

Health Needs Assessment of Neurodiverse Adults in Kent

2023



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1 Executive summary

Life expectancy for males in Kent with a learning disability is 67 years and 66 years for females. This is 13 and 17 years respectively lower than the general population. People with a learning disability [LD] are more likely than others in the general population to live in rented accommodation which may be overcrowded and of a poor standard.

A call to action is required to address avoidable causes of death caused by medical causes, untimely interventions, and health inequalities. E.g., addressing low prevalence rates and risk factors, impacts upon people with a learning disability, healthcare and treatment, social determinants, information provision and signposting to resources.

The number of neurodiverse people in Kent known to the health and care system is lower than expected. The predicted trend of the number of people with neurodiversity for Kent, the southeast region and England is an increasing one. It is likely the number of people living in Kent with a learning disability will increase each year to 33, 631 by 2040. The number of autistic people in Kent is predicted to increase by 100 people every five years.

The rate of hospital admissions in Kent for people with Attention Deficient Hyperactive Disorder [ADHD], learning disability [LD] or autism is greater than that of the general population, with those with a LD being admitted to hospital in greater numbers than autistic or people with ADHD. New research indicates autistic individuals are more likely to have chronic mental and physical health conditions and report lower quality healthcare than others.

Since 2019, there has been an increasing trend for adults aged 18+ years with a learning disability receiving long-term support and day-care support in Kent.

In April 2022, there were almost 6000 Personal Independence Payment [PIP] awards for neurodiverse adults in Kent. Just over 50% of the PIP awards were to people with a learning disability.

There is notable variation of paid employment for adults with learning disabilities across local authorities and rates of pay do not appear to be increasing over time. At 4%, Kent is lower than the region at 6.6% and England 4.8%. The current cost of living pressures of higher energy and food costs are particularly affecting low-income households and those living in the rental sector. Disabled people are 42% more likely than non-disabled people [31%], to reduce their spending on food, energy, and essentials.

The development of a *Kent All Age Strategy* has superseded the development of separate strategies for people with a learning disability and autism. The key aspirations of the strategy are that people can live the lives they wish to, feel valued

and supported by communities and receive personalised and appropriate support from health and care services.

To support this the strategy also aims to grow and develop a value led and skilled workforce to ensure people with learning disability and/or autistic people have better access to health and social care. To this end, several key areas of focus have been identified to underpin and drive forward system transformation including:

- Co-production
- Workforce
- Resources (to support transformation)
- Quality Improvement
- Children and young people (preparation for adulthood)
- Autism without a learning disability (pathway mapping, finance, and performance)

The risks to fully implementing and achieving the aims of the strategy include the lack of skilled workforce in particular social care providers. This means community support and provision cannot be developed resulting in people staying in hospital settings for too long. The challenge of the system to find solutions to increase community provision to address the high number of hospital admissions and long stays is a major risk.

Increasing the safety of vulnerable people especially those in domiciliary, residential, and supported care where most assaults take place, mostly by other service users, is necessary. There is a lack of support for victims and their families. That there is no standard inter-agency information sharing agreement in place, nor one for GP data sharing for people being placed out-of-area, for sexual or violent assaults, should be addressed.

Many challenges and frustrations faced and voiced by the neurodiverse population in Kent are amendable to local system improvement. E.g. perceived discriminatory adjustments such as bus pass period of travel, which is uncondusive to attending hospital appointments, accessibility to stores, unhelpful store opening time adjustments for people with sensory needs amongst others.

The challenges faced by the Kent system to improve the health and wellbeing for the Kent population is sizeable. However many opportunities exist to implement high-impact service redesigns, with many solutions being amenable to change at the Kent level when working collaboratively in partnership throughout the system and, with people with lived experience in Kent.

2 Introduction

Historically people who were neurodiverse were often seen as being abnormal but the concept of neurodiversity which emerged in the 1990s informed us that differences in how our brains work are natural variations. Consequently, neurodiverse individuals are increasingly being recognised as a huge asset to society, especially in the workplace.

People are unnecessarily disabled by the failure of society to adapt and adjust for people with different needs and health conditions. Despite the Equalities Act 2010¹ requiring employers to make reasonable adjustments for employees, many conditions remain 'invisible'. A poor understanding of the meaning of reasonable adjustments and the legal definition is prevalent. One solution which may be helpful are to provide examples of reasonable adjustments.

The pressure for neurodivergent individuals to conform to societal norms by 'camouflaging' themselves to present/copy neurotypical behaviours, can subsequently be experienced in a variety of ways.

There are many types of health inequalities and different ways the term may be used but those individuals with autism and/or a learning disability experience health inequalities across many different domains which will be explored in this assessment.

The system response in Kent to support individuals with learning disability who were statistically vulnerable, is recognised as exemplary and best in class by NHS England [NHSE]. Efforts to ensure the physical and mental health and wellbeing of individuals with learning disability and the addressing of inequalities, was and remains at the forefront of the learning disability support system in Kent.

For example, people with learning disabilities were included in the first wave of covid-19 vaccinations. PHE published guidance in an easy read format: keeping your mind and body well, advice about staying at home, 'shielding' - advice for people who are most likely to be very poorly if they get Coronavirus.

There is opportunity to improve processes and work in a more cohesive and integrated way across the system to share care responsibility between health and care organisations for the benefit of individuals. Common areas of challenge include when individuals move from children to adults' services aged 18 which can be planned for. Other problematic areas are the point of hospital discharge, police custody and respite care provision.

People with a LD are more likely than others in the general population to live in rented accommodation which may be overcrowded and of a poor standard.

¹ GOV.UK (2015). *Equality Act 2010: guidance*. Available at [Equality Act 2010: guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/equality-act-2010-guidance)

2.1 Aim

The aim of this assessment is to describe the health status of adults in Kent with neurodiversity and /or have a learning disability and assess how well services and systems in Kent are meeting their needs. There have been significant societal and legislative changes since the last health needs assessment for these groups was undertaken in 2017 which will be reflected in this assessment.

This assessment will help to inform strategy development and commissioning arrangements for the Kent and Medway Integrated Care System [KMICB]. It will do so by highlighting those areas where service improvements can be made by either stopping services that are unsuitable or starting new services to better meet need. It will identify where gaps may exist in knowledge, systems, policy, and those areas of inequity to be addressed and areas for further research.

Most importantly, it will incorporate the views of people with neurodiversity on how well they feel they are supported by services in Kent and provide suggestions for how their needs can be better met.

2.2 Definitions

Neurodiversity is a collective term to describe neurodiverse and neurodivergent people. Neurodiversity is the term used to describe the different ways the brain can work and interpret information. For example, being naturally better at some things and not others. These differences can mean that some people can be diagnosed with a variety of neurological conditions. For example, dyslexia, dyspraxia, and autism.

Neurotypical is a term describing most people meaning that our brains functions and processes information in way society expects. It is estimated that around 15 per cent of people in the UK are neurodivergent.

Updated in 2021, the National Institute for Health and Care Excellence [NICE] issued clinical guidance [CG142], for the diagnosis and management of autism spectrum disorders in adults. It included terminology amendments for 'people with autism' to 'autistic people', and 'symptoms' to 'features', 'challenging behaviour' to 'behaviour that challenges'.²

'Behaviour that challenges' [i.e., is challenging to others e.g., family, carers, or services], is a term associated with some individuals with learning disabilities at rates of about 5-15% in educational, health or social care settings and around 30-40% in hospital settings. Behaviours can include withdrawal, aggression, self-injury,

² NICE [2012]. Autism spectrum disorder in adults: diagnosis and management [CG142]. Updated 2021. Available: [CG142](#). Last accessed: July 2022.

stereotypic behaviour e.g., repetitive language, compulsions, and rituals for example. Disruptive or destructive behaviour such as arson, violence and sexual abuse can lead to contact with the criminal justice system. ^{Ibid.}

Some factors increase the risk of behaviours that challenge. E.g., age, the presence of other physical conditions such as dementia or communication difficulties, and the severity of disorder or disability. Several environmental factors such as too much or too little stimulation or demands upon individuals, a change in routine or place, abusive or inappropriate care settings. ^{Ibid.}

2.2.1 Learning disability

The National Institute of Health and Care Excellence (NICE) states that 'a learning disability is generally defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood'.³

'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', is how the Department of Health in the UK defines a learning disability.

The World Health Organisation [WHO] defines intellectual disability as 'a condition of arrested or incomplete development of the mind typified by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence classifying intellectual disability correspondently as mild, moderate, severe, profound.

Limited functioning in three areas: social skills, conceptual skills, practical skills is the definition of the Diagnostic and Statistical Manual of Mental Disorders, 2013 (DSM-V) definition under the umbrella term of 'Intellectual Disability'.

Risk factors for learning disability as published by the National Institute of Social and Care Excellence [NICE, 2022] cite: chromosomal and genetic anomalies, some non-genetic congenital malformations, pre-natal exposures including alcohol, sodium valproate, congenital rubella infection and zika virus, birth complications resulting in hypoxic brain injury/cerebral palsy, extreme prematurity, childhood illness and brain injury childhood neglect and lack of stimulation in early life. Neurodevelopmental disorders that may be associated include autism and attention-deficit hyperactivity disorder [ADHD]. ^{Ibid.}

2.2.2 Autism

NICE describes autism spectrum conditions [henceforth autism], as a lifelong neurodevelopmental condition. Core features of the condition include 'persistent

³ [Diagnosis | Diagnosis | Learning disabilities | CKS | NICE](#)

difficulties in social interaction and communication and the presence of stereotypic [rigid and repetitive] behaviours, resistance to change or restricted interest.’⁴

2.2.3 Attention deficit hyperactivity disorder [ADHD]

Attention deficit hyperactivity disorder [ADHD] is a diverse disorder typified by the core symptoms of hyperactivity, impulsivity and inattention which are deemed to be excessive for the person’s level of overall development or age. The causes of ADHD are not fully understood but several risk factors are associated with the condition. Genetic factors may be influential and familial missed diagnoses should be considered.⁵

2.2.4 Health inequalities

Health inequalities [HI] are differences in health between groups or people that can be considered unfair as these are systematic and avoidable. For example, those living in the most deprived areas of England can on average expect to have poorer health and die earlier than those living in the least or lesser deprived areas⁶.

2.3 Methodology

- Administrative data collections
- National guidance and reviews
- Literature reviews
- Contributors’ insights

A review of the literature focusing on literature published since the last health needs assessments for autism spectrum conditions in 2017.⁷ Key health and social care databases were searched, along with those cited.

Data collection

Several data sources were accessed for this assessment, and these will be cited as appropriate. It should be remembered that the data source largely dictates the presentation format and level of detail available. As far as possible, data is presented at Kent and Integrated Care Partnership [ICP] and Primary Care Networks [PCNs] levels.

Sources include the five providers of neurodevelopmental diagnostic services across Kent and Medway who have committed to report consistent data regarding their services. The first phase of this data collection focusses on establishing the number of accepted referrals, number of completed assessments and number of children and Young [CYP] on the waiting lists for autism and attention deficit hyperactivity disorder [ADHD] services across the system in Kent.

⁴ Autism spectrum disorder [CG142] [2012]. Updated 2021. Available: [CG142](#). Last accessed: July 2022.

⁵ Attention deficit hyperactivity disorder: diagnosis and management. NICE guideline [NG87], [2018]. Updated 2019. Available: [NICE \[NG87\]](#). Accessed July 2022.

⁶ Public Health England [2017] [Chapter 5: inequality in health - GOV.UK \(www.gov.uk\)](#) [Accessed: 21/10/22]

⁷ [Disability - Kent Public Health Observatory \(kpho.org.uk\)](#)

Whilst data reporting and quality has improved throughout 2021/22, there is not a full years' worth of data to report currently. Subsequent phases of the data collection will include data such as number of diagnoses made, waiting times and number of unattended appointments.

The collated data shows that the number of accepted referrals received is approaching double the number of completed assessments per year for autism. For ADHD, the number of accepted referrals received is approximately three times the number of completed assessments⁸.

⁸ Source: Kent and Medway Clinical Commisisoning Group [KMCCG [KMICB]], 2022

3 Guidelines, Policy, Standard, and legal duties

Relevant legislation, policy, and guidance:

- Health and Care Act 2022
- Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care, and education. NICE guideline [NG213], 2022.
- Sexual incidents in Adults Social Care; Evidence Review Briefing [SCIE, 2022]
- Social work with adults experiencing complex needs [NG216] 2022⁹
- Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care, and education [NG213] 2022¹⁰
- Down Syndrome Act 2022
- Mental Wellbeing at work [NG212, 2022]
- NICE impact people with a learning disability [NICE, 2021]
- Autism spectrum disorder [NICE [Clinical Guidance] CG142], updated 2021
- The national strategy for autistic children, young people and adults: 2021 to 2026
- People with a learning disability and autism in the criminal justice system LGA, 2021
- Learning from lives and deaths-People with a learning disability and autistic people [LeDeR] policy 2021
- Social Work England's professional standards 2019
- The NHS Long Term Plan 2019
- Attention deficit hyperactivity disorder: diagnosis and management. NICE guideline [NG87], 2018. Last update: 2019
- Learning disability: behaviour that challenges [QS101] 2019
- Learning disability: care and support of people growing older [QS187] 2019
- Care and support of people growing older with learning disabilities [NG96] 2018
- Accessible Information Standard [NHSE] 2017
- Learning disability: identifying and managing mental health problems [QS142] 2017
- Care Act 2014 and associated guidance
- Autism Quality Standard [QS51] 2014
- Equality Act 2010

⁹ National Institute for Health and Care Excellence [2022]

¹⁰ Ibid

- Autism Act 2009

Awaiting publication | Guidance pending

- Children and young people with disabilities and severe complex needs: integrated health and social care support [GID-QS10146].
- Social work interventions for adults with complex needs (including learning disabilities) and mental health needs [GID-QS10148].

Training

Introduced in the Health and Care Act 2022 effective from 1 July 2022, all Care Quality Commission [CQC] registered health and social care providers as appropriate to their role, must ensure that staff receive training in how to appropriately interact with people with a learning disability and those with autism.¹¹

An accompanying consultation and Code of Practice which outlines the content, delivery, monitoring, and evaluation of the training – the Oliver McGowan Mandatory Training¹², seeks to train staff, raise awareness and understanding and improve health and care outcomes for people with autism and learning disability. The anticipated publication date will be sometime in July 2023 following public consultation. Meantime the CQC will provide statutory guidance for this Regulation.¹³

The Down Syndrome Act [2022] was introduced to ensure that certain health, education, and local authorities take account and have ‘due regard’ of the specific needs of people with Down syndrome. The accompanying guidance for the Act is being developed by the Department of Health and Social Care [DHSC] in consultation and engagement with stakeholders, people with lived experience, their families, and carers.

Pertaining to the areas mentioned in the Act: The National Health Service [NHS], Social care, Housing, Education and youth offending, the guidance is for organisations to have a ‘due regard’ to the relevant legislation in the exercising of their functions to meet the needs of people with Down syndrome¹⁴.

Research published in 2022, called for an urgent raising of awareness of autism within the Criminal Justice System [CJS] and mandatory training to ensure

¹¹ [Health and Care Act 2022 \(legislation.gov.uk\)](https://www.legislation.gov.uk)

¹² The Oliver McGowan Mandatory Training is based on the Core Capabilities Framework for [Supporting autistic people and/or people with a learning disability](#) and the Core Capabilities Framework for Supporting Autistic People. [Autism Capabilities Framework \(Oct 2019\)](#). It has been co-designed by autistic people, people with a learning disability, family carers and subject matter experts.

¹³ Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 18. [Link](#) Accessed: July 2022

¹⁴ [Down Syndrome Act 2022 \(legislation.gov.uk\)](https://www.legislation.gov.uk) Accessed: July 2022

defendants with autism are treated fairly within the CJS¹⁵. This follows an extensive literature review published by the Local Government Association in 2021, which included recommendations and educational resources for staff.¹⁶

¹⁵ Slavny-Cross, R et al. Autism and the criminal justice system: an analysis of 93 cases. [2022] Available [Link](#) [Accessed 27-7-22]

¹⁶ Local Government Association [2021] People with a learning disability and autism in the criminal justice system. Available from: [People with a learning disability and autism in the criminal justice system | Local Government Association](#) Accessed: 2 August 2022

4 Research and analysis

4.1 Autism

New research has found that autistic individuals are more likely to have chronic mental and physical health conditions and report lower quality healthcare than others.¹⁷

The largest topic international study to date with 54% of participants from the UK, researchers at Cambridge university assessed the rates of mental and physical health conditions and the quality of healthcare experiences of over a 1000 autistic participants with over a 1000 non-autistic individuals.

Participants self-reported lower quality healthcare across 50 of 51 survey items. They felt less able to describe their symptoms, pain levels and understand what healthcare professionals mean when discussing their condition. I.e., they can experience sensory overload, feel overwhelmed and find it difficult to focus on conversations. They were less likely to know what to expect during healthcare encounters and feel they receive appropriate support post diagnosis.

A 'health inequality score' data analytic tool was devised and used by the team and the models could predict whether the participant was autistic or not based upon their 'health inequality score' with a 72% accuracy. Striking differences emerged with concerningly high rates of chronic physical and mental health differences such as: arthritis, obsessive compulsive, panic, and personality disorders, post-traumatic stress disorder, seasonal affective disorder, and self-harm. The study concluded that

'...current health care systems are failing to meet very fundamental needs of autistic people'.

Diet, exercise, and sleep patterns in autistic adults were investigated in a 2021 statistical analysis study which found that autistic adults were more likely to have atypical eating patterns, sleep disturbances and more likely to be underweight or obese and less likely to be engaging in regular physical activity.

These behaviours may contribute to increased health risks amongst individuals who are already experiencing markedly increased risks of health comorbidity and premature death.¹⁸

4.2 Girls and women

Girls and women with autism are more likely to receive a diagnosis later than males, remain undiagnosed or misdiagnosed. These missing diagnoses has led to the assumption that more males than females have autism or Asperger syndrome. They

¹⁷ Weir, E, Allison, C, & Baron-Cohen, S. [Autistic adults have poorer quality healthcare and worse health based on self-report data](#). Molecular Autism (2022).

¹⁸ Weir, E., Allison, C., Ong, K.K. and Baron-Cohen, S. (2021). *An investigation of the diet, exercise, sleep, BMI, and health outcomes of autistic adults*. Available from [Link](#) Accessed [27-7-22]

experience adverse outcomes related to their wellbeing, mental health, education, employment, and independence.¹⁹

Gender differences in social behaviour was evident in a study by Dean et al. [2017] who suggested that girls camouflage their symptoms in many ways. The use of camouflaging tactics to mask social challenges which is the predominant area of struggle for girls, makes them vulnerable and less likely to receive intervention.

As social interaction becomes more complex in adolescence, problems are more likely to be identified in younger girls. Improved identification and understanding of these masking symptoms and behaviours would facilitate timely diagnosis and intervention for children²⁰.

Adolescent girls have high rates of depression and anxiety [34 and 36 percent respectively]²¹. Several studies have suggested an interesting overlap between eating disorders and autism²².

A study exploring associations between the sex differences in brain structure between male and females regarding social cognition [SoC] and autism spectrum disorder [ASD], confirmed the notion of the female advantage of SoC may contribute to women's underrepresentation in SoC in associated ASD.²³

In 2020, a study of autistic females diagnosed over the age of 40 years of age, four superior themes emerged: A *"hidden condition"* which is pretending to be normal to fit in and mental health mislabelling, the *"process of acceptance"* (initial reactions and search for understanding; re-living life through a new perspective, *"the impact of others post diagnosis"* (stereotyped assumptions and first reactions), and *"A new identify on the autism spectrum"* (negotiating relationships, connections and community; changing wellbeing and self-regard; the meaning of a diagnosis).

This study highlighted new factors affecting late diagnosis in females including the broadly limited understanding of others of autism spectrum conditions. Diagnosis facilitated several participants to move from being self-critical to self-compassionate and increased their sense of agency. The change in identify enabled greater acceptance and understanding however coming at such a late stage, it was distressing to adjust to.

¹⁹ Leedham, A. et al. 'I was exhausted trying to figure it out': the experiences of females receiving an autism diagnosis in middle to late adulthood. [2020]. Autism 2020, Vol. 24(1) 135–146. Available at: sagepub.com/journals.sagepubl.com.

²⁰ Dean et al. (2017) As found in Gould, J., [2017] Towards understanding the under-recognition of girls and women on the autism spectrum. Autism 2017, Vol. 21[6] 703-705.

²¹ Croen, LA, et al. The health status of adults on the autism spectrum. Autism. 2015 Oct;19(7):814-23. doi: 10.1177/1362361315577517. Epub 2015 Apr 24. PMID: 25911091.

²² Karlsson L, Råstam M, Wentz E. The Swedish Eating Assessment for Autism spectrum disorders (SWEAA)- Validation of a self-report questionnaire targeting eating disturbances within the autism spectrum. Res Dev Disabil. 2013 Jul;34(7):2224-33. doi: 10.1016/j.ridd.2013.03.035. Epub 2013 Apr 30. PMID: 23643773.

²³ Cauvet et al. [2020]. The social brain in female autism: a structural imaging study of twins. Social Cognitive and Affective Neuroscience. 423-436

4.3 Diagnosis

The Autism Quality Standard [QS51] published by the National Institute of Clinical and Care Excellence [NICE] in 2014, and updated in the NICE CG142 [2021], states where possible, referral for a diagnostic assessment with a local adult multi-disciplinary autism team should begin within three months. Team composition for example, should include primary care personnel, clinical psychologists, nurses, psychiatrists, social workers, speech, and language therapists and advisors for housing, education, employment, finance, personal and community safety enablement, equality, and diversity assessment.

A useful measure to assess the quality of care and / or service provision, the use and implementation of personalised plans as developed in partnership between individuals, family and carers and the autism team. Personalised plans should be based upon assessment of the individual's need in conjunction with their skills, strengths, mental and physical impairments, within their social and educative context and individuals should be offered a key worker liaison.

4.4 Children and young people with complex needs [0-25 years]

To encourage education, health, and social care to provide more coordinated support to children, young people, their families, and carers, in 2022 the National Institute for Health and Care Excellence [NICE] issued guidance [NG213]. For more information see Health Needs Assessment of Children with Special Educational Needs and Disability (SEND), [KPHO, 2019]²⁴

4.5 Adults with complex needs

This term is used to describe any adult needing a higher level of support with multiple aspects of their daily lives and who depend upon an array of health and social care services. This need may arise from illness, disability or wider life circumstances or any combination of these.

Need may be present at birth or develop over a life course and may vary over time. In 2022, the National Institute for Health and Care Excellence [NICE] issued guidance for social work with adults experiencing complex needs [NG216].

These needs and how these are met can be challenging to individuals. Being unable to access support when required means individuals are vulnerable to secondary preventable conditions and premature mortality.

²⁴ [JSNA-CYP-SEND-and-Learning-Disability-Report.pdf \(kpho.org.uk\)](#) ; [SEND-HNA-June-2020.pdf \(kpho.org.uk\)](#)
[Updated 2020].

4.6 Criminal Justice System

In June 2020, the Equality and Human Rights Commission highlighted that the criminal justice system [CJS], was failing people with learning disabilities and autism.²⁵

A UK study to investigate the treatment of adult defendants with autism during the pre-trial phase within the CJS concluded that they were not being fairly treated and not offered reasonable adjustments or support which can place them at significant disadvantage. For example, only half of defendants with autism were considered by the police to be vulnerable although in law they are recognised as such.²⁶

‘Appropriate adults’ were not provided to over a third [35%] of autistic defendants during investigations although their diagnosis was known to police, whilst 18% did not have an appropriate adult present as their diagnosis was unknown to police.

In Kent, if an individual declares themselves to be neurodiverse or if staff have reason to believe they may be, an autism assessment is requested. I.e., a risk assessment takes place when an individual is booked into custody which seeks to understand vulnerability and specifically neurodiversity.

A quarter of people in the study received ‘reasonable adjustments’ whilst the remainder did not due to a mixture of police being unaware of their diagnosis [33%] or failing to take account of their diagnosis. Some examples of reasonable adjustments included visual aids to facilitate communication and additional time to process information.

One in five [22%] of cases which proceeded to trial, defendants did not have reasonable adjustments made for them despite lawyers stating this would be beneficial. In Kent, neurodivergent detainees are provided with distraction boxes, visual aids, fidget tools, and distraction toys such as footballs and reading and drawing materials.

For jury trials, in just under half of the cases were the jurors made aware that the defendant had autism, and most judges, prosecution barristers and magistrates said or displayed behaviours which raised concerns that they had an inadequate understanding of autism. Atypical behaviours and failing to consider mitigating circumstances could negatively influence sentencing decisions.

The stress of interacting with the CJS, being subject to criminal proceedings coupled with additional stresses of anxiety and mental health problems for people with autism, means at such times many are unable to cope and so ‘meltdown’ and ‘shutdown’ as a result.

²⁵Equality and Human Rights Commission [2020]. Inclusive justice: a system designed for all. Available from [Link](#) [Accessed July 2022].

