



Learning Disabilities Research Priority Setting Partnership Report

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This report has been updated to contain the methods and results of phase two of the RCSLT learning disabilities research priority setting partnership project.

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Foreword

by Rebecca Palmer, Della Money and Viki Baker

Note: This foreword was written at the start of phase one of the project.

Children, young people and adults with a learning disability have the right to the same opportunities as anyone else to live satisfying and valued lives, and to be treated with dignity and respect. They should have a home within their community, be able to develop and maintain relationships, and get the support they need to live healthy, safe and rewarding lives (LGA/ADASS/ NHS England, 2015).

Unfortunately, people of all ages with a learning disability continue to face significant health inequalities. They have a higher incidence of communication, eating, drinking and swallowing needs, and are more likely to live with a range of coexisting conditions such as autism, sensory impairments, or mental health difficulties.

Learning disability care and support requires ongoing research to address questions that remain unanswered and support the ongoing development of evidence-based support services. This includes further research into health inequalities, prevention, services and interventions (NHS, 2019), underpinned by coproduced approaches that include people with a learning disability, their families and carers. Research needs to reflect ethical considerations and reasonable adjustments, including inclusive communication, to enable people with a learning disability to participate as much as possible.

The RCSLT's learning disabilities research priority setting partnership (PSP) asked people with learning disabilities, their families and carers, speech and language therapists (SLTs), and a diverse range of other stakeholders what areas of learning disabilities we most urgently need to know about.

This report introduces the top 10 research priorities relating to communication and swallowing for people with learning disabilities across the life span from a UK-wide perspective. These cover



a range of areas, including: developing our understanding of communication and dysphagia for people with a learning disability; identifying what helps and what gets in the way of assessing and delivering interventions that achieve meaningful and personalised outcomes; careful consideration of the impact of multidisciplinary working, communication environments, staff skills and more.

So what next? The work doesn't end at the setting of priorities – this is just the beginning. The RCSLT is committed to working collaboratively to achieve a system-wide, collaborative push from all key stakeholders, to enable this research to happen. The priorities provide a clear focus, allowing specific research questions to be identified within these broad areas. Further work on shaping these questions is planned in the next stage of the RCSLT's research priorities project.

Please join us in supporting research into these vitally important areas. Share the report and the top 10 priorities. Connect with the RCSLT and research active colleagues. Consider how you will support this work – whether as a co-investigator, a participant, a disseminator or a user of the emerging research evidence. Please play your part to connect front line clinical practice with the evidence base. Delivering on these research priorities is imperative if we are going to enable the best possible lives for children, young people and adults with learning disabilities.



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The RCSLT learning disabilities research priority setting partnership

- The mission of the Royal College of Speech and Language Therapists (RCSLT) is to enable better lives for people with communication and swallowing needs. One way we aim to achieve this is by supporting quality practice among speech and language therapists (SLTs) and others. Such practice should be evidence-based, with practitioners using their clinical expertise to draw upon the best available research evidence and their service user preferences to provide a responsive, expert, needs-led service. A growing body of evidence is helping SLTs, service users, and other professionals to understand speech, language, communication and swallowing needs, and to plan and develop approaches to treat and manage these difficulties to minimise their impact. However, there are many gaps in our knowledge making it difficult to know what should be prioritised for new research.
- The RCSLT's learning disabilities research priority setting partnership (PSP) aims to address this issue, regarding learning disabilities, a lifelong condition impacting communication and eating and drinking. We have asked people with learning disabilities, their families and carers, SLTs, other professionals who work with people with learning disability, charitable organisations and research funders what areas of learning disabilities we most urgently need to know about.
- This report introduces the top 10 research priorities relating to communication and swallowing for people with learning disabilities across the life span from a UK-wide perspective and describes how we developed them in phase one of our project. The report has been updated to include how we translated the research priorities into specific research questions in phase two of our project.
- Involving a wide and diverse mix of individuals in our research priority setting partnership gives a voice to the individuals who are set to benefit from new knowledge that research can generate and ensures their views are represented.
- Please join us in supporting research into these vitally important priority areas, research that is imperative if we are going to enable the best possible lives for people with this impactful, lifelong condition.

Join the conversation on Twitter using #LDResearch

Top 10 priority research areas

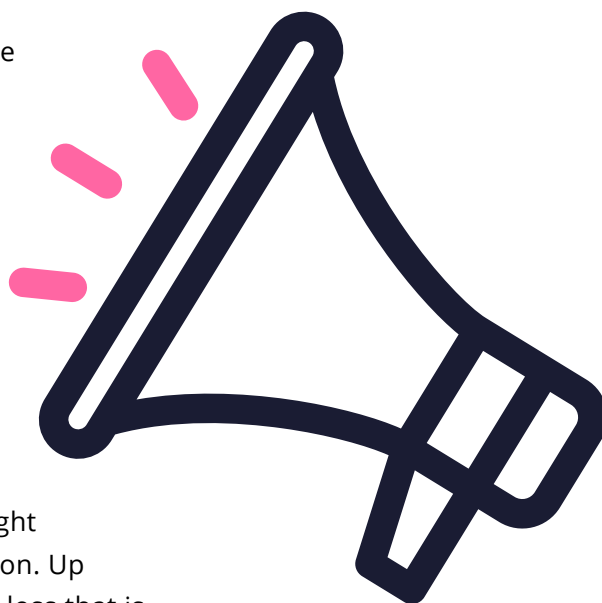
- 1 Effective dysphagia interventions for people with learning disabilities to achieve personalised and holistic outcomes.
- 2 Inclusive communication environments and staff's skills in supporting speech, language and communication needs of people with learning disabilities.
- 3 Impact of a multidisciplinary approach to dysphagia management for people with learning disabilities.
- 4 Most appropriate ways of measuring long-term personalised and holistic outcomes for a) people with learning disabilities and b) their parents/carers.
- 5 Effectiveness of different service models of speech and language therapy input for people with learning disabilities to reach personalised and holistic outcomes.
- 6 Facilitators and barriers to instrumental assessment of swallowing for people with learning disabilities.
- 7 Presentation of eating and drinking difficulties for people with learning disabilities across the lifespan and their associations with dysphagia (including aspiration, choking, safety, nutrition and hydration and enjoyment).
- 8 Selecting appropriate approaches to information gathering for individualised and holistic speech and language therapy assessment for people with learning disabilities.
- 9 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.
- 10 The role of the SLT in end of life care for people with learning disabilities.

What are learning disabilities?

A learning disability is a lifelong condition, and while not an illness in itself, may be accompanied by a number of difficulties, including a high prevalence of communication and swallowing disabilities.

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

Around **1.5 million** people in the UK have a learning disability (Public Health England, 2016). It's thought up to **350,000** people have a severe learning disability. This figure is increasing. Learning disabilities can affect anybody, regardless of race or gender, and may be caused by problems during brain development before, during or after birth. People with learning disabilities may have complex and coexisting conditions. Research evidence suggests that children and young people with a learning disability are four to five times more likely to have mental health problems than other children. Adults with a learning disability are also more likely (at least twice as likely) to experience some kind of mental health problem (Emerson and Hatton, 2007). The incidence of additional sensory impairments, including sight and hearing, is much greater than in the general population. Up to **40%** of people with learning disabilities have a hearing loss that is often missed or undiagnosed (Emerson and Baines, 2010a).



