Position Paper: Learning Disabilities (children, young people and adults)

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Introduction

This position paper is written for a speech and language therapy audience, inclusive of students, assistants, registered speech and language therapists (SLTs), managers and lecturers. Its purpose is to support speech and language therapy provision to work towards the ultimate outcomes for children, young people and adults with learning disabilities of maximising communication potential, reducing risk associated with communication and dysphagia and enabling inclusion and access to education, employment, healthcare as well as the wider community and society.

This all-age document is the result of collaboration across the speech and language therapy profession, inclusive of clinicians and academics, representing provision across different sectors, nations and specialisms within learning disabilities. It builds upon a network of values which underpin all the interventions that SLTs provide. These include upholding the Human Rights Act (1998) and the articles relating to the rights for liberty and freedom (choice); for privacy, family life and the right to marry; freedom of speech; education and to be free from inhuman and degrading treatment. This paper focuses on the voice of the individual, whether expressed verbally or non-verbally, through formal recognised systems or behaviour. Individuals with learning disabilities should be heard, respected and be influencing all that we do.

This document does not stand alone, and it recognises the multiple additional health needs and adaptive functioning faced by individuals and their families throughout their lives, including health and social inequalities.

Children, young people and adults with learning disabilities

Definition and incidence

For the purpose of this document, learning disabilities is the agreed terminology. The Department of Health and Social Care in the UK defines a learning disability as:

> "A learning disability, not to be confused with a learning difficulty such as dyslexia and dyspraxia, is a label given to a group of conditions that are present before the age of 18. This impacts on the way individuals develop in all core areas, and ultimately how they live their lives and access health care."

Learning disabilities is an overarching term for a myriad of definitions, including:

- The World Health Organization (WHO)'s International statistical Classification of Diseases and related health problems-11 (ICD-11) definition of 'disorders of intellectual development'
- American Psychiatric Association's Diagnostic and Statistical Manual (DSM-5) definition of 'intellectual developmental disorder'
- Other terminology such as intellectual disabilities, complex or special needs
- Sub-categories from profound and multiple, to mild learning disabilities.

Learning disabilities are lifelong and can affect both cognitive difficulties and functional adaptation. While not an illness in itself, a learning disability may be accompanied by several complexities associated with physical, social, sensory or psychological difficulties. The impact may vary across an individual's lifespan. Young on children may be given a diagnosis of 'global developmental delay'. The DSM-5 suggests this diagnosis is only appropriate until the age of 5, usually when it is unclear why a child has had delayed or different developmental progression of skills.

This paper does not discuss specific learning disorders of reading (commonly known as dyslexia), written expression (dysgraphia) or maths (dyscalculia). Specific learning disorders are different to learning disabilities. Individuals with specific learning disorders will usually live independent lives and can learn well (although they may need additional support in certain areas) and therefore differ from many individuals with learning disabilities.

Historically, intelligence quotient (IQ) scores determined the severity of a person's learning disability but today the relationship between environment, physical, behavioural, psychological, and social factors is well-recognised (WHO, 2001). This biopsychosocial perspective focuses on

adaptive behaviours, daily skills and facilitating participation and means that learning disabilities policies are underpinned by the core principles of independence, choice, rights and inclusion, reflecting a biopsychosocial model of disability (Department of Health, 2007; NHS England, 2015). This model views disability as a combination of barriers, rather than solely individual impairment (Walmsley, 2001).

Around 1.5 million people in the UK have a learning disability. Up to 350,000 people currently have a severe learning disability. Those numbers are increasing, with a predicted 34% increase of individuals with severe learning disabilities by 2027 (Idriss et al, 2020). Despite policy aspirations, children, young people and adults with learning disabilities remain some of the most vulnerable and socially excluded in our society.

As a diverse population with wide-ranging abilities and support needs across their lifespans, individuals with learning disabilities face multiple challenges with complex and co-existing health and social determinants creating significant and preventable social and health inequalities.

In 2012, the Public Health Observatory described five discernible determinants of the health inequalities commonly experienced by people with learning disabilities:

- social determinants
- genetic and biological determinants
- communication difficulties and reduced health literacy
- personal health behaviour and lifestyle risks
- deficiencies in access to and quality of health provision.

Exposure to each of these determinants predicts experiencing greater health inequalities in comparison with the whole population. The consequences of these inequalities are significant and include premature mortality, increased experience of ill health and an impoverished quality of life. However, if we focus on identifying needs and providing support rather than profiling the complexity of a person's needs, specific conditions or presentations, many inequalities can be mitigated through greater understanding, intervention, and resource (NDTI, 2013; Emerson & Baines, 2010).

Social determinants

The impact of learning disabilities extends beyond health. Individuals with learning disabilities and their families face disadvantage: from healthcare to housing; education to employment and in relationships and social participation (NHS Digital, 2018; Hatton & Emerson, 2015).

These disadvantages contribute to a lack of choice and involvement in everyday decisions.

Examples of social determinants for individuals with learning disabilities include:

- fewer social networks outside their families
- digital exclusion (Williams, 2020)
- communication difficulties increasing risks of social isolation (Smith et al, 2020)
- less participation in leisure activities (Solish et al, 2010; Taheri et al, 2016)
- less likely to be in employment (Emerson & Hatton, 2008)
- greater vulnerability and risk of bullying and exploitation, including sexual abuse, with increased isolation (Peckham, 2007)
- increased prevalence of learning disabilities within some communities e.g.
  - moderate learning disabilities within traveller communities and profound and multiple learning disabilities within in Bangladeshi and Pakistani communities (Gov UK, 2022)
  - Foetal Alcohol Spectrum Disorder (FASD) in the looked after children population than general population (27% vs 3.2%)
  - higher risk for individuals from diverse cultural backgrounds, such as Black, Asian or minority ethnic, of either not being identified and needing more inclusive and culturally sensitive services (Emerson, 2012)

Many of these lead to loneliness and the impact of the COVID pandemic has exacerbated this. Research found that nearly half of adults with a learning disability said the pandemic had made them feel lonelier (Hft, 2021). Around a third reported that:

- they felt lonely nearly always or all of the time
- they hardly ever or never go out to socialise
- they do not feel part of their local community
- they are not confident making friends.

Parents of disabled children responded to the Disabled Children's Partnership surveys during the Covid 19 pandemic. In July 2021, 9 in 10 children and 6 in 10 parents reported social isolation despite schools reopening (Disabled Children's Partnership, 2021).

Many individuals with learning disabilities live in family homes, with much of their daily care needs being met by family members. Family carers hold vast reservoirs of knowledge about their relation and their context and co-ordinate services to meet existing needs. Approximately, half of family carers of an adult with learning disabilities spend over 100 hours a week caring for that person, with almost three quarters being in a caring role for over 20 years. Family carers are vulnerable to feeling emotionally and physically drained, and this can increase the risk of the family becoming socially isolated. Almost a third are not in paid employment due to their caring responsibilities (Public Health England, 2015). They have poorer health outcomes and need information, practical emotional/ psychological support to do the work they do.

Several inquiries and investigations have found that some private and NHS organisations are failing to adequately respect and protect people's rights, with devastating consequences for them and their families.

In recent years, the learning disabilities and autism workforce has been the focus of greater attention. Programmes such as the Transforming Care Programme in England and the Improving Lives Programme in Wales aim to develop health and care services so that people with a learning disability and/or autism can live in the community, with the right support, and close to home.

Genetic and biological determinants

Learning disabilities can be caused by various factors, including genetic conditions (such as Down's syndrome or fragile X syndrome) or biological determinants (leading to cerebral palsy or foetal alcohol spectrum disorder). Some learning disabilities have no identified cause.

Increasingly though, medical advancements and projects (e.g.) are identifying rare genetic conditions that have some specific health issues related to the diagnosis (e.g. dementia in Down's syndrome, obesity in Prader Willi syndrome). It is important to consider these factors and predispositions when working with a person with a known diagnosis.

Each family's journey to awareness and acceptance of someone's strengths and needs is different. They may be aware of a diagnosis of learning disabilities and any associated conditions before birth, shortly after birth or later as difficulties present themselves.

