



A Study of Asian Children Who are Diagnosed with Autism Spectrum Disorder and Available Support Services in Auckland, New Zealand

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Published online: 28 February 2019
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Abstract

This study reviews the demographic characteristics of Asian children diagnosed with autism spectrum disorder (ASD) in Auckland, New Zealand, the support services they can access, and how more equitable access to health services can be provided. We examined government and non-government support services for Asian children diagnosed with ASD and their families. The findings reflect the complexities of navigating and accessing health, disability, education and social support services. Analysis of Ministry of Health Disability Support Services (DSSs) data suggest that Asians in New Zealand are underrepresented in utilizing DSSs. Drawing on Andersen's health care utilization model, suggestions for more equitable access to health, disability, education and social support include culturally and linguistically appropriate health care and social policies.

Keywords Asian · Equity · Support services · Fragmentation · Demographic characteristics

Introduction

Children with autism spectrum disorder (ASD) have complex and varying support needs (American Psychiatric Association 2013; Lauritsen 2013; Lord et al. 2000; Manning-Courtney et al. 2013; Myers and Johnson 2007), and a high chance of experiencing unmet needs (Bromley et al. 2004; Kogan et al. 2008; Thomas et al. 2007). ASD can cause stress for families (Bromley et al. 2004; Lang et al. 2013) who need to be able to access appropriate support services for their children as well as support to cope with the stress of caring for their children, such as counselling and respite care (Floyd and Gallagher 1997; Thomas et al. 2007). However, it is often complicated to navigate the services available for children with ASD because a range of government and non-government agencies are involved in providing support and services to these children (Kohler 1999; Reilly and Wicks 2016).

Asian families with ASD children may experience more stress because Asian cultural norms and beliefs can be a barrier for them to access support services (Welterlin and LaRue 2007). In many Asian cultures, ASD can be associated with mental illness and behavioral issues, and attracts stigma and shame (Hughes 2011; Lam 2013; Lam et al. 2010; Waldman et al. 2016). Eastern philosophical and religious influences, originating in historical Confucian, Taoist, and Buddhist beliefs and teachings (Lam et al. 2010), encourage people to practice self-control, and focus on maintaining social harmony and not express emotions openly within the group. There are expectations that individuals maintain harmony and be considerate towards others in order to achieve peaceful coexistence within family and with those in the community at large (Kramer et al. 2002). Disrupting this social harmony by displaying symptoms of a mental illness can be seen as defying the social order and causes stigma (Kramer et al. 2002).

The stigma can taint the whole family and subsequently there may be great shame felt by parents of children with ASD in the Asian culture (Shea and Yeh 2008). Some Asian mothers may have a sense of self-blame for having a child with ASD and wonder if they might have eaten the wrong food or done a wrong thing (Lam 2013). Hence, some Asian families try to hide their child with ASD from relatives and

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friends and may be reluctant to seek help and community support (Lam 2013).

Furthermore, cultural differences may influence the perception of ASD symptoms (Bevan-Brown and Moldovanu 2016; Dyches et al. 2004; Ravindran and Myers 2012). Some ASD symptoms may be perceived as “normal” so may be ignored or go unnoticed by parents in certain cultures (Morrison et al. 2008). For example, lack of eye contact, particular nonverbal gestures, lack of emotional expression and non-direct communication are usual in certain situations in Asian and Pacific cultures (Welterlin and LaRue 2007).

Screening and diagnostic measures for ASD rely on parental reports, especially for younger children, so parents’ perceptions, judgement and beliefs about their child’s development are crucial in diagnosis. A cross-cultural comparison between Israel, South Korea, the UK and the US showed different perceptions of ASD symptoms, resulting in cultural variations in making a diagnosis (Matson et al. 2011). Similarly, comparison between Japan, Greece, Italy, Poland and the US also highlighted cross-cultural differences between Europeans and Asians in their perception of ASD symptoms in children (Matson et al. 2017). While socialization and communication were more similar, there were more variations in interpretation of restrictive repetitive behavior (RRB). RRBs are more culturally subjective in parents’ perceptions, which may affect the diagnostic process and outcome measures (Matson et al. 2017).

The Western medical model for ASD diagnosis and treatment (e.g., using DSM 5 TR criteria) does not match with some Asian cultural norms (Daley 2004; Welterlin and LaRue 2007). For example, researchers examined four assessment instruments from a Chinese cultural perspective: the Vineland Adaptive Behaviour Scale (VABS), the Checklist for Autism in Toddlers (CHAT), the Modified Checklist for Autism in Toddlers (M-CHAT); and the Childhood Autism Rating Scale (CARS) (Zhang et al. 2006). They found questions or observation items that included pointing and eye contact with adults were not relevant to a Chinese upbringing, where it is considered rude for children to make eye contact with adults and pointing with the index finger is seldom used (Zhang et al. 2006).

