LEARNING DISABILITIES JSNA

2020

Swindon Borough Council

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Introduction

A Joint Strategic Needs Assessment (JSNA) helps us to understand:

- What we know about the current health and wellbeing needs of local people
- How their needs are currently being met
- What we think their future needs are likely to be
- How these future needs can be met

We want to understand changes in Swindon's population and to investigate what makes a difference to people's health and wellbeing, which will help us to plan effectively for the future. The Swindon Health and Wellbeing Board oversees the development of the JSNA, as well as any resulting recommendations.

The population in scope for this JSNA chapter is adults with a learning disability (LD). A JSNA chapter for adults with LD was completed in 2012 and this report intends to provide a full review and update of the previous needs assessment.

Key messages

Population

The estimated total population of adults with LD in Swindon has increased by around 300 people since 2012. The total estimated population is currently 4081. Around 860 adults have moderate or severe LD.

Future population projections for Swindon suggest that there will be a significant increase in the population of older adults with LD over the next 15 years. It will be important to plan for these demographic changes, including preparing for more complex health needs, and the likelihood of an increasing proportion of people with dementia. In addition, there is likely to be a larger group of older carers who may need additional support or be at risk of being unable to continue their caring role.

Population estimates suggest that the proportion of people in Swindon with LD from minority ethnic backgrounds is likely to have increased. Based on national data, adults with LD from minority ethnic backgrounds have poorer health outcomes and a shorter life expectancy than adults with LD from white backgrounds.

Health

Nationally, adults with LD are consistently more likely to have poor health outcomes, leading to a significantly shorter life expectancy and healthy life expectancy. Across the southwest, approximately 70% of deaths of adults with LD were notified to the National Learning Disability Mortality Review (LeDeR). 23% of reviewed cases in Bath and Northeast Somerset, Swindon and Wiltshire (BSW) were under the age of 45, which is similar to the

England average. The mean age of death was 57, compared to an average of 60 in England. Notification of deaths amongst ethnic minorities is very low in BSW.

Some health conditions are more prevalent in adults with LD, both in Swindon and nationally. This includes:

- Dementia
- Epilepsy
- Diabetes (Type 1 and non-Type 1)
- Asthma
- Mental health conditions
- Poor oral health

Admissions to Great Western Hospitals NHS Foundation Trust for adults with LD have been increasing over the last three years. The most common reasons for admission were epilepsy, acute lower respiratory tract infection, and urinary tract infection. Pneumonia contributed to the greatest number of bed days.

Primary care offers an important preventative opportunity for improving the health of adults with LD. The best mechanism for doing this is by being included on the GP LD Register and receiving a high quality annual health check. The GP LD Register in Swindon has been highlighted as a specific issue of concern in the development of this report. Feedback from practitioners and LD Representatives indicates that the criteria for joining the register is unclear and can vary between practices. In addition, a large proportion of people on the register do not receive an annual health check, though this has been increasing. Covid-19 is likely to further affect this issue.

Screening is another important preventative mechanism. In Swindon, people with LD are less likely than people without LD to attend their routine screening appointments for cervical, breast and bowel cancer. National research into barriers relating to screening highlights that scarcity of information, fear of medical intervention, and embarrassment can all contribute to lower proportions of people with LD attending screening.

Adult Social Care

Legislation introduced since the 2012 JSNA prioritises personalisation and the involvement of adults with LD in decision-making about the support they need. Strengths-based working and the "three-conversation model" that have been introduced all help to increase personalisation. Personal budgets and direct payments[1] have been introduced as part of the overall shift. Fewer adults in Swindon use a direct payment than the England average, and there is scope to increase this.

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[1] A personal budget is the amount of funding allocated to a person, based on their specific care needs. People who use direct payments are able to choose how to spend their personal budget, for example by directly hiring a care worker.

Personalisation is clearly a priority of adults with LD and carers. This has been highlighted both through previous LD Forums and insights from these are included in the report.

Transition services have undergone significant changes since 2012. A new Transitions Strategy and Protocol was introduced in 2020 in collaboration with partners, young people, parents and carers. Transition is an important point for capturing the needs of young people who will be moving into ASC services. From a health perspective, transition offers an opportunity for the health system to identify needs early and consider the health support needs that a young person with SEN, including LD, will need as an adult.

In Swindon, 686 adults with LD were supported by ASC in 2018/19. It is estimated that around 3400 more people with LD live in Swindon and are not supported by ASC. This could be because they have milder LD and do not need regular support, or are supported solely by their families. Nationally, it is recognised that people with milder LD who are not supported by ASC may still be at risk of poorer health outcomes as well as vulnerable to safety issues such as “cuckooing”.

For all adults (LD and non-LD) in Swindon, there has been an increase in concerns raised to the Swindon Safeguarding Partnership (SSP). The SSP will be putting systems in place in 2021 to ensure that people with LD who require help and support are able to engage with SSP and have their voice heard.

The LD/Autistic Spectrum Disorder Programme Board is reviewing services for adults with LD across BSW. Pathway mapping in Swindon as part of this work has identified gaps in crisis and support services, a lack of a clear referral pathway, a need for raised awareness of transitions services, and concerns over silo working. These findings are contributing to work that will take place across the CCG and should be closely linked to the actions that develop from the JSNA.

Wider determinants of health

The wider determinants are a diverse range of social, economic and environmental factors that influence people’s mental and physical health. The wider determinants considered in this report are employment, housing and independent living, social life and relationships, and community safety and crime.

Employment for adults with LD who are supported by ASC has improved from 3.5% in 2012/13 to 6.3% in 2018/19, but the overall proportion employed is still very low though similar to the England average. Adults with LD have provided useful insights in how to improve employment numbers through contributions at the LDPB Forum, including suggestions of buddy schemes and being able to access work trials. Full details of comments are included in the report. In addition, a Supported Employment Strategy 2018-22 has been developed, with a target of increasing employment to 10%. The impact of Covid-19 is not yet fully understood, but it is likely to have a significant negative effect on employment rates for adults with LD.

More adults with LD are living in stable and appropriate accommodation when compared to 2012, while the proportion living in residential or hospital accommodation has reduced by

13%. However, 55% of adults with LD who are in residential accommodation are placed outside of Swindon. Housing and independent living was highlighted as a priority by the LD Representatives on the LDPB. There was a particular request that more support is needed on budgeting, so that people are better able to manage their money when they live independently.

Community Safety is important for adults with LD. Nationally, 73% of adults with LD have experienced hate crime. Swindon-based data indicates that adults with LD are also more likely to be victims of sexual assault than the general population. Hate Crime Advisors are available at Wiltshire Police to provide support to adults with LD for hate crime, and the Sexual Assault Referral Centre (SARC) provides support to victims of sexual assault. Adults with LD are over-represented in the criminal justice system nationally and are more likely to experience poor treatment and suffer from mental health conditions while imprisoned.

Carers

There are an estimated 268 carers of adults with LD living in Swindon. Specific research was carried out in 2017 to consider the role of older carers, as this is likely to be increasingly common as the overall population of older adults with LD increases. This research found that there were 102 carers in Swindon over the age of 65. The risk of a carer being unable to continue to provide their unpaid caring role is increased as the carer ages. This could result in increased demand for ASC going forward and is an important consideration for future planning.

Legislation and Policy

The Care Act 2014 has been a major legislative change since the 2012 JSNA. The Act aims to strengthen person-centred working and provides a legal framework for the increase in provision of personal budgets and direct payments. All social care work and decision-making must take account of a person's wellbeing.

In addition, the Children and Families Act 2014 places a duty on local authorities to complete transition assessments for people that are likely to need support from Adult Social Care once they leave children's care and support services.

LeDeR has been introduced. Deaths of adults with LD are reviewed to improve understanding of common themes and risks and the findings collated into an annual report. The overall aim is to make improvements to the lives of adults with LD.

Details of other relevant legislation and policy are included in the report.

General points

The population of adults with LD is diverse and has a wide variety of needs, depending on their circumstances and disability. There are some clear patterns emerging from the research that has been carried out, which may help with future service planning and providing the best support possible for adults with LD. These include recognising the likelihood of an ageing population, the importance of personalisation, and supporting people to live independently where possible. From a preventative perspective, the LD GP

Register should offer an opportunity for early intervention through the annual health check, but this depends on the quality and accessibility of checks.

Recommendations

1. Determine the governance and accountability arrangements for monitoring the progress of the following recommendations, including the scrutiny role of the LD Partnership Board (LDPB)

2. Develop an action plan to take forward the recommendations from this JSNA, led by a working group of relevant partners. Reasonable adjustments should be considered as part of all recommendations.

3. Consider the impact of Covid-19 as part of all recommendations, including in relation to access to annual health checks, screening, and the ongoing impact on the mental health of adults with LD

4. In line with national requirements for the roll out of mandatory LD training for health and social care staff from April 2021, agree and deliver a local training programme to include;
    a. How to assess and make reasonable adjustments
    b. How to communicate effectively with adults with LD
    c. How to support adults with LD who have been victims of sexual assault

5. Ensure that the appropriate systems and services are in place to support the projected increase in older adults with LD, including risks around increased co-morbidities.

6. Include the JSNA findings in relation to carers of adults with LD within the upcoming review of the Carers Strategy. In particular consider the implications of the expected increase in older carers and their specific needs

7. Improve the recording, analysis and understanding of the local Black, Asian and Minority Ethnic (BAME) population with LD and any specific needs, paying particular attention to the findings and recommendation in;
    a. The national Learning Disabilities Mortality Review Report (LeDeR) (University of Bristol - Norah Fry Centre for Disability Studies, 2019)
    b. ‘Reaching Out’ (Foundation for people with learning disabilties, 2012)

8. Continue to deliver on the LeDeR requirements ensuring;
    a. Alignment with BSW-wide review of LeDeR; Learning into Action
    b. Better identification and appropriate notification of cases
    c. Adequate numbers of health and social care reviewers
    d. Ensure reviews are completed within the six months target of notification to LeDeR

   e. Ensure a local process is in place to act promptly on the findings of the LeDeR reviews

9. Increase the numbers of adults with LD attending screening for bowel, cervical and breast cancer.

10. Clarify pathways for the provision of mental health support for adults with LD

11. Ensure the outcomes from the BSW Programme Board review of LD pathways are implemented including:
    - Transition
    - Crisis and support
    - Referral routes
    - Silo working

12. Incorporate The Good Practice Guidance in Working with Parents with LD in to any policies, processes and training for supporting parents with additional needs

13. Improve the relationship between the Swindon Safeguarding Partnership (SSP) and the Learning Disability Partnership Board so that adults with LD are fully engaged in the work of the SSP to address safeguarding and community safety concerns

14. Continue to improve ‘personalisation’ in services, and have ongoing dialogue with adults with LD and their carers about whether services meet their needs. As part of this, increase the proportion of people receiving direct payments.

15. Support adults to live as independently as possible. This has been highlighted as a priority by LDPB representatives and should incorporate supporting adults’ social life and relationships, as well as housing itself.

16. Support the delivery of the employment targets set out in the Supported Employment Strategy

Learning Disability GP Register – specific recommendations

1. Use the QOF Quality Improvement domain 2020/21 – supporting people with learning disabilities to improve the accuracy of the GP Register (increasing registrations) and to increase annual health checks

2. Increase the number of young people joining the LD Register at transition (14-25yrs)

3. Standardise eligibility criteria between GP Practices for the register

4. Meet the NHS England target of 75% of people on the register receiving an annual health checks

5. Undertake an audit of the quality of annual health checks and health action plans

6. Review format and delivery of hospital passport in line with findings from the March 2020 Forum

7. Ensure there are regular progress reports to the LDPB regarding use of the easy-read letter, pre-health check questionnaire and follow-up letter that have been developed to support GPs

Impact of Covid-19

The Covid-19 pandemic has had a significant impact on the health and social care needs of adults with LD. The LD Reps for the LDPB gave an update on how Covid-19 has affected them when they gave comments on this report and highlighted that it is very important that the points below are considered:

- The lockdown and subsequent restrictions on activities are likely to have a long lasting effect on mental and physical health, as well as on availability of services
- Mental health was particularly considered to be more of a priority since lockdown due to people experiencing social isolation and loneliness
- A specific issue relating to payments was highlighted. Currently a number of shops and services are not accepting cash due to Covid-19 and this is having a negative impact on adults with LD being able to access things in town independently.

In addition, carers of adults with LD have highlighted some concerns related to Covid-19:

- How will health needs of adults with LD be prioritised as routine clinics start again
- Preventative interventions [which are currently harder to access] are vital with LD to manage conditions and ensure that life-threatening situations do not occur
- Covid-19 may increase health inequalities for adults with LD if they are not prioritised
- There is a need to ensure that commissioned providers have appropriate contingency plans for future epidemics, particularly when providing 24/7 care to an individual

Impact on report

This report has been researched and written during 2020. The context has changed significantly in timeframe due to Covid-19, and some specific changes to research activities were made in response to the pandemic:

- Some of the planned qualitative research and engagement activities were unable to take place. A planned focus group with adults with LD and another one with carers were cancelled as it was not feasible to run virtual alternatives at the time. To address this, Carer representatives had an opportunity to comment on a draft of the report. In addition, Swindon Advocacy Movement (SAM) and SBC developed an easy-read briefing paper of this document and worked with the LD representatives to capture their comments. Comments from both of these groups have been built into this final version. A full easy-read version of the overall document needs to be completed.
- The LDPB Forum in April was planned as a focused session on reviewing changes since the 2012 JSNA. This session was cancelled, but comments have been captured from LDPB representatives as detailed above.
- There have been some limitations in staff capacity for reviewing and commentary on the report as it has developed.

Introduction

Scope

A needs assessment is a systematic method of identifying the unmet needs of a population, with the goal of informing the planning and commissioning of health, wellbeing and social care services within the local authority area. The aim of a needs assessment is to improve health and care services, and reduce inequalities.

A Joint Strategic Needs Assessment (JSNA) is a type of needs assessment that is co-produced by a number of partners with a focus on longer-term strategic issues. Each Health and Wellbeing Board has a statutory obligation to produce an annual JSNA which must describe the current and future health, wellbeing and social care needs of the local population. In Swindon, an overall JSNA Summary is produced each year, alongside a programme of thematic ‘deep-dive’ JSNAs on specific topics or population groups, of which the present report is part.

The population in scope for this JSNA chapter is adults with a learning disability (LD). A JSNA chapter for adults with LD was completed in 2012 and this report intends to provide an update on this paper. The recommendations from the 2012 report are included in Appendix A with commentary provided on progress against the recommendations.

Objectives

- To provide an up-to-date analysis of the demographics and needs of adults with LD in Swindon
- To summarise the views of adults with LD, professionals and carers in regard to their needs and any identified service provision gaps
- To provide a baseline of the local and national data that are available for reviewing and assessing the needs of adults with LD on an ongoing basis
- To highlight any inequalities in access to health and social care, and inequalities in outcomes for adults with LD
- To provide a baseline document that can be used for service planning, commissioning and strategy development
- To propose recommendations from the quantitative and qualitative data gathered

The report is split into four main sections. The first section considers what we know about the LD population in Swindon, and how it is projected to change over the next decade and a half. The second section specifically looks at physical and mental health needs, and considers whether health services in Swindon meet these needs. The third section considers the role of adult social care and the services offered, and the final section focuses on the wider determinants of health (e.g. education, housing, employment, social life and relationships).

Definitions

The 2001 Department of Health White Paper *Valuing People* provided a comprehensive definition of learning disabilities which is still widely used (Department of Health, 2001):

"Learning disability includes the presence of:

- *A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;*
- *A reduced ability to cope independently (impaired social functioning);*
- *Which started before adulthood, with a lasting effect on development*

This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as some people with Asperger's Syndrome.

Learning disability does not include all those who have a 'learning difficulty' which is more broadly defined in education legislation."