However, genetic and biological determinants of individuals with learning disabilities do not explain their poorer health outcomes. Lower standards of healthcare and more inpatient admissions are routinely recorded for individuals with learning disabilities. The Learning Disabilities Mortality Review (LeDeR) Programme highlighted in 2020 that during the COVID pandemic, adults with learning disabilities were three times overrepresented among the numbers of deaths with an even larger disparity across younger age groups (Genomics England 2022; Public Health England, 2021.

Individuals with learning disabilities face at least the same risks to other health conditions as those without learning disabilities. Difficulties communicating pain or distress effectively make recognition and diagnosis of illness more challenging (RCSLT, 2018). Barriers to accessing healthcare, including misdiagnosis, diagnostic overshadowing and poor medical management, result in higher rates of illness and premature deaths (Heslop et al, 2013).

Several neurological and health conditions that more often co-exist alongside learning disabilities include epilepsy and respiratory conditions (LeDeR, 2019). Some health conditions significantly impact on speech, language and communication needs (SLCN) and/or eating, drinking and swallowing (EDS), and are therefore key for SLTs to be aware of, as they may not necessarily be diagnosed or recognised, creating even greater health and social inequalities. These include:

Mental health

Children and young people with a learning disability are 4.5 times more likely to have mental health problems than other children, and adults with a learning disability are at least twice as

likely to experience some kind of mental health problem (Emerson et al, 2007; Cooper et al, 2007). Increased risks are multi-factorial across biological (physical ill health and polypharmacy); psychological (abuse and neglect); social (poverty, isolation and stigma); and developmental domains (NICE, 2015). This increased incidence also leads to over reliance by staff on restrictive approaches and interventions, overuse of specialist learning disability services and 'out of county' placements, which in itself can increase incidence of behaviour which challenges, mental health distress, or offending.

Sensory loss

Additional needs around sight and hearing are greater than in the general population. One in ten of the learning disability population of England are or will become blind or partially sighted. Adults with learning disabilities are 10 times more likely to have a serious sight loss than the general population and children with learning disabilities. Children with learning disabilities are 28 times more likely to have vision loss than their peers (SeeAbility, 2016). Up to 40% of people with learning disabilities have a hearing loss (Foundation for People with learning Disabilities). Some individuals have dual sensory loss (RCSLT, 2021).

The more profound and complex an individual's learning disability, the more likely it is that they will have a serious sensory and/or motor impairment (Mansell 2010). Certain learning disabilities, including Down's syndrome, as well as other health conditions, such as diabetes and ageing, are also associated with sensory conditions (Doukas et al, 2017; Kiani and Miller, 2010). The evidence is that individuals are missing out on sight and hearing tests and treatments. The NHS plan specifically has a target for sight and hearing test access (NHS England, 2022). Reasonable adjustments are required alongside education for those supporting people with learning disabilities (SeeAbility, 2016; Public Health England, 2020).

40%-80% of young people with developmental concerns may experience functional impacts related to sensory symptoms (Pfeiffer, May-Benson, & Bodison, 2017).

Dysphagia

Individuals with a learning disability have a greater risk of unsafe eating and drinking leading to:

- discomfort/reduced mealtime enjoyment
- malnutrition and dehydration
- aspiration, leading to poor respiratory health and chest infections
- choking (asphyxiation/airway blockage), potentially leading to death.

Individuals with learning disabilities and dysphagia are especially vulnerable to health inequalities, and their eating and drinking difficulties can have a negative impact on their psychosocial wellbeing (Robertson et al, 2017). 8% of people with learning disabilities, known to health and social care services, will have dysphagia, and 15% will require support to eat and drink (Public Health England, 2016). However, consensus in speech and language therapy Practice is

that this figure is much higher, and likelihood of dysphagia increases with:

- severity of the individual's learning disability (Robertson J et al 2017)
- poor oral health and hygiene
- individual's eating practice- cramming, speed, chewing
- requirement for physical mealtime support (Ball et al, 2012)
- dementia.

Risks associated with dysphagia are more likely to go undetected (Robertson et al, 2017) or be delayed in diagnosis, for example silent aspiration is reported to be common in some conditions and may go unnoticed (Jackson et al, 2016; Speyer et al, 2019). Dysphagia underlies the high rates of hospitalisation and death from aspiration pneumonia, as well as being associated with risk of sudden death from choking and in malnutrition in people with a learning disability who are underweight (NHS Digital, 2016). 17% of notified deaths to the LeDeR programme cited aspiration pneumonia as a cause, or contributory cause, of death in 2017 (LeDeR, 2018). The NHS Long Term Plan has a specific target regarding dental checks for people with learning disabilities with poor oral health known to be a contributing factor to aspiration pneumonia and more common in this population (Public Health England, 2017).

Epilepsy

Individuals with learning disabilities have a higher incidence of epilepsy – 'About 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy.' (Epilepsy Society). Epilepsy and the medications to manage it can impact on speech, language, communication, eating and drinking skills.

Physical and/or motor impairment

Individuals with neurodevelopmental motor disorders e.g. cerebral palsy have a high incidence of associated learning disabilities (Reid et al, 2018). Motor disorders have associated risks related to speech development and dysphagia due to dysarthria and oropharyngeal incoordination. Those with more severe and profound learning disabilities are more likely to also experience physical impairments.

Neurodiversity

Neurodiversity refers to the fact that all human beings vary in the way our brains work. We take in and process information in different ways, which means we behave in different ways. The Neurodiversity Paradigm therefore recognises that neurodiversity is naturally occurring with no one way of being better than another. Neurodiversity is just like other equality and diversity dimensions like race and gender. We recognise that there is strength in diversity itself, with a focus on collective not individual value (adapted from Professor Sue Fletcher-Watson at CRAE Annual Lecture 2022). Currently, our diagnostic systems define and categorise different ways that brains work in comparison to the majority group, where

impairments and disabilities are experienced. People with such diagnoses can be described as neuro-divergent. This also means that one person may receive more than one diagnosis; this applies to learning disabilities.

Recent research by the Learning Disabilities Observatory indicates that around 20-30% of children, young people and adults with a learning disability are also autistic, and approximately 50% of autistic children also have a learning disability (Emerson and Baines, 2010). Autistic individuals experience lifelong communication differences around social communication, social interaction and social imagination (Department of Health, 2010). In England, between 2020-2021, the percentage of individuals with a learning disability, who also have a diagnosis of ADHD is significantly greater (7.4%) than the percentage of the population who have a diagnosis of ADHD but do not have a learning disability (0.7%) (NHS Digital, 2021).

Dementia

Adults who have a diagnosis of learning disability are 5.1 times more likely to have a diagnosis of dementia and age-related dementia is more common at earlier ages in people who have a Learning Disability. People with Down's Syndrome are at increased risk of early onset Alzheimer's (Public Health England, 2019).

Additionally, they have an increased risk of preventable risk factors for dementia, including diabetes, obesity, inactivity and depression (NHS Digital, 2016). Dementia diagnosis for people with learning disabilities can be complicated by psychosocial masking (such as pre-existing difficulties with memory, communication and skills of daily living), and diagnostic overshadowing (Stanto and Coetzee, 2004). While symptoms of dementia for individuals with learning disabilities are broadly similar to the general population, some differences have been identified. For people with Down's syndrome and dementia, there is often an earlier onset of frontal lobe symptoms, including general slowness in activities and speech, language problems, loss of interest in activities, social withdrawal, balance problems, sleep problems and a loss of pre-existing skills along with the emergence of emotional and behavioural difficulties (Deb et al, 2007). Adult-onset seizures are common in people who have Down's syndrome and dementia (Epilepsy Research UK, 2021).

It is key for individuals with learning disabilities and their families to be informed about the risks of dementia, as well as being supported to understand as much as possible about their condition, assessment, and the options for treatment, care and support. Despite this, individuals with learning disabilities are often not informed of their diagnosis and information sharing can be poor (Dementia Action Alliance, 2017). Early screening for dementia for people with Down's syndrome is recommended from age 30 (Public Health England, 2018; Improvement Cymru, 2021). Communication assessment, support and training for people being assessed for or with a diagnosis of dementia, and their families and carers is core to maintaining a good quality of life. For people with pre-existing communication needs due to their learning disabilities, this specialist input can be even more important.