Cultural barriers are also evident in studies about delivering services to Asian children and families living in Western countries. Some educational philosophies and naturalistic autism interventions or approaches such as floor time programs (where parents spend time with the child on the floor for 20 to 30 min sessions of shared and joint attention and problem solving interactions followed by the child leading creative pretend play for cognitive development and abstract thinking Wieder and Foley 2018), can be contradictory to some Asian families’ teaching philosophy and cultural expectations of teaching children using repetitive, structured learning of practical skills by rote learning and

memorization (Fung and Roseberry-McKibbin 1999). This was also noted in parents from the Korean ethnic group, compared to Māori and Pacific minority ethnic groups, in a study of an early intervention program in New Zealand to equip parents with knowledge and strategies to raise their child with autism (Birkin et al. 2008). Korean participants reported that the program requirement to participate in group discussions was challenging from both language and cultural perspectives (Birkin et al. 2008).

Moreover, language and communication barriers can cause additional hardship for Asian children and families living in Western countries in accessing appropriate information about ASD, health care and social services. A language barrier often hinders effective communication between Asian families and health professionals, which contributes to inadequate disability awareness, and difficulties in gaining more knowledge about their children’s illness (Kim and Keefe 2010; Welterlin and LaRue 2007). In a Canadian study, researchers reported that immigrant mothers who did not have sufficient English or French experienced barriers understanding terminologies used by providers, such as ‘respite care’ (Khanlou et al. 2015). Consequently, migrant mothers with language difficulties do not ask for the services, which can create population disparities in service delivery to children with disabilities.

Andersen’s Health Care Utilization Model for Equitable Access to Health Care Services

Andersen’s model for understanding health care service use was initially developed in the 1960s, with ongoing refinements and revisions since (Andersen 1968, 1995; Andersen and Newman 2005; Rebhan 2011). The resulting behavioral model incorporates three components: (1) primary determinants, including characteristics of the population (i.e., demographics), the health care system (i.e., resources and organization), and the external environment (i.e., political, physical, and economic influences on utilization), (2) health behaviors, which include personal health practices (i.e., diet and exercise) and the use of health services, and (3) health outcomes, which include self-perceived health status, clinically evaluated health status, and consumer satisfaction in five dimensions of convenience (accessibility), quality (acceptability), availability, affordability and provider characteristics (accommodation). Primary determinants are explained as the direct cause of health behaviors, which determine health outcomes and quality of life in a linear relationship (Andersen 1995).

Contextual characteristics (for instance, population demographics as a predisposing factor, and health indices as an indicator of need), and individual characteristics (including genetic predisposition, such as for ASD, and perceived needs) which determine health behavior, have

also been added (Andersen et al. 2011). Efficient access to health care, and health policy, financing and organization factors are important enabling contextual characteristics.

According to the model, access to health care services is inequitable when social structure, health beliefs and enabling resources determine who gets medical care. For instance, social structure (e.g., language difficulties, lack of knowledge of existing services) and cultural health beliefs (e.g., stigma and shame associated with disability) of Asian communities may impede access to health care services.

New Zealand is a multicultural country with a population of 4.8 million, with the Asian population the third largest ethnic group (Statistics New Zealand 2018). The Auckland region was chosen for this research because nearly two-thirds (65.1%) of New Zealand's Asian population live in the region (Auckland Council 2014). Almost a quarter (23.1%) of Auckland's resident population identify with an Asian ethnicity, whereas the corresponding figure for all of New Zealand is 11.8% (Auckland Council 2014). In New Zealand, ASD support services are provided under different government ministries, and a range of non-government entities.

The service provision landscape for diagnosis and post-diagnostic support for children with autism and their families is highly complex and very difficult to navigate. Layers of complexity exist not just because of the wide range of services and variety of providers, but also because many services are in high demand and have long waitlists (for example publicly-funded behavioural support services have waitlists of many months or even years). Moreover, little is known about the characteristics of minority service users especially in this area. With new, more self-directed models of care currently being trialled and likely to be adopted throughout New Zealand in the future (Enabling Good Lives 2018), the complexity of the ASD support landscape is likely to become even more problematic, especially for groups already struggling with managing different cultural and language barriers. One of the first conditions of access to services is knowing about services and how to access them. This paper seeks to address this knowledge gap.

Aims and Research Questions

The aims of this study were first, to identify the range of available support services for children with ASD provided by government and non-government agencies in the Auckland region; and second, to analyze the available demographic data on Asian children under 20 years with ASD who have accessed the Ministry of Health's Disability Support Services (MOH DSSs) in the Auckland region of New Zealand.