²⁶ Slavny-Cross, R et al. Autism and the criminal justice system: an analysis of 93 cases. [2022] Available [Link](#) [Accessed 27-7-22]

A positive finding was that when a defendant was found guilty of a crime, 60% of judges saw their autism as a mitigating factor with the majority receiving a suspended or reduced sentence. A research recommendation called for an urgent raising of awareness of autism within the CJS and mandatory training to ensure defendants with autism are treated fairly within the CJS.

4.7 Crime and anti-social behaviour

In updated multi-agency guidance updated in 2022, the Kent and Medway Violence Reduction Unit in collaboration with Kent district, county, and partners, highlighted several common vulnerability factors which make individuals more likely to experience home invasion and cuckooing. These include people who experience social difficulties and isolation, and those who have a physical disability, autism or learning disability²⁷.

Cuckooing is a term used to describe a form of antisocial and criminal exploitation, most usually conducted by a drug dealer or group of drug dealers who take over the premises of a vulnerable person either by friendship, force, or a combination of both, before turning it into a base to deal drugs from. It is widely recognised that vulnerable adults and children as often the victims of this practice.

4.8 Criminal Justice System

Published in 2021, a local government report about neurodivergent people conducted analysis upon a wide range of relevant published reports and strategies at local, regional, and national levels. The report highlighted information and areas of good practice including community and voluntary sector input pertaining to neurodivergent individuals and the criminal justice system.²⁸

Key themes emerged concerning systemic pathways issues relating to identification, diagnosis, diversion, support, and treatment:

- Early identification of learning disability and autism

As previously mentioned, in Kent most custody sergeants are aware of the need to seek to identify neurodivergent detainees when they are booking them in to custody via risk assessments when booking in and releasing detainees. The effectiveness of the assessment however is subjective – depending on the skills and experience of the Sergeant.

Once vulnerabilities are identified with detainees, custody staff complete referrals to Forensic Health Practitioners and Liaison and Diversion Practitioners who will assess in custody as well as make referrals to community healthcare professionals.

²⁷ Canterbury city Council [No date]. Tackling Cuckooing, Multi Agency Guidance. Available from: [Tackling-Cuckooing-Multi-Agency-Guidance.pdf \(kscmp.org.uk\)](#) Accessed 28 July 2022.

²⁸ [People with a learning disability and autism in the criminal justice system | Local Government Association](#)

This process [pathway] identifies people who would benefit from the Victim and Witness Care Unit. The unit supports all witnesses attending court including police and public witnesses. Again, a vulnerability assessment takes place and Special Measures can be applied for to support those giving evidence in court. This may include having their statements read out in court due to dyslexia or asking for permission for witnesses to give evidence via an audio-visual virtual link.

- Data protection issues inhibit and block information flow and sharing

Information sharing with partners could be better in Kent. Police rely on the information sharing with Liaison and Diversion practitioners and mental health teams, however there is no standard information sharing agreement in relation to vulnerability and in particular neurodiversity.

- Eligibility criteria often precludes individuals with autism only, from access support services or services are absent [UK study]. Kent police have a high level of awareness to Dyslexia, Autism, ADHD, Bipolar and Mental Health conditions.
- Access to inpatient services to facilitate early intervention is difficult especially for those with mild learning disability e.g., services absent or eligibility criteria
- Inconsistent practice
- Local diversion panels should be in contact with people and utilise appropriate pathways and links
- Review into cybercrime and related activity upon autistic individuals who may have good information technology [IT] skills but who may find themselves susceptible to IT related crime, terrorism, sexual exploitation, and theft
- Support required for families of alleged victims or perpetrators
- Interview technique with neurodivergent individuals should follow best practice

Within Kent police, there is a heightened awareness that those who may be arrested for cyber-crime may be neurodivergent. Interview environments need to be improved to cater for ND. However, it is fair to say that those who may be being interviewed for other crimes such as shoplifting who may not be deemed to be divergent require additional support.

- [Reasonable] adaptation and adjustment within the custody environment to alleviate stress with learning from mental health settings.

In Kent, previously mentioned adjustments are in place, e.g., distraction boxes, fidget spinners etc.

- Review of neurodivergent people's experience of the criminal justice system and the 'revolving door' cycle of offending behaviours

- Application of gender appropriate responses

The Kent and Medway Gangs Strategy [2018-21], included the aspiration to 'bridge the data gap' by 'improving multiagency data recording, collation, analysis and sharing processes', as one approach to ending the criminal exploitation of vulnerable children and adults.²⁹ Exploitation is well understood in Kent Police and there is a heightened awareness of neurodiversity within the organisation. However, links between vulnerability, exploitation and neurodiversity differs depending upon the skills and experience of officers.

Within the 'Prevent' element of the strategy is the commitment to improve identification and safeguarding of vulnerable individuals who may be targeted by gangs along with improved data sharing between agencies to facilitate earlier intervention and preventative work. A call-to-action to extend this approach to service providers of all ages and functions was made – 'every age and stage' to raise awareness and effectively reduce risks and threats posed.

Kent Police provide all staff with neurodiversity training; the AQ50 test and dyslexia screening is offered to every new student officer and employee and is available to existing staff. Occupational Health [OH] processes in relation to referral pathways are clear. Employees receive ND awareness training via equality and diversity training.

This training has increased staff awareness which the Kent [police] Staff Support Association 'Enable' promotes enabling staff to recognise ND individuals and offer the appropriate support when dealing with the public, victims of crime, witnesses, and detainees.

Much work has been undertaken and is in progress within the police estate in Kent and it is recognised that this is an ongoing consultative process with partners and people with lived experience. For example, to identify, suitably accommodate and safeguard ND adults within custody suites which have been adapted and equipped to prevent sensory overload with the sensitive placement of furniture, use of appropriate lighting.

The provision of concentration aids such as soft balls and fidget spinners to provide people with a focus of attention and a means to expel excess nervous energy during interview have been introduced. Raising awareness and the establishment of training of first point of contact staff groups such as within the control room and those in public facing roles, to communicate with ND individuals effectively and successfully, is another example of the work implemented.

A remaining challenge being addressed is the recording of ND as a protected characteristic when individuals chose not to disclose and how to engage effectively and provide support in such instances. Workforce upskilling and training is underway

²⁹ Kent and Medway Gangs Strategy: Our Approach to Ending the Criminal Exploitation of Vulnerable Children and Adults by Gangs, 2018-2021. Available from: [*Kent and Medway Gangs Strategy 2018-21.pdf](#). Accessed 28 July 2022.

to facilitate this as is enhanced partnership collaboration, networking, and resource sharing with the wider Kent Health and Care system.

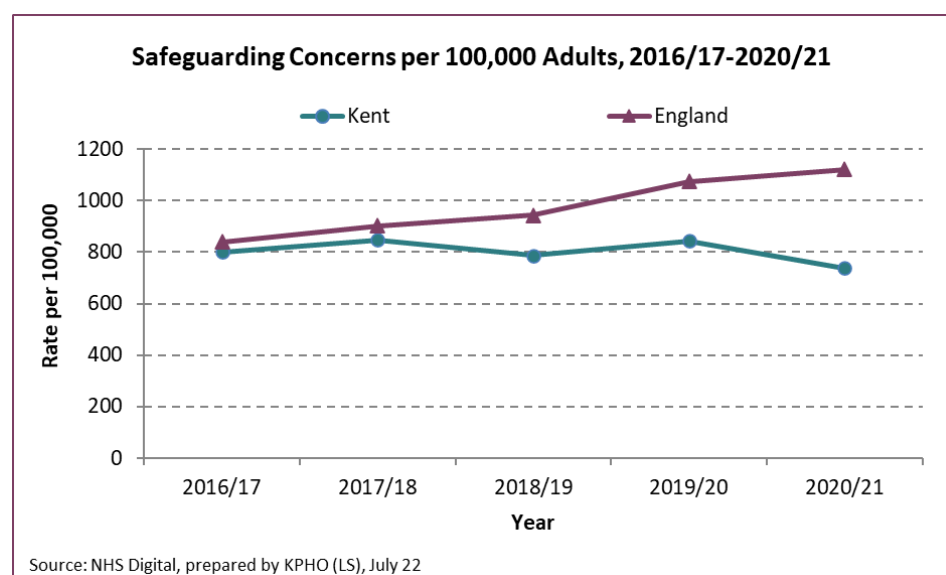
4.9 Safeguarding

The Care Quality Commission [CQC] reviews the quality and standard of care services provided by organisations. Published reports for the period 2018-2022 of inspections of the 37 commissioned services for people with Learning disability in Kent and Medway, assessed 23 of 37 organisations as requiring improvements; six [26%] were in Kent and 17 [74%] were in Medway. The date of the assessments ranged over a five-year period; ten reports were published in 2022, five in 2021, three in 2020, four in 2019, and one in 2018.^{30,31}

‘Safeguarding concerns’ is a term which relates to incidences where there is reasonable cause to suspect there is harm of individuals. When concerns are raised, it is the duty for the local authority to undertake a safeguarding enquiry which is triggered by the three key tests being met, and is not based on the consent of the adult [Section 42]³².

Since 2019 there has been a decreasing trend in the rate of adult social care safeguarding concerns and enquiries reported to Kent County Council unlike the trend for England. The majority of section 42 and safeguarding concerns related to people with a learning disability.

Figure 1 Safeguarding concerns trend 2016-21, Kent and England

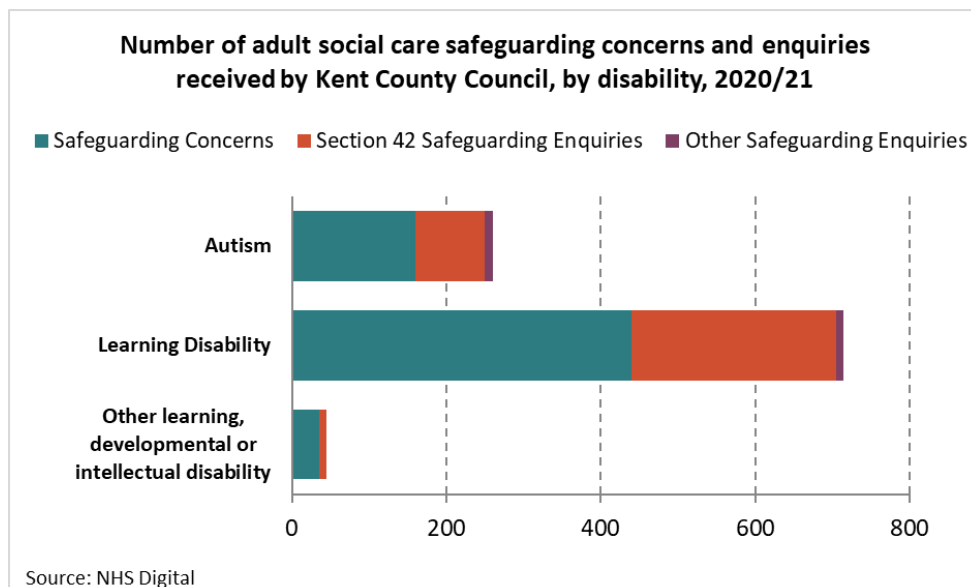


³⁰ [Search Results - Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk/search-results)

³¹ [Quality of life tool for inspecting services for people with a learning disability - Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk/quality-of-life-tool-for-inspecting-services-for-people-with-a-learning-disability)

³² [Quick guide to understanding what constitutes a safeguarding concern | Local Government Association](https://www.local.gov.uk/quick-guide-to-understanding-what-constitutes-a-safeguarding-concern)

Figure 2 Number of adult social care safeguarding concerns by disability reported to Kent County Council, 2020/21



For the period 2020/21, the rate of Section 42 enquiries received by Kent County Council [KCC] was 409, similar to the regional average. The top five types of concern were physical abuse, psychological abuse, neglect, and acts of omission, and financial or marital abuse, respectively.

Figure 3: The Number of Section 42 enquiries per 100,000 adults per local authority, 2020/21

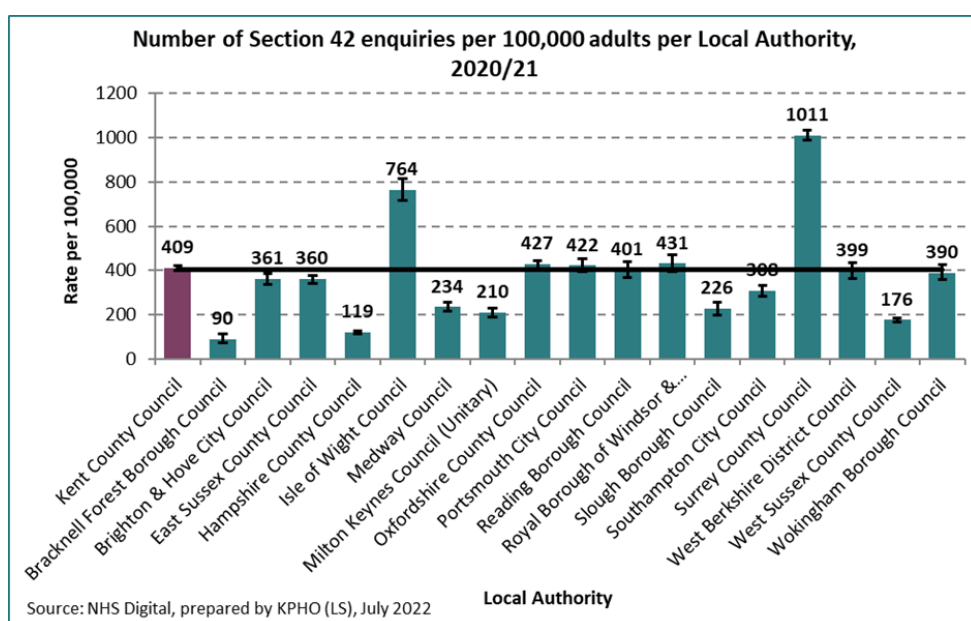
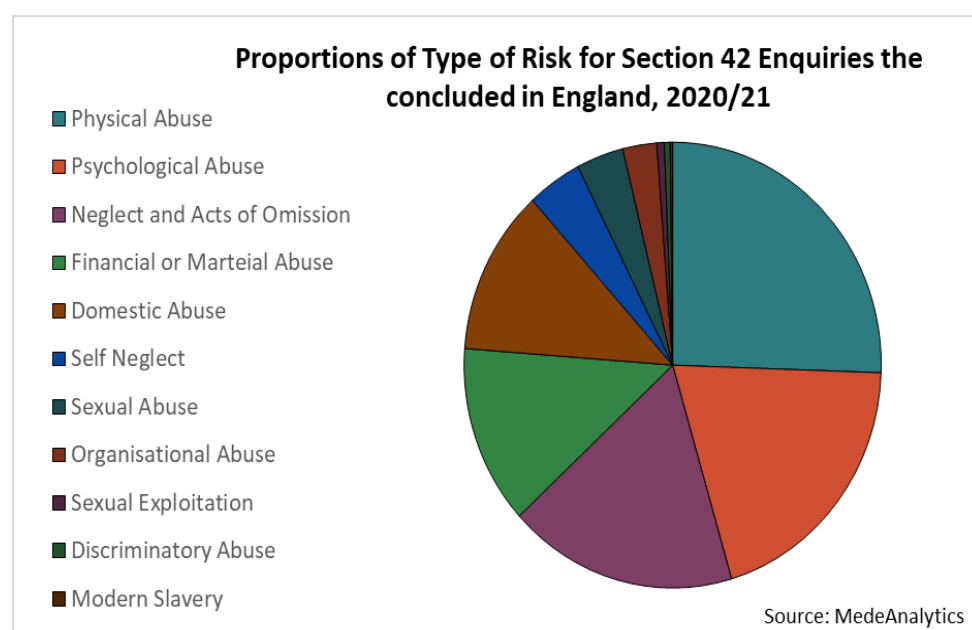


Figure 3: Proportions of risk of types of section 42 enquiries completed, England, 2020/21



Source: KMPHO, 2022

4.10 Housing

Inclusive and age-friendly design helps disabled and older people live more independently and can reduce social and healthcare costs. The needs of people with disabilities and reduced mobility should be addressed in national and local policy development and implementation. Lack of adequate housing and homelessness for the unemployed or on low incomes leads to street homelessness. Support to alleviate the distress of street homelessness is constrained by funding issues.

Most homes in the UK [91%], do not provide the minimum level of accessibility. This means that fewer than 1 in 10 are suitable for older or disabled people to visit and live in. The three categories of accessible housing are defined as: visitable, accessible, and adaptable, and wheelchair user housing. It costs less to build 'M4 [1] category 1: visitable dwellings' housing and so this is the most favoured by developers.³³ In 2015, the annual attributed cost of low-quality housing to the NHS alone was estimated at £1.4 billion for the first-year treatment costs [Nichol et al, 2015].³⁴

A 2017 report by the Centre for Ageing Better and the King's Fund stated that around £177 million of costs related to people falling in their own home and that some low-cost adaptations to homes can result in a reduction in falls of 26%. Further costs are incurred when people cannot leave hospital because their homes are

³³Centre for Ageing Better [no date]. Homes for Life: Its time to build the homes we need. Available at: [Accessible-Housing-Report-111120.pdf \(ageing-better.org.uk\)](#) [Accessed: 27/9/22]

³⁴ Nicol et al, 2015] as found in Centre for Ageing Better. The Good Home Inquiry: Good homes for all. [2021]. Available from: [good-homes-for-all-a-proposal.pdf \(ageing-better.org.uk\)](#) [Accessed: 12 August 2022]

unsuitable for recovery.³⁵ Housing condition and suitability should be introduced by the wider workforce in conversation with people to reduce poor health outcomes at the start of processes to move away from a reactive response to a proactive preventable one.

4.11 Supported living

Estimates from Ageing Better propose the additional cost of making homes accessible and adaptable as standard is modest compared to the costs incurred of providing one-off payments of Disabled Facilities Grants and annual residential care costs when homes become unsuitable. Local Authorities respondents [$n=32$], to a survey by the Centre for Ageing Better [2020], supported changes to raise accessibility standards in building regulations³⁶.

First published in 2015 as part of the Transforming Care Programme, the NHS, the Local Government Association [LGA] and Directors of Adult Social Services [ADASS], provided a framework for 'Building the right support' provided guidance to housing providers to provide increased opportunities for ND people to live outside of mental health in-patient settings. This included shared budgets across NHS and councils to deliver more integrated services. The guidance is due for review in 2022/23.

Delivering upon these aspirations is a complex challenge. Published in 2020, a National Statement of Expectations [NSE] for housing support described the government's concept for the planning, commissioning, and delivery of supported housing. Aimed at housing providers and partners, this guidance highlights best practice examples to encourage local authorities to ensure supported housing provision is of good quality and value for money³⁷.

4.12 National housing policy and local delivery

The Kent Housing Group represents the 'voice of housing' in Kent and Medway. It is comprised of representation from the 12 Kent District Councils and affiliated organisations. Published in 2021, in its Kent and Medway Housing Strategy 2020-25, the group committed to inform and influence countywide strategies that impact upon housing support and care provision for all vulnerable groups.³⁸

The disconnect between national policy and local delivery is a significant barrier to improving housing stock. With each having their own housing policies and funding

³⁵ Centre for Ageing Better, Room to improve: The role of home adaptations in improving later life (2017). Available at: [The role of home adaptations in improving later life | Centre for Ageing Better \(ageing-better.org.uk\)](https://ageing-better.org.uk/the-role-of-home-adaptations-in-improving-later-life/) Accessed: August 2022

³⁶ Homes for Life: It's time to build the home we need [no date]. Available from [Accessible-Housing-Report-111120.pdf \(ageing-better.org.uk\)](https://ageing-better.org.uk/accessible-housing-report-111120.pdf). Accessed: August 2022.

³⁷ Department for Levelling Up, Housing & Communities [2020]. Guidance, [Supported housing: national statement of expectations - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/publications/supported-housing-national-statement-of-expectations) Accessed: August 2022

³⁸ Kent Housing Group [2021] [Kent & Medway Housing Strategy 2020-2025 'A Place People want to call Home' - Kent Housing Group](https://kenthousinggroup.org.uk/kent-medway-housing-strategy-2020-2025-a-place-people-want-to-call-home/) Accessed: August 2022

cuts, this leaves local and district authorities with considerable obstacles to overcome. Further adversity presents with the policy impacts of restructuring personalised care funding i.e., ‘uncoupling’ care provision and accommodation payments. This is / may act as a disincentive for landlords to provide and maintain accommodation without long-term reliable care-funding contracts.

Housing our Ageing Population Panel for Innovation [HAPPI] are principles based on 10 key design criteria. For example, good light, ventilation, room to move around with ample storage and amendable to adaptation for changing needs. Most local authorities in Kent develop housing to HAPPI standards either as policy or as an aspiration³⁹.

4.13 Housing needs of different groups

The customary method of assessing local housing need uses the minimum overall average figure of housing need. This does not differentiate between the housing need of different groups. Updated in 2021, the Department for Levelling UP, Housing and Communities and the Ministry of Housing, Communities & Local Government published guidance to strategic policy-making authorities [DLHC, HC&LG, 2019].⁴⁰

In addition to their duties under the Equality Act 2010 and the Public Sector Equity Duty, Authorities must consider and reflect in their policies how to identify and address the specific housing needs within their communities cognisant of the overall housing need, viability of delivery and evidence suggestive of higher levels of need are present, which is understood to be the case in Kent which has lower-than-expected prevalence of ND people. Specific guidance is available for other specific groups such as disabled and older people⁴¹.

In July 2022, the Government announced the outcomes of a consultation on raising accessibility standards for new homes. The recommendations are mandated changes to the building regulations to Requirement M4(2), introduced in 2015, which sets a higher standard for accessible homes, which is broadly equivalent to the Lifetime Homes Standard. Known as “Category 2: Accessible and adaptable dwellings”.⁴² In Kent on new developments of 100% affordable housing, only Ashford council requires 7.5% of these homes to be M4[3] standard.⁴³ It would be useful if local authorities could provide data on types and categories of units in use.

³⁹ [HAPPI - Design - Topics - Resources - Housing LIN](#)

⁴⁰ [Housing needs of different groups - GOV.UK \(www.gov.uk\)](#)

⁴¹ [Housing for older and disabled people - GOV.UK \(www.gov.uk\)](#)

⁴² [Raising accessibility standards for new homes: summary of consultation responses and government response - GOV.UK \(www.gov.uk\)](#) [Accessed: 18/10/22]

⁴³ Requirement M4(3) sets a standard for wheelchair accessible homes. Known as “Category 3: Wheelchair user dwellings” within building regulations.

Of all main types of impairment, disabled people aged 16-64 with severe or specific learning difficulties were least likely to own their own home [4.1%] compared with 42% of disabled people overall for the same age group [ONS, 2019].⁴⁴

In Kent for the period 2020-21, the number of adults n=3,214 [81.5%] with a learning disability aged 18-64 who live in appropriate and stable accommodation has increased and continues to improve and is better than the England average of 78.3%. [OHID, 2022].

Figure 4: Adults aged 18 to 64 years with a learning disability who live in stable and appropriate accommodation in Kent for the period 2020/21

Kent	England	Kent compared to England	Kent recent trend	Kent change from previous value
81.5	78.3	Significantly better	Getting better	Getting better

Source: Public Health Outcomes Framework, OHID.

The proportion of adults with LD who lived in their own home or with family for the period 2021-22, was 84.4% compared regionally [76.2%] and England [78.8%]. This sees Kent rank 6th regionally and 56th nationally [NHSDigital, 2022].

Although most ND people have good tenancies in place, the housing shortage has impacted upon waiting times for suitable accommodation – according to one report of up to 24 months for those within MH services awaiting accommodation. For people with ND who may experience crisis or changing circumstances or needs during this period, this can have profound impacts on health and wellbeing.

In 2022 KCC employed a Housing and Accommodation Project Lead to work with borough councils to improve housing and tenancy options for people with LD and autistic people – specially to support the need to prevent people going into mental health hospitals and to enable those in hospital to be discharged and supported in the community.

4.14 Employment

There is a high unemployment rate for adults with autism. A study to assess the cost-effectiveness of supported employment for adults with autism found that also

⁴⁴ Office of National Statistics [2019] Disability and housing, UK:2019. Available at: [Disability and housing, UK - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk/disabilityandhousing) [Accessed: 27/9/22]

setup costs were higher these reduced overtime. Gains included those to individuals and reduced costs to health and social care and wider society.

In updated guidance for Mental Wellbeing at work [NG212], NICE recommended a supportive, equitable and inclusive work environment with individualised support programmes to aid job recruitment and retention for adults with autism.^{45,46}

A research study by the Autism Research Centre at Cambridge nearly twenty years ago highlighted the qualities autistic people bring to neurodiversity in the workplace.

‘These individuals are on average, strong systemisers with excellent pattern-recognition skills, excellent attention to detail, and an aptitude in understanding how things work’. Supporting their talents would help them to achieve their potential bringing benefits to society ⁴⁷.

For the period 2017-18, 6% [7,907 people] amongst those using long-term social care, very low rates of paid and self-employment amongst working age with learning disabilities was reported with a higher proportion amongst men [6.6%] than women [5.2%]. With marked variation across authorities, most people were working less than 16 hours per week.

