



What do we need to know about learning disabilities?

Next steps for important research

April 2023

Easy Read

Introduction.



Speech and language therapy is help

for people who have difficulties with:

- **communication. Communication**

is telling people something and

understanding what they tell you.

- and eating, drinking and swallowing.

The people who do this are called **Speech and Language Therapists** or **SLTs**.

We need to know how SLTs can support people with learning disabilities in the best way.

We need to understand what life is like for people with learning disabilities.

For this we need to do more research.

Research means looking at something in a careful planned way to understand more.

What we had already done.



In 2019, we made a list of the most important things to research.



We called this first step **phase 1**.



We looked at communication and swallowing for people with learning disabilities.



We looked at people of all ages and from all across the UK.



We made the list with help of:

- SLTs
- people with learning disabilities
- parents and carers of people with learning disabilities
- and researchers.

More about what we had already done



What we did with the list.

We did a lot to tell people about the list. Some of the things we did were:



We put the list on our website to tell SLTs about the list.



We published the list in an **academic journal** to tell researchers about it. An **academic journal** is a collection of new research. It is printed a few times a year.



We told researchers we would write letters to help them get funding. This was for research that looked at the areas on the list.



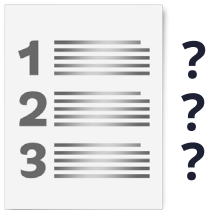
We started to work with the National Institute for Health and Care Research.

They help to pay for research to be done in the areas on the list.

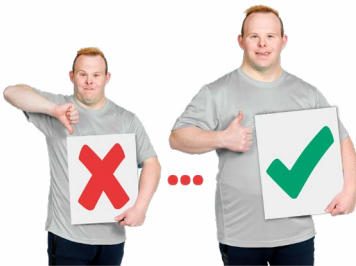
About phase 2 of the project.



The next step of the project was called **phase 2**.



We still need to get answers to the important research on the list.

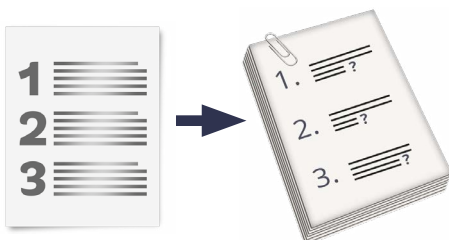


This is to make the services better and people's lives better.



The aims of phase 2:

- See what we still need to find out more about.



- Use the list from phase 1 to come up with new research questions.



- Tell the people who fund and do research about the new questions.

Planning for phase 2.



We tested out a way of working with a project group. This was a group of:

- adults with learning disabilities who have speech and language therapy
- an SLT
- and an expert researcher.



We listened to the people in the project group.



We agreed the best way of doing the project.

How we did phase 2.



Who took part in phase 2 of the project?

Researchers, SLTs, and a speech and language therapy student took part in the project.

More about how we did phase 2



They were put into groups based on what they know about.



Experts by experience also told us what they think. **Experts by experience** means people with learning disabilities, their carers and support workers.



How did we come up with the research questions?

Each project group met online. They chose which areas to make into a research question.



The researchers helped to work out where more research was needed.



SLTs told us what it was like working in speech and language therapy. They told us what might make it hard to answer the questions.

More about how we did phase 2



They made sure that what we find out will help people.



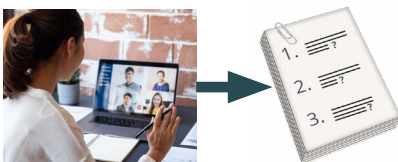
Experts by experience helped to make sure we were asking the right questions.



People with learning disabilities did special activities to tell us what they thought.



They did these in small groups or one-to-one.



The researchers and SLTs met online again. They came up with the research questions.



They included everyone's views.

Results - The research questions.

We came up with 29 questions:



1. What is known about **communication partner** training for parents or paid carers? A **communication partner** is someone you are talking to.



2. How do SLTs support people in **forensic settings**? A **forensic setting** is a place where someone who has broken the law can get mental health treatment.



3. What speech and language therapy support do people in forensic settings find most helpful?



4. What do SLTs think they should do to support people with **PMLD**? **PMLD** means people who have a lot of complex needs.