The research questions were:

1. What types of support services are available to children with ASD in the Auckland region?
2. What ethnic-specific health and DSSs are available to Asian children with ASD in the Auckland region?
3. What are the demographic characteristics of Asian children under 20 who are diagnosed with ASD living in the Auckland region?

Identifying the available support services and the demographic characteristics for Asian children with autism is a necessary precursor to better understanding the impeding and enabling factors for Asian children to have equitable access to support services. The analysis and identification of support services for Asian children will give a useful picture of service gaps for forming a better, more culturally responsive health care system to support the needs of Asian families of children with ASD, who are currently an under-researched population.

Methods

ASD support services are provided directly and indirectly by a wide variety of organizations in New Zealand's support system. Data were gathered from health, disability, education and social support services at national [MOH, Ministry of Education (MOE), Ministry of Social Development (MSD)] and local level (Auckland, Waitemata, and Counties Manukau District Health Boards), along with various recent local texts (Bevan-Brown and Dharan 2016; Reilly and Wicks 2016). The latest edition of the *New Zealand Autism Spectrum Disorder Guideline*, jointly prepared by the Ministries of Education and Health (2016), was the key resource for identifying the process of diagnosis of ASD. For clarity, and to attempt to disentangle the complexity of the landscape of ASD support services, we present the data on the ASD support system in four post-diagnostic support layers, or 'maps' (publicly funded support services; charitable and non-governmental supports; private sector options; and Asian-specific supports).

Data about specific support services for Asian children with ASD in the Auckland region were gathered from the three district health boards (DHBs) that cover the region and Asian cultural support workers involved with the other DHBs. We also approached autism and disability support agencies such as Disability Connect and the Children's Autism Foundation.

We used MOH demographic data on people allocated Ministry-funded DSSs, which includes age (5-year age groups from 0 to 4 to 70–74), gender (male, female), ethnic group (Māori, Pacific, Asian, European/Other, Not stated), disability type (intellectual, physical, ASD, sensory, neurological, other) and geographical location (16 regional

councils), as at September 2016 (Ministry of Health 2017a). We extracted data, at the country level, on Asian DSS clients under 20 years of age and examined their number, and age and gender distribution, and compared Asian DSS clients as a proportion of all DSS clients in New Zealand against the proportion of Asians in the total New Zealand population, as recorded in the 2013 census.

We also extracted and analyzed data on total DSS clients under 20 years of age whose primary disability was ASD, and total Asian DSS clients living in the Auckland region. The more specific dataset required for our research—that is, the number, age and gender distribution of DSS clients from the main Asian ethnic sub-groups, whose primary disability was ASD and who lived in the Auckland region—required a specific application and formal approval from the main database managers, via the MOH's Auckland agency that collects information on DSS clients in the region.

Results: Support Services for ASD children in Auckland

New Zealand has a wide variety of services available for diagnosis and support for children with autism and their families. While this provides many opportunities and resources for families, the system is also complex and difficult to understand. These difficulties are further exacerbated for Asian families for whom English is not the first language, or who are not familiar with the culture of the New Zealand health system. Families need to know what services are available and how to navigate the system in order to be able to access them. In the case of autism where early intervention is known to be best practice, extra delays in accessing services have serious implications.

Diagnostic Process

New Zealand's diagnosis process acknowledges the latest edition of the Diagnostic and Statistical Manual (DSM 5) and uses the revised criteria for the diagnosis of children with autism (Ministries of Health and Education 2016). Referrals for diagnosis can come from family, early childhood or school teachers, family doctors (GPs), speech language therapists, public health nurses and Plunket (infant health) nurses. In New Zealand's publicly funded health-care system, a child and their family can be referred to the multidisciplinary hospital-based pediatric team within child developmental services teams of DHB regions; it is also possible to seek diagnoses from community-based, privately funded specialists such as developmental pediatricians. Once a child's diagnosis is confirmed, a variety of interventions and educational, health, social and disability supports are potentially available.

In the publicly funded system, the hospital-based developmental pediatrician (or multidisciplinary team) who made the ASD diagnosis creates a clinical report including a support plan for a child who is newly diagnosed with ASD (New Zealand Guidelines Group 2010). The pediatrician or a developmental support/ASD coordinator from Child Developmental Services based at each of the DHBs (usually at the local hospitals) will then send onward referrals for families to access government-funded support services (Ministries of Health and Education 2016). On receiving these referrals, the respective agencies contact the families within an agreed timeframe (which varies depending on the agencies and their triage process and available resources).