Mencap provides a summary of different types of LD:

"There are different types of learning disability, which can be mild, moderate, severe or profound. In all cases a learning disability is lifelong.

It can be difficult to diagnose a mild learning disability as the individual will often mix well with others and will be able to cope with most everyday tasks. However, they may need support in other areas of their life such as filling out forms.

People with a severe learning disability or profound and multiple learning disability (PMLD), will need more care and support with areas such as mobility, personal care and communication. People with a moderate learning disability may also need support in these areas, but not definitely."

Identification and diagnosis of learning disabilities

The causes of LD fall broadly into three categories:

- Prenatal period
    - Chromosomal and genetic anomalies, including Down's syndrome, Williams syndrome and Rhett syndrome
    - Maternal infections, for example rubella (this is now very rare due to vaccination)

  - Environmental/social issues, for example fetal alcohol syndrome
- Perinatal period
  - Lack of oxygen during birth
  - Prematurity
- Postnatal period
  - Infection in infancy or early childhood, for example measles, meningitis, encephalitis
  - Injury

Context

Legislation

The legislation set out below is relevant when considering the needs of adults with LD and the services that they use.

Care Act 2014

The Care Act sets out local authorities' duties in relation to assessing people's needs and their eligibility for publicly funded care and support. All social care work and decision-making must take account of a person's wellbeing.

The Care Act aims to strengthen person-centred working and provides the legal framework for the significant increase in personal budgets and direct payments that has taken place since the 2012 JSNA.

Equality Act 2010

The Equality Act legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws by combining them into one Act, including the Disability Discrimination Act. The Act aims to protect people from discrimination, harassment and victimisation.

Under the Equality Act, all disabled people have the right to reasonable adjustments when using public services. Organisations are legally required to put adjustments in place to remove barriers that disabled people would otherwise face when accessing services.

Mental Capacity Act 2005

The Mental Capacity Act states that every adult has the right to make their own decisions wherever possible. People should always be supported to make their own decisions if they can. This might mean giving them information in a format that they can understand (for example this might be easy read information for a person with a learning disability) or explaining something in a different way. If a decision is too complicated for a person to make, even with appropriate information and support, then people supporting them must make a 'best interests' decision for them.

Human Rights Act 1998

The Human Rights Act 1998 sets out the fundamental rights and freedoms that everyone in the UK is entitled to. The Act brought the convention rights from the European Convention on Human Rights (ECHR) into British law. Any new law passed in the UK must be compatible with the Convention rights.

The Act requires all public authorities (such as government departments, councils, hospitals, the police, and those acting on behalf of public authorities) to act in a way which respects and protects an individual's human rights.

The Act places a duty on all public authorities to ensure that decisions that are made take human rights into account, including for adults with learning disabilities. This includes the right to respect for private or family life, the right to marry, and the right to protection from discrimination.

Children & Families Act 2014

The Children and Families Act places a duty on local authorities to complete transition assessments for children that are likely to need support from Adult Social Care once they leave children's care and support services. For children with an Education, Health and Care Plan (EHCP), the transition assessment usually takes place as part of the annual review.

In addition to considering children already receiving support from children's services, local authorities should consider how they can identify young people and carers who are not currently receiving services but may have support needs as adults.

National policy

Transforming Care

The Transforming Care programme aims to improve health and care services so that more people with LD and/or Autistic Spectrum Disorder (ASD) can live in the community, with the right support, and close to home. It aims to reduce the number of people that need to go into hospital for their care. The Transforming Care agenda was developed following the review into abuse at the Winterbourne View hospital.

National Learning Disability Mortality Review (LeDeR)

LeDeR is a national programme which aims to improve the lives of the people with LD. It was set up to review deaths of people with LD and to explore why there is a large gap in life expectancy between people with and without LD. Deaths of people with LD are reviewed locally and the data is collated nationally, with the aim of identifying what can be changed to make a difference to people's lives. LeDeR publishes annual reports and will be a useful ongoing source of data.

Relevant recommendations from the 2018 LeDeR report are (University of Bristol, 2019):

- Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic (BAME) groups notified to LeDeR are representative of that area and use the findings to take appropriate action

- Guidance continues to be needed on care-coordination and information sharing in relation to people with learning disabilities, at individual and strategic levels.

- The Royal College of Paediatrics and Child Health has been asked to identify and publish case examples of best practice and effective, active transition planning and implementation for people with learning disabilities as they move from children's to adults' health services

The publication of the information referenced in the third point should be monitored for identification of best practice.

Following publication of the second LeDeR annual report, the government consulted on proposals for mandatory learning disability (and autism) training. This was based on a recommendation in the report for mandatory learning disability training for all health and social care staff. The responses to the government's consultation were supportive and the decision has been made to introduce mandatory training for all from April 2021.

NHS Long Term Plan

The NHS Long Term plan was published in 2019 and sets out the vision for the health service over the next ten years. It indicates a continued shift towards giving people more control over their own health and the care that they receive. The Plan includes specific commitments for people with LD:

- Action will be taken to tackle the causes of morbidity and preventable deaths in people with LD. Uptake of the annual health check for people aged 14 and over with LD will be increased to 75%
- The LeDeR programme will continue to be funded
- NHS staff will receive information and training on supporting people with LD. Sustainable Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) will be expected to make sure that all local healthcare providers are making reasonable adjustments to support people with LD.

All Our Health

All Our Health is a national call to action for all healthcare professionals to use their skills and relationships to maximise their impact on avoidable illness, health protection and promotion of wellbeing and resilience. This is important for staff working with adults with LD, as good communication is critical to improving prevention and beginning to reduce inequalities in health outcomes for adults with LD.

Public Health England (PHE) has published core principles for health staff to support them to communicate with adults with LD (PHE, 2018). In addition, it outlines a set of interventions that can be taken at the population level to improve the health of adults with LD:

- Developing, promoting and accessing learning disability awareness e-learning/training and the positive impact of early intervention

- Promoting identification of people with learning disabilities across service systems, such as ensuring registration in primary care on GPs' learning disability Quality and Outcomes Framework (QOF) registers
- Promoting reasonable adjustments in services such as easy to understand information on services, advising on easy read materials and implementing the Accessible Information Standard
- Doing all possible to prevent hospital admissions, but when admission to hospital is needed or an admission is planned, offering specialist input and support, refer to the acute liaison nurse for people with a learning disability in the acute hospital
- In line with the Equality Act, make reasonable adjustments to support access to services
- Supporting changing attitudes to a positive and asset-based way of thinking and planning services

Reasonable adjustments

Reasonable adjustments are measures taken to remove barriers to accessing and using services for people with a disability, including a learning disability. Reasonable adjustments are a legal requirement under the Equality Act 2010. They apply to all services, including health and social care services, as well as employment, education, housing, and businesses.

The NHS provides examples of reasonable adjustments that could be made in a health setting (NHS, 2020):

- Providing easy read appointment letters
- Giving someone a priority appointment if they find it difficult waiting in their GP surgery or hospital
- Longer appointments if someone needs more time with a doctor or nurse to make sure they understand the information they are given.

Ensuring provision of reasonable adjustments by health providers was a recommendation in the 2012 JSNA chapter. Qualitative data collected through the Learning Disability Partnership Board (LDPB) Forums and for the JSNA update suggest that this is not the case for all services and the reasonable adjustments made can depend on the skills and knowledge of the individual practitioner. It is important to emphasise that reasonable adjustments need to be made across a wide range of services, not just health, to support adults with LD to be able to live as independently as possible. Consistent provision of reasonable adjustments will also improve preventative action and is likely to influence the wider determinants of health, including access to employment and housing.

On reviewing a draft of this report, the LD Representatives made comments on reasonable adjustments. They commented that many places need better, clearer signage. The Enter &

View reports created by Healthwatch can help with this and were directly referred to by the LD Representatives. In addition, leisure facilities and banks need to be more accessible. In particular, the representatives discussed difficulties accessing the cinema, theatre, gyms, and leisure centres.

A summary of the Enter & View reports is available on the Healthwatch website. This includes an easy read summary of the main improvements needed that were found at multiple sites.

Suggestions of reasonable adjustments have been made at LDPB Forums over the period since the 2012 JSNA chapter, which could be applied to a range of different services and activities. For example, the 'Get Active, Stay Active' Forum in 2016 made some suggestions for reasonable adjustments that could be made at sports centres and clubs:

- Allow people with learning disabilities to visit their club to see how it runs and to build their confidence to attend
- Clubs to make sure their information is easy to understand, use pictures and put up in places where adults with learning disability go and live
- Clubs could ask Swindon Advocacy Movement (SAM) and Open Door to help them with easy read versions of their information and staff training
- Clubs to consider offering a trial period where there would be no fee. This would be arranged on an individual basis to suit their specific circumstance. Maybe a reduced rate or free membership for a support worker
- Clubs could look into specialist equipment

Reasonable adjustments are critical to enable adults with LD to live as independently as possible.

Methodology

Needs Assessment

This is primarily an epidemiological needs assessment. The data collected will illustrate changes over time and projected future trends in the numbers of people with LD and any changing demographics. It will also consider current service provision, whether this meets the needs of the population. The effectiveness of services will be considered and specifically the need for additional reasonable adjustments in service provision. Understanding need will come from reviewing outcomes of people with LD and through consultation with stakeholders.

Quantitative data

Data for the report was collected using the following tools and information sources:

- Projecting Adult Needs and Service Information (PANSI)
- Projecting Older People Population Information (POPPI)
- Public Health Outcomes Framework from PHE
- LeDeR 2018 annual report (published May 2019)
- Bath & Northeast Somerset, Swindon and Wiltshire (BSW) SEND Steering Group LeDeR report, 2020
- Individual data requests to health and care services

Qualitative data

Focus groups and 1:1 interviews

Focus groups were planned to inform the development of the JSNA. The themes of the focus groups were:

- Community safety
- Health
- Carers
- Service users
- LD Providers

Due to Covid-19 restrictions, only the community safety focus group took place in person. The health focus group was replaced by 1:1 interviews, while the carers and service users groups were cancelled as it was not feasible to hold these virtually. Further information about this is included in the Covid-19 section of the report.

The aim of the focus groups and interviews was to understand the main touch points for different services with adults with LD, to understand changes since the 2012 JSNA, and to identify gaps in training and provision. The results of the focus group and interviews are included in the relevant sections of the report below. The questions used for the focus group and interviews are included in Appendix B.

In addition, information from the January 2020 BSW Programme Board workshop which mapped the LD pathway in Swindon has been used.

Swindon Learning Disability Partnership Board (LDPB) Forums

The Swindon LDPB ensures that the voice of adults with a learning disability is heard, promoting choice and control within their daily lives. It runs three engagement and participation forums a year based on themes highlighted by adults with LD as important to them. Reports from these past forums have been used to inform the report as part of the qualitative data and provide some insights from service users that are particularly important. These insights take on even more significance due to the scheduled focus groups having been cancelled as a result of Covid-19 restrictions. These reports collect input from 60-70 attendees on a range of relevant topics.

Reports from the following forums were used:

- Going to hospital, March 2020
- "Your annual health check", July 2018
- Employment Forum, March 2018
- Annual health checks and hospital passports, November 2017
- Talking about relationships, November 2017
- Looking after yourself now and in the future, March 2017
- What Does Good Support Look Like, November 2016
- Get Active, Stay Active, July 2016

Where possible, qualitative data has been triangulated to quality assure the information included in the report. This includes comparing qualitative insights against quantitative data. One example of this is the feedback from LD representatives on the variation in the availability and quality of annual health checks. This is supported by data from GP practices in Swindon which shows that the number of people on the LD register and the proportion of health checks carried out varies between practices.

Population

Context

A summary of the general population is below. For an in-depth population profile please refer to the Swindon Joint Strategic Needs Assessment (JSNA, 2018/19).

- The 2018 mid-year ONS estimate for Swindon residents is 221,996.
- At the time of the 2011 census the average (mean) age of residents was 38.1 years, and 90.7% of residents identified as English/Welsh/Scottish/Northern Irish/British. (NOMIS, 2019).
- The 2016 mid-year projections for the Swindon Borough Council (SBC) area are that Swindon's resident population will increase by 11% between 2018 and 2028, and a further 7% by 2038. The largest increases in population will be in the 65 plus age group (JSNA, 2018/19).

LD population

The current estimate of the number of adults with LD in Swindon is 4081 (PANSI, 2019). This is projected to increase by 9% over the next 15 years. Table 1 shows that this will largely be driven by a 51% increase in adults with LD in the 65 and over age group, as well as 17.8% increase in people aged 18-24.

Swindon's overall population (people with and without LD) aged 65 and over is projected to increase by 54% between 2020 and 2036, which is similar to the projected increase in the number of older adults with LD (Swindon JSNA, 2019).

Table 1: Projected population change for all adults with LD between 2020 and 2035, by age group

Age band	2020	2035	Percentage change (%)
18-24	416	490	17.8
25-34	702	665	-5.3
35-44	766	771	0.7
45-54	768	732	-4.7
55-64	651	674	3.5
65+	779	1176	51
Total	4081	4448	9

Table 2 shows the current estimate of adults with moderate and severe LD in Swindon is 861 (PANSI/POPPI, 2019). This is projected to increase by 5.2% over the next 15 years. The largest increase of 46.2% will be in adults aged 65 and over, followed by an increase of 20.6% in adults with moderate or severe LD aged 18-24.

Table 2: Projected population change for adults with moderate or severe LD between 2020 and 2035, by age group

Population

Age band	2020	2035	Percentage change (%)
18-24	97	117	20.6
25-34	151	143	-5.3
35-44	193	179	-7.3
45-54	173	167	-3.5
55-64	142	145	-2.1
65+	106	155	46.2
Total	861	906	5.2

This local data is from the Projecting Adult Needs and Service Information (PANSI) and the Projecting Older People Population Information (POPPI) databases. POPPI and PANSI data is calculated for each local authority in the UK, based on national research and estimates. There may be some expected local variations that are not captured in the POPPI and PANSI dataset. For example, larger than average population growth is expected in Swindon due to new housing developments.

This data source indicates that services will need to adapt to work with a much greater number of older adults with LD, as well as older carers. There is also a risk of an increasing number of older adults losing support provided by carers as they age. In addition, there is likely to be an increase in the number of young adults with moderate and severe LD, which could add pressure for the Transitions team.[2]

Adult Social Care (ASC) Clients

In 2018/19, ASC supported 686 adults with LD. Adults supported by ASC are a relatively small proportion of the overall number of estimated adults with LD in Swindon. The numbers supported by ASC are lower than the PANSI and POPPI projections of adults with moderate or severe LD. This suggests that there are carers in the borough supporting adults with more complex needs, without the input of the local authority. Not every family will need support but, combined with the increasing older population, there is a risk for adults with LD who may have older carers that become unable to support them. This is considered in the older carers section later in the report.

Figure 1 shows the number of ASC clients in Swindon over the last five years. The number of people supported by ASC increased by 77 between 2014/15 and 2017/18, then reduced by 31 to 2018/19, suggesting that the numbers are currently relatively stable. Overall, 4.16 per 1000 adults in Swindon are receiving long-term support for LD from ASC (PHE, 2018/19).