There is notable variation of paid employment for adults with learning disabilities across local authorities and rates of pay do not appear to be increasing over time. No regular national statistics of paid employment for working age adults with learning disabilities is reported. ⁴⁸

The trend remains unchanged for the gap in the employment rate between those with a learning disability and the general population for the period 2019/20 at 74.4% which is below the England average of 70.6%. [OHID, 2022]. ⁴⁹

The Kent trend for adults with a learning disability in paid employment for the period 2016/7-2020/21, has shown a *slight* downturn on the previous year which is in line with the southeast and England trend. ^{Fig.6} At 4%, Kent is lower than region at 6.6% and England 4.8%. Nationally Kent is ranked 78th for this indicator [NHS Digital, 2023].

⁴⁵ [Recommendations | Mental wellbeing at work | Guidance | NICE](#) [Accessed 21/10/22]

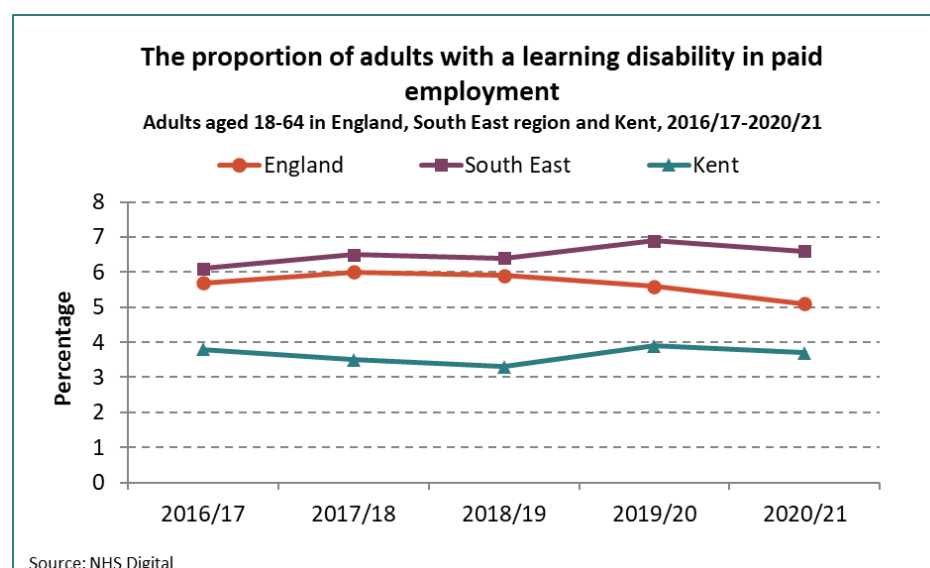
⁴⁶ National Collaborating Centre for Mental Health (UK). Available: [Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum - PubMed \(nih.gov\)](#) [Accessed: 21/10/22]

⁴⁷ [2013 Mavranouzouli Autism The cost-effectiveness of supported employment.pdf \(autismresearchcentre.com\)](#)

⁴⁸ [People with learning disabilities in England - GOV.UK \(www.gov.uk\)](#)

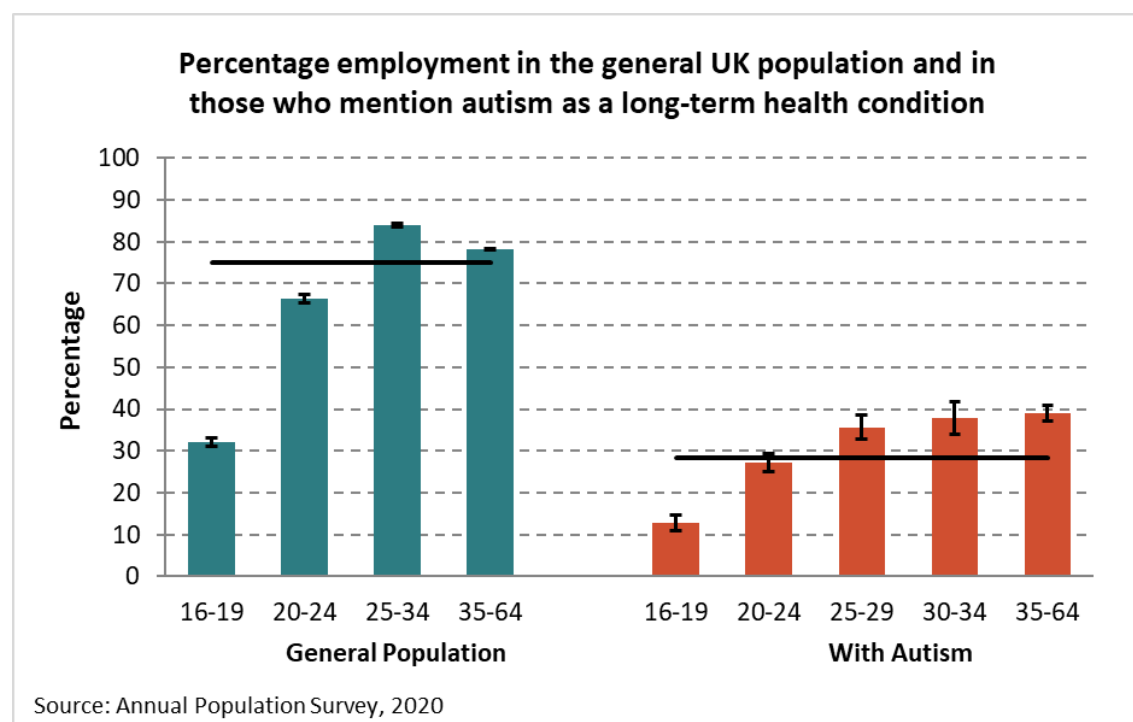
⁴⁹ [Public Health Outcomes Framework - at a glance summary \(phe.org.uk\)](#)

Figure 5: Proportion trend of adults with a learning disability in paid employment in England, southeast and Kent



The percentage of people in employment as surveyed in 2020 who identify as autistic compared to the general population, is shown in the next figure. More people are in employment corresponding with increasing age. Autistic people aged between of 35-64 years remain in employment compared to those in the general population of the same age grouping. Fewer people in the general population aged 20-24 years were in employment compared to autistic people of the same age group.

Figure 6: Percentage employment and the general UK population and in those who mention autism as a long-term health condition



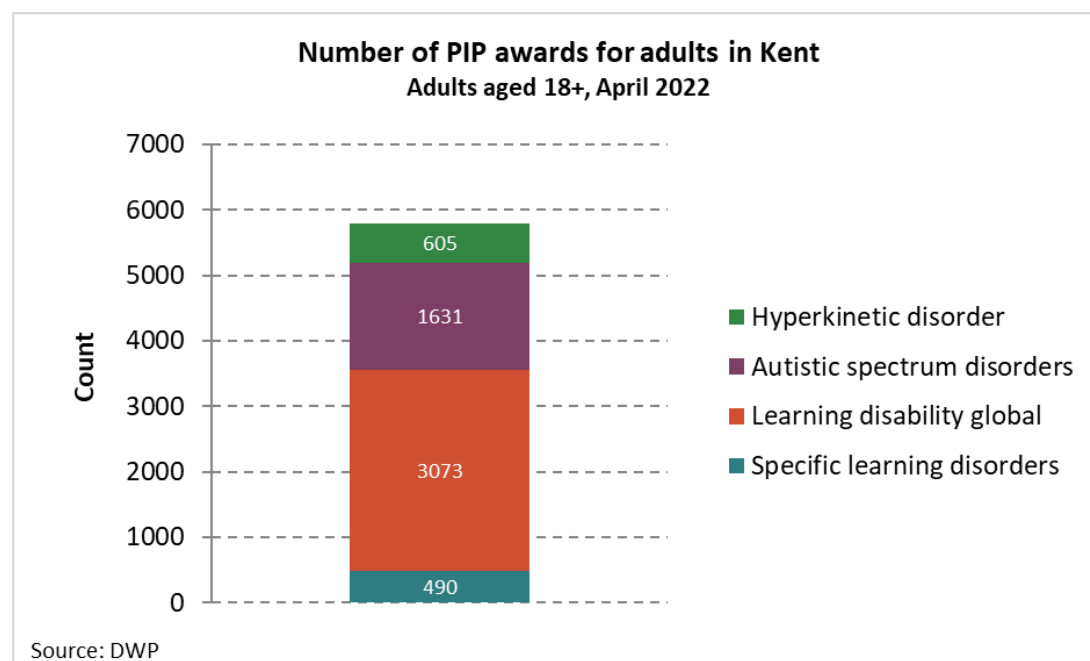
4.15 Disability benefits

The Department of Work and Pensions [DWP] is responsible for regularly reviewing and assessing disability status and benefit entitlement. This process can provoke huge levels of anxiety and frustration for ND individuals. For example, it is difficult for individuals to understand when an award has been made due to an unchanging neurological condition like autism, that further assessments would be required.

In 2019, 99% [296,885] of people categorised as having learning difficulties and eligible, were in receipt of disability living allowance. The majority [70%] being children and young people under 18 years old. Since the introduction of Personal Independence Payment [PIP] in 2014, there has been a rapid increase of those aged 16 years or over with learning difficulties or autism spectrum disorders [68,847 in 2019] receiving this payment. In 2019, 8% and 32.6% of people with learning difficulties and autism spectrum disorders respectively, have had this benefit disallowed.

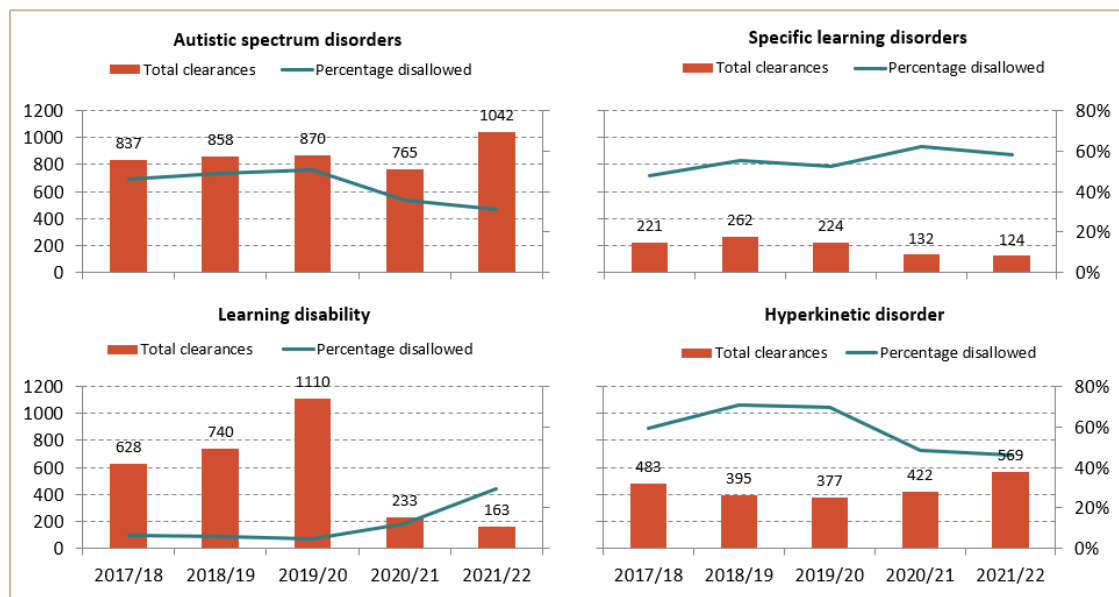
In April 2022, in Kent there were almost 6000 PIP awards for neurodiverse adults and people with a learning disability accounted for just over 50% of these.

Figure 8: Number of awarded Personal Independence Payments by classification for Kent adults aged 18+, April 2022.



The percentage of PIP claims that are disallowed varies according to the main disabling condition. The large reduction in total clearances for learning disability in 2020/21 may be due to the change in the way that claims were processed in response to coronavirus. Coincidental to the reduction in total clearances, is the increase in the percentage disallowed which has increased from 5% in 2019/20 to 29% in 2021/22. [KPHO].

Figure 9: Personal Independence Payment clearances by main disabling condition, Kent, 2017/18-2021/22



5 Health profiles and health inequalities

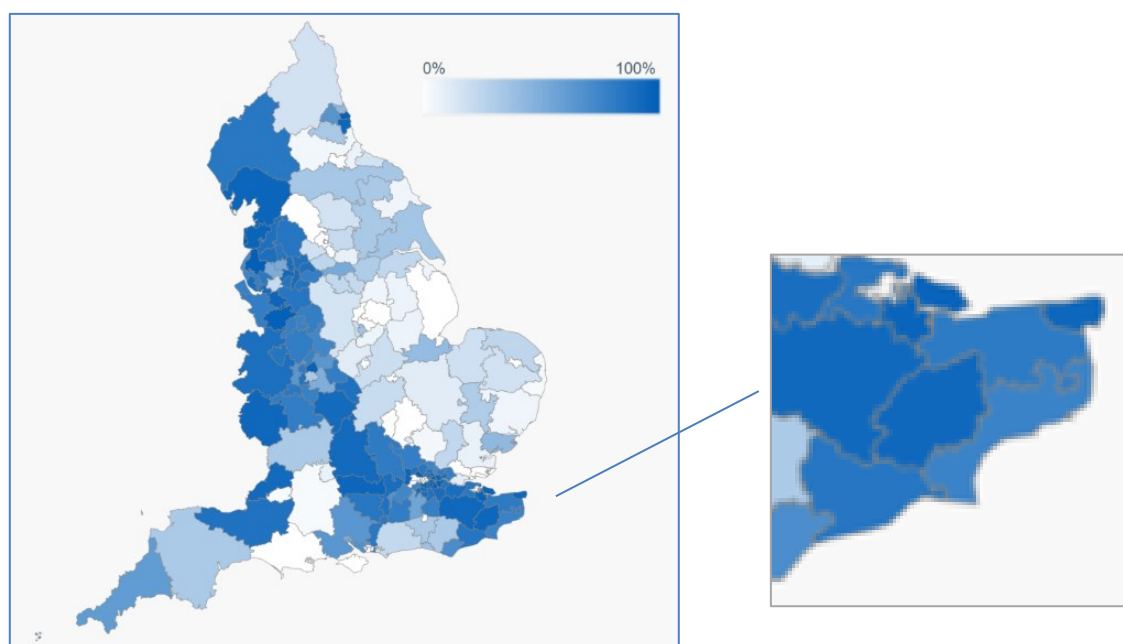
Both the Race Equality Foundation⁵⁰ and Learning Disability England [LDE]⁵¹ have been commissioned to understand the inequalities faced by people with LD from minority ethnic communities and identify actions to address these and strengthen self-advocacy.

In 2021 NICE published a report *NICE impact people with a learning disability*. The report's aim is to recommend actions across a range of guidance to reduce health inequalities for people with a learning disability. Compared with the general population, people with LD are 3 to 4 times more likely to die from an avoidable medical cause of death. Most avoidable deaths were due to untimely and ineffective treatment. Summaries of specific health inequalities experienced by people with learning disabilities include:

- evidence on prevalence and risk factors
- impact on people with learning disabilities
- healthcare and treatment
- social determinants
- signposting to resources

In 2018-19 to compare information on people with and without learning disabilities, experimental statistical data was collected from 54% of GPs in England (96.2% of Kent GPs were included), to identify potential differences in treatment, health status and outcomes.

Figure 10: Proportions of the LD population cared for coverage by CCGs, 2018-19



⁵⁰ [Race Equality Foundation – Promoting equality in health, housing, and social care](#)

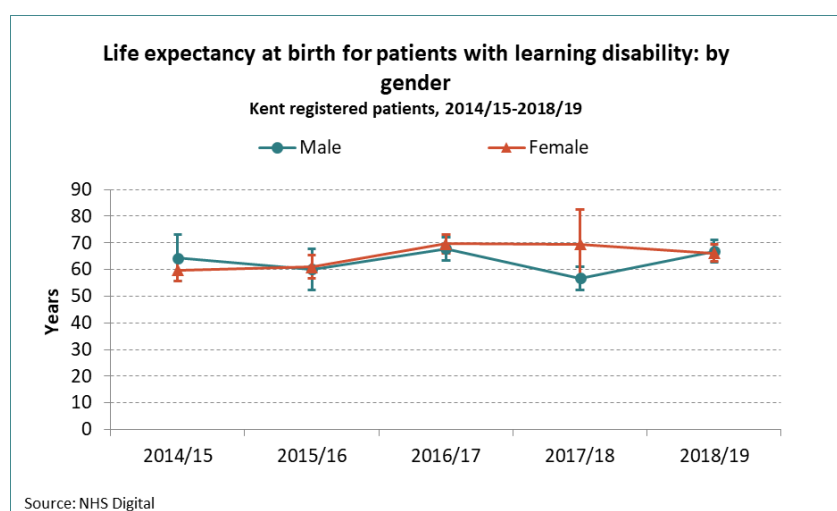
⁵¹ [Learning Disability England – Stronger, Louder, Together!](#)

5.1 Mortality

There has been no statistically significant change in life expectancy at the national level for patients with a learning disability between 2014-15 and 2018-19. In England, males with a learning disability have a life expectancy at birth of 66 years. This is 14 years lower than for males in the general population. Females with a learning disability have a life expectancy of 67 years. This is 17 years lower than for females in the general population.

In Kent, males with a learning disability have a life expectancy at birth of 67 years. This is 13 years lower than the general population. Females with a learning disability have a life expectancy of 66 years. This is 17 years lower than the general population.

Figure 11: Life expectancy at birth for people with a learning disability by gender for the period, Kent, 2014/19



6.1.1.Mortality review

The learning disability morality review [LeDeR]: Action from learning report 2020/21, and the related supporting policy document [NHSE, 2021],⁵² aimed to embed the core aims and values of the LeDeR programme into health and care systems.⁵³ The LeDeR service improvement programme aims to reduce health inequalities, premature death and improve services for people with a learning disability [LD] and / or autism.

⁵² [NHS England » Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) policy 2021](#)

⁵³ [LeDeR-Action-from-learning-report-202021.pdf \(england.nhs.uk\)](#)

The Kent and Medway Integrated Care Board [KMICB] is responsible for ensuring the progress towards implementing actions derived from health and care reviews of people with a LD and people with autism aged over 4 years who have died. These reviews will inform systematic service quality improvements of services wider than those designed for people with LD and autism.

KMICB is accountable to NHS England [NHSE] for the implementation of identified actions required as integral to the KMICB assurance processes to improve services to meet the needs in Kent and Medway of people with LD and autism. Reviews are expected to be completed within 6 months of notification with exceptions allowed, and ICSs must measure and evaluate improvements introduced.

The requirement for reliable data on health inequalities [HIs] experienced by autistic people was highlighted by the NHSE Autism Programme and has now been included within the LeDeR remit. All policy changes must be implemented by ICSs by April 2022 ⁵⁴.

The successful implementation of the LeDeR review programme locally will derive:

- Fewer recurrent themes found within reviews
- Fewer areas of concern and for improvement
- Reduced frequency of avoidable deaths or those that may have been mitigated by good quality healthcare
- Evidence of service improvements
- Improved experience of local processes for bereaved families
- Increased use of reasonable adjustments within health and care services
- Improved outcomes for individuals
- Increased awareness of main causes of death for people with LD and autism both locally and nationally amongst professionals within health and care services
- Improved data capture for people with autism

5.2 Cost of living

The current cost of living pressures of high energy and food are particularly affecting low-income households and those living in the rental sector. Disabled people are 42% more likely than non-disabled people [31%], to reduce their spending on food, energy, and essentials due to these pressures [ONS, 2022]. ⁵⁵

⁵⁴ Subject to legislation.

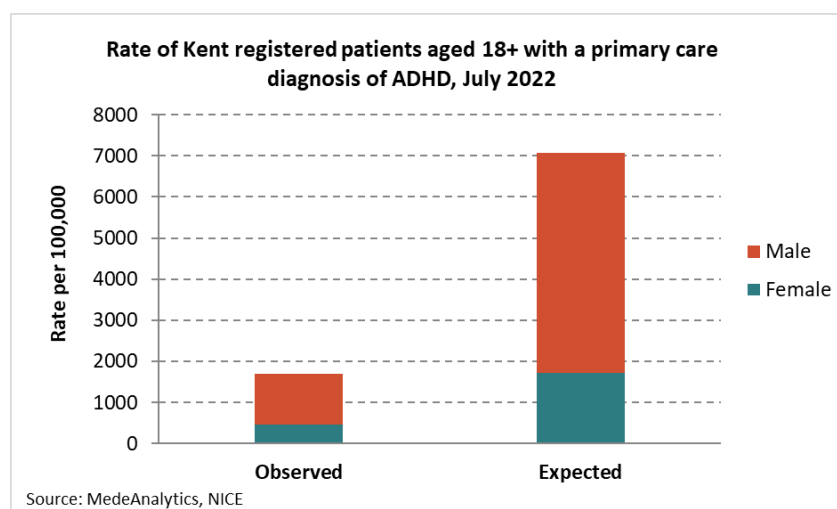
⁵⁵ [What actions are people taking because of the rising cost of living? - Office for National Statistics](#) Accessed: October 2023

5.3 Measurement of Prevalence and Needs

5.3.1 Attention Deficit Hyperactivity Disorder [ADHD]

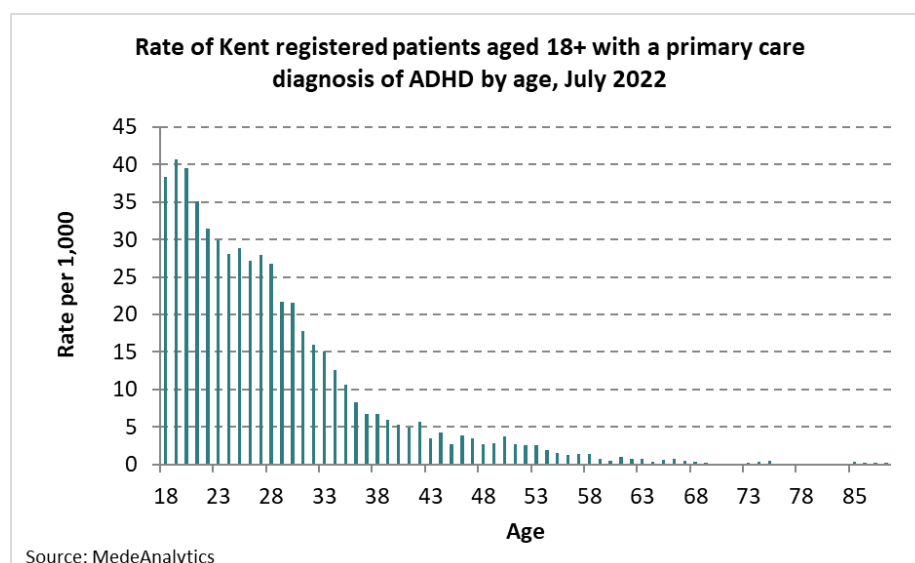
The expected registration rate with GP practices in Kent of people with a diagnosis of ADHD falls far below the numbers registered. The expected rate is around 7000 people per 100,000 of the population. The observed rate in Kent is approximately 1500 per 100,000 population.

Figure 12: A comparison of observed and expected rates of people with ADHD by gender, registered by GP in Kent, July 2022 [KPHO, 2022]



The age trend for Kent adults aged 18+ diagnosed with ADHD shows that most are diagnosed around 18-20 years old. Further spike increases are noted in the mid and late 20s before tapering off with advancing age.

