

Research priorities relating to communication and swallowing for people with learning disabilities across the lifespan

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Research priorities relating to communication and swallowing for people with learning disabilities across the lifespan

Katie Chadd, Lauren Longhurst, Amit Kulkarni, Jaya Simpson, Emma Pagnamenta, Fiona Brettell, Della Money, Rosie Dowty, Josephine Wallinger, Sai Bangera, Rebecca Palmer and Victoria Joffe

Abstract

Purpose – This research priority setting partnership (PSP) aims to collaboratively identify the “top ten” research priorities relating to communication and swallowing for children and adults with learning disabilities, across the lifespan in the UK, using a modified James Lind Alliance approach.

Design/methodology/approach – A steering group and reference group were established to oversee the PSP. A survey of speech and language therapists (SLTs) resulted in 157 research suggestions. These were further developed into 95 research questions through a multi-stakeholder workshop. Questions were prioritised via an online card-sort activity completed by SLTs, health-care or education professionals and carers. Research questions were analysed thematically. Ten adults with learning disabilities were supported to assign ratings to themes reflecting their prioritisation. The top ten research priorities were identified by combining results from these activities.

Findings – The top ten research priorities related to intervention, outcome measurement and service delivery around communication and dysphagia.

Originality/value – To the best of the authors’ knowledge, this is the first UK-wide research PSP on learning disabilities and speech and language therapy across the lifespan. It uses a novel approach to incorporate the preferences of people with learning disabilities in the prioritisation.

Keywords Research priorities, Communication, Learning disabilities, Intellectual disability, Dysphagia, Speech and language therapy

Paper type Research paper

(Information about the authors can be found at the end of this article.)

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Royal College of Speech and Language Therapists.
Ruth Gilchrist Legacy.

Introduction

Approximately 1.5 million individuals in the UK have learning disabilities (Mencap, 2021). Recent research (Smith *et al.*, 2020) estimates that 58% of people with learning disabilities have difficulties with communication. Furthermore, eating, drinking and swallowing difficulties (dysphagia) may affect between 8.1% and 11.15% of individuals with learning disabilities (Robertson *et al.*, 2017). State-provided speech and language therapy (SLT) services can be variable across the UK (Children’s Commissioner, 2019 in England) including the degree to which provision is aimed at dysphagia (which poses a high patient safety risk) versus communication difficulties.

Despite the requirement to use evidence-based practice (EBP), many gaps exist in the literature regarding approaches to SLT for individuals with learning disabilities. Research in to communication-based interventions for individuals with learning disabilities are often

underpowered and of poor quality (Wood and Standen, 2021). Additionally, interventions pertaining to dysphagia specifically for the population of people with learning disabilities are not well-explored, with most studies investigating enteral feeding only, of which also lack robustness (Manduchi *et al.*, 2020)

Given this dearth of research, there is an abundance of potential research avenues across a range of areas of SLT. Historically, researchers and funders set research agendas (Crowe *et al.*, 2015), but these may conflict with the preferred research focus of research consumers (Crowe *et al.*, 2015). Research priority setting partnerships (PSPs) aim to address this mismatch and identify research priorities, as defined by all key stakeholders (Stewart *et al.*, 2011).

The James Lind Alliance (JLA) (2020) method empowers multiple stakeholders to collaboratively identify and prioritise topics that can be used to shape research agendas. Earlier PSPs have considered areas related to learning disabilities but have not focused on communication and swallowing for people with learning disabilities across the lifespan. Here, we drew on the established JLA PSP methodology (JLA, 2020), but used a differentiated set of activities to bolster meaningful patient and public involvement (PPI) to facilitate inclusion.

Thus, this PSP aimed to collaboratively identify a long list of and the “top ten” research priorities (for new or further research) relating to communication and swallowing for individuals with learning disabilities.

Methods

Methods were developed in consultation with the National Institute of Health Research (NIHR) and the JLA. Full data sets and templates are available on request. The PSP took place over three years and involved six key stages. The report aligns with guidelines set by Tong *et al.* (2019).

Ethical considerations

The SLT survey was approved by the City University Research Ethics Committee.

Research priority setting exercises are service evaluations therefore do not require formal ethics approval. The principles of ethical research were adhered to, including obtaining consent from people with learning disabilities who were involved, using supported communication methods.