Dysphagia is common in dementia, and again, can be complicated by pre-existing difficulties: early assessment, and management is key to maintaining quality of life.

Communication difficulties and reduced health literacy

Speech, language and communication needs (SLCN) are significant determinants of health and social care with both individual and environmental factors.

Individual factors

Most children, young people and adults with learning disabilities experience communication challenges at some point related to developmental progress, illness, stress and anxiety associated with challenging situations. For example, when they are in unfamiliar surroundings or doing an unfamiliar task. Across a lifespan, huge demands are placed on communication for effective participation in daily life. Wide ranging SLCN can arise at any time. The communication challenges faced at different times in an individual's life vary; however, any difficulties will usually be lifelong, can be complex and may be hidden or overlooked.

Communication difficulties within learning disabilities are described as a core characteristic (NHS England, 2018) creating increased risk of health inequality (Emerson and Baines, 2010). This includes greater likelihood of:

- being misunderstood, or unable to communicate health needs
- experiencing barriers to accessing quality health, education and social care services both in understanding information and expressing themselves
- developing mental health and psychiatric disorders
- having limited involvement and engagement in decisions, activities and relationships.

There are no definitive, prevalence figures for people who experience communication difficulties, but it is consistently reported that around half have significant difficulties with both expressing themselves and understanding what others say, with between 60% (Smith et al, 2020) to 90% prevalence rate.

Communication difficulties reduce levels of health literacy (APPG for Education, 2011). These are broadly categorised as:

- functional (being able to read or access information through symbols, sign or images),
- interpersonal (having the ability to discuss health issues with family, friends and professionals) and
- critical (being able to synthesise health information and discern the relevant and useful parts).

Only 5-10% of people with learning disabilities have recognised literacy skills, suggesting that a large percentage are not able to read or fully understand standard written information at a functional level (Rudd et al, 2003).

People with learning disabilities also find it challenging to negotiate the interpersonal and critical aspects of health independently due to the unfamiliar language and vocabulary used and the cognitive complexities required to navigate more abstract concepts within healthcare (Buell et al, 2020). This has been exacerbated by the COVID pandemic leading to more online health communication and increasing digital and technology exclusion for individuals with learning disabilities (Chinn, 2014; Chadwick et al, 2022).

Social and environmental factors

Communication does not occur in a vacuum. In addition to individual communication factors, social and environmental factors also influence the success of communication for people with learning disabilities. Many rely heavily on the people they interact with. People with severe and profound disabilities may use idiosyncratic signals or behaviours that are bearers of meaning, and communication partners may have difficulty interpreting communicative intent and responding sensitively to communicative behaviours (Chadwick et al, 2018). Conversely, people with mild learning disabilities may have sufficient verbal skills to engage in everyday conversation, masking hidden but significant difficulties with understanding complex spoken and written information and unfamiliar vocabulary. They might also have difficulty expressing more complex or abstract thoughts and emotions effectively.

Many communication partners (including family carers, support staff and professionals) do not generally interact with the people they support in a way that enables individuals to achieve greater levels of independence, participation or integration (Mansell, 2007). Paid carers do not routinely make the reasonable communication adjustments required to maximise engagement, involvement and inclusion (Mansell, 2007; Bradshaw, 2020). Staff teams consistently overestimate individual's abilities, impacting negatively on staff perceptions and affecting the individual's overall care. Many lack the knowledge, skills and training required to recognise emerging health problems or the resources to effectively promote health literacy.

Education, health and social care providers need to develop their expertise to provide meaningful interaction and good communication environments. The good communication environment has been described as the place occupied by individuals, such as the classroom, home or residential setting where information is shared, relationships develop, and interactions occur for multiple purposes.

To facilitate good communication environments, additional support is required to develop knowledge, skills and motivation for others to make reasonable adjustments to enable meaningful interaction and maximise engagement, involvement and inclusion. The recommendation by the LeDeR for mandatory training (the Oliver McGowan Mandatory Training in Learning Disability and Autism), includes a strong focus on communication within

the reasonable adjustments section.

Personal health behaviour and lifestyle risks

SLTs need a good understanding of their nation's mental capacity framework:

- Mental Capacity Act (Gov UK, 2005)
- Adults with Incapacity (Scotland) Act (Gov UK, 2000)
- Mental Capacity Act (Northern Ireland) 2016.

These frameworks cover day to day decisions through to serious life changing decisions and require staff to take steps to encourage participation doing whatever is possible to enable decision making.

There is often a mismatch between communication strategies used by communication partners and the communication needs of the individual (McConkey et al, 1999). SLTs need to support others to do all they can to enable people to make their own decisions or contribute to component aspects of a decision. Changing communication practice depends not just on changing awareness and knowledge, but also changing behaviour including values and attitudes. Individuals with learning disabilities, families and staff can hold strong beliefs about their individual's communication. Research consistently indicates a mismatch between the level of an individual's communication and their perceived abilities by carers (Banat et al, 2002; Bradshaw, 2001). This means even when individuals have well documented needs around using alternative and augmentative communication approaches such as signs or visual supports, many interactions remain solely verbal (Bradshaw, 2020).

If an individual lacks the capacity to make some informed choices, SLTs need to be able to consider harm, balanced by potential reduction in behaviours of concern, improvements in quality of life, community participation and the reduction of stigma and exclusion. All professionals need awareness around the impact of trauma on an individual's overall health, wellbeing and communication presentation. Identifying someone who may be experiencing the effects of trauma is a key role for healthcare professionals, and individuals with learning disabilities may be at increased risk of trauma due to many of the factors already outlined in this paper.

Within a Positive Behaviour Support framework, all behaviours of concern are understood as communicating an unmet need which we need to understand and proactively support. Some may be challenging for services to manage. With increased communication difficulties, behaviours of concern typically increase in frequency, intensity or duration (Royal College of Psychiatrists et al, 2007). Good expressive and receptive communication support at the right level underpins the capable environment that prevents behaviours of concern from being needed (Allen et al, 2013). Functional communication skill teaching can often supply people with a better

way of making their needs met that is more efficient and effective and result in less restrictive practices than the original behaviour.

Additionally, it is well recognised that individuals with learning disabilities and behaviours of concern may be over prescribed psychotropic medicines. Public Health England has reported that everyday 30,000-35,000 adults with a learning disability are taking medicines when they do not have the health conditions they are for, leading to unnecessary side effects. The national projects STOMP (Stopping over medication of people) and STAMP aim to help people have a good quality of life and stay well so that they need less medication, or none at all.

Deficiencies in access to and quality of health provision

A reduced ability to process, understand and use healthcare information to make decisions, access screening and appointments, and subsequently follow instructions for treatment can have a long-term negative impact on an individual's health status.

Individuals with learning disabilities do not have the same access to public health, health promotion and health prevention programmes e.g. healthy eating, accessing immunisations, cervical screening, safe sex. Developing accessible programmes and building capacity in the mainstream is key (see section *whole systems approach to speech and language therapy activities and intervention*). Improving health literacy and easy read is one component, but there are other barriers including physical access, sensory issues, time allowed for appointments and appropriate support.

See:

- Population screening: reducing inequalities for people with a learning disability, autism or both (Public Health England, 2021)
- Obesity and weight management for people with learning disabilities: guidance (Public Health England, 2020)

Specialist learning disability provisions may also not provide quality healthcare and overuse restrictive interventions – see Out of Sight report (Mencap, 2012).

At times, it may be necessary for teams to use practices that are restrictive. In these circumstances it is imperative that teams follow guidance e.g. in England, Positive and Proactive Care: reducing the need for restrictive interventions (Department of Health, 2014) and SLTs understand the implications and practice and the role communication may play, including de-escalation and de-briefing for individuals.

Reasonable adjustments for communication

It is internationally recognised that communication is a fundamental human right, a right that people with learning disabilities have, the same as everyone else (NHS Improvement, 2018).