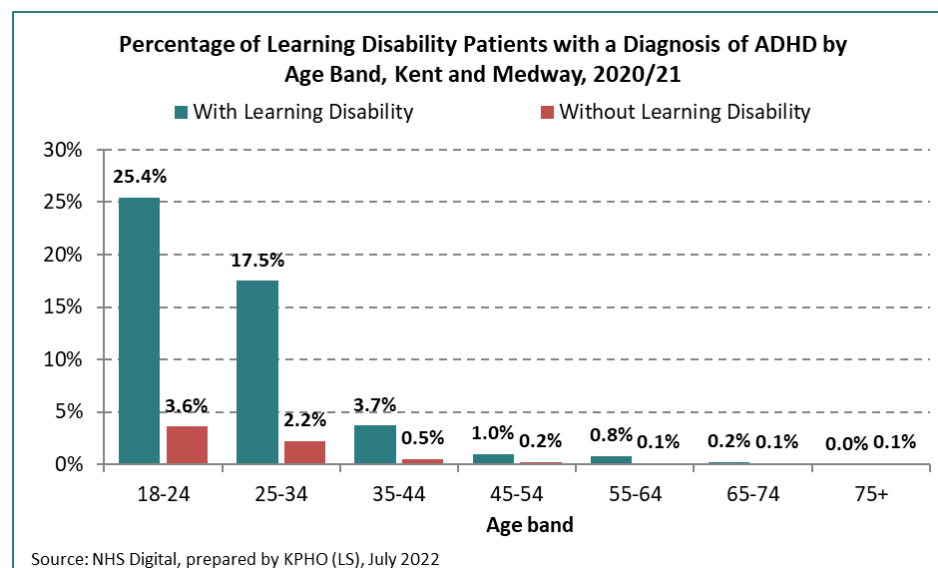
Figure 13: Rate of GP registered patients in Kent aged 18+ diagnosed with ADHD by age, July 2022



Source: KPHO, 2022

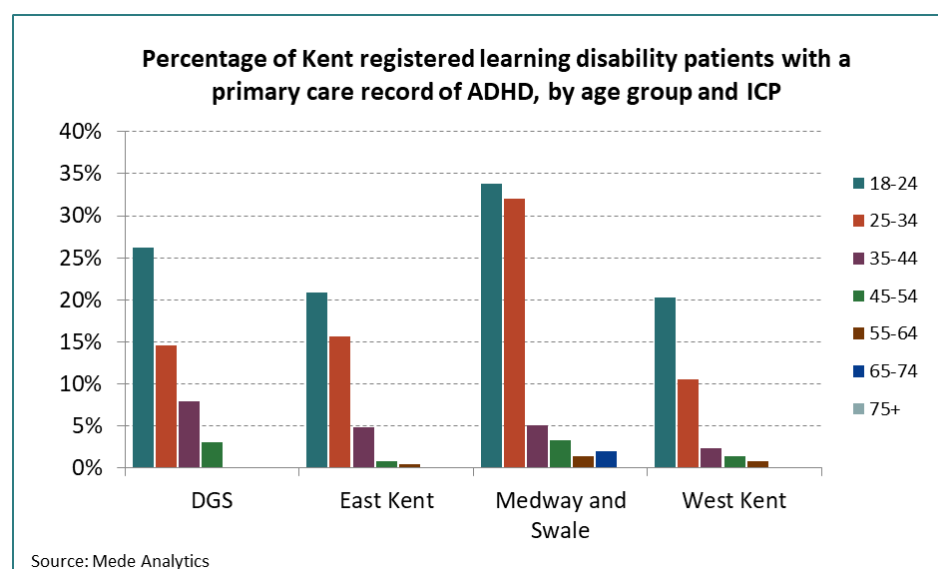
For the period 2020-21, most GP registered people in Kent and Medway with both ADHD and a learning disability, are between the ages of 18-24 and 25-34. Medway and Swale have the most of these age groups in comparison to other Kent Integrated Care Partnerships [ICPs] – over 30%. Dartford, Gravesham and Swanley [DGS] have over 25% of people aged 18-24 years, followed by East and West Kent with 20%.

Figure 14: Proportion of people with a learning disability and diagnosed ADHD by age band, KM 2020/21



Source: KPHO, 2022

Figure 15: Kent GP registered patients with LD and ADHD, by age and ICP



Source: KPHO, 2022

5.3.2 Autism Spectrum Disorders

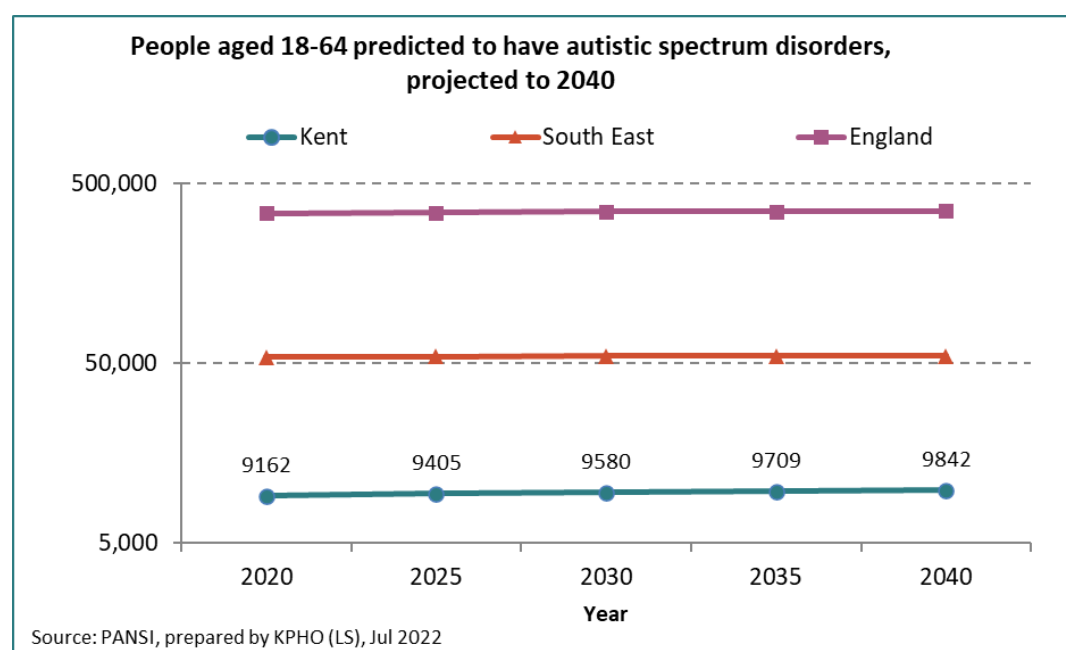
The Adult Psychiatric Morbidity Survey 2014 estimated the prevalence of autism amongst adults in England to be 0.8%. Applied to the Kent registered population in

April 2022, this gives a count of 9,964 adults with autism. Analysis of Kent general practice data shows that in July 2022 there were 9,019 adults (2,463 female and 6,554 male) with a record of autism diagnosis.

The National Institute for Health and Care Excellence states that the prevalence of ADHD is estimated to be between 3% and 4%. Applying a prevalence of 3.5% to the Kent adult population gives a count of 43,594 adults with ADHD. Analysis of Kent general practice data shows that in July 2022 there were 10,402 people registered with ADHD [KPHO, 2022] indicating a considerable gap in autistic people either diagnosed, recorded, or registered with GPs in Kent.

The predicted number of autistic people is anticipated to steadily increase each five-year period to 2040. Like the Southeast and England, the Kent trend is likely to increase by 243 people in the next period to 2025, with an approximate increase of 100 people every five years to 47,698 in 2040.

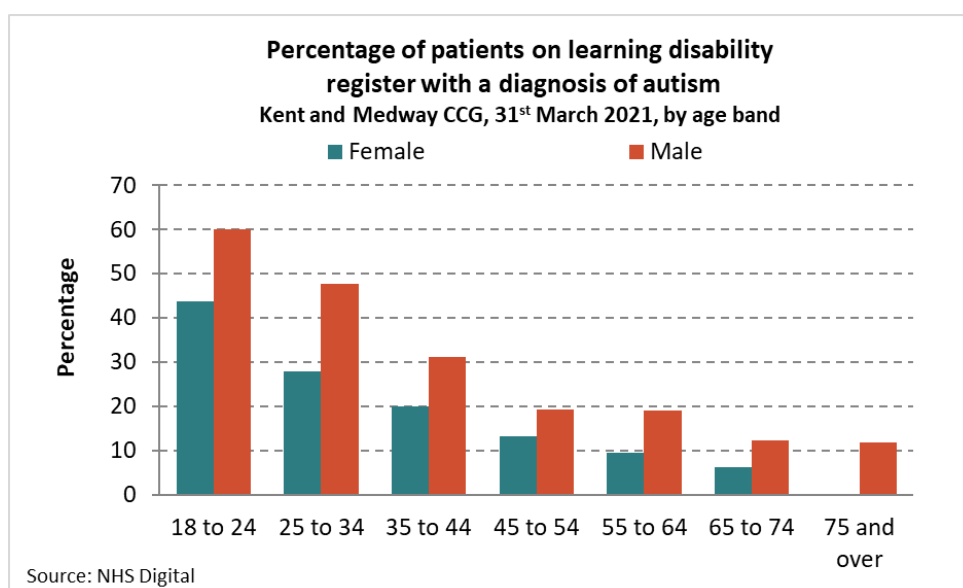
Figure 16: Projected autistic population for Kent, Southeast and England, 2020-2040



Source: KPHO, 2022

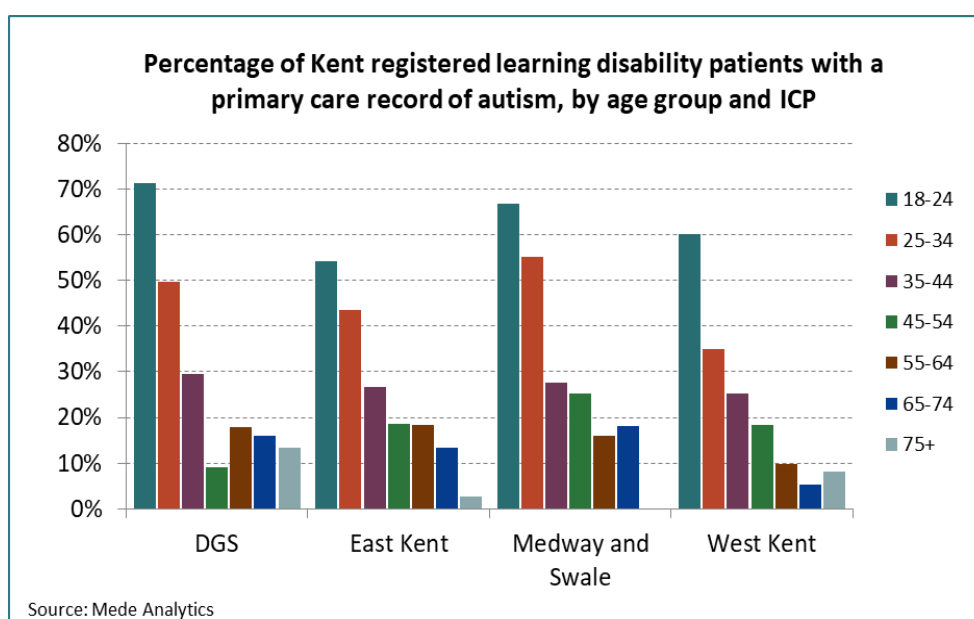
In 2021, there were more males than females registered in Kent and Medway with autism and a LD than females, with no females aged 75+ unlike those recorded for with a LD and without autism. Of Kent ICPs, DGS has the most autistic people with a LD followed by Medway and Swale.

Figure 17: Percentage of Kent GP registered autistic and LD population



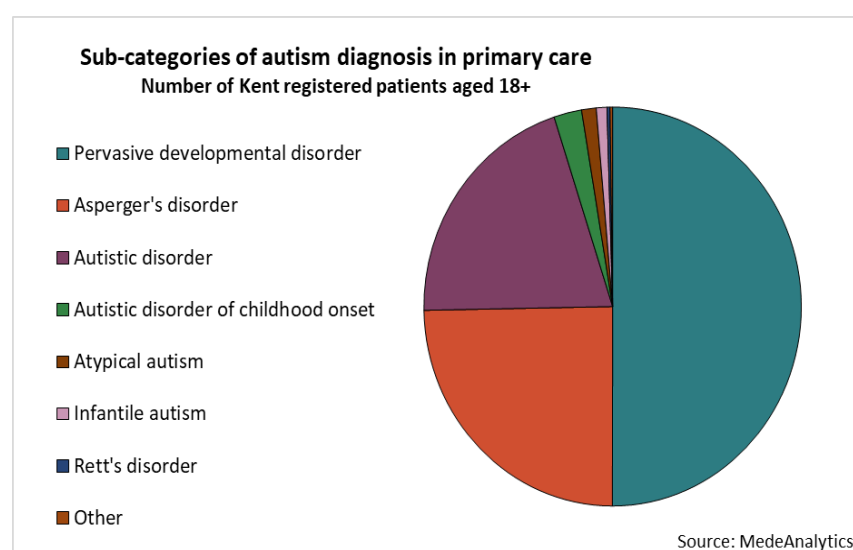
Source: KPHO, 2022

Figure 18: Percentage of Kent GP registered autistic and with a LD by age, ICP



Pervasive developmental disorders (PDD) refer to a group of disorders characterized by delays in the development of socialization and communication skills. Pervasive developmental disorders (PDD) refer to a group of disorders characterized by delays in the development of socialization and communication skills. Approximately half of autistic people registered with GPs in Kent are in this category with a quarter having Asperger's syndrome. The remaining quarter is mainly autism with variants.

Figure 19: Subcategories of the GP registered autistic population, aged 18+



Source: KPHO, 2022

5.3.3 Learning disabilities

In 2015, Public Health England [PHE] estimated that there were approximately 1.1 million people with learning disabilities [LD] although PHE found the number of these registered within health and welfare systems to be much lower.⁵⁶

For Kent in 2020, information from Projecting Adult Needs and Service estimated that there were 29,246 adults with a learning disability. However according to NHS Digital's Health and Care of People with Learning Disabilities dataset, only 7,436 people aged 18 or over were registered on GP Learning Disability Registers in Kent and Medway at the end of 2020/21.

Analysis of Kent GP patient records in July 2022 shows that there were 6,616 people aged 18 or over on Learning Disability Registers. There are more males than females with a LD in Kent and Medway, most noticeably between the ages of 18-34, across all age groupings. Of GP registered patients, show that just under half are classified as having mild to moderate LD.

⁵⁶ [Learning disabilities | NICE | 2022](#) Accessed: June 2022

Figure 20: Rates of primary care registered patients in Kent aged 18+ diagnosed with a learning disability, age grouped, July 2022 [KPHO, 2022]

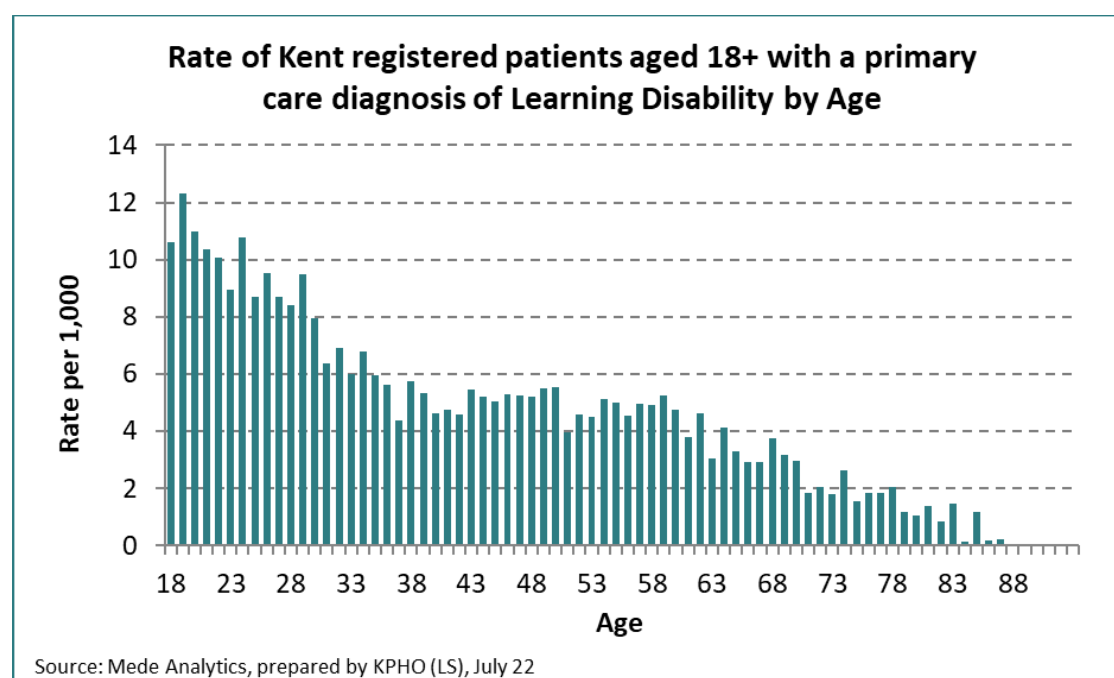


Figure 21: Percentage of people with a learning disability by sex and age band in Kent and Medway, 2020/21

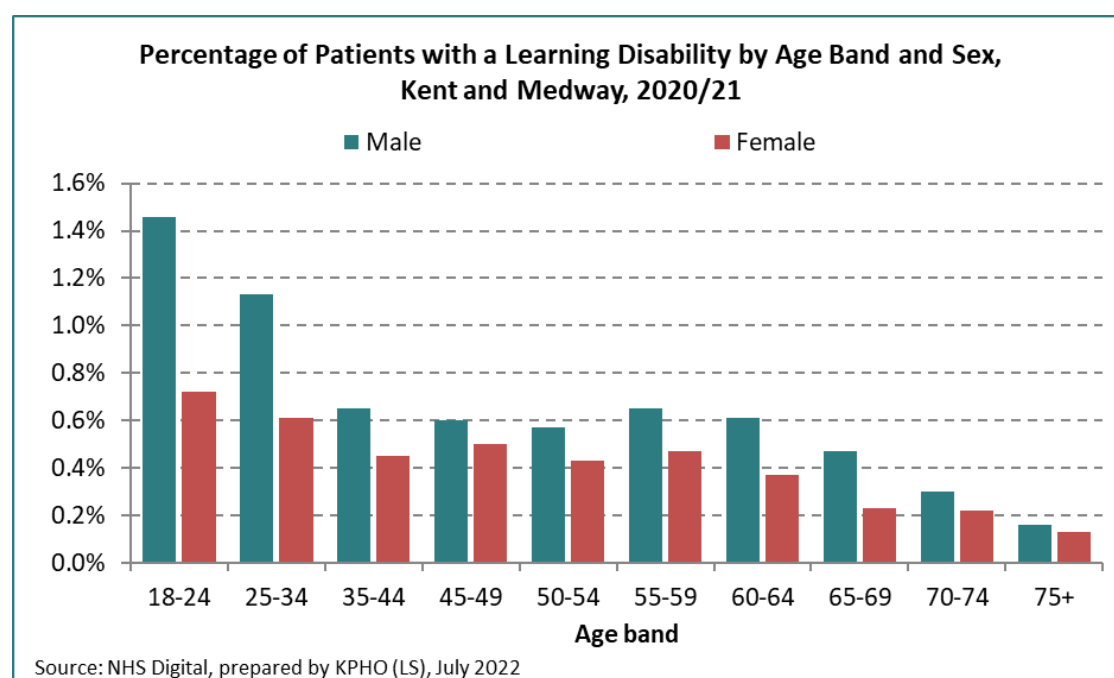
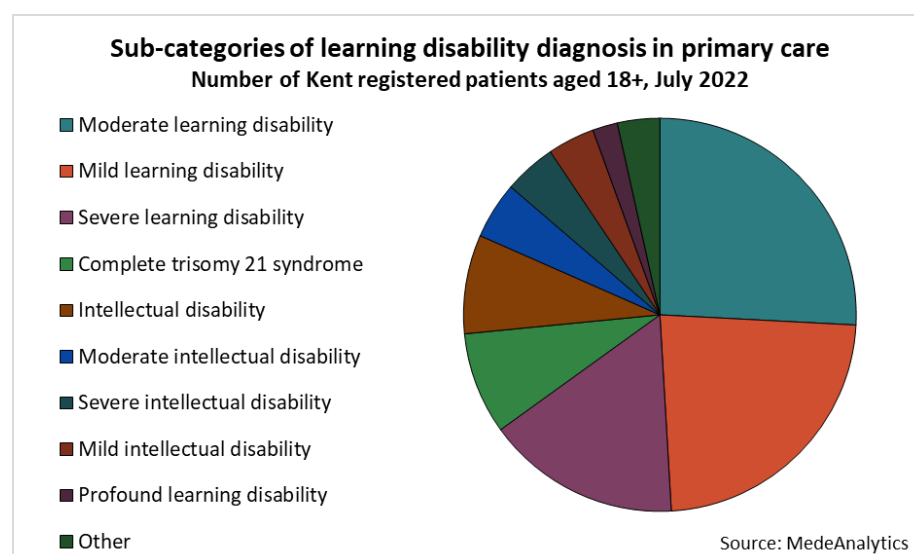
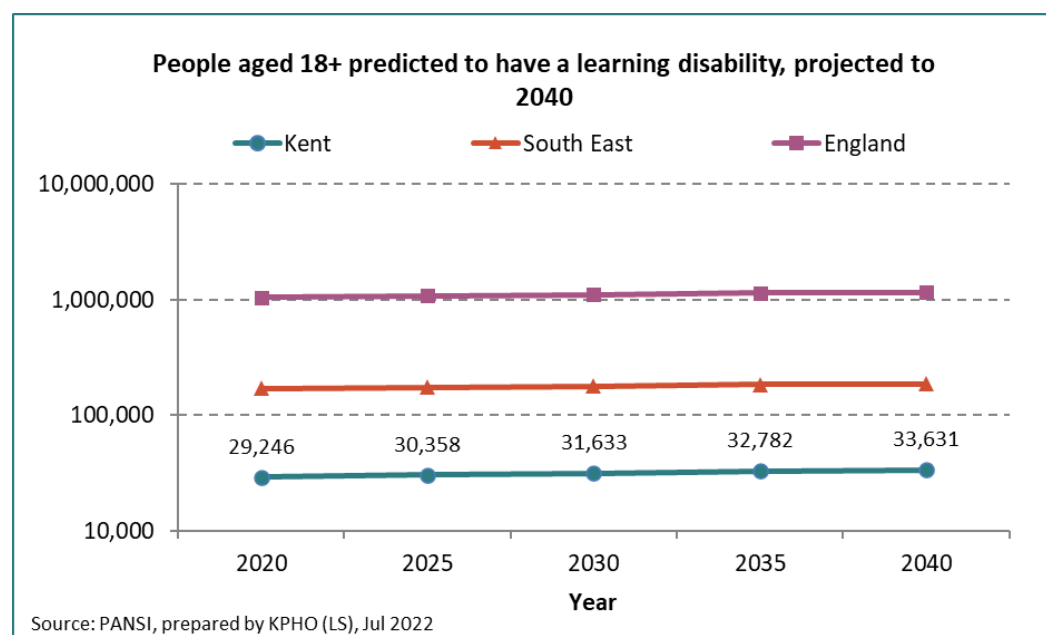


Figure 22: Sub-categories of learning disability diagnosis in primary care [registered patients, aged 18+ July 2022 {KPHO, 2022}]



Following a similar year-on-year trend for the Southeast region and England, the number of people with a learning disability living in Kent is projected to steadily increase every year to 33,631 by 2040.

Figure 23: Projected counts of people aged 18+ with a diagnosis of a learning disability between 2020-2040, for Kent, Southeast region, and England.



5.4 Co-morbidities

Comorbidity is the medical term to describe having one or more other conditions simultaneously. Around 50% of people with a LD have another physical condition due to a combination of factors. E.g., increased rates of obesity and being underweight, hearing and visual impairments, and compared to background population rates, increased rates of epilepsy, eating and drinking problems, pneumonia, thyroid disorders, skin conditions, and Parkinson's disease. They also experience more problems accessing healthcare. ^{Ibid.}

In England in 2020-21, 16.6% of individuals with a LD also had epilepsy and epilepsy was 24.6 times more prevalent in individuals with a LD than those without. Coronary heart disease (CHD) is almost half as common for people with a LD compared to the general population. 1.1% of individuals with a LD had a diagnosis of CHD in 2020-21.⁵⁷

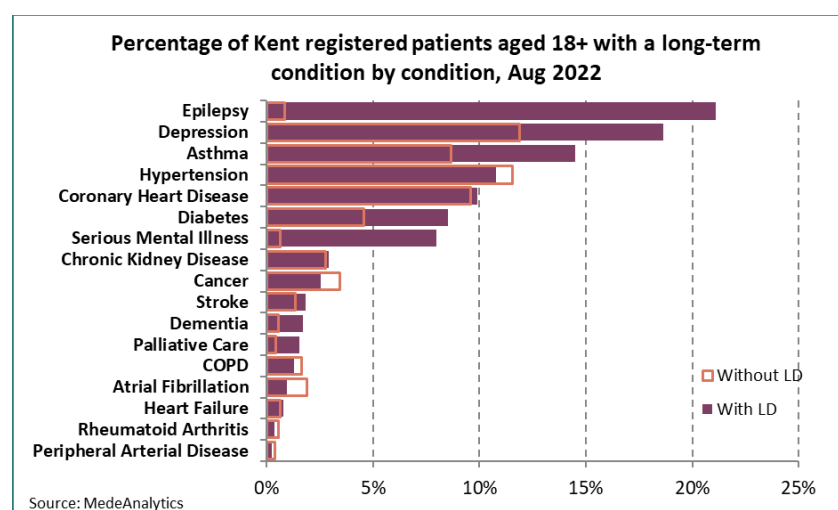
In England in 2020-21, those with a LD had lower rates of cancer screening than those without a LD. This was most pronounced in cervical screening. 30.5% compared to 66.8% of patients without a LD. 62.6% of those without a LD received breast cancer screening compared to 48.1% of those with a LD. ^{Ibid}

In Kent and Medway, the gap in cancer screening rates between those with and without a LD is slightly narrower: 31.5% compared to 66.4% respectively for cervical cancer; and 45.6% compared to 55.6% respectively for breast cancer. No reliable denominator for 2018/19. [KPHO, 2022].

For adults with learning disability, mental health concerns are experienced by 40% or if challenging behaviour is excluded, by 28% of people. [Approximately 36% of children, or if challenging behaviours are excluded 24%]. These concerns include anxiety, depression, phobias, psychosis, bipolar disorder, and schizophrenia. Dementia has an earlier onset for those with LD [6%] compared to the general population [22%].

