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DEVELOPING AND DISSEMINATING GUIDES FOR TERTIARY EDUCATORS
ON AUTISTIC LEARNERS' NEEDS IN AOTEAROA NEW ZEALAND:
REFLECTIONS AND RECOMMENDATIONS

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DEVELOPING AND DISSEMINATING GUIDES FOR TERTIARY EDUCATORS ON AUTISTIC LEARNERS' NEEDS IN AOTEAROA NEW ZEALAND: REFLECTIONS AND RECOMMENDATIONS

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INTRODUCTION

Over the past two decades, researchers have paid increasing attention to the experiences of autistic students in tertiary education (Accardo et al., 2019; Anderson et al., 2017, 2020b; Anderson et al., 2018, 2020a; Cai & Richdale, 2016; Sarrett, 2018). Much of this research has focussed on the US and UK, whereas research into the tertiary education experiences of autistic students in Aotearoa New Zealand has been limited. Anderson et al. (2020a) surveyed autistic university students in Australia and New Zealand; as only 13 of the 102 respondents had studied in New Zealand, the data from both countries was combined for analysis. In a separate study, the same authors interviewed 11 autistic people who had previously studied at an Australian or New Zealand university, with only one participant having studied in New Zealand (Anderson et al., 2020b). Finally, a thesis submitted for the Master of Applied Psychology in Behaviour Analysis at the University of Waikato examined distress and coping skills in students who had an autism diagnosis, and those who had no diagnosis but showed high levels of autistic traits (Bruwer, 2019). The vast majority of the 430 respondents were studying at universities in Aotearoa New Zealand, with two studying at polytechnics.

The Tertiary Education Commission | Te Amorangi Mātauranga Matua (TEC) is the Crown entity responsible for funding and monitoring the performance of Aotearoa New Zealand's tertiary education sector (Tertiary Education Commission, 2021). The TEC's Ōritetanga Learner Success programme acknowledges that the sector does not work well for many groups of learners, including disabled learners, and aims to create a tertiary education system that works for everyone (Tertiary Education Commission, 2022). As part of this work, the TEC recognised that information for tertiary educators in Aotearoa New Zealand about best practices for supporting autistic learners was lacking. They approached Altogether Autism, a New Zealand-based autism information and advisory service, to create appropriate resources for this audience ('Guides').

The Guides were developed throughout the first half of 2022 and were published on Altogether Autism's website in September 2022 (Corlett et al., 2022). Since their publication, we have delivered workshops to raise awareness about the Guides amongst tertiary educators in Aotearoa New Zealand. Here we reflect on what we have learnt from the process of writing and publicising the Guides, and make recommendations for others seeking to translate research on autistic learners' tertiary experiences into practice.

AUTHOR POSITIONALITY

This project involved surveying and analysing data from autistic tertiary learners, their support people and tertiary staff in Aotearoa New Zealand, using that data and other research to develop the Guides, and increasing awareness about the Guides by delivering workshops to tertiary educators. Rachael Wiltshire wrote this paper. She has been involved in all stages of the project: providing feedback on the proposed survey questions and on the initial data analysis, writing three of the Guides ('Communication,' 'Mental Health' and 'Social Interactions') and designing and presenting all the workshops that we have delivered on the Guides. Rachael is autistic and has studied at both university and polytechnic in Aotearoa New Zealand. The challenges she faced during her own tertiary study, and her deep desire to see the system improve for future students, have necessarily shaped her approach to writing the Guides and delivering workshops. Joanne Lawless analysed the survey data that was used to inform the Guides. She is the mother of two autistic adults and is passionate about increasing awareness and creating systemic change in the way autistic people are supported in the education system. Rebekah Corlett and Timothy Folkema both provided feedback on the proposed survey questions and on the initial data analysis, as well as writing Guides. Rebekah Corlett wrote 'Sensory Experiences' and Timothy Folkema wrote 'Executive Function' and 'Self-Advocacy.' Rebekah is a parent and activist who became a Member of the New Zealand Order of Merit in 2022 for services to education. Timothy has studied at a polytechnic in Aotearoa New Zealand up to a postgraduate level and has worked alongside many other autistic and disabled tertiary students in his career. He feels a lack of understanding about autism meant he did not fully benefit from the tertiary experience and hopes this project will result in better outcomes for autistic students. Luella Wheeler has provided an external review of the conclusions drawn in this paper, having not been involved in the initial writing of the Guides. Luella is Māori and autistic, has studied at two universities and one wānanga in Aotearoa New Zealand as an on-campus student and as a distance learner, and has experienced first-hand some of the barriers and challenges presented to autistic learners.

