

Southampton Strategic Assessment (JSNA)

People with learning disabilities

Last Updated July 2019

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1. Executive Summary

The health of adults with learning disabilities has improved over the last 30 years and this has been demonstrated through increased life expectancy. However, it is widely acknowledged that they still have poorer health than the general population, a shorter life expectancy and an increased risk of premature death.

Improving the lives of adults with learning disabilities has become a national priority, with identified primary reasons being;

- increased risk of specific health problems and/or personal health risks, health behaviours and greater exposure to social determinants of poorer health, associated with learning disabilities
- barriers to healthcare provision such as access, communication difficulties including reduced health literacy

Learning disability is defined by the Department of Health & Social Care as a “significant 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”. It is a term given to a group of conditions that are present before the age of 18 and can be categorised as mild, moderate, severe or profound. This is not to be confused with a learning difficulty such as dyslexia and dyspraxia.

This needs assessment details the local and national strategic context and assesses the need and demand for health and social care services for people with learning disabilities. The purpose being to ensure people with learning disabilities can live long, healthy and independent lives. The recommendations aim to support the strategic planning and development of services and support for people with learning disabilities encompassing:

- SEND (Special Educational Needs and Disabilities) - Children and Families Act 2014 and Southampton SEND Strategy (2017-2020)
- Strengths Based Approach – Care Act 2014 and the Southampton, Hampshire, Isle of Wight and Portsmouth Transforming Care Plan (2016-2019),
- Southampton’s Better Care Plan supporting by the CCG’s Operating Plan (2017–19) the local STP, NHS 5 Year Forward View, Care Act 2014, Southampton’s Health and Wellbeing Strategy (2017-25) and Local System Plan
- NHS Long Term Plan including in conjunction with the Learning Disabilities NHS Improvement Standards

People with learning disabilities face a range of health and wellbeing inequalities that need to be recognised by commissioners when service planning. Services must be designed in a way that includes provision for people with learning disabilities and ensures that reasonable adjustments become integral.

In 2014/15-2016/17, females with learning disabilities had almost an 18-year lower life expectancy compared to females without a learning disability. Males with a learning disability had a 14-year lower life expectancy compared to males with no recorded learning disability.¹ Around 20 people in 1,000 are estimated to have a learning disability; 5 in 1,000 are registered on GP registers as having a learning disability (with a significantly higher prevalence among males than females) showing a gap of those identified and those being signposted to appropriate service. The prevalence is highest for males in the 10 - 19 years and 55 - 59 years age bands and for females, in the 50 - 54 years and 60 - 69 age bands.

Prevalence of learning disabilities in the most deprived areas of the city is four times higher than in the least deprived areas (5.31 per 1,000 population compared to 1.34 per 1,000 population). Redbridge, Bevois and Coxford have the highest recorded prevalence rates in Southampton. One in four people with learning disabilities and known to adult social care live in supported living settings.

The number of people with a learning disability in Southampton is forecasted to increase by approximately 20 by 2023 to a total number of 5,110 people and to increase by approximately 70 people by 2038². These figures are likely to underestimate the true total number of people with learning disabilities, especially those with complex (severe or profound) learning disabilities due to the ageing of the population.

There is a higher prevalence of many health conditions among people with a learning disability than those without a learning disability. These tend to be those that involve self-management. It is possible that poor self-management allows conditions to exacerbate to a diagnostic level. In addition, these conditions tend to occur at an earlier age for people with a learning disability compared to those without. Furthermore, a person with a learning disability is more likely to experience communication difficulties, which can contribute to undiagnosed health conditions.

For instance, the prevalence of asthma is nearly double the prevalence for people with a learning disability (11%) compared to those without (6%). Furthermore, Type 1 and Type 2 diabetes has been identified is higher in people with a learning disability compared to the general population. This is also the case for excess weight³. Identified risk factors include: having (on average) a more sedentary lifestyle, having higher fat diets and a higher rate of prescribed antipsychotic medication. One in 11 Southampton registered patients with a learning disability are diagnosed with diabetes (9%). This is a significantly higher prevalence compared to 1 in 20 patients without a learning disability (5%).

¹ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 05/12/18

² Projected prevalence figures estimated from Emerson, E and Hatton, C. Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. Institute for Health Research, Lancaster University: Lancaster, 2004 applied to ONS 2017 population projections

³ Emerson and Baines (2010) Health Inequalities and people with learning disabilities in the UK: 2010. IHaL and Department of Health

Mental health and neurological conditions are more commonly diagnosed in people with learning disabilities. The prevalence of severe mental health conditions, depression, and schizophrenia are all significantly higher in Southampton patients with learning disabilities compared to those without. One in 6 people with a learning disability have epilepsy, significantly higher than the 1 in 100 people without a learning disability. Lastly, cancer screening for people with a learning disability is significantly lower across all three national programmes (bowel, breast and cervical), this is recognised as both a national and local issue.

This needs assessment describes in depth the health inequalities experienced by people with learning disabilities. Through understanding these needs, characteristics of individuals and their location we can better direct services and facilitate community action to support these needs. The following facilitators for action are key to improving outcomes:

1. People with learning disabilities and their carers hold a wide range of views about how services should support them. Carers are often the best advocates for the people they care for and can provide valuable insight, which professionals don't have. People with learning disabilities, and their carers, should be central to decision making both at an individual and service level.
2. There are hundreds of dedicated staff who are passionate about supporting people with learning disabilities. This ranges from learning disability nurses, social workers & GPs to support workers in residential homes, supported living and day services. All have particular skills sets, knowledge and abilities to contribute which should be recognised, celebrated and put to best use.
3. There is a significant amount of local and national good practice and guidelines, which can be used to develop and/or adapt services. There needs to be a regular stock take to ensure that local provision is aware of and responding to the latest national guidance, such as NICE guidelines, CQC requirements and Public Health England advice.
4. Funding for services to support people with learning disabilities should ensure that the health inequalities described in this needs assessment are reduced.

Recommendations from this needs assessment are as follows:

Reasonable Adjustments

1. All services, both specialist and universal, should be designed and delivered in a way that considers the needs of people with learning disabilities. Reasonable adjustments should become integral to service planning and address the range of needs not just the average. This is relevant for the commissioners and providers of all health & social care services but in particular:
 - a) Sexual Health

The availability of specific sexual health 'SHIELD' clinics for people with learning disabilities should be promoted more widely and if take-up continues to be low, a more in depth exploration of the reasons for this should be completed.
 - b) Mental Health

The Green Light Tool Kit should continue to be used and reviewed regularly by providers and commissioners of both mental health and learning disability services.

c) Substance Use Disorders (SUDs)

SUDs specialists have limited training and expertise around learning disabilities and learning disability services have limited training and expertise around SUDs. Commissioners in both areas need to work collaboratively in address this gap and regularly assess if there is suitable provision amongst the staff equipped with LD awareness and up-to-date training to support those clients with LD.

Monitoring & Auditing Recommendation

2. There should be ongoing regular monitoring of how the recommendations in this needs assessment are being implemented as well as reporting on a range of inequalities so that improvements can be recognised.
3. This needs assessment has identified a number of national and local policy documents as well as guidelines. A stock take should be completed to establish how effectively these are being implemented within local service provision. This should include: NHS Improvement Standards and Learning Disabilities Mortality Review (LeDeR) findings,
4. Findings and recommendations from local and national LeDeR reviews of deaths of people with learning disabilities should be shared with commissioners as soon as they are available and commissioners take responsibility for putting in place relevant actions within local services.

Demographic Recommendations

5. Commissioning of services should take account of the demographics identified within this needs assessment, in particular:
 - a) The higher prevalence of learning disabilities amongst males than females
 - b) Forecast increase in number of people with learning disabilities, especially those which severe or profound learning disabilities and associated complex needs
 - c) High prevalence of people with learning disabilities living in more deprived areas of the city
 - d) High prevalence of people with learning disabilities within traveller and Asian communities.

Health Needs Recommendations

6. Health, as a system, needs to respond and adapt to the changing needs in the learning disabilities population. To drive forward this change, commissioners will work in partnership with Southern Health Foundation Trust to develop, describe and implement an offer, working in partnership with health partners, and based on where our priorities are. The offer will ensure that there is a toolbox of resources/supports that can be used by any provider. As an example, providing a training and development offer (mentoring/coaching

programmes), and partnering the system with essential services, such as LD Strategic Health Facilitation/Acute Liaison.

7. Specialist health services (SHFT), will play a more active role in supporting primary care with Annual Health checks, by aligning their Clinical Assessment with the Annual Health Check
8. A number of conditions have a higher diagnosed prevalence among people with a learning disability, these tend to be those that involve self-management. It may be possibly that poor self-management allows conditions to exacerbate to a diagnostic level. Generally higher prevalence occurs earlier in age for people with a learning disability compared to those without. It is recommended that mechanisms to improve the self-management of higher prevalent conditions be explored for people with learning disabilities.
9. Service commissioning for respiratory conditions particularly pneumonia linked with dysphagia and resulting aspiration pneumonia needs to be linked with the guidance of reasonable adjustments for this condition⁴implemented. Liaison with GP surgeries promoting vaccination for people with LD, including their carer outside of these age groups is recommended to address the identified inequality.
10. 1 in 11 Southampton registered patients with a learning disability are diagnosed with diabetes, a significantly higher prevalence compared to patients without a learning disability. Joined up commissioning supporting a holistic approach encompassing risks would be beneficial for improving the health of people with a learning disability. Utilising the Strategic Health Facilitators with the overarching knowledge of bespoke programmes such as WiLD, SHIELD etc. to allow professionals such as ASC workers to signpost and refer in a preventative way before needs escalates as well as to support existing health risks.
11. 1 in 6 people with a learning disability have epilepsy. It is recommended that services supporting people with epilepsy are regularly audited to ensure LD leads and the soft skills required are evident with the staff.
12. The gap in the proportion in paid employment between those with learning disabilities and those without is lower than the national average and increasing overall. Efforts to support more people with learning disabilities into employment should be reviewed.
13. To support an increase in uptake of cancer screening for people with learning disabilities:
 - a) Awareness should be raised amongst people with learning disabilities and their carers (both family carers and paid carers) about the importance of cancer screening and the adjustments which can be made to.

⁴ Public Health England (2016) Dysphagia in people with learning difficulties: reasonable adjustments guidance <https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-disabilities/dysphagia-in-people-with-learning-difficulties-reasonable-adjustments-guidance> Accessed 4/12/18

- b) Training should be provided to support workers about how they can support access to cancer screening including practical steps such as supporting someone to collect a stool sample.
 - c) There should be exploration whether the cervical HPV vaccine could be provided to women with learning disabilities (specifically for those who would otherwise refuse to access cervical screening)
14. There is a gap in knowledge locally and nationally for substance use disorders (SUDs). SUDs specialists have limited training and expertise around learning disabilities and vice versa; learning disability services have limited training and expertise around SUDs. Commissioners in both areas need to work collaboratively in address this gap and regular assess there is suitable provision amongst the staff equipped with LD awareness and up-to-date training in support those clients with LD.
15. Sexual health services for people with learning disabilities have been developed however there is a gap in knowledge and promotion of the 'SHIELD' clinic resulting in this service not being used. Signposting material for stakeholders within relevant pathways need to be distributed and used.

2. Background

2.1 Introduction

The health of adults with learning disabilities has improved over the last 30 years⁵ and this has been demonstrated through increased life expectancy⁶. However, it is widely acknowledged that they still have poorer health than the general population, a shorter life expectancy and an increased risk of premature death⁷.

Improving the lives of adults with learning disabilities has become a national priority. Recent national reviews of the health and care of people with learning disabilities demonstrate significant inequalities. There have been improvements in the care of individuals with learning disabilities and as a result, life expectancy has gradually increased. However, adults with learning disabilities are still vulnerable to significant health inequalities and social exclusion.

Public Health England have identified five primary reasons for health inequalities experienced by adults with learning disabilities:⁸

1. Increased risk of health problems associated with specific genetic, biological and environmental causes of learning disabilities.
2. Personal health risks and behaviours such as poor diet and lack of exercise.
3. Greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness.
4. Communication difficulties and reduced health literacy
5. Deficiencies relating to access to healthcare provision.

All of the above factors can impact on quality of life and are intertwined in a complex relationship. Factors that are important to quality of life for people with learning disabilities include: being healthy, being respected, having a purpose, having relationships and having choice. Choosing a healthy lifestyle can be difficult for many people but it can be even more challenging for an individual with a learning disability.

⁵ Hardy S. et. Al. (2011) Meeting the health needs of people with learning disabilities: RCN guidance for nursing staff. Royal College of Nursing: London http://www.complexneeds.org.uk/modules/Module-4.1-Working-with-other-professionals/All/downloads/m13p040b/meeting_health_needs_people_with_ld.pdf Accessed 22/10/18

⁶ Public Health England (2016) People with learning disabilities in England 2015: Main report https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf Accessed 22 /10/18

⁷ Turner S. & Robinson C. Health Inequalities and People with Learning Disabilities in the UK: 2011 Implications and actions for commissioners of Social Care. Evidence into practice report no. 1 (revised). Improving Health & Lives Learning Disability Observatory & National Development Team for Inclusion: London (Nov 2011)

⁸ Public Health England (2017) Improving the health and wellbeing of people with learning disabilities: guidance for social care providers and commissioners (to support implementation of the Health Charter) <https://www.scie-socialcareonline.org.uk/improving-the-health-and-wellbeing-of-people-with-learning-disabilities-guidance-for-social-care-providers-and-commissioners-to-support-implementation-of-the-health-charter/r/a110f00000RCw78AAD> Accessed 22/10/18

Many people with learning disabilities have limited opportunities and ability to make choices. Those who do make choices should have an understanding of the impact of their choices. This may be time-consuming for health professionals and carers but it is important. Some choices will involve an element of risk, and these must be supported or honoured appropriately. Choices made on someone’s behalf should be made in that persons best interest, following the Mental Capacity Act. These should be based on the individuals’ likes and dislikes, and not solely on the views or opinions of the decision maker.

Following national reviews, NHS England has launched a National Learning Disability Mortality Review (LeDeR)⁹ programme to identify common themes in mortality and gaps in care provision. The Wessex region has been a pilot area for the LeDeR programme. It also brings together a range of intelligence on the health of people with a learning disability and the particular risk factors that they experience. The programme aims to review the deaths of people with learning disabilities to understand the circumstances that lead to a death. This can then inform areas for improvement and new ways of working to prevent similar situations reoccurring.

This health needs assessment explores the key areas from the national reviews in more detail at a local level to enable a better understanding of the needs in service provision for the future. Intelligence from current services are brought together to inform and shape recommendations in line with the local and national strategic agendas.

This needs assessment is designed to support the Learning Disability Market Position Statement 2018-23 which pays due regard to the following:

- Southampton City CCG Strategic Plan (2014-19): A healthy Southampton for all
- The Joint Health and Wellbeing Strategy (2017-25) for Southampton
- Southampton City Council Strategy (2016-20)
- Autism Joint Commissioning Strategy (all ages) Southampton (2015–20)
- Southampton Joint Strategic Needs Assessment
- Southampton Housing Strategy (2016-25)
- Market Position Statement: Housing Solutions for People with Care and Support Needs (2015-18).

2.2 Defining learning disabilities

Learning disability is defined by the Department of Health & Social Care as “significant 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”¹⁰. It is a

⁹ University of Bristol (2015), Learning Disabilities Mortality Review (LeDeR) Programme
<http://www.bristol.ac.uk/sps/leder/about/> Accessed 11/10/2018

¹⁰ HM Government (2009) Valuing People Now: a new three-year strategy for people with learning disabilities
http://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf Accessed 22/10/18

term given to a group of conditions that are present before the age of 18 and can be categorised as mild, moderate, severe or profound. This is not to be confused with a learning difficulty such as dyslexia and dyspraxia.

Learning disabilities are caused by something affecting the development of the brain. This may occur before birth, during birth, or in early childhood. Learning disabilities can be caused by any one of a variety of factors, or by a combination. Sometimes the specific cause is not known. Possible causes include the following:¹¹

- An inherited condition, meaning that certain genes passed from the parents affected the brain development, for example Fragile X.
- Chromosome abnormalities such as Down's syndrome or Turner syndrome.
- Complications during birth resulting in a lack of oxygen to the brain.
- A very premature birth.
- Mother's illness during pregnancy.
- The mother drinking during pregnancy, for example Foetal Alcohol Syndrome.
- A debilitating illness or injury in early childhood affecting brain development, for example a road traffic accident or child abuse.
- Contact with damaging material (like radiation).
- Neglect, and/or a lack of mental stimulation early in life.

Learning disabilities can be categorised as mild, moderate, severe or profound with the following aspects¹²:

Mild Learning Disability

- 85% of the learning disability population
- Characterised by some learning difficulties in school but people can generally learn to read, write and do basic maths. Many adults with mild learning disabilities are able to work, live independently, maintain good social relationships and contribute to society.
- People may struggle to understand written instructions, keep appointments, grasp the purpose of procedures, stick to treatment regimens and understand consent procedures

Moderate Learning Disability

- 10% of the learning disability population
- Characterised by marked developmental delays in childhood. People may be able to learn basic reading and writing and most can learn to develop some degree of independence in self-care and adequate communication skills. Adults with moderate learning disabilities will need varying degrees of support or supervision to live and work in the community.

¹¹ Mental Health Foundation (2018) 'What causes a learning disability' <https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/l/learning-disabilities> Accessed 2/11/18

¹² PHE and NHS England (2017) PHE and NHS England Joint Webinar Learning Disabilities and End of Life Care <http://www.endoflifecare-intelligence.org.uk/view?rid=992> Accessed 17/12/18

Severe and Profound Learning Disability

- 5% of the learning disability population
- People with severe learning disabilities are probably unable to read or write. They may learn self-help skills and routines and some verbal skills but often need augmented communication aids and support in most aspects of daily living.
- 1% of the learning disability population have a profound learning disability.
- People with profound learning disabilities need intensive support relating to;
 - Self-care
 - Continence
 - Mobility
 - Communication
- They may have complex medical conditions that require ongoing therapy or nursing care
- Challenges for people with severe and profound learning disabilities include; communicating pain and other symptoms, understanding and coping with changes in circumstances, complex co-morbidities, making health management a challenge and assumptions made about their quality of life.

2.3 Scope, purpose and national / local strategic context

This needs assessment investigates the health, wellbeing and causes of mortality in adults with learning disabilities in Southampton. It considers adults with learning disabilities (aged 18 and over) who are resident or registered with a GP within Southampton, living in the community or in residential care.

This report sets out information on the need and demand for health and social care services for people with learning disabilities to ensure they can live long, healthy and independent lives. The recommendations aim to support the strategic planning and development of services and support for people with learning disabilities.

The Government launched the three year strategy 'Valuing People Now' in 2009.¹³ The strategy was based on the fundamental principle that people with learning disabilities have the same human rights as everybody else and set out 15 key objectives, building on the 2001 strategy 'Valuing People'. The objectives focused on creating more choice, confidence and control for people with learning disabilities in order to live as independently as possible, as equal citizens in society. The Valuing People Now strategy has since been archived, an updated strategy is yet to be released.

Although there is an absence of a recent national strategy, there are national agendas (outlined below) aimed at improving the health of people with learning disabilities at a local level.

¹³ HM Government (2009) Valuing People Now: a new three-year strategy for people with learning disabilities http://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf

2.3.1 SEND (Special Educational Needs and Disabilities)

The Children and Families Act 2014¹⁴ introduced significant reforms to the system for assessing and meeting the needs of children, young people and young adults aged 0-25 with Special Educational Needs and Disabilities (SEND). The Act requires health and local authority partners to work together to commission and deliver services for this group, ensuring strong integration between education, health and social care provision, where this will promote wellbeing and improve the quality of provision.

One of the notable changes within the Act is the extension of the age range to 0-25 years. From school year 9 (age 14) the SEND reforms require those supporting young people to focus on ordinary life outcomes in preparing them for adulthood. Support from Year 9 must be focused on the young person's aspirations and the following outcomes:

- Higher education and/or employment – exploring different employment options, such as support for becoming self-employed and help from supported employment agencies
- Independent living – young people having choice, freedom and control over their lives, their support, and their accommodation and living arrangements, including supported living
- Participating in society – having friends and supportive relationships, and participating in and contributing to the local community.
- Being as healthy as possible in adult life.

The plans and priorities outlined in the Southampton SEND Strategy (2017-2020) aims to support all children and young people in Southampton having a good start in life, so they can fulfil their potential and become successful adults engaged in their local communities. Through partnership working the council, health services and other partners are committed to ensure that children and young people with SEND, their families and carers receive the support they need, when they need it, so that they can achieve and aspire in all aspects of their lives.

2.3.2 A Strengths Based Approach (linked to the Care Act 2014¹⁵)

The Southampton system has adopted a strengths based approach using the following definition from the Social Care Institute for Excellence (SCIE):

'A Strengths Based Approach is a collaborative process between the person supported by services and those supporting them, allowing them to work together to determine an outcome that draws on the person's strengths and assets. As such, it concerns itself principally with the quality of the relationship that develops between those providing support and those being supported, as well as the elements

¹⁴ Children and Families Act 2014. <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted> Accessed 11/10/2018

¹⁵ Children and Families Act 2014. <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted> Accessed 11/10/2018

that the person seeking support brings to the process. Working in a collaborative way promotes the opportunity for individuals to be co-producers of services and support rather than solely consumers of those services.’¹⁶

The shift in practice as a result of adopting the strengths based approach is outlined in figure 2.3.1 and demonstrates the ambition to support increased independence.

Figure 2.3.1 Strengths based approach

Moving from a System Characterised By..	To One Where There is....
Doing things to/for people and creating dependence	A focus on enabling people to do things for themselves, promoting independence
Seeing the individual in isolation	An emphasis on family and social networks
Highlighting what people cannot do	Attention given to what people can do
Undertaking assessments for services which offer standard solutions	An assessment conversation which provides more in-depth understanding of the person and offers tailored solutions
Arranging support managed by the council	A use of creative solutions family-first or through a range of voluntary and community sector services
A large amount of care for people with long term conditions being provided in institutional settings	A priority for providing support, when it is needed in the home, wider family network or local community

2.3.3 Transforming Care (2016–2019)

NHS England also launched a transforming care programme in 2015, aiming to improve health and care services so that more people with a learning disability can live in the community, with the right support, and close to home. This includes closing in-patient centres and creating more community services. The closure of in-patient services can help to improve quality of life, as community integration offers the opportunity to access activities, employment and social networks. For Hampshire, a programme is being led by the Southampton, Hampshire, Isle of Wight and Portsmouth (SHIP) Transforming Care Partnership (TCP)¹⁷. The SHIP Transforming Care Plan (2016-2019) is a three year plan and covers people with learning disabilities and/or autism through the whole life span.

The vision of the Plan is:

‘To build on a child, young person’s or adult’s unique strengths and abilities, getting it right for the person first time through ensuring there is the right care in the right place at the right time that is consistent across the SHIP TCP.’

¹⁶Care Act guidance on Strengths-based approaches <https://www.scie.org.uk/strengths-based-approaches/guidance> Accessed 11/10/2018

¹⁷ NHS England, Learning Disabilities Transforming Care Partnership (TCP) <https://www.england.nhs.uk/learning-disabilities/tcp/south7/#southampton> Accessed 11/10/2018

SHIP TCP wants to prevent the ‘revolving door syndrome’ trying to fit people into a traditional solution that does not meet the person’s needs that results in regular placement breakdown and more restrictive regimes being put in place. This plan aims to build on the person’s unique strengths and abilities, not seeing them as a problem and get it right for the person first time. People with complex needs and those in crisis are often managed through reactive strategies rather than having proactive strategies agreed and in place in the event of requiring intensive support, avoiding a hospital admission.

The main aims of the SHIP TCP are to:

- Develop learning disability liaison services in hospitals
- Expand the intensive support team to provide a service to people aged 14-18 years
- Develop a community service for people who have been in contact with the criminal justice system or are at risk of doing so
- Increase the offer and uptake of personal budgets
- Increase the number of annual health checks in GP practices

This is achievable through a model that focusses on:

- Early intervention and prevention to avoid people being admitted to hospital, this includes supporting good physical health, mental health and having ‘learning disability friendly GP practices’
- Reducing the number of people with learning disabilities inappropriately placed within hospitals (locked rehabilitation/low and medium secure)
- Reducing the Length of Stay for those individuals requiring assessment, diagnosis and treatment
- Training and development for health and social care staff
- Increasing the offer and uptake of personal budgets
- Increasing the number of personal assistants available in the TCP region
- Working with providers in the use of Positive Behavioural Support
- Having robust care planning with relapse prevention strategies agreed and pre-agreed funding in place either directly funded or via personal budgets to help keep people well
- Establishing a TCP community forensic rehabilitation service
- Developing a joint Regional approach to Housing Development and a portfolio of housing options for individuals

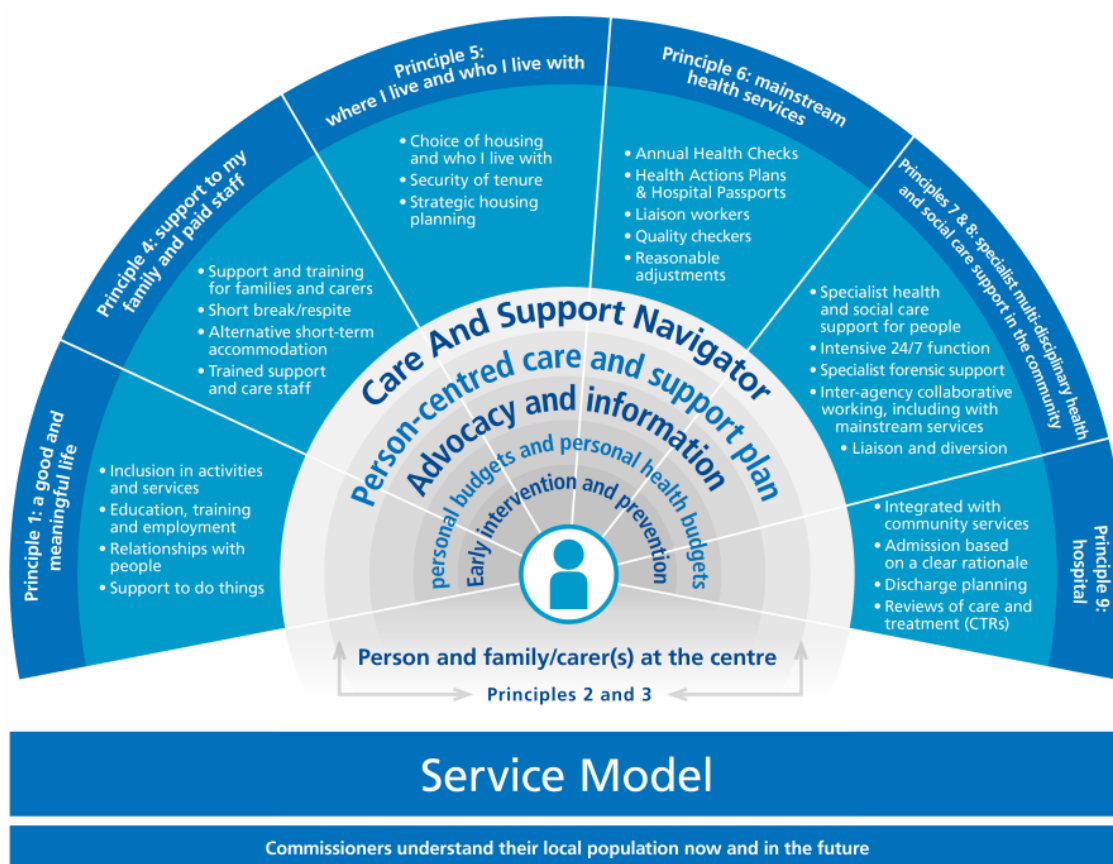
The TCP has been effective in delivering some of the key requirements set out in Building the Right Support (BTRS) Service Model 2015¹⁸. This service model forms the basis for commissioning intentions.

¹⁸Association of Directors of Adult Social Services (ADASS), Local Government Association (LGA) and NHS England (2015), Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a

The model (with its nine principles) states that each local area is different (see figure 2.3.2)

Local populations have different needs, and their range of providers have different strengths and weaknesses. The mix of services they put in place will need to reflect that diversity. However, there does need to be some national consistency in what services look like across local areas, based on established best practice.

Figure 2.3.2 Building the Right Support (BTRS) Service Model 2015



2.3.4 Better Care Southampton

The vision for Better Care Southampton is as follows:

‘Southampton is our city where everyone thrives; we build on the strengths of our communities and our services are joined up around individuals’

mental health condition <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf> Accessed 22/10/2018

The vision has evolved out of strong and inclusive partnerships between commissioners, providers, communities and citizens, built up over a number of years - based on the notion of Better Care that is joined up and co-produced with people, respecting their independence as individuals and drawing strength from the resourcefulness of communities. Better Care applies across all age groups.