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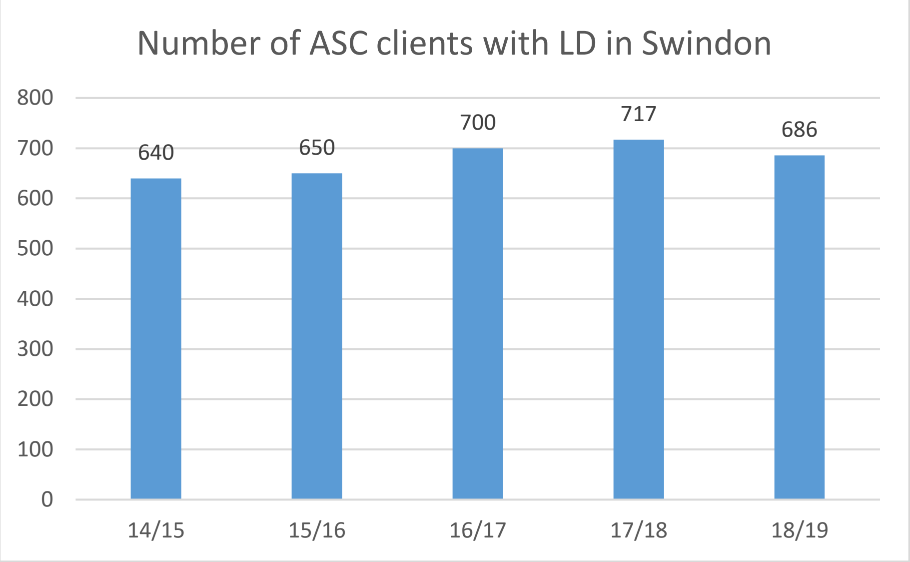
[2] The Transitions team support young people who are likely to use adult social care services to plan and prepare for adulthood

Figure 1: Number of ASC clients with LD in Swindon (SBC, 2019)



Adults with LD who are not supported by ASC

ASC clients are likely to have complex needs and require significant support for their LD. However, when considering the overall population of adults with LD, it is also important to consider those people that come under the threshold for ASC support. A 2011 article by E. Emerson, *Health Status and Health Risks of the "Hidden Majority" of Adults with Intellectual Disability*, highlighted that people with LD who do not receive support from ASC were "more likely to smoke tobacco and less likely to access some health services and promotion activities than those who do use these [ASC] services. In addition, they are more likely to be exposed to some known social determinants of poorer health (greater material hardship, greater neighbourhood deprivation, reduced community, and social participation) (Emerson, 2011). It is therefore particularly important that preventative measures, including the GP Register, are targeted at all people with an LD, not only those with moderate and severe LD.

Black, Asian and Minority Ethnic (BAME) people with LD

In Swindon, the overall population of people from BAME backgrounds increased from 8.5% in 2001 to 15.4% in the 2011 census. Based on projections by the Public Health analyst team, it can be assumed that this figure has continued to increase by around 1% per year. The exact number of adults with learning disabilities from BAME backgrounds in Swindon is unknown. However, the number of BAME adults with LD supported by adult social care services is small but is increasing. The BSW LeDeR report identified that notifications to LeDeR about deaths of people from BAME backgrounds in BSW is very low.

Nationally, BAME adults with LD have poorer outcomes than white adults with LD. The 2018 national LeDeR Report (University of Bristol - Norah Fry Centre for Disability Studies, 2019) identified that there is a significant difference in the median age at death for people from BAME groups compared to people with a white ethnic background. In the cases studied during the report period, the median age at death for people of BAME background was 35 years, compared to 61 years for people of white British ethnicity. Some caution should be applied to interpreting these results as there may be under-reporting of BAME adults with mild and moderate LD due to under-representation and lower engagement with services.

Nationally, people from BAME backgrounds with LD are often under-represented in the client base of both voluntary and statutory service providers (Race Equality Foundation, 2010). People can be at risk of ‘double discrimination’, due to both their ethnic background and learning disability (Race Equality Foundation, 2010). A report by the Foundation of People with Learning Disabilities identified the key elements to improving engagement and understanding of BAME communities in the context of learning disability (Foundation for people with learning disabilties, 2012). The relevant points are set out below:

- Effective identification of the needs, concerns, and aspirations of different local communities
- Making sure that people understand what is available and how local systems work
- Personalisation
- Developing local responses with community organisations
- Being able to measure the impact of policies and practices on different BAME communities

The steps identified in the report fit closely with the personalisation agenda in Swindon. The first step locally is to being able to identify BAME people with LD that need support, and building relationships with these communities. Having good data and understanding of local communities will help to identify specific local needs so that services can be developed matched accordingly. The LD representatives supported this issue being talked about and highlighted that the Board should consider what they can do to make themselves more diverse.

Older people with LD

As identified above, growth in the population of adults with LD in Swindon will be driven by growth in the 65 and over age group. Older people are more likely to develop serious or multiple health problems. An increasing older population is more likely to lead to an increase in the prevalence of certain conditions, for example dementia.

According to The National Institute for Health and Care Excellence (NICE), older people are also more likely be affected by late diagnosis which can lead to delayed treatment and increased risk of death. (NICE, 2018). They may also find it more difficult to access services because of hearing and sight problems. NICE has produced guidance for the care and support of people growing older with learning disabilities (NICE, 2018). This covers identifying changing needs, planning for the future, and delivering services including health, social care and housing.

In March 2017, there was an LDPB Forum which focused on 'ageing well' which raised many important points. Some adults with LD found the concept of 'older' difficult to understand and this was recognised as a barrier that could prevent people from accessing services specifically designed to support older people. However, many people attending were also able to identify some of the common issues that older people might face, for example related to mobility or social isolation.

Issues discussed at the forum included:

- Need for early identification and prevention of issues
- Identification of additional support needs
- Discussion of whether retirement care is inappropriate for younger people with LD
- Recognition that many of the issues discussed could be identified and addressed through an annual health check but not everyone with LD is on the GP Register and many people do not receive a check.

The LD Representatives commented that they were concerned about this group of adults with LD, and would like to visit some older adults with LD in Swindon if they can do this within Covid-19 restrictions.

Parents with LD

The Public Health team in Swindon completed a review of the situation of parents with LD in Swindon in 2016. This report sets the context for adults with LD who are parents:

> "Adults with learning disabilities have become more likely to develop relationships and form their own families. Many experience poverty and unemployment, poor housing and difficult neighbourhoods, smaller support networks and lack of information. Harassment and bullying, and sometimes violence and financial or sexual exploitation, can be a major problem for parents with learning disabilities and their children (Scottish Consortium for Learning Disability, 2015); (Wilson, 2013).

> Having a learning disability in itself is not a reliable indicator of poor parenting, yet high numbers of parents with learning disabilities have their children removed. Around 40% of parents in the English National Survey of Adults with Learning Disabilities were not living with their children. (In some cases this may have been because their children had grown up and left home). (University of Bristol, 2016)".

At a national level, PHE research has identified that pregnant women with LD are less likely to seek or attend regular antenatal care and more likely struggle to understand the information provided to them (PHE, 2020). Women with LD are also more likely to be younger mothers than their counterparts without LD, with 12% of women with LD being mothers at 17-18, compared to 4% of women without LD (PHE, 2020). National research also shows that parents with an LD "can be reluctant to ask for support with parenting issues because of fears that this will raise child protection concerns" (Best Beginnings, 2020).

Table 3 provides estimates from 2016 of the population of parents with LD in Swindon. The precise number of parents with a learning disability is unknown for a variety of reasons. These include inconsistencies in assessment and that some adults with mild learning disabilities may only come to the attention of statutory services when they have a child and need to seek help.

Table 3: Data on parents with LD in Swindon

Information available	Number
Number of parents with LD (estimated 2016)	260
Number caring for children themselves (estimated 2016)	146
Care proceedings for parents with LD (2017/18)	18

From the 18 care proceedings identified in Table 3, one parent was able to keep their child following the proceeding. However, parents with LD make up a very small proportion (less than 1%) of overall referrals to children's social care in Swindon.

Most parents with LD are identified during pregnancy, either at booking or at the 12 week check as this includes a specific question on learning disability. Where a woman has LD, the midwife should complete a safeguarding notification which is reviewed by the Midwifery Safeguarding Team. Where a person does not have an LD diagnosis, a referral for assessment will be made if necessary. Information in an accessible format is available for all stages of pregnancy and birth.

Carers

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. In 2015, it was estimated that there were 21,000 unpaid carers living in Swindon (SBC, 2018/19). This figure is likely to have increased further due to the increasing population of people aged 65 and over. Being a carer can have a negative impact on the carer's physical and mental health. The strategic direction for supporting and working with carers in Swindon is set out in the Swindon Carers Strategy.

The Care Act in 2014 expanded the rights of carers, meaning that they are now entitled to an assessment if they need support. The carer's assessment must establish whether the carer is willing and able to continue providing care to the disabled person they are caring for, what impact this has on the carer's wellbeing, what outcomes the carer wishes in day-to-day life, and whether the carer wishes to access education, training, or recreational activities. The carer will have the same rights to an assessment and support as the disabled adult themselves. Therefore once a carer's assessment has been carried out, the local authority will see which of the carer's needs are eligible for support, and will then produce a support plan to meet the carer's needs. Local authorities are under a duty to meet a carer's eligible needs, subject to a financial assessment (Mencap, 2020). Assessments are an important part of future planning, and also help social care services maintain contact with carers.

In Swindon, it is estimated that there are currently 268 carers of adults with LD. This is based on ASC data and people registered with the Carers Centre, and it is possible that there is some crossover between the data, meaning that some people are counted twice. 134 reviews of carers of adults with LD took place in 2018/19, compared to 80 in 2012. This indicates some increase in support available for carers.

Older carers

The largest population increase for adults with LD is predicted to be for people aged 65 and over. This means that there is likely to be an increase of older parents. Based on 2017 data, there were 31 carers over 65 in contact with Swindon Carers Centre, and 118 carers over 65 caring for an adult on the ASC caseload. Table 11 below shows the age band of older carers by the age band of the adults that they care for.

Table 4: Age band of older carers and ages of 'cared for'

	Carer age band			
Cared For Age Band	65-74	75-84	85+	Total
17-25	2	1		3
26-45	29	11	1	41
46-64	21	25	7	53
65-74	1	1	1	3
75-84	1	1		2
Grand Total	54	39	9	**102**

At the point that this data was collected, there were 45 people being cared for at home by people aged 65 and over. This included 21 people being cared for by people over the age of 75. The risk of a carer being unable to continue to provide their unpaid caring role is increased as the carer ages. This could result in and an increase in demand for ASC going forward. Sudden illness or death of an older carer can raise issues relating to future guardianship, ongoing care for the person with LD, and power of attorney. A report into older carers completed in 2015 recommended that all carers should have the opportunity for an assessment from ASC.

An Age UK study in 2015 identified that 60% of older carers stated that their health is not good, and this rose to 72% of carers aged over 85 (Age UK, 2015). The Carers Trust has also found that two-thirds of older carers have long-term health problems, including arthritis and joint problems, back problems, heart disease, cancer, and depression. Ensuring that older carers are in touch with services is an important preventative and future planning action that may help to avoid serious escalation of cases in the future.

Feedback from Carer Representatives

- The carer representatives agreed that this area about older carers was of significant concern. Carers asked "What happens when they can't provide the care anymore?" and "what happens when they are not around anymore?"
- Help and support can be slow to be provided. An example was given of eighteen months for a re-assessment of needs for a carer
- It is important to consider support and provision for people with LD who are grieving, and those that need to move out of home at short notice
- A dedicated post supporting older carers would be useful

Needs and service use

Adults with LD have poorer health outcomes than people who do not have LD, and many of these poorer outcomes are preventable. Adults with LD are more likely than others of the same age to be admitted to hospital as an emergency and there is good evidence to show that annual health checks in primary care can improve preventative action (NIHR, 2020).

PHE has highlighted the importance of wider social determinants on the health of adults with LD (PHE, 2016). In a 2016 report which considered the ‘hidden majority’ of adults with mild LD, the odds of some common diseases were calculated. The increased odds of the common health problems and risk factors dropped significantly once socio-economic factors and opportunities for social participation were accounted for. Table 4 below shows the odds (how many times more likely) the risk factor is in adults with mild LD compared to the general population, before and after adjustment for social factors. The social factors adjusted for were being employed for 16 hours or more per week, living in a high quality neighbourhood, feeling safe outside in the dark, having two or more friends to go out with socialy, and being financially comfortable.

Table 5: Increased odds of risk factors, before and after adjustment for social factors

Risk factor or health issue	**Overall odds of risk factor for adults with mild LD compared to general population**	**Odds of risk factor once social factors are accounted for**
Type II diabetes	3.9	2.4
Current smoker	3.6	2.0
Obesity	2.1	1.7

This table demonstrates that health and other life outcomes for adults with LD cannot be considered solely from a health perspective; the impact of broader social factors must be taken into account.

Health needs

Life expectancy

The 2018 LeDeR (University of Bristol, 2019) found that the median age at death (for those aged four and over) for all people with LD was 60 for men and 59 for women. During the same period, the median age of death for people without LD was 83 for men and 86 years for women. This difference is significant and gives an indication of the severe inequality in health outcomes for people with LD. For people with severe and profound learning disabilities, the median age of death was 40.

In the 2018 LeDeR report (University of Bristol, 2019), 93% of the cases reviewed had at least one long-term health condition in addition to having LD. The mean number of long-term health conditions was 2.9. Tables 5 and 6 show the most long-term health conditions in England for adults with LD and the most common causes of death in England respectively. In the general population (LD and non-LD combined), the leading cause of death in 2018 was Alzheimers, which accounted for 12.7% of deaths registered (ONS, 2020).

Table 6: Most common long-term health conditions of LeDeR cases (LeDeR, 2019)

Condition	**Prevalence**
Epilepsy	39%
Dysphagia	38%
Cardiovascular problems	28%
Dementia	25%
Mental illness	23%

Table 7: Most common cause of death of LeDeR cases (LeDeR, 2019)

Cause of death	**Percentage**
Pneumonia	25%
Aspiration pneumonia	16%
Sepsis	7%
Dementia	6%
Ischaemic heart disease	6%
Epilepsy	5%

Pneumonia and aspiration pneumonia were identified as a cause in 41% of deaths of people with LD. The LeDeR report highlights that some of these are likely to be preventable, and recommends that national guidance on minimising the risk of pneumonia and aspiration pneumonia in people with LD is developed (University of Bristol - Norah Fry Centre for Disability Studies, 2019).

31% of deaths of people with LD were reported to the coroner compared to 43% of people without LD. However, once reported, referrals were more likely to lead to a post-mortem or inquest.

LeDeR has identified a specific concern related to Do Not Attempt CPR (DNA CPR) orders for adults with LD of which services should be made aware. LeDeR reviewers identified that 79% of DNA CPR orders were appropriate. However, 19 cases had the reason for DNA CPR listed as “learning disabilities” or “Down’s Syndrome”, which is inappropriate and indicates lack of training for staff. Note though that this is national data and at the local level, all hospital deaths of adults with LD are reviewed by the Head of Adult Safeguarding at GWH in addition to being notified to LeDeR.