Inclusive communication supports all members of society to be equal by reducing communication barriers for all people with communication difficulties, promoting positive and inclusive relationships, reducing a person's vulnerability to risks and is essential to improving quality of life (Bercow, 2008). Communication disability is cited in all key strategic drivers across the UK as a reason for people with learning disabilities often being socially excluded or marginalised within their own communities (Department of Health, 2008; Department of Health NI, 2005; Wales, National Assembly, 2001; Scottish Executive, 2000).

Inclusive communication recognises that the responsibility for communication support needs moves beyond the individual who is experiencing difficulty to those communicating with them. This social model of disability believes that communication partners being able to make reasonable adjustments and overcome communication barriers is the ultimate factor reducing the impact of communication disability. If these adjustments are not made, people with learning disabilities will continue to face significant inequalities in violation of their rights (NHS England, 2015; RCSLT, 2013). Compliance with the legal requirements of Human Rights Act (Gov UK, 1998), Disability Discrimination Act (Gov UK, 1995) and Equality Act (Gov UK, 2010) all rely on communication.

Since July 2016, all organisations providing NHS or adult social care in England are obliged to follow the Accessible Information Standard (NHS England, 2015). The standard is a legal requirement to ensure that people who have a disability, impairment or sensory loss get information that they can access and understand, and to receive the communication support that they need to do so. This includes making sure that people get information in different formats if needed, but also making sure that people get any support they need to express themselves, such as interpreters, advocates or other communication partners (NHS England, 2016). Failure to make reasonable adjustments to meet communication needs means failure to design, commission and provide best-practice services, alongside continuing health inequalities faced by individuals, in contravention of these legal responsibilities. Government guidance on Accessible Information Formats (Gov UK, 2021), Scottish Government guidance on the Principles of Inclusive Communication (Scottish Gov, 2011), Welsh Government guidance on Creating accessible documents (Welsh Government, 2021), and the All Wales Standards for Accessible Communication and Information for People with Sensory Loss (NHS Wales, 2013) set out similar recommendations for Wales.

Communication Access UK is an initiative, led by RCSLT and developed in partnership by charities and organisations that share a vision to improve the lives of people with communication difficulties. Organisations commit to training and standards and then they can display the Communication Access Symbol. This symbol is a new disability access symbol, ensuring individuals with communication difficulties can use an organisation's services with greater confidence.

In 2013, the RCSLT produced the Five Good Communication Standards highlighting the need for services to strive for inclusive communication where carers are aware and value the different ways a person may communicate. Inclusive communication at individual, environment and community levels has been advocated for across disability services, with the emphasis on those without communication needs making adjustments (Money, 2016).

Principles of speech and language therapy delivery

SLTs promote communication awareness; safe, efficient and enjoyable eating and drinking; and reduce risks within the context of the biopsychosocial model of disability. They:

- enable others to address the barriers to communication that individuals with learning disabilities experience
- maximise the opportunities for positive interactions, participation and choice.
- work as an integral part of multidisciplinary team to ensure:
    - optimal support so individuals can eat and drink as safely and enjoyably as possible.
    - access to partners and environments with capacity and capability to enable individuals' communication.

While there is wide variation in speech and language therapy service delivery across the UK, all services should be underpinned by these principles, whether delivering direct or indirect individualised care or wider work outside of individualised care. Each SLT, speech and language therapy service, organisation and sector will draw on different structures and drivers, leading to eclectic, flexible and broad approaches to service delivery, with few explanations as to whether this variation is warranted, and not necessarily reflecting population need. Post pandemic referrals are increasing and need is greater impacting on capacity of speech and language therapy services. Variation in capability of speech and language therapy services reflects:

- the range of services required to meet the multi-factorial needs from community and acute health providers, education and voluntary sector (such as advocacy groups), through to services for specialist child and adolescent mental health services (CAMHS), adult mental health, criminal justice, forensic, older people and end of life services.
- the national and regional variation in commissioning, context and geographies across pathways and agencies, impacting on access and eligibility criteria, plus duration and intensity of interventions. For example, some speech and language therapy services are commissioned more for dysphagia than communication.
- the workforce strategy in terms of recruitment and retention impacting on vacancies and career structures.
- the range of recommendations included in legally binding documents outlining educational, health, and social care needs e.g., in England, Education Health and Care Plans (EHCPs), which may be the result of a tribunal process.
- the limited evidence-base for service delivery and no single speech and language therapy intervention appropriate to meet all communication needs.

SLTs have an important role in supporting maximal developmental progression of functional skills. They should intervene as early as possible, focussing on safely and effectively meeting the full and potential range of needs, alongside prevention and health promotion. For some this will be from birth. Whatever the context for service delivery, there are core principles for SLTs to consider in terms of optimising communication success and enabling reasonable adjustments so individuals can access and benefit from speech and language therapy services. These principles will reduce the risks of exclusion, inequality and poor health and wellbeing associated with disability and communication difficulties.

These principles are:

- The design, development and delivery of services should put the individual and their family or carers at the heart of a service. Services should be personalised and designed to meet their needs, reflecting person-centred principles, culture and values.
- Across the age range there should be a balance and transition of the focus of interventions, from developmental and impairment-based work towards functional communication skills. Depending on the context and needs, there will usually be a balance of direct skill teaching or generalisation with the individual alongside working with their communication partners and environment to ensure that communication is used at the right level.
- SLTs should work in partnership with a variety of stakeholders. These include individuals with learning disabilities, their families as well as other professionals (within education, health and social contexts, and inclusive of third sector providers, organisations and communities). Optimum communication promotes more effective education, health, social care and access to justice through more successful understanding, discussion and negotiation.
- Speech and language therapy services should be available and accessible to all individuals who have learning disabilities and SLCN and/or EDS needs. Services should be open to learning from and sensitive to an individual's culture (including all protected characteristics).
- SLTs should be person-centred from the outset in clarifying the reason why a speech and language therapy referral has been made, the impact on the individual's life and the desired outcome(s). This will help everyone concerned to determine what speech and language therapy intervention(s) will be the most useful and effective.
- Communication disability is cited in all key strategic drivers across the UK. SLTS have a key role in raising awareness, influencing and collaborating to create a more inclusive society. Whilst individualised work can help build inclusive communication capability in others, there is a need to sustainability build the capacity and capability for better inclusive communication across communities as well as the health, education, and social care sectors.
- Dysphagia is cited as one of the most common long-term conditions experienced by people with a learning disability (NHS England and NHS Improvement, 2019). SLTs' work

in dysphagia has a key role in reducing preventable premature deaths. All elements of speech and language therapy are integrated, and good communication is integral to successful dysphagia outcomes.

Models of speech and language therapy service delivery

Achieving sustainable improvements in communication requires a 'whole systems approach', including both individualised care and working outside of individualised care. SLTs working across learning disabilities provide a range of clinical interventions that are proactive and preventative in nature, as well as meeting individual needs.