Post-diagnostic Support Services

ASD support services include government-funded information and education, respite care, and behavioral support, which may be funded by any of several ministries and provided by a variety of public and non-governmental organizations. Several non-government funded organizations also provide services such as information and education.

The New Zealand ASD Guideline (2016) outlines recommendations for social development, which include encouraging functional development in ASD children, teaching skills for independent living, and minimizing stress for the person with ASD, as well as their family and whānau (wider family).

The post-diagnostic support layers we have identified are:

1. Publicly funded support services,
2. Charitable and non-government agency support services,
3. Private sector options for children with ASD,
4. Asian-specific support services.

Publicly Funded Support Services: Layer 1

Publicly funded support services are funded by the MOH, the MOE, the MSD and the Ministry for Children. These are mapped out in Fig. 1 and grouped by Ministry.

The MOH via the local DHBs provides free health care at various hospitals, designed mainly to address behavioral, emotional, and mental health difficulties and comorbid conditions, some dental services, social work services and interventions for a child with ASD such as speech therapy, occupational therapy and physiotherapy (Group 1).

The MOH also funds DSSs (MOH 2015, 2016a, b, 2017a), and as ASD is listed as a disability, children and their families can be eligible for these services (Group 2). DSS are contracted by the MOH to 15 regionally based Needs Assessment and Service Coordination Agencies

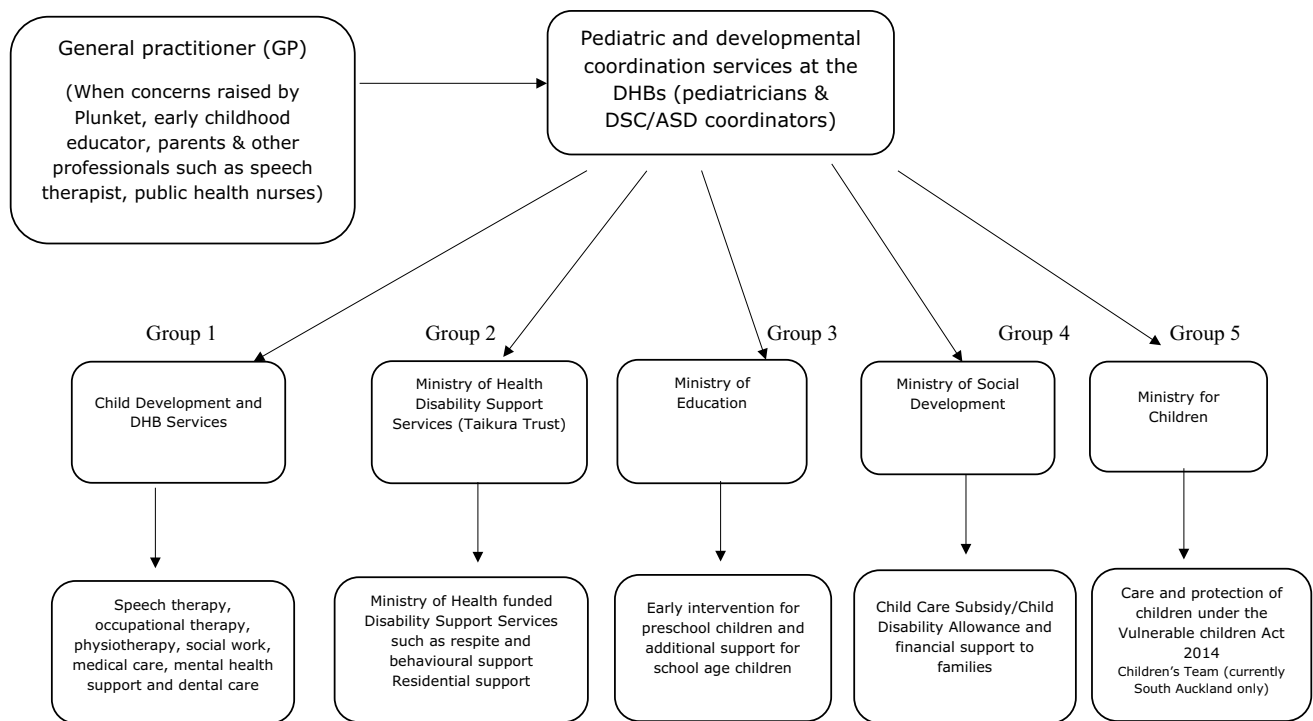


Fig. 1 Initial referral process and map of services from government agencies to meet health, disability, education and social needs of children with ASD—Layer 1

(NASC). Taikura Trust is the NASC agency for the Auckland region, which covers all three DHB catchment areas.

