



minds for minds
Unlocking Autism Together

Newsletter July 2021

Kia ora!

We apologise for the lack of newsletter updates from Minds for Minds over the past year. We are excited to get peer reviewed research content out to you once again. We have joined with the team at the Werry Centre to bring you updates from our local researchers and from the wider international literature.

Publications

Our New Zealand Minds for Minds genetics team have published a paper describing the development of a novel software tool to detect deletions and duplications of genetic material, developed by Dr Whitney Whitford during her PhD.

Our research involves state-of-the art analyses to perform the highest-quality work. The genetics group published a piece of software called Read Balance Validator (RBV) to improve the interpretation of copy number variants (CNVs). Copy number variants are increases or decreases in genetic

content (deletions or duplications), which can contribute to, or cause ASD in some cases. The software uses changes in the sequencing reads caused by CNVs to distinguish real variants from false positives. The group are using RBV to assist in their identification of causative CNVs in our New Zealand studies.

Article details: RBV: Read balance validator, a tool for prioritising copy number variations in germline conditions. *Whitford et al. Scientific Reports. Volume 9, issue: 16934, 2019*

Read the abstract [here](#).

Werry Centre Research Updates

Order out of chaos? Autism spectrum disorder coordinators' impact on service delivery in New Zealand

This national survey by Matt Eggleston from Canterbury DHB of the experience of families of children with autism found using Autism Coordinators (ASDC) found that ASDCs are well regarded by parents and improve key aspects of the process of obtaining an autism diagnosis and post-diagnostic supports. Given the particularly low rates of parent satisfaction with post-diagnostic supports (23%) and their coordination (19%), ASDCs may be of most value when employed post-diagnosis to assist parents in navigating key supports and co-developing comprehensive individualised care plans.

For more information, click [here](#).

Autism spectrum disorder/ Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand

This University of Otago-led study showed that administrative information in a national dataset known as the Integrated Data Infrastructure (IDI) can be used to identify autistic individuals. Around 9555 individuals with autism were identified via the IDI, suggesting a rate of 1 in 102. Co-occurring mental health problems were found in 68% of the autism group. The authors concluded that although the IDI may undercount people with autism, it may be useful for monitoring service provision, treatment-related trends, types of co-occurring conditions and examining social outcomes.

For more information, click [here](#).

National prescribing rates and polypharmacy for children and young people in New Zealand with and without autism spectrum disorder

Using the IDI, this University of Otago-led study found that New Zealand children and young people receive a number of medications, especially of a gastro-intestinal and psychotropic nature. Prescribing rates were higher than that for non-autistic individuals and more than half of the included children and young people had received three or more medications. The authors make recommendations for improved care of this group.

For more information, click [here](#).

Consensus or chaos: Survey of prescribing practices of New Zealand child and adolescent psychiatrists for children and adolescents with autism spectrum disorder

This Werry Centre-led study found that New Zealand child psychiatrists generally agree about medication use for anxiety, sleep problems, ADHD and depression, but less so about medication use for managing restricted and repetitive behaviours (RRBs) in autistic children. Improved national guidance on prescribing is recommended.

For more information, click [here](#).



Werry Centre Research Updates

An investigation of adherence to best practice guidelines for autism diagnosis in New Zealand

This study run by Autism CRC in Australia in conjunction with Autism New Zealand, the Werry Centre and University of Otago explored the current diagnostic processes, and adherence to the Guideline in New Zealand, for an opportunity sample of 117 health professionals who practice across a wide range of diagnostic services, health professionals and geographic regions in New Zealand. The results show considerable variability in practice, and suggest specific areas for improvement. These include the robustness of diagnostic evaluations conducted in private settings, the provision of specialist assessment services for youth and adults presenting for autism diagnosis, and the uniformity of post-diagnostic supports and services.

