Joint Strategic Needs Assessment

Learning disability needs assessment

2017 Summary

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Summary

Learning disability is a lifelong condition that affects the way a person learns new things in any area of life. It affects people's understanding of information and their communication skills. Learning disability is often classified by severity, which ranges from mild learning disability to moderate or severe learning disabilities. People with learning disability can have difficulty in understanding new or complex information, learning new skills and coping independently. This means that people with a learning disability often suffer many disadvantages and poorer health outcomes than their non-disabled peers. This may be due to impairments associated with a learning disability (intellectual, medical and physical), discrimination, negative attitudes and social exclusion. This may also be due to "diagnostic overshadowing". This means that in some cases symptoms of physical ill health are mistakenly attributed to either a mental health/ behavioural problem or as being inherent in the person's learning disabilities.

This needs assessment provides an update on the 2012 Learning Disability Joint Needs Assessment (LDNA), which gives a comprehensive picture of the needs of people with learning disabilities. Since 2012, there has been some progress made in implementing the diverse range of recommendations made. This update provides information about new evidence, policy and structural changes and assesses the health and social needs of people with learning disabilities across Cornwall and the Isles of Scilly. It is hoped that it will inform current and future service provision to meet the needs of this population. The aspiration is to build on this needs assessment as new evidence becomes available so that it can be incorporated into the strategic planning cycle (e.g. the Community Based Support and Housing Commissioning strategy and Transforming Care Plan), which is due to commence during 2019/20.

This update of the needs assessment has been developed in collaboration with the Public Health Intelligence team and the learning disability needs assessment working group comprising of;

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Introduction

Joint strategic needs assessments (JSNAs) are a regular statutory task for Health and Wellbeing board partners to jointly produce information about people from defined groups of the population, and to inform future policies and strategies. The first learning disability needs assessment was produced in 2012, which provided a comprehensive overview of the health and wellbeing of people with a learning disability and the demand / supply of existing services. This LDNA represents the first part of the update. The second update aims to incorporate the views, experiences and aspirations of service providers and people with learning disabilities, their family and/or carers.

The following provides an extended summary of the needs assessment. It aims to provide a national context, policy update, prevalence of learning disabilities, health needs, supply and demand of services, advocacy, community voice and complaints. There is a brief section providing an overview of the effectiveness of interventions targeting the health and wellbeing of people with learning disabilities. However, additional research is needed to fully understand the implications for this evidence base. The last section concerns key recommendations made from the full needs assessment, which should be incorporated in the development of future policy and practice across key stakeholders, including Cornwall Council, Kernow Clinical Commissioning Group, Cornwall Partnership Foundation Trust and Healthwatch for example. Please refer to the full needs assessment for further information.

Background

People with learning disabilities are people first, with the right to be treated with dignity and respect. People with a learning disability do not want to be defined solely by their learning disability as they have many other identities, such as friend, neighbour, relative or colleague. Moreover, people with a learning disability have the right to enjoy the same opportunities and responsibilities as other local citizens. This includes access to suitable housing, education and employment, achieving good health outcomes, and leading active and fulfilling lives.

People with learning disabilities often suffer many disadvantages and poorer health outcomes. This can in part be due to intellectual, medical and physical impairments, but it is also due to disabling barriers, discriminatory negative attitudes and social exclusion that also need to be overcome.

The term ‘learning disability’ is useful in identifying some of these barriers, identifying the problems and solutions, and in planning responses. However, there is a need to recognise people also have a gender, age, ethnicity, faith and sexuality and may have other disabilities, impairments or disadvantages that are of equal or greater importance.

The LDNA update aimed to assess the health and social needs of people with learning disabilities across Cornwall and the Isles of Scilly. To identify gaps in current service provision; make recommendations for changes to meet people’s needs; and reduce the health inequalities experienced by this population group. This needs assessment should be read in conjunction with the 2017 Special

Educational Needs and Disability needs assessment and the 2017 Autism focus paper.

National context

The department of Health describes 'learning disability' as someone with a reduced ability to understand new or complex information, to learn new skills and cope independently. Children and young people may also experience learning difficulties in the education sector. The definition of a learning disability excludes specific disorders such as having reading, writing or maths problems, physical impairments or behavioural difficulties.

Nationally, it is estimated that around 2% of people have a learning disability, but according to Public Health England only 0.44% of people are known to services (GP practices). This means that the majority of people with a mild learning disability remain unknown to health and social care, and may only begin to access help and support when their family/carers become too old or frail to provide the support that people with learning disabilities need. Also around 1.3% of households across England contained a parent with a learning disability, which can affect the health and wellbeing of the family. Current forecasts predict that the number of people with learning disabilities and need for social care is set to rise by up to around 8% by 2026.

