

# Altogether Autism Supporting Autistic Tertiary Learners



## EXECUTIVE SUMMARY

The Tertiary Education Commission / Te Amorangi Mātauranga Matua (TEC) approached Altogether Autism as it had identified a gap in information for tertiary educators around best practice to support their autistic learners. TEC contracted Altogether Autism to consult, research and design a set of guidance documents (Guides) to assist tertiary educators to understand what autistic learners need from them to support their educational journey.

There are six main topics, based on common themes that emerged from the consultation process. Lived experience, published research and educational best practices inform the Guides.

Altogether Autism consulted with three key groups:

1. Autistic learners with experience on tertiary education
2. The family/whānau of autistic learners with experience of tertiary education
3. Tertiary educators and support staff.

Overall, autistic and the family/whānau of autistic responders felt the key areas requiring more support

and understanding were around communication needs, executive functioning needs and self-advocacy.

Family/whānau also talked about the difficulties in finding and accessing support, and the lack of understanding and knowledge for anxiety and mental health issues.

The Guides offer information and strategies under six themes:

1. Communication
2. Executive Function
3. Self-Advocacy
4. Sensory Experiences
5. Mental Health
6. Social Interactions

### TOP TIPS

Altogether Autism identified 10 top tips to help lecturers and tutors better support their autistic learners. These tips cut across the themes: for example, access to lecture recordings helps learners who cannot attend class on campus due to anxiety or sensory difficulties and makes the material more accessible for s who struggle with note taking due to executive function difficulties.

Remember that these tips help all learners, not just autistic learners. All learners benefit from access to lecture recordings, for example. There are also many self-identified or undiagnosed autistic people who would benefit from support but may be unable to access this without an official diagnosis. By building as many supports as possible into the way the course is taught and assessed, you give all learners the best chance of success in tertiary education.

Listen to what each individual learner needs. Not everyone has a diagnosis: diagnoses are difficult to access as an adult and learners who did not get a diagnosis in childhood still need support. Rather than making exceptions/accommodations only when required to do so because the learner has a diagnosis, recognise the individual need of diverse learners.

Be openly accepting of difference and recognise that every autistic person is different and may have diverse needs. Encourage awareness and acceptance of neurodiversity.

Offer different options and accommodations around tutorials, assessments, and exams. Think about group work – is it essential? Can you offer different options? If group work is a non-negotiable part of your course, think about ways you can make it less stressful and more reflective of the real world. What exam accommodations does the individual need, and can these be implemented, even if they are not standard accommodations offered by student support? Can tutorials be offered in different formats (e.g., on campus, on Zoom, via discussion board)?

Always make lecture recordings available online. - Access to lecture recordings helps with so many of the challenges autistic learners faced. They allow learners to catch up if anxiety or burnout prevents them from attending class in person. They mean learners can watch lectures from an environment that meets their sensory needs. They help learners who have difficulties with executive function - being able to pause and rewind the lecture makes taking notes easier.

Ensure all communication is clear. Present written and verbal communication in a manner that works for and is understood by the autistic learner. Understand that communication might be difficult even though the person may seem to understand, and check that they have understood.

Validate the need for flexibility around supports and needs. Work with the learner to identify what works best for them, and work with them to help them meet the requirements of the course in a way that works for them.

Encourage and normalise the use of sensory aides in all places, including exams.

Encourage disclosure. Autistic people may be uncomfortable with sharing their diagnosis/es, so utmost care and privacy is important to ensure the best outcomes. Being openly accepting to difference can encourage sharing. Support learners to access accommodations regardless of diagnosis. Listen to what learners say would help them. Encourage your organisation to support learners whether they have a diagnosis or not.

Recognise sensory needs. The tertiary learning environment may be difficult for some learners: they may find lecture theatres overwhelming or spaces noisy. They may only be able to cope with being there for a short time or may not be able to learn in that space. Recognise and make allowances for this, for example by allowing the person to leave if they need to, providing information in other ways, and making use of sensory profiles.