Building capability

Speech and language therapy service delivery can be broadly mapped onto models that describe different levels or tiers from building communication capability within communities to providing specialist intervention tailored to meet individual needs. This model has been adapted from successive RCSLT ALD position papers (2003; 2010) describing 4 different levels for speech and language therapy intervention:

Level 1: Capability in the community/population health

Level 2: Capability in mainstream services

Level 3: Capability in specialist learning disability services

Level 4: Specialist interventions to address the needs of individuals

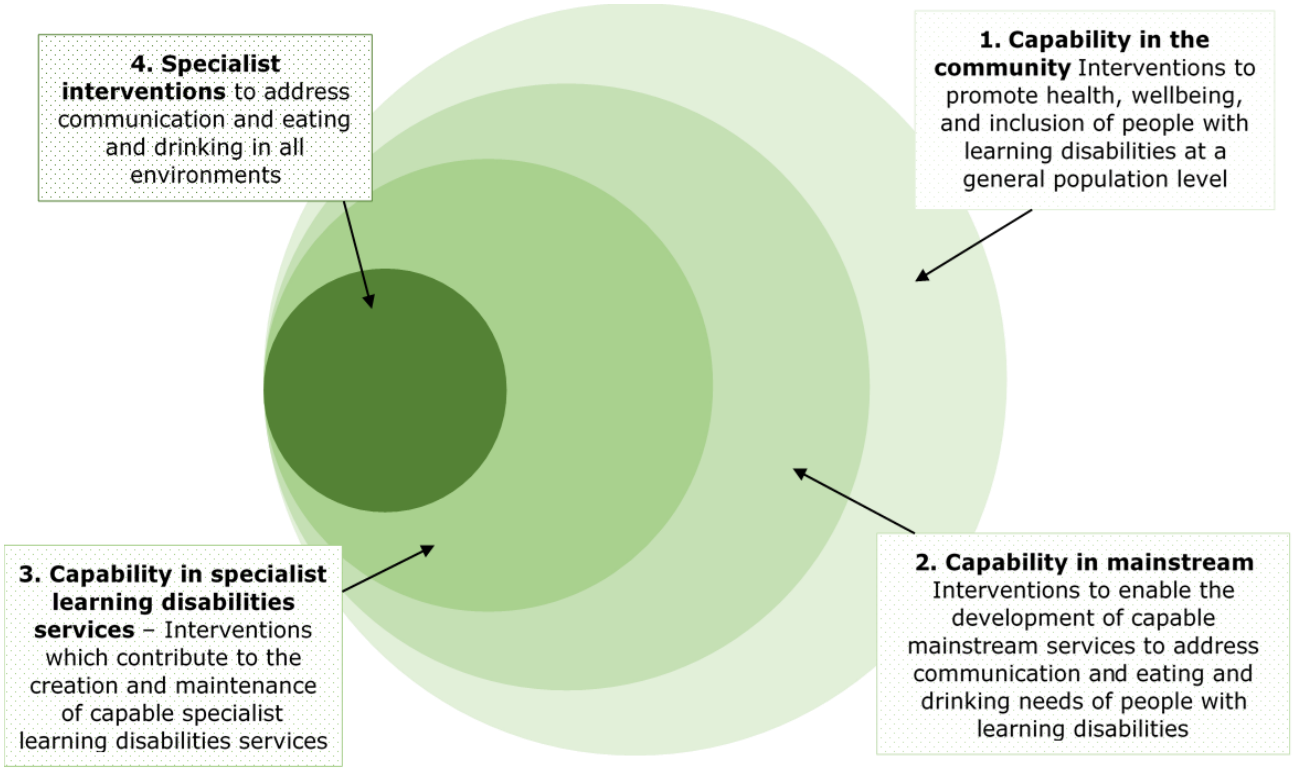

Figure 1: Based on tiered model of health and social care services (Baker et al., 2010)

Regardless of the service level or tier, speech and language therapy intervention strives for optimum communication. Speech and language therapy interventions may involve individualised care or work outside of individualised care, both underpinned by a range of activities.

Individualised care

Speech and language therapy intervention that aims to enable an individual to develop their interaction skills and/or others to develop and implement effective intervention techniques, strategies and guidelines for the individual. Goals will be individual, co-produced, and considering holistically both what is important to and important for individuals and their families in the short and long term. Ultimate outcomes might include accessing community, making friends, gaining employment and keeping safe. Intervention may include:

- direct assessment and intervention with the individual – face to face, via telehealth, on their own or in groups.
- directly working with the individual's support network to develop their capacity and competencies to interact with the individual or to provide optimal support at mealtimes.

- a targeted indirect or environmental approach tailored to the person's communication and/or eating and drinking strengths and needs, such as communication profiling, learning, development and/or training.

Work outside of individualised care

Clinical speech and language therapy intervention outside of individualised care aims to improve communication and safe eating, drinking and swallowing across populations, communities, services and/or teams. It delivers a range of learning opportunities and access to resources, skills and knowledge, as well as signposting on for referral for individualised assessment and treatment. Work outside of individualised care can also be in raising awareness and upskilling services to identify and meet these needs. Work outside of individualised care is described using interchangeable terminology (i.e. universal, targeted, community and/or environmental interventions). In the last two national audits of time completed by the ALD network this work is attributed to approximately 10% of clinical work (Money, 2018; Money, 2019). It may include:

- raising general communication and/or dysphagia awareness across communities and different sectors and agencies.
- education around broad communication and/or dysphagia related conditions and issues, targeted at staff working within learning disabilities.
- building capacity for specific communication skills as part of specialist intervention, such as mental capacity or restraint.
- ongoing supervision that is psychologically minded and considers the staff's own thoughts about the individuals they work with and how this impacts their relationship and the therapeutic environment.
- developing effective communication and/or dysphagia strategies, guidelines and standards.

Outcomes of service delivery

While speech and language therapy activities and roles vary according to the context and levels in which services are being delivered, the ultimate outcome of any speech and language therapy intervention is improvement in the quality of a person's life. Ultimately this means SLTs responding to national policies and drivers to:

- reduce preventable ill health and fewer people dying prematurely
- improve involvement in decisions around care
- reduce vulnerability to abuse
- provide equal access to appropriate educational opportunities.

To achieve this ultimate outcome, speech and language therapy delivery strives towards the interim outcome of achieving optimum communication as key to reducing the social, health and

educational determinants of equality. The aim is to build capacity and capability for individuals, their communication partners, services and communities by striving towards achievement of the 5 Good Standards of Communication. The RCSLT's Five Good Communication Standards were developed recognising that support needs will vary from person to person but the outcome for an individual should mean (Thurman, 2009):

- Whatever communication methods work best for me are used and valued.
- People communicate effectively with me because of their underpinning knowledge, skills and attitudes.
- People actively listen to me and take time to support my communication.
- I get the professional support I need to communicate to my full potential.
- The communication tools, techniques or technology I need are freely available to me.
- Policies and strategies that affect me take into account my communication and include me in appropriate ways.

The activities (approaches or interventions) to deliver these interim outcomes of the Five Good Communication standards vary. In relation to individuals, activities will include assessment, formulation, intervention, learning and development. For learning disabilities or mainstream services, activities will include advice, supervision and training to support access, reasonable adjustments and the development of positive communication environments. Community activities will include leadership, developing standards of good practice and guidance, advice and support on engaging and involving people with learning disabilities, and consultation around developing more inclusive communication.

For effective approaches, SLTs need to know what is important to individuals with learning disabilities (their ultimate outcome), what approaches or interventions to deliver (activities for change), and how to measure and capture their impact.

Four examples of models of change for communication, for both individualised care and work outside of individualised care, moving through from activities that SLTs deliver to the ultimate outcome can be found in the resources page.

A whole systems approach to speech and language therapy activities and intervention

Level 1: Capability in the community/population health

Building communication capability in the community aims to improve communication access and inclusion, through promoting awareness and knowledge of SLCN and/or eating, drinking and swallowing needs. It involves influencing across agencies to raise issues around reasonable adjustments, and may include working with transport, leisure, retail, restaurants and cafes, employment, housing, religious and faith organisations. Organisations need to demonstrate a commitment to inclusive communication at a strategic level, by anticipating that people with SLCN will be their service users and staff development therefore required to ensure inclusive communication strategies are in place (see Communication Access Symbol).

Speech and language therapy activities include:

- leadership and support for national and local inclusive communication strategy development and implementation.
- engaging and involving individuals with communication support needs.
- advising services on how to make reasonable adjustments to communication and/or mealtimes for individuals.
- supporting national and local organisations to develop more inclusive information – providing resources and skills to enable others to adapt and deliver information to meet the needs of people with communication needs.

Examples:

INCLUDE – A small charity based in Surrey, UK. It aims to break down barriers for people with communication needs and bring people who have understanding and speaking difficulties together with the wider community.

See full case study (The Social Model of Disability: Speech & Language Therapy in Action) on our resources page.

The Learning Disabilities Charter West Wales – The Learning Disabilities Charter West Wales was developed by 'The Dream Team', a group of individuals with Learning Disabilities, who, through their LD Charter, advocate for the rights of people who have Learning Disabilities, promote the Charter to organisations, who are encouraged to sign up to it, and to provide training to organisations around the LD Charter.

