

People with Learning Disabilities in Scotland: 2017 Health Needs Assessment Update Report

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Summary overview

People with learning disabilities are individuals who want to lead full and equal lives as part of their community. Scotland has had a strong policy focus on improving the lives of people with learning disabilities for many years. The Scottish Government strategy, *The Keys to Life* builds on the work of *The same as you?*, and considerable progress and developments have been and are taking place across Scotland. Much has changed over the past ten years and Scotland has seen changes and developments in legislation and policy that collectively impact on the lives and opportunities of all the people of Scotland, including those with learning disabilities and their families.

NHS Health Scotland is a national Health Board working with public, private and third sectors to reduce health inequalities and improve health. The organisation published the original health needs assessment in 2004, setting out an overview of the evidence of the health needs experienced by children and adults with learning disabilities. The report made a series of recommendations aimed at improving the health and well-being of people with learning disabilities in Scotland.

Significant changes are being introduced across Scotland through the integration of adult health and social care services for community care groups, including adults with learning disabilities, since the publication of the 2004 health needs assessment report. New legislation has brought about Integrated Joint Health and Social Care Boards to deliver health and social care services and drive forward improvements in health and well-being for local communities, including adults with learning disabilities. This is important as the number of people with learning disabilities living into older age is increasing, with many presenting with a diverse range of complex and multiple interrelated health conditions. Life expectancy overall for people with learning disabilities is increasing, however it remains shorter when compared to the general population, often due to avoidable, preventable and manageable conditions. The situation is compounded by barriers that people with learning disabilities experience when accessing healthcare.

People with learning disabilities have a different pattern of health conditions from the general population and different causes of death. It is therefore important that reasonable adjustments are made to include them in all health services and preventative health screening programmes aimed at the whole population, and design and deliver specific services and supports. These changes in the learning disability population will therefore impact on current and future service provision for this population.

There is therefore a need for an updated health needs assessment that provides policy makers, service planners, service commissioners, and funders and practitioners with a broad overview of the current research evidence on the health needs of adults with learning disabilities. The evidence and recommendations provided in this 2017 update of the health needs assessment report will enable service and workforce review their existing provision and initiate and plan developments, necessary to ensure that the care and support needs are provided now and for the future.

People with Learning Disabilities in Scotland: 2017 Health Needs Assessment Report

This report, commissioned by NHS Health Scotland, is an update of the 2004 Health Needs Assessment report. The original 2004 Health Needs Assessment report set out research evidence regarding the health needs of people with learning disabilities. The 2017 update report presents an overview of influential research evidence; it is not intended to be an exhaustive systematic review of all research studies related to people with learning disabilities. That would be out with the scope and purpose of this update report. This updated report draws on the original health needs assessment format to report on and present an overview of the research evidence of the health needs experienced by people with learning disabilities. The report concludes with a series of recommendations to inform service priorities and delivery in the future.

Aims of the Health Needs Report

The aim of this updated health needs assessment report is to provide policy makers, service planners, service commissioners and funders and practitioners with a broad overview of the evidence of the health needs of adults with learning disabilities.

The current research evidence of health needs

The original 2004 Health Needs Assessment report was ground breaking in drawing together an analysis of the up-to-date research evidence. Since then there have been considerable advances in the knowledge and understanding of the scope and extent of the health needs and inequalities experienced by many people with learning disabilities. There have been significant legislation and policy developments in Scotland over the past ten years which impact on the lives of people with learning disabilities. Additionally, there is a growing national and international research evidence-base regarding the health of people with learning disabilities and the extent of the health inequalities that many experience and the barriers to accessing health services appropriate to the needs of the individual.

There is therefore an on-going need to ensure that policy makers, service planners, service commissioners and funders and practitioners have access to the evidence of the health needs of people with learning disabilities. This is necessary because of the legislative changes in Scotland that have brought together health and social care services for community care groups, including adults with learning disabilities. The review and analysis of the research evidence base regarding the health needs of adults with learning disabilities will therefore inform and shape decisions and priorities, strategically and locally, to ensure that they take account of and respond to the different pattern of health needs experienced by this population, thereby reducing and not widening the health inequalities gap.

Selection of studies and evidence extraction

To inform the 2017 health needs assessment update report, the broad criteria to guide the search for evidence were to identify, review and present the findings from published research within the past 13 years since the publication of the 2004 health needs assessment report. The search and extraction of evidence was undertaken by searching research data bases and through manual hand and library searches and reviewing and scanning references in existing published papers. The following electronic databases were used; Medline, Cumulative Index to Nursing and Allied Health Literature, CINHAL, Embase and PsychINFO.

The past ten years has seen a significant increase in the number of research studies on the wide range of health needs of people with learning disabilities. Researchers have undertaken systematic reviews and syntheses and meta-analyses of the research evidence, thereby building up a comprehensive picture and understanding of the true scope and extent of the health inequalities and health needs of people with learning disabilities and the actions necessary to address them.

Defining the term learning disabilities

The updated Health Needs Assessment Report will adopt the terminology of learning disabilities as used in the 2004 Health Needs Assessment Report. The term learning disability is commonly used in the UK and is synonymous with previous terms such as mental retardation and mental handicap and intellectual disabilities, which is used internationally.

In Scotland, within the Keys to Life strategy (Scottish Government, 2013), people with learning disabilities are described as having a significant, lifelong, condition that started before adulthood, which affected their development and which means they need help to:

- understand information;
- learn skills; and
- cope independently.

Changing population of people with learning disabilities

The Keys to Life provided an overview of the changing and increasing life expectancy of people with learning disabilities. While life expectancy is increasing, it remains shorter by some 20 years when compared to the general population and is shorter for people with severe learning disabilities (Scottish Government, 2013). As a population, people with learning disabilities are experiencing a change in their demographic profile. The changes include increased longevity and changing patterns of morbidity and mortality. The past decades have seen a similar increase in life expectancy as those found in the general population, except for those with Down syndrome, epilepsy or multiple disabilities (Hosking et al., 2016; Kelly & Kelly, 2012; Coppus, 2013). Older adults are proportionally the largest and fastest growing group in the learning disabled population (Emerson and Hatton, 2008). The life expectancy for a person with a learning disability is currently approximately 70 years, with a projected 164% increase in the number of people with learning disabilities aged 80 and over using social care services by 2030 (Emerson & Hatton, 2011).

One of the reasons for the global increase in life expectancy for people with a learning disability is their improved neonatal care and improved access to health and social care services (Lay, 2015). However, reports have continued to highlight that this population do not receive equal access to services (Disability Rights Commission, 2006; Mencap, 2007, 2012; Michael, 2008). Therefore, health conditions can remain undetected and untreated (Haveman, 2004), and the mortality rates associated with treatable conditions for people with learning disabilities remain high when compared to the general population (Heslop et al., 2014). Life expectancy for people with learning disabilities has been found to be 13 years lower for men and 20 years lower for women than for the general population (Public Health England, 2014).

As life expectancy has increased, more people with learning disabilities are experiencing multi-morbidities, which is 2 or more long-term, chronic health conditions (McCarron et al., 2013). Some are experiencing a prolonged period of dying, because of cancer and other life limiting illnesses. This growing population with complex health needs brings about new challenges for health professionals and care services. The planning and provision of quality healthcare is crucial to improving the health and quality of life of people with learning disabilities. This is important as the life expectancy of this population is reduced by associated mortality, much of which is avoidable (Heslop et al., 2014; Hosking et al., 2016).

Background to the 2017 Health Needs Assessment Report

The Scottish Government is committed to improving the lives of people in Scotland and this includes those with learning disabilities. There has been a range of policy initiatives implemented across Scotland that takes account of the changing demographics, economics and changing complexity of care and public expectations of public services.

Legislation in Scotland: A brief overview

Clear legislative frameworks are in place in Scotland that individually and collectively seek to support people to protect their rights and have control over their lives and enable access to assessment, treatment and supports required. All Scottish legislation applies equally to people with learning disabilities and there are specific Acts of relevance due to the nature of their disability and need for special consideration.

- *Adults with Incapacity (Scotland) Act 2000* is an important piece of Scottish legislation that provides a legal framework to safeguard the welfare and manage the finances of adults, aged 16 and over, who lack capacity due to mental illness, learning disability or a related condition, or due to an inability to communicate. The main care groups covered by the Act include people with dementia, people with a learning disability, people with an acquired brain injury, people with severe and long-term mental illness, and people with a severe sensory impairment. Part 5 of the Act is important in relation to medical treatment, and allows treatment to be given that safeguards or promotes the physical or mental health of an adult who is unable to consent.
- *Mental Health (Care and Treatment) (Scotland) Act 2003* is legislation that applies to people who have a mental illness, learning disability or related condition. Usually when patients are unwell they consent to their assessment and treatment, however in some cases when someone is mentally unwell and unwilling or unable to consent, it is necessary to

intervene. The Mental Health Act sets out when and how patients can be treated if they have a mental disorder, when they can be treated and taken into hospital against their will and how their rights are protected.

- *Adult Support and Protection (Scotland) Act 2007* is legislation that enables the protection of adults who may be at risk of harm. The Act requires councils and a range of public bodies to work together to support and protect adults who are unable to safeguard themselves, their property and their rights. Central to the legislation is that any intervention in the affairs of an individual must provide benefit and be the least restrictive option as the means to meet the purpose of the intervention.
- *The Equality Act 2010* and the *Public Sector Equality Duty* is UK-wide legislation that provides the legal framework to protect the rights of individuals and advance equality of opportunity for all, including those with disabilities. Under the legislation, people are protected from discrimination based on their protected characteristics in employment, education, access to goods and services and membership of clubs and associations. The characteristics specified in the Act are, age, race, religion or belief, disability, sex, sexual orientation, gender reassignment, pregnancy and maternity and marriage and civil partnerships. There is a specific requirement for public bodies to make 'reasonable adjustments' for people with a disability. The Public Sector Equality Duty in the Equality Act 2010 came into force in April 2011 and places an obligation on public authorities, including health services, to act to eliminate unlawful discrimination, harassment and victimisation, advance equality of opportunity between different groups and foster good relations between different groups.
- *The Social Care (Self-Directed Support) Scotland (Act 2013)* is legislation that provides the right for the people of Scotland to receive direct payment in lieu of services thereby affording greater control over the decisions about the types of services and supports they receive. The self-directed support

act places a statutory duty upon social work services to fund direct payment options and make them available to people in receipt of care and support services.

- *The Public Bodies (Joint Working) (Scotland) Act 2014* is the legislation that provides the framework for integrating adult health and social care. Bringing together adult health and social care services aims to provide a consistent level of quality and sustainable care services for the aging and increasing Scottish population, many of whom will require care and support from both health and social care services due to their multiple, complex, long-term conditions. A major policy initiative, the integration of adult health and social care services brings together budgets for care services to create a single commissioning budget. This enables the partner health and social care organisations to commission services that will improve outcomes for adults requiring assessment, treatment, care and support.

Policy in Scotland: A brief overview

Getting it Right for Every Child – GIRFEC

GIRFEC is the Scottish Government's national approach to improving the outcomes of, and support for, children and young people by ensuring the right help is provided, at the right time and from the right people. The policy supports children and young people and their families and carers to work with services and receive the support they need. There is a clear focus on the rights and wellbeing of children and young people at the centre of services, in areas such as early years services, schools, and health and social care. The initiatives arising from GIRFEC are relevant to children and young people with learning disabilities by ensuring that they receive access to early interventions and support, necessary to help them reach their potential.

The Same as You?

In 2000 the Scottish Government published *The Same as You?*, which set out a 10-year programme for service improvement and development focusing on:

- Equality and citizenship
- Community participation and presence
- A life free from discrimination and harm
- Equality of access to mainstream services
- An individualised approach to service delivery
- Access to locally based services and supports
- Coordinated care and support across agencies

A significant outcome arising from *The Same as You?* was the closure of long-stay institutions and a focus on care and support in the community. In 2010, ten years after the publication of the report, the Scottish Government undertook a review of the achievements and outcomes arising from *The Same as You?*. While improvements were identified, it was recognised that there was a need for on-going work, notably in developing day activities, supporting access to employment and lifelong learning, and improving access to health services.