Recognise executive functioning difficulties and offer supports around these.

## NGĀ TINO WHAKAMŌHIO

Kua tautohu mātou i ētahi tino whakamōhio tekau hei āwhina i ngā kaikauhau me ngā kaiwhakaako ki te tautoko i ā rātou ākonga whaitakiwātanga. Ka whiti ēnei whakamōhio i te whānuitanga o ngā kaupapa: hei tauira, te āheinga o ngā hopunga kauhau ki te āwhina i ngā ākonga kāore e taea te tae ā-tinana ki te akomanga nā te manawapā, ngā taumahatanga tairongo rānei, kia māmā ake ai hoki ngā kauhau mō ngā ākonga he uaua ki a rātou te tuhi kupu tīpoka nā te taumaha o te whakahaere whaiaro.

Kia maumahara tātou, ka āwhina ēnei whakamōhio i ngā ākonga katoa, ehara ko ngā ākonga whaitakiwātanga anake. Hei tauira, he āwhina nui ki ngā ākonga katoa te āhei ki te toro atu ki ngā hopunga kauhau. Arā atu anō te tokomaha tāngata kāore anō kia whakatauria he whaitakiwātanga rātou, nā rātou anō i whakatau rānei, ka whai painga i te tautoko, engari kāore pea e taea te toro atu nā te kore whakataunga haumanu ōkawa. Mā te hanga o te maha o ngā tautāwhi e taea ana, i ngā whakahaere o te akomanga me ngā aromatawai, ka piki te angitu o ngā ākonga katoa e whai ana i te mātauranga matua.

Whakarongo ki ngā kōrero o ia ākonga mō ōna hiahia. Kāore he whakataunga o te katoa: he uaua te whiwhi ki ngā whakataunga mō ngā pakeke me ngā ākonga kāore i whakataungia i te wā e tamariki ana, engari e tika



ana kia tautoko atu i a rātou. Mahue kē te tangongi/whakangāwari ina kua herea nā te whiwhinga o te ākonga ki te whakataunga, engari me tautoko ngā matea whaiaro o ngā ākonga kanorau.

Kia tuwhera ki te whakamana i te rerekētanga kia āhukahuka hoki he rerekē tēnā tāngata whaitakiwātanga ki tēnā, ka rerekē hoki pea ngā matea. Whakahaua te āhukahuka me te ngākaupai ki te kanorau ā-roto.

Tukuna ngā kōwhiringa me ngā ara tautoko e pā ana ki ngā akoranga, ngā aromatawai, ngā whakamātautau hoki. Whakaarohia te mahi ā-rōpū – he mea waiwai tērā, ka tika? Ka taea te tāpae ētahi atu kōwhiringa? Mēnā kāore he kōwhiringa mō te mahi ā-rōpū i tō akoranga, whakaarohia ngā ara hei whakaheke i te tāmitanga, kia kaha ake te whakaata i te ao tūturu. He aha ngā whakangāwari whakamātautau ka matea e te kiritahi, ka taea rānei te whakatinana, ahakoa ehara pea i te whakangāwari māori ka tukuna ai e te rōpū tautoko ākonga? Ka taea te whakaako mā ngā momo akoranga kē (hei tauira: kei te akomanga, kei runga Zoom, kei tētahi papa kōrero ā-ipurangi rānei)?

Me whakaū ki te tuku i ngā hopunga kauhau katoa ki te ipurangi. - Ko te āhei ki te toro atu ki ngā hopunga kauhau he āwhina nui mō te maha o ngā wero e pā atu ana ki ngā ākonga whaitakiwātanga. Nā tērā ka taea e ngā ākonga te mahi te whakatutuki, ki te āraia te taenga atu ā-tinana e te manawapā, e te whakapaunga kaha rānei. Ka taea e ngā ākonga te mātakitaki i ngā kauhau i te wāhi e tika ana mō ō rātou matea tairongo. Ka āwhina hoki i ngā ākonga kua uaua te whakahaere whaiaro - ka taea te pupuri, te whakahoki rānei i te hopunga kauhau, kia ngāwari ai te tuhi kupu tīpoka.