WRITING THE GUIDES

Given the lack of existing research into the experiences of autistic tertiary learners in Aotearoa New Zealand, we began the process of developing the Guides by consulting with autistic students who either had studied or were currently studying at a tertiary education organisation in Aotearoa New Zealand, whānau members who had supported an autistic person through tertiary study, and tertiary staff in Aotearoa New Zealand. Background information on the project and links to the surveys were hosted on Altogether Autism's website, and the survey was advertised through Altogether Autism's networks, including our social media and email list. The surveys were open from 11 February to 7 March 2022. All data were anonymous.

The survey of autistic learners included questions about demographics, study history, how challenging different aspects of tertiary study were, and where support was needed. The survey of whānau included questions about demographics, the respondent's relationship to their autistic learner, the challenges their learner had faced, how they had supported their learner, and what support they would like to see tertiary education organisations provide. Some questions asked participants to identify how challenging something was on a three-point scale; others asked participants to rank challenges or support needs from "most challenging"/"most support needed" to "least challenging"/"least support needed." All questions included space for respondents to comment further on the support they felt tertiary education organisations should provide.

The survey of tertiary staff began with a question asking respondents what type of tertiary education organisation they worked at, and what their role was. Respondents were asked what areas they supported autistic learners with, what support they provided teaching staff to help them understand autistic learners, and where they felt more support for autistic learners was needed. These questions asked respondents to rank each area from "most support needed" to "least support needed." Space was provided so respondents could elaborate on their rankings.

We received responses from 99 autistic learners, 47 whānau and 11 tertiary staff. The low response rate from tertiary staff was disappointing. We think it might have been because the survey ran at the beginning of the academic year, when staff are particularly busy. Further, in February 2022, Aotearoa New Zealand was experiencing widespread community COVID-19 transmission for the first time, so tertiary staff were busy adapting their programmes to this new environment. Thus, staff may not have had time to respond to a survey. Following consultation with the TEC, we decided not to keep the survey open longer to seek further responses. The survey helped us understand what support autistic tertiary learners needed, so that we could frame the Guides around these areas; the responses from autistic learners and their whānau were more helpful in answering this question than the responses from tertiary staff were.

Our analysis of the survey responses focussed on identifying key areas where support was needed and quotes and experiences that illustrated learners' needs in these areas. However, two other themes emerged from the data which are worth noting, even though they were not related to specific support needs and thus did not form the basis of a Guide.

Firstly, there was a significant gap between the support tertiary staff thought they provided, and the support that autistic learners and their whānau experienced. Staff felt that they made sure communication and educational needs were supported, whereas autistic learners and their whānau generally did not feel they received clear communication or good support from their tertiary education organisation. It would be worth exploring this discrepancy in future research. It might be that learners experience different levels of support depending on what type of tertiary education organisation they study at. Only three of the 11 respondents to the survey of tertiary staff worked at a university, with the remaining eight working at Te Pūkenga. We did not directly ask autistic learners what type of institution they had studied at (many respondents had multiple enrolments and may have studied at more than one type of institution). However, in 46 cases it was possible to ascertain what type of institution(s) respondents had studied at from their open-ended responses. Of these 46 respondents, 32 had studied at university, nine had undertaken some form of vocational training (for example, at Te Pūkenga) and five had studied both at a university and at Te Pūkenga. Thus, it is possible that the difference between autistic learners' experiences of support and the perceptions of tertiary staff about the support they provided is because the support provided by Te Pūkenga, where most of our staff respondents worked, is better than the support provided by universities, where it seems that most of our autistic learner respondents studied. However, our data does not allow us to fully examine the relationship between institution type and experiences of support, and it would be worth exploring this relationship in future research.

Secondly, 18.2 percent of our autistic learners did not have an autism diagnosis, but did self-identify as autistic (note that we did not verify diagnostic status). Previous research has largely focussed on those with a confirmed autism diagnosis (Accardo et al., 2019; Anderson et al., 2017, 2020b; Anderson et al., 2018, 2020a; Cai & Richdale, 2016). This suggests that many students who identify as autistic but lack a formal diagnosis may have been missed in previous research. Autistic learners who lack a formal diagnosis are often not eligible to receive the formal supports offered through their institution's disability services, but still need support. Respondents who did not have a formal diagnosis whilst they were studying explained that without support they risked mental health challenges and withdrawing from or failing their course. They also pointed out that only offering supports to students with a formal diagnosis is an equity issue, as costs, wait times, and stereotypes about how autism presents can make a diagnosis difficult to access. Thus, future research should consider the unique challenges that autistic learners who lack a formal diagnosis face in tertiary education and how their support needs can best be met.

