Standards of Practice for Physiotherapists

Working with adults with a learning disability

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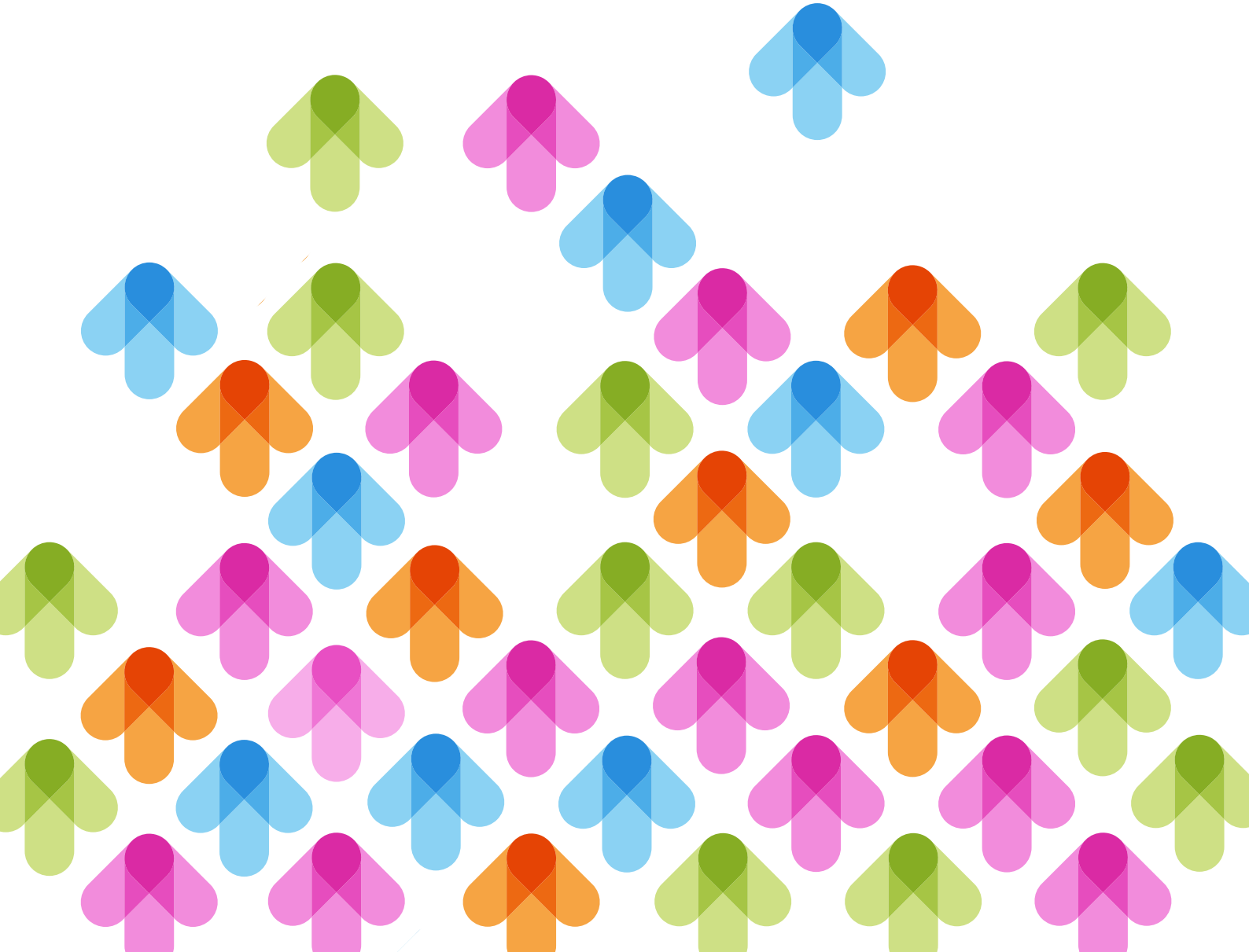

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Introduction

Adults with a learning disability experience poorer health than the general population.

(Emerson et al. 2010).

They have a shorter life expectancy and are at greater risk of premature death.

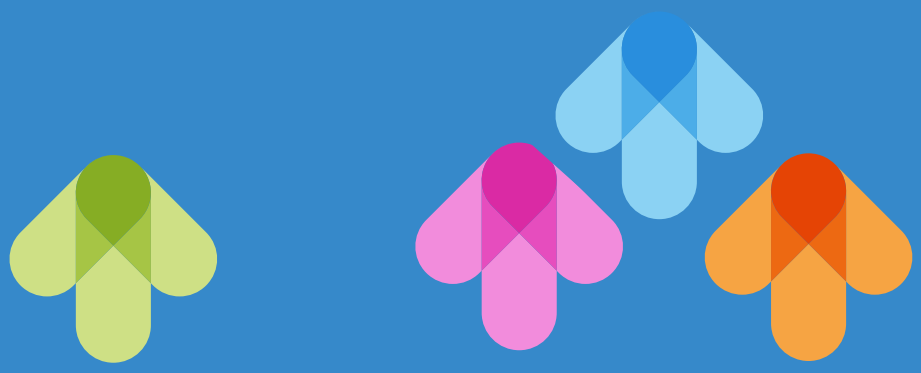
(Hollins et al. 1998; Heslop et al. 2013).

Adults with a learning disability have the same rights to access mainstream health services as the general population but may require reasonable adjustments to facilitate positive access and outcomes.

(Equality Act 2010).

However, they regularly receive inadequate health care.

(Mencap 2004, 2007 and 2012; Michael and Richardson 2008; Department of Health 2009; Heslop et al. 2013).



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Introduction

There are a number of potential barriers to adults with a learning disability successfully accessing mainstream health care. All public services, including the health sector have a legal obligation to make reasonable adjustments to overcome these barriers. Specialist learning disability health professionals have an important role to play in supporting the health and wellbeing of people with a learning disability. They are required to both support mainstream practice and directly serve those with the most complex needs (Department of Health 2000 and 2009; RCGP 2013; Learning Disability Professional Senate 2015). Specialist learning disability teams should be delivering person centred services within the community that respect and promote the rights of people with a learning disability as full citizens. To do this, there needs to be in place good commissioning, a competent workforce and a robust system to check quality and outcomes (Moore and Thorley 2011).

It is estimated that there are around 1.4 million people in the United Kingdom (UK) who have a learning disability (Mencap n.d.). Adults with a learning disability are likely to require access to physiotherapy at some point over their lifetime. There are a number of factors that predispose them to developing physiotherapy related problems. These include associated physical impairments and conditions, premature aging, increased risk of injuries and falls, poor health literacy, and leading sedentary and unhealthy lifestyles. Many people will be able to access mainstream services with reasonable adjustments (ACPPLD 2016). However, some people will require adjustments that go beyond what is reasonable and will require access to specialist learning disability physiotherapy to achieve successful outcomes.

One group of adults with a learning disability that are very likely to require regular life-long access to specialist physiotherapy are people with a complex physical disability, such as individual's with severe cerebral palsy and profound and multiple learning disabilities (PMLD). Research conducted by the Centre for Disability (2009) estimated that in an 'average' area in England with a population of 250,000 the number of adults with PMLD needing health and social care services will rise by 1.8% per year from 78 in 2009 to 105 in 2026; and the number of young people with PMLD becoming adults in any given year will rise from 3 in 2009 to 5 in 2026. This growth is attributed to more young people surviving into adulthood and an increase in life expectancy due to improvements in medical care. Although this is a relatively small increase, this population of people are among the most disabled and vulnerable individuals in our community (Mansell 2010) and are likely to require intensive access to specialist learning disability physiotherapy services to manage their health needs throughout their lives.

Without a clear definition and national standards, specialist learning disability physiotherapy services have evolved guided by local priorities and pressures, dependent on local commissioning. This has led to individuals and local teams developing their own standards, resulting in wide variations in the commissioning and delivery of services across the UK. The researchers have anecdotal evidence and received feedback from specialist learning disability physiotherapists across the UK that highlighted a number of concerning emerging themes relating to individual specialist learning disability physiotherapists and physiotherapy services.

These include:

- Poor understanding of the role of physiotherapy for adults with a learning disability, especially amongst commissioners; service managers and policy makers.
- Specialist physiotherapy posts being downgraded and, in some areas, completely decommissioned.
- Physiotherapists being asked to take on roles that are outside of their scope of practice and divert them from their primary roles.
- Limited access to adequate supervision with a suitably qualified and experienced clinician.
- A lack of standards regarding the training and education that specialist learning disability physiotherapists require to become competent professionals.
- A paucity of skilled and experienced specialist learning disability physiotherapists in positions of management and influence to advocate the need for commissioning and retention of specialist physiotherapy posts.
- Published research, local evidence and wider anecdotal information indicates an increase in the numbers of adults with a learning disability who have complex health needs who require specialist 24 hour postural management.

In response, the researcher's conducted a five round Modified Delphi Technique study to develop a definition and standards of practice for specialist learning disability physiotherapists. This involved a systematic review of the current literature pool and four rounds of questionnaires to explore the views and opinions of an expert panel recruited via the Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD).

Research Methodology and Results

Literature review

The results of the research have led to the development of the 'standards of practice' which aim to:

- enhance specialist learning disability physiotherapists in their everyday clinical practice through supporting clinical reasoning and evidence based arguments;
- to provide support and evidence for specialist learning disability physiotherapists to influence service leads, managers and commissioners to improve, standardise and shape the delivery, development and commissioning of services across the UK; and
- raise awareness of the role of the specialist learning disability physiotherapist to commissioners, service managers, the multidisciplinary team and mainstream health and social care professionals.

> *It is the researcher's belief that proactive specialist learning disability physiotherapy can deliver high-quality cost-effective interventions that are person centred and needs led.*

Standards of practice

Physiotherapists must meet the standards of proficiency to become registered with the Health and Care Professions Council (HCPC) (HCPC 2018). The HCPC, regulates the physiotherapy profession and clinicians must work within the standards in order to maintain their registration to practice. As an autonomous professional, the physiotherapist needs to make informed, reasoned decisions about their practice. This includes seeking advice and support from education providers, employers, colleagues, professional bodies, unions and others to ensure that the wellbeing of service users is always safeguarded.

The HCPC recognises the role played by the Chartered Society of Physiotherapy (CSP), in providing guidance and advice about good practice that help physiotherapists meet the HCPC standards. There are more than thirty physiotherapy professional networks that are self-governing bodies responsible for providing the clinical leadership for their specialism, as well as managing their own financial and organisational liabilities.

The Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD) is the professional network for specialist learning disability physiotherapists. The group aims to provide a platform for information update and exchange; national networking; support; promotion of evidence-based practice and research; and to improve the awareness of the rights and needs of people with a learning disability. The authors have worked in collaboration with members of the ACPPLD to develop the standards of practice.

The standards of practice and definition of the specialist learning disability physiotherapist detailed within this document were derived through analysis of the available evidence and expert opinion of experienced specialist learning disability physiotherapists. They are systematically developed statements about the role of the specialist learning disability physiotherapist. The statements are not a mandate for practice but assist service development, delivery and commissioning; and clinical reasoning about appropriate health care for specific circumstances. Regardless of the strength of the evidence on which the recommendations are made, it is the responsibility of the individual clinician and service to interpret their application for each situation, taking account of the individual needs, preferences and values of service users, as well as the local context.

Definition of a learning disability

> *"Adults with a learning disability are people first, who should be valued and respected for their differences. They have the same rights as any other citizen."*
>
> (Joint committee of Human Rights 2008 – Life like any other)

For the purposes of this standards of practice document the term 'learning disability' will be adopted throughout. People can often find the term learning disability confusing because there are many different definitions and terms which are used interchangeably. In the UK, the most common definition for learning disability is from Valuing People: a new strategy for learning disability for the 21st century. This government White Paper for England about health and social care support for people with a learning disability (Department of Health 2001) states that a learning disability includes the presence of:

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

It is internationally recognised that three criteria must be met before a learning disability can be identified or diagnosed.

1. Intellectual impairment (Intellectual quota (IQ) <70)
2. Social or adaptive dysfunction combined with IQ <70
3. Early onset.

Learning disability; intellectual disability or learning difficulty

The words we use to describe a particular impairment or disability change as a result of listening to people with personal experience; and as a result of changing values and attitudes in society. There have been many different terms used to describe a person with a learning disability from mental sub-normality, mental retardation, mental handicap and to eventually, in the 1990's, learning disability.

The same words can have different meanings in different countries. Although we share a common language with countries such as America and Australia the words we use to describe particular disabilities related to learning are different. An increasing number of international organisations and countries such as the USA, Canada and Australia use the term 'intellectual disability'. This term has also been used in Professor Mansell's report on services for people with severe and profound learning disabilities (Mansell 2010).

Another term that is frequently used is 'learning difficulty'. The terms 'learning difficulty' and 'learning disability' are often confused, or even used interchangeably. It is important to understand that in the education system in the UK, the term learning difficulty relates to specific conditions such as dyslexia, dyspraxia, developmental co-ordination disorder, dyscalculia and attention deficit hyperactivity disorder (ADHD). Unlike a learning disability, these conditions do not affect general intelligence (IQ).

As a child develops and their learning needs become acknowledged, there is no formal process for diagnosing a learning disability. This can cause challenges for young people and services as they transition into adult services. In the UK, adults with a learning disability should have their

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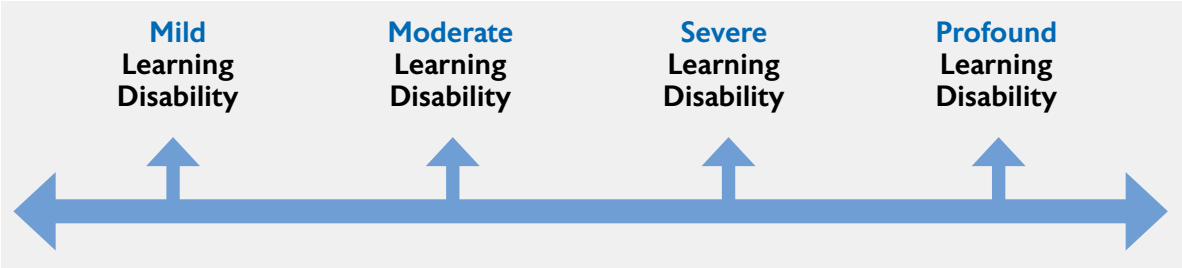
diagnosis coded on the general practitioner register. Unfortunately, due to the confusion around the terminology they are not always accurate resulting in most adult services requiring some form of eligibility pathway.

The term learning disability is used to describe a varied group of individuals from those requiring a high level of support to those who only need support in a few areas. The UK categorises people with a learning disability in relation to their needs or level of cognition. Degrees of learning disability are conventionally estimated by standardised intelligence tests which can be supplemented by scales assessing social adaptation in a given environment. These measures provide an approximate indication of the degree of learning disability. In an attempt to explain the wide range of different abilities the British Institute of Learning Disabilities (n.d.) adopt the idea of a continuum of learning (Figure 1).

Figure 1: The continuum of learning disability



Mild:	People with an IQ score of 50-70. Many people with a mild learning disability will be able to work and maintain good social relationships. They may require support to understand complex ideas.
Moderate:	People with an IQ score of 35-50. People with a moderate learning disability can communicate their day-to-day needs and wishes. They may need some assistance and guidance with their personal care and may require longer time to learn new skills.
Severe:	People with an IQ score of 20-35. They often use basic words and gestures to communicate their needs. They may need a high level of support with activities of daily living. Some may have additional medical needs and require more support with mobility.
Profound:	A person with a profound learning disability will have an IQ score under 20, with severely limited understanding.

The definitions of the different categories of the continuum of a learning disability are not rigid. For example, some people who have a complex physical disability and multiple health needs who require full support for all daily living activities may have an IQ in the 'mild' range. Therefore, it is important to always see the person first; not make assumptions about a person's cognitive and functional abilities; and adapt communication and intervention to that person's individual needs.

Causes of a learning disability

There are many factors that may cause a person to have a learning disability. A learning disability occurs when a person's brain development is affected. A child may be diagnosed at birth, or during early childhood. But for some people it may be many years before they receive a diagnosis, while others may never receive a diagnosis at all.

The causes of a learning disability include genetic factors, infections and brain injury or damage.

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For many who are diagnosed with having a learning disability the cause remains unknown. There are three critical events where a learning disability could become present:

1. Before birth

Chromosomal conditions

Chromosomes make up the genetic blueprint for humans. Everyone has 23 pairs of chromosomes in their cells. Abnormality in chromosomes can result in a learning disability. For example, conditions such as Down's syndrome, Fragile-X syndrome, Williams syndrome, Wolf-Hirschhorn syndrome and Prader-Willi syndrome have a high prevalence of an associated learning disability.

Maternal factors

Infections such as cytomegalovirus, toxoplasmosis and rubella may be passed on to the unborn child and may lead to a learning disability. Other maternal factors that can cause a learning disability include diet deficiencies and excessive consumption of alcohol (foetal alcohol syndrome) during pregnancy.

Metabolic disorders

A person's metabolism controls all the chemical reactions in the body. Certain conditions affecting metabolism can result in a learning disability. For example, phenylketonuria (PKU) is a rare but potentially serious inherited disorder that increases the levels of an amino acid called phenylalanine. People with PKU can't break down phenylalanine which then builds up in the blood and brain. This can lead to brain damage and a learning disability.

2. During birth

Oxygen deprivation is a significant risk for babies during the labour and delivery process. Lack of oxygen at birth can have long-term effects for the infant and can cause long-term disabilities, developmental delays and a learning disability.

3. After birth

Some childhood illnesses and infections such as encephalitis and meningitis can cause a learning disability. Neurological events such as stroke, traumatic brain injury and haemorrhage can also cause a learning disability. Social and environmental factors, such as poor housing conditions, poor diet and health care, malnutrition, lack of stimulation and all forms of child abuse may also lead to learning disability.

Numbers of people with a learning disability

It is estimated that there are around 1.4 million people in the UK who have a learning disability (Mencap n.d.). The number of adults with a learning disability known to Clinical Commissioning Groups in England; Health and Social Care Trusts in Northern Ireland; National Health Service (NHS) boards in Scotland; and local authorities in Wales are significantly less (Northern Ireland Assembly 2014; Public Health England 2016; Scotland Commission for Learning Disability 2017; Welsh Government 2018). The data used in this document to reference the numbers of people with a learning disability is related to England. The researchers acknowledge that the population numbers will vary in Northern Ireland, Scotland and Wales but the trends described are likely to be similar and thus should not detract from the application of the Standards of Practice in these countries.

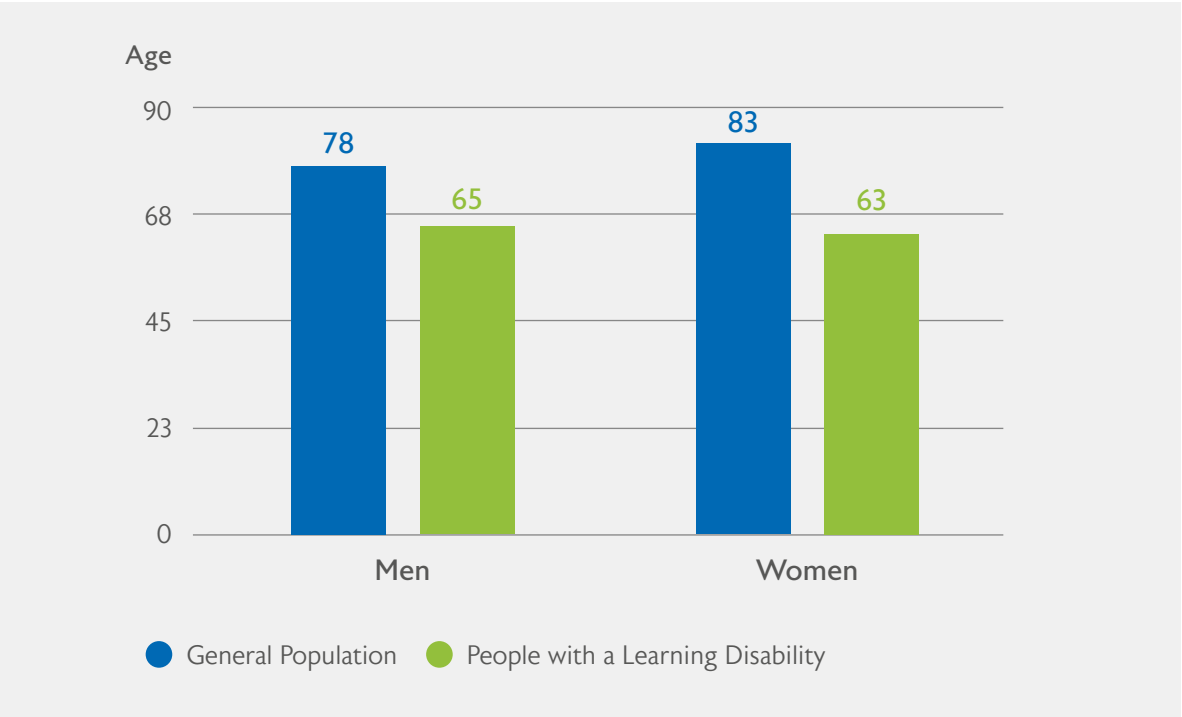
Public Health England recognises that there is no definitive record of the number of people with a learning disability in England. As a result, population estimates are made using particular services, overall population predictions for England and the results of epidemiological research (Public Health England 2016).

In 2016-17, 0.46% people were recorded by clinical commissioning groups as having a learning disability (NHS Digital 2017). However, the prevalence of a learning disability is estimated to be 2.16% of the English adult population (Public Health England 2016a). The number of people with a learning disability are expected to rise steadily. Emerson and Hatton (2008) recognise that it is not possible to accurately determine whether the numbers of people with a learning disability are changing and by how much. However, they acknowledge that several factors are likely to result in the growth of this population. These include the future size and composition of the English population; potential changes in the incidence and prevalence of a learning disability; the increase in proportion of younger English adults who belong to South Asian minority ethnic communities; an increase in survival rates among young people with severe and complex disabilities; and reduced mortality among older adults with a learning disability.

Health outcomes

Adults with a learning disability have higher morbidity rates than the general population. They have higher incidence of cancer, coronary heart disease, respiratory disease, diabetes, reflux, and constipation (Emerson and Baines 2011). Many people have multiple health problems and long-term conditions. As a result, people with a learning disability often die younger. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) found that 42% of the 247 deaths reviewed were premature. On average men die 13 years younger than the general population and women 20 years (Figure 2). The average age of death of people with PMLD was significantly lower at 41. Life expectancy was linked to severity of learning disability and the number of multi-morbidities. The most common reasons for these findings were delays or problems with diagnosis or treatment; difficulties with identifying needs; and challenges in providing appropriate care in response to changing needs (Heslop et al. 2013).

Figure 2: Life expectancy of people with a learning disability vs. general population (Heslop et al. 2013)



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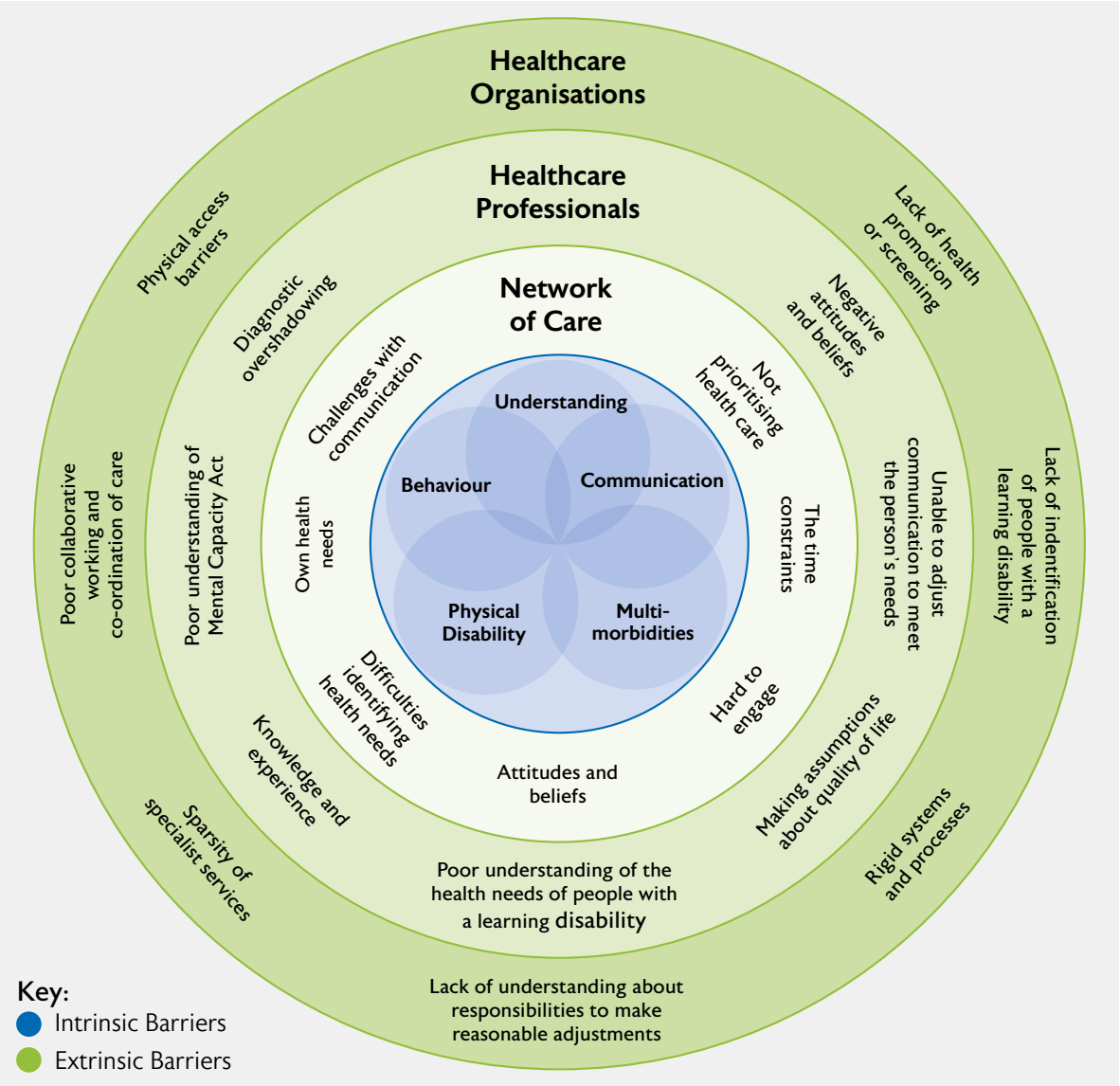
Barriers to adults with a learning disability accessing healthcare

Adults with a learning disability have the same right as the general population to access mainstream healthcare services and to receive the most current evidence-based treatments and techniques (Department of Health 2001). However, there are often a number of barriers that prevent someone with a learning disability having equal access to care (Department of Health 2009; Equalities Act 2010; Heslop et al. 2013). Barriers to accessing health services are factors that prevent an individual gaining access to successful healthcare. These can manifest as physical, psychological, financial, graphical, cultural, language and resource barriers.

Barriers can be categorised into intrinsic and extrinsic. The intrinsic barriers to adults with a learning disability accessing successful healthcare are those related to the person, usually as a result of the individual's communication difficulties, limited understanding and ability to learn new information, physical disability, and complex health background. The extrinsic barriers to adults with a learning disability accessing successful healthcare arise from factors outside of the individual's control such as the person's network of care, the professionals that provide care, and health and social care organisations (Figure 3).

Figure 3: Diagram illustrating the barriers to providing successful healthcare to adults with a learning disability

Barriers to adults with a learning disability accessing healthcare



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Reasonable adjustments

Under the Equality Act (2010), all disabled people have the right to reasonable adjustments when using public services, including healthcare. These adjustments aim to overcome the barriers that disabled people would otherwise face ensuring they have equal access to good quality healthcare (Mencap 2018).

Public Health England (2016) states that reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to policies, procedures and staff training to ensure that services work equally well for people with a learning disability. Public sector organisations should not simply wait and respond to difficulties as they emerge, the duty on them is 'anticipatory'. This means they have to think about what is likely to be needed in advance. In addition, all organisations that provide NHS or adult social care must follow the accessible information standard by law. This standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support, so they can communicate effectively with health and social care services (Public Health England 2016).

There is a body of literature that evidences that when the appropriate adjustments are made, adults with a learning disability can have successful outcomes from accessing mainstream healthcare services (Michael and Richardson 2008; Heslop et al. 2013; RCGP 2013). Public Health England have produced a series of guidance papers on making reasonable adjustments to manage some of the key health problems of people with a learning disability. These include constipation, dementia, dysphagia, obesity and weight management, oral care and postural care and falls.

Mencap (2018) produced guidance for healthcare professionals on making reasonable adjustments for people with a learning disability in hospital. They report that 1,200 people with a learning disability die avoidably every year, when good healthcare could have saved their lives. Thus, making reasonable adjustments in hospital is important. Reasonable adjustments can be simple changes made by one healthcare professional, or they can be more complex and need multiple teams to work together. Mencap states that making reasonable adjustments can mean removing barriers that people with a learning disability face or providing something extra for someone to enable them to access the healthcare they need. Mencap recognise that every person is different, therefore the adjustments people with a learning disability need will differ from person to person. However, there are common adjustments that help lots of people with a learning disability such as speaking clearly and using simple words; taking time; working with the person's network of care; being flexible with appointment times; listening to specialist learning disability professionals; providing written information in an accessible format; and not making assumptions.

In 2017 the ACPPLD launched the 'so your next patient has a learning disability' campaign. This involved publishing an information booklet and poster providing advice and guidance for physiotherapists not specialising in learning disability services on making reasonable adjustments to support people with a learning disability to access mainstream physiotherapy. The advice covers a range of intrinsic and extrinsic adjustments mainstream physiotherapists may need to make through the service user's journey to directly support adults with a learning disability to access successful physiotherapy.

The reasonable adjustments to support adults with a learning disability to access successful physiotherapy outcomes.

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Some adults with a learning disability are unable to access mainstream services even when reasonable adjustments are made. The intrinsic and extrinsic barriers to these individuals accessing mainstream services are often wide ranging and to overcome them requires individually tailored adjustments. As a result, the adjustments required to provide successful healthcare and physiotherapy may go beyond what is reasonable and possible for mainstream services. To implement this level of adjustments requires specialist knowledge, skills and services. Therefore, individuals will require support from specialist learning disability physiotherapists to either support positive access to and responses from services; or to provide direct assessment and intervention (Department of Health 2009; Heslop et al. 2013; Learning Disability Professional Senate 2015; National Quality Board 2017).

Physiotherapy

Physiotherapy is an allied health care profession which promotes and restores movement and function when someone is affected by injury, illness or disability. Physiotherapy is a science-based profession and takes a 'whole person' approach to health and wellbeing, which includes the patient's general lifestyle (CSP 2019). Physiotherapists are autonomous practitioners who provide expert, holistic interventions to help restore movement or, in the case of permanent injury or disease, to lessen the effects of any dysfunction (WHO n.d.).

Physiotherapists have worked with adults with a learning disability since before the 1960's. Although there have been many changes in attitudes and beliefs, laws, legislation, government and local policy, models of care, and significant advancement in technology and health care the core functions of the role of the specialist physiotherapist remain mostly the same. Physiotherapists continue to predominantly support adults with a learning disability with the most severe and complex physical disabilities; those with mobility problems and at risk of falls; and those who are unable to successfully access mainstream healthcare services.

History of physiotherapy for adults with a learning disability.

20th century timeline of key legislation, publications, national developments, policies, guidelines and labelling related to the health needs of adults with a learning disability.

Physiotherapy for adults with a learning disability

Adults with a learning disability have a number of factors and associated conditions that increase the prevalence of developing **physiotherapy related problems** either from an early age or within their lifetime. These manifest due to:

1. Associated conditions that result from the initial neurological event or genetic abnormality
2. The impact of the person's physical and neurological disability such as increased risk of injuries and falls and premature aging
3. The person's learning disability and cognitive impairment
4. Making poor lifestyle choices, such as leading sedentary and unhealthy lifestyles
5. Poor access to healthcare due to intrinsic and extrinsic barriers and health inequalities

Physiotherapy needs of adults with a learning disability.

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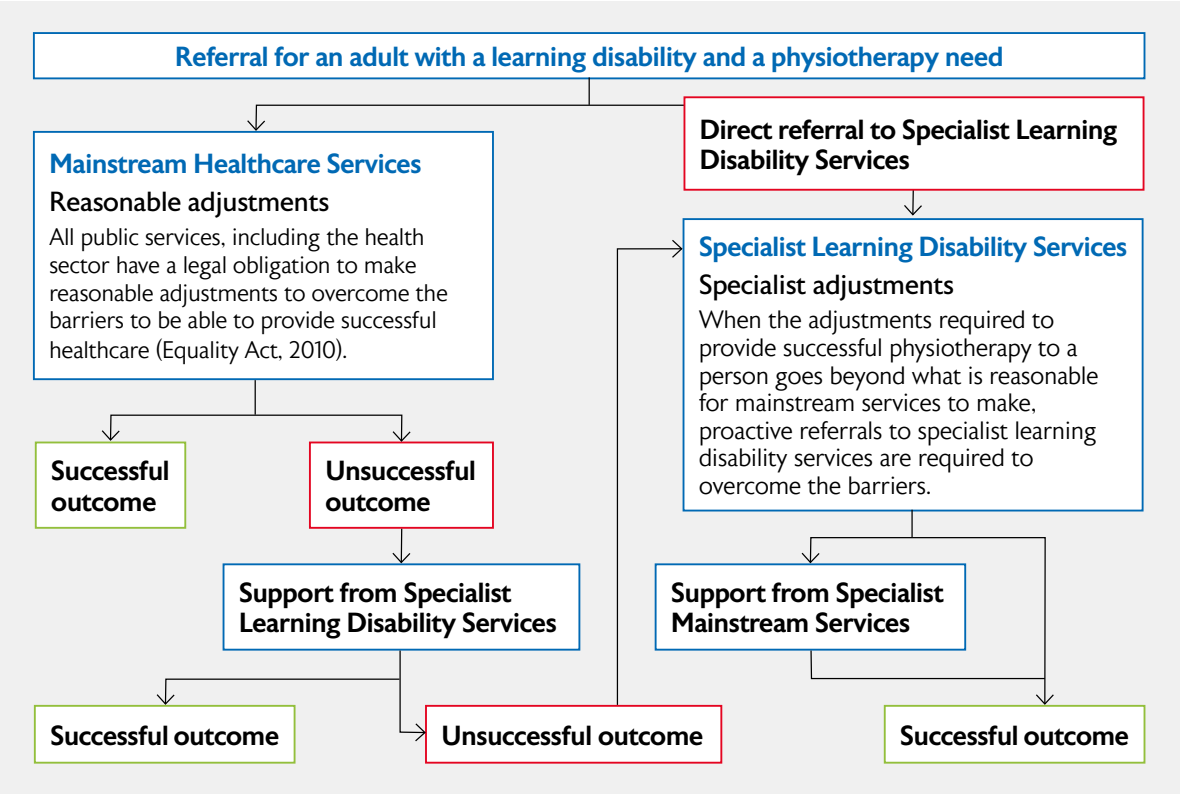
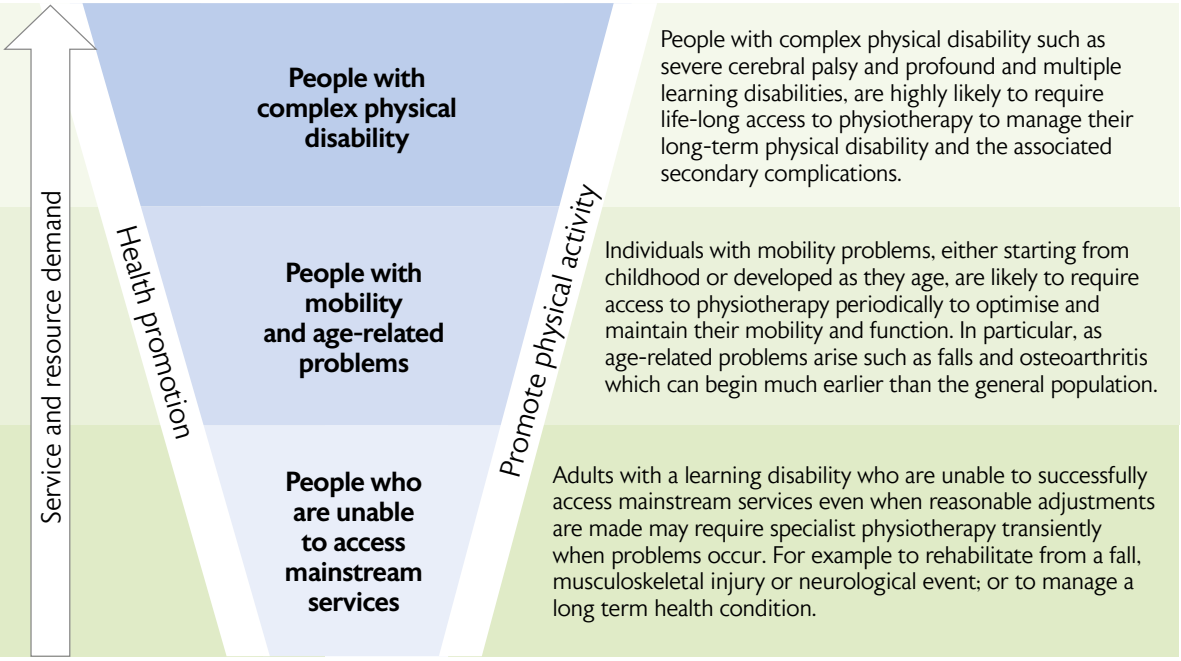
As a result, many adults with a learning disability will require access to physiotherapy at some point within their lifetime. The pathway to people receiving a successful outcome can occur via mainstream physiotherapy services or through specialist learning disability physiotherapy services. Often mainstream and specialist services are required to work in collaboration to share and combine their knowledge and skills to deliver a successful outcome (Figure 4).

Figure 4: Pathway to providing successful physiotherapy to adults with a learning disability



The main areas where specialist learning disability physiotherapists provide services fall within three groups (Figure 5). There are likely to be some variations to this model depending on local drivers, populations and services.

Figure 5: The main areas where specialist learning disability physiotherapists provide services



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A new definition for the 'Specialist Learning Disability Physiotherapist'

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A new definition for the 'Specialist Learning Disability Physiotherapist'

'Learning disability physiotherapists provide specialist assessment, treatment and management to adults with a learning disability whose needs cannot be successfully met by mainstream services, even when reasonable adjustments are made. Physiotherapists will work in collaboration with the person, their network of care, mainstream health services, and the multidisciplinary team to enhance, optimise and maintain the person's physical presentation, function and quality of life."

Supporting Evidence

For specialist learning disability physiotherapy service leads and physiotherapists to deliver the new definition it is ESSENTIAL they:

- Be accessible and equitable to ALL adults with a learning disability with a physiotherapy need that cannot be met successfully by mainstream services even when reasonable adjustments are made. This includes:
  - Where mainstream physiotherapy services provide the appropriate reasonable adjustments but are unable to successfully meet the person's physiotherapy needs.
  - Where mainstream physiotherapists lack the specialist skills required to provide successful physiotherapy to the adult with a learning disability.
  - When the adjustments required for the adult with a learning disability to successfully access mainstream physiotherapy services go beyond what is reasonable.
  - Where mainstream physiotherapy services are not available and accessible locally to meet the physiotherapy needs of adults with a learning disability.
- Be based on clinical need, not on an assumed level of a person's learning disability.
- Consider whether mainstream services are best placed to successfully meet the individual's physiotherapy needs and support positive access to and responses from mainstream services where appropriate.
- Work in collaboration with mainstream physiotherapy and other relevant healthcare services in the assessment, management and monitoring of adults with a learning disability to ensure positive access and successful outcome.
- Support mainstream physiotherapy and relevant health services to make the reasonable adjustments required to ensure adults with a learning disability have positive access to and responses from services where extra support from specialist learning disability services is indicated.
- Make the adjustments required to provide successful physiotherapy to adults with a learning disability that go beyond what is reasonable for mainstream services.
- Seek specialist support from mainstream physiotherapy and other related healthcare services to provide physiotherapy to adults with a learning disability where appropriate.

- Work in collaboration with the multidisciplinary team to provide a co-ordinated approach to care and contribute to local co-ordination processes and pathways through supporting communication and providing appropriate documentation as required.
- Develop links, open lines of communication and direct referral pathways with local health and social care services critical to the effective delivery of physiotherapy services to adults with a learning disability. This aims to support collaborative working and positive access to and response from services.
- Support the development of local integrated multi-disciplinary and agency pathways for adults with a learning disability who have or are at high risk of developing physiotherapy and health problems.
- Develop and target service provision, delivery and priorities on the changing and evolving physiotherapy needs of adults with a learning disability locally.

Conclusion

To deliver the new evidenced based definition effectively, specialist learning disability physiotherapists and services have the responsibility to ensure local practice meets the expected level of performance outlined in this document. As a minimum, it is essential that specialist learning disability physiotherapy services be based on clinical need not on an assumed level of a person's learning disability; are accessible and equitable to all adults with a learning disability and a physiotherapy need which cannot be met successfully by mainstream services, even when reasonable adjustments are made; make the adjustments required to provide successful physiotherapy to adults with a learning disability that go beyond what is reasonable for mainstream services; and offer and deliver the different aspects of the role of the specialist learning disability physiotherapist to the standards outlined within this document. To achieve this expected level, it is essential that specialist learning disability services are commissioned and resourced appropriately. Staff must have the knowledge, skills and experience to provide physiotherapy to adults with a learning disability in all settings, providing specific and additional input as required to respond to their health care needs.

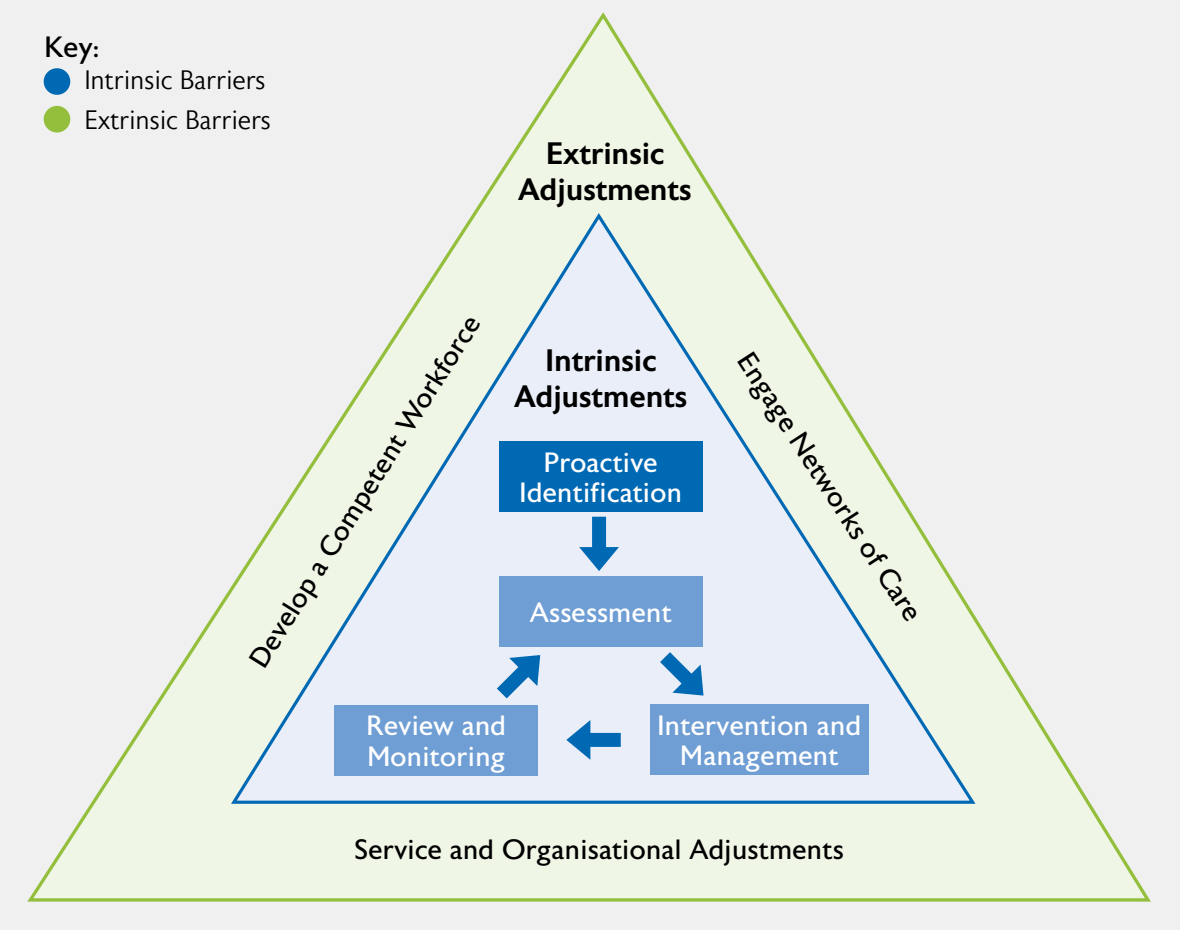
Specialist adjustments

The unique attributes of the specialist learning disability physiotherapist.