LeDeR in Bath & Northeast Somerset, Swindon and Wiltshire

From December 2018 to December 2019, 74 deaths of people with LD in BSW were notified to LeDeR. At the point of publication of the BSW 2019 LeDeR report in April 2020, 33 notifications had yet to be assigned to a reviewer. There were some differences between the characteristics of deaths reviewed at the national and regional level and those reviewed in BSW:

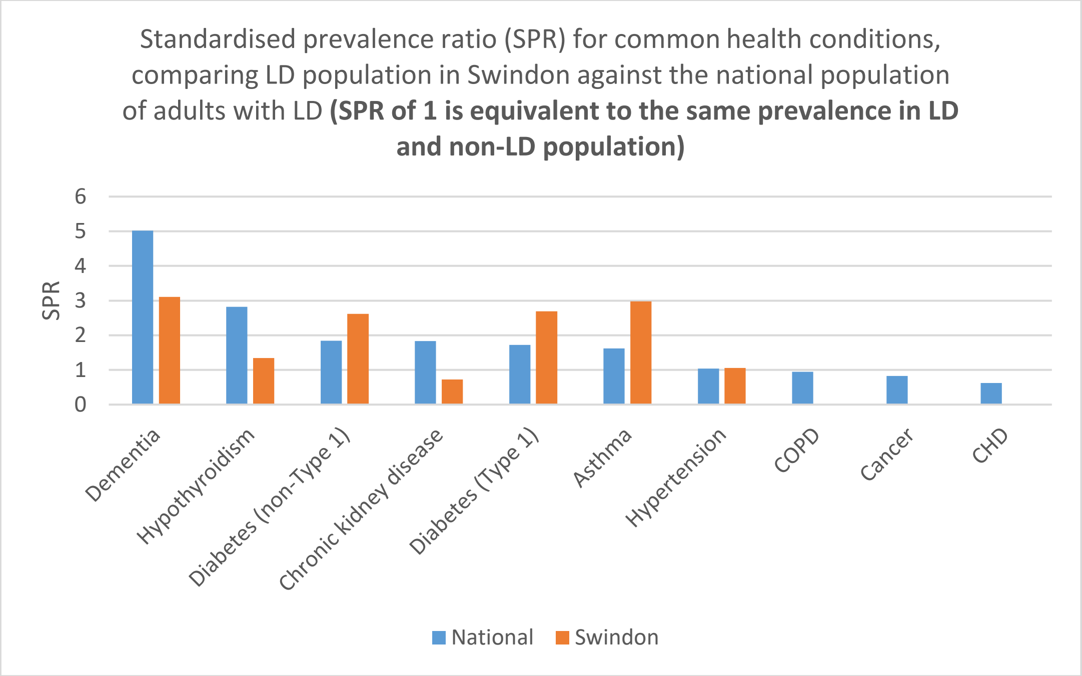
- 23% of deaths in BSW were in under 45s, compared to 17% in the south west. However, national figures were similar to BSW (24%)
- Deaths in the 45-54 age group were 5% higher in BSW than both the regional and national rates
- 13% of deaths were in the 65-74 age range, compared to 26% in the south west and 23% in England
- The mean age of death was 57, compared to 62 in the south west and 60 in England
- 68% of deaths were in hospital, compared to 59% in the south west and 58% in England
- Notification of deaths in the BAME population is very low

Of the deaths reviewed between October 2018 to December 2019, care in four cases fell short of best practice in one or more significant areas. However, this was not considered to have had an adverse impact on the case. No cases fell short of best practice to the extent that learning from a fuller review was required. In the southwest in 2018, it is estimated that 70% of deaths of people with LD were reported to LeDeR to be reviewed.

Specific health conditions

Some health conditions are more common in adults with LD than in the general population. Figure 2 below shows the standardised prevalence ratio for common conditions within the LD population in Swindon and nationally.

Figure 2: Standardised prevalence ratio (SPR) for common health conditions



Source: NHS Digital, Health and Care of People with Learning Disabilities; 2018/19

Figure 2 shows that people with a LD are more likely to have dementia, hypothyroidism, diabetes, chronic kidney disease and asthma. In addition to the data available through NHS Digital, people with LD are more likely to have epilepsy, some forms of cardiovascular disease (CVD), poor oral health, and a mental health condition. The specific health conditions are considered below. Figure 2 also shows that in Swindon, prevalence of diabetes and asthma are higher than the national prevalence rates for people with LD. The overall numbers for the Swindon data are small, meaning that the results lack precision. However, the national data are based on a large dataset and can be used as a guide.

Epilepsy

Epilepsy is the most common long-term condition for adults with LD and the prevalence is much higher than in the general population. Epilepsy and convulsions have been identified as a common, possibly preventable cause of death of adults with LD (G Glover, 2010). People with LD and epilepsy are more likely to have other health problems, for example arthritis or gastrointestinal disease, and they also have a higher risk of fractures (PHE, 2014).

A study in 2013 of hospital admissions nationally for people with LD showed that epilepsy and convulsions was the main cause of 40% of avoidable admissions (G Glover, 2013). This indicates that there may be not be enough support for management of epilepsy for adults with LD and their carers. Epilepsy was the most common reason for admission to Great Western Hospital (GWH) for people with LD between 2017/18 and 2019/20. Further exploration of the reasons for admission due to epilepsy at GWH may be useful to help identify areas for prevention and early intervention.

Dementia

People with LD are at increased risk of developing dementia. Table 7 below shows prevalence of dementia in the general population, adults with LD (other than Down's Syndrome), and adults with Down's Syndrome. The risk of developing dementia at a younger age is greater, particularly for those with Down's Syndrome (Alzheimer's Society, 2020). National estimates indicate that 2% of people with Down's Syndrome will develop dementia in their 30s, and more than 50% of people with Down's Syndrome in their 60s will have dementia (Alzheimer's Society, 2020).

Table 8: Comparison of dementia prevalence

Population	**Age**	**Dementia prevalence estimate**
General population	65	5%
Adults with LD (other than Down's Syndrome)	50-65	10%
Adults with Down's Syndrome	60-69	50%

Diabetes

The prevalence of Type 1 and Type 2 diabetes is higher in adults with LD than in the general population. Prevalence of Type 2 diabetes is higher for three main reasons (Taggart L, 2014; NHS England, 2017):

- People with learning disabilities leading a more sedentary lifestyle, undertaking low levels of exercise
- Consuming high fat diets
- Being prescribed high levels of antipsychotic medications, all of which can contribute to obesity

This highlights the importance of preventative action and provision of a healthy, balanced diet in all care and accommodation settings. Annual GP health checks and improving the number and quality of subsequent health actions plans based on the LD Register have a key role in supporting people to manage diabetes and preventing admissions.

Higher prevalence of Type 1 diabetes may be attributable to higher rates of autoimmune conditions in people with Down's Syndrome (NHS England, 2017).

Respiratory disease

Respiratory disease is the most common cause of death for adults with LD. A study of 343 GP Practices in England found that deaths caused by respiratory disease were nearly seven times greater among adults with LD when compared to the general population, and deaths caused by pneumonia and aspiration pneumonia were ten times greater in adults with LD than in the general population (Hosking, 2016). Higher rates of asthma, chronic obstructive pulmonary disease (COPD) and upper respiratory tract infections have been reported for adults with LD as well as poorer measured lung function (PHE, 2020). In addition, dysphagia is common in adults with LD and the most common complication of dysphagia is aspiration pneumonia (Robertson, 2017).

There is relatively little evidence on healthcare and treatment for respiratory disease for adults with LD (PHE, 2020). However, it is likely that preventative action where possible is important for reducing the risk of respiratory diseases. Supporting people to stop smoking, improved recognition and management of dysphagia, and support for adults with LD with asthma to use their medication correctly are all steps that may reduce risk. This should form part of the LD Health check and is another reason why health checks are a useful preventative tool.

Cardiovascular disease (CVD)

Prevalence of some forms of CVD is higher in adults with LD. PHE published a report into health inequalities for adults with LD and identified that a review of primary care records indicated lower rates of ischaemic heart disease (IHD) in adults with LD (Public Health England, 2020). However, rates of heart failure, stroke, and transient ischaemic attack (TIA) were higher. It should be noted that the report highlighted that research into this area is scarce and therefore the data is limited (Public Health England, 2020).

Both genetics and behavioural factors contribute to higher rates of CVD in adults with LD. People with Down's Syndrome have almost a 50% chance of being affected by congenital heart defects (Public Health England, 2020). However, they are protected from atherosclerosis, arterial hypertension and coronary artery disease. Research indicates that people with LD are more likely to have poor diets, be sedentary, and have high rates of obesity, which are all risk factors for CVD (T Seekins, 2009); (Harris, 2018); (Melville, 2018). Rates of smoking are higher among male adolescents and young adults with mild or moderate LD, parents with LD, and people with LD who do not use LD services (PHE, 2019).

For the behavioural risk factors, preventative action will be the most effective measure for reducing prevalence of CVD. The risk to people with mild LD highlights the importance of efforts to reach this group, including through inclusion on the LD GP Register.

Oral health

Research shows that adults with LD consistently have (PHE, 2019):

- 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
- consistent higher levels of untreated tooth decay

Poor oral health can have a negative impact on both mental and physical health. Pain caused by poor oral health may be difficult to communicate. In addition, where a person with LD is missing teeth, this can have an impact on their ability to eat a healthy diet and therefore increases their risk of CVD and diabetes.

There are multiple barriers to both accessing dental care and maintaining good oral hygiene for people with LD. Dental practices and dentists need to be able to make reasonable adjustments to make care accessible and to ensure that individuals feel comfortable to attend. Anxiety is a major barrier influencing access to dental care for adults with LD. The people most likely to miss out on care due to anxiety are women and people with more severe LD (PHE, 2019). In addition, national research shows that adults with LD may have poor oral hygiene in situations where they do not understand the importance of tooth brushing, if they have limited mobility meaning it is difficult to brush their own teeth, or where they don't like being touched (PHE, 2019).

The following points were raised through the qualitative research for this report in Swindon:

- Support and services available for adults with LD is practice and practitioner dependent
- The Community Dental Service can offer specialist support where needed
- The availability of easy-read information for adults with LD is practice dependent
- Refresher training on the best way to accommodate and communicate with adults with LD for dentists would be useful.

NHS England and NHS Improvement completed a review of Special Care Dental Services in the southwest in 2019. The report has not yet been published but the findings should be reviewed once published.

Mental health

Nationally, people with LD are 8.29 times more likely to have a mental health condition than the general population (standardised data, NHS Digital, 2018/19). In Swindon, people with LD are 6.23 times more likely to have a mental health condition than the general population (standardised data, NHS Digital, 2018/19).

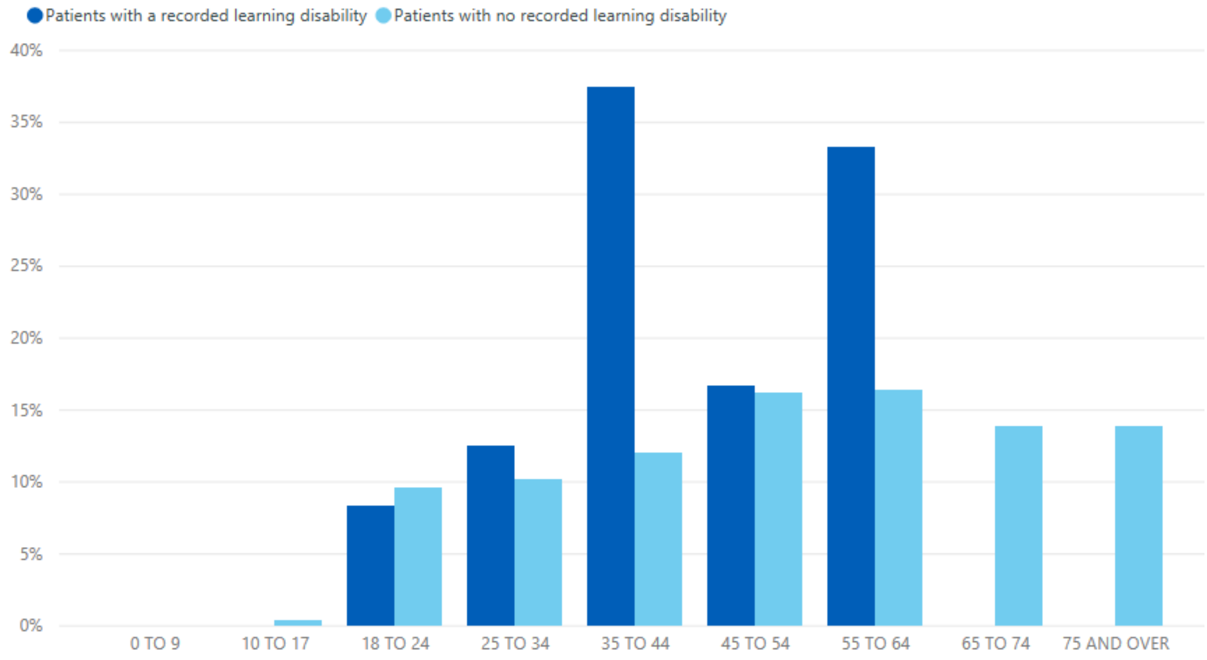
NHS Digital provides the prevalence of mental health conditions in Swindon (NHS Digital, 2020). However, there are significant limitations to the data as it only captures 8% of registered adults with a LD. It can offer some indication of the prevalence of mental health conditions but is unlikely to be robust enough data to be used for service planning.

Figure 3 indicates that prevalence of mental health conditions increase with age, and at all age groups between 35 and 65, prevalence is higher in the LD population. The data for younger age groups and 75+ is missing, likely due to the low numbers captured in the dataset.

Figure 3: Prevalence of mental health conditions in Swindon for people with and without LD, by age group (NHS Digital, 2018/19)

Figure 4 shows that prevalence of depression is similar for younger adults with LD to the general population, but more than three times higher for adults aged 35-44 and double for adults aged 55 to 64. Again, it appears that missing data is affecting the results.

Figure 4: Prevalence of depression in Swindon for people with and without LD, by age group (NHS Digital, 2018/19)



A review of evidence by the NIHR found that people with LD are more likely to be prescribed psychotropic medicine over long time periods (NIHR, 2020). There is also a risk of adults with LD being prescribed medication to control behaviours described as challenging, rather than for a psychiatric condition.

Malnutrition

Adults with LD are both more likely to be underweight and more likely to be overweight than the general population (PHE, 2020). National GP record data of BMI suggests that:

- BMI was classed as underweight for 6.4% of people with learning disabilities and 4.9% of other people
- Overweight for 27.4% of people with learning disabilities and 32.0% of other people
- Obese for 37.5% of people with learning disabilities and 29.9% of other people

Some groups of adults with LD are at greater risk of obesity. This includes women, people with Down's Syndrome, people of higher ability and people living in less restrictive environments (PHE, 2020). The most consistent risk factor for obesity is being female.

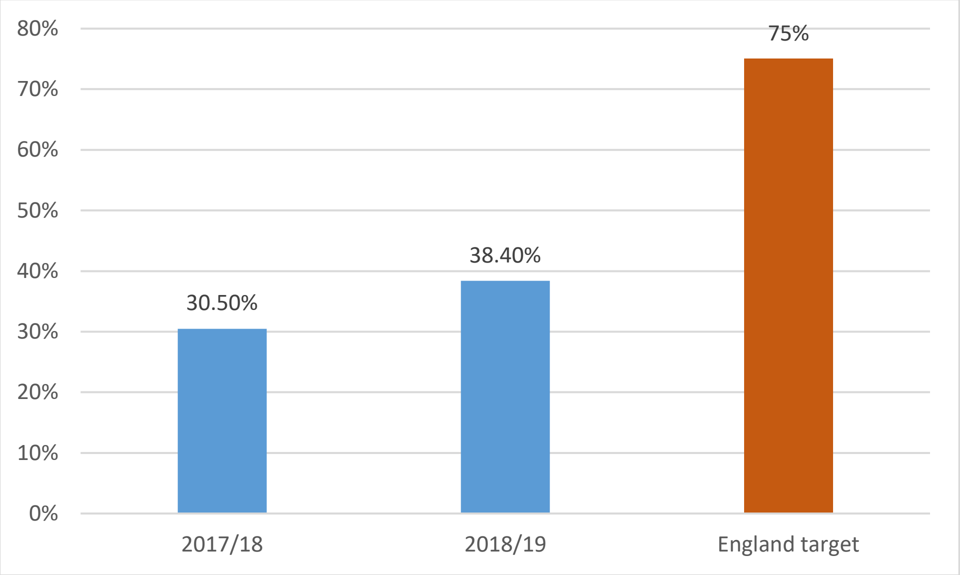
Health service use

Primary care

GP Practices must hold a register of patients with LD and should offer all those registered an annual health check. Completing health checks for people with LD forms part of the Quality Outcome Framework (QOF). Action-planning through the health check provides the opportunity to promote health by encouraging cancer screening uptake, immunisations and a healthy lifestyle. NHS England and NHS Improvement have set a target for GPs and CCGs to improve access to healthcare for people with LD so that by 2020, 75% of people on a GP LD register are receiving their annual health check (Public Health England, 2017). BSW LeDeR reviews are now noting an emerging theme of inconsistent LD diagnosis/data recording in GP practices and the absence of reasonable adjustments flags, annual health checks, and health action plans following annual health checks.