The Learning Disabilities Mortality Review (LeDeR) Programme 2019 annual report highlighted that people with learning disabilities in England continue to die prematurely and from treatable causes of death. The persistence of preventable health inequalities means people with a learning disability die, on average, **15-20 years** sooner than people without a learning disability. Key recommendations of the LeDeR programme include the provision of reasonable adjustments, greater awareness of the health problems that are more common for people with a learning disability and that mandatory learning disability awareness training should be provided to all staff and be delivered in conjunction with people with a learning disability and their families (LeDeR, 2020).

Up to **90%** of people with learning disabilities have communication difficulties (Kelly, 2000). Additionally, an estimated **8%** of individuals known to health and social care services will have dysphagia, and **15%** will require support to eat and drink (Public Health England, 2016). Overall, around **89%** of people with learning disabilities will require speech and language therapy intervention (Bradshaw, 2007).

Communication difficulties associated with learning disabilities

Communication is a significant risk factor contributing to increased mental health issues and behaviour described as challenging. This is because:

- Around half of people with a learning disability have significant difficulties with both expressing themselves and understanding what others say (RCSLT, 2010).
- Only **5-10%** of people with learning disabilities have recognised literacy skills and most are not be able to access standard written information (Barker, 2011).
- Recent research by the Learning Disabilities Observatory indicates that around **20-30%** of people with a learning disability also have an autistic spectrum condition, and approximately **50%** of children with autism also have a learning disability (Emerson and Baines, 2010b).



- As communication difficulties increase, behaviours that are considered challenging typically increase in frequency, intensity or duration (Royal College of Psychiatrists, British Psychological Society and RCSLT, 2007).

The individual risk of having a communication difficulty means individuals are misunderstood, experience failure and exclusion from events, activities and relationships. However, communication is also an environmental risk factor. Evidence shows staff 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). This indicates that providers of learning disability services need to develop their expertise to provide meaningful interaction and good communication environments. Staff need the skills to make reasonable adjustments to maximise engagement, involvement and inclusion.

Good communication only exists as part of positive everyday relationships, boosting self-esteem and success. Good communication crosses all dimensions of care, support and enablement. Without good communication individuals struggle to learn, achieve, make friends and interact – all fundamental for citizenship and humanity and central to improving quality of life (Bercow, 2008).

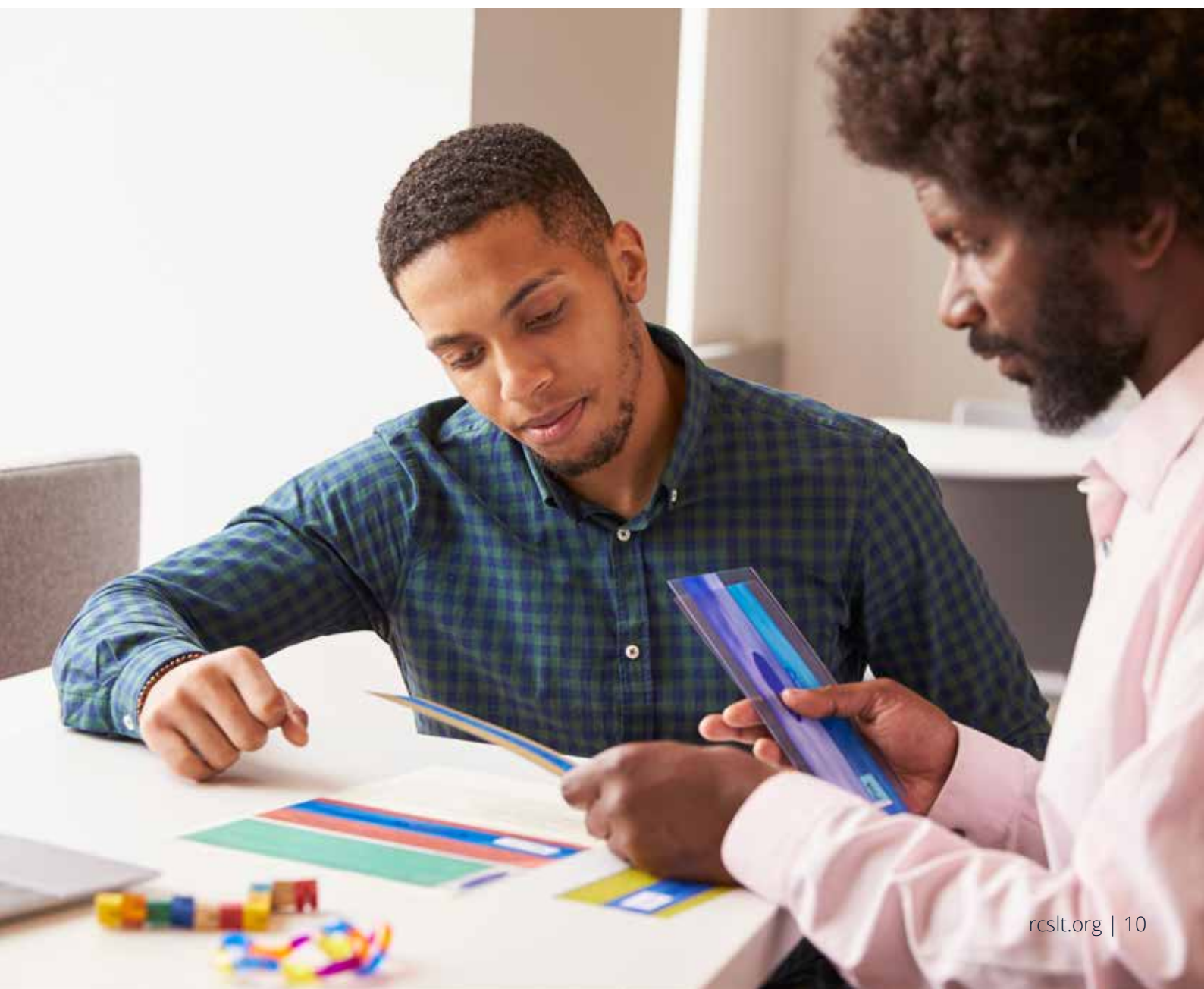
Eating, drinking and swallowing difficulties associated with learning disabilities

People with learning disabilities may have difficulties with eating, drinking or swallowing for a number of reasons, including:

- Motor control for the act of feeding, which may involve someone else supporting and setting pace of mealtimes.
- Difficulties coordinating or stimulating the muscles for chewing, so bolus is not always broken up.
- Issues with the swallowing mechanism, with risk of choking or aspirating.
- Sensory aversion to tastes or textures.

What is the impact of learning disabilities?

Adults with learning disabilities generally have poorer health than the typical population, though it is considered that many of the factors leading to this can be mitigated through greater understanding, intervention, and resource (Emerson and Baines, 2010a). Communication differences impose challenges for those who support people with learning disabilities. For example, research suggests that staff in residential settings do not generally interact with the residents with learning disabilities in a way that enables individuals to achieve greater levels of independence, participation or integration (Mansell, 2007). Further to this, research has highlighted that those 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, Chadwick, Baines, Emerson and Hatton, 2018).