The core aims of person centred care are:

- Putting individuals and families at the centre of their care and support, meeting needs in a holistic way
- Providing the right care, in the right place, at the right time, and enabling individuals and families to be independent and self-resilient wherever possible.
- Making optimum use of the health and care resources available in the community
- Intervening earlier and building resilience in order to secure better outcomes by providing more coordinated, proactive services.
- Focusing on prevention and early intervention to support people to retain and regain their independence.

Shared commissioning promotes the development of fully integrated city provision based on the following principles:

- Using the now established six Better Care Clusters as the building blocks around which to organise integrated teams
- A fully integrated model of care bringing together the three dimensions of primary and community healthcare, health and social care, physical and mental/emotional health
- Co-production of care with empowered individuals, carers, families and communities moving away from dependency / paternalism towards a strengths-based approach that prioritises prevention and early intervention.

This vision of integration also supports the CCG's Operating Plan (2017–19) and Council's Strategy which in turn supports the delivery of the local STP, NHS 5 Year Forward View, Care Act 2014 and Local System Plan.

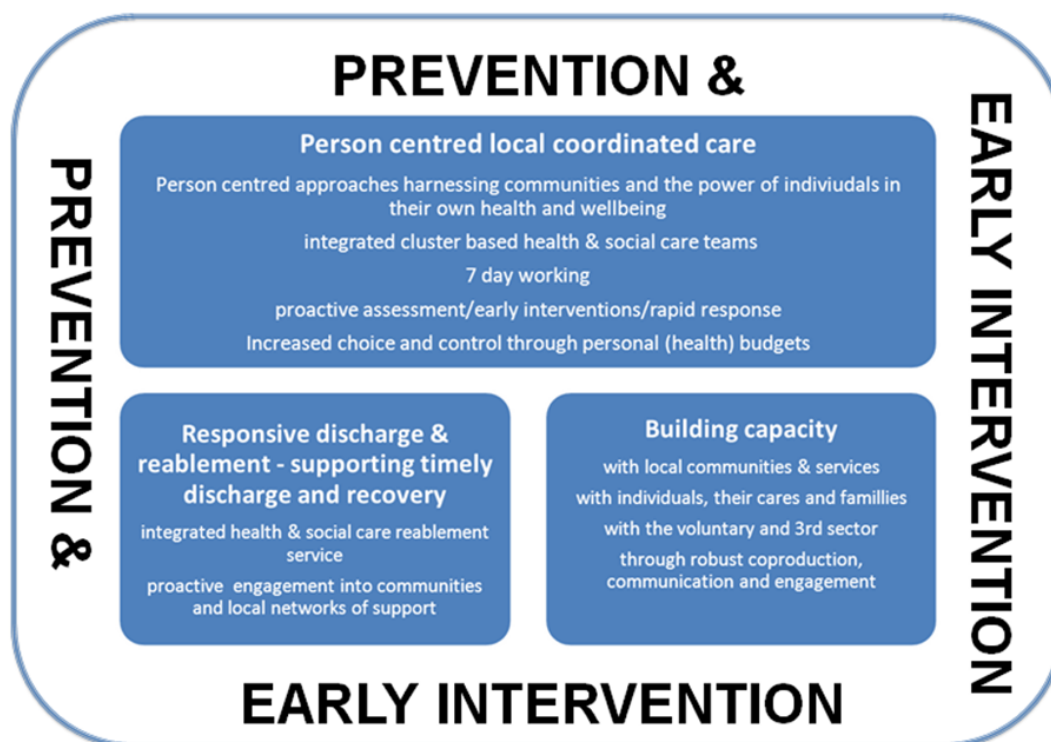
Southampton's Better Care Plan also supports the delivery of Southampton's Health and Wellbeing Strategy (2017-25) which sets out the following 4 priorities:

1. People in Southampton live active, safe and independent lives and manage their own health and wellbeing
2. Inequalities in health outcomes and access to health and care services are reduced.
3. Southampton is a healthy place to live and work with strong, active communities

People in Southampton have improved health experiences as a result of high quality, integrated services.

Figure 2.3.3 illustrates Southampton's three areas of focus for its Better Care Programme. Running through all three areas is a strong emphasis on prevention and early intervention.

Figure 2.3.3 Southampton's Better Care Programme aims and vision



2.3.5 Learning Disabilities NHS Improvement Standards

NHS Improvement published standards in June 2018 which aim to help NHS trusts measure the quality of care they provide to people with learning disabilities, autism or both.

The standards were developed with people with learning disabilities and families from a number of outcomes which clearly state what they expect from the NHS.

There are four standards, which include:

1. Respecting and protecting rights
2. Inclusion and engagement
3. Workforce
4. Learning disability services standard

The first three standards should be met by all NHS trusts, the fourth standard is specifically for trusts that are commissioned to provide services that are exclusively for people with learning disabilities, autism or both (for example specialist community or inpatient learning disability health services provided by Southern Health NHS Foundation Trust).

Trusts are expected to publish their performance against the standards in their annual report as well as improvement measures being put in place. Due to the standards only recently being introduced it is too early to assess performance however this will be a priority going forward.

2.3.6 Learning disabilities and mental health agenda

As will be shown later in this document, people with learning disabilities are more likely to experience mental health issues than the general population. However mental health services sometimes do not provide the adjustments necessary for a person with a learning disability to effectively access and benefit from mental health support.

The Building the Right Support service model (see section 2.3.3) recognises these challenges and states that:

*“Everyone should expect mainstream mental health services to regularly audit how effective they are at meeting the needs of people with a learning disability and/or autism. The Green Light Toolkit should be used to both **evaluate services and to agree local actions** to deliver real improvements.”*

(Building the Right Support, Service model for commissioners, October 2015, section 6.4, page 20)

The Green Light Toolkit is a framework and self-audit toolkit for improving mental health support services for people with learning disabilities. It provides a picture of what services should be aiming to achieve, including quality outcomes, and a self-assessment checklist.

Locally, the Green Light Toolkit is used regularly to audit performance of mental health services in supporting people with learning disabilities and reported on at local forums and quality review meetings.

2.3.7 Learning disabilities and the NHS Long Term Plan

The NHS Long Term Plan was published in January 2019 and sets out how the NHS will improve the quality of patient care and health outcomes over the next 10 years.

The plan has a section specifically on learning disability and autism which includes:

- Investment in community support so that by 2023/24 every local health system would have a seven day specialist multidisciplinary service and crisis care to support people in their communities.
- Implementing in full ‘Building the Right Support’: by March 2023/24, inpatient provision will have reduced to less than half of 2015 levels.
- Over the next three years, waiting times for autism diagnosis will be included alongside work with children and young people’s mental health services to test and implement the most effective ways to reduce waiting times for specialist services.

- Children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker.
- The STOMP programme – a national project involving different organisations to stop the over medication of people with a learning disability, autism or both - will continue to expand.
- Every person with a learning disability, autism or both will have a digital flag in their patient record to ensure staff have a better understanding of their needs.
- Eyesight, hearing and dental services for children will be invested in and included in reviews as part of general screening services and supported by easily accessible, ongoing care.
- Over the next five years NHS Improvement learning disability improvement standards will be implemented and will apply to all services funded by the NHS.
- The NHS will continue to offer more work opportunities to people with a learning disability and autistic people.

2.3.8 Transforming health and care outcomes for the people of Southampton Five Year Strategic Plan 2019 – 2023

Detailed analysis into the health and wellbeing of the population, linked to deprivation and service use took place in 2018/19. In discussion with partners, it was agreed to develop a response to these needs that goes beyond the NHS into social care and wider, which can be owned by all of our partners in the City. It remains, nonetheless, a subset of the wider ten year strategy for health and wellbeing led by the Health and Wellbeing Board. The new five year strategy for health and care in the City provides our vision, mission and goals to take forward stronger action and deliver fundamental changes in how services are shaped and support the city's outcomes.

The Vision of the Southampton Five Year Strategic Plan is 'One city, our city, a healthy Southampton where everyone thrives.'

The Mission of the Southampton Five Year Strategic Plan is that:
Effective system partnerships delivering safe, sustainable, coordinated care with the people of Southampton

The Goals of the Southampton Five Year Strategic Plan are to:

- Reduce health inequalities and confront deprivation
- A strong start in life for children and young people
- Tackle the city's three 'big killers': Cancer, Circulatory diseases and Respiratory diseases
- Improve whole-person care
- Improve mental and emotional wellbeing

- Build resourceful communities
- Reduce variation in quality and productivity

A review of the strategy, against key needs for the learning disabilities population, shows that key challenges and needs align closely.

3. Prevalence of Learning Disabilities

3.1 Estimated prevalence

The Centre for Disability Research (CeDR) estimate 1.2 million people in England have a learning disability; this is about 2% of the population, or roughly 20 people in every 1,000. This suggests only around a quarter of people with a learning disability are recorded as having a learning disability with their GP. The majority live their lives without support from specialist services and may not be recorded. Some people with learning disabilities live independently with no formal support, others live in supported living or residential care, but half of all adults with a learning disability live in the family home.¹⁹

Due to the inconsistencies in definitions of a learning disability and the challenge of integration of data systems, there is no central register of people with a learning disability across health and social care. This means that it can be difficult for service commissioners to understand the level of need in their population.

Applying the predicted learning disability prevalence based on Emerson et al. (2004) to Southampton's 2016-based population estimates from the Office for National Statistics, it can be estimated that in Southampton for 2018 there are approximately:

- 5,090 residents aged 15+ predicted to have a learning disability (mild, moderate or severe)
- 1,100 residents aged 15+ predicted to have a moderate or severe learning disability
- 360 residents aged 20 to 64 years predicted to have a moderate or severe learning disability and be living with a parent
- 90 residents aged 15+ with a learning disability, predicted to display challenging behaviour

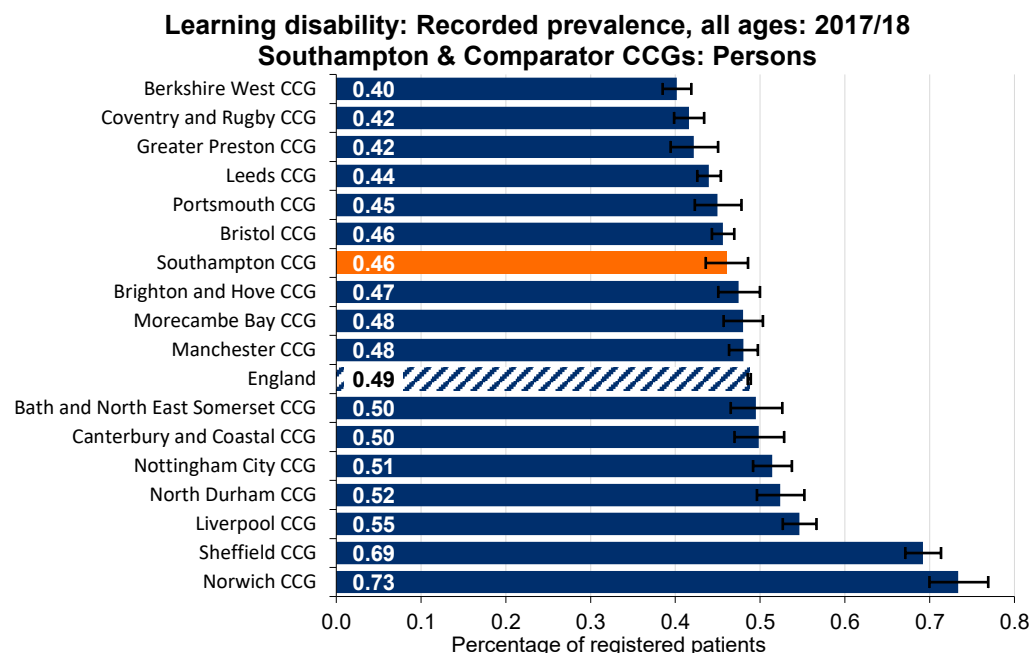
¹⁹ Public Health England (2018) Learning disabilities: applying All Our Health
<https://www.gov.uk/government/publications/learning-disability-applying-all-our-health/learning-disabilities-applying-all-our-health> 1/11/18

3.2 Recorded prevalence

The most reliable source of data is the GP Learning Disability register within the Quality Outcome Framework (QOF). However, it is widely acknowledged that the QOF learning disability register underestimates the actual number of people with learning disabilities in the population.²⁰

Based on the 2016/17 QOF, there were 1,293 registered patients in Southampton of all ages with a learning disability. This is approximately 0.47% of the GP registered population; similar to the national average and ranked mid-way amongst comparator areas. The 2017/18 QOF data has only been released so far at CCG level. Figure 3.2.1 shows the 1,320 patients registered with their GP with learning disabilities in Southampton equates to a recorded prevalence of 0.46%, lower but not significantly than the national prevalence of 0.49%. The 7th lowest among Southampton’s modified²¹ CCG comparator set.

Figure 3.2.1



Sources: Quality Outcomes Framework (QOF)

3.3 Age and gender

²⁰ Glover G., Emerson E and Baines S. Learning Disabilities Observatory NHS Data Gaps for Learning Disabilities
<https://webarchive.nationalarchives.gov.uk/20160704145804/http://www.improvinghealthandlives.org.uk/gsf.php5?f=10876&fv=11422>
Accessed 19/12/18

²¹ The **bold names** are the CCG comparators previously held in Southampton’s CCG comparator list before merges. At time of publication an updated list of comparators is not yet available. **NHS Lancashire North CCG** was given approval for a boundary change in 2017 to include South Lakes and Furness in South Cumbria and be named Morecambe Bay CCG accommodating the move of 32 practices. NHS Leeds North, NHS Leeds South and East and **NHS Leeds West** CCGs merged to form NHS Leeds CCG. NHS Newbury and District, NHS North and West Reading, **NHS South Reading** and NHS Wokingham CCGs formed NHS Berkshire West CCG.

Figure 3.3.1 uses recorded learning disability data from the ACG tool to compare the age structure of the learning disability registered population with the overall registered population Southampton.

The population with learning disabilities has higher proportions of females aged 15-19 years old, 45-54 years old and 60-64 years old. The figure (3.3.1) also shows higher proportions of males 10-19 years old and 25-34 years old.

Figure 3.3.1

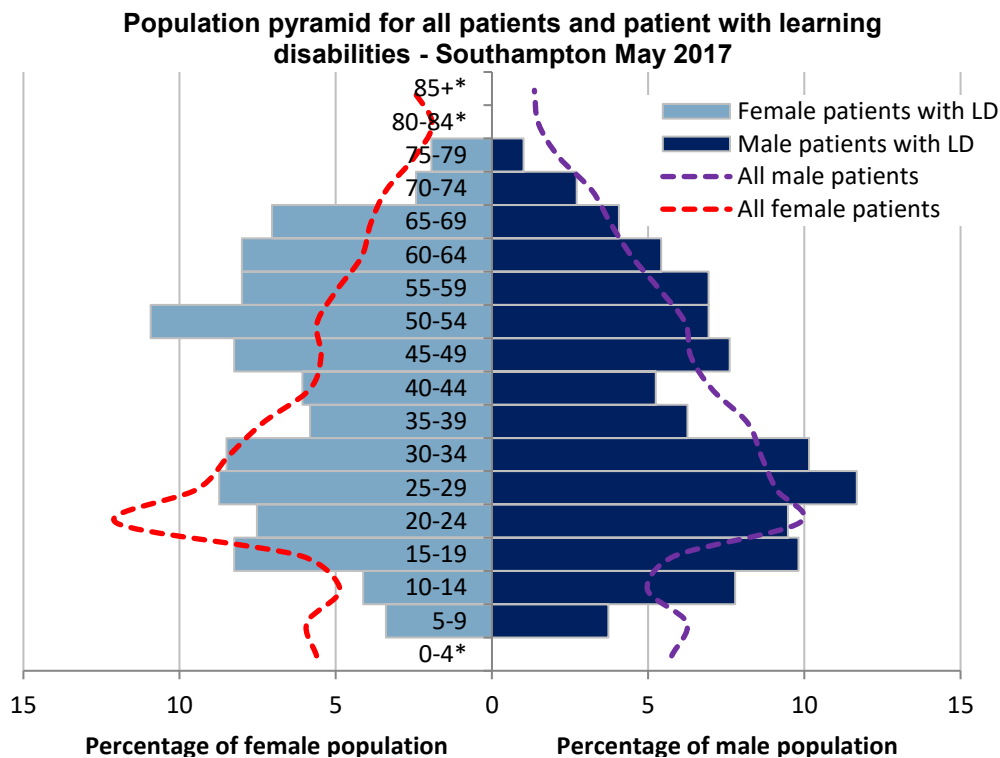


Figure 3.3.2 shows the prevalence of people with learning disabilities within each gender specific age band of Southampton registered patients. The chart illustrates that a higher proportion of males have learning disabilities compared to females. The overall prevalence amongst males is 0.49%, significantly higher compared with the prevalence for females at 0.33%.

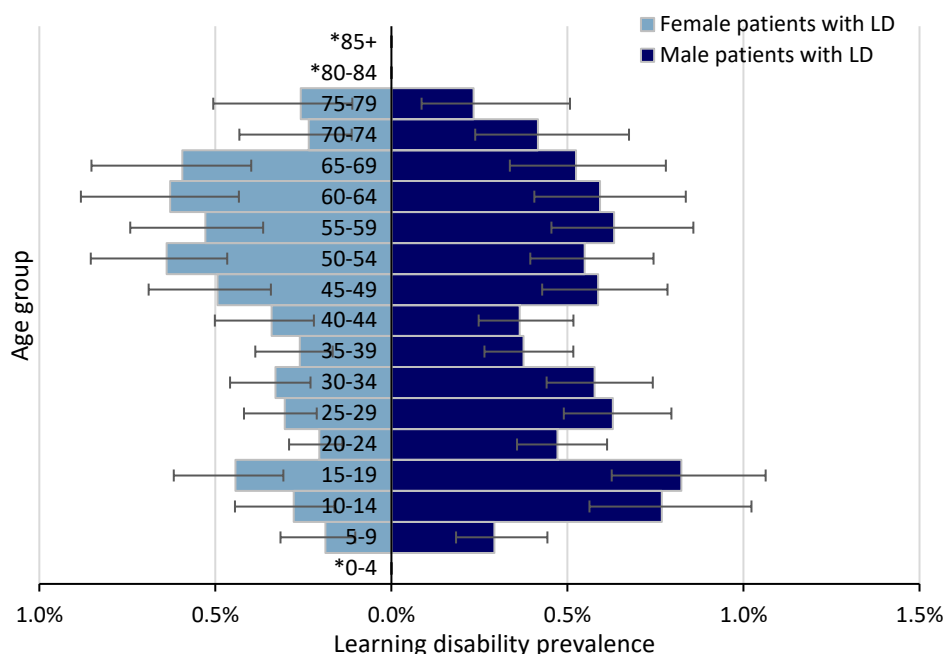
Life expectancy contributes to the age distribution of a population. Amongst Southampton’s general population, females have a higher life expectancy than males. National mortality studies and reviews of people with learning disabilities (see section 4.1) provide mixed evidence; one found life expectancy

was the same for males and females with learning disabilities whilst another two studies showed males had a higher life expectancy than females.^{22 23 24}

For males with learning disabilities, there is higher recorded prevalence among older children and young people, whereas for females in the city higher prevalence of learning disability is recorded among the older working age population. More specifically, as illustrated in figure 3.3.2, higher prevalence is recorded among males in the 10 to 19 years and 55 to 59 years age bands, whilst there is a higher prevalence among females in the 50 to 54 years and 60 to 69 age bands.

Figure 3.3.2

Learning disability prevalence of GP registered population by age band and gender: Southampton May 2017



Source: Adjusted Clinical Groups database

²²NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017>

²³ Public Health England (2016) People with learning disabilities in England 2015: Main report https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf Accessed 22 /10/18

²⁴ Heslop, P., Blair, P., Fleming, P., Hoghton, M. & Marriott, A. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report. (2013). www.bris.ac.uk/cipold/fullfinalreport.pdf Accessed 28/11/18

3.4 Ethnicity

Emerson (2010) conducted a national cross-sectional survey of intellectual and developmental disabilities in children aged 7 to 15 years. The study found that Black and Minority Ethnic (BME) groups had lower rates of learning disability than White British, with two exceptions; rates of mild intellectual disability were higher in Gypsy/Romany and Traveller children and rates of severe learning disabilities were higher in children of a South Asian origin.

The reasons for this increased prevalence are yet to be confirmed, but researchers have hypothesised it could be due to a range of factors including:

- Inequalities in access to maternal healthcare
- Higher rates of genetic or environmental risk factors
- Increased levels of material and social deprivation

The majority of Southampton's population is White British, however ethnic diversity is increasing. The 2011 Census data shows there are some Electoral wards with a higher proportion of their population from ethnic groups associated with an increased risk of learning disabilities (compared to the Southampton average); these are highlighted blue in figure 3.4.1 below. The highest counts for these combined ethnic groups are in Bargate, Bassett and Bevois electoral wards. Swaythling is the only ward with proportions higher than city average for all four ethnic groups that were evidenced to have a higher than average proportion of people with learning disabilities.

Figure 3.4.1 Ethnic groups associated with an increased risk of learning disabilities by ward

Area	Total resident count	Asian/Asian British: Indian		Asian/Asian British: Pakistani		Asian/Asian British: Bangladeshi		White: Gypsy or Irish Traveller	
		Number	%	Number	%	Number	%	Number	%
Bargate	18,762	678	3.6%	279	1.5%	257	1.4%	24	0.1%
Bassett	14,532	739	5.1%	243	1.7%	126	0.9%	6	0.0%
Bevois	16,844	1,639	9.7%	1,352	8.0%	369	2.2%	22	0.1%
Bitterne	13,800	77	0.6%	19	0.1%	10	0.1%	48	0.3%
Bitterne Park	14,026	267	1.9%	91	0.6%	31	0.2%	12	0.1%
Coxford	14,046	258	1.8%	30	0.2%	14	0.1%	21	0.1%
Freemantle	15,937	631	4.0%	166	1.0%	117	0.7%	14	0.1%
Harefield	14,035	129	0.9%	65	0.5%	27	0.2%	7	0.0%
Millbrook	15,382	352	2.3%	107	0.7%	74	0.5%	9	0.1%
Peartree	14,203	158	1.1%	31	0.2%	25	0.2%	16	0.1%
Portswood	14,831	484	3.3%	342	2.3%	58	0.4%	6	0.0%
Redbridge	14,490	120	0.8%	8	0.1%	44	0.3%	27	0.2%
Shirley	14,425	685	4.7%	74	0.5%	94	0.7%	32	0.2%
Sholing	14,053	69	0.5%	14	0.1%	6	0.0%	44	0.3%
Swaythling	13,664	413	3.0%	185	1.4%	132	1.0%	21	0.2%
Woolston	13,852	43	0.3%	13	0.1%	17	0.1%	32	0.2%
Southampton	236,882	6,742	2.8%	3,019	1.3%	1,401	0.6%	341	0.1%

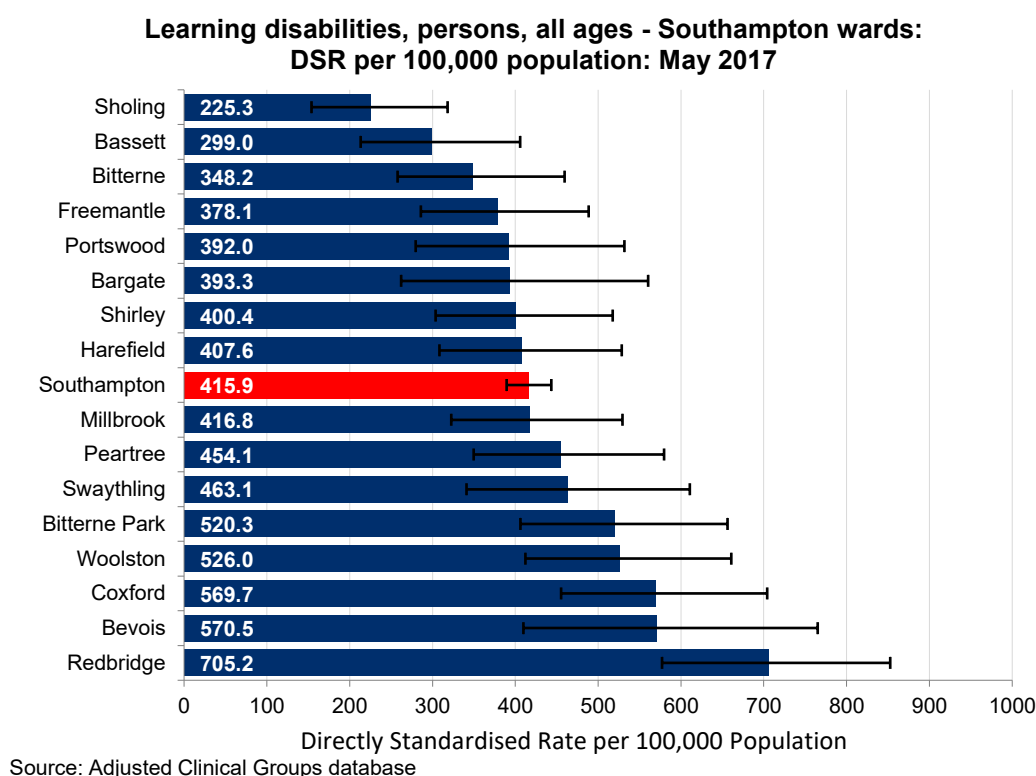
3.5 Inequalities within Southampton

Geographical differences in prevalence highlight potential inequalities within Southampton; the following section looks at the difference in prevalence between Electoral wards, Better Care Clusters and Index of Multiple Deprivation (2015) quintiles.

3.5.1 Prevalence at ward level

At sub city level, Redbridge has a significantly higher (705 per 100,000 population) age standardised rate of people with a learning disability compared to the city average (416 per 100,000 population). In contrast, Sholing has a significantly lower rate (225 per 100,000 people). These ward values are the maximum and minimum ranges at ward level for the city (Figure 3.5.1) and also have the highest and lowest recorded prevalence for males and females separately. The recorded rate for males (490 per 100,000 population) is significantly higher than the rate for females (328 per 100,000 population).

Figure 3.5.1



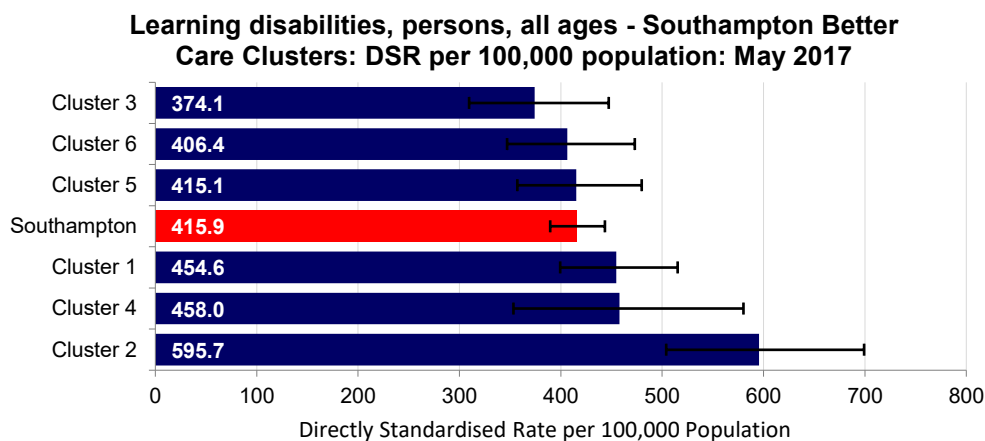
The ACG data shows in figure 3.5.1 Coxford and Redbridge are two of the three wards with the highest prevalence on GP system. Additional data sourced from Southampton City Council (SCC) Adult Social Care systems show at the end of November 2018, Peartree, Redbridge and Coxford wards have the highest counts of people with learning disabilities known to adult social care and receiving services.

Southampton City Council (SCC) adult social care data also indicates that around 1 in 4 people with learning disabilities known to adult social care and receiving services are in supported living group shared accommodation. Wards with the highest GP registered rates for LD do not appear related to the locating of shared accommodation for people with learning disabilities recorded by Adult Social Care. Therefore, the location of shared accommodation does not appear to explain the geographical variation in GP recorded prevalence. However, this does suggest specific areas in which supported living accommodation should be developed.

3.5.2 Prevalence at Better Care Cluster level

Figure 3.5.2 displays the range of the recorded learning disability prevalence by Better Care Cluster. Cluster 2 has the highest prevalence at 596 per 100,000 population, which is significantly higher than Clusters 3, 5 and 6 and the city average. In contrast, Cluster 3 has the lowest prevalence (374 per 100,000 population).