See our resources page for further examples.

Level 2: Capability in mainstream services

Beyond the community, various mainstream services support individuals at various points of their life across education, health, and social care services, e.g.

- nurseries, schools, further education, higher education.
- primary and secondary healthcare, hospital and community settings including mental health and forensics.
- safeguarding, criminal justice system, child and family services, family courts, and police and emergency services.

Neither having a learning disability nor a communication need should be a barrier to receiving mainstream provision.

Access to quality mainstream services for individuals with learning disabilities is a key determinant of health and social care.

SLTs working in learning disabilities are the key professionals to develop awareness, knowledge and skills in others in order to maximise communication and improve access. This includes access to services such as 'mainstream' children and adult speech and language therapy services providing specialist support around stroke, dysfluency, hearing, dementia, dysphagia etc. Success will depend on both the complexity of the individual's needs and the capability of the mainstream service. If accessing mainstream services, these must be appropriate and agile to deliver wrap-around care, with adapted interventions that consider communication as a primary need. For many individuals with communication needs, specialist learning disability service support will be required to ensure communication needs are front and central to supporting well-being.

Where levels of risk and complexity are lower, individualised speech and language therapy involvement may not be required. However, work outside of individualised care could include training, support, consultation and signposting to access speech and language therapy support and resources.

Staff should be aware of factors that impact on communication:

- sight
- sensory integration
- comprehension and expressive language abilities
- hearing.

They need to know how to make reasonable adjustments to their communication, recognising that people understand and express themselves in different ways. Staff need to understand that what they say and how they say it matters and can impact positively or negatively on an individual's health and wellbeing in the short, medium and longer term.

Staff also need to understand how good communication underpins informed consent and capacity, as well as the broader benefits of inclusive communication (RCSLT, 2016).

Speech and language therapy activities include:

- supervision and/or partnership working to develop the understanding, capability and competencies of mainstream SLTs in working with individuals with a learning disability
- supporting development of positive inclusive communication environments; including supervision and training in use of appropriate communication strategies and resources for specific environments or services (e.g., schools, hospitals, prisons, day, residential and nursing services) including the ability to determine key needs e.g., pain, signs of abuse
- supporting access to mainstream speech and language therapy services where appropriate e.g., videofluroscopic swallow assessment, voice clinic
- working with public health colleagues to improve access to health promotion materials e.g., covid vaccination, breast screening
- working with primary care colleagues e.g., GP training to ensure that individuals with Learning Disabilities have dysphagia identified as part of their annual health care check (NHS England, n.d.) and supporting dental teams
- training and support around mental capacity assessments.

Examples:

Acute liaison *- Although Acute Liaison is typically delivered by Registered Learning Disability Nurses, there is a growing recognition of the support that Speech and Language Therapists (and other Allied Health Professionals) can offer. The Acute Liaison service in Leeds Teaching Hospitals Trust is a multi-disciplinary team (MDT) led by an SLT. Many individuals with a learning disability need support with communication in an acute hospital setting. Acute Liaison SLTs can offer support in a variety of ways, for example:*

- *Communication screening/support with mental capacity assessment*
- *Support with signage and wayfinding*
- *Environmental support - sensory perspective*
- *Prompt referral to an SLT and support with specialist assessment*
- *Patient information leaflets*

The NHS East London Foundation Trust SLT service *to mainstream schools offers different training options to schools on identification and support for children with speech, language and communication needs which can include learning disabilities. These options include how to create communication friendly classrooms and specific approaches such as Colourful Semantics and Intensive Interaction. Schools request whole school training or training for groups of teaching staff according to the needs within their school.*

See our resources page for further details.

Level 3: Capability in specialist learning disability services

To communicate effectively, it is essential that everyone understands and values an individual's speech, language and communication strengths and needs. Individuals should be supported and involved, together with the people who know them best, to develop a rich understanding of the best ways to interact together.

SLTs facilitate development of this rich understanding and enable others to implement the best interaction strategies. Work within specialist learning disability services aims to:

- improve knowledge and skills of staff working with individuals with learning disabilities in understanding and responding to people with a learning disability with SLCN
- improve knowledge and skills of the learning disabilities workforce in understanding and responding to people with a learning disability who have eating, drinking and swallowing needs
- ensure environments are capable of meeting the needs of people with SLCN and/or eating, drinking and swallowing needs
- develop responsive environments that support inclusive communication and empower individuals.

Speech and language therapy activities include:

- evaluation and research
- developing resources for specialist assessments or environments – timetables, choice tools, menus, daily living, MDT reviews, case conferences etc
- accessible/inclusive communication environments, e.g., objects of reference/signing/visual timetables/promoting use of easy read resources
- supportive and responsive communication environments, e.g., Intensive Interaction
- SLTs delivering co-produced learning and development for staff on both specific learning disability good practice, wider health needs (such as postural management and respiratory health) and speech and language therapy interventions around supporting

communication and eating and drinking e.g., modifying the environment, signing/Talking Mats/communication passports/mealtime place mats
- consultation and support to advise on communication issues, e.g. workforce development subgroups/person centred planning/inclusive communication projects/transition
- supporting/leading development of service-wide communication and/or eating, drinking and swallowing strategies
- working collaboratively with psychology and social work teams to support vulnerable children and adults.

Examples:

Core Capabilities framework for supporting people with a Learning Disability

This framework highlights core skills SLTs can develop and help foster in anyone who works within the Learning Disabilities sector e.g. Capability 9: Nutrition, hydration and dysphagia, Capability 13: Communication.

SLT Role in Mental Capacity (MCA) / Deprivation of Liberty (DoLs) in Northern Ireland, a regional Mental Capacity Assessment speech and language therapy *steering group developed a pack outlining the multifaceted role of speech and language therapy in the MCA process, alongside a suite of resources that SLTs and other professionals could employ to facilitate the capacity assessment. Resources included:*

- *training on "Communication Support in Mental Capacity"*
- *a summary of the* speech and language therapy *roles in the MCA process*
- *Easy read information on MCA and DoLs*
- *a communication checklist that professionals outside of* speech and language therapy *could complete, to determine if a communication need may exist and if additional communication supports (reasonable adjustments) would be valuable*
- *a photo library that all staff could access and utilise to support communication during the capacity assessment*
- *a referral pathway to ensure appropriate referrals to* speech and language therapy *services*
- *a glossary of terms related to MCA and DoL.*

Narrative work with Looked After Children (LAC) - Supporting children and young people who access short-break facilities and residential care, and their caregivers in these settings. SLTs can provide assessment and advice on how multi-disciplinary and multi-agency colleagues could best support

CYP when engaging with them to complete narrative work for a specific purpose e.g., supporting CYP and professionals in relation to court.

Support to transition - to understand behavioural presentation, accessible information about the service, and facilitate effective communication between the individual and their carers.

Case example from a community CAMHS Learning Disability Service and Adult LD services in Southwest London: A client approaching age 18 was transitioning from CAMHS to the local adult Mental Health Learning Disability Service. There were several concerns including possible psychosis. CAMHS speech and language therapy attended MDT transition meeting sharing language assessment and client's views expressed through Talking Mats. The SLTs wrote an Easy Read letter to client to say goodbye and introduce new practitioners from the adult service.

Level 4: Specialist interventions to address the needs of individuals

At an individualised level, SLTs engage in person-centred and individualised support for people with a learning disability, complex communication and/or dysphagia who have been referred to a service (eligibility criteria varies locally). The credibility and value of speech and language therapy depends on its commitment to and ability to help people at the most vulnerable times of their lives. It is the core business of SLTs to deliver wrap-around personalised speech and language therapy services, working directly with the individual and indirectly with their significant others to provide assessment, formulation, diagnosis, interventions, learning and development to enable behaviour change and to implement strategies known to minimise communication difficulties and/or dysphagia and optimise strengths/assets.