"Learning disability physiotherapists provide specialist assessment, treatment and management to adults with a learning disability whose needs cannot be successfully met by mainstream services even when reasonable adjustments are made. Physiotherapists will work in collaboration with the person, their network of care, mainstream health services, and the multidisciplinary team to enhance, optimise and maintain the person's physical presentation, function and quality of life."

To successfully deliver the definition, it is essential that specialist learning disability physiotherapists make the adjustments required to provide successful physiotherapy to adults with a learning disability. Providing these adjustments requires specialist knowledge and skills and a model of working which facilitates the development of relationships with adults with a learning disability and their network of care. Adjustments are required at a strategic level to develop a competent network of care and local workforce, as well as the systems to support adults with a learning disability to access the healthcare they need in a timely manner (Figure 5). This level of adjustment are not possible or reasonable for mainstream services and it is essential they are be delivered by specialist learning disability physiotherapy services to achieve successful outcomes.

Figure 6: The domains where specialist learning disability physiotherapists make adjustments to provide successful physiotherapy



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NB: The following statements were developed through thematic analysis of the available evidence, the roles, statements of each role and qualitative data extrapolated through the questionnaire rounds. They outline the unique attributes of the specialist learning disability physiotherapist compared to mainstream physiotherapy services. These statements overarch all the roles and standards of practice within this document.

Intrinsic adjustments

Proactive Identification

Specialist learning disability physiotherapists:

1. Be proactive in identifying, managing and monitoring high risk groups of adults with a learning disability who have, or are at risk of developing physiotherapy problems. For example, people with complex physical disabilities, profound and multiple learning disabilities, cerebral palsy, Down's syndrome, adults with a learning disability and dementia, and young people transitioning from paediatric to adult services.
2. Work in collaboration with health and social care professionals in the early detection and treatment of health problems to address the health inequalities experienced by adults with a learning disability. For example, dementia in people with Down's syndrome, recognition of the signs of dysphagia and aspiration, and the early detection of falls and risk of falls.

During Assessment

Specialist learning disability physiotherapists:

1. Offer assessments over a prolonged period and multiple contacts where required to ensure that they are able to accurately assess and diagnose physiotherapy and other health related problems. This supports the development of long term relationships and builds knowledge and understanding of the individual and their network of care.
2. Develop an understanding of the person's comprehension, communication style and needs and adapt communication appropriately.
3. Where available use specialist assessment tools and outcome measures that are specifically designed and validated for use with adults with a learning disability.
4. Adapt mainstream physiotherapy assessments to meet the specific needs of the adult with a learning disability taking into consideration evidence-based assessments, assessment protocols, their learning disability, and social circumstances.
5. Complete assessments in the different environments and situations adults with a learning disability access. Adults with a learning disability often present differently dependent on the environment and support provided; and assessments are often not reliably transferable between settings.
6. Gain subjective information by proxy from many sources such as the network of care, family members, and external agencies to accurately assess and diagnose adults with a learning disability. Use a proxy reporter who has the most day to day contact with the person and knows them well such as a key worker/family member where the person is unable to self-report.
7. Individually tailor assessments to the person's diagnosis, learning disability, social circumstances, behaviour, specific risk factors, drug history, past medical history.
8. Link information from different sources to form part of the assessment process and provide an overview and summary to the adults with a learning disability and their network of care in a way that they can understand.
9. Make assessments flexible, adaptable and creative where the adult with a learning disability is unable to tolerate standardised assessment methods and tools.

During intervention and management

Specialist learning disability physiotherapists:

1. Work in collaboration with mainstream physiotherapy and other related health services to develop and adapt management plans that take into consideration the person's learning disability, home environment, social circumstances, daily routines and activities.
2. Develop individually tailored management plans that take into consideration the person's learning disability, complex physical disability, behavioural presentation, home environment, social circumstances, daily routines and activities. Plans should be integrated into the person's and their network of care's daily routine, activities and lifestyle. This aims to improve compliance with recommendations and not increase the care burden or impact on quality of life.
3. Offer a holistic long term disability management approach which enhances engagement with physiotherapy and takes a long term view of rehabilitation, intervention and management.
4. Set functional and long-term goals and work over a prolonged period of time to achieve the goals.
5. Disseminate management plans that are written in an accessible format to ensure that they are can be understood and implemented.
6. Make onward referrals to relevant health and social care services and support positive access to and responses from services where extra support from the specialist learning disability physiotherapy team is indicated and critical to the outcome.
7. Offer specialist interventions to address physiotherapy goals which are creative, fun and enjoyable to improve compliance and outcomes. For example, group exercise, hydrotherapy/aquatic therapy and physiotherapy on a trampoline/rebound therapy. Adults with a learning disability are often unable to complete specific exercise programmes and/or understand the benefits which impacts on compliance. Therefore, utilising specialist interventions can help to overcome these problems.
8. Support a positive risk management approach to ensure that the needs of the adult with a learning disability are met in a person-centred manner, that maximises personal choice and quality of life as well as evidence based intervention.

Review and monitor

Adults with a learning disability are often unable to express when their needs have changed or when they experience side effects of treatments or management plans. They may also be unable to seek medical support and are reliant on others to identify and meet their health needs. Changes can be very subtle making it difficult for the person's network of care to detect. Therefore, reviews are required to monitor the person's physical presentation and following any treatment, especially in people with communication difficulties, and complex presentations and social situations.

1. Offer regular monitoring and reviews for adults with a learning disability in a timely manner as clinically indicated depending on the level of risk; and the complexity of the person's disability, associated health problems and social circumstances.
2. Offer access to regular reviews, monitoring and supervision where management plans have been delegated in line with the CSP guidance on the delegation of tasks to support workers.
3. Provide monitoring and review immediately after implementation of new or changes to management plans to ensure that there is no adverse impact.
4. Contribute to reviewing and monitoring of mainstream physiotherapy and relevant healthcare service management plans to ensure that adults with a learning disability and their network of care implement treatment plans correctly and feedback as needed.

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Extrinsic Adjustments

Engage the person's network of care

Specialist learning disability physiotherapists:

1. Invest time into developing relationships with the network of care and engaging them in physiotherapy. Adults with a learning disability are often reliant on their network of care to provide physical care and to advocate on their behalf. Hence, are integral to providing successful physiotherapy to adults with a learning disability.
2. Develop physiotherapy management plans that consider their impact on the person's network of care.
3. Engage networks of care in service development and design to ensure local specialist learning disability physiotherapy teams are serving the needs of the local population.
4. Delegate management and treatment plans to the person's network of care for completion on a daily and sustainable basis. Adults with a learning disability often require support from their network of care to complete their management plans either due to their learning disability or physical limitations.

Develop a competent local workforce

Specialist learning disability physiotherapists:

1. Provide training and education to healthcare professionals, networks of care and the local community workforce to
   a. develop a competent local workforce that supports adults with a learning disability;
   b. raise awareness of the physiotherapy needs of adults with a learning disability;
   c. provide advice on how to make reasonable adjustments; and
   d. promote the role of the specialist learning disability physiotherapist.

Service and Organisational

Specialist learning disability physiotherapists:

1. Offer a model of service delivery which facilitates the development of relationships with adults with a learning disability and their network of care. This includes offering extended episodes of care; allowing more time to assess and treat; providing a continuity of care; taking a proactive approach; and being able to review and monitor people regularly.
2. Offer flexible working patterns to take account of the individual's and their network of care's needs. For example, a late appointment to observe an evening routine.
3. Deliver bespoke learning disability physiotherapy services to meet the needs of the local population of adults with a learning disability were mainstream services are not available or accessible. For example:
   - 24 hour postural service where there is a lack of local mainstream service provision.
   - Falls prevention and intervention, where mainstream services are commissioned to only see people over the age of 65.
4. Support adults with a learning disability and their network of care to have positive access to and responses from health and social care services where attendance is critical to the outcome of the appointment. This includes supporting communication of the person's health needs to healthcare professionals; improving understanding of the rationale behind assessment and treatment options; and facilitating the implementation of recommendations into the community.
5. Use specialist knowledge, skills and experience in working with adults with a learning disability to support the development of local healthcare services, activities and environments.
6. Work in collaboration with the person's network of care, multidisciplinary team, social services, mental health, and external agencies to provide a co-ordinated approach to care.

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The role of the specialist learning disability physiotherapy service

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The role of the specialist learning disability physiotherapy service

"Learning disability physiotherapists provide specialist assessment, treatment and management to adults with a learning disability whose needs cannot be successfully met by mainstream services even when reasonable adjustments are made. Physiotherapists will work in collaboration with the person, their network of care, mainstream health services, and the multidisciplinary team to enhance, optimise and maintain the person's physical presentation, function and quality of life."

To successfully deliver the definition, it is essential that specialist learning disability physiotherapists offer and deliver the roles within this document to the standards outlined. The 15 different facets of the roles of the specialist learning disability physiotherapist have been categorised further into **Lead**, **Contributory** and **Supporting** roles. These have been developed into an Onion Diagram representing the roles of the Specialist Learning Disability Physiotherapy Service. The evidence for each of the roles is documented in the supporting information.

LEAD roles

These are the roles that are ESSENTIAL for the specialist learning disability physiotherapist to take lead responsibility for providing where the adult with a learning disability is unable to successfully access mainstream services, even when reasonable adjustments are made. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream local physiotherapy and healthcare services.

It is ESSENTIAL that physiotherapists develop specialist knowledge, skills and experience in these areas to be able to successfully deliver physiotherapy to adults with a learning disability.

CONTRIBUTORY roles

The specialist learning disability physiotherapist will contribute to and work in collaboration with members of the multidisciplinary team or mainstream services to deliver the contributory roles. Physiotherapists will contribute their specialist knowledge, skills and experience and be versatile in developing new skills and competence. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream physiotherapy and healthcare services.

SUPPORTING roles

The supporting roles underpin the successful provision of the lead and contributory roles of the specialist learning disability physiotherapist. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream local physiotherapy and healthcare services.

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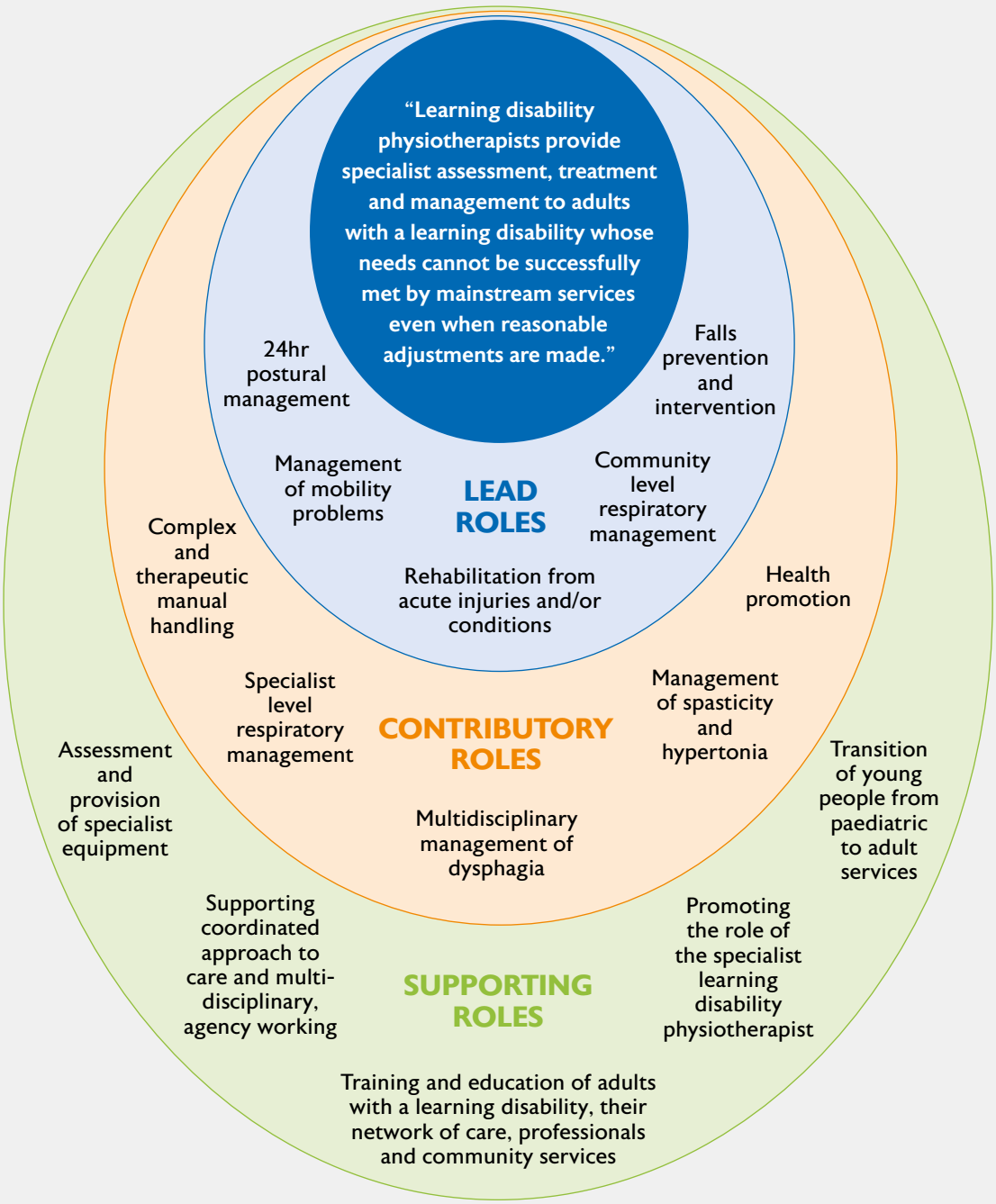
Onion Diagram

The Roles of Specialist Learning Disability Physiotherapy Services



Click on the individual roles within the diagram to take you to the relevant section.

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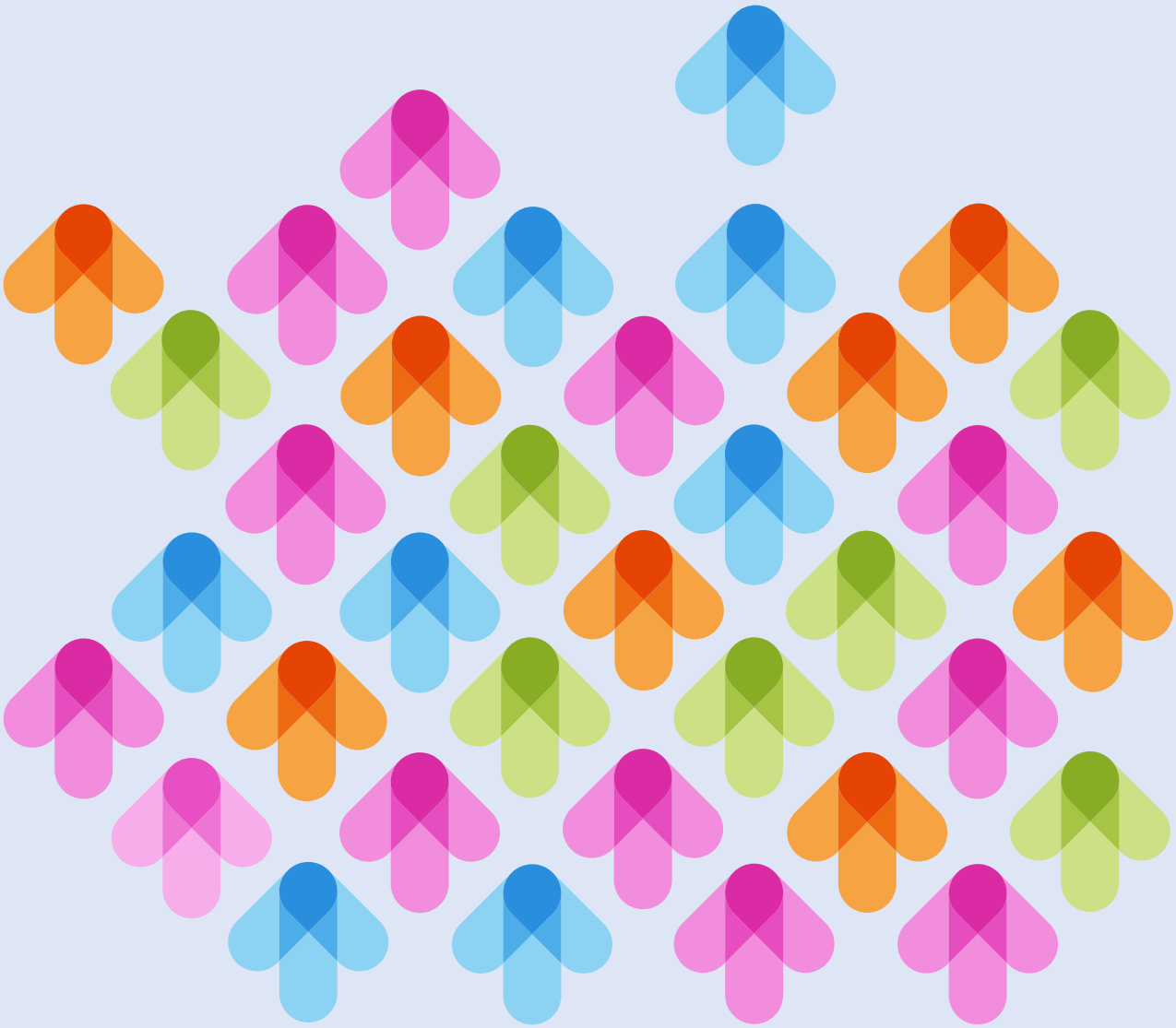
LEAD roles

These are the roles that are ESSENTIAL for the specialist learning disability physiotherapist to take lead responsibility for providing where the adult with a learning disability is unable to successfully access mainstream services, even when reasonable adjustments are made. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream local physiotherapy and healthcare services.

It is ESSENTIAL that physiotherapists develop specialist knowledge, skills and experience in these areas to be able to successfully deliver physiotherapy to adults with a learning disability.

Onion Diagram



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24 hour postural management

It is ESSENTIAL that specialist learning disability physiotherapy services offer 24hr postural management to adults with learning and complex physical disabilities whose needs cannot be met successfully by mainstream services even when reasonable adjustments are made.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

NB: Readers should also consider standard of practice statements under the management of spasticity and hypertonia; and the assessment and provision of equipment when providing 24hr postural management.

Assessment

Specialist learning disability physiotherapists:

1. Complete comprehensive holistic and person-centred postural assessments for adults with complex physical and learning disabilities. This may include using a standardised assessment tool such as the Management of Physical Disability 24-7 assessment tool for purposes of repeatability and ongoing monitoring.
2. Use validated objective outcome measures to determine the effectiveness of postural management interventions. The recommended measures that are consistently used in practice are: The Goldsmith indices of body symmetry; range of motion (ROM) measures using a goniometer and a measuring protocol; repeated measures from baseline assessment; Goal Attainment Scale (GAS); Therapy Outcome Measures (TOMs).
3. Complete postural assessments that are flexible and adaptable where people are unable to tolerate standardised assessment tools because of their complexity, compliance or behaviour.
4. Assess the causes of the person's physical and neurological presentation to project any future deterioration and the development of secondary complications.
5. Assess for the presence and risk of developing secondary complications of complex physical disabilities.
6. Assess the person's neurological presentation including hypertonia, spasticity, dystonia, movement disorders, retained reflexes and sensory impairment; and how this may be impacting on the person's physical and functional presentation.
7. Screen the person's respiratory and chest health as part of the postural assessment and complete a community respiratory assessment where indicated.
8. Assess the person's hand management including their function, hygiene, skin integrity and range of movement and make onward referral to hand therapy and/or orthotic services where indicated.
9. Assess day-to-day levels of pain and discomfort as part of postural assessments. Where the person is unable to self-report, use a proxy reporter who has the most day to day contact with the person and knows them well. For example, a key worker or family member. Consider using a validated pain and discomfort assessment tool such as DisDAT (Disability Distress Assessment Tool) and the Paediatric Pain Profile.
10. Assess whether a medical issue is contributing to the person's presentation. Where a medical cause is suspected or indicated make an onward referral to the person's GP and/or relevant healthcare professionals for further assessment and management, and support positive access to and responses from services.

11. Assess bowel elimination habits and identify any signs and symptoms of constipation. Where indicated, work with the multidisciplinary team and the person's network of care to develop a constipation care plan. This includes non-pharmacological treatments such as healthy diets, hydration, regular exercise, movement, good toilet habits and abdominal massage. Make onward referrals to the GP or specialist services for advice on pharmacological management.

Abdominal massage for constipation

12. Assess and monitor spinal position and deformities as indicated using objective measurements as well as taking into consideration the impact of the person's spinal position on their function, respiratory health and pain.

Intervention and Management

Specialist learning disability physiotherapists:

1. Develop postural management plans that aim to promote and maintain function and quality of life; prevent and reduce body shape distortion; and reduce the impact of associated secondary complications.
2. Develop a person centred realistic postural management plan based on the outcome of a postural assessment. Postural management plans may require multi-disciplinary and multi-professional involvement and includes:
   - Identifying the optimal positioning for sitting, lying and standing (if applicable) in relation to the person's physical and neurological presentation.
   - Recommendations for regular changes of position over a 24-hour period that effectively supports the person's posture whilst facilitating function, comfort, engagement and quality of life.
   - Contributing to and advising on the medical management. For example, the person's neurological presentation, orthopaedic conditions, respiratory health.
   - The management of the person's critical range of movement.
   - Optimising function and quality of life.
   - Therapeutic activities. For example, movement and counter movement programmes, physiotherapy on a trampoline/rebound therapy, gym programmes, and community activities.
   - Considering the impact of the programme on the person's network of care.
3. Postural management plans should consider the person's '24-hour profile'; the different environments the person's accesses; and be integrated into the person daily activities and lifestyle.
4. Document any recommendations that have not been possible to deliver including the reasons and rationale for the actions not implemented.
5. Disseminate postural management plans in an accessible format to ensure that they are fully understood and embedded into daily routines.
6. Make recommendations for and support the assessment and provision of specialist equipment assessed as essential to the individual's postural management plan. This may include equipment such as wheelchairs, alternative seating, standing frames, sleep systems and orthotic devises.

7. Work in collaboration with relevant healthcare professionals to support the assessment and provision of specialist equipment. Develop funding applications for equipment and resources assessed as essential to the individual's postural management plan. These should include sound clinical reasoning and justification considering the cost versus benefit as well as the impact on the person and their network of care.

8. Make onward referrals to relevant health and social care professionals and services as indicated by assessment and support positive access to and responses from health and social care professionals and services where required.

9. Work in collaboration with local wheelchair and special seating services to support the successful assessment and provision of equipment. Wheelchairs should support the person's posture and facilitates function whist providing comfort; and be practical for the families and carers to use within their daily lives and routines.

10. Develop a person-centred management plan of the person's spinal position where indicated by spinal assessment. This should include:
    - Conservative physiotherapy interventions and techniques in the management of the person's spinal deformities such as postural management, positioning, stretching and muscle strengthening.
    - Making onward referrals to specialist orthotics services and orthopaedic consultants for assessment and consideration of spinal bracing and surgery as clinically indicated and support positive access to and responses from services as required.
    - Contributing to post surgery physiotherapy management in collaboration with the spinal consultant and relevant mainstream physiotherapy services.

11. Work in collaboration with specialist orthotic services to support the successful assessment and provision of orthotics where indicated. This may include assisting in the monitoring of orthotics following prescription to ensure that they are introduced and implemented correctly and that they are not causing any adverse effects such as pressure sores, pain or discomfort.

12. Work in collaboration with district nursing, tissue viability nursing, occupational therapy, dietetics and the network of care in the management of pressure ulcers. This will include advising on the positioning and repositioning of people with complex postural needs and making recommendation for appropriate equipment as indicated.

13. Delegate postural management plans and specialist interventions to the person's network of care adhering to the CSP guidance on the delegation of task to support workers to ensure that programmes and plans are delivered competently and in a regular sustained manner.

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Review and Monitoring

Specialist learning disability physiotherapists:

1. Offer regular monitoring and reviews of postural assessments and management plans to monitor functional and postural needs; to manage potential deterioration; and to assess the effectiveness of current postural management intervention. Reviews should be conducted in a timely manner as clinically indicated depending on the level of risk; and the complexity of the person's disability, associated health problems and social circumstances.
2. Provide the person and their network of care with the relevant information to recognise decline and deterioration in an individual's postural presentation to encourage timely re-referral back to the team.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists develop specialist knowledge and skills in providing 24hr postural management to adults with a learning disability.

Community level respiratory management

It is ESSENTIAL that specialist learning disability physiotherapy services offer community level respiratory management services to adults with a learning disability whose needs cannot successfully be met through mainstream services even when reasonable adjustments are made; and to people with complex physical disability who have respiratory problems and/or at risk of developing respiratory complications.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Complete community level respiratory assessments of adults with a learning disability who have/are at risk of developing respiratory complications.

   Community Level Respiratory Assessment includes:

   - A subjective assessment including history of present condition, baseline respiratory measures, past medical history, social history and drug history.
   - An objective assessment including colour, alertness, perfusion, peripheral or central oedema, chest wall deformity, body posture and tone, work of breathing, breathing pattern, temperature and clamminess.
   - Auscultation where appropriately trained.
   - Clinical observations such as respiratory rate, heart rate, oxygen saturations, blood pressure, temperature, sputum volume, viscosity, colour, odour/foul breath, and previous chest X rays.
   - Cough effectiveness, strength, productive, reflexive or voluntary.

2. Work in collaboration with speech and language therapists and the multidisciplinary team to identify adults with a learning disability who have saliva management dysfunction and make onward referrals to GP's or specialist respiratory services for further assessment and consideration for medical management where clinically indicated.

Intervention and Management

Specialist learning disability physiotherapists:

1. Develop, implement and delegate community level respiratory management plans working in collaboration with the multidisciplinary team where indicated.

   Community Level Management plans may include:

   - Treatment techniques aimed at maintaining or improving airway clearance dysfunction including:
     - Positioning
     - Movement programmes
     - Therapeutic activities such as physiotherapy on a trampoline/rebound therapy and hydrotherapy/aquatic therapy
     - Chest physiotherapy
     - Oral suction
     - Positive Expiratory Pressure (PEP)

- Treatment programmes aimed at maintaining or improving thoracic deformity including:
  - Postural management
  - Positioning
  - Therapeutic activities such as physiotherapy on a trampoline/rebound therapy and hydrotherapy/aquatic therapy
  - Exercise
  - Onward referrals to orthotics and orthopaedics
- Treatment programmes to maintain or improve pulmonary fitness such as:
  - Movement programmes
  - Therapeutic activities such as physiotherapy on a trampoline/rebound therapy and hydrotherapy/aquatic therapy
  - Supported walking
  - Standing programmes
  - Pulmonary rehabilitation
- Making onward referrals to relevant health and social care professionals as indicated by assessment such as specialist respiratory services and support positive access to and responses from services as required.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Provide regular monitoring and reviews of adults with a learning disability assessed at risk of developing respiratory complications. Reviews should be conducted in a timely manner as clinically indicated depending on the severity of the person's respiratory health and its impact on the person's function, independence and care needs.

2. Offer regular monitoring and reviews to adults with a learning disability and respiratory complications who have been delegated respiratory care plans that have been developed by the learning disability physiotherapy team in line with the CSP guidance on the delegation of tasks to support worker.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists working with adults with a learning disability develop appropriate knowledge and skills to conduct community level respiratory assessments and management plans.

Falls prevention and intervention

It is ESSENTIAL for specialist learning disability physiotherapy services to consider whether mainstream falls prevention and intervention services are better placed to successfully meet the physiotherapy needs of the adult with a learning disability in the first instance and support positive access to and responses from mainstream services where appropriate.

It is ESSENTIAL for specialist learning disability physiotherapy services to support mainstream falls services to make person centred reasonable adjustments to facilitate adults with a learning disability to have positive access to and responses from services.

It is ESSENTIAL for specialist learning disability physiotherapy services to offer specialist learning disability falls services to adults with a learning disability whose needs cannot be successfully met by mainstream service even when reasonable adjustments are made.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Include falls screening tools within multidisciplinary assessments with the aim to identify people who have fallen/are at high risk of falling and may benefit from further support and/or intervention.
2. Offer individually tailored multifactorial falls assessments to adults with a learning disability that require access to specialist learning disability falls services.
3. Administer evidence based outcome measures that have been validated for use with adults with a learning disability as part of assessment and for evaluation of intervention.
   For example:
   - Timed up and go test.
   - One-leg stance test.
   - Tinnetti Balance Assessment.
   - Berg Balance Score.
   - Rivermead Mobility Index.
   - Barthel Activities of Daily Living Index.
4. Screen for fear of falling during assessments. If the person reports fear of falling assess using an appropriate recognised tool such as Falls Efficacy Scale (FES).

5. Refer people to their GP or specialist services for assessment of fracture risk and consideration for bone sparring treatment if they are a:
   - Women aged 65 years and over
   - Man aged 75 years and over
   - Women aged under 65 years and men aged under 75 years in the presence of risk factors, for example:
   - Previous fragility fracture.
   - Current use or frequent recent use of oral or systemic glucocorticoids.
   - History of falls.
   - Family history of hip fracture.
   - Other causes of secondary osteoporosis.
   - Low body mass index (BMI) (less than 18.5 kg/m2).
   - Smoking.
   - Alcohol intake of more than 14 units per week for women and more than 21 units per week for men.

   Use a standardised osteoporosis risk assessment tool such as FRAX or Q fracture to support this referral where appropriate.
6. Assess whether pain is a contributing factor to the person's falls and deterioration in function. Where pain is suspected or indicated this may involve a multidisciplinary assessment using specialist pain assessments for people with a learning disability such as DISDAT or Paediatric Pain Profile.
7. Assess whether medical causes are contributing to the person's falls such as dizziness on standing and black outs. Where a medical cause is suspected make an onward referral to the person's GP and/or relevant healthcare professionals for further assessment and management and support positive access to and responses from services.
8. Develop joint SMART goals with the person and/or their network of care to evaluate the outcomes of interventions.

Management

Specialist learning disability physiotherapists:

1. Develop an individualised falls rehabilitation and prevention programme based on the outcome of the assessment taking into consideration the person's learning disability, physical disability, behavioural presentation, home environment, social circumstances and daily routines and activities.
2. Delegate programmes to the person and their network of care where indicated in line with the CSP guidance on the delegation of tasks to support workers.
3. Contribute to the development of risk assessments which support adults with a learning disability to lead as active and as inclusive lives as possible in their communities. This may involve positive risk taking.

   A POSITIVE RISK MANAGEMENT APPROACH: ensures that the needs of the adult with a learning disability are met in a person-centred manner, to maximise personal choice, quality of life as well as evidence based falls intervention.

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4. Offer specialist interventions such as specialist falls groups, physiotherapy on a trampoline/rebound therapy, hydrotherapy/aquatic therapy and gym programmes as part of the person's falls prevention and management plans.
5. Make onward referrals to local health and social care services such as general practitioner and/or specialist falls services for medical reviews, orthotics, social services and occupational therapy as clinically indicated and support positive access to and responses from services where required.
6. Make recommendations for the provision of specialist equipment to reduce the risk of falls and promote functional independence. This may require collaborative working with occupational therapy colleagues and depend on local equipment provision agreements.
7. Support adults with a learning disability to access community-based exercise groups and activities where appropriate and available to ensure long term sustainable falls prevention and as part of health promotion.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Offer timely monitoring and reviews to people who are frequent fallers or at high risk falls and where falls management plans are delegated. The frequency of reviews should be proportional to the level of risk of injury and may depend on associated health problems and social circumstances.
2. Provide the person and their network of care with the relevant information to recognise decline and deterioration in an individual's mobility to make timely re-referrals back to the team.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists working with adults with a learning disability develop specialist knowledge and skills to offer evidence-based falls prevention and intervention services to adults with a learning disability whose needs cannot be successfully met by mainstream services. It is also essential that physiotherapists have specialist knowledge of the risk factors that increase the prevalence of falls in adults with a learning disability. Evidence suggests that these include:

1. Abnormal patterns of walking because of neurological impairment.
2. Concurrent medical problems.
3. Impulsiveness and distractibility.
4. Visual deficits.
5. Taking more than four medications, especially epilepsy and antipsychotic medications.
6. Epilepsy.

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Management of mobility problems

It is ESSENTIAL that specialist learning disability physiotherapy services consider whether mainstream mobility and rehabilitation services are better placed to successfully meet the physiotherapy needs of adults with a learning disability in the first instance and support positive access to and responses from services where appropriate.

It is ESSENTIAL that specialist learning disability physiotherapy services support mainstream mobility and rehabilitation services to make reasonable adjustments to support adults with a learning disability to have positive access to and responses from services.

It is ESSENTIAL that specialist learning disability physiotherapy services offer services to manage the mobility problems of adults with a learning disability whose needs cannot be successfully met by mainstream services even when reasonable adjustments are made.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

NB: Readers should also consider standard of practice statements under the management of spasticity and hypertonia; and the assessment and provision of equipment when providing management of mobility problems.

Assessment

Specialist learning disability physiotherapists:

1. Offer comprehensive mobility assessments using evidence-based outcome measures where applicable. Outcome measures that have been validated for use with adults with a learning disability include:
   - Timed up and go test,
   - Two-leg stance test,
   - Rivermead Mobility Index,
   - Barthel Activities of Daily Living Index.

2. Refer people to their GP or specialist services for assessment of fracture risk and consideration for bone sparring treatment if they are a:
   - Women aged 65 years and over,
   - Men aged 75 years and over,
   - Women aged under 65 years and men aged under 75 years in the presence of risk factors, for example:
   - Previous fragility fracture.
   - Current use or frequent recent use of oral or systemic glucocorticoids.
   - History of falls.
   - Family history of hip fracture.
   - Other causes of secondary osteoporosis.
   - Low body mass index (BMI) (less than 18.5 kg/m2).
   - Smoking.
   - Alcohol intake of more than 14 units per week for women and more than 21 units per week for men.

   Use a standardised osteoporosis risk assessment tool such as FRAX or Qfracture to support this referral where appropriate.

3. Assess whether pain is a contributing factor to the person's mobility problems and deterioration in function. Where pain is suspected or indicated this may involve a multidisciplinary assessment using specialist pain assessments for adults with a learning disability such as DISDAT or Paediatric Pain Profile.
4. Assess whether a medical issue is contributing to the person's change in presentation as part of physiotherapy assessments. Where a medical cause is suspected or indicated make an onward referral to the person's GP and/or relevant healthcare professionals for further assessment and management and support positive access to and responses from services.
5. Complete assessments of the person's mobility in different environments to consider extrinsic factors such as busy environments, uneven surfaces and changes in light.

Intervention and Management

Specialist learning disability physiotherapists:

1. Develop individualised management plans based on the outcome of the assessment taking into consideration the person's learning disability, physical disability, behavioural presentation, home environment, social circumstances and daily routines and activities.
2. Offer specialist interventions such as exercise groups, physiotherapy on a trampoline/rebound therapy, hydrotherapy/aquatic therapy, gym programmes as part of the person's mobility management plan.
3. Set functional SMART goals with the person and/or their network of care to evaluate intervention.
4. Work in collaboration with occupational therapy colleagues to make recommendations to improve any environmental factors assessed to be contributing to the person's mobility problems.
5. Support adults with a learning disability to access community-based exercise groups and activities where available, to facilitate long term outcomes and management of mobility problems.
6. Develop, disseminate and delegate accessible individualised mobility management plans to the person and their network of care.
7. Make recommendations for the provision of specialist equipment to improve mobility and promote functional independence. This may require collaborative working with occupational therapy colleagues and depend on local equipment provision agreements.
8. Develop funding applications to justify the provision of essential specialist equipment, increased support hours and funding for community activities where they are deemed essential to physiotherapy management.
9. Make onward referrals to local health and social care services such as spasticity clinics, wheelchair services, orthotics, social services, occupational therapy, and orthopaedics as clinically indicated and support positive access to and responses from services where required.
10. Work in collaboration with specialist orthotic services in the assessment and provision of orthotics assessed as clinically needed to enhance and optimise the person's function and/or physiotherapy management. This may include assisting in the monitoring of orthotics following prescription to ensure that they are introduced and implemented correctly; and that they are not causing any adverse effects such as pressure sores, pain or discomfort.

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Review and Monitoring

Specialist learning disability physiotherapists:

1. Offer timely monitoring and reviews to people who have ongoing mobility problems and are at risk of deterioration. The frequency of reviews should be proportionate to the level of risk of injury and the risk of deterioration; and could depend on associated health problems and social circumstances.
2. Provide the person and their network of care with the relevant information to recognise decline and deterioration in an individual's mobility to encourage timely re-referral back to the team.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists develop specialist knowledge and skills to manage the mobility needs of the adult with a learning disability. This includes developing in depth understanding of the mobility problems of high risk groups and how to successfully manage these issues including:

1. People with cerebral palsy (GMFCS Level I, II and III).
2. People with Down's syndrome.
3. People with severe epilepsy.
4. People taking antipsychotic medication.
5. People with conditions which predispose them to develop mobility problems.
6. Older adults with a learning disability.
7. People aging with physical disabilities.

Rehabilitation from acute injuries and/or conditions

It is ESSENTIAL that specialist learning disability physiotherapy services work in collaboration with mainstream physiotherapy and other related healthcare services in the rehabilitation from acute injuries and conditions of adults with a learning disability whose needs cannot be met successfully by mainstream services even when reasonable adjustments are made. For example, fractures, musculoskeletal injuries and neurological events. This will involve:

1. Mainstream physiotherapy services leading on rehabilitation with support of the specialist learning disability physiotherapist.
2. Specialist learning disability physiotherapists and mainstream services working in collaboration to provide rehabilitation to the person.
3. Specialist learning disability physiotherapists leading on the rehabilitation with support from mainstream physiotherapy and other related healthcare services.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Complete or contribute to assessments taking into consideration evidence-based practice, any protocols in place, and the person's learning disability.

Intervention and Management

1. Develop or contribute to a person-centred treatment programme taking into consideration the recommended treatment protocols for the injury and the person's learning disability.
2. Make recommendations for the provision of equipment to facilitate rehabilitation with support from mainstream services where appropriate.
3. Make onward referrals to relevant health and social care services where appropriate and support positive access and responses from services.
4. Delegate individualised management plans to the person's network of care.
5. Support mainstream services to provide accessible information to the person and their network of care to enhance their understanding of recommended rehabilitation; any proposed surgery or procedures; to maximise their capacity to make decisions; and to contribute to best interest decisions where needed.
6. Support adults with a learning disability to have successful hospital admissions and to facilitate safe and timely discharges where extra support from the specialist learning disability team is indicated and critical to the outcome. This includes supporting assessments and rehabilitation; providing advice on the postural management of people with complex physical and learning disabilities; sharing information about baseline presentations and previous physiotherapy input; and advocating and supporting access to appropriate post discharge rehabilitation services.

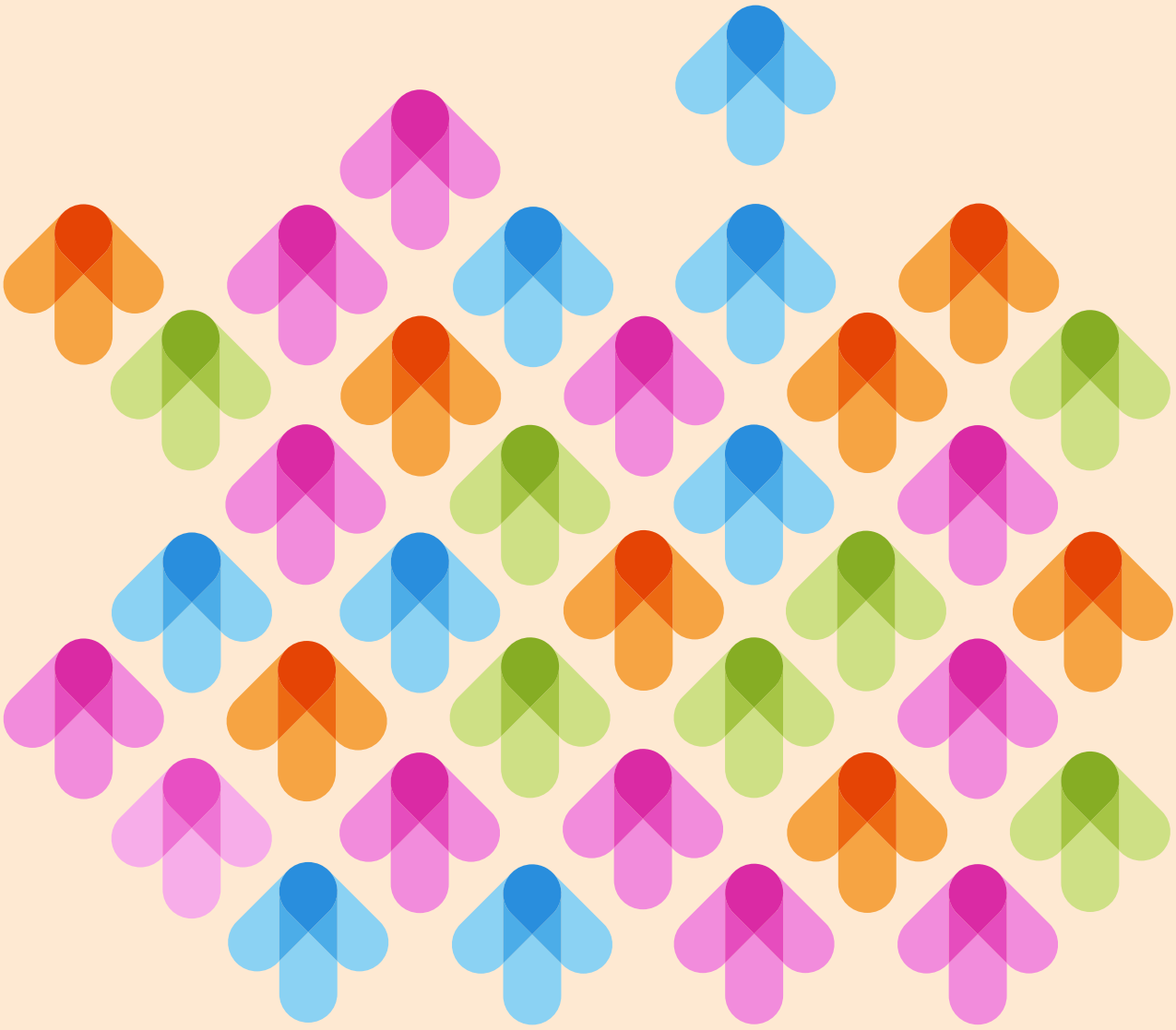
Knowledge and Skills

It is ESSENTIAL that specialist learning disability physiotherapists apply their specialist skills in providing physiotherapy to adults with a learning disability; supporting them to access mainstream services; and supporting mainstream services to make reasonable adjustments. They will also need to be versatile in developing new skills and competence in the specific area of physiotherapy depending on the reason for referral.