Figure 3.5.2



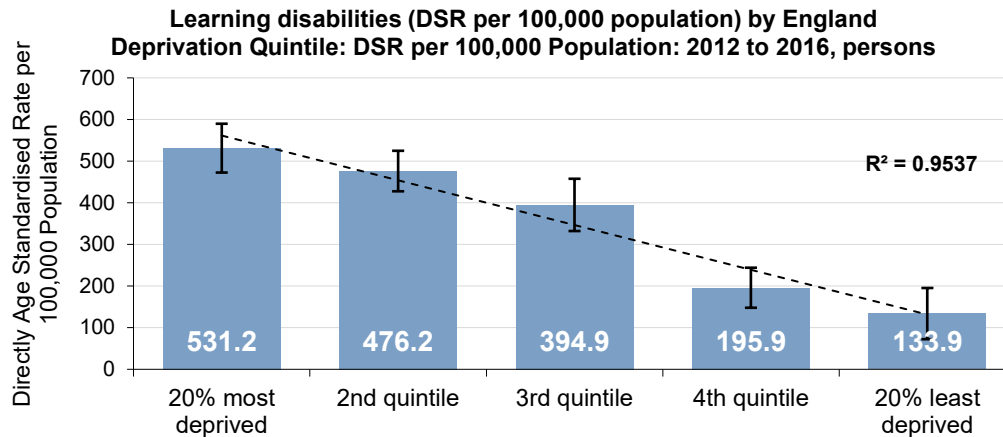
Source: Adjusted Clinical Groups database

SCC adult social care data shows clusters 1, 5 and 6 have the highest counts of people with learning disabilities known to Adult Social Care and receiving services living in that area. Cluster 1, 2 and 6 have the highest counts of learning disabilities known to adult social care and receiving services that are in group shared accommodation within the city. It should be noted that these numbers are not based on rates (and also not standardised for age) and so should not be compared with the GP registered data presented above.

3.5.3 Prevalence by deprivation quintile

Figure 3.5.3 illustrates there is a strong correlation between the prevalence of learning disabilities and the national deprivation quintile. Prevalence in the most deprived areas of the city is four times higher than in the least deprived areas (531 per 100,000 population compared to 134 per 100,000 population). The high R² value (0.95) indicates a strong relationship between the prevalence of learning disabilities and residential area deprivation.

Figure 3.5.3



3.6 Estimated future prevalence

Earlier in this chapter, the estimated prevalence of people with learning disabilities in the city was presented based on data developed by the PANSI and POPPI tools.²⁵ Using the same methodology used to produce these estimates, it is possible to forecast prevalence estimates for the same categories using up to date population estimates. A summary of these forecasts is shown below:

- The number of people with any level of learning disability (mild, moderate or severe) in Southampton is forecasted to increase by around 20 to approximately 5,110 people by 2023 and increase by around 70 people to approximately 5,160 people by 2038 (see figure 3.6.1) However these are likely to underestimate the total number of people with learning disabilities especially those with complex (severe or profound) learning disabilities at each end of the life course (this is suggested to be due to the ageing of the population, increased diagnoses of dementias and improved neonatal advances).
- Approximately 1,100 people are estimated to have a moderate or severe learning disability in Southampton in 2018; this is estimated to rise by another 20 people by 2023, and by 35 people by 2038 (see figure 3.6.2)
- Estimates of people with learning disabilities living with a parent, helps with the planning of carer support. In 2018, it was estimated around 360 people with a learning disability lived with a parent; this is predicted to increase by 30 people over the next 20 years (see figure 3.6.4)
- In 2018, it was estimated that there were 94 people with a learning disability displaying challenging behaviour; this is estimated to increase by 11 people to 105 overall by 2038 (see figure 3.6.5)

²⁵ Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI) and developed by the Institute of Public Care (IPC), Oxford Brookes University explores and uses evidence based estimates on the possible impact that demography and certain conditions may have on populations aged 18-64 years and 65 and over. <http://www.poppi.org.uk/> Accessed 18/10/2018

Figure 3.6.1 Estimated number of people with a mild, moderate or severe learning disability

Southampton	2018	2023	2028	2033	2038
15 to 24	1,353	1,351	1,350	1,349	1,346
25 to 34	1,066	1,074	1,068	1,066	1,072
35 to 44	771	771	778	780	783
45 to 54	656	650	640	636	629
55 to 64	544	558	575	586	594
65 to 74	397	401	402	404	401
75 to 84	210	215	223	229	243
85+	94	94	93	94	94
Total: 15+	5,092	5,114	5,129	5,144	5,162

Figure 3.6.2 Estimated number of people with a moderate or severe learning disability

Southampton	2018	2023	2028	2033	2038
15 to 24	316	320	358	378	372
25 to 34	229	231	217	220	239
35 to 44	194	198	204	205	194
45 to 54	147	141	147	151	157
55 to 64	119	129	128	121	124
65 to 74	64	66	73	80	80
75 to 84	22	26	29	30	34
85+	9	9	10	12	14
Total: 15+	1,099	1,120	1,164	1,198	1,214

Figure 3.6.3 Estimated number of people with a Severe Learning Disability

Southampton	2018	2023	2028	2033	2038
18-24	89	89	89	88	87
25-34	64	65	64	64	65
35-44	52	52	53	53	53
45-54	33	32	32	32	31
55-64	28	28	29	30	30
Total: 18-64	266	267	267	267	267

Figure 3.6.4 People aged 20-64 predicted to have a moderate or severe learning disability and be living with a parent

Southampton	2018	2023	2028	2033	2038
Aged 20-24	125	121	134	148	145
Aged 25-34	119	119	112	114	124
Aged 35-44	76	77	80	80	76
Aged 45-54	34	32	34	35	36
Aged 55-64	11	12	11	11	11
Total 20-64	364	362	372	387	392

Figure 3.6.5 People aged 15 and over with a learning disability, predicted to display challenging behaviour

Southampton	2018	2023	2028	2033	2038
15 to 24	23	23	25	26	26
25 to 34	19	19	18	19	20
35 to 44	14	14	15	15	14
45 to 54	13	12	12	13	13
55 to 64	11	12	12	11	11
65 to 74	8	8	9	10	10
75 to 84	5	6	6	6	7
85+	2	2	2	3	3
Total aged 15 and over	94	96	100	103	105

4. Level of population need: Health and wellbeing

People with learning disabilities have poorer health than the general population, much of which is avoidable. These health inequalities often start early in life and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care. As well as having a poorer quality of life, people with learning disabilities die at a younger age than people without a learning disability.²⁶

The following sections address leading morbidities for people with learning disabilities and how they compare to the general population. Identified patterns and trends will help inform decision-making to reduce health inequalities for people with learning disabilities.

4.1 Life expectancy and mortality

Information from a range of sources consistently reports that people with learning disabilities in England die much younger than the general population (13 to 20 years younger for men with learning disabilities; 20 to 26 years younger for women with learning disabilities). As with the general population, the median age of death for people with learning disabilities is increasing. The faster improvement in male mortality is largely driven by changes seen in tobacco smoking and advances in health treatments for circulatory illnesses.²⁷

Mortality for people with learning disabilities comes from numerous sources and approaches, each of which, is examined in more detail in this section:

- Health and Care of People with Learning Disabilities: Experimental Statistics
- Death certification data

²⁶ Glover G & Ayub M (2010) How people with learning disabilities die Learning Disabilities Observatory http://webarchive.nationalarchives.gov.uk/20160704150527/http://improvinghealthandlives.org.uk/uploads/doc/vid_903_3_IHAL2010-06%20Mortality.pdf Accessed 03/12/18

²⁷ East Sussex Learning <http://www.eastsussexjsna.org.uk/briefings>

- The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)
- The Mazars report
- The National mortality study of people with learning disabilities
- Learning Disabilities Mortality Review (LeDeR) Programme Annual report 2017/2018

4.1.1 Health and Care of People with Learning Disabilities: Experimental Statistics²⁸

Information on people with and without learning disabilities was collected from over half of GP practices in England in 2014/15, 2015/16 and 2016/17, to identify potential differences in the treatment, health status, and outcomes of people with learning disabilities compared with the rest of the population. Within this data set, in 2016/17, 1 in 218 people (0.46 per cent of the population) were recorded as having a learning disability, similar to the Quality Outcome Framework prevalence (Figure 3.2.1).

Combining data from 2014/15 to 2016/17, a female with learning disabilities had almost an 18 year lower life expectancy compared to females without a learning disability (a 66 year life expectancy compared to 84 years). Males with a learning disability had a 14 year lower life expectancy compared to males with no recorded learning disability (66 years compared to 80 years).

In Wessex²⁹, there was an increase in the crude death rate for people with a learning disability between 2014/15 and 2016/17. The crude mortality rate for people with learning disabilities the rates were 8.7 deaths per 1,000 (n=46), 15.5 deaths per 1,000 (n=86) and 11.3 per 1,000 (n=63) respectively. The sample varies year on year because the data does not include data recorded on the GP system, the sample was 51% in 2014/15, 48% in 2015/16 and 48% in 2016/17 (It should be noted that in December 2015, the Mazars report was published on the mortality patterns of people with learning disabilities. Recommendations on the monitoring and learning from this could have been implemented improving data quality for the years 2015/16 and 2016/17.)

The experimental statistics for NHS Southampton CCG showed there were 21 deaths of people with learning disabilities in the sample covering around 48% of GP registered patients for the years 2014/15 to 2016/17. Twenty of these deaths were recorded in 2015/16 and 2016/17. This increase again may be a result of improved data quality and recording. Breaking the data down at age and gender levels for Wessex and NHS Southampton CCG for the years there were no patterns amongst the small numbers.

²⁸ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 05/12/18

²⁹ Includes NHS Dorset CCG, NHS Fareham and Gosport CCG, NHS North East Hampshire And Farnham CCG, NHS North Hampshire CCG, NHS Portsmouth CCG, NHS South Eastern Hampshire CCG, NHS Southampton CCG and NHS West Hampshire CCG

4.1.2 Death certification data

Approximately 450,000 deaths are reported each year in England. It is estimated that around 3,000 of these deaths would be of people where a GP identifies them as having a learning disability.³⁰ In 2014/15, death certificate analysis showed only a third of this estimate; approximately 1,000 death certificates were issued indicating the deceased had a learning disability – these had the learning disability either clearly stated or identified from an additional diagnosis such as Down’s syndrome. This work was undertaken by Glover et al for the Learning Disabilities Observatory³¹ and suggests death certificates identifying people with learning disabilities, may only represent a third of expected deaths. Further analysis of these deaths in this national data set showed the following:

- For men with learning disabilities, the median age at death has risen from 52 years in 2001 to 60 in 2014. For women it has risen from 53 to 58 years.
- The median age at death has also risen over this period for people without learning disabilities, although not by so much (for men from 76 to 79 years and for women from 82 to 84 years)
- The gap in life expectancy for people with learning disabilities compared to those without learning disabilities has fallen in the recent past from 24 to 19 years for men with learning disabilities and from 29 to 26 years for women.
- A closer inspection of the data shows that the largest changes for people with learning disabilities have been decreases in the proportion dying between the ages of 50 and 59 years and increases in the proportions dying between 60 and 69 years of age.

4.1.3 Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)³²

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) studied all deaths in a two year period (between 1 June 2010 and 31 May 2012) of people known to have had a learning disability, who were resident in five primary care trust areas in the South West of England.

The Inquiry found:

- The median age at death for people with learning disabilities was 65 for men and 63 for women; 13 years younger than the national figure for men in the general population, and 20 years younger than that for women
- A fifth (22%) were at ages less than 50 at death, compared with 9% for the general population
- The median age at was lower for more severe degrees of learning disability, being 67.5 for mild, 64 for moderate, 59 for severe and 46 for profound learning disability

³⁰ Public Health England (2016) People with learning disabilities in England 2015: Main report https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf Accessed 22 /10/18

³¹ Glover G & Ayub M (2010) How people with learning disabilities die Learning Disabilities Observatory http://webarchive.nationalarchives.gov.uk/20160704150527/http://improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf Accessed 03/12/18

³² Heslop, P., Blair, P., Fleming, P., Hoghton, M. & Marriott, A. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report. (2013). www.bris.ac.uk/cipold/fullfinalreport.pdf Accessed 28/11/18

- The most common certified, underlying causes of death were heart and circulatory disorders (22%) and cancer (20%). These were also the two most common causes in the general population at the time in whom they accounted for 29% and 30% of deaths respectively

4.1.4 The Mazars report³³

In 2013, NHS England commissioned an independent review into the deaths of people with learning disability or mental health conditions in contact with Southern Health NHS Foundation Trust. Southern Health NHS Foundation Trust provides specialist mental health and learning disability services to patients in Hampshire and parts of Oxfordshire.

The report published in 2015 focussed on the systems in place for reporting, investigating and handling deaths among people with a learning disability. There were a number of recommendations for the trust and their commissioners; learning from deaths can be powerful and can lead to improvements in patient care, increased life expectancy and reduce preventable mortality.

4.1.5 The National mortality study of people with learning disabilities

In 2015/16, the Learning Disabilities Observatory³⁴ studied deaths between April 2010 to March 2014, in collaboration with the national Learning disability mortality review programme (LeDeR)³⁵ and the Medicines and Healthcare products regulatory authority (MHRA). Similarly to CIPOLD, the three most common causes of death for people with learning disabilities were found to be circulatory diseases (22.9% of deaths), respiratory diseases (17.1%) and neoplasms (cancers) (13.1%).

4.1.6 Learning Disabilities Mortality Review (LeDeR) Programme Annual report 2017-2018

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives.

The latest review conducted in 2017/18 shows:³⁶

- Just over half of the deaths (57%) were males
- 96% were single and 9% of them usually lived alone

³³ Mazars LLP (2015) Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015

<https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf> Accessed 4/01/2019

³⁴ Glover, G. & Ayub, M. How people with learning disabilities die. (Improving Health and Lives: Learning Disabilities Observatory, 2010).

https://webarchive.nationalarchives.gov.uk/20160704181356/https://www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf

³⁵ Learning Disabilities Mortality Review (LeDeR) Programme (2016). <http://www.bristol.ac.uk/sps/leder/about/> Accessed 28/11/18

³⁶ Shannon A. NHS Southampton CCG (2018) Learning Disabilities Mortality Review (LeDeR) Programme Annual report 2017-2018 (unpublished at present)

- 93% were of white ethnic background
- 27% had mild learning disabilities, 33% had moderate learning disabilities, 11% had profound learning disabilities, the remainder were unspecified
- 64% of them died in hospital compared to 47% of the general population. Those with profound learning disabilities were more likely to die in hospital (71%) than all the other people with learning disabilities (59%)
- Deaths of younger people with learning disabilities are more likely to occur in hospital than older people with learning disabilities (76% of those under 24 years of age compared to 63% aged 65 and over)
- The median age at death for people with learning disabilities is 59 years for males and 56 years for females; a significant difference to the general population average of 79.2 years for males and 82.9 years for females
 - 28% were people aged under 50 years
 - Median age at death of people with profound learning disabilities was 41 years
 - Median age at death of people with mild or moderate learning disabilities was 63 years

The main causes of death (as identified on part 1 of the death certificate) showed that:

- 31% related to the respiratory system
 - Distributed across all age groups from 18 years+ but more common in 25 – 44 age group
 - 16% pneumonia; 9% aspiration pneumonia
- 16% related to the circulatory system
 - Distributed across all age groups from 18 years+ but more common in the oldest age group
- 10% neoplasms
- 8% nervous system
- 7% diseases of the digestive system
- 7% mental and behavioural disorders
- 6% congenital malformations and chromosomal abnormalities
- 5% diseases of the genitourinary system
- 10% other conditions/diseases

The programme has developed and rolled out a review process for the deaths of people with learning disabilities. This is designed to help to promote and implement the new review process, and provide support to local areas to take forward the lessons learned in the reviews in order to make improvements to service provision.

Locally, the LeDeR review process has had a number of challenges around resourcing. Not enough people have been trained in the processes, and those that are, do not have enough time away from other duties to be able to perform this role, which is not formally mandated or substantively funded locally.

The completed reviews have identified in a number of cases, the health of a person with learning disabilities had been adversely affected by one or more of the following issues:

- Delays in care or treatment
- Gaps in service provision
- Organisational dysfunction
- Lack of reference to the annual learning disability health checks
- Poor follow-up and follow through with the national screening programs

4.2 Prevalence of key morbidities and smoking status

Using data extracted from the Adjusted Clinical Groups (ACG) tool³⁷, which covers the majority of registered patients within NHS Southampton CCG, the prevalence of key morbidities can be compared between people recorded with a learning disability and those without (see figure 4.2.1). For the majority of conditions (with the exception of circulatory), prevalence appears to be higher amongst the learning disability population, although the difference is not always significant. Recorded smoking prevalence is also higher amongst people with a learning disability (18.4% compared to 16.1%), although this is not a statistically significant difference.

Figure 4.2.1

ACG condition group	People without LD				People with LD				LD vs. Non LD Significance
	No.	%Prev	LCI	UCI	No.	%Prev	LCI	UCI	
Smoker	41,945	16.1%	16.0%	16.3%	195	18.4%	16.1%	20.9%	Higher, not sig
Seizure Disorder	2,547	1.0%	0.9%	1.0%	185	17.5%	15.2%	19.9%	Sig-higher
Hypertension	28,914	11.1%	11.0%	11.2%	115	10.8%	9.0%	12.9%	Lower, not sig
Depression (15+)	16,662	6.4%	6.3%	6.5%	110	10.4%	8.6%	12.4%	Sig-higher
Asthma	14,546	5.6%	5.5%	5.7%	115	9.0%	9.0%	12.9%	Sig-higher
Diabetes (15+)	12,818	4.9%	4.8%	5.0%	93	8.8%	7.1%	10.6%	Sig-higher
Hypothyroidism	5,914	2.3%	2.2%	2.3%	59	5.6%	4.3%	7.1%	Sig-higher
Schizophrenia	1,686	0.6%	0.6%	0.7%	56	5.3%	4.0%	6.8%	Sig-higher
Chronic Renal Failure	6,437	2.5%	2.4%	2.5%	35	3.3%	2.3%	4.6%	Higher, not sig
COPD	6,010	2.3%	2.3%	2.4%	31	2.9%	2.0%	4.1%	Higher, not sig
Heart Disease (IHD)	5,925	2.3%	2.2%	2.3%	18	1.7%	1.0%	2.7%	Lower, not sig
Glaucoma	2,765	1.1%	1.0%	1.1%	18	1.7%	1.0%	2.7%	Higher, not sig
Bipolar Disorder	961	0.4%	0.3%	0.4%	10	0.9%	0.5%	1.7%	Sig-higher
Total	259,998				1,060				

Source: Adjusted Clinical Groups

³⁷ The ACG tool or the Adjusted Clinical Groups tool is a person-based system for identifying and measuring patients' morbidity burden, based on demographic, diagnostic and pharmacy data. The tool uses registered patient data to map people and their diseases to different diagnostic groups to facilitate disease profiling at a population level. The tool also records the smoking status of patients.

Some conditions are not available through the ACG tool but can be sourced from the NHS Digital's 'Health and Care of People with Learning Disabilities: Experimental Statistics'³⁸ described in section 5.1.1. Both sources are used in the following sections to compare health diagnoses of people with and without a learning disability. Where possible the ACG tool has been used as it covers the majority of registered patients in Southampton, whilst the data from NHS Digital has a lower coverage, sampling 50% of the GP registered population. Nonetheless, this provides a useful indication and has been used in this section where ACG data is not available (prevalence for indicators that can be extracted from both sources have been compared, showing the NHS Digital sample is representative).

It is worth noting that diagnostic accuracy (and therefore recorded disease prevalence) is likely to be higher for those conditions with more overtly diagnosable clinical symptoms such as epilepsy or chronic renal failure that are diagnosed through biochemical/clinical methods with a lower measurement error such blood/urine tests. This is compared to diagnoses requiring recall and verbalisation (depression) or a consultation assessment requiring the following of specific instructions (e.g. using a machine when blowing out as fast as you can and how much air lung can hold for a spirometry test for asthma) which would have a higher measurement error. This may be especially true for people with a learning disability who may not be able to fully verbalise symptoms or follow diagnostic instructions.

4.3 Circulatory disease

Circulatory disease was found to be the most common cause of death in individuals with learning disabilities in both the CIPOLD (see section 4.1.3) and the LeDeR studies (see sections 4.1.5 and 4.1.6). Circulatory disease is an umbrella term used to describe diseases affecting the heart and connecting blood vessels. As with the general population, coronary heart disease (CHD) is one of the most common causes of death and ill-health (12% of deaths compared to 29% in general population). Additionally, half of those with Down's syndrome have a congenital heart defect.³⁹

The prevalence of diseases of the circulatory system (hypertension, ischaemic heart disease (IHD), heart failure and stroke or transient ischaemic attack) show that, although the overall prevalence of the diseases was either lower than or similar to that in the general population, the diseases are presenting at a much earlier age in people recorded as having a learning disability.

4.3.1 Hypertension

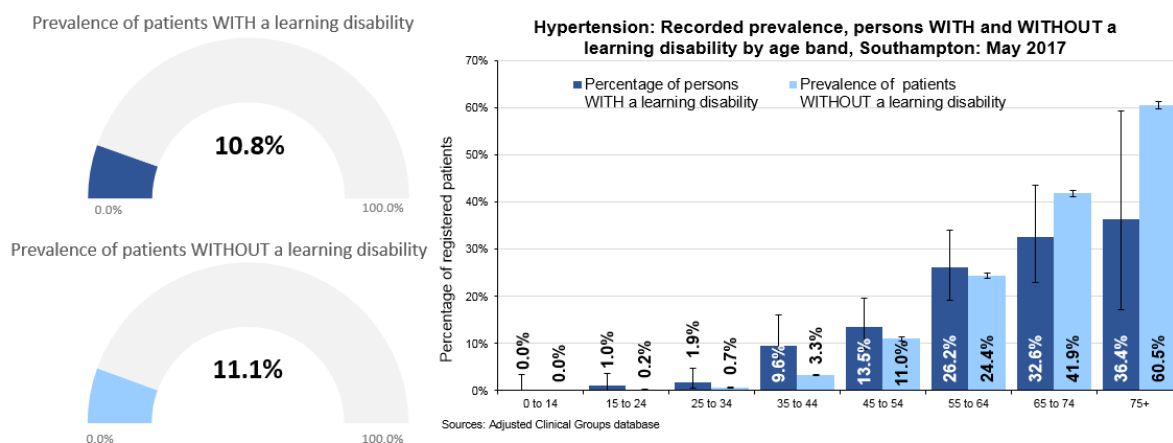
The ACG tool extract shows the prevalence of hypertension among people with a learning disability was lower (10.8%) but not significantly compared to patients without a learning disability (11.1%).

³⁸ NHS Digital (2017) <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/health-and-care-of-people-with-learning-disabilities> Accessed 4/12/18

³⁹ Glover, G. & Ayub, M. How people with learning disabilities die. (Improving Health and Lives: Learning Disabilities Observatory, 2010).
https://webarchive.nationalarchives.gov.uk/20160704181356/https://www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf Accessed 4/12/18

Figure 4.3.1 illustrates the prevalence is higher among those aged 35 to 64 who have learning disabilities. Onset of hypertension appears to be earlier for those with a learning disability, with prevalence significantly higher in the 35 to 44 age group (9.6% compared to 3.3%); this is a statistically significant difference despite the small numbers at this level.

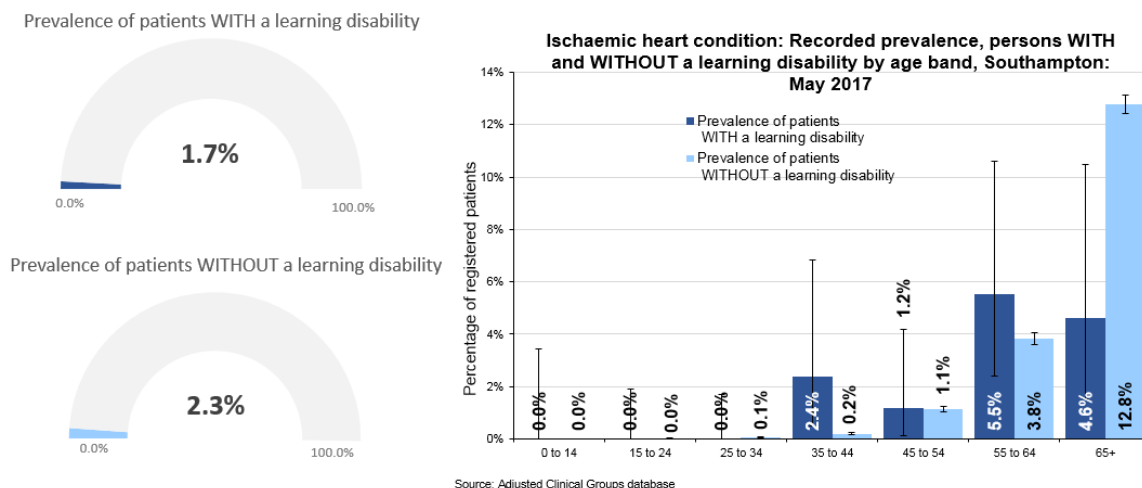
Figure 4.3.1



4.3.2 Ischaemic heart condition

The prevalence of ischaemic heart disease is lower (1.7%) but not significantly so in patients with a learning disability compared with the prevalence in patients without a learning disability (2.3%). The data from the ACG tool again reflects the patterns seen for hypertension, with figure 4.3.2 illustrating a higher prevalence of ischaemic heart disease among those aged 35 to 64 who have learning disabilities, and significantly so for those aged 35 to 44 years old. Local practice data provided by NHS Southampton CCG from the TPP and EMIS system for the financial year 2017/18 puts the prevalence of heart disease in patients with learning disability as 2.3%.

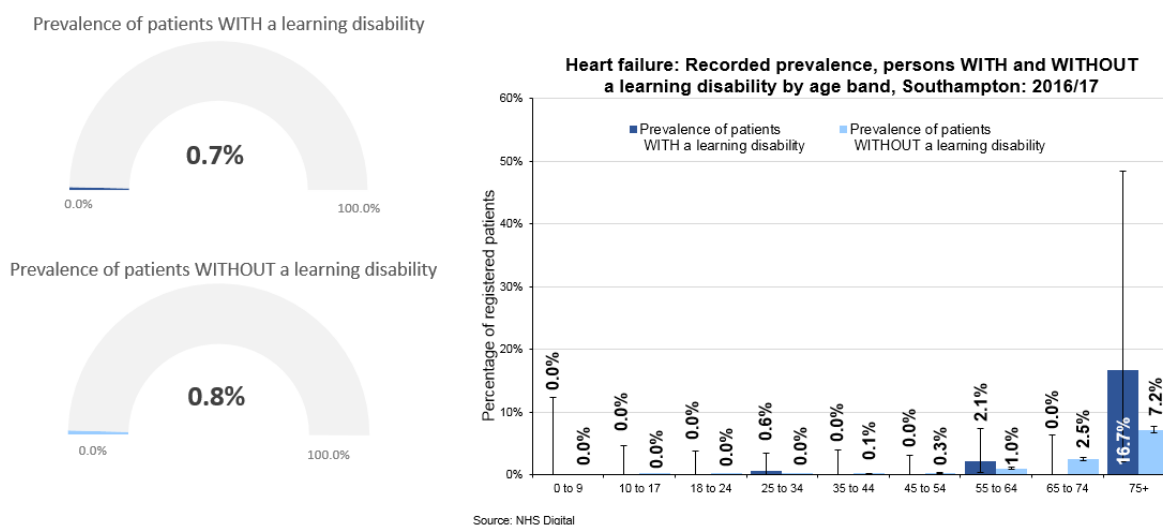
Figure 4.3.2



4.3.3 Heart Failure

Heart failure is not available in the ACG tool. However, in the NHS Digital 2016/17 sample of Southampton patients, a small number of patients with learning disabilities were recorded as having had heart failure (0.7%); lower but not significantly than the prevalence for patients without a learning disability (0.8%). Figure 4.3.3 shows by age band higher prevalence occurs in younger age groups for people with learning disabilities.⁴⁰

Figure 4.3.3

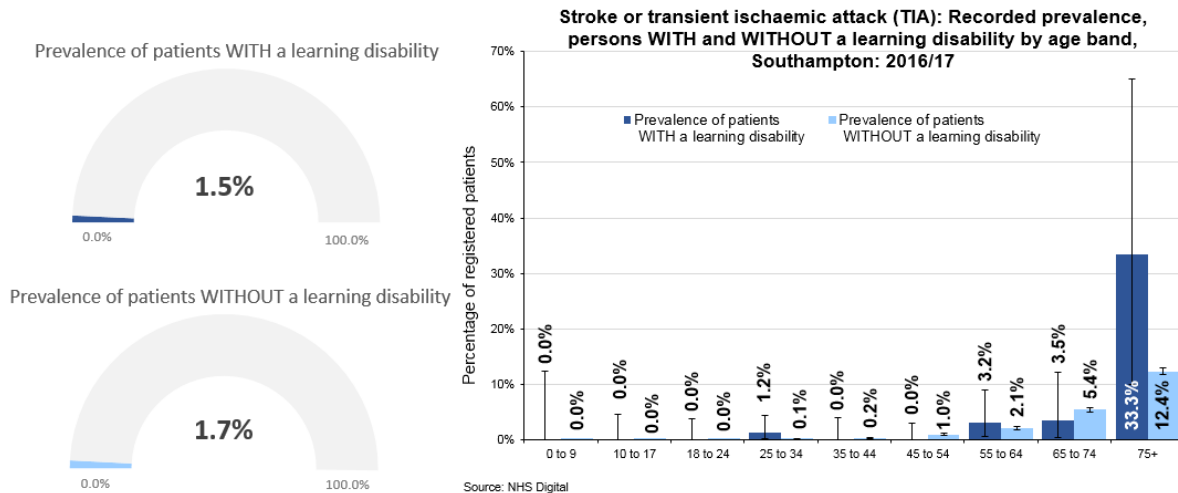


4.3.4 Stroke or transient ischaemic attack (TIA)

Stroke is not available in the ACG tool. However, the sample of 50% of Southampton’s registered patients shows the prevalence of stroke or transient ischaemic attack (TIA) in 2016/17 was lower (1.5%) but not significantly for patients with a learning disability compared with the prevalence for patients without a learning disability (1.7%). As with previously discussed circulatory conditions, higher prevalence of stroke or TIA is evident in the younger age groups for patients with a learning disability, although the numbers are small and differences not statistically significant (see figure 4.3.4).