The communication difficulties experienced by people with learning disabilities puts them at increased risk of health inequality (Emerson and Baines, 2010a). This includes greater likelihood of:

- Being misunderstood, or unable to communicate their health needs.
- Experiencing barriers to accessing quality health and social care services.
- Developing mental health and psychiatric disorders.
- Having limited involvement and engagement in decisions, activities and relationships.

People with learning disabilities who have dysphagia are also at greater risk of unsafe eating and drinking (Manduchi, Fainman and Walshe, 2020), which can lead to:

- Discomfort.
- Malnutrition and hydration.
- Aspiration, leading to poor respiratory health.
- Choking, potentially leading to death.

The impact of learning disabilities extends beyond health. Those with learning disabilities are less likely to have social networks outside of their families (Kamstra, van der Putten and Vlaskamp, 2014). They are also less likely to be in employment (Emerson and Hatton, 2008): approximately only **5.7%** of working age adults (**7,422 people**) with learning disabilities receiving long-term social care in England are in paid/self-employment (Hatton, 2018).

However, people who have learning disabilities can excel given the appropriate support. Individuals with learning disabilities can succeed in fostering and maintaining friendships (Emerson, Friedman and Rizzolo, 2018), obtaining a fulfilling job (Beyer and Beyer, 2017), and having a good quality of life (Beadle, Brown et al, 2016).

Some groups of people with learning disabilities, such as those who are Black or minority ethnic, can be at greater risk of either not being identified (Emerson, 2012) or having poorer access to services (Magaña, Parish, Morales, Li and Fujiura, 2016). Research has highlighted the need for more 'inclusive and culturally sensitive services' for people with learning disabilities (Raghavan and Small, 2004) as well as there being a need for more research to be conducted which specifically looks at supporting people with intellectual disabilities from minority ethnic groups (Robertson, Rhagavan, Emerson, Baines and Hatton, 2019). To reduce perpetuating any further health inequalities, speech and language therapy services should be available and accessible to all individuals who have learning disabilities and communication or swallowing needs, which should be sensitive to the client's cultural background, including awareness of Black, Asian and minority ethnic populations, cultural groups, protected characteristics, and social class.

What role does speech and language therapy play in supporting individuals with learning disabilities?

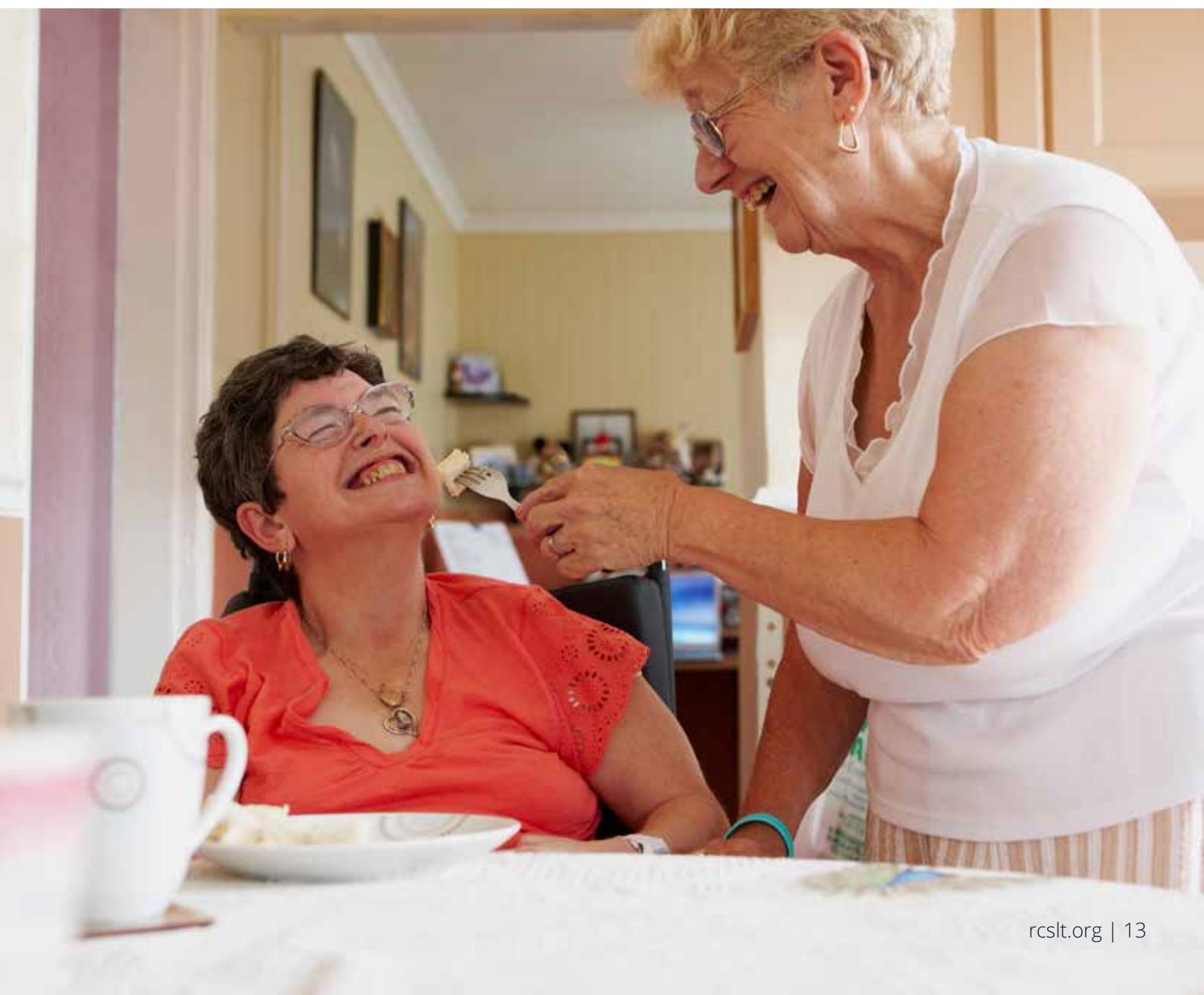
Speech and language therapy is a core part of a multidisciplinary approach to supporting people with learning disabilities. Speech and language therapists work with individuals with learning disabilities, their family, friends and professionals who may be involved in their lives, to help remove barriers to communication and promote safe eating and drinking. This may be through a number of ways, including providing the means, reasons and opportunities for meaningful interaction (Money and Thurman, 2002) and by providing recommendations for creating an optimal mealtime environment or modifying food textures (Harding and Cockerill, 2014).



Facilitating augmentative and alternative modes of communication is often a core part of speech and language therapy. Intervention approaches used by speech and language therapists include intensive interaction, using objects of reference, facilitating multi-sensory approaches

to communication, developing communication passports, implementing symbolic approaches, training others on supporting communication, modifying the environment and supporting use of switches (Goldbart, Chadwick and Buell, 2014). Speech and language therapists are also integral to advising on safe dysphagia management for people with learning disabilities. Approaches to this may include advising on the seating position which the person adopts for eating and drinking, use of specialist feeding equipment, support with pacing, modifying food textures, recommending alternative or supplementary feeding methods, programmes to reduce sensory aversions and carer support or training (Harding and Wright, 2010).