People with learning disabilities are amongst the most socially excluded and vulnerable groups, with greater health needs than their non-disabled peers. These include typical health problems such as; respiratory diseases and infections, gastro-oesophageal reflex disease and swallowing problems, heart disease, cancer, gastrointestinal disorders, poor oral health and sensory impairments, metabolic and endocrine disorders (e.g. osteoporosis, thyroid disease and diabetes), posture/mobility/sensory and mental health problems.

Between 20% and 33% of people with learning disabilities also have autism, and around 22% have epilepsy, which can have a significant impact on health and wellbeing. Furthermore, between 10% and 15% of people may also display challenging behaviours and have mental health problems. This behaviour can be described as challenging when it is of such "intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion".

This means that people with a learning disability have a shorter life expectancy and increased risk of early death when compared to their non-disabled peers. For example, men and women die between 13 to 20 years and 20 to 26 years younger than the general population, respectively. However, due to improvements in care, for example, there is evidence that life expectancy is increasing, particularly for people with Down's syndrome. There is also some evidence suggesting that the life expectancy of those with a mild learning disability is approaching that of the general population.

Between 30% and 50% learning disability cases are thought to be due to genetic or hereditary causes. Lifestyle and other environmental factors during prenatal through to neonatal periods are also thought to play an important role in

developing a learning disability. These may include for example maternal age, ethnicity, low education, alcohol/tobacco use, diabetes, hypertension, epilepsy and maternal asthma. Other risk factors include a preterm birth, being of male sex and low birth weight of the child.

A range of factors influence the health and wellbeing of children and adults with learning disabilities. These are wide ranging and may include a host of adversities such as communication difficulties, reduced health literacy or access to healthcare, poverty, poor housing, unemployment, overt discrimination, poor diet, inactivity, obesity or being underweight, substance use (e.g. smoking, alcohol, drugs and medication misuse), underuse of health care, sexual health and social disconnectedness and isolation.

For example, people with a learning disability have lower physical activity levels than the general population, which puts people at greater risk of heart disease, high blood pressure, strokes, diabetes, several types of cancer and mobility difficulties. While the number of people with a learning disability and misusing drugs and alcohol is lower than the general population, they are particularly vulnerable and may be at increased risk in a community setting. Furthermore, those misusing substances may increase as a result of more independent living and increased access to drugs and alcohol. People with learning disabilities are also more likely to be victims and perpetrators of crime. Specialist interventions are required to protect these vulnerable populations to avoid problems later in adulthood.

The number of people with learning disabilities and living more independently is increasing. However, around 55% of people continue to live with their families, although this varies by the severity of learning disability. Increased employment may help promote more independent living, but the number of adults with learning disabilities in any paid/self-employment is dropping (now currently a 6% employment rate). Barriers to transport can affect employment, as well as other factors such as relationships, social isolation and access to health care.

There is also a need to help people with learning disabilities to gain better access to specialist palliative care services. This requires ongoing staff development focusing on staff confidence, collaborative working between professionals and the empowerment of people with a learning disability to be involved in decisions about their end-of-life care. The care and support of people with learning disabilities is influenced by changes in national/local policy and guidance.

Key Policy and guidance

Over the past 10 years, there have been several national policy changes and government documents about how health and social care services should be delivered in the future. The following provides a summary of key policy and strategies presented in the needs assessment:

- The Care Act 2014 sets out the care and support people with a learning disability and their carers should expect to receive.
- The Equality Act 2010 (Directgov, 2013) places a duty on service providers to make reasonable adjustments to services and physical premises to meet the needs of people with learning disabilities.