Whakaūgia kia mārama rawa ngā whakawhitinga kōrero katoa. Tukuna ngā tuhinga me ngā kōrero

ā-waha kia pai te hanga mō te ākonga whaitakiwātanga (ka rerekē pea tēnei mō ngā ākonga rerekē), kia whai mārama hoki te ākonga. Kia mārama koe, ka uaua pea te whakawhiti kōrero, ā, ahakoa ki tō tirohanga atu, kua mārama te tangata, me hihira koe kua mārama rātou.

Whakaūgia ngā whakaritenga mō te pīngore o ngā ara tautoko, ngā matea hoki. Mahi i te taha o te ākonga, ki te tūtohi i ngā mea e tika ana māna, ā, mahi tahi hoki ki te āwhina i a ia ki te whakatutuki i ngā herenga o te akoranga mā ngā tikanga e pai ana mōna.

Whakahaua, whakapikitia te whakamahi i ngā taputapu tairongo ki ngā wāhi katoa, tae ana ki ngā whakamātautau.

Whakahaua te whakapuakitanga. Ka anipā pea ngā tāngata whaitakiwātanga ki te whakaatu i tō rātou whakataunga nā reira he mea hiranga te āta tiaki, te āta tūmataiti hoki kia whakaū ai he pai rawa atu ngā otinga. Mā te whakaae ki te rerekētanga, te whakaatu e whakamanawa. Tautokona ngā ākonga kia whiwhi whakamāmātanga ahakoa te whakataunga haumanu. Whakarongo ki ngā kōrero a ngā ākonga mō ngā mea e āwhina i a rātou. Whakahaua tō tari ki te tautoko i ngā ākonga, ahakoa he whakataunga ōkawa, kāore rānei.

Āhukahuka i ngā matea tairongo. He uaua pea te ako ki ngā whare mātauranga matua mō ētahi o ngā ākonga, tērā pea ka haukerekere ngā wāhi kauhau, ka hoihoi rānei ngā wāhi. Tēnā pea ka taea e rātou te noho ki taua wāhi mō te wā poto noa, kāore pea e taea rānei e rātou te ako ki taua wāhi. Āhukahuka kia manawanui hoki ki ērā, hei tauira, tukuna te tangata kia wehe atu mēnā e hiahia ana, tukuna ngā pārongo mā etahi atu ara anō, whakamahia ngā mahere tairongo hoki.

Āhukahuka i ngā uauatanga whakahaere whaiaro, ā, tukuna he tautoko e hāngai ana.





## AUTISTICS CAN CHANGE THE WORLD

Alex\* thinks universities would be far more welcoming spaces for everyone if there was an autistic lens applied over all of them.

The 45-year-old wants to continue her psychology studies but is prepared to put her master's off if 70-80 per cent of the course must be in person.

It is something her lecturers are insistent would be better for her, but Alex (not her real name) knows otherwise.

The mother-of-two was diagnosed with autism five years ago, something of a relief given she thought for more than 30 years that she had an intellectual disability.

She started university in 2020 picking up one paper originally and then more as her A grades showed she was anything but stupid, which is what teachers at high school told her she was.

In those early university days, before Covid restrictions kicked in, Alex attended on campus classes.

"I could hear the lights sounding like they were screaming at me; those fluorescent lights and I could see them flickering.

"For me that was a massive challenge in the beginning and then a lot of people flicking their pages, clicking their pens, and kicking the back of the seat and I couldn't even concentrate.

"Even the air conditioning would go cold and then hot. I would find myself so focused on the sensory input it was very difficult to even hear what they were saying in real life."

If she could avoid going in, she did and then lockdowns came.

"Luckily, I could do it online and that became very easy for me. I didn't have to deal with people. It takes the anxiety completely away."

*"I want to harness the good things about autism. What I've found out now through studying psychology is that autistics would like to change the world. And we can," she says.*

Alex can adjust her own lights, get herself a cup of tea, check if she is warm enough and then put her full focus into her studies.