⁴⁰ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 05/12/18

Figure 4.3.4



4.4 Respiratory disease

Respiratory disease in people with learning disabilities is the most common cause of death (49% compared to 16% in general population). Lung problems (from solids or liquids going down the wrong way) account for 14% of all deaths yet may be preventable. In addition, 4 out of 10 of those having eating and swallowing difficulties have recurrent respiratory tract infections (dysphagia can cause aspiration pneumonia). Respiratory disease particularly common for those with cerebral palsy.^{41 42}

4.4.1 Chronic Obstructive Pulmonary Disease (COPD)

Chronic Obstructive Pulmonary Disease (COPD) is the umbrella term for serious lung conditions that include chronic bronchitis and emphysema and is usually prevalent in adults over the age of 35. As many as 3 million people suffer from COPD in the UK, of which only around a third of cases have been diagnosed. People with COPD have difficulties breathing, which is caused by narrowing of the airways that take air into their lungs. This is called airflow obstruction. Typical symptoms of COPD include increasing breathlessness when active, a persistent cough with phlegm, and recurring chest infections.⁴³

⁴¹ Glover, G. & Ayub, M. How people with learning disabilities die. (Improving Health and Lives: Learning Disabilities Observatory, 2010).

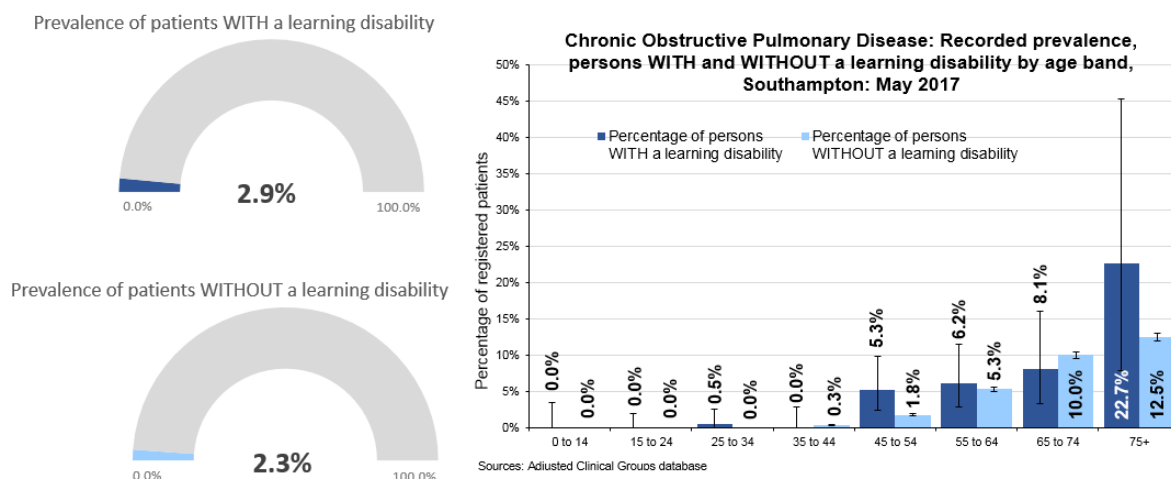
https://webarchive.nationalarchives.gov.uk/20160704181356/https://www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf Accessed 04/12/18

⁴² Public Health England (2016) Health and Care for people with learning disabilities. Gyles Glover IHaL conference presentation

⁴³ NHS Choices COPD page- <http://www.nhs.uk/Conditions/Chronic-obstructive-pulmonary-disease/Pages/Introduction.aspx> Accessed 24/07/2018

Figure 4.4.1 illustrates the ACG data extract for patients diagnosed with COPD. The COPD prevalence for patients with a learning disability (2.9%) is higher, but not significantly so, compared to patients without a learning disability (2.3%).

Figure 4.4.1



The NHS digital tool⁴⁴ shows a lower (but non-significantly different) prevalence of COPD (2.0%) in patients with a recorded learning disability compared to patients without a learning disability (2.4%). However, this is based on a 50% sample and doesn't include GP surgeries that use the TPP System1 system.

Surgeries using the TPP System1 system have patients living, on average, in areas with a slightly higher deprivation score. COPD is linked to deprivation and therefore practices in these areas may have slightly higher rates and may also have GPs specialising in the diagnosis, which may explain some of the difference with the ACG data. Right care pathway for COPD has highlighted the importance of accurate diagnosis and early detection, and there will be further information released next year regarding misdiagnosis of respiratory conditions.

Local practice data provided by Primary Care commissioning at NHS Southampton CCG from the TPP and EMIS system for the financial year 2017/18 puts the prevalence of COPD in patients with learning disability as 2.7%. The prevalence recorded on TPP System1 alone was 3.4%.

4.4.2 Influenza

Influenza is a common cause of potentially avoidable hospital admission. Following the CIPOLD report, a recommendation was made to make the influenza vaccination available to all adults with a learning disability. This was implemented in 2014/15⁴⁵ and the uptake according to NHS Digital was 43.2%.

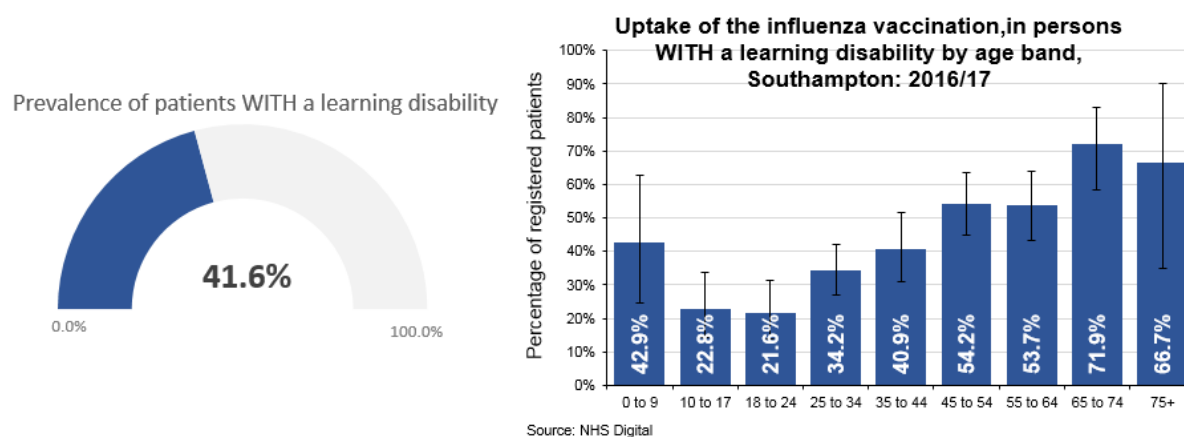
⁴⁴ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 05/12/18

⁴⁵ Data set coverage for 2014/15 was 46% of GP registered patients

The most recently available figures for uptake in 2016/17 show 308 patients with learning disabilities (41.6%) received a seasonal influenza immunisation, up from 39% in 2015/16⁴⁶. Figure 4.4.2 shows the 2016/17 uptake by age band and illustrates how uptake is higher in the very young and pensionable older age groups, perhaps reflecting where there is more focus and promotion for the vaccine among the general population.

Although uptake has increased slightly over the last few years there remain reports on the confusion of eligibility since the programme was spread more widely for both people with a learning disability and their carer or carers.

Figure 4.4.2



As a means of making the programme more accessible to patients with learning disabilities, those that were distressed by needles could use the nasal spray vaccine. It is also important for carers of people with learning disabilities to get immunised against influenza as this can prevent the onward transmission of the virus. In addition, longer appointment times could be allowed for those people with learning disabilities so they can be put at ease by a nurse practitioner; this would fall under the reasonable adjustments approach.

In Southampton, approximately 40% of people with Learning Disabilities had the flu vaccine during 2017/18 flu season, which reflects national statistics. During the 2018/19 flu season, the Strategic Health Facilitator has put an emphasis on increasing uptake by releasing a Learning Disability specific communications alert on influenza to all GP surgery staff, sharing easy to read information and a video to all day services in the city, supported living providers and the Community Learning Disability Health Team. Social media has also been a platform for raising awareness.

Local practice data provided by Primary Care commissioning at NHS Southampton CCG from the TPP and EMIS system for the financial year 2017/18 puts 'flu vaccination uptake in patients with learning disability as 37.7%.

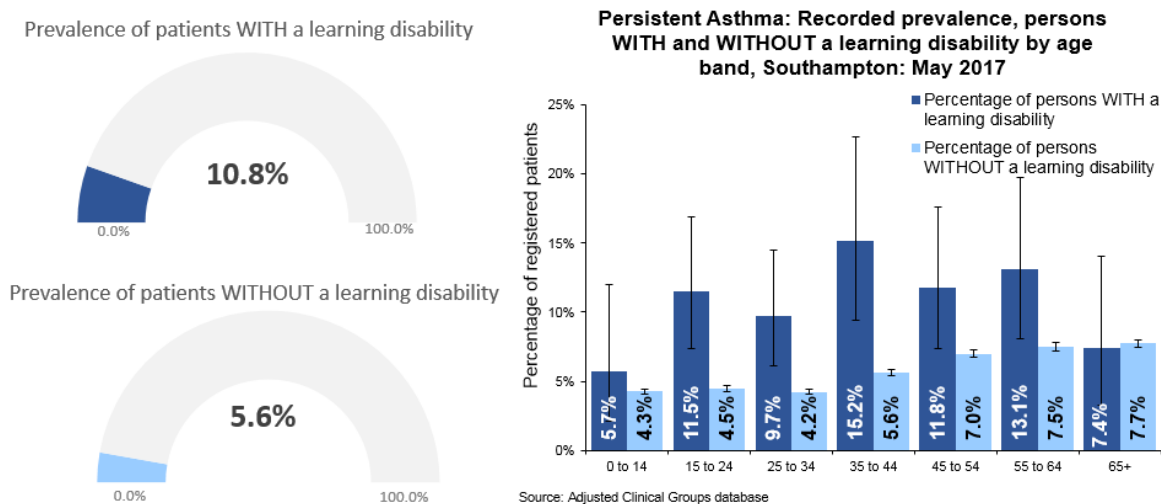
⁴⁶ Data set coverage for 2015/16 was 39% of GP registered patients

4.4.3 Asthma

The ACG tool showed 115 GP patients with learning disabilities had an active diagnosis of asthma. This was a prevalence of 10.8%, about 1 in 9 people, significantly higher than the prevalence of an active diagnosis of asthma in patients without a recorded a learning disability (5.6%). Prevalence was significantly higher for those with a learning disability aged 15 to 54 years, with the prevalence in those aged 35-44 years 2.7 times higher (see figure 4.4.3).

The NHS Digital tool showed the prevalence of an active diagnosis of asthma in 2016/17 in the 50% sample of Southampton GP registered patients to be 8.6% for patients with a learning disability and 5.9% for patients without.⁴⁷

Figure 4.4.3



Local practice data provided by Primary Care commissioning at NHS Southampton CCG from the TPP and EMIS system for the financial year 2017/18 puts the prevalence of asthma in patients with learning disability as 21.9%.

4.4.4 Dysphagia and Aspiration Pneumonia

Dysphagia is the medical term for swallowing problems. There are different causes and types of dysphagia. Some people have difficulty swallowing specific types of food or liquids. Some people cannot swallow at all. Difficulties in any of the main stages of the eating, drinking and swallowing process can be called dysphagia.

There are no reliable data on the prevalence of dysphagia in people with learning disabilities. Historically, estimates have ranged from 36% (based on speech and language therapy caseloads) to

⁴⁷ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 05/12/18

over 70% (based on inpatient populations). More recent studies have shown that about 15% of adults with learning disabilities require support with eating and drinking and 8% of those known to learning disability services will have dysphagia.⁴⁸

Local estimates, using the 50% sample of Southampton GP registered patients, estimate 8.2% (61 patients) of those with a learning disability have a diagnosis of dysphagia. The same data source records the prevalence of gastric oesophageal reflux disease (GORD), which is 8.0% for Southampton CCG patients with a learning disability. Both have a higher prevalence in older age groups.⁴⁹

It is generally accepted that people with learning disabilities are more likely to have dysphagia than other people. As far back as 2004, the National Patient Safety Agency (NPSA) identified it as a significant health risk for people with learning disabilities. Dysphagia can result in choking and may lead to death. The Mazars report (see section 4.1.4) highlighted particular concerns around dysphagia assessments and the management of eating and drinking difficulties. The report made a number of recommendations, including the need to investigate the quality, timing and follow-up of dysphagia assessments.

Swallowing problems can result in people breathing in food or drink, which can then lead to aspiration pneumonia. Figures show that 40% of people with learning disabilities and dysphagia experience recurrent respiratory tract infections. The confidential inquiry into premature deaths of people with learning disabilities (CIPOLD) identified aspiration pneumonia as a significant cause of death.⁵⁰

Of the deaths⁵¹ notified to the LeDeR programme almost a third (31%) had an underlying cause related to diseases of the respiratory system, with the most common individual cause of death being pneumonia (16%) and the third most common being aspiration pneumonia (9%).⁵²

In the Wessex region there were six deaths as a result of choking in 2016. The Southampton LeDeR Program Local Area Contact has found death certificates do not always record choking when choking was a contributory factor or underlying cause; aspiration pneumonia is related to choking as it is caused by inhaling food, stomach acid, or saliva into your lungs. In neighbouring Hampshire, between 2005 and 2010, there were five deaths as a result of choking incidents in people with learning disabilities. As a result of identifying common themes in these deaths, data were submitted to the

⁴⁸ Public Health England (2016) Dysphagia in people with learning difficulties: reasonable adjustments guidance <https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-disabilities/dysphagia-in-people-with-learning-difficulties-reasonable-adjustments-guidance> Accessed 4/12/18

⁴⁹ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 05/12/18

⁵⁰ Public Health England (2016) Dysphagia in people with learning difficulties: reasonable adjustments guidance <https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-disabilities/dysphagia-in-people-with-learning-difficulties-reasonable-adjustments-guidance> Accessed 4/12/18

⁵¹ From 1st July 2016 to 30th November 2017, 1,311 deaths were notified to the LeDeR programme.

⁵² University of Bristol Norah Fry Centre for Disability Studies and NHS England (2017) The Learning Disabilities Mortality Review Annual Report 2017 http://www.bristol.ac.uk/media-library/sites/sps/leder/leder_annual_report_2016-2017.pdf Accessed 11/12/18

Hampshire Safeguarding Adults Board. A multi-agency steering group was formed in order to identify areas for improvement and to prevent future deaths. There were many recommendations consisting of simple measures that commissioners and providers could already take. This included supporting uptake of annual health checks, dental health checks and the hospital passport, optimising the use of guidance from speech & language therapists and following guidance to assess and manage the risk of choking.⁵³

People with learning disabilities have greater unmet oral health needs, poorer access to dental services and less preventative dentistry than people in the general population (Public Health England)

4.4.5 Dental and Oral Health

Guidance⁵⁴ published by Public Health England in March 2019 states that:

The evidence shows that people with learning disabilities have poorer oral health and more problems in accessing dental services than people in the general population. People with learning disabilities may need additional help with their oral care and support to get good dental treatment because of cognitive, physical and behavioral factors.

The guidance goes on to describe that:

Support for good oral and dental care is an essential part of promoting good health and quality of life for people with learning disabilities³. However, national and international research, including systematic reviews, consistently shows that people with learning disabilities have:

- *higher levels of gum (periodontal) disease*
- *greater gingival inflammation*
- *higher numbers of missing teeth*
- *increased rates of toothlessness (edentulism)*
- *higher plaque levels*
- *greater unmet oral health needs*
- *poorer access to dental services and less preventative dentistry*

The guidance gives example of what is known to work well in supporting people with learning disabilities to have good oral health, including:

- At an individual level:
 - Making adjustments which will reduce anxiety about visiting a dentist

⁵³ Hampshire Safeguarding Adults Board Multi-agency Partnership (2012) Reducing the risk of choking for people with a learning disability: A Multi-agency review in Hampshire
<http://documents.hants.gov.uk/adultservices/safeguarding/Reducingtheriskofchokingforpeoplewithalearningdisability.pdf>
Accessed 20/12/2018

⁵⁴ PHE England (2019) Oral Care and People with Learning Disabilities: <https://www.gov.uk/government/publications/oral-care-and-people-with-learning-disabilities/oral-care-and-people-with-learning-disabilities#what-we-know-about-what-works-at-a-service-level> Accessed

- Building a relationship
- At a service level:
 - Training and education for dental professionals as well as carers and people with learning disabilities
 - Collaborative working between mainstream and specialist learning disability health services
 - Managing situations where a general anaesthetic is needed
 - Assessing population needs

Community Dental Services are commissioned for patients who may have difficulty accessing mainstream dental services. This often includes people with learning disabilities.

4.5 Endocrine, renal and digestive system disorders

The main glands of the endocrine system are the adrenal glands, ovaries and testicles, pancreas, pituitary gland, parathyroid glands and thyroid gland. These glands secrete hormones (chemical messengers) into the circulation which have an effect on specific organs of the body. Diabetes and hypothyroidism are key endocrine conditions. Diabetes is near twice as common in people with learning disabilities (1.9 times) than in the general population, influenced in part by higher rates of obesity.⁵⁵ Hypothyroidism is common among those with Down's syndrome.⁵⁶

The urinary system also known as the renal system, produces, stores and eliminates urine, the fluid waste excreted by the kidneys. The kidneys make urine by filtering wastes and extra water from blood. Urine travels from the kidneys through two thin tubes called ureters and fills the bladder. Chronic renal failure is also called chronic kidney failure, which can be caused by diabetes.⁵⁷ Section 4.5.3 shows in Southampton, chronic renal failure has a higher prevalence in people with learning disabilities.

4.5.1 Diabetes

The prevalence of both Type 1 and Type 2 diabetes were identified to be higher in people with a learning disability compared to the general population. Identified risk factors for those with learning disabilities include, having (on average) a more sedentary lifestyle, having higher fat diets and a much higher rate of prescribed antipsychotic medication which can contribute to obesity. Higher rates of obesity were also seen in people with a learning disability compared to those without.

⁵⁵ Glover, G. & Ayub, M. How people with learning disabilities die. (Improving Health and Lives: Learning Disabilities Observatory, 2010).

https://webarchive.nationalarchives.gov.uk/20160704181356/https://www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf Accessed 04/12/18

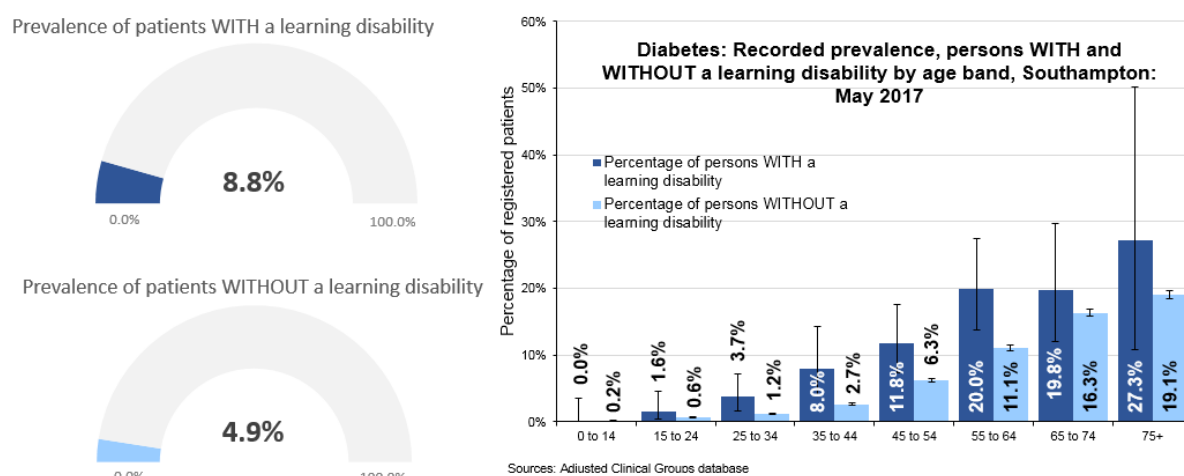
⁵⁶ Public Health England (2016) Health and Care for people with learning disabilities. Gyles Glover IHaL conference presentation

⁵⁷ NHS Choices Chronic Kidney Disease (2016) <https://www.nhs.uk/conditions/kidney-disease/> Accessed 04/12/18

Making reasonable adjustments for those with diabetes and a learning disability will not only improve diagnosis and detection of the condition but has other benefits including reducing GP visits, missed appointments, diabetes related A&E appointments and complications arising from diabetes such as amputations.⁵⁸

In 2017, registered patients (aged 15 years and over) with a learning disability in Southampton CCG had a significantly higher prevalence of diabetes (8.8%) compared to the diagnosed diabetes prevalence in patients without a learning disability (4.9%). Figure 4.5.1 shows a higher prevalence of diabetes in most age groups for people with a learning disability compared to those without.

Figure 4.5.1



The NHS Digital tool⁵⁹ showed the prevalence Type 1 and non-Type 1 diabetes Mellitus to be 8.5% in 2016/17 for patients with a learning disability; significantly higher than the prevalence of 5.1% for patients without. The prevalence is similar to the prevalence from the ACG tool. Prevalence by age group was also similar.

Evidence⁶⁰ suggests that around one in 10 learning disabled adults are likely to be blind or partially sighted, ten times higher than the general population. Learning disabilities and conditions that may have a direct impact on vision are Down’s syndrome, Fragile X, Cerebral Palsy and Willams Syndrome. Analysis of the ACG tool data extract for May 2017 found 18 patients (1.7%) with learning disabilities in the city were diagnosed with glaucoma, higher but not significantly than the prevalence of glaucoma in patients without a learning disability (1.1%). Diabetes can also cause sight loss. Therefore, it is

⁵⁸Kachika J. NHS RightCare (2017) NHS RightCare Pathway: Diabetes Reasonable adjustments for people with a learning disability who have diabetes <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2017/11/rightcare-pathway-diabetes-reasonable-adjustments-learning-disability-2.pdf>

⁵⁹Which uses 50% sample of Southampton GP registered patients

⁶⁰Emerson R & Robertson J, RNIB and SeeAbility Learning Disabilities Observatory (2011) The estimated prevalence of visual impairment among people with learning disabilities in the UK. <https://www.rnib.org.uk/knowledge-and-research-hub/research-reports/prevention-sight-loss/prevalence-vi-learning-disabilities> Accessed 11/12/18

important to encourage diabetic retinopathy screening among people with learning disabilities with diabetes.

Reasonable adjustments are set out by NHS Rightcare⁶¹ who recommend that:

- Commissioners should work with their GP practices to develop a local process to enhance the National Diabetes Audit data to have better understanding of local needs for those with diabetes
- Commissioners should work with GPs providing Annual Health Checks for people with a learning disability as part of the Directed Enhanced Service (DES) and increase uptake
- Services should work to improve diabetes management as this has the potential to improve general health outcomes in people with a learning disability and avoid unnecessary hospital admissions (diabetes accounts for 7.0% to 7.5% of avoidable hospital admissions in people with diabetes)
- Reducing lengthy hospital stays through specialist care teams; for example Multi-Disciplinary Foot Care Teams (MDFTs) and Diabetes Inpatient Specialist Nurses (DISNs) play a vital role in reducing hospital stays as well as reducing complications of diabetes such as amputations. Co-ordinated services between specialist learning disability services and mainstream services allows clinical discussions that achieve better results
- Supporting a healthy lifestyle using Community Learning Disability Nurses that build up skills and knowledge on how to manage diabetes in the local community with a particular focus on family carers and the third sector
- Supporting structured education and self-management as people with a learning disability and diabetes can benefit from personalised support with weight management, physical activity and self-management, provided as part of an adjusted evidence-based programme.

4.5.2 Hypothyroidism

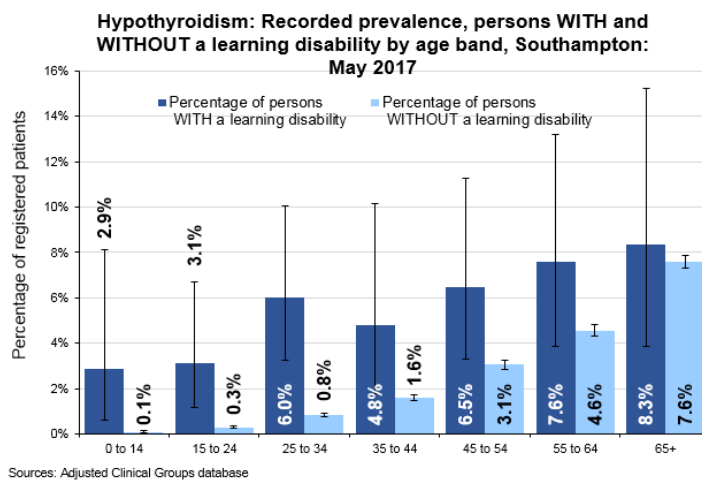
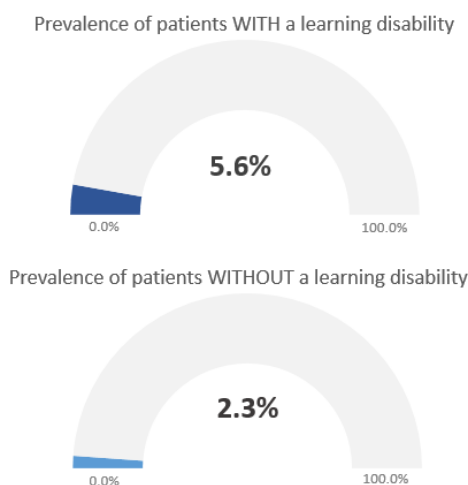
An underactive thyroid gland (hypothyroidism) is where your thyroid gland doesn't produce enough hormones. Common signs of an underactive thyroid are tiredness, weight gain and feeling depressed. A recent study by Carey *et al.* found patients with learning disabilities experienced a moderately increased risk (double) of hypothyroidism 2.7 times higher for those with a learning disability compared to those without - 7.9% compared to 3.1%).⁶²

Figure 4.5.2 uses data from the ACG tool (May 2017 extract) and shows the prevalence of hypothyroidism among patients with a learning disability to be 5.6% in Southampton; significantly higher than the prevalence in patients without a learning disability (2.3%).

⁶¹Kachika J, NHS England (2017) NHS RightCare Pathway: Diabetes Reasonable adjustments for people with a learning disability who have diabetes <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2017/11/rightcare-pathway-diabetes-reasonable-adjustments-learning-disability-2.pdf> Accessed 11/12/18

⁶²Carey IM, Shah. SM, Hosking F, DeWilde S, Harris T, Beighton, Cook DG. British Journal of General Practice (2016) Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice. <https://bjgp.org/content/66/645/e264> Accessed 6/12/18

Figure 4.5.2

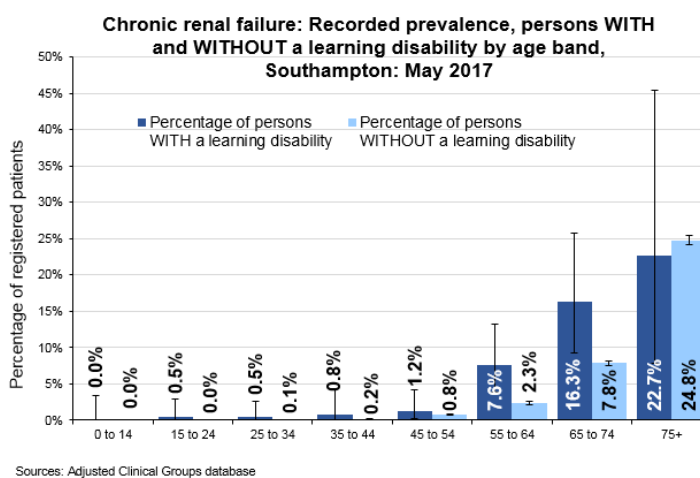
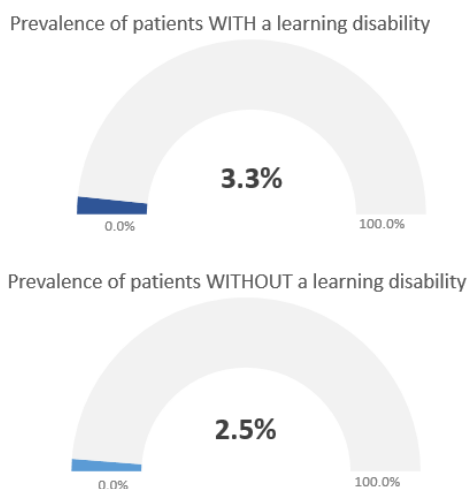


The 2016/17 national data from NHS Digital reported the prevalence of hypothyroidism as 8.1% for patients with learning disability and 3.6% for those without a learning disability. Locally the tool showed the prevalence for Southampton CCG to be 6.8% and 3.0% respectively.⁶³

4.5.3 Chronic renal failure

The chronic renal failure data extracted from the ACG tool is illustrated in figure 4.5.3 and shows the diagnosed prevalence of chronic renal failure for patients with learning disabilities to be 3.3%; once again higher but not significantly than the prevalence amongst people without learning disabilities (2.5%). Prevalence appears to be generally higher in people with a learning disability across all ages up to 75.