Given respondents were asked to opt-in to participating in the survey, it is also important to acknowledge that the sample may not fully represent the experience of all autistic tertiary learners. In terms of ethnicity, European learners were overrepresented, with 87.9 percent of our autistic learners identifying as European, compared to 57.3 percent of all tertiary students in 2022 (total tertiary population percentages from Education Counts

(2023)). Pasifika and Asian learners were underrepresented, accounting for 2.0 percent and 9.1 percent of our sample respectively, compared to 9.2 percent and 24.1 percent of the total tertiary student population. The percentage of our sample who identified as Māori was 14.1, which is similar to the 18.8 percent of the total tertiary student population who identify as Māori. Respondents were also asked about other aspects of their identity – “nonspeaking,” “AAC user,” “migrant,” “refugee,” and “LGBTQIA+” were given as options and there was also an “other” box where respondents could write in aspects of their identity, with “ADHD,” “gifted,” and “dyslexic” given as examples. It is difficult to find out what percentage of the total tertiary student population identifies with any of these options, and the phrasing of the question may have affected responses (for example, respondents may have been more likely to write “ADHD” into the “other” box as this was one of the examples). However, of the 99 respondents, 45 identified as LGBTQIA+, 31 as having ADHD, 6 as gifted, 12 as having a mental health condition, 14 as having a learning disability, 2 as being AAC users and 3 as migrants. Finally, it is important to note that completing the survey required respondents to read and answer questions online, and thus it may have been inaccessible for some people.

Our analysis of survey responses revealed six key areas where autistic tertiary learners needed support: executive function, communication, mental health, self-advocacy, sensory experiences, and social interactions. These themes aligned with support needs identified in other studies of autistic tertiary learners (Accardo et al., 2019; Anderson et al., 2017, 2020b; Anderson et al., 2018; Cai & Richdale, 2016; Sarrett, 2018). A Guide was written for each area. We primarily used the stories that learners had shared with us to inform the Guides, and used quotes from survey respondents to ensure that learner voice was a strong feature of the Guides. We also incorporated other research where this was necessary: for example, autistic burnout emerged as an important mental health challenge for autistic tertiary learners, so the Guide on mental health references research on autistic burnout to help tertiary educators understand this phenomenon.

The intended audience for the Guides was tertiary educators; that is, people working in a teaching role at a tertiary education organisation, such as lecturers and tutors. Whilst we realised the Guides would likely also be of interest to staff working in disability services and learning support, they were not our primary audience; this project specifically aimed to address the paucity of information available for tertiary educators. Recognising that tertiary educators are busy people, we made the Guides as user-friendly as possible. Each Guide begins with an introduction explaining the challenge that the Guide addresses and finishes with a list of actions tertiary educators can take to support their autistic learners. This means readers can easily navigate to the actions if they are short on time.

PUBLICISING THE GUIDES

The Guides were published on Altogether Autism’s website in September 2022 (Corlett et al., 2022). Since then, we have undertaken outreach activities designed to increase awareness of the Guides amongst tertiary educators. In 2023, we ran two seminars on the Guides for Ako Aotearoa, a government-funded organisation that provides professional learning and development for tertiary educators. In the same year, we were contracted by three tertiary education organisations to deliver training on the Guides directly to their staff and presented on the Guides at two conferences.

We noticed two key trends in undertaking this work to publicise the Guides. The first is that educators working at Te Pūkenga have been much more interested in learning about the Guides than educators working at universities. All three of the tertiary education organisations that contracted us to deliver workshops directly to their staff were subsidiaries of Te Pūkenga. Of the 33 people registered to attend our seminars with Ako Aotearoa, just four worked at a university. Secondly, although the Guides are aimed at an audience of tertiary educators, attendees at the Ako Aotearoa seminars (the only presentations where we were able to record people’s roles) were more likely to work in a student support role than in a teaching role: only ten of the

attendees at these seminars worked in a teaching role. This suggests more work needs to be done to increase awareness in universities of the importance of supporting autistic learners. Teaching staff must be encouraged to understand that supporting autistic learners is an important concern for them as educators, and not something that should be left to disability services and learning support staff.