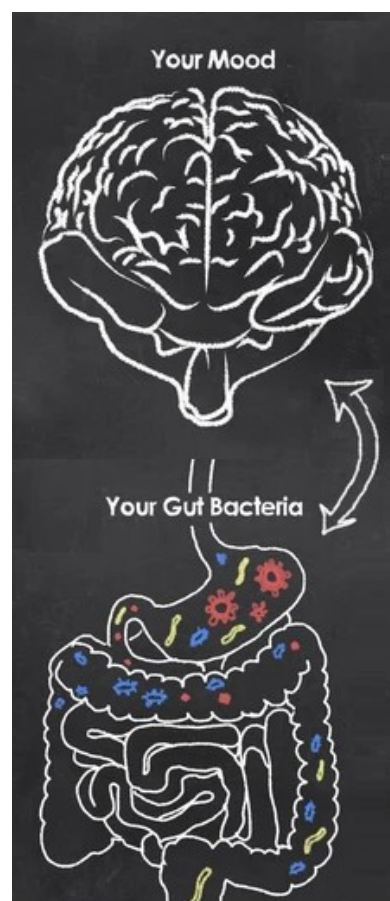
For more information, click [here](#).

A Survey of Autistic Adults from New Zealand on the Autism Diagnostic Process During Adolescence and Adulthood

This study run by Autism CRC in Australia in conjunction with Autism New Zealand, the Werry Centre and University of Otago explored the diagnostic experiences of 70 autistic adults living in New Zealand and how these related to satisfaction during three stages of the diagnostic process. The results show that autistic adults were reasonably satisfied with the early query and diagnostic assessment stages, but were dissatisfied with the post-diagnostic support stage, with significant unmet needs. Dissatisfaction

during the post-diagnostic support stage was also related to satisfaction during previous stages and poor coordination of supports. Suggestions are made on how to improve the autism diagnostic pathway for autistic adults in New Zealand.

For more information, click [here](#).



Efficacy of faecal microbiome transfer to improve gut issues in autism

The Werry Centre is also partnering with the Liggins Centre at the University of Auckland in a study to see whether transfer of bugs from the guts of non-autistic individuals can improve gastro-intestinal symptoms and well-being in autistic young adults. Recruitment for this study will commence in mid-late 2021.

For more information, please contact Dr Hiran Thabrew: h.thabrew@auckland.ac.nz

Publications

Our friends in Australia have published two interesting articles.

The first investigates a novel intervention for infants showing signs of autism spectrum disorder (ASD). The 103 infants in the study were aged 9-14 months and showed at least three early behavioural signs of ASD. The infants either received a novel parent-mediated video intervention (called iBASIS-VIPP) or continued their normal clinical care. iBASIS-VIPP is video-aided feedback to help parents understand and adapt to their infant's communication style.

They assessed the outcomes at the start of the study and at the 6-month endpoint. There was no significant difference in early ASD behavioural signs between the two groups after 6 months, however, they identified a positive effect on parent-rated infant communication skills. The team is now assessing longer-term developmental effects in this group of infants.

Article details: Pre-emptive intervention versus treatment as usual for infants showing early behavioural risk signs of autism spectrum disorder: a single-blind, randomised controlled trial. *Whitehouse et al. The Lancet: Child and Adolescent Health. Volume 3, issue 9, pages 605-615, Sep 1 2019.*

Read the abstract [here](#).

The second article looks at understanding loneliness in autistic adults. The study included questionnaires from 252 adults with autism and 146 adults without autism (all aged 25+ years). It identified that autistic adults were often lonelier than non-autistic adults, and this was largely related to social skills and dissatisfaction with social support. Importantly, autistic adults told the research team that there is a difference between loneliness and being alone. The study provides steps to better understanding loneliness and aloneness in autistic adults, which will help advise strategies to help people be less lonely.

Article details: Loneliness in adults on the autism spectrum. *Ee et al. Autism in Adulthood. Volume 1, number 3, Sep 11, 2019*

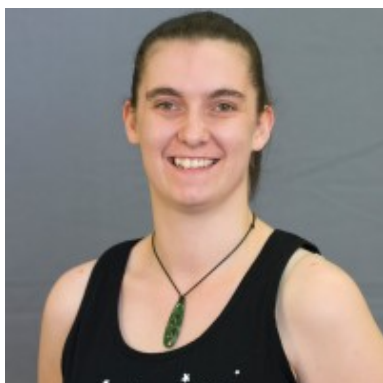
Read the abstract [here](#).