The Keys to Life

Following on from the review of *The Same as You?*, the Scottish Government launched *The Keys to Life: Improving quality of life for people with learning disabilities* in 2013. Set within a human rights framework, *The Keys to Life* is being implemented over a 10-year period, supported by an implementation framework, with significant attention being paid to tackling the health inequalities experienced by many people with learning disabilities. One of the outcomes of *The Keys to Life* was the setting up of the Scottish Learning Disabilities Observatory. The Learning Disabilities Observatory has been funded by the Scottish Government to produce research-based evidence that builds the understanding of the range of causes that contribute to the poor health and health inequalities experienced by people with learning disabilities and people with autism.

Scottish Learning Disabilities Observatory

The Scottish Learning Disabilities Observatory is making a specific contribution to the improvement of the health of people with learning disabilities and people with autism by publishing information, data, and interpreting the evidence, to inform and shape service responses and improve health over time. To achieve these aims, the Learning Disabilities Observatory seeks to increase the visibility of people with learning disabilities within routinely collected data, analyse and present evidence and data about the health of people with learning disabilities and autism, and disseminate widely to practitioners, commissioners of services, policy makers and users of services and their carers. The work of the Learning Disabilities Observatory is therefore central to providing the long-term evidence upon which to base the care and support required by people with learning disabilities and enable the identification of changes and improvement in their health overtime.

Integration of Health & Social Care Services

The older population of Scotland is estimated to increase by around two thirds in the next 20 years (Scottish Government, 2011). In response to the needs of an increasing population of older people and other groups in need of health and social care services, the Scottish Parliament passed the *Public Bodies (Joint Working) (Scotland) Act 2014*. The legislation places a duty on health and social care partnerships to have local planning arrangements in place to inform the delivery of strategic commissioning plans, drawing on the expertise of practitioners from adult health and social care services. The aim of the legislation is to shift the balance of care towards prevention, early intervention and anticipatory care, avoiding hospital admission wherever possible and supporting people to live independently in their own home or a homely environment.

The Health Needs Evidence

Accidents

People with learning disabilities are prone to accidents and associated injuries and have a different pattern when compared to the general population (Finlayson et al., 2010). There are a range of factors that contribute to accidents and injuries in this population, including seizures, vision and hearing impairments, osteoporosis, poor balance and coordination, muscular strength and endurance issues and side effects of medications (Wagemans et al., 2006; Chiba et al., 2009; Finlayson et al., 2010; Oppewal et al., 2013; Oppewal, 2014). Accidents result in injuries in adults with learning disabilities and include fractures, cuts, grazes, bruising, burns, scalds, swelling, tenderness and poisoning (Finlayson et al., 2010). Falls are a concern for adults with learning disabilities due to frequency and the injuries that occur and result in hospitalisation. Falls are common in both formal and non-formal care settings (Cox et al., 2010). Falls were identified in up to 57% of people with learning disabilities, accounting for between 50–62% of all recorded injuries. Risk factors regarding falls in people with learning disabilities have been identified, including older age, impairment of mobility, epilepsy and behavioural problems. There is limited research evidence regarding effective interventions to prevent and manage falls, however evidence suggests that addressing environmental safety issues, the management of medical conditions and exercise interventions can reduce fall-related injuries (Willgoss et al., 2010).

Injuries resulting from accidents and falls are linked to the presence of epilepsy, polypharmacy, physical activity, hyperactivity and impulsiveness, arthritis and urinary incontinence. Falls and injuries increase with age in the population of people with a learning disability (Chiba et al., 2009; Finlayson et al., 2010; Enkelaar et al., 2013; Oppewal et al., 2014). People with Down syndrome appear less likely to experience injuries due to falls (Oppewal et al., 2014). Multi-factorial assessments are required to identify areas of risk and inform prevention strategies and support plans. Teams with a specific remit on falls prevention need to take

account of and respond to the different presentation in the adult learning disability population (Finlayson et al., 2010).

Bone health

As people with learning disabilities are living longer, they are more susceptible to developing degenerative conditions associated with ageing (Emerson et al., 2012). People with learning disabilities are at increased risk of low bone mineral density (BMD), for example, osteopenia, osteoporosis and fractures, compared with those in the non-disabled population (Srikanth et al., 2011; Burke et al., 2016; Hess et al., 2017). People with learning disabilities are at greater risk due to their high prevalence of comorbidities associated with secondary causes of low BMD including high risk medication use, poor mobility and endocrine disorders, such as hypogonadism and thyroid disease as well as sedentary lifestyles, lack of weight bearing exercise, poor diet, difficulty accessing and complying with screening for BMD, bone health omitted from annual health checks, and lack of screening for vitamin and mineral deficiencies (Emerick & Vogt, 2013; Hawli et al., 2009; Jasien et al., 2009; Srikanth et al., 2011; Vice et al., 2015; Emerson and Baines, 2010; Frighi et al., 2014; Burke et al., 2016).

Severity of learning disability has also been found to have an adverse effect on bone health as those with more severe to profound learning disabilities are more likely to present with increased co-morbidities (McCarron et al., 2013).

In addition, females are known to be at greater risk of osteoporosis. Women with Down syndrome are at greater risk of developing osteoporosis because of late menarche and early menopause (Knickmeyer et al., 2006). Nearly half of adults with Down syndrome have hypothyroidism, which is treated with levothyroxine. High levels of this drug have been associated with osteoporosis (National Osteoporosis Society, 2014).

Bone mineral density is measured by dual-energy X-ray absorptiometry (DXA), which is the 'gold standard' for diagnosis of osteoporosis, evaluation of fracture risk and monitoring skeletal changes (Kanis et al., 2008). While there is a wide

range of non-invasive techniques available for determining BMD, the use of quantitative ultrasound instruments has received attention as the method of choice for assessment for people with learning disabilities, due to the behavioral and physical limitations of this population (Srikanth et al., 2011; Vice et al., 2015).

Communication challenges among this population make it difficult for people to express their own health needs, discomfort or pain, which in turn can contribute to osteoporotic fracture going undiagnosed (Burke et al., 2016).

Harper (2017) in a review of the evidence on bone health in people with learning disabilities examines the benefits of vitamin supplements and dietary approaches. Recommendations highlighted that healthy lifestyles that reduce obesity and ensure adequate levels of vitamin D, calcium, protein and a variety of vegetables, can protect people from developing musculoskeletal diseases and support bone health. It also emphasized the need for practitioners who support people with a learning disability to ensure that annual health checks are completed, which include monitoring and review of BMD, prescribed medication, and vitamin D levels.

Cardiovascular Disease

Cardiovascular disease (CVD), which includes coronary heart disease (CHD), diseases of the circulatory system, and stroke, is the most common cause of premature death across the world, with deaths expected to rise to 2.3 million by 2030 (WHO, 2008). For people with learning disabilities, cardiovascular disease is the second commonest cause of premature death (Tyrrer & McGrother, 2009). Cardiovascular disease has been found to be as common in the population of adults with learning disabilities when compared to the general population and is experienced at a younger age (Haveman et al., 2010).

Congenital heart defects are common in people with Down syndrome, with 13% identified in children and 23% in adults. In relation to cause of death in adults with Down syndrome in older age, 10% was attributed to coronary artery disease (Bittles et al., 2007). Disorders of the heart and circulatory system have been reported to affect 21% of adults with learning disabilities and contribute to the

underlying cause of death (Heslop et al., 2014). A total prevalence of cardiac diseases of 14% was found in people with learning disabilities, with a higher prevalence among women, the elderly, and those with milder learning disability (van Den Akker et al., 2006). People with learning disabilities are more likely to experience high blood pressure, be overweight or obese, and be physically inactive; all risk factors for developing cardiovascular disease (Merriman et al., 2005; Sohler et al., 2009; Haveman et al., 2011; Haveman et al., 2014; Cooper et al., 2015). With the ageing and increasing population of older adults with learning disabilities, it can be anticipated that there will be a rise in morbidity and mortality from cardiac diseases in the future. There is therefore a need for early intervention and prevention strategies.

Metabolic syndrome is common in the general population and now within the learning disabled, with patients presenting with an increased risk of coronary heart disease and type 2-diabetes (Lin et al., 2010). The prevalence of cardio-metabolic related risk factors was found to be high in the young population with intellectual disabilities (Wallén et al., 2009). In a Dutch sample of older adults with mild to moderate learning disabilities, aged ≥ 50 , the prevalence of metabolic syndrome was found to be higher at 25% when compared to the general Dutch population (de Winter et al., 2010).

The development of research-based, individualised prevention programs and intervention strategies aimed at lowering the risk of cardiovascular disease is required (Draheim, 2006). Prevention and intervention programmes need to focus on educating people with learning disabilities and their family and carers about issues including appropriate dietary concepts, increased physical activity and access to regular health screening (Lennox et al., 2007; McGuire et al., 2007; Wallace & Schluter, 2008; Heller et al., 2011; Robertson et al., 2011).

Cancer

Globally, it is estimated that over 12 million people are diagnosed with cancer every year. The global cancer burden has doubled in the last 30 years of the

twentieth century, and it is estimated that this will double again by 2020 and nearly triple by 2030 (Boyle and Levin, 2008). While increasing, the overall incidence of cancer among people with a learning disability has been reported to be lower than in the general population (Bonell, 2010). In a review of the research literature, Bonell (2010) found that children and adults with Down syndrome experienced specific cancers such as leukaemia and lymphomas when compared with to the non-disabled population, and from an earlier age. Other cancers such as testicular, pancreatic, ovarian, uterine, skin, retinoblastoma and malignant tumours of the brain are also evident in people with Down syndrome (Satge et al., 2006; Sullivan et al., 2007).

People with learning disabilities experience a different cancer profile when compared to the general population. Evidence highlights the higher prevalence of cancer of the oesophagus, stomach and gallbladder, with lower prevalence rates of cancers commonly found in the general population (Heslop et al., 2013). People with learning disabilities have been found to experience *Helicobacter pylori* gastric infection at twice the rate of the general population. Recurrence following triple drug treatment is seven times more common than in the general population. Gastrointestinal malignancy is reported to account for about 50% of all cancer deaths in the learning disabled population (Kitchens et al., 2007). Cancers were found to be higher in people with genetic conditions including Down syndrome and Fragile X syndrome (Tuffrey-Wijne et al., 2007).

There are national cancer screening programmes aimed at the whole population, including adults with learning disabilities, aimed at detecting breast, cervical and bowel cancers. There is a need to ensure that all people with learning disabilities have equal access to national cancer screening programmes and the necessary support and reasonable adjustments (Collins et al., 2014). In a systematic review of the research literature, issues related to the assessment and management of pain and symptoms were identified, in addition to ethical issues and the need for service planning and the education and training of people with learning disabilities,

their families and carers, and professionals (Tuffrey-Wijne et al., 2007; Hanna et al., 2011; Truesdale-Kennedy et al., 2011).

Barriers to accessing mammography have been identified, including literacy problems, consent issues and physical health conditions (Willis et al., 2008). Practical barriers such as transport and timing of appointments, and barriers attributed to healthcare professionals, including staff attitude and lack of awareness and access to resources and training, have also been identified (Tuffrey-Wijne et al., 2005; McIlfatrick et al., 2011). Therefore, screening approaches and services need to be individualised to the needs of people with learning disabilities to ensure equality of access (Wilkinson & Cerreto 2008; Truesdale-Kennedy et al., 2011; Willis et al., 2011).

Communication

Effective communication and information exchange is essential within all healthcare settings. However, communication difficulties are a significant problem for many people with learning disabilities and include issues related to expression, comprehension and confidence when providing their health history (Sowney & Barr, 2006; Backer et al., 2009; Bradbury-Jones et al., 2013). Due to their greater health needs, people with learning disabilities access all health services, including primary care, community health services, unscheduled care, tele-health, accident and emergency, diagnostic services, general hospitals and palliative care services (Scior et al., 2013; Dunkley & Sales 2014; Iacono et al., 2014; Perry et al., 2014). Communication is recognised as a significant barrier when people with learning disabilities access healthcare and contributes to their ability to share information regarding their health concerns and health needs (Lennox et al., 2013; Mastebroek et al., 2014; Boardman et al., 2014). Additionally, health professionals can lack confidence and experience in communicating with and identifying the needs of people with learning disabilities in health care settings and require further education, training and support (Gibbs et al., 2008; Cooper et al., 2014; Ryan & Scior 2014; Wark et al., 2014; Hemm et al., 2015; Tracy & McDonald 2015; Trollor et al., 2016). As a result, there are difficulties in health assessment, diagnosis,

investigations and treatments and the provision of care that is family and person-centred (Heslop et al., 2014).