Figure 4.5.3



⁶³NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 0/12/18

The NHS Learning Disabilities Experimental Statistics tool⁶⁴ shows a similar picture, with the prevalence of patients with an active diagnosis of chronic kidney disease (CKD) at stages 3-5 to be 3.8% for people with a learning disability; higher but not significantly than the prevalence amongst people without a learning disability (2.6%). Once again there was a higher prevalence in the older age bands but increasing earlier in age for people with a learning disability.

4.6 Sepsis

Sepsis is a serious complication of an infection in any part of the body. Sepsis is often referred to as either blood poisoning or septicaemia, these terms refer to the invasion of bacteria into the bloodstream. Sepsis can affect multiple organs or the entire body, even without blood poisoning or septicaemia. The most common sites of infection leading to sepsis are the lungs, urinary tract, tummy (abdomen) and pelvis. There are around 250,000 cases of sepsis a year in the UK according to the UK Sepsis Trust. At least 46,000 people die every year as a result of the condition.⁶⁵

In 2017, 11 per cent of notified deaths to the LeDeR programme cited sepsis as a cause, or contributory cause, of death. Between January 2018 and June 2018, nine per cent of notified deaths to the LeDeR programme cited sepsis as a cause, or contributory cause, of death. The key areas of focus for better prevention, detection and treatment of sepsis include⁶⁶:

- Sharing of important information, including electronically, about people with learning disabilities between health and care professionals across settings (e.g. Purple folder/Red bag schemes, or All About Me' passport)
- Supporting health and care professionals to spot the signs of acute deterioration, including sepsis, in people with learning disabilities
- Supporting carers to spot the signs of acute deterioration, including sepsis, in people with learning disabilities (though tools like Hampshire's Restore 2 tool⁶⁷).
- Facilitating the promotion and sharing of best practice.

4.7 Mental health, mental wellbeing and neurological conditions

The 2011 cross-government mental health outcomes strategy for people of all ages was entitled '*No health without mental health*'⁶⁸, building on the parity of esteem between physical and mental health

⁶⁴ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 05/12/18

⁶⁵ NHS Health A-Z (2016) Sepsis <https://www.nhs.uk/conditions/sepsis/> Accessed 31/12/2018

⁶⁶ Learning Disabilities Mortality Review (LeDeR) Programme (2018) Learning into Action Bulletin <https://www.bristol.ac.uk/media-library/sites/sps/leder/SepsisSeptnewsletterFINAL.pdf> Accessed 31/12/2018

⁶⁷ A patient/carer facing safety netting tool containing visual representation.

⁶⁸ HM Government and Dept. of Health (2011) No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf Accessed 6/12/18

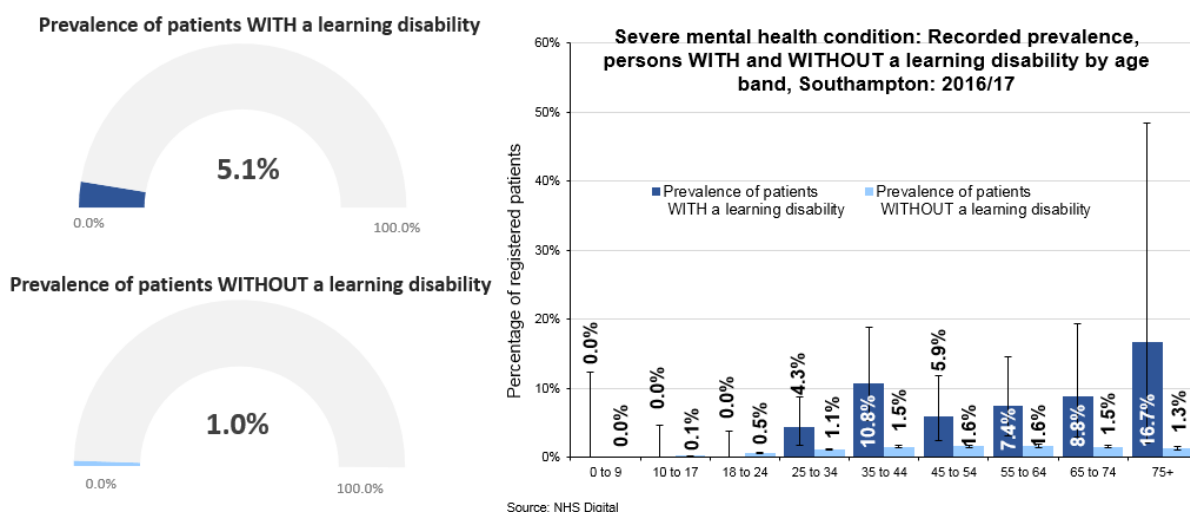
services set out by the Government white paper ‘Healthy lives, healthy people’ with the foreword stating ‘*tackling poor mental health could reduce our overall burden by nearly a quarter*’.⁶⁹ Good mental health underpins good physical health.

A significantly higher proportion of people with a learning disability have a mental health problem than in the general population,⁷⁰ with evidence published by PHE suggesting that prevalence is higher amongst people with learning disabilities for many mental health conditions.⁷¹ Key findings include:

- Three times higher prevalence for schizophrenia than the general population
- Anxiety and depression higher than general population, particularly among those with Down’s syndrome
- 36% of children with learning disabilities have a psychiatric disorder compared to 8% in general population
- Of all children with a psychiatric disorder, 14% have learning disabilities

NHS Digital data from 2016/17 displayed in figure 4.7.1 shows that approximately 5.1% of the 50% sample of the Southampton GP population with a learning disability have a severe mental health condition, significantly higher when compared to 1.0% of the population without learning disabilities. The breakdown by age group is based on very small numbers with wide confidence intervals, and therefore should be treated with some caution.

Figure 4.7.1



⁶⁹ Department of Health. Healthy Lives, Healthy People: our strategy for public health in England, CM7985. London: Stationery Office; 2010.

⁷⁰Mencap. Learning Disability Explained: Mental Health <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health-research-and-statistics/mental-health> Accessed 6/12/18

⁷¹ Public Health England (2016) Health and Care for people with learning disabilities. Gyles Glover IHaL conference presentation https://www.phe-events.org.uk/HPA/media/uploaded/EVHPA/event_553/PHE_Learning_Disabilities_Conference_2016_slides.pdf Accessed 6 December 2012

Risk factors for poor mental health can affect anyone, but people with learning disabilities have an increased risk and/or poorer prognosis for a number of specific mental health problems. These are schizophrenia, generalised anxiety disorders, affective illnesses and dementia. Mencap⁷² have summarised some of the reasons why people with a learning disability are more susceptible to mental health problems:

- Biology and genetics may increase vulnerability to mental health problems (long term pain potentially leading to distress, irritability and anger)
- A higher incidence of negative life events (deprivation, poverty and other adverse life events)
- Access to fewer resources including ‘resilience’ and coping skills
- The impact of other people’s attitudes

The NHS Mandate for 2014/15 directly states that ‘NHS England’s objective is to put mental health on a par with physical health’⁷³, known as ‘parity of esteem’. The parity approach ensures that an individual receives a ‘whole-person’ attitude throughout health services, including in the local authority and addresses the ‘unacceptable variations of care provided to patients, which can have devastating effects on individuals and their families’.⁷⁴

All individuals face barriers to this approach due to stigma associated with mental ill health. However, people with learning disabilities may face additional barriers. The lack of services available, timely diagnosis, physical barriers to accessing services and failures to make reasonable adjustments have been identified as organisational barriers for people with learning disabilities to access the care they need⁷⁵.

4.7.1 Depression

Reported prevalence rates for anxiety and depression among adults with learning disabilities vary widely, but are generally reported to be at least as prevalent as in the general population and higher among people with Down syndrome.⁷⁶

⁷² Mencap (2017) Learning disability explained: Mental health <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/mental-health> Accessed 10/12/18

⁷³ Department of Health and Social Care (2013) A mandate from the Government to NHS England: April 2014 to March 2015 <https://www.gov.uk/government/publications/nhs-mandate-2014-to-2015> Accessed 10/12/18

⁷⁴ NHS England (2014) NHS Five Year Forward View <https://www.england.nhs.uk/publication/nhs-five-year-forward-view/> Accessed 10/12/18

⁷⁵ British Medical Association Board of Science. 2014 Recognising the importance of physical health in mental health and intellectual disability. Achieving parity of outcomes. British Medical Association: London

⁷⁶ Emerson E & Baines S. Tizard Learning Disability Review (2011) Health inequalities and people with learning disabilities in the UK. http://complexneeds.org.uk/modules/Module-4.1-Working-with-other-professionals/All/downloads/m13p020c/emerson_baines_health_inequalities.pdf Accessed 7/12/18

Figure 4.7.2

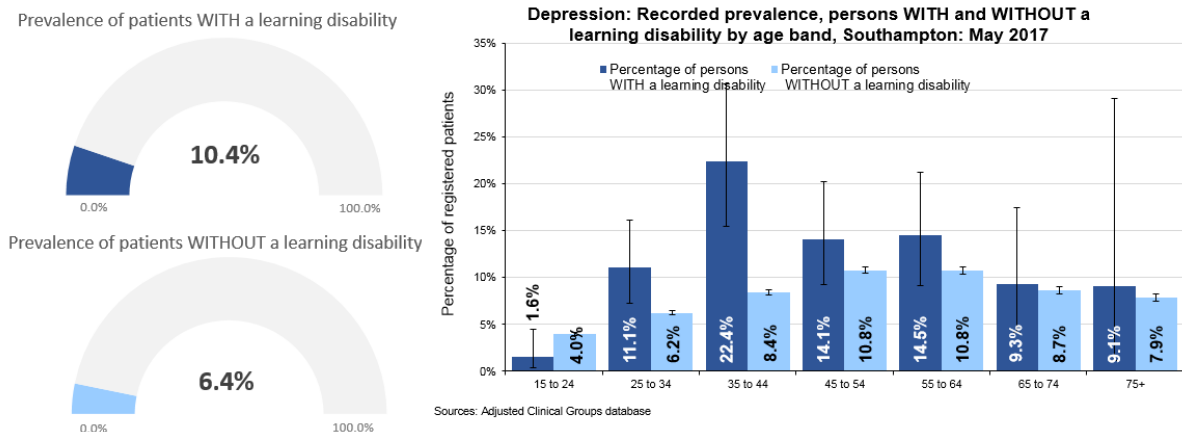


Figure 4.7.2 shows the prevalence of depression using data extracted from the ACG tool. The recorded prevalence of depression in patients with a recorded learning disability is 10.4%, significantly higher than in people without a learning disability (6.4%). For patients over the age of 25, a higher prevalence by age band are seen in people with learning disabilities compared to peers of a similar age. For those aged 25 to 34 years and 45 to 54 years the recorded prevalence is significantly higher.

4.7.2 Dementia

Due to improved diagnosis and care of people with learning disabilities, life expectancy has dramatically increased from approximately 25 years in 1983 to over 60 years in 2015. As people with learning disabilities are now living longer, they are living to an age where they are more likely to develop dementia. Nationally, one in fourteen of the total population aged over 65 are predicted to develop dementia.⁷⁷ This compares to one in five people with a learning disability over the age of 65.⁷⁸ In Southampton, this equates to 20 people based on the current prevalence of patients with learning disabilities aged over 65 years (May 2017 ACG tool extract).

Down’s syndrome is a major risk factor for developing dementia. It is estimated that 1 in 50 people with Down’s syndrome will develop dementia in their 30s and this rises to more than half when an individual reaches 60 and over. Epileptic seizures are more common in people with Down’s syndrome than the general population. However, a sign that someone with Down’s syndrome has dementia is if that individual starts to develop epileptic seizures later in life. These should be fully investigated to aid early diagnosis and preparation for future care.⁷⁹

⁷⁷King’s College London and the London School of Economics 2014 Alzheimer’s Society: Dementia UK report https://www.alzheimers.org.uk/info/20025/policy_and_influencing/251/dementia_uk Accessed 10/12/18

⁷⁸ Emerson E & Baines S. Tizard Learning Disability Review (2011) Health inequalities and people with learning disabilities in the UK. http://complexneeds.org.uk/modules/Module-4.1-Working-with-other-professionals/All/downloads/m13p020c/emerson_baines_health_inequalities.pdf Accessed 7/12/18

⁷⁹ Alzheimer’s Society (2015) <https://www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia> Accessed 11/12/18

Dementia largely presents in a similar manner for people with and without learning disabilities. However, there are some important differences that need to be recognised. The Alzheimer's Society⁸⁰ listed a number of these; people with learning disabilities:

- Often show different symptoms in the early stages of dementia
- Are more likely to have other physical health conditions which are not always well managed
- Are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis
- May experience a more rapid progression of dementia, although this can be complicated by difficulty or delay in diagnosis
- Need specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses

When an individual develops dementia it is important to enable those who are using services to continue to receive the support they need for their learning disability throughout their dementia journey. When care changes suddenly, health tends to deteriorate and this change can be confusing for people with both learning disabilities and dementia. If an individual with a learning disability living in a residential care setting develops dementia, needs are assessed on an individual basis as to whether they stay residing in a learning disability setting or transfer to either nursing care or older people's care. In either case, there needs to be consistency in the support available to meet the requirements for both elements of their health care needs.

The ACG tool shows 9 patients with learning disabilities who had a diagnosis of dementia in Southampton in May 2017; a prevalence of 0.8%. This is higher than the prevalence amongst the general population (0.6%), although this difference is not significant. The Tizard review⁸¹ found the prevalence of dementia is higher among older adults with learning disabilities than in the general population (22% vs 6% for those aged 65+), and is associated with a range of potentially challenging behaviours and health problems.

4.7.3 Schizophrenia

The Tizard review also found there is some evidence that the prevalence rates for schizophrenia in people with learning disabilities are approximately three times as great as for the general population.

⁸⁰Alzheimer's Society (2015) Learning disabilities and dementia Factsheet 430LP

https://www.alzheimers.org.uk/download/downloads/id/1763/factsheet_learning_disabilities_and_dementia.pdf

⁸¹ Emerson E & Baines S. Tizard Learning Disability Review (2011) Health inequalities and people with learning disabilities in the UK. http://complexneeds.org.uk/modules/Module-4.1-Working-with-other-professionals/All/downloads/m13p020c/emerson_baines_health_inequalities.pdf Accessed 7/12/18

Figure 4.7.3

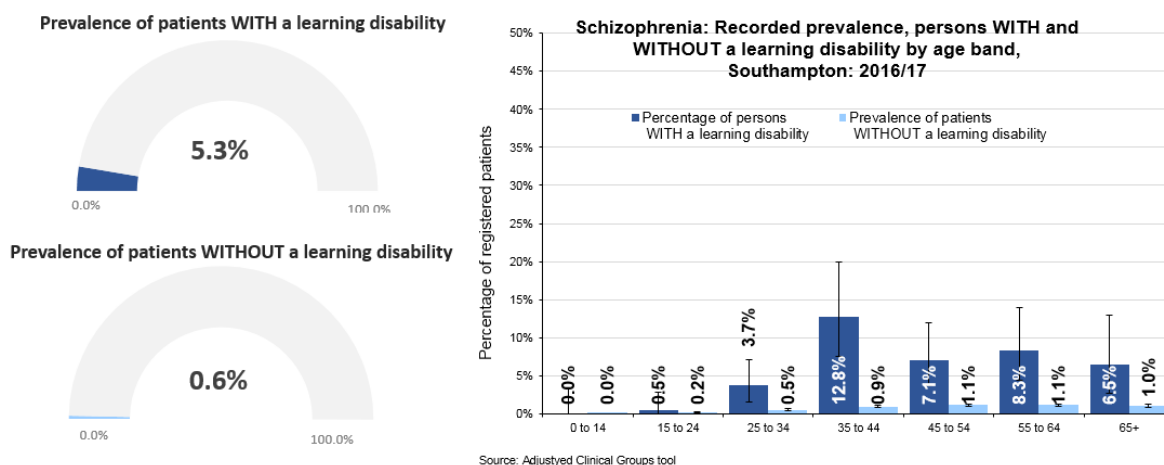


Figure 4.7.3 shows locally the prevalence of people with learning disabilities diagnosed with schizophrenia is significantly higher (5.3%), compared to the prevalence of schizophrenia in patients without a learning disability (0.6%). Amongst those aged 25 years and over, the prevalence of schizophrenia in patients with learning disabilities is significantly higher than those without a learning disability; patients aged 35 to 44 had the most noticeable difference.

4.7.4 Bipolar disorder

Recent research by Cooper et al.⁸² found the standard incidence ratio for bipolar episodes was twice as high in people with a learning disability compared to the general population.

Locally, the ACG tool shows 10 patients with learning disabilities in May 2017 with a diagnosis of bipolar disorder, a prevalence of 0.9%. This is higher than the prevalence amongst the general population (0.4%), although the difference is not significant. The numbers were too small when broken down by age band to show indicative trends.

4.7.5 Autism

Autism is known as a spectrum condition because of both the range of difficulties that affect people with autism and the way it presents in different people. In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychological Association) the condition is described with two core dimensions:

- Social communication difficulties, which incorporates both communication and social interaction as these are intertwined.

⁸²British Journal of Psychiatry (2018) Cooper A, Smiley E, Allan L Morrison J Incidence of unipolar and bipolar depression, and mania in adults with intellectual disabilities: prospective cohort study <https://doi.org/10.1192/bjp.2018.12> Accessed 10/12/18

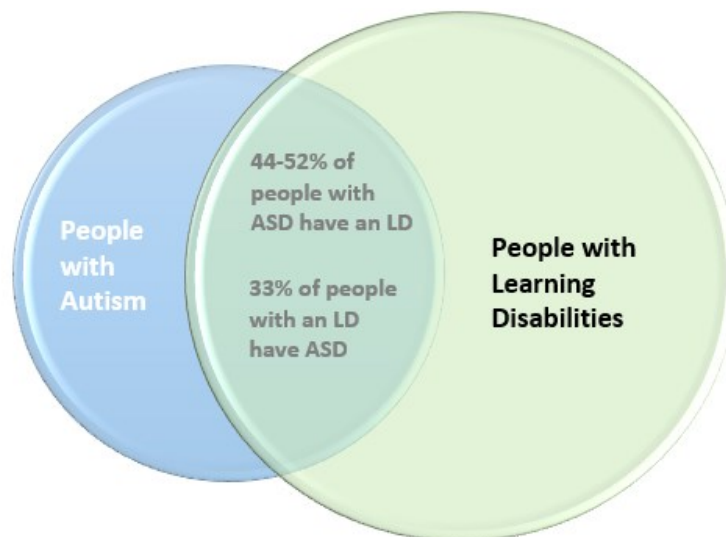
- Strongly repetitive behaviour (e.g. difficulties in adapting to change and unusually narrow interest).

In addition people with autism (ASD) may experience some form of sensory sensitivity and often prefer to have a fixed routine and can find change difficult to cope with. However every person's experience of autism is unique to each individual who will have a range of strengths as well as needs.

An estimated 1% of the population have autism, applying this national prevalence to the ONS 2017 population for Southampton estimates 2,524 people of all ages in the city have autism - 577 from birth to 19, and 1,876 aged 20 and above. Information from the Jigsaw service and education, the Child and Adolescent Autism Service and the Special Education Needs EHC list identifies 403 children and young people aged under 20 years have autism (including Asperger's) and data from GP clinical systems show that 120 people aged 18 and over are recorded as having an ASD, with only 4 of these being aged 65 and above.⁸³ This suggests that there are a higher proportion of undiagnosed autistic people in the adult population compared to in the city's population of children and young people.

It is estimated that between 44% and 52% of autistic people may have a learning disability⁸⁴, and around a third of people with a learning disability may also be autistic⁸⁵, this is illustrated in figure 4.7.5

Figure 4.7.5



⁸³ Southampton City Council and NHS Southampton City CCG (2018) Autism: Joint Commissioning Strategy Southampton, April 2015 – March 2020 (Unpublished)

⁸⁴ Emerson, E. and Baines, S. (2010) *The estimated prevalence of autism among adults with learning disabilities in England*. Stockton-On-Tees: Improving Health and Lives.

⁸⁵ The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care

4.7.6 Epilepsy / Seizure disorders

Some people may have epilepsy and learning disabilities, and both may be caused by the same underlying problem in the way their brain works. Epilepsy is more common in people with a learning disability than in the general population⁸⁶. There is no causal link between epilepsy and learning disabilities, however both are outward symptoms of underlying brain dysfunction or damage and sometimes their cause is the same.

- About 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy
- The more severe the learning disability, the more likely that the person will also have epilepsy
- Around 1 in 5 people (20%) with epilepsy also have a learning disability

For people with a learning disability, seizures can be more frequent and can go on for longer. They can also have multiple seizures and also have movements or behaviours during a seizure seen as atypical.⁸⁷

The ACG tool records diagnosis of a 'seizure disorder'. A seizure disorder may not be just epilepsy, seizure disorders can be non-epileptic seizures also called dissociative seizures⁸⁸. It is not detailed if the ACG uses 'seizure disorder' as an alternative name of 'epileptic disorder' or includes 'non-epileptic disorders'.

As stated above, people with learning disabilities are more likely to have epilepsy. Evidence could not be found if people with learning disabilities are more likely to have non-epileptic seizures. The Quality Outcome Framework 2017/18 put the prevalence of epilepsy in the national population as 0.8% and locally as 0.7%.⁸⁹ It should be noted that combining the two types of seizures and comparing with patients with and without a learning disability may not be comparing like with like, however, the overall prevalence of dissociative seizures is between 2 and 33 sufferers per 100 000 persons⁹⁰, perhaps making the effect of this possible sub-group minimal.

Figure 4.7.6 shows the prevalence of diagnosed seizure disorders among people with a learning disability is 17.5%, significantly higher than the prevalence amongst people without a learning disability (1.0%). The figure also shows that the prevalence is significantly higher among people with a learning disability, regardless of age within the life course.

⁸⁶Epilepsy Society (2016) <https://www.epilepsysociety.org.uk/learning-disabilities#.XA90gGe7KUK> Accessed 10/12/18

⁸⁷Epilepsy Society (2016) <https://www.epilepsysociety.org.uk/learning-disabilities#.XA90gGe7KUK> Accessed 10/12/18

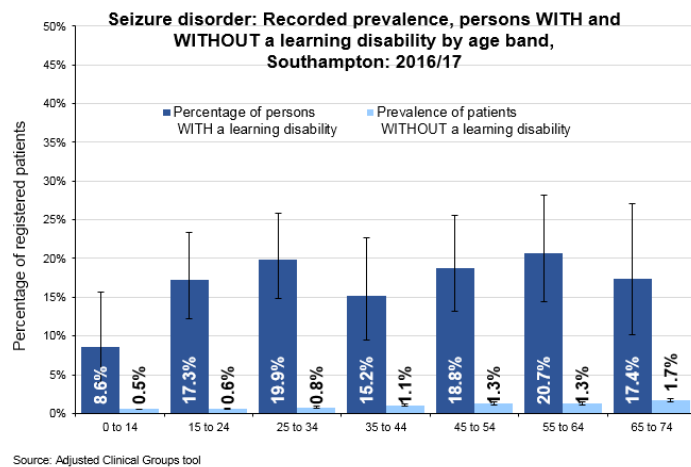
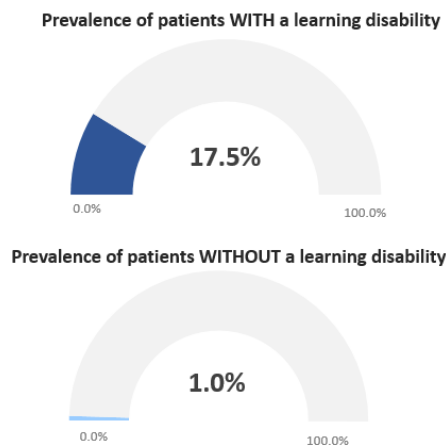
⁸⁸Great Ormond Street Hospital Trust Conditions we treat: Non-epileptic seizures (NES)

<https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/non-epileptic-seizures-nes> Accessed 04/01/2019

⁸⁹NHS Digital (2018) Quality Outcome Framework 2017/18 <https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2017-18> Accessed 4/01/2019

⁹⁰Fritzsche et al.(2013) Dissociative Seizures: a Challenge for Neurologists and Psychotherapists <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3647137/> Accessed 01/04/2019

Figure 4.7.6



Based on data from the NHS Digital tool, the prevalence of an active diagnosis of epilepsy (and on drug treatment for epilepsy) is 17.8% nationally for patients with a learning disability compared to 0.6% of the population without learning disabilities. In Wessex the prevalence is 18.3% and 0.6% respectively and in Southampton 14.1% and 0.6% respectively.⁹¹ The CIPOLD report highlighted that the most commonly reported long term condition in people with learning disabilities is epilepsy (43%).⁹²

Local practice data provided by Primary Care commissioning at NHS Southampton CCG from the TPP and EMIS system for the financial year 2017/18 puts the prevalence of epilepsy in patients with learning disability as 22.0%, which is higher than both the ACG and NHS Digital data.

Having a learning disability does not cause someone to have epilepsy and vice versa. Both a learning disability and epilepsy are symptoms of underlying brain damage or dysfunction.⁹³ Diagnosis of epilepsy is difficult as there is not one single test to confirm the diagnosis. It can be particularly difficult to diagnose an individual with a learning disability with epilepsy due to behaviours such as repeated movements and staring that can be mistaken as a seizure. It can also be more difficult for a person with a learning disability to communicate how they are feeling.⁹⁴

People with learning disabilities and epilepsy are at an increased risk of death. Epilepsy has been highlighted as one of the most common preventable causes of death for people with learning

⁹¹ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 05/12/18

⁹²University of Bristol and Department of Health (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf> Accessed 10/12/18

⁹³Mencap (2009) Epilepsy and learning disability Fact sheet (2009) https://www.thh.nhs.uk/documents/_Patients/PatientLeaflets/proceduresConditions/Epilepsy_LD-MENCAP.pdf Accessed 10/12/18

⁹⁴ Epilepsy Action (2018) Diagnosing Epilepsy <https://www.epilepsy.org.uk/info/carers/learning-disabilities/diagnosing-epilepsy>

disabilities. The Learning Disabilities Mortality Review reported that epilepsy contributed to 5% of deaths in England.⁹⁵

The CIPOLD programme reported that NICE guidelines for epilepsy and learning disabilities were not always adhered to (CG137). It was found that there was not always a trained person on duty able to administer emergency medication when required.⁹⁶ This highlights both training needs and the importance of planning staff rotas appropriately.

Local clinical leads have found the risk of seizures is generally higher in patients with congenital learning disability and significantly higher in patients with acquired (through head injury) learning disability than those without learning disability. Opportunities for improvement may be identified within the learning disability reviews that are carried out under the learning disability DES (Direct Enhanced Service) in primary care. A local example of this is a learning disability trained nurse who carries out a one hour reviews with patients and the discusses this with the GP learning disability lead, often resulting in a referral to the learning disability team for further support. Part of this review includes a review of recent history, which may pick up on smaller seizures that have occurred and not been previously noted, and ensuring meds optimisation. In Southampton, people with a learning disability diagnosed with epilepsy are either reviewed by GP or Neurology. The Community Epilepsy Nurse in the city is a Registered LD Nurse.

4.8 Cancer screening

People with learning disabilities have poorer health and are more likely to die at a younger age than people in the general population, in part because of poor access to health services. The risk for an individual developing a type of cancer can be influenced by a combination of factors, which can be genetic, personal, environmental and lifestyle factors. For example, obesity, alcohol consumption, lack of exercise, exposure to tobacco smoke and some infections from sexually transmitted diseases are associated with common types of cancer.

Early diagnosis and prompt treatment are important to cancer survival. This may be difficult for some people with learning disabilities due to the ability to act on the warning signs and navigate through the health system. The Tizard review found overall, the incidence of deaths from cancer⁹⁷ in the UK among people with learning disabilities is currently lower than in the general population (12–18% vs 26%). However, the incidence and pattern of cancer amongst people with learning disabilities are rapidly changing, due, in part, to increased longevity.