Speech and language therapy activities include:

- screening and Assessment of individual needs and strengths/assets.
- formulation and planning of interventions.
- design and provision of individualised communication/eating, drinking and swallowing support strategies and resources.
- specific interventions.
- learning, developing, training, advising, coaching, mentoring and supervising staff/ carers, families and MDT colleagues to address the communication/eating and drinking needs of individuals and provide environmental support and modification.

Examples of communication and dysphagia individualised assessments and interventions include:

Communication screening and assessment

Individuals may initially be screened to establish urgency and timelines before being directed to the most appropriate services for assessment. In some specialist contexts, screening is a key part of MDT care, and must be completed within agreed timeframes (e.g. justice system, prisons or learning disability quality networks and accreditation (Royal College of Psychiatrists, n.d.).

This screening is key for early diagnosis and support, especially where undiagnosed communication needs may exist, so that services can make reasonable adjustments for individuals at the beginning of their pathway.

Detailed and in-depth, individualised assessment underpins all service delivery. Assessment must consider the whole person, short and long-term goals, and involve the individual and their families, MDT and staff as appropriate. Assessment may lead to new or reviewed diagnosis and formulation, or diagnostic signposting. For example, for children over 5 years SLTs could be key to reviewing a DSM diagnosis of 'global developmental delay' to a more suitable alternative.

Communication interventions

There is no definitive list of approaches for improving communication. It is not possible or appropriate to list all interventions and resources as they vary with local agreements and licences available, across pre-school, school age and adult services.

However, in principle the focus will be to enable means, reasons and opportunities for meaningful interaction (Money and Thurman, 2002) and may range from increasing opportunities for social interaction to enhancing performance rather than increasing competence (Chadwick et al, 2018). Attention will be paid to all health and social determinants and risks, such as behaviours of concern; social skills, cultural appropriacy; trauma, relationships and safeguarding; times of transition; capacity and consent etc.

For the purposes of this paper, a few of the most familiar intervention approaches are summarised in broad categories below. It must be noted that these are neither exhaustive or endorsed, and while there is growing consensus, there is limited formal, wide-scale research evidence available at time of writing.

Communication profiles (passports, guidelines, dictionaries) – gathering and sharing key information about an individual's communication skills, abilities and support needs in an accessible way. These approaches all produce a resource which as a minimum provides a summary of the individual's communication skills and needs. They are widely used by SLTs across the UK and are supported by carers, researchers and practitioners (Goldbart & Calton, 2010). They aim to help communication partners understand the individual's communication needs and make necessary adjustments to both their communication and the environment. In spite of the

frequent use of these approaches within clinical practice, limited empirical evidence and significant variation in the depth of assessment, collaboration, contents and intended use remains. These approaches are therefore poorly defined and variably delivered without consensus or formal evaluation (Wood and Standen, 2021; Bradshaw 2020). Typically, SLTs provide training to support communication profiles (Wood, 2019), aiming to improve understanding and enable carer communication behaviour change.

Augmentative and alternative communication (AAC) – this refers to aided or unaided systems which support or replace spoken or written communication (see RCSLT's AAC guidance):

- Unaided communication: the use of body movements, facial expressions, gestures, signing, eye-pointing and vocalisations. An Unaided system requires a communication partner to understand the person's communicative meaning and includes sign systems – British Sign Language, Signalong, Makaton, etc.
- Aided communication: low-tech or un-powered can involve visual representations of meanings, ideas and concepts, e.g., Objects of Reference, photos, symbols – (Picture Communication Symbols, Talking Mats, Widgit Rebus, Makaton) or traditional orthography and may be paper-based communication charts, visual timetables, life story books etc.
- Aided communication: high-tech or powered device-based methods have speech or written output e.g., a Voice Output Communication Aid (VOCA). A wide variety of VOCAs are available using the same visual representations as above but a variety of access solutions from direct hand/eye pointing, to keyboards, joysticks and switches. Aided communication varies in cost and individuals with learning disabilities often do not meet AAC Hub criteria and may be unable to fund and maintain an AAC device.

Narrative approaches – these approaches use storytelling, personal narrative, life history and shared reminiscence. They may help individuals process, develop understanding or learn specific skills. Examples include multi-sensory story telling (MSST), Social Stories (Carol Gray), comic-strip conversations, and Books Beyond Words. Some approaches have been developed that focus on individuals with severe and profound and multiple learning disabilities (Bunning et al, 2018; Bunning et al, 2017; Ten Brug et al, 2015; Young et al, 2011) empowering and enriching their lives through multi-sensory storytelling.

Narrative approaches rely on more than just the written or spoken word, are fully inclusive and accessible, and may be to meet an individual's specific identified needs or for groups.

Intensive Interaction: a social interaction approach – building on and supporting development of the fundamentals of communication such as facial expressions, vocalisations, turn taking and eye contact to develop enjoyable and meaningful interactions (Intensive Interaction Institute, n.d.).

Responsive Communication has 3 key elements:

1. Observing the individuals experience of sensory inputs (visual, auditory, tactile etc) and identifying which inputs cause distress or discomfort and which are neutral or positive.
2. Creating a sensory rich environment by reducing or eliminating sensory inputs that are causing the person distress (inputs to which they are hyper-sensitive) and increasing those sensory inputs which they experience as positive or to which they are hypo- or under-sensitive.
3. Tuning into and responding to the person's body language using Intensive Interaction (mirroring and then developing the body language the person is using to communicate with themselves e.g. particular hand movements, foot tapping, breath holding/releasing and so on (see The Caldwell Autism Foundation).

It is recognised that autistic people and people with a learning and/or developmental disability often encounter difficulties relating to how they process sensory information. This can result in a variety of behavioural responses depending on whether the person is under, or over-registering sensory input. There is a mutual correlation between how a person processes sensory information and their levels of emotional arousal, which explains how sensory strategies can be used to support people to manage distress/anxiety etc.

Sensory approaches – individuals with learning disabilities may encounter difficulties processing sensory information. Because of the mutual correlation between how a person processes sensory information and their levels of emotional arousal, sensory strategies can be used to support people to manage distress/anxiety etc. It is therefore becoming more widely used by practitioners working with individuals with learning disabilities, including SLTs for whom facilitating engagement and participation is fundamental to their practice.

- Sensory-based interventions (SBIs) approaches offer generic or passive prescribed sensory experiences/sensory diets typically occurring in the individual's natural environment. They are a compensatory approach, impacting on self-regulation, attention or behavioural organisation (Watling and Hauer 2015).
- Sensory Integration (Ayres Sensory Integration® ASI) aims to change neurophysiological processing of sensation. It is intended to be carried out in a formal context where an individual's communication and/or eating, drinking and swallowing needs have an identified sensory component, and uses specific intervention techniques for an approved ASI Practitioner (see Sensory Integration Clinical Excellence Network).

LEGO®-Based Therapy – this is used by many practitioners working with individuals with learning disabilities, including SLTs. It is a social development intervention, aiming to develop social skills through collaborative play (with opportunities to practise skills such as turn-taking, listening, initiation, eye contact, sharing ideas, communication, compromise, problem solving and shared attention).

Dysphagia interventions

The SLT's role when working with individuals with a learning disability and dysphagia involves balancing the valuable opportunities that eating and drinking provide with the risks associated with dysphagia. An SLT will do this by assessing and making recommendations to manage the dysphagia and avoid acute or chronic symptoms and health implications (Tredinnick and Cocks, 2014).

SLTs work in an individualised and holistic way, considering the social, health, communication, sensory and psychological needs of the individual when completing their intervention. As with communication interventions, the support network around the individual and the environments in which they eat and drink are vital components of both assessment and intervention to create positive and safe mealtime experiences. Speech and language therapy approaches in this area include:

- **Compensatory strategies** – many of the compensatory strategies used in other dysphagia specialisms are inaccessible to individuals with a learning disability due to the cognitive demands they place on the person. All strategies need to be carefully identified with the individual and their support network. For example, Belfast Help Stop Choking resources provide visual support to encourage appropriate pacing or to reduce choking risk.
- **Eating and drinking guidelines** – these include all meals and snacks, and detail person-centred recommendations to meet the needs of the individual and their support network. They may include food and drink texture, equipment, positioning, support, communication and environment. These guidelines may be co-developed and take different formats (e.g., accessible eating and drinking place mats, including assessment findings and clear guidance on how to support safe and enjoyable mealtimes).