Challenging behaviours are common within the learning disabled population and can make assessment, care and treatment more difficult within health services. Diagnostic overshadowing, where symptoms of physical ill health are mistakenly attributed to the learning disability, mental illness, or challenging behaviour, also contributes to health conditions not being identified, assessed and treated (Mason & Scior, 2004; Jones et al., 2008; Weiss et al., 2009). Collectively these issues contribute to health needs remaining unidentified and unmet, with evidence highlighting the link with avoidable and premature death in this population (Heslop et al., 2014). To comply with the Equality Act (2010), all public services, including health services, are legally required to make 'reasonable adjustments' to enable equality of health service access (Bradbury-Jones et al., 2013; Tuffrey-Wijne et al., 2014; MacArthur et al., 2015). Therefore, the use of enabling communication methods such as hand-held health records, and providing accessible information, can contribute to improving communication and help to ensure that people with learning disabilities have their health needs assessed and effectively met (Baumbusch et al., 2014; Nguyen et al., 2014).

Diabetes

According to the International Diabetes Federation (2013) the prevalence of diabetes worldwide is 8.3%, affecting 382 million, and is projected to rise to 10.1% or 592 million by 2035. It is estimated that some 175 million have undiagnosed diabetes and are potentially at risk of developing associated health problems (International Diabetes Federation, 2015). The UK has seen a rise of 1.2 million between 1996 and 2009 of those diagnosed with diabetes bringing the total to 2.6 million (Diabetes UK, 2009).

The exact prevalence of diabetes among people with learning disabilities is unknown (Bergholdt et al., 2006; Rey-Conde & Lennox, 2007; McVilly et al., 2014). Two systematic reviews of the research evidence identified a prevalence rate of

between 8.3 and 8.7% (McRae 2015; McVilly 2014). A recent meta-analysis of the research evidence, conducted by Dunkley (2017), derived from a small number of studies (n=5) where type 2 diabetes has been considered separately from other types of diabetes suggests an overall pooled prevalence of 7.6%. However, this rate includes known cases; none of the studies focused specifically on screen-detected type 2 diabetes. Anwar et al., (2004) found type 1 diabetes to be more prevalent in people with Down syndrome compared with other genetic causes of learning disability. Type 2 diabetes is recognised as a common comorbidity in people with Prader-Willi syndrome and learning disability (Hermans & Evenhuis, 2014).

Poorly managed or untreated type 2 diabetes can lead to serious complications, including heart attacks, stroke, blindness, renal failure, nerve damage, amputation and associated mortality, and remains a public health priority (International Diabetes Federation, 2015). People with learning disabilities are more susceptible to developing diabetes as they age due to many risk factors. The risk factors associated include family history and age (Haveman et al., 2011), gender (Sohler et al., 2009) ethnicity (Lanting et al., 2005), obesity (Krahn & Fox, 2014, Melville et al., 2007), physical inactivity (Temple et al., 2006) medications such as antiepileptics (Sankar, 2004), genetic conditions such as Down syndrome, Klinefelter syndrome, Prader-willi syndrome, Noonon syndrome and William syndrome (Anwar et al., 2004; De Winter et al., 2009) and cardiovascular disease (WHO, 2013).

It has been recognised that diabetes prevention is a priority for people with learning disabilities, given their increased risk of developing the disease (NICE, 2012). Early detection, monitoring, management and control are necessary to ensure good glycaemic control as well as blood pressure and cholesterol levels necessary to reduce the risk of conditions such as metabolic syndrome (Taggart et al., 2013). Currently little is known about whether screening for asymptomatic glucose disorders is viable in people with learning disabilities; there is a lack of evidence on feasibility, acceptability, outcomes and benefits (Dunkley et al., 2017). Weight

loss and weight management are necessary to help prevent diabetes and improve diabetes management. The NICE guidelines (NICE, 2015) recommend structured education for the management of type 2 diabetes in adults, however no guidelines currently exist specifically for people with a learning disability despite their increased susceptibility to developing the condition. Brown et al., (2017) in a study exploring the perceptions and experiences of diabetes and learning disability practitioners, highlighted the need for access to diabetes education and adapted resources for this population. An example of a national structured education programme for people with newly diagnosed type 2 diabetes called DESMOND (Diabetes education and self-management for on-going and newly diagnosed) has recently been adapted for people with a learning disability, now known as DESMOND-ID (Taggart et al., 2015).

Epilepsy

Epilepsy is a neurological condition with an overall prevalence of about 1%, and an incidence of 61 per 100,000 in the general population (Linehan et al., 2010; Fiest et al., 2017). Epilepsy is the most common co-morbid health condition experienced by people with learning disabilities. In a systematic review of the research evidence regarding prevalence of epilepsy among people with learning disabilities, findings indicate a prevalence of 22%, increasing with the level of learning disability. In relation to people with Down syndrome a prevalence rate of 12% was identified and increased with age and was particularly present in people with Alzheimer's and dementia (Robertson et al., 2015a). Prevalence rates of epilepsy in older adults with learning disabilities was found to be 31%, with no significant difference between genders. The highest prevalence was found in the 40-49 age groups, declining with age. Older people with mild to moderate learning disabilities were more likely not to be receiving antiepileptic medication to control seizures (McCarron et al., 2014a).

Across the spectrum of people with learning disabilities, the presentation of epilepsy is more complex, with multiple seizures and polypharmacy when compared to the non-learning disabled. Epilepsy has significant psychosocial

implications and impacts on their quality of life and opportunities. Due to seizures, people with learning disabilities can experience soft tissue injuries, falls, fractures and head injuries. Epilepsy is linked to mortality in people with learning disabilities and there is a risk of Sudden Unexplained Death (SUDEP) (Young et al., 2015; Glover et al., 2017).

With regards to epilepsy and neuropsychiatric comorbidity presentation in people with learning disabilities, a tendency towards negative mood symptoms has been identified. Learning disability is related to higher rates of epilepsy and comorbid neuropsychiatric conditions. Neuropsychiatric comorbidities appear to be more prevalent in patients with learning disabilities with severe forms of epilepsy (Van Ool et al., 2015).

The behaviours that can be present in some people with learning disabilities can impact on the identification of and management of their epilepsy. Therefore, a comprehensive assessment is needed before pharmacological treatment is commenced and supported by regular monitoring of side effects. There are interventions available to enable and support some people with learning disabilities to learn more about and self-manage their epilepsy (Dannenberg et al., 2016). A learning disability is not a contraindication for epilepsy surgery, however it is important to note that the precise impact cannot be predicted. Evidence supports the use of antiepileptic drugs for the management of epilepsy in people with learning disabilities to reduce seizure frequency. Side effects appear to be like those in the general population, with the need for discontinuation being uncommon (Beavis et al., 2007).

Due to the complex nature of epilepsy presentation in young adults with learning disabilities, planning and support is required for patients, their family and carers at the time of transition from child to adult health services (Young-Southward et al., 2016; Kerr et al., 2016). Additional support and access to both specialist learning disability and epilepsy services is required for people with learning disabilities to

ensure there is effective assessment, review and monitoring (McCarron et al., 2014).

Gastrointestinal Disorders

Gastrointestinal disorders are common in people with learning disabilities and require specific assessment, treatment and management (Timmeren et al., 2017a; Timmeren et al., 2017b). There is evidence that patients with more severe learning disabilities, those with cerebral palsy, taking anticonvulsive medication experience gastro-oesophageal reflux disease (GORD) and an association with vomiting, rumination and haematemesis (de Veer et al., 2008). Haematemesis, the vomiting of blood, can result from untreated GORD and lead to iron deficiency anaemia for which investigation and treatment may be required (de Veer et al., 2008). There is a link between people with more severe learning disabilities, GORD and agitation, self-injurious behaviour and rumination, necessitating investigation and, where indicated, treatment (de Winter et al., 2011). Assessment and treatment of underlying physical conditions is required, as well as function-based interventions and diet manipulations to reduce vomiting and rumination in people with learning disabilities (Lang et al., 2011).

Medication is commonly used to manage gastric disorders, including gastric ulceration and GORD experienced by people with severe learning disabilities and there is a need for regular review and monitoring of effectiveness and to identify possible side effects (van Der Heide et al., 2008). Gastrointestinal disorders were identified in older people with learning disabilities, in addition to a range of other long-term health conditions (McCarron et al., 2013). Consequently, some people with learning disabilities across the lifespan may require access to investigations, treatment, monitoring and review to ensure gastrointestinal disorders are diagnosed and managed effectively.

Haematological Disorders

People with learning disabilities can experience blood disorders for several reasons. Genetic conditions such as Down syndrome are associated with

leukaemia and lymphomas and occur more frequently when compared to the non-disabled population, and from an earlier age (Bonell, 2010). A high frequency of mild normocytic normochromic anaemia was identified in an institutionalised population of people with learning disabilities. Males with learning disabilities experienced anaemia more frequently than females and it was more common in males with low body mass index (BMI) and taking antiepileptic medication and major tranquilizers (Ohwada et al., 2006).

Gastrointestinal disorders are common, notably amongst those with severe learning disabilities, with an associated impact on their general health and can lead to conditions such as anaemia (Petry et al., 2009). There is a link between gastro-oesophageal reflux disease (GORD) and haematemesis in people with severe learning disabilities, which if untreated can result in iron deficiency anaemia for which investigation and treatment may be required (de Veer et al., 2008).

Due to the range of health conditions experienced by some people with learning disabilities, drug treatments are necessary. The most common neurological condition experienced by people with learning disabilities is epilepsy, for which antiepileptic medication may be required. Blood dyscrasias can occur because of side effects from some medications, such as thrombocytopenia and occasionally aplastic anaemia arising from antiepileptic medication (Sipes et al., 2011). Agranulocytosis can occur with some antipsychotic medication (Matson & Mahan 2010). Therefore, regular review is important to minimise potential haematological side-effects of these medications.

Infections

Infections are common in some people with learning disabilities. Respiratory infections are the commonest cause of death within the learning disabled population (Heslop et al., 2014). People with profound and multiple learning disabilities are particularly at risk of infections including chest infection, pneumonia and gastro-oesophageal reflux disease (Tyler & McGrother, 2009). Chest

infections may be secondary to dysphagia, estimated to be about 8.15%, and is more common in those with severe learning disabilities (Chadwick et al., 2009). Pathogenic microorganisms in the oral cavity and poor oral health contribute to the risk of developing respiratory infections, including pneumonia, in people with learning disabilities, despite routine daily tooth brushing (Binkley et al., 2009). Effective oral and dental care is therefore essential for this population.

In relation to people with Down syndrome and those with Prader-Willi syndrome, respiratory infection is common and can lead to pneumonia and premature death. Respiratory infection and pneumonia is the commonest cause of death in people with Down syndrome, with 23% in adulthood, increasing to 40% into older age (Bittles et al., 2007).

Urinary Tract Infections (UTIs) are also experienced by people with learning disabilities, notably those with associated physical disabilities, with urinalysis required to exclude infection of the urine and associated health conditions (Henderson et al., 2009; Charlot et al., 2011). UTI has been linked to post-void residual urine volume in adults with severe learning disabilities and may be associated with genetic conditions, anatomical anomalies and the use of medication for epilepsy and behavioural mood stabilisation because of the anticholinergic effect (de Waal et al., 2009).

Helicobacter pylori, tuberculosis and hepatitis are common in people with learning disabilities (Ouellette-Kuntz, 2005). *Helicobacter pylori* is a bacterial infection of the lining of the stomach. The infection is common in the general population and is also found in people with learning disabilities; many people are unaware of the presence of the infection. The spread is associated with overcrowding, poor sanitation and hygiene; prevention is important. *Helicobacter pylori* is linked to gastric carcinoma in people with learning disabilities, including those with Down syndrome (Kitchens et al., 2007; Sullivan et al., 2007). People with learning disabilities and their carers require access to education regarding *Helicobacter*

pylori and the need for effective hygiene, screening and treatment to enable eradication and prevent gastric cancer (Hanna et al., 2011).