More information about the autism CRC in Australia and their research can be found [here](#).

New projects

PhD student Victoria Hawkins at the University of Auckland is working with Professor Russell Snell to develop a new model of Fragile X syndrome.



Fragile X syndrome (FXS) is the leading inherited cause of intellectual disability in the world. The neurodevelopmental condition affects over 1000 New Zealanders. The FMR1 gene responsible for FXS is located on the X chromosome; hence males (who have a single X chromosome) are more commonly affected than females.

FXS symptoms are highly varied and affect individuals to varying degrees. Intellectual disability is a very common symptom. Approximately 95% of FXS individuals have an IQ below 70 (the threshold for mental retardation). Autism Spectrum disorder (ASD) (Takiwātanga) commonly presents in people with FXS. So much so that FMR1 is the most common single gene cause of ASD, accounting for 2-4% of ASD cases.

There is no current treatment for FXS that targets the underlying cause. A major step in developing new treatments is pre-clinical animal trials to determine the drug is both safe and effective. Over 90% of FXS rodent trials progressed to human clinical trials, but this has not yet resulted in any effective treatments for FXS. This has thought to be due to the differences in size and structure

between the human and mouse brain. We are creating a sheep model of FXS to address this issue. Sheep have more similar brains to humans compared to mice making them an ideal model. This sheep model will be used to screen potential new treatments for FXS. This work is being generously funded by Cure Kids and the Health Research Council (HRC) of New Zealand.

Minds for Minds Charitable Trust co-funded research

1. Targeting a zinc link in autism spectrum disorder: does the gut microbiome influence the efficacy of zinc treatment in a mouse model of autism?

Gut tissue and faecal samples from wild-type mice (unaffected) and Shank3-negative mice (showing ASD-like characteristics) were collected from mice that were given either a control (normal) zinc diet or a high zinc diet. Although the gut microbiomes vary a lot between individual mice, the dominant bacterial phyla were consistently *Firmicutes*, *Bacteroidetes* and *Verrucomicrobia*, with notable genera including *Akkermansia* and *Muribaculaceae*. So, overall there were not major differences in terms of the identity (i.e. who's there?) of the



bacteria present. However, differences were seen between treatment groups when it came to functional gene profiles (i.e. what are the bugs doing?). For example, membrane transporters and various zinc metalloenzyme-associated genes differed, suggesting that dietary zinc treatment and genetic background may contribute to functional changes in the gut microbiota. This research is part of a project supported by Minds for Minds and the NZ Health Research Council, and is being carried out by PhD student Giselle Wong at the University of Auckland.



2. Understanding genetic variation in our unique New Zealand ASD population

The frequency of a genetic variant is a critical determinant when assigning causality in clinical genetics (e.g. a causal variant should not exceed the frequency of the condition in the unaffected population). However, the frequency of genetic variants can be affected by the geography of a population, and therefore, assessment of a variant's causality requires knowledge of its frequency in a population closely representing the affected individual's ethnicity. Although

large international efforts have determined population frequencies for variants occurring in many populations, their combined sample size for some of New Zealand's unique populations remains too small to support diagnostics and research. This suggests that recent breakthroughs in genomic medicine will not benefit all New Zealanders equally, unless this knowledge gap is closed. This research aims to investigate the genetics underlying ASD in some of our unique New Zealand populations to try and improve long-term outcomes for all New Zealanders.

Update on the New Zealand genetics project

We have completed the analysis and sequencing of 300 New Zealanders, with 41% of cases harbouring a causal or likely causal variant. A summary of the results are outlined below.

1. Variants in 10% of cases have been clinically translated to families or are in the process of being confirmed for clinical translation. For some families, the result has had an immediate impact, even beyond clinical management (e.g. qualifying them for funding from the ongoing resourcing scheme (ORS) funding).
2. A further 34% of cases harbour a likely causal variant but we do not have access to parental DNA to confirm inheritance (the study focussed on sequencing the proband only).