"It makes a massive difference.

"They pushed it at the beginning that you have to come to the lectures. I asked whether I would be penalised and even when I say that I'm

autistic, they are still insistent it would be better for me. But it's more for their own sake."

Alex wants universities and tertiary institutions to consider the needs of hypersensitive people like her and to introduce compulsory seminars for lecturers and teachers about autism and neurodiversities.

"Where the problem is with the individuals – the lecturers etc are just not educated at all. The lecturers think they know it all and when it comes to considering other ways, they might be set in their ways."



Alex makes a point of letting lecturers know she is autistic but for most it makes very little difference.

"I think people relax a bit and then they just think you're weird."

Student services were outstanding. "When I needed more time on tests, they helped me navigate that, told me how to get extended times etc."

She likes to be given course notes as pdfs and then she has an app which converts them into audio and she can listen. Student services put her onto how to access other people's notes to do that.

"The lean towards making education more accessible to everybody is good but the problem is with the individual lecturers."

Alex believes there is a gross misunderstanding in tertiary institutions around autism and the abilities of autistics.

"There is incredibly still quite an ignorance – even when I was 13 and in school, they thought I was intellectually disabled. I'm quite traumatised by what happened in school."

"Even now in psychology I get that same feeling that's what they are thinking."

That is why online studies are so good for her; she has the space to operate and focus.

"When I can use those autistic traits I have – if I can use those traits, my work is easier, I do it faster and I get better grades."

Alex says when she finishes her studies, she wants to improve the lives of autistics, make people understand what it is like for all sorts of people outside the mainstream.

*\*Alex is not her real name.*



## TERTIARY JOURNEY MADE EASIER FOR AUTISTICS

It took Rachael Wiltshire nine years to complete her tertiary education, but it could easily have taken half that time if she knew then what she knows now.

Rachael graduated last year with a Bachelor of Creativity in Commercial Dance from Te Kāhui Auaha in Wellington and currently dances at events around the capital.

Her educational journey as an autistic student was fraught with challenges and she is now using what she learned to help other students facing similar predicaments.

The Altogether Autism autistic advisor has helped research and write six guides commissioned by the Tertiary Education Commission (TEC) aimed at lecturers and tutors in tertiary institutions to understand what autistic learners need from them while studying.

"We surveyed 99 autistic tertiary students and whilst their comments often made for harrowing reading, it was also validating to see that I was in no way the only person who had struggled in these ways," said Rachael.

She and others at Altogether Autism analysed the results and concluded the most critical areas that required more support and understanding in tertiary institutions were around communication needs, executive functioning and self-advocacy.

Autistic students and their family/whānau also commented strongly on the difficulties in finding and accessing support, and the lack of understanding and knowledge for anxiety and mental health issues.

Tertiary Education Commission chief executive Tim Fowler said learner success was a priority for the commission.

"We have large groups of learners who are currently underserved by the tertiary education system, including neurodiverse learners, and we need to change that.

"TEC is working with a range of organisations including Altogether Autism to develop resources for tertiary organisations so they better understand the specialist needs of neurodiverse learners and can develop systems to support them complete their education," he said.

Whaikaha – Ministry of Disabled People chief executive Paula Tesoriero said she was pleased to see the Tertiary Education Commission had engaged with people working in the autism community to develop guides.

"I would like to acknowledge the autistic learners that contributed to this important mahi by sharing their knowledge and experience," she said.



*Tertiary Education Commission  
chief executive Tim Fowler*

*Whaikaha – Ministry of Disabled  
People chief executive Paula Tesoriero*





## OPEN SPACE LEARNING

Anne\* likes classrooms because they have walls. She can sit at the front, know exactly where the lecturer is, sit next to them and concentrate.

So, when open plan learning was introduced at the tertiary institution she attended, Anne (not her real name) was furious.

“Only one teacher is teaching and you can focus. I wanted somewhere I could put my back to the wall or know where the teacher was going to stand so I could sit next to them. That way I can focus and not get distracted.