CONTRIBUTORY roles

The specialist learning disability physiotherapist will contribute to and work in collaboration with members of the multidisciplinary team or mainstream services to deliver the contributory roles. Physiotherapists will contribute their specialist knowledge, skills and experience and be versatile in developing new skills and competence. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream physiotherapy and healthcare services.

Onion Diagram



Multidisciplinary management of dysphagia

It is ESSENTIAL that specialist learning disability physiotherapy services work in collaboration with speech and language therapists and the wider multi-disciplinary team in the identification of potential signs of dysphagia and aspiration, and the assessment and management of dysphagia in adults with a learning disability.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Identify potential signs of dysphagia and aspiration in adults with a learning disability and make onward referrals to appropriate services to ensure their needs are addressed in a timely manner.
2. Work in collaboration with speech and language therapists and the wider multi-disciplinary team to complete meal time and dysphagia assessments for adults with a learning disability. This includes completing assessments:

   - of the optimal position for a safe and effective swallow; and
   - to facilitate and optimise independent eating and drinking.
3. Complete community level respiratory assessments for adults with a learning disability and dysphagia where clinically indicated and make onward referrals to specialist respiratory services if required.

Intervention and Management

Specialist learning disability physiotherapists:

1. Contribute to the development of multidisciplinary, person-centred dysphagia and mealtime care plans.
2. Work in collaboration with speech and language therapists and wider multidisciplinary team to develop an individualised positioning plan based on the outcome of the assessment. This aims to optimise a safe and effective swallow to reduce the risk of aspiration.
3. Contribute to the development of multi-disciplinary risk assessments and management strategies that support a positive risk management approach to ensure that the needs of adults with a learning disability are met in a person-centred manner, to maximise personal choice, quality of life as well as evidence-based dysphagia intervention.
4. Work in collaboration with the multidisciplinary team to implement advice on the optimal position to reduce risk of reflux where the person has complex positioning needs.
5. Advise on physiotherapy management techniques to aid saliva clearance such positioning to encourage anterior loss of saliva and/or the use of oral suction.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Monitor the effects of any changes made to the individual's position during their meal time to ensure there is no negative impact on their ability to swallow safely or increase the risk of aspiration or choking. People may use compensatory movements of their body and head to improve their swallow efficiency and safety thus changing their position may impact of their ability to utilise these strategies.
2. Provide the person and their network of care with the relevant information to identify signs of aspiration and changes in dysphagia to encourage them to make timely re-referrals to back to the team.
3. Work in collaboration with speech and language therapists and the multidisciplinary team to review dysphagia and mealtime care plans and risk assessments as clinically indicated.

Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists develop the appropriate knowledge, skills and experience in the physiotherapy aspects of the assessment and management dysphagia. This includes:

1. The assessment and development of an individualised positioning plan for the optimal position for safe and effective swallowing; reducing the risk of reflux; and promoting anterior loss of saliva.
2. Optimising independent eating and drinking skills.
3. Community level respiratory assessments.

Health promotion

It is ESSENTIAL that specialist learning disability physiotherapy services support adults with a learning disability to lead an active lifestyle in line with the public health agenda and offer long-term preventative management of physiotherapy related problems.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Specialist learning disability physiotherapists:

1. Work in collaboration with health and social care professionals, the person's network of care, service providers, leisure centres, voluntary and charity organisations, local healthy lifestyle initiatives, and local disability sports and activity groups to support adults with a learning disability to lead an active lifestyle in line with the public health agenda.
   This may include:
   - Developing knowledge of the exercise groups and activities available locally.
   - Acting as specialist advisors to support services to make reasonable adjustments for adults with a learning disability.
   - Sign posting people to activities where indicated.
   - Facilitate engagement in physical activities and exercise opportunities where there are specific physiotherapy related barriers to inclusion and access.
   - Contributing to training and education to improve awareness of the needs of adults with a learning disability.
2. Develop and maintain local directories of community activities and groups that people and their network of care may access to lead an active lifestyle and support preventative long-term disability management.

Knowledge and Skills

To deliver this role successfully it is essential that learning disability physiotherapists develop specialist knowledge, skills and experience in supporting adults with a learning disability to engage in physical activity and lead an active and healthy lifestyle in line with the public health agenda. To achieve this physiotherapist will need to understand:

1. The reasons why adults with a learning disability lead sedentary lives.
2. The barriers to adults with a learning disability engaging in the recommended amount of daily physical activity.
3. How to support adults with a learning disability and their network of care to lead an active lifestyle.
4. How to support local community services, facilities and groups to make reasonable adjustments to support adults with a learning disability to access physical activity.
5. The availability and accessibility of local community services, facilities and groups for adults with a learning disability.

Specialist level respiratory management

It is ESSENTIAL that specialist learning disability physiotherapy services work in collaboration with mainstream and specialist respiratory services where available, to provide specialist level respiratory management to adults with a learning disability with complex respiratory presentations.

Where specialist respiratory services are not available, physiotherapy services should proactively seek to develop links and pathways with local specialist and community respiratory services. For example, respiratory services for people with neurological conditions with a respiratory component such as Duchenne Muscular Dystrophy or Motor Neuron Disease; or services who manage people who require long-term ventilation and/or tracheostomies.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

NB: Readers should also consider standard of practice statements under 24hr postural management and community respiratory management.

Assessment

Specialist learning disability physiotherapists:

1. Work in collaboration with mainstream and specialist respiratory services to provide specialist level respiratory assessments.

Intervention and Management

Specialist learning disability physiotherapists:

1. Specialist respiratory management plans may include:
   - Specialised physiotherapy treatment techniques aimed at maintaining or improving airway clearance dysfunction. Including:
     - Airway clearance devices such as cough assists, lung volume recruitment bags, vest.
     - The assessment, provision and implementation of specialist respiratory equipment.
     - Medication.
2. Work in collaboration with healthcare professionals to support end of life planning such as facilitating and contributing to the development of advance and escalation of care plans where extra support from the specialist learning disabilities physiotherapist is indicated. For example, where there is an established relationship with a person and their network of care; or where deterioration in health is likely to impact on physiotherapy management such as respiratory complications in people with complex physical disability.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Work in collaboration with mainstream or specialist respiratory services to provide regular monitoring and reviews of adults with a learning disability assessed at risk of developing respiratory complications. Reviews should be conducted in a timely manner as clinically indicated depending on the severity of the person's respiratory health and its impact on the person's function, independence and care needs.

Knowledge and Skills

To deliver this role successfully it is essential that physiotherapists working with adults with a learning disability develop the knowledge of specialist respiratory assessment and treatment options to inform onward referrals to and support access to specialist respiratory services.

Management of hypertonia and spasticity

Specialist learning disability physiotherapy services will work in collaboration with specialist neurology services and the multidisciplinary team in the assessment, treatment and monitoring of hypertonia and spasticity in adults with a learning disability.

Specialist learning disability physiotherapists will lead on community level assessment, treatment and monitoring of hypertonia and spasticity, usually through postural management, management of mobility problems and falls services.

Specialist learning disability physiotherapists will support specialist services to deliver, optimise and monitor medical management plans for hypertonia and spasticity in adults with a learning disability. This may involve:

1. Supporting specialist services to make the appropriate reasonable adjustments to support positive access to and outcomes for adults with a learning disability and their network of care.
2. Supporting the person and their network of care to understand the positive and negative implications of proposed medical treatment options and to contribute to capacity assessments and best interest decisions regarding the management approach.
3. Supporting the optimisation of treatments to manage hypertonia and spasticity such as stretching post Botox injection or optimisation of medication dosage.
4. Monitoring any adverse effects of treatment and providing feedback.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

NB: Readers should also consider standard of practice statements under 24hr postural management and management of mobility problems.

Assessment

Specialist learning disability physiotherapists:

1. Complete assessments of hypertonia and spasticity as part of postural and mobility assessments using a validated outcome measure, such as Motor Assessment Scale or Tardieu Scale, taking into consideration the impact of the person's neurological presentation on their function and independence.
2. Assess whether pain is a contributing factor to the person's hypertonia and spasticity. Where pain is suspected or indicated this may involve a multidisciplinary assessment using specialist pain assessments for adults with a learning disability such as DISDAT or Paediatric Pain Profile.

Intervention and Management

Specialist learning disability physiotherapists:

1. Develop individualised physiotherapy management plans in collaboration with the multidisciplinary team to treat and manage hypertonia and spasticity considering:
   - Conservative physiotherapy interventions and management techniques such as positioning, stretching, casting, splinting and muscle strengthening before proposing medication and medical interventions.
   - The positive and negative features of the person's hypertonia and spasticity when developing spasticity management plan.
   - The impact of the management approach and treatment on the person's physical presentation, health, care needs and quality of life.
2. Delegate individualised management plans to the person's network of care.
3. Make onward referrals to general practitioner and specialist neurology services for further assessment of hypertonia and spasticity, and consideration of medical management where a conservative approach is not achieving agreed outcomes and goals. Supporting positive access to and responses from services as required.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Monitor and review adults with a learning disability with an ongoing hypertonia and spasticity problems as clinically indicated.
2. Provide the person and their network of care with the relevant information to recognise changes and/or deterioration in an individual's hypertonia and spasticity to encourage timely re-referral to back to the team.

Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists develop the appropriate knowledge, skills and experience of physiotherapy assessment, treatment and monitoring of hypertonia and spasticity and understand the medical treatments available to support appropriate onward referrals to specialist services.

Complex and therapeutic manual handling

Specialist learning disability physiotherapists will work in collaboration with the occupational therapy team, multidisciplinary team, family members, network of care, and service providers to contribute to manual handling assessments, management and training of adults with a learning disability with complex manual or therapeutic handling needs.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Assessment

Specialist learning disability physiotherapists:

1. Work in collaboration with the occupational therapy team, multidisciplinary team, and network of care to complete individualised manual handling assessments for adults with a learning disability where they have complex manual handling needs. Such as people with complex body shapes and movement disorders; or where there are therapeutic handling requirements to maximise functional abilities or rehabilitation.

Intervention and Management

1. Specialist learning disability physiotherapists work in collaboration with the occupational therapy team, wider multidisciplinary team and network of care to:
   - Develop person centred accessible manual handling guidelines for adults with a learning disability with complex manual or therapeutic handling needs as indicated by assessment and delegate them to the person's family and/or network of care.
   - Advice on the provision of manual handling equipment for adults with a learning disability where they have complex manual and/or therapeutic handling requirements. The assessment and provision of manual handling equipment may depend on local equipment pathways and agreements.
2. Make onward referrals to relevant services where manual handling issues and concerns are identified. Where these issues put the person, and/or their network of care at risk of injury; develop and implement risk management plans to reduce the level of immediate risk.

Review and Monitoring

Specialist learning disability physiotherapists:

1. Provide the person and their network of care with the relevant information to be able to identify manual handling problems and risks to encourage timely referrals to the appropriate services as required.

Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists apply their knowledge and skills in contributing to the assessment of adults with a learning disability and complex manual or therapeutic handling needs. This will involve:

1. Developing an understanding of manual handling legislation.
2. Maintaining up to date manual handling training.
3. Keeping up to date with manual handling equipment and products available locally.
4. Developing knowledge, skills and experience in postural management, the management of mobility problems and falls intervention and prevention, and how these impact on a person's manual handling.

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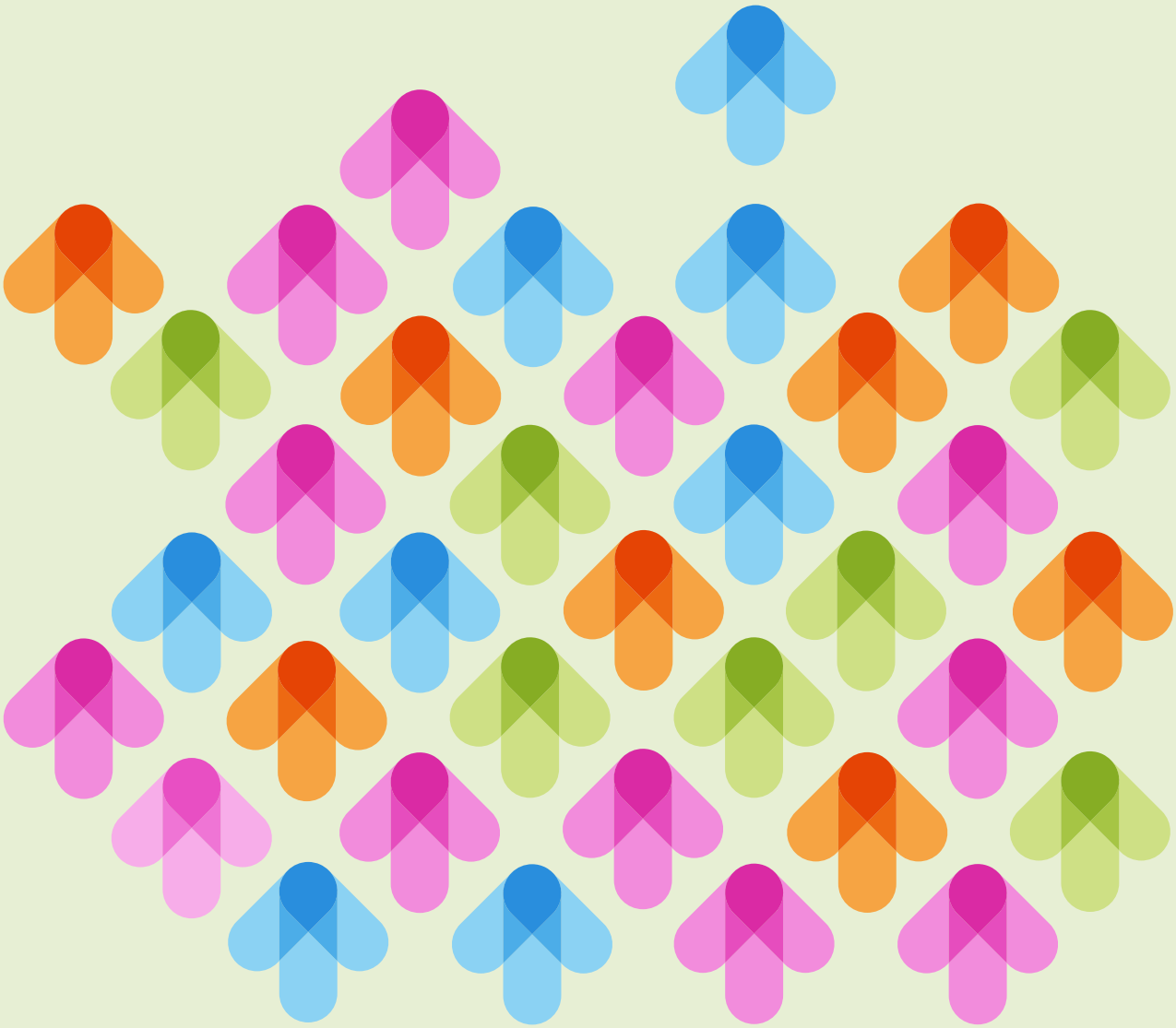
SUPPORTING roles

The supporting roles underpin the successful provision of the lead and contributory roles of the specialist learning disability physiotherapist. The provision of these roles is likely to depend on the physiotherapy needs of the local population of adults with a learning disability and the accessibility and provision of mainstream local physiotherapy and healthcare services.

Onion Diagram



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Assessment and provision of specialist equipment

Specialist learning disability physiotherapy services will complete the assessment and provision of specialist equipment as part of the lead or contributory roles.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Specialist learning disability physiotherapists:

1. Complete comprehensive assessments for the provision of specialist equipment taking into consideration the clinical need, the cost versus benefit, the available evidence, the competence of the network of care, compliance of the person and the practicality of the equipment.
2. Develop funding applications for specialist equipment. These should include sound clinical reasoning and justification considering the cost versus benefit of the equipment as well as the impact it may have on the person and their network of care.
3. Liaise with equipment manufacturers and providers to trial specialist equipment as part of an assessment and consider available options.
4. Provide training, demonstration and education to the person and their network of care to ensure that specialist equipment is implemented and used competently.
5. Develop or contribute to the development of specific manual handling plans to ensure the equipment is used safely and effectively.
6. Keep abreast of the available research and evidence that supports the provision and clinical benefits of specialist equipment.
7. Develop an accessible treatment plan and delegate to the person's network of care to ensure that specialist equipment is used competently and integrated into the person's daily routines and management plans.
8. Make onward referral to health and Social care professionals and services as indicated by assessment to support the use and implementation of specialist equipment such as orthotics, spasticity services and social services.

Knowledge and Skills

To deliver this role successfully specialist learning disability physiotherapists will:

1. Apply their specialist knowledge, skills and experience in providing physiotherapy to adults with a learning disability, in particular 24hr postural management, management of mobility problems, and falls prevention and intervention to inform the appropriate prescription of specialist equipment.
2. Need to develop a breadth of knowledge of the specialist equipment available to be able to effectively support the assessment and provision of equipment to adults with a learning disability.

Training and education: Adults with a learning disability and their network of care; health and social care professionals; and local community services

It is ESSENTIAL that specialist learning disability physiotherapy services deliver and contribute to multi-disciplinary training and education of health and social care professionals, commissioners, and service providers to raise the awareness of the physiotherapy needs of adults with a learning disability and support positive access to and responses from services and providers.

It is ESSENTIAL that specialist learning disability physiotherapy services deliver and contribute to the training and education of adults with a learning disability and their network of care as part of providing safe and successful physiotherapy.

Onion Diagram

Supporting Evidence

Training and Education of health and social care professionals and non-professionals, commissioners, and service providers

Topics could include

Health inequalities and reasonable adjustments	Deliver and/or contribute to training and education to raise aware of the health inequalities of adults with a learning disability and the barriers to accessing healthcare. This includes advice on the reasonable adjustments that mainstream services and professionals are legally obligated to make to overcome these barriers. In addition, highlight the adjustments specialist learning disability physiotherapists make that go beyond what is reasonable to provide successful physiotherapy to adults with a learning disability.
Role of the specialist learning disability health and physiotherapy team	Deliver training and education to raise awareness of the role of the specialist learning disability health and physiotherapy teams to promote appropriate referrals and improve the profile of the service.
Supporting adults with a learning disability	Deliver and/or contribute to the training and education to raise the awareness of the needs of adults with a learning disability to facilitate positive access to and responses from healthcare services including providing advice on making appropriate reasonable adjustments.
Postural management	Contribute to the delivery of multi-disciplinary, multi-agency postural management training to raise the awareness of the postural needs of adults with complex physical and learning disabilities and the importance of delivering postural management.
Respiratory management	Work in collaboration with mainstream and specialist respiratory services to deliver multi-disciplinary training and education to highlight the incidence and impact of respiratory problems for people with a learning disability; raise awareness of the risk factors that contribute to the development of respiratory complications; and to promote the importance of respiratory management.
Fall prevention and intervention	Contribute to training and education to raise the awareness of the incidence and impact of falls; the risk factors that are specific to adults with a learning disability; and on the importance of falls prevention.

Training and Education of adults with a learning disability where applicable, and their network of care

1. Provide training and education to adults with a learning disability and their network of care in areas where physiotherapy provide assessment and intervention to enhance knowledge, skills and competence. This may include contributing to multidisciplinary or external agency training and education sessions where appropriate.

Topics could include

Postural management	Deliver training and education to raise the awareness of the postural needs of adults with complex physical and learning disabilities; the importance of 24 hour postural management; and the role of the network of care.
Respiratory management	Deliver training and education to highlight the incidence and impact of, and risk factors for respiratory complications in adults with a learning disability. Teaching sessions should raise awareness of: • the importance of respiratory care; • the role of the multidisciplinary team; • the role of the network of care in the person's management; and • where to seek appropriate support and advice.
Falls prevention and intervention	Contribute to training and education to raise awareness of the importance of falls prevention and the management of ongoing falls risk.
Adults with a learning disability and dementia	Contribute to person centred multidisciplinary training and education to the families, support teams and service providers of adults with a learning disability and a diagnosis of dementia where there are physiotherapy related needs. Training should focus on the physiotherapy related secondary complications such as mobility problems, falls, sudden deterioration in mobility and function, postural changes, and respiratory complications as their dementia progresses.
Preventative management of mobility problems	Contribute to training and education to promote healthy lifestyles and management of ongoing mobility problems.
Health promotion	Include information about health promotion into education and training sessions to promote the benefits of physical activity and healthy lifestyle; and highlight the consequences of physical inactivity.
Hypertonia and spasticity management	Contribute to multi-disciplinary training and education to improve awareness and knowledge of hypertonia and spasticity; the impact this can have on a person's presentation and function; and raise the awareness of the different treatment and management approaches available.

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2. Provide training and education to the person's network of care to teach the theoretical background to the specific treatments or techniques that are delegated to ensure competent performance of the task. It is essential that training and education is delivered in an accessible language and format.

   Treatments and techniques may include:

   - Hydrotherapy/aquatic therapy
   - Exercise programmes
   - Physiotherapy on a trampoline/rebound therapy
   - Gym programmes
   - Movement programmes
   - Passive movement programmes
   - Complex manual or therapeutic handling programmes in collaboration with occupational therapy services
   - Postural management programmes
   - Respiratory management plans
   - Falls management programmes
   - Mobility management programmes
   - Hypertonia and spasticity management plans
   - Dysphagia management plans
   - Provision of specialist equipment

3. Support and contribute specialist knowledge of providing physiotherapy to adults with a learning disability in the development of training and education packages provided by mainstream physiotherapy and other related health services.

4. Evaluate training and education sessions to ensure the content is appropriate and accessible for the audience; that the learning objectives are met; and the participants apply new knowledge into practice.

Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists develop competence in developing, presenting and evaluating training and education packages for adults with a learning disability and their network of care; health and social care professionals; and local community services.

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Transition of young people with a learning disability from paediatric to adult services

It ESSENTIAL that specialist learning disability physiotherapy services work in collaboration with paediatric physiotherapy teams, special education college physiotherapy teams and the multi-disciplinary team to support the smooth transition of young people with a learning disability and ongoing physiotherapy needs from paediatric to adult services in line with National Institute of Clinical Excellence (NICE) recommendations.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Specialist learning disability physiotherapists:

1. Proactively identify and transition young people with a learning disability and long-term physiotherapy needs from paediatric to adult services.
2. Support young people with a learning disability to access mainstream physiotherapy services where appropriate and clinically indicated.
3. Work in collaboration with the young person's "named worker" to facilitate a smooth transition of care from paediatric to adult services where the person has ongoing physiotherapy needs.
4. Work in collaboration with paediatric physiotherapy teams to provide young people and their families or carers with information about what to expect from the adult specialist learning disability physiotherapy services following transition.
5. Aim to meet the young person with a learning disability and their family or network of care before they transition where their primary needs are physiotherapy related and they will require ongoing, long term physiotherapy support.
6. Contribute to local multidisciplinary and multiagency transition pathways and processes to support the smooth transition of young people with a learning disability and ongoing physiotherapy needs.
7. Contribute to and support the smooth transition of young people with a learning disability and their families or network of care from special education colleges to community specialist learning disability physiotherapy services where the person has ongoing physiotherapy needs. For example, make recommendations for suitable day service provision and community activities; and support the continuation of physiotherapy programmes delivered at college into the community.
8. Work in collaboration with paediatric and special education college physiotherapy teams to support the smooth transition of young people with a learning disability and ongoing physiotherapy needs between education settings where appropriate.
9. Contribute to the development of Education Health Care Plans (EHCP) for young people with a learning disability and ongoing physiotherapy needs where requested and appropriate.

Knowledge and Skills

To deliver this role successfully it is essential that specialist learning disability physiotherapists develop appropriate knowledge, skills and experience to support the transition of young people with a learning disability from paediatric to adult services. This involves:

1. Keeping abreast with government and NICE recommendations regarding transition.
2. Understanding the changing needs of young people with a learning disability transitioning from paediatric to adult services.
3. Partnership working in line with CSP recommendations.

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Promoting the role of the physiotherapist working with adults with a learning disability

A key role of specialist learning disability physiotherapists is to raise the awareness and improve the understanding of the physiotherapy needs of adults with a learning disability and promote the role of the specialist learning disability physiotherapy team at a local, regional and national level. This aims to support the delivery, development and commissioning of specialist learning disability physiotherapy services.

To achieve this specialist learning disability physiotherapists:

1. Develop relationships with local commissioners, mainstream services and service managers.
2. Contribute to special interest groups; research studies and opportunities; NICE publications and quality standards; and nationally recognised campaigns that address and explore topics relevant to the physiotherapy needs of adults with a learning disability.
3. Support the development of literature and resources regarding the physiotherapy needs and management of adults with a learning disability.
4. Play an active role in research, service development and quality improvement projects with the view to improve the delivery of physiotherapy services to adults with a learning disability and disseminate the results.

Onion Diagram

Co-ordinated approach to care and multi-disciplinary, multi-agency working

Adults with a learning disability will often have multi-morbidities that require a co-ordinated approach to care and multi-disciplinary and multi-agency partnership working to successfully manage their physiotherapy and wider health needs.

Onion Diagram

Supporting Evidence

Standard of Practice Statements

Specialist learning disability physiotherapists:

1. Identify adults with a learning disability who may benefit from a co-ordinated approach to care. For example; individuals with multi-morbidities; young people transitioning from paediatric to adult services; or people with dementia.
2. Work in collaboration with the multidisciplinary team to provide a co-ordinated approach to care for adults with a learning disability who have complex physical disabilities and health issues requiring long term physiotherapy management.
3. Contribute to local co-ordination processes and pathways through supporting communication, providing appropriate documentation and attending co-ordination meetings as required.
4. Develop links, open lines of communication and direct referral pathways with local health and social care services critical to the effective delivery of physiotherapy services to adults with a learning disability. This includes:
   - Mainstream and specialist respiratory services.
   - Falls prevention and intervention services.
   - Local neurological services that provide assessment and management of hypertonia and spasticity.
   - Community rehabilitation services.
   - Paediatric physiotherapy teams.
   - Specialist education college physiotherapy teams.
   - Wheelchair services.
   - Orthotic services.
   - Social services occupational therapy.
   - Commissioners.
   - Equipment providers.
5. Support and develop of local integrated multi-disciplinary and multi-agency pathways for adults with a learning disability who have or are at high risk of developing physiotherapy and health problems. This should include:
   - Integrated care pathway for the delivery of 24-hour postural management.
   - Integrated care pathway for adults with a learning disability and dysphagia.
   - Integrated care pathway for adults with a learning disability and dementia.
   - Physiotherapy transition pathways for young people with a learning disability and ongoing physiotherapy needs.
   - Integrated falls and mobility pathway.

6. Work in collaboration with commissioning and local healthcare providers to support the development of local specialist healthcare services where there is a lack of local access or provision for adults with a learning disability. In particular:
   - specialist respiratory services.
   - postural management services.
   - local mainstream falls and rehabilitation services.

7. Work in partnership with other physiotherapists from mainstream services, education and paediatric services to ensure that the person is receiving optimal management across all settings. Where the person is receiving therapy from more than one physiotherapy service, professionals will develop local working agreements following the recommendations set out in the CSP information paper '*Concurrent and subsequent treatment: advice to physiotherapists working in the NHS and private sector.*'

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THERAPUETIC MODALITIES

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Therapuetic Modalities

Therapeutic modalities are used to augment therapy and help achieve physiotherapy goals. These include aphysiotherapy on a trampoline/rebound therapy and therapeutic riding or hippotherapy. They are recommended and delivered by a physiotherapist with specialist knowledge and skills in the area. Treatment modalities are particularly valuable and important when providing physiotherapy to adults with a learning disability as they offer the physiotherapist a tool to conduct assessments and deliver treatments that are engaging and fun which can enhance compliance. Adults with a learning disability are often non-compliant with specific exercises because they are not enjoyable, or they do not understand the reason for completing the task. Therefore, engaging people in activities rather than specific exercises can be an effective way deliver physiotherapy treatment and goals.

Hydrotherapy/aquatic therapy

Physiotherapy on a trampoline/rebound therapy

Therapeutic riding or hippotherapy

Training, education and development of specialist learning disability physiotherapists

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Training, education and development of specialist learning disability physiotherapists

Introduction

Physiotherapists working with adults with a learning disability are specialist in providing physiotherapy to adults with a learning disability who are unable to access mainstream services even when reasonable adjustments are made. To achieve this it is essential that physiotherapists have specialist knowledge and skills in:

- the health, social, learning and physiotherapy needs of adults with a learning disability;
- making the adjustments required to successfully provide physiotherapy;
- supporting positive access to and responses from mainstream physiotherapy and relevant healthcare services; and
- supporting mainstream physiotherapy and relevant healthcare services to make reasonable adjustments required to provide successful physiotherapy.

To manage the physical needs of adults with a learning disability it is essential that learning disability physiotherapists develop specialist knowledge and skills in specific areas of physiotherapy critical to delivering successful outcomes. In particular 24hr postural management, falls intervention and prevention and the management of mobility problems.

It is essential that specialist learning disability physiotherapist also have general knowledge and skills in a broad range of aspects of physiotherapy and other areas of healthcare. And be versatile in applying their specialist knowledge to meet the physiotherapy needs of an individual. Physiotherapists must acknowledge when the physiotherapy needs of an individual are beyond the scope of their knowledge and skills and then seek further support from healthcare professionals from different specialisms. Thus, it is essential that services focus on developing links and direct referral pathways with local mainstream physiotherapy and relevant healthcare services to ensure that adults with a learning disability can access the specialist knowledge and skills they require as needed.

Specialist learning disability physiotherapists are required to undertake specific and targeted training and education programmes to develop their specialist and generalist knowledge and skills of the role to become a competent and capable practitioner. It is essential that this be completed in line with and alongside the training and development requirements to be compliant with the HCPC standards of proficiency for physiotherapists; the CSP professional's value codes; and their employer's mandatory training. Training, education and development is everyone's responsibility and should occur at an individual, organisational, regional and national level.

Specialists, Generalists and Generalising Specialists

Training, Education and Development Responsibilities

Training and education requirements of the specialist learning disability physiotherapist

1. **The health, social and learning needs of adults with a learning disability:**

   It is essential that learning disability physiotherapists develop specialist knowledge and skills in the following areas:

   - Tier 3 in the learning disability core skills education and training framework (Skills for Health 2019).
   - The rights of adults with a learning disability and the relevant legislation such as:
     - Human Rights Act 1998.
     - Valuing People (Department of Health 2001).
     - Valuing People Now (Department of Health 2009).
     - Autism Act 2009.
     - Equality Act 2010.
   - Communication with adults with a learning disability.
     - It is essential that Specialist learning disability physiotherapists are able to identify the communication needs of adults with a learning disability and develop a wide range of communication styles and formats to communicate effectively depending on the individual's communication support needs. For example accessible written documentation, simple verbal communication, talking mats, using pictures, Makaton, facial expression, and demonstration.
   - The Mental Capacity Act (England and Wales); Adults with incapacity (Scotland) and Mental Capacity Act Northern Ireland (Northern Ireland).
     - Specialist learning disability physiotherapists need to be aware of and compliant with the Acts as well as how they apply to clinical practice and their own role in implementing the guidance.
   - Safeguarding Vulnerable Adults (England); Adult Support and Protection (Scotland); Adult Safeguarding (Northern Ireland) and Safeguarding Adults (Wales).
     - Specialist learning disability physiotherapists need to be aware of and compliant with the legislation as well as how they apply to clinical practice and their own role in implementing the guidance.
   - The CSP guidance on Supervision, Accountability and Delegation (CSP 2017).
   - The evidence and literature addressing the health, learning and physiotherapy needs of adults with a learning disability.

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2. **Supporting adults with a learning disability to have positive access to and responses from mainstream physiotherapy and relevant healthcare services including supporting services to make the reasonable adjustments required to provide successful physiotherapy:**

It is essential that specialist learning disability physiotherapists develop specialist knowledge and skills in the following areas:

- The legislation, policies and guidance relevant to adults with a learning disability accessing healthcare including:
  - Healthcare for all (Michael and Richardson 2008).
  - Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report (Heslop et al. 2013).
  - Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers (Learning Disability Professional Senate 2015).
  - Improving the health and wellbeing of people with learning disabilities: An evidence-based commissioning guide for Clinical Commissioning Groups (CCGs)-revised. Improving Health and Lives (RCGP 2013).
  - Learning Disabilities Mortality Review (LeDeR) Programme (NHS England 2016 and 2018).
- The role and function of different healthcare professionals and services that an adult with a learning disability may need to access.
- The issues that an adult with a learning disability may face when accessing a variety of healthcare services.

3. **Specific areas of physiotherapy that are critical to managing the physical needs of the adult with a learning disability**

It is essential that learning disability physiotherapists develop specialist knowledge and skills in the following areas:

- 24 hour postural management.
- Management of mobility problems associated with adults with a learning disability.
- Falls prevention and intervention.

Learning disability physiotherapists have become specialists in the 24 hour postural management of people with complex physical and learning disabilities. The evolution of this aspect of the role has resulted from a significant increase in the number and complexity of people with complex physical and learning disabilities entering into adulthood; an increase in the life expectancy of adults with a learning disability with complex disability; and a dearth in the availability of specialist postural management services across the UK. The latter was recently acknowledged by Murphy et al. (2010) who advocates for the development of specialist services across the British Isles dedicated to the 24 hour postural management of people with complex physical disability. The other specialist areas are falls intervention and prevention; and the management of mobility problems. This is due to the significantly increased incidence of falls and impairment of gait in this population of people. Dr. Janet Finlayson and Jennifer Crocket lead the way in this particular area of practice within the UK (Finlayson et al. 2010 and 2014; Crocket et al. 2015; Finlayson et al. 2015).

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4. General training and education requirements:

It is essential that learning disability physiotherapists develop general knowledge, skills and competence in a broad range of aspects of physiotherapy and other related healthcare disciplines including:

- Assessment and management of hypertonia and spasticity
- Community and specialist level respiratory assessment and management
- Dementia
- Dysphagia
- End of life care
- Epilepsy
- Health promotion
- Manual handling
- Musculoskeletal physiotherapy
- Neurological rehabilitation
- Orthopaedic surgery and rehabilitation
- Pain management
- Specialist equipment such as standing and walking frames, sleep systems and night time positioning aids
- Specialist interventions such as hydrotherapy/aquatic therapy and physiotherapy on a trampoline/rebound therapy
- Supporting adults with a learning disability who display behaviours that challenge successfully such as positive behavioural support training, de-escalation, restraint and self-protection techniques; and sensory integration training
- Wheelchair assessment and provision

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Continued professional development

The HCPC standards of proficiency for physiotherapists states that registrant professionals must understand the key concepts of the knowledge base relevant to their profession and be able to draw on appropriate knowledge and skills to inform practice. To achieve this mandate, physiotherapists are obligated to complete and evidence that they complete regular continued professional development (CPD) as part of their HCPC registration. The HCPC reports that "CPD is the way in which registrants continue to learn and develop throughout their careers so they keep their skills and knowledge up to date and are able to practise safely and effectively."

The HCPC state that it is the responsibility of professionals to keep up CPD themselves. The HCPC regulates individual professionals, which means their employers do not have a responsibility to keep up CPD themselves, but as employers are responsible for the safety of their employees' practice. Therefore, they may want to encourage CPD upkeep amongst their staff. The CSP support this view, stating that members are required to engage in CPD in order to remain registered with the HCPC. They also expect that all employers, whether in the NHS or other sectors, will facilitate CPD opportunities for their employees, and that all CSP members, whatever their working context, will allocate time to their learning.

In order to deliver excellent healthcare, members need access and engage with learning opportunities and then to consolidate and integrate their learning into practice. The NHS constitution for England (Department of Health and Social Care 2015) pledges that all NHS employers will "provide all staff with personal development, access to appropriate education and training for their jobs, and line management support to enable them to fulfil their potential." Therefore, it is crucial, for employers to facilitate individuals' learning and development in the form of physical access to learning communities, materials and technologies and/or time out of their working role to engage in learning and development activity.

The researchers support the views of the HCPC and CSP. Concurring that regular CPD ensures services deliver high standards of care that is progressive and innovative; and provide evidence-based practice. This improves the delivery of healthcare and health outcomes for adults with a learning disability. CPD ensures physiotherapists keep up to date with evidence and practice; develop their knowledge and skills; and maintain their generalist and specialist competences.

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Supervision

The HCPC and CSP recognise the importance of supervision as part of CPD; and the development and maintenance of competent physiotherapists. The HCPC standards of proficiency for physiotherapists states that registrant professionals must be able to practise as an autonomous professional, exercising their own professional judgement. To achieve this standard, physiotherapists must understand the importance of participation in training, supervision and mentoring.

The CSP recognises the Butterworth and Faugier (1992) definition for clinical supervision which states that it is 'an exchange between practising professionals to enable the development of professional skills'. The CSP states that this is a useful definition because of how it aligns with an outcomes-based approach to CPD which is consistent with the HCPC's expectations of registrants and the CSP's expectations of its members.

The CSP recognises that clinical supervision in practice must strike a balance between professional development and organisational governance. The CSP has published a brief overview paper on clinical supervision in which it outlines the aims and principles of good supervision (CSP 2017b).

It is critical that specialist learning disability physiotherapists receiving adequate supervision with a suitably qualified and experienced clinician. Ideally, this would be a specialist learning disability physiotherapist. In addition to one to one clinical supervision, professionals should develop opportunities for multidisciplinary and peer group supervision; and training and support with local professionals with an expertise in working with adults with a learning disability.

Conclusion

The specialist and generalist nature of the specialist learning disability physiotherapist makes developing and maintaining the appropriate knowledge and skills challenging. Professionals will need to attend appropriate training and education courses, undertake extensive CPD, actively seek learning opportunities, and have access to appropriate supervision. They will have to keep abreast of the literature and evidence pool for their chosen area of specialism and be proactive to supporting the learning of others. There is currently no structured framework to inform the training and education of the clinical area. The standards of practice can be used as a framework to design, plan and deliver training, education and CPD opportunities that are focused and targeted. Learning opportunities should be planned at an organisational, regional and national level and be accessible for all, including students, to ensure that the broad range of topics and roles are covered regularly for new professionals entering the area as well as to refresh and update the knowledge and skills of established physiotherapists.

Implementing the standards of practice

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Implementing the standards of practice

Introduction

The standards of practice outline the optimal role of specialist learning disability physiotherapy services based on the available evidence and opinion of an expert participants. However, in reality, there are often a range of local drivers that impact the way specialist learning disability services are delivered. These include local employers' agendas; staffing resources; service commissioning; local mainstream health and social care services; and population variations and needs. As a result, it is essential that specialist learning disability physiotherapy services develop an in-depth understanding of current physiotherapy provision; the local population of adults with a learning disability; and the availability and accessibility of local mainstream physiotherapy and other relevant healthcare services. It is important to take these into consideration when implementing the standards of practice.

Understanding current physiotherapy service provision

Before starting to plan changes to services or implementing new guidance, it is important to understand how the service currently works. This is the baseline and can be used to measure the effect of any change. It is possible to find out about how the service works in lots of different ways. Informal discussions, online questionnaires, workshops or a review of local policies and procedures could help. It is also important to look outside of the organisation and see how the service fits into the wider community. The following methods can be used to develop an understanding of current physiotherapy provision:

1. **Referral numbers and trends:**

   A yearly referral audit can be very useful to understand current service provision and specific areas of demand. This can then provide a baseline to measure any change that may impacts on service delivery and demand.

2. **Job planning:**

   Job planning is an effective method of profiling the clinical workforce to match available clinical resources to the organisation's objectives and clinical priorities. A job plan is a prospective, professional agreement describing each staff member's duties, responsibilities, accountabilities and objectives. It aims to articulate how much of each physiotherapist's role will be allocated to clinical care and how much to any other supporting professional activities, so trusts can manage their capacity and demand.

   NHS Improvement have developed a best practice guide for allied health professionals job planning.

NHS Improvement: **Allied health professionals job planning: a best practice guide**

3. **Staff workload tracker tool:**

Conducting a time limited analysis of staff day to day activities can provide valuable information about daily demands on physiotherapy staff. There are a number of limitations to this methodology, in particular whether the chosen period of time during which the tool is completed truly represents a 'typical' working week. However they can develop some understanding and reduce dependence on anecdotal evidence.

NHS Improvement have developed a staff workload tracker tool to allow staff groups such as multidisciplinary team co-ordinators to track their activity. Teams and their leaders can identify the important areas of their activity and assess the time spent on each during the course of a week. This can identify those activities more appropriately performed by another person or role, and facilitate discussions about team development, expansion or modification.

NHS Improvement: **Staff workload tracker tool: user guide**

4. **Baseline assessment tool:**

Baseline assessment tools can be used to evaluate whether practice is in line with national recommendations and can help to plan activity to meet any identified gaps. Tools can be used by services and organisations to develop a picture of activity either on an individual level or within the local area.

The researchers have developed a baseline assessment framework to support readers to develop an understanding of their current physiotherapy services against the guidelines and recommendations in the standards of practice. The baseline assessment tool includes:

- Analysis of current physiotherapy provision against the standards of practice.
- Analysis of the training and education needs of the members of the physiotherapy team.
- The development of an action plan to implement any identified gaps in services into practice.

Toolkit: **Baseline assessment tool**

Understanding the local population

The learning disability professional senate recognise that specialist community learning disability services must be commissioned with sufficient capacity to support individuals across their life-course, and target adults with a learning disability who have additional severe, complex or recognises support needs (Learning Disability Professional Senate 2015). The government recognise that commissioning, and staff skill mix and resources must reflect the health and social care needs of the local population of adults with a learning disability (Department of Health 2007 and 2009; Learning Disability Professional Senate 2015; National Quality Boards 2017). To achieve these aims, it is essential that services develop an in-depth understanding of their local population of adults with a learning disability.

Michael and Richardson (2008) in Healthcare for All recommends that all health care organisations should ensure that they collect the data and information necessary to allow people with a learning disability to be identified by the health service and their pathways of care tracked. Mansell (2010) in Raising Our Sights specifically supports the need to develop an understanding of people with profound and multiple learning disabilities who are a relatively small population of people, and should therefore be easily identifiable within society, in order to shape services

for this group of people. Mansell recommends that health partners, "should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected in future to enable effective planning of services." It is beyond the scope of the specialist learning disability physiotherapist to have an understanding of the whole local population of adults with a learning disability but they do have a role to play in identifying high risk groups of people with physiotherapy needs such as those with specific diagnosis such as cerebral palsy and dementia; and people with postural needs or recurrent falls.

Understanding the needs of the local population helps to inform and guide the development and planning of safe, effective and fit for purpose physiotherapy workforce and services. This improves effectiveness and quality of physiotherapy provision. There are a range of resources available to develop an understanding of the number of people with a learning disability living locally.

Resources to develop an understanding of the local population of adults with a learning disability.

The researchers have developed a database which provides an estimated number of people with a learning disability in each region and CCG in England, Health and Social Care Trust in Northern Ireland, region of Scotland and local health boards in Wales. The database includes evidence based population estimates for the numbers of adults with a learning disability with health problems that are relevant to physiotherapy. The data was developed from the following sources:

- Population of people (Office of National Statistics 2011).
- Number of adults with a learning disability (Public Health England 2016; Northern Ireland Assembly 2014; Scotland Commission for Learning Disability 2017; Welsh Government 2018).
- Common causes of death (NHS England 2018).
- Falls (Cox et al. 2010; Finlayson et al 2010; Hsieh et al. 2012).
- Cerebral Palsy (Westbom et al. 2011; NICE 2012; Australian cerebral palsy register (ACPR) 2013; NICE 2017).
- Numbers of people with profound and multiple learning disabilities (Hogg et al. 2007; Emerson 2009).
- Levels of physical inactivity (Diaro et al. 2016; NHS Digital 2017).

It is important to understand that these are estimates based on research and data. Therefore the results need to be compared to local data for accuracy. However, they provide a platform to develop evidence based arguments for discussions with commissioners and building business cases.