Speech and language therapists can play a crucial role in supporting children, young people and adults with learning disabilities in all aspects of their life. For therapy to be of a high quality, meaningful and delivered in the best way, professionals need to know what is important to individuals with learning disabilities. They also need to know how to deliver appropriate interventions to support people with learning disabilities in these areas, and how to measure and capture the impact of this support. Doing so requires a robust evidence base for clinicians to draw upon. Given that there are currently many gaps in our knowledge (Golbart, Chadwick and Buell, 2014; Snell et al, 2010), as reported by SLTs themselves, identifying the priority areas for research is key.



How did we identify the priorities (phase one)?

We opted to use an approach that was adapted from the James Lind Alliance (JLA) methodology (Cowan and Oliver, 2013), which puts the input of service users and professionals at the centre of the process. This recognised process aims to identify areas for research collaboratively, so that the priorities reflect a range of opinions.

We began in 2015 by asking RCSLT members to name their 'uncertainties' about any aspect of speech and language therapy and reviewed those specifically related to learning disability.

A literature search was undertaken to identify whether existing learning disabilities research might clarify any of the uncertainties that had been reported, or whether it highlighted any that had been missed. For a few of the uncertainties, some evidence did exist, but for many others, there was no high-level, quality research addressing them.

The 'unanswered' uncertainties were reviewed and summarised, and developed into 14 broad research categories:

- Communication interventions for children with learning disabilities
- Communication interventions for adults with learning disabilities
- Phonological awareness interventions
- Wider team around the person with learning disabilities
- Assessment of communication and mental capacity
- Social skills interventions
- Intervention for speech difficulties in young people with learning disabilities
- Alternative and augmentative communication
- Interventions for profound and multiple learning disabilities
- Interventions for challenging behaviour
- Enhancing social participation
- Parent delivered interventions/communication partners
- Autism spectrum disorders and learning disabilities across the life course

In 2017, we invited 35 individuals to consider these categories at a multi-stakeholder workshop. This brought together a wide range of voices including speech and language therapists, parents/carers of people with learning disabilities, researchers, third sector representatives, and other health and social care professionals, for example psychologists and occupational therapists.

Workshop attendees looked carefully at each of the research categories, identifying specific research areas within these broader categories. This included careful consideration of the specific populations, interventions or outcomes to which each research area applied.

The output of the workshop was a list of 95 research areas, which were then re-condensed into 10 updated categories:

- Intervention
- Assessment
- Dysphagia
- Service delivery
- The wider world
- Quality of life
- Comorbidities with learning disabilities
- Augmentative and alternative communication
- Speech sounds
- The role of the speech and language therapist

We visited two pre-established service user groups of adults with learning disabilities and invited them to be involved in the project, asking them to share their opinions on which categories were important to them. Through one-to-one activities to develop their understanding of the key concepts and use of communication-friendly strategies such as visual supports, individuals were enabled and empowered to be involved. In total, ten individuals with learning disabilities told us the extent to which they felt categories were, or were not, a priority for research.

Analysis of this data showed that people with learning disabilities had very varied opinions about what research is most urgently required but ultimately research within all the identified categories was considered important. As a result, all 95 specific research areas were considered for the next stage of the process.

A further round of refinement took place which considered whether there were any similarities or repetition in the 95 areas and explored whether this list could be shortened. Following this, some research areas were removed, or absorbed into other ones, leaving 87 research areas.

A final list of 87 areas (see Appendix) were put into an online card sorting activity which went live at the end of 2017, which required participants to sort topics into those that they thought were a priority, and those that weren't. This card sort activity was completed 135 times, representing the views of 171 individuals, which included speech and language therapists, parents/carers of individuals with learning disabilities, researchers and other health care professionals.

The results from the card sort activity and the earlier work with adults with learning disabilities were combined by ascribing a point to a research area, every time it was either identified as a priority, or the category in which it belonged to was identified as a priority. This meant that all areas within a category were given a point every time the category was selected as a priority by the service users. This gave an overall ranking for each research area from which the top 10 research priorities were identified (the highest research priority topic was identified as a priority 82 times). The top 10 list was published in January 2018 and disseminated through RCSLT communications channels and our website.



Developing research questions (phase two)

Since the publication of the top 10, the research priorities relating to communication and swallowing for people with learning disabilities across the lifespan have been published in an academic journal (Chadd et al., 2022) and presented internationally (Heelan et al, 2022).

RCSLT members have contributed to campaigns to highlight the research progress in areas identified by the research priorities (Royal College of Speech and Language Therapists, 2020) and the priorities have been used by clinicians as discussion points and reflected on as part of clinical practice (Backhouse and Howells, 2022). In addition, the RCSLT research team has offered letters of support for research project proposals that address areas of the RCSLT research priorities for learning disabilities.

The RCSLT research priorities for learning disabilities are explicitly cited in the scope of the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research Programme commissioned call titled: “Improving access and use of services for people with speech, language, and communication needs” published in August 2022.

Why did we conduct phase two?

In phase one, the RCSLT committed to undertake a second phase of this project aiming to maximise the appeal and suitability of the research priorities to key national and international research funding institutions as well as others wishing to carry out research.

There is a continued need to shape the scope of future funding calls and raise awareness of the research priorities relating to people with learning disabilities.

Lai et al. (2020) suggests that priority areas defined by the first phase of a research priority setting partnership require collaboration with funders and researchers to translate research priorities into specific clinical research questions and to maximise the suitability of the research priorities to national and international research funding institutions.

This section of the RCSLT learning disabilities report focuses on the methods used to intricately consider the priority areas identified in phase one and reports the newly developed, answerable research questions generated in phase two.

The aim of the second phase of the project was to:

- identify ongoing priorities from the long list of research priorities generated in the first phase.
- use these priorities to generate specific, answerable research questions with input from service users and expert clinicians and researchers.
- communicate these research questions to targeted funders and to the learning disabilities research community.

As per phase one of this project, the second phase encompassed communication and swallowing for individuals with learning disabilities across the lifespan, from a UK-wide perspective.

Methods

What do we know about translating research priority areas to research questions?

Translating research priority topics into 'fundable' research questions can be a challenging process, with this project proposing an additional challenge of supporting meaningful involvement of individuals with learning disabilities. There has been limited literature published which explicitly presents robust and replicable methods to translate top ten priority areas into fundable research questions.

Staley and Crowe (2019) suggest the translation phase of turning a priority topic into a research project, involves a) mapping which aspects of the topic remain unanswered by research; b) identifying and shaping the research question(s) that still need to be answered; and c) designing a project to address the research question.

Examples of how previous priority setting partnerships have achieved translation of research priorities into fundable research questions includes the 'Multiple Sclerosis (MS) PSP' who used a 'round table' discussion of people with MS, healthcare professionals and researchers to specify questions from four priority areas. In 2020, the Heart Surgery PSP held a series of webinars run by nine working groups called 'clinical study groups'. The aim of these groups was to further define areas of uncertainty within the prioritised topics by identifying knowledge gaps, establishing key themes and potential trial proposals and research questions (Lai et al., 2020).

Despite some examples of strategies used to translate priorities into research questions, reports contained few details on the exact methods used and limited approaches to involve people with complex communication and cognitive needs, such as people with learning disabilities.

What approach was taken and why?