- Valuing People (Department of Health, 2001), Valuing People Now (Department of Health, 2009b) and Valuing Employment Now (Department of Health, 2009a) sets out key government strategies for people with learning disabilities.
- The Autism Act 2009 placed a duty on the Government to produce a strategy for autistic adults. It explains the different things that the Government will do to make sure autistic adults get the help that they need. The strategy also tells local councils and health services how they can help autistic people. Following the initially entitled "Fulfilling and rewarding lives" (2010) and following consultation, "Think Autism", was published in April 2014.
- Under the Accessible Access Standard, all organisations that provide NHS care and / or publicly-funded adult social care are legally required to follow the Accessible Information Standard.
- Mansell report (Department of Health, 2007) provides good practice guidance on the delivery of services for people with learning disabilities and challenging behaviour or mental health needs.
- Transforming Care (Department of Health, 2012b) and the Government's Concordant (Department of Health, 2012a) required a fundamental change in the delivery of inpatient care. Transforming Care – the next steps (NHS, 2015) aims to enable more people to live in the community with the right support. This is supported by "Building the Right Support" (NHS England, 2015a) and the service model (NHS England, 2015b) for commissioners of health and social care services.
- The pledge made in the Government's Concordat (Department of Health, 2012a) was missed (Transforming Care and Commissioning Steering Group, 2014), although these are still valid. They require community-based support to safely discharge people currently in inpatient settings; and support people in the community to prevent admissions in the first place.
- The confidential inquiry into deaths of people with learning disabilities (CIPOLD) (HeslopBlair *et al.*, 2013) identified reduced life expectancy and that 42% of the 238 deaths reviewed were premature.
- A number of reports and recommendations followed the 2007 Mencap report, which led to the "Healthcare for all" (Department of Health, 2008) and "Six Lives" (Local Government Ombudsman, 2009, Department of Health, 2013) inquiries.
- Echoing the requirements of the Mansell guidelines, the Vision for adult and Social Care (Department of Health, 2010) for a modern system included personalisation, partnerships, plurality, protection, productivity and people.
- Government response (Department of Health, 2015a) to the consultation for people with learning disabilities, autism and mental health conditions "No voice unheard, no right ignored" (Department of Health, 2015b) called for sustained momentum, legislative changes and radical solutions to long-term issues.
- Next steps on the NHS 5 year forward view (NHS, 2017) aims to improve national strategies, nurse training, inappropriate hospitalisation, employment and learning from deaths.
- The Health Equality Framework (HEF) (NDTi, 2013) is an outcomes tool based on the determinants of health inequalities designed to help

commissioners, providers, people with learning disabilities and their families understand the impact and effectiveness of services.
- Local Transformation Plan 2016-2019. The purpose of this local Transforming Care Plan (TCP) is to set out intentions to transform services for people of all ages with a learning disability and/or autism in Cornwall and the Isles of Scilly who display challenging behaviour, including those with a mental health condition, in line with Building the Right Support
- Learning disabilities Mortality Review (LeDeR) Programme aims to make improvements to the lives of people with learning disabilities; clarifying any potential modifiable factors associated with a person's death, and preventing them from being repeated.

A range of additional strategy and advice publications are available in the full learning disability needs assessment and on the Khub website[1]. The original Learning Disability Observatory Website was set up in 2010 following one of the recommendations from the Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities, the Michael report.

What's happening in Cornwall and the Isles of Scilly

Cornwall and the Isles of Scilly is the second largest local authority area in the South West region, covering an area of 3,559 sq. km, and has the longest coastline of all English counties at 697 km. It is an area of many contrasts; with varied landscapes including remote rural, coastal and environmentally sensitive areas, interspersed with villages and historic market towns; where affluence sits alongside some of the most disadvantaged areas in England. In line with national trends, Cornwall has a growing and aging population, although this is not consistent across all areas of Cornwall. Typical challenges include areas of deprivation and associated health inequalities, high demand for affordable housing, transport infrastructure, employment and the economy. However, Cornwall is a relatively safe place, and its environmental assets are extremely valuable to the economy and quality of life

Prevalence of learning disabilities

Learning disability is an extremely stigmatising condition and involves the utilisation of public health resources. However, there is no definitive record of the number of people with learning disabilities (HattonEmerson *et al.*, 2013). It is difficult to be exact with the prevalence of learning disabilities at the national or local level. This is because there are a range of complex factors that underlie the predictions in numbers of people such as the number of people who remain unknown to services.

General practice (GP) registers represent the best estimate for the number of people with a learning disability being known to services, which includes those accessing social care and specialist services such as Cornwall Partnership Foundation Trust. While the actual number of people being known to these services remains unknown, there is still no information on the number of people accessing both health and social care and how these overlap across services. In 2014/15, 0.5% of people in Cornwall were registered on GP learning disability

[1] Knowledgehun, Library https://www.khub.net/group/quest/library *[Accessed: 12/01/2018]]*

registers (i.e. the administrative prevalence of people known to services), which is higher than the average across England and one of the highest in the South West. The prevalence of learning disabilities is lower in the Isles of Scilly (0.2%), although this is likely to be a result of differences in local demographic characteristics. Also, the higher prevalence in Cornwall may be a result of awareness raising programmes carried out by primary care nurses and health promotion for example. It is important to note that the actual or true prevalence of learning disabilities (i.e. those known plus those unknown to services) in Cornwall is estimated to be around 2% of the population.

The number of people with learning disabilities in Cornwall is projected to increase through to 2030, which varies by age and gender. More men than women have a learning disability and there appears to be an increased number of people reaching older age. The number of people with a learning disability and autism, moderate or severe learning disability and those living with a parent are also predicted to increase. The number of people with a behaviour that is challenging or have Down's syndrome appear to remain stable according to national estimates.