Figure 5 (p.39) shows that 38.4% of people on the LD register received a health check in Swindon in 2018/19. This was an improvement of 7.9% when compared to 2017/18. To reach the NHS England national targets, a further improvement of 36.6% is needed. The health check percentage should not be considered in isolation as it is also important to increase the overall number of people included on the GP Register and therefore eligible for a health check, to make sure that preventative services are available to a wider pool of adults with LD.

Figure 5: Proportion of people on the LD Register that received an annual health check (Swindon compared to England target)



Swindon currently has 1074 people on its LD registers across all GP Practices. PANSI and POPPI data estimate that there are 4081 adults with LD living in Swindon. The register therefore captures only around a quarter of all people living in Swindon with LD. This is similar to the England average but there is widespread recognition that improvement is needed nationally (NHS England & NHS Improvement, 2020).

NHS England & NHS Improvement have made improving the number of people captured on the LD Register and the proportion receiving health checks one of its QOF Quality Improvement targets for 2020/21 (NHS England & NHS Improvement, 2020). The aims set out in this target are:

- Improve the accuracy of the GP Register
- Increase uptake of annual health checks
- Optimise medicines
- Record the need for and type of reasonable adjustments required
- Consider the use of wider community support

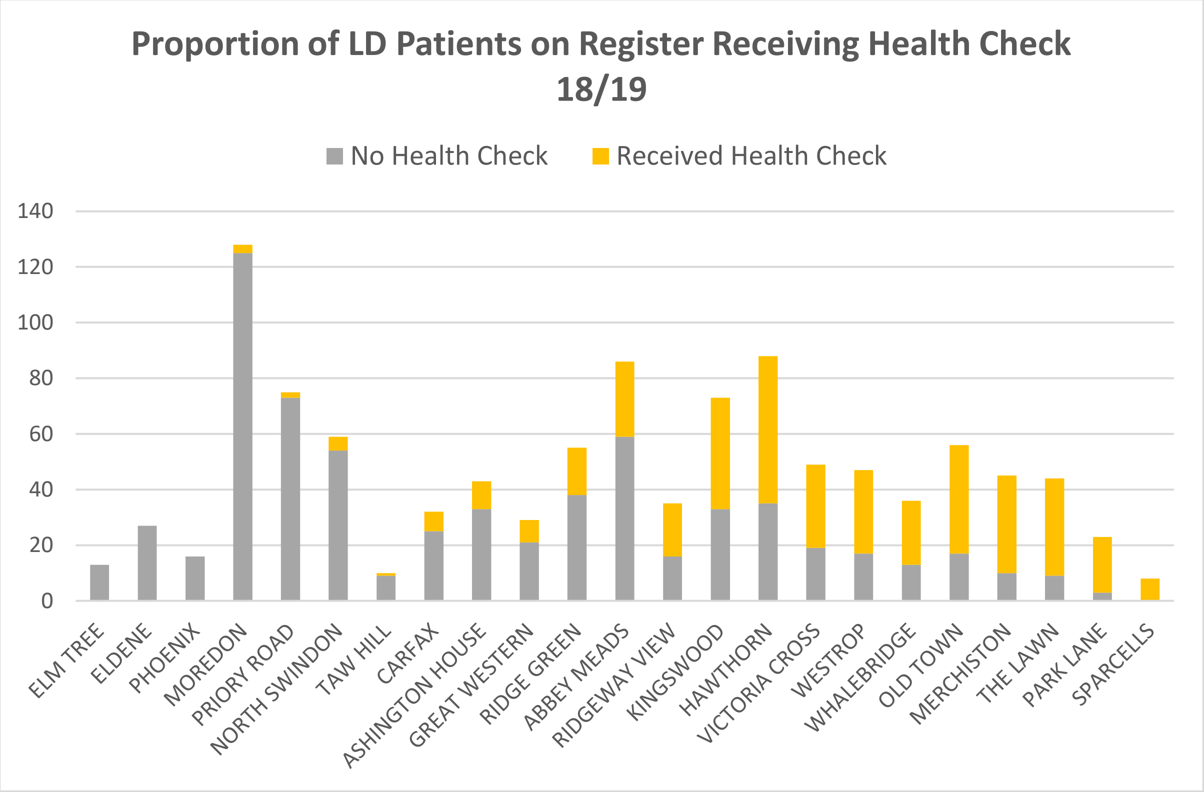
It is therefore an opportune time for improving the quality of LD Registers across Swindon and the QOF Quality Improvement target sets out steps for supporting GP Practices.

The criteria for joining the LD register needs clarifying. The NHS website advises that anyone aged over 14 can go onto the register if they think that they have a learning disability. However, from the stakeholder consultation with primary care and reviewing the number of people on the register, it is clear that the registration process can vary between practices. There appears to be an expectation that a person will need to have had a diagnosis of LD from a specialist to be considered eligible for inclusion. It is important to maintain the integrity of the register and to be confident that it is available for the most appropriate people. However, there is a risk that those with a milder learning disability are not being identified, supported and included in the register.

60.3% of people on the LD registers in Swindon are receiving long-term support from the local authority (Public Health England, 2017/18). This indicates that a high proportion of people with mild or moderate LD are not included on the register. This is of concern as studies clearly indicate that this group are at risk of poor health outcomes and would benefit from preventative interventions (Public Health England, 2016).

In Swindon, the variation in the number of people on the register and the proportion receiving health checks between practices is very high, as shown in figure 6 below.

Figure 6: Numbers LD Patients on the register receiving a health check in 18/19 (CCG, 2019).



There are a number of recommendations that should be put in place to improve the number of people on the LD Registers, and the proportion receiving an annual health check. These are set out in detail at the end of the report.

Stakeholder consultation and report comments

LD Representatives

- The LD representatives agreed that in their experience there are lots of adults with LD in Swindon who don't have a health check.
- They felt it was very important that adults with LD should be made aware of the LD Register and annual health checks and that GPs could help them with this

- The reps feel like some GP surgeries are very good and do a lot to support people with LD but others still don't do enough.

Carers

Carers raised concerns about health checks, including that there are practices that do not carry out any health checks. The key points raised by carers are summarised below:

- It would be useful to have clarity on why not all GPs can carry out health checks (note: Royal College of General Practitioners guidance does not indicate that a specialist qualification or course is needed). Practices that have only one GP that carries out health checks risk having a single point of failure
- Are there examples of good practice where merged/partnered GP practices share their resources?

LDPB Forums

In July 2018, an LDPB Forum was held which focused on the annual health check. Feedback from this forum was used to develop an easy read pre health check questionnaire to help adults prepare for their annual health check and support GPs. However, these are not currently being used regularly.

Some important points were raised in the Forum by people with LD about using health services:

- It is very important that information about all health topics is made available in an easy read format so they are accessible to people with learning disabilities.
- It is really helpful to have time to think about health before appointments
- Longer appointments with doctors means people won't be rushed and there is time for explanations.
- It is important that GPs or other healthcare practitioners speak directly to the person with LD, rather than to their parent/carer or support worker

Health checks were also discussed at a LDPB Forum in November 2017. One issue raised was that people may not feel comfortable disclosing that they have a LD to a GP receptionist. Training for receptionists should be made available to support an increase in the number of people signing up to the register. Clarification of the registration process and eligibility is also important.

From a primary care perspective, the following points were raised in discussions with health professionals:

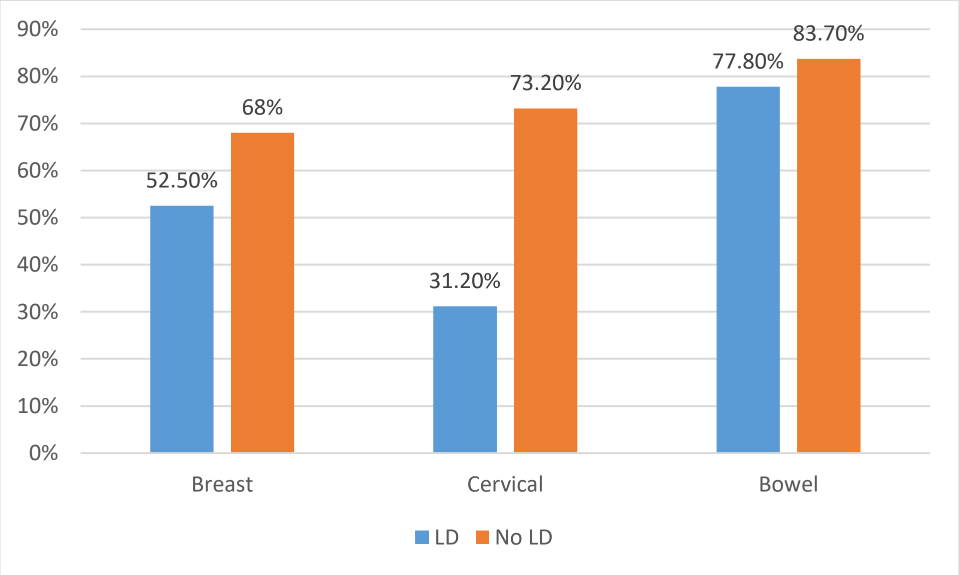
- There were concerns that identification of people for the LD register tends to occur due to a crisis situation, rather than proactive work to add people to the register. A particularly important opportunity for identifying people for the register is when young people are beginning to consider the transition from child to adult services. People aged 14 and over can be included on the register.

- The criteria for inclusion on the LD register can be unclear at times.
- The health action plan developed following a health check is not usually in easy read format. This is given to the carer or support worker after the appointment, and therefore follow up on actions is dependent on this person.

Screening services

PHE recognises that health inequalities exist in screening services for many disadvantaged groups, including adults with LD (PHE, 2019). This means that some of the people at greater risk of developing a condition are least likely to access the screening service. Figure 7 below shows a comparison of national screening rates for eligible people with and without a learning disability. For the three cancer major screening programmes, adults with LD were less likely to be screened. The greatest gap was for cervical cancer, followed by breast, then bowel cancer screening.

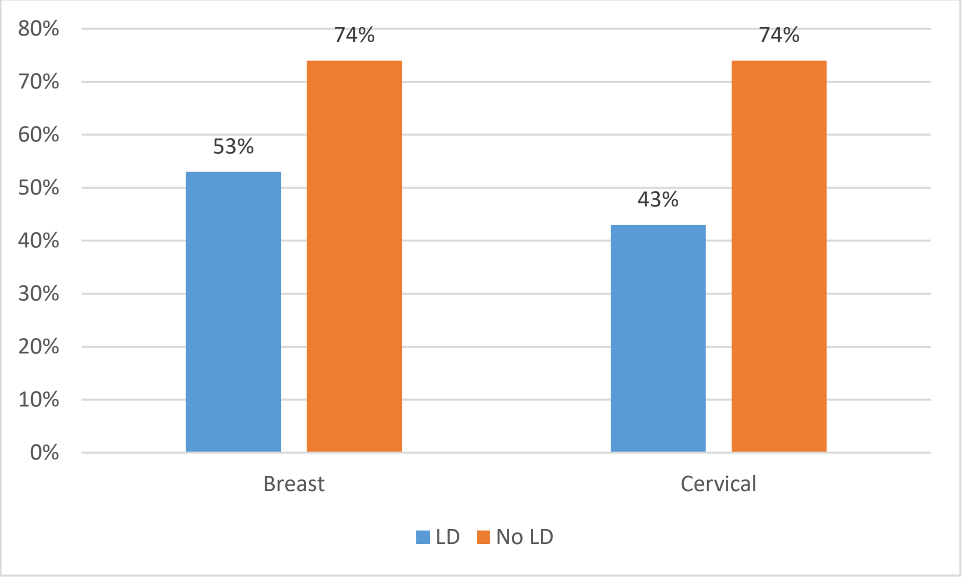
Figure 7: Comparison of % people screened for breast/cervical/bowel cancer, LD and non-LD population in England; (NHS Digital, 2019)



Data on use of screening services in Swindon is based on the LD Register, and is therefore of limited quality because of under-representation on the register. However, it can give some indication of the use of screening services by adults with LD. Figure 8 below compares screening data in Swindon for women with LD against women without LD. Screening rates are higher in the general population for women without LD for both breast and cervical cancer.

Breast cancer data is based on a small sample and the data should be interpreted with caution. Due to the small sample, the difference between the rates in the LD and non-LD population is not significant. Cervical screening data is based on a larger number of women and the difference is significant. However, for both groups, actual numbers screened are very small (8 for breast cancer; 20 for cervical cancer) which is a concern in itself. Data on bowel cancer screening in Swindon is only available for 5 participants and is too small to be included.

Figure 8: Comparison of % women screened for breast/cervical cancer, LD and non-LD population in Swindon; 5 years to 2017/18 (NHS England & NHS Improvement)



National research into barriers to attending screening for adults with LD have identified three main themes (Connolly, 2013):

- Scarcity of information
- Fear of medical intervention
- Embarrassment

The annual health check is an important opportunity to begin to address some of these themes. In addition, the provision of easy-read information and clear explanations of the screening process are needed. Better understanding of local data is also needed, as the current numbers captured are very low. Screening has been identified as a possible topic to cover at the LDPB Forum. Screening is an important preventative measure and it is critical that the very low numbers of adults with LD being screened is reviewed, and greater understanding of local barriers is captured through the LDPB Forum.

Specialist health services

The Specialised LD Health (and ASD) Team in Avon & Wiltshire Mental Health Partnership (AWP) provides support for both mental and physical illnesses, but it must be for a specialist health need that cannot be met by mainstream services. If people without an LD diagnosis are referred to the service, they will undergo a specialist assessment. Firstly, an LD Screening Questionnaire is completed with a practitioner. If this comes back as unclear, the individual will then be referred to one of the psychologists for a cognitive assessment.

A pathway mapping workshop which took place in January 2020 identified some limitations relating to the capacity of team. Firstly, the team is small and capacity is stretched. The criteria for receiving support is relatively tight. People must have a diagnosed LD to receive support which can exclude people with a borderline diagnosis. Only individuals who are under the care of a psychiatrist remain on the caseload over the longer-term. Lack of crisis support has been identified as a gap; this is due to lack of resources.

Early identification of mental health issues is important and another opportunity that annual GP health checks can offer. NICE guidance for mental health problems in people with learning disabilities is that a mental health review should take place at the annual health check. The guidance includes information and examples of good communication and information on capacity and consent.

Secondary care services

Great Western Hospitals NHS Foundation Trust (GWH) is the secondary care provider for Swindon.

Table 8 shows admissions by primary and secondary diagnosis of LD for the last three years in Swindon. Admissions have been increasing steadily. Table 9 shows that more men with LD are admitted to the GWH than women. However, the gap between men and women has been closing and admissions for women have increased more sharply. Please note that this data includes children as well as adults.

Table 9: Admissions for people with LD by diagnosis type, 2017/18-2019/20 (CCG, 2020)

Diagnosis	**No. of admissions**		
	2017/18	**2018/19**	**2019/20**
Primary diagnosis code for LD	10	15	10
Secondary diagnosis code for LD	395	430	465
Total	**405**	**445**	**475**

Table 10: Admissions for people with LD by gender, 2017/18-2019/20 (CCG, 2020)

Diagnosis	**No. of admissions**		
	2017/18	**2018/19**	**2019/20**
Female	180	180	230
Male	225	260	245
Total	**405**	**445**	**475**

The most common specialty for admission was general medicine followed by paediatric and general surgery. The most common reasons for admission were epilepsy, followed by acute lower respiratory tract infection and urinary tract infection. Pneumonia contributed to the greatest number of bed days.