  Although these resources are recommended by many (Public Health England, 2017), there has been limited research into their use and effectiveness (Morgan et al, 2018).

- **Rehabilitation** – for some people with learning disabilities, dysphagia has an acute onset and is not a life-long condition. These individuals may benefit from different and direct therapy techniques and there will be close liaison with acute speech and language therapy services.

- **Person-centred dysphagia training** – sharing the individual's dysphagia needs and how best to meet these with their support network, including problem solving and rationale for recommendations. This is especially important given that dependency on others for feeding is a predictor for aspiration pneumonia for people with dysphagia (Langmore et al, 1998).

Speech and language therapy workforce skills

As with the whole learning disabilities workforce, SLTs need to be well trained and develop their competencies to ensure they are equipped to meet national policy direction.

Alongside Health Education England, NHS Education for Scotland, Health Education and Improvement Wales and Department of Health, Northern Ireland, we need to ensure a flow of future SLTs working in learning disabilities. This requires the current workforce to engage and work collaboratively with RCSLT, NHS and HEIs to ensure learning disabilities work placements, undergraduate student placements, well supported early careers and mid careers, as well as advanced practice and consultant opportunities.

To do this, speech and language therapy leaders or aspiring leaders in learning disabilities need to be identified to explore opportunities for their potential leadership development. SLT roles can be open to workforce redesign and transform across traditional, professional and agency boundaries. Speech and language therapy skills lend themselves to new ways of working, including care coordination functions, health promotion and prevention, specialist training competencies and advanced skills in diagnostics.

SLTs must work within their expertise and in partnership, especially when considering care and treatment in an individual's best interests. Collaboration is likely to produce a better decision than if taken by any professional in isolation. They need to be well informed about a broad range of factors and able to consider risks of potential harm against benefits. For example:

- trauma informed care
- positive behaviour support
- positive risk taking
- safeguarding
- capacity and consent
- restrictive practice.

Co-design and co-production

People with learning disabilities express feelings of frustration that they are not listened to, are treated unfairly and excluded from decision making about important aspects of their lives and care. Policies across the four nations of the United Kingdom expect services and organisations to co-produce and engage with people who use their services. Communication underpins the outcomes that individuals and governments value. This requires reasonable adjustments to communication, to reduce barriers and inequality (RCSLT, 2016).

SLTs have a unique role supporting service users to engage and feedback their experience, contribute to satisfaction surveys, be involved in service developments, and empower them to compliment or complain. SLTs need to ensure there are meaningful consultation opportunities bound by the reasonable adjustments to avoid tokenism. There is a risk that their needs and opinions are assumed, misinterpreted or ignored, and they are not valued as 'experts by experience'. There is a need to reduce communication barriers, and subsequent prejudice and exclusion of and from society.

All speech and language therapy provision, across the whole system, needs to build capacity and develop partnerships with people with a learning disability (peer supporters as well as individuals who need support) and their families. This recognises that people with a learning disability are the people who are experts in what it is like to live with a communication support need and therefore can support a variety of projects, e.g. training staff, advising on accessible information, quality assurance activities (Cameron and Boa, 2009).

Individuals must receive information and be supported to express themselves in ways that meet their needs. All evaluation methods require inclusive feedback techniques, for example: Easy Read questionnaires, Talking Mat approaches and one-to-one communication support (Mander and Rigby, 2014).

Evidence and effectiveness

It is widely acknowledged that across learning disabilities there is limited evidence to support speech and language therapy interventions. This is for multiple reasons, including for example:

- people with learning disabilities are a relatively small and heterogeneous population
- that there are ethical and quality challenges about involving individuals who may lack the capacity to provide consent
- people with learning disabilities have historically received less funding or been excluded from research designs when research has focussed on common co-occurring conditions (Russell et al, 2019)
- outcomes for speech and language therapy interventions are not clearly defined and understood
- when speech and language therapy research is child-focused, it is predominantly preschool and primary age making it difficult to draw conclusions across the lifespan for young people and adults
- research is focussed on specific conditions (e.g. cerebral palsy or Down's syndrome), where not all participants may have a learning disability, and although relevant to that diagnostic group, may not be applicable to others within the learning disability population
- research is focussed on specific interventions or approaches, and these interventions frequently lack clearly agreed parameters (such as timeliness, dosage, intensity, and frequency) or defined roles for SLTs, posing challenges for selecting appropriate research study design
- communication difficulties are multifactorial, present for individuals in multiple ways, and are further impacted by the physical and social environment. speech and language therapy is a core part of a collaborative multidisciplinary approach to supporting people with learning disabilities, and communication interventions may be designed and/or delivered by a range of professionals
- research is targeted at direct individualised approaches, rather than interventions that are either an indirect individualised approach or outside of individualised work
- the attitudes and beliefs of communication partners vary and need to be addressed to maximise speech and language therapy recommendations being implemented in practice
- randomised controlled trials (RCTs) continue to be considered the optimal way of evaluating treatments across healthcare, despite difficulties in their use due to the complexity of human communication alongside exclusion criteria for multi-morbidities or specific clinical attributes that co-exist for the majority of people with communication needs (Moyse et al, 2020).

Because of these complexities, professional opinion, rather than research evidence continues to shape speech and language therapy delivery (Wood, 2017). Wood & Standen's 2021 systematic review 'Is speech and language therapy effective at improving the communication of adults with intellectual disabilities' indicated that although there was some evidence supporting the

effectiveness of speech and language therapy interventions, it was not reflective of speech and language therapy practice in the UK.

For example, two widely used approaches are communication profiles and training:

- **Communication profiles:** The survey of speech and language therapy ALD service leads (Wood, 2019) found communication profile approaches (including passports and dictionaries) were used by 100% of the responding speech and language therapy services. Additionally, parents, researchers and practitioners support the use of these approaches (Goldbart and Calton, 2010). However, communication profiles are not well defined as an approach and subsequently there is large variability – including development process, authors, involvement, detail, format, purpose and use.

  Speech and language therapy input also varies from screening to in-depth assessment with information gathered from a variety of contexts and communication partners. Consequently, some communication profiles are generic, one-page proformas that are not useful. In comparison, multimedia resources are actively used by individuals and their carers, because they are dynamic and meaningful, derived from in-depth collaborative assessment and formulation, and based on consensus.

- **Learning and development:** The most common approach to upskilling the workforce is to provide training and education. Training aims to skill-up a range of parents, carers, paid staff and professionals to address both the communication partners' communication skills alongside environmental factors impacting on participation (Money, 2016). Training is generally well received by participants and evaluated positively. However, there is limited evidence as to whether it improves outcomes for individuals.

In 2021, the RCSLT's learning disabilities research priority setting partnership established the top priorities for research in speech and language therapy and intellectual disability (Palmer et al, 2021). Through a priority-setting partnership, RCSLT identified the top 10 focus areas for research, collaborating with SLTs, parents/carers, service users, researchers, third-sector representatives, and other education, health and social care professionals to explore and prioritise. Six of the final ten are strongly aligned to the communication complexities discussed above:

1. Inclusive communication environments and staff's skills in supporting speech, language and communication needs of people with learning disabilities.
2. Most appropriate ways of measuring long term personalised and holistic outcomes for a) people with learning disabilities and b) their parents/carers.
3. Effectiveness of different service models of speech and language therapy input for people with learning disabilities to reach personalised and holistic outcomes.
4. Selecting appropriate approaches to information gathering for individualised and holistic speech and language therapy assessment for people with learning disabilities.

5. Level of speech and language therapy input (including timeliness, dosage, intensity, and frequency) in achieving and maintaining long-term personalised holistic outcomes for people with learning disabilities.
6. The speech and language therapy role in end-of-life care for people with learning disabilities.

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The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists in the UK. As well as providing leadership and setting professional standards, the RCSLT facilitates and promotes research into the field of speech and language therapy, promotes better education and training of speech and language therapists, and provides its members and the public with information about speech and language therapy.

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