As per the original identification of the priorities, principles from the James Lind Alliance methodology were used throughout the project to collaboratively identify research questions (Cowan and Oliver, 2013). It was imperative that the methods used for the translation stage was especially sensitive to the principles of involvement and inclusivity with the most relevant service user population for this project i.e. individuals with learning disabilities.

An approach was co-produced and then piloted with a service user group of adults with learning disabilities, a speech and language therapist (SLT) and an expert researcher in the field of intellectual and learning disability. The approach was modified based on feedback and ongoing reflection from the project group, which was then built into an agreed protocol.

The agreed and tested protocol used the three pillars identified within the triad of an evidence based practice approach (Sackett, 1997); to incorporate the best available research, service users' views and to value expert opinion. This was achieved by working with groups of expert researchers, experts by experience including service users with learning disabilities and their carers and expert clinicians who represented each pillar correspondingly.

Who was involved in phase two of the project?

Eight researchers and sixteen clinicians (15 speech and language therapists, one speech and language therapy student) were recruited to the project and formed seven project groups. Each group was assigned one of the long list topic areas (see appendix) based on group members' expertise and interest, which included:

- The role of the SLT
- Information gathering and assessment
- Environment and staff around the individual
- Communication partners
- Augmentative and alternative communication
- Dysphagia
- Service delivery

Speech and language therapists and researchers approached 36 experts by experience relevant to their topic area to be involved with the project.

How did we generate the research questions?

Each project group met virtually to familiarise themselves with the project, protocol and supporting materials, and to review the long list of established priorities. The groups were asked to consider which areas warranted further refinement and development into a specific, answerable research questions.

Project groups were asked to take forward priorities identified in the top 10 list and those determined by the researchers and clinicians working in the expert field as being clinically or politically relevant.

Researchers used their knowledge of the evidence base to provide an overview of relevant literature and to identify and define knowledge gaps concerning the established research priority areas. The review of the literature supported the researchers to determine what research would move the evidence base forward in that area. Researchers recorded search terms and summaries of the literature found using an adapted question verification form provided by the James Lind Alliance.

Clinicians used their clinical insights and real-world examples of clinical practice to identify challenges faced 'on the ground' and ensured that if answered, the research questions identified would directly impact clinical care.

Experts by experience helped the groups to clarify concepts within the research priority areas and to ensure that identified research questions fit with the research priorities developed in phase one. People with learning disabilities were supported to share their views via specially designed activities, which considered their level of understanding and ability to communicate and were delivered in small groups or one-to-one discussions depending on the support needed. In line with national guidance, fee or 'honorary' payments were offered to contributors who were a member of the public (as defined by INVOLVE), and who are being asked to provide a public perspective and are not in receipt of a full-time salary from public funds (Department of Health & National Institute for Health Research, 2015).

The researchers and clinicians met virtually to generate specific research questions considering the evidence base, reflections from clinical practice and perspectives of service users they had met. This helped to ensure that the research questions produced genuinely reflected the service users interests and concerns, as opposed to just those of the researchers or clinicians and that the final research questions held true to the original topic area. Where it was not feasible to develop a research question from a priority area, groups provided a written explanation of the current available evidence.

The research questions

Twenty-nine specific research questions were formulated.

1. What is currently known about communication partner training approaches for parents/paid carers of people with learning disabilities (using a realist review)?
2. How do SLTs support clients with learning disabilities in forensic settings both in the inpatient environment and the community?
3. What areas of speech and language therapy support do people with learning disabilities in forensic settings consider to be most helpful?
4. What are SLT and parent/caregiver perceptions of the SLT's role in identifying and supporting long-term outcomes for people with a profound and multiple learning disability (PMLD)? How do these compare with each other?
5. What areas of the community do people with learning disabilities have difficulty accessing due to communication barriers? How could a SLT be involved in advocating for people with learning disabilities in these areas?
6. How do SLTs advocate for people with learning disabilities in the wider community through approaches such as awareness campaigns, training programmes etc.?
7. What is the SLT's role in end-of-life care when working with people with learning disabilities when compared to people without learning disabilities?
8. What methods do SLTs use to facilitate involvement of people with learning disabilities in end-of-life decision making?
9. What are the benefits of having SLTs involved in end-of-life dysphagia management for people with learning disabilities?
10. What are the benefits of having SLTs involved in end-of-life communication support for people with learning disabilities?
11. What is the prevalence and nature of speech, language and communication needs amongst young people and adults with learning disabilities?
12. What is the prevalence and nature of eating, drinking and swallowing needs amongst young people and adults with learning disabilities?

13. How are assessments of mental capacity carried out with young people and adults with learning disabilities? And what adjustments are made to support their cognitive and communication needs?
14. What is the acceptability, effectiveness, and efficiency of using a video reflection model compared to a traditional staff training approach when considering uptake and adherence to SLT suggested recommendations for staff working with people with learning disabilities and behaviour that challenges?
15. How does an indirect model of service delivery for school-aged children compare with a direct or combined approach to service delivery within an educational setting? Or within a residential setting for adults with learning disabilities?
16. How does a training model of indirect service delivery impact significant other understanding of the communication skills of adults with learning disabilities? Or of school-aged children with learning disabilities?
17. How does classroom-based learning generalise to the natural communication environment for children with learning disabilities?
18. What training models of indirect service delivery are employed by SLTs in adult learning disability services and how are they evaluated?
19. How do the service values affect the speech and language therapy intervention process for SLTs working with people with learning disabilities?
20. What factors increase the risk of dysphagia in people with learning disabilities?
21. What impact does dysphagia have on the quality of life of people with learning disabilities?
22. What should an assessment of eating, drinking, and swallowing difficulties include for people with learning disabilities to inform dysphagia management towards the enhancement of quality of life with the inclusion of all key stakeholders?
23. How can caregiver reports be used as an effective way in diagnosing dysphagia in people with a learning disability?
24. What are the most meaningful, reliable, valid, and robust outcome measures to measure dysphagia related change for people with learning disabilities?
25. What are the best screening tools to assess eating, drinking, and swallowing difficulties for people with learning disabilities? Is it better for the dysphagia screening tool to be delivered by highly trained staff or direct carers?

26. What novel practice-based approaches do SLTs use to manage people with dysphagia and learning disabilities? How are they best used and are they effective?
27. Which are the most effective intervention components for managing eating, drinking, and swallowing difficulties in people with learning disabilities?
28. Are mealtime mats useful and understood by carers to support adherence to dysphagia management guidance for people with learning disabilities and dysphagia, when compared with standard care?
29. How do the complex interpersonal interactions between family, paid and unpaid carers and SLTs impact personalised care plans, training and responsibility of risks relating to dysphagia and people with learning disabilities?



What's next?

As stated in the introduction to this report, further research is urgently needed to fully understand learning disabilities, the lives of people with learning disabilities, and the ways in which we can work together to ensure the best possible support systems are put in place. In phase one of our priority setting partnership we identified the top 10 priority areas for research. In phase two of this work, we used novel methods to develop specific research questions relating to the research priorities.

The work doesn't end there, and for this focus to become realised, a system-wide, collaborative push from all key stakeholders is needed. The RCSLT is committed to this process and will:

- Promote the research priorities and research questions to research-active, multi-professional clinicians and students, clinical academics, researchers, research centres, organisations and academics who may be interested in carrying out research in these areas.
- Engage key research funding bodies to influence the allocation of funding to address these specific research questions.
- Collaborate with researchers to support their proposals, projects, and the dissemination of their findings related to the research priorities and specific questions generated.
- Facilitate clinicians to implement new research evidence into practice and encourage people with learning disabilities to take part in research to help answer these questions.

