



Autism Research Centre  
Aotearoa New Zealand



## Autistic Partnership Principles

The AP-NZ have developed a set of principles that all members agree to follow. Those not following these principles may be asked to leave the AP-NZ. The principles also apply to interactions with ARC researchers.

- Everyone's input is important
- Include all Autistic perspectives
- Support different forms of communication
- Use Autistic-preferred language
- Respect confidentiality

### Principle 1: Everyone's input is important

The input and feelings of every member of the AP-NZ is important. Members of the AP-NZ do not need to agree with each other, but they must still be respectful. This means giving everyone time and space to share their perspectives. This may also mean compromising when making decisions.

The AP-NZ will always strive to make everyone feel valued and represented. Many members of the AP-NZ have lived experience of being Autistic and of being a member of the wider autism community. They may also be parents, carers, whānau, support workers, educators, researchers, and clinicians.

Many different identities and intersectional experiences are represented in the AP-NZ. Members of the AP-NZ identify with a range of different ethnicities, cultures, gender, life stages, and additional disabilities. The perspectives of those with lived experience of these identities must be appropriately centralised.

### Principle 2: Include all Autistic perspectives

The AP-NZ was founded because there should be nothing about us without us. This means that all research about autism needs to have Autistic input. All Autistic people deserve to be fully included in research. This includes Autistic people with a learning (intellectual) disability or higher support needs.

All Autistic people are individuals with their own individual needs. Some members of the AP-NZ may need individualised supports to have equal access to opportunities to be involved and contribute to discussions.

Sometimes support might come from a support person whose role is to ensure that the Autistic person can fully participate as a member of the AP-NZ. The support person must agree to follow the AP-NZ principles. Always address the Autistic person directly, even if they have a support person assisting them.

Some Autistic people may have a support person who acts as a meeting assistant. They may help translate complex information into something easier for the Autistic person to understand. The support person may also facilitate their inclusion in discussions and help them to provide feedback afterwards.

### **Principle 3: Support different forms of communication**

All members of the AP-NZ should have equal opportunity to participate and understand in their preferred form(s) of communication. This may mean restating information or phrasing questions in multiple ways.

Some members of the AP-NZ may use augmentative and alternative communication (AAC). They may communicate using writing, speech-generating devices, sign language, or visual aids. They may also use multiple forms of AAC or they may use both speech and AAC.

It is important to always presume competence and respect how someone communicates, even if it requires more time. This means not assuming that a person with limited or no speech does not understand. This also means not trying to finish a person's sentence for them or cutting them off if they are using AAC.

Every effort will be made to ensure that all members are fully included in discussions and communications. It may not always be possible to accommodate all forms of communication in all situations. An alternative solution may need to be found, such as live transcription if a sign language interpreter is unavailable.

### **Principle 4: Use Autistic-preferred language**

Members of the AP-NZ agree not to use terms that could be harmful, excluding or stigmatising to others. Instead of using function or severity labels, please refer to specific support needs and experiences.

Individuals may have their own preferences for the language they use for themselves. These should be respected. If individuals cannot be asked for their personal preferences, use the community preferences.



The ARC and AP-NZ follow Autism New Zealand's Autism Terminology Guidance from the Autistic Community of Aotearoa New Zealand. This guide can be accessed here: [Autism Terminology Guide](#)

### **Principle 5: Respect confidentiality**

Everyone's right to privacy and confidentiality must be respected. The names and contact details of AP-NZ members will not be shared with anyone without the members explicit permission.

Any information shared by ARC researchers must be treated as strictly confidential. This means that details and discussions of research projects must not be shared with people outside of those projects.

Sometimes multiple members of the AP-NZ may be in hui together. Members of the AP-NZ must not share any personal information or the content of discussions outside of the hui, including who attended the hui.

**Any breach of confidentiality should be reported immediately** to either:



The AP-NZ Chair: Ruth Monk at [ruth.monk@canterbury.ac.nz](mailto:ruth.monk@canterbury.ac.nz)

The ARC Director: Professor Laurie McLay at [laurie.mclay@canterbury.ac.nz](mailto:laurie.mclay@canterbury.ac.nz)