Since the 2012 JSNA chapter, a significant amount of work has taken place to improve reasonable adjustments in the hospital. It is now mandatory for all new staff to complete e-learning on how to deliver reasonably adjusted care.

A Learning Disabilities Liaison Nurse started in post in June 2020 and this role will support the provision of coordinated care for people with learning disabilities coming to hospital.

Stakeholder consultation

LD representatives

One of the LD representatives commented that it would be helpful to know what to do in a health emergency. The representative commented that people may try to contact their support worker or carer, but if they were unable to contact them they would not be sure what to do.

LD Forum

A Forum on ‘Going to Hospital’ took place in March 2020. This included discussion of the hospital passport. It was agreed (following discussion of a choice of three names), that ‘hospital passport’ is the best name for the document because it is familiar and makes the most sense.

In addition, the following points were raised:

- The hospital passport should be in colour and include the use of pictures
- Some people preferred cartoons and others preferred photos of real people
- There was a discussion about the most important things for the hospital to know about the person, which were ‘how I communicate’, ‘how I need you to communicate with me’, ‘things I am allergic to’, and ‘my medication and how I take it’

The report also contains detailed information on things that people worry about before going to hospital, and the steps that can be put in place to help address these worries.

Three actions were agreed;

1. CCG to lead a group including GWH, SBC, AWP and GPs to work together, using the feedback from the Forum, to update the Hospital Passport and how it is used.
2. GWH to test new ways of supporting adults with LD to attend their appointments using Radiology Department as a starting point
3. GWH to improve the information about how to give feedback and make it easier for people to know how to do it

Adult Social Care

Context

Across all areas of ASC, the numbers of people requiring support is expected to rise, in line with the projected ageing population. ASC services have changed considerably since the 2012 JSNA chapter on LD was completed. The ASC Strategy 2018-22 states that "there is a growing understanding that councils cannot do many of the things that have been done previously" (SBC, 2020). Going forward, the role of partners, communities and individuals will be increasingly important. Support for adults with learning disabilities is the largest spend for ASC in terms of primary support (SBC, 2016/17).

The introduction of the Care Act in 2014 increased the shift towards personalisation in ASC, including for adults with LD. The Care Act 2014 requires Local Authorities to ensure that any adult with the appearance of care and support needs and any carer with the appearance of support needs receive an appropriate and proportionate assessment to identify the extent of their need and to explore the range of responses to meet those needs.

Since 2012, Swindon Borough Council transferred Learning Disability social work services from SEQOL (an independent employee-owned social enterprise company) into the local authority following financial difficulties. This led to development of a new management structure including the Head of Transitions post, Head of Commissioning, Head of Social Work and Regulated Services Manager.

Support from ASC for people with LD begins at the transition phase, which helps to prepare people to move from children's into adults' services for those that are eligible under the Care Act.

Personalisation

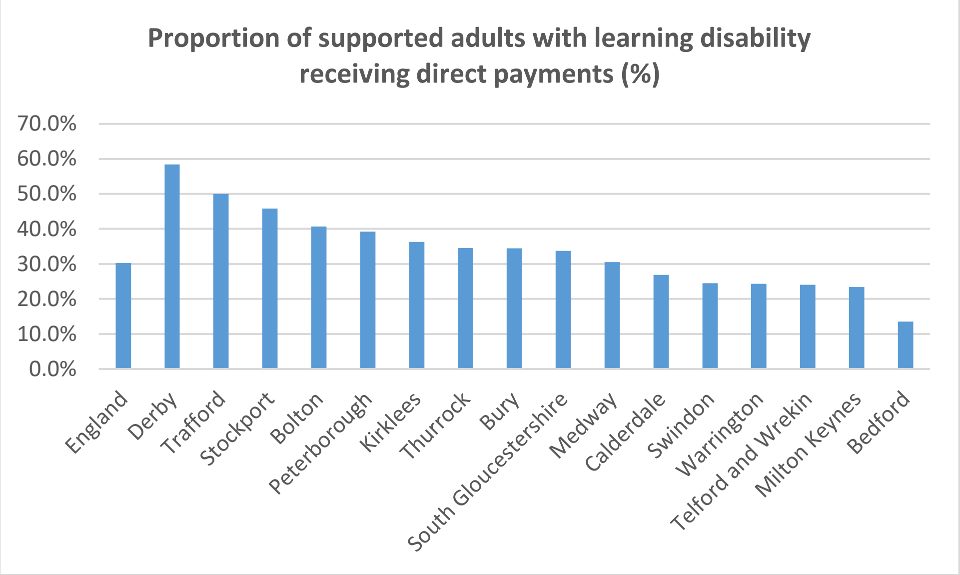
Government policy has driven a major shift towards personalisation over the last decade and local planning in Swindon has been adapting to meet this change. The 2012 JSNA included a recommendation to fully implement personalisation and increase self-directed support. Since this review was carried out, the number of all people receiving self-directed support has increased from 10% to 88% in Swindon.

Direct payments, along with personalised care planning, which the Care Act made mandatory, provide the platform to deliver a care and support system which aims to place each individual at the centre of their care and support planning process. Minimal restrictions are placed on how the direct payment is used as long as it is being used to meet an eligible need. Many people in Swindon using direct payments are employing a personal assistant to provide them with greater independence.

84 adults with LD in Swindon currently receive a direct payment (ASC, 2020). This is 24.5% of the total population of adults with LD supported by social care (PHOF, 2018/19). Figure 9 shows that Swindon has a lower proportion of people receiving direct payments than the England average. In addition, a lower proportion of people are receiving a direct payment

when compared to the majority of its statistical neighbours. Increasing the proportion of people receiving direct payments will support this shift towards personalisation and independence for adults with LD.

Figure 9: Proportion of supported adults with LD receiving direct payments (PHOF, 2018/19)



The LDPB Forum “What does good support look like?” held in 2016 considered the personalisation agenda. Adults with LD and people that support them completed (in separate groups) activities about support planning, care plans, and what good support looks like.

Key points related to personalisation were:

- It is important for people to be able to share what they like doing, as long as it is taken notice of
- People that support an individual should know about them and their individual personality, preferences and needs. If a person with LD does not know the staff member, it is difficult to share.
- It is important to be able to express dreams
- Personalised planning must develop into action. People attending the forum commented that they had done lots of one-page profiles previously which are used for planning, but they weren’t usually asked if they had done one before or if they need to do another one
- Not everyone at the forum felt that they had enough choice
- Care plans should be living documents that can be used to show changing needs. People should know when they can request a review and who will be able to support them

- Communication methods are really important and will be different for each person. Consideration of how to involve adults who are unable to communicate verbally is important.

Carer representatives were offered the opportunity to comment on a draft of the LD JSNA and highlighted concerns relating to personalisation. Their view is that services are significantly under-resourced and that there is still a lack of joined-up thinking and innovation. They suggested that individuals could be matched and jointly purchase services together to enable them to benefit financially and socially. This could be explored as a pilot.

The representatives also wanted to highlight that it can take over a year to get an assessment of need and that the system can be confusing, even for people who are familiar with the systems and processes in place.

Market position statement

Swindon's Market Position Statement 2017-22 sets out an overview of the population and the approach to commissioning that will be taken locally. The commissioning intentions are set out in the document and the following commitment to adults with needs is made regarding involvement in commissioning services:

- Ensuring that the voice of people using services contribute to our JSNA
- Ensuring that we meet with adults with needs/their families when conducting annual monitoring visits
- Request satisfaction surveys from providers and action plans in response to these
- Ensure that we co – produce the development of new services with adults with needs and their carers
- Ensure that the communication from user forums is fed into provider forums and that actions are monitored and fed back to the user forums on what has changed.

Transition

Transition was identified as an area for improvement in the 2012 JSNA. Transition services have undergone significant change and improvement in the intervening period. The team has been restructured, with link workers appointed who work across both the Transitions and Learning Disabilities teams. A new Transitions Strategy and Protocol was developed in 2020 in collaboration with partners, young people, parents and carers. Parents and carers requested that the new Transitions Pathway would be interactive, with a list of who is responsible for tasks at each stage, to ensure that professionals are accountable and parents know who they can speak with.

The Transitions team supports young people from the age of 14 through to 25 as they transfer from children's to adults services. Transition support is available for young people with special educational needs (SEN), including learning disabilities, children in care or those who are looked after, care leavers, and young people accessing health services.

For young people with SEN, work begins in Year 9 to support the transition to adult services. The key decision for young people is whether referral to LD Adult services is needed. The Transitions Protocol, first developed in 2010, was most recently updated in 2020. It sets out guidance for the workforce across education, health and social care services for the transitions process. It also identifies the advice, guidance and support that young people and their parents should expect.

The transition process forms a core part of capturing how a young person wants to live as an adult. Putting the right support in place is critical to young adults being able to engage in society in the way that they want to. This includes thinking about independent living, employment opportunities, education opportunities good health, community involvement, social life, and relationships.

From a health perspective, transition offers an opportunity for the health system to identify needs early and consider the health support needs that a young person with SEN, including LD, will need as an adult. The Transitions Protocol sets out that contact should be made with the GP to ensure that they have a copy of the Health Plan. In addition, young people should be supported to go onto the LD Register so that they can have an annual health check. However, this can be challenging due to differing interpretations of the Register criteria by practices and different levels of prioritisation of the LD Register and annual health checks. The Transitions team is willing to provide further support for young people to be included on the LD Register, but needs greater confidence that there is a consistent approach to the register across GP Practices in Swindon.

Safeguarding

Swindon Safeguarding Partnership is designed to bring together the range of organisations that deliver or commission services to support adults with care and support needs.

The purpose of the Swindon Safeguarding Partnership (SSP) is to;

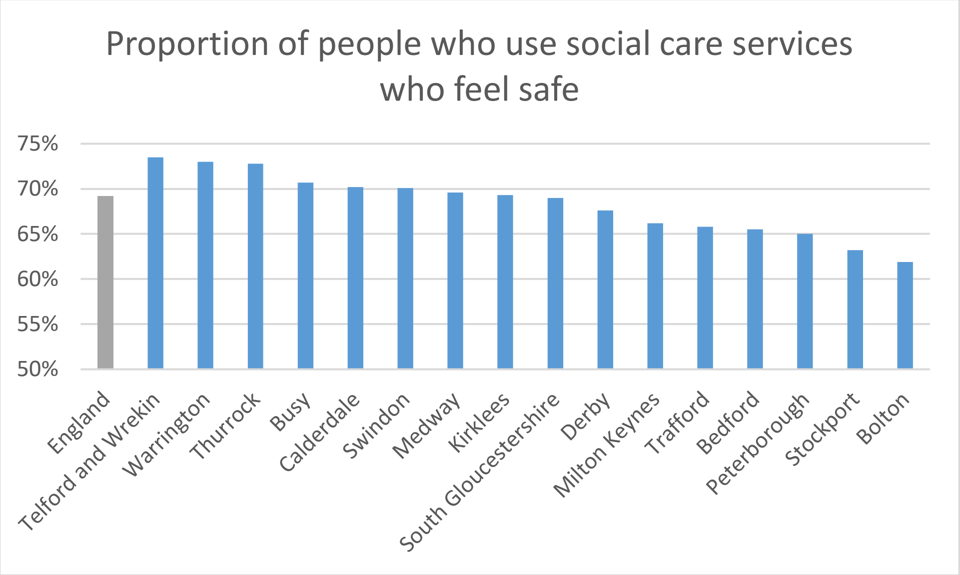
- Provide effective and informed leadership to the local safeguarding system
- Deliver our shared responsibility for the safeguarding of children, young people and adults at risk in the borough
- Promote positive working relationships with each other and children, adults and families
- Identify and act on learning
- Provide assurance to the Swindon community

Listening to the voice of people with LD who require help and support is a priority of the SSP. Systems to secure this engagement will be developed in 2021. The LDPB is required to embed safeguarding and engagement with service users on safeguarding in its work and provide feedback to the SSP.

For all adults, there has been an increase in concerns raised to the Swindon Safeguarding Partnership in Swindon, which is similar to other local authorities. For adults with LD, 99.1 per 1000 people on the LD GP Register have been involved in section 42 safeguarding enquiries (PHOF, 2017/18). This is almost double the England average and higher than the majority of statistical neighbours. There are likely to be limitations with this data due to use of the LD Register.

In Swindon, the overall proportion of adults that use social care services (including people without LD) that feel safe is 70.1%. This is similar to England and better than around two-thirds of statistical neighbours as shown in Figure 10.

Figure 10: Proportion of people who use social care services who feel safe (PHOF, 2015/16)



Views of LD Representatives

- The Representatives commented that more needs to be done to make all adults with LD aware about safeguarding and what to do if they have a safeguarding issue
- More training should be done with the staff who work with adults with LD, and with adults with LD themselves, around the safeguarding process in Swindon.
- It has previously been agreed that there would be a safeguarding forum and the representatives highlighted that this should be a priority in the future.

Services for parents with LD

Services available for parents with LD include Baby Steps, which is a perinatal education programme which helps parents to prepare for the arrival of their baby and the transition into parenthood. This programme is designed to support vulnerable adults, including adults with LD.

All services that are supporting parents with LD should use The Good Practice Guidance on Working with Parents with a Learning Disability, produced in 2007 and updated in 2016 by the Working Together with Parents Network and the Norah Fry Centre (WTPN 2016, DH/DfES 2007). The guidance states that "Adult and children's services, health and social care, should jointly agree local protocols for referrals, assessment and care pathways in order to respond appropriately and promptly to the needs of parent and child."

Services for children and adults working with parents with LD in Swindon have undertaken a self-assessment process in line with the Good Practice Guidelines for Working with Parents with LD. Swindon's Children's and Adults services are currently reviewing relevant policies and protocols to ensure the features of good practice are applied.

Learning disability pathway

A pathway mapping workshop for learning disabilities was held jointly between health and social care in January 2020. The workshop will contribute to a review taking place across the BSW LD/ASD Programme Board. The workshop described here relates to Swindon only. The workshop was an opportunity to reflect on areas for development in the pathway.

Attendees at the workshop were asked to feedback on gaps and issues in the pathway. Once collated, four main themes emerged:

- Transition
  - A need for regular tracking meetings
  - Widening tracking meetings to include education, health, LD health and social care, and a transitions lead within all of these teams
  - A need for raised awareness about transitions with all stakeholders; roadshows were suggested as a mechanism for this
  - Possibility of transition champions in other services

- Crisis and support
  - Currently there is no dedicated crisis support for individuals with LD; if in place, this would need to be a 24/7 service
  - There is a need for a single point of access across social care, mental health and LD
  - There is a need for an Assessment and Treatment unit for LD (and ASD) patients
  - Prevention is very important; care coordinators may reduce the amount of people reaching crisis points

- Referral routes
  - All services need a clear pathway
  - One simplified referral form would help to streamline the process, and align with the idea of a single point of access identified above
  - A single point of information that is kept up-to-date would also be useful
  - Information would need to be made available to GPs so that it is clear which service they should be referring into

- Silo working
    - It would be useful to have quarterly meeting with all service providers
    - Beneficial to have health and social care services co-located
    - Professionals need to know how to access other services
    - Shared records and good information sharing protocols would aid joint working
    - Care coordinators were also identified as a gap under this heading
    - Opportunity for secondment to other services
    - Increased LD training across all services.

The wider determinants of health and wellbeing

Employment

Opportunities for employment are important for adults with LD. It gives people a regular routine, opportunity to earn a salary, and greater independence. There is also consistent evidence that paid employment improves people’s mental and physical health (SBC, 2018). However, there are many barriers to people obtaining paid work and many people are excluded from employment (Foundation for People with Learning Disabilities, 2005).

