

Autism Research Centre Aotearoa New Zealand



We are delighted to share our Spring 2025 Autism Research Centre – Aotearoa NZ (ARC) newsletter. This quarterly publication is intended to highlight current and upcoming autism-focused research, showcase the achievements of researchers and students, and celebrate community and media engagement across Aotearoa.



Our **Autistic Partnership network** continues to grow, with around 40 Autistic people now involved from across Aotearoa. We welcome Autistic people with an interest in shaping autism research to join us. Anyone interested can learn more or sign up via the [Get Involved](#) page on our website, or by contacting the Autistic Partnership Chair directly at ruth.monk@canterbury.ac.nz.

This year, members of our steering group contributed to key consultations for the Autism Living Guidelines Group. We provided feedback on the latest supplementary paper for the Aotearoa New Zealand Autism Guideline and offered our prioritisation of proposed topics for the next update.

We also heard from several steering group members at the ARC Symposium, where they took part in a panel discussing recent findings from autism population data in Aotearoa New Zealand. They shared insights grounded in lived experience and provided recommendations for future research, policy, and practice.

Autistic Partnership members have continued to contribute to autism research through the ARC, including providing input into study protocols and postgraduate student projects. These opportunities highlight the value of Autistic expertise in informing guidelines, policy, and research directions.

Looking ahead, we hope to share further opportunities to be involved in shaping research design, particularly as new student projects and proposals emerge in the new year.

Research Projects

Raupī te Raupō (RtR)

A research team at Victoria University of Wellington is currently recruiting **young children (aged 1–5 years) who show signs of autism or social communication difficulties** and their whānau/families to take part in a trial of a new programme, **Raupī te Raupō (RtR)**. RtR, which was co-designed with Autistic people and Māori, aims to support whānau and family members to better understand and help these children. Recruitment is limited to the **Wellington region** and will **close at the end of 2025**. For more information, please see the flyer below. The accompanying photo shows the research team.

Contact: autism-clinic@vuw.ac.nz. Phone: 022 010 6855.

TRIAL OF RAUPĪ TE RAUPŌ - AN AOTEAROA EARLY SUPPORT PROGRAM

Do you want to participate in a trial of a new program for whānau/families of young children with social communication differences?

Raupī te Raupō was designed alongside autistic people and Māori. It aims to support children with social communication differences and their whānau to flourish. We want to know if Raupī te Raupō is more beneficial than community services.

If you choose to take part you will be randomly placed in one of two groups. Support in each group will last for 5-months. Those in the **Raupī te Raupō group** will receive weekly, hour-long support sessions. Those in the **community group** will receive monthly, 30-minute support calls and help with referrals.

To take part, your child needs to be:

- showing signs of autism/social communication differences
- **not** (yet) diagnosed as autistic
- aged between 1 and 5 years.

To find out more or take part, email autism-clinic@vuw.ac.nz or call 022 010 6855

This research has been approved by the Northern A Health and Disability Ethics Committee (2023 FULL 18346)

KIA ORA | TALOFA LAVA | MALO E LELEI | KIA ORANA | FAKAALOFA LAHI ATU | MĀLO NI | NI SA BULA VINAKA | FAKATALOFA | KAM NA MAURI

WOULD YOU LIKE TO BE PART OF AN ADVISORY GROUP ABOUT EARLY AUTISM SUPPORT?



We are developing *Digital Raupī te Raupō*, a wellbeing programme for young Autistic children and their whānau. We're inviting people to take part in online focus groups and surveys to help shape the programme's design, content, and features. **We need 6–10 people with lived experience of autism (personal, family, or professional) to join each of our three advisory groups:**

- 1**
Autistic Partnership Group
- 2**
Māori Advisory Group
- 3**
Pasifika Advisory Group

This opportunity is available to people in Aotearoa New Zealand who are comfortable joining discussions in English and can commit around 3–4 hours of online participation over six months. Koha will be offered as gift vouchers.

Interested? Contact Prof. Laurie McLay
University of Canterbury
(03) 369-3522
laurie.mclay@canterbury.ac.nz



A research team at the **University of Canterbury**, led by **Prof. Laurie McLay** is currently co-designing a digital version of the RtR programme. They are currently facilitating focus groups with Māori, Pacific and Autistic people to help shape the digital programme design, functions and features. The team are currently seeking Pacific People's with a connection to autism to joining our Pasifika Advisory Group.

For more information, please see the flyer below.