Initial gene network analyses show many of the genes these variants reside in share common neurobiological and chromatin remodelling pathways, giving us some insight into the biological mechanism underlying ASD.

Our custom-built bioinformatic pipeline has proven to be robust and the results interpretable by non-experts. We are now working with the diagnostic lab to trial the panel in the clinic.

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Help us continue our research

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Study opportunities, workshops, and new developments from the wider Minds for Minds team and their community partners



U21 Autism Research Network



The U21 Autism Research Network was set up with funds from the Universitas 21 Researcher Resilience Fund, bringing together 6 autism research groups from U21 universities. Researchers from the School of Psychology at the University of Auckland are part of this team. The Network aims to make a starting point in addressing challenges to collaboration across borders as well as the lack of diversity and inclusion in autism research. If you would like to sign up to take part in autism research with us, please do email us at u21autismresearchnetwork@contacts.bham.ac.uk.



Auditory Processing and Functional Language in Autism Spectrum Disorder (ASD)

We are seeking **children who have ASD, with no hearing difficulties,**
aged 4-12 years old, who live in Auckland.

Auditory processing deficits have been demonstrated in children with ASD. This may play a role in the communication difficulties children with ASD experience. We want to see if there is a relationship between auditory processing and functional language in children with ASD.

This study requires up to 2 hours of participant time. This can be done in one or two sessions, as preferred by the participant. It will include:

- A basic hearing screen.
- An assessment of non-verbal intelligence.
- An oral language assessment that looks at spoken language comprehension.
- Two listening assessments with different patterns of tones.
- A social perception assessment looking at understanding of communicative speech cues.
- A prosody assessment looking at understanding of stress, intonation, and emotion in speech.
- Parent/caregiver questionnaires about autism symptoms, communication skills, and sensory sensitivities.

A \$20 voucher will be given to you upon completion of your participation in the project.

We hope to gain a better understanding of communication difficulties in children with ASD and to explore whether they are related to auditory processing problems.

If you are interested, or would like more information, please contact:

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People with Autism Spectrum Disorder often experience auditory processing difficulties

Common auditory processing difficulties

- Difficulty hearing speech against background noise
- Difficulty listening with several people talking at the same time
- Being overwhelmed by noisy or complex auditory environments e.g. classrooms, shopping malls
- Difficulty following, processing, and remembering spoken instructions unless brief and simple
- Problems with speech, language, phonics, spelling, reading, or written language

Auditory processing difficulties can lead to increased anxiety in noisy environments, difficulty understanding subtle nuances of speech such as emotion or humour, difficulty engaging socially in a large group, having undue sensitivity to loud sounds or noise, and having poor listening skills.

Auditory processing difficulties can be effectively treated

Research shows that treatments for auditory processing disorder (APD) are also effective in reducing similar difficulties in children with autism spectrum disorder (ASD).

Research in New Zealand, Australia, and the USA has shown benefits from both auditory training and the use of specialised assistive listening devices, also known as remote microphone hearing aids (RMHAs).

Benefits shown for children with ASD are:

- RMHAs improve listening in noise, ease communication, and reduce stress levels in noisy classroom environments
- RMHAs can be used along with auditory training to improve listening skills
- RMHAs can be used along with social perception training to improve social skills
- Using RMHAs may lead to changes in brain activity that indicate improved sensitivity to tones of voice

SoundSkills specialises in the diagnosis and treatment of APD to help enable better learning.

The multi-disciplinary team of professionals at SoundSkills is experienced in assessing auditory processing skills in people with ASD and providing appropriate treatment.

For more information, a brochure, or to attend a **FREE SEMINAR about APD please contact SoundSkills at:**

 clinic@soundskills.co.nz  Call 09 930 8573

SoundSkills Clinic: The Stichbury Bidwill Centre, 251 Campbell Rd, Greenlane

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