

Advocating for yourself

As an autistic person, getting what you need from disability support organisations and other service providers can be difficult and seem impossible. Learning self-advocacy skills can be vital to having your needs met by service providers. This is deeply unfair, but the more that autistic people and their support networks[Lv1] advocate for themselves, the more disability agencies and service providers will be forced to recognise that they need to be accessible to autistic people, and make changes to meet the needs of the autistic community.

Learning to advocate effectively for yourself can be a long, difficult process. Below are some strategies to start building your self-advocacy skills:

- Know what you're entitled to. Some organisations may not have clear guidelines, but others will have concrete rules about what they are supposed to provide for you. Reading through an organisation's rules and guidelines and working out which ones apply to you before you interact with the organisation can help to stop you from being confused or intimidated out of getting what you need. (Some organisations use complex language, or link to legislation; if you're not sure what something means, ask a friend or whānau member to help you. You can also contact an advocacy organisation to help you out – there is a list at the end of this resource.
- Make a list before your appointment. Interacting with disability services can be confusing, upsetting, and overwhelming – writing down everything you need to talk about and what you want from the service can help you remember everything. It can also help to organise your thoughts beforehand, and prioritise what you want to talk about.

- Schedule some downtime after interacting with services. Advocating for your needs in a system that is not designed for you is exhausting! As much as possible, make sure you have time to rest and recover from interacting with disability services.
- Get comfortable standing up to service providers. Preparing some scripts beforehand can help, and so can roleplaying through the encounter with a friend or whānau member. (If this is something you really struggle with, roleplaying it through a few times and asking the other person to be increasingly harsh can be a good way to build yourself up to the real interaction.)
- Take a support person if you need one. This could be someone supporting you in an official capacity, like a WINZ advocate or a support worker; or it could just be a friend or whānau member who's good at keeping meetings on track and standing up for themselves.
- Take notes at meetings, or bring a support person to take notes for you. As well as helping you remember what was discussed and decided, this can be useful when pushing back against a service provider that is trying to take back support.
- Don't be afraid to escalate issues. This could mean asking to speak to a manager, or making a formal complaint against a service provider. Remember that it's the service provider's job to provide you with a service – if they're refusing without a good reason, then they should expect escalation.

There are a few organisations that can help advocate for you when dealing with disability agencies and other service providers:

The Nationwide Health & Disability Advocacy Service can help you understand your rights, find an advocate, make a complaint about a service, or just listen to your experiences.

<https://advocacy.org.nz/>

CCS Disability Action is Aotearoa's largest disability-focussed support and advocacy organisation, and can help you advocate for yourself and get the support you need.

<https://www.ccsdisabilityaction.org.nz/>

Community Law can help you fight an unlawful decision by a service provider, or help you work out what you are entitled to.

<https://communitylaw.org.nz/>

There are several advocacy services in various regions that can help you navigate Work and Income.

- The Beneficiary Advisory Service (BAS) in Christchurch and Waimakariri: <https://www.bas.org.nz/>
- Hutt Valley Benefit Education Service Trust (HV BEST) in Wellington and the Hutt Valley: <https://hvbest.co.nz/>
- Beneficiaries Advice Mt Albert: <http://bama.org.nz/>
- Beneficiaries Advocacy & Information Service in the North Shore and Rodney districts (also available for phone consultations from outside those areas): <https://www.bais.org.nz/>
- Vaka Pasifika in Auckland, providing advocacy and support for Pacific families: <https://www.vakapasifika.org.nz/>
- Peoples Advocacy in Hawkes Bay: <https://www.advocate.org.nz/>

Your local Autism New Zealand Outreach Coordinator may also know of other advocacy services in your region – you can find a list of Outreach Coordinators by region here: <https://autismnz.org.nz/support-from-us/>