Hepatitis is experienced by some people with learning disabilities and has been noted in institutional populations; screening and immunisation may be required (van Schroyen Lantman-de. & Walsh., 2009; Haveman et al., 2010). There is also a risk of Hepatitis in relation to substance use and sexual activity (Servais, 2006; Yen et al., 2009). Regarding Hepatitis A, screening has been identified as having a positive effect on the uptake of vaccination, and protocols have been developed and used in relation to Hepatitis B (Cooper et al., 2006; Lennox et al., 2010; Robertson et al., 2011).

Due to the risk of infections, people with learning disabilities require access to early oral and dental health assessment and physical health assessment. Screening by way of blood tests, x-rays, ultrasound, videofluoroscopy and MRI scanning may be necessary to confirm a diagnosis and inform treatment options to prevent complications, pain and discomfort and avoidable death (Somerville et al., 2008; de Waal et al., 2009; Robertson et al., 2011).

Mobility, balance, co-ordination and foot care

Mobility problems are common in people with learning disabilities and increase in people with severe learning disabilities and those with cerebral palsy. Balance and gait issues are apparent from an early age in people with learning disabilities and were found to continue across the lifespan, with an age-related decline. Research studies on people with Down syndrome involving gait analysis found that the spatiotemporal characteristics of gait showed a lower walking speed, higher cadence, shorter step length, larger step width and longer double support time. People with learning disabilities experience greater instability during standing and walking, and present with a more variable body sway than the general population. Due to their balance and gait problems, people with learning disabilities are prone to falls and providing training in falls prevention can minimise the potential (Enkelaar et al., 2012).

Some people with learning disabilities have abnormal walking patterns involving low motor control, with a slowing of motor responses to postural perturbations. Many risk factors also contribute to mobility difficulties, including medical conditions, medication, the context and environment of falling, movement impulsiveness and distractibility and visual impairments (Hale et al., 2007). People with learning disabilities have been found to have slower walking speed, shorter step lengths, and increased knee flexion angles at heel contact, which increases the likelihood of slips and falls. Despite the modifications to gait pattern, people with learning disabilities experience greater slip distances, highlighting greater slip severity (Haynes & Lockhart, 2012). From the perspective of older adults with learning disabilities, mobility limitations were identified and were more common in women than men. With the increasing population of people with learning disabilities living into older age, there are implications for service providers and policy-makers (Cleaver et al., 2009).

People with learning disabilities can gain positive benefits from exercise therapy interventions, including increased muscle strength, improvement in gross motor skills and functional independence. Some people with learning disabilities have difficulty accessing and engaging with mainstream physiotherapy and modified or alternative programmes may be required (Hocking et al., 2013). Targeting physiotherapy to improve balance capabilities can help to prevent falls (Hale et al., 2009).

Podiatric conditions are common in adults with learning disabilities when compared to the general population and often go unrecognised and untreated (Jenkins et al., 2015). Podiatric conditions including overpronated gait, abducted gait, restriction in both the ankle and the first metatarsal phalangeal joint, pes planus, metatarsus adductus, brachymetatarsia, hallux abducto valgus, onychomycosis, onychocryptosis and tinea pedis have all been identified in adults with learning disabilities (Jenkins et al., 2015). Poorly fitting shoes has also been identified as an issue that needs to be addressed, with 59% of a sample of people with learning

disabilities wearing correctly fitting shoes, 29% shoes that were too big and 13% too small (Jenkins et al., 2012). Due to the high prevalence of podiatric conditions within the learning disabled population, there is a need for regular assessment, and treatment and management (Jenkins et al., 2011).

Nutrition

Poor diets such as consuming high-fat foods and not eating fresh fruits and vegetables play a role in the development of excessive weight and obesity and elevated risk for CVD and diabetes among adults with learning disabilities (Draheim et al., 2006).

Few studies have examined nutrition in adults with a learning disability, or their food choices. Koritsas and Lacono (2016) found that more than half of their study participants with learning disabilities had a little choice not only in the type of food they ate but also when they ate. Similarly, in an Irish study of adolescents and adults with learning disabilities, McGuire et al. (2007) reported that few participants complied with the recommended intake for fruit and vegetables, carbohydrates, dairy and protein, but the majority complied with the recommended intake for sugar and fat (i.e. did not go beyond the recommended intake). According to Frighi et al. (2014) people with learning disabilities living in England were nearly twice as likely to be either vitamin D insufficient or vitamin D deficient, compared to the general population.

Being low-income and poorly informed about sound nutritional practices may limit access to healthy food and healthy food choices. Nutritional practices among adults with learning disabilities living independently may be less than ideal and this finding may apply also to those living in congregate care (Draheim et al., 2006).

Obesity & Metabolic Disorders

With more than one-third of adults in the world being reported as overweight or obese (Ng et al., 2014) this remains a central concern for people with learning disabilities. In a recent narrative review focusing on prevalence and the potential

factors associated with overweight and obesity in adults with learning disabilities during the past decade Ranjan et al., (2017) reported that the prevalence of being overweight and obese among adults with learning disabilities is reportedly 28-71% and 17-43%, respectively.

The evidence is mixed on whether the prevalence of being overweight and/or obese is similar or proportionally higher or lower for people with learning disabilities versus the general population. While some researchers have found higher prevalence of both being overweight and obese among people with learning disabilities than the general healthy population (Melville et al., 2007, 2008; de Winter et al., 2012), others report only the prevalence of obesity and morbid obesity being higher than the general population (Hsieh et al., 2014). Moreover, one report (Stancliffe et al., 2011) highlighted the same prevalence of obesity as the general population, and another found people with severe or profound learning disability being significantly more likely than their peers to be underweight (Hsieh et al., 2014).

People with learning disabilities are more susceptible to being overweight or obese due to risk factors including genetic conditions such as Prader-Willi syndrome and Down syndrome (Bhaumik et al., 2008; Rimmer et al., 2010; de Winter et al., 2012; Hsieh et al., 2014). Co-morbid health problems such as cerebral palsy, spina bifida or other conditions that limit mobility may also lead to overweight and obesity (Rimmer et al., 2010). Other determinants of obesity include age (Flegal et al., 2010; Stancliffe et al., 2011), female gender (Emerson 2005; Moran et al., 2009; Yamaki, 2005; Bhaumik et al., 2008; Melville et al., 2008; Stancliffe et al., 2011; de Winter 2012; Hsieh et al., 2014), living in less restrictive environments (Melville et al., 2008), severity of learning disability (Emerson, 2005; Melville et al., 2007, 2008; Stancliffe et al., 2011; de Winter et al., 2012) and taking medications that cause weight gain (Hsieh et al., 2014). The population are less likely to seek or make use of health screening services and are more likely to have poor diets (Malik et al., 2006; Rosenheck, 2008) and lead a sedentary lifestyle with little or no physical activity (Emerson, 2005; Handschin & Spiegelman, 2008; Hsieh et al., 2014).

Obesity is a major concern due to obesity-related health conditions such as cardiovascular disease, cancer and type two diabetes (Lavie et al., 2009; Dixon, 2010; Haidar & Cosman, 2011).

The UK guidance for obesity and weight management recommends multicomponent weight management interventions (MCIs) for people who are obese (National Institute for Health and Care Excellence (NICE, 2014a, 2014b; Scottish Intercollegiate Guidelines Network (SIGN, 2010). These interventions should be tailored to meet the needs of different population groups. In 2016, Public Health England published guidance on making reasonable adjustments to weight management services for people with learning disabilities (Public Health England, 2016). The guidance provided examples of easy-read leaflets from five providers and eleven case studies (only three of which had received some form of evaluation). However, the reasonable adjustments guidance case studies provided were solely focussed on the management of weight through diet only or exercise only and not MCIs. The existing UK guidance for obesity and weight management (NICE, 2014a, 2014b; SIGN, 2010) may fail to adequately address the needs of people with learning disabilities and in turn contribute to the inequalities regarding outcomes and access to services as experienced by this group (Mizen et al., 2012).

In an integrative review of multicomponent weight management interventions for adults with learning disabilities, Doherty et al., (2017) identified no comprehensive multicomponent weight management interventions for adults with, or without learning disabilities. Previous reviews of weight management interventions for adults with learning disabilities tended to focus on stand-alone dietary interventions, stand-alone physical activity interventions, behavioural and/or educational interventions, health promotion interventions and various combinations of these (Hamilton et al., 2007; Jinks et al., 2011; Spanos et al., 2013).

Oral and dental health

There is a growing research evidence-base regarding the poor oral health and hygiene experienced by people with learning disabilities. Many people with learning disabilities experience poor oral hygiene that leads to higher prevalence and severity of periodontal disease, and a higher incidence of untreated caries when compared to the general population (Clifford et al., 2013). A systematic review of the research evidence identified that people with learning disabilities experienced poorer oral hygiene and higher levels and severity of periodontal disease. In a systematic review of the research evidence regarding bruxism and people with learning disabilities, a two-step assessment process, comprising dental screening followed by behavioral assessment and interventions is recommended (Lang et al., 2009). Untreated dental caries was found to be higher in people with learning disabilities who could not cooperate with dental care, with people with Down syndrome also experiencing significant oral health problems (Anders & Davis, 2010). Untreated dental problems are related to challenging behaviour in people with severe learning disabilities (Poppes et al., 2010).

Pathogenic microorganisms in the oral cavity and poor oral health contribute to the risk of developing respiratory infections, including pneumonia, in people with learning disabilities, despite routine daily tooth brushing (Binkley et al., 2009). Effective oral and dental care is therefore essential for this population.

In relation to people with Down syndrome and those with Prader-Willi syndrome, respiratory infection is common and can lead to pneumonia and premature death. Respiratory infection and pneumonia is the commonest cause of death in people with Down syndrome, with 23% in adulthood, increasing to 40% into older age (Bittles et al., 2007).

Evidence points to the need for the appropriate use of sedation within the learning disability population to facilitate oral care and treatment. There is also a need for education and behavioral interventions to enable treatment and prevention,

directed specifically at people with learning disabilities and their family and carers (MacGiolla Phadraig et al., 2013).

Poor oral health can result in chronic pain, affect the ability to eat and communicate, and adversely affect physical health and quality of life for people with learning disabilities. Intervention strategies include enhanced prevention and improved access to routine dental care, and education for dentists and other dental professionals (Clifford, 2013). There is some evidence of the impact of pain associated with dental caries, dental cleaning procedures and pain due to dental abscess (Knecht et al., 2013). Gastro-oesophageal reflux disease (GORD) contributes to dental erosion and requires assessment, investigation, treatment and management (De Veer et al., 2008).

Preventative strategies include the use of fluoride and chlorhexidine, and improved access to dental services (Clifford et al., 2015). Targeting oral health services to people with learning disabilities is required to help reduce the effects of poor oral and general health associated with delayed treatments, dental pain, access to emergency dental care, tooth loss and periodontal disease (Petrovic et al., 2016). Evidence therefore supports strategies to increase patient acceptance of routine care, additional training for dentists to provide this care, and the development of more effective preventative strategies to minimize the need for this care.

Physical Activity

Research evidence has highlighted the positive effects of physical activity on physical and psychological health among people with learning disabilities and the non-disabled population (DHSS, 2008; Bartlo & Klein, 2011). Despite the advantages of physical activity, most people with a learning disability tend to avoid participating in physical activities (Lotan et al., 2010).

Many people with learning disabilities have very low physical activity levels (Temple et al., 2006; Frey et al., 2008; Kilgenkamp et al., 2012) and fail to participate in the recommended levels of physical activity. Finlayson et al., (2009)

reported that in a sample of 433 adults with a learning disability, only 5% met the Government recommendations for physical activity. Finlayson et al., (2011) also found in a study investigating measurement of physical activity involving a sample of 62 adults with mild-to-moderate intellectual disability, only six (15%) met Government recommendations.

Those with severe/profound disability and aged over 50 years are more likely to be inactive (Stanish & Draheim, 2007; Melville et al., 2009; Hilgenkamp et al., 2012). A recent systematic review on physical activity levels in adults with learning disabilities, conducted by Dairo et al., (2016) found that learning disability severity, living in care, gender and age were independently significantly correlated with the number of participants achieving physical activity guidelines with the strongest predictor being severity of learning disability.