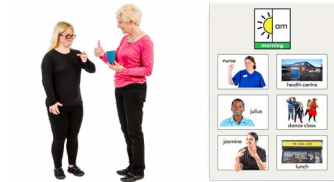
What do **caregivers** think SLTs should do to support people with PMLD? A **caregiver** is someone who looks after a person.

More research questions



5. What areas of the community do people find hard to access due to communication?

How could a SLT help?



6. How do SLTs speak up for people with learning disabilities in the wider community?



7. SLTs can help with end-of-life care for people with learning disabilities. How is their role different when compared to people without learning disabilities?



8. How do SLTs help people to make choices as they come to the end of their life?



9. Towards the end of life a person may have difficulty swallowing. How does it help to have an SLT support at this time?



More research questions



10. SLTs can support communication as people come to the end of their life. What is good about this?



11. How many people with a learning disability have difficulties with communication?



What are the difficulties that they have with communication?



12. How many people with a learning disability have difficulties with eating, drinking and swallowing?



What are the difficulties they have with eating, drinking and swallowing?



13. How is **mental capacity** checked with people with learning disabilities? What adjustments are being made? **Mental capacity** is what people can understand and make choices about.

More research questions



14. SLTs can give advice to staff working with people with behaviour that challenges.

Do these staff mind being videoed to help them support people in the best way?

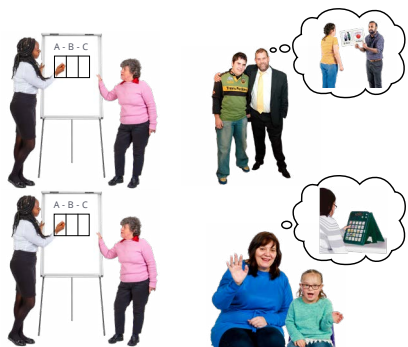
Do they prefer other ways of being trained?

Which way is most useful?

15. In a school OR in a home for adults. How do these ways of helping compare?:

- Working with staff, parents and carers only.
- Working with staff, parents and carers and the person with a learning disability.
- or working only with the person with a learning disability.

More research questions



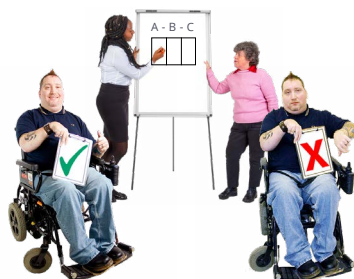
16. SLTs train carers or parents of people with a learning disability. How does this training change their understanding of communication skills?



17. Does what a child learnt in the classroom work in other places?



18. How do SLTs train people who work with adults with a learning disability?



How do they decide if the training works?



19. How do **service values** change the way SLTs help people?

Service values are the things that are important to a service.



20. What makes it likely that a person has eating, drinking and swallowing problems?

More research questions



21. How do swallowing problems and the way these are managed change a person's **quality of life**?

Quality of life means how a person feels about their life.



22. What should an **assessment** of eating, drinking and swallowing include?

Assessment means looking at a person's needs.



23. How can **caregivers** help us work out if someone has swallowing difficulties?



24. What is the best way to measure changes in difficulty with swallowing?



25. Which is the best **screening tool** to check eating, drinking, and swallowing difficulties? A **screening tool** is a way of checking something.



Should this tool be used by staff who have had a lot of training?

More research questions



26. What do SLTs do to help people with swallowing difficulties?

Does what they do work?



27. What works best when helping someone with eating, drinking and swallowing difficulties?



28. When caring for someone who finds swallowing difficult is it best to use a **mealtime mat**? A **mealtime mat** shows how a person needs their food and drink.



29. When families, carers and SLTs need to work together this can be complicated. How does this make a difference to:

- personalised care plans?
- training?
- and who keeps people safe if they have eating, drinking and swallowing problems?



Next steps.



We need to work together to help make sure this important research is done.

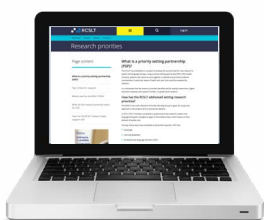


We will work with researchers, SLTs, and funders to answer the research questions.



We would like people with learning disabilities to take part in this important research.

Where to find out more.



Visit the RCSLT website for more information: www.rcslt.org/members/research/research-priorities/

Thank you.



Thank you to everyone who took part in this project.