

# CASE STUDY



## Building partnerships in cerebral palsy research

CP-Achieve is an NHMRC-funded Centre of Research Excellence dedicated to improving the lives of young people with cerebral palsy through research. In a new resource, [Navigating consumer involvement in health and disability research](#), CP-Achieve shares success stories, challenges faced and strategies for effectively involving people with disability in research. Two of these success stories are highlighted in the following case studies.

### Case study 1 - Gaurav Thakkar and James Czencz

Gaurav is a consumer research partner with lived experience of cerebral palsy, and James is a PhD candidate. Gaurav and James worked together to research how physical activity can improve the lives of people with cerebral palsy. Their partnership improved the research and led to a lasting friendship.

When James first approached CP-Achieve for assistance with his PhD, he had no previous experience with consumer involvement in research. CP-Achieve connected James with Gaurav, who had been part of CP-Achieve's advisory group of young adults with cerebral palsy, 'CP Unite', but had not yet worked on a research project in an ongoing way.

One of James' studies involved interviewing adults with cerebral palsy that use wheelchairs about their wants and needs when participating in physical activity. Gaurav gave feedback to James on the style and approach of interview questions. This ensured that the questions were relevant and easily understood by people with cerebral palsy.

Before James started formally interviewing people, he and Gaurav trialled the questions together. At this point, James realised how important consumer involvement was to his research. Trialling the questions allowed James to build skills and confidence and

improve the interview process, guided by people with lived experience.

The research also led to new experiences for Gaurav, including presenting at conferences, and going surfing and snorkeling, while travelling interstate for the first time. Gaurav and James have travelled together twice as part of the research:

**Port Campbell beach inclusion day:** James and Gaurav trialled a range of beach-related physical activities at Port Campbell Beach. This sparked James' interest in developing an aquatic-based physical activity program for people with cerebral palsy in the future.

**Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference:** James and Gaurav travelled to Cairns together to present the results of the research they collaborated on.

Gaurav and James have also made a video about researching together. View the [Building confidence in consumer involvement - YouTube video](#).



Gaurav and James at the Great Barrier Reef.



Gaurav and James co-presenting their research findings at the AusACPDM conference.



*"Gaurav practiced the interview with me, providing feedback on my technique. This was when I learned how beneficial consumer involvement can be to research. It gave me the opportunity to practice the interview, receive constructive feedback and build my confidence before conducting interviews with actual participants."*

James Czencz



# Case study 2 - Involving young adults who use augmentative and alternative communication in research

One-third of people with cerebral palsy have complex communication needs. This means that they cannot communicate through speech alone and use augmentative and alternative communication (AAC). AAC refers to the range of ways a person communicates besides talking. It may be augmentative, meaning that it adds to spoken communication, or an alternative to spoken communication. Examples of AAC tools include text to speech apps, symbol-based communication techniques like picture boards or apps, gestures, facial expressions and [Key Word Signing](#).

People with cerebral palsy who use AAC are under-represented in cerebral palsy research. Sometimes, researchers are hesitant to involve AAC users because they are afraid of saying or doing the wrong thing. This means many people with cerebral palsy face missing out on shaping research that impacts them.

## One Group, Our Voice

CP-Achieve established a consumer advisory group of AAC users to address the gap in their involvement in health research. This group is called One Group, Our Voice. The four group members worked with researchers to co-produce a series of resources to support involvement of AAC users as research partners and participants in research. One Group, Our Voice was involved in all stages of the project, from design right through to sharing the results. Together with researchers, the group members produced:

- an [inclusive research toolkit](#) for involving AAC users in research
- a [journal article](#) and supplementary [plain language video](#)
- presentations and webinars about the resources.

These resources have enabled AAC users to be involved in research projects at CP-Achieve. One of these focused on mental health needs of AAC users. Because the AAC users were involved from the very beginning, they were able to shape the research so that it didn't focus only on mental health problems, but also on promoting positive mental health for AAC users. Their input influenced the research direction to ensure it aligned with the needs and priorities of AAC users. The co-produced resources will also promote inclusion of people with complex communication needs in health and medical research more broadly.



Brenton Ponza



Brodie Shaw



Penelope Manning



Shirley Wong

## What is cerebral palsy?



Cerebral palsy is a lifelong neurological condition that affects the way a person moves and their posture. It is caused by an injury to the brain, which can occur before, during or soon after birth. The symptoms and severity of cerebral palsy vary from person to person. People with cerebral palsy may experience muscle stiffness, uncontrolled movements, difficulties with speech and swallowing, problems with hearing and vision and intellectual disability. Health and other professionals work alongside people with cerebral palsy and their families, throughout the lifespan, aiming to achieve their goals for participation in life and the community.



***“Our aim was to enable young people with cerebral palsy and complex communication needs to shape the priorities, direction, implementation and communication of research which will make a difference to their quality of life, wellbeing and participation, and that of other young people.”***

Megan Walsh, CP-Achieve researcher