Contact: Prof. Laurie McLay,
laurie.mclay@canterbury.ac.nz if you are interested.



Co-Producing an Autism Curriculum for the Aotearoa Mental Health & Addictions Workforce

This doctoral project, led by Taylor Scott (supervisor Prof. Laurie McLay and Ann-Marie Kennedy) aims to co-produce a curriculum framework for an autism focused mental health-related training programme in partnership with healthcare professionals (HCPs) and Autistic rangatahi. Autistic rangatahi experience disproportionately high rates of mental health diagnoses and service provision yet face inequities in healthcare access. Insufficient autism-specific training among some professionals represents an inherent barrier here. No research to date has examined the autism focused training needs of HCPs, nor Autistic rangatahi experiences with mental health services in Aotearoa. The first phase of this project will comprise focus groups and interviews with HCPs and Autistic rangatahi. Findings will inform the co-design of a training need survey which will be administered to larger groups of professionals and Autistic rangatahi in a subsequent project phase.

We want to hear from: Registered medical, nursing or allied healthcare professionals, and Pukenga Atawhai (specialist Māori mental health workers), who are currently employed (or were employed within the past 5 years) in a role that involves providing mental health supports in Aotearoa.

To register or to find out more, please visit the following link: https://ucliveac-my.sharepoint.com/:w:/g/personal/tsc67_uclive_ac_nz/EZqwrzuRS7ZOg_Y4_GpU2YwB9IzvwNYhV3iKUK2qiO6QQQ?e=8lVXvY

Queries can be directed to Taylor Scott, at: taylor.scott@pg.canterbury.ac.nz

Research Funding and Outputs

Dr Hannah Waddington (Victoria University of Wellington) and **Lee Patrick** (Autism NZ) are leading a newly funded Marsden project titled **A Difference, Not a Deficit – Changing Attitudes to Autism in Aotearoa**. This study aims to transform how autism is understood by shifting from a deficit-based model to a neurodiversity-affirming perspective. The research will develop and evaluate a support programme, Raupī te Raupō, co-designed with Autistic people and Māori, to empower children and their whānau. Learn more here: <https://www.royalsociety.org.nz/what-we-do/funds-and-opportunities/marsden/celebrating-marsden-research/in-focus/a-difference-not-a-deficit-changing-attitudes-to-autism-in-aotearoa/>

Building International Relationships to Support Indigenous Autism Research: Funded by a Catalyst Seeding Grant, this project is led by **Dr Jessica Tupou**, **Fran Kewene** and **Dr Hannah Waddington** from **Victoria University of Wellington**, alongside **Bianca Elkington (Ngāti Toa)** and **Dr Grant Bruno (University of Alberta)**. This project aims to increase the visibility and accessibility of Indigenous autism knowledge by establishing an ongoing partnership between Te Herenga Waka – Victoria University of Wellington, Ngāti Toa, the University of Alberta and the First Nations community of Maskwacîs, Alberta, Canada. The project will involve whakawhanaungatanga (building relationships) and mamawihchitowin (supporting each other) through face-to-face connection in Canada and Aotearoa. Throughout this process, the partners will work with their communities to co-design a resource to capture and share Indigenous autism knowledge. This resource will be a living document to be built upon beyond this project.



A newly funded Autism CRC study, **Mind the Gap: Addressing Autism Research and Translation Gaps**, led by researchers from **La Trobe University**, **Griffith University**, and **Autism NZ**, aims to systematically review existing literature and consultation outputs, aiming to identify gaps between research data and lived community experiences in Australia and Aotearoa New Zealand between 2019 and 2025. The study will also examine shortcomings in translating evidence into practice – particularly for underrepresented intersectional groups. The outcomes of this project have the potential to inform early deliberations by the National Autism Strategy Reference Group, its associated Working Groups, and the Commonwealth. These insights will help prioritise actions related to research and research translation, including evidence-based policy, services, supports and programs. In addition, the findings may guide future directions for research organisations, funding bodies, government agencies, and sector-wide capacity-building initiatives.

Understanding school attendance among students with neurodevelopmental conditions: a sequential mixed methods study: **Dr Nick Bowden** (University of Otago) and colleagues are leading the first population-level study on school attendance patterns among students with neurodevelopmental conditions (NDCs) in Aotearoa New Zealand, funded by the University of Otago Research Grant. Using a sequential mixed-methods design, the study combines quantitative analysis of attendance data from the Integrated Data Infrastructure (IDI) with qualitative, disability-led interviews involving students, whānau, kaiako (teachers), and practitioners. Grounded in kaupapa Māori principles, it prioritises tāngata whaikaha Māori and aims to inform equitable, culturally responsive strategies to improve school attendance. Findings will be shared through a report, policy brief, and infographic to support policy and practice.