In a study conducted by Koritsas and Iacono (2016), 60.3% of the study participants did not meet the national physical activity guidelines. Similarly, Dixon-Ibarra et al., (2013) reported that only 32% of adults with a learning disability met physical activity recommendations and Barnes et al., (2013) reported that 23.7% of adults with a learning disability met current physical activity recommendations. Temple et al., (2006) reviewed the literature and reported that only 17.5-33% of participants in the studies identified engaged in physical activity at the intensity required for health benefits.

Shin and Park (2012) conducted a meta-analysis of the effect of exercise programmes for people with learning disabilities. The study revealed that short-duration exercise programmes are more effective than those of longer duration, and an exercise programme that runs four times per week had a better effect than one that runs three times per week. The most effective length of session for exercise was 31-60 minutes, and exercise was more effective for older people than for younger people.

In terms of weight management, a recent study by Schijndel-Speet et al., (2017) reported that well executed physical activity programmes can produce positive effects on outcome measures regarding health.

Overall, the lack of physical activity is problematic because at the appropriate intensity and frequency, there is evidence that it reduces the risk of several health conditions including CHD, stroke, osteoporosis, colon cancer, osteoarthritis and lower back pain (Warbuton et al., 2006). Everyone with a learning disability should be educated on the benefits of physical activity and supported to engage in regular physical activity taking into consideration their own capabilities and interests.

Respiratory Disorders

People with learning disabilities experience respiratory disorders, which are the leading cause of death for this population (Heslop et al., 2014; Trollor et al., 2017). There is an increased risk of chest infections in people with learning disabilities and which are secondary to dysphagia, with an estimated prevalence of about 8.15% (Heslop et al., 2014). Chest infections are more common in people with severe learning disabilities and are a contributory factor in their premature death (Chadwick et al., 2009; Heslop et al., 2014). There is an increased prevalence of swallowing and eating problems in people with severe learning disabilities linked to swallowing difficulties, which if untreated result in aspiration leading to chest infections and pneumonia, which if untreated can result in death (Tyler & McGrother, 2009). Pathogenic microorganisms in the oral cavity and poor oral health contribute to respiratory infections in people with learning disabilities (Binkley et al., 2009).

At present, people with learning disabilities experience a lower prevalence of respiratory cancer compared to the general population. This is because people with a learning disability tend not to smoke; of those that do, they are twice as likely to experience asthma (Davis et al., 2016). The prevalence of people with learning disabilities who smoke varies across studies, depending on living arrangements, age, gender, degree of cognitive impairment and community versus institution

living (Singh et al., 2011). Emerson and Turnbull (2005) for example cite a prevalence of 14% with Kalyva (2007) reporting 26% of adolescents with mild learning disabilities as smoking.

Asthma has been found to be common in people with learning disabilities, notably those who are obese and smoke (Gale et al., 2009). Asthma and Chronic Obstructive Pulmonary Disease (COPD) were identified as part of the multimorbidity health profile experienced by older adults with learning disabilities (McCarron et al., 2013; Hermans & Evenhuis, 2014). Asthma has been identified as a condition that, if not managed appropriately within the community through primary care services, can result in hospital admission (Balogh et al., 2010; Dunn et al., 2017).

The evidence highlights the need for primary care services to identify people with learning disabilities who have asthma and are obese and smoke. This is necessary to ensure the effective management of asthma within primary care services and to support weight reduction and participation in programmes to quit smoking. Strategies to effectively manage asthma within primary care need to be in place, including medicines management, thereby decreasing the number of ambulatory care conditions that require hospital admission. More effective management would improve the health of this population and their quality of life, and reduce costs within acute care (Lin et al., 2006; Balogh et al., 2010; Dunn et al., 2017).

Sensory Impairments

The prevalence of sensory impairment, visual and hearing, is greater in adults with a learning disability than in the general population.

Visual impairment

Worldwide, visual impairment is increasing in prevalence. The World Health Organisation (WHO, 2011) indicates that 284 million people have impaired vision, 10% of whom live in the developed world. In the UK, sight loss affects about two

million people (Bosanquet and Mehta, 2008), including an estimated 80,000 of working age and 25,000 children.

People with a learning disability are 10 times more likely to have a visual impairment, compared with the general population (Emerson & Robertson, 2011; Woodhouse, 2010). Emerson and Robertson (2011) reported that approximately 31,000 adults with learning disabilities who are known to services in the UK have visual impairment, of whom 11,000 adults are blind. They also reported that there may be an additional 44,000 adults with learning disabilities and visual impairments, and 11,000 with learning disabilities and blindness who are not known to adult health or social care learning disability services. Those with severe or profound learning disability are most likely to have sight problems (Emerson and Robertson, 2011). The visual impairments often experienced by this population include keraconus, coloboma, microphthalmus, cataracts, macular degeneration and diabetic retinopathy (van Splunder et al., 2004). Six in 10 people with learning disabilities need to wear spectacles, many of whom require support to get used to wearing them, and to continue to wear them (Turner et al., 2013).

Previous research on the vision of people with learning disabilities has highlighted concerns about the lack of regular eye examinations for this population (Woodhouse et al., 2004). Research has highlighted that those people living independently or with family are significantly less likely to have had a recent eye examination than those living with paid support staff (Starling, 2006). In addition, carers of people with learning disabilities often fail to identify sensory impairment, including cerebral visual impairment. A study in a typical Dutch care organisation found that 92% of people with severe and profound learning disabilities had visual impairment, with nearly two-thirds of cases going unnoticed by carers (van den Broek, 2006).

Difficulties in detecting sight loss in people with learning disabilities are often attributed to their cognitive limitations and/or communication difficulties. Signs of sight loss may manifest as changes in the person's behaviour (Desrochers et al.,

2014). As many as 40% of people with learning disabilities can display challenging behaviour, for example aggression or self-injurious or stereotypical behaviours such as rocking or repetitive hand movements, with higher rates reported for those with visual impairments (Desrochers et al., 2014).

Health checks are recommended as one method to detect any difficulties with vision among this population, however uptake of health checks can be low (Turner, 2011). Vision awareness training addresses a recognised barrier to effective vision health care delivery for people with learning disabilities (Dick et al., 2015).

Hearing Impairment

Globally, it is estimated that more than 275 million people have some form of moderate or profound hearing impairment, although population-based studies are limited (Stevens et al., 2013). It is known from previous research that whilst profound congenital hearing loss is seen in at least 1 in 1,000 people in the general population, the prevalence of hearing impairment is at least 40 times higher in people with a learning disability (Carvill, 2001). The screening of 3,500 Special Olympic athletes for hearing impairments identified hearing deficits in 30% of athletes, with the incidence increasing with age (Special Olympics, 2005). Hild (2008), in a later study, identified deficits in 25% of 552 Special Olympic athletes, 48% of whom required referral to a hearing specialist, while 42% required removal of ear wax. The assessments were carried out on people with mild to moderate learning disabilities; the potential for hearing deficits in people with more severe and profound disabilities may be much higher, which can impact on their interactions and subsequent behaviours.

People with learning disabilities experience hearing loss a decade earlier compared with the general population, and in those with Down syndrome it is apparent three decades sooner (Meuwese-Jongejeugd et al., 2006). Structural anomalies of sensory organs, for example narrow ear canals, keratoconus, are common in people with Down syndrome. People with learning disabilities are also more prone to ear infections, structural ear abnormalities and wax occlusion

(Hardy et al., 2011; Fransman, 2006). Behavioural challenges such as head banging and poking and picking of the ears may also be evident in some people with learning disabilities, which can impact on and damage their hearing (Brown & Goddard, 2014).

Screening for hearing loss is a good method for detecting hearing impairment in people with learning disabilities (Hild et al., 2008), though research evidence has shown people with learning disabilities are less likely to access hearing tests than the general population. Some people with learning disabilities have never had their hearing tested (Timehin, 2004; Hardy et al., 2011). People with learning disabilities are more likely to have hearing loss than adults in the general population, yet are less likely to have this diagnosed or to be given hearing aids (McShea, 2013). Health education and information is required by people with learning disabilities, their families and carers to support effective communication (Melville et al., 2009).

Kiani and Miller (2010), in a review of sensory impairment in learning disabilities, report that difficulty in accessing generic services and the deficits in language and communication skills found in this population make the assessment of sensory impairment a challenge. The authors highlight that in practice, diagnostic overshadowing can occur, with changes in behaviour attributed to the learning disability or to mental illness rather than to sensory impairment, which can lead to people receiving inappropriate treatment which does not address the underlying problem.

Sleep Disorders

Sleep disturbance is common in people with learning disabilities. The reported prevalence of sleep problems in adults with learning disabilities ranges from 9-27% for settling problems and from 11-34% for night waking problems. Nine percent reported significant sleep disturbance (van de Wouw et al., 2012). Adults with learning disabilities are more likely to experience a significant sleep problem if they have a mental illness, problem behaviours and respiratory disease. People with

learning disabilities who take antiepileptic medication experience broken sleep (Boyle et al., 2010).

In a systematic review of the research evidence regarding sleep disturbances experienced by people with learning disabilities, a range of factors were identified that contribute, including physical health problems such as respiratory conditions and visual impairment. Psychological and behavioural problems were also identified and include psychiatric conditions such as bipolar disorder and mania and depression in people with Down syndrome. The use of antidepressants, antiepileptic medication and psychotropic drugs were identified as contributory factors to sleep disturbance. There is some evidence regarding interventions for people with learning disabilities who experience sleep disturbance, such as behavioural approaches and making environmental changes, thereby suggesting that non-pharmacological approaches may be beneficial (Priday et al., 2017).

In a meta-analysis of the research evidence, Melatonin was found to affect sleep latency and the number of nights awake per week and increased the total amount of sleep time (Braam et al., 2009). Limited evidence exists in relation to older people with learning disabilities and sleep problems. With life expectancy increasing for many people with learning disabilities, there is a need to more fully understand how sleep patterns change and if it is similar to the older general population (van de Wouw et al., 2012).

Sexuality & Sexual Health

There is a growing and evolving research evidence base regarding sexuality issues and adults with intellectual disabilities. Individuals can face challenges, including the right to express their sexuality and to access necessary education and support. The expression of sexuality, including how individuals form and maintain intimate relationships, is a fundamental human right of all individuals (World Health Organisation, 2015). Yet there are recurring issues in relation to adults with intellectual disabilities having control and autonomy over decisions regarding their sexual expression (Friedman, 2014). Adults with learning

disabilities have the same aspirations as their peers and want friendships, meaningful relationships and, for some, intimacy (Box & Shaw, 2014).

From the perspective of adults with learning disabilities, there are mixed experiences and messages, with some having positive experiences of dating and relationships while others feel confused about what constitutes 'acceptable' behaviours such as intimate touching and what would be considered 'acceptable' and set boundaries (Eastgate et al., 2011; Bernert & Ogletree, 2013; Sullivan et al., 2013). Adults with learning disabilities want access to education regarding the expression of their sexuality, advocacy, and support to understand their rights and responsibilities; this also includes protection from exploitation and abuse (Rushbrooke et al., 2014; Schaafsma et al., 2015). Families and paid carers also require access to education and training regarding the sexuality of their family member with learning disabilities (Ward et al., 2014). This is important as some adults with learning disabilities have limited knowledge and understanding of how legislation can afford protection, and of their own responsibilities (O'Callaghan & Murphy, 2007). There are tensions regarding concerns from families and carers that brings challenges in providing support that is the least restrictive and enabling, while responding to and preventing abuse, exploitation and harm (Murphy & O'Callaghan, 2007; Healy et al., 2009; Rushbrooke et al., 2014; Bryne, 2017).

A systematic review of the research evidence was published that focused specifically on people with learning disabilities who identify as lesbian, gay, bisexual and transgender (LGBT) (McCann et al., 2016). The review identified 5 key issues impacting on LGBT people with learning disabilities. The issues identified were

- (i) improving equality of access to health services and the making of reasonable adjustments;
- (ii) access to support and counselling to address gender and sexual identity issues and challenging heteronormative attitudes;
- (iii) access to support and counselling to address individual attitudes regarding their LGBT status;

- (iv) access to education about being LGBT and social support networks; and
- (v) access to therapeutic interventions.