Toolkit: **Population estimates**

Understanding the availability and accessibility of local mainstream physiotherapy and other relevant healthcare services

The learning disability professional senate recognises that effective community learning disabilities health teams should be able to establish a detailed understanding of all local resources relevant to support individuals with a learning disability and their network of care. They should promote effective integrated working maximising the health and well-being outcomes of individuals. This role supports one of the key functions of the community learning disability team to enable others to provide effective person-centred support to people with a learning disability (Learning Disability Professional Senate 2015).

The integral relationship between specialist learning disability and mainstream health services means that it is critical for physiotherapists to develop an understanding of the availability and accessibility of local provision. There are number of mainstream physiotherapy and other relevant services that are critical to the delivery of the different roles of the specialist learning disability physiotherapist. The researchers have developed a tool to map out the relevant services locally.

Toolkit: Local services map

Prioritising and rationing service delivery

Prioritising some individuals and interventions over others are difficult choices faced by most health care systems. There is no obvious set of ethical principles or analytical tools to determine what decisions should be made at which level of the health system, or how to allocate limited resources. The researchers explored the views of the expert participants on how they would prioritise the roles of the learning disability physiotherapist if there were restrictions on service provision and resources.

Participants were asked to prioritise the roles that reached consensus using the MUST, SHOULD, COULD method of prioritisation and justify their choice. Participants categorised all the roles under either must or should.

The definition for each category for the study is:

Must do:	Roles that are essential to the successful delivery of specialist learning disability physiotherapy services to adults with a learning disability. **Without these roles the service would not be viable.**
Should do:	Roles that are important and would have a positive impact on the overall delivery of successful physiotherapy services to adults with a learning disability but are not essential or vital. **The omission of these roles would have a negative impact on service provision but it would be viable.**
Could do:	Roles that would improve delivery of specialist learning disability physiotherapy services to adults with a learning disability, but if left out, they would not have a significant negative impact on service provision. **These are roles that would be desirable resource permitting.**

MUST

Definition	'Learning disability physiotherapists provide specialist assessment, treatment and management to adults with a learning disability whose needs cannot be successfully met by mainstream services, even when reasonable adjustments are made. Physiotherapists will work in collaboration with the person, their network of care, mainstream health services, and the multidisciplinary team to enhance, optimise and maintain the person's physical'.
Delivering the Definition	1. Support adults with a learning disability to have positive access to and responses from mainstream physiotherapy and relevant healthcare services. 2. Support mainstream physiotherapy and related healthcare services to make appropriate reasonable adjustments to facilitate adults with a learning disability to have positive access to and outcomes from services.
Lead Roles	1. 24-hour postural management. 2. Community level respiratory management. 3. Falls assessment and intervention: delivering a reactive service. 4. Management of mobility problems: delivering a reactive service. 5. Rehabilitation of acute injuries and conditions for adults with a learning. disability whose needs cannot be met successfully by mainstream services. even when reasonable adjustments are made.
Contributory Roles	1. Contribute to multidisciplinary manual handling assessments and management of adults with a learning disability with complex manual or therapeutic handling needs. 2. Contribute to the management of hypertonia and spasticity. 3. Contribute to the multidisciplinary management of dysphagia.
Supporting Roles	1. Assessment and provision of specialist equipment. 2. Deliver training and education to adults with a learning disability and their network of care. 3. Provide a co-ordinated approach to care. 4. Transition of young people with a learning disability from paediatric to adult services.

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SHOULD

Lead Roles	1. Falls prevention: delivering a proactive service. 2. Management of mobility problems: delivering a proactive service.
Contributory Roles	1. Health promotion. 2. Specialist level respiratory assessment and management.
Supporting Roles	1. Deliver training and education to health and social care professionals and non-professionals, commissioners, and service providers. 2. Develop links and direct referral pathways with local health and social care services. 3. Play an active role in research, service development and quality improvement projects. 4. Work in collaboration with commissioning and local healthcare providers to support the development of and improve access to relevant local specialist healthcare services. 5. Work in collaboration with multi-disciplinary and multi-agency teams to develop local integrated care pathways to improve the physiotherapy management and health outcome of adults with a learning disability. 6. Work in partnership with other physiotherapists from mainstream services, educational settings and paediatric services in the provision of physiotherapy to adults with a learning disability.
Specialist Interventions	1. Aquatic therapy/hydrotherapy/aquatic therapy. 2. Physiotherapy on trampolines/ rebound therapy.

NB: Falls prevention and intervention, and management of mobility problems have been divided into providing reactive or proactive physiotherapy services. The definition of these terms are:

Delivering a reactive service: Physiotherapy management of falls or mobility problems post event based on referral. For example:

• Post falls • Near miss • Sudden deterioration in mobility • Insidious change in mobility

Delivering a Proactive Service: Actively identifying people at risk of falls and developing mobility problems and offering physiotherapy intervention and management aimed at preventing an incident or event.

The factors to consider when prioritising and rationing specialist learning disability physiotherapy services are multifactorial (figure 7). The results of questionnaire four found that the vast majority of participants prioritise service provision due to expert opinion developed through personal experience and reflective practice. Participants stated that physiotherapists with experience of working with adults with a learning disability are well placed to design services because of their expert knowledge and understanding of the population's physiotherapy needs.

A number of participants prioritised based on the unique specialist knowledge and skills set of the learning disability physiotherapist because these services cannot be delivered by mainstream services. Thus prioritising and rationing services towards these roles result in all adults with a learning disability receiving some form of physiotherapy intervention, either through specialist or mainstream services. This prioritisation method targets services towards high risk groups of people and where physiotherapy is most effective. These include adults with a learning disability who are unable to access mainstream services; and those with long term physiotherapy needs such as people with postural needs and mobility problems.

Another important consideration for prioritisation was the quality, willingness, availability and accessibility of local mainstream healthcare services, care providers, activities, and facilities to meet the physiotherapy needs of people with a learning disability. As discussed, there are wide variations across the UK therefore developing an understanding of local services is essential.

Some participants stated that they would prioritise based on the demand for specialist physiotherapy services locally. They would develop an understanding of this need through analysis of referral trends and caseload pressures. One potential risk of prioritising based on current service provision is that it does not take account of potential gaps in current service delivery.

Participants recognised that it is essential that services always consider national best practice guidelines, government white papers, acts and publications, and the available evidence base which can add weight to prioritisation and rationing decisions. The experts recognised that prioritisation would need to be balanced with the available funding, staffing levels, resources and commissioning.

Figure 7: Factors to consider when prioritising and rationing specialist learning disability physiotherapy services

It is critical where prioritisation and rationing of physiotherapy occurs that the resulting gaps in services are highlighted to managers and commissioners along with the potential risks of not providing this aspect of physiotherapy. This information and data is critical when developing evidence based arguments that will resonate with managers and commissioners to influence service development and provision.

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Evidencing the impact of specialist learning disability physiotherapy

Evidence states that physiotherapists are an integral part of specialist learning disability teams (RCGP 2013; Learning Disability Professional Senate 2015). There is widespread anecdotal evidence and opinion that the profession has a positive impact on health outcomes; quality of care; and experiences of the adult with a learning disability and their network of care, as well as having potential cost implications and savings for health and social care. However, there is a lack of research or literature that evidences the impact of specialist learning disability physiotherapy. In the current landscape it is essential that services can evidence the impact of specialist learning disability services on quality, experience and the cost of health and social care.

Recommendations of further research

Conclusion

The aim of the standards of practice are to improve and standardise the delivery, development and commissioning of specialist physiotherapy to adults with a learning disability across the UK. To achieve this, physiotherapists working in community learning disability teams will need to implement the standards of practice into their local area. They will need to develop an understanding of the demand and gaps in current services; the local population; and relevant mainstream services. This information is critical to be able to target and prioritise resources appropriately; manage risk; and offer timely intervention within the limitations of services.

Final Comments

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Final Comments

The aim of the 'Standards of Practice for Physiotherapists Working with Adults with a Learning Disability' are to influence a range of people, professionals and organisations to improve and standardise the delivery, development and commissioning of specialist physiotherapy to adults with a learning disability across the UK. As specialist learning disability physiotherapists, we have a passion for working with adults with a learning disability, we therefore hope we have achieved our aim. This document has evolved beyond our initial expectations, however we felt it important to share the learning we gained throughout the research process. It can be very difficult to find the time to complete this level of background reading whilst completing clinical work. Therefore, it is our intention, at the very least, to guide people in the right direction.

We believe and have evidence that the role of the specialist learning disability physiotherapist is not always fully understood and valued by some commissioners and service managers. This has resulted in the decommissioning and downgrading of posts, and professionals being asked to take on roles that are outside of their scope of practice or that divert them from their lead roles. This has led to wide variations in the provision of specialist learning disability physiotherapy services around the UK. Some services are well resourced, led by experienced physiotherapists and managers. Whilst, others have one physiotherapist who may not have the time, supervision and support to manage the day to day clinical caseload as well as promote and develop service provision. This has had a significant impact on the provision of physiotherapy services for adults with a learning disability. We believe the reasons for this are multi-factorial. However, we hope that the standards of practice will help to change the current situation by providing an evidence based outline of the role and provide the tools for professionals to develop the arguments to highlight the essential services physiotherapists provide for adults with a learning disability.

We explore the adjustments that specialist learning disability physiotherapists make to provide successful physiotherapy to adults with a learning disability that go beyond what is reasonable for mainstream services. There is significant literature that documents what adjustments are reasonable but very little that explores what is required when these are not sufficient to achieve a successful outcome. To our knowledge we are the first to explore this concept in physiotherapy. We feel strongly that we should use the concept of specialist adjustments to articulate the unique selling point of the specialist learning disability physiotherapist. Delivering these adjustments is what makes us different from mainstream services.

We hope we have done justice to specialist learning disability physiotherapists across the UK and have outlined our role in a way that supports the profession into the future. We have started the conversation on a national level, but this needs to continue locally. It is essential that we promote the role of the specialist learning disability physiotherapist at every opportunity. This may be time consuming and may take away from clinical work in the short term, however, this is an essential aspect of our role. It raises the awareness of the needs of adults with a learning disability; supports the development of a competent workforce; and cultivates systems to improve access to healthcare and community services. Adults with a learning disability, especially the population physiotherapists tend to manage, often do not have a voice and are unable to advocate for themselves. Thus, it is our responsibility to promote services on their behalf. In the past, this would have been the responsibility of more senior physiotherapists and service managers. But in a culture where this level has disappeared from some community learning disability teams the responsibility is on all physiotherapists.

We believe that it is a good time to promote the role of the specialist learning disability physiotherapist. There has been investment into the NHS for the first time in a number of years; the NHS 10 year plan includes recommendations directly for people with a learning disability; LeDeR continues to highlight areas where services must improve; and the health and social care of people with a learning disability remains in the public forum. We hope that the standards of practice provide the evidence, knowledge and tools to have the conversations with service managers and commissioners to improve the quality and performance of physiotherapy services for adults with a learning disability across the UK. Indeed, the researchers have already received feedback of how the results have been used to secure physiotherapy posts, influence training and education opportunities, and to develop service specifications. We hope that the document will result in many more of these cases and improves the health needs and quality of life of adults with a learning disability.

Sarah Bruce and David Standley

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Standards of Practice for Physiotherapists

Working with adults with a learning disability

SUPPORTING INFORMATION

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Research methodology and results

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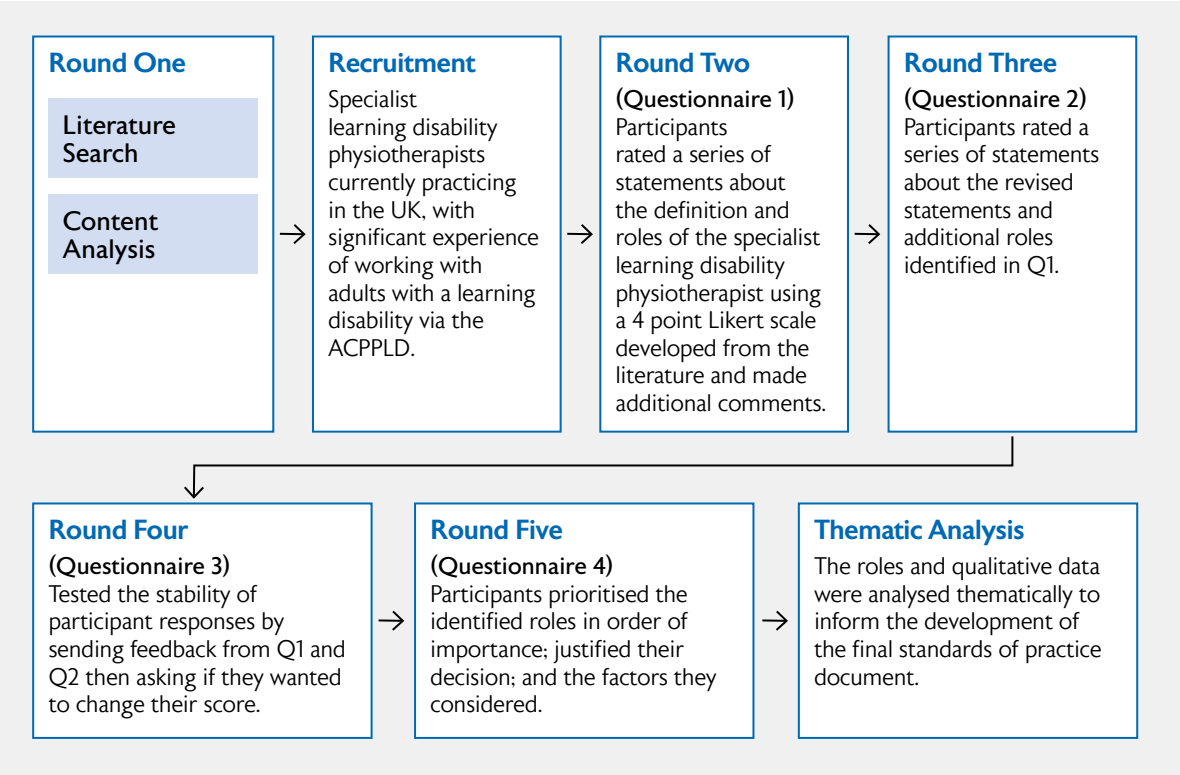
Methodology

The researchers conducted a five round Modified Delphi Technique study to develop the standards of practice for physiotherapists working with adults with a learning disability. This involved a review of the current literature; four rounds of questionnaires to explore the views and opinions of an expert panel recruited via the ACPPLD; and thematic analysis of the data. Figure 8 outlines the structured and stringent research process.

Figure 8: Research methodology flowchart



Data analysis: The research team used Statistical Package for Social Sciences (SPSS) to manage and analyse the quantitative data and Microsoft Word the qualitative data. Descriptive statistics were used to analyse the demographics; participant scores on the Likert scale; and prioritisation of role. Consensus was set a priori at 90% scoring the roles slight, somewhat or very important; and 80% scoring agree or strongly agree for the standard of practice statements for each role. Stability of responses in round four was analysed for statistical significance using Wilcoxon Signed Rank test ($p>0.05$). Qualitative data was analysed thematically.

Blinding: Participants were anonymised to the researcher handling the data to reduce the risk of bias. Questionnaires were anonymised using a unique coding system before data analysis.

Ethical considerations: The research involved NHS staff therefore an Ethics Committee review was not required for the research study.

Sponsorship and approval: Guy's and St Thomas' NHS foundation Trust sponsored the study and the Health Research Authority approved the study.

Results

Literature Search:

84 relevant publications including 16 government publications, 13 NICE guidelines, 27 research papers and 28 grey literature met the inclusion criteria for the research study. Content analysis resulted in a draft definition for physiotherapists working with adults with a learning disability; 14 different roles; and statements outlining the features of these roles.

Participants:

53 physiotherapists returned questionnaire one. 39 participants completed questionnaire two and three, and 37 completed questionnaire four. The mean number of years' experience working as a physiotherapist was 18.6 and 11.8 working with adults with a learning disability. The majority of participants were working at band 7 level. There was an even distribution across the regions of the UK

Consensus rating:

Definition:

The 9 statements which made up the definition developed in round one reached consensus but a number of amendments were recommended. These were taken into consideration and sent to the participants for rating in questionnaire two in form of two statements. Consensus score increased for the two statements. Therefore, this was adopted as the new definition for the specialist learning disability physiotherapist.

Roles:

In round two, all 14 roles identified in the literature review reached consensus (93.7% to 100%). Participants identified 14 additional roles which were distributed for rating in the second questionnaire. 12 out the 14 reached consensus (92.3% - 100%). Two were rejected (82.1% and 84.6%). Stability of responses was achieved for 25/28 roles demonstrating that participants were not influenced in their decision by their peers for the majority of the scores.

Consensus was demonstrated for the definition and 26 out of the 28 different roles of the specialist learning disability physiotherapist identified by the research and participants. This highlights that the profession covers a wide scope of practice; that there are significant variations in delivery across the UK; and that the research and literature does not accurately represent the clinical picture.

The researchers conducted thematic analysis to group the 26 roles into 15 under the three main categorises to develop the Onion model which outlines the roles of the specialist learning disability physiotherapist. Agreement was also reached for the features of each role which have been developed into the standards of practice statements. These outline the expected level of performance for each role.

Thematic Analysis:

The qualitative data in the form of the comments made by participants were thematically analysed by the researchers to derive:

1. Standards of practice that outline an expected and achievable level of performance for specialist learning disability physiotherapy services across the UK;
2. The specialist adjustments learning disability physiotherapists make to provide successful outcomes to adults with a learning disability;
3. The specialist and generalist knowledge and skills of the learning disability physiotherapist and the training and education requirements for the profession; and
4. The recommendations for implementing the standards of practice into practice.

Literature review

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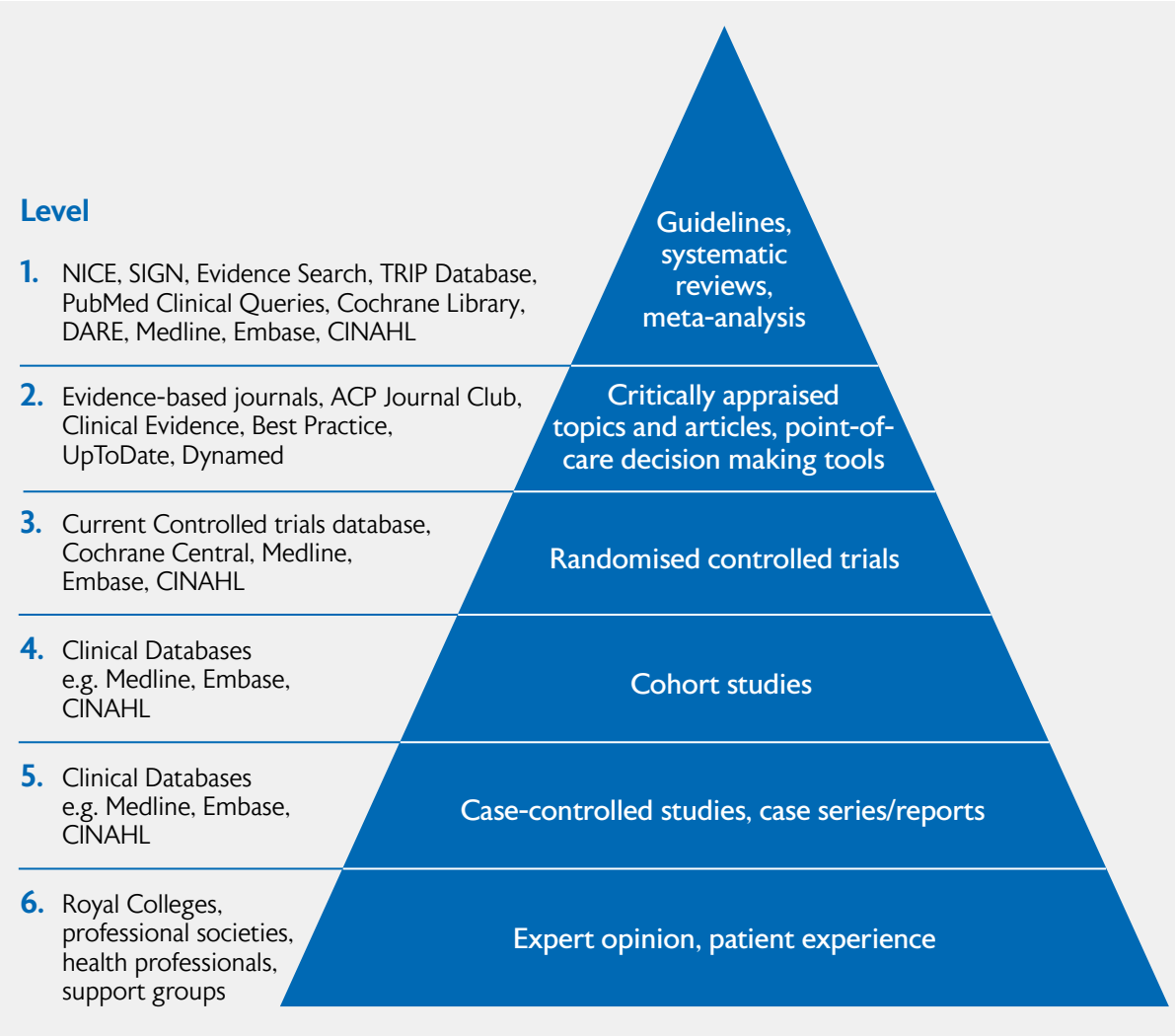
Figure 9: Hierarchy of evidence pyramid



Adapted from DiCanso A, Bayley L and Haynes RB 2009. Accessing pre-appraised evidence: fine tuning the 5S model into a 6S model. Evidence-Based Nursing, 12(4), 99-101 in Brun CD. 2013 Finding the evidence: A key step in the information production process. The Information Standard Guide. Available at https://www.england.nhs.uk/wp-content/uploads/2017/02/tis-guide-finding-the-evidence-07nov.pdf lasted accessed on the 08.08.17

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Ref	Name	Journal	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Research Papers						
Bott et al.	Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient	Thorax	2009	Systematic Review	1	• Respiratory Management
Bott J, Blumenthal S, Buxton M, Ellum S, Falconer C, Garrod R, Harvey A, Hughes T, Lincoln M, Mikelsons C and Potter C 2009. Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient. Thorax, 64 (Suppl 1), i1-i52.						
Burt	Physiotherapy for service users: a personal account.	Learning Disability Practice	2014	Professional Opinion	6	• Supporting access from mainstream health services • Training and Education
Burt JA 2014. Physiotherapy for service users: a personal account. Learning Disability Practice, 17(6).						
Castle et al.	A 24-hour postural care service: Views, understanding and training needs of referring multidisciplinary staff	International Journal of Therapy and Rehabilitation	2014	Mix method – questionnaire and focus groups	5	• 24hr Postural Management • Training and Education
Castle D, Stubbs B, Clayton S and Soundy A 2014. A 24-hour postural care service: Views, understanding and training needs of referring multidisciplinary staff. International Journal of Therapy and Rehabilitation, 21(3), 132-139.						
Crockett et al.	Promoting Exercise as Part of a Physiotherapy-Led Falls Pathway Service for Adults with Intellectual Disabilities: A Service Evaluation	Journal of applied research in intellectual disabilities	2015	Test - Restest Study	4	• Falls Prevention and Intervention
Crockett J, Finlayson J, Skelton DA and Miller G 2015. Promoting Exercise as Part of a Physiotherapy-Led Falls Pathway Service for Adults with Intellectual Disabilities: A Service Evaluation. Journal of applied research in intellectual disabilities, 28(3), 257-264.						
Diaro et al.	Physical activity levels in adults with intellectual disabilities: A systematic review	Preventive medicine reports	2016	Systematic Review	1	• Health Promotion
Dairo YM, Collett J, Dawes H and Oskrochi GR 2016. Physical activity levels in adults with intellectual disabilities: A systematic review. Preventive medicine reports, 4, 209-219.						
Emerson	Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England	Journal of Intellectual Disabilities	2005	Cohort Study	4	• Health Promotion
Emerson E 2005. Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. Journal of Intellectual Disability Research, 49(2), 134-143.						

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Research Papers						
Farley et al.	What is the evidence for the effectiveness of postural management?	British Journal of Therapy and Rehabilitation	2007	Literature review	4	• 24hr Postural Management
Farley R, Clark J, Davidson C, Evans G, Maclennan K, Michael S, Morrow M and Thorpe S 2003. What is the evidence for the effectiveness of postural management? British Journal of Therapy and Rehabilitation, 10(10), 449-455.						
Foran et al.	Expanding assessment of fear of falling among older adults with an intellectual disability: A pilot study to assess the value of proxy responses	Geriatrics	2013	Interview	4	• Falls Prevention and Intervention
Foran S, McCarron M and McCallion P 2013. Expanding assessment of fear of falling among older adults with an intellectual disability: A pilot study to assess the value of proxy responses. ISRN Geriatrics.						
Finlayson et al.	Understanding predictors of low physical activity in adults with intellectual disabilities	Journal of applied research in intellectual disabilities	2009	Prospective cohort design	4	• Health Promotion
Finlayson J, Jackson A, Cooper SA, Morrison J, Melville C, Smiley E, Allan L and Mantry D 2009. Understanding predictors of low physical activity in adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 22(3), 236-247.						
Finlayson at el.	Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study.	Journal of Intellectual Disability Research	2010	Prospective cohort design	4	• Falls Prevention and Intervention
Finlayson J, Morrison J, Jackson A, Mantry D and Cooper SA 2010. Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. Journal of Intellectual Disability Research, 54(11), 966-980.						
Finlayson et al.	Measuring the actual levels and patterns of physical activity/inactivity of adults with intellectual disabilities	Journal of applied research in intellectual disabilities	2011	Observational Cohort Study	4	• Health Promotion
Finlayson J, Turner A and Granat MH 2011. Measuring the actual levels and patterns of physical activity/ inactivity of adults with intellectual disabilities. J. Appl. Res. Intellect. Disabil. 6, 508–517.						
Finlayson et al.	The provision of aids and adaptations, risk assessments, and incident reporting and recording procedures in relation to injury prevention for adults with intellectual disabilities: cohort study	Journal of intellectual disability research	2015	Qualitative methodology using mixture of questionnaires and interviews	4	• Management of Mobility Problems • Falls Prevention and Intervention
Finlayson J, Jackson A, Mantry D, Morrison J and Cooper SA 2015. The provision of aids and adaptations, risk assessments, and incident reporting and recording procedures in relation to injury prevention for adults with intellectual disabilities: cohort study. Journal of intellectual disability research, 59(6), 519-529.						

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Research Papers						
Finlayson et al.	The circumstances and impact of injuries on adults with a learning disability	The British Journal of Occupational Therapy	2014	Qualitative methodology using Interveiws	4	• Falls Prevention and Intervention
Finlayson J, Morrison, J, Skelton DA, Ballinger C., Mantry, D., Jackson, A. and Cooper, S.A., 2014. The circumstances and impact of injuries on adults with learning disabilities. British Journal of Occupational Therapy, 77(8), pp.400-409.						
Hawkins and Look	Levels of engagement and barriers to physical activity in a population of adults with a learning disability	British Journal of Learning Disabilities	2006	Cohort Study	4	• Health Promotion
Hawkins A and Look R 2006. Levels of engagement and barriers to physical activity in a population of adults with learning disabilities. British Journal of Learning Disabilities, 34(4), 220-226.						
Hallawell et al.	Physical activity and learning disability	British Journal of Nursing	2012	Scholar Paper	6	• Health Promotion
Hallawell B, Stephens J and Charnock D 2012. Physical activity and learning disability. British Journal of Nursing, 21(10). 609-612.						
Humphrey and Pountney	The development and implementation of an integrated care pathway for 24-hour postural management: a study of the views of staff and carers.	Physiotherapy	2006	Qualitative methodology using focus groups	5	• 24hr Postural Management
Humphreys G and Pountney T 2006. The development and implementation of an integrated care pathway for 24-hour postural management: a study of the views of staff and carers. Physiotherapy, 92(4), 233-239.						
Katalinic et al.	Stretch for the treatment and prevention of contractures	Cochrane Database	2010	Cochrane Meta-Analysis Review	1	• 24hr Postural Management
Katalinic OM, Harvey LA, Herbert RD, Moseley AM, Lannin NA and Schurr K 2010. Stretch for the treatment and prevention of contractures. Cochrane Database of Systematic Reviews, (9).						
McKeon	A pilot survey of physical activity in men with an intellectual disability	Journal of Intellectual Disabilities	2013	Observational cohort study	4	• Health Promotion
McKeon M, Slevin E and Taggart L 2013. A pilot survey of physical activity in men with an intellectual disability. Journal of Intellectual Disabilities, 17(2), 157-167.						
Middleton and Kitchen	Factors affecting the involvement of day centre care staff in the delivery of physiotherapy to adults with intellectual disabilities: An exploratory study in one London borough.	Journal of applied research in intellectual disabilities	2007	Interview	6	• Training and Education
Middleton MJ and Kitchen SS 2008. Factors affecting the involvement of day centre care staff in the delivery of physiotherapy to adults with intellectual disabilities: An exploratory study in one London borough. Journal of Applied Research in Intellectual Disabilities, 21(3), 227-235.						

Ref	Name	Journal	Date	Type of Publication	Hierarchy of Evidence	Roles informed
Research Papers						
Petropoulou et al.	Injuries reported and recorded for adults with intellectual disabilities who live with paid support in Scotland: A comparison with Scottish adults in the general population.	Journal of Applied Research in Intellectual Disabilities	2016	Service Evaluation	4	• Falls Prevention and Intervention
Petropoulou E, Finlayson J, Hay M, Spencer W, Park R, Tannock H, Galbraith E, Godwin J and Skelton DA 2017. Injuries reported and recorded for adults with intellectual disabilities who live with paid support in Scotland: a comparison with Scottish adults in the general population. Journal of applied research in intellectual disabilities, 30(2), 408-415.						
Proesmans et al.	Respiratory morbidity in children with profound intellectual and multiple disability	Paediatric pulmonology	2015	Observational Cohort Study	4	• Respiratory Management
Proesmans M, Vreys M, Huenaerts E, Haest E, Coremans S, Vermeulen F and Feys H 2015. Respiratory morbidity in children with profound intellectual and multiple disability. Pediatric pulmonology, 50(10), 1033-1038.						
Robertson et al.	Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review	Journal of Applied Research in Intellectual Disabilities	2018	Literature Review	2	• 24hr Postural Management
Robertson J, Baines S, Emerson E and Hatton C 2018. Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review. Journal of applied research in intellectual disabilities, 31, 11-28.						
Sackley et al.	The reliability of balance, mobility and self-care measures in a population of adults with a learning disability known to a physiotherapy service	Clinical rehabilitation	2002	Reliability Study	4	• Falls Prevention and Intervention
Sackley C, Richardson P, McDonnell K, Ratib S, Dewey M and Hill HJ 2005. The reliability of balance, mobility and self-care measures in a population of adults with a learning disability known to a physiotherapy service. Clinical rehabilitation, 19(2), 216-223.						
Standley	The aquatic therapy competency assessment tool for support workers.	Aqualines	2010	Professional Opinion	6	• Training and Education
Standley D 2010. The aquatic therapy competency assessment tool for support workers. Aqualines: Journal of the Aquatic Therapy Association of Chartered Physiotherapists. 22 (2): 5-10.						
Standley	Respiratory Care in People with PMLD and Complex Physical Disability	PMLD Link	2016	Professional Opinion	6	• Respiratory Management
Standley D 2016. Respiratory Care in People with PMLD and Complex Physical Disability. PMLD Link. 28(3): 85; 23-28.						

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Research Papers						
Stewart et al.	Residential carers' knowledge and attitudes towards physiotherapy interventions for adults with a learning disability	British Journal of Learning Disabilities	2009	Interview	5	• Supporting access from mainstream health services • Management of Mobility Problems • Health Promotion
Stewart S, Macha R, Hebblethwaite A and Hames A 2009. Residential carers' knowledge and attitudes towards physiotherapy interventions for adults with learning disabilities. British Journal of Learning Disabilities, 37(3), 232-238.						
Wolff et al.	Development and evaluation of a community respiratory physiotherapy service for children with severe neuro-disability	BMJ quality improvement reports	2015	Retrospective Service Evaluation	3	• Respiratory Management
Wolff A, Griffin H, Flanigan M, Everest S, Thomas D and Whitehouse W 2015. Development and evaluation of a community respiratory physiotherapy service for children with severe neurodisability. BMJ Open Quality, 4(1), u208552-w3411.						

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NICE Guidelines					
NICE CG42	Dementia: supporting people with dementia and their carers in health and social	2006	Clinical Guidelines	1	• Adult with Learning Disabilities and Dementia
NICE 2006. Dementia: supporting people with dementia and their carers in health and social care (CG42). London					
NICE CG145	Spasticity in under 19s: management	2012	Clinical Guidelines	1	• 24hr Postural Management • Falls Prevention and Intervention • Management of Mobility Problems • Spasticity Management • Transition
NICE 2012. Spasticity in under 19s: management (cg145). London					
NICE CG146	Osteoporosis: assessing the risk of fragility fracture	2012	Clinical Guidelines	1	• Falls Prevention and Intervention • Management of Mobility Problems
NICE 2012. Osteoporosis: assessing the risk of fragility fracture (cg 146). London					
NICE CG 161	Falls in older people: assessing risk and prevention	2013	Clinical Guidelines	1	• Falls Prevention and Intervention • Management of Mobility Problems
NICE 2013. Falls in older people: assessing risk and prevention (cg161). London					
NICE CG 179	Pressure Ulcers: prevention and management	2014	Clinical Guidelines	1	• 24hr Postural Management
NICE 2014. Pressure Ulcers: prevention and management (cg179). London					
NICE CG11	Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges	2015	NICE Guidelines	1	• Behaviour that Challenge
NICE 2015. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NG11). London					
NICE NG16	Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset	2015	NICE Guidelines	1	• Health Promotion
NICE 2015. Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset (NG16). London					
NICE QS86	Falls in older people	2015	Quality Standards	1	• Falls Prevention and Intervention
NICE 2015. Falls in older people (qs86). London					

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NICE Guidelines					
NICE CKS	Osteoporosis - prevention of fragility fractures	2016	Clinical Knowledge Summary	1	• 24hr Postural Management
NICE Clinical Knowledge Summaries 2016. Osteoporosis - prevention of fragility fractures. London					
NICE NG 43	Transition from children's to adult's services for young people using health or social care services	2016	NICE Guidelines	1	• Transition • Case Co-ordination
NICE 2016. Transition from children's to adult's services for young people using health or social care services (ng43). London					
NICE NG56	Multimorbidity: clinical assessment and management	2016	NICE Guidelines	1	• Management of Mobility Problems • Case Co-ordination
NICE 2016. Multimorbidity: clinical assessment and management (ng56). London					
NICE NG62	Cerebral palsy in under 25s: assessment and management	2017	NICE Guidelines	1	• 24hr Postural Management • Spasticity Management • Dysphagia Management • Transition • Case Co-ordination
NICE 2017. Cerebral palsy in under 25s: assessment and management (NG62). London					
NICE QS149	Osteoporosis	2017	Quality Standards	1	• Falls Prevention and Intervention • Management of Mobility Problems
NICE 2017. Osteoporosis (qs149). London					

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Government Publications					
CSP	Supervision, Accountability and Delegation	2017	Information Paper	1	• Training and Education
Chartered Society of Physiotherapy 2017. Supervision, Accountability and Delegation. London. Available at: https://www.csp.org.uk/system/files/supervision_accountability_delegation_final.pdf Last accessed 04.04.19					
CSP	Safe practice in rebound therapy	2016	Best Practice Guidance	6	• 24hr Postural Management • Respiratory Management • Management of Mobility Problems • Falls Prevention and Intervention • Health Promotion
Chartered Society of Physiotherapy 2016. Safe Practice in Rebound Therapy (2016). Rebound Therapy Association for Chartered Physiotherapists					
Department of health	Valuing people	2001	Strategy	6	• Supporting access from mainstream health services • Health Promotion • Case Co-ordination • Training and Education
Department of Health 2001. Valuing People: A New Strategy for Learning Disability for the 21st Century. London. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf					
Department of health	Commissioning specialist adult Learning disability health services	2007	Best Practice Guidance	6	• Supporting access from mainstream health services • Training and Education
Department of Health 2007. Commissioning Specialist Adult Learning Disability Services: Good Practice Guidance. London. http://www.debramooreassociates.com/Resources/DH%20Commissioning%20Specialist%20LD%20Adult%20health%20services.pdf					
Department of health	Valuing people now	2009	Strategy	6	• Supporting access from mainstream health services • Health Promotion • Case Co-ordination • Training and Education
Department of Health 2009. Valuing People Now: A New Three Year Strategy for People with Learning Disabilities. London					
Heslop et al.	Confidential inquiry into premature deaths of people with learning disabilities	2013	Inquiry	2	• Supporting access from mainstream health services • 24hr Postural Management • Respiratory Management • Case Co-ordination • Training and Education
Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L 2013. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Bristol: Norah Fry Research Centre.					

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Government Publications					
RCGP et al.	Evidence-based commissioning guide for clinical commissioning groups	2013	Best Practice Guidance	6	• Supporting access from mainstream health services • 24hr Postural Management • Health Promotion • Transition • Training and Education
Royal College of General Practitioners (RCGP) 2013. Improving the health and wellbeing of people with learning disabilities: An evidence-based commissioning guide for Clinical Commissioning Groups (CCGs)-revised. Improving Health and Lives: Learning Disabilities Observatory, Durham.					
Learning Disability Professional Senate	Delivering effective specialist community learning disabilities health team support to people with learning disabilities and their families or carers	2015	Best Practice Guidance	6	• Supporting access from mainstream health services • 24hr Postural Management • Respiratory Management • Management of Mobility Problems • Transition • Behaviours that Challenge • Case Co-ordination • Manual handling • Training and Education
Learning Disability Professional Senate 2015. Delivering effective specialist community learning disabilities health team support to people with learning disabilities and their families or carers. London. Available at: http://acppld.csp.org.uk/documents/national-ld-professional-senate-briefing-paper last accessed 10.06.19					
Mansell	Raising our sights	2010	Strategy	6	• 24hr Postural Management • Respiratory Management • Transition • Training and Education
Mansell J 2010. Raising our sights: services for adults with profound intellectual and multiple disabilities. Tizard Learning Disability Review, 15(3), 5-12					
Michael and Richardson	Healthcare for all	2008	Inquiry	6	• Supporting access from mainstream health services
Michael J and Richardson A 2008. Healthcare for all: the independent inquiry into access to healthcare for people with learning disabilities. Tizard Learning Disability Review, 13(4), pp.28-34.					
National Quality Board	Safe, sustainable and productive staffing: An improvement resource for learning disability services	2018	Best Practice Guidance	6	• Supporting access from mainstream health services • 24hr Postural Management • Health Promotion • Transition • Training and Education • Manual handling
National Quality Board 2018. Safe, Sustainable and Productive staffing: An improvement resource for learning disability services. London. Available at: https://improvement.nhs.uk/documents/588/LD_safe_staffing20171031_proofed.pdf last accessed 28/07/19.					
NHS England	Right care pathway for adults with dysphagia	2017	Best Practice Guidance	1	• Respiratory Management • Dysphagia Management
NHS England 2017. Right Care Pathway for adults with Dysphagia (DRAFT). London.					

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Government Publications					
NHS Quality Improvement	Quality indicators learning disabilities	2004	Quality Improvement Paper	6	• Supporting access from mainstream health services • 24hr Postural Management • Respiratory Management • Transition • Training and Education
NHS Quality Improvement Scotland (2004) Quality Indicators Learning Disabilities. Scotland. Available at: https://www.choiceforum.org/docs/qualindic.pdf last accessed 01/08/19.					
Public Health England	Postural care services: making reasonable adjustments	2018b	Best Practice Guidance	1	• 24hr Postural Management • Respiratory Management • Training and Education
Public Health England 2016. Dysphagia in people with a learning disability: reasonable adjustments guidance. Available at: https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-disabilities/dysphagia-in-people-with-learning-difficulties-reasonable-adjustments-guidance last accessed 13.06.19					
Truesdale and Brown	People with learning disabilities in Scotland: Health needs assessment update report	2017	Health Needs Assessment	6	• Supporting access from mainstream health services • Falls Prevention and Intervention • Health Promotion • Training and Education
Truesdale M and Brown M 2017. People with a learning disability in Scotland: 2017 Health Needs Assessment Update Report. NHS Health Scotland, Edinburgh					

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Grey Literature					
ACPPLD	So your next patient has a learning disability	2016	Resource Guide	6	• Supporting access from mainstream health services
ACPPLD 2016. So your next patient has a learning disability. Available at: https://www.csp.org.uk/publications/so-your-next-patient-has-learning-disability-guide-physios-not-specialising-learning last accessed 01/08/19.					
Cole	Into the mainstream: physio access for those with learning disabilities	2016	Frontline Article	6	• Supporting access from mainstream health services
Cole A 2016. Into the mainstream: physio access for those with learning disabilities. Frontline; 22(11). Available at: http://www.csp.org.uk/frontline/article/mainstream-physio-access-those-learning-disabilities last accessed 01/08/19.					
Crooks	Adult learning disability physiotherapy service guidelines	2013	Service Spec	6	• Supporting access from mainstream health services • Respiratory Management • 24hr Postural Management • Falls Prevention and Intervention • Management of Mobility Problems • Health Promotion • Dysphagia Management • Training and Education
Crooks L 2017. Adult Learning Disability Physiotherapy Service Guidelines: NHS Shetland. Available at: http://www.shb.scot.nhs.uk/departments/physiotherapy/LDPGuidelines.pdf last accessed 01/08/19.					
Doukas et al.	Supporting people with profound and multiple learning disabilities	2017	Campaign	6	• 24hr Postural Management • Management of Mobility Problems • Falls Prevention and Intervention • Transition • Training and Education
Doukas T Fergusson A. Fullerton M. Grace J. 2017. Supporting people with profound and multiple learning disabilities: Core and lEssential Service Standards. Edition 1. Available at: http://www.pmldlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf last accessed 01/08/19.					
Finlayson	Injury and Fall Prevention for People with Learning Disabilities	2016	Resource Guide	6	• Falls Prevention and Intervention
Finlayson J 2016. Injury and Fall Prevention for People with Learning Disabilities; A resource Guide for People who care for, or support people with learning disabilities. Available at: https://agile.csp.org.uk/system/files/?file=injury-and-fall-prevention-for-people-with-learning-disabilities-resource-guide.pdf last accessed 01/08/19.					
Hodges	Getting to grips with learning disabilities	2005	Frontline Article	6	• Supporting access from mainstream health services • Management of Mobility Problems • Health Promotion • Training and Education
Hodges C 2005. Getting to grips with learning disabilities. Frontline; 11(12).					

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Grey Literature					
Hunt	Fit for purpose	2007	Frontline Article	6	• Health Promotion
Hunt L 2007. Fit for purpose. Frontline. 13 (4)					
Hunt	Home care: unbreakable bonds	2017	Frontline Article	6	• 24hr Postural Management • Respiratory Management • Dysphagia Management • Training and Education
Hunt L 2017. Home care: Unbreakable Bonds. Frontline. 23(10) Available at: http://www.csp.org.uk/frontline/article/home-care-unbreakable-bonds last accessed 01/08/19.					
Johnson	Physiotherapy intervention groups for people who fall and have a learning disability – A pilot study.	2007	ACPPLD newsletter	6	• Falls Prevention and Intervention
Johnson S 2007. Physiotherapy Intervention Groups for People who Fall and have a Learning Disability – A Pilot Study. FINAL NEWSLETTER March. 9-15.					
Lowes	An exploration of the attitudes and perceptions of NHS physiotherapists not specialised in learning disability towards treating adults with a learning disability in primary and secondary healthcare settings in Northumberland.	2006	ACPPLD newsletter	6	• Supporting access from mainstream health services
Lowes L 2006. An exploration of the attitudes and perceptions of NHS physiotherapists not specialised in learning disability towards treating adults with learning disabilities in primary and secondary healthcare settings in Northumberland. ACPPLD Newsletter.					
Lowes	Can tasks be delegated to non-qualified staff without consistency or effectiveness being affected?	2007	ACPPLD newsletter	6	• Training and Education
Lowes L 2007. Can tasks be delegated to non-qualified staff without consistency or effectiveness being affected? ACPPLD Newsletter.					
Mencap	Treat me well	2018	Campaign	6	• Training and Education
Mencap 2017. Treat me well: Simple adjustment make a big difference. Available at: https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well last accessed on 16.05.19.					
McMillan	Pedal Power	2013a	Frontline Article	6	• Health Promotion
McMillan I 2013. Pedal Power. Frontline. 19(1).					
McMillan	Physios could play crucial role following launch of learning disability strategy	2013b	Frontline Article	6	• Supporting access from mainstream health services
McMillan I 2013. Physios could play crucial role following launch of learning disability strategy. Frontline. 19(13).					