⁵⁷ Health and Care of People with Learning Disabilities, Experimental Statistics, 2021. [Accessed June 2021]. *Aggregated experimental statistical data on key health issues for people who are recorded by their GP as having a learning disability, and comparative data about a control group who are not recorded by their GP as having a learning disability.*

Figure 24: A comparison of the percentage of Kent registered patients aged 18+ with and without a learning disability and at least one long-term condition, August 2022



Source: KPHO, 2022

Figure 25: Percentage of people with long term conditions, with and without a diagnosis of a learning disability

No. of long-term conditions	With LD	Without LD
1	37.8%	18.6%
2	33.7%	8.7%
3	16.7%	4.0%
4	6.9%	1.8%
5+	3.8%	1.2%

Source: KPHO, 2022

5.5 Suicide

Autistic traits and autism are risk factors for suicide. According to one study in 2022, a significant number of people who died by suicide were likely autistic but undiagnosed. The study concluded that elevated autistic traits are significantly over-represented in those who die by suicide. A high proportion of individuals with depression and women with borderline personality disorder meet diagnostic criteria for co-occurring autism.

Those with co-occurring diagnoses, had the most suicide attempts. Concerningly, a much earlier study in 2001 found that over 40% of individuals who attempted suicide soared above the cut-off point for clinical concern for possible autism on the Autism

Spectrum Quotient.⁵⁸ This discounted those with a self-reported or suspected diagnosis of autism.

The study concluded that of those who died, traits were broadly similar irrespective of evidence of autism, with groups facing a comparably high number of multiple risk markers before they died. The study called for an urgent need for earlier diagnosis and tailored support for suicide intervention.⁵⁹

5.6 Coronavirus [Covid-19]

The Office of National Statistics [ONS] collect mortality data as recorded on death registration certificate as cause of death and circumstance of the accident or violence with caused the fatal injury. Unless a person's learning disability is recorded as an underlying cause or contributing factor, where a someone has a LD is not recorded on the death certificate. As such, the ONS consider this information not held.⁶⁰

Using linked data sets and self-reported disability status, diagnosed learning disability status, the ONS published estimates of Covid-19 mortality in May 2022 with the caveat that estimates for the third wave may extend beyond the study period⁶¹. It is also possible that some deaths and vaccinations occurring during this period have not yet been registered or recorded.⁶²

The report states that for all waves of COVID-19, age-standardised mortality rates involving COVID-19 remained higher for disabled people of both sexes compared to non-disabled people. A significantly greater risk of death remains for all disabled people compared to non-disabled after adjusting for a variety of factors e.g., age, socio-economic and demographic factors.

The largest effect was associated with those living in care or communal home settings. There is a degree of consensus that pre-existing inequalities and health conditions and susceptibilities increased the risk of mortality.

5.6.1 Learning

In the 2021 parliamentary committee report of coronavirus lessons learned to date, it was recommended that in the development of protocols the NHS should “consider

⁵⁸ Baron-Cohen, S., et al (2001). The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists, and mathematicians. Available from [Link](#) Accessed [27-07-22]

⁵⁹ Cassidy, S., et al. Autism and autistic traits in those who died by suicide in England. *The British Journal of Psychiatry*. Available from [Link](#) [Accessed 26/7/22]

⁶⁰ [Deaths in adults with learning disabilities 2015 to 2021 - Office for National Statistics \(ons.gov.uk\)](#)

⁶¹ Third wave- deaths occurring between 12 September 2020 and 11 June 2021

⁶² [Updated estimates of coronavirus \(COVID-19\) related deaths by disability status, England - Office for National Statistics \(ons.gov.uk\)](#)

the importance of maintain access for people accompanying some patients such as advocates for people with learning disabilities...”.⁶³

Whilst guidance and provisions for elderly residential care settings were a key focus for action, it was less so for notably less so despite the significant mortality risk, for those with learning disabilities. The lack of primary care data on patients with learning difficulties or disabilities impeded the identification and early phase provision of vaccines for these vulnerable groups.

The committee recommended that for future health emergencies, agencies should ensure that the specific difficulties encountered by people with learning disabilities and their families should be recognised and overcome to prevent avoidable deaths of vulnerable people. Health and Care Services

⁶³ [Coronavirus: lessons learnt \(parliament.uk\)](#) 2021. Accessed: June 2022.

6 Health and care services

6.1 National and local context

Strategies set out the priorities of organisations and the measures they will take to enable the best health and wellbeing for autistic people in Kent and those who care for them. Strategies are developed in collaboration with people with autism, their families, carers, and professional and voluntary organisations. The development *Kent All Age Strategy* has superseded the development of separate strategies for LD and autism.

The key aspirations of the strategy are that people can live the lives they wish to, feel valued and supported by communities and receive personalised and appropriate support from health and care services. Key steps include improving peoples experience when moving from children and young peoples' services to adult services and improving how service funding is used to support better diagnosis, information and preventative support being offered, better personalised care and support when required and, access to homes and jobs in the local community.

To support this the strategy also aims to grow and develop a value led and skilled workforce to ensure people with learning disability and autistic people have better access to health and social care. To this end, several key areas of focus have been identified to underpin and drive forward system transformation including:

- Co-production
- Workforce
- Resources (to support transformation)
- Quality Improvement
- Children and young people (preparation for adulthood)
- Autism without a learning disability (pathway mapping, finance, and performance)

6.1.1 Implementation

Delivery of the strategy is through the Learning Disability & Autism Delivery Partnership Executive Board which reports to the Integrated Care System (ICS) Mental Health, Learning Disability and Autism Provider Collaborative.

The strategy will be complimented via reorganisation of health and social care services to a place-based model aligned with the four Health and Care Partnerships (HCPs) across Kent and Medway.

KMPT provides universal MH services to the people of Kent and Medway including that of people with learning disability and autistic people who require support with acute mental illness and associate conditions. In addition Kent Community Health NHS Foundation Trust [KCHFT] provide an Adult Autism and Attention Deficit

Hyperactivity Disorder Service that offers pre-diagnostic, diagnostic and post diagnostic help, and support. It should be recognised that during periods of reorganisation and changes to service provision, it often can take a period for services to become established and optimise functions.

Published in 2015, 'Building the Right Support by NHS England [NHSE], the Local Government Association [LGA] and the Association of Directors of Adult Social Care Services [ADASS] as part of the Transforming Care Programme which aimed to improve health and care services to enable more people to live in the community closer to home with the right support.

Most of the services and functions recommended within the principles of the service model are available in Kent. Notable exceptions include the lack of primary care support for people with conditions of autism, personality disorder and females transitioning between services e.g., children to adulthood.

Figure 26: Kent service comparisons against the 'good care model' NHSE

Principle category	Model ideals	Comment	Suggested improvements
Principle 1 <i>A good and meaningful life</i>	1. Inclusion in activities and services 2. Education, training, and employment 3. Relationships with people 4. Support to do things	The access to, and quality of these services is variable ⁶⁴	
Principle 4 <i>Support to my family and paid staff</i>	1. Support and training for families and carers 2. Short break /respite 3. Alternative short-term accommodation 4. Trained support and care staff	♦ Respite provision is inadequate and may not be available to all ♦ <i>Shared lives</i> ⁶⁵ and <i>respite care</i> are different. ⁶⁶	a) Improve respite provision b) Quality service checkers i.e., secret shoppers
Principle 5 <i>Where I live and who I live with</i>	1. Choice of housing and who I live with 2. Security of tenure 3. Strategic housing planning	♦ Most people have good tenancies ♦ Insufficient housing stock available – lead in time 24 months presently ♦ Staff training and upskilling is required	c) Increase utilisation of information management and technology d) Borough councils to be encouraged /motivated to offer

⁶⁴ <https://www.theeducationpeople.org/our-expertise/specialist-employment/supported-employment-for-jobseekers> : <https://www.kent.gov.uk/social-care-and-health/care-and-support/disability/supported-housing/sharing-a-home>

⁶⁵ Shared lives schemes support adults with LD, mental health or who have other needs. The schemes match individuals with needs to an approved carer. The carer shares their family and community life, providing care and support. [Shared lives schemes - NHS \(www.nhs.uk\)](https://www.nhs.uk/shared-lives-schemes)

⁶⁶ Respite provides for carers to take a break from providing care. There are many options from a few hours cover to taking a longer break e.g. to go on holiday. [A break from caring - Kent County Council](#)

		◆ Incidences of landlords leaving people at Accident and Emergency departments to free up tenancies ◆ Police frustrated at having to arrest people to give them shelter	more help
Principle 6 Mainstream health services	1. Annual health checks 2. Health Action Plans [HAPs] and Hospital Passports [HPs] 3. Liaison workers 4. Quality checkers 5. Reasonable adjustments	◆ The Kent system works in silos ◆ There is variable use of hospital passports due to time poor staff ◆ There is a poor understanding at all levels within organisations of reasonable adjustments and the legal definitions. ◆ Need to improve the use of Care plans in secondary mental health settings ⁶⁷ ◆ The shared care record is limited by the number of data fields available	e) Improve collaboration and integration of services f) Make improvements to the functionality of shared care records g) Extend the use of barcodes for SOS emergency data [DVH]⁶⁸ h) Develop a range of examples of adjustments i.e., an example 'menu'. E.g. like those commonplace for accessibility adjustments. i) Increase use of information technology. j) Implement the reasonable adjustment digital flag on all health and social care records k) Increase offer and uptake of annual health checks so all people with LD and autistic people 14 years and above

⁶⁷ They are present but possibly not effective, measurable or person owned

⁶⁸ Reference effective use at Darenth Valley Hospital, Kent.

			have health check annually l) Increase the number of health action plans that are produced following annual health checks and ensure they are of good quality
Principles 7-8 <i>Specialist multi-disciplinary health and social care community support</i>	◆ Specialist HC support ◆ Intensive 24/7 support ◆ Specialist forensic support ◆ Inter-agency working ◆ Liaison and diversion insitu	◆ Specialist MDT in community for LD [health and SC] but <u>not for autism</u> ◆ Services only accessible if you have a diagnosis. E.g., complex care is only accessible for those known to service. No assistance if not known to 'the team' ◆ Only generic support within hours - none for people with specialist needs ◆ That LD OoH cover is not needed is disputed – this has never been assessed ◆ Tier 2 MH provision is only for people known to team; no other access route is available to people Only 2 services in situ; one small group provision for Mental Health Learning Disabilities [KMPT], and a	m) A service specification is being developed for a community based multi-disciplinary and voluntary sector service

		larger service in primary care Community Learning Disability Team [KCHFT] for all other needs ◆ Specialist forensic support is provided by a very small team resource as provided by community provider Kent, Surrey, and Sussex [KSS] LDA provider collaborative via National Health Service England: ▪ Has 10 bed provision for males LD only ▪ No provision for females or autistic people in Kent and Medway though provision is shared across the KSS footprint.	
Principle 9 <i>Hospital care</i>	◆ Integrated with community services ◆ Admission based on clear rationale ◆ Discharge planning ◆ Reviews of care and treatment [CTRs]	◆ Need to focus more on physical health in MH settings. E.g., access to GPs, dentist, physical exercise etc. ◆ Need acute admission data to inform ill health prevention care optimisation ◆ Review MH specialist hospital in patient stays for Kent. I.e. 66 people compared to the national average of 0-6 people at time of	6. Homes not Hospitals group established to provided multiagency leadership and governance of inpatient discharges and preventing hospital admissions 7. Market engagement with community providers to increase community support for those with complex needs 8. Commissioner oversight visits

		writing ◆ 2nd care teams and MH teams operate independently but may be colocated in some areas ◆ Admissions should be based on clear rationale ◆ C(e)TR: Care (education) and treatment reviews [<i>TT Education [CYP] term</i>]. In the new MH ACT see current Mental Health Bill ◆ MDT offered in some cases ○ e.g. helpful and weaponised carers ○ Not joined up or available in all Kent ◆ Health commissioner led process	undertaken 8 weekly to all settings where K&M citizens are inpatients 9. Audit CTRs to monitor quality and impact on care 10. Improve MDT working around those with complex needs especially autistic adults 11. Embed use of Dynamic Support Register (DSR) into all areas of health and social care to prevent escalation to crisis
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6.1.2 Priorities and Workstreams

To support the delivery of the strategy several systemwide workstreams / group have been developed in Kent:

- Improving Health
- Homes not Hospitals (community housing and support)
- Communication and Engagement
- Quality Improvement
- Skilled Workforce

Other workstreams being developed include:

- Community Autism Support
- Children and Young People (outcomes and transition)
- Community Infrastructure (jobs, occupations, support)

6.1.3 Quality, Performance and Finance

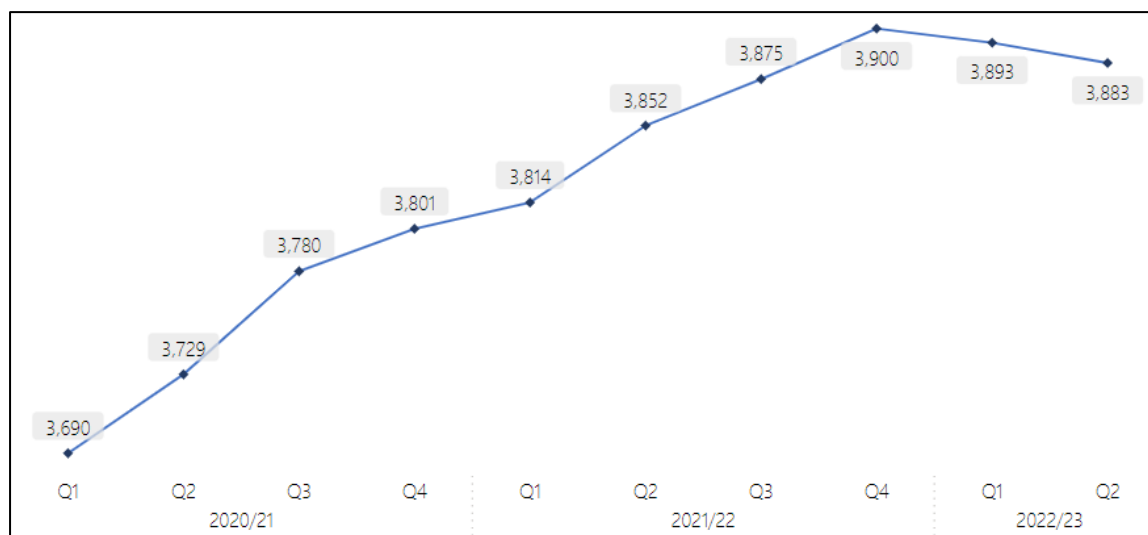
Key performance and quality indicators associated with the LDA programme are being reviewed and mapped to enable a comprehensive reporting dashboard to be developed. To enable this to be completed and to ensure a robust reporting function to update and provide assurance and highlight risks, the delivery partnership requires resources is in place to support this.

Work is progressing on reviewing the finances associated with the LDA programme across health and social care to ensure these are transparent and used effectively. A monthly LDA finance subgroup has been set up with representation from all parties. The system programme lead is working with the ICB, and KCC finance leads to develop a finance dashboard and monthly report.

Since 2019, there was an increasing trend for adults aged 18+ years with a learning disability receiving long-term support in Kent. The Kent rate per 1,000 was 3.55 [4,390], which was higher than both regionally [3.32] and England [3.46], [OHID, 2022].

The recent trend for autistic people and those with a LD being supported in Kent steadily increased over the period 2020-21 until the latter part of 2022 when it started to decrease.

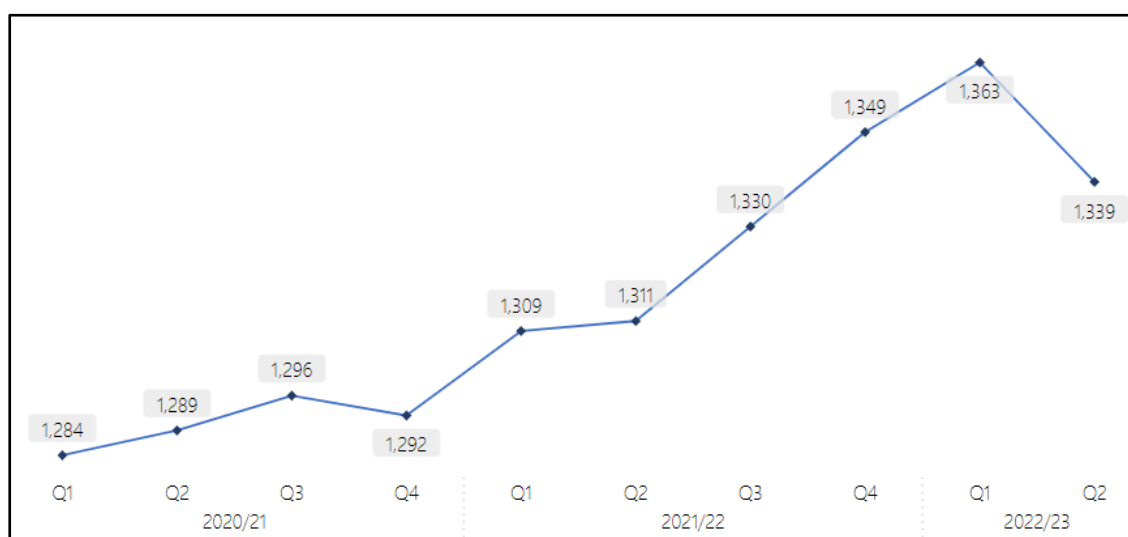
Figure 27: People with LD and / or autistic people supported in Kent 2020/21 to Q2 2022/23



Source: Mosaic, 2022 [subject to change]

Dependent upon their needs, autistic and people with LD are supported by a variety of services in Kent.

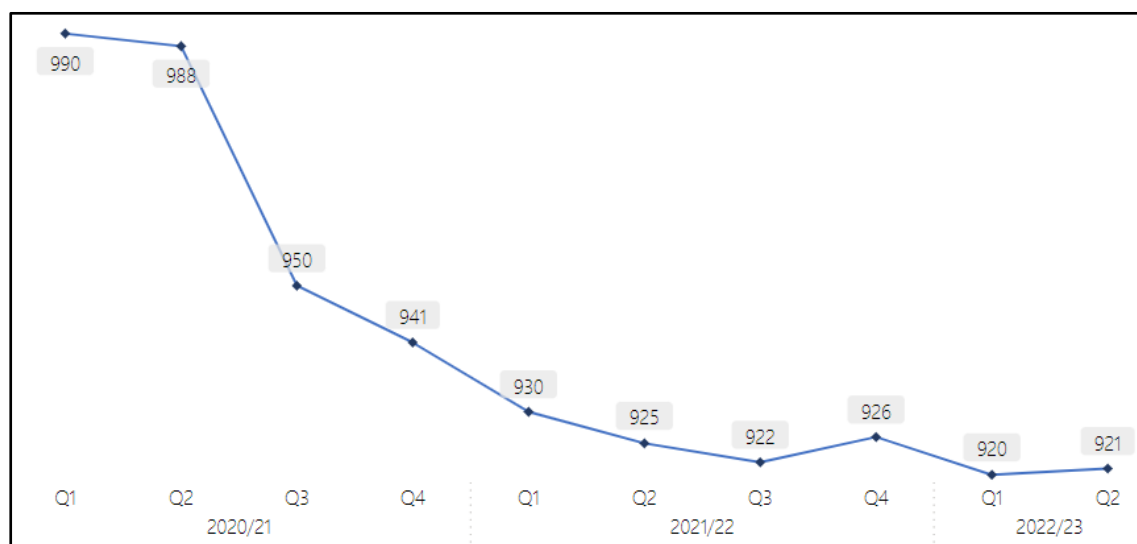
Figure 28: Attending Day Care Services: the number of autistic and people with LD attending day care services in Kent, active each quarter (financial year) 2020/21 to Q2 2022/23



Source: Mosaic, 2022 [subject to change]

A priority of Kent Adult Social Care and Health [ASCH] is to support people to live independently at home for as long as possible. The number of autistic and people with LD living in residential care or nursing services has decreased since the first wave of the pandemic from 990 [7%] in 2020-21 to 921 in Quarter 2 of 2022-23.⁶⁹

Figure 29: Residential or Nursing Service (Short term & Long Term): The number of people we support in Services with Learning Disabilities or Autism, active each quarter (financial year), 2020/21 to Q2 2022/23



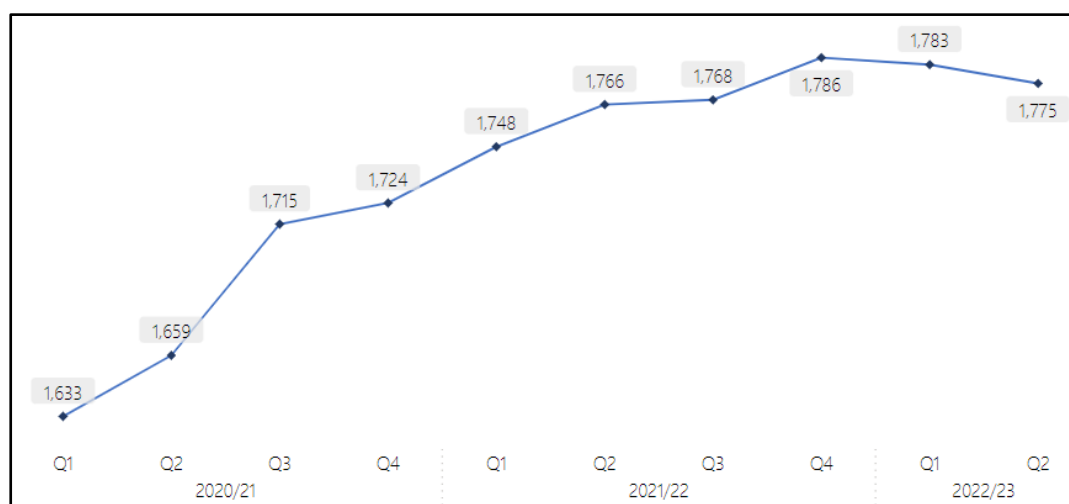
Source: Mosaic, 2022 [subject to change]

Between 1st April 2022 - 30th September 2022, ASCH provided services or some other form of support to 6,064 people with Learning Disabilities in Kent. Ranging between 25-90 years of age, the average age of those supported was 53 years, with 46% being Female and 54% Male.

From a steadily increasing trend during 2020-21, the recent trend of people receiving support via Supporting Independence Service [SIS] or supported living has slightly decreased for the period 2021/22 -2022/23.

⁶⁹ 7% as calculated from Kent GP practice registered people with a diagnosis of LD [6,616].

Figure 30: Number in SIS/Supported Living: The number of people of autistic and people with Learning Disabilities, actively receiving care support services (financial year), 2020/21 to Q2 2022/23.



Source: Mosaic, 2022 [subject to change]

Increasing the number of people receiving Direct Payments is a priority of ASCH. Doing so facilitates people to have greater independence and control over their support and care. The proportion of people in Kent in receipt of Direct Payments is 26.6 which is the same as the Southeast Region and just below England [26.7]. Buckinghamshire has the most people in receipt of Direct Payments [44.4%] and Portsmouth the least [4.6%].

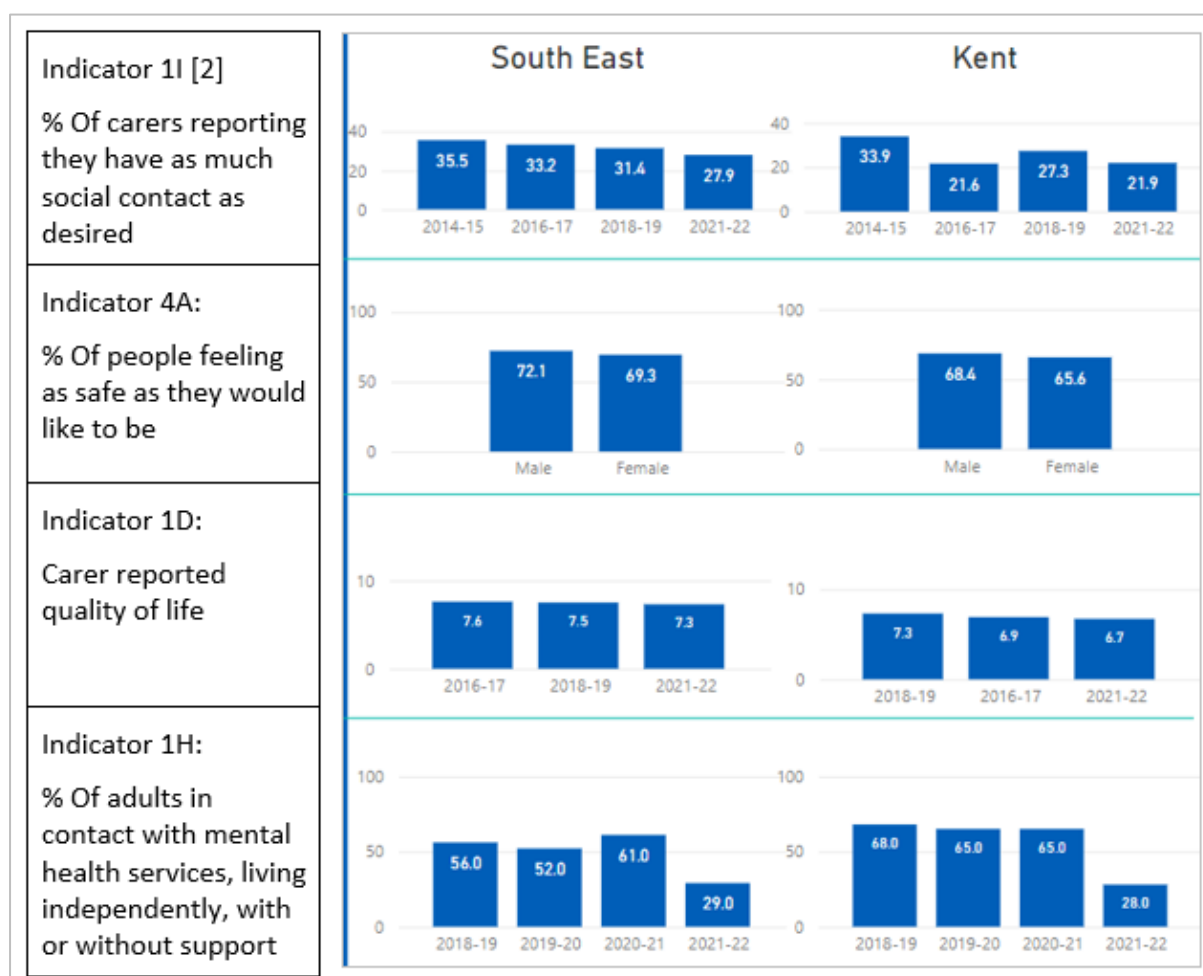
To enhance health and wellbeing support for people using self-directed support services in Kent, ASCH is facilitating the work of community catalysts in Kent. Community catalysts link people who need care or support with local people who might help. Local organisations and small businesses who offer care and support, can receive information, support, and publicity. For example, services offering transport in rural locations, small cleaning companies offering deep cleaning and domiciliary care service start-ups⁷⁰.