How you can contribute to the process

Publicise the research priority questions:

- Cascade the priorities for research through your own networks. Share the report, start conversations about them, and make use of social media (using the hashtag #LDResearch).
- Let us know who you have spoken to, or put us in touch with them if you think they may be interested in supporting the research priorities in some way.

Carry out or support research into the priority areas:

- Tailor your funding calls to take account of these co-produced priorities and research questions.
- Use the top 10 to inform your research strategy.
- Support recruitment to research projects aiming to address the priorities.
- Take part in research in these priority areas, whether as a co-investigator, a supervisor or a participant.
- Help to share research findings.
- Refer to this new evidence when planning your learning disabilities services.

If you are planning research into any of the top 10 priority areas, please get in touch with us at info@rcslt.org to let us know. We would love to hear about your plans, and may be able to offer support. Working together, we can help to enable better lives for people with learning disabilities.

Appendix

The 'long list' of research areas for learning disabilities, as identified in phase one of the priority setting partnership.

* denotes those that are in the top 10

The role of the SLT

1. The SLT role in end of life care for people with learning disabilities.*
2. The SLT role working with breath control with people with cerebral palsy and learning disabilities.
3. The SLT role working on speech with people with cerebral palsy and learning disabilities.
4. The SLT role in identifying and supporting sensory needs of a person with profound and multiple learning disabilities.
5. The SLT role in working within forensic settings with adults with learning disabilities.
6. Specialist learning disabilities SLTs' role in providing additional support for other speech, language and communication needs (eg stammering, selective mutism) for people with learning disabilities.
7. Perceptions of a) SLTs and b) parents/carers of the SLT role in identifying and supporting long term outcomes for people with profound and multiple learning disabilities.
8. The SLT role in advocating for people with learning disabilities in the wider community.

Information gathering and assessment

9. Selecting appropriate approaches to information gathering for individualised and holistic speech and language therapy assessment for people with learning disabilities.*
10. Most appropriate ways of measuring long-term personalised and holistic outcomes for a) people with learning disabilities and b) their parents/carers.*
11. Impact of SLT findings on outcomes of mental capacity assessment of a person with learning disabilities.

12. Measuring impact of social skills intervention for people with learning disabilities.
13. Measuring suitability for social skills intervention for people with learning disabilities.
14. Measuring suitability for beginning language intervention for people with profound and multiple learning disabilities.
15. Measuring access to and uptake of social participation opportunities for people with learning disabilities.

Environment and staff around the individual

16. Inclusive communication environments and staff's skills in supporting speech, language and communication needs of people with learning disabilities.*
17. Impact of having a communication champion in a residential setting on staff awareness and support for people with learning disabilities.
18. Impact of local versus Care Quality Commission (CQC) promotion of the 'five good communication standards' on the implementation of them by health and social care services.
19. Impact of environmental factors on achievement of speech and language therapy outcomes of people with profound and multiple learning disabilities.
20. Facilitators and barriers to carrying out SLT recommended communication strategies in the school setting as perceived by teachers.
21. Effectiveness of a written communication care plan versus communication partner training on the uptake of SLT recommendations for a person with learning disabilities by staff in an educational or residential setting.
22. Impact of training on speech, language and communication needs (SLCN) for employers when considering the experiences of a person with learning disabilities who is seeking employment/ currently employed.
23. Impact of inclusion of the 'five good communication standards' as a service objective alongside frontline staff training on the implementation of the standards in practice.
24. Effectiveness of modelling strategies compared with providing written instructions to education staff on the implementation of SLT recommendations for people with learning disabilities.

25. The impact of joint occupational therapy and speech and language therapy input on the readiness of people with profound and multiple learning disabilities to communicate their needs during activities of daily living, compared with speech and language therapy input alone.
26. A video reflection model compared to a traditional staff training approach when considering uptake and adherence to SLT suggested recommendations for staff working with people with learning disabilities and behaviour that challenges.
27. Impact of public awareness raising activities around learning disabilities and communication skills on the social participation outcomes of people with learning disabilities.
28. The experiences and perceptions of SLTs in Scotland since the launch of the inclusive communication standards, in terms of the standards' impact on social participation and quality of life of people with learning disabilities.

Language and communication intervention

29. Effectiveness of using a picture exchange system (PECS) compared to a) applied behaviour analysis (ABA) and b) pragmatic organisation dynamic display (PODD) book for people with learning disabilities, in terms of the individual's ability to request in activities of daily living.
30. Indication of readiness for extended communication therapy by level of engagement of people with learning disabilities with Intensive Interaction programmes compared to informal assessment by an SLT.
31. Effectiveness of the Derbyshire Language Scheme as an intervention, on the language skills of children with learning disabilities, when compared with an informal or eclectic direct therapy approach.
32. Impact of using a consistent set of symbols across a forensic setting on adults with learning disabilities understanding of language.
33. Facilitators and barriers to generalisation of strategies learnt in social skills interventions for people with learning disabilities.
34. The perception of the term 'social skills' by people with learning disabilities compared to SLTs and implications for practice.
35. Effectiveness of a targeted approach compared to a developmental norms approach on functional skills of children with learning disabilities.

36. Impact of post-diagnostic education from SLTs given to individuals with autism and learning disabilities, and their carers, compared to no direct education, in terms of a) awareness of the individual's diagnoses and b) the individual's quality of life.
37. The current evidence base behind vocabulary interventions aimed at children with learning disabilities, commonly used by SLTs.
38. The impact of using video interaction guidance speech and language therapy compared to non-video feedback programmes for a) people with learning disabilities and b) people with learning disabilities and foetal alcohol syndrome in terms of the individual's perceived level of communication competence.
39. Effectiveness of intensive interaction with a person with learning disabilities when carried out by an SLT only versus the team around the person in terms of their level of engagement with a communication partner.
40. Effectiveness of using socially-relevant narrative approaches in SLT for people with learning disabilities and autism, in terms of their narrative skills, compared to narrative approaches using generic texts.
41. The clinical and cost-effectiveness of a sliding in approach in improving meaningful outcomes for people with coexisting selective mutism and learning disabilities, compared to alternative behavioural therapy approaches.
42. Effectiveness of Makaton signing compared to other signing systems when used with people with learning disabilities, in terms of their receptive and expressive language skills.
43. Impact of speech and language therapy input on the personalised long-term outcomes of people with learning disabilities who are also accessing forensic services, compared with no speech and language therapy input.
44. Important goals relating to social skills for people with learning disabilities, and perceived facilitators and barriers to personalised goal attainment.
45. The impact of setting additional parent/carer goals compared to goals relating to the skills of an individual with learning disabilities only, on the individual's quality of life.
46. Impact on attainment of personalised goals for people with profound and multiple learning disabilities when involving parents/carers and staff in addition to the individual with profound and multiple learning disabilities.
47. The impact of intensive interaction carried out by parents/carers or staff on reducing communication-related behaviours that challenge of people with learning disabilities, compared to no behaviour-focused intervention.