To access DSS, a written referral to the NASC is needed with a confirmed diagnosis of ASD. This is typically sent by medical professionals or social workers; however, families can also apply directly to a local NASC agency for a needs assessment with the supply of a confirmed ASD diagnosis made by a pediatrician for their child (Ministry of Health 2017b). The NASC is responsible for determining the eligibility of children with disability for MOH-funded DSSs, using a formal needs assessment. NASC identifies the strengths, resources, goals and support needs of children with ASD, informs families of available DSS, and organizes support. MOH-funded DSS include carer support funding, respite services, behavioral support services, one-to-one support at home, and community, Individualised Funding, Equipment and Modification Services (EMS), Community Choice in Living, and residential support.

The MOE (Group 3) provides early intervention and speech therapy for preschool children. The MOE also provides additional support in school classrooms such as teacher aide support. Resource Teachers of Learning Behavior (RTLBs), educational psychologists and other professionals such as occupational therapists also provide support to children and schools as required. There are also some special schools in the Auckland region, and satellite classes attached to some mainstream schools. Parents of

children with severe ASD can seek advice and guidance from the MOE early intervention team to either enrol their children in a local mainstream, or a special school if they meet the criteria once their children with ASD turn five.

The MSD (Group 4) provides a child disability allowance of \$47 per week for families who qualify, through one of its agencies, Work and Income New Zealand (WINZ 2017). WINZ also provides a childcare subsidy for 20 h paid childcare per week, which is available to all children in New Zealand from 3 years of age. Another MSD subsidiary agency, Strengthening Families, can organize interagency meetings to support families struggling to deal with various government agencies and support services or uncertain of how to access these (Strengthening Families 2017). Strengthening Families has local coordinators based in offices around the Auckland region.

The Ministry for Children Oranga Tamariki (Group 5) is the statutory child-welfare agency that provides care and protection support to vulnerable children with ASD under the Vulnerable Children Act 2014 (Oranga Tamariki 2017). This includes a new Children's Team formed as a cross sector action plan through the Children's Action Plan 2012 (Ministry of Health 2018) and the Vulnerable Children Act 2014. This team sits under the auspices of Oranga Tamariki and is designed to enable iwi (tribal, extended kinship group), justice, health, education and social service agencies to jointly support children at risk

of abuse and neglect; the service currently operates only in South Auckland.

There need to be bilateral relationships between various professionals from different government agencies and ministries to ensure the education, health, social and disability needs of children with ASD are met through collaborative action. An agency such as a school can refer children with ASD who need more than two agencies involved in their care to a Strengthening Families coordinator to set up such collaboration.

Charitable and Non-government Agency Support Services: Layer 2

Layer 2 includes information and advocacy services, which can be partly or fully funded by government, but are run by charitable community and non-government organizations (Ministry of Health 2016a; Reilly and Wicks 2016). In addition, some parenting and ASD information courses are provided for parents of children with ASD by community agencies who get funding from sources other than government (Ministry of Health 2016a). Families can self-refer to those agencies or can request a referral to their ASD coordinators, social workers or NASC coordinators to access support services. The pediatrician may also refer them.

The services identified under Layer 2 are:

- ASD-specific Disability Information and Advisory Services (DIAS)
- Autism courses supporting parents and sometimes teachers of children with ASD with information, strategies, and support (e.g., Early Bird Program for early intervention by the NGO called Autism New Zealand, ‘More than words’ for under 5-year-old children with ASD and social communication difficulties, TIPS for Autism which is a 3-day course for teams of parents and school teachers who support primary school age children with ASD aged 5 to 12, ASD Plus and Growing up with Autism parenting courses for families of ASD children, and The Incredible Years parenting program which provides positive parenting strategies to address children’s behaviour problems and promote their social, emotional, and academic competence and is run by various agencies all over Auckland (Webster-Stratton 2013; Werry Workforce Wharaurau 2017). These courses are required as parents of ASD children need more knowledge about autism so that they know how to manage behavior of their child and also to support children to develop social communication. The courses are also designed to support ASD children to improve in their cognitive abilities and communication development.
- School holiday programs targeted towards children with ASD and other types of diagnoses of disabilities.

- Health and Disability Commissioner’s Services provide “free, confidential and independent services” to the families of children with disabilities, including advocacy services to be able to access good quality health and DSSs and to raise concerns about such services (Health and Disability Commissioner 2017).

Privately Funded Support Services: Layer 3

Many parents may fund their children out of their own pocket to access support and therapy services, which may be due to perceived inadequacy or lack of government-funded services, such as floor time therapy. These services include private pediatricians, speech and occupational therapists, and Applied Behavioral Analysis therapy. Some services such as Rainbow House’s psychological and counselling support are not funded through any government ministries or agencies, but can be partly paid by parents with the Carer Support Subsidy from MOH and/or with Child Disability Allowance from the MSD via WINZ.