Recruitment

A voluntary steering group was established to provide strategic oversight and approve the project’s scope, aims and methodology. A SLT reference group was convened to provide ad-hoc expert knowledge of learning disabilities. Steering group membership required expertise in research and experience of working in learning disability services was required for reference group. Adults with learning disabilities were invited to join the partnership through pre-existing NHS community service-user groups. SLTs in the reference group facilitated access to these groups via their professional links.

Research stages

A survey distributed to approximately 16,000 RCSLT members between September 2015 and January 2016 aimed to explore SLT’s EBP. The survey included the following questions:

In your specialist clinical area, what would you say are the significant gaps in the evidence base that challenge you in delivering evidence-based care?

If you were a research funder and you could only fund one piece of research, what would it be?

The suggestions for research were then classified as in or out of scope dependent on inclusion of key words (e.g. “intellectual disability”, “complex needs”) as agreed by the reference group. Coding for in/out of scope was carried out by two independent raters, with 95% agreement.

Literature reviews or meta-analyses in the relevant areas published within 12 years of the start of the project and clinical guidelines (<3 years old) were identified and research recommendations extracted from them ([RCSLT, 2022](#)). The reference group were invited to make any further suggestions. Following this, the research team removed duplicate suggestions, and reached consensus on grouping the remaining research suggestions into broad topic areas to facilitate planning of the multi-stakeholder workshop.

A multi-stakeholder workshop was held. Attendees were invited via RCSLT communications (SLTs) or a targeted email (non-SLTs). Deviating from JLA protocol, clinical-academics and researchers were invited to participate as it was considered their involvement may enhance the uptake of the research priorities. SLTs were asked to share the opportunity with parents/carers of individuals with learning disabilities.

Relevant organisations were identified by the research team through a desk-based scoping activity, and prioritised for invitation based on the alignment of the organisation’s mission with the PSP’s scope (i.e. charities supporting individuals with learning disabilities, or funders of disability research). Six groups comprising different professionals working with individuals with learning disabilities, patient organisations and carers of individuals with learning disabilities participated, and were guided by a trained facilitator. All received training on developing research questions using the “Population-Intervention-Comparator-Outcome” (PICO) format. Groups were assigned three broad topic areas and their corresponding original research suggestions. Group discussions explored the topics’ importance, and how research could address it. Based on this, groups formulated “PICO” questions. Feedback on the process was invited via a post-event evaluation questionnaire. This exercise resulted in collaboratively developed research questions.

The research questions were modified to ensure appropriate and consistent terminology and structure and reviewed by workshop attendees and the reference group following circulation of the draft outputs. Following amendment, the research questions were presented in an online card-sort targeted at professionals and parents/carers of individuals with learning disabilities, via RCSLT’s communications, the PSP partners’ networks, [the People in Research website \[I\]](#) and [the CHAIN Network \[II\]](#). In the card-sort, each research question was randomly presented on a “virtual” card which was to be sorted into one of three piles: an “immediate key priority”, “a priority” or “important, but not a priority”. When a research question was identified as an “immediate key priority”, it received one “vote”. No analysis was undertaken of those sorted in either of the other two piles. Participants were invited to leave feedback about the process online.

Involvement of people with learning disabilities

As a test-bed for the new UK Patient Involvement Standards ([The Standards Development Partnership, 2018](#)), the project sought to implement innovations in PPI ([The Standards Development Partnership, 2020](#)). Thus, we introduced a novel step to the JLA process to facilitate involvement of individuals with learning disabilities. Rather than presenting the long list of questions, we produced a list of ten broad themes, identified through thematically analysing the long list of questions using inductive analysis at a semantic level. Each question was coded to three or fewer themes. Two research team members conducted this analysis independently and reached consensus on discrepancies. These themes were the basis of the “theme-rating exercise”.

The researchers visited two pre-existing community service-user groups to seek involvement of adults with learning disabilities. Participants were paid for their involvement. A pilot session aiming to involve service users in shaping the PPI methods was held first. This involved discussing the topics and trialling materials, which informed the “theme-rating exercise”. Subsequent sessions, which included two service users from the pilot, included activities tailored to ensuring that the adults with learning disabilities understood terminology and key concepts (e.g. “research”, and “priority”) (see approach outlined in [Chadd et al., 2020](#)). Evidence-based approaches were used to aid communication, such as using visual supports, key word signing, modified language, repetition and other individualised accessible communication supports ([Scottish Government, 2011](#)). The theme-rating exercise required adults with learning disabilities to rate each theme on a 10-point scale in terms of how important they considered it was that research should “find out more” about the theme (where 10 indicated utmost importance, and 1 indicated not important at all). Service user groups were also invited to review communication materials produced to promote the research priorities.

