

'I Didn't Know That in the Background They Write Reports About Me': Understanding the Health Literacy Implications of Allied Health Reports through the Experiences of People With Lifelong Communication Disability

A Plain Language Summary of a Research Study

Who are the researchers?



Harmony Turnbull is a PhD research student at the University of Technology Sydney (UTS) and a speech pathologist with a lot of experience talking to people with disability of all ages.

Harmony's research supervisors are Professor Bronwyn Hemsley from UTS, Dr Ian Skinner from Charles Sturt University, Dr Leigha Dark from Scope Victoria.

You can email Harmony if you want to know more or ask for a copy of the published research paper: Harmony.M.Turnbull@student.uts.edu.au

You can see the published research paper online:
<https://onlinelibrary.wiley.com/doi/10.1111/1460-6984.70216>

About this study

This study is about people with lifelong communication disability. It is about their experiences reading their own allied health reports.

Allied health reports are often about the supports that a person needs because of their health or a disability.

Allied health professionals like speech pathologists, occupational therapists, psychologists, and physiotherapists write these reports.

The researchers wanted to understand:

- Do people get their reports?
- Can they understand and use their reports?
- What changes would make reports easier to read and understand?



Harmony spoke to nine adults with lifelong communication disability for this research.

The people who participated in this research were generous in sharing their stories.

What people said

1. “This is personal”

Allied health reports are about people’s lives, abilities, and support needs.

The research participants said that reading their reports can feel personal and emotional.

➔ People want access and understanding

Some people did not know reports were being written about them.

Some people did not get copies of their own reports.

Even when they did get their report, it was often:

- hard to read
- full of complicated or technical language
- written in ways that didn’t make sense to them

People said reports should be written:

- in plain language
- in accessible formats such as Easy Read
- with clear layout, bigger text, headings, and sometimes helpful images

They also said allied health professionals should ask them what they need to help them understand their reports.

➔ Reading reports can bring up emotions

People described feeling:

- upset
- frustrated
- confused

This happened especially when reading reports that were mostly about problems or deficits.

Some said reading these reports felt traumatic or confronting.

Other people talked about times that were positive when:

- the report was respectful
- the allied health professional included them in writing the report
- the report had information about their strengths



➔ Trust matters

People said they need trusting relationships with their allied health professionals.

Trust grows when allied health professionals:

- listen
- understand their disability
- involve them in decisions
- check information is correct
- give them their own reports before sending them to other people, including the NDIS



2. “These are our documents”

Participants said reports should belong to the person they are written about.

➔ People use their reports to get what they need

Reports often help people to get the supports, therapy, or equipment they need.

People want the reports to be:

- written in a way they can understand
- helpful for achieving their goals

➔ Reports should be accurate

People said sometimes reports:

- have mistakes
- focus on deficits
- leave out strengths
- describe them in ways that do not feel right



Incorrect information often gets reused in future reports.

Some people said that sometimes they don't ask for changes because asking to fix mistakes was too hard.

➔ People want to give feedback

People want allied health professionals to:

- Ask for feedback
- listen to feedback



- make changes to reports
- share draft reports with the person

Some people said experienced clinicians were more collaborative and open to feedback.

What this means for allied health professionals

People in this research said that allied health professionals should:

- Tell people when they are writing a report
- Give people a copy of reports that are about them
- Check with the person to make sure the report meets their needs and doesn't have mistakes
- Write in plain, clear, and respectful language
- Use accessible formats such as Easy Read when needed
- Include strengths and support needs
- Ask for feedback and listen to it
- Be aware that reading a report can be emotional



Why this research matters

People with lifelong communication disability have the right to access their own information in ways they can understand and use it to make decisions and reach their goals.

This research shows that allied health professionals should try to make written information accessible, respectful, and useful.

Reference

Turnbull, H., Dark, L., Carnemolla, P., Skinner, I., & Hemsley, B. (2026). 'I Didn't Know That in the Background They Write Reports About Me': Understanding the Health Literacy Implications of Allied Health Reports through the Experiences of People With Lifelong Communication Disability. *International Journal of Language & Communication Disorders*, 61(2), e70216. <https://doi.org/10.1111/1460-6984.70216>