Current and future services need to account for these demographic changes and associated policy and practice previously discussed. There needs to be a continued timely diagnosis, along with a structured and appropriate support through childhood. This includes the effective management of future transitioning out of children's education and health services into adult social services, as well as supported living / extra care housing and palliative care into older age.

Future services should also take into account geographic changes in the number of people with learning disabilities, particularly in urban areas such as Penzance, Camborne, Redruth, Falmouth, St. Austell, Newquay and Truro where there appears to be a higher number of people with a learning disability. These reflect the size of the urban areas, location of residential care and potentially historic changes in the delivery of services such as the transition from institutionalised to community settings.

Needs of people with a learning disability

In 2014/15, NHS Digital carried out a census on people with learning disabilities, which involved contacting all GPs across England to assess the health needs of this population. The publication of the interactive toolkit provides a useful method of comparing health status of people with a learning disability across participating practices. A higher number of GP practices participated in Cornwall (61%) than across England, however, this response rate must be taken into consideration when interpreting these results. The survey was based on 1,581 patients with a learning disability and being registered with a participating GP practice. This means nothing is known about the remaining 1,295 people with learning disabilities who were are registered with GP practices but were not included in this survey.

The review of health records highlighted a number of health conditions which were more prevalent in Cornwall when compared to the general population. In many cases the prevalence of health conditions varied considerably by age,

gender and location. In summary, greater health problems were found with, for example, constipation, asthma, dementia, epilepsy (including reduced time being seizure free), severe mental illness and hyperthyroidism. However, there was no information on the extent and impact of people with learning disabilities having more than one disease.

There were specific issues associated with people with a learning disability being classified underweight (BMI <18.4 kg/m^2) and overweight to obese (BMI >25 kg/m^2), particularly among women. Cornwall had a higher rate of people being underweight, but there were a similar proportion of people with a learning disability falling into the overweight and obese categories when compared to England and the general population. Factors contributing to problems with weight among people with a learning disability are yet to be fully explored. This represents an opportunity for health promotion programmes.

Little is known about wider determinants of health across Cornwall. People with learning disabilities face many challenges, including access to healthcare and support, housing, transport and unhealthy lifestyles or choices (e.g. physical inactivity, poor diet, smoking, drinking alcohol and misuse use of drugs). Furthermore, there is no information locally about the issues and challenges faced by parents with a learning disability and how this affects the health and wellbeing of their children.

There is some information available on the number of people with learning disabilities in education and employment. Cornwall has a higher proportion of primary and secondary school age children with severe learning disabilities when compared to England. However, the definitions used includes 'learning difficulty' so the numbers reported may be an over estimate. These are based on the number of children in primary, secondary and specialist schools with statements of special educational needs (SEN) rather than a formal clinical diagnosis. In terms of employment, Cornwall has a greater gap in employment rate between those with a learning disability and the overall employment rate (according to national figures). This maybe compounded by potential barriers to transport, particularly between rural and urban areas. For example, there have been a number of issues raised concerning the renewal of bus passes and time tabling problems that may inhibit people from using bus services.

Safeguarding, crime, discrimination and diagnostic overshadowing among this population group are a concern. According to Public Health England during 2014/15, Cornwall had a higher number of referrals of people with learning disabilities (89%) for adult safeguarding when compared to the South West (67%) and England (62%). It is possible that access was easier for individuals with learning disabilities in Cornwall; however, the reasons behind this remain yet to be fully explored. Potential explanations include the ease of reporting, raised awareness through the learning disability partnership board and slightly higher use of supported living. While data is available for adults with safeguarding referrals, identifying children is problematic because having a learning disability may not necessary be the primary reason for care and support. A recent review of 948 adult presentations at the Cornwall Liaison and Diversion Service during 2016/17 identified ten people with a learning disability, which included five people with an identified social and communication difficulty.

Understanding these wider determinants of health (e.g. housing, education and employment) and healthy lifestyle behaviours (e.g. levels of physical activity and diet) would help further our understanding into factors contributing to a range of health problems experienced by people with a learning disability. This is essentially required to help inform future health protection, promotion strategies and interventions among this vulnerable population.

Health, Care and Support Services

According to GP registers there were 3,002 people (all age groups) with a learning disability in Cornwall last year, which is predicted to increase by around 8% by 2030. As indicated above, this does not account for the true prevalence of learning disabilities (i.e. the number of people unknown to services), which is also predicted to rise by around 10% by 2030. There are around 1,300 people with a specific learning disability in primary and secondary schools. As indicated above, the number of children with a clinical diagnosis remains unknown and this may influence the prevalence of learning disabilities in childhood. Also, one of the diagnostics for learning disability is the establishment of a functional impairment before the age of 16, presenting some issues for early diagnosis. There is a lack of information about those transitioning from childhood into adulthood. But at the last data download, a total of 1,700 adults with a learning disability accessed adult social services and 449 people (plus 183 people with epilepsy) received care from Cornwall Partnership Foundation Trust.