A Cure Kids–funded project, **Trends in autism prevalence and health service use in Aotearoa**, led by **Dr Nick Bowden** (University of Otago) and **Professor Laurie McLay** (University of Canterbury), will use New Zealand’s whole-population level data (Integrated Data Infrastructure) to examine ten-year trends in autism prevalence among youth aged 0–24 and to investigate patterns of health-service use among Autistic young people. It places special emphasis on Māori, Pacific, and gender-diverse populations. The findings will inform an evidence-based, co-designed policy brief to provide policymakers with concise, well-researched recommendations to inform decision-making and promote effective policy solutions for improved provision of healthcare for Autistic youth.

Community Reports

Lifecourse Outcomes

Commissioned by the Laura Fergusson Trust and the Joyce Fisher Endowment Fund Trust, this Autism NZ report examines life-course outcomes for Autistic children, young people, and their families using population-level linked data from the Integrated Data Infrastructure (IDI). The study found that Autistic individuals were less likely to complete secondary education, more likely to experience unemployment, and faced significant disparities in health and wellbeing. The findings highlight the urgent need for inclusive policies and targeted supports that align with the UN Convention on the Rights of Persons with Disabilities. The report provides evidence to inform future policy, service



design, and systemic change to improve outcomes across education, health, and employment – read the full report here: <https://autismnz.org.nz/community-report-course-life-outcomes/>

Let's Play/MoSAIC Research

A team led by Prof. Laurie McLay evaluated two early-support programmes — the educator-training MoSAIC and the caregiver-led Let's Play intervention — designed to improve outcomes for young autistic or potentially autistic children. The MoSAIC training, delivered to 73 early-childhood educators, significantly increased knowledge, confidence and cultural appropriateness in identifying early autism signs. The Let's Play programme, involving 91 families, resulted in improved caregiver-child engagement, enhanced child health-related quality of life, and reduced parental distress compared with a wait-list control. Overall, the study underscores that early identification and interim support are critical for autistic children and their whānau, especially while waiting for formal diagnosis and services – read the full report here: <https://autismnz.org.nz/community-report-lets-play-mosaic-research/>

Research Outputs

Members of the ARC have produced a number of interesting research outputs. Many of these are provided below. To read the full text of each article, you can click on the links provided.

Berry, L. M., Sutherland, D., Monk, R., Lim, M., & McLay, L. (2025). “The world needs autistic and non-autistic people to be the best world it can be”: A qualitative study of the perspectives of autistic youth on the future of research in Aotearoa New Zealand. *Research in Neurodiversity*. <https://doi.org/10.1016/j.rin.2025.100003>.

Bowden, N., Anns, F., Vu, H., Dacombe, J., Muir, C., Russell, J., ... & Clendon, S. (2025). School attendance among autistic students in Aotearoa/New Zealand: A population cross-sectional study using the Integrated Data Infrastructure. *Journal of Paediatrics and Child Health*, 61(4), 609-616. <https://doi.org/10.1111/jpc.16795>.

Bruno, G., Lindblom, A., Tupou, J., Kewene, F., Waisman, T., & Magiati, I. (2025). Decolonizing autism research: Integrating Indigenous ways of knowing, being, and doing. *Autism*, 29(11), 2637-2643. <https://doi.org/10.1177/13623613251382398>

Bruno, G., Lindblom, A., Masternes, J.-A., Tupou, J., Waisman, T., Toby, S., Vining, C., & Magiati, I. (2025). Global Indigenous perspectives on autism and autism research: Colonialism, cultural insights and ways forward. *Autism*, 29(2), 275-283. <https://doi.org/10.1177/13623613251318399>

English, M. C. W., Poulsen, R. E., Maybery, M. T., McAlpine, D., Sowman, P. F., et al. (2025). Psychometric evaluation of the Comprehensive Autistic Trait Inventory in autistic and non-autistic adults. *Autism*. <https://doi.org/10.1177/13623613251347740>

Hinten, A. E., van der Meer, L., Waddington, H., Jamieson, I., Andrew, C., Bowden, N., ... & McLay, L. (2025). An evaluation of the MoSAIC training for early childhood educators in New Zealand. *Early Childhood Education Journal*, 1-13. <https://dx.doi.org/10.1007/s10643-025-01890-2>.