The research team formed consensus that a proxy for “a priority” in the theme-rating exercise was a rating of eight or above. All research questions belonging to a theme rated as such by a service user, were allocated additional “votes”. This combined total of votes from the card-sort and the theme-rating exercise was used to identify the top ten research priorities, presented as statements

Results

The steering group agreed that the PSP’s scope extended to individuals with learning disabilities across the lifespan, with or without co-occurring conditions, and all aspects of care and service delivery relevant to speech and language therapy, and any type of research question. One hundred and fifty seven of the 257 suggestions from the survey of SLTS were taken forward following consideration by the reference group. Following further consultation, 95 research areas were developed and then prioritised into top ten research priorities ([RCSLT, 2022](#)).

The partnership

Steering and reference group members were recruited to ensure diverse representation across employers, the client group served as a practitioner and region ([Table 1](#)). Detailed information was not collected about the ten adults (across two groups) with LD that participated in the project. Of these, nine predominantly used verbal communication, one individual predominantly used key word signing to communicate.

Developing research questions

The SLT survey was completed by 1,035 SLTs, 624 of which gave research suggestions. In total, 128 of these participants offered 257 research suggestions relating to learning disabilities (see [Table 2](#)). Following the addition of recommendations from the literature and reference group, and removal of duplicates, 157 research suggestions were collated, which were synthesised into 16 broad topics.

The workshop was attended by 36 individuals, including 16 SLTs, six academics/researchers, 12 representatives from patient organisations and two carers of individuals with learning disabilities ([Table 2](#)). At the workshop, 79 research questions were developed.

Via post-workshop feedback, and consultation with the working group, 16 questions were added, and duplicate ideas collapsed, leading to 95 research questions. Ten themes were identified following thematic analysis of these questions (see right-hand column in [Figure 1](#)), some of which mapped onto the original broad topics, whereas others showed a degree of

Table 1 Characteristics of the Partnership steering and reference groups

Member background	Steering group (N = 12)	Reference group (N = 11)
<i>Employer</i>		
NHS	4	9
Independent practice	1	2
School/college	1	0
Not for profit/third-sector	1	2
Social enterprise	0	1
Higher education institution	5	1
Other	2	0
<i>Client group</i>		
Children with LD	3	2
Adults with LD	0	9
Other	9	0
<i>Region</i>		
England	10	9
Northern Ireland	1	0
Scotland	0	1
Wales	0	1
International	1	0

Table 2 Stakeholder participation and representation throughout key stages of the PSP

Stakeholder	Number SLTs who submitted one or more research suggestions related to LD (SLT survey)		Attended workshop N (%)	Completed online card-sort activity N (%)	Participated in theme-rating exercise N (%)	
	N	(%)			N	(%)
Total		128	36	171	10	
Individual with LD	0	0.0	0	0.0	10	100.0
SLT	128	100.0	16	44.4	154	90.0
Patient organisation	0	0.0	12	33.3	0	0.0
Carer	0	0.0	2	5.6	6	3.5
Clinical academic/ HEI/ Researcher	0	0.0	6	16.7	12	7.0
Other health-care or education professional	0	0.0	0	0.0	6	3.5
Other	0	0.0	0	0.0	5	2.9
<i>Region</i>						
Northern Ireland	5*	3.9	0	0.0	5	2.9
Scotland	9*	10.9	0	0.0	14	8.1
Wales	4*	14.1	2	5.6	12	7.0
England	110*	71.1	34	94.4	134	78.0
UK-wide	0	0.0	0	0.0	n/a	n/a
International	0	0.0	0	0.0	7	4.0