Communication partners

48. Impact of training by SLTs for parents on facilitating communicative opportunities during play dates, on the social skills of a child with learning disabilities.
49. Impact of training on communication partner understanding and implementation of recommendations in communication passports for adults with learning disabilities.
50. The most effective way of SLTs involving parents in supporting achievement of the communication goals of a child with learning disabilities.
51. Comparative impact of communication partner training approaches for parents/paid carers of people with learning disabilities, on the quality of their shared communication experiences.
52. Impact of parent/carer traits on achievement of personalised speech and language therapy targets, including following communication partner training.

Speech intervention

53. Suitability and impact of including a phonological awareness component within speech and language therapy intervention on the long-term personalised outcomes of adults with learning disabilities.
54. Perceptions of a) people with learning disabilities b) their families/carers, c) school staff and d) SLTs on the importance of targeting speech in interventions.
55. Facilitators and barriers to people with a) learning disabilities b) their families/carers and c) school staff in highlighting their priorities for speech intervention to an SLT.
56. Provision of speech interventions for people with learning disabilities across UK-wide speech and language therapy services.
57. Measuring suitability for speech intervention for people with learning disabilities.
58. Effectiveness of a specific phonological awareness intervention compared with a comprehensive speech-processing intervention in terms of a) speech recognition and b) speech production for people with Down's syndrome.

Augmentative and alternative communication (AAC)

59. Impact of implementation of a high-tech versus low-tech AAC approach on personalised long-term outcomes of children with Down's syndrome.

- 60. Components of communication partner training packages that facilitate opportunities for people with learning disabilities to communicate using augmentative and alternative communication.
- 61. Use of voice output communication aids by people with moderate learning disabilities, compared with using paper-based augmentative and alternative communication aids in terms of communication competence across different settings.
- 62. Perceived facilitators and barriers of SLTs to implementing high-tech augmentative and alternative communication for children with Down's syndrome.
- 63. Facilitators and barriers to sustained communication partner competency and motivation of using augmentative and alternative communication with people with learning disabilities.

Dysphagia

- 64. Presentation of eating and drinking difficulties for people with learning disabilities across the lifespan and their associations with dysphagia (including aspiration, choking, safety, nutrition and hydration and enjoyment).*
- 65. Effective dysphagia interventions for people with learning disabilities to achieve personalised and holistic outcomes.*
- 66. Impact of a multidisciplinary approach to dysphagia management for people with learning disabilities.*
- 67. Facilitators and barriers to instrumental assessment of swallowing for people with learning disabilities.*
- 68. Effectiveness of speech and language therapy intervention on the health and wellbeing outcomes for a) children and b) adults with learning disabilities and sensory feeding difficulties.
- 69. Perceptions of caregiver-led interventions for people with learning disabilities and dysphagia from the perspectives of a) SLTs and b) families/carers, in terms of the level of risk of unfavourable outcomes.
- 70. The beliefs, attitudes and practices relating to mealtimes of (a) adults with learning disabilities and (b) their carers and impact on care.
- 71. Facilitators and barriers in managing dysphagia for people with learning disabilities and multiple health conditions compared to management of dysphagia for people with learning disabilities only.

- 72. Similarities and differences in the management of dysphagia for people with learning disabilities across UK-wide speech and language therapy services.
- 73. The most meaningful tools for measuring outcomes following dysphagia intervention, for people with learning disabilities as perceived by SLTs.
- 74. Effectiveness of thickened liquids and free water protocol, compared to thickened liquids alone in terms of health and wellbeing outcomes for people with learning disabilities with good oral hygiene.

Service delivery

- 75. Effectiveness of different service models of speech and language therapy input for people with learning disabilities to reach personalised and holistic outcomes.*
- 76. 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.*
- 77. The impact of service delivery approach (1:1 versus group) of social skills interventions for people with learning disabilities.
- 78. Impact of specific dosage of direct speech and language therapy on desired outcomes for people with learning disabilities.
- 79. Parent-delivered intervention compared to SLT-delivered intervention for children with learning disabilities.
- 80. Comparative effectiveness of engaging children with learning disabilities in speech and language therapy interventions across 1:1, group or classroom-based delivery models, in terms of their rate of progress towards personalised goals.
- 81. Impact on communication skills of people with profound and multiple learning disabilities of using computer-delivered therapy compared to traditional approaches.
- 82. Clinical reasons informing on an individual with learning disabilities' entry to and exit from different UK learning disabilities services, from SLTs' perspectives.

Comorbidities with learning disability

- 83. Typical presentation of speech, language and communication skills in people with foetal alcohol syndrome and learning disabilities.

- 84.** Impact of communication difficulties experienced by children with foetal alcohol syndrome and learning disabilities on a) quality of life and b) educational attainment, compared to children with typically developing language profiles.
- 85.** Tactile signing for sensory learners (TaSSeLs) compared with a high contrast symbol set as a communication method for children with cortical visual impairment (CVI) and learning disabilities.

Miscellaneous

- 86.** Facilitators and barriers to adults with learning disabilities being involved in research studies.
- 87.** Experiences of adults with a learning disability in communicating with people working in the criminal justice system.

References

Backhouse, A., Howells, S., 2022. Commentary on "Research priorities relating to communication and swallowing for individuals with learning disabilities across the lifespan." *Tizard Learning Disability Review* 27, 105–111. <https://doi.org/10.1108/TLDR-04-2022-0009>

Barker, R. (and the All-Party Parliamentary Group for Education) (2011) *Report of the Inquiry into Overcoming the Barriers to Literacy*. Online. Available from: <https://dera.ioe.ac.uk/15786/1/APPG-for-Education-Literacy-Inquiry-final-report.pdf> [Accessed 7 January 2021]

Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T. and Bradshaw, J. (2016) Quality of Life and Quality of Support for People with Severe Intellectual Disability and Complex Needs. *Journal of Applied Research in Intellectual Disabilities*. 29 (5), 409-421.

Bercow, J. (2008) *The Bercow Report: A Review of Services for Children and Young People (0-19) with Speech, Language and Communication Needs*. Online. Available from: https://dera.ioe.ac.uk/8405/7/7771-dcsf-bercow_Redacted.pdf [Accessed 7 January 2021]

Beyer, S. and Beyer, A. (2017) *A systematic review of the literature on the benefits for employers of employing people with learning disabilities*. Mencap. Available from: <http://orca.cf.ac.uk/103127/1/Beyer%202017.061%20Benefits%20of%20employing%20PWLd%255b1%255d%20%281%29.pdf> [Accessed 8 June 2020]

Bradshaw, J. (2007) Between you and me: developing communication in partnership with people with learning disabilities. In: Carnaby, S. (2007) *Learning Disability Today: a handbook for everyone committed to improving the lives of people with learning disabilities*. Pavilion Publishing, Brighton, 67-78.

Chadd, K., Longhurst, L., Kulkarni, A., Simpson, J., Pagnamenta, E., Brettell, F., Money, D., Dowty, R., Wallinger, J., Bangera, S., Palmer, R., Joffe, V., 2022. Research priorities relating to communication and swallowing for people with learning disabilities across the lifespan. *TLDR* 27, 95–104. <https://doi.org/10.1108/TLDR-06-2021-0018>

Cowan K, and Oliver, S. (2013) **The James Lind Alliance Guidebook, version 5**. Online. Available from: <http://www.jlguidebook.org/pdfguidebook/guidebook.pdf> [Accessed 24 November 2020]

Emerson, E. (2012) Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. *Journal of Epidemiology and Community Health*. 66 (3), 218-224.