- Jordan, P., Tupou, J., Wallace-Watkin, C., Pillar, S., & Waddington, H. (2024). “I wouldn’t want one or the other”: Understanding parents’ preferences for direct therapy or parent coaching for young autistic children. *Autism*. <https://doi.org/10.1177/13623613241287300> (A **lay abstract** is available in the Appendix).
- McLay, L. K., Schluter, P. J., Williams, J., Anns, F., Monk, R., Dacombe, J., ... & Bowden, N. (2025). Health service utilization among autistic youth in Aotearoa New Zealand: A nationwide cross-sectional study. *Autism*, 29(5), 1143-1156. <https://dx.doi.org/10.1177/13623613241298352> (a **lay abstract** is available in the Appendix).
- Poulsen, R., Tan, D. W., Sowman, P. F., McAlpine, D., & Pellicano, E. (2025). Auditory environments influence the link between autistic traits and quality of life. *Scientific Reports*, 15(1), 10612. <https://doi.org/10.1038/s41598-025-10612>
- Poulsen, R., Williams, Z., Dwyer, P., Pellicano, E., Sowman, P. F., & McAlpine, D. (2024). How auditory processing influences the autistic profile: A review. *Autism Research*, 17(12), 2452–2470. <https://doi.org/10.1002/aur.3125>
- Rapaport, H., & Sowman, P. F. (2024). Examining predictive coding accounts of typical and autistic neurocognitive development. *Neuroscience & Biobehavioral Reviews*, 167, 105905. <https://doi.org/10.1016/j.neubiorev.2024.105905>
- Schluter, P. J., Bowden, N., Dacombe, J., McLay, L., & Lee, M. (2025). Hospital dental admissions and caries experience among children with neurodevelopmental disabilities: A population-based record linkage cohort study. *Community Dentistry and Oral Epidemiology*, 53(2), 160-169. <https://dx.doi.org/10.1111/cdoe.13018>.
- Sulek, R., Edwards, C., Monk, R., Patrick, L., Pillar, S., & Waddington, H. (2024). “It depends entirely on the nature of those supports”: Community perceptions of the appropriateness of early support services for autistic children. *Autism*. <https://doi.org/10.1177/13623613241302372> (A **lay abstract** is available in the Appendix)
- Tupou, J., Kewene, F., Morrison-Young, I., Wi-Hongi, A., Sporle, A., Diamond, T., Theodore, R., & Bowden, N. (2025). Identification of autistic Māori in Aotearoa New Zealand: A national cross-sectional study. *Autism*. <https://doi.org/10.1177/13623613251380927> (**Supporting materials** are available in the Appendix)
- Noble, B., & Isaacs, N. (2024). Autistic people’s perception of interior electric lighting systems: An initial study. *Lighting Research & Technology*. <https://doi.org/10.1177/14771535251366853> (An **abstract** is available in the



Appendix).

Waddington, H., Minnell, H., Wallace, H., Moriah, C., Noble, B., & Wallace-Watkin, C. (2025). “It was a completely different lens”: Autistic adult and parent perceptions of an autistic-led autism information workshop. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0337> (A **summary of key findings** is available in the Appendix).

Media Commentary

Joanne Dacombe, a member of the ARC community, responded to recent claims by Donald Trump and Robert F. Kennedy Jr. alleging links between prenatal paracetamol (Tylenol) use and autism. Her commentary appeared in RNZ and the NZ Herald.

- NZ Herald: <https://www.nzherald.co.nz/nz/he-would-look-to-eliminate-us-trumps-autism-claim-slammed/BXT3JRXUTWGVUUEFCWAVRQJXJM/>
- RNZ: <https://www.rnz.co.nz/news/what-you-need-to-know/573878/what-america-s-changes-on-paracetamol-and-vaccines-might-mean-for-new-zealand>
- See also: <https://www.sciencemediacentre.co.nz/2025/09/23/trumps-autism-and-paracetamol-comments-disputed-expert-reaction/>

Beth Noble was the keynote speaker at the Autism New Zealand Parliamentary Breakfast (April 2025), where she spoke about what support looks like and how it has such an impact on quality of life from a personal perspective.

- Listen to her speech here: <https://www.youtube.com/watch?v=UFBjDiAt4pE>
- A transcript is available on request for anyone who prefers or requires a text version.

Beth has also published her research — see the *Research Outputs* section for full details.