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Grey Literature					
Miller	Rebound therapy – Where is the evidence?	2007	Frontline Article	6	• 24hr Postural Management • Respiratory Management • Falls Prevention and Intervention • Management of Mobility Problems
Miller A 2007. Rebound Therapy – Where is the Evidence? Available at: https://www.reboundtherapy.org/edu/ last accessed 01/08/19.					
Miller A 2015 Lanarkshire physios help people with learning disabilities get fit. Frontline.					
Millet	Body works: postural care for people with profound learning disabilities	2015b	Frontline Article	6	• 24hr Postural Management
Millet R 2015 Body works: postural care for people with profound learning disabilities. Frontline 2015; 21(12). Available at: http://www.csp.org.uk/frontline/article/body-work-postural-care-people-profound-learning-disabilities last accessed 01/08/19.					
Roberts	Bounce benefits	2006	Frontline Article	6	• 24hr Postural Management • Respiratory Management • Falls Prevention and Intervention • Management of Mobility Problems • Health Promotion • Spasticity Management
Robert D 2006. Bounce Benefits. Physiotherapy Frontline 12 (3), 12-14.					
Physiopedia contributors	The role of the physiotherapist in learning disabilities: Communication and health literacy	NK	Resource Guide	6	• Supporting access from mainstream health services • Falls Prevention and Intervention • 24hr Postural Management • Respiratory Management • Health Promotion • Training and Education
Physiopedia contributors 2017 The Role of the Physiotherapist in Learning Disabilities: Communication and Health Literacy, Physiopedia, Available at: https://www.physio-pedia.com/index.php?title=The_Role_of_the_Physiotherapist_in_Learning_Disabilities:_Communication_and_Health_Literacy&oldid=174440 Last accessed 01/08/19.					
Standley	Integrated respiratory pathway for people with complex physical and learning disabilities	2016	ACPPLD newsletter	6	• Respiratory Management • Dysphagia Management • Training and Education
Standley D 2016. Integrated Respiratory Pathway for People with Complex Physical and Learning Disabilities. ACPPLD Newsletter: Autumn Issue: 27-38					
Tinkler	Learning disabilities: help to build the right support	2015	Frontline Article	6	• Supporting access from mainstream health services
Tinkler J 2015. Learning disabilities: help to build the right support. Frontline. 21 (21).					

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Grey Literature					
Tinkler	Twenty-four hour postural management for adults with a profound intellectual and multiple disability (PIMD) and body shape distortion: A Delphi consensus study exploring physiotherapists' perceptions of practice	2016	ACPPLD newsletter	6	• 24hr Postural Management • Training and Education
Tinkler J 2016. Twenty-four hour postural management for adults with a profound intellectual and multiple disability (PIMD) and body shape distortion: A Delphi consensus study exploring physiotherapists' perceptions of practice. ACPPLD Newsletter. Spring Edition. 14-19					
Tinkler	The physiotherapy role in the NHS England service model supporting people with a learning disability and /or autism who display behaviour that challenges, including those with a mental health condition.	2016	ACPPLD newsletter	6	• Behaviours that Challenge
Tinkler J 2016. The physiotherapy role in the NHS England service model supporting people with a learning disability and /or autism who display behaviour that challenges, including those with a mental health condition. ACPPLD Newsletter. Spring Edition.					
Tinkler	Twenty-four hour postural management for adults with profound intellectual and multiple disabilities (PIMD) and body shape distortion: A Delphi consensus study exploring physiotherapists' perceptions of practice.	2017	PHD	6	• 24hr Postural Management • Training and Education
Tinkler J 2017. PHD Thesis: Twenty-four hour postural management for adults with profound intellectual and multiple disabilities (PIMD) and body shape distortion: A Delphi consensus study exploring physiotherapists' perceptions of practice.					
Tinkler	STOMP it out	2018	Frontline Article	6	• Behaviours that Challenge
Tinkler J 2018. STOMP it out! Frontline 24 (2)					
Whyte	Improving mobility, balance and falls risk in adults with a learning disability: an analysis of two community-based exercise groups.	2016	ACPPLD newsletter	6	• Falls Prevention and Intervention
Whyte A 2016. Improving mobility, balance and falls risk in adults with learning disabilities: an analysis of two community-based exercise groups. ACPPLD Winter Newsletter. 33-42					
Wilde	Learning to keep fit	2006	Frontline Article	6	• Health Promotion
Wilde L 2006. Learning to Keep Fit. Frontline. 12 (17).					
Whitaker and Cooper	The role of the specialist physiotherapist in learning disabilities	2006	ACPPLD newsletter	6	• Supporting access from mainstream health services
Whitaker L 2006. The role of the specialist physiotherapist in learning disabilities. ACPPLD newsletter. 1(Mar). 16-21.					

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Barriers to adults with a learning disability accessing healthcare

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Intrinsic barriers

The main intrinsic factors that have been identified to cause barriers to adults with a learning disability accessing successful healthcare include:

Barrier	Description
Apprehension about accessing healthcare	Adults with a learning disability may have apprehensions about accessing healthcare thus avoid seeking help when required which leads to delay in assessment, diagnosis and treatments.
Behaviours that challenge	Some adults with a learning disability display behaviours that challenge. These can be a significant barrier to successful access to healthcare (Alborz et al. 2005; Emerson et al. 2010).
Capacity to consent	Adults with a learning disability may lack the capacity to make decisions about their own healthcare. They are therefore reliant on others to make decisions in their best interest. It is well evidenced that carers have difficulty identifying health needs and perceive the person they care for to be healthier than suggested by the results of medical examination (Heslop et al. 2013).
Challenges identifying and communicating health needs	Adults with a learning disability may have difficulty identifying and/or communicating needs to carers and health professionals due to poor body awareness and depressed pain responses. This can result in poor timely responses to physical symptoms (Alborz et al. 2005; Emerson et al. 2010). Adults with a learning disability are often unable to express when their needs change and do not proactively seek medical support to manage these changes. They are also less able to communicate side effects of drug changes and management plans. Limited communication skills reduces the capacity of people with a learning disability to convey health needs effectively to healthcare professionals, relatives, friends, paid support workers. This reduces their ability to advocate for themselves when accessing healthcare. This increases their reliance on others to interpret this limited communication, to diagnosis and treat presenting problems (Emerson et al. 2010).
Higher prevalence of health problems	Adults with a learning disability have a higher prevalence of cancer, coronary heart disease, respiratory disease, mental health problems, dementia, epilepsy, sensory and physical impairments, poor oral health, dysphagia, diabetes, gastro-oesophageal reflux, constipation, osteoporosis, endocrine disorders and injuries, accidents and falls (Emerson et al. 2010).

Personal health risks and behaviours	Adults with a learning disability are less likely to have a healthy body mass index and weight. They are more likely to be over or underweight. Adults with a learning disability are less likely to eat a balanced diet, with sufficient intake of fruit and vegetables, especially if they live in supported accommodation. They are more likely to lead sedentary lifestyles and are less likely to engage in the minimum recommended level of physical activity as advised by the Department of Health. Thus, they have a higher incidence of obesity, which is likely to be associated with an increased risk of diabetes (Emerson et al. 2010).
Poor access to health promotion or screening	Adults with a learning disability are less likely to receive preventative healthcare due to the challenges in providing healthcare for a presenting condition. In addition, the uptake for health promotion and screening is lower than the general population (Robertson et al. 2010).
Poor health literacy	Adults with a learning disability often have poor health literacy which is the degree to which individuals have the capacity to obtain, process, and understand basic health information. This can result in poor understanding and compliance with healthcare (Alborz et al. 2005; Emerson et al. 2010).
Social determinants of health	Adults with a learning disability are more likely to be exposed to common 'social determinants' of poorer health such as poverty, poor housing conditions, unemployment, social disconnectedness and discrimination (Alborz et al. 2005; Emerson et al. 2010).
Specific genetic and biological causes of a learning disability	Associated conditions increase the risk of people with a learning disability having and developing specific health problems. For example: • People with Down's syndrome have congenital heart problems at a much higher rate than the general population and they have higher risk of developing Alzheimer's disease (Emerson et al. 2010). • Cerebral palsy increases risk of postural deformities, hip dislocation, chest infections, dysphagia, gastro-oesophageal reflux, constipation and incontinence (NICE 2017 and 2019).
Unmet health needs	A high proportion of adults with a learning disability have unmet health needs (Emerson et al. 2010). 72% to 94% of adults with a learning disability have one or more unmet health needs (Alborz et al. 2005).

Extrinsic barriers

Network of care

Adults with a learning disability are often reliant and dependent on their network of care to identify, communicate and treat their health needs. This introduces potential external barriers to managing the health of adults with a learning disability. The network of care may have a poor understanding of the health needs of adults with a learning disability and where to access appropriate healthcare. The barriers posed by a person's network of care are increased significantly in multi-care environments and where there are complex social circumstances.

Barrier	Description
Difficulties identifying the health needs of adults with a learning disability	Carers regularly have difficulty recognising expressions of need, particularly if the person concerned does not communicate verbally. Identifying insidious and gradual deteriorations in health can be particularly challenging (Alborz et al. 2005; Emerson et al. 2010).
Not prioritising health care over activities	Carers may prioritise health management less than other activities of daily living which can result in high rates of non-compliance with health recommendations and appointments (Stewart et al. 2009)
Compliance with recommendations	Some carers have a poor understanding of and compliance with their own health recommendations. Thus, are not always the most appropriate person to advocate for the health needs of the person they support. They may make wrong assumptions about their health and be reluctant to seek help for what they consider 'trivial' issues or where they consider the person would not benefit from intervention (Emerson et al. 2010).

Healthcare professionals

Adults with a learning disability represent a small percentage of the general population. Therefore, healthcare professionals working in mainstream often not have the opportunity to develop the necessary knowledge, skills and experience required to provide effective healthcare. As a result, healthcare professionals can present as another extrinsic barrier. Mencap (2017) recognises this knowledge and skills gap and recommends the need to provide training that focused on learning disability for all healthcare professionals. Mencap's campaign has been supported by the Department of Health and Social Care (2019) who are proposing learning disability and autism training for all health and care staff. At the time of writing, the Department of Health and Social Care (2019) document was still in the consultation phase but recommends that training is mandatory and is based on the learning disabilities core skills education and training framework (Skills for Health 2019).

Barrier	Description
Challenges with Communication	Healthcare professionals working in mainstream healthcare settings lack the skills to communicate effectively with people with a learning disability. Thus, are reliant on the person's network of care which can be a barrier in itself (Alborz et al. 2005; Emerson et al. 2010).

Negative attitudes of healthcare professionals.	There is evidence that some healthcare professionals and services have negative and disablist attitudes towards adults with a learning disability. This can result in assumptions about the appropriateness of performing tests and treatments and about quality of life. These views may deter people with a learning disability and their network of care from seeking healthcare because they perceive that their complaints are not taken seriously, or that staff are judgemental about their capabilities (Emerson et al. 2010).
Lack of involvement of network of care	A lack of engagement with the network of care is cited within the literature as one of the main contributing factors to poor access to healthcare for adults with a learning disability. There is often poor communication with the network of care about assessment and treatment options; and a lack of involvement in capacity assessment and best interest decisions (Alborz et al. 2005; Emerson et al. 2010).
Diagnostic overshadowing	Diagnostic overshadowing is the term used by the Disability Discrimination Act (1995) and others to describe the tendency to attribute symptoms and behaviour associated with illness to the learning disability, Thus, concerns are not taken seriously, and medical conditions are overlooked which leads to delays and failure to make the correct diagnosis (Mencap 2007; Michael and Richardson 2008; Department of Health 2009; Heslop et al. 2013).
Poor understating of Mental Capacity Act	Healthcare professionals working in a mainstream health setting may lack an understanding of the Mental Capacity Act and therefore do not apply the framework appropriately. It is common that consent is sought from the person's network of care rather than taking the time to gain consent or follow a best interest process (Emerson et al. 2010; Tuffrey-Wijne et al. 2014).
Poor understanding of the role of specialist learning disability services	Poor understanding of the role of specialist learning disability services reduces the appropriate use of the teams in supporting the healthcare of people with a learning disability.
Poor understanding of the health needs of people with a learning disability	Healthcare professionals often lack awareness of the specific health needs of adults with a learning disability which further leads to challenges in diagnosis and treatments (Tuffrey-Wijne et al. 2014).

Healthcare organisations and services

In addition to the barriers relating directly to the individual, their network of care, and healthcare professionals a range of organisational barriers to accessing successful healthcare have been well documented and evidenced.

Barrier	Description
Time constraints	Adults with a learning disability often require additional time to access healthcare including longer appointments and episodes of care. These are particularly challenging when accessing the GP or during hospital admissions.

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Lack of understanding about responsibilities to make reasonable adjustments	There is often a lack of understanding about the responsibility of health services to make reasonable adjustments to support adults with a learning disability to access quality healthcare (Tuffrey-Wijne et al. 2014).
Sparsity of specialist services	There is a lack of local specialist learning disability services to meet the needs of adults with a learning disability. Specialist services are critical to supporting people with a learning disability to access mainstream services and provide management where the person is unable to access services successfully (Department of Health 2009; RCGP 2013; Heslop et al. 2013).
Poor collaborative working	Collaboration between the network of care, GPs, primary health care teams and specialist services for adults with a learning disability is generally regarded as poor often resulting in disjointed care and management (Heslop et al. 2013).
Physical access barriers	There are several physical barriers to accessing healthcare including a lack of accessible transport links; changing facilities, hoisting equipment and quiet areas. There are also inaccessible signs and notices which are problematic for people with low literacy levels or sensory disabilities.
Identification of people with a learning disability	There is a lack of effective flagging systems to identify patients with learning disabilities therefore patients are not being identified and reasonable adjustments put in place whilst they access healthcare (Heslop et al. 2013; Tuffrey-Wijne et al. 2014).

Summary

There are a wide range of potential barriers to providing successful healthcare to people with a learning disability. In reality, there is usually a combination of barriers that are dependent on the person's learning, physical and sensory disabilities; their social circumstances; and the local healthcare services. In the same way, the adjustments required to overcome these barriers to provide successful healthcare to people with a learning disability need to be individually tailored. The more barriers an individual presents the more adjustments are required which increases the challenges for professionals and services. Under the Equality Act 2010, all disabled people have the right to reasonable adjustments when using public services, including healthcare. These adjustments aim to overcome the barriers that disabled people would otherwise face ensuring they have equal access to good quality healthcare (Mencap 2018).

Reasonable adjustments to support adults with a learning disability to access successful physiotherapy outcomes.

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The adjustments that are reasonable for mainstream physiotherapists to make to provide successful physiotherapy to adults with a learning disability are well documented within the literature (Public Health England 2016; ACPPLD 2017; Mencap 2018). These are collated in the following tables. It is essential that adjustments are made both at an intrinsic and extrinsic level and mainstream physiotherapy and healthcare services should be expected to make these adjustments before signposting and referring to specialist learning disability services. However, they may require some advice or support to make these adjustments which is recognised as one of the core functions of the community learning disability team (Department of Health 2009; RCGP 2013; Learning Disability Professional Senate 2015; National Quality Board 2018).

Intrinsic adjustments	
1	Acknowledge that behaviours that challenge are usually a method of communication.
2	Adapt communication, for example using simple language; avoiding medical terms; using imitation and demonstration to minimise words; use visual aids such as pictures, symbols, videos.
3	Arrange appointments via telephone or using accessible letters.
4	Be flexible and relaxed during the appointment.
5	Develop person centred treatment plans that are meaningful to the adult with a learning disability.
6	Ensure that appointments are on time for adults with a learning disability who are unable to wait.
7	Offer a flexible treatment approach including keeping treatment simple with slow progressions.
8	Set rehabilitation goals that are person centred and relevant to the adult with a learning disability.
9	Focus the assessment and consider its format to improve engagement.
10	Make assessment and treatment functional and fun.
11	Offer flexible appointments in terms of the length, time and location.
12	Provide information and any treatment plans in an accessible format that are easy to follow and understand.
13	Recognise when an appointment is not effective, re-schedule to another time and consider another approach.
14	Talk directly to the person with a learning disability as well as the carer.
15	Triage appointments to ask about the adjustments required to provide successful physiotherapy to the adult with a learning disability.
16	Utilise specialist assessment tools to support communication such as the disability distress assessment tool (DisDAT).
17	Work within the Mental Capacity Act (2005) including performing capacity assessments and leading best interest decisions where required.

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Extrinsic reasonable adjustments	
Service and organisation level adjustments	
1	Understand the legal responsibility to provide services to adults with a learning disability and their duty to provide reasonable adjustments.
2	Develop a culture that encourages its employees to make reasonable adjustment to support people with a learning disability to have positive access to and responses from their services.
3	Ensure physiotherapists have time to prepare for appointments with adults with a learning disability. This includes time to contact the person or their network of care prior to the appointment to find out what adjustments are required; contacting the specialist learning disability team; and/or preparing the environment.
4	Have an appropriate environment to support the adult with a learning disability including hoisting equipment, changing facilities, quiet areas and additional space when required.
5	Develop an appropriate flagging system to highlight when adults with a learning disability are attending mainstream physiotherapy services.
6	Develop links with local specialist learning disability services to support collaborative working.
7	Offer a flexible did not attend (DNA) policy for adults with a learning disability who are reliant on their network of care to support them to appointments.
8	Ensure physiotherapists receive training to develop an awareness and understanding of the Mental Capacity Act (2005) and how it impacts on practice.
9	Support employees to attend learning disability awareness training in line with Department of Health and Social Care recommendations.
Engaging the person's network of care	
1	Request support from the carer that best knows the adult with a learning disability such as a key worker.
2	Allow carers to accompany the person with a learning disability on transport.
3	Consider accessibility of physiotherapy for the network of care including the time of the appointment and the physical environment.
4	Gather information about the person prior to the appointment in particular their communication needs, likes and dislikes.
5	Include the person's network of care in physiotherapy assessment and management processes.
6	Provide the carer supporting the appointment with the information from them to hand back to the rest of the team if required.
7	Delegate physiotherapy programmes to the person's network of care when required in line with Chartered Society of Physiotherapy (CSP) guidance.
8	Ensure physiotherapy treatment plans are easy for the network of care to follow.

History of physiotherapy for adults with a learning disability

The emergence of the community learning disability team and the future

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Physiotherapy began as a profession in 1894 with the 'Society of Trained Masseuses'. Established by four nurses who wished to protect and legitimise their occupation. Examinations in anatomy, physiology and massage were held straight away. Initially for women only the society began to train men in 1920 and is granted a Royal Charter by King George V changing its name to the 'Chartered Society of Massage and Medical Gymnastics'. The Society adopted its current name 'The Chartered Society of Physiotherapy' (CSP) in 1944. The CSP has merged with many rival organisations over the years, the last one being in 1986 when they amalgamated with the Society of Remedial Gymnastics and Recreational Therapists. The term physiotherapy encompasses a range of interventions, services and advice aimed at maintaining, restoring and improving people's function and movement and thereby maximising the quality of their lives. As a profession physiotherapy has changed over the years from in the 1940's working with patients as prescribed by doctors, to the autonomous practitioners of today. However, whilst the establishment of physiotherapy as a profession and physiotherapy techniques may have changed over the years, human movement remains something of a constant.

It is believed that therapists began working in institutions for adults with a learning disability as early as the late 1800's, however, their role was not well documented. Physiotherapists were slow to enter the field of learning disability. At Larbut Hospital (Falkirk Scotland) formal physiotherapy was in place by the 1950's but this was unusual (Swain and French 1999). In 1960 in Northgate hospital in Morpeth Northumberland physiotherapists began working towards a multi-disciplinary approach. Physiotherapists visited for three sessions a week, handing on their skills to the nurses who carried out the treatment programmes (Auty 1991).

The National Health Service (NHS) was created in July 1948, based on three core principles 1. To meet the needs of everyone. 2. To be free at point of delivery and 3. Be based on clinical need, not on the ability to pay. At the beginning of the 1950s there were thought to be 55,000 adults with a learning disability living in hospitals/ institutions in England and Wales. The institutions became hospitals and inmates became patients, encouraging the belief that learning disability was an illness requiring doctors and psychiatrists. Thus the 'medical model' of care was established that was to continue until the 1959 Mental Health Act urged a move towards community-based services.

Although the Mental Health Act of 1959 required that more community care should be provided, the number of people being admitted into the long stay hospitals continued to rise, with more hospitals being built to meet demand. However, conditions in these hospitals continued to be poor, and in 1969 the Ely report exposed dreadful treatment of patients, care was described as old fashioned and 'custodial'.

The 1971 White Paper 'Better Services for the Mentally Handicapped' recognised that "not enough progress had been made in developing community services and getting people out of hospitals". The government outlined a desire to move away from caring for people with a 'mental handicap' in institutional hospital settings and to increase the provision of local and community care.

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In the 1970's specialist learning disability physiotherapists were working with adults who had 'severe and multiple handicaps and those with severe deformities' and their focus was on postural positioning, seating, promoting mobility and developing adapted equipment, including wheelchairs. Mostly they were working within a hospital setting within therapy departments in line with the medical model, treating patients, wearing a uniform and reporting to a medical doctor. In some areas physiotherapy was still prescribed by the doctor and was very specific. It was not until 1977 that physiotherapists gained autonomy and could take direct referrals. For many people their physical disability had not been managed since birth and they were either left in bed or on bean bags. Therefore, in the early years, physiotherapists were treating people with very severe and fixed postures. Specialist equipment for postural management was not available and adaptations to wheelchairs were very primitive. In the 1970's there is evidence of physiotherapists working in large institutions such as Fieldhead Hospital in Wakefield, which was built in 1972 for the treatment and care of the 'mentally handicapped'. A report written in 1978 'Helping Mentally Handicap People in Hospital' stated that there were only 80 full time physiotherapists in mental handicap hospitals in the whole country (Swain and French 1999).

There were several reports, papers and studies throughout the 1980's and 90's that supported the move from NHS care in institutions to community care. This coincided with a big shift in attitude. It was following the Jay Report in 1979 that the principles of 'normalisation' began to influence social policy discourse. 'Normalisation' as a concept was founded in Denmark 'letting the mentally retarded live as close to normal as possible'. Normalisation was a framework for understanding and influencing service values and practices, which later became known as Social Role Valorisation (SRV). SRV and specifically in 1981 research by' John and Connie O'Brien' led to the development of the 5 accomplishments:

1. **Community Presence** – ensuring that service users are present in the community by supporting their actual presence in the same neighbourhoods, schools, workplaces, shops, recreation facilities and churches as ordinary citizens.

2. **Choice** – ensuring that service users are supported in making choices about their lives by encouraging people to understand their situation; the options they face and to act in their own interest both in small everyday matters; and in such important issues as who to live with and what type of work to do.

3. **Competence** – developing the competence of service users by developing skills and attributes that are functional and meaningful in natural community environments and relationships, i.e. skills and attributes which significantly decrease a person's dependency or develop personal characteristics that other people value.

4. **Respect** – enhancing the respect afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, and forms of dress and use of language promote perception of people with a learning disability as developing citizens.

5. **Community participation** – ensuring that service users participate in the life of the community by supporting people's natural relationships with their families, neighbours and co-workers and when necessary widening each individual's network of personal relationships to include an increasing number of people.

(O'Brien and Tyne's Five Service Accomplishments 1981)

Following the introduction of the O'Brien and Tyne's Five Service Accomplishments there was a steady stream of policy and legislative documents that influenced service provision for adults with a learning disability. By 1984 the long stay hospitals started to close, and people moved into residential care homes in the community. It was at this time that specialised community teams started to emerge. Health and social services for adults with a learning disability were commonly

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provided through specialised community teams. This model of health and social care has existed for nearly 20 years and has expanded since the closure of hospitals. It is responsible for direct services e.g. occupational therapy and physiotherapy (Swain and French 1999).

One example of the different models that districts took when planning for the return of their residents is from Darenth Park Hospital. In 1948 this was home to 2260 residents from across London and the south east. In 1977 it was sectorised and split into "mini-hospitals" each serving its own catchment area- thus paving a way towards community-based care. In 1987 Bromley borough moved their residents out of Darenth to 'Bassetts' which was a cluster of 9 houses for 72 people. In the neighbouring borough of Lewisham they had a staggered return to borough for their residents with 'not for profits' set up that developed bespoke homes within the community, each assessed and provided to meet an individual's needs, mostly in 1- 5 bedded homes. A few residents moved to the smaller hospital at Grove Park that already had a few residents, whilst appropriate accommodation was found. Grove Park finally closed its doors in 1994. In South Southwark they built a core and cluster (Bowley Close in Crystal Palace) which had flexible accommodation in a small housing estate next to a day centre that had a hydrotherapy pool, hairdressers etc. Across the country each district was developing its own local services. Alongside this the community multi-disciplinary teams were also developing. Again, documented accounts of these early community teams, how they were set up and how they functioned is very sketchy and therefore some of the accounts is from lived history, from staff who worked in teams in the 80's and early 90's. Although there is limited documentation, physiotherapists were very much a part of these early teams and as a result in 1985 'The Association of Chartered Physiotherapists in Mental Handicap', a special interest group was founded, having previously been a regional group in Trent. This group started with 26 members and enabled physiotherapists working in learning disability in the local area and wider afield to come together to facilitate learning, share ideas and support each other. Later, they changed their name to the Association of Physiotherapy for People with Learning Disabilities (ACPPLD). There are currently 9 regions with 333 members across the UK.

In 1985 Craft, Hollins and Bicknell wrote 'A multi-disciplinary approach to Mental Handicap'. This was a textbook of interest to a number of professional groups and those responsible for service planning and the allocation of funds. It was not a "hands on" book in the sense of telling a newly appointed professional how to begin. There was a short section on 'The role of the physiotherapist'. It covered topics such as mobility, postural management, additional support within wheelchairs, positioning for eating and drinking, respiratory function and management and discusses the assessment and treatment options for common medical conditions.

Services were developing at a very different pace across the UK and Scotland. In some areas there was a strong drive to close the institutions and support the residents to move into the community. One of the first large long-stay institutions for adults with a learning disability to close was the 'Royal Western Counties Hospital 'Starcross' in Exeter, which closed as early as 1986. The last long stay hospital to close was Orchard Hill Hospital in Sutton which only closed as recently as 2009.

Community based learning disability teams also developed at a different pace across the UK. In 1998 a key document that supported the development of these community teams was 'Signposts for Success'. The aim of this document was to promote good practice by clarifying the role of the NHS in providing services to adults with a learning disability. This became the standard by which community health teams benchmarked their service. Coming at a time when the impetus to close long stay institutions was gathering momentum, it acknowledged the need for specialist community learning disability services and set out basic best practice guidelines and checklists for action. The role of the specialist community health teams was considered vital. ''A wide range of professional skills are required by people with learning disabilities to build and maintain their skill and abilities and to address particular difficulties or problems.

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Communication, mobility and daily living skills are important components of the enabling process and health services such as speech and language therapists, physiotherapists, occupational therapists and learning disability nurses all have relevant skills''. This good practice guidance laid out the expectation that specialist learning disability services needed to work with the service user, families and network of care to support access to health professionals in primary care or hospital. ''It is often necessary to work with or alongside staff from other and agencies, and skills in working across boundaries are also required. It is essential that community learning disability specialists place particular emphasis on working with other health professionals including the primary care team and other community and hospital services''. It also stated that most services are delivered in the community, offering various therapies to address a specific problem. ''The professional skills in the care of people with learning disabilities and the additional needs relating to mental health problems, epilepsy, sensory impairments and physical disabilities should be available''. The guidance stated community learning disability health services should:

- Offer a wide range of co-ordinated support and advice for people with a learning disability their families and carers
- Provide therapeutic services
- Offer training for people with a learning disability, their families, carers and staff of other organisations
- Work closely with other agencies
- Help the development of good practice in relation to health promotion and health care
- Facilitate access to general health services.

Considering this document was written in 1998 the principles within its guidance could just as easily apply to the core roles of the community learning disability team today.

There had been very little written specifically about the roles or standards of practice for the provision of physiotherapy for adults with a learning disability until in 1991 Patricia Auty, a specialist learning disability physiotherapist working in South London wrote 'Physiotherapy for People with Learning Difficulties'. This was the first book specifically for physiotherapists working with adults with a learning disability. It provided a historical background to services for people with a learning disability and outlined specific roles and ways of working for the specialist learning disability physiotherapist including assessment, individual programme plans, treatment methods, teaching guidelines and multi-disciplinary working. Later in 2001 Jeanette Rennie wrote 'Learning Disability, Physical Therapy, Treatment and Management, A Collaborative Approach,' which was updated in 2007. This book provided a comprehensive overview of the diverse approaches to treatment and management issues, as well as methods to help physiotherapists achieve the rehabilitation aims. Split into three sections, the book covers 1 Underlying theory; 2 Assessment; 3 Practical methods of physical treatment and management.

The five accomplishments initially development by O'Brien and Tyne's (1981) were a foundation stone for Valuing People: A New Strategy for Learning Disability for the 21st century (Department of Health 2001). This was the first white paper about adults with a learning disability for 30 years and was the first policy that signalled a new approach to the delivery of care, and a new relationship between the state and the citizen. It provided a vision for the lives of adults with a learning disability and their families based on the four principles of rights, independence, choice and inclusion. It sought new ways to give people and families a voice, to be at the centre of their own plans, and to have some control over how resources were spent on them through Direct Payments.

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The key elements were:

- An end to the last long-stay hospitals.
- A five-year programme to modernise local council day services.
- A new national learning disability information centre and helpline in conjunction with the charity Mencap.
- A national forum for adults with a learning disability.
- A learning disability task force.
- Specialist local services for people with severe and challenging behaviour and integrated facilities for children with severe disabilities and complex needs.
- An extension of eligibility to "directs payments", a scheme which allows service users to choose and purchase their own care.

As time went on and the move from long stay hospital to the community was completed, community teams needed to review and adjust their core roles. Whereas much of their work initially was supporting the relocation, they now needed to develop how they were going to support people in the future. Legislation also continued to develop and shape the direction of services. Albeit initially the thought was that all health services for adults with a learning disability should and would be provided by mainstream services (Valuing people 2001). There was an awareness from the therapists within community learning disability teams that mainstream services were not able to provide all the health support and that some people needed specialist support. This was especially true of people who had complex postural health needs; those who had mobility difficulties or at risk of falls; or where someone's learning disability impacted on the level of care they were able to receive from mainstream services. Therefore, community teams continued to develop and change over the years in both structure and role.

In 'Commissioning Specialist Adult Learning Disability Health Services Good Practice Guidance' (Department of Health 2007). Rob Grieg stated that there is growing concern that some areas of the country found it difficult to develop commissioning strategies for specialist adult learning disability health services, which reflect both current policy and best practice. This led to, in places, inappropriately funded services, outdated service models, poor development of community infrastructures and the lack of appropriately funded and skilled specialist learning disability health services.

Three major factors were creating change in the demand for specialist learning disability services:

1. Significantly increased numbers of adults with a learning disability, partly caused by people living substantially longer as a result of medical and technological advances. Therefore people needed additional support around illnesses linked to old age, in particular dementia and people with Down's syndrome.
2. Significant changes in the demographic profile with increased numbers of people with complex needs requiring input from specialist health professionals. This particularly applies to young people with multiple disabilities and, together with the above point, will require commissioners to consider levels of investment in both mainstream and specialist health services.
3. The increasing empowerment of adults with a learning disability and their families, resulting in them expecting and demanding better quality services located nearer to their home and communities.

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Rob Grieg acknowledged that the most critical component of specialist learning disability health services is the commissioning and employment of a range of staff with the skills to support adults with a learning disability in all settings, providing specific and additional input as required to respond to their health care needs. There will need to be a range of staff skills commissioned and recruited as part of these community health infrastructures. This will include, but not necessarily be limited to, physiotherapists, occupational therapists, speech and language therapists, psychiatrists, clinical psychologists and learning disability nurses.

Debra Moore Associates, wrote 'the role of specialist health services in supporting the health needs of people with a learning disability' in 2011 (Moore and Thorley 2011). The authors make recommendation about the future role and function of community learning disabilities teams. They stated that 'specialist learning disability health professionals continue to have an important role to play in supporting the health and wellbeing of people with learning disabilities and their families. They are required to both support mainstream practice and directly serve those with the most complex needs.' Political and demographic changes provide the back drop in which we have to consider role and function of specialist health professionals in community teams. Specifically, how we can make best use of this valuable resource now and in the future. Evidence suggested that the capability of mainstream services to appropriately support people with learning disabilities was still problematic. At the time, a raft of documents, guidance and inquiry papers were published that described the failings of the mainstream NHS to meet the needs of this group. A common theme within all these reports is a requirement to provide training for mainstream health professionals and to provide expert support and advice as required. The source of this expertise is often identified as the local community-based learning disability teams.

The evolution of community teams continued but not in a structured or uniform way and not always guided by National policy. As a result, it is possible to visit ten different community learning disability teams and each one will have a very different configuration. Some of this is determined by the host provider and whether it was a NHS Health Trust, Mental Health Trust, Private Enterprise or Integrated Social Care Teams. Some will have been influenced by Government led agenda's and the national awareness of the needs of adults with a learning disability.

One of the most significant events that has happened in the last 8 years that has influenced the delivery of services to adults with a learning disability is the Winterbourne View scandal. In May 2011 the BBC broadcast a documentary that shocked the country and raised the alarm over the care of patients in a private hospital, Winterbourne View that provided assessment and treatment for adults with a learning disability and challenging behaviour. Panorama sent in an undercover journalist using hidden cameras that showed residents were being bullied and physically and emotionally abused by staff. In 2012, 11 members of staff were convicted of over 40 offences. There was an immediate response that all services that provide care and treatment to adults with a learning disability were inspected, some were issued with improvement notices and some were closed. The Government made a commitment to close long-stay institutions such as Winterbourne View, and for all adults with a learning disability and/or autism who were inappropriately placed in hospital to be moved to community-based support by June 2014. This commitment was known as Concordat.

Winterbourne View was truly shocking and there is no doubt that significant change in the provision of services and support to adults with a learning disability and challenging behaviour had to happen. However, this client group are not those that specialist learning disability physiotherapists routinely see. They would make up only a very small percent of a specialist physiotherapist's caseload. A recent audit found that under 5% of the referrals received by Guy's and St Thomas' NHS Foundation Trust Specialist learning disability physiotherapy team were related to people with a learning disability and behaviours that challenge. This trend may vary across UK.

The implementation of the Health and Care Act in 2012 was another significant change that impacted on the delivery of services. This was an extensive reorganisation of the NHS which abolished Primary Care Trusts and Strategic Health Authorities transferring commissioning to Clinical Commissioning Groups (CCG's), removing day to day management from central government and passing this on to NHS England.

In 2012 the 'Learning Disability Professional Senate' (LD senate) was established. The aim of the 'LD senate' is to provide a single voice through which professionals can lead and inform NHS England, the Department of Health, and other strategy leads about the needs of children and adults with a learning disability. It brings together professional leaders from across the UK to provide cross-professional collaboration; strategic advice and innovation; and to develop both mainstream and specialist services.

A member of the national executive committee of the ACPPLD sits on the 'LD Senate'. Their role is to act as a conduit to promote the importance of the role of the specialist learning disability physiotherapist. Championing the needs of people with a learning disability that have physiotherapy needs. The ACPPLD representative also feeds back to the NEC and wider ACPPLD membership on national directives and strategies.

In 2013 the Confidential Inquiry into deaths of people with learning disabilities (CIPOLD) published its' final report following an independent inquiry into the premature deaths of people with learning disabilities. The report presented 18 key recommendations. Much of the impact of CIPOLD 'came from arming practitioners, family carers, people with learning disabilities and policy makers with the research findings and encouraging them to take on the mantle of change. For example, by increasing the provision of training or reviewing their current practice (Heslop et al. 2013). Specialist learning disability physiotherapists should review these 18 key recommendations and relate them back to their own service delivery and use them to provide evidence to support practice. Recommendation nine is of particular importance and directly relates to the population of adults with a learning disability that specialist physiotherapists take the lead in providing health support. It states that adults with a learning disability should be considered a high-risk group for deaths from respiratory problems. It recommends that CCGs must ensure they are commissioning sufficient, and sufficiently expert, preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural care support (Heslop et al. 2013).

In 2015 the Learning Disability Senate produced 'Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers: a briefing paper on Service Specifications and Best Practice for Professionals, NHS Commissioners, CQC and Providers of Community Learning Disability Health Teams'. This is a significant document that highlights that "there remain particular groups at risk of unnecessarily restrictive lifestyles, poor access to services and opportunities, and serious health inequalities" and that "locally commissioned effective specialist Community Learning Disabilities Health Teams are critical to providing the essential support needed by people with learning disabilities and their families. And their success can only be judged if this group of vulnerable people live full lives with more opportunities and less exposure to harm, as well as experience health outcomes in line with the wider general population". Physiotherapy was outlined as one of the lead areas for health activity. The LD senate described the role of the physiotherapist as:

> *"To prevent and reduce the incidence/impact of complex health issues and profound or multiple physical/sensory disabilities, including clinical case management for the delivery of packages of care through collaborative working with colleagues within primary and secondary care"*

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"Providing support to individuals with health facilitation/access issues for people with learning disabilities and their carers across health and social care communities, including issues in relation to primary/secondary health care access, and the provision of specialist moving and handling assessments, respiratory/dysphagia/postural care, mobility assessments, specialist equipment/access issues, systematic skills teaching/rehabilitation and complex support needs."

The learning disabilities mortality review (LeDeR) programme commenced in June 2015, initially for 3 years, but since has been extended until May 2020. The programme is the first national programme of its kind in the world. Its overall aims are to:

1. Support improvements in the quality of health and social care service delivery for people with learning disabilities.
2. Help reduce premature mortality and health inequalities for people with learning disabilities.

It was being implemented at the time of considerable spotlight on the deaths of patients in the NHS. The first LeDeR annual report was published in 2018 and covered reported deaths from July 2016 to November 2017. Of the 103 completed reviews there were 189 learning points or recommendations identified. The most commonly reported learning and recommendations were made in relation to the need for a) inter-agency collaboration and communication b) awareness of the needs of people with learning disabilities c) the understanding and application of the Mental Capacity Act (2005). LeDeR data identified that almost a third of deaths (31%) had an underlying cause related to disease of the respiratory system. Public Health England (2018b) report that respiratory problems are the main reason people with profound and multiple learning disabilities need primary or secondary medical care, and pneumonia is the most common cause of death in this group. They recognise that some of the risk factors for respiratory problems that can be reduced by good postural management are airway clearance dysfunction, saliva management difficulties, immobility, reflux, sleep disordered breathing and thoracic deformity.

In 2018 the National Quality Board wrote 'Safe and sustainable staffing. An improvement resource for learning disability services'. The authors reviewed the available literature to outline the roles of the specialist learning disability multidisciplinary team. They reviewed one document that outlined the role of the specialist learning disability physiotherapist to continue to the development of the 'right staff' section. This was provided by the learning disability senate (2015) titled 'The role of physiotherapy in the NHS England service model supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition'. Unfortunately, this document did not describe the main roles of the specialist learning disability physiotherapist or include the cohort of people with a learning disability who have physiotherapy needs. For example, people with postural needs, mobility problems, fallers or at risk of falls, and respiratory complications.

NICE published guidelines on cerebral palsy in adults in 2019. NICE recognise learning disability services are a key part of the local network of care for people with cerebral palsy. They acknowledge that the presence of a learning disability in addition to cerebral palsy increases the complex needs of the person and impacts on their health outcomes and their access to health and social care. They recommend that all adults with severe cerebral palsy (GMFCS level 4 and 5) and a learning disability should have an annual review by a healthcare professional with expertise in neuro-disability. The other key recommendations from the guidelines that are particularly relevant to specialist learning disability physiotherapy services include:

1. Supporting adults with cerebral palsy to engage with physical activities (including sport) and tasks of daily living.
2. Being aware that, because of abnormal musculoskeletal development, adults with cerebral palsy are more likely to have bone and joint disorders.
3. Adults with cerebral palsy at high risk of lower respiratory tract infections should be considered for a prophylactic review of their chest care including the assessment of the person's postural management. NICE recognise that adults with severe cerebral palsy and aspiration pneumonia, chronic cardiorespiratory disorders, chronic suppurative lung disease, kyphoscoliosis, poor saliva control, and/or recurrent chest infections are at high risk of developing respiratory complications. This describes a large population of the people specialist learning disability physiotherapists manage under their postural management pathways.
4. Adults with cerebral palsy and persistent or multiple signs and symptoms of respiratory impairment, or risk factors for respiratory impairment should be referred to specialist services.

Although not solely applicable for adults with a learning disability, a high prevalence of people with cerebral palsy have a learning disability, especially those with more severe manifestations of the condition. People with cerebral palsy and a learning disability make up a large percentage of the specialist learning disability physiotherapy caseload therefore the guidance is very relevant to the profession and can be used to evaluate and develop services.

Specialist physiotherapy services for adults with a learning disability continue to evolve.

20th century timeline

The key legislation; publications; national developments; policies; guidelines and labelling related to the health needs of adults with a learning disability

Go Back

This is not an exhaustive list, but gives a flavor of the change in attitudes and approaches to supporting adults with a learning disability.

LABELLING 1900 - c.1950. 'Mental defective' and 'mental deficiency' most common terms.

1904 Royal Commission on the Care and Control of the Feeble-Minded. Set up by Winston Churchill who was a strong supporter of eugenics.

1907 Formation of the Science of Eugenics Education Society. Only the fit and healthy should have children. 'Mental defectives' were seen as genetically tainted; they should be both separated from society and prevented from reproducing.

1908 Radnor Report Royal Commission on the care of the feeble minded. This was the main influence on the 1913 The Mental Deficiency Act. It recommended one central authority for the general protection and supervision of mentally defective persons, and for the regulation of the provision for their accommodation and maintenance, care, treatment, education, training, and control. Under the heading" Mentally Defective Persons" (Radnor Commission 1908).

1913 The Mental Deficiency Act (Replaces the 1886 Idiots Act). This act adds two new categories of 'feeble minded persons' and 'moral imbeciles' to the older laws two categories of 'idiot' and 'imbecile'. This Act initiated institutionalisation. It meant that people with a learning disability could be forced to live in asylums, many never returning to their families. In particular this influential Act made it possible to institutionalise women with illegitimate children who were receiving poor relief. At the height of the Mental Deficiency Act 65,000 individuals were institutionalised.

1914 Elementary Education (defective and epileptic) Act extended the right for an education to children who were 'mentally defective and epileptic'.

1918 The Education Act made schooling for all disabled children compulsory. It was a very significant piece of legislation. By 1921, there were more than 300 institutions for blind, deaf, 'crippled', tubercular and epileptic children. It was often thought that children with disabilities were better off away from their families, so even though a small number of them stayed in mainstream education, many left home to go off to residential schools.

1927 Mental Deficiency (Amendment) Act replaced the term 'moral defective' with 'moral imbecile'; crucially allowed for mental deficiency resulting from illness or accident. Previously it had to have been there from birth.

1929 The Wood report on Mental Deficiency published. The report was important because it argued that 'mentally deficient' children should not be isolated from the mainstream of education. Its view of special education as a variant of ordinary education advanced a principle which would later be extended to all forms and degrees of disability (Wood Report 1929).