⁹⁵ Public Health England (2016) People with learning disabilities in England 2015: Main report https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf Accessed 22/10/18

⁹⁶ University of Bristol Norah Fry Centre for Disability Studies and NHS England (2017) The Learning Disabilities Mortality Review Annual Report 2017 http://www.bristol.ac.uk/media-library/sites/sps/leder/leder_annual_report_2016-2017.pdf Accessed 11/12/18

⁹⁷ although people with learning disabilities have proportionally higher rates of gastrointestinal cancer (48–59% vs 25% of cancer deaths

Cancer screening is available for breast⁹⁸, cervical⁹⁹ and colorectal cancer¹⁰⁰. The prevalence of deaths from breast and cervical cancer in women with learning disabilities is not particularly different to the prevalence of deaths from the same cancers in the general population. However, there was a significantly higher prevalence of colorectal cancers in those with learning disabilities. In all three types of cancer, screening was lower in people with learning disabilities than the general population (see figure 4.8.1).

The NHS Digital dataset¹⁰¹ suggests of the three national screening programmes, breast screening has the lowest coverage rate of the screening programmes for people without learning disabilities. This is summarised in figure 4.8.1.

Figure 4.8.1 National cancer screening programme coverage for people with and without learning disabilities 2016/17

	Breast screening		Cervical Screening		Colorectal screening	
	Patients WITHOUT a learning dis.	Patients WITH a learning dis.	Patients WITHOUT a learning dis.	Patients WITH a learning dis.	Patients WITHOUT a learning dis.	Patients WITH a learning dis.
England	66.2%	50.2%	75.4%	30.4%	86.0%	79.5%
Wessex	68.6%	49.1%	75.1%	25.0%	91.4%	88.0%
Southampton	65.0%	53.2%	72.8%	41.0%	88.2%	79.5%

Source NHS Digital

Public Health England (PHE) research¹⁰² has found a number of practical barriers preventing people with learning disabilities being screened for cancer. These include:

- Lack of routine use of easy-read invitations
- Difficulties using appointment systems
- Time pressures
- Mobility issues
- Communication difficulties

⁹⁸ Breast cancer screening coverage is the percentage coverage of women aged 50-69 years in the previous 5 years prior to Reference Year End Date

⁹⁹ Cervical cancer screening coverage is the percentage of females eligible for cervical cancer screening, aged 25 to 64 with no history of hysterectomy on whom an adequate cervical smear test has been performed in the five years prior to Reference Year End Date.

¹⁰⁰ Colorectal cancer screening coverage is the percentage aged 60 to 69 who are eligible for colorectal cancer screening and who have a record of having a colorectal cancer screening result recorded in the five years prior to Reference Year.

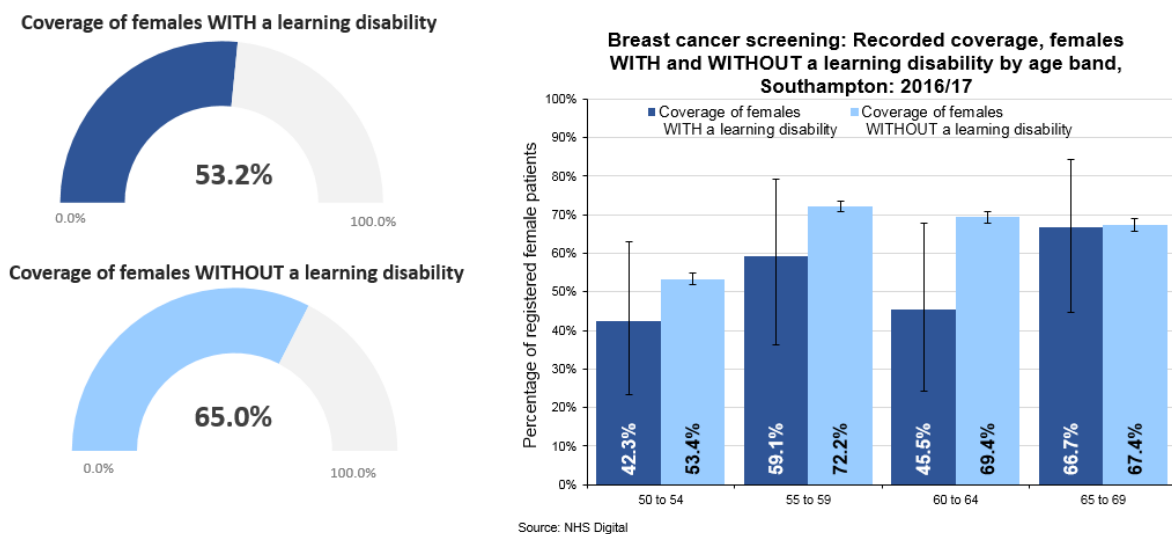
¹⁰¹ NHS Digital Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017 (2017) <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 12/12/18

¹⁰² Public Health England (2016) Guidance: Cancer screening: making reasonable adjustments <https://www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities/cancer-screening-making-reasonable-adjustments> Accessed 12/12/18

4.8.1 Breast screening

The NHS digital experimental statistics covering 50% of GP registered patients in Southampton found breast screening coverage in those women aged 50 to 69 years to be significantly lower for women with a learning disability (53.2%) compared to those women without a learning disability (65.0%) – figure 4.8.2. Coverage is on a par for older women aged 65 to 69 for both groups. However, despite the large confidence intervals the coverage for women aged 60 to 64 years is significantly lower for women with learning disabilities compared to women without.

Figure 4.8.2



Public Health England research has found barriers affecting breast screening uptake among women with learning disabilities include¹⁰³:

- Practical barriers, including mobility issues, difficulty using appointment systems and lack of accessible information and resources
- Lack of knowledge among professionals of learning disabled needs
- Lack of family or carer(s) to support attendance at screening and local support services
- Communication barriers between women and health professionals, which could be reduced by pre-screening visits if offered
- Negative attitude towards health promotion and screening or a lack of knowledge among people with learning disabilities
- Difficulties around consent for people with learning disabilities
- Lack of awareness among screening staff about easy read information

¹⁰³ Public Health England (2018) Guidance: Supporting women with learning disabilities to access breast screening <https://www.gov.uk/government/publications/breast-screening-programme-supporting-women-with-learning-disabilities/supporting-women-with-learning-disabilities-to-access-breast-screening> Accessed 12/12/18

Public Health England have published an easy-guide on the breast screening service to help women with learning disabilities make an informed choice on accessing the service¹⁰⁴.

The Strategic Health Facilitator in Southampton has worked closely with the Breast Imaging Department at Princess Anne Hospital to look at increasing the uptake of breast screening of woman with Learning Disabilities. Education around reasonable adjustments was included in discussions. The Breast Imaging Department are planning to hold an open morning specifically for woman with Learning Disabilities in Southampton who meet the criteria for this service. It is anticipated this will become a regular event.

4.8.2 Cervical screening

All women over 25 years, whether they are sexually active or not, are entitled to cervical screening. It is then the woman's decision if she takes up the invitation. This decision can only be made by the woman or through a best interest decision made by others. NHS England has produced an easy guide to cervical cancer and a picture book called 'Keeping healthy down below' to give information about cervical screening.¹⁰⁵ PHE has also produced guidance about communication to increase understanding so a woman can make her own decision, and where a woman has not understood enough to make her own decision on cervical screening, how to proceed in making a 'best interest decision' for her.¹⁰⁶

Conversations with people working with patients with learning disabilities have described an additional barrier being a misconception both from carers and GP practice staff that cervical screening is not needed if a woman is not sexually active. This reflects the national finding in the CIPOLD review.¹⁰⁷

Using the NHS Digital data, we can see in figure 4.8.3 that the coverage of cervical screening is significantly lower in women aged 25 to 64 years with learning disabilities (41.0%) compared to women without (72.8%). Not only this, but it is significantly lower for all age groups.

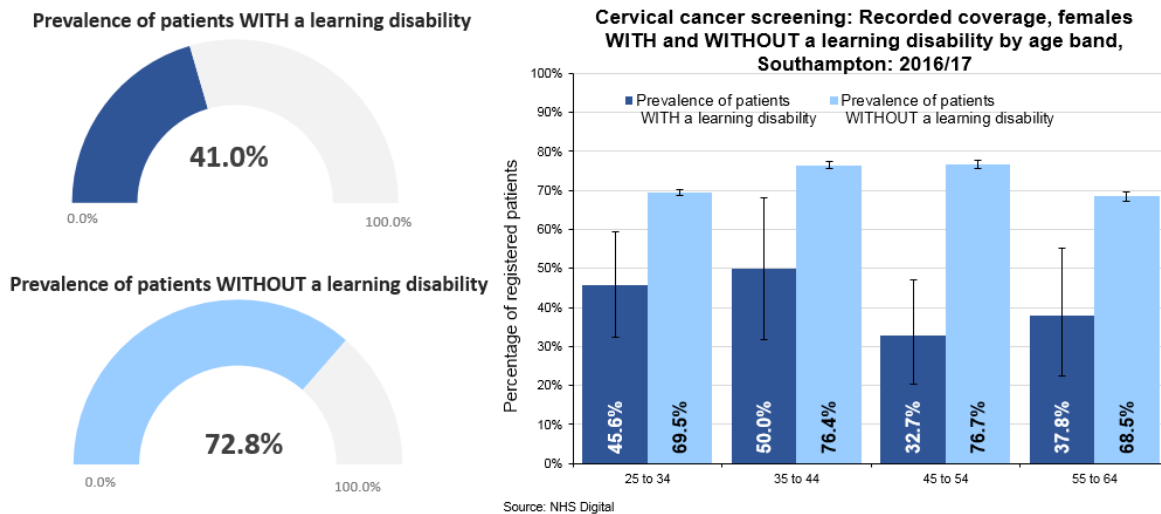
¹⁰⁴Public Health England (2018) Breast screening: easy guide <https://www.gov.uk/government/publications/breast-screening-information-for-women-with-learning-disabilities> Accessed 12/12/18

¹⁰⁵ NHS Cancer Screening Programmes, (2013) Cervical Screening: An easy read guide https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/433757/easy-guide-cervical-screening.pdf Accessed 12/12/2018

¹⁰⁶Public Health England and NHS England (2017) Guidance: Supporting women with learning disabilities to access cervical screening <https://www.gov.uk/government/publications/cervical-screening-supporting-women-with-learning-disabilities/supporting-women-with-learning-disabilities-to-access-cervical-screening> Accessed 12/12/18

¹⁰⁷Public Health England (2016) Guidance: Cancer screening: making reasonable adjustments <https://www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities/cancer-screening-making-reasonable-adjustments> Accessed 12/12/18

Figure 4.8.3



4.8.3 Colorectal screening

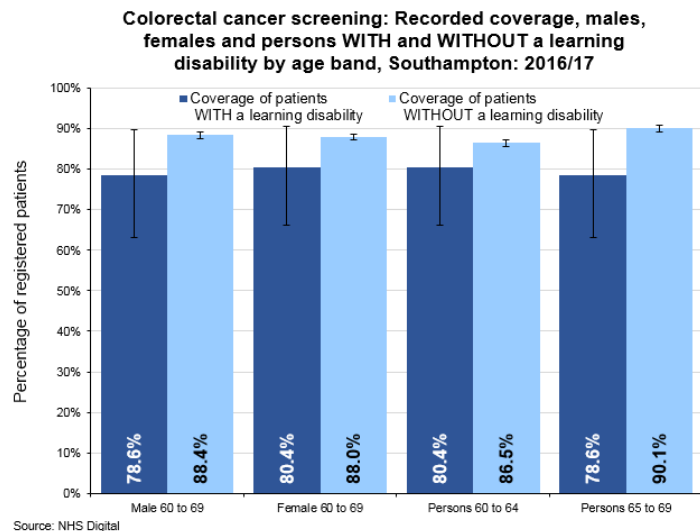
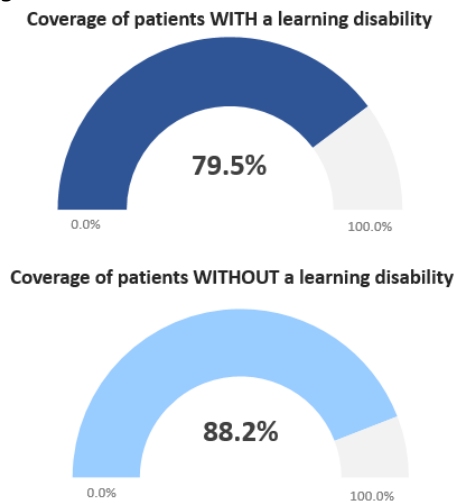
The NHS bowel cancer screening programme offers screening every 2 years to all men and women aged 60 to 74. All those eligible for screening receive an invitation letter explaining the programme and an information leaflet. About a week later, a faecal occult blood (FOB) test kit is sent out along with step-by-step instructions for completing the test at home and sending the samples to the hub laboratory. The test is then processed and the results sent within 2 weeks.

All screening programmes require participants to give informed consent before testing. People with learning disabilities should be assumed to have the capacity to consent to have the test unless there are good reasons to think they lack the ability to make this decision at this time. Where an individual is considered not to have the capacity to consent, staff involved would need to decide if it's in the individual's best interests to be screened. Where the test is non-invasive and painless, such as bowel screening, the decision to proceed would depend on behavioural compliance, as screening is likely to be in the patient's best interests.¹⁰⁸

NHS Digital data illustrates that colorectal screening coverage for patients with a learning disability was 79.5% in 2016/17, significantly lower than for patients without a learning disability (88.2%). There is little difference between the two groups by gender, however there is a greater difference between the groups in coverage for those aged 55-64 years compared to the difference those aged 45 to 54 years (see figure 4.8.4).

¹⁰⁸ Public Health England (2016) Guidance: Cancer screening: making reasonable adjustments <https://www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities/cancer-screening-making-reasonable-adjustments> Accessed 12/12/18

Figure 4.8.4



The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that cancer was one of the most common underlying causes of death for people with learning disabilities (20% vs 30% in the general population). Deaths from cancer occurred at a much younger age in people with learning disabilities, particularly for women and the cases reviewed showed that access to cancer screening services for people with learning disabilities was variable and the CIPOLD report highlighted engagement in the bowel screening programme as being especially problematic.¹⁰⁹

- Some people with learning disabilities received an invitation and pack but did not participate in the bowel screening; possibly because of misunderstanding the importance of screening and lacking the support required to complete the process
- Some paid staff did not return a sample as they were unaware stool samples could be collected from incontinence pads
- Other employees reported they needed guidance on how to collect a sample from an individual who could not do this themselves

Local discussions with stakeholders have shown that examples of these national issues are representative of Southampton and reflected with local case studies, additionally including carers themselves misunderstanding the importance of screening or viewing collecting stool samples as part of their duty of care and within the remit of their role.

A common symptom of colorectal cancer is a change in bowel habits, including increased constipation.¹¹⁰ Constipation is a frequently reported issue in people with learning disabilities.

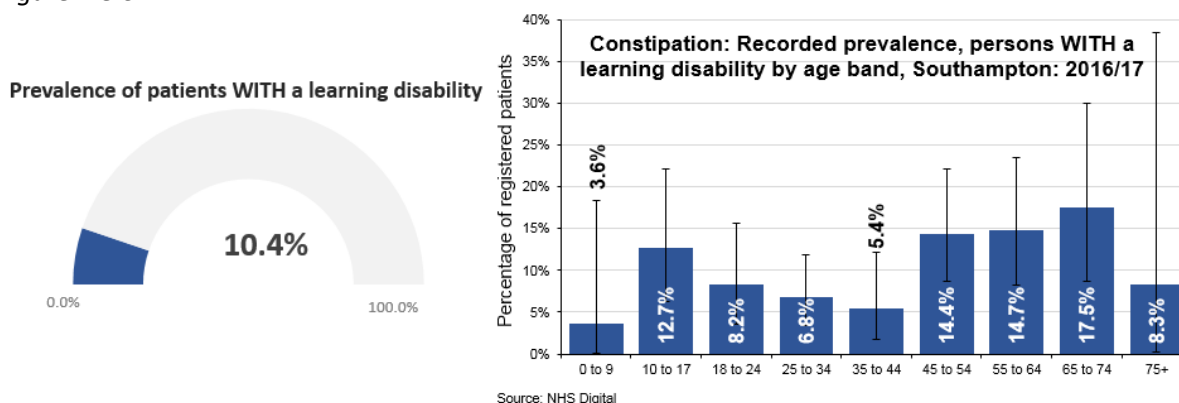
¹⁰⁹ Public Health England (2016) Guidance: Cancer screening: making reasonable adjustments <https://www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities/cancer-screening-making-reasonable-adjustments> Accessed 12/12/18

¹¹⁰ NHS Conditions – Bowel Cancer: Symptoms <https://www.nhs.uk/conditions/bowel-cancer/symptoms/> Accessed 12/12/18

Constipation affects up to 30% of the general adult population. However, we know that individuals with learning difficulties have an increased risk, with some studies reporting it being a problem for up to 70% of people with learning disabilities. Lack of understanding of the importance of going to the toilet, not drinking enough fluids and poor diet, reduced mobility and lack of exercise, side effects of some medications and anxiety.¹¹¹

Constipation, which can disguise cancer, is common in people in Southampton with learning disabilities as demonstrated in figure 4.8.5. The data from the NHS tool sampling 50% of Southampton’s GP registered patients found the prevalence of diagnosis or the treatment of chronic constipation in the five years to 31st March 2017 to be 10.4%, showing 1 in 10 have constipation. Those aged 45 to 74 years have the highest prevalence. Therefore, it is important to prevent constipation and to also identify when it should be investigated further.

Figure 4.8.5



A systematic review of 31 studies, published between 1990 and 2016, on the number of people with learning disabilities who have constipation found prevalence was generally high, with rates of 50% or more being reported in 14 of the 31 studies, and 21 studies reporting rates of over 33%. In the most representative study, 25.7% of people with learning disabilities received a repeat prescription for laxatives in one year compared to 0.1% of people without learning disabilities.¹¹²

In one year, 18.8% of people with Down syndrome were prescribed laxatives compared to 3.4% of people without learning disabilities. People with Down syndrome or cerebral palsy have an increased risk of constipation. Other medical conditions that exacerbate constipation include hypothyroidism, depression and diabetes. Recent primary care data has shown that people with learning disabilities have significantly higher rates of diabetes and hypothyroidism and slightly higher rates of depression. People with more severe learning disabilities are at an even higher risk of constipation. This may in part be related to complex health needs requiring a variety of pharmacological treatments that can

¹¹¹Bladder and Bowel UK (2017) Understanding constipation in people with learning difficulties – the importance of identification and treatment <http://www.bladderandboweluk.co.uk/wp-content/uploads/2017/05/Understanding-constipation-in-people-with-learning-difficulties-for-review.pdf>

¹¹² Public Health England (2016) Guidance Constipation: making reasonable adjustments <https://www.gov.uk/government/publications/constipation-and-people-with-learning-disabilities/constipation-making-reasonable-adjustments> Accessed 12/12/18

contribute to constipation. They're also more likely to be less active and do less exercise, which is another associated factor.¹¹³

4.9 Health checks and weight management

People with a learning disability often have poorer physical and mental health than other people. Anyone aged 14 or over recorded on a GP's learning disability register is eligible for a free annual learning disability health check (AHC).

During the learning disability health check¹¹⁴ a range of areas are covered:

- Physical checks; weight measurements, blood pressure, heart rate, blood test and urine samples are taken
- Conversations about common conditions; epilepsy, constipation, dysphagia, asthma, diabetes and other health issues
- Health information, such as advice on healthy eating, exercise, contraception or stopping smoking
- Discussion about medicines, other health appointments and how to stay well
- Discussion with carers about received support
- Help ensure a smooth transition when children move to adult services at the age of 18

Figure 4.9.1 shows 44.8% of people with learning disabilities had a learning disability annual health check during 2016/17, which is lower than the national average of 48.9% (although not significantly) and ranked 5th highest amongst Southampton's ONS comparators.

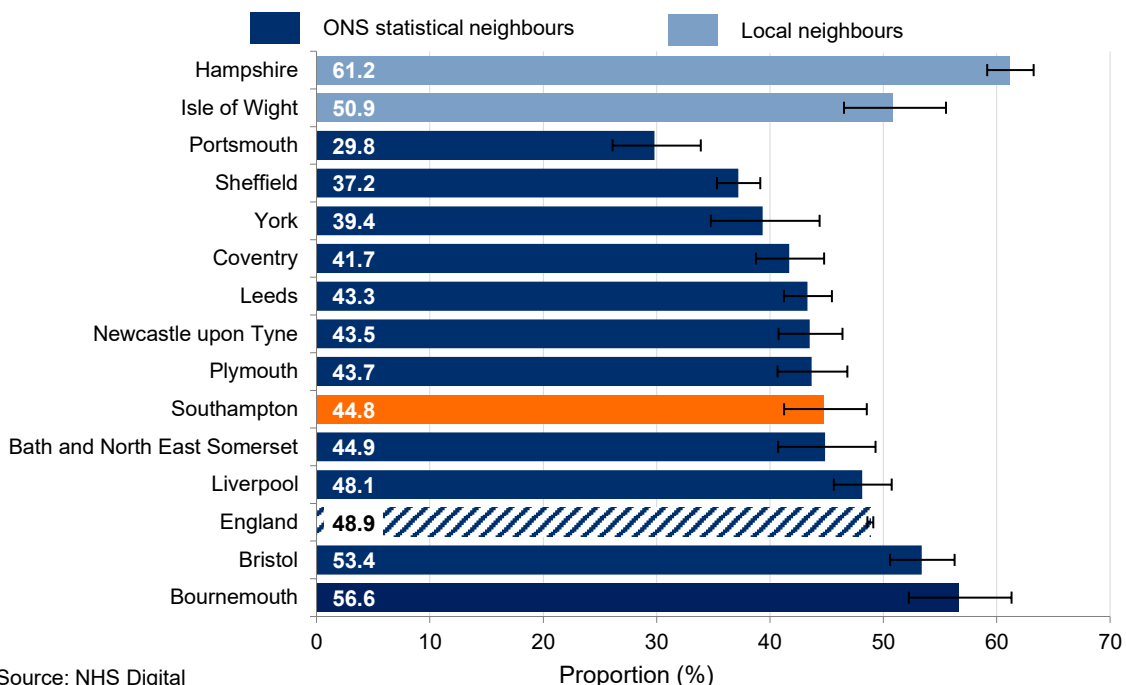
¹¹³ Public Health England (2016) Constipation and people with learning disabilities

<https://www.gov.uk/government/publications/constipation-and-people-with-learning-disabilities> Accessed 4/12/18

¹¹⁴NHS Annual health checks - Learning disabilities <https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/> Accessed 12/12/18

Figure 4.9.1

Proportion (%) of eligible adults with a learning disability having a GP health check- Southampton and ONS Comparators: 2016/17



Source: NHS Digital

As well as directly working with GP Surgeries across the city, work is well underway educating people with Learning Disabilities, their carers and / or relatives on the benefits of the Learning Disability AHC. Work has included teaching sessions delivered by the Strategic Health Facilitator to some day-services, information drop in events for relatives, carers newsletters, educating Learning Disability Social Workers, attending carers groups and teaching Shared Lives carers in the city. Health Professionals within the Southampton Community Learning Disability Team also check that people with Learning Disabilities open to the team are having their AHC. The Strategic Health Facilitator in Southampton has been validating all the GP Surgeries Learning disability registers which are used to invite people along for their Learning Disability AHC. An audit on the quality of the Learning Disability AHC in Southampton was completed in 2018 across 10 surgeries. A total of 50 AHC were audited. Findings and recommendations will be shared across all GP Surgeries.

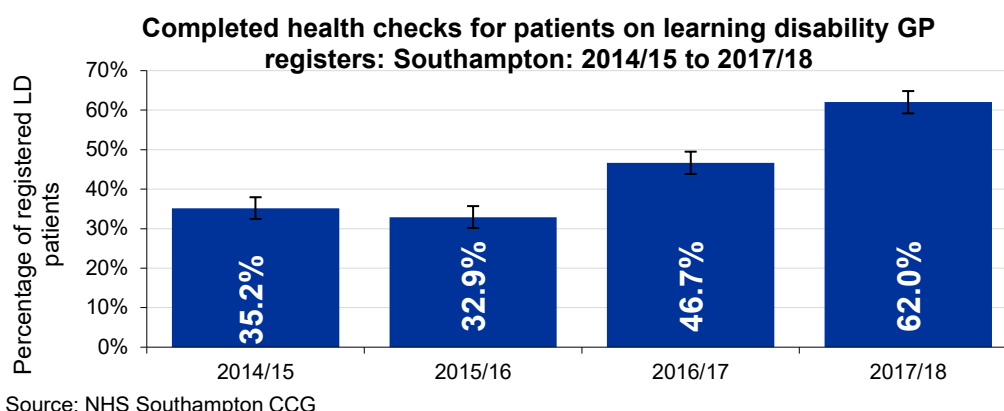
Autism and Asperger’s syndrome are not a learning disability, however around half of the people with autism may also have a learning disability¹¹⁵ or have behaviours linked with health and wellbeing similar to that of patients with a learning disability. Those individuals have had an administrative code applied to local data systems so they may also receive the health check.

The uptake of Learning Disability Annual Health Checks (AHC) in Southampton has increased significantly in recent years. Figure 4.9.2 shows the proportion people with Learning Disabilities having

¹¹⁵Mencap. Learning disability explained: Autism and Asperger's syndrome <https://www.mencap.org.uk/learning-disability-explained/conditions/autism-and-aspergers-syndrome> Accessed 12/12/18

a Learning Disability AHC has risen from 35.2% in 2014/15 to 62.0% in 2017/18 (provisional data); this equates to 724 people with a learning disability or a learning disability administrative code receiving a health check in 2017/18. GP Surgeries individually set themselves annual targets and are all working towards achieving NHS England’s target of 75% by 2020. The figures differ from national figures as local figures include those people with autism and Asperger’s who have had the learning disability administrative code applied.

Figure 4.9.2



A learning disability can make it difficult to maintain a healthy weight. Obesity is far more prevalent in the learning disability population than the general population, with women, people with Down’s Prader-Willi, Cohen or Bardet-Biedl Syndromes, and those living in less restrictive environments such as in their own homes particularly at risk of excess weight; this ultimately results in an increased risk of circulatory disease.¹¹⁶

Support to enable an individual with learning disabilities to make healthy food choices can reduce their risk of circulatory disease mortality. The specific type of learning disability an individual has should be taken into consideration for weight management programmes. Those with a learning disability and a limiting illness are one and a half times more likely to be overweight or obese than those without a limiting illness or a learning disability, with the likelihood of being obese increasing with age.¹¹⁷

The Medical Research Council funded research looking at reasonable adjustments to the Slimming World programme called WILD (**W**eight Loss for people with a **L**earning **D**isability) which identified modifications to the current programme, conducted a feasibility study and a small trial; all 6 participants completed the trial, lost weight and choose to continue. The modified ‘easy read’ materials helped people feel included. Further modifications were identified and currently a large multi-centre study is being planned.¹¹⁸

¹¹⁶ Emerson and Baines (2010) Health Inequalities and people with learning disabilities in the UK: 2010. IHaL and Department of Health

¹¹⁷ Chimat (2011) Disability and obesity: the prevalence of obesity in disabled children Chimat (2011) Disability and obesity: the prevalence of obesity in disabled children

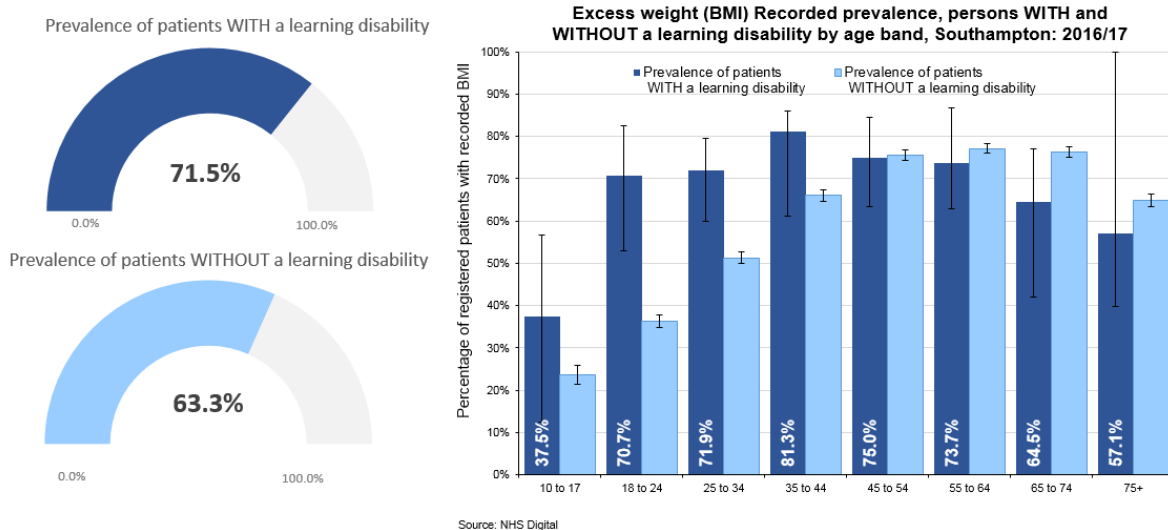
¹¹⁸ Public Health England (2016) Obesity and weight management services for people with learning disabilities 15th November 2016

Prevalence of underweight is also more common among people with learning disabilities; potentially leading to poor bone growth, a weakened immune system, tiredness¹¹⁹ and reduced respiratory function¹²⁰. Underweight is more prevalent in individuals with profound learning disabilities due to poor feeding and swallowing (dysphagia).¹²¹

Height and weight is measured during Learning Disability Annual Health Checks in order to calculate BMI (Body Mass Index) and work out if an individual's weight is healthy. The BMI calculation divides an adult's weight in kilograms by their height in metres squared. For example, A BMI of 25 means 25kg/m².¹²² A separate BMI percentile scale is used for people with Downs Syndrome as they have a different growth pattern and final height.¹²³

Figure 4.9.3 uses the NHS Digital 50% sample of Southampton's GP registered patients to illustrate the proportion of patients with excess weight. It should be noted that within the sample, BMI records were only recorded for 45% of patients with a learning disability and 31.5% of patients without a learning disability. The data shows that patients with a learning disability have a higher prevalence of excess weight (71.5%) compared to those without (63.3%), and that this increased prevalence begins earlier in life for those with a learning disability.