Swindon has developed a Supported Employment Strategy (2018-22). This aims to provide all young people and adults with LD, supported by social care, the opportunity to gain paid employment or volunteering work. The key objectives are set out in the strategy alongside actions needed to improve the rate. By March 2022, the aim is that 10% of adults with LD in Swindon known to ASC will be in paid employment.

Figure 11 shows the proportion of adults with LD supported by ASC in paid employment in Swindon, compared against statistically similar neighbours. In 2018/19, Swindon has an employment rate of 6.3% which is similar to the England average. This is an increase from 3.5% in 2012. However, a number of similar local authorities have managed to achieve an employment rate of over 10%.

Figure 11: Proportion of supported working age adults with LD in paid employment (%); comparison of statistical neighbours (PHOF, 2018/19)

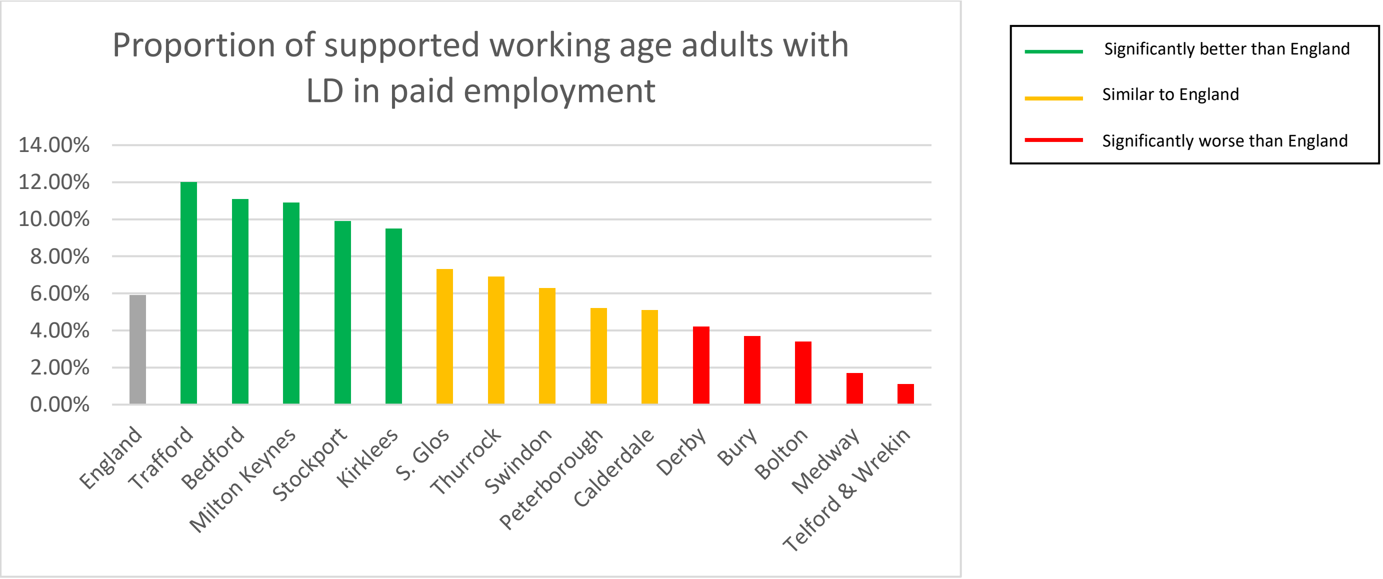
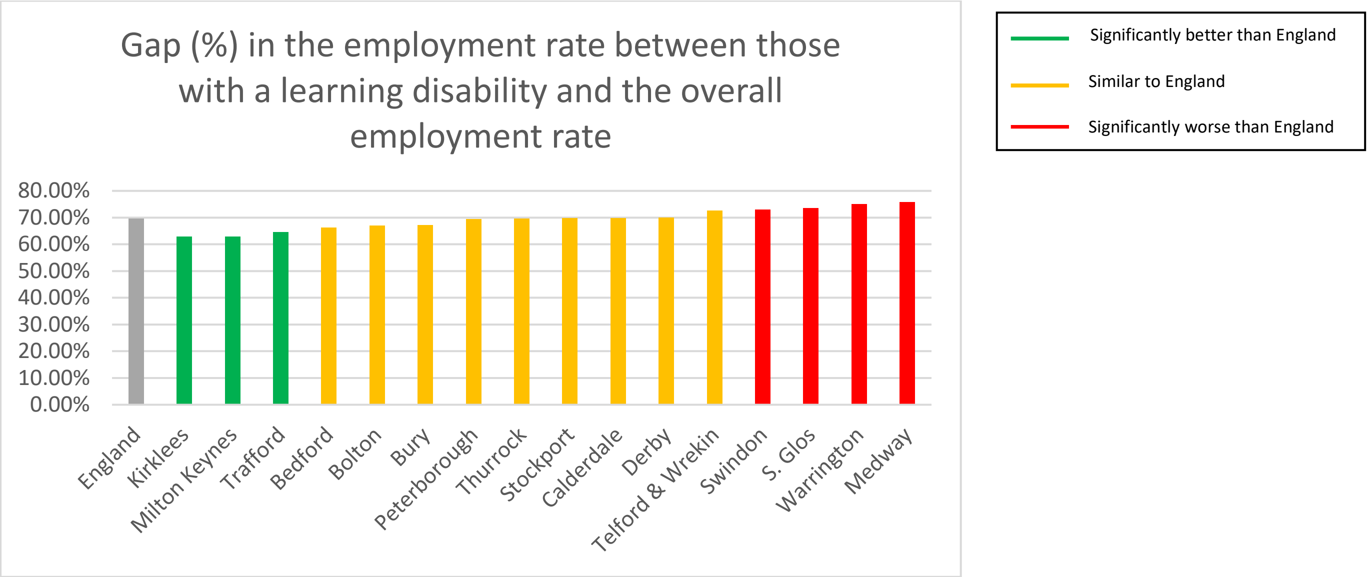


Figure 12 provides the difference between the employment rate of the general population and the population of adults with LD supported by the local authority. This is a useful comparison which puts the local employment rate in context. By this measure, the difference between the general employment rate and the employment rate for adults with LD is significantly worse in Swindon than in England. Swindon also performs poorly against its statistical neighbours.

Figure 12: Gap (%) in the employment rate between those with LD and the overall employment rate (Public Health Outcomes Framework, 2018/19)



In addition to people supported by social care, adults with milder learning disabilities are also less likely to be in work. Based on data from Mencap, 80% of adults with LD have either mild or moderate LD, but only 20% of this group are in employment (Mencap, 2016). Employment is an important determinant of health, and being out of work will have a significant impact on both physical and mental health.

Stakeholder consultation and comments

LD Representatives

On reviewing the easy-read version of this report, LD Representatives commented that more information could be provided to adults with LD about employment. Not all of them had heard of the Supported Employment Strategy and they thought that more people should be made aware of it and should understand how it works. In addition, they were pleased to see that there has been an improvement in employment rates and thought that it would be helpful for this to be shared more widely among adults with LD to inspire and encourage others.

LD Forum

In March 2018, the LDPB Forum in Swindon held a session focused on employment. As part of the discussion, attendees listed the things that would make a good workplace. The statements made clearly capture the needs of people with LD in the workplace:

- All staff should have LD awareness training including good awareness of relevant legislation
- Buddy schemes should be in place
- Support should be provided in work
- There should be willingness for employees to continue with college release

- Reasonable adjustments should be put in place
- Hours should be flexible
- Work trials should be available
- Travelling costs should be covered if it is a work placement; and training should be available to support people with LD with travel
- Training needs to be ongoing
- Support should be available to complete paper applications, as computer access is not always possible
- The workplace should have good health and safety

Housing and Independent Living

The majority of people with LD known to local authorities nationally live in one of three types of accommodations:

- With family or friends
- In a registered care home
- In supported accommodation

Based on a survey carried out by Mencap, the majority of adults with LD that live with family or friends want greater independence (Mencap, 2012). In 2018/19, 490 adults with LD supported by ASC in Swindon were living in their own home or with family (NHS Digital, 2019). This is 71% of all adults with LD supported by ASC.

Swindon's Support Living Framework is aimed at supporting greater independence for adults with LD, which is an important part of the personalisation agenda. Providers are measured on their ability to achieve individual outcomes with the adults that they support and are expected to use a person-centred approach. Greater expectations are placed on providers than were traditionally placed on them, and work is still needed to fully develop the infrastructure around supported living. This includes greater development of the market, which is recognised regionally as an issue.

Swindon Local authority currently support over 100 individuals in community based supported living services. Recently, the growth in demand for supported living services has been in region of 3% annually.

There have been improvements since 2012 on the main metrics measured for adults with LD on housing and independent living. Figure 13 (p.57) shows that an increasing number of adults with LD in Swindon are living in stable and appropriate accommodation, which should support both their health and broader wellbeing. The development of the Hawthorn Bungalows has increased the provision of supported living options. However, finding suitable accommodation continues to be a challenge.

Figure 13: Percentage of adults with LD who live in stable and appropriate accommodation (PHOF, 2018/19)

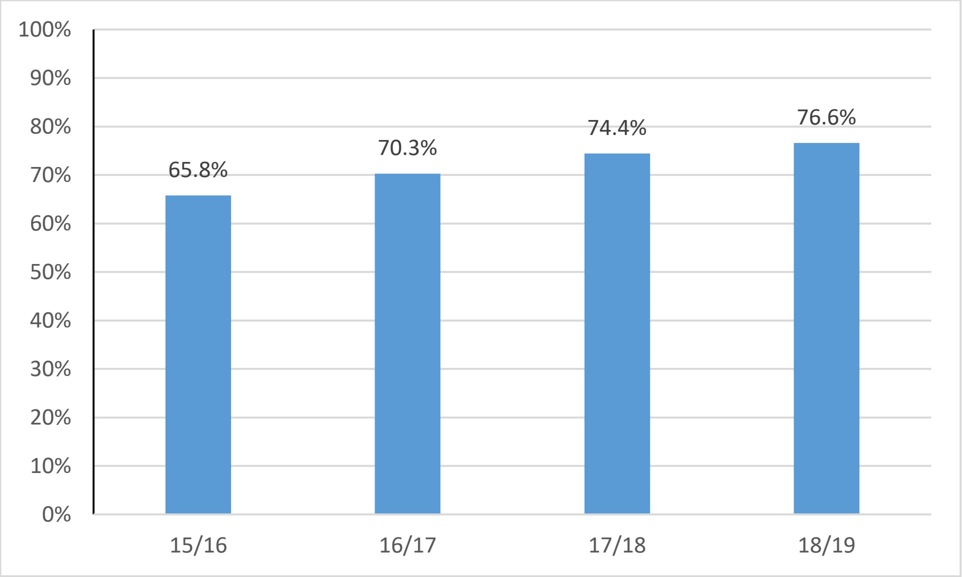


Figure 14 shows a reduction by 13% in the number of people in residential or hospital accommodation. This is consistent with the *Transforming Care* agenda. Figure 15 shows that there has also been a 5% reduction in the number of clients in residential care who are placed outside of Swindon since 2014/15, although this figure has stabilised over the last three years. The proportion of the LD budget spent on residential care homes has increased since the last JSNA, from 51% to 55%.

Figure 14: Percentage of Adult Social Care clients with LD placed in residential or nursing care (PHOF, 2018/19)

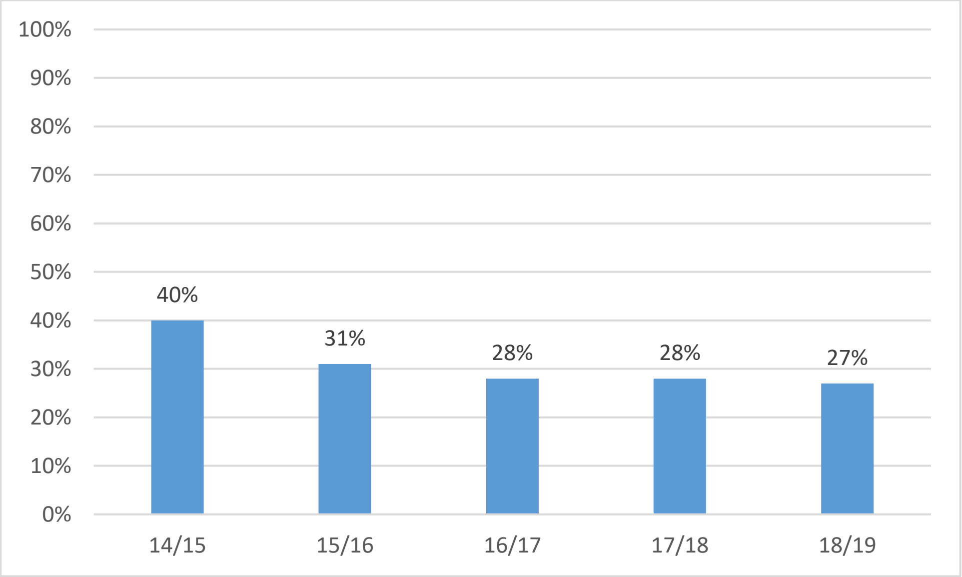
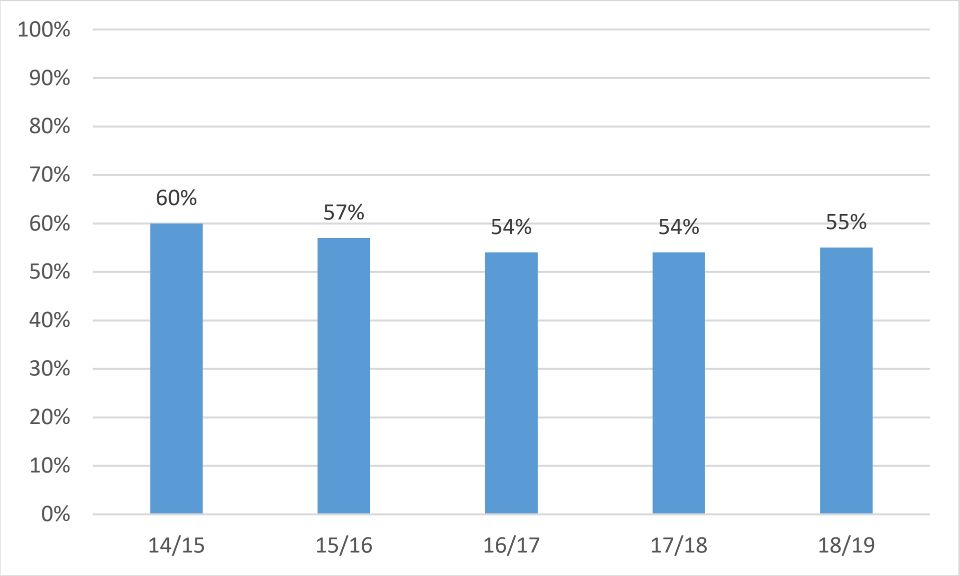


Figure 15: Percentage of Adult Social Care clients with LD in residential or nursing care who are placed outside of Swindon (PHOF, 2018/19)



Stakeholder consultation and comments

LD Representatives

- The representatives highlighted that being independent is one of the most important issues but having to move is very stressful and can be confusing
- Quotes regarding housing were that "People want to be able to move on from family and they need support to do this" and "A lot of people who moved in the last year have been told they can only stay there for a couple of years"
- A particular concern highlighted was a need for more support on budgeting so that people are more comfortable managing money when they live independently

Carer representatives

- Some progress in housing has been made but suitable and flexible housing provision for adults with LD is very limited
- In order to live independently you have to move over the other side of town leaving behind your family/support networks, your volunteering opportunities, your church, in order to have your own accommodation
- It would be helpful if people with LD could be supported to find others who want to live independently, so that they could live together in shared accommodation
- There is a need to address how to support vulnerable but capable people more appropriately.