1930 The eugenics movement was at its height. Some 60,000 people were subjected to sterilisation in Sweden between 1935 and 1976. Most were women and the majority were labelled as mentally defective, although most probably had only minor physical or social disability.

1933 Forced sterilisation of 360,000 disabled people in Germany.

1934 The Brock Report of the Departmental Committee on Sterilisation chaired by Lord Brock recommended legislation to ensure the ‹voluntary› sterilisation of ‹mentally defective women›. Brocks report listed 10 western nations which had either introduced or were in process of introducing sterilisation laws. The eugenics movement was powerfully supported within the social establishment, and Britain seemed to be on the brink of introducing one of the most wide-ranging sterilisation laws. Although the Report had great support from Churchill and the government, British legislation never adopted sterilization laws. However, both institutionalization and segregation were employed to help prevent "multiplication of the unfit" (Brock 1934).

During World War 2 between 75,000 and 250,000 learning disabled and physical impaired people were murdered by the Nazis. Following World War 2 the Eugenics movement had been discredited.

1944 Education Act involved a thorough recasting of the educational system. That it was a requirement of secondary education for all, a requirement that meant that no school fees could be charged in any school maintained by public authority; and the replacement of the former distinction between elementary and higher education by a new classification of three progressive stages to be known as primary education, secondary education, and further education.

LABELLING c 1940's 'Uneducable' label, introduced by 1944 Education Act, used with regard to people with a learning disability.

1944 Disabled Person Employment Act. 'An Act to make further and better provision for enabling persons handicapped by disablement to secure employment, or work on their own account, and for purposes connected therewith'.

1946 Judy Fryd, a mother of a child with a learning disability formed the National Association of Parents of Backward Children founded (later Mencap).

1948 Birth of the NHS. The NHS took over the responsibility for the care of people with a learning disability living in the large institutions.

1948 Darenth Park Hospital was an example of the type of institution the NHS took control

over. It had 2260 beds. A special ward was opened in 1949 for maladjusted patients whose behaviour was undisciplined and irresponsible. A Social Adjustment Centre was established, and patients were employed by outside companies. In this way, contracts were procured for box and carton-making, finishing plastic products, wiring electronic organs and fitting plugs. In 1951 over 3000 books had been bound and over 500,000 forms printed. There was a mattress making shop, upholsterers, mat making, brush making, and basketwork. The tailors' shop made and repaired the patients' clothes and the women made all their own dresses. The shoemakers made six pairs of orthopaedic boots needed for patients and repaired over 8000 pairs of shoes. Patients were paid 5 to 10 shillings (25-50p) weekly pocket money (the exact amount depended on performance). They were able to buy clothes and sundry items with this and the remainder of their wages was banked for them. In the 1960's, it was decided to close large institutions for mental illness. Darenth Park was too big, too old, too run down and too isolated to meet modern standards of care. There was only one lift in the entire complex and the blocks were 3 storeys high. The central heating system was too old and not powerful enough to heat the hospital properly in winter. The decoration was poor, and it needed re-wiring. The hospital was isolated and difficult to reach. Its catchment area was huge which meant that relatives had a long and difficult journey. The hospital was closed slowly as four out of ten

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patients had spent more than 25 years there. In 1977 the hospital was sectorised – split into "mini-hospitals" each serving its own catchment area- thus paving a way towards community-based care. The Darenth Park Hospital finally closed in 1988 – One the first NHS institutions of its kind to close as a result of government policy to move mental health care out of hospitals and into 'the community'.

1948 United Nations Universal Declaration of Human Rights. Article 3 states everyone has the rights of life; liberty and security of person.

1948 National Assistance Act. ''An Act to terminate the existing poor law (The Act for the Relief of the Poor 1601, popularly known as the Elizabethan Poor Law,) which directed via the National Assistance Board , local authorities; to make further provision for the welfare of disabled, sick, aged and other persons and for regulating homes for disabled and aged persons and charities for disabled persons'. Established a social safety net for those who did not pay National insurance contributions (such as the homeless, the physically handicapped, and unmarried mothers) and were therefore left uncovered by the National Insurance Act 1946.

1951 National Council for Civil Liberties (NNCL) and advocacy group led the campaign to reform the mental health system. The NNCL Published '50,000 Outside the Law', a ground-breaking report on those unjustly incarcerated under the 1913 Mental Deficiency Act. This publication was pivotal in the repeal in 1959 of the 1913 Mental Deficiency Act.

1953 Nearly half the National Health Service›s hospital beds were for ‹mental illness or mental defect›. Concerns about the level of spending were likely to be a factor in shifting government thinking towards Community Care policies.

1954-7 Royal Commission on the Law Relating to Mental Illness and Mental Deficiency (under Lord Percy); National Association of Parents of Backward Children gave evidence to Royal Commission.

1957 The Report of the Royal Commission on the law relating to 'Mental Illness and Mental Deficiency (the Percy Commission) was published in June 1957. The commission concluded that: 'the law should be altered so that whenever possible suitable care may be provided for mentally disordered patients with no more restriction of liberty or legal formality than is applied to people who need care because of other types of illness, disability or social difficulty'. One of its recommendations was 'where possible, people with mental disorders should be treated in the community and not in large psychiatric institutions – this required an expansion of community services' (Percy 1957).

1958 The Brooklands experiment by Professor Jack Tizard at the Maudsley Hospital. Showed that children who lived in small houses in the community developed better than those who l ived in hospitals.

1959 'The 1913 **Mental Deficiency Act** is abolished'.

1959 Extra 21st Chromosome identified as a cause for Downs Syndrome by Jerome Lejeune

1959 Mental Health Act. This repealed the 1913 Mental Deficiency Acts: espoused 'community care' but little funding; and said that patients should only be admitted on a voluntary basis unless seen as a danger to themselves or others (subsequently know as being 'sectioned'). Ended the compulsory certification enabling the discharge of many people with a learning disability from long stay institutions.

1960 The Brooklands experiment by Professor Jack Tizard at the Maudsley Hospital showed that children who lived in small houses in the community developed better than those who lived in hospitals (Tizard 1960).

LABELLING c1960 'Subnormal' 'and 'severely subnormal' terms used in 1959 Mental Health Act. 'Backward' came into vogue as a descriptive term.

1961 Enoch Powell, Minister of Health, says mental hospitals to close in 15 years.

1962 Ministry of Health Report: A Hospital Plan for England and Wales – a 10-year report that included the development of hostels (Ministry of Health 1962).

1964 Tizard›s Community Services for the Mentally Handicapped argues for small residential units.

1967 A long-stay hospital for people with a learning disability hit the headlines in a way which had rarely happened before. Ely Hospital, built in 1862 as a Poor Law institution and converted to a long-stay NHS hospital in 1948, was hit with allegations of endemic maltreatment of its patients, including cruelty, verbal abuse, beatings, stealing of food, clothes and other items, indifference to complaints, lack of medical care and medication used to sedate patients.

1969 Independent inquiry following the whistle blowing to the news of the world by a nursing staff assistant at Ely Hospital, Cardiff of allegations of abuse and ill treatment of vulnerable long stay patients and other irregularities. It is seen as the first modern inquiry into the NHS. It confirmed the truth of the allegations and described problems of poor clinical leadership, an isolative and inward-looking culture, inadequate management structures and systems and inadequate resources.

Ely Hospital men's ward

1970 Education (Handicapped Children) Act made education universal.

1970 Chronically Sick and Disabled Persons Act required local authorities to provide welfare services. Welfare services are those services that involve the provision of benefits and assistance to those in need. To disabled people who fell within section 29 of the National Assistance Act 1948 (those who were blind, deaf, people with a learning disability or mental illness and disabled people).

1971 Department of Health and Social Security White paper 'Better Services for the Mentally Handicapped'. Advocated 50% reduction in hospital places by 1991 and an increase in provision of local authority based residential day care. Multi professional teams encouraged to support (Department of Health and Social Security 1971).

1971 Professor Gerry Simon set up British Institute of Learning Disabilities (BILD) because he was convinced there could be better support in the community for people with disabilities.

1972 Wolfensberger introduced the principle of normalisation in human management services.

'Utilisation of means which are as culturally normative as possible, in order to establish and maintain personal behaviours and characteristics which are as culturally normal as possible' (Wolfensberger et al. 1972).

1975 The United Nations proclaimed the "Declaration on the Rights of Disabled Persons." In doing so, they reaffirmed that disabled individuals have the same rights as all other persons, including rights to medical, psychological; functional treatments, economic and social security, protection against exploitation; and a right to respect of their inherent human dignity.

1979 Jay Report published that called for a 'normal life' and investment in an appropriate workforce. The Jay Report said that the lives of people with a learning disability should be normal and they should be part of their communities and re-emphasised the need for local authority led care, this was based on an idea called 'Normalisation' that had been followed in Denmark since the late 1950s (Jay 1979).

1980 'An Ordinary Life'. David Towell and his colleagues at The Kings Fund worked to alert society to the rights of each person to live an ordinary life alongside other citizens. They included the rights to live in the mainstream of life, in ordinary houses, to have the same range of choices as other citizens and to mix equally as members of the community. Since the 1980's this philosophy has been kept alive by John O'Brien's Five Accomplishments, and it was at the core of Valuing People later published in 2001 (Towell 1980).

LABELLING c.1980 'People with Mental Handicap' became the preferred term.

1981 Education Act laid down that children should be educated in mainstream schools or classes wherever possible.

1981 O'Brien's 'The principle of normalisation': a foundation for effective services. Five essential accomplishments for quality of life (O'Brien and Tyne 1981).

1981 Three residents of Calderstones Hospital (for people with learning difficulties) successfully campaign for the right to vote in General Elections.

1983 Wolfensberger redefined normalisation as Social Role Valorisation (SRV) (Wolfensburg 1983).

1983 Mental Health Act. Law that sets out the criteria for admission, treatment (and if appropriate) the detention of patients with mental health issues in a hospital setting.

1984 People First group founded in England. In 1984 Gary Bourlet, a campaigner for people with a learning disability, created the self-advocacy group People First groups are often known as self-advocacy groups. They are groups of people with learning difficulties, people with intellectual disabilities, people with developmental disabilities and/or people with disabilities who speak up for themselves and work to improve the lives of their members.

LABELLING 1985 'People with learning difficulties' adopted by self-advocacy groups.

Having previously been a regional group in Trent, 'The Association of Chartered Physiotherapists in Mental Handicap' was founded in 1985 with 26 members. This enabled physiotherapists in learning disabilities from across their local area and wider afield could join together to facilitate learning, share idea and a support each other. Later changed their name to the Association of Chartered Physiotherapist for People with Learning Disabilities (ACCPLD) there are now 9 regions with 333 members across the UK.

1986 The first closure of a large long-stay institution for people with learning difficulties – Starcross, Exeter. The Royal Western Counties Hospital Starcross was built in 1874-1877 in Starcross in Kenton, Devon. The building was originally known as the Western Counties Idiot Asylum. This institution was founded in 1864 and housed 40 patients by 1870 and a larger building was needed which opened in 1877 and was able to house 60 boys and 40 girls. Additions to the building were added in 1886 and 1909 and a total of 1,451 patients were admitted by 1913. A national policy of transferring people with psychiatric problems and learning difficulties back into the community in 1986 marked the Royal Western Counties Hospital for closure. The building was demolished in 1990.

1988 Griffin Review. Commissioned by the secretary of state to undertake a review of community care policy (Griffin et al. 1988).

1989 Caring For People. White paper confirmed the government's commitment to the development of locally based health and social care services. Many group homes were developed as long stay institutions were closed.

1990 NHS and Community Care Act provided the necessary support structures to enable, where possible, people to remain in their own homes thereby reducing the demand for long term care. These structures included an increase in the range of domiciliary, respite and day services including the promotion of independent care options and a greater emphasis on supporting informal carers.

LABELLING c1990 Department of Health official term: 'people with learning disabilities'.

1991 Book published by Patricia Auty called Physiotherapy for People with Learning Difficulties (Auty 1991).

1995 Disability Discrimination Act published which made it unlawful to discriminate against disabled persons in connection with employment, the provision of goods, facilities and services, or the disposal or management of premises. The act also made provision about the employment of disabled persons; and established the National Disability Council.

1996 Mencap›s 50th anniversary Judy Fryd 1909 – 2000 Campainger and founder member.

1998 Human Rights Act. Contains 15 basic rights including

The right not to be tortured or treated in an inhumane or degrading way* e.g. an older person from being subject to abuse, exploitation or violence by those supposed to care for them or others.

1. The right to liberty and security. e.g. to support a person's right to choose to move from one local authority area to another while maintaining their package of care and support.
2. The right to a fair trial e.g. in relation to detention under the Mental Health Act (1983) and complaints processes
3. The right to respect for private and family life, home and correspondence e.g. ensuring that lesbian, gay or bisexual people living in residential care do not face discrimination in maintaining their relationships and friendships
4. The right to freedom of thought, conscience and religion* e.g. to support people with religious observance such as prayer, diet or the opportunity to participate in religious festivals
5. The right to freedom of expression* e.g. accessing communication support or independent advocacy

Human rights belong to everyone and cover aspects of everyday life such as rights to food, shelter, education and health, freedoms of thought, religion and expression. Rights are underpinned by core values or principles, including fairness, respect, equality, dignity, autonomy, universality and participation.

1998 Signposts for Success. An NHS Executive good practice guide in the commissioning and provision of health service for people with a learning disability. The aim of this document was to promote good practice by clarifying the role of the NHS in providing services to people with a learning disability. People with learning disabilities are known to have much greater health needs than the general population. They have high rates of general health problems, sensory impairments, mental health problems (including challenging behaviour), epilepsy, cerebral palsy and other physical disabilities. It stated that there was a risk that people with a learning disability and that carers may not recognise health needs and ensure appropriate help is obtained. There is evidence that they do not use primary care as much as would be expected from their needs. People with a learning disability need to have equal access to primary care, community and hospital services and in addition will also require specialised services to meet some of their mental and physical health needs (NHS Executive 1998).

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2000 The first Scottish white paper 'The Same as You' detailed a comprehensive review of services for people with a learning disability in Scotland and included a series of recommendations for future development (Scottish Executive 2000).

2001 Valuing people: A new strategy for learning disability for the 21st century published emphasis on consultation with parents and the principles of rights, independence, choice and inclusion (Department of Health 2001).

2001 Special Educational Needs and Disability Act (SENDA): removed two of three caveats for mainstream education; made educational discrimination unlawful.

2001 Book published. Learning Disability, Physical therapy, treatment and management, a collaborative approach by Jeanette Rennie (Rennie 2001).

2004 Mencap 'Treat me Right!' report and campaign exposed the unequal healthcare that people with a learning disability often receive from healthcare professionals. The report made clear that much work needs to be done within the NHS to ensure that people with a learning disability are treated decently and equally (Mencap 2004).

2005 Mental Capacity Act. People with a learning disability have the right to make their own decisions if they have the capacity to do so.

2006 White Paper, Our Health, Our Care, Our Say, sought greater integration of health and social care, and to manage performance against shared outcome target (Department of Health 2006).

2007 Mencap published Death by indifference, reported the appalling deaths of six people with a learning disability – deaths that the six families involved and Mencap believe were the result of failings in the NHS. The report highlights that mainstream service cannot meet the need of adults with a learning disability alone and exposes the fatal consequences of inequalities in NHS healthcare (Mencap 2007).

2007 Putting People First: Department of Health›s commitment to making individual budgets a choice for anyone receiving social care (Department of Health 2007).

2007 UN Convention on Rights of Persons with Disabilities: UK a signatory to this Convention which commits states to uphold human rights for disabled people.

2007 Updated version of the book 'Physical therapy, treatment and management, a collaborative approach 'Jeanette Rennie (Rennie 2007).

2007 Several organisations came together to form the Learning Disability Coalition to campaign against cuts and for better funding for social care for people with a learning disability.

2008 Healthcare for All: An independent inquiry into access to healthcare for people with a learning disability following the publication of the Mencap report Death by Indifference, The Disability Rights Commission Formal Investigation into equal treatment had also raised questions about the quality of healthcare for people with a learning disability who were physically ill. The Independent Inquiry into Access to Healthcare for People with a learning disability emphasises the need for urgent change to improve grossly inadequate NHS healthcare. Community learning disabilities teams highlighted (Michael and Richardson 2008).

2008 Transition: Moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs for a disability. Provides guidance in relation to planning transition, multi-agency working, and the planning and commissioning of services (Department of Health 2008).

2009 Estimating Future Need for Adult Social Care Services for People with Learning Disabilities published by the Centre for Disability Research. The aim of the project was to estimate changes in the needs of adults with a learning disability in England for social care services from 2009 to 2026 (Emerson 2009).

2009 Valuing People Now' reviewed progress from Valuing People in 2001 and set new goals to support more people with a learning disability to get homes and jobs and lead fulfilled lives. Recognition of the importance of the specialist learning disabilities team and physiotherapy as part of this team (Department of Health 2009).

2009 Orchard Hill Hospital Sutton closes. The last NHS learning disabilities hospital to close. Most learning disability institutions in England were closed by 2004 but Orchard Hill remained because of delays in finding alternative accommodation.

2010 Raising our Sights was released which was a review of services for adults with profound intellectual and multiple disabilities by Jim Mansell (Mansell 2010).

2010 Mencap and the PMLD Network produced a series of how to guides and films to help local areas meet the needs of people with PMLD based on the key recommendations from the Mansell report 'Raising our Sights' in 2010 funded by the Department of Health (Mencap 2016).

2010 Equality Act was released. The Three aims of the equality act are:

1. eliminate unlawful discrimination, harassment and victimisation;
2. advance equality of opportunity between different groups; and
3. foster good relations between different groups

The Equality Act recognised nine protected characteristics. Age; disability; gender(sex); gender reassignment marriage and civil partnership; pregnancy and maternity; race; religion and belief; and sexual orientation (Parliament of the UK 2010).

2011 Health inequalities and people with a learning disability in the UK was published by Emerson and Baines. This is the third in a series of annual reports from the Learning Disabilities Public Health Observatory. In this series they summarise the most recent evidence from the UK on the health status of people with a learning disability and the determinants of the health inequalities they face. The series builds on a previous review of the UK research literature on the health needs of people with a learning disability and the response of health services (Emerson and Baines 2011).

2010 Improving Health and Lives (IHAL) of people with learning disabilities published information on characteristics of people with learning disabilities in England, the services and supports they use, and their carers is collected by several government departments and made publicly available through a number of diverse channels. The aim of this report is, within a single publication, to provide a concise summary of this information and to provide links to key data collections (Emerson et al. 2010).

2011 Winterbourne View Hospital scandal. BBC Panorama programme in revealed widespread abuse by staff of people with a learning disability. Six members of staff were prosecuted and sentenced to service time in prison.

2011 The role of the specialist health services in supporting the health needs of people with learning disabilities was published by the Debra Moore associates. Report on the future role and function of community learning disabilities teams. The authors recognised that specialist learning disability health professionals continue to have an important role to play in supporting the health and wellbeing of people with learning disabilities and their families. They are required to both support mainstream practice and directly serve those with the most complex needs. A key message from the document was that community learning disability teams should be

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delivering person centred services, within the community that respect and promote the rights of people with a learning disability as full citizens. To do this, there needs to be in place, good commissioning, a competent workforce and a robust system to check quality and outcomes. Community learning disability teams provide assessment, care management, care co-ordination, therapeutic intervention and health professional training and support for people with a learning disability (Moore and Thorley 2011).

2012 Mencap›s Death by Indifference: 74 Deaths and counting a progress report 5 years on highlights continuing critical inequalities in NHS health care for people with learning difficulties (Mencap 2012).

2012 Health and Care Act. Extensive reorganisation of the NHS. Abolished Primary Care Trusts and strategic Health authorities transferring commissioning to Clinical Commissioning groups (CCG's). Removed day to day management from central government and passed it to NHS England.

2012 Transforming care: A national response to Winterbourne view. Department of Health paper outlining the steps that needed to be taken in response to the findings of the investigation into Winterbourne View hospital (Department of Health 2012).

2012 Learning Disability Professional Senate was established with the aim to provide a single voice through which we can lead and inform NHS England, Department of Health and other strategy leads about the needs of children and adults with a learning disability. Brings together professional leaders from across the UK to provide cross-professional collaboration; strategic advice and innovation; and to develop both mainstream and specialist services for children and adults with a learning disability. The senate recognises and works with the range of professionals working with children and adults with a learning disability to champion inter-agency, multi-disciplinary, holistic approaches.

2012 Improving health and lives: The Learning Disabilities Public Health Observatory published which highlights the significant health inequalities people with intellectual disabilities experience. This paper describes an innovative approach to helping local agencies make the best use of available information in order to commission services that may reduce these inequalities (Emerson et al. 2012).

2012 NHS England produced 'Learning Disabilities Guidance for CCGs' in collaboration with improving health and lives learning disability public health observatory (iHAL). This guide was written to help Clinical Commissioning Groups to:

- commission high quality cost effective general and specialist health services for people with a learning disability;
- jointly commission services for people who challenge services and those with complex needs; and
- work with health and wellbeing boards, local authorities and others to address the social factors which affect the health of people with a learning disability.

(NHS England 2012)

2013 The Confidential Inquiry into premature deaths of people with learning disabilities in England (CIPOLD) was commissioned to provide evidence about contributory factors to avoidable and premature deaths in this population. The Confidential Inquiry reviewed the deaths of 247 people with intellectual disabilities. Nearly a quarter (22%, 54) of people with intellectual disabilities were younger than 50 years when they died, and the median age at death was 64 years (range 52-75). The median age at death of male individuals with intellectual disabilities was 65 years (range 54-76), 13 years younger than the median age at death of male individuals in the general population of England and Wales (78 years). The median age at death of female individuals with intellectual disabilities was 63 years (range 54-75), 20 years younger than the

median age at death for female individuals in the general population (83 years). Avoidable deaths from causes amenable to change by good quality health care were more common in people with intellectual disabilities (37%, 90 of 244) than in the general population of England and Wales (13%). CIPOLD made eighteen key recommendations from their findings to improve the health outcome of people with learning disabilities (Heslop et al. 2013).

2013 Government response to the Confidential Inquiry into premature deaths of people with learning disabilities was published (Department of Health 2013).

2013 Connor Sparrowhawk (known as Laughing Boy, or LB) drowned in the bath in an NHS Assessment and Treatment Unit (Slade House) in Oxford. He was 18 and diagnosed with epilepsy and autism. Two months after LB's death, an unannounced Care Quality Commission inspection of Slade House found the unit to be inadequate in all 10 measures of assessment.

2013 Guidance developed by the Royal College of Nursing Learning Disability Nursing Forum, 'Dignity in health care for people with learning disabilities, 2nd edition. This guidance aims to improve dignity in health care for people with learning disabilities (Hardy 2013).

2013 Royal College of Nursing guidance for nursing staff. 'Meeting the health needs of people with learning disabilities' an updated guide that has been developed to support registered nurses and nursing students across the range of health services, who are trained in fields other than learning disabilities, to deliver high-quality health care to people with a learning disability. It highlights the specific health needs of people with learning disabilities and supports staff in making their services more accessible (Royal College of Nursing 2013).

2013 The Royal College of General Practitioners publish Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups. A practical guide designed to support Clinical Commissioning Groups, with Local Authorities and Learning Disability Partnership Boards, to commission health services in ways that achieve better health outcomes for people with a learning disability in a challenging financial climate (RCGP 2013).

2014 Southern Health NHS Foundation Trust published an independent report into the death of 18-year-old Connor Sparrowhawk that found his death was the outcome of a combination of poor leadership and poor care in the unit. The results indicated:

1. That Connor's death was preventable
2. That there were significant failings in his care and treatment
3. That the failure of staff to respond to and appropriately risk assess Connor's epilepsy ed to a series of poor decisions around his care
4. That the level of observations in place at bath time was unsafe and failed to safeguard Connor
5. That if a safe observation process had been put in place and Connor had been appropriately supervised in the bath, he would not have died on 4 July 2013
6. That the STATT unit lacked effective clinical leadership
7. That there had been no comprehensive care plan in place for the management of Connor's epilepsy and his epilepsy was not considered as part of Connor's risk assessment, in breach of NICE epilepsy guidance.

2015 NICE Guideline (NG11) Challenging behaviour and learning disabilities: prevention and interventions for people with a learning disability whose behaviour challenges. This guideline covers interventions and support for children, young people and adults with a learning disability and behaviour that challenges. It highlights the importance of understanding the cause of behaviour that challenges and performing thorough assessments so that steps can be taken to

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help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers (NICE 2015).

2015 Transforming care for people with learning disabilities – Next steps published which set out an ambitious programme of system wide change, to drive forward improvements, at pace, for people with a learning disability. The work aimed to ensure

- a substantial reduction in the number of people placed in inpatient (hospital) settings;
- a better quality of care for people who are in inpatient and community settings;
- a reduction in the length of stay for all people in inpatient settings; and
- a better quality of life for people who are in inpatient and community settings.

The publication highlighted five key priority areas:

1. **Empowering individuals.** Giving people with a learning disability and/or autism, and their families, more choice and say in their care. This area is led by the Department of Health (DH) and the Local Government Authority (LGA).
2. **Getting the right care in the right place.** Ensuring that we deliver the best care now, whilst re-designing services for the future. This area is led by NHS England, the LGA and Assistant Directors of Adult Social Services (ADASS).
3. **Workforce.** Improving care quality and safety by developing the skills and capability of the workforce to ensure we provide high quality care. This area is led by Health Education England (HEE).
4. **Regulation and inspection.** Tightening regulation and the inspection of providers, strengthening providers' corporate accountability and responsibility, to drive up the quality of care. This area is led by the Clinical Quality Commission (CQC).
5. **Data and information.** Making sure the right information is available at the right time for the people that need it. This area led by the Department of Health, working closely with NHS England and the LGA.

(ADASS, CQC, DH, HEE, LGA and NHS England 2015)

2015 Public Health England and Learning Disabilities Observatory publish People with Learning Disabilities in England 2015. This report, the fifth in a series, and reports the most recent data available at the time of writing (typically for 2014/15) for people with a learning disability in England. The authors also publish the data table from which the population estimates are derived (Hatton et al. 2015).

2015 Learning Disability Professional Senate published Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers. The briefing paper on service specifications and best practice for professionals, NHS commissioners, CQC and providers of community learning disabilities health teams (Learning Disability Professional Senate 2015).

2015 The establishment of national mortality review based on CIPOLD's eighteenth recommendation. On 18 June 2015 NHS England, the Healthcare Quality Improvement Partnership (HQIP) and the University of Bristol announced the world's first national review of deaths of people with a learning disability. Known as the Learning Disability Mortality Review Programme (LeDeR), the three-year review aims to "get to the bottom of why people with learning disabilities typically die much earlier than average, and to inform a strategy to reduce this inequality".

2016 The first national annual review report for the LeDeR Programme was produced and details the progress made in establishing the programme in its first year during the 11 months from 01 June 2015 to 01 May 2016. The LeDeR programme was established to support local areas to establish steering groups to review the deaths of people with a learning disability; identify learning from those deaths; and take forward the learning into service improvement initiatives. The programme has developed a review process for the deaths of people with a learning disability. All deaths receive an initial review. And those where there are any areas of concern in relation to the care of the person who has died; or if it is felt that further learning could be gained receive a full multi-agency review of the death (NHS England 2016).

2016 NICE Guideline (NG54) Mental health problems in people with learning disabilities: prevention, assessment and management and NICE pathway Mental health problems in people with learning disabilities published (NICE 2016b).

2016 Care Quality Commission (CQC) report 'Learning Candour and Accountability'. The report describes what the CQC found when it reviewed how NHS Trusts identify, investigate and learn from the deaths of people under their care. The report authors indicated that there was a 'common' level of acceptance and sense of inevitability when people with a learning disability or mental illness died, and that the lack of a single framework for NHS Trusts that sets out what they need to do to maximise the learning from deaths that may be the result of problems in care was problematic (CQC 2016).

2017 NICE Guidance in Spasticity in under 19s: management. This guideline covers managing spasticity and co-existing motor disorders and their early musculoskeletal complications in children and young people (from birth up to their 19th birthday) with non-progressive brain disorders. It aims to reduce variation in practice and help healthcare professionals to select and use appropriate treatments (NICE 2017).

2017 National Guidance on Learning from Deaths was published by the National Quality Board. It provides a framework for NHS Trusts and NHS Foundation Trusts in England for identifying, reporting, investigating and learning from deaths of people in their care. The guidance emphasises the importance of learning from reviews of the care provided to patients who die, and that this should be integral to a provider's clinical governance and quality improvement work. It requires providers to have a clear policy for engagement with bereaved families and carers, and an updated policy on how they respond to, and learn from, deaths of patients who die. From April 2017, Trusts have been required to collect and publish on a quarterly basis specified information on deaths (National Quality Board 2017).

2017 NICE Guidance (NG62) Cerebral palsy in under 25s: assessment and management. This guideline covers diagnosing, assessing and managing cerebral palsy in children and young people from birth up to their 25th birthday. It aims to make sure they get the care and treatment they need for the developmental and clinical comorbidities associated with cerebral palsy, so that they can be as active and independent as possible (NICE 2017).

2017 A National Project stop over-medicating people with a learning disability, autism or both (STOMP) with psychotropic medicines. The project involves many different organisations which are helping to stop the over use of these medicines. STOMP aims to help people to stay well and have a good quality of life (NHS England 2018).

2017 NICE Quality Standard (QS142) Learning disabilities: identifying and managing mental health problems. This quality standard covers the prevention, assessment and management of mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice). It also covers family members, carers and care workers (NICE 2017b).

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2017 NICE Quality standards (QS162) Cerebral palsy in children and young people. This quality standard covers diagnosing, assessing and managing cerebral palsy in children and young people under 25. It describes high-quality care in priority areas for improvement (NICE 2017c).

2018 LeDeR annual report published for 1st July 2016 to 30th November 2017. 1,311 deaths were notified to the LeDeR programme. The report highlights that the average age at death of people with a learning disability was 59 for males and 56 for females. More than a quarter (28%) of deaths were of people aged under 50 years (NHS England 2018).

2018 MENCAP 'Treat me well' campaign launched that advocated for improved treatment of people with a learning disability in hospital (MENCAP 2018).

2018 NICE Guideline (NG93) Learning disabilities and behaviour that challenges: service design and delivery. This guideline covers services for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges. It aims to promote a lifelong approach to supporting people and their families and carers, focusing on prevention and early intervention and minimising inpatient admissions (NICE 2018).

2018 National Quality Board publish Safe, sustainable and productive staffing: An improvement resource for community and inpatient learning disability services developed in the context of reducing health inequalities and increasing the life-expectancy of people with a learning disability, as well as enabling sustainability and transformation plans in the NHS (National Quality Board 2018).

2019 NHS Long Term Plan published which present the five ways that they will improve the care of people with a learning disability and autism:

1. Tackle preventable deaths: stopping overmedication and improving health checks;
2. Improve understanding of learning disabilities and autism within the NHS;
3. Reduce waiting times for specialist services;
4. Increase investment in community support: reducing inpatient admissions; and
5. Improve quality of inpatient care across NHS and independent sector.

(NHS England 2019)

2019 NICE guidance (NG119) Cerebral palsy in adults. This guideline covers care and support for adults with cerebral palsy. It aims to improve health and wellbeing, promote access to services and support participation and independent living (NICE 2019).

2019 (May) MENCAP. Profound impact Day. Focussing on the issues facing people with profound and multiple learning disabilities in hospital.

2019 (July) UPDATED NICE guidance. Service model for people with learning disabilities and behaviour that challenges [QS101] (NICE 2019a).

2019 (July) UPDATED NICE guidance. Care and support of people growing older with a learning disability. [QS187] (NICE 2019b).

Publications to look out for:-

2020 (January) NICE Quality Standards for Cerebral Palsy in Adults (GID-QS10080).

Physiotherapy needs of adults with a learning disability

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Adults with a learning disability have are a number of factors and associated conditions that increase the prevalence of developing physiotherapy related problems either from an early age or within their lifetime. Some common conditions that increase the need for adults with a learning disability to access physiotherapy include:

Cerebral palsy

Cerebral palsy is the name for a group of lifelong conditions that affect movement and co-ordination, caused by a problem with the brain that occurs before, during or soon after birth (NHS 2017). The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, learning, cognition, communication, behaviour, epilepsy and secondary musculoskeletal problems' (Rosenbaum et al. 2006).

Palisano et al. (2007) developed the Gross Motor Functioning Classification System (GMFCS) to classify children with cerebral palsy into categories depending on their physical level and functional presentation (Table 1). The GMFCS has been validated for children and adolescence with Cerebral Palsy up to the age of 19 years old (Palisano et al. 2007). Recently, NICE (NICE 2019) recognised the classification system as an accurate tool for adults with cerebral palsy in the absence of an alternative descriptive system.

Table 1: Gross Motor Function Classification System (Palisano et al. 2007)

Level	Descriptor of Disability	Illustration
I	Walks without assistance	
II	Walks without assistive devices, limitations outdoors and in the community	
III	Walks with assistive devices, limitations outdoors and in the community, requiring wheelchair use in these settings	
IV	Self-mobility in wheelchair with limitations, transported or uses power mobility in a community	
V	Very limited self-mobility, even with assistive tech	

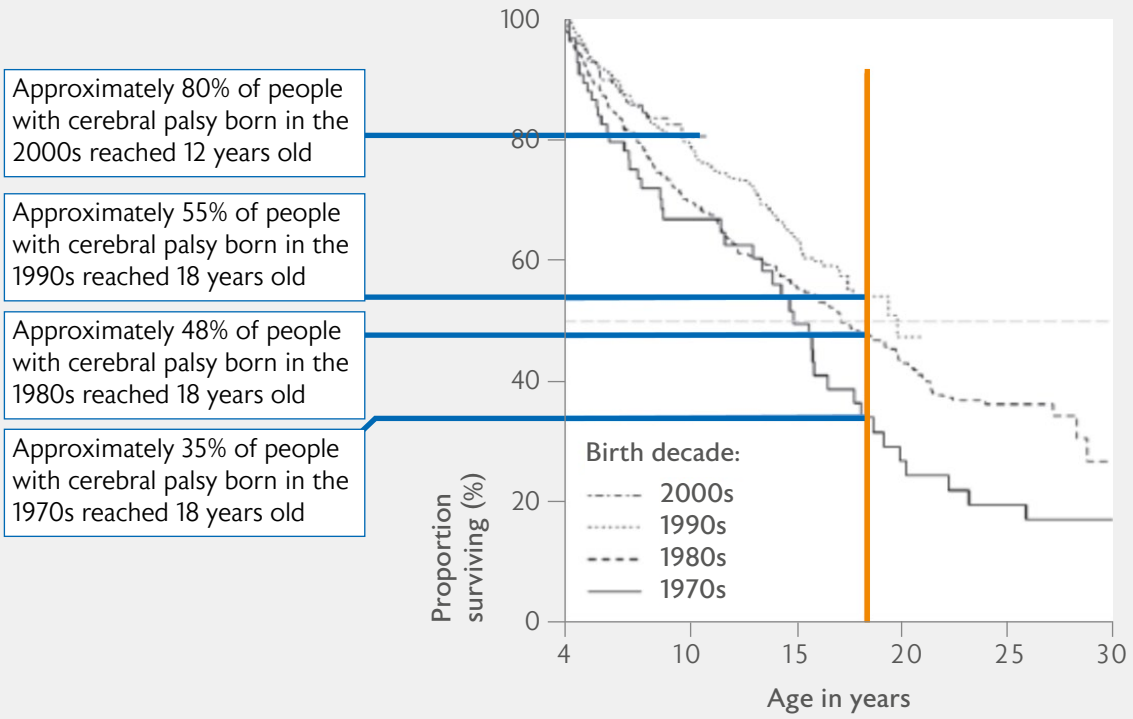
NICE (2017) state that 50% of people with cerebral palsy will have a learning disability (IQ below 70) and 25% will have a severe learning disability (IQ below 50). The presence of a learning disability can be associated with any functional level, but prevalence increases with severity of motor impairment. 33.3% of people with cerebral palsy (GMFCS level 1 or 2) have a learning disability. This increases to 66.6% in people with more severe cerebral palsy (GMFCS level 3, 4 and 5). As a result, people with cerebral palsy are one of the most common cohorts to require access to specialist learning disability physiotherapy services. The researchers conducted a cohort study of the people with complex physical disability (GMFCS level 4 and 5) accessing the local postural management pathway (Standley 2019b). The results indicated that 78% (115/147) of people had cerebral palsy.

Cerebral palsy is thought to occur in 2 to 2.5 per 1000 live births and is the most common severe physical disability affecting children (Hutton and Paroah 2006). Developments in modern medicine, in particular improvements in neonatal care, enteral feeding and spinal surgery have had an impact of the number of people with severe cerebral palsy surviving birth. They have also had a profound effect on the number of individuals reaching adolescence and adulthood.

Research indicates that life expectancy for people with cerebral palsy is similar to the general population unless the person has no ability to change their position, are unable to feed by mouth, and have severe learning disabilities (Hutton and Phoroah 2006; Westbom et al. 2011; Young et al. 2011; NICE 2016). Westbom et al. (2011) report that 60% of people with cerebral palsy GMFCS level 5 survive to the age of 19. Hatton and Phoroah (2006) reported that the survival rate of wheelchair users to 35 years of age was reduced from individuals who walked, with or without an aid. Interestingly they found that life expectancy markedly reduced in people who required a carer-operated wheelchair in comparison to those who self-propelled.

Brookes et al. (2014) performed an observational cohort study of 51,134 people with cerebral palsy aged 4 years and older registered with the California Department of Developmental Services between 1983 and 2010. 6% of this cohort of people had severe cerebral palsy defined as not being able to lift their head in prone. The authors developed survival curves for 4 year olds born in the 1970s, 1980s, 1990s and 2000s categorised by level of disability. They found that there was no significant difference in the survival rates of those with mild to moderate disability but found a significant increase in the cohort with severe disability (figure 10). The results of Brookes et al. study are particularly important and relevant to adult services because it provides evidence of an increasingly complex group of people reaching adulthood whom are likely to require access to specialist services.

Figure 10: Survival curves of 4-year-old children with cerebral palsy who do not lift their heads when lying in the prone position born in the 1970s, 1980s, 1990s, and 2000s (n=1147) born (Adapted from Brooke et al. 2014).



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People with complex physical and learning disabilities

Complex physical disability is an umbrella term used to describe people who typically, but not exclusively, have non-progressive neurological conditions which significantly affects their physical presentation and functional abilities (Table 2). This population have severe physical disabilities which affects all four limbs and their trunk, resulting in postural abnormalities and movement disorders. Individuals require wheelchairs and assistive devices to mobilise and maintain themselves upright against gravity (GMFCS level 4 and 5). Morbidity and mortality are, in general, attributed to the development of secondary complications such as osteoporosis, contractures, joint dislocations, urinary infections, pressure sores and respiratory infections (Pope 2007; Department of Health 2009; Tosi 2009; Mansell 2010; Young et al. 2011). People with complex physical disability can present with a learning disability anywhere on the continuum from mild to profound.

Table 2: Potential causes of complex physical disability

	Common conditions	Morbidity and mortality
Non – progressive neurological conditions	Cerebral palsy Spinal bifida Chromosomal abnormalities Traumatic brain Injury in childhood	Associated with the development of secondary complications, and are not, in the main, the direct manifestation of the pathological impairment
progressive neurological conditions	Duchene muscular dystrophy Leukodystrophies	Associated with the trajectory of the neurological condition and the development of secondary complication

Adults with a learning disability and dementia

Adults with a learning disability are living longer thanks to improvements in healthcare. As a result, age related problems and conditions such as dementia are becoming more prevalent. Public Health England (2018a) recently published reasonable adjustment guidance for people with a learning disability and dementia. They state that estimates of the prevalence of dementia in people with a learning disability vary, in part because there has not always been good recognition, assessment and diagnosis. Research suggests that age-related dementia of all types is more common at earlier ages in people with a learning disability than in the rest of the population (about 13% in the 60 to 65 year old age group compared with 1% in the general population). Prevalence is estimated at 2 to 3 times greater in people with a learning disability than the general population in all over-60 age groups. People with Down's syndrome are at particular risk of early onset Alzheimer's disease. Approximately 30% of people will have Alzheimer's in their 50s and 50% by their 60s.

Adults with a learning disability and dementia, especially those with Down's syndrome and Alzheimer's disease are at high risk of developing physiotherapy related secondary complications as their dementia progresses. This includes mobility problems and falls in the early to mid-stages of dementia; and postural, swallowing and respiratory problems towards the later stages.

Epilepsy

About 1 in 3 people (33.3%) who have a mild to moderate learning disability also have epilepsy (Epilepsy Society 2016). Over 60% of people with profound and multiple learning disabilities have epilepsy and it is one of the most common and persistent health problems. In general, the more severe the developmental delay, the higher the risk of epilepsy (Mencap 2016). Seizure activity or side effects of medication can further compromise cognitive ability and have a significant effect on mobility and movement. People can also present with wide fluctuations in functional abilities in line with seizure patterns.

Profound and Multiple Learning Disability

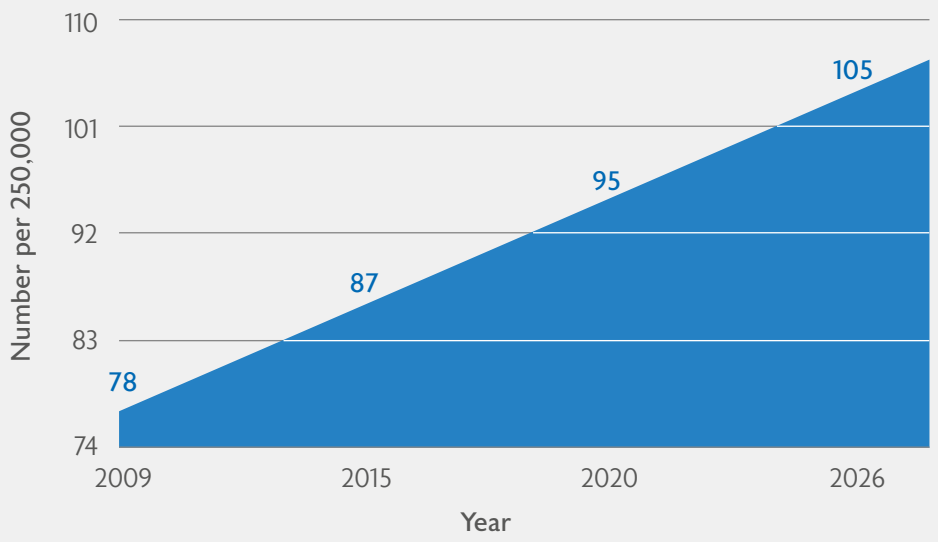
Jim Mansell (2010) uses the term profound intellectual and multiple disabilities to describe a group of people who have a profound learning and multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help. People with profound intellectual and multiple disabilities need high levels of support from others with most aspects of daily living, including help to eat, to wash, to dress, to use the toilet, to move about and to participate in any aspect of everyday life. They have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols. They often show limited evidence of intention. Some people have, in addition, problems of challenging behaviour such as self-injury.

Bellemy et al. (2010) conducted a study to define the term profound and multiple learning disabilities. They reviewed the available literature to determine the different definitions available within the literature. They then explored these definitions with different stakeholders through interviews and group work. The study agreed the on following definition:

> *"People with profound and multiple learning disability (PMLD) have extremely delayed intellectual and social functioning; may have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch, gestures); often require those who are familiar with them to interpret their communication intent; and frequently have an associated medical condition which may include neurological problems, and physical or sensory impairments. They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support and an individualised relationship with a carer."*

Research conducted by the Centre for Disability Research suggests there will be a sustained and accelerating growth in the numbers of adults with profound intellectual and multiple disabilities receiving health and social care services in England. There will be an average annual increase of 1.8 per cent from 78 in 2009 to 105 in 2026 (per 250,000 population) (Figure 11). And the number of young people with profound intellectual and multiple disabilities becoming adults in any given year will rise from 3 in 2009 to 5 in 2026 (per 250,000 population) (Mansell 2010).