The country’s first dedicated Autism Research Centre (ARC), based at the University of Canterbury, has launched with a neurodiversity-affirming mission to improve the well-being of autistic people across Aotearoa. This was reported on RNZ’s *Nine to Noon* programme, highlighting ARC’s focus on inclusive, community-engaged, and evidence-based research.

- RNZ: <https://www.rnz.co.nz/national/programmes/ninetoon/audio/2019002476/country-s-first-autism-research-centre-opens>
- See also: UC News: <https://www.canterbury.ac.nz/news-and-events/news/2025/uc-launches-new-zealand-s-first-autism-research-centre->

Research Student Completions and Highlights

Congratulations to **Rajat (Raj) Chauhan**, a second-year medical student at the University of Otago, on receiving the Freemason’s Summer Student Scholarship. Rajat will examine geographic variation in autism rates across Aotearoa, supervised by Dr Emma Heydon and Associate Dr Karen Tustin, with advisory support from Paul Sowman.



Arofa Cafe

Arofa Cafe, a neurodivergent-led and run cafe in **Whakatere (Ashburton)**, opened on 25 August 2025 and has received an overwhelmingly positive response from the community. Since opening, the cafe has become a welcoming space for rangatahi, neurodivergent individuals, and their whānau, offering connection, empowerment, and a strong sense of belonging. Arofa Cafe's kaupapa focuses on breaking barriers and fostering inclusivity within the neurodivergent community. The team is also encouraging collaboration with organisations and individuals who share similar goals, through referrals, joint events, or shared resources. Learn more: https://www.facebook.com/p/Arofa-Cafe-61579924136896/?utm_source=chatgpt.com.

Events

If you are hosting or attending autism-focused events this spring/summer — including seminars, workshops, or community forums — please share your event details (name, date, registration link, and contact) with Laurie (laurie.mclay@canterbury.ac.nz).

Job Opportunities & Scholarships

Please share any opportunities relevant to autistic researchers, postgraduate students, or community collaborators — including academic roles, research assistantships, and scholarships.

Opportunities for Research Involvement

If your team has projects or initiatives that would benefit from Autistic input, co-design, or feedback, we encourage you to connect with us. The Autistic Partnership can support researchers in shaping study design and ensuring research aligns with Autistic priorities and the values of the ARC.

We also welcome opportunities to circulate calls for research participation in an approved study through our networks.



Appendix

Abstracts for some of the featured papers are provided below.

- **Jordan, P., et al. (2024):** Professionals often support autistic children by working with them directly (direct support) or by coaching their parents. We know a lot about what parents think about parent coaching, but we do not know as much about what they think about direct support. We also do not know whether parents prefer parent coaching or direct support. The current study involved 22 parents who each received 2h a week of direct support for their autistic child and up to 1h a week of parent coaching for 6 months. At the end of 6 months, all these parents indicated in a survey whether they preferred parent coaching or direct support. Eleven of these participating parents also chose to take part in an interview to understand more about these preferences. Our findings suggest that parents generally liked both supports and believed they worked well together; however, they preferred direct support over parent coaching. While parents think that both approaches are beneficial, there are strengths and challenges of each. These findings emphasise the importance of parent choice in the delivery of support. It may also be possible to adapt both approaches to address some of the identified challenges and improve the whole family's experience.
- **Sulek, R., et al. (2024):** We do not know much about what support services people think are okay for young autistic children. This study was a survey of 253 people. We asked autistic adults, parents, and professionals from Australia and New Zealand whether they thought it was okay to provide support services to autistic children. About half the people who shared their thoughts said it was okay to provide support services to autistic children and the other half said it depended on what the support service was like. They had three main ideas about whether support services were okay or not. The first one is that we should remember that these autistic children are children first, so we need to keep their childhood experiences in mind and let them have a say in decisions. The second is that we should not try to 'fix' the child, but instead, use supports that respect and understand the unique ways the child thinks. The final idea is that early, personalised help is good for autistic children and can make a positive difference in their lives. This study suggests that we should focus on what each child needs, think about how children can join in, and provide help in ways that respect autistic children.
- **McLay et al., (2025):** Autistic youth generally use healthcare services more often than non-autistic youth. However, we know very little about the factors that can affect health service use and the types of services that are used, and this has not been explored in Aotearoa New Zealand. We analysed data from New Zealand to compare health service use among autistic and non-autistic youth (0 to 24-year-olds). Data were available for 19,479 autistic youth and 1,561,278 non-autistic youth. We compared hospitalizations, specialist visits, emergency department visits and use of different types of medications. In this study, autistic youth were found to have been hospitalized for medical and mental health reasons, more often than non-autistic youth. Autistic youth were also more likely to have attended specialist appointments and to have been given medication. These differences were particularly large for medications commonly used for mental health conditions (e.g. anxiety, depression, attention deficit