Asian-Specific Support Services for Asian Families of Children with ASD: Layer 4

Overall, limited services are available to Asian children diagnosed with ASD and their families, and there are few culturally-specific support services, sparsely distributed across the region with severe funding limitations.

There are some limited and particular support services available to Asian children with autism; among these, some are DHB services and some are community support services. These services include interpreting and translation services provided by DHBs. A few very specific cultural support services are provided by some DHBs as well as community agencies who are contracted by MOH and MSD, but these are mostly targeted at the larger Asian ethnic groups such as Chinese and Indian. For example, the Auckland DHB ‘South Asian and Other Families Support Group’ meets monthly, and aims to support and provide information and education sessions to the families of Asian children with ASD. Each of the three DHBs in the Auckland region offers a Culturally and Linguistically Diverse (CALD) Child Disability service (a caseworker’s team in Waitemata, community health workers in Auckland, and a contract with Disability Connect for cross-cultural services in Counties Manakau). Additional resources include: a cultural competency course for the health and disability workforce offered by Waitemata DHB; autism translated resources posted on the eCALD website (ecalld.com); the MSD Parenting Information SKIP website (<http://www.skip.org.nz>) with information about children with special needs translated into 19 languages; Disability Connect videos on how to use the New Zealand health system translated into Korean and Chinese; CALD Disability

Newsletters for health professionals and service users available at <http://www.ecald.com/news/cald-child-disability-newsletters/>.

Demographic Characteristics of Children with ASD in the Auckland Region

According to New Zealand MOH's database, as at September 2016, there were 33,804 people allocated MOH-funded DSSs throughout New Zealand, of which only 1913 people were of Asian ethnicity. A majority of DSS clients (12,876 people) were children under 20 years of age, of which 1127 (8.8%) were Asian children. In the 2013 census, the proportion of Asian children under 20 years of age living in New Zealand was 11.6% (Ministry of Health 2017a). This comparison suggests that Asian children could be significantly underrepresented in DSSs.

Across regional councils, the Auckland region has the largest proportion (30.4%) of DSS clients. As at September 2016, there were 10,275 DSS clients living in the Auckland region (Ministry of Health 2017a), of which 1287 (12.5%) were Asian. The proportion of Asian people living in the Auckland region at the 2013 census was 21.7%. Again, this indicates that Asian people living in the Auckland region are significantly underrepresented in DSSs.

Nationally, 6620 (19.6%) have ASD as their primary disability, representing 27.5% of all male DSS clients and 8.8% of all female DSS clients (Table 1). The gender ratio for ASD was 4.26 to 1, similar to the average gender ratio reported by the American Psychiatric Association (2013) and others (Charman 2008; Howlin 2006; Kim et al. 2011).

In terms of age, ASD clients were predominantly young, with 80.9% (5356) aged under 20 years.

Just over half (53.2%, or 3524 people) of all ASD clients in New Zealand were living in the Auckland region in 2016, of which 675 (19.2%) were Asian (Table 1). The age distribution and gender of Asian ASD clients in the Auckland region compares well with national figures—most (83.3% or 562) were under 20 years of age.

Table 2 gives the number of Asian ASD children under 20 years of age living in the Auckland region by ethnic subgroup and sex. There were 455 males and 107 females, a gender ratio of 4.25:1. The majority of ASD Asian clients were from the five largest Asian ethnic groups in New Zealand: 183 (32.6%) were Chinese, 147 (26.2%) Indian, 64 (11.2%) Filipino, 45 (8%) Korean and 16 (2.8%) Japanese. The rest were made up of a range of other ethnicities such as Cambodian, Indonesian, Vietnamese and Sri Lankan. It is important to note that 0–19 years are important ages for these clients and their families to have access to health, disability, education and social support services, in order to enable these children to achieve their full potential.

Discussion

The New Zealand support system is based on the assessed needs of individual children; support services for children diagnosed with ASD and their families are provided by a range of government and non-government agencies, across the health, disability, education and social sectors (Reilly and Wicks 2016). With such a wide variety of players, clear

Table 1 Total ASD clients in NZ, ASD clients in the Auckland region and Asian clients with ASD in the Auckland region, by age and sex, as at September 2016