Figure 11: The projected increase in the number of people with PMLD between 2009 to 2026 (Mansell 2010)



People with profound and multiple learning disabilities are among the most disabled individuals in our community (Mansell 2010). They are likely to require life long and regular access to health care services. They often present with physiotherapy related problems because of the physical disability and associated conditions. Therefore, they will require access to specialist physiotherapy services throughout their lives.

Behaviours that challenge

It is relatively common for people with a learning disability to develop behaviours that challenge, and more common for people with more severe disability. People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges (NICE 2015).

People with a learning disability who display behaviours that challenge are predisposed to developing physiotherapy issues due to the long term use of particular antipsychotic medications, and problems caused by repetitive or ritualistic movement. In addition, people may display an exacerbation in their behaviour because of a physiotherapy related problem such as musculoskeletal pain or deterioration in mobility. Behaviours that challenge can be a significant barrier to accessing healthcare. Thus, people require support to positively access mainstream healthcare and frequently require specialist learning disability services.

Supporting Evidence

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Definition

Supporting evidence:
Valuing people recognised that professional staff employed in local community learning disability team provide a vital role as health facilitators to support for people with a learning disability gain full access to the health care they need, whether from primary or secondary NHS services (Department of Health 2001).
In 2007 the Department of Health published good practice guidance on commissioning specialist adult learning disability health services. The Department of Health recognised that the focus of specialist community health staff commissioned by the Primary Care Trust Care Trust should be on supporting mainstream health services to ensure the delivery of good quality general health care to people with a learning disability. They state that specialist learning disability health services have an essential clinical and therapeutic role, which will include providing support to people and their families when their needs cannot be met by mainstream services alone (Department of Health 2007).
Valuing People Now (Department of Health 2009) reported that some people with a learning disability and additional complex or profound physical disabilities will require health professionals from mainstream and specialist learning disability services to work in partnership in order to access essential therapeutic assessments and interventions. Similar partnership arrangements are also needed to ensure that people with more complex needs gain access to the best care and treatment in the full range of health services, from maternity services through to end of life care.
Royal College of General Practitioners reports that one of the main functions the community learning disability team is to offer specialist provision and direct support to people and their families when their needs cannot be met by mainstream services alone. The second is enabling adults with a learning disability to access other services through health facilitation and providing support to primary and secondary care to ensure reasonable adjustments are in place to allow people to access services (RCGP 2013).
CIPOLD recommended that the barriers to people with a learning disability accessing healthcare should be addressed by proactive referral to specialist learning disability services. The authors recommend that commissioners and other agencies, review their eligibility criteria for access to specialist learning disability services to ensure they are based on vulnerability and need, not on an assumed level of a person's learning disability. CIPOLD also reported that where specialist expertise is required, the community learning disability team should be involved in working with the individual, their family and carers to create a bridge to primary and secondary health services to facilitate familiarisation and desensitisation (Heslop et al. 2013).
The learning disability professional senate states that supporting positive access to and responses from mainstream services should be seen as a non-negotiable component of a community learning disabilities health team's service specification. This is because their understanding of learning disability will be critical to achieving high quality health and social care outcomes. To achieve this, community learning disability services must engage in work that supports better universal access to mainstream services and positive outcomes to reduce the known health inequalities. They should also provide on-going support, supervision and advice to mainstream services to support them in the provision of 'reasonable adjustments' and positive support plans (Learning Disability Professional Senate 2015).
The National Quality Board report that commissioned community learning disabilities health teams must be available to all people with learning disabilities in the commissioning clinical commissioning groups (CCG) locality and in all locations where CCG registered patients reside (National Quality Board 2018).

24-hour postural management

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Supporting Evidence:
Mansell (2010) reports that people with profound intellectual and multiple disabilities face several specific health problems including in postural care. The report recognises that postural management services for adults are often not sufficiently well-developed to recognise and intervene effectively. This can lead to discomfort, pain and premature death. The author recommends that NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities which focus on protection of body shape and the resolution of pain and distress (Recommendation 12).
NICE (2012) recommend that young people with spasticity have timely access to equipment necessary for their management programme (for example, postural management equipment such as sleeping, sitting or standing systems).
The Royal College of General Practitioners reports that clinical commissioning groups (CCGs) should consider investing in postural care interventions to improve quality of life and save money. They recognise that postural care challenges the assumption that changes in body shape are inevitable for people who have movement difficulties. They acknowledge that changes in body shape, particularly chest distortion, result in secondary problems such as chest infections and aspiration, which result in a poor quality of life and can lead to premature death. The authors state that body distortion is costly in terms of equipment and increasingly complicated medical intervention. They recommend that adults with a learning disability and postural care needs have access to services, equipment and training to support the long-term management of their body shape (RCGP 2013).
CIPOLD established the link between a failure to protect body shape and resultant premature death. It recommended that CCGs should ensure they commission expert, preventative services including proactive postural care support (Heslop et al. 2013).
NICE (2014) acknowledge that people who have a neurological condition; impaired mobility; impaired nutrition; and/or poor posture or a deformity are potentially at risk of developing a pressure ulcer. NICE recommend that adults who have been assessed as being at high risk of developing a pressure ulcer should change their position frequently and at least every 4 hours. If they are unable to reposition themselves, professionals should ensure that repositioning equipment is available and ensure that patients, parents and carers understand the reasons for repositioning.
Poor postural care can have severe and life-threatening complications for people who have a limited ability to change position (Crawford and Stinson 2015). Body shape distortion is associated with physical health problems including: • Respiratory problems; • Problems with the musculoskeletal system, such as hip dislocation, contractures, curvature of the spine and reduced movement; • Impairments of the neurological system, including problems with spasticity/ muscle tone, reflexes, altered sensation and joint position sense, pain and weakness. • Difficulties in swallowing and risk of choking; • Constipation; • Pressure on internal organs; and • Recurrent pressure sores. Additional areas where problems may arise include respiratory function, kidney/renal function, personal hygiene, personal care; functional ability (e.g. weight bearing, transfer and hand function); environment interaction (sensory perception, body aesthetics, learning, communication); sleep pattern; and irritability. Complications will cause discomfort and possibly severe pain. They will certainly have a negative impact on the person's quality of life and can lead to emotional and psychological problems (NHS Purchasing and Supply Agency 2009; Crawford and Stinson 2015; Public Health England 2018b).

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The learning disability professional senate recognise that specialist learning disability physiotherapists support people with a learning disability in the provision of postural care (Learning Disability Professional Senate 2015).
NICE (2017a) recognise that people with cerebral palsy are at risk of having low bone mineral density especially those who are non-ambulant (GMFCS level IV or V); have the presence of eating, drinking and swallowing difficulties; concerns about nutritional status; are low weight for age; have a history of low-impact fracture; and/or use of anticonvulsant medication. NICE recommend that professionals consider an active movement programme, active weight bearing, and minimising risks associated with movement and handling as possible interventions to reduce the risk of reduced bone mineral density and low-impact fractures.
NICE (2017) recognise that common condition-specific causes of pain, discomfort and distress in young people with cerebral palsy include musculoskeletal problems (for example, scoliosis, hip subluxation and dislocation), increased muscle tone (including dystonia and spasticity), and muscle fatigue and immobility.
Public Health England recognise that the provision of 24-hour postural care reduces health risks and improves quality of life for individuals. It can also benefit those caring for the person. Although postural care can be an expensive service it does reduce the need for invasive and costly interventions including surgical procedures; complex equipment for mobility; adaptation to the home; enteral feeding; pain management; and increased need for medications such as Botox or Baclofen (Public Health England 2018b).
NICE (2019) recommend that adults with cerebral palsy at high risk of lower respiratory tract infections should be considered for a prophylactic review of their chest care including the assessment of the person's postural management. NICE define a review of 24-hour postural needs as an assessment that considers all the relevant postures that an individual has the ability to adopt over the 24 hours of any given day, including postures to allow for participation in daily activities. The panel who developed the guidance report that postural care is likely to prevent respiratory infections and their associated costs which offsets the investment required to resource postural management services. NICE (2019) recommend an annual review for people with cerebral palsy who have complex needs such as GMFCS levels IV and V, communication difficulties, learning disabilities, living in long-term care settings, living in the community without sufficient practical and social support, or multiple comorbidities. NICE define a review as a planned clinical appointment between an adult with cerebral palsy and a healthcare professional or multidisciplinary team. They may explore common concerns, physical symptoms, mental health, pain, nutrition and communication to ensure an individualised approach to care. The healthcare professional may be a GP, specialist nurse, rehabilitation specialist or therapist. This also allows the opportunity to address general health issues that affect people as they grow older. NICE report that annual review is likely to prevent an emergency department visit per year for this group and thus would be cost effective.
A number of reports have noted gaps in postural management services for people with a learning disability (Michael and Richardson 2008; Mansell 2010; Murphy et al. 2010; RCGP 2013; Heslop et al. 2013; Public Health England 2018b). Murphy et al. (2010) report that the provision of physical management is ad hoc in nature, and patchy in effectiveness.

Community level respiratory management

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Supporting Evidence:
National Quality Board recognise that a role of the specialist learning disability physiotherapist is to support individuals with respiratory care (National Quality Board 2017).
CIPOLD found that respiratory disease (usually pneumonia) was reported as the final illness from which adults with a learning disability included in the study died, and the immediate cause of their death in over a third of people (Heslop et al. 2013). This finding is supported by a number of authors (Truesdale and Brown 2017; Public Health England 2018b). In response, Heslop et al. (2013) recommends that adults with a learning disability are considered a high-risk group for deaths from respiratory problems. They recommend that CCGs must ensure they are commissioning expert, preventative services to manage people with a learning disability at high risk of respiratory illness which includes expert and proactive postural management.
NICE (2019) acknowledge that adults with cerebral palsy, many of who have a learning disability, are at increased risk of respiratory failure. NICE recognise that risk factors for respiratory impairment are more common in adults with severe cerebral palsy (GMFCS level IV or V). These include aspiration pneumonia, chronic cardiorespiratory disorders (for example, cor pulmonale or pulmonary, circulation hypertension), chronic suppurative lung disease, kyphoscoliosis, poor saliva control and recurrent chest infections. NICE (2019) recommend that if an adult with cerebral palsy is at high risk of lower respiratory tract infection, they should be receive a prophylactic physiotherapy chest care review. This should include postural management; advice on exercise and opportunities to move; positional changes; and interventions to assist ventilation and secretion control management. In addition, the person's network of care should receive adequate advice and training to help with ongoing chest care. NICE predict that there may be a small increase in the number of referrals for chest reviews but state that this demand is likely to be balanced by improved ongoing chest care, which would reduce respiratory infections and the costs associated with them.
Wolff et al. (2015) found that a community based respiratory service reduced hospital admissions from 36 to 24 and emergency department attendances from 48 to 33 in a 12 month period in 34 children and young people (aged 1 to 19) with neurological disability. Community respiratory physiotherapy included: 1. The development of a daily tailored chest physiotherapy programme involving manual techniques, suction airway management, and use of equipment to increase lung volumes and instigate cough; 2. Delegation of the specific chest physiotherapy programme to the person's network of care including training and education to ensure the programme is delivered competently; and 3. A rapid response respiratory physiotherapy service, between 8:30 am to 4:30 pm Monday to Friday. The authors conclude that a community respiratory physiotherapy service can lead to reduced hospital admissions and reduced hospital bed days for children and young people with severe disability and can pay for itself in reduced admission costs.
Public Health England (2018b) report that respiratory problems are the main reason people with profound and multiple learning disabilities need primary or secondary medical care, and pneumonia is the most common cause of death in this group. Some of the risk factors for respiratory problems that can be reduced by good postural management are airway clearance dysfunction, saliva management difficulties, immobility, reflux, sleep disordered breathing and thoracic deformity.

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Falls prevention and intervention

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Supporting Evidence:
Finlayson et al. (2010) conducted a longitudinal cohort study to determine the incidence and types of injuries experienced by a community-based cohort of 511 adults with a learning disability in a 12-month period. The results found that 40% of people with a learning disability experience at least one fall (with or without injury) and 22.5% more than once in a 12-month period. 30% of people who fell injured themselves as a result. The results also found that adults with a learning disability are more likely than an aged matched population to fracture as a result of an injury.
Petropoulou et al. (2017) completed an observational cohort study of 593 adults with a learning disability living with paid support to determine the incidence, causes and types of injuries experienced over a 12 month period of time. The results found that adults with a learning disability are twice as likely to experience injury as the aged matched population. Falls were the most common cause of injury (16.2%). The author defined an injury as those which required medical, nursing or certificated first-aider support worker attention or treatment.
Falls in the elderly population costs the NHS an estimated £2.3 billion per year (NICE 2013) with 1.5billion spent on A&E admissions (CSP 2015). Evidence suggest that adults with a learning disability experience similar rates of falls as older adults in the wider population, but at a younger age (Sherrard et al. 2001; Finlayson et al. 2010; Finlayson et al. 2016).
The factors that increase the risk of falls in people with a learning disability are abnormal patterns of walking; greater instability during standing and walking; more variable body sway; decreased motor responses to balance perturbances; concurrent medical problems; poly pharmacy; issues with impulsiveness and distractibility; visual deficits; and epilepsy (Finlayson et al. 2010; Enkelaar et al. 2012; Hsieh et al. 2015; Hale et al. 2016;). Providing training in falls prevention for adults with a learning disability can minimise the potential for and reduce severity of falls (Enkelaar et al. 2012).
Crockett et al. (2014) implemented a tailored 12 week home-based tailored strength, balance and aerobic exercise programme designed by a physiotherapist on 27 adults with a learning disability who reported having experienced one or more falls (age range 28-81; mean 58). Intervention included an assessment and development of falls programme; a training session for the network of care; follow up visit at 4, 8 and 12 weeks; review at 16 weeks; and development and issuing information leaflets to prevent future falls. Crockett et al. found that the programme significantly reduced the number of reported falls from 3.2 (range 1 to 14) to 1 (range 0 to 3) over the 16 week programme. The authors conclude that physiotherapists have a key role to play in promoting exercise to prevent falls within multidisciplinary falls services for adults with a learning disability. In addition, exercise which improves mobility/balance, increases physical activity and reduces falls is important for the overall health and well-being for adults with a learning disability.
Hale et al. (2016) conducted a mixed method study on 27 adults with a learning disability at risk of falls or active fallers to evaluate the clinical benefit; and acceptability, utility and feasibility of a 6 month falls prevention intervention (PROFAID). PROFAID included a training workshop for network of care; a tailored community accessible exercise programme; and weekly or biweekly telephone follow up. Intervention was completed over 3 visits by a physiotherapist and followed up at 6 months. Results indicated a statistically significant improvement in balance scale for adults with intellectual disability and a trend to improvement in other outcome measures. Semi-structured interviews of the network of care demonstrated that the intervention is realistic and feasible to complete within daily routines and activities. The authors conclude that targeting physiotherapy to improve balance capabilities can help to prevent falls.

Public Health England published guidance in preventing falls in people with learning disabilities as part of the making reasonable adjustments series in August 2019. They recognise that people with learning disabilities are at risk of falls throughout their lives with 25-40% experiencing at least one fall per year. This is similar to the rate reported for older people in the general population (30%). Falls are the leading cause of injury, including fractures, in people with a learning disability. Around one-third of falls are reported to result in injury; the rate of fractures is higher than in the general population and fractures can occur in younger people. They acknowledge that the growing evidence relating to falls in people with a learning disability suggests that much of the policy and guidance for preventing and responding to falls in older people is equally relevant. Therefore they recommend that policy developed from work with the general population can be applied, with consideration of the factors specific to people with a learning disability. These include:

- Providing accessible information for individuals and information for family members and paid support staff;
- Ensuring that risk assessments cover those to be associated with having a learning disability;
- Making reasonable adjustments to enable full assessment of bone density;
- Tailoring interventions to the individual, their lifestyle and the support available to them; and
- Providing adapted interventions such as strength and balance exercise programmes.

The document links readers to the Public Health England's consensus statement that sets out a collaborative, whole system approach to prevention, responses and treatment of falls in older people for further guidance on delivering falls services to people with a learning disability (Public Health England 2017).

Public Health England acknowledges that falls and injuries are avoidable causes of frailty and reduced wellbeing, in addition to causing significant cost to health and social care. The authors review the available evidence regarding falls in people with a learning disability and use the results to develop the document. Some of the key findings that are relevant to the specialist learning disability physiotherapist include:

1. Sedentary lifestyle and problems with gait and balance are risk factors for falls.
2. Given the high risk of falls in people with learning disabilities, and the associated risk of injury, proactive primary prevention will be useful as part of person-centred health action planning. This involves promotion of healthy lifestyles with encouraging physical activity (accompanied by individual risk assessment and management where appropriate).
3. Following a fall or a 'near miss', a structured approach to prevention is required involving an individually tailored risk assessment and management plan. This focuses on (amongst other factors):
   - general health and fitness, including levels of physical activity;
   - balance and gait problems; and
   - mobility aids and adaptations.
4. There is some evidence from studies with people with a learning disability to support the finding from the general population that promotion of physical activity can help to improve general health and wellbeing. However, more structured strength and balance exercise programmes are required to make a difference to falls risk.
5. A formal assessment of environmental hazards (both at home and out and about) and of the ways the individual interacts with their environment may be appropriate based on the individual's falls risks.

The publication provides an evidence based guide to preventing falls in people with a learning disability including examples of good practice from around the UK, and resources for people with a learning disability; family and paid carers; and health and social care professionals. The guidance can be used to support current practice as well as provide evidence for developing and commissioning specialist learning disability falls services.

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Management of mobility problems

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Supporting Evidence:
National Quality Board recognise that the specialist learning disability physiotherapist support individuals with mobility assessments (National Quality Board 2017).
CIPOLD reviewed the deaths of 247 people with a learning disability over the 2-year period in 2010–2012. Two-thirds lacked independent mobility which was most prevalent health and social care needs of the population reviewed (Heslop et al. 2013).
Adults with a learning disability who are immobile are at a sevenfold increase risk of early death then those who are fully mobile. And adults with a learning disability who are partially mobile are at twofold increased risk of early death (Emerson and Baines 2011).
Mobility problems are common in people with a learning disability. The prevalence increases in people with severe learning disabilities and those with cerebral palsy. Balance and gait issues are apparent from an early age and have been found to continue across the lifespan, with an age-related decline (Truesdale and Brown 2017).
People with a learning disability have been found to have slower walking speed, abnormal walking patterns, slower motor responses to postural perturbations, shorter step lengths, and increased knee flexion angles at heel contact which increases the likelihood of slips and falls (Hale et al. 2007; Haynes and Lockhart 2012).
People with a learning disability can gain positive benefits from exercise therapy interventions, including increased muscle strength, improvement in gross motor skills and functional independence. Some people with a learning disability have difficulty accessing and engaging with mainstream physiotherapy and modified or alternative programmes may be required (Hocking et al. 2013).

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Rehabilitation from acute injuries and/or conditions

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Supporting Evidence:
People with a learning disability are 14 times more likely to have musculoskeletal impairments than the general population (Emerson et al. 2010).
Finlayson et al. (2010) report that people with a learning disability are 1.78% more likely to have at least one injury more than the general population that requires medical or nursing attention or treatment in a 12-month period. The high prevalence of injuries is likely to increase the need for people with a learning disability to access mainstream physiotherapy and services to received rehabilitation from their injuries.
People with a learning disability are at increased risk of low bone mineral density (BMD), for example, osteopenia, osteoporosis and fractures, compared with those in the non-disabled population (Emerson et al. 2010; Burke et al. 2016; Hess et al. 2017; Truesdale and Brown 2017). Contributory factors include lack of weight-bearing exercise, delayed puberty, earlier-than-average age at menopause for women, poor nutrition and being underweight. In addition, people with cerebral palsy are at high risk of low bone mineral density and fragility fracture due to being non-ambulant (GMFCS level IV and V); having vitamin D deficiency; the presence of eating, drinking and swallowing difficulties; concerns about nutritional status; low weight; a history of low-impact fractures; and using of anticonvulsant medication. Low bone density increases the risk of sustaining fragility fractures from low impact injuries. This is likely to increases need to access mainstream services for rehabilitation post fractures and soft tissue injuries.
The ACPPLD (2016) recognise that the majority of people with a learning disability can successfully access mainstream physiotherapy services when reasonable adjustments are made. However, some will require access to specialist services to receive effective rehabilitation.

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Multidisciplinary management of dysphagia

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Supporting Evidence:
The Royal College of General Practitioners report that organisations providing services for people with a learning disability and dysphagia should have a lead clinician (probably a speech and language therapist) with overall responsibility for dysphagia services. Care and support from trained practitioners should also be available (RCGP 2013).
National Quality Board recognise that the specialist learning disability physiotherapist support individuals with dysphagia (National Quality Board 2017).
People with a learning disability are more likely to have dysphagia than the general population, and even more so if they have severe cognitive impairment (Robertson et al. 2018). Over 60% of people with a profound and multiple learning disability have been found to have problems with swallowing, either difficulties with dealing with food and drink in the mouth or the process of swallowing. There can be serious consequences of having dysphagia including coughing and distress when eating or drinking, choking, recurrent chest infections, aspiration pneumonia, weight loss, dehydration, malnutrition, and social isolation. In the worst cases it can contribute to an individuals' death (Mencap 2016b).
Public Health England (2017) acknowledge that there are no reliable data on the prevalence of dysphagia in people with a learning disability. Historically, estimates have ranged from 36% (based on speech and language therapy caseloads) to over 70% (based on inpatient populations). More recent studies have shown that about 15% of adults with a learning disability require support with eating and drinking and 8% of those known to learning disability services will have dysphagia.
Research has found that 99% of the people with severe cerebral palsy are affected by dysphagia (Marks 2008; Summerville et al. 2008; Kim et al. 2013). 50-80% of people with severe cerebral palsy aspirate with 60-97% doing so silently (Kim et al. 2013).
Emerson et al. (2010) report that 40% of people with a learning disability and dysphagia experience recurrent respiratory tract infections.
Mansell (2010) reports that people with profound intellectual and multiple disabilities face several specific problems with their health including dysphagia. The report recognises that dysphagia services for adults are often not sufficiently well-developed to recognise and intervene effectively. This can lead to discomfort, pain and premature death. The author recommends that NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities which focus on protection of dysphagia (Recommendation 12).
NICE (2017) recognise that people with cerebral palsy under the age of 25 are at high risk of swallow problems. To manage dysphagia NICE recommends that healthcare professionals create an individualised plan for managing eating, drinking and swallowing difficulties taking into account the understanding, knowledge and skills of the network of care. Management plans should consider the role of postural management and positioning in reducing the risk of aspiration.
NHS England (2018) recognise the integral role of the specialist learning disability physiotherapist in the multidisciplinary management of dysphagia in the soon to be pushed national Dysphagia pathway for people with a learning disability. The document is in draft form at the time of writing but states that physiotherapy is a core health professional in a dysphagia pathway. NHS England report that physiotherapy services should be adequately commissioned to maximise the postural care of people with a learning disability; to assess for the optimal position for safe swallow; and actively monitor and review postural care plans to reduce the risks associated with eating, drinking and swallowing problems. NHS England also acknowledge physiotherapists role in the respiratory management of people with a learning disability with dysphagia.

CIPOLD found that people with a learning disability experience respiratory disorders, which are the leading cause of death for this population. There is an increased risk of chest infections in people with a learning disability and dysphagia, with an estimated prevalence of about 8.15% (Heslop et al. 2013). Analysis of information from death certificates has shown that people with a learning disability are much more likely to die of the consequences of solids or liquids in their lungs or windpipe than those in the general population (Public Health England 2017).
There is an increased prevalence of swallowing and eating problems in people with severe learning disabilities, which if untreated result in aspiration, chest infections, pneumonia and can result in death. Pathogenic microorganisms in the oral cavity and poor oral health contribute to respiratory infections in people with a learning disability (Binkley et al. 2009).
Public Health England (2016) report that dysphagia has been linked to avoidable hospital admissions from problems such as dehydration, constipation and aspiration pneumonia. Eating and drinking is a fundamental aspect of a person's and their network of cares' lives. Therefore, successful management of dysphagia has the potential to improve physical health, psychological wellbeing and to reduce hospital admissions. Public Health England support the inter-professional dysphagia framework which stresses a holistic approach to the assessment and management of dysphagia. The model highlights issues beyond a physical assessment of the swallow such as environment, levels of alertness, behavioural issues, psychological issues, cultural issues and posture. Public Health England recognises that posture is an important factor to consider because poor posture can negatively affect breathing and swallowing. Thus recommend careful consideration of positioning during dysphagia assessment and management to help improve swallow efficacy and safety; and decrease the risk of aspiration and choking.

Health promotion

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Supporting Evidence:
Research indicated that 92-50% of people with a learning disability have low physical activity levels (Emerson 2005; Hawkins and Look 2006; Finlayson et al. 2009; Emerson et al. 2010; Finlayson et al. 2011; McKeon 2013; Dairo et al. 2016) compared to 38% of the general population (NHS Digital 2017). Thus, they have a higher incidence of obesity, which is associated with an increased risk of diabetes, and predispose the person to other health problems (Emerson et al. 2010).
People with a learning disability 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).
The predictors of low levels of physical activity in adults with a learning disability includes older age, severity of learning disability, being female, having epilepsy, immobility, no day opportunities, faecal incontinence, and living in supported/residential care (Finlayson et al. 2009). The main barriers to adults with a learning disability participating in physical activity include a lack of understanding of the benefits of physical activity; the client's mood; client's lack of awareness of the available options for physical activity; risk assessment issues; and financial constraints (Hawkins and Look 2006).
The Royal College of General Practitioners recognise that one of the main roles of the community learning disability teams is to enable adults with a learning access to other services. This includes supporting people to access health promotion and screening services to promote healthy eating, weight loss and physical exercise (RCGP 2013).
Learning disability professional senate (2015) acknowledge that an increase and change in intensity of needs for people with a learning disability can affect the community learning disability team's public health role and its capacity to prevent ill health; improve health outcomes; and support people with the less demanding and urgent needs of maintaining good health.
Valuing People (2001) recognised that specialist learning disability teams and professionals have a health promotion role.
Valuing people now (2009) acknowledges that good health and well-being begins with healthy active lifestyles and this is the same for people with a learning disability.
NICE (2019) recognise that physical activity can help people with cerebral palsy to improve strength and range of movement, as well as maintain their general fitness and a healthy weight. NICE recommend that physical activity should be promoted by providing information and discussing the benefits with the adult with cerebral palsy. Some adults with cerebral palsy may need extra support to overcome barriers to participation in physical activities. In these cases, NICE recommend referring people with cerebral palsy to services with experience and expertise in neurological impairments, such as physiotherapy, that can provide support with physical activities (including sport) and tasks of daily living.
Co-morbid health problems such as cerebral palsy, spina bifida or other conditions that limit mobility may lead to people with a learning disability being 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; Bhaumik et al. 2008; Melville et al. 2008; Moran et al. 2009; Stancliffe et al. 2011; de Winter et al. 2012; Hsieh et al. 2014); living in less restrictive environments (Melville et al. 2008); severity of learning disability (Emerson 2005; Melville et al. 2008; Stancliffe et al. 2011; de Winter et al. 2012); and taking medications that cause weight gain (Hsieh et al. 2014).
Finlayson et al. (2011) conducted a cohort study measuring the activity levels and pattern of activity and inactivity in adults with a learning disability. The results conclude that the population in this study were significantly less likely to participate in sufficient physical activities of at least moderate intensity than men and women in the general population.

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Finlayson et al. (2009) recommend that to increase adults with a learning disability participation in physical activity healthcare professionals need to engage more with the network of care to instil an active support ethos. They also found that walking was the most common form of regular physical activity undertaken by adults with a learning disability across all levels of disabilities. However individuals are not walking at a sufficient intensity or duration. In response, the authors recommend that healthcare professionals develop walking interventions to build on these findings.
Stewart et al. (2009) explored the perceptions of physiotherapy by carers working with adult with a learning Disability living in residential homes; and the priority given to completing daily physiotherapy programmes. The results indicated that the average priority rating was higher for leisure activities than physiotherapy programmes. Carers also perceived therapeutic activities such as rebound therapy and hydrotherapy as fun and enjoyable which increase priority. This indicated that physiotherapists working with adults with a learning disability need to be creative in the way they develop physiotherapy programmes and plans.

Specialist level respiratory management

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Supporting Evidence:
NICE (2019) recommend referring adults with cerebral palsy and persistent or multiple signs and symptoms of respiratory impairment; or have risk factors for respiratory impairment to specialist services. NICE agreed that referral for specialist assessment would enable prevention or treatment of respiratory complications in people at high risk. NICE recognise that risk factors for respiratory impairment are more common in adults with severe cerebral palsy (GMFCS level IV or V). These include aspiration pneumonia, chronic cardiorespiratory disorders (for example, cor pulmonale or pulmonary, circulation hypertension), chronic suppurative lung disease, kyphoscoliosis, poor saliva control and recurrent chest infections. NICE recognise that there are relatively few respiratory specialists with a special interest in adults with cerebral palsy available. They report that better survival of children with cerebral palsy into adulthood means that specialist adult respiratory services is an emerging area of practice. NICE admit that the recommendation might affect practice by an increase in referrals to and pressure on limited specialist services. However, earlier recognition and treatment will lead to improved outcomes. Respiratory conditions can often lead to hospital admission and reducing the need for this would potentially lead to cost savings.
A service evaluation of Guy's and St Thomas' NHS Foundation Trust's Integrated Respiratory Pathway for People with Complex Physical and Learning Disabilities concluded that specialist multi-disciplinary services are critical to managing the respiratory health of this cohort of people. The author reported that 30% of the population required access to specialist assessment and management completed via respiratory consultants. The respiratory health of the remaining 70% could be managed successfully by the community multidisciplinary team. People were escalated to specialist level respiratory management when they required regular access to primary and secondary healthcare despite community level respiratory management (Standley 2019a).

Management of hypertonia and spasticity

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Supporting Evidence:
NICE (2016) report that all young people with spasticity should be promptly assessed by a physiotherapist and offered a physical therapy programme tailored to their individual needs. This should take into account the balance between possible benefits and difficulties of completing the programme; the view of the person and their network of care; and who will be delivering the programme. Programme should be integrated into daily routines where possible. Physiotherapists should consider 24-hour postural management strategies to prevent or delay the development of contractures or skeletal deformities; and to enable the person to take part in activities appropriate to their stage of development.

Contribute to multidisciplinary manual handling assessments for adults with a learning disability with complex manual or therapeutic handling needs.

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Supporting Evidence:
The Learning disability professional senate recognise that Specialist physiotherapists provide support to people with a learning disability with the provision of specialist moving and handling assessments (Learning Disability Professional Senate 2015).

Assessment and provision of specialist equipment

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Supporting Evidence:
National Quality Board recognise that specialist learning disability physiotherapists support the provision of specialist equipment (National Quality Board 2017).
The Royal College of General Practitioners recognise that in order for people with a learning disability to have good postural care they require access to services, equipment and training to support the long term management of their body shape (RCGP 2013).
Public health England (2018b) acknowledge that a barrier to the provision of good postural care services is the lack of provision of specialist equipment. They report that the range of equipment an individual needs is often provided by different departments or statutory bodies with different commissioning and assessment arrangements. This makes securing funding for essential equipment challenging with wide variations across the UK.

Training and education: Adults with a learning disability and their network of care; health and social care professionals; and local community services

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Supporting Evidence:
Learning Disability professional Senate (2016) state that community learning disabilities health teams have a key role in providing targeted teaching and accessible materials to people with a learning disability and family carers about healthy living and specific health topics. The learning disability professional senate also report that professionals have a role in providing and supporting local multi-agency and multi-professional training programmes.
National Quality Board (2017) report that staff in NHS-commissioned learning disability services have a role in ensuring the wider workforce is skilled in provide healthcare to adults with a learning disability. This should be accomplished through teaching and role modelling the delivery of person-centred healthcare and interventions.
The Royal College of General Practitioners report that CCG's should commission community learning disability services to provide teaching, advice and support to both mainstream and specialist services to enable people with a learning disability to access other services (RCGP 2013).
Valuing People (2001) recognised that specialist learning disability professionals should recognise the importance of enhancing the competence of local services.
CIPOLD identified that gaps in the knowledge and skills level of non-specialist health and social care providers makes the person more vulnerable to a premature death. The authors found that the most common training and education needs for health and social care staff related to: • Learning disability awareness. • The Mental Capacity Act. • Decisions not to attempt CPR. • End-of-life care and the use of end-of-life care pathways. • Communication skills. • Commonly used medications. • Dementia. • Risk assessments. • The prevention and management of pressure sores. • The prevention and management of falls. • The prevention and management of venous thromboembolism. (Heslop et al. 2013)

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Transition of young people with a learning disability from paediatric to adult services

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Supporting Evidence:
The Royal College of General Practitioners recommend a well-planned, person centred transition for young people with a learning disability to reduce the risk of serious health outcomes following disengagement with health services (RCGP 2013).
Mansell (2010) acknowledges that despite very substantial attention over many years, transition from children's to adult services is still typically a very difficult and poor experience for people with a learning disability who have complex needs and their families. In response, the author recommends that the government continue to lead the development of more effective transition arrangements for people with a learning disability so that there is proper planning and timely provision of appropriate services as people move into adulthood.
The learning disability professional senate (2015) reports that specialist community learning disabilities health teams should be available for joint working with young people with complex health support needs from 14 years.
NICE (2017) recognise that challenges for young people with cerebral palsy continue into adulthood and that functional challenges (including those involving eating, drinking and swallowing, communication and mobility) and physical problems (including pain and discomfort) may change over time. NICE states that this should be taken into account in transition planning and that as a minimum standard of care, young people should have access to adults' services both locally and regionally that include healthcare professionals with an understanding of managing cerebral palsy.

Co-ordinated approach to care and multi-disciplinary and multi-agency working

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Supporting Evidence:
The learning disability professional senate (2015) reports that one of the key functions of the community learning disability team is to enabling others to provide effective person-centred support to people with a learning disability through short-term care coordination.
CIPOLD found that many of the deaths reviewed had complex needs which necessitated multi-agency input. The inquiry found that the care of people with the most complex health needs can seem poorly coordinated which contributed to vulnerability and premature death of the people studied. They recognise that a key issue was the lack of coordination of care across and between the different disease pathways and service providers, and the episodic nature of care provision. The authors recognise the importance of good communication and of having a named coordinator when many agencies are involved. Thus, recommends a named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions. In addition, commissioners should ensure that the coordination of care role is enshrined and monitored in contracts across health and social care, with named lead professionals to coordinate care across and beyond episodic reviews (Heslop et al. 2013).
NICE (2016) acknowledge that people with multi-morbidities are at particular risk of deterioration in their health through uncoordinated care. NICE defined multi-morbidity as the presence of 2 or more long-term health conditions, which can include defined physical and mental health conditions such as diabetes or schizophrenia; ongoing conditions such as learning disability; symptom complexes such as frailty or chronic pain; sensory impairment such as sight or hearing loss; and alcohol and substance misuse. NICE recommend that these individuals receive an approach to care that takes account of multi-morbidity. This involves personalised assessment and the development of an individualised management plan that aims to improve quality of life by reducing treatment burden, adverse events, and unplanned or uncoordinated care. The approach takes account of a person's individual needs, preferences for treatments, health priorities and lifestyle. It aims to improve coordination of care across services, particularly if this has become fragmented. NICE states that healthcare professionals should consider an approach to care that takes account of multi-morbidity if the person requests it; if they find it difficult to manage their treatments or day-to-day activities; they receive care and support from multiple services and need additional support; they have both long-term physical and mental health conditions; they have frailty or falls; they frequently seek unplanned or emergency care; and/or they are prescribed multiple regular medicines.

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Hydrotherapy/Aquatic therapy

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Specialist learning disability physiotherapy services may use hydrotherapy/aquatic therapy as a treatment modality to manage the physiotherapy problems of adults with a learning disability especially where they are non-compliant with; are unable to engage successfully in land-based treatment; or to supplement their management programmes.

Standard of Practice Statements

Where hydrotherapy/aquatic therapy is indicated specialist learning disability physiotherapists:

1. Complete a person centred hydrotherapy/aquatic therapy assessment to develop a treatment plan utilising the properties of warm water.
2. Develop a person centred hydrotherapy/aquatic therapy treatment plan based on the person's individual physiotherapy needs and goals.
3. Complete relevant risk assessments to support the provision of safe and effective hydrotherapy/aquatic therapy.
4. Document an accessible hydrotherapy/aquatic therapy treatment plan and delegate to the person's support team following the CSP guidance on the delegation of tasks to support workers where clinically indicated and appropriate.
5. Develop pathways for hydrotherapy/aquatic therapy provision in the community using local resources and trained staff where appropriate.

Knowledge and Skills

Specialist learning disability physiotherapists will need to develop competence in the delivery of hydrotherapy/aquatic therapy to adults with a learning disability especially those with neurological dysfunction. This will also include knowledge and skills in delegating hydrotherapy/aquatic therapy programme to support workers. Physiotherapists should consult the guidance on good practice in Aquatic Physiotherapy available via the Aquatic Therapy Association of Chartered Physiotherapists.

Supporting Evidence:
Aquatic therapy is defined as "a therapy program utilising the properties of water, specifically designed by a suitably qualified physiotherapist for an individual to maximise their level of function whether physical, physiological or psychological. Treatments ideally should be carried out in a purpose built and suitably heated hydrotherapy pool by appropriately trained personnel" (Aquatic Therapy Association of Chartered Physiotherapist 2007).
Geytenbeek (2002) conducted a systematic literature search to appraise the quality of evidence supporting clinical effectiveness of Aquatic therapy. The author found that most clinical trials were conducted in populations with rheumatic conditions, chronic low back pain and older adults. Neurological populations are under-investigated, and there was a dearth of studies for people with complex disability. The study concluded that the body of evidence supporting the effectiveness of Aquatic therapy is incomplete. However, they acknowledge that there are a number of perceived advantages to water based over land based exercises.
Becker (2002) conducted a narrative review of the research base supporting aquatic therapy, both within the basic science and clinical literature. The article describes the many physiological changes that occur during immersion applied to a range of common rehabilitative issues and problems. The reported benefits of aquatic therapy include reduced pain due to hormonal, thermal, circulatory and neural effects; improved circulation; reduced muscle tone; enhanced sensory stimulation; reduced mechanical stress on the joint and soft tissue due to the reduced effect of gravity; reduced weight bearing; increased motivation and empowerment due to increased independent movement which is not possible on land; and enhance cardio-vascular response to exercise to maintain fitness despite physical disabilities. The author reviews the evidence base finding literature that support aquatic therapy in the areas of cardiovascular and cardiopulmonary rehabilitation; applications in respiratory and athletic rehabilitation; musculoskeletal rehabilitation; applications in athletic training; geriatrics and osteoporosis; pain and psychiatric; and obesity. The author concludes that aquatic exercise and rehabilitation remains vastly underused and that there is potential public health benefits to be achieved through programs targeted at the most costly chronic diseases.
Novak et al. (2013) in their systematic review exploring treatments for spasticity in children with cerebral palsy found low level evidence to support hydrotherapy in improving motor function in the population of people.
Lambeth PMLD project (Mencap 2010) conducted survey of families and carers of people with profound and multiple learning disabilities. The aim of the paper was to scope the local scene in relation to the national picture and recommendations set out in Raising our Sights (Mansell 2010). The results highlighted that parents valued hydrotherapy to help maintain health and as a meaningful activity.
Pope (2007) dedicates a chapter of her book on the Management of the Physical Condition of people with Severe and Complex Neurological Disability to hydrotherapy as a therapeutic activity for this population of people. The chapter is written by Babara Cook who concludes that therapists who are skilled in the use of hydrotherapy as a therapeutic tool are convinced of the benefits to people who enjoy the medium, but there is little robust evidence or scientific research to prove the benefits of hydrotherapy.

Physiotherapy on a trampoline/ rebound therapy

Go Back

Specialist learning disability physiotherapy services may use physiotherapy on a trampoline/ rebound therapy as a treatment modality to manage the physiotherapy problems of adults with a learning disability especially where they are non-compliant with; are unable to engage successfully in land-based treatment; or to supplement their management programmes.

Standard of Practice Statements

Where Rebound therapy/physiotherapy on a trampoline is indicated specialist learning disability physiotherapists:

1. Complete a person-centred physiotherapy on a trampoline/rebound therapy on a trampoline assessment to develop a treatment plan utilising the properties of the trampoline.
2. Develop a person-centred physiotherapy on a trampoline/rebound therapy treatment plan based on the person's individual physiotherapy needs and goals.
3. Complete relevant risk assessments to support the provision of safe and effective physiotherapy on a trampoline/rebound therapy.
4. Document an accessible physiotherapy on a trampoline/rebound therapy treatment plan and delegate to the person's support team following the CSP guidance on the delegation of tasks to support workers where clinically indicated and appropriate.
5. Develop pathways for Physiotherapy on a trampoline/rebound therapy provision in the community using local resources and trained staff.

Knowledge and Skills

Specialist learning disability physiotherapists will need to develop competence in the delivery of physiotherapy on a trampoline/rebound therapy to adults with a learning disability safely and effectively. Physiotherapists should consult the Safe Practice in Rebound Therapy paper developed by the Rebound Therapy Association for Chartered Physiotherapists.

Supporting Evidence:
Rebound therapy is the therapeutic use of the trampoline. Rebound therapy is currently used with people with a wide range of abilities from mild to profound physical and learning disability, sensory needs, mental health needs and some neurological and other medical conditions. In addition to providing a physical therapy, rebound therapy provides many people with a valuable opportunity to enjoy movement and interaction (Rebound Therapy Association for Chartered Physiotherapists 2016).
Miller (2007) conducted a narrative review of the available research which is published on the rebound therapy official website. The author reports that there are a wide range of benefits reported for Rebound therapy but there has been minimal research conducted into its effectiveness to confirm these benefits. Miller reports that there is some evidence to support the use of the properties of a trampoline for physical, psychological, learning and social benefit (Carr and Shepherd 1998; Roberts 2006; Smith and Cook 2007). Rebound therapy has been observed to: • Reduce hypertonia and increase hypertonia with the correct application of bounce; • Work the cardio-respiratory system increasing exercise tolerance and fitness; • Provide a good source of cardiovascular exercise for children with profound and multiple learning disabilities who may have limited access to exercise activities; • Stimulate postural mechanisms through utilising the unstable surface of the trampoline bed; • Improve balance and develop protective and saving reactions; • Facilitate movement; • Stimulate gaseous movement and improve bowel function particularly in non-ambulatory people who can often suffer with constipation; • Assist chest clearance through the combination of shaking of the lungs, increasing respiratory rate and stimulating of the cough reflex; • Induce relaxation; • Provides the sense of freedom and independence in people who are dependent on their network of care; and • Increase vocalisation, eye contact and concentration, confidence and self-esteem. The author concludes that Rebound therapy is a useful adjunct to therapy similar to that of hydrotherapy and therapeutic horse riding, providing an enjoyable method of exercise with therapeutic effects and some time for independence and free movement.

Therapeutic riding or hippotherapy

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Specialist learning disability physiotherapy services may deliver or recommend the use of therapeutic riding or hippotherapy as a treatment modality to manage the physiotherapy problems of adults with a learning disability, especially where they are non-compliant with; are unable to engage successfully in land-based treatment, or to supplement their management programmes.

Standard of Practice Statements

Where therapeutic riding or hippotherapy are indicated and available specialist learning disability physiotherapy services:

1. Consider the use of therapeutic riding and hippotherapy as a specialist intervention in the physiotherapy management of adults with a learning disability where clinically indicated.
2. Contribute to the development of a person-centred treatment plan based on the person's individual physiotherapy needs and goals.
3. Contribute to the development of relevant risk assessments to support the provision of safe and effective therapeutic riding and hippotherapy.
4. Advise on moving and handling issues in relation to mounting and dismounting the horse.
5. Provide advice and educate on specific conditions as per guidance from Chartered Society of Physiotherapy Special Interest Section, Riding for the Disabled.