The Adult Social Care Outcomes Framework [ASCOF, England] for 2021-22 [NHS Digital], shows a decrease in Kent compared to previous periods and near neighbours, across four domains of the key findings of: social contact for carers, feeling safe, quality of life and access to mental health services.

These figures pertain to all not just LD and Autistic people in Kent. It is notable that women feel less safe than men and the proportion of adults in contact with mental health services has declined sharply in 2021-22.

⁷⁰ [Community Catalysts | unlocking potential | effecting change](#)

Figure 31: ASCOF Key findings Kent and Southeast, [2021-22].



Source: [Microsoft Power BI](#) NHS Digital, 2023. Prepared by L. Smith.

Accessing service information

As reported in the ASCOF for 2021-22, the proportion of people in Kent who use services and who find it easy to find information about services, was 60.9%. This compares to the best in the region of 74.9% ranking Kent near the bottom regionally – 17th of 19th. Compared to England [64.6%], Kent ranks 123rd [NHS Digital, 2023].

The proportion of carers in Kent who found it easy to find information about services was slightly better [65.9%] for the same period. This compares to 58.7% regionally and 57.7% for England, placing Kent in 15th place nationally for this indicator [NHS Digital, 2023].

6.2 Risks to Delivery

Implementing a systemic transformation programme for learning disability and autism that goes beyond the specific requirements of health and social care requires commitment from all partners to dedicate resources to the delivery of this plan.

It is also imperative that the voices of people with learning disability and autistic citizens are included in all areas of this work plan and that the resources and infrastructure are in place to enable true engagement and coproduction to occur.

There is a strong appetite to create sustainable change for people with learning disability and autistic people across Kent & Medway as well as systemic leadership, ambition and realise how best to support this within the Learning Disability and Autism Delivery Partnership.

6.2.1 Risks, Challenges and Mitigations

- Lack of skilled **workforce** in particular social care providers which means community support / provision cannot be developed resulting in people staying in hospital settings for too long.
- **Hospital admissions and long stays remain high.** The 'Homes not Hospital' strategic oversight group has been established to provide strategic leadership and oversight at a system level to ensure effective community provision is in place. This group is the point of escalation for the Cedar House Improvement Planning and the Adult Discharge Planning meetings.
- **Capacity** within the commissioning / programme delivery team to progress strategic and programme priorities. Job roles and responsibilities are being reviewed and vacancies being recruited to.
- **Limited housing and supported living accommodation** are hampering the transforming care programme and hospital discharge / avoiding admissions. Recruitment of a housing and accommodation programme lead to progress delivery of this workstream is taking place. Learning from CYP Designated Keyworker roles and 'wraparound' community support model which has been successful in reducing the need for individuals to go into hospital and/or reduce the length of time they spend in hospital and its application to other parts of the system are being explored.
- The limited resources available to the LDA programme for **data collection, analysis, and reporting** poses a significant risk to the delivery of timely and accurate data and the ability to robustly monitor performance and quality. Options to increase capacity and source additional support for this are being explored.

6.3 Commissioned services and transitional care processes

Access to mental health services and housing are two key areas where people still struggle to get adequate and timely support. For example, gaps as identified in the neurodevelopment pathway. Access to specialist training for staff is also problematic, and access to specialist support services is variable across Kent.

Under the current arrangement any autistic person who requires support with a mental health need such as acute mental illness can and does receive support from universal secondary mental health services KMPT. If an autistic adult does not present with any treatable mental health needs, but instead present with psychological and social needs associated with being an autistic person they can be provided with post diagnostic support from KCHFT's ND service, and if they are at immediate risk of requiring an inpatient stay, they can also be supported by Kent and Medway Complex Autism Service [KAMCAS].

Just because a person is challenged by or challenges services because of psychological and social challenges related to being an autistic person, this does not mean that they automatically have a mental illness. They may have a comorbid mental illness or a lack of support for their needs may lead to a mental illness. MH services are only effective in meeting the needs of people with challenges related to mental illness, other needs related to being an autistic person as discussed above require different and specialist support and intervention that may differ from what is offered by MH service. This is also true for people with ADHD.

The above services work well for known people and people that require support to prevent a further escalate in their needs but are best described as reactive services. Until very recently, a gap in services was for proactive services across health and care that offer preventative, or low-level support for ND adults [and CYP], especially those with a newly diagnosed condition who often only need signposting to support services to meet their needs at this stage.

Until recently this was offered in a limited way by small charities as there were only two services in situ: one small group provision for Mental Health Learning Disabilities [KMPT], and a larger service in primary care Community Learning Disability Team [KCHFT] for all other needs.

Failure to provide early support can often result in the deterioration of health and wellbeing both physical and mental, to crisis point before threshold criteria to access services is reached. Equally failure to provide the right support either because of diagnostic overshadowing and/or miss diagnosis can also lead to further deterioration. To address this gap, the KAMCAS service has recently begun to provide out of hours service provision for preventative purposes.

A separate service specification is being developed for a community based multi-disciplinary and voluntary sector service to provide specialist support to people within core business hours. Currently only generic support is available.

KCHFT ND service offers access to pre-diagnostic, diagnostic and post diagnostic support which may include prescribing and titration of medication for adults with ADHD. A service / support gap appears to be no service provision is available for individuals requiring routine health monitoring and regular prescribing once their medication titration is complete and they do not require further post diagnostic support.

6.4 Kent and Medway Complex Autism Service [KMCAS]

The Kent and Medway Complex Autism Service [KMCAS], is a specialist service offered as an alternative to in-patient treatment options for adults with complex autism and/or behavioural issues which may put them at increased risk of self-harm, harm to others or engagement with the criminal justice system.

Anecdotally losing accommodation and problems with funding are frequent triggers which commonly cause people to enter a crisis phase often resulting in people resorting to overdosing with paracetamol. The service affords the opportunity for adults to remain in or return earlier to their own community with support. Referrals are only accepted via mental health teams or social services, not primary care services.

There is a very long waiting list to access this service with priority is given to those aged 18-20 years. KCC has recently commissioned an out-of-hours service for young adults which is working well to expedite the process. Historically KCC had provided support services for those aged 16-25 years. It has been commented upon that these changes appear to have left a gap for people with autism who do not get 'followed-up' in the same manner as before the legal status changes for people aged 18+ were introduced.

An apparent gap in support services is the 'Health' service provision for people with autism. For example, although there is an autism team county wide, there are no locality specialist teams unlike those for learning disability and older people, personality disorder services. The need to upskill staff groups with regards to a specialist knowledge base, and any attendant transitional service impacts are also factors to be accounted for, along with capacity and capability planning for psychological, occupational and speech and language therapies.

Approximately 50% of calls to the KCC Single Point of Access are from autistic people and ADHD and not from individuals with mental health issues. Currently there is only one referral option which is to refer to the Kent Autism Trust⁷¹.

Out of hours help for individuals experiencing extremely stressful episodes with a mental health issue can be assisted by professionals applying the appropriate section of the Mental Health Act [1983]⁷². A pilot within the KCAS service was

⁷¹ www.kentautistictrust.org

⁷² Mental Health Act [1983]. Available from: www.legislation.gov.uk/ukpga/1983/20/contents Accessed: 17/10/22

initiated to support professionals who care for individuals with these requests for help but an evaluation is not available at the time of writing.

Such initiatives have been developed as part of the Neurodiversity care pathway in Kent and Medway to address service provision gaps. For example, a service to increase self-education and skills enablement in those people newly diagnosed with neurodiversity which recently launched. Support for individuals who experience anxiety and would benefit from prevention and coping strategies, remains to be addressed.

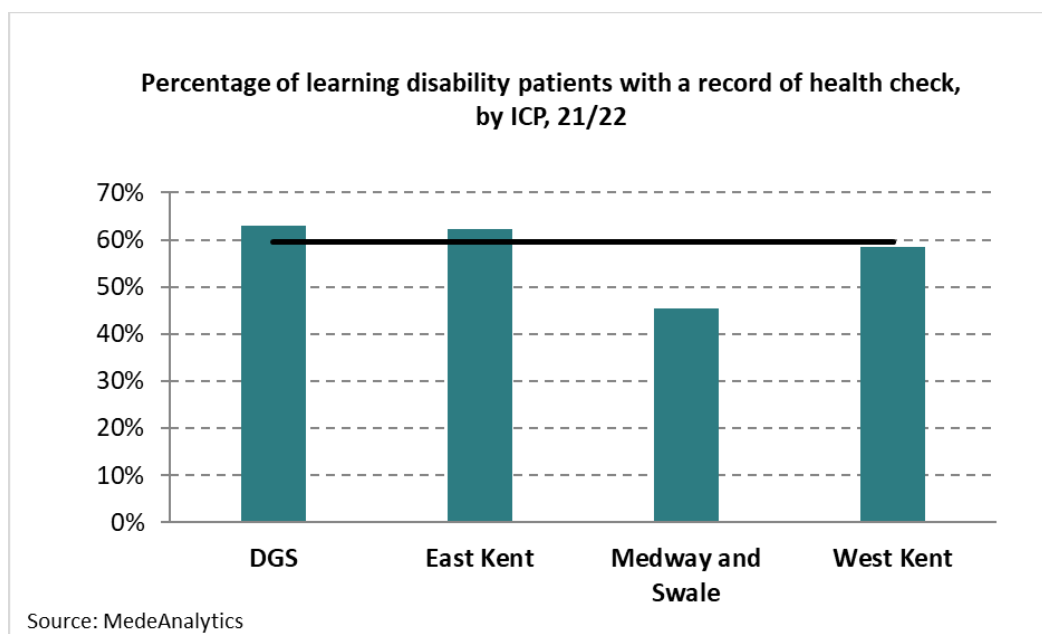
6.5 Annual health checks

To facilitate equitable, appropriate, and timely access and patient-centred provision of care of older people, annual learning disability health checks were published in 2016. These proactive health checks are designed to identify a broader range of unmet health needs than those for individuals without learning disabilities. It is crucial that individuals with learning disability are known to and registered with their GP as having a learning disability so they can have access to annual health checks which include creation of health action plans.

Some pilots are underway in secondary care [hospitals] and other settings, to improve uptake, access, and quality of these annual health checks. Kent and Medway [KM] Clinical Commissioning Group [CCG] appointed a GP clinical lead for LD and autism who provides strong clinical leadership. Kent GPs have a link nurse and training provision.

These checks are important as primary care services usually react to patient concerns and people with learning disabilities, their families, and carers, but may not attribute symptoms to physical or mental conditions or recognise the consequences of late illness detection or consequences. The proportion of Kent registered patients aged 18+ with a primary care record of learning disability and had a learning disability annual health check in 2021/22 is shown in the next figure.

Figure 32: Adults in Kent with a learning disability having a recorded health check by Integrated Care Partnership [ICP], 2021-22



6.6 Screening

A range of screening programmes are available for early detection and treatment for a range of conditions.

Dementia

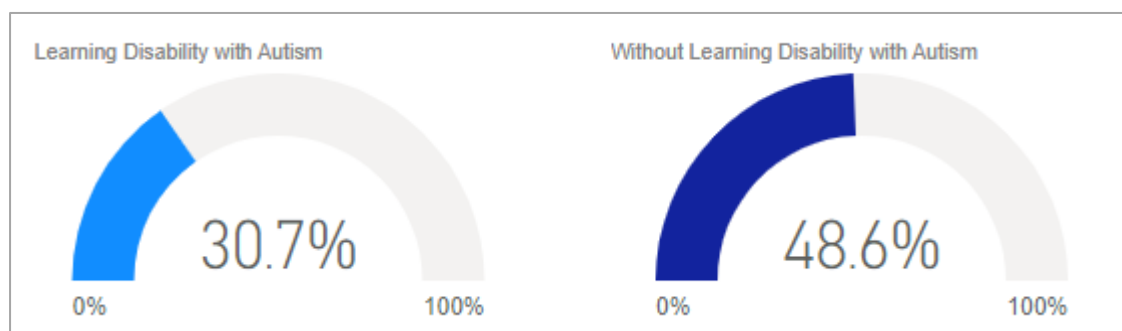
People with Down's Syndrome can develop dementia at an earlier age and so it is recommended that they be assessed at the age of 30.⁷³ If no concerns are noted, they should be retested at 40 years of age and then every two years. Early detection is important as medication can slow down the disease symptoms of progression and impacts.

Breast screening

Breast screening is to detect breast cancer and should be conducted every 3 years for women aged 50-71 years. Nearly 18% fewer women in Kent with ND had a breast screening check compared to women without a ND condition.

⁷³ Dementia screening tool for individuals with intellectual disabilities [DSQIID].

Figure 33: Percentage of female patients aged 50-59 with a diagnosis of Autism, who had a breast cancer screening test as of 31 March 2021 [Kent and Medway]. Experimental statistics⁷⁴



Source: Experimental statistics, NHS Digital, 2022

6.7 Vaccination

According to primary care event data, 59.7% of Kent patients with a record of learning disability received an influenza vaccination in 2021-22. For the period 2021-22, females received a higher proportion of flu immunisation (61%) compared to males (54%) (MedeAnalytics, 2022). No reliable data is available for pneumococcal vaccination.

6.8 Medication

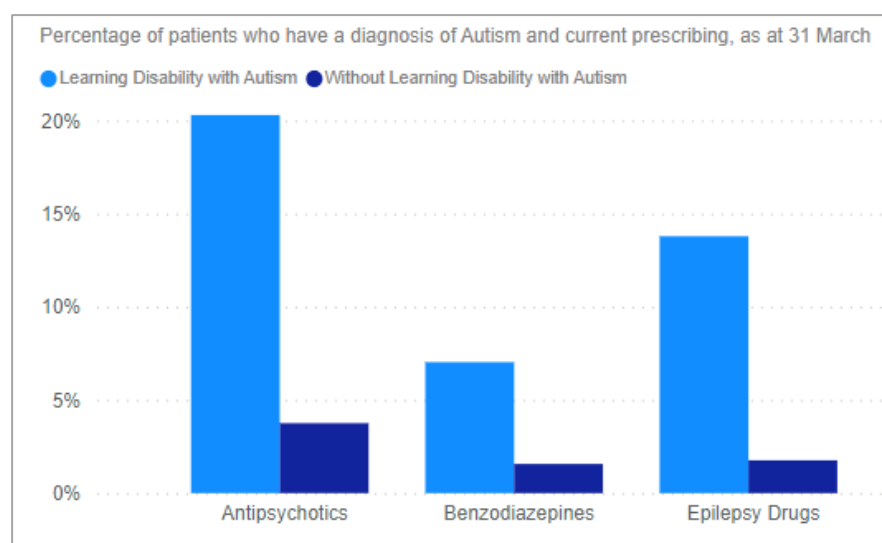
Too many people with a LD are kept in long-term hospital care against their best interests, or prescribed medication inappropriately. People with learning disabilities and autism are more likely to be given medications for perceived challenging behaviour. Psychotropic medicines affect brain function and may be prescribed for anxiety, depression, sleep problems and epilepsy.

Autistic people should not be prescribed medication to address the core features of autism as pharmacological treatments are demonstrably ineffective to address core features of autism and associated drug treatments also present significant potential risks.

The percentage of patients registered for medication dispensation in Kent and Medway for the period 31 March 2020/21, was 86.3%. In comparison to people with and without with autism and a learning disability, those with ASD/LD conditions receive more medication across the three main classes of therapeutic agents of antipsychotic, benzodiazepines, or epilepsy medication.

⁷⁴ Ibid.

Figure 34: Percentage of patients with autism being prescribed medication in Kent and Medway and prescribed medication— patient coverage 86.3%, period 2020/21 ⁷⁵



Source: Experimental statistics, NHS Digital, 2022

Figure 35: Percentage of Kent registered patients (as of September 2022), with a learning disability and a record of prescription issued (MedeAnalytics):

Group	Antidepressant drugs	Antipsychotic drugs	Epilepsy drugs	Hypnotic & sedative drugs
LD	16.4%	10.3%	15.7%	4.0%
LD with autism	16.6%	13.4%	14.2%	4.8%
Autism without LD	13.9%	4.2%	3.8%	1.0%

The mapping of existing integrated services and gaps include reviewing prescribing data patterns to review the utilisation and prevent the overuse of such medicines in adults, is underway via a Kent project called 'Stopping Over Medication of People' [STOMP]. There is a similar one for children and young people called Supporting Treatment and Appropriate Medication in Paediatrics [STAMP]. ⁷⁶

Planned activity includes re-engaging with people, family members and professionals about STOMP, developing new supporting resources and educational platforms to raise awareness, delivery of pilot projects in primary care, and community pharmacy workforce training to deliver STOMP health checks.

⁷⁵ A series of statistics in the developmental stage which are not yet fully tested due to data limitations. E.g., poor coverage [40% of GP data missing], quality issues or which require evaluation.

⁷⁶ Learning disability mortality review [LeDeR]: Action from learning report 2020/21 [National Health Services]. Available from [LeDeR-Action-from-learning-report-202021.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/ledeR-action-from-learning-report-202021.pdf) Accessed: August 2022.

6.9 Physical activity

This section will describe the health interventions for people with ASD and LD, related to physical activity and healthy weight advice as recorded in Kent primary care General Practice [GP] clinical systems [July 2022]. In Kent, most people with LD or ASD have no clinical record of having been given advice or related referrals for interventions even if they are overweight or obese.

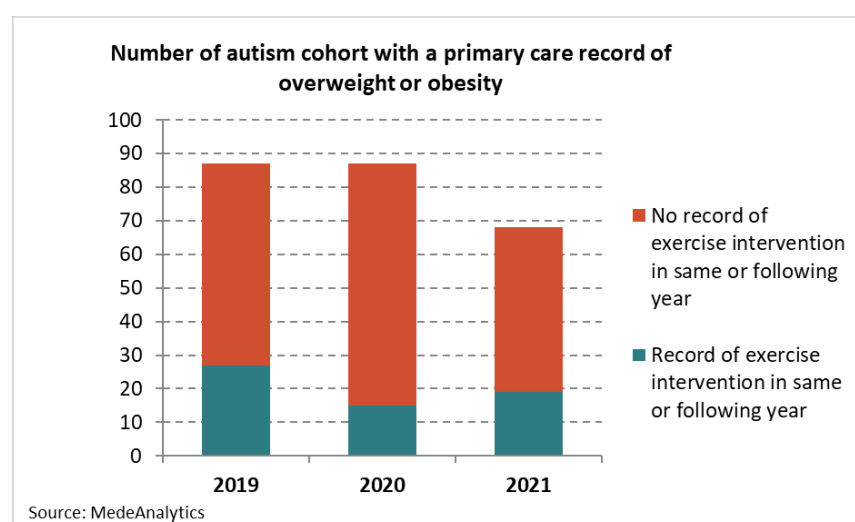
For those that do, advice is the predominant recorded action with a small proportion receiving an exercise referral. The variation in types of codes used for recording exercise and advice given on GP clinical record systems [patient records], is notable.

6.9.1 Autism

The percentage of those with a record of an activity related health intervention of any kind was 20%.

Of those recorded as obese or overweight, most people are not recorded as having received advice or referral

Figure 36: Three-year trend of autistic people classed as overweight or obese with a recorded intervention, 2019-2021 [KPHO, 2022]



The number of GP registered patients in Kent with autism was 7,266. The majority of which had no record of any type of exercise related intervention.

Figure 37: Number and type of exercise intervention as recorded within primary care for autistic people [KPHO, 2022].

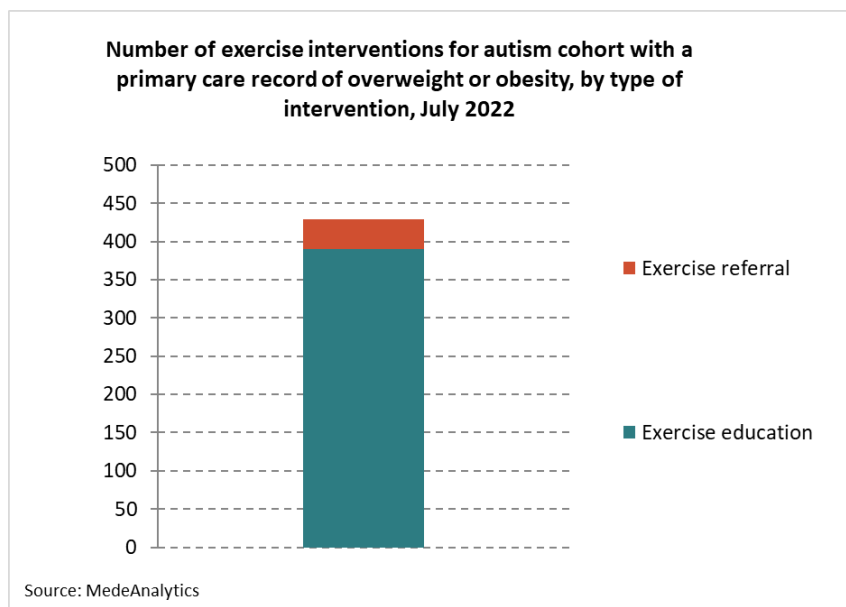
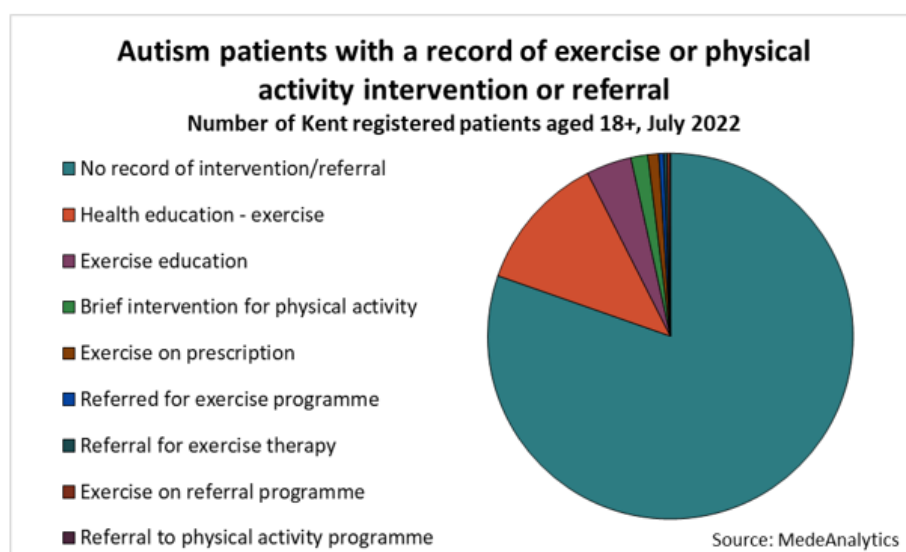


Figure 38 : Proportions and counts of autistic people with a record of exercise or physical activity intervention or referral by type [Kent GP registered patients aged 18+], July 2022



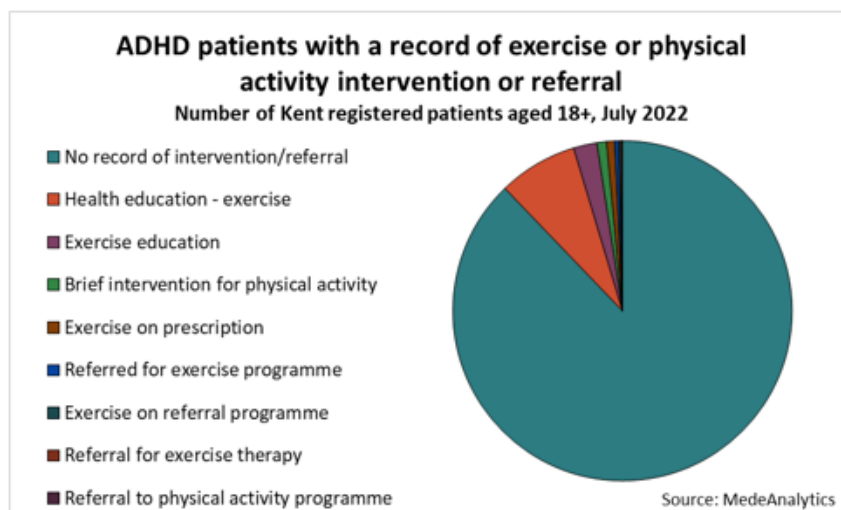
Type of referral/intervention	No. of autism patients
Health education - exercise	883
Exercise education	291
Brief intervention for physical activity	109
Exercise on prescription	70
Referred for exercise programme	31
Referral for exercise therapy	22
Exercise on referral programme	19
Referral to physical activity programme	2
No record of intervention/referral	5839

Source: KPHO, prepared by L. Smith

6.9.2 ADHD

The percentage of people with ADHD with an exercise related GP recorded intervention was 12%.