Physical and psychosocial challenges were identified for transgender people with learning disabilities, with some experiencing mental health concerns and tackling stigma and discrimination and barriers to accessing services (Parks 2009). There is limited research evidence regarding lesbian women with learning disabilities (Löfgren-Mårtenson, 2009). Adults with learning disabilities and HIV present with complex health needs and utilise health services more when compared to HIV-negative adults with learning disabilities. Mental illness and substance misuse is common. There is a need for closer collaborative working between sexual health and learning disability services to ensure that the health and support needs of the population are met (Durbin et al., 2017; Lunskey et al., 2017).

Mental Ill-health

Many people with learning disabilities have a mild learning disability (Harris, 2006). Compared to the general population, they are at increased risk of mental ill-health, mostly for psychotic disorders, attention deficit hyperactivity disorder (ADHD), and autism. There is an equal risk of depression and anxiety (Smiley, 2005; Baird et al., 2006; Cooper et al., 2007; Simonoff et al., 2007).

The exact prevalence rates of mental ill-health among adults with learning disabilities remains unknown. Two systematic reviews (Whitaker & Read, 2006; Buckles et al., 2013) reported prevalence rates ranging from 3.9% to 46.3% or from 13.9% to 75.2% respectively. Cooper et al. (2007), when analysing the reported prevalence rates in studies, found a range from 7-97%, attributed to methodological limitations.

Reported prevalence rates of anxiety and depression vary widely among adults with learning disabilities but are generally reported to be at least as prevalent as in the general population and higher among people with Down syndrome (Mantry et al., 2008). Schizophrenia is also reported to be common in people with learning

disabilities (Hemmings, 2006). Apart from behavioural phenotypes, little is known of the factors associated with mental ill-health in adults with intellectual disabilities (Smiley, 2005). Older people with learning disabilities seem to be more likely to have psychiatric diagnoses in inpatient or outpatient specialist care than their peers in the general population (Axmon et al., 2017). Deficits in communication and health literacy, and difficulties in accessing services may mean that mental ill-health in people with learning disabilities is under-recorded.

People with learning disabilities are at greater risk of developing mental ill-health due to their increased exposure to adverse life events and environmental stressors, for example violence, poverty, sexual abuse (Pestka & Wendt, 2014; Emerson & Brigham, 2014; van der Put, 2014a; Emerson, 2007, 2013). Moreover, their limited access to social support and communication may further increase their vulnerability to developing post-traumatic stress disorder (PTSD) following a traumatic event (Tomasulo & Razza, 2007) which may impact on their well-being, manifesting as, for example, challenging behaviour and substance misuse (Wigham & Emerson, 2015).

An accurate psychiatric diagnosis for a person with learning disabilities can be difficult to make due to, for example, communication difficulties, physical health issues (Bhaumik et al., 2008a), diagnostic overshadowing (Mevisen & de Jongh, 2010) and a lack of assessment tools adapted for people with learning disabilities (Moreland et al., 2008; Hermans & Evenhuis, 2010). Having one psychiatric disorder seems to be a risk factor for more psychiatric disorders among people with learning disabilities (Lidher et al., 2005; Bakken et al., 2010).

A valid and reliable assessment of a person's mental health problem is crucial when considering psychological interventions with adults with learning disabilities. There is little evidence concerning the assessment of mental ill-health in this population with little consensus regarding mental health assessment tools (Hatton & Taylor, 2010). A previous meta-analysis has highlighted that functional analysis is crucial in attaining a positive outcome for behavioral interventions for people with

learning disabilities (Carr, 1999).

Psychological interventions including behavioural approaches, cognitive behavioural therapy (CBT) and psychodynamic therapy can effectively treat mental ill-health (Sturmey, 2004). However, standard psychosocial interventions designed for the general population may not be accessible for people with mild intellectual disabilities, and drug usage tends to be modified.

Behaviour Challenges

A significant proportion of people with learning disabilities display challenging behaviours, also known as behaviours that challenge or problem behaviours. Challenging behaviours are shown by 10-15% of people with learning disabilities, age-specific prevalence peaking between ages 20-29 (Holden & Gitlesen, 2006). The National Institute for Health and Care Excellence conceptualises these behaviours in terms of, aggression, self-injury, stereotypic behaviour, agitation, disruptive or destructive acts, withdrawn behaviour, arson and sexual misconduct (NICE, 2015).

Cooper et al. (2009a), in a community-based epidemiological study, found a prevalence rate of 4.9% for self-injurious behaviour and of 9.8% for aggression (Cooper et al., 2009b). With a prevalence of 82% for self-injurious behaviour and stereotypical behaviour and 45% for aggressive/destructive behaviour, challenging behaviour seems to be more pervasive in those with profound and multiple disabilities (Poppes, 2010). In some instances, challenging behaviours result from pain associated with untreated medical disorders (Kwok & Cheung, 2007; Desrochers et al., 2014).

The causes of challenging behaviour are complex and multifactorial (Ali et al., 2014). Biological factors contributing to challenging behaviour include genetic disorders associated with behavioral phenotypes, for example Prader-Willi syndrome and aggression; Lesch-Nyhan syndrome and severe self-injury, physical illness, for example epilepsy and associated symptoms such as constipation, pain, urinary incontinence and visual impairment (de Winter, 2011),

and side-effects of medication, including anti-epileptics. According to Ali et al. (2014), recent advances in genetics suggest that rare chromosomal abnormalities such as microdeletions or duplications may be associated with learning disabilities and challenging behaviour (Vissers, 2010).

The NICE guidelines (2015) for challenging behaviours and learning disabilities recommend that annual health checks include a review of any known or emerging behaviours that challenge and how they may be linked to any physical health problem; a physical health review; a review of all current health interventions, including medication and related side effects, adverse events, drug interactions and adherence; as well as an agreed and shared care plan for managing any physical health problems, including pain (NICE, 2015).

The management of challenging behaviours includes both psychosocial interventions as well as pharmacological interventions. However, the management of challenging behaviours in people with learning disabilities can be difficult. A survey of psychiatrists reported that non-pharmacological interventions are the first-choice treatment for aggression where no psychiatric condition is confirmed (Unwin, 2008). Many interventions have been used to manage challenging behaviours including Nidotherapy (Tyrer, 2007), active support (Toogood, 2009), cognitive behavioural therapy (Willner, 2013), mindfulness (Harper, 2013), applied behavioural analysis and positive behavioural support (Hassiotis, 2009, 2011). Pharmacological interventions have included antipsychotics (Grey, 2005; Tyrer, 2009; Gagiano, 2005), although there is currently insufficient evidence that antipsychotic medication is either helpful or harmful for adults with learning disabilities and challenging behaviour (Deb, 2007).

Antipsychotic medications are commonly prescribed where other strategies have failed. Concern has arisen regarding the inappropriate use of psychotropic drugs. In general antipsychotics are overused in people with learning disabilities and are prescribed for challenging behaviour rather than diagnosed mental illness, despite a lack of efficacy (Brylewski & Duggan, 2004; Tsiouris, 2010). Among psychotropic

medications, atypical antipsychotics, particularly Risperidone, are used most commonly to manage challenging behaviours in people with learning disabilities (Deb, 2013). It has been reported that 20–45% of people with learning disabilities are on psychotropic medication and 14–30% are receiving medication to manage problem behaviour such as aggression or self-injurious behaviour (SIB) in the absence of a diagnosed psychiatric disorder (Deb, 2013; Sheehan et al., 2015). Almost two thirds of psychotropic medications prescribed to people with learning disabilities are antipsychotics (Deb, 2013).

There is little support for the use of pharmacological treatments for people with challenging behaviour and learning disability in the absence of coexisting mental illness and an emerging interest in behavioural interventions for reducing challenging behaviour including positive behavioural support (Ali et al., 2014).

Dementia

People with learning disabilities have a greater risk of developing dementia (Strydom et al., 2016). People with Down syndrome have a well-established genetic risk for Alzheimer's disease, which has been found to develop two to three decades earlier than those in the general population (Wiseman et al., 2015). According to McCarron et al. (2014b), the prevalence of Alzheimer's disease in adults with Down syndrome is less than 5% under the age of 40 and roughly doubles with each 5 year interval until the age of 60 years: approximately 5-15% of those aged 40-49 years and over 30% of those aged 50-59 years experience significant cognitive decline. Approximately 80% of people with Down syndrome develop Alzheimer's disease beyond 60 years (Wiseman et al., 2015).

Among those with other causes of learning disability, the prevalence of dementia is estimated to be greater than 18% in those aged 65 years or over, approximately three times higher than in the general population (Strydom et al., 2007). Alzheimer's disease is the most common type of dementia in people with learning disabilities, as with the general population. Early screening is recommended particularly for people with Down syndrome from the age of 40 and from 50 in

others. The screening and diagnosis of dementia in people with learning disabilities is usually dependent on obtaining information from carers (Walker et al., 2015). It is recommended that standard diagnostic criteria are used to diagnose dementia in people with learning disabilities, however the rate of diagnoses has been found to vary depending on the criteria used (Strydom et al., 2007). Among people with moderate to profound learning disabilities, deaths from dementia are more common in men than women (Tyrer & McGrother, 2009).

The Department of Health (2009) highlights the need to educate carers not only about dementia and the changes that the person might experience, but also in raising their awareness of early warning signs. Baseline assessments are useful in people with Down syndrome given their increased risk for dementia; they enable early recognition of any deterioration and are recommended as early as the age of 30 years old (British Psychological Society (BPS) and Royal College of Psychiatrists (RCP), 2015).

Both pharmacological and non-pharmacological interventions are used for managing dementia. Pharmacological interventions include medications that aim to improve cognitive function, behavioural and psychological symptoms of dementia and comorbid physical health problems (Prasher and Fernando, 2009).

Non-pharmacological interventions support quality of life proactively and reactively and should also involve identifying the needs of the carers (Jokinen, 2014). There is a limited evidence base for non-pharmacological interventions, although they appear to have features that could potentially improve quality of life for the person with dementia and their carers (Courtenay et al., 2010; Jokinen et al., 2013; BPS and RCP, 2015).

Recommendations for best practice and service improvement in caring for adults with dementia and learning disabilities include baseline assessments and regular screening for people with Down syndrome, and consideration of the environment to improve the quality of life post-diagnosis (Strydom et al., 2016).

Forensic Care & People who Offend

There are 9 million prisoners worldwide, however it is unclear how many have a learning disability. There are concerns about their vulnerability within the criminal justice system due to mental illness, abuse and victimisation (Fazel et al., 2008). Using the Learning Disability Screening Questionnaire (LDSQ) in 3 English prisons, 2,825 prisoners were screened for a diagnosis of learning disability. A total of 169 were identified, equating to 7% of the prison population. The authors concluded that the LDSQ is an acceptable tool to screen for the presence of learning disability in the prison setting (Murphy et al., 2015). Based on a review and analysis of international data, a prevalence of prisoners with learning disabilities of between 7 and 10% has been identified. The most frequent coexisting health issues among the population are hearing and vision impairments, obesity, diabetes and a range of mental health disorders, including anxiety and personality and conduct disorders (Hellenbach et al., 2016). People with learning disabilities who offend and were diagnosed with both Attention Deficit Hyperactivity Disorder (ADHD) and Conduct Disorder were found to have a history of problematic behaviour (Lindsay et al., 2013).

In a sample of people with learning disabilities in prison in England and Wales with an IQ of less than or equal to 65, a significantly higher prevalence of psychosis, attempted suicide and cannabis use was found, with the need for interventions for substance use and to support coping in the prison environment (Hassiotis et al., 2011). From the perspective of women with learning disabilities with a history of forensic and offending behaviours, the evidence-base is less evolved. The numbers of women with learning disabilities is smaller when compared to men with learning disabilities and it has been reported that some have been held in excessive levels of security in relation to their offending. In a systematic review of the published research undertaken into the mental health of women with learning disabilities who offend it was identified that over half (51%) experienced significant longstanding mental illness; 47% a major depressive disorder, 6% psychosis and 3% schizophrenia. Thirty percent of the women with learning disabilities were

known to mental health services before going into prison and 73% were prescribed benzodiazepines (42%), methadone (36%), antidepressants (14%) and sleeping medication (10%).