RECOMMENDATIONS

The following recommendations are based on what we learnt from our survey data and delivering training sessions.

Engaging teaching staff in training about autistic learners' needs

The biggest challenge we have faced since publishing the Guides has been getting the resources directly in front of teaching staff; people working in disability services and learning support have been more interested in learning about the Guides. It is possible that disability services and learning support staff are attending our presentations and sharing information about the Guides with teaching staff at their institutions. It may also be that teaching staff cannot find the time to attend our seminars. However, there may also be an attitudinal problem; it is possible that teaching staff do not view the needs of autistic learners as their responsibility, and instead rely on disability services and learning support to look after the needs of these learners. Our survey data showed that autistic learners found dealing with the attitudes of teaching staff was one of the hardest aspects of studying; in contrast, the support that disability services or learning support provided was generally considered good. Thus, changing the attitudes of teaching staff towards autistic learners could make a significant difference to their experience of tertiary study.

Previous research has advocated for more resources and training to be provided to tertiary educators (Anderson et al., 2020b; Sarrett, 2018). Our experience shows that simply providing resources and training is not enough; the resources must get to their intended audience. We recommend further research into what prevents tertiary educators from engaging with resources and training on the needs of autistic learners, so that resources and training can be developed that will engage tertiary educators.

Support needs may differ depending on institution type or subject

Much previous research has only looked at autistic university students or, when students at other types of tertiary education organisation were included, data was not examined to see whether students' experiences differed based on institution type (Anderson et al., 2018, 2020a; Cai & Richdale, 2016). However, our data suggests that autistic learners at university might have different support needs, and different experiences of the quality of support they receive, from autistic people undertaking vocational education. Further, after two decades of research looking at the experiences of autistic learners in tertiary education, broad themes (such as the heterogeneity of autistic learners and the need for increased understanding among tertiary staff) have largely been established. We suggest that it is now time for researchers to turn their attention to the different types of institution that make up a tertiary education system, and how autistic learners' experiences differ based on the type of institution they attend. Similarly, researchers should explore the unique challenges that different subjects pose. For example, some of our respondents reported that they encountered stigmatising attitudes about autism when they were studying psychology, and this presented a barrier to them continuing with the subject. Such research will enable tertiary education organisations to provide supports for their autistic learners that best suit the needs of students at each specific institution type and within each subject.

Lack of diagnosis should not be a barrier to support

Students who identify as autistic, but do not have a formal diagnosis, have been largely ignored by previous research. However, our survey showed that self-identified autistic people make up a significant proportion of autistic tertiary learners (nearly one-fifth of our sample). They also face unique challenges, as without a diagnosis they are often unable to access formal supports through their institution. Limiting support to those with a formal diagnosis is an equity issue; people may have been unable to receive a formal diagnosis because of cost barriers, wait lists, or because they do not fit within the stereotypical view of autism. Further, some students might not know enough about autism to recognise that they could be autistic. We thus have two recommendations. Firstly, rather than excluding self-identified autistic learners from their studies, researchers should investigate what specific support needs this group has and how tertiary education organisations can better meet these needs. Secondly, tertiary education organisations should offer needs-based, rather than diagnosis-based, support. In many cases, a tutor or lecturer can accommodate an autistic learner's needs without needing formal accommodations through the institution's disabilities office. Teaching staff can approve accommodations such as making changes to groupwork requirements or enabling someone to participate in a class discussion by writing their answers rather than speaking, for example. All tertiary learners, regardless of diagnostic status, should feel empowered to have a discussion with their teachers about what they need to be able to do well in their course. For this to happen, teaching staff need more understanding about the needs of autistic learners, which is why researching the barriers to tertiary educators engaging with resources and training on autistic learners is our first recommendation.

Small changes can make a big difference

Many autistic learners' needs can be met with relatively small changes. For example, lecture recordings made a major difference for many of the participants in our survey. They helped with both mental health and sensory challenges; if a student was unable to attend class in person due to anxiety, autistic burnout, or the campus sensory environment, lecture recordings enabled them to still learn the course content. Lecture recordings also helped with executive function challenges. Many learners mentioned that they had trouble with notetaking because they struggled to keep up with the lecturer and felt anxious when they missed something, meaning they found it harder to take in the rest of the lecture. Lecture recordings can enable autistic learners to more fully engage with the course content, because they know that if they do miss something they can refer back to the recording of the lecture later.