Emerson, E. and Baines, S. (2010a) *Health Inequalities and People with Learning Disabilities in the UK: 2010*. Briefing paper. Online. Available from: https://strathprints.strath.ac.uk/34862/1/vid_7479_IHaL2010_3HealthInequality2010.pdf [Accessed 8 June 2020]

Emerson, E. and Baines, S. (2010b) *The Estimated Prevalence of Autism among Adults with Learning Disabilities in England*. Online. Available from: http://www.wecomunities.org/MyNurChat/archive/LDdownloads/vid_8731_IHAL2010-05Autism.pdf [Accessed 7 January 2021]

Emerson, E. and Hatton, C. (2007) Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*. 191, 493-49.

Emerson, E., Friedman, C. and Rizzolo, M.C. (2018) Friendship, Quality of Life, and People with Intellectual and Developmental Disabilities. *Journal of Developmental and Physical Disabilities*. 30, 39-54.

Goldbart, J., Chadwick, D. and Buell, S. (2014) Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning disability. *International Journal of Language & Communication Disorders*. 49 (6), 687-701.

Harding, C. and Cockerill, H. (2014) Managing eating and drinking difficulties (dysphagia) with children who have learning disabilities: What is effective?. *Clinical Child Psychology and Psychiatry*. 20 (3), 395-405.

Harding, C. and Wright, W. (2010) Dysphagia: the challenge of managing eating and drinking difficulties in children and adults who have learning disabilities. *Tizard Learning Disability Review*. 5 (1), 4-13.

Hatton, C. (2018) Paid employment amongst adults with learning disabilities receiving social care in England: trends over time and geographical variation. *Tizard Learning Disability Review*. 23 (2), 117-122.

Heelan, M., Chadd, K., Kulkarni, A., Longhurst, L, and Pagnamenta, E. 2022. "Top 10" research priorities for dysphagia, learning disabilities (LD) and developmental language disorder (DLD). Presented at the ESLA Congress 2022, Salzburg, Austria.

Kamstra, A., van der Putten, A.A.J. and Vlaskamp, C. (2015) The Structure of Informal Social Networks of Persons with Profound Intellectual and Multiple Disabilities. *Journal of Applied Research in Intellectual Disabilities*. 28, 249-256.

Kelly, A. (2000) *Working with Adults with a Learning Disability*. Winslow Press. Bicester, UK. *Learning Disabilities Mortality Review (LeDeR) Programme (2020) Annual Report 2019*. Online. Available from: http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf [Accessed 7 January 2021]

Lai, F.Y., Abbasciano, R.G., Tabberer, B., Kumar, T., Murphy, G.J., 2020. Identifying research priorities in cardiac surgery: a report from the James Lind Alliance Priority Setting Partnership in adult heart surgery. *BMJ Open* 10, e038001. <https://doi.org/10.1136/bmjopen-2020-038001>

LGA/ADASS/NHS England (2015) *Building the right support: A national plan to build community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*. LGA/ADASS/NHS England.

Magaña, S., Parish, S., Miguel A. , Morales, M. A., Li, H. and Fujiura, G. (2016) Racial and Ethnic Health Disparities Among People With Intellectual and Developmental Disabilities. *Journal of Intellectual and Developmental Disabilities*. 54 (3), 161-172.

Manduchi, B. Fainman, G. M. and Walshe, M. (2020) Interventions for Feeding and Swallowing Disorders in Adults with Intellectual Disability: A Systematic Review of the Evidence. *Dysphagia*. 35 (2), 207-219.

Mansell, J. (2007) *Services for people with learning disability and challenging behaviour or mental health needs*. Department of Health. Available from: https://webarchive.nationalarchives.gov.uk/20130124041359/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_080128.pdf [Accessed 8 June 2020]

Money, D. and Thurman, S. (2002) Inclusive Communication. *Speech and Language Therapy in Practice*. Autumn, 2002, 4-6.

NHS (2019) *Learning Disability Framework: Core Capabilities Framework for Supporting People with a Learning Disability*. Available from: <https://www.skillsforhealth.org.uk/wp-content/uploads/2020/11/Autism-Capabilities-Framework-Oct-2019.pdf> [Accessed 17 March 2023]

Public Health England (2016) *Making reasonable adjustments to dysphagia services for people with learning disabilities*. Available from: <https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-disabilities/dysphagia-in-people-with-learning-difficulties-reasonable-adjustments-guidance> [Accessed 8 June 2020]

Public Health England (2016) *People with learning disabilities in England 2015: Main report*. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf [Accessed 8 June 2020]

Raghavan, R. and Small, N. (2004) Cultural diversity and intellectual disability. *Current Opinion in Psychiatry*. 17 (5), 371-375.

Robertson, J., Raghavan, R., Emerson, E., Baines, S. and Hatton, C. (2019) What do we know about the health and health care of people with intellectual disabilities from minority ethnic groups in the United Kingdom? A systematic review. *Journal of Applied Research in Intellectual Disabilities*. 32 (6), 1310-1334.

Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) *Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. Online. Available from: https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr144.pdf?sfvrsn=73e437e8_2 [Accessed 7 January 2021]

Royal College of Speech and Language Therapists (2010) *Adults with learning disabilities (ALD) Position Paper*. Online. Available from: http://www.accessibleinfo.co.uk/pdfs/ald_position_paper%5B1%5D.pdf [Accessed 7 January 2021]

Royal College of Speech and Language Therapists (2020) *RCSLT Learning Disabilities clinical guidance*. Online. Available from: <https://www.rcslt.org/members/clinical-guidance/learning-disabilities/learning-disabilities-guidance> [Accessed 7 December 2020]

Royal College of Speech and Language Therapists (2020). *RCSLT Learning disabilities research priorities. Current member research and quality improvement projects*. Available from: https://www.rcslt.org/wp-content/uploads/media/docs/research/RCSLT-Learning-disabilities-research-priorities-follow-up-projects_document.pdf [Accessed 17 March 2023]

Sackett, D.L., (1997). Evidence-based medicine. *Seminars in Perinatology* 2(1), 3–5. [https://doi.org/10.1016/S0146-0005\(97\)80013-4](https://doi.org/10.1016/S0146-0005(97)80013-4)

ior, K., Addai Davis, J., Kenyon, M. and Sheridan, J. C. (2013) Stigma, public awareness about intellectual disability and attitudes to inclusion among different ethnic groups. *Journal of Intellectual Disabilities Research*. 57 (11), 1014-1026.

Snell, M. E, Brady, N., McLean, L., Ogletree, B. T., Siegel, E., Sylvester, L., Mineo, B., Paul, D., Romski, M. A. and Sevick, R. (2010) Twenty years of communication intervention research with individuals who have severe intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*. 115 (5), 364-380.

Staley, K., Crowe, S., (2019). *More than a Top 10: How James Lind Alliance Priority Setting Partnerships transform research, people and organisations*. Available from: <https://www.twocanassociates.co.uk/wp-content/uploads/2019/10/More-Than-a-Top-10-1-Oct-19.pdf> [Accessed 17 March 2023]

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