Figure 39: Proportions and counts of people with ADHD and a record of exercise or physical activity intervention or referral [number of Kent GP registered patients aged over 18 years [KPHO, July 2022]



Type of intervention/referral	No. of ADHD patients
Health education - exercise	800
Exercise education	237
Brief intervention for physical activity	97
Exercise on prescription	81
Referred for exercise programme	37
Exercise on referral programme	23
Referral for exercise therapy	17
Referral to physical activity programme	1
No intervention/referral	9309

Source KPHO, prepared by L. Smith

6.9.3 Learning disability

Of GP registered patients with a learning disability and a record of being overweight or obese for the period 2019-2021, most people had no record of an exercise intervention for that year or the following [64%]. Of the 36% in receipt of an intervention, 94% received advice only, with 6% [114] receiving an exercise referral.

Figure 40: Number of people with a learning disability who are recorded as being overweight or obese as recorded on General Practitioner care records in receipt of an exercise intervention.

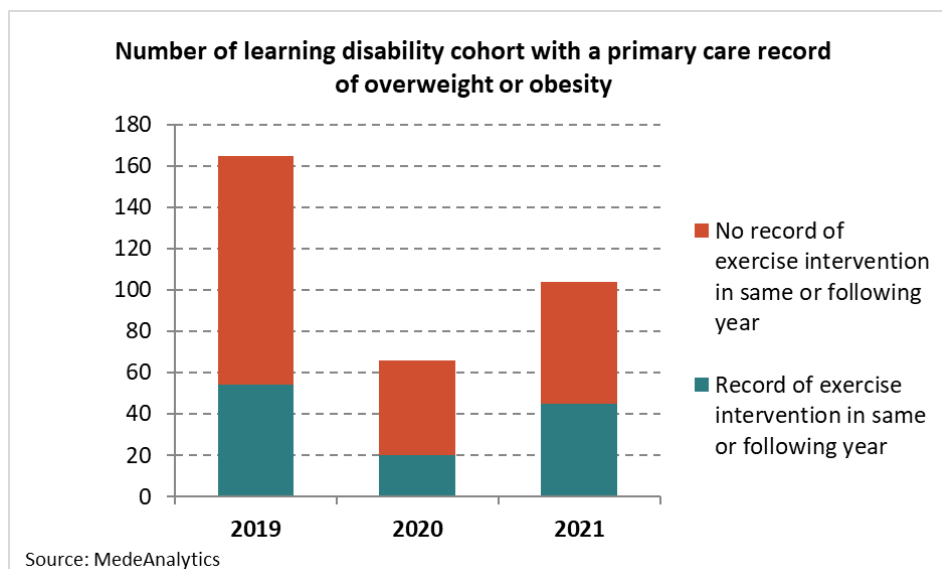


Figure 41: Number of people with a learning disability who are recorded as being overweight or obese who have received advice or exercise referral by type as recorded on General Practitioner care records.

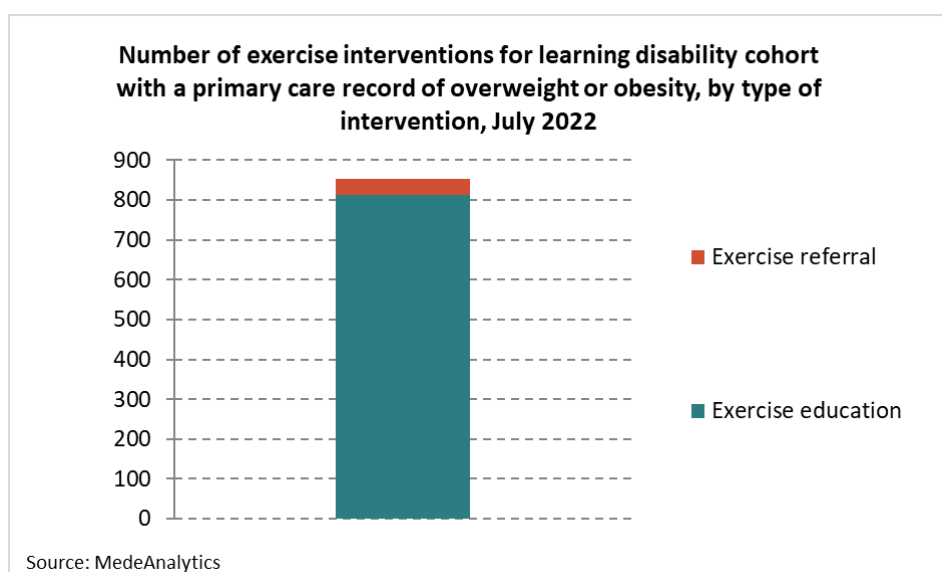
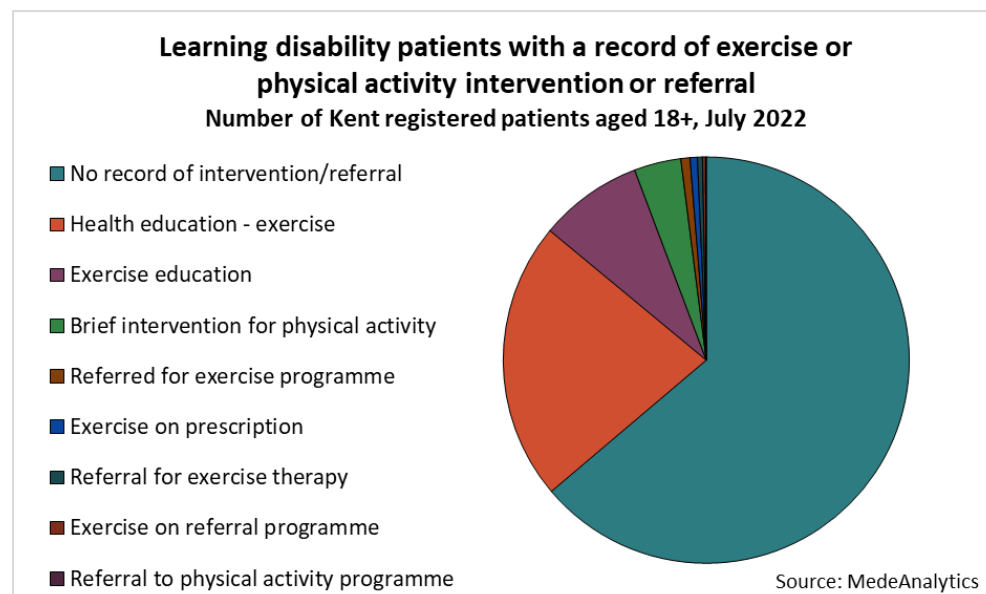


Figure 42: Counts of people with a learning disability who are recorded as being overweight or obese who have received advice or exercise referral by type as recorded on General Practitioner care records.

Intervention type	Count
Advice:	
Health education - exercise	1558
Exercise education	580
Brief intervention for physical activity	262
Total	2400
Referrals:	
Referred for exercise programme	51
Exercise on prescription	41
Referral for exercise therapy	28
Exercise on referral programme	17
Referral to physical activity programme	4
Total	141
Total cohort	7023
No record of intervention/referral	4482 [64%]
Receipt of intervention for:	2541 [36%]
Advice	2400 [94%]
Exercise referral	141 [6%]

Figure 43: A comparison of exercise related intervention types for those people with a learning disability who are recorded as being overweight or obese on General Practitioner care records [July 2022].



6.10 Hospital settings and admissions

In England, 35% of people with a learning disability autism or both, have been in a mental health hospital for more than five years [NICE, 2021]. To facilitate the shortest possible hospital in-stays in any type of hospital, community or care home setting, NICE recommends that links between home, relationships, education, employment are maintained and, that discharge planning should begin on admission.⁷⁷

In 2017, NHSE introduced Care and treatment reviews [CTRs] policy for adults and care [education] and treatment reviews for children and young people [C(E)TRs]. These are due to be updated mid-2022. These reviews are aimed at transforming care for people with LD and autism who are at risk of or have been, admitted to a mental health hospital. I.e., that admission to hospital for these groups will only be when necessary and the period spent there will be as short as possible⁷⁸.

Hospital passports are documents about individuals and their health needs. These were designed for use with people with LD but can be used more widely. It also has useful information such as likes, dislikes, communication preferences and reasonable adjustments that would be helpful.

For example, having a carer stay overnight in hospital, meeting a learning disability nurse before going into hospital. All the Kent hospitals NHS Trusts and the Kent Community Health NHS Foundation Trust have this provision.

⁷⁷ [NICE impact people with a learning disability | Reviewing the impact of our guidance | Measuring the use of NICE guidance | Into practice | What we do | About | NICE](#) Accessed: 2022

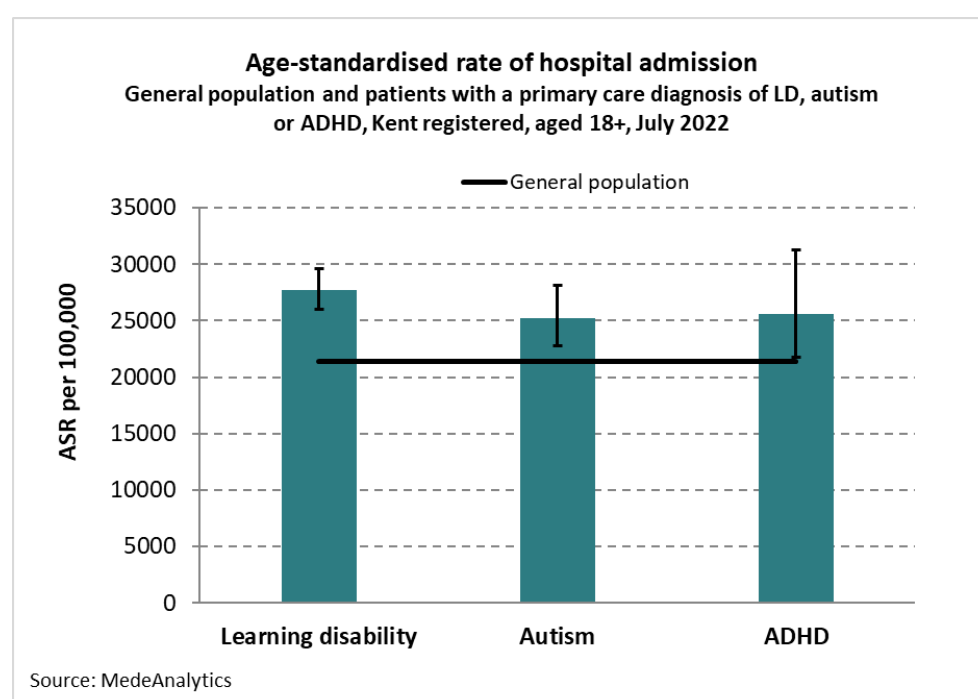
⁷⁸ [NHS England » Care \(education\) and treatment reviews](#)

For people with LD who have a life-limiting illness, a specialist team is available to assist with symptom management and palliative care. There are also several organisations who can provide additional support.

6.10.1 Hospital admissions

The age standardised rate of hospital admissions in Kent for people with ADHD, learning disability or autism is greater than that of the general population, with those with a LD being admitted to hospital in greater numbers than autistic or people with ADHD.

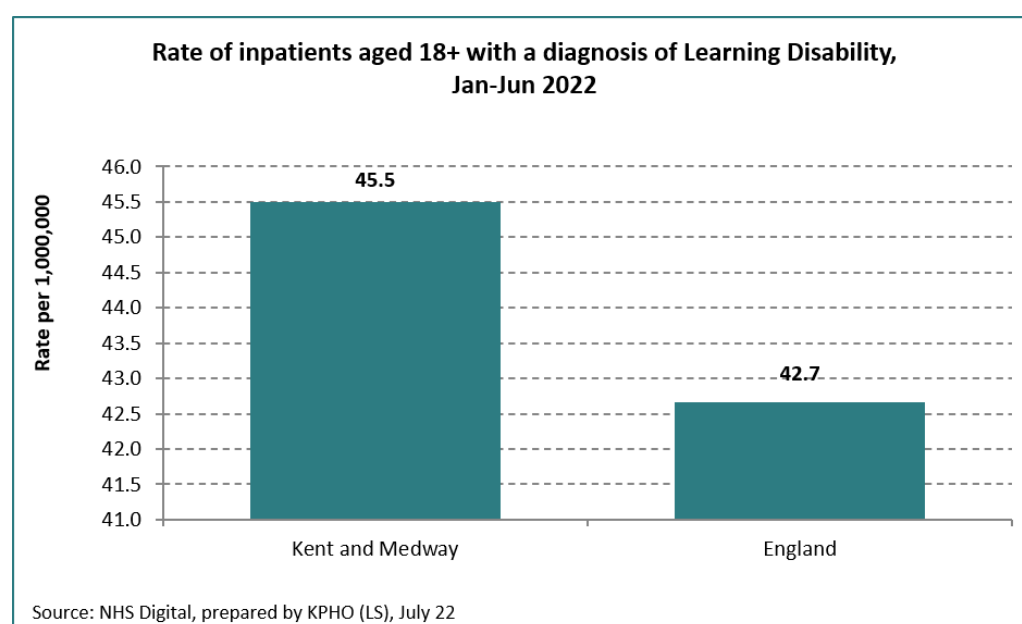
Figure 44: Hospital admission, age-standardised rate per 100,000 for people with autism, learning disability or ADHD [Kent, 2022]



Source: KPHO, 2022

Hospital in patients with a learning disability is presented in the next figure.

Figure 45: Rate of hospital stays for people with a learning disability in Kent compared to England [2022].



6.10.2 Autism - hospital admissions

The most common reason for autistic people in Kent to be admitted to hospital is for Abdominal and pelvic pain [4.3%]. The second most common reason for admission is for Poisoning by nonopioid analgesics, antipyretics and antirheumatics [3.4%].

The exception is for autistic people in West Kent where this order is reversed and where the proportion of autistic people being admitted by poisoning was 6.1%.

Figure 46: Top ten most common reasons for hospital admission for people with autism - Kent

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	4.3%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	3.4%
Pain in throat and chest	2.6%
Symptoms and signs involving emotional state	2.5%
Crohn disease [regional enteritis]	1.9%
Epilepsy	1.8%
Poisoning by psychotropic drugs, not elsewhere classified	1.6%
Convulsions, not elsewhere classified	1.2%
Other soft tissue disorders, not elsewhere classified	1.1%
Headache	1.1%

Source: KPHO, 2022. Prepared by L. Smith.

6.10.3 ADHD – hospital admissions

Abdominal and pelvic pain were the most common reason for hospital admission for autistic and those with ADHD, whilst epilepsy was the most common reason for those with learning disabilities [4.5%].

West Kent differed from other HCPs with regards to the most common reason for admission for autistic and people with learning disabilities. Dartford, Gravesham, and Swanley HCP differed for people with LD having ulcerative colitis as the most common reason for hospital admission [4.8%]. The exact reason for ulcerative colitis is unknown however associated risks include food habits and preventative factors include dietary and exercise advice. Detail by HCP is presented in appendix 1.

Figure 47:: Ten most common reasons for hospital admission for people with attention deficit hyperactivity disorder [ADHD] - Kent

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	4.9%
Pain in throat and chest	3.0%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	2.0%
Symptoms and signs involving emotional state	1.9%
Dorsalgia ⁷⁹	1.5%
Poisoning by psychotropic drugs, not elsewhere classified	1.5%
Asthma	1.3%
Perineal laceration during delivery	1.2%
Maternal care for other known or suspected foetal problems	1.2%
Ulcerative colitis	1.1%

KPHO, 2022. Prepared by L. Smith.

6.10.4 Learning disabilities – hospital admissions

Epilepsy was the most common reason for hospital admission for people with a learning disability in Kent [4.5%] and seen in the next figure. In west Kent, this was the third most common reason after pain in throat [4.4%] which was the most common, and chest and abdominal and pelvic pain [4.0%] which was second most common.

⁷⁹ Backpain

Figure 48: The ten most common reasons for hospital admission for people with a learning disability - Kent

Primary diagnosis	Proportion of total admissions
Epilepsy	4.5%
Abdominal and pelvic pain	3.3%
Pain in throat and chest	3.0%
Pneumonia, organism unspecified	2.1%
Convulsions, not elsewhere classified	2.1%
Other soft tissue disorders, not elsewhere classified	1.8%
Other disorders of urinary system	1.7%
Pneumonitis due to solids and liquids	1.3%
Symptoms and signs involving emotional state	1.3%
Unspecified acute lower respiratory infection	1.3%

KPHO, 2022. Prepared by L. Smith.

6.11 Sexual orientation and health

'Gender diverse' is a term used to describe individuals whose gender identities differ from their sex at birth. Cisgender or cis, refers to people whose gender identify and sex at birth match. In 2020, an estimated 3% of the population aged over 16 years identified as lesbian, gay, or bisexual [LGB], an increase from 2.7% in 2019.⁸⁰

People aged 16-24 years remain the most likely to identify as LGB [8.0%] continuing the increasing trend since 2014 for this group, with 2.7% identifying as gay or lesbian and 5.3% identifying as bisexual. [ONS, 2020] ^{Ibid.}

Research published in 2021 suggests that autistic individuals are more likely to identify with a diverse range of sexual orientations and less likely to identify as heterosexual than non-autistic people. The largest of its kind, the study reported that approximately 30,000 [5%] of cisgender people participating in the study had autism compared to 895 [24%] of the gender diverse cohort.⁸¹

The gender-diverse cohort were also five times more likely to believe they may have undiagnosed autism.⁸² On average, gender-diverse people scored higher on measures of autism traits and lower on empathy measure than did their cisgender peers. These findings are published within the context of limited research into this area and with notable study limitations.

⁸⁰ [Sexual orientation, UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/sexualorientationandgenderdiversity/articles/sexualorientationandgenderdiversityintheuk/2020) Accessed: November 2022

⁸¹ Weir, E., Allison, C., & Baron-Cohen, S. [The sexual health, orientation, and activity of autistic adolescents and adults](https://www.autismresearch.org/2021/05/12/the-sexual-health-orientation-and-activity-of-autistic-adolescents-and-adults). Autism Research (2021).

⁸² Based on one dataset of 1,803 people in the study who were asked this question.

The world's largest ever study of typical sex differences and autistic traits, confirmed two long-standing psychological theories: the Empathising-Systemising theory of sex differences and the Extreme Male Brain theory of autism.⁸³

A key conclusion the study reached was that although autistic people struggled on average with 'cognitive' empathy – recognition of other people's thoughts and feelings – they do have intact 'cognitive' empathy – they care about others. It is untrue that all autistic people struggle with all forms of empathy.

Individuals with autism identifying as Lesbian, Gay, Bisexual, Trans, Queer, Asexual [LGBTQ+] and others not listed here, report lower self-efficacy and satisfaction with healthcare services and higher likelihoods of unmet healthcare needs. Previous studies suggest that autistic females may be more prone to having hormonal-associated conditions and other gynaecological conditions which may present an increased risk of developing diabetes, cardiovascular conditions, and cancer. ^{Ibid}

The intersection of sexuality and experiences of individuals with autism may have notable implications for health care. For example, it may include worsening mental and physical health symptoms, lack of or even refusal of adequate healthcare due to marginalization by healthcare providers and institutions.

Sexual health screenings and education should be a priority for all individuals and healthcare professionals should be aware that people with autism may be more likely to identify as diverse gender identities which may put them at greater risk of negative health impacts due to discrimination.

6.12 Abuse

In August 2021, the Social Care Institute for Excellence [SCIE], issued an evidence review briefing of Sexual Incidents in Adult Social Care⁸⁴. Sexual abuse within the care sector is most often defined as an incident involving sexual behaviour "which is unwarranted or makes another person uncomfortable" and may be broadly described as physical or non-physical i.e., contact, or non-contact. Examples of non-contact sexual abuse include inappropriate looking, sexual teasing, harassment, innuendo or forced use of photography [SCIE, 2015].

There is a lack of support guidance for victims and families, older people, and those with a learning disability. Detailed safeguarding recommendations for the areas of addressing the data and evidence gaps, training, and development for staff and those with lived experience, conducting risk assessments and safeguarding, can be found within the briefing document.⁸⁵

⁸³ [Over half a million people take part in largest ever study of psychological sex differences and autistic traits](#)

Accessed: November 2022

⁸⁴ [Sexual Incidents in Adults Social Care briefing_final.docx \(scie.org.uk\)](#) Accessed 15-6-22

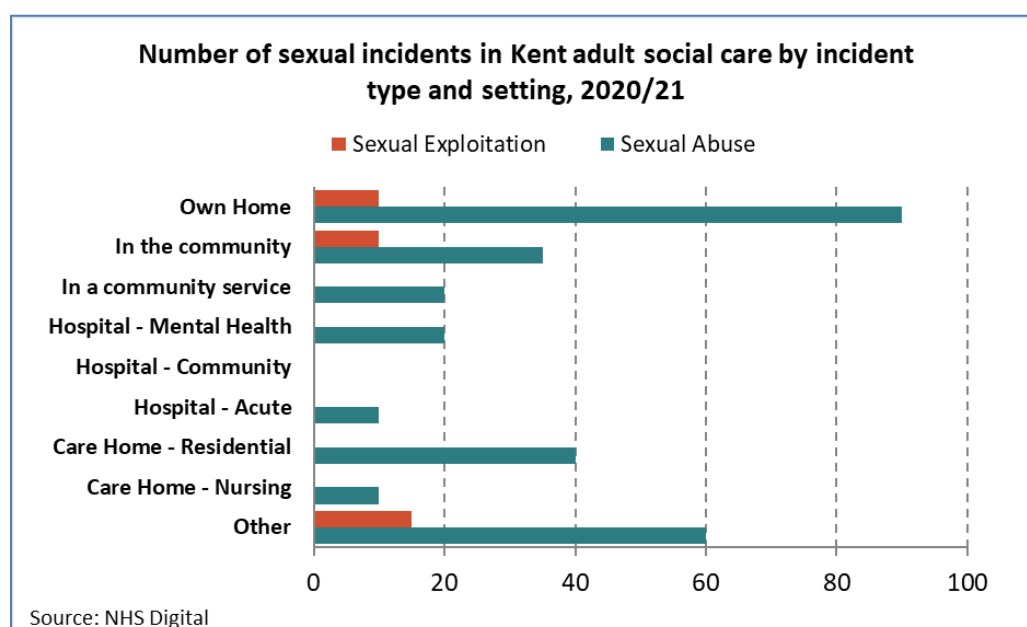
⁸⁵ [Sexual Incidents in Adults Social Care briefing_final.docx \(scie.org.uk\)](#)

Over a three-month review period in 2021, the Care Quality Commission [CQC] reviewed 661 notifications. Findings indicated that women were over three times more likely to be affected by sexual incidents than men.

For the older population, emergent risk factors include being a woman, increasing age and limited mental capacity based upon research findings within the UK and international studies. No data was found to indicate staff were victims of sexual abuse. This signifies a gap in data rather than lack of prevalence.⁸⁶

Managing and regular risk assessment reviews of the existing care population, of their changing behaviours and needs and those of new arrivals should be undertaken to assure the population mix is safe and appropriate. Lack of data sharing and collaboration between service providers was highlighted as a factor in some studies relating to older adults and those with LDs.

Figure 49: Sexual incidents in Kent by type and setting 2020/21



Managing and regular risk assessment reviews of the existing care population, of their changing behaviours and needs and those of new arrivals should be performed to assure the population mix is safe and appropriate. Lack of data sharing and collaboration between service providers was highlighted as a factor in some studies relating to older adults and those with LDs.

⁸⁶ Ibid.

6.13 Safeguarding Adults Reviews (SARs)

No national standard exists to stipulate what information and in what format should be shared between agencies when someone with risks of sexual or violent offending is placed out of area. GPs are responsible for commissioning evaluations to inform them about the type of victims who may be at risk and the types of offences likely to be committed. This is not routinely done. If no criminal charge results following a sexual offence, no risk assessment is performed for either party with care and support needs or staff.

International studies report concerns of staff cultures lacking in respect or knowledge when discussing the most serious reported incidents and highlight the inability of staff to identify sexual incidents contributing to underreporting. Emotional responses to sexual assault including agitation, distress and confusion are like symptoms of cognitive impairment.