Figure 4.9.3



¹¹⁹ NHS Live Well (2017) Healthy weight: Managing weight with a learning disability <http://www.nhs.uk/Livewell/Goodfood/Pages/Underweightadults.aspx> Accessed 14/12/2018

¹²⁰University of Bristol (2017), Learning Disabilities Mortality Review (LeDeR) Programme: Fact Sheet 28 – Nutrition and Diet <https://www.bristol.ac.uk/media-library/sites/sps/leder/leder---fact-sheets/28.%20Nutrition%20and%20diet.pdf> Accessed 14/12/2018

¹²¹ NHS Live Well <http://www.nhs.uk/Livewell/Disability/Pages/weight-management-learning-disabilities.aspx> Accessed 14/12/2018

¹²² Health A-Z (2016): What is body mass index <https://www.nhs.uk/common-health-questions/lifestyle/what-is-the-body-mass-index-bmi/> Accessed 14/12/18

¹²³ Myreliid Å, Gustafsson J, Ollars B, et al Growth charts for Down's syndrome from birth to 18 years of age Archives of Disease in Childhood 2002;87:97-103. <https://adc.bmj.com/content/87/2/97> Accessed 24/12/2018

5. Social Determinants of health

People with learning disabilities, especially people with less severe learning disabilities, are more likely to be exposed to common ‘social determinants’ of poorer health, such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination.¹²⁴

5.1 Poverty

Poverty can disproportionately affect people with learning disabilities. This can be due to many factors including inequity in employment (described below), poorer education, organisational barriers and additional expenses¹²⁵. There is funding available from the government to support people with a learning disability, known as the Personal Independence Payment, and this is in the process of being transferred from the Disability Living Allowance. Unlike the Disability Living Allowance, the Personal Independence Payment only has two levels of support for daily living; there is no longer support available for the lower level of need.

Organisational barriers can lead to a reduction in a person’s autonomy to look after their own money. Access to banking is important for people with a learning disability, because many people need a bank account in order to get their benefits, spend their money, and manage direct payments¹²⁶. It is important to challenge the stigma facing individuals with learning disabilities regarding their capacity to live independently, while maintaining a duty of care.

5.2 Employment

Employment offers financial rewards, the chance to use existing skills and develop new ones, self-respect and opportunities to contribute to and be valued by the community. This has a significant impact on quality of life. The Government has committed to “ensuring that all disabled people have the opportunity to fulfil their potential and realise their aspirations”.¹²⁷

In 2017/18, 4.6% of adults with learning disabilities in Southampton receiving long term support from their local social services department were in paid employment. This is lower than both the South East (6.5%) and England (6.0%) averages, although provisional data for 2018/19 suggests this has improved to 6.6% (see figure 5.2.1)

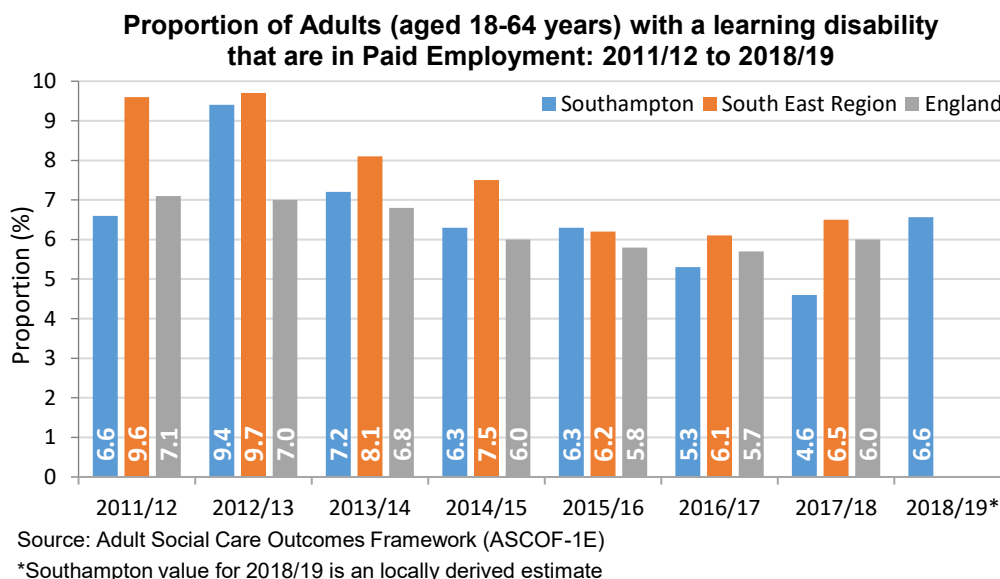
¹²⁴Emerson and Baines (2010) Health Inequalities and people with learning disabilities in the UK: 2010. IHaL and Department of Health

¹²⁵ Mencap (2016) Learning disability explained: Money and banking <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/money-and-banking> Accessed 14/12/18

¹²⁶ Mencap (2016) Learning disability explained: Money and banking <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/money-and-banking> Accessed 14/12/18

¹²⁷ Parkin E, Kennedy S, Bate A, Long R, Hubble S and Powell A. (2018) House of Commons Briefing Paper (Number 07058) Learning Disability - policy and services <http://researchbriefings.files.parliament.uk/documents/SN07058/SN07058.pdf> Accessed 14/12/18

Figure 5.2.1



The gap in the proportion in paid employment between those with learning disabilities and those without is used a measure within the Public Health Outcomes Framework (PHOF) to monitor inequality. Figure 5.2.2 shows the gap in Southampton was 66.1% in 2016/17, which is lower than the England average of 68.7% (although not significantly) and mid-ranked among Southampton’s comparators.

Figure 5.2.2

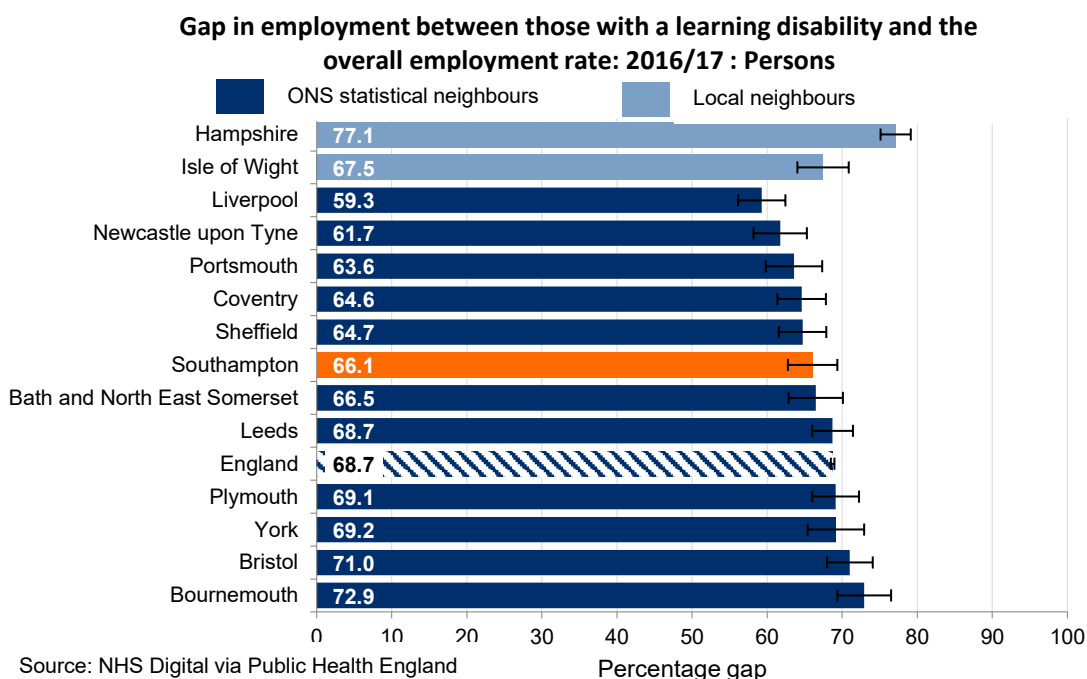
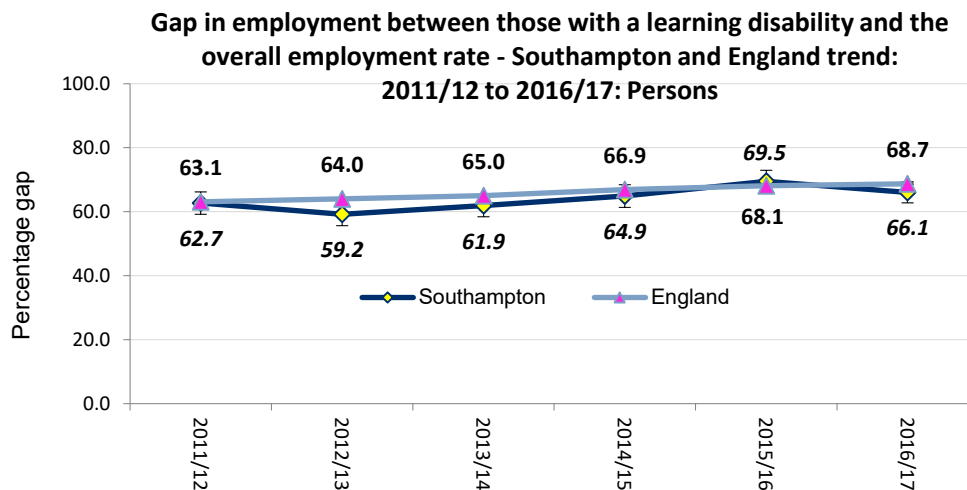


Figure 5.2.3 shows the trend in the employment gap for Southampton and England between 2011/12 and 2016/17. The gap in Southampton has increased from 62.7% to 66.1% over the entire period, mirroring the trend for England. However, a reduction in the gap by 2 percentage points in the most recent period (2016/17) suggests that the gap may be beginning to narrow once more. Investigation is required to identify what is working and how this decrease can be encouraged further.

Figure 5.2.3



Source: NHS Digital via Public Health

5.3 Housing and accommodation

‘Good quality housing, with the right care and support, can enable almost anybody to live independently. It makes it possible to choose where and with whom to live. It should enable people with a learning disability to link in with their local community; to access services and opportunities such as leisure, employment, transport and education. This enables building wider networks of support both formal and informal.’¹²⁸

The Valuing People Now strategy of 2009 acknowledged that accommodation options for adults with learning disabilities have improved with the shift away from hospital campus-based care.¹²⁹ However, there is still less choice and control over where to live than the general population.¹³⁰

¹²⁸ Maxwell Y & King N. Enhancing Housing Choices for People with a Learning Disability. Housing Learning & Support Network, Department of Health: London (Nov 2011)

¹²⁹ Valuing People Now: The Delivery Plan: ‘Making it happen for everyone. Department of Health: London (Jan 2009)

¹³⁰ Wood A & Kirkpatrick K. Valuing People Now & PSA 16 Housing Delivery Plan 2010-11: Housing Delivery Plan for People with Learning Disabilities. Department of Health: London (Mar 2010)

Figure 5.3.1

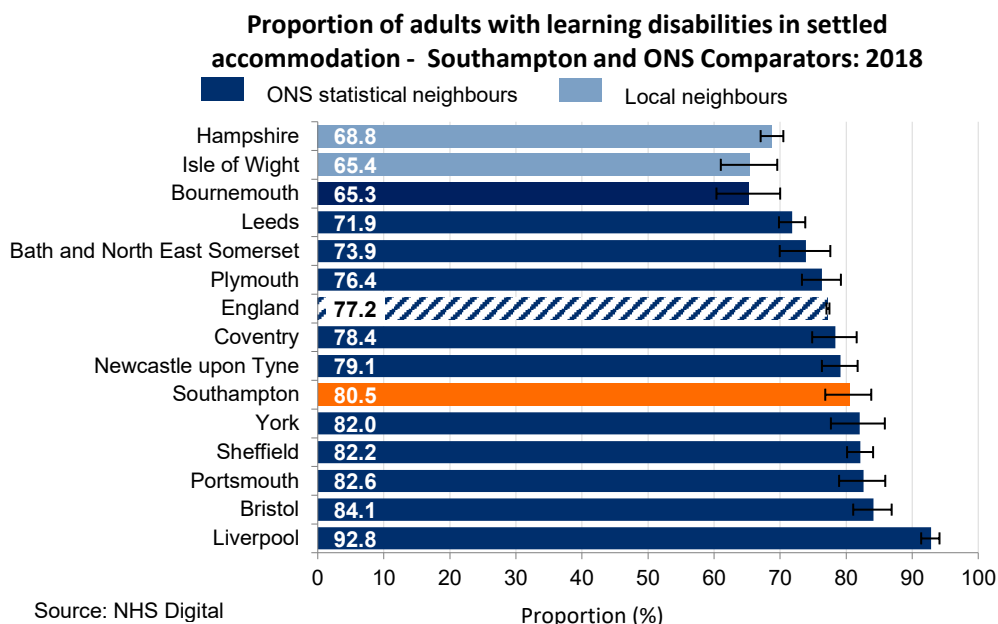
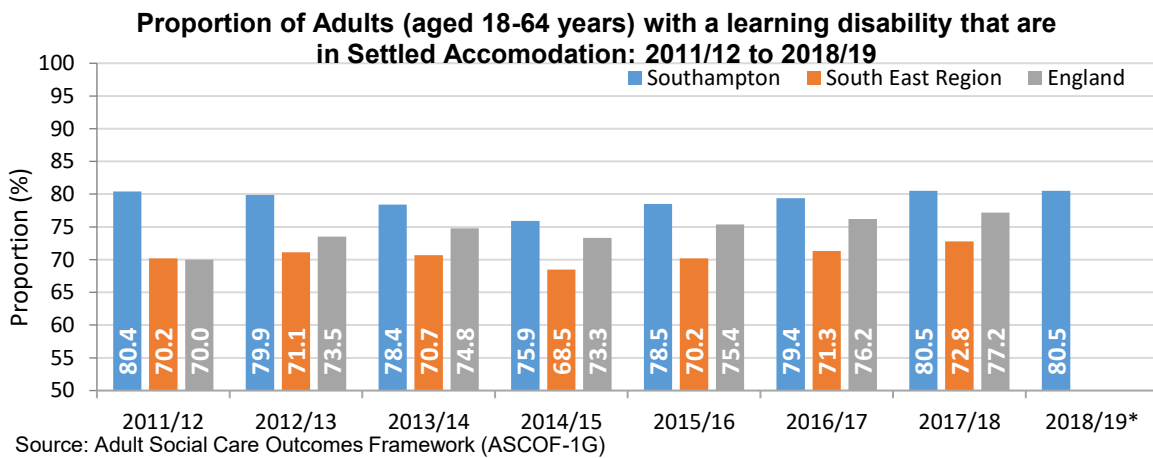


Figure 5.3.1 illustrates adults with a learning disability who live in settled accommodation.¹³¹ Settled accommodation is where the person can reasonably expect to stay as long as they want, whereas unsettled accommodation is either unsatisfactory, or where residents do not have security of tenure, such as in residential care homes. This indicator is also monitored within the Public Health Outcomes Framework. In 2017/18, 80.5% of adults with learning disabilities who are known to Southampton City Council were recorded as living in their own home or with their family. This is higher but not significantly than the England average of 77.2%, and places Southampton mid-rank among the ONS comparator group. The estimated figure for 2018/19 for Southampton is 80.5%.

Figure 5.3.2 shows the trend between 2011/12 and 2018/19 for Southampton, England and the South East Region. The proportion of adults with a learning disability in settled accommodation has remained fairly stable in Southampton and has consistently been above both the England and South East average.

¹³¹NHS Digital (2018) Adult social care activity and finance report, Short and Long Term Care statistics <https://fingertips.phe.org.uk/profile/learning-disabilities/data#page/0/gid/1938132704/pat/6/par/E12000004/ati/102/are/E06000015> Accessed 20/11/2018

Figure 5.3.2



6. Accessing services

6.1 SEND transition

Understanding the trends of SEND provision in Southampton' schools compared to national trends can help prepare service design and support commissioning programme risk management as it helps understand the level and numbers of need transitioning into adult services.

Figure 6.1.1 illustrates Southampton has a significantly higher proportion of school aged pupils in primary, secondary and special schools that have a Learning Disability (9.0%) compared to the national average of 5.6% and is ranked highest among its ONS comparators.

Figure 6.1.1

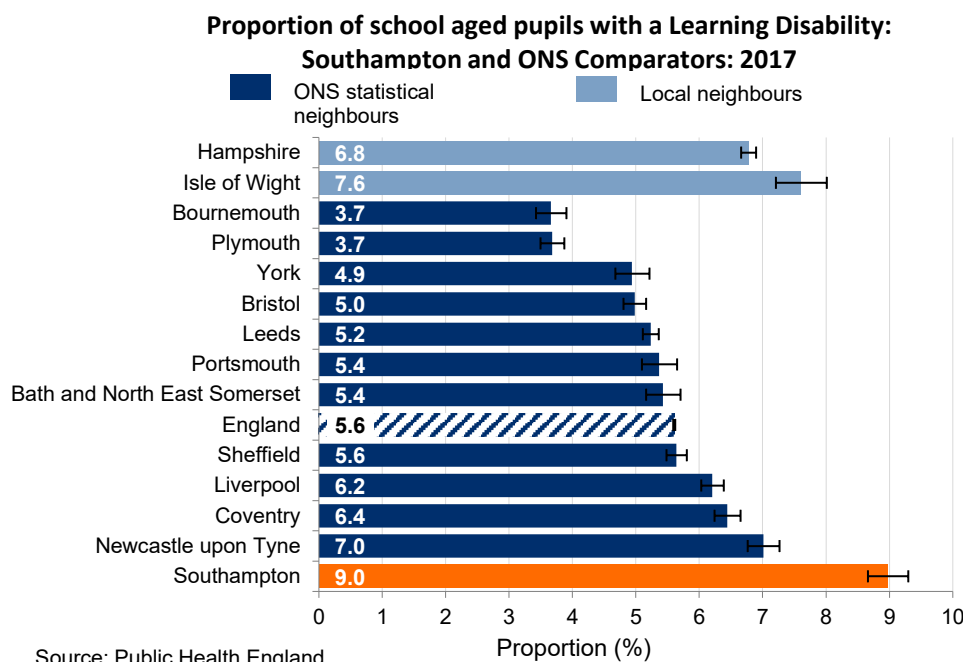










Figure 6.1.2 shows the change in numbers of children & young people with a learning disability by type. This includes those with an Education, Health and Care Plan (EHCP) as well as those receiving SEN Support.

Figure 6.1.2

Southampton	School aged pupils				Sparkline
	2015	2016	2017	2018	
Specific Learning Difficulty	594	645	694	616	
Moderate Learning Difficulty	1,933	2,041	1,854	1,774	
Severe Learning Difficulty	169	186	176	178	
Profound & Multiple Learning Difficulty	53	55	59	59	

England	School aged pupils				Sparkline
	2015	2016	2017	2018	
Specific Learning Difficulty	135,505	151,153	146,873	147,679	
Moderate Learning Difficulty	241,125	273,627	259,713	252,431	
Severe Learning Difficulty	32,090	32,304	32,338	32,680	
Profound & Multiple Learning Difficulty	10,910	10,914	10,981	10,969	

6.2 Adult Social Care

Research estimated that only approximately 25% of all people with learning disabilities in a local area would be known to adult social care services.¹³² These would primarily be those with profound or severe learning disabilities or those with complex health and social care needs. Those with mild or

¹³² Emerson, E and Hatton, C. Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. Institute for Health Research, Lancaster University: Lancaster, 2004.

moderate learning disabilities are often supported by families, friends and social networks. However the needs of all people with a learning disability must be considered during the planning and commissioning of mainstream and specialist health and social care services.

Adult social care services provide support to people who may need help with tasks of everyday living. This can range from personal care, support to access the community, daytime activities which support a person's wellbeing and advocacy services as well as housing based provision such as shared lives, supported living and residential care. The Care Act 2014 set a national eligibility criteria and statutory requirement for local authorities to assess a person's social care needs and put in place support to meet those eligible needs.

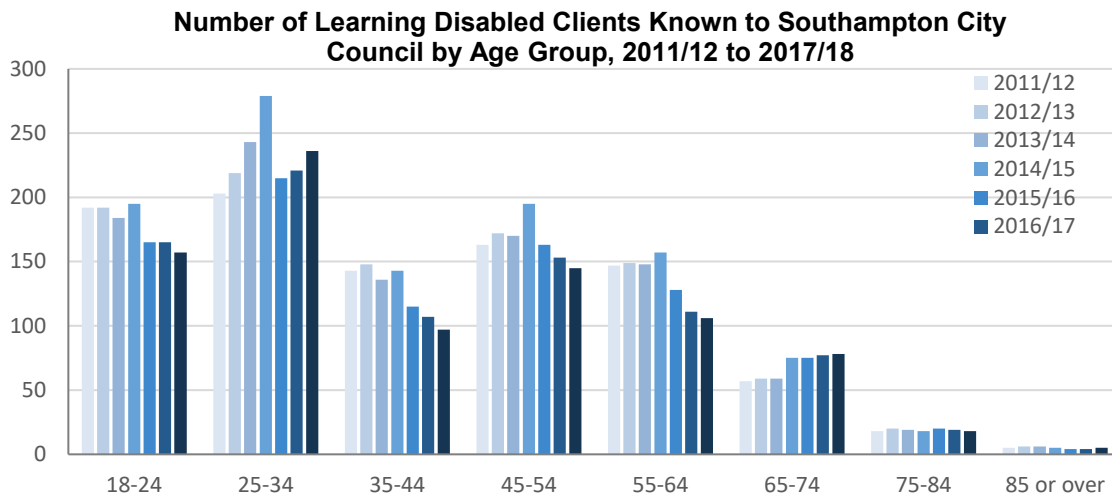
Southampton City Council is introducing a strengths based approach to assessing needs and providing support packages. A strengths-based approach to care is a collaborative process that draws upon an individual's strengths and assets and those within their community. Using this approach in practice maximises an individual's independence. It is often described as a model that focusses on what a person can do rather what they cannot. The strengths based approach is being introduced within adult social care with training for social workers. It is also being encouraged with service provider approaches.

Adult social care support can be either short term or long term. Short term care is provided as a means of rehabilitation, such as when a person needs extra help for a short period after leaving hospital. Long term care can include support for an individual to live independently in their own home or can include residential care where a person's needs cannot be met through other means.

Data from the Southampton City Council Paris system shows 73% of adult social care services for people with learning disabilities is for long term support. Many people using social care services will be receiving more than one type of support. Overall, 601 people with learning disabilities use long term social care of which 59% of clients are male. This is consistent with the higher prevalence of learning disabilities in males as mentioned in section 2.3, the prevalence amongst males is 0.49% significantly higher compared with the prevalence for females of 0.33%.

Figure 6.2.1 displays the change in use of social care by age band between 2011/12 and 2017/18. Although representing smaller numbers, the over 65 year age groups show a larger percentage increase in use of services. This may be reflective of the ageing population in Southampton, and in people with learning disabilities.

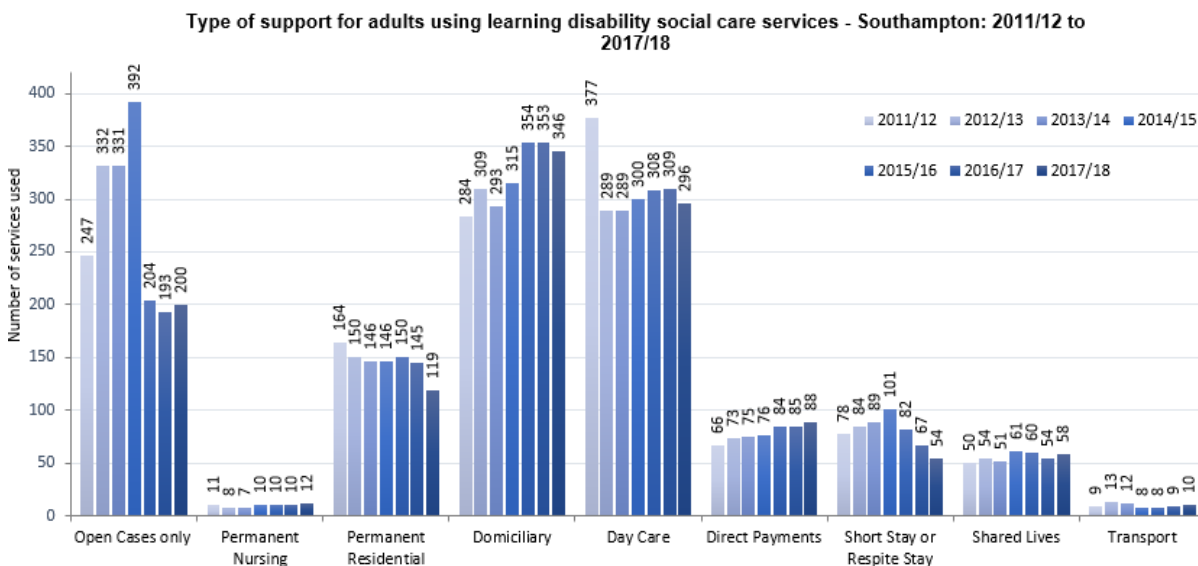
Figure 6.2.1



Source: Southampton City Council

Data from PARIS shown in the figure 6.2.2 below, illustrates that domiciliary care (also called home care) is the most common use of care in adults with learning disabilities, and has seen an increase over time. Domiciliary care covers both supported living as well as support for people living with their parents or other family. The use of direct payments has increased overtime, which may demonstrate that people using social care have more choice and independence. Those using direct payment may now be more likely to manage their own care and spend money on the support they feel they need most, in a way which is suitable for their individual needs. This may demonstrate increased levels of independence in some people with learning disabilities through self-management of their own finances.

Figure 6.2.2



Source: PARIS Southampton City Council

6.3 Telecare

A range of electronic devices are available to support individuals with learning disabilities to live independently. These can be used in a person’s home, both in the community and in residential care settings. As established in a previous chapter, epilepsy is common in people with learning disabilities and some people require regular checks at night to ensure their safety meaning they are awoken frequently. Devices such as the epilepsy sensor can aid a person to have undisturbed sleep. The sensor is placed underneath their mattress and monitors epileptic activity while an individual is in their bed. A carer is then alerted if a person has a seizure. This allows individuals to sleep at night without being regularly checked or woken by staff. This can lead to better quality sleep which can then lead to less challenging behaviour, improved mental wellbeing and a more active lifestyle.

Southampton’s City Telecare Service are providers of a wide range of telecare equipment. This offer includes two types of GPS tracking – GPS devices (similar to a mobile phone) and GPS watches. Both forms of GPS tracking can operate as a panic button and contact telephone numbers can be programmed in depending on the client’s needs – they can be connected to either the telecare control room or to a carer. GPS tracking gives individuals the freedom to move around and go out into the community independently while still having a connection to someone, giving both them and their family’s reassurance that they are safe. This type of tracking functionality also affords the client the opportunity to build levels of confidence in accessing the community that perhaps otherwise wouldn’t exist, so supporting a strength based approach to their care by enabling them to use and develop their independence skills.

Around 50-60 people with learning disabilities currently access some form of care technology however given the rapid advancement in technology there is significant scope for increasing access.

GPS Case Study

An individual on the autism spectrum was very keen to access the community but lacked the confidence to do this independently. They had always done this with support staff and gradually staff supported them to learn to travel some routes on their own. Keen to take their independence further but at the same time anxious at the prospect, a GPS tracking device was arranged to see if this helped to manage their anxiety. However, eventually a GPS watch proved to be a better solution. The individual was a regular caller to the responding staff unit as they got used to their device, using it as a means to provide almost a running commentary of where they were going and what they were doing. This meant they got to know the telecare staff well! It also served to provide them with the reassurance they needed that someone was always contactable and aware of their movements, enabling them to grow in confidence. Within a short space of time, the individual now accesses shops and local facilities independently and confidently on a regular basis.