From a therapy perspective, adapted cognitive behavioural therapy (CBT)-orientated group interventions for people with learning disabilities reported some improvements and a reduction in problem behaviour. However, a significant gap in relation to research-based therapies for women with learning disabilities and forensic and offending care needs was identified (Hellenbach et al., 2015). A systematic review of the research literature published in 2017 concluded that there is limited evidence on the effectiveness of psychological interventions for sex offenders with learning disabilities and a need for further research in the area (Jones & Chaplin, 2017).

Life Events & Trauma

There has been a growing body of literature exploring the experience and impact of trauma in the lives of people with learning disabilities. The past decade has seen an increase into the examination of the various aspects of trauma among people with learning disabilities. Areas have included adverse life events (Wigham et al., 2011a), complicated grief (Guerin et al., 2009), the relationship between abuse and trauma and psychological symptoms (Wigham et al., 2011b), the application of diagnostic criteria for PTSD (Shabalala & Jasson, 2011), and trauma treatment (Lund, 2011).

According to Hatton and Emerson (2004), people with learning disabilities are more likely to be exposed to traumatic life events than the general population. For some, this can lead to post traumatic stress disorder (PTSD). Whilst the prevalence rates of trauma in people with learning disabilities are limited, estimated variable rates of PTSD within learning disabled populations range from 2.5%-6% (Mevisen & de Jongh, 2010). Lower levels of intellectual functioning have been associated with higher rates of PTSD, suggesting that the range of

potentially traumatic experiences is greater in people with learning disabilities (Tsakanikos, 2007).

A variety of problem behaviours can be considered as symptoms of PTSD, including aggression and anger outbursts, self-injurious behaviour, non-compliance, social isolation, sleeping problems and restlessness. Overshadowing, that is attributing behavioural problems as part of a learning disability itself, is a well-known feature in mental health care for people with learning disabilities.

The identification and treatment of trauma for people with learning disabilities may be compounded by high rates of psychiatric comorbidity and other factors. Mental health professionals may fail to consider the possibility of trauma as the root cause of an individual's distress, especially when presenting symptoms have endured for a prolonged period of time (Mitchell & Clegg, 2005). Individual behavioural manifestations may be solely attributed to diagnostic overshadowing (Mevissen & de Jongh, 2010). In addition, common treatment modalities such as behaviour management and psychiatric medications are often minimally effective in treating the complexity of trauma (Barol & Seubert, 2010).

Moreover, the lack of PTSD diagnostic instruments prevents professionals from considering PTSD among this population. At present, there are no available validated diagnostic instruments aimed at assessing PTSD among people with learning disabilities, which consequently leads to the lack of prevalence rates for PTSD for this population. Appropriate assessment is central in guiding clinical decisions, particularly when deciding the nature and style of the psychological intervention to be delivered.

The National Institute of Clinical Excellence (NICE) currently recommends two evidence-based treatments for PTSD; trauma-focused cognitive behavioural therapy (Tf-CBT) and Eye Movement Desensitisation and Reprocessing (EMDR). Both these methods have been found to be highly effective in a range of clinical populations (APA, 2004; NICE Guidelines, 2005).

The empirical evidence for treatment for PTSD in people with a learning disability, including EMDR, trauma-focused CBT and psychodynamic interventions, is small and evolving, offering promising potential treatment options (Mevisen & De Jongh, 2010). A recent case study review undertaken by Jowett et al. (2016), reported that within each of the six case studies reviewed, improvements were shown in PTSD symptoms following EMDR therapy, of which half stated no disturbance at post treatment and at follow-up assessments. No adverse effects were reported, demonstrating that EMDR is well tolerated by people with learning disabilities. The authors concluded that EMDR is a safe and acceptable intervention for people with learning disabilities. Although this recent review provides support for the successful use of EMDR in learning disabled populations, the protocol adaptations necessary for people with learning disabilities remain unreported to date.

Due to the lack of robust research evidence, there is no specific recommendation for people with learning disabilities and PTSD.

Pharmacotherapy

People with learning disabilities experience a wide range of co-morbid, complex physical and mental health conditions for which medication is often prescribed (McCarron et al., 2014; Cooper et al., 2015; Carey et al., 2016). Medication is frequently prescribed in relation to the management of epilepsy and mental illness; both are common in people with learning disabilities (Whitaker & Read, 2006; Cooper et al., 2007; Robertson et al., 2015). Challenging behaviour is common in some people with learning disabilities (Lloyd & Kennedy, 2014). There is evidence that the use of medications in the management of challenging behaviour in adults with a learning disability is widespread; including the use of antipsychotics, sedatives, tranquillisers, antidepressants, and mood stabilisers for over 50-year olds, with limited supporting research evidence (Tyrer et al., 2014). The prescribing of unlicensed medication for use with people with learning disabilities was found to be common, with Risperidone being prescribed for aggression (Ghosh et al., 2010). In a systematic review, some evidence exists regarding the use of Lithium and Carbamazepine as a mood stabilizer medication

for the management of challenging behaviours in adults with learning disabilities (Debs et al., 2008). In a primary care-based study, 35% of the sample had been prescribed psychotropic medications, such as antipsychotics, and 26% anticonvulsants for seizure management. Complementary medications, such as vitamins, minerals, herbal medicines and amino acids were used by 29% of the sample, highlighting that people with learning disabilities are prescribed a diverse range of medications by primary care practitioners to help manage and treat their health conditions (Doan et al., 2013).

A 2010 systematic review regarding the use of antipsychotic medications among adults with learning disabilities identified that they are used to manage a range of behaviour related problems, including pica and self-injury, without adequate research evidence (Singh et al., 2010). The review looked specifically at the use of the antipsychotic medicine Clozapine for managing challenging behaviour and found that there was no conclusive evidence of the effectiveness of the drug. In a study regarding the prescribing of antipsychotic medication for people with learning disabilities and mental illness, the researchers concluded that there is evidence for the use of psychotropics for psychopathology and challenging behaviours. It is recommended by best-practice guidelines that there is a need to identify underlying causes of challenging behaviours and exclude or treat physical health conditions or consider the use of other treatment options that do not involve medication. Where medication is prescribed there is a need for regular review and monitoring of the effectiveness and side-effects (Edelsohn et al., 2014).

A systematic review of the research evidence in 2016 identified that antipsychotics could be reduced or stopped in some adults with learning disabilities. There is research evidence supporting the review and discontinuation of antipsychotic medication that has been prescribed for challenging behaviour, however the benefits to the individual need to be balanced against possible harm. The authors concluded that antipsychotic medication used for challenging behaviour needs to be reviewed regularly and an individualised approach taken to patient management (Sheehan & Hassiotis, 2016).

In relation to medication that is prescribed 'off-label' for challenging behaviour, the prescribing clinician must be clear about the research evidence being used to inform the decisions, oversee the treatment, maintain detailed records and inform patients and carers. A national audit is recommended to develop a larger data-set, to provide practitioners with evidence on the appropriate use of medication for the management of challenging behaviours (Glover et al., 2014). Researchers in the United States concluded that there is a shift in clinical practice in relation to the prescribing of psychotropic medications primarily to treat psychiatric disorders and not the effects of challenging behaviour (Tsiouris et al., 2013).

A systematic review of the research evidence regarding self-injurious behaviour in adults with learning disabilities identified four research studies comparing the effects of Naltrexone, used to treat substance dependency, versus placebo, and one study involving Clomipramine, used to treat obsessive compulsive disorder, panic disorder, depression and chronic pain, versus placebo. The researchers concluded that there is limited evidence that any medication is effective when compared to placebo for managing self-injurious behaviour in adults with learning disabilities (Gomez et al., 2014).

In another systematic review of the research evidence regarding Post Traumatic Stress Disorder (PTSD) in people with learning disabilities, treatments included establishing and addressing environmental factors, the use of medication and psychological treatments, such as cognitive behavioural therapy, EMDR and psychodynamic based treatments (Mevissen & de Jongh, 2010). From a medication perspective, pharmacological interventions should focus on targeting the presenting complaint and symptoms, following a full physical and mental health assessment. There is limited research evidence regarding medication treatment for PTSD in people with learning disabilities (Focht-New et al., 2010).

People with severe learning disabilities who experience a wide range of complex health conditions are routinely prescribed a range of drugs to help treat and manage their conditions. The majority are prescribed anticonvulsants to manage

seizures, laxatives for constipation, medication for gastric ulcers and gastro-oesophageal reflux disease (GORD) and psycholeptic drugs. Effective recording, monitoring and review of the polypharmacy used for people with severe learning disabilities is required (van der Heide et al., 2009).

As the population of adults with learning disabilities increases and ages, there is now a focus on older people within this population. This is important given their different health profile and multiple health morbidities and the high rates of polypharmacy (McCarron et al., 2013; Krahn & Fox, 2014; Cooper et al., 2015).

In a 2017, a research study identified that people with learning disabilities who have dementia were more likely to be prescribed antipsychotics than those without dementia, when compared to people with dementia in the general population. The prescribing of Benzodiazepines, Anticholinesterases (AChEIs) (medication prescribed for dementia), and Memantine (used to treat Alzheimer's disease) was not associated with learning disability among people with dementia. There was an association with dementia among people with learning disabilities. The researchers recommended that due to the communication difficulties experienced by some people with learning disabilities, the inappropriate use of these medications in older adults needs to be monitored and assessed for side-effects (Axmon et al., 2017).

In an Irish study involving older adults with learning disabilities, the findings highlight that antipsychotic medication is the most commonly used of the psychotropic drugs, and polypharmacy is also common for older adults with learning disabilities. Psychotropic medication combinations were identified with a need for regular review to identify on-going need, monitor effectiveness and identify side-effects. Older people with learning disabilities and with epilepsy experienced less polypharmacy (O'Dwyer et al., 2017).

Psychological interventions

The existing evidence for the clinical effectiveness of psychological treatments for people with learning disabilities is limited despite the high prevalence of mental health problems in this population, and the resulting greater demand for psychological treatments (Emerson, 2006; Cooper et al., 2007). A 2016 systematic review carried out by Osugo and Cooper (2016) highlighted that there are few evidence-based interventions for people with mild learning disabilities and mental ill-health. It was noted that existing literature is restricted in terms of quantity and quality. A few randomised controlled trials (RCTs) have provided some evidence for the efficacy of psychological interventions, although generally the studies have been of poor quality for a number of reasons (Sturmey et al., 2004). Most studies lack adequate numbers of participants and are of poor design, therefore it's very difficult to draw any meaningful conclusions from the findings.

Although standard psychosocial interventions may not be accessible, some may be if modified. A previous review searched the literature up to July 2012 and suggested that modified cognitive behavioural therapy (CBT) may be effective in treating anger and depression (Vereenoghe & Langdon 2013). A number of studies support the effectiveness of group cognitive-behavioural interventions at treating depressive symptoms, and this is maintained at follow-up (McCabe et al., 2006; McGillivray et al., 2008; McGillivray 2013; McGillivray & Kershaw, 2015). Positive outcomes have been indicated for psychoanalytic and psychodynamic psychotherapy with people with learning disabilities (Shepherd and Beail, 2017).

One small feasibility RCT assessed the impact of individual CBT, and did not find efficacy in treating patients with depression and/or anxiety (Hassiotis et al., 2013). A small non-randomised feasibility study suggested that behavioural activation may have efficacy in treating depression (Jahoda et al., 2015).

A recent systematic review and meta-analysis conducted by Koslowski et al. (2017) exploring the effectiveness of interventions for adults with mild to moderate learning disabilities and mental health problems revealed that there is no

compelling evidence supporting interventions (psychotherapy, biological or system level) aimed at improving the mental health problems in people with mild to moderate learning disabilities. The authors reported that the number of trials found was too low for definite conclusions, and whilst some interventions are promising, they should be further evaluated in larger and more rigorous trials.

Health checks

People with learning disabilities have a greater number of health problems than the general population, for example higher rates of mental ill-health, sensory problems, epilepsy, diabetes and disorders of the respiratory, gastro-intestinal and endocrine systems (Buszewicz et al., 2014; Chauhan et al., 2010; Robertson et al., 2014; Sullivan et al., 2011), yet are less likely to receive preventative care. Lower than expected rates for proactive health screening, prevention and promotion activities have been found among this population compared to the general population (Buszewicz et al., 2014; Chauhan et al., 2010; Lennox et al., 2007; Ouellette-Kuntz et al., 2015).