Universal provision of lecture recordings is a small change to make. The barrier is generally attitudinal, with some tertiary educators worrying that if students are not attending class in person, they are not engaged in the course. However, our results show that lecture recordings can be as useful for people who do attend class in person as they are for those who do not, and that autistic people can experience real barriers to attending classes on campus but still engage well online. Thus, universal provision of lecture recordings is an example of a relatively small change that tertiary education organisations can make that makes a major difference for autistic learners. As well as being easy to implement, small changes such as this can generally be made available to the whole class, which removes barriers for those students who need support but do not have a formal diagnosis.

Listen to individual autistic learners

Previous research has highlighted the heterogeneity of the autistic population and the need for supports to be individualised (Accardo et al., 2019; Anderson et al., 2018, 2020a). Our survey data backed this up. For example, because our study took place in early 2022, many respondents reflected on how the transition to online learning because of COVID-19 impacted their studies. Many respondents found online learning much easier than on-campus learning, as it meant they did not have to deal with the sensory and social challenges

that being on campus posed. Others found learning online much harder than learning on campus had been; without the routine and contact with tutors that being on campus provided, they found it harder to engage with their learning. This heterogeneity means that there is no one-size-fits-all approach to supporting autistic tertiary learners. Rather than trying to provide standardised supports for autistic learners, tertiary education organisations should take the time to have a conversation with each learner to identify what type of support they need to do well in tertiary education. This should not be a one-off conversation, as students' support needs evolve as they move through their studies.

We recommend that learners have the option to be matched with a single person who can remain their key point of contact throughout their studies. This person could be someone who works in disability services or learner support, or it could be a tutor or lecturer. Having a single point of contact reduces communication barriers for autistic learners, as it means they know exactly who they should contact when they need help. An ongoing relationship enables the key point of contact to better understand the learner's challenges and suggest appropriate supports, thus supporting the learner to develop confidence in advocating for themselves as they are not constantly having to explain their needs to new people. Given the barriers to diagnosis discussed previously, we recommend this support be available to anyone who feels they need it, regardless of whether they have a formal diagnosis. Making this support available as an opt-in for students who need it makes it feasible regardless of the size of the student population, as it is unlikely that all students would choose to use this support.

CONCLUSION

Autistic tertiary learners in Aotearoa New Zealand have similar support needs to those identified amongst autistic tertiary learners in other countries. Previous research has identified that more resources and training are needed to help tertiary educators better understand the needs of their autistic learners. However, our experience of developing such resources shows that simply providing resources is only part of the challenge; getting the resources in front of the people who need them is also important. We also found that autistic learners' support needs and the quality of the support they receive may differ depending on what type of institution they study at. We thus recommend that future research should investigate barriers to tertiary educators participating in training on autism, and how autistic learners' support needs differ depending on what type of institution they study at. We also recognise that many autistic tertiary learners do not have a formal diagnosis and recommend that future research takes these learners into account. Finally, we suggest two supports (lecture recordings and a key point of contact) that tertiary education organisations can implement that both make a significant difference for autistic learners and can be made available to all students, regardless of diagnostic status.

Rachael Wiltshire is autistic and works as a live chat agent/researcher at Altogether Autism. Previously, she was a member of Altogether Autism's Consumer Advisory Group. She regularly delivers training sessions on the Guides discussed in this article as part of her role.

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Joanne Lawless is an experienced facilitator in adult learning and currently works at Altogether Autism. Her two adult sons are both autistic. She has wide experience in both volunteer and paid roles in disability settings and has worked in a disability advisory role for disability training organisations.

Rebekah Corlett is a parent and activist who became a Member of the New Zealand Order of Merit in 2022 for services to education. She was a member of Altogether Autism's Consumer Advisory Group from 2020–2023.

Timothy Folkema is the chairperson of Voices from the Spectrum Charitable Trust, a charity set up by, and for, autistic adults who do not require supervisory care. He is also a member of Your Way | Kia Roha's National Disability Leadership Group and was a member of Altogether Autism's Consumer Advisory Group from 2020–2023.

Luella Wheeler is a current member of Altogether Autism's Consumer Advisory Group, and previously worked as a live chat agent/researcher for Altogether Autism. She has a background in science and has previously held botany and microbiology research positions.

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