The increasing prevalence of learning disabilities is partly a result of increased life expectancies. Predicted demographic profile changes show that a greater number of people will reach older adulthood. This increases through to 2030 and is likely to impact services because of the need for additional support. Furthermore, it is thought that around 25% of those previously unknown to services become 'known' when their family/carers become too old and/or frail to continue with care. The uncertainty of the potential combined future impacts of both an ageing population with learning disabilities and the carers' population represents a challenge for the future delivery of learning disability strategies and services.

The delivery of appropriate services maybe further compounded by projected increases in the number of people with learning disabilities leaving the county or coming into Cornwall to receive care. The impact on current and future services may be further impacted because it is thought that Cornwall is a net importer of people with complex needs, although there is a lack of evidence to quantify this. This is important to consider because the impact of out of county placements (e.g. individuals being separated from family, friends and the community) may be traumatic and have a severe impact on individuals with a learning disability. This can also have a negative impact on families/carers and service providers, hence the Transformation Care Plan.

Meeting the challenges of the increased prevalence rates, increased life expectancies, an aging population of carers and increasing levels of complex needs requires collaborative working across a range of stakeholders. For example, involving commissioners, service providers, specialist learning disability services, carers' network and service users could deliver more person centred and tailored individual support. However, these need to consider the

potential benefits and impacts on people with a learning disability living more independently in the community (e.g. understanding levels of crime and discrimination).

These challenges may also influence the cost of providing health and social care. For example, the cost of delivering adult social care varies considerably. The number and cost of support and care at home packages varies from 1016 to 1078 (care packages at home) and £357,921 to £381,319 (net weekly costs), respectively. Packages for residential nursing vary from 310 to 330 packages of care, which costs between £431,710 and £437,248. It is important to note that this level of data is not available for children, which is due to the difficulty in identifying those with a primary care need for a learning disability. This further supports the need of better data on children with a learning disability.

The provision or offer of personalised budgets is emphasised by national policy, which can help promote more independence for people with learning disabilities. However, the proportion of adults with learning disability receiving long term support who are receiving direct payments or part-direct payments is lower in Cornwall (14%) when compared to rates across England (17%). In the future, all new referrals of people with learning disabilities that result in eligibility for social care will be offered a personalised budget; therefore, the number of direct payments in Cornwall is expected to increase. However, little is known about variations in demographics (e.g. levels of deprivation, age, gender and ethnicity) and how these may affect those with a learning disability accessing services and/or living more independently.

Healthcare

Annual health checks are offered to people with a learning disability to; identify undetected health conditions; ensure the appropriateness of ongoing treatment; and establish trust and continuity in care. There has been a rising trend in the number of annual health checks completed across England and Cornwall. However, consistent with national trends, recent data released from NHS Digital show that during 2015/16 the number of health checks completed declined from 64% to 39% in Cornwall. It is not clear how much of this downward trend is due to data quality, although the trend appeared to be consistent across England. For example, NHS Digital cannot extract information from GP practices using 'Microtest', which is used widely across Cornwall. Hence the number of completed health checks is likely to be an underestimate. Data from the 2016/17 health checks will help to clarify this further. The evidence also suggests the uptake rates vary considerably by geographic location. While this may be a result of previous changes in the eligibility criteria (i.e. offer to those aged >14 years) and potential issues associated with data collection and reporting, further investigations into the decline in health checks is required, particularly among poorer performing practices.

To improve uptake rates, the provision of health checks should utilise guidance from tool kits such as the Royal College of Chartered Practitioners, as well as local evidence identifying barriers and facilitators to annual health checks for people with learning disabilities. These focus on building trust, helping people to take responsibility for their own health, easy read promotion and health check materials, reminders for appointments, more choice and consistency of who

conducts the health checks, provision of special adjustments and offers to speak privately about a health check. However, this evidence was obtained from a limited sample and the extent of barriers and facilitators across Cornwall remains unknown. Furthermore, little is known about people accessing other health services such as dental care and health promotion, or about those with sensory impairments (e.g. experiences in accessing local services).

The Flu Plan prioritises people with learning disabilities for flu immunisation as a clinically at risk group. While rates across England and Cornwall are comparable, the proportion of people eligible and receiving flu immunisation (27%) is much lower than the general population. Although, the uptake in other high risk groups (49%) is lower than those among older adults (70%) nationally. Improving our understanding into potential barriers may help to improve uptake rates and the health and welling of people with a learning disability.