Knowledge and Skills

Where appropriate specialist learning disability physiotherapists will need to develop competence in the delivery of therapeutic riding or hippotherapy to adults with a learning disability safely and effectively. Physiotherapists should consult advice by the Chartered Society of Physiotherapy Special Interest Section, Riding for the Disabled.

Supporting Evidence:

Therapeutic riding is an equine-assisted activity for the purpose of contributing positively to the cognitive, physical, emotional and social well-being. Therapeutic riding provides benefits in the areas of health, education, sport and recreation and leisure. All sessions are conducted by a certified instructor and periodically reassessed by a licensed therapist.

Hippotherapy literally means" treatment with help of the horse". It's a treatment strategy that utilises equine movement in a therapeutic way for patients with movement dysfunction. Hippotherapy is done by a therapist who has been specially trained to use the movement of the horse to facilitate improvements. Therapists use traditional techniques such as neurodevelopmental treatment and sensory integration along with the movement of the horse as part of their treatment strategy. All goals are therapy directed such as improving balance, coordination, posture, fine motor control, articulation and increasing cognitive skills.

The evidence to support the use of therapeutic riding or hippotherapy as a therapeutic modality for adults with a learning disability is lacking. The chartered physiotherapists in therapeutic riding and hippotherapy have a number of resources on their website that outline up to date guidance on the area. Christine Bowes writes chapter 9 of the Management of the Physical Condition of people with Severe and Complex Neurological Disability (Pope 2007) on the value of horse riding in the management of severe and complex physical disability. Bowes outlines the range of physical, psychological and social benefits to riding. The physical benefits include:

- facilitating the optimal sitting position and postural alignment;
- stimulates normal movement;
- balance and righting reactions;
- mobilisation of joints;
- normalisation of muscle tone;
- improves general fitness;
- provides a multi-sensory experience; and
- develops spatial awareness.

Bowes also reports that riding provides psychological and social benefits because it:

- provides an enjoyable, normal, recreational activity;
- is motivating;
- empowers the rider to make choices and gives control;
- teaches new skills;
- improves self-confidence and social image;
- counters social stigmatism;
- encourages communication and social skills; and
- provides an opportunity to bond with animals and people.

The author concludes that horse riding is a useful way of providing continuity of therapy to people with severe and complex physical disability across their lifetime in a more acceptable way than convention therapies.

(Pope 2007)

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Abdominal Massage for Constipation

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Specialist learning disability physiotherapists may use abdominal massage as a treatment modality for constipation in people with a learning disability as part of a holistic constipation care plan.

Standard of Practice Statements

Where abdominal massage for constipation is indicated, specialist learning disability physiotherapists:

1. Complete an assessment of the person's bowel elimination to identify signs of constipation. This includes a subjective and objective assessment of elimination patterns supplemented by bowel charts and the Bristol stool charts.
2. Work in collaboration with the multidisciplinary team to support the person and their network of care to develop a person-centred constipation care plan. This includes non-pharmacological interventions such as a healthy diet, fluid intake, mobility and exercise, toileting positioning and routine, social and psychological factors and abdominal massage. Make onward referrals to the GP and specialist services for further advice on the pharmacological management of constipation.
3. Gain relevant medical clearance and complete appropriate risk assessments to support the safe provision of abdominal massage for constipation.
4. Complete abdominal massage with the person, taking into consideration the person's learning, sensory and physical disability to evaluate the effectiveness of the technique.
5. Document an accessible abdominal massage treatment plan and delegate to the person's network of care in line with CSP guidance on the delegation of tasks to support workers.
6. Monitor the effectiveness of abdominal massage after delegation of the technique using subjective feedback and bowel and Bristol stool charts.
7. Work in collaboration with the GP to reduce dependency on laxatives where appropriate.
8. Develop local multidisciplinary pathways and networks to support constipation management and abdominal massage.

Knowledge and Skills

Specialist learning disability physiotherapists will need to develop knowledge, skills and competence in the delivery and delegation of abdominal massage for constipation. This includes:

- The causes, incidence, risk factors and impact of constipation.
- Anatomy and physiology of the intestinal tract.
- Assessment of bowel elimination and identification of constipation.
- Non-pharmacological and pharmacological treatments for constipation.
- Indications, benefits and contraindications for abdominal massage.
- Abdominal massage technique.
- Teaching and delegation of the abdominal massage technique to the person's network of care.

Supporting Evidence:
Constipation is a symptom-based disorder which describes defecation that is unsatisfactory because of infrequent stools, difficulty passing stools, or the sensation of incomplete emptying. Constipation is characterised by not having a poo for 3 or more days; not having a poo at least 3 times in a week; having poo that is sometimes difficult to push out without straining; having poo that is larger than usual, dry, hard, like pellets; and/or after a long time between poos passing lots of soft, smelly poo (LeDeR 2019; NICE 2019c).
Robertson et al. (2018a) conducted a systematic literature review as part of the Centre of Disability Research supported by Public Health England to explore the prevalence of constipation in people with intellectual disability. 31 studies published between 1990 to January 2016 were included into the study. The results indicated that constipation rates of 33% to 50% or more were reported. Over 25% of people received a repeat prescription for laxatives in one year, compared to 0.1% of the general population. Constipation was more common in those with cerebral palsy and profound intellectual disability and was associated with immobility but not age. The researchers conclude that constipation is a significant issue for people with intellectual disability across the life course and should be actively considered as a diagnosis in this population.
NICE guidelines on constipation in children and young people acknowledge that some children and young people with physical disabilities, such as cerebral palsy, are more prone to idiopathic constipation as a result of impaired mobility. Children and young people with Down's Syndrome or autism are also more prone to the condition (NICE 2010c).
The Learning Disability Mortality Review (LeDeR) programme released a learning into action bulletin in 2019 on constipation called 'Dying for a poo'. LeDeR found that constipation can affect up to half of all people with a learning disability and that unrecognised, untreated constipation has been known to cause death. They report that this is rare, but is an entirely avoidable and unnecessary, thus it can be stopped from happening. In addition, LeDeR report that constipation can cause pain and distress, hence the effective monitoring and management of constipation in people with a learning disability is essential to maintain their safety and well-being. They state that unplanned hospital admissions which could be prevented by effective interventions in the community and the bill for laxative prescription a year could be reduced (LeDeR 2019a). In response the Learning Disability Programme, have developed Poo Matters information booklets for families and carers to raise awareness of the problem of constipation in people with a learning disability. This includes a tool to develop a care plan to improve the management of constipation and bowel habits. There is also an information leaflet for healthcare professionals which outlines the assessment of constipation and the treatment options available (NHS England 2019a).

Public Health England published guidance on constipation in people with a learning disability as part of their making reasonable adjustments series in 2016. They recommend that anybody supporting people with a learning disability should be aware that they are at a high risk of having constipation; know how to recognise the signs and symptoms; and who to approach for advice on management.

Public Health England report that people with a learning disability mainly get constipation because of inadequate diet and fluid intake; reduced mobility and lack of exercise; side effects of certain medications; and anxiety or depression. People with Down's Syndrome or cerebral palsy have an increased risk of constipation and people with more severe learning disabilities are at an even higher risk. Immobility and environmental factors can also increase the likelihood of constipation.

The report highlights the impact of constipation for people with a learning disability. In addition to the physical consequences, there is a body of research demonstrating the link between chronic constipation and behavioural problems, including self-harm.

Public Health England recommend a holistic and personalised approach to bowel management including both pharmacological and non-pharmacological treatments delivered by the multidisciplinary team and the person's network of care. This includes:

- family or paid carers;
- learning disability nurse;
- GP;
- Physiotherapist;
- occupational therapist; and
- dietician.

The guidance makes recommendation for the different treatment options available including diet and exercise, toileting position and routine, physical health, medication, abdominal massage, and laxatives. Public Health England recognises that abdominal massage can be as effective as laxatives in the treatment of constipation. They recognise that holistic bowel management can be time consuming but can help to improve the bowel habits of people with a learning disability and can lead to a reduction or cessation of laxatives.

Public Health England identify that constipation is a significant problem for people with a learning disability that impact on their health and quality of life. They recommend the need for a total bowel management approach which includes abdominal massage delivered by a multi-disciplinary team with physiotherapy as an integral part. This can improve the health outcomes for people with a learning disability as well as having potential cost savings for the NHS.

(Public Health England 2016c)

In a follow up to the systematic review exploring the prevalence of constipation in people with intellectual disability, Robertson et al. (2018b) summarised the international research pertaining to the management of constipation. The authors reviewed 18 studies published from 1990 to 2017.

The results found that the main management response to constipation in people with intellectual disability is laxative use, but this is not effective for all people. Studies also reported positive results for dietary fibre and abdominal massage although study quality was limited.

In relation to abdominal massage, the authors reported that whilst the effectiveness of abdominal massage was found not to be demonstrably different to that of laxatives, a number of other positive outcomes have been attributed to the technique. Such as improved sleep (in children), pain, mood and behaviour; and enhanced therapeutic relationships between those implementing and receiving the abdominal massage across a range of settings. However, it was not clear to what extent positive results can be attributed solely to abdominal massage, with implementation being confounded by the introduction of toileting plans or by additional components of a total bowel management programme.

The authors conclude that further robust research is required to better understand what works well in managing constipation in people with intellectual disability. But in the meantime, services should consider adopting the guidelines for the management of chronic constipation of adults within the community outlined by Emly and Marriott (2017).

Management of chronic constipation of adults within community (Emly and Marriott 2017).

Conor et al. (2014) completed an audit of the benefits of abdominal massage as part of a total bowel management programme for people with a learning disability living within the locality. Total bowel management is a multidisciplinary approach to constipation management which was introduced in 2006 by community learning disability physiotherapists and nurses. The authors describe the approach as a systematic regime including:

- A baseline assessment of elimination habits over a two week period. Including completion of the Bristol Stool chart and attention to diet, fluid intake, mobility, toilet regime and positioning.
- Assessment for the suitability for abdominal massage including GP medical clearance and a risk assessment.
- If agreement is reached, the professional (either a physiotherapist or nurse) completes the initial abdominal massages and evaluates the effectiveness of the technique. The service adopts the abdominal massage technique described by Marian Emly (Emly 2008).
- If effective, classroom based and one to one training is provided for the person's network of care and their competence assessed before the task is delegated.
- The performance of network of care is reviewed after six months, and they can contact the team for updates or reviews as required.

The authors outline the evidence base for abdominal massage in people with a learning disability and acknowledge it is limited. They report that abdominal massage can:

1. Increase peristalsis in the gut and reduce colonic transit time.
2. Make stools easier to pass by softening their consistency.
3. Resolve constipation in some patients where diet and laxatives have failed.
4. Reduce cost of pharmaceutical treatments of constipation.

The authors report that other advantages include a lack of known side effects; limited number of contraindications; and the non-invasive nature of the technique making it preferable to more invasive treatments such as suppositories and enemas.

To evaluate abdominal massage as part of total bowel management the authors sent questionnaires to families and carers to identify positive and negative aspects of abdominal massage. The results found that all feedback was positive. They indicated that abdominal massage improved bowel elimination; reduced pain and associated behaviours that challenge; and lessened reliance on laxatives. The findings are supported with four case studies.

The results of the study indicate that abdominal massage could be used by an appropriate trained professional as part of a total bowel management programme to improve pain, discomfort and laxative use in people with a learning disability who have constipation.

Specialists, generalists and generalising specialists

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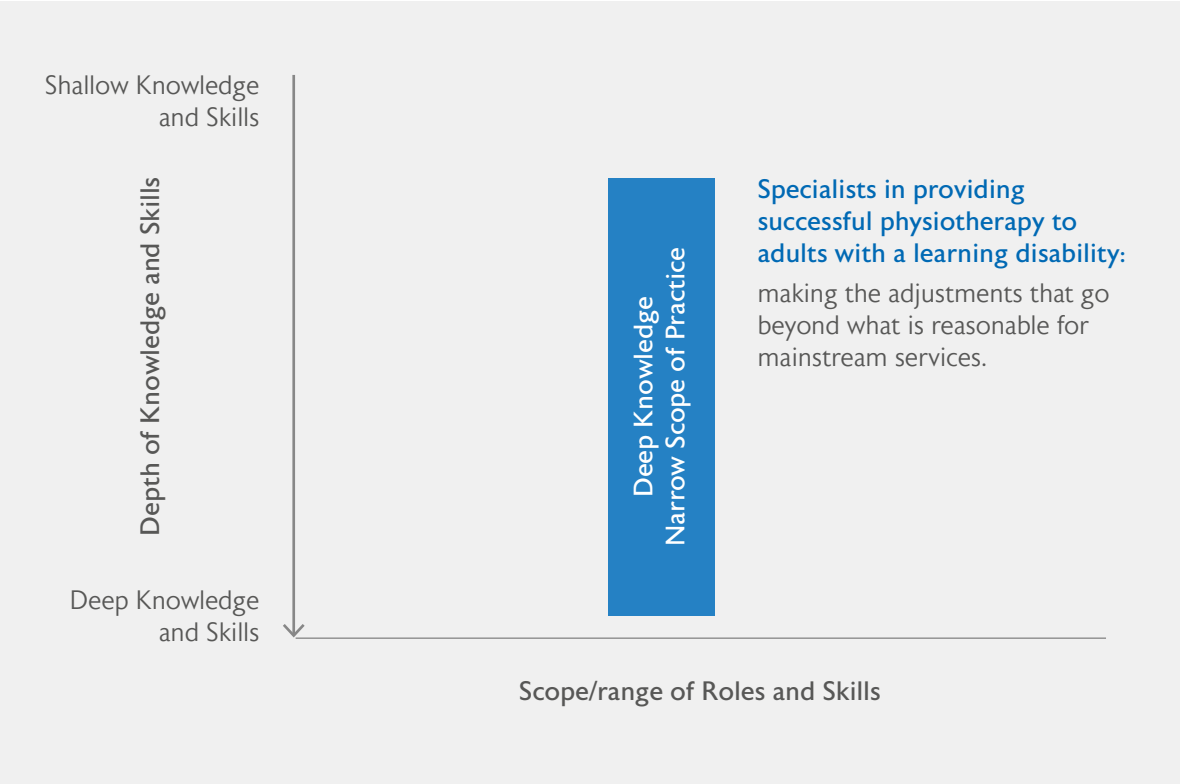
The Specialist

Specialists are defined as people who have deep knowledge and skills relating to a particular role or area of study. Specialists can be described as the letter 'I', they are 'Master of one', and are experts in their specific field (Figure 12). Specialists are valued within organisations because they have deep knowledge and skills within their chosen area and thus become the 'go to' for specific problems. The disadvantage of being a specialist is they can only work within a specific field and their opinion and input on other issues is less valid and important.

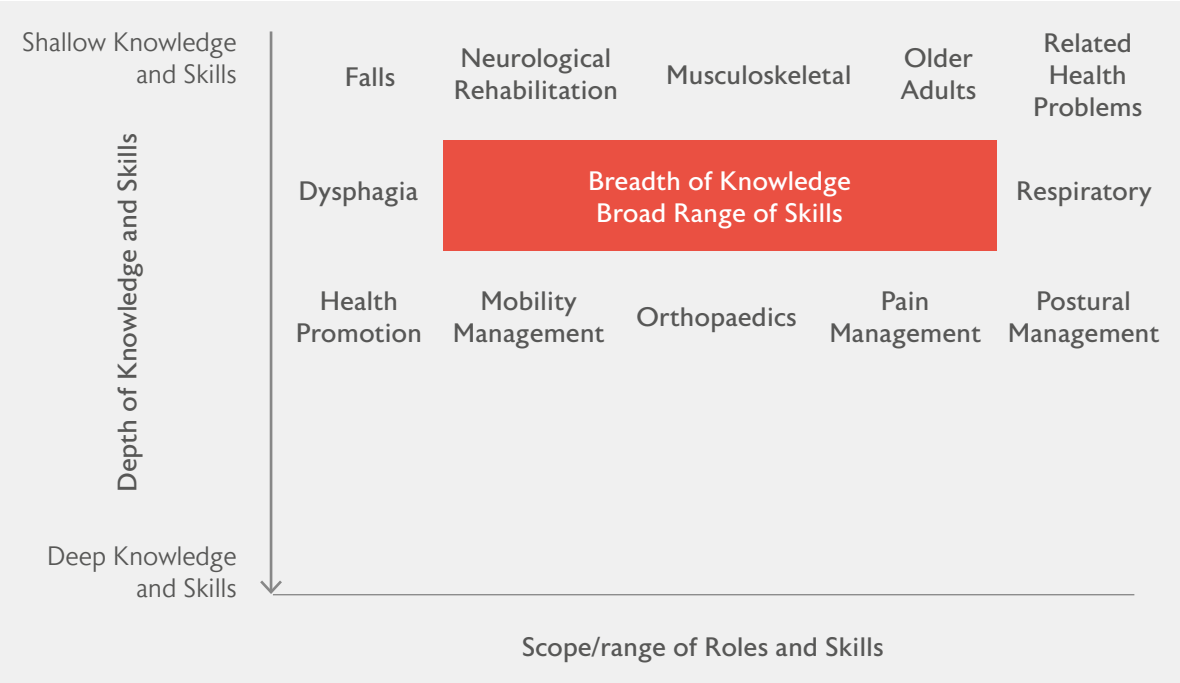
Figure 12: Specialist knowledge and skills of the learning disabilities physiotherapist



The Generalist

The simple definition of a generalist is a person who knows something about a lot of subjects. They are employees with broad knowledge across different disciplines and fields of experience, but they do not possess a deep level of knowledge or expertise in one area (Figure 13). There are a number of advantages having generalist knowledge and skills, especially when working in an area where a broader more holistic view is required. A broader approach and wider understanding can help the professional see the bigger picture and think outside the box.

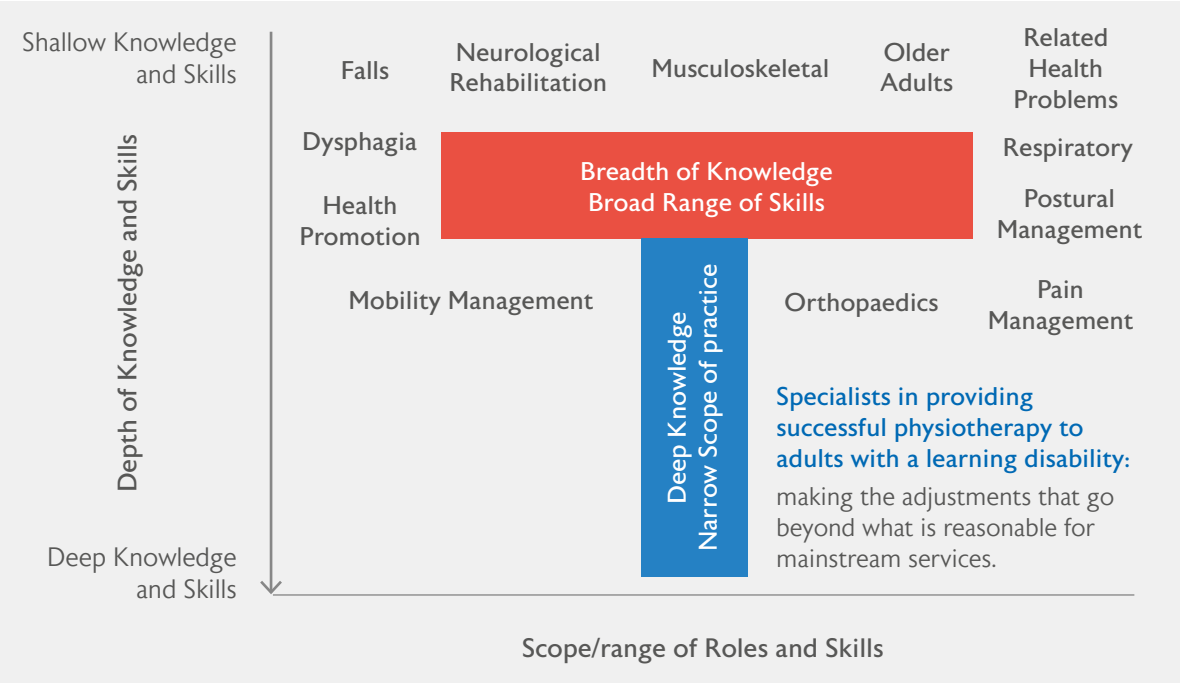
Figure 13: Generalist knowledge and skills of the learning disabilities physiotherapist



Generalising Specialists

The generalist and specialist elements of the role of the physiotherapist working with adults with a learning disability results in them becoming a generalising specialist. There are a number of advantages to becoming a generalising specialist both for the person and the organisation that they work for. They not only have specialist knowledge in one or more specific areas, they also are able to take a holistic view and contribute to a range of areas. The generalising specialist is common within the healthcare setting where many professionals are trained as generalists before specialising in certain area of clinical practice. A generalising specialist can be represented as the letter "T". The horizontal bar illustrates the broad range of knowledge, and the vertical bar or bars demonstrates the deep knowledge in their specialist area (Figure 14).

Figure 14: T-shaped generalising specialist



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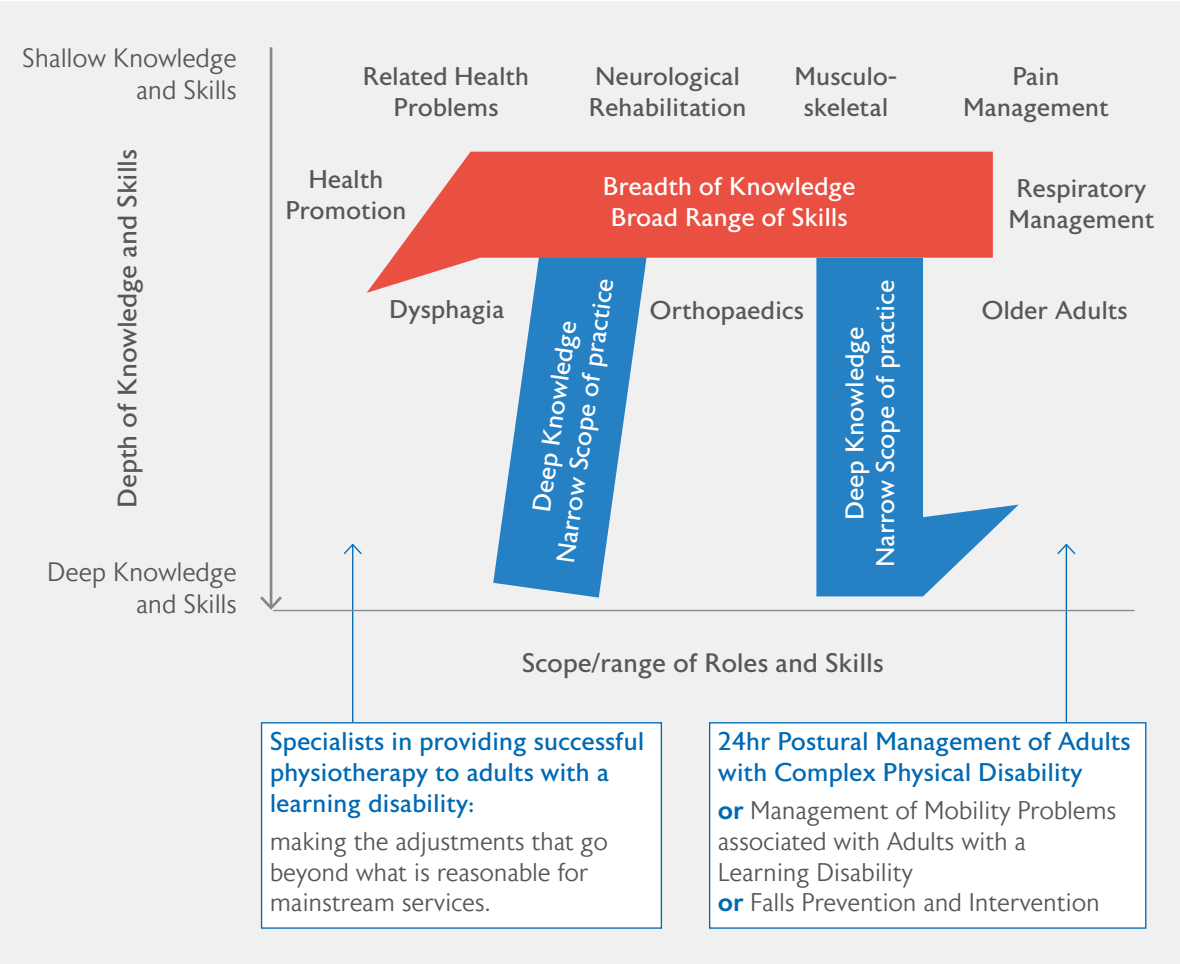
It is essential that learning disability physiotherapists develop specialist knowledge in the specific aspects of physiotherapy that are critical to managing the physical needs of adults with a learning disability and where there are gaps in service provision. As a result, specialist learning disability physiotherapists will often develop into Pi shaped generalising specialist with specialism in two areas of practice (Figure 15). Although this shape is preferable to T-shaped people, maintained specialist knowledge in two domains as well as their general knowledge can be challenging and takes dedication.

Figure 15: Pi shaped generalising specialist



For services where there is one physiotherapist per team this significantly restricts the ability of the professional to develop into a Pi shaped practitioner. Instead they remain as a T shaped generalising specialist due to a lack of time, resources, supervision and support in developing specialist knowledge and skills in another domain.

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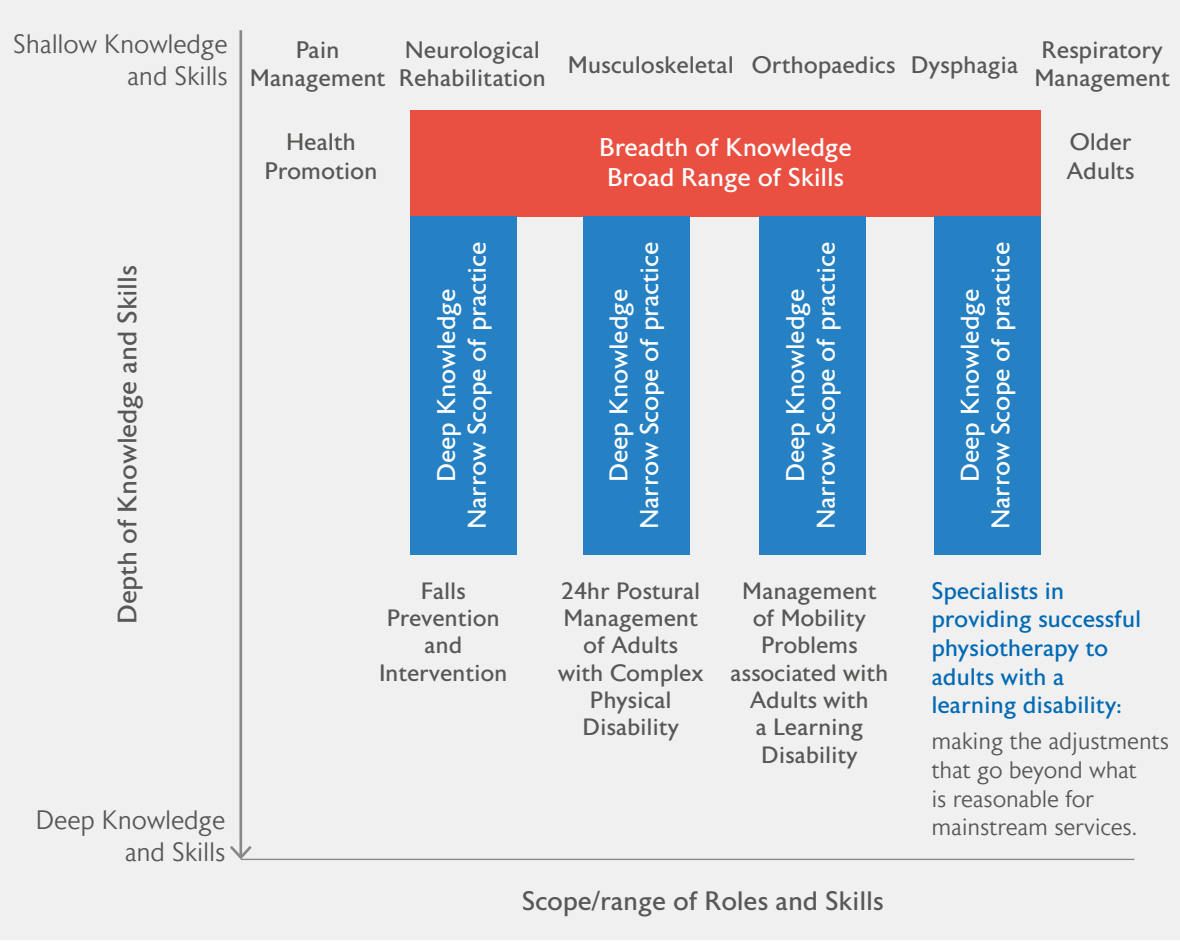
Ideally, community learning disability physiotherapy teams employ a number of physiotherapists that each develop specialist knowledge and skills in the different aspects of physiotherapy critical to meeting the physical needs of adults with a learning disability. This creates a service with a comb shaped set of knowledge and skills (figure 16). This unfortunately is not the reality for many services across the UK. This can impact on the team's ability to successfully meet the physiotherapy needs of adults with a learning disability locally. Therefore, services need to be commissioned and resourced appropriately to enable the right knowledge and skills mix.

Figure 16: Comb spaced generalising specialist learning disability service



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Training, education and development responsibilities

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Individual

1. Active in supervision and peer supervision
2. Actively participate in special interest groups and professional networks
3. Actively sharing own practice and experience via the ACPPLD newsletter and website
4. Attend relevant training and education course
5. Be actively involved in professional, multi-disciplinary and/or multi-agency in-service training sessions
6. Complete relevant post graduate training opportunities e.g. Oxford Postural Management course.
7. Complete yearly appraisals including personal development plan
8. Critically appraise and synthesise the outcome of relevant research, evaluation and audit
9. Critically engage in research activity
10. Engage in continued professional development
11. Engage in self-directed learning
12. Engage on Social Media including Twitter and iCSP
13. Keep abreast of relevant research, NICE guidelines, and publications
14. Present case studies to support clinical reasoning and reflection
15. Reflection and Learning through Action
16. Support student placement

Regional

1. Develop and run specialist training and education events to update skills to keep abreast of developments in current practice
2. Provide a platform for peer support, shared learning and practices
3. Run regular learning events on relevant topics
4. Support opportunities for research

Organisational

1. Develop a culture that encourages service development, audit and research
2. Develop and run in-service training programmes including professional, multi-disciplinary and/or multi-agency sessions
3. Develop opportunities for multidisciplinary and peer group supervision
4. Facilitate a culture of learning through action and reflection through adverse incidents
5. Offer mentoring opportunities
6. Offer yearly appraisals
7. Provide a platform to implement knowledge and skills into practice
8. Provide opportunities to implement any training and education into practice
9. Provide regular supervision with a suitably qualified and experienced clinician
10. Provide time and resources to support continue professional development
11. Seek opportunities to bench mark service against local teams and national guidelines such as NICE
12. Support multidisciplinary working, training and education
13. Support opportunities for employee's continued professional development

National

1. CPPLD yearly objective – improve membership engagement and participation
2. Development and endorsement of standards of practice
3. Development of competence framework
4. Development of standardised assessment tools and measures
5. Publish professional newsletter which supports research, shared learning and practices
6. Run regular learning events on relevant topics
7. Support opportunities for research

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Resource to develop an understanding of the local population of adults with a learning disability

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Population statistics

There are a range of resources available to develop an understanding of the number of people with a learning disability living locally. Some resources provide exact numbers of people whereas others rely on applying estimated population statistics for adults with a learning disability to population demographics available through the Observatory of National Statistics or equivalent in Northern Ireland, Scotland and Wales.

England

Public Health England: Learning Disability Profiles (2019).

Public Health England: Learning disabilities Observatory (2016).

Northern Ireland

Northern Ireland Assembly: Statistics on people with a learning disability in Northern Ireland (2014).

Scotland

Scotland Commission for Learning Disability: Learning Disability Statistics Scotland (2017).

Wales

Welsh Government: Learning Disability Improving Lives Programme (2018).

Evidence based local estimates

There are a number of resources and cohort studies available that state the percentage or incidence of people with a learning disability with specific health problems. For example:

- Percentage of people with cerebral palsy with a learning disability.
- Prevalence of falls and rates of fracture.
- Percentage of people with a learning disability and dysphagia.
- Number of people with profound and multiple learning disabilities.
- The percentage of the leading causes of death in people with a learning disability.

The statistics can be applied to the number of people with a learning disability to develop evidence-based estimates of the number of people with specific health problems. This provides a baseline to compare local data and to develop an understanding of needs and gaps in service provision.

Local databases

Once the population estimates have been developed it is critical to assess how accurately the statistics represent the local population. This can be a challenging task due to the reliance on the accessibility and quality of local data. The methods of collecting data will vary locally therefore their data will need to be harvested from different sources. For example:

- GP data for people with a learning disability.
- Data from A&E admissions for learning disabilities and falls, fractures, respiratory infections, etc.
- Number of referrals received for falls in a calendar year.
- Local database of people with complex physical disability.
- Number of people who have received postural assessment in a year.
- Caseload trends and numbers.

Recommendations of further research

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Introduction

The researchers conducted a systematic literature search of available evidence and uncovered limited robust research exploring the role of the specialist learning disability physiotherapist. The research that is available is mainly cohort studies describing the characteristics and needs of the population of people with a learning disability especially the incidence of accidents, falls and sedentary lifestyles. There is also very few studies examining the clinical outcomes of physiotherapy assessment and interventions.

The lack of robust research into people with a learning disability is well acknowledged within the literature and government publications (Public Health England 2018b; Robertson et al. 2018; NICE 2019). There are additional challenges when conducting research which includes people with a learning disability (Robertson et al. 2018). Firstly, there are challenging ethical and logistical problems when conducting randomised controlled trials with people with a learning disability. Secondly, the population of people with a learning disability who are likely to require a specific treatment or intervention, such as postural management, is relatively small and scattered across services where geographically there is a lack of consistency in the provision of services. Thirdly, behavioural issues may influence the participation of people with a learning disability. Finally, people may be unable to cooperate or tolerate the study protocol.

The inclusion of people with a learning disability who may lack capacity to consent is governed by law. The applicable legislation depends on the country where the research is to be conducted.

England and Wales: Section 30-33 of the Mental Capacity Act (2005)

Scotland: Adult with Incapacity Act (2000)

Northern Ireland: Part 8 of the Mental Capacity Act Northern Ireland (2016)

There is a wealth of further information on completing health research available on-line. The following websites can be a good starting place:

England and Wales: Health Research Authority

Scotland: NHS research Scotland

Northern Ireland: Health and Social Care Research and Development Department

If readers are interested in conducting research, local research and development departments of employers and universities are an important way of accessing support and supervision. These can support the development of research ideas, protocols and ethical considerations. There are also a number of potential funding bodies who fund health and social care research. Local research and development offices should provide the relevant information and advice on costing research appropriately.

Recommendations for further research

A number of researchers have made recommendations and suggestions for further research into specific aspects of physiotherapy for people with a learning disability (Finlayson et al. 2010; Crockett et al. 2014; Dairo et al. 2016; Public Health England 2018b; Robertson et al. 2018; NICE 2019).

24 hour postural management: Public Health England (2018b) acknowledge that there is a lack of evidence to support postural management in people with a learning disability and that the existing research does not provide the evidence required by commissioners. The authors state that there is an urgent need for evidence about the clinical and cost effectiveness of 24-hour postural care programmes and services. This could support the calls for improved specialist services and better funding for equipment, such as night time positioning systems.

Robertson et al. (2018) conducted a systematic review of the relevant research literature on the postural management of people with a learning disability. They identified a number of gaps in the evidence base. The authors make recommendations for further research priorities which they propose would begin to ascertain how best postural care interventions can be employed to help improve the health and quality of life of people with a learning disability. These include:

- Large-scale survey work could identify the potential needs that exist for postural care and map the current picture of service provision relating to postural care for people with a learning disability.
- Evaluation work investigating the impact on people and families of living in an area with a comprehensive postural care service versus areas without such a service.
- Health economic modelling could consider the costs and effectiveness of postural care as a whole, and also particular components of postural care.

Respiratory: NICE (2019) in the guidelines on cerebral palsy in adults recommend that one of the key priorities for research is to determine the most effective methods of detecting and managing respiratory disorders in primary and community care.

Falls prevention and intervention: There is a body of evidence that explores falls in people with a learning disability. Finlayson et al. (2010) make recommendations for further study on fractures/osteoporosis with this population; and the development and piloting of balance, safety, and staff training interventions for high-risk groups of people with a learning disability for fall injuries. Crockett et al. (2014) report that further work is needed to address issues related to non-participation or non-compliance with prescribed exercise and to learn more about clinical benefit outcomes of falls prevention pathways.

Health promotion: Dairo et al. (2016) conducted a systematic review of physical activity levels in adults with a learning disability. The findings highlighted a crucial need to increase physical activity in this population. To inform measurement and intervention design for improved physical activity the authors recommend that there is an urgent need for future studies. This includes people with severe and profound learning disability who have the lowest levels of physical activity.

In addition to the areas for further research identified in the evidence a number of priority areas where identified by the participants and researchers. These include:

1. Analysis of the current provision of specialist learning disability physiotherapy around the UK in comparison to the standards of practice.
2. Assessment of the appropriate time between reviews and the factors that influence these decisions.
3. Case studies published in peer review journals.
4. Clinical effectiveness of treatment and management approaches.
5. Cohort studies of the adults with a learning disability accessing specialist learning disability physiotherapy services especially people with complex physical disability.

6. Cost effectiveness of specialist learning disability physiotherapy management.
7. Development and validation of standardised assessment tools.
8. Impact of specialist learning disability physiotherapy on access to primary and secondary healthcare.
9. The adjustments specialist learning disability physiotherapists make to provide successful physiotherapy to adults with a learning disability.
10. The experiences of people with a learning disability and their network of care with specialist learning disability physiotherapy.

Evidencing the impact of specialist learning disability physiotherapy

It is the responsibility of all specialist learning disability physiotherapists and services to contribute to the literature pool and to evidence the impact of the profession. This does not mean that all physiotherapists need to conduct research, but it would beneficial if they evidence, publish and share how their current practice improves clinical outcomes; the experiences of people with a learning disability and their network of care; and/or the potential cost effectiveness of their interventions.

Clinical Outcomes: Clinical outcomes are broadly agreed, measurable changes in health or quality of life that result from care. Clinical outcomes can be measured through a range of tools including validated outcome measures, an individualised measure, or specific outcome.

For example:

- Improved Tinnetti assessment score post exercise programme.
- Achieved goal evidenced through Goal Attainment Scale (GAS) following intervention.
- Reduced number of falls through implementation of a falls pathway.
- Reduced number of chest infections per year through implementing prophylactic postural management.
- Reduced number of A&E admission through implementing annual reviews of people with severe cerebral palsy and a learning disability.
- Reduced number of chest infections through multidisciplinary dysphagia assessment and management.

Experience of Care: Experience is one of the three key components of quality and needs to be given equal emphasis along with safety and effectiveness. There is a link between experience and health outcomes i.e. people who have a better experience of care generally have better health outcomes. There is also a link between experience and cost of care i.e. poor experiences generally lead to higher costs as people may have poorer outcomes and require longer and multiple episodes of care (NHS England 2013).

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Assessing the experiences of people with a learning disability can be challenging due to the impact of their communication impairments therefore, assessment of the experiences of the network of care may be more achievable and realistic. Table 3 outlines examples of methods to gain feedback of service user experiences.

Table 3: Methods to gain feedback of service user experiences

	Less descriptive	More descriptive
More generalisable	Surveys Comment cards Kiosk questions	In-depth interviews Focus groups Patient panels
Less generalisable	Online ratings Public meetings	Patient stories Patient feedback Complaints and compliments

Cost Effectiveness: For managers and commissioners who invest money into services it is important to see the return on their investment. Not only from the improved outcomes but also how services can save money in the long term. In addition, evidencing potential cost saving is an essential part of developing a business case for service development especially where increased investment is required. Cost effectiveness and saving can be demonstrated through evidencing or projecting the impact of an intervention or service has on clinical outcomes that are attributable to a unit cost of health or social care. For example:

- Number of bed days saved.
- Discharge from hospital or services.
- Delay/avoidance of admissions to hospital.
- Reducing a person's package of care through maintenance of standing transfers.
- Reduction in the number of care visits involved in delivering care e.g. reduction in the need for double handed care.
- Reduced hospital length of stay through hospital in-reach.
- Reduction in use of emergency and crisis response services.
- Reduced access to mainstream health services.
- Reduction in GP visits and medication prescriptions.

The Royal College of Occupational Therapy has launched the Improving Lives, Saving Money campaign which has a range of resources that demonstrate how occupational therapists improve lives and save money for the health and social care services on a daily basis. In line with this campaign, the researchers have developed resources to help services and professionals demonstrate the financial impact of specialist learning disability physiotherapy. This includes a case study outline including a summary of the relevant unit costs of health and social care to specialist learning disability physiotherapy.

Toolkit: Evidencing the cost effectiveness of physiotherapy

Shared learning and disseminating results

Sharing the results of any service developments, case studies, audits and research projects is essential. Communicating the findings with the wider audience ensures that others working in the same field are able to learn from the results to improve care and knowledge; and influence policy or service planning. It also adds to the literature and evidence pool supporting the role of the specialist learning disabilities physiotherapist. Ideally, results would be published in a peer review journal because these have the biggest impact factor and widest audience. It is important to remember that there are a range of journals available all with different criteria for publication which give authors a number of options for publishing their results (Table 4). All journals will have specific aims and scope; as well as guidelines and instructions for authors which details the style and format of the manuscript.

Table 4: Examples of relevant research journals

Physiotherapy Related Journals	• Clinical Rehabilitation • Physiotherapy • Physiotherapy Research International • Physiotherapy Theory and Practice: An International Journal of Physical Therapy
Learning Disability Journals	• British Journal of Learning Disabilities • Focus on Autism and Other Developmental Disabilities • Journal of Applied Research in Intellectual Disabilities • Journal of Intellectual Disabilities • Journal of Intellectual Disability Research • Journal of Learning Disabilities • Learning Disabilities • Learning Disabilities Research and Practice • Learning Disability Practice • Research in Developmental Disabilities
Disability Journals	• Disability and Rehabilitation • Research and Practice for person with Severe Disabilities • Disability and Society • British Journal of Therapy and Rehabilitation • International Journal of Therapy and Rehabilitation

If disseminating the results in a peer reviewed journal is not feasible there are a range of other options which may be interested in publishing work. These platforms are often retrievable by other researchers and contribute to the pool of grey literature which can contribute to narrative and literature reviews. These include:

- Newsletters from different special interest groups.
- NICE, Public Health England, NHS England, and other government and charitable organisations regularly request examples of good practice to support policy and recommendations.
- The ACPPLD website has a document sharing section in which case studies and examples of good practice can be posted and attributed to the author.

Presenting at conferences may involve poster or oral presentations and the opportunity to discuss or debate the findings with peers. These can be extremely valuable, but information presented at conferences may not be so easily retrievable by other researchers.

CONCLUSION

The evidence for the role of the specialist learning disability physiotherapist will not increase on its own. Therefore, it is the responsibility of all professionals with an interest and a passion for working in the area to promote the role and contribute to the literature pool. Professionals are all guilty of completing service developments; a quality improvement project, an audit, presenting a case study; or local research but not disseminating the results beyond the local team. The researchers recognise that finding the time to complete this task and prioritise it over clinical work is challenging. Including objectives relating to research and sharing learning could be a way to dedicate and ring fence time to commit to this important aspect of the role, CPD and development of the profession. Sharing the outcomes and impact of specialist learning disability physiotherapists on the lives of adults with a learning disability and their network of care, as well as demonstrating how we can save money at the same time is critical to developing and safeguarding the profession moving forwards.

Standards of Practice for Physiotherapists

Working with adults with a learning disability

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