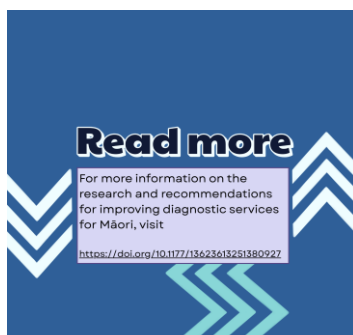
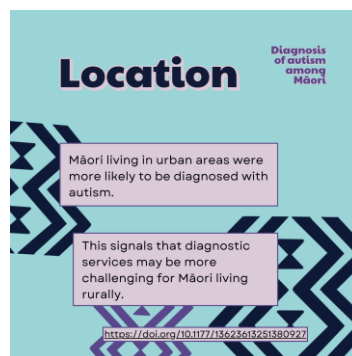
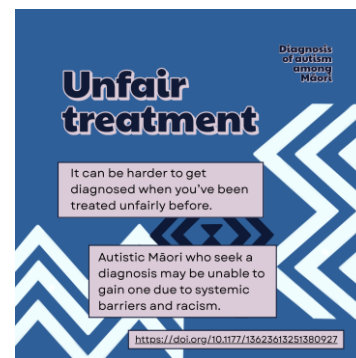
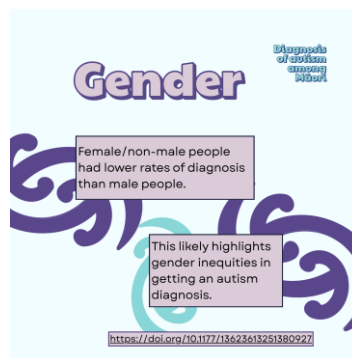
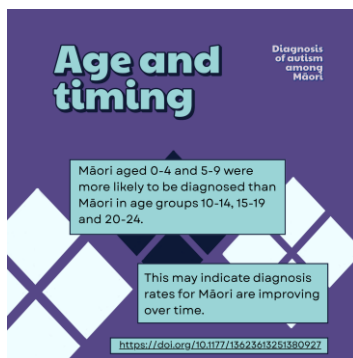
hyperactivity disorder) or associated symptoms. Autistic youth who also had an intellectual disability were more likely to use healthcare services for physical health conditions, but were less likely to use mental health services, when compared with autistic youth who did not have an intellectual disability. These findings, along with other research, suggest that the healthcare needs of autistic youth are not always being met. Further work is needed to enhance our understanding of co-occurring conditions among autistic youth, including those that result in high rates of health service use, in order to inform the development of healthcare services and training for healthcare professionals to better cater to the needs of autistic youth.

- **Noble, B., & Isaacs, N. (2024):** This mixed-methods research used participatory photography with an online questionnaire to collect data on autistic people's response to lighting systems in the everyday built environment. It was designed to be accessible to autistic participants and accommodate the needs of this autistic researcher. Four main themes were identified, opening opportunities for future lighting improvements to better meet the needs of the wider community: (1) lighting systems (layout, lamp shapes and types, number of lamps), (2) technical factors (flicker, noise, brightness, colour temperature), (3) reactions-to-lighting (both positive and negative) and (4) use of descriptive language. While the strong dislike of linear-grid lights was expected, the extent of the dislike towards lighting systems in Library/Community spaces and medical buildings, particularly waiting rooms, was concerning. As these are spaces likely to be used by autistic people, lighting improvements are urgently required. As a result of the direct participation, the rich data expand the understanding of autistic people's perception of everyday indoor electric lighting systems. The research has identified avenues for future research to create more accessible indoor environments for autistic and neurotypical people, or in brief, all users.

Supporting Materials

From **Tupou, J., et al. (2025):** These visuals summarise key findings from the study on autism diagnosis among Māori, highlighting factors such as inequities, age, gender, location, and cultural values influencing access to diagnosis. A te Reo Māori version of the materials is also available upon request.





Thank you for your continued support and collaboration! Together, we aim to make autism research in Aotearoa more inclusive, evidence-based, and community-led.

Ngā mihi nui,

Laurie, Ann-Marie, and Ruth and the wider Autism Research Centre team