In contrast, cancer screening rates are high locally when compared against averages across England. The support provided by the team of Cancer Screening Nurses provides an example of national best practice. The two Cancer Screening Nurses offer support to increase uptake rates across screening programmes, which has resulted in higher rates of breast, cervical and bowel cancer screening rates when compared to England. However, there are some challenges associated with identifying people and delivering these services.

According to the 2014/15 census on people with learning disabilities, Cornwall had higher breast cancer (64%) and bowel (77% in men and 83% in women) screening rates than England (52% and 69%, respectively). While cervical smear testing was higher in Cornwall (38%) than England (30%), these uptake rates are much lower than those in the general population. Improving our understanding into the barriers and facilitators of screening programmes locally may help further improve uptake rates, which should be considered alongside more information on Diabetic Retinopathy and Aortic Aneurysm screening.

A range of health promotion services are delivered locally. The health promotion services employ CHAMPS (the Cornwall Health and Making Partnerships) to undertake advocacy and promote healthy lifestyles, safe places and dental hygiene for example. The Service and CHAMPS also arrange and participate in a range of programmes including physical activity, healthy eating, eat well for less and Fresh for example. There is limited information about the reach of these programmes, uptake and impact on people with learning disabilities. Further research would help inform and promote these health promotion programmes in the future.

End of life or palliative care was raised as an area requiring further investigation due to the lack of information about awareness and choices around this, particularly among women. Rates of those registered as being in need of palliative care and support was lower in Cornwall (0.22%) than across England (0.55%). In Cornwall, there were 0.49%, 0.44% and 1.07% of adults in age bands 18 to 24, 25 to 24 and 45 to 54 years, respectively. The primary care nurses have linked with the palliative care nurses to start the process of making sure there are sufficient resources in the county for palliative care nurses to use. This will also help raise the awareness of the needs of people with learning disabilities within the generic health care services. It is possible that the

Community Specialist Palliative Care Service ran by Cornwall Partnership Foundation Trust and/or Cornwall Hospice Care can provide more information on palliative care across Cornwall in the future.

Specialist adult learning disability and epilepsy services are provided by Cornwall Partnership Foundation Trust. Majority of the referrals are white British adults with a learning disability, with a smaller proportion of adults with learning disability and epilepsy. Referrals appear to rise with increasing age (>25 years), which could indicate various levels of diagnosis, complex needs or the fact that people can still access children's services up to the age of 25. Alternatively, this could be a result of other lifestyle factors such as moving home or leaving education. The outcomes and impact of these services should be provided by the Health Equality Framework (HEF) or another suitable reporting mechanism. Other outcome tools are important to consider because HEF is seen by some as not being sensitive enough to show the effect of services on patient outcomes. To be effective, these need to be rolled out across health and social care services.

Self-advocacy

There are a range of (self) advocacy groups and services across Cornwall, which is sign-posted via Cornwall council's website. The Learning Disability Partnership Board (LDPB) was established to take forward local priorities and is now being facilitated by Healthwatch. The LDPB provides a forum for people to raise and progress specific issues, however, there is limited support for people to attend and take part in the meetings. Healthwatch are currently reformatting the LDPB to meet the needs of local people with learning disabilities.

Cornwall People First is also an important self-advocacy body. They undertake forums for people with learning disabilities to speak up about things that are important to them, have fun, meet old and new friends, share information, learn new skills, meet visitors like councillors or liaison nurses, visit places in the community like the fire station and connect with their communities. Cornwall People First also report at the LDPB, which is used as a forum to raise concerns and progress issues such as bus pass renewals, social care assessments and support.

Information about other help and support can be found on Cornwall Council's website, which includes groups such as Volunteer Cornwall, Advocacy in Cornwall, Victim Service for adults with learning disabilities and autism, HFT Cornwall, United Response and Brandon Trust.

Community voice

Recent consultations (a series of focus groups) have highlighted support for more independent living for people with learning disabilities. A range of barriers to independence were expressed by those attending the focus groups. These mainly revolved around issues such as money, discrimination, feeling safe, delays in processes, transport, housing, work benefits and family being worried about living independently. To overcome these barriers requires appropriate support from trained staff, improved communications, development of independent living skills, better transport and appropriate housing options,

facilitation of walking and cycling and assistive technology. Further research is needed to identify the type of new technologies that could help support people with learning disabilities.

While there is evidence on the health of disabled people and social determinants of health nationally (Emerson, 2011), little is known about the life experiences, facilitators or barriers/challenges to improved health and wellbeing of people with learning disabilities across Cornwall. Future research should aim to assess the opportunities to help support people with learning disabilities to live more independent, healthy and fulfilling lives.