This indicates a concern amongst carers that housing does not meet the needs of adults with LD in some situations. There is work ongoing to improve the housing offer from SBC and it will be important to consider these concerns going forward and ensure that the voice of service users and carers is captured.

Housing for parents with LD

A report by Public Health into parents with LD identified the following key points regarding housing:

> "Housing is a large and important issue for people with learning disabilities, but an even greater one for parents with a learning disability. There are several housing options available in Swindon;
>
> - Two specialist learning disability places, which can be accessed through ASC and include Shared Lives
> - Three supported living schemes which are for single people or couples which have single bedroom flats or studios
> - General needs properties are available
>
> If a women became pregnant whilst in a supported living scheme then a new housing option would have to be found, but the women/couple would not be moved until a new option had been found.
>
> Some issues around housing are
>
> - Many two bedroom flats are at 'affordable' rather than 'social' rent.
> - There is no empty accommodation so it is difficult to move people quickly.
> - There is no specific accommodation for homeless people with a learning disability.
> - Generally there needs to be a care package in place to ensure that tenancy is successful."

Social life and relationships

Having access to a support network, social life, and relationships are all important for the mental health and wellbeing of adults with LD. Friendships and relationships can help people be happier and to feel included and valued. Mencap has highlighted that "*Children and adults with a learning disability tend to have smaller social networks and their relationships are not as strong as those of children and adults without a learning disability. Their social networks are often characterised by relationships with support staff and the people they live with. 34% of adults with a learning disability have no more than yearly contact with friends"* (Mencap, 2016)

To develop friendships and relationships people need opportunities to meet others, support to do the things that they want to do, support staff and care workers that understand that making friends having relationships is important for people with LD, and information that is easy to understand.

Personal and sexual relationships can bring fulfilment and companionship for adults with LD. It can also help to offer more freedom and greater self-determination. According to Mencap, only 3% of people with a learning disability live as a couple, compared to 70% of the general adult population (Mencap, 2016). Adults with LD have the right to choose their relationships and to understand their sexuality. They also have a right to learn about their bodies, sexual health and healthy relationships.

Support workers and health professionals working with adults with LD regularly need to be comfortable to talk to adults with LD about friendships and sexual relationships. This can be challenging and nationally there is a lack of training and information on this topic.

Feedback from LD Forum and Carer Representatives

In 2017, there was an LD Forum that focused on the topic of relationships. This provides insight into the views of adults with LD in Swindon on relationships and helped adults with LD to consider what is and what is not likely to be safe and appropriate to discuss with strangers.

Carer representatives for adults with LD provided feedback that there are a limited amount of activities and opportunities for adults with a complex learning disability to socially interact outside of their support network. When activities are closed and not replaced, this restricts their quality of life.

Community safety and crime

Victims of crime

In 2018/19, there were 23 disability hate crimes that took place in Swindon (Swindon Borough Council, 2019). Nationally, it is estimated that only 12% of disability hate crimes were reported (Dimensions, 2019). It is not possible to differentiate from the data what proportion of these crimes took place against people with LD. Hate crime can include verbal abuse, physical abuse, threatening behaviour, bullying/teasing, online/phone abuse and damage to property or theft (Mencap, 2018). ‘Mate crime’, where a person with LD is exploited or abused by a person they believe to be their friend, is a form of hate crime.

A survey completed by Dimensions found that 73% of people with LD and/or autism had been a victim of hate crime (Dimensions, 2019). It is therefore highly likely that learning disability hate crime is underreported and under recognised.

Wiltshire Police has a network of Hate Crime Advisors who will support victims of hate crime, including giving advice about where they can seek extra help and support. The Hate Crime Advisor Coordinator is able to provide more information to adults with LD through Forums or other appropriate settings.

Criminal Justice System

Evidence from the Prison Reform Trust shows that up to 7% of adult prisoners have an IQ under 70, which would indicate a learning disability (Foundation for People with Learning Disabilities, 2012). The report identified some notable inequalities in treatment and outcomes for adults with LD in prison:

"Prisoners with learning disabilities are five times more likely than other prisoners to experience control and restraint, three times more likely to experience segregation and three times more likely to have depression or anxiety. Serious concerns are still being raised about whether people with learning disabilities accused of a crime will get a fair trial and, if found guilty, whether sentencing will take account of the reasonable adjustments they may need in order to comply with the sentence."

In Swindon, 2% of people on the National Probation Service caseload have been identified as having a learning disability. However, this relies on people having a diagnosis of LD and many people with a milder LD may not have been diagnosed. People on probation are at risk of poor mental health and adults with LD on the caseload will need reasonable adjustments to access support and services.

Sexual assault

Based on feedback from the Sexual Assault Referral Centre (SARC) in Swindon, adults with LD are over-represented as victims of sexual assault. Table 10 shows that, based on recent data over a short period, adults with LD appear to be over-represented in victims of sexual assault, compared to the general population.

Table 11: Proportion of people supported by the SARC who had LD (SARC, 2020)

Month	%
January	9
February	10
March	10

The SARC was included in the qualitative data collection for this JSNA and highlighted some key points. People with LD are very vulnerable to sexual assault. Often, usual key workers do not have enough knowledge to understand the impact of sexual assault or to support adults with LD when they have experienced it. This means that even once a person has been supported by the SARC, they may be at greater risk of self-harm and suicide following an assault due to trauma. Day-to-day key workers often do not have the specific expertise to be aware of these risks.

Stakeholder consultation

The Community Safety focus group included representatives from Wiltshire Police, Dorset & Wiltshire Fire & Rescue and Swindon Community Safety Partnership. Additional 1:1 conversations were held with the Swindon & Wiltshire Sexual Assault Referral Centre (SARC), Horizons, and Victim Support. The following key points were raised:

- For both the police and the fire service, knowledge of a person's learning disability is usually dependent on the person raising it as an issue
- Both services felt that there was more awareness of working with people with learning disabilities, when compared to 2012, when the most recent JSNA took place
- However, both services indicated that additional training about reasonable adjustments would be welcome. There are clear training systems in place in each organisation and slots could be made available for LD training. This was also raised by Horizons.
- Issues relating to "cuckooing" have been increasing, where an occupant of a house is forced out or to share their home by people dealing drugs. This is usually related to county lines drug dealing. Adults with LD will be more vulnerable to "cuckooing", particularly those with a mild or moderate learning disability who are not in contact with social care or other support services.
- It was raised that for other community safety concerns, (e.g. domestic violence, sexual health, homelessness), there is usually a clear contact point for inclusion in multi-agency groups. For LD, it is less clear who should be included and a clearer contact point would be helpful.

The LD Representatives commented on community safety and crime as part of their response to the draft report. They noted that it would be helpful to know how to report a hate crime and what happens if you do. They also commented that it should be a priority to make sure that staff working with adults with LD have the right training so that they know how to support people if they are the victim of an assault or other crime.

Voluntary, community and commissioned services

In addition to council and NHS run services, there are a number of voluntary and community sector services accessed by adults with LD and their carers in Swindon. A number of community services are commissioned by SBC and meet regularly via the Community and Building Based Forums. Elected LD Provider Reps from these two Forums are members of the LDPB to ensure key messages from adults with LD and their carers are shared and acted upon.Full details of services in Swindon are available on the Swindon Local Offer page.

A snapshot of service use is provided below:

Table 12: Snapshot of day service use in Swindon 2019/2020 (prior to Covid-19), including details of direct payments

Service	**How many attendees**
Open Door	116 in 2019 (note: not a commissioned service)
Uplands Enterprise Trust	36 attendees, with 31 paying using direct payments (others commissioned by SBC)
Jubilee Gardens	11 places commissioned by SBC
Penny Hooks Farm	4 places commissioned by SBC
The Inclusion Project	32 attendees, with 27 using direct payments (others commissioned by SBC)
OK4U	Average attendance is approx. 60-70 per day; with around 130 people attending across an average week

Advocacy

As well as day services, community sector organisations advocate for the rights of people with LD in the local area, including ensuring a voice at the LDPB. Swindon Advocacy Movement (SAM) aims to support adults with LD to have their voice heard on issues that are important to them, to help safeguard their rights, and to have their wishes considered when decisions are being made.

SAM operates Project Boost, which is a community based project available for any adult in Swindon with LD over the age of 18. The project supports adults with LD to develop confidence and their ability to live independently, for example through improving their cooking or shopping skills. They can also help people to budget or support them with skills needed in the workplace.

Conclusions

This report was started with the aim of reviewing the 2012 JSNA for adults with LD. There have been major changes in policy and practice over the last eight years. There have been notable improvements in some key areas, including transition services, housing, and steps towards personalisation within services. However, feedback from LD Representatives and carers make it clear that more can be done, particularly in relation to personalisation and independent living.

Health outcomes continue to be poor and this is recognised as a national issue. Nationally, the LD GP Register has been recognised as a Quality Improvement area for 2020/21 and this provides an additional driver for moving this work forward. Locally, a BSW Programme Board review of the LD pathways has been taking place which provides insight into local issues. These provide a good catalyst for change and the recommendations in this report should provide more detail of specific improvements in Swindon that can be built into this work where relevant.

Covid-19 has significantly affected the lives of many adults with LD. It is more difficult to get face-to-face support and people have indicated that they are at greater risk of social isolation, and associated poor mental health. The uncertainty related to Covid-19 is likely to continue for many months, and will need to be accounted for when planning for the future.

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Appendix A – progress against 2012 JSNA action plan

Recommendation		**Progress**
1	Develop a joint strategic vision for learning disability in Swindon to include action on these recommendations	There is no overarching joint strategic vision specifically for learning disabilities in Swindon. There are a number of useful strategies and frameworks focusing on specific areas (e.g. Employment Strategy, Transitions Protocol, and Supported Living Framework). There is an LD/ASD Transformation workstream at the BSW CCG. Any future strategic vision for Swindon should consider alignment with the overall BSW vision.
2	Ensure implementation of the adult social care change programme including:	
2a	Full implementation of personalisation and increase of self-directed support	Personalisation and self-directed support has increased since the 2012 JSNA. Introduction of strengths based working and planning and the three-conversation model has supported the shift towards personalisation. Direct payments and personal budgets have both increased. Individual Service Funds (a model of direct payments which should be more straightforward to administer) needs to be further developed.
2b	Reduced reliance on residential and nursing care while ensuring person-centred planning	Since 2014/15, the proportion of adults placed in residential or nursing care has reduced from 40% to 27%. There are still challenges which have been identified in the report e.g. local market for residential care needs further development. The number of people with LD living with their parents is predicted to remain stable between 2020 and 2035.

Recommendation		Progress
2c	Provision of a suitable range of housing and supported living models	Updates in this area: • Change to the Supported Living Framework contracts • Development of the Hawthorn bungalows • Regular housing panel and improved relationships between ASC and Housing • Data indicates overall movement in a positive direction
2d	Development of the market locally to enable people to use personal budgets effectively	ASC Commissioning team has been developing work streams to identify how providers can work together more collaboratively than competitively Further work is needed with providers to support them to use person-centred and goal planning approaches
2e	Engage more proactively via targeted support in order to help support people to stay in their own homes/communities	There has been a reduction in the number of adults placed in residential and nursing care, and a reduction (though this has remained static over last three years) in the number of adults placed outside of Swindon There is still an ongoing need to ensure that accommodation meets the needs of adults with LD, including provision of high quality residential and nursing care where this is needed
2f	Improved support for carers and better understanding of their needs	The Swindon Carers Strategy 2018-2021 was formally published in November 2018. The Swindon Carers Leads Strategy Group develops annual action plans throughout the duration of the strategy to benchmark progress on the 5 outcomes and planned key achievements against the outcomes.
2g	Increase in the proportion of timely person-centred reviews	By March 2020, it was forecast that 26.9% of adults with LD on the ASC caseload would have received a person-centred review, so there is significant space for improvement on this recommendation.

Recommendation		Progress
2h	Cultural and language sensitivity	A number of organisations have highlighted that they need further support to provide reasonably adjusted care and to produce easy-read information Additional focus is needed on BAME adults with LD – the first step is to better understand the population so that planning to meet their needs can be carried out
3	Increase employment aspirations, options and support, with clear strategic links to education providers, Job Centre Plus and local employers (including the Local Authority and NHS).	The Supported Employment strategy sets out a target of having 10% of known adults with LD in employment by 2022. The employment rate has increased from 3.3% to 6.8% since 2012 The gap between the general rate of employment and the rate of employment among adults with LD is poorer than the England average, indicating the continued focus needed in this area
4	Improve the transition process for young people into adult services, taking account of the expected Children and Families Bill, and including development of shared aspirations, expectations and outcomes as well as shared information systems across agencies.	There have been significant changes to the structure of the Transition service which have taken account of the Children and Families Act 2014. Link workers have been appointed into the team. The transition protocol has been refreshed and a Transition Strategy was developed in 2020.
5	Develop Health Checks to improve the local offer and uptake through the Learning Disability Partnership Board health sub-group.	This has been discussed in detail throughout the report. Many adults with LD do not receive a health check and accessibility varies considerably between practices. The recommendations set out in the report should be followed to address this issue. The health-sub group no longer meets.

Recommendation		Progress
6	Ensure 'reasonable adjustments' are made by health providers to ensure people with learning disabilities have full access to mainstream health services through the Learning Disability Partnership Board health sub-group.	Progress has been made in some health services. For example, at GWH, it is now mandatory to complete e-learning on how to deliver reasonably adjusted care. In addition, an LD Liaison Nurse is now in post who will be able to support adults with LD to receive the care they need. However, delivery of reasonable adjustments across all health services can depend on the skills and knowledge of individual practitioners and does vary. Reasonable adjustments need to be considered across all services, not just health. The health sub-group no longer meets.
7	Develop, agree and implement a Joint working protocol between Avon and Wiltshire Mental Health Partnership NHS Trust and Community teams.	The structure of services has changed since this recommendation was written. The BSW Programme Board is considering the pathway of adults with LD across the system; recommendations from the Programme Board and those identified by the pathway mapping workshop from January 2020 should be supported.
8	Improve life-chances of parents with learning disabilities and their children by improving early identification and support, and developing a joint working protocol between Children and Adult Social Services.	A public health review into parents with LD in Swindon took place in 2016, identifying recommendations. This group should continue to be a priority group for additional support as needed. The Good Practice Guidance for supporting parents with LD was updated in 2016 and should be used to frame future work in this area.
9	Improve information and intelligence systems to better inform providers and commissioners. Specific recommended projects include:	
9a	Investigating the recent increase in care packages	This recommendation appears to have been time-related to 2012
9b	Developing better transition information to inform current service planning	Transition services discussed above

Recommendation		Progress
9c	Improving transition information systems which work across agencies	Transition services discussed above
9d	Developing use of the Swindon Learning Disability register to fully include children and young people with learning disabilities	The LD register should include people from aged 14 and above. The Transitions team is willing to support young people to join the register but needs greater confidence that practices have more consistent criteria.
9e	Analysing data on children and young people with learning disabilities, using information from education and other sources to improve understanding of need and inform service planning	A clear route into the Transitions team has been created and all schools are participating. There is a regular panel in place that reviews this process.
10	To engage with One Swindon and influence in order to gain partner and business wide support for supporting and encouraging future LD employment opportunities.	Work with businesses is set out in the Supported Employment Strategy
11	Full implementation of the Winterbourne View recommendations.	The Transforming Care agenda has been supported and there has been a continued shift away from residential and nursing care

Appendix B – Focus group questions

Questions

- In your role, what experiences do you have engaging and working with adults with LD?
- The most recent JSNA was completed in 2012. Over the last decade, how has community safety for people with LD changed? What are the positive and negative changes?
- What services or support are provided by your organisation for adults with LD? (Do this on post-its)
- In your work, what issues and concerns are arising in terms of services and support for adults with LD?
- What could be done to improve or change services and support for people with LD?

Appendix B