effectively to others (e.g., relatives, friends, paid support workers). As a result, carers (unpaid and paid) play an important role in the identification of health needs for many people with more severe learning disabilities.



In Kent the top 3 genetic indicators of health inequality are understanding and choice, communicating needs and body/pain awareness. The top 3 health inequality reductions are carers response, understanding and choice and carers awareness.

Service Quality

People with learning disabilities can find it hard to access mainstream health services for a number of reasons, including the failure of health services to make reasonable adjustments to enable access.



In Kent the top 3 genetic indicators of health inequality are screening and promotion, primary and secondary care and non-health services. The top 3 health inequality reductions are screening and promotion, primary and secondary care and organisation.

Endnote

Key principles for people using services include the need to put the individual and their surrounding family or carers at the heart of the service which should be personalised and designed to meet their needs.

Services should plan and intervene early, focusing on safely meeting the full range of need to improve the person's quality of life. At all times people using services should be treated with dignity and respect and should be included in planning and receiving care and treatment.
Staff working in services should be trained, offered CPD opportunities, and supported to be able to provide high quality services.

The following standards of practice are set out by the LD Professional Senate to help promote effective working.

1. People will be supported to exercise their universal human rights to be healthy, full and valued members of their community with respect for their culture, ethnic origin, religion, age, gender, sexuality and disability.
2. All people who are at risk of presenting behavioural challenges have the right to have their needs identified at an early stage, leading to co-ordinated early intervention and support.
3. All families have the right to be supported to maintain the physical and emotional wellbeing of the family unit.
4. All individuals have the right to receive person centred support and services that are developed on the basis of a detailed understanding of their support needs including their communication needs. This will be individually-tailored, flexible, and responsive to changes in individual circumstances and delivered in the most appropriate local location.
5. People have the right to a healthy life, and be given the appropriate support to achieve this.
6. People have the same rights as everyone else to a family and social life, relationships, housing, education, employment and leisure.
7. People have the right to supports and services that create capable environments. These should be developed on the principles of positive behavioural support and other evidence based approaches. They should also draw from additional specialist input as needed and respond to all the needs of the individual.
8. People have the right not to be hurt or damaged or humiliated in any way by interventions. Support and services must strive to achieve this.
9. People have the right to receive support and care based on good and up to date evidence

Areas for Further Inquiry

Primary Care - Consider uptake of annual health checks to improve people's general health

Acute - Consider increase use of the hospital passport to support people's hospital experiences and care

Universal and Specialist Services - Consider this report for people accessing and receiving services and to support the reduction in people's health inequality

References

[1] M.Varshney and K.Shaw (2015). Kent Adults with Learning Difficulties JSNA Chapter Summary Update 2015.
[2] Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century
[3] Smith and Varshney (2014). Learning Disability Needs Assessment.
[4] Smith and Varshney (2014). Learning Disability Needs Assessment.
[5] E.Emerson, S.Baines, L.Allerton and V.Welch (2012). Health Inequalities & People with Learning Disabilities in the UK: 2012. Improving Health and Lives, Learning Disabilities Observatory.
[6] Atkinson, D. et al. (2015). Health Equality Framework: *The Complete Practitioner's Guide.*
[7] Thorne S. Data analysis in qualitative research. Evidence-Based Nursing 2000;3:68-70.
[8] East Sussex Learning Disability Needs Analysis 2017 National Picture (2017).
[9] Public Health England (2013) People with Learning Disabilities in England 2013.
[10] Public Health England (2015) People with Learning Disabilities in England 2015: Main Report
[11] E.Emerson and C.Hatton (2011). Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An Update
[12] P.Black (2014). What Councils Need to Know about People with Learning Disabilities.
[13] E.Emerson and C.Hatton (2008). Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England
[14] E.Emerson and C.Hatton (2011). Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An Update
[15] M.Varshney and K.Shaw (2015). Kent Adults with Learning Difficulties JSNA Chapter Summary Update 2015.
[16] Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final Report. Norah Fry Research Centre
[17] 4.A Step by Step Guide for GP Practices: Annual health checks for people with a learning disability; Royal College of General Practitioners (2010)
[18] Public Health England (2013) People with Learning Disabilities in England 2013.
[19] Emerson E, Hatton C. Response to McGrother et al. (Journal of Intellectual Disability Research, 46, 299-309) 'The prevalence of intellectual disability among South Asian communities in the UK'. J Intellect Disabil Res 2004;48(Pt 2):201-2.
[20] Smith and Varshney (2014). Learning Disability Needs Assessment.
[21] Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final Report. Norah Fry Research Centre
[22] E.Emerson, S.Baines, L.Allerton and V.Welch (2012). Health Inequalities & People with Learning Disabilities in the UK: 2012. Improving Health and Lives, Learning Disabilities Observatory.
[23] Turk V, Khattran S, Kerry S, Comey R, Painter K. Reporting of Health Problems and Pain by Adults with An Intellectual Disability and by their carers. Journal of Applied Research in Intellectual Disabilities 2012;25:155-65.
[24] National Patient Safety Agency. Understanding the patient safety issues for people with learning disabilities. London: National Patient Safety Agency, 2004.
[25] Smith and Varshney (2014). Learning Disability Needs Assessment.
[26] Tiller & Wilson et al., Oral health status and dental service use of adults with learning disabilities, in Community Dental Health, Vol.18,pt3, 2001
[27] Tiller & Wilson et al., Oral health status and dental service use of adults with learning disabilities, in Community Dental Health, Vol.18,pt3, 2001
[28] Sensory Needs Assessment, Kent County Council, 2013, p.50
[29] Public Health England (2015) People with Learning Disabilities in England 2015: Main Report
[30] Cooper, S.-A., Smiley, E., Morrison, J., Williamson, A. & Allan, L. (2007) 'Mental ill-health in adults with intellectual disabilities: prevalence and associated factors,' The British Journal of Psychiatry, 190: 27-35
[31] Haveman, M., Heller, T., Lee, L. Maaskant, M, Shooshtari, S and Strydom, A. (2010) 'Major health risks in aging persons with intellectual disabilities: an overview of recent studies,' Journal of Policy and Practice in Intellectual Disabilities, 7(1), 59-69
[32] Moseley, D., Tonge, B., Bereton, A. and Einfeld, A. (2011) 'Psychiatric comorbidity in adolescents and young adults with autism,' Journal of Mental Health Research in Intellectual Disabilities, 4: 229-243.
[33] McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran, S. and McCallion, P. (2011) Growing Older with an Intellectual Disability in Ireland in 2011: First Results from The Intellectual Disability Supplement of The Irish Longitudian Study on Ageing. School of Nursing and Midwifery, Trinity College Dublin
[34] Kent County Council (2014). Kent Joint Health and Wellbeing Strategy
[35] M.Varshney and K.Shaw (2015). Kent Adults with Learning Difficulties JSNA Chapter Summary Update 2015.