“I’d know which way the room’s going to be and it doesn’t change on me.

“With open plan, four lectures could be going on at once.

“I heard more of the other lectures than my own. It was so loud all the time because every conversation in the entire room, you could hear,” says Anne.

“I complained every semester and got nowhere.

“‘Dude,’ I’d say, ‘you could easily put a door on that room, get me a door! I will build it for you. I will buy the timber and put a door in there.’ And nobody listened to me.”

Anne, 26, finished her civil engineering degree six years ago and was diagnosed as autistic soon afterwards.

She is not using the degree and is currently unemployed after working at several unrelated jobs, mostly in retail.

“Open plan wasn’t necessarily an autistic thing; it was an extrovert vs introvert thing. Half the population was not happy with this move,” said Anne.

“A lot of the teachers when they found out they were teaching in those rooms, they petitioned to move.”

The three-year degree took her four years because of the challenges put in her way – open plan learning was just one of them, the others included crippling endometriosis and depression, which she believed were linked.

The medication for her intense period pains, which she experienced since she was 12, made her depressed.

“Everything was grim,” until an endoscopy resulted in her finally having surgery three years ago. She was still depressed though, and it was while she was under the service of Adult Mental Health, the autism diagnosis came about.

Anne liked attending lectures when she was at her tertiary institution, until the introduction of open plan but there were other issues which six years later, she can reflect on.

Student support services were hard to access; counsellors seemed unobtainable and so she relied on her own general practitioner (a male) for help.

“I scraped by, I got medical deferrals, but I needed help. I wish they would have told me what was available. I didn’t quite know what they did.

“Don’t just say we have this thing over in the corner – tell us what they do,” she said.

“I liked the lecturers that did exercises. They gave us a problem and gave us time to work on them.

“I liked the ones who said, ‘come talk to me if you’re having any problems.’”

Anne says there were lecturers who just read their slides, they were fixed on their presentation and that was that.

“That was absolutely horrible and they tell them not to do that.”

Six years on, Anne describes her tertiary studies as “fairly neutral.”

“Some lecturers were good, some didn’t get it, I was undiagnosed at the time and those open plans and I didn’t know how to access the counsellors so I went to my doctor and my doctor wasn’t linked to where I was studying. The lecturers who I told didn’t seem to know how to do anything either. That was my experience,” she says.

*\*Anne is not her real name.*



## PREPARATION THE KEY TO TERTIARY SUCCESS

Damien Peers is about to enter the workforce with a Diploma in Science from Waikato University and admits it would have been harder had it not been for the “accepting” lecturers he encountered.

His journey through tertiary studies was made easier by a formal diagnosis of autism when he was in Year 12 which meant he could tap into Accessibility Services at the university.

And he credits Helen Kato, his Year 13 English teacher at St John's College in Hamilton who is also the school's dedicated Special Needs Coordinator (SENCO), for preparing the way.

Damien, 21, was born in South Africa and moved to New Zealand with his family in 2010.

Being told he was autistic explained why he had issues in the classroom and in life.

“When I got to high school, I was finding it was taking me longer to write tests and stuff. I'm mainly a slow writer because it takes me a long time to process things sometimes. I was good at science, maths and stuff so long as I could follow the process.”

He was always interested in science and biology but struggled with National Certificate of Educational Achievement (NCEA) getting a mix of achieved and not achieved in English.

But that changed in Year 12 when smaller class sizes and extra attention from his teacher, saw him achieve his first merit in English.

“She helped a lot and the extra time gave me the ability to get things done. It was gold. I was so lucky in Years 12 and 13. Those are the years I started getting merits in English.”

Before he left secondary school, Helen Kato introduced him to Accessibility Services at the university. Its role is to support students with impairments to be successful in their studies and to ensure the university is inclusive and accessible.

“I had a meeting with them and was able to chat with them about how I learn best.

“Settling in wasn't too bad. Early on they got me 10 minutes for every hour extra, that still wasn't enough. I wasn't finishing all my assignments,

so they were able to get me 25 minutes for every hour extra and then I was able to get a lot more done.



