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The New Zealand minds for minds autism spectrum disorder self-reported cohort

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ABSTRACT

Background: To improve our understanding of autism spectrum disorder (ASD) in New Zealand, a multi-disciplinary research network, Minds for Minds, was created. This network has established a cohort of self- and proxy-reported individuals and their family members with ASD in New Zealand. The aim of this manuscript is to present the New Zealand Minds for Minds Autism Spectrum Disorder Self-Reported Cohort, M4M cohort for short, and to provide preliminary insights into the trends of ASD in New Zealand through the analysis of diagnostic and sociodemographic information of 972 members (ages 2–83) of this cohort, the majority of which were carer-reported.
Method: The participants were recruited via an internet-based questionnaire, and social network analysis was used to visually analyse the mutual interactions of the cohort.
Results: We observed the well-reported gender bias and an ethnic structure that reflects New Zealand's most recent census. Comorbidity patterns were consistent with epidemiological literature: anxiety disorders, depression and epilepsy were highly prevalent amongst individuals with ASD and their families.
Conclusions: This is the first national large-scale ASD research cohort, which contains an ethnic composition unique to the country. It is anticipated that the multi-disciplinary research approach of this cohort will help inform health policies in New Zealand and contribute to the international effort to better understand ASD.

1. The New Zealand minds for minds autism spectrum disorder self-reported cohort

The prevalence of autism spectrum disorder (ASD) is currently estimated to be 1 in 68 children in the general population (Christensen et al., 2012). The epidemiology of ASD and other neurodevelopmental disorders is not well studied in New Zealand. The centralised health care system in New Zealand means the majority of ASD diagnoses are made by relatively few

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clinicians, which could improve the consistency and comparability of ASD diagnoses. The New Zealand population is therefore in a unique position to make a significant contribution to the international effort to better define ASD.

In 2013, a New Zealand-based research network, Minds for Minds, commenced collecting self- and proxy-reported diagnostic information relating to ASD and other neurological disorders. These data conformed the New Zealand Minds for Minds ASD Self-reported research cohort, M4M cohort for short, with the primary purpose of identifying appropriate individuals and families willing to be involved in specific research projects, with the aim to enable multidisciplinary studies.

The aim of this manuscript is to present the characterisation of ASD in New Zealand by way of a series of sociodemographic and family comorbidity descriptive and social network analyses of the M4M cohort. We anticipate the findings resulting from the M4M cohort will inform educational, social and health policies in New Zealand.

2. Methods

2.1. Internet-Based questionnaire

Interest to participate in the M4M cohort is collected via an HTML interface (www.mindsforminds.org.nz). Participation is encouraged via public media outlets and through clinical collaboration. Only name, e-mail address, and condition are required for successful registration. Individuals can then choose to enter further details. Individuals either proxy-reported or self-reported their diagnostic status through a four-choice item which included ASD, Asperger syndrome, other neurodevelopmental disability, or not diagnosed. Participants selecting ASD or Asperger syndrome were included in the current analysis. As an additional means to establish the credibility of the diagnostic status, participants were asked about the age at diagnosis and the name of the specialist who diagnosed the condition. The process of formally confirming diagnostic status and consenting the individuals in the cohort for genetic, public health, and behavioural research is on-going. The registration period remains open and individuals from all areas of New Zealand are eligible to register. Access is restricted to Principal Investigators. (Ethics approval Northern B Health and Disability Ethics Committee: 12/NTB/59). Following registration of interest, all individuals are formally consented for relevant research programmes through direct contact.

2.2. Descriptive analysis

Sociodemographic and clinical characteristics included: (1) date of birth and age, (2) gender, (3) reporting source (self-reported vs. proxy-reported), (4) target diagnosis (ASD, Asperger syndrome, other neurodevelopmental conditions), (5) age at the time the target diagnosis was made, (6) comorbidity of the proband, and (7) self-reported comorbidity of first-degree relatives (parent, siblings, children). Only individuals reporting the seven variables above were included in the descriptive analysis.

2.3. Social network analysis

Social network graphing can help to visually analyse the mutual interactions of an array of co-occurring conditions in a group of individuals (Cramer, Waldorp, van der Maas, & Borsboom, 2010). We used force-directed social network graphs (Fruchterman & Reingold, 1991) with the following attributes:

(1) *Bidimensional space*. Diagnostic entities (nodes) and individual instances of comorbidity (connecting lines or connections) were represented over a bi-dimensional space with a tendency to become circular as the complexity of the network (number of nodes and connecting lines) increases.

(2) *Minimal distance.* A node's location within the network results from minimizing the distances between all connected nodes. The length of a particular connecting line is the function of the number of times that the two nodes (diagnostic conditions) connected by the line co-occur. For example, in the event that dyspraxia co-occurs with depression twice as often as it does with hyperactivity, the distance between dyspraxia and depression will be half as long as that between dyspraxia and hyperactivity.

(3) *Distribution of nodes*. Conditions that tend to co-occur with multiple other conditions (which may themselves be related or unrelated) will tend to acquire relatively central locations within the wider network. By contrast, conditions that rarely co-occur with others will acquire peripheral positions in the network.

(4) *Degree*. Number of times that a given diagnostic entity co-occurs with any other diagnosis. For example, if dyspraxia co-occurs with epilepsy in five individuals, with depression in eight individuals, and with gastrointestinal disorders in 10 individuals, the degree of dyspraxia would be 23.

Force-directed graphs minimize the distances between those diagnoses that co-occur frequently. As a result, it is possible to determine if a particular diagnosis operates as a comorbidity "hub" within the network or unrelated to other diagnoses. If a target diagnosis frequently occurs in the shortest paths that connect a given pair of comorbidities, the target condition would be a greater contributor to the comorbidity network structure. Such nodes are referred to as having a relatively high level of centrality. Eigenvector centrality estimates the influence of a node based on the number of connections received and on the degree of the connecting nodes (Hansen, Shneiderman, & Smith, 2011).

We used the Girvan and Newman (2002) cluster analysis method for small networks to identify clusters or conditions with a tendency to correlate with one another. In order to provide an indication of the comprehensiveness of clusters in the