By 2025, the aim is that Telecare will have transitioned from analogue to digital services. City Telecare are currently planning for this upgrade which will enable digital connectivity via a cloud based device management system which will deliver an improved speed of connection, and a more efficient, future

proofed service for its telecare solutions. An example of what will change is that devices will be able to be reconfigured remotely – so for example, a telecare operator will be able to go online to amend activation times for a device rather than having to visit a property to make the adjustments.

Southampton City Council’s PARIS system records the primary telecare item that has been supplied to a client with learning disabilities. There may be secondary/additional telecare supplied by the council or through external agencies. For example, digital memory clocks can be purchased privately through online product shops for dementia support. Figure 6.3.1 shows the range of telecare for people with learning disabilities in the city. The most common is epilepsy monitors.

Figure 6.3.1 ‘Caretech’ telecare installation for people with learning disabilities in the city

Primary care reason group of learning disabilities	Number of clients in the primary support reason group for learning disabilities
Epilepsy Monitors	13
Alarm Unit	9
Carer Alert	8
Fall Detector	7
Bed Exit Monitor	6
GPS	4
Digital Memory Clock	4
Pendant Alarm	2
Pill Dispenser	2
Door Exit Monitor	1
Enuresis Sensor	1
Total	57

Source SCC PARIS dataset

6.4 Health Charter

The national Health Charter aims to support adult social care providers to improve the wellbeing of people with learning disabilities by reducing inequalities in health and social care. By signing up to the Health Charter, organisations commit to a number of pledges including;

- listening to, respecting and involving family/carers to achieve the best possible outcomes for the individual.
- providing accessible information.
- tackling over-medication by following the actions set out in ‘Stopping Over-Medication of People with a Learning Disability, Autism or Both’ (STOMP).
- ensuring each person supported by that organisation, and who wants one, has a health action plan and hospital passport.

The Health Charter can aid organisations to ensure that care and support provided is suitable for, and meets the needs of, people with learning disabilities. This in turn can help to reduce health inequalities.

6.5 'All about me' – Hospital Passports

The 'All About Me' booklet is designed to educate mainstream health professionals about the person's individual needs. It provides guidance to health professionals of the reasonable adjustments the individual needs whilst accessing health care services, including hospitals and GP Surgeries. People with Learning Disabilities are encouraged to have their own 'All About Me' (also referred to as Hospital Passport) booklet which can be used in all mainstream health care services.

People with Learning Disabilities living in Southampton suggested having a smaller version of the 'All About Me' booklet, highlighting that health professionals do not always fully read it. The Strategic Health Facilitator in Southampton co-produced a two sided A4 Emergency Health Grab Sheet with Choices Advocacy, Busy People Group and a Paramedic employed by South Central Ambulance. People are encouraged to keep the Emergency Grab Sheet in the green Lions Bottle in the fridge as this is an established system which Emergency Services use. It is aimed at Paramedics and Emergency Service staff to read in such time critical situations.

Local hospital staff feedback has included views the 'All About Me' booklet as long and 'unwieldy'. Grab Sheets are viewed more positively, feedback included that currently the All About me booklet is not fit for purpose and needs revamping, perhaps making it more inclusive to all health and wellbeing services may help collaborative approaches of care. Opportunities to review and improve through stakeholder working should be utilised.

6.6 Hospital Learning Disability Liaison Nurses

Over a quarter of people with a learning disability are admitted to hospital every year almost double the risk of being admitted, compared to the general population (14%). Approximately 0.5% of the general population have a learning disability and University Hospital Southampton see on average 17,605 patients every week, so around 149 patients with a learning disability are seen by UHS services every week.

Hospital Liaison Nurses are qualified learning disability nurses who work with hospital staff. They help people with learning disabilities who are using hospital care to get their needs identified quickly so that the right arrangements can be made to support them in using hospital services.

The Mazars report highlighted that these services are an important aspect of ensuring reasonable adjustments are made to make acute care a safe place for people who cannot readily communicate their needs and whose behaviour can become challenging when either in pain or in a strange environment .

Qualitative research nationally has shown that the hospital liaison nurses are seen as effective and valued. Another national study focusing on quantitative outcomes identified that an epilepsy risk assessment was more likely to be conducted in hospitals where a learning disability liaison nurse was employed (p.0.043). There was also a non-significant trend towards greater use of an 'All about me' health passport, or similar (p.0.055). The study was considered underpowered which can contribute to significance not always being achieved in the latter analysis. However there are many opportunities for Hospital Liaison Nurses to have an impact, including their role as an advocate, facilitating reasonable adjustments, mediating between services and professionals, and enhancing communication. A further study suggested that Hospital Liaison Nurses contributed to NHS hospitals achieving safer practices, however, there was a risk of a lack of structural support.

Hospital liaison nurses are recognised within the University Hospital Southampton Foundation Trust (UHS) Learning Disability Strategy with aims are centred on a triangulated approach of Patients First, Always Improving and Working Together:

- Patient first: Make UHS a learning disability friendly organisation with environments and processes that aim to improve quality, access and positive patient experience whilst at UHS.
- Always Improving: Have a skilled and effective workforce
- Always Improving: Clear and effective leadership of the Learning Disability Strategy
- Always Improving: Provision of learning disability specific resources, including accessible information in line with Accessible Information Standard (2016) and PIF¹³³.
- Deliver person centred care which supports the patient with learning disabilities and their carers / families
- Working Together: Deliver person centred care which supports the patient with learning disabilities and their families / carers

Timely and effective discharge from hospital for people with learning disabilities has recently been identified as a challenge. Anecdotally, there are an increasing number of people with learning disabilities having delayed discharges due to the rehabilitation pathway not being suitable for them, a higher risk of readmission to hospital and increasingly being unable to return back to their home as either the environment or the support staff team can no longer meet the person's needs. Further work is required to establish accurate data and put in place a plan to improve the situation.

6.7 Strategic Health Facilitators

Southern Health NHS Foundation Trust has a dedicated Strategic Health Facilitator covering the whole of Southampton. The role of the Health Facilitator covers joint working with a range of different health professionals within primary and secondary health services to advise on how to provide better care to people with learning disabilities. Recent projects in Southampton have included:

¹³³ NHS England (2017) The Accessible Information Standard (DCB1605 Accessible Information)
<https://www.england.nhs.uk/ourwork/accessibleinfo/> Accessed 19/07/2019

- Increasing the uptake of specific health campaigns and Learning Disability Annual Health Check by releasing specific communications through a range of platforms and methods (see section 4.4.2)
- Working closely with the Breast Imaging Department at Princess Anne Hospital to look at increasing the uptake of breast screening of woman with Learning Disabilities (see section 4.8.1).
- Validating all the GP Surgeries Learning disability registers which are used to invite people along for their Learning Disability Annual Health checks (see section 4.9)

The Health Facilitator provides training and resources to GP practices to enable their delivery of the Learning Disability Annual Health Check. This can also include advice on making reasonable adjustments such as improved signage, using easy read information, having longer appointment times and planning initial visits to the surgery first. Barriers service users experience when accessing services include; not being able to read appointment letters, lack of reasonable adjustments, dependency on staff/relatives to recognise there is a health concern and to seek help, limited knowledge of health professionals on communication.

6.8 Substance Misuse and Alcohol

Some people with learning disabilities misuse alcohol or illicit drugs and some misuse prescribed medications. Various studies have looked at the extent of substance misuse in people with learning disabilities. These are likely to underestimate the problem, as some used self-report measures and others only included people known to learning disability services. There is little known about the health of the 'hidden majority' of adults with learning disabilities who don't use learning disability services. It's this group of people with more mild learning disabilities who are most likely to misuse alcohol or drugs.¹³⁴

Part of the current strategic service approach to people with learning disabilities is increasing the number of those living more independently in local communities. Living independently allows easier access to alcohol and drugs, so having the appropriate services to recognise if someone has learning disabilities, especially mild learning disabilities and adjust the treatment and support process is important.¹³⁵

It is recognised in this document and in local conversations that the risks and challenges, presented by co-occurring learning disabilities and difficulties (LD) and substance use disorders (SUDs), are concerning, and both for individuals and for the services seeking to support them. SUDs specialists

¹³⁴ Public Health England (2016) Substance misuse in people with learning disabilities: reasonable adjustments guidance <https://www.gov.uk/government/publications/substance-misuse-and-people-with-learning-disabilities/substance-misuse-in-people-with-learning-disabilities-reasonable-adjustments-guidance> Accessed 7/12/18

¹³⁵ Public Health England (2016) Substance misuse in people with learning disabilities: reasonable adjustments guidance <https://www.gov.uk/government/publications/substance-misuse-and-people-with-learning-disabilities/substance-misuse-in-people-with-learning-disabilities-reasonable-adjustments-guidance> Accessed 7/12/18

receive little training around people with learning disabilities, LD services receive little training around SUDs. Added to this, challenges presented by the wide range of cognition, communication and capacity within this cohort that, in turn fluctuate with substance use, can make addressing risks and concerns seem overwhelming.

PHE Guidance states that whilst;

‘There is a lack of evidence-based guidance about effective treatment for this group. However, some approaches and strategies may be helpful such as:

- *addiction services and learning disability teams integrating their services together to provide a link between these services*
- *a personalised approach that tailors interventions to someone’s individual needs*
- *interventions and information need to meet the particular communication and learning needs of individuals*
- *people with learning disabilities may benefit from a one-to-one approach rather than group work*
- *both substance misuse services and learning disability services should be screening for misuse problems/learning disabilities at initial assessments*
- *training for mainstream addiction staff in how to work with people with learning disabilities and how to modify their assessment and treatment approaches*
- *training for learning disabilities professionals around substance misuse*
- *widening the person’s social support networks*
- *greater family involvement in treatment*
- *appropriate training and resources for support workers*
- *access to support services including bereavement and sexual abuse that can help people to address the reasons behind their substance misuse*
- *techniques such as motivational interviewing¹³⁶*

6.9 Sexual and reproductive health, and relationships

Specialist sexual health clinics for people living with a learning disability, known as SHIELD (Sexual Health Information Education Learning Disability) Clinics, were developed in Hampshire, Portsmouth and Southampton in 2016 in response to noticeable increases in STIs in adults with a Learning Disability in Portsmouth and South East Hampshire and increasing attendances at mainstream sexual health services by adults with a Learning Disability. The SHIELD clinic provides a friendly service for people with a learning disability. This contraception, STI screening and treatment clinic offers patients access to extra support, regardless of age. Referrals can be made through a professional parent or carer but not through self-referrals.

¹³⁶ Public Health England (2016) Substance misuse in people with learning disabilities: reasonable adjustments guidance <https://www.gov.uk/government/publications/substance-misuse-and-people-with-learning-disabilities/substance-misuse-in-people-with-learning-disabilities-reasonable-adjustments-guidance> Accessed 7/12/18

The aim of the Shield clinics is to provide a service for people with a Learning Disability at a designated time with a named nurse with a special interest in this field and a named sexual health practitioner. This is an appointment clinic and the patient would be seen at the appointment time, they would be expected, they would not have to wait more than a few minutes in the waiting area, this would mean their levels of anxiety would be reduced and their Key worker/ carer would not be kept waiting any longer than the arranged and agreed time. The patient would then be seen by a nurse and maybe a Dr if necessary in a 30 minute appointment they would then be seen by the sexual health practitioner and this would ensure that they have understood everything that has happened and nurse/ practitioner would have the time to answer all their questions in a way that they would understand. Permission to share information documents would have already been signed and a Health passport completed if appropriate. All information would be given in easier to read/ understand formats.

Research has found among women with learning disabilities there is a greater use of long term contraceptive methods and significantly less use of barrier methods.^{137 138} Women with learning disabilities are not given sufficient information and are not fully involved in decisions about contraception.^{139 140} Problems with menstruation in women with learning disabilities may not be appropriately recognised by carers. Earlier menopause can occur, particularly in women with Down's Syndrome¹⁴¹ with carers often poorly resourced to help women understand the menopause.¹⁴²

Research cited in a needs assessment conducted by NHS Solent¹⁴³ found that people with a learning disability (LD) are at higher risk of sexual exploitation. The research was summarised as this is mainly due to: lower levels of educational attainment, communication barriers, low self-esteem, and inability to understand when they are potentially in dangerous exploitive situations, issues around consent (lack of understanding about consent / capacity to consent, lack of ability or knowledge to report an offence or recognise if an offence has taken place.^{144 145}

¹³⁷ McCarthy M. 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum* 2009;32:198-208.

¹³⁸ Servais L. Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 2006;12:48-56.

¹³⁹ McCarthy M. Exercising choice and control - women with learning disabilities and contraception. *British Journal of Learning Disabilities* 2010;38:293-302

¹⁴⁰ McCarthy M. 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum* 2009;32:198-208.

¹⁴¹ Schupf N, Zigman W, Kapell D, Lee JH, Kline J, Levin B. Early menopause in women with Down's syndrome. *Journal of Intellectual Disability Research* 1997;41:264-67.

¹⁴² Willis DS, Wishart JG, Muir WJ. Menopausal experiences of women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 2011;24:74-85.

¹⁴³ Gordon Atkins, Annie Clark, Jacqui Oates and Laura Davies: NHS Solent (2017) Learning Disability Sexual Health Needs Assessment 2016-2017 Unpublished

¹⁴⁴ Brown, H., Stein, J. and Turk, V., 1995. The sexual abuse of adults with learning disabilities: report of a second two-year incidence survey. *Journal of Applied Research in Intellectual Disabilities*, 8(1), pp.3-24.

<https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1468-3148.1995.tb00139.x> Accessed 13/12/18

¹⁴⁵ Franklin, A., Raws, P. and Smeaton, E., 2015. Unprotected, overprotected: Meeting the needs of young people with learning disabilities who experience, or are at risk of, sexual exploitation. Barnardo's.

http://www.barnardos.org.uk/cse_learning_and_disability_report_2015a.pdf Accessed 13/12/18

Garbutt's¹⁴⁶ 3 year study found misunderstands relating to experiences and understanding of sexual health in people with learning disabilities included:

- Several of the young people thought that gay sex was illegal
- In contrast, several didn't realise that the police investigate cases of sexual abuse
- Others were unaware that sex could lead to pregnancy
- Some had little or no understanding of contraception
- Few knew that pregnancy would last 9 months

It is recommended that with the launch of the national comprehensive SRE (Sex and Relationship Education), reasonable adjustments taking into account evidenced research as above are included into making an enhanced programme for people with learning disabilities.

At time of publication, although the SHIELD clinic is operating in Portsmouth, the clinic in Southampton is not operating due to insufficient referral numbers. Local investigation is being undertaken to work proactively with referral agencies to ensure equal opportunities for sexual health support for people with learning disabilities is available Hampshire wide.

6.10 Learning Disability Specialist Health Services

The Southern Health NHS Southampton City Community Learning Disability Team work with people with learning disabilities in the city within seven Clinical Areas of Practice (CAP):

- Autism
- Challenging Behaviour
- Complex Physical health
- Mental health
- Forensic
- Dementia
- Epilepsy

¹⁴⁶ Garbutt, R., 2009. Let's talk about sex: using drama as a research tool to find out the views and experiences of young people with learning disabilities. *Creative Approaches to Research*, 2(1), p.8.

Figure 6.10.1 Community Mental Health Team Client profile of clinical pathway group

Clinical Pathway Group	Females		Males	
	Count	Percentage	Count	Percentage
Autism	<5	suppressed	26	21.1%
Challenging Behaviour	8	10.5%	24	19.5%
Complex Physical Health	42	55.3%	48	39.0%
Dementia	13	17.1%	9	7.3%
Epilepsy	<5	suppressed	<5	suppressed
Forensic	<5	suppressed	<5	suppressed
Mental Health	18	23.7%	33	26.8%
No CAPS	<5	suppressed	<5	suppressed
Totals	76		123	

Source: Southern Health Learning Disability Community team

Figure 6.10.2 shows the number of clients for each pathway group by gender. Three-fifths of the clients are males (62%). The counts do not add to the totals as a client could belong to more than one pathway. Autism and challenging behaviour pathway groups have more male clients (in counts and proportions). The clinical pathway more common among female clients is complex physical health.

The caseload covers approximately 200 to 220 people with learning disabilities within the city and the team receives on average 22 referrals a month. The team of 29 staff (24.4 FTE) includes occupational therapists, physiotherapists, clinical psychologists and an art psychologists, community nurses, a health facilitation nurse, supports workers, technical assistants and speech and language therapists.

Females clients range from 18 years old to 78 years old, the mean average age is 44.4 years. Male clients range from 17 years to 74 years of age and the mean average age is 38.7 years.

Figure 6.10.2

Age group	Females		Males	
	Count	Percentage	Count	Percentage
17-24	13	17.1%	27	22.0%
25-34	13	17.1%	31	25.2%
35-44	10	13.2%	22	17.9%
45-54	18	23.7%	21	17.1%
55-64	12	15.8%	15	12.2%
65+	10	13.2%	7	5.7%
Totals	76	100.0%	123	100.0%

Similar to the age profile seen in figure 4.3.2, most people with learning disability seen by the service are older females aged 45-54 years and younger males between 17-34 years.

Linking the age, gender and pathway data together, analysis shows:

- females aged 55 to 64 years are on the dementia, complex health needs pathway or both
- females aged over 65 years are on the dementia pathway and complex health needs pathway or both

- clients on the autism pathway are likely to be males aged 17 to 24 years or 25 to 34 years
- complex health needs is the most common pathway for male clients aged 55 years and over

6.11 Mental Health & Learning Disabilities

Evidence suggests that people with learning disabilities can benefit from Cognitive Behaviour Therapy (CBT), particularly those with mild to moderate learning disabilities who experience depression and anxiety.

The Improving Access to Psychological Therapies (IAPT) programme¹⁴⁷ aims to provide equitable access to NICE-recommended psychological therapies to people from all sectors of the community. There is evidence that people with mild to moderate learning disabilities can benefit from the therapies offered by IAPT services, especially when reasonable adjustments are made to the way in which these therapies are delivered.

Commissioner guidance from the Positive Practice Guide, is as follows:

- Developing an understanding of local demographics in order to provide equity of access to IAPT. There are other groups, such as ethnic minorities, the elderly and the young, those living in deprived areas and LGBT people, who are finding access difficult. The different life experiences of people with learning disabilities need to be taken into account as well.
- Auditing access to talking therapies for people with learning disabilities in the same way as other people with protected characteristics.
- Introducing a screening tool to identify people needing reasonable adjustments.
- Adapting the referral form so referrers flag people with learning disabilities.
- Allowing a range of referral pathways for people with learning disabilities.
- Publicising the IAPT offer to people with learning disabilities and referrers to ensure access.
- Making it a requirement that IAPT data systems flag people with learning disabilities and the reasonable adjustments that each person requires.
- Funding ongoing training for IAPT staff to ensure that they have the confidence, competencies and expertise to assess and undertake therapy with people with learning disabilities.
- Developing a service specification that requires joint working between mainstream and specialist services.
- Adjusting the funding and data collection requirements for IAPT services to allow more time to ensure effective engagement of people with learning disabilities at referral and assessment and during therapy.
- Setting specific objectives for IAPT services and people with learning disabilities.
- Ensuring people with learning disabilities are still able to access IAPT services if they are receiving secondary care.

¹⁴⁷ Mental health Foundation Learning Disabilities: IAPT Positive Practice Guide (2015)
<https://www.mentalhealth.org.uk/learning-disabilities/publications/learning-disabilities-iapt-positive-practice-guide>
Accessed 19/07/2019

- Incentivising inclusion of people with learning disabilities to IAPT services through other measures such as CQUIN.
- Making reasonable adjustments a requirement and ensuring services are flexible and responsive to the needs of people with learning disabilities.

6.12 End of life care

Palliative care for people with learning disabilities is similar to that of the general population but it is more difficult to meet needs because of communication challenges, symptoms masked by unconventional behaviour and also a high incidence of behavioural and psychiatric problems. Other areas to consider include mental capacity and decision making, relationships with family, friends and support staff and complex social circumstances.

The *Palliative Care for People with Learning Disabilities Network*¹⁴⁸ brings together service providers, people with a learning disability and carers working for the benefit of individuals with learning disabilities who have palliative care needs. The network worked with NHS England to produce guidance¹⁴⁹ providing resources and tips for commissioners, service providers and health and social care staff providing, or delivering care to people with a learning disability at the end of their lives.

Key guidance includes:

- Support people with a learning disability to develop their awareness about death and dying
- Involve families/friends/supporters and the person's usual paid carers as partners in care
- Support people to engage in Advance Care Planning (ACP) (ensuring mental capacity is considered). If the person is assessed as not having mental capacity to create an ACP it is still very important to ensure the person can express their end of life preferences and participate in personalised care and support planning
- Remember bereavement support for those left behind is an important part of palliative and end of life care
- Parallel planning in commissioning is essential, considering people with a learning disability when commissioning end of life care and end of life care when commissioning learning disability services

The Community Learning Disability Team (part of Southern Health NHS) has a champion for End of Life care. The Community Learning Disability Team manager attends the End of Life Steering Group alongside colleagues from acute hospitals, hospices, end of life and palliative care teams, bereavement organisations and SCAS. This meeting is a forum to share good practice, information and developments. The team have made use of the Future Planning document developed in partnership with Age-UK and the NHS. All deaths of people who have been in receipt of Southern Health learning

¹⁴⁸ Palliative Care for People with Learning Disabilities Network www.pcpld.org Accessed 17/12/18

¹⁴⁹ NHS England and Palliative Care for People with Learning Disabilities Network (2017) Delivering high quality end of life care for people who have a learning disability <https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf>

disability services in the 12 months leading up to their death are reported, and reviewed to assess the care and support provided, highlight and share good practice, and identify gaps, concerns or opportunities for development.

7. Recommendations

This needs assessment clearly demonstrates that people with learning disabilities experience a wide range of health inequalities when compared to the general population. These recommendations and any future health & social care policy decisions related to learning disability services should have as a primary aim to actively reduce these inequalities. They should clearly state which inequalities are being targeted and how they will be reduced.

Reasonable Adjustments

- 1) All services, both specialist and universal, should be designed and delivered in a way that considers the needs of people with learning disabilities. Reasonable adjustments should become integral to service planning and address the range of needs not just the average. The use of the assessment means that our services can be more scientific about the way in which we target resources.

This is relevant for the commissioners and providers of all health & social care services but in particular:

- a) Sexual Health

The availability of specific sexual health 'SHIELD' clinics for people with learning disabilities should be promoted more widely and if take-up continues to be low, a more in depth exploration of the reasons for this should be completed. This will be particularly relevant to the significantly higher proportion of SEND young people that Southampton supports in our schools and colleges.

- b) Mental Health

The Green Light Tool Kit should continue to be used and reviewed regularly by providers and commissioners of both mental health and learning disability services.

- c) Substance Use Disorders (SUDs)

SUDs specialists have limited training and expertise around learning disabilities and learning disability services have limited training and expertise around SUDs. Commissioners in both areas need to work collaboratively in address this gap and regularly assess if there is suitable provision amongst the staff equipped with LD awareness and up-to-date training to support those clients with LD. This will be particularly relevant to the significantly higher proportion of SEND young people that Southampton supports in our schools and colleges.

Monitoring & Auditing Recommendation

- 2) There should be ongoing regular monitoring of how the recommendations in this needs assessment are being implemented as well as reporting on a range of inequalities so that improvements can be recognised.
- 3) This needs assessment has identified a number of national and local policy documents as well as guidelines. A stock take should be completed to establish how effectively these are being implemented within local service provision. This should include: NHS Improvement Standards and LeDeR findings,

- 4) Findings and recommendations from local and national LeDeR reviews of deaths of people with learning disabilities should be shared with commissioners as soon as they are available and commissioners take responsibility for putting in place relevant actions within local services.

Demographic Recommendations

- 5) Commissioning of services should take account of the demographics identified within this needs assessment, in particular:
 - a) The higher prevalence of learning disabilities amongst males than females
 - b) Forecast increase in number of people with learning disabilities, especially those with severe or profound learning disabilities and associated complex needs
 - c) High prevalence of people with learning disabilities living in more deprived areas of the city
 - d) High prevalence of people with learning disabilities within traveller and Asian communities.
 - e) Higher proportion of school aged pupils in primary, secondary and special schools that have a Learning Disability

Health Needs Recommendations

- 6) Health, as a system, needs to respond and adapt to the changing needs in the learning disabilities population. To drive forward this change, commissioners will work in partnership with Southern Health Foundation Trust to develop, describe and implement an offer, working in partnership with health partners, and based on where our priorities are. The offer will ensure that there is a toolbox of resources/supports that can be used by any provider. As an example, providing a training and development offer (mentoring/coaching programmes), and partnering the system with essential services, such as LD Strategic Health Facilitation/Acute Liaison.
- 7) Specialist health services (SHFT), will play a more active role in supporting primary care with Annual Health checks, by aligning their Clinical Assessment with the Annual Health Check. Work with adults will align closely with the 14-17 year old Annual Health Checks, to ensure the good uptake and improved quality of the health checks.
- 8) A number of conditions have a higher diagnosed prevalence among people with a learning disability, these tend to be those that involve self-management. It may be possible that poor self-management allows conditions to exacerbate to a diagnostic level. Generally higher prevalence occurs earlier in age for people with a learning disability compared to those without. It is recommended that mechanisms to improve the self-management of higher prevalent conditions be explored for people with learning disabilities.
- 9) Service commissioning for respiratory conditions particularly pneumonia linked with dysphagia and resulting aspiration pneumonia needs to be linked with the guidance of reasonable adjustments for this condition¹⁵⁰ and implemented. Liaison with GP surgeries promoting

¹⁵⁰ Public Health England (2016) Dysphagia in people with learning difficulties: reasonable adjustments guidance <https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-disabilities/dysphagia-in-people-with-learning-difficulties-reasonable-adjustments-guidance> Accessed 4/12/18

vaccination for people with a learning disability, including their carer outside of these age groups is recommended to address the identified inequality.

- 10) 1 in 11 Southampton registered patients with a learning disability are diagnosed with diabetes, a significantly higher prevalence compared to patients without a learning disability. Joined up commissioning supporting a holistic approach encompassing risks would be beneficial for improving the health of people with a learning disability. Utilising the Strategic Health Facilitators with the overarching knowledge of bespoke programmes such as WiLD, SHIELD etc. to allow professionals such as ASC workers to signpost and refer in a preventative way before needs escalates as well as to support existing health risks.
- 11) 1 in 6 people with a learning disability have epilepsy. It is recommended that services supporting people with epilepsy are regularly audited to ensure LD leads and the soft skills required are evident with the staff.
- 12) The gap in the proportion in paid employment between those with learning disabilities and those without is lower than the national average and increasing overall. Efforts to support more people with learning disabilities into employment should be reviewed.
- 13) To support an increase in uptake of cancer screening for people with learning disabilities:
 - a) Awareness should be raised amongst people with learning disabilities and their carers (both family carers and paid carers) about the importance of cancer screening and the adjustments which can be made to.
 - b) Training should be provided to support workers about how they can support access to cancer screening including practical steps such as supporting someone to collect a stool sample.
 - c) There should be exploration whether the cervical HPV vaccine could be provided to women with learning disabilities (specifically for those who would otherwise refuse to access cervical screening)
- 14) There is a gap in knowledge locally and nationally for substance use disorders (SUDs). SUDs specialists have limited training and expertise around learning disabilities and vice versa; learning disability services have limited training and expertise around SUDs. Commissioners in both areas need to work collaboratively in address this gap and regular assess there is suitable provision amongst the staff equipped with LD awareness and up-to-date training in support those clients with LD.
- 15) Sexual health services for people with learning disabilities have been developed however there is a gap in knowledge and promotion of the 'SHIELD' clinic resulting in this service not being used. Signposting material for stakeholders within relevant pathways need to be distributed and used.

8. Appendix - Evidence of What Works

8.1 Guidelines and Guidance

8.1.1 NICE Guidelines

<https://www.nice.org.uk/guidance/population-groups/people-with-learning-disabilities#panel-pathways>

[Care and support of people growing older with learning disabilities](#) (NG96) Published date: April 2018

[Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges](#) (NG11) Published date: May 2015

[Learning disabilities and behaviour that challenges: service design and delivery](#) (NG93) Published date: March 2018

[Mental health problems in people with learning disabilities: prevention, assessment and management](#) (NG54) Published date: September 2016

8.1.2 NICE Quality standards

[Learning disabilities: challenging behaviour](#) (QS101) Published date: October 2015

[Learning disabilities: identifying and managing mental health problems](#) (QS142) Published date: January 2017

8.1.3 PHE Guidance

[Flu vaccinations for people with learning disabilities](#) Published date: 25 September 2018

[Dementia and people with learning disabilities](#) Published date: 18 June 2018

[Blood tests and people with learning disabilities](#) Published date: 26 September 2017

[Pharmacy and people with learning disabilities](#) Published date: 23 June 2017

[Substance misuse and people with learning disabilities](#) Published date: 8 May 2016

[Dysphagia and people with learning disabilities](#) Published date: 8 May 2016



[Constipation and people with learning disabilities](#) Published date: 8 May 2016

[Cancer screening and people with learning disabilities](#) Published date: 8 May 2016

[Annual health checks and people with learning disabilities](#) Published date: 8 May 2016