Age group (years)	Total ASD clients in NZ			ASD clients in the Auckland region			Asian clients with ASD in the Auckland region		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
0–4	309	78	387	192	52	244	56	17	73
5–9	1515	321	1836	796	162	958	149	34	183
10–14	1528	331	1859	810	182	992	134	25	159
15–19	1027	247	1274	542	142	684	116	31	147
20–24	443	116	559	243	68	311	48	15	63
25–29	215	63	278	105	34	139	27	4	31
30–34	115	29	144	47	13	60	9	2	11
35–39	60	21	81	29	11	40	4	0	4
40–44	45	18	63	20	8	28	2	2	4
45–49	29	8	37	14	5	19	0	0	0
50–54	40	11	51	17	9	26	0	0	0
55–59	20	5	25	7	5	12	0	0	0
60–64	7	6	13	3	2	5	0	0	0
65–67	6	4	10	4	1	5	0	0	0
70–74	2	1	3	1	0	1	0	0	0
Total	5361	1259	6620	2830	694	3524	545	130	675

Table 2 Asian clients with ASD aged under 20 years in the Auckland region by ethnic sub-groups and sex, as at September 2016

Asian ethnic groups	Male	Female	Total
Chinese	145	38	183
Indian	122	25	147
Filipino	51	13	64
Korean	36	9	45
Japanese	16	0	16
Cambodian	11	3	14
Indonesian	8	5	13
Vietnamese	10	3	13
Sri Lankan	7	5	12
Pakistani	10	0	10
Thai	9	0	9
Afghani	5	1	6
Burmese	4	0	4
Bangladeshi	2	1	3
Malay	2	0	2
Laotian	1	0	1
Asian not elsewhere included	16	4	20
Total	455	107	562

Source MOH Auckland data from Socrates

coordination is often lacking. For instance, MOE provides support at school and MOH DSS are targeted at home and community support. As a result, a child who has behavioral issues at school cannot get support from a psychologist under DSS. In other words, DSS support needs during school hours are not covered by DSS, but instead under MOE funding (Ministry of Health 2016a).

Some language and cultural supports are currently available for Asian families in Auckland, depending on the DHB region in which they live. These are run by localized agencies and groups across the region, so there are gaps in cultural support in various areas of Auckland. Families are supported by DHB interpreting services at their health and medical appointments, and in accessing health and DSSs under the protection of client rights provided by the Health and Disability Commissioner. One possibility might be for MOH and DHBs to consider introducing cultural ‘brokers’ to help navigate and engage successfully with the services available.

Nationally, for all ASD clients, the majority of clients are aged under 20 years of age. In Auckland, the Asian children with ASD under 20 was 83.3% (562) of total Asian ASD clients (675) in the region. There are more Asian children with ASD identified in the age group of 5–19 years in the Auckland region, and that pattern is consistent with national data.

The gender distribution among Asian clients is 545 males and 130 females, or a gender ratio of 4.19:1. The Asian gender ratio in Auckland is slightly higher than the gender ratio

of all ASD clients in Auckland (4.08:1). The number of Asian children was 455 males and 107 females and hence the gender ratio of Asian children with ASD under 20 is 4.25:1 which compares well with the gender ratio of all ASD clients in New Zealand (4.26:1). The gender ratio is similar to the 2002 finding for 5- to 11-year-olds in Cambridge, UK, as well as the current international ratio of 4:1 (American Psychiatric Association 2013; Charman 2008; Elsabbagh et al. 2012; Howlin 2006).

The analysis of ASD demographic data suggests that rates of ASD diagnosis increased significantly nationwide, including amongst Asian children in the Auckland region, from 2013 to 2016 (Ministry of Health 2015, 2017a). This increase is in line with international findings that ASD prevalence rates are increasing (Rice et al. 2012; Sun and Allison 2010; Taylor et al. 2013). We do not know exactly why the ASD rate is increasing in New Zealand; however, as elsewhere, there may be some correlation with 2013 changes in the DSM diagnostic criteria (Lauritsen 2013). Nevertheless, it is crucial that government agencies provide adequate support services for children diagnosed with ASD in the Auckland region, as the number is increasing each year.

Andersen’s Health Care Utilization Model and Asian Children with ASD in Auckland

Asians are significantly underrepresented in utilization of DSSs locally and nationally. Andersen’s health care model suggests that health beliefs can cause inequitable access to health services. In this regard, Asian cultural health beliefs may cause families to be reluctant to seek professional support as parents may interpret ASD symptoms in a child, such as no eye contact or reciprocal conversation, as normal for their culture, or even think that the child is just being ‘naughty’ when they throw tantrums or injure themselves (Bevan-Brown and Moldovanu 2016; Dyches et al. 2004; Welterlin and LaRue 2007). On the other hand, some parents feel shame and guilt about their child with ASD symptoms due to the stigma attached, so they do not seek help (Lam 2013). In addition, language barriers may prevent them from seeking help in accessing health services, which is a social structural factor as per Andersen’s model (Khanlou et al. 2015). Hence, there can be inequitable access to support for Asian people in the community, due to a lack of awareness about ASD among Asian families and therefore less perceived need for their children with ASD to access services, as well as other cultural and structural (language/ethnicity) barriers. Subsequently, Asian families are underrepresented in utilization of DSSs in the Auckland region. Therefore, there may be a need for more support from early childhood education and school teachers as well as other professionals regarding a child who may have ASD.