Staff report lacking confidence and the requisite skill set to talk with individuals regarding sexual activity, managing boundaries and assessing capacity to consent. The erroneous assumption that older people do not engage in sexual activity, violent or aggressive behaviours affects the accuracy of risk assessments.

NICE guidance NG11 'challenging behaviour and learning difficulties: prevention and interventions for people with learning disabilities who behaviour challenges' [2015] is more often not applied by staff when assessing risks present in individuals sex lives.

Commissioners are failing to robustly assure the expertise and requisite skill set of service providers. The lack of contract specificity of adhering to expert advice and robust contract management oversight has led to inadequate or absent risk management care plans for individuals at risk of offending. Contracts are neither reviewed regularly for compliance and delivery nor regulated. Where disagreement resolution is required between placing and hosting authorities, there is currently no escalation route.⁸⁷

The increased use of technology in care settings should be considered to improve overall safety of the environment e.g., the use of audio sensors. Although called for in the report, a literature review in 2016 found limited evidence that educational interventions would improve knowledge and attitudes towards elder abuse among health professionals.

Educational interventions for those with LD to increase sexual understanding and feel empowered to discuss unwanted sexual behaviour was highlighted in the report and academic literature.⁸⁸

⁸⁷ CQC, 2020, Backhouse et al. 2018.

⁸⁸ CQC, 2020, Wilmott et al. 2020 and Brkić-Jovanović et al. 2021.

7 Community Views

7.1 Advocacy informed service development and improvement

In 2021, people belonging to the neurodiversity community in Kent were asked their views on a range of topics. Advocacy organisations were found to be active in Kent and providing groups e.g., social networks, book clubs and unpaid support for people without access to support.⁸⁹

A wealth of expertise and people with a variety of experiences were found who were contributing to the community, improving services and how these are designed. However, people felt uninformed about people when they were in hospitals in Kent, nor did they feel they knew what Kent County Council was doing for them. Access to services and information is a huge cause of concern for the ND community in Kent.

Key challenges include having to navigate multiple options and different telephone lines, excessive response waiting times in their view, and being unable to access timely services. This inability to access timely services and support can often exacerbate and compound difficulties being experienced by individuals.

To address these concerns KCC launched a new interactive easy to navigate website in May 2022 to help people find accessible and easy information, advice and support for themselves, relatives, or friends. Indicative content includes what support is available to them locally, eligibility for social care funding, what happens after leaving hospital, what care homes can offer, how to buy equipment and an information finder tool. It is unknown at this time if these measures are effectively addressing the concerns raised.

Other comments which could be applied to local services in Kent, is that individuals find it difficult to cope with cancellations or invites at short notice, lack of detail and information about what to expect, and unempathetic or ND educated [service provider] individuals to interact with. This point underlines the importance of sufficient intergenerational and ongoing education of workforces and wider society

Consequently, both the assessments and the period leading up to these for ND individuals, anywhere between every 3-4 years, often results in deterioration of physical and mental health for individuals and who subsequently require support from health and care services.

Other concerns of the ND community in Kent include:

- Inadequate recompense for participating in coproduction of services
- Disillusionment that time and effort spent contributing to service development and redesign, often appears to be fruitless. It is unknown if this is due to insufficient or absent feedback to contributors, or if the work is suspended or

⁸⁹ Local Government Association [2021] What people said: speaking to people with a learning disability and autistic people in Kent.

assimilated into other programmes. This disillusionment and inadequate recompense may lead to lower levels of community involvement in this type of activity in the future.

- ND individuals experience bullying in the workplace. This can take various forms and includes the failure of workplaces to adapt to the needs of ND employees.

KCC commissions an advocacy service – Advocacy For All [AFA] to facilitate ND people's voices to be heard and to inform and coproduce services. An important element provided by AFA, is the provision of workforce training funded by a European Union grant until recently. It is unknown if this will continue now funding has ceased.

In 2022, AFA community members were asked to provide their views on how they felt about available support services in Kent⁹⁰. Following a group discussion where four members and two staff were present, several themes emerged.⁹¹ The group wanted to highlight the national strategy for autistic children, young people, and adults: 2021 to 2026, to opinion leaders and policy makers in Kent for consideration and action, as they felt this ably 'covered a lot of how they felt, and things which should be done for people with autism'.⁹²

They particularly agreed with the need to improve understanding and acceptance of autism within society, supporting more autistic people into employment, tackling health and care inequalities for autistic people, and building the right support in the community.

A perception was that the government relied upon charitable organisations to supplement local service provision. If this is indeed the case this should be reflected in funding allocations. Whilst many comments concerned national structures and functions, e.g., benefits, several suggestions were and may be amendable to action at the Kent level.

For example, sources of frustration include the term of using the disabled bus pass which was felt to be discriminatory operating only between the hours of 9.30 a.m. to 11 p.m. For example, the hour set aside in supermarkets for individuals with sensory needs, is allocated before the bus pass is allowed to be used, and the travel restrictions also affected attendance at hospital appointments. It was also noted that there was no provision for quiet carriages [on trains].

⁹⁰ The Service Users Representative Group [SURG].

⁹¹ The full list of observations submitted are displayed in the Appendix.

⁹² <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>

Emergent themes were:

- Lack of meaningful partner collaboration / lack of understanding of service professionals/ institutions / processes
- Not being listened to / no point in contacting them /fears of losing support / not ticking the box / all short-term fixes / no help if you are academic
- Not knowing where to turn to for help / service gaps/ all detective work in Kent to find out about support services/ Kent services poor /poor communication from services/ all life-long support services disappeared [moving to Kent]

The full list of comments provided are presented in the Appendices.

7.2 Pandemic impacts and neurodiverse people

When receiving vaccination, people felt that reasonable adjustments were made for them. For example, having it at home if they had a needle anxiety. There were delays receiving their second dose for some who had to 'chase' to have this administered.

'Day' and advocacy services supported people to get meals and shopping and whilst this obviously helped, the impact of Covid-19 on individuals being unable to do shopping and other activities they normally enjoyed, made them feel lonely and joyless.

7.3 Transport

Difficulties using wheelchairs and walking aids continue to be a challenge along with inaccessible buildings. E.g., no electric doors, vehicles parking on pavements restricting usage. Instore removal of stands to facilitate distancing between people now make it difficult to access and move around in stores.

Accessibility issues with public transport and being unable to travel together with friends on public transport was cited as problematic. People are eager to collaborate to improve transport arrangements. It would be helpful to use these insights to conduct accessibility audits for people with both learning disabilities and autism relating to travel across Kent and within towns.

The hours of the disabled bus passes are problematic and work contrary to service provision for those with sensory needs e.g., quiet times in supermarkets and getting to health and care appointments if these fall outside of the hours of 09.30 – 22:00 hours. The lack of quiet areas on transport vehicles is also challenging.

9 Findings, recommendations and areas for research

9.1 Findings

- Most sexual abuse takes place in domiciliary, residential, and supported care settings. Victims are most likely to be white, female with a learning disability. Perpetrators are most likely to be service users.
- There is a lack of support guidance for victims and families, older people, and those with a learning disability.
- In Kent there is no standard information sharing agreement in relation to vulnerability which should be addressed
- Identifying information to be shared between agencies when someone with risks of violent or sexual offending is placed out of area is not routinely done.
- Many challenges and frustrations faced by the Kent ND population are amendable to local system improvement.
- Referral to guidance and support for this population who are overweight or obese is limited
- Access to mental health services has reduced

9.2 Recommendations

- Address avoidable causes of death caused by medical causes, untimely interventions, and health inequalities.
- Development of a shared data set which captures types and categories of accommodation units in use
- Improved data capture, sharing, mandatory training and raising of awareness of autism within the Criminal Justice System [CJS] to ensure defendants with autism are treated fairly within the CJS
- Improved access to timely support for individuals who experience anxiety and would benefit from prevention and coping strategies
- Access to evidence based physical activity advice and development of an accessible referral system
- Increased use of technology in care settings should be considered to improve overall safety of the environment e.g. the use of audio sensors.
- Development of a system wide agreement to stipulate what information and in what format information is shared between agencies when someone with risks of violent or sexual offending is placed out of area.

9.3 Areas for research

Research into the following as relating to ND people would be of value for:

- Long term impact of ADHD

- Living with Autism
- Living with addiction – neurodiverse individuals
- Suicide in people with ADHD and Autism
- Prevalence of sexual incidents within UK social care settings relating to older adults and those with learning disabilities
- Research gaps exist into sexual education programmes including for those with LD.
- Only parts of the statutory notification data and Section 42 safeguarding enquiries held by local authorities are used in top-line statistical reporting. Further in-depth research of these files may be of value.

10 Glossary of Terms

- **ADHD**
Attention Deficit Hyperactivity Disorder is a group of behavioural symptoms that include inattentiveness, hyperactivity, and impulsiveness.
- **All Age Neurodevelopmental Pathway**
The route of care and support from childhood to adulthood for people with autism and ADHD based on good practice, including integrated psychological, social and medical assessment, early intervention, and support of both people with autism and their families and carers.
- **Asperger's Syndrome**
A form of autism that has now been removed from one of the main diagnostic manuals. The condition is characterised by difficulties with social interaction, social communication and flexibility of thinking or imagination. In addition, there may be sensory, motor, and organisational difficulties. People with Asperger's Syndrome generally are of average or higher ability.
- **Autism**
A diagnostic term that tends to be used in reference to people who have Autistic Spectrum Conditions and adults who also have learning disabilities. We recognise that some people prefer the terms 'autistic people' or 'autistics' to 'people with autism'.
- **Carer**
A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who has autism, is ill, frail, disabled or has mental health or substance misuse problems.
- **Commissioners**
A commissioner of health or social care is a person who works in partnership with local people and organisations to identify the needs of local people and ensures that services are in place which meets those needs within available resources.
- **Commissioning**
The process by which health or social care services identify the needs of their population and make decisions to secure care to meet those needs within available resources.
- **Challenging Behaviour**
Culturally abnormal behaviour(s) of such an intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities (Emerson, 2001).
- **Criminal Justice System**

Made up from several agencies, including police, courts, prisons, probation service, etc.

- **Diagnosis**
The process of identifying the nature and cause of a medical condition through the evaluation of a patient's history and through undertaking specific medical assessments.
- **Direct Payment**
These are cash payments made to individuals who have been assessed as needing services by Local Authorities. Direct payments allow you to receive cash payments from your local authority instead of care services. This can give you much more flexibility and greater control of your support package.
- **Epilepsy**
Epilepsy is a condition that affects the brain. When someone has epilepsy, it means they tend to have epileptic seizures.
- **GP**
General Practitioner: A doctor whose practice is not limited to a specific medical speciality but instead covers a variety of medical conditions in patients of all ages.
- **Governance**
Is a framework within which health and social care organisations and individual workers are accountable for continuously improving the quality of their services.
- **Good governance supports maintaining and improving service provision and practice to the highest possible standards.**
- **Health and Wellbeing Board**
The purpose of the Board is to improve the health and wellbeing of Bristol's communities by leading the development of improved and integrated health and social care services.
- **Health Care Partnerships [HCPs]**
Health and care partnerships (previously called Integrated care partnerships or ICPs) bring together all provider health organisations in each area to work as one. There are four in Kent: Dartford, Gravesham and Swanley, East Kent, West Kent, Medway, and Swale.
- **Intellectual disability**
refers to limited functioning in three areas: Social skills, Conceptual skills, Practical skills.[The Diagnostic and Statistical Manual of Mental Disorders, 2013 (DSM-V)]
- **Kent County Council**
In most of England, there are two levels of councils: a County Council and a District Council. County Councils, such as Kent County Council, cover large

areas and provide most public services, including schools, social services, and public transport.

- Kent County Council is divided into 12 District Councils. The District Councils provide more local services, including council housing, gym and leisure facilities, local planning, recycling and rubbish collections.
- Kent Autism Collaborative
A group of people and organisations in Kent interested in adults with autism and who meet regularly. The purpose of the Autism Collaborative is to inform commissioning decisions and development of services for people with autistic spectrum conditions and their carers.
- Learning disability
'A learning disability is generally defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood'. (NICE)

Defines a learning disability as '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'. The Department of Health and social Care [DHSC].

Defines intellectual disability as 'a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor and social abilities'.

Severity of classification: Mild, moderate, severe, and profound. [World Health Organisation, WHO]

- Positive Behaviour Support (PBS) Framework: Positive Behaviour Support (PBS) is a 'person centred framework' for providing long-term support to children and adults with learning disabilities, autism, or dementia, who have, or may be at the risk of displaying distressing behaviours
- People with lived experience or experts by experience: anyone who is autistic, has a learning disability or is a family member of someone who experiences either of those.
- Pervasive developmental disorders (PDD) refer to a group of disorders characterized by delays in the development of socialization and communication skills.

- **Prevalence**
Describes the total number of people who have a condition in the population at a given time. It helps commissioners planning services for local people who have autism.
- **Primary care networks**
Primary Care Networks [PCNs] include groups of general practices working together, and in partnership with community, mental health, social care, pharmacy, hospital, and voluntary services in their local area, to offer more personalised, coordinated health and social care to the people living in their area.

There are approximately 40 PCNs in Kent and Medway. Networks are aligned to an area HCP which supports them to work more closely with other partners in the area.
- **Residential Care**
Accommodation that is registered with the Care Quality Commission (CQC) for people who need more than just housing to help them meet their needs. Residential care provides 24 hour shared support and accommodation to people where it is assessed that living in less supportive accommodation would not meet their needs. Residential care can help people achieve health and well-being and learn skills for greater independence.
- **Symptoms and signs involving emotional state:**
Nervousness, Restlessness and agitation, Unhappiness, Demoralization, and apathy, Irritability and anger, Hostility, Violent behaviour, State of emotional shock and stress, unspecified, Other symptoms and signs involving emotional state, Low self-esteem, Worries, Excessive crying of child, adolescent or adult, Anhedonia, Homicidal and suicidal ideations, Homicidal ideations, Suicidal ideations, Emotional lability, Impulsiveness, Non-suicidal self-harm, Other symptoms and signs involving emotional state
- **Transforming Care Programme**
A National programme to improve services for people with learning disabilities and/or autism, who display behaviour that challenges, including those with a mental health condition.
- **Transition**
The process of change a person goes through, for example growing from childhood into adulthood. For people with disabilities this process of reaching adulthood can mean changing the services from which they receive support, and this can take place over a long period

11 Appendices

Appendix 1- Ten most common reasons for hospital admission for people with autism by HCP in Kent

Ten most common reasons for hospital admission for people with autism - Dartford, Gravesham, and Swanley HCP

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	4.9%
Pain in throat and chest	2.9%
Ulcerative colitis	2.8%
Type 1 diabetes mellitus	2.8%
Lymphoid leukaemia	2.4%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	1.9%
Epilepsy	1.6%
Other functional intestinal disorders	1.6%
Symptoms and signs involving emotional state	1.5%
Disorders of mineral metabolism	1.5%

KPHO, 2022. Prepared by L. Smith.

Ten most common reasons for hospital admission for people with autism - East Kent HCP

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	3.5%
Crohn disease [regional enteritis]	2.3%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	2.2%
Symptoms and signs involving emotional state	2.1%
Epilepsy	2.0%
Pain in throat and chest	1.9%
Poisoning by psychotropic drugs, not elsewhere classified	1.7%
Depressive episode	1.5%
Convulsions, not elsewhere classified	1.3%
Other soft tissue disorders, not elsewhere classified	1.3%

The ten most common reasons for hospital admission for people with autism - Medway and Swale HCP

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	4.3%
Symptoms and signs involving emotional state ⁹³	3.6%
Epilepsy	2.7%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	2.5%
Asthma	2.5%
Pain in throat and chest	2.1%
Dental caries	1.7%
Calculus of kidney and ureter	1.5%
Cholelithiasis	1.5%
Convulsions, not elsewhere classified	1.5%

KPHO, 2022. Prepared by L. Smith.

The ten most common reasons for hospital admission for people with autism - West Kent HCP

Primary diagnosis	Proportion of total admissions
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	6.1%
Abdominal and pelvic pain	5.1%
Pain in throat and chest	3.6%
Symptoms and signs involving emotional state	3.2%
Medical observation and evaluation for suspected diseases and conditions	1.7%
Crohn disease [regional enteritis]	1.7%
Poisoning by psychotropic drugs, not elsewhere classified	1.6%
Epilepsy	1.4%
Headache	1.2%
Pneumonia, organism unspecified	1.1%

KPHO, 2022. Prepared by L. Smith.

⁹³ See glossary

Ten most common reasons for hospital admission for people with ADHD by HCP in Kent

The ten most common reasons for hospital admission for people with attention deficit hyperactivity disorder [ADHD] - Dartford, Gravesham and Swanley

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	4.8%
Pain in throat and chest	3.6%
Multiple myeloma and malignant plasma cell neoplasms	3.0%
Ulcerative colitis	2.2%
Type 1 diabetes mellitus	1.8%
Symptoms and signs involving emotional state	1.8%
Lymphoid leukaemia	1.7%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	1.7%
Asthma	1.6%
Poisoning by psychotropic drugs, not elsewhere classified	1.3%

KPHO, 2022. Prepared by L. Smith.

The ten most common reasons for hospital admission for people with attention deficit hyperactivity disorder [ADHD] - East Kent

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	3.9%
Pain in throat and chest	2.6%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	2.1%
Dorsalgia	1.9%
Symptoms and signs involving emotional state	1.8%
Poisoning by psychotropic drugs, not elsewhere classified	1.6%
Maternal care for other known or suspected foetal problems	1.6%
Other diseases of digestive system	1.3%
Asthma	1.3%
Perineal laceration during delivery	1.2%

KPHO, 2022. Prepared by L. Smith.

The ten most common reasons for hospital admission for people with attention deficit hyperactivity disorder [ADHD] - Medway and Swale

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	4.5%
Pain in throat and chest	2.5%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	2.3%
Asthma	2.0%
Multiple myeloma and malignant plasma cell neoplasms	1.8%
Cholelithiasis	1.6%
Perineal laceration during delivery	1.4%
Symptoms and signs involving emotional state	1.4%
Fracture of lower leg, including ankle	1.4%
Poisoning by psychotropic drugs, not elsewhere classified	1.3%

KPHO, 2022. Prepared by L. Smith.

The ten most common reasons for hospital admission for people with attention deficit hyperactivity disorder [ADHD] - West Kent

Primary diagnosis	Proportion of total admissions
Abdominal and pelvic pain	6.7%
Pain in throat and chest	3.2%
Symptoms and signs involving emotional state	2.4%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	2.0%
Ulcerative colitis	1.9%
Headache	1.6%
Inflammatory polyneuropathy	1.6%
Poisoning by psychotropic drugs, not elsewhere classified	1.5%
Dorsalgia	1.4%
Perineal laceration during delivery	1.4%

KPHO, 2022. Prepared by L. Smith.

Ten most common reasons for hospital admission for people with a learning disability by HCP in Kent

The ten most common reasons for hospital admission for people with a learning disability in Dartford, Gravesham and Swanley

Primary diagnosis	Proportion of total admissions
Ulcerative colitis	4.8%
Pain in throat and chest	4.1%
Epilepsy	3.7%
Abdominal and pelvic pain	3.6%
Type 1 diabetes mellitus	2.8%
Convulsions, not elsewhere classified	2.1%
Symptoms and signs involving emotional state	1.9%
Other soft tissue disorders, not elsewhere classified	1.7%
Poisoning by nonopioid analgesics, antipyretics and antirheumatics	1.7%
Pneumonia, organism unspecified	1.5%

KPHO, 2022. Prepared by L. Smith.

The ten most common reasons for hospital admission for people with a learning disability in East Kent

Primary diagnosis	Proportion of total admissions
Epilepsy	5.1%
Pneumonia, organism unspecified	2.6%
Abdominal and pelvic pain	2.5%
Other soft tissue disorders, not elsewhere classified	2.2%
Complications of genitourinary prosthetic devices, implants, and grafts	2.1%
Pneumonitis due to solids and liquids	1.9%
Convulsions, not elsewhere classified	1.9%
Pain in throat and chest	1.8%
Cerebral palsy	1.7%
Other disorders of urinary system	1.6%

KPHO, 2022. Prepared by L. Smith.

The ten most common reasons for hospital admission for people with a learning disability in Medway and Swale

Primary diagnosis	Proportion of total admissions
Epilepsy	6.1%
Abdominal and pelvic pain	4.5%
Other functional intestinal disorders	3.0%
Dental caries	1.9%
Pneumonia, organism unspecified	1.8%
Convulsions, not elsewhere classified	1.8%
Cholelithiasis	1.5%
Other joint disorders, not elsewhere classified	1.4%
Calculus of kidney and ureter	1.3%
Iron deficiency anaemia	1.2%

KPHO, 2022. Prepared by L. Smith.

The ten most common reasons for hospital admission for people with a learning disability in West Kent

Primary diagnosis	Proportion of total admissions
Pain in throat and chest	4.4%
Abdominal and pelvic pain	4.0%
Epilepsy	3.6%
Convulsions, not elsewhere classified	2.3%
Other disorders of urinary system	2.2%
Pneumonia, organism unspecified	1.9%
Symptoms and signs involving emotional state	1.6%
Other soft tissue disorders, not elsewhere classified	1.5%
Dental caries	1.5%
Dorsalgia	1.4%

KPHO, 2022. Prepared by L. Smith.

Appendix 2

Advocacy for all

Notes from Service user Representative Group [SURG] meeting - 26/09/2022

The following section displays the responses as submitted from members of the SURG group in response to being asked about all the things that they [the community], needed to be happy and healthy - the sort of things they would start, change, or stop. [Thinking of services like the NHS, the council, housing, work, getting help when you need it, other people, and how things are done now].

Advocacy for All is a Kent-based advocacy organisation funded by a variety of local authorities [councils], grants from elsewhere, and donations.

Points and quotes provided:

- The social KCC, physical health, CCG, mental health services all need to communicate together. There is not enough collaborative work. To work in a meaningful way there needs to be change.
- Not sure where to turn when we need help. KMPT is not very inclusive for autism, there are still barriers to accessing services, and this can include the 'doorkeepers' to services i.e., reception staff and referral process.
- "There is no autism team in the council anymore and this is a step backwards, none of us agree with this. There is now no autism service."
- Quote from member "no point in contacting as not listened to".
- Quote from member regarding getting help "autism is a lifelong condition so why not lifelong support?" knowing where support is, is vital.
- Once you have used a service you are discharged and dismissed. There is no offer of a personalised service.
- Do you feel it's a box fit service? Yes, it is not personalised at all and or is very blurred lines. You are passed from pillow to post. There are people asking for help but there is no bridge to support this.
- Quote from member "if you are academic, you don't fit the category".
- Kent employment support service that people drop of the radar because of lack of support.
- Quote from member "we are asked to communicate but services don't!"
- Quote from member "I moved to Kent and the whole support service I had in place to support my career and daily life disappeared. Out of area services seem to realise that autism is lifelong so once you are registered on a service it's there for life".

- Quote from member “I feel that services don’t want people to be individual and just fit in a box”.
- Quote from member “you are made to feel like a problem”.
- This is very much a Kent issue. Service users that have moved to Kent have lost so much support.
- The government strategy / report, why is this not being followed?
- Quote from member “when you try and access benefits to feed yourself you are made to feel there is nothing wrong with you. You are then forced into employment that won’t last. Any help is a short fix”.
- There is no welcome package to the area it is all detective work online. There is no continuation of care / support.
- Quote from member “as soon as you turn 18 the services diminish”.

How do you feel about re-applying for support?

- You shouldn’t have to re-ask for support.
- I don’t fully trust what people are saying to me.

Treatment

- You are treated inconsistent; you live in fear of decisions for losing ALL support. This is particularly relevant for benefits assessments, like PIP and ESA
- Your award may go up and down so this shows that it is a gamble

Do you feel these people in services have enough knowledge of autism?

- I don’t think any services have a full understanding of autism and don’t think they will ever be fully adaptable.
- I feel they think if you can hold a full conversation then you are not autistic and you are not meeting expectations of autism.
- The government relies on charities to do the support, but charities are restricted on the areas they can cover.
- Quote from member “there are so many gaps in support. The system in Holland for autism support is far better than anywhere”.

Other comments:

- For sensory we get an hour in supermarkets, but this is BEFORE bus pass is allowed to be used!”
- Disabled bus pass is 9.30am until 11pm, this is discriminating as hospital appointments do not always start at 10am!”
- There is no quiet carriage on a train which is a sensory overload.
- Quote from member “charities are trying to pick up where the gov is failing so the gov should support the charities”.
- “There is no support for trying to work. The old benefit system allowed you to have a break to try employment but if you wanted to do this on ESA you’d have to reapply

again. There should be some kind of system where you can slowly increase your hours and reduce your benefits because it's too big a jump to go from being on benefits to working full time."

The group want to highlight a government paper that they felt covered a lot how they felt, and things that should be done for people with autism. They want this to be taken on board and read:

<https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>

Responders agree with the following points on the paper:

- improving understanding and acceptance of autism within society
- supporting more autistic people into employment
- tackling health and care inequalities for autistic people
- building the right support in the community