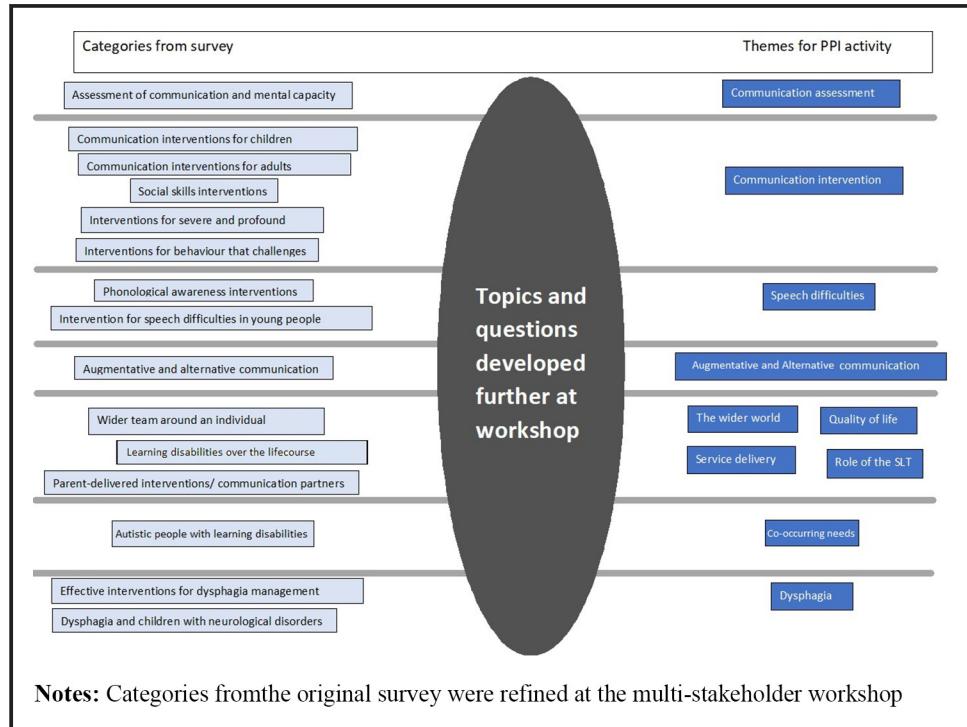
divergence (outlined in [Figure 1](#)). These were taken forward into the theme-rating exercise with adults with learning disabilities.

Prioritisation process

Card-sort participants were mostly SLTs (90%) but included parents/carers of individuals with learning disabilities and other healthcare or education professionals ([Table 2](#)).

In the card-sort, all individual research questions received some votes (range = 6–82). In the theme-rating exercise by adults with learning disabilities, “dysphagia”, “quality of life”

Figure 1 Process for the development of final themes for the PSP PPI activity



(QoL) and “AAC” were the most predominantly highly rated themes, all being rated as a priority by 8 out of the 10 individuals (thus each question related to these themes received 8 additional votes, see [Table 3](#)). In contrast “service delivery” was only identified as a priority by one individual. During this exercise, some instances occurred where individuals with learning disabilities did not demonstrate understanding of the concept or theme. These were not rated and thus excluded from analysis.

Top ten research priorities

Following integration of votes from the card-sort and theme-rating exercise ([Table 3](#)), the top priority scored 96 votes, and the tenth scored 69. Some relatively low-scoring priorities in the card-sort entered the top ten only following the integration of the theme-rating data (e.g. number 3). The full “long list” of research priorities has been published by the RCSLT ([RCSLT, 2019](#)).

Discussion

This UK-wide PSP used a novel methodology, adapted from the JLA approach which brought together a range of stakeholders, including adults with learning disabilities, to identify the top ten research priorities relating to communication and swallowing for individuals with learning disabilities across the lifespan. The priorities are broad and reflect multi-disciplinary aspects including communication and swallowing.

Four priorities relate to dysphagia, which may reflect current challenges facing SLTs in clinical services, as the outcome was strongly driven by SLTs. Dysphagia is increasingly part of a SLTs role due to commissioning of services ruled by risk-management, which can be to the detriment of SLT resource for communication. As such, the dominance of dysphagia in the top ten may reflect the needs and preferences of SLTs to have evidence

Table 3 The top ten research priorities

Top ten research priorities	Card-sort	Votes		Total
		Theme (Votes from theme-rating exercise)		
1. Effective dysphagia interventions for individuals with learning disabilities to achieve personalised and holistic outcomes	82	QoL (8)	Dysphagia (8)	98
2. Inclusive communication environments and staff's skills in supporting speech, language and communication needs of people with learning disabilities	83	Wider world (4)		87
3. Impact of a multi-disciplinary approach to dysphagia management for people with learning disabilities	69	Dysphagia (8)	Service Delivery (1)	82
4. Most appropriate ways of measuring long-term personalised and holistic outcomes for people with learning disabilities and their parents/ carers	76	Assessment (2)		78
5. Effectiveness of different service models of speech and language therapy input for people with learning disabilities to reach personalised and holistic outcomes	77	Service Delivery (1)		78
6. 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)	68	Dysphagia (8)		76
7. Facilitators and barriers to instrumental assessment of swallowing for people with learning disabilities	67	Dysphagia (8)		75
8. Selecting appropriate approaches to information gathering for individualised and holistic speech and language therapy assessment for people with learning disabilities	69	Assessment (2)		71
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	70	Service delivery (1)		71
10. The SLT role in end-of-life care for people with learning disabilities	56	SLT role (5)	QoL (8)	69