Accordingly, health professionals such as developmental pediatricians need to provide family-centered support to build trust with Asian parents, particularly in convincing them that an ASD diagnosis in a child is not a shameful thing. It also needs to be made clear that while ASD is more common among boys, it also affects girls in many ethnicities (Ravindran and Myers 2012). Professionals also need to let Asian parents know there is strong evidence that early intervention leads to better outcomes (Bevan-Brown and Moldovanu 2016).

Government agencies should also focus on providing children and adolescents in the under-20 age group with more resources to provide better outcomes for them in the future, as per Andersen's model, including developmental pediatricians, early intervention teachers, speech therapists, occupational therapists, RTLBs and behavioral psychologists who are specialized in ASD and can deliver culturally appropriate services in the Auckland region.

This work has shown that Andersen's model can be applied to consider how to enhance enabling factors and a better health care system by improving policies supporting the provision of resources by government agencies to families and communities, so that there will be equitable access for everybody to health, disability, education and social support services (Andersen 1995). The dimensions of availability, accessibility, accommodation, affordability and acceptability of services can be applied to improve support services provision and access for Asian families who have children with ASD (Andersen et al. 2011). Predisposing factors such as demographic characteristics and social characteristics, including levels of community support, alongside organizational beliefs and values as enabling factors are important in supporting Asian children. For example, the Early Bird Intervention Program run by Autism New Zealand could be tailored to suit Asian families by having Asian staff to run the services for Asian families funded by the MOH (Andersen and Newman 2005; Birkin et al. 2008).

A limitation for this research has been the paucity of literature on support services for ASD children, particularly in New Zealand. There are also limitations in the data analysis as this research only accounts for Asian children with ASD who are registered with DSS in the Auckland region. It does not account for people who are not registered with DSS or people who have not been diagnosed, therefore it cannot confirm actual prevalence rates.

Recommendations for Future Research

There are no epidemiological studies of ASD in New Zealand; therefore, research on ASD prevalence rates is required. More research is recommended on Asian children with ASD, as numbers diagnosed are increasing in New Zealand as in other Western countries. Future studies could also

explore Asian families' experiences of the journey through diagnosis and getting support. It is apparent that the New Zealand government has acknowledged the importance of cultural support to families, as there are some DHB cultural services, but further research is required to measure and understand their adequacy for Asian families of children with ASD. It is also recommended that future research focus on professional perspectives of what types of services are required, and how delivery of support services can be improved to meet the needs of Asian children with ASD in the Auckland region.

Moreover, future research is recommended into support and interventions for other ethnic groups such as Māori and Pacific, as well as for NZ European children who are diagnosed with ASD in New Zealand. Such future research and findings will contribute to equitable access to support and services for all ethnic groups.

Conclusion

We have presented new knowledge about available support services and the demographic characteristics of Asian children who are diagnosed with ASD in the Auckland region, which we hope will inform better policy making and, in turn, access to services and support for Asian children with ASD.

Asian and other parents need to have more knowledge about ASD so that they can recognize developmental issues and consult their family doctor, who in turn needs to have access to appropriate specialists, like developmental pediatricians, and support services to refer on to in the Auckland region.

It is good to see that New Zealand has educational, social, health and disability support systems for children with ASD as per the NZ ASD Guidelines (Reilly and Wicks 2016). Further, language and cultural support are available to Asian children with ASD and their families so that they can access available support services in the Auckland region in their local DHB area. However, the current system is complex and fragmented and difficult to navigate. As Asian children with ASD are proportionally the second highest group in the whole Auckland ASD population, more culturally appropriate services will be needed to meet demand (Bevan-Brown and Moldovanu 2016). We hope this paper fills a knowledge gap to help services support Asian families to navigate systems and overcome the social structural and other barriers for easier access to services, specifically with appropriate cultural and language support.

Author Contributions MH conceived the study, participated in its design, conducted the data analysis and drafted the manuscript; EH and JW provided guidance on the design of the study, participated in

the interpretation and presentation of results, and made critical review and revision of the manuscript. All authors read and approved the final manuscript.

Funding No funding was obtained for this study.

Compliance with Ethical Standards

Conflict of interest All authors declare that they have no conflict of interest.

Ethical Approval This article does not contain any studies with human participants performed by any of the authors.

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