Complaints

The Acute Liaison Nurse Service (ALNS) works very closely with Patient Advisory Service (PALS). They ensure that any concern or complaint raised by or on behalf of a patient with a learning disability and or autistic spectrum disorder is looked into by a member of the ALN team. This year there have been two complaints raised and the service has supported the staff, patients and family involved. To ensure lessons are learnt Trust wide, examples from complaints form part of the ALN service, development and education sessions.

The Patient Advice and Liaison Service (PALS) received a total of 84 complaints over the last five years, predominantly for access to healthcare, clinical treatment, provision of information and to relative/carer and nursing care. Unfortunately, it was difficult to identify complaints made to Cornwall Council from people with a learning disability or their carers.

Effective interventions

A range of potential interventions exist to improve the health and wellbeing of people with a learning disability. A rapid literature search identified evidence in support of annual health checks to identify and treat unmet health needs. Generally, the review identified low to medium quality evidence across other areas that inconsistently demonstrated some positive health outcomes. Lifestyle interventions resulted in mixed findings, but highlighted the importance of increasing physical activity in this population. There appears to be some evidence supporting interventions targeting parent training programs, motor functioning and physical activity (e.g. to help address challenging behaviour). Further higher quality research is needed, particularly in areas such as behavioural change techniques, physical activity, substance misuse, carer-led, mental health and health services interventions. From the limited searches conducted, there was a lack of evidence concerning co-morbid conditions, falls and life course interventions such as those focusing on peri-natal through to early years, as well as, older adults with a learning disability and/or ageing carers.

Recommendations

This needs assessment update has identified a number of recommendations that should be incorporated into the development of future strategies and service developments. It should also be noted that many of these recommendations focus on health care, which is a reflection of the accessibility of the data.

Needs assessment recommendations	
	Lead organisation / service
1. Stakeholders to review and incorporate national guidance and policies described in the policy update (Section 3.0) in commissioning and service delivery. In particular the National Service Model: mainstream NHS services (NHS England, 2015b), PHE guidance (PHE, 2017) and NICE guidance (NICE, 2017).	All
2. It is recommended that the findings of this needs assessment inform the strategic planning cycle in commissioning organisations. There is a need for increased collaboration between key stakeholders and planning to inform future needs assessment updates and development of future strategies	Children, Families and Adults, Cornwall Council; Kernow Clinical Commissioning Group; and Cornwall Partnership Foundation Trust
3. Cornwall Council holds diverse information on children and adults (e.g. education, employment, finance, complaints, safeguarding and social care etc.) with learning disabilities, but data is not readily available. It is recommended that a standard template is developed and an annual report produced for the needs assessment process.	Performance management data, Children, Families and Adults, Cornwall Council
4. Learning Disability Partnership Board to take ownership of this needs assessment, promote more collaborative working and review progress made in implementing these recommendations. This should be delivered alongside the monitoring and reporting of how local services are performing against the recommendations made by national policy (EmersonBaines *et al.*, 2011) and (HeslopBlair *et al.*, 2013).	Cornwall Council & Healthwatch
5. In line with the previous needs assessment, this update highlights the continual trend in the increasing number of people with learning disabilities. Commissioners and service providers should ensure that plans are in place to meet the needs of: • Increasing numbers of children and adults with learning disabilities, particularly those with more severe learning disability. • Those coming through transition. • Increasing numbers of older adults with learning	Children, Families and Adults, Cornwall Council

disabilities. • Increased number of carers becoming too old and frail to continue with care.	
6. This needs assessment highlighted the need for additional research to fill the information gap and inform future health promotion and protection strategies across Cornwall. These include: a) Wider determinants of health (e.g. housing, employment, education, transport and unhealthy lifestyle characteristics such as substance misuse). Including factors impacting quality of life, quality of care and support, loneliness, social exclusion and isolation, lack of control and feelings of respect, feeling empowered and having self-determination to play an active role in a community; b) The extent, impact and benefits of personal budgets, alongside potential challenges faced by people living independently (e.g. levels of deprivation, crime and discrimination) and the impact this has on population sub-groups; c) Parents with a learning disability and its impact on their children; d) Co-morbid conditions (i.e. more than one health problem) among people with a learning disability; e) Experiences and perceptions of health care systems at the population level (e.g. quality of health checks, immunisation and screening); f) The appropriate use of sign posting; g) The impact and experiences of in county placements; h) Accessing dental and sensory impairment services; i) The challenges faced by an aging learning disability population and their carers, as well as the impact of age specific problems such as falls, sensory impairments and profound learning disabilities; j) Extent and type of complaints made, themes and actions taken; k) Experiences and perceptions of people transitioning from childhood into adulthood; and l) Community voice – understanding the views, experience and perceptions of stakeholders.	Public Health, Cornwall Council
7. Improvements should be made in the routine collection of service data across all equality groups, including learning disabilities, in order to better monitor outcomes for groups with protected characteristics and fulfil the public sector duty of the Equality Act.	Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust
8. There was no information available on the BME population with learning disabilities, which is a requirement of the Equality Act 2010. Service providers to ensure that there are monitoring and reporting mechanisms in place to feed	Cornwall Council, Kernow Clinical Commissioning Group and Cornwall