Note: Number of Votes are shown are from the cart-sort, the theme-rating exercise and overall combined total

relating to dysphagia, which they are increasingly under pressure to prioritise in their own clinical caseloads. Nonetheless, dysphagia was also prioritised by adults with learning disabilities. One PPI group member described their experience of swallowing difficulties and subsequent hospital care which may have "brought to life" the issue of dysphagia. A personal and emotive account may have supported the groups' understanding of dysphagia, which potentially validly influenced their prioritisation. Thus, the dominance of themes in the priorities may be the result of a more complex combination of factors, including the experiences of services users involved and clinicians' specialist interest.

Six priorities related to supporting individuals with learning disabilities speech, language and communication needs, including exploring an individual's environment, their needs and progress; one regarding SLTs' specific roles and responsibilities and just one specifically exploring communication intervention. While communication interventions feature heavily in the "long list" of priorities, it is noteworthy that only one was ranked in the top ten. The priorities also appear to reflect the stakeholders' preference for research to focus on the social model of disability and quality of life. This highlights the importance of taking a multi-stakeholder approach to prioritisation, as traditional research and funding streams from medically based research councils are likely to perpetuate only that agenda.

Including a range of stakeholders may have unintentionally resulted in diluted focus on the SLTs role in learning disability services. As aforementioned, there is limited research available regarding people with learning disabilities and SLT, which may

mean that clinicians and other stakeholders found it difficult to prioritise specific areas of research need.

Limitations

We acknowledge there are limitations in our PSP. The data collected on SLTs who completed the surveys was limited and we cannot ascertain the clinical specialities of participants. Thus, we did not account or correct for bias that may emerge from, for example, having an imbalance between the amount of dysphagia versus communication specialists. The potential un-corrected imbalance in specialities may mean that the priorities simply reflect the number of specialists in these areas participating in the surveys. Further to this, the representation of other non SLT-professionals was neither consistent nor equal throughout the PSP which may have biased the outputs. Similarly, the overall participation of individuals with learning disabilities was low compared with professionals. Further demographic information about the involved adults with learning disabilities was not collected. There were also occasions where barriers to involvement persisted due to unresolved communication breakdowns. In future, “communication accessible” research methods or more creative methods such as life stories could be employed to resolve this (Dee-Price *et al.*, 2020).

This work was not fully co-produced: involvement of individuals with learning disabilities could have been earlier, and in more depth, in line with current best practice (NIHR, 2021), such as having a patient representative in the steering group to ensure relevance throughout. Engagement at later stages of the project was not always successful, e.g. reviewing communications material, though some engagement was maintained. This is likely due to substantial time gaps between communication with the groups, and/or indeed this was not an interesting or motivating enough project to pursue. The involved groups were quite unrepresentative: the preferences of children, individuals with PMLD, those who have co-occurring conditions, users of a wider range of AAC types or those who were culturally and linguistically diverse were not elicited which limits the generalisability of the preferences indicated. Absence of diverse perspectives may introduce bias in the research priorities identified (Ekezie *et al.*, 2021) and risks further perpetuating the pattern of individuals with learning disabilities becoming “voiceless subjects” (Mietola *et al.*, 2017).

A strength of this project was the use of a pilot session with service users to inform on the most appropriate way in which preferences regarding research priorities could be understood and communicated, resulting in the “theme-rating” exercise. Involving individuals (including those with learning disabilities) in method design is challenging but was achieved to a degree in this PSP.

Future directions

The next stage of this project is to co-produce (with SLTs, researchers and adults with learning disabilities) and implement a protocol that aims to map the evidence base and “further translate” the research priorities into researchable questions and projects. Subsequent activities will involve influencing and lobbying work to shape future research agendas.

The top ten research priorities relating to communication and swallowing for individuals with learning disabilities across the lifespan identified through this UK-wide PSP offer leverage and legitimacy for conducting multi-disciplinary research in these fields. The outputs can act as a legitimate call to action for researchers and funders to address these much-needed areas of research, with the ultimate aim of improved outcomes for individuals with learning disabilities and their families/carers.

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