“The lecturers were very accepting and happy to help any person who needed help. I found them very supportive.”

Covid lockdowns and studying online complicated things for Damien.

“Certain aspects were easy online, some of the tests I was getting more done probably because I could have more notes etc.

“It was a bit sad though because we missed all the practical stuff that I really enjoy like working in the lab and doing fieldwork,” he says.

“Socially I'm quite confident. I've been told sometimes I might repeat myself. Otherwise socially I can hold a conversation. It's just mainly the processing, slow writing skills that I struggle with.”

He completed his diploma in July 2022 and is now going to interviews to do what he likes best.

“I enjoy the practical fieldwork than trying to write reports. With reports I struggle to get the structure right.”

Damien's advice to other autistic students is to follow your heart, know what you are good at and know what you enjoy.

“Otherwise, it's going to be a real battle. I hear some (autistic) people barely get out of high school.

“But I was lucky, I was well prepared.”

There were some difficulties, but he overcame them.

“There have been times I have been quite down and sad through my experiences. But most of the time I've been able to find a solution that works for me.”

Talking to family members and accessing university services helped.

That desire to get into the workforce and his struggles with writing assignments was why he went for a science diploma rather than a degree.

***“That's probably me done at university. You never know in 10 years but at this point I'm ready to start working.”***

## SPECIAL ROLE FOR SENCO IN TERTIARY JOURNEY

Helen Kato was taken by surprise when former student Damien Peers singled her out for mention because of her role in guiding him through secondary school and onto tertiary studies.

Helen is the Special Educational needs coordinator (SENCO) at St John's College in Hamilton. All mainstream schools must ensure they have a qualified teacher designated as a SENCO.

The role is a pivotal leadership role for ensuring that students with high needs have the learning programmes and support they need to achieve at school.

We asked Helen to tell us about herself, why she became a SENCO and what that involves.

"I went to Taupo-nui-a-tia College, received my Master's degree and teaching qualification at Waikato University and have been at St John's College since 2017.

Before that I spent time at the Institute of Professional Learning at Waikato University on a contract as a literacy facilitator for the Waikato and Bay of Plenty. I was also Head of Faculty at Te Kauwhata College and English and Japanese teacher at Morrinsville College.

I moved into the SENCO role fulltime recently as it became vacant within St John's and I thought I might be able to make a difference for the boys who struggle.

Support from the principal and board is essential in terms of time to do the work, funding for the support staff, encouraging innovation, collaboration etc.

It is the most rewarding job I have ever done.

I have been a teacher for many years and the ability to contribute to student success at a systemic as well as a personal level is magic.

The role involves working with outside agencies (both Government and private), tertiary institutions, parents, caregivers, teachers across the educational spectrum, kahui ako, deans and counselling staff, all to support the student to be the best that they can be.



***My advice to parents and whanau is to find a school where there is success and collaboration.***

Because I have never had this role at any other school, I am unsure if the special nature of St John's College – it is a Catholic state integrated school - makes it easier for a SENCO.

However, I do think the support that comes from the board and the principal is there because of a fundamental belief in equity and fairness and support of each other within the St John's community.

Seeing this in practical actions as well as just in theory is very positive.

The expectation on all staff to live by these principles reinforces and strengthens the SENCO role and ability to work effectively.

My advice to parents and whanau is to find a school where there is success and collaboration.

Support from principal and board and other staff is crucial, both in terms of funding and time.

I was shocked that Damien singled me out because he was so easy to work with.

I just needed to have a listening ear, give constructive, structured and focussed feedback and some flexibility in terms of deadlines and giving him time.

To be honest this was the same way I treated all the boys in his class.

I deal with tertiary providers as and when I need to.

I just plunge in and contact them with my questions, concerns and add this new knowledge to my kete for the benefit of the students in front of me now, and those to come.

I find tertiary providers to be helpful, knowledgeable, and full of information, once I have made contact with the right person.

The only mission is finding who that is!!!"