into the needs assessment process. This may be covered by the following recommendation, but requires further investigation.	Partnership Foundation Trust
9. Routine monitoring and reporting of key outcome measures such as those highlighted in the Health Equality Framework (HEF) or similar mechanism is required across health and social care services. This will help improve our understanding of the health needs of people with learning disabilities and assess the impact of specialist services. Consistently sharing reports with Public Health would significantly improve the health needs assessment process.	Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust
10. Develop systems that enable the identification of complaints being made by people with learning disabilities and their carers, which will help identify any potential trends. Develop mechanisms to share with Public Health to improve the needs assessment process.	Children, Families and Adults, Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust (including PALs)
11. To audit, monitor and report on the uptake of learning disability health checks and health action plans via the health check framework when established. This should include an investigation into whether NHS Digital can accurately monitor the number of health checks being completed by GP practices.	Kernow Clinical Commissioning Group
12. Health promotion activities to consider the development of specialist programmes appropriate for people with learning disabilities who are under and overweight increasing physical activity, and improving uptake of immunisations and cancer screening.	Health Promotion, Cornwall Council
13. To understand the reach and effectiveness of interventions, health promotion should put in measures to enable the effective evaluation of learning disability programmes.	Health Promotion, Cornwall Council
14. Support independent living; a. Increase uptake of direct payments/personal budgets and make appropriate plans for future housing, extra care and support needs for people with learning disabilities which promote independent living, healthy ageing and protect vulnerable adults living in the community. b. The introduction of universal credit presents particular risks to people with a learning disability (e.g. opening bank account). These risks should be reviewed and mitigated against to reduce impact on this vulnerable group.	Children, Families and Adults, Cornwall Council Shaping Our future (Integrated Care)

15. The use of new technologies has the potential to help support people with learning disabilities. Opportunities for research and innovation should be explored to identify the most effective technologies. Including support in the use of better communication systems in health and social care services to improve some of the communication difficulties that may exacerbate challenging behaviour in people with learning disabilities.	Children, Families and Adults, Cornwall Council and Cornwall Housing
16. Improved training and professional development; a. Provision of reasonable adjustments, including health checks for example; b. Maternity and social services to ensure adequate awareness of child welfare and supporting parents with a Learning Disability; c. Consider role of the learning disability Acute liaison nurses/ Screening liaison nurses and expertise in supporting development of integrated care teams and training future workforce; d. Improve staff confidence in supporting people with learning disabilities during palliative and end of life care and ensure reasonable adjustments are considered. Also, need to consider adopting the ReSPECT framework (ReSPECT, 2017) for advance care planning; e. Raising awareness to help ensure that early years risk factors for children with Learning Disabilities (e.g. breastfeeding, parenting, exposure to violence) are adequately addressed to reduce health inequalities; f. Ensure adequate education and support is available for people with learning disability to enjoy healthy sexual relationships.	Children, Families and Adults and Public Health and Wellbeing, Cornwall Council, Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust Shaping Our Future (Integrated Care) NHS Community Education Provider Network
17. Address delays in access to treatment, diagnosis and needs of people with learning disability in treatment pathways, particularly circulatory disease, respiratory disease and cancer to reduce premature death.	Royal Cornwall Hospital Trust, Shaping Our Future Pathways Board,
18. Work with employment agencies and employers to ensure that people with learning disability have access to appropriate education, training and employment opportunities (including supported employment opportunities).	Employability Cornwall, Cornwall Council Local Economic Partnership
19. Review specialist interventions to prevent offending amongst people with a learning disability.	Community Safety Partnership Cornwall Council and Cornwall Partnership Foundation Trust
20. The needs of parents/carers of people with learning	Cornwall Council

disability should be proactively assessed and plans put in place that considers their concerns about the lack of planning for the future. This should be integrated into the development of the Carers Strategy (Cornwall Council, 2017).	(Carers Strategy) Kernow Clinical Commissioning Group (primary care)
21. Simplify the application process for concessionary bus fares for people with a learning disability, and review other issues such as making bus timetabling etc. more accessible.	Transportation Service, Cornwall Council
22. Review locality team support for people with learning disability is adequate and appropriate for current and future projected population.	Economic Development & Culture, Community Network Areas, Cornwall Council
23. Review policy and service delivery to prevent the over medicalisation of people with learning disabilities.	Kernow Clinical Commissioning Group and Cornwall Partnership Foundation Trust

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