



Self-Advocacy Te Hapahapai-Whaiaro

Writer – Timothy Folkema

Understanding Self-Advocacy

Many autistic people who receive a diagnosis are sent on their way with little or no community connections or links to support services. Many autistic people are also peer or self-diagnosed, this being equally valid; equitable or perhaps greater supports will be required as there may not be many, if any, external supports in place.

As autistic identity is often developed through community discussion and interaction it can be challenging for autistic people to know, or discover, 'what it means to be autistic.' Being able to advocate for yourself and your needs, when you have difficulty in identifying those needs within yourself, can present a barrier to engaging with mainstream services. Therefore, peer-connectivity can go a long way to help autistic individuals understand how to better advocate for themselves – particularly in situations where they are unable to have support people with them. Equitable and flexible supports; external non-autistic people or staff, internal autistic staff, or peers, family/whānau and professionals should be employed as and where required to help impart self-advocacy skills.

A large percentage of the time spent during study will not be with other neurodivergent (ND) learners or ND tutors and staff who 'get it' and have a great or even limited knowledge of being autistic. This is why being able to advocate for oneself and one's needs is crucial. It can be very tiring to have to explain diagnosis and meaning such as, 'what does being autistic mean to you?' repeatedly. Patience and care must be taken when requesting this information from a student.

Survey Findings

Learners in our survey felt that they faced challenges with self-advocacy in many aspects of their tertiary experience, including disclosing their diagnosis, accessing support from disability and student learning services, communicating their needs, and having these needs understood, in addition to accessing mental health support.

Disclosure

Some autistic people are well-connected to their peer groups and/or organisational supports and have a level of understanding of their diagnosis. However, many learners are undiagnosed, or are diagnosed and not receiving support from peers or organisations.

Autistic people may be uncomfortable with sharing their diagnosis/es, so utmost care and privacy is important to ensure the best outcomes.

As one parent put it: "My son was not comfortable approaching support services unfortunately and as a result some things were much harder than needed."

Learners may be comfortable meeting with Disability Support Services (DSS) but not disclosing anything to their tutors. It is important to note that disclosure should be initiated by the student themselves, rather than by a parent, for example, as external disclosure could be seen as a breach of trust. It may be helpful to work with the student alongside a parent or caregiver, or autistic peer, permission granted.

It is important for DSS to be aware of what supports and community/peer groups are available in your area, as the best supports for autistic people are often autistic-led supports.

It may also be helpful for DSS to indicate whether they hold facility and resources to support learners who are not formally diagnosed as well. Many autistic people are unable to access formal diagnoses due to a variety of economic and well-being related factors. Undiagnosed autistics are equally deserving of support.

"I perceive that there could have been better support available if my son had been willing and able to access it. Identifying as autistic is not easy and there is fear about how that will be received. It would be great for inclusivity to be known."

Finding and Receiving Support from Disability or Student Learning Services

Family/whānau have felt in the past that learning support services were either not available, or, where they were available, learners did not know about them, did not have enough support from services or services were difficult to access.

One comment for our recent survey reads: "No idea what support might be available. We have assumed that autistic people are probably unwelcome and are the ones the University wants to screen out with their interview admissions."

It is important from the get-go to note in accessible external literature that all persons with disabilities and neurological differences are welcome; particularly using the term 'autistic' as this will resonate more clearly with autistic potential learners.

If an autistic person identifies themselves to DSS or Student Learning Services, a meeting may need to be called to discuss the individual's needs. This first meeting is critically important. One must be aware of sensory-related issues such as lighting, temperature, sounds, smells, etc. For example, can the meeting be done in a quiet, low-lit, room? How busy is the access to this space? Can an autistic or neurodivergent support person be present?

If the first meeting goes well, and a study support plan is implemented, it may be useful to have regularly scheduled catchups to review progress and supports. It will not be fully possible to identify up-front what needs require accommodation, as the student will need time in the course to figure these things out. As many autistic people function better with routines, any catch-up sessions should be well-planned in advance, and preferably at a regular time each month or two – depending on the level of support required, i.e., same time, same day, etc.

Communicating Needs and Having Individual Support Needs Understood

Autistic learners may have difficulty translating their experiences and needs into neurotypical language. This could be frustrating for the student and challenging for the support services. If the student permits, having a neurodivergent support person or a parent/caregiver present may help in interpreting these needs during an initial needs assessment and during any further catch-up sessions.

One parent wrote: *“Information needs to be passed on between tutors. Yes, I know there is a privacy act but if as a parent you have to contact every tutor it becomes very challenging.”*

Flexible, Easily Accessible Support Available for Mental Health Needs

Some useful questions to ask:

- Does the campus offer counselling and other health-related supports as physical health can impact significantly on mental health? One parent wrote: “When it became clear that he needed support for his mental health, the support wasn’t there.”
- What organic/peer and organisational supports are available in the community?
- Is there an on-campus peer group for neurodivergent learners? One student mentioned that they would like “Access to communication with other disabled/autistic learners”?

Answering these questions can benefit all learners, although it might particularly benefit neurodivergent learners. In this way, a roadmap of internal and external supports can be offered to incoming learners who may benefit from these extra supports. Tying-in with International or Queer/Rainbow groups and community networks where applicable is also useful as the needs of these often-intersecting groups can be similar in nature and support can be shared.

Training is available for better understanding around autistic matters such as that offered by Altogether Autism. It is suggested that tutors and support services staff access this training and any other training available on mental health and well-being.

One survey respondent wrote that they would like to see, “Understanding of autism, neurodiversity generally and anxiety, social implications. Set up of support systems that are easy to access, information, support groups?”

You Can Support Your Learners by:

- **Making sure learners have access to the full range of supports available.** This includes student-tutors, dictation/note-takers, and reader/writers, etc., alongside regular scheduled access to disability support staff.
- **Making recorded content available.** It is important to note that autistic learners may work their best if they can tailor content reception to their own internal schedules and energy levels. Whilst this is not always practical, any opportunity to do so could help the student with relieving stresses and/or anxieties relating to timeframes, etc.
- **Making sure you are openly supportive and approachable.** Ensure that your learners know the best way to approach you and make sure they have information on how to approach Student support services.

Final Words

A greater understanding from you as educators goes a long way to ensuring a student feels welcome, valued, and confident to ask for help. Not all autistic folk will be formally diagnosed, and they deserve as much support and care as those who have a formal diagnosis.

Further Reading

[On Being Authentically Autistic – Altogether Autism](#)

[Learning to be ourselves – Altogether Autism](#)

[Unmasking in the workplace – the late diagnosed autistic dilemma – Altogether Autism](#)

Meet Timothy Folkema



Timothy Folkema is an autistic person and a member of the Altogether Autism Consumer Advisory Group. He continually works to share the voice of autistic people and make positive ground-breaking changes for the Autistic communities of Aotearoa New Zealand, working with many organisations to achieve this.