In the United Kingdom, there have been policy initiatives to promote health checks for people with learning disabilities. Both the Disability Rights Commission and the Healthcare for All: Report of the Independent Inquiry (Michael, 2008) recommended the introduction of health checks for people with learning disabilities.

There is a growing body of evidence on the benefits of health checks for people with learning disabilities. Health checks are associated with increased prevention activities (for example immunisations, cancer screening), increased detection of disease (thyroid and gastrointestinal disease, psychiatric disorder), increased detection of other conditions (dental problems, skin conditions), and improved follow-up management (Buszewicz et al., 2014; Robertson et al., 2014). Health checks can also enhance practitioner knowledge of the health needs of people with learning disabilities, and may help to identify gaps in health services (Lennox et al., 2013; Robertson et al., 2014).

A systematic review of international evidence on health checks for adults with learning disabilities has been recently undertaken by Robertson et al. (2011) which concluded that the introduction of health checks had resulted in 'the detection of unmet, unrecognised and potentially treatable health conditions (including serious and life-threatening conditions such as cancer, heart disease and dementia)' (Robertson et al., 2010: 24). The health checks also led to targeted actions to address health needs such as the promotion of healthier lifestyles. Moreover, health checks seem to be cost-effective as early detection reduces the costs associated with managing chronic conditions (Buszewicz et al., 2014).

Healthy Lifestyles, Health Improvement & Health Promotion

The need to improve the health of people with learning disabilities is reflected in Scottish, UK and international policy (Emerson and Baines, 2010). Although accessible and evidence-based health promotion initiatives could significantly contribute to a healthier lifestyle and lead to an increase in quality of life (van Schroyen Lantman-de Valk & Walsh, 2008; Havemen et al., 2011; Taggart & Cousins, 2014), such programmes specifically tailored to people with learning disabilities are not common (Krahn et al., 2006). Existing mainstream health promotion programmes should be adapted and evaluated for their feasibility, accessibility and effectiveness for this population. One such study conducted by Taggart et al. (2015) adapted a UK national education programme for adults with type 2-diabetes, DESMOND, now known as DESMOND-ID.

Further programme development for this group could benefit from research on bridging the gap between mainstream and learning disability health promotion (Naaldenberg et al., 2013). However, available evidence does not readily translate into practice (Naaldenberg et al., 2013).

To improve the effectiveness of lifestyle change interventions for people with learning disabilities, it is necessary to identify the effective ingredients for interventions (Michie et al., 2011). However, reporting of intervention content in published articles is heterogeneous with regards to the descriptions used (Michie

et al., 2009). For the general population, behaviour change techniques (BCTs) have been found to be an effective component of interventions changing health behaviours (Bird et al., 2013; Olander et al., 2013). It is unclear, however, whether these BCTs can be used in the same ways in interventions for people with learning disabilities (Van-Schijndel-Speet, 2015).

What the research evidence means

The life expectancy of children, adults and older people with learning disabilities is increasing which means that more are living into older age. As a result, all care services will see an increase in the number of people with learning disabilities requiring access to education, health, social care and housing services in the future. There is therefore a need for strategic and local planning and investment to ensure that there is capacity within services and the workforce to meet their needs now and in the future.

The health profile of people with learning disabilities differs from the general population and therefore specific attention and service responses are required to address their health needs and reduce the many health inequalities they experience. This is important as many of the health conditions are avoidable and preventable. Addressing these concerns at an early stage benefits people with learning disabilities, by improving their health and quality of life, their families and carers and reduces the burden on all care services over time.

The causes of death in people with learning disabilities differ from those of the general population and therefore specific actions are required to prevent avoidable deaths and ensure that assessment, treatment and interventions are timely and appropriate. While mortality rates have improved for people with learning disabilities, too many continue to experience health inequalities that are avoidable and amenable to interventions and supports. These require a sustained focus and attention over time.

People with learning disabilities have a different and more complex set of health needs, including both physical and mental health conditions and those related to their intellectual and developmental disabilities. There is a growing body of research evidence that has identified the complex morbidities experienced by a growing number of children, adults and older people with learning disabilities. These complex morbidities have major implications for people with learning disabilities and their families and carers, and the care services upon which they

rely. Early intervention, prevention and management is therefore required from universal health and social care services and specialist learning disability services. All people with learning disabilities require access to health and social care services to enable equality of health outcomes. This means that action is required in two areas. The first is to enable all people with learning disabilities to be included in and have access to universal health services available for the general population. The second is to ensure that there is access to specialist health services with practitioners with advanced knowledge, skills and expertise to undertake assessments, treatments and interventions and provide support and education to people with learning disabilities and their families, and practitioners in health social care and independent sector providers.

There is a legal duty for public services to make reasonable adjustments to ensure the needs of people with learning disabilities are assessed and met. Due to their different pattern of morbidity, specific responses are required for people with learning disabilities to ensure that care is individualised and person-centred and that reasonable adjustments are made.

People with learning disabilities experience cognitive impairments and have communication disorders that affect their ability to communicate their health needs and problems effectively. As a result, many physical and mental health conditions remain unrecognised and untreated, contributing to their discomfort, pain and distress and increased mortality and avoidable death. Improving access to universal health services and education and training is necessary as well as building capacity within specialist learning disability services.

People with learning disabilities experience many barriers when accessing healthcare that have a detrimental impact on their health and well-being and contribute to their high health needs and avoidable and preventable deaths.

Evidence-based recommendations and ways forward

Population identification and improvement

Arising from the recommendations from *The Keys to Life*, the Scottish Government has established a programme of work to develop a fuller understanding of the health and health needs of people with learning disabilities. This is necessary given the complexity of health needs experienced by the population and the impact on their health and well-being. The evidence produced is important in informing and shaping service responses across care services in Scotland to ensure that health needs are addressed. There are long term benefits from the work to monitor and evidence the changes and improvements in the health of people with learning disabilities in Scotland and the possibility of national and international collaborations to pool anonymised population data and evidence of health needs and develop evidence-based policy, guidelines, care pathways and interventions.

Action: *Supporting the work of the Scottish Government's programme to identify the health needs of people with learning disabilities is a critical key action. However, if this work is to be used effectively, local approaches to how the use the identification of need to inform future service design and delivery will need to be developed. Ensuring that local and national systems are in place to monitor progress and improvement over time will also be required. .*

A Scottish national health check programme

With the clear evidence of the extent of the health needs experienced by people with learning disabilities, there is evidence of the benefits derived from health screening programmes. Systematically undertaking health checks with people with learning disabilities leads to the identification and management of common health conditions that improves both health and quality of life and reduces the burden and long-term cost on care services. There is therefore a need for Scotland to consider developing a national health check programme for people with learning disabilities.

Action: *The Scottish Government, NHS Boards, and Local Authorities in Scotland should consider developing a national health check programme for people with learning disabilities.*

Health and social care integrated services

The setting up of Health and Social Care Partnerships (HSCPs) has brought about the delegation and devolvement of responsibilities and functions from NHS Boards and Local Authorities. Whilst NHS Boards retain wider Public Health functions, including undertaking population assessments of healthcare need, identifying the health needs of the local population, including those of people with learning disabilities, is a delegated function for HSCPs. Given the evidence of the extent of the health needs experienced by people with learning disabilities, HSCPs need to ensure that as part of their local health improvement activities, they develop and implement approaches that are open to, or specifically developed for people with learning disabilities, thereby contributing to reducing the health inequalities gap.

Action: *NHS Boards and Integrated Joint Boards (or Lead Agencies) need to ensure that the health needs of people with learning disabilities within their locality are identified and included in all local outcome improvement plans and that action is taken to develop and implement necessary activities.*

Improving health and the role of independent sector care providers

Many people with learning disabilities receive care and support in their own home or in care services, funded by Self-Directed Support or directly by the Health and Social Care Partnership. Improving the health of people with learning disabilities extends beyond health services and is a shared responsibility. The Care Inspectorate, through their national care standards and service review processes need to ensure that care providers have in place clear organisational policies regarding improving the health of people with learning disabilities within their care. There is a need for care providers to develop clear health improvement policies within their organisations that set out their position regarding improving the health of people with learning disabilities in their care.

Action: *The Care Inspectorate and care providers should ensure that health improvement policies are developed and implemented to ensure that the health needs of people with learning disabilities are identified and met.*

Specialist learning disability services

With the evidence of the increasing population of people with learning disabilities living into older age with a wide range of complex morbidities, there is a need to review the capacity and capability of specialist learning disability services to ensure that they can provide access to highly specialist services now and in the future. Specialist learning disability services provide a range of highly specialist services and supports, including the assessment of complex health needs and the delivery of treatments, therapies and interventions, and advice, education and support for people with learning disabilities, their family and carers and professionals in health, social care and independent sector services.

Action: *NHS Boards, Local Authorities and their Integrated Joint Boards need to ensure that their specialist learning disability services have the capacity and expertise to deliver specialist assessment, treatment, interventions, advice, education and support across the lifecourse of people with learning disabilities.*

Barriers to accessing healthcare

Due to their high and complex health needs, people with learning disabilities are high and frequent users of all healthcare services, including primary care, out-of-hours and unscheduled care services, acute hospitals, mental health services palliative care and end-of-life services and specialist learning disability services. With the clear evidence of the significant barriers that people with learning disabilities experience when accessing health services, there is a need to ensure that health services review all their services to respond to the needs of people with learning disabilities, thereby meeting their legal duty as required by the Equality Act. Services must also make reasonable adjustments in order to provide quality, person-centred assessment, treatment and care, and prevent avoidable harm.

Actions: *NHS Boards, Local Authorities and Integrated Joint Boards, supported by Healthcare Improvement Scotland, should reassure themselves that all health services they provide or commission are fully accessible to people with learning disabilities and meet their legal duty and prevent avoidable harm.*

Pre-registration education and practice development

A recurring theme arising from the research evidence relates to the knowledge and confidence of practitioners in health services in assessing and identifying the health needs of people with learning disabilities and providing assessments, treatments and interventions that are person-centred and respectful. There is therefore a need to ensure that all undergraduate programmes for doctors, nurses, allied health professionals and other practitioners include a clear focus on both theory and practice related aspects of working with and meeting the needs of people with learning disabilities when they access health care.

Practitioners in all areas of health services need access to education regarding the health and support needs of people with learning disabilities to ensure that the workforce has the necessary knowledge and skills required to meet the needs of this changing population, presenting with complex health morbidities.

Action: *NHS Education for Scotland, Higher Education Providers, Health and Social Care Partnerships and other key stakeholders need to collaborate to develop, implement, embed and evaluate learning materials on the health and support needs of people with learning disabilities within health services to ensure that the future and current workforce have the knowledge and skills required.*

Areas for future learning disability research

It is evident from the research studies that have been identified and included in this updated health needs assessment report that the last ten years have seen a significant increase in the number and quality of research studies being undertaken in Scotland and nationally across the United Kingdom and internationally. As a

result, there has been an increase in the number of systematic reviews and meta-analysis of research studies focusing on specific physical and mental health conditions. There has also been an increase in the number of studies researching the changing demographics of the learning disability population, including issues such as mortality, morbidity and life expectancy.

There is a growing focus on people with learning disabilities who present with morbidities and the complexity of need that they have. There is a body of research evidence that sets out the complex array of physical, mental health and cognitive and developmental disabilities. These studies set out the challenges that a new generation of people with complex health needs are presenting and will continue to present to health and care services,. There is therefore a clear need for health services and their partner services to understand and respond to the needs of an increasing and ageing population of people with learning disabilities with complex morbidities.

Arising from this is the need for further research, both within Scotland, nationally and internationally. There are a number of priority areas, including for example, population health and data linkage, complex morbidities, the needs of people with profound and multiple learning disabilities, health care transitions, ageing and people with learning disabilities, psychological interventions and treatments, impact and outcomes of interventions and treatments, adjustments to care systems to enable equality of access and outcome, the impact of education and practice development programmes on practice, patient experience and person-centred care

Action: *There is a need for targeted funding support for researchers in Scotland to collaborate on shared research projects and to work with research collaborators nationally and internationally as a means to grow and develop the evidence-base on what works to meet the current and future needs of people with learning disabilities.*

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