


Inclusion, acceptance, shame and isolation: Attitudes to autism in Aboriginal and Torres Strait Islander communities in Australia

Autism
1–14
© The Author(s) 2020
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1362361320928830
journals.sagepub.com/home/aut


Rozanna Lilley¹, Mikala Sedgwick^{1,2} and Elizabeth Pellicano¹

Abstract

This is the first qualitative study to investigate experiences of, and attitudes towards, autism in Aboriginal and Torres Strait Islander communities in Australia. Understanding the complexity of these attitudes is crucial because they influence the recognition of autism as well as the ways in which individuals and families are supported. Twelve families with 16 autistic children living in diverse regions of Australia participated in a semi-structured interview. The interviews were thematically analysed using the six-step process outlined by Braun and Clarke. The analysis identified a marked tension in participants' accounts. On the one hand, participants described negative feelings, including shame associated with atypical behaviour, stigmatisation and the social isolation of families, which potentially point towards under-identification or misdiagnosis. On the other hand, they also described inclusive attitudes, including 'looking after each other' and a growing acceptance of autistic differences. This positive model of support for and acceptance of autistic children and their families may well contribute to good outcomes for autistic children and adults in Aboriginal and Torres Strait Islander communities. More research is needed on cross-cultural and pluralistic understandings of autism, parental perceptions and family experience.

Lay Abstract

There has been almost no research done about autism in Aboriginal and Torres Strait Islander communities in Australia. This article is the first detailed report on attitudes to autism in these communities. Understanding attitudes to autism is important because they influence whether or not children are diagnosed, as well as the kinds of support autistic people are getting. Twelve families who lived in different parts of Australia were interviewed. They told us that there is a range of attitudes to autism in Aboriginal and Torres Strait Islander communities. These include negative ideas such as sometimes feeling shame associated with children's unusual behaviour, as well as feeling stigmatised and socially isolated. The negative attitudes reported may mean that some children are missing out on an autism diagnosis or being wrongly diagnosed with a different condition in these communities. They also included positive ideas such as the importance of looking after each other and of accepting autistic people and their differences. We can all learn from these positive attitudes. It will be interesting to know in future projects whether these accepting attitudes lead to better outcomes for autistic children and adults in these communities. This research helps us to understand how autism is thought about in different cultures and how attitudes impact diagnosis and support. It will also help people to plan supports that reflect what Aboriginal and Torres Strait Islander families actually want and need.

Keywords

aboriginal, attitudes, Australia, autism, cross-cultural, families, First Peoples, Indigenous, mothers, Torres Strait Islander

Autism is a lifelong neurodevelopmental condition, affecting people across the globe (Baxter et al., 2015; Elsabbagh et al., 2012). The vast majority of autism research, however, has been conducted in high-income countries and contexts, which means that little is known about the ways in which autism is understood and experienced in different

¹Macquarie University, Australia

²Australian National University, Australia

Corresponding author:

Rozanna Lilley, Macquarie School of Education, Macquarie University,
29 Wally's Walk, Sydney, NSW 2109, Australia.

Email: rozanna.lilley@mq.edu.au

cultures and communities (Hahler & Elsabbagh, 2015; Kim, 2012). This article investigates attitudes towards autism in one specific sociocultural context: Aboriginal and Torres Strait Islander communities in Australia. Such an understanding is crucial because the ways in which autism is conceptualised and understood in different socio-cultural contexts has a direct impact on the lives of autistic people and their families, profoundly influencing how autism is identified, managed and supported (Grinker, 2015; Ravindran & Myers, 2012).

Aboriginal and Torres Strait Islander people constitute 3.3% of the total Australian population (Australian Bureau of Statistics [ABS], 2019). Over 700,000 people make up this culturally diverse population, comprised of more than 250 different language groups. Aboriginal Australians represent one of the longest continuous cultural complexes known, with archaeological evidence for their continent-wide presence dating back approximately 50,000 years (Tobler et al., 2017). The Torres Strait Islands are a group of very remote islands located off the northern tip of Australia. Torres Strait Islanders are predominantly of Melanesian origin with the majority now living in mainland Australia. They have a distinct history and cultural traditions. The capitalised term Indigenous is commonly used to refer to both Aboriginal and Torres Strait Islander peoples. The terms First Peoples or First Nations, which apply to all indigenous peoples across the globe, are also sometimes used in the Australian context to refer to Aboriginal and Torres Strait Islander peoples.

The qualitative research presented herein contributes to the growing literature on cross-cultural and pluralistic understandings of autism, parental perceptions and family experience (e.g. Barrio et al., 2019; Dyches et al., 2004). The diagnostic features of autism – persistent difficulties in social communication and interaction as well as restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013) – may be variously interpreted according to culturally-framed notions of ability and disability, health and illness (Grinker, 2007) as well as local behavioural expectations and conventions (Ochs et al., 2004).

There is a very limited research literature addressing experiences of autism in Indigenous or First Nations contexts across the globe. Lindblom (2014) has argued that autism is under-detected among First Nations children in British Columbia, Canada, due to a combination of factors, including a lack of culturally sensitive diagnostic and assessment tools and limited access to healthcare in remote regions. Disparities in Indigenous peoples' access to autism diagnosis and supports have also been documented in the United States (Di Pietro & Illes, 2014). Other scholars have addressed how core cultural values of Māori in New Zealand (Bevan-Brown, 2013) and Navajo Native Americans (Kapp, 2011) support the inclusion of family members with developmental disabilities, including autism,

providing a positive framework that encourages the provision of culturally appropriate care across the lifespan.

In the Australian context, research on autism in Aboriginal and Torres Strait Islander communities suggests under-identification. In Western Australia (WA), Aboriginal mothers are more likely to have a child identified with Intellectual Disability and less likely to have a child diagnosed with autism (Leonard et al., 2005, 2011). Diagnostic substitution has been confirmed by a review of 14 adult Aboriginal psychiatric patients previously identified with schizophrenia in WA. Thirteen of these patients were reassessed as autistic when a developmental history was taken (Roy & Balaratnasingam, 2010). Cultural factors, including language barriers as well as an accepted ethos of accommodating a broad range of individual differences and capacities within families, have been raised as potentially contributing to under-ascertainment (Parker et al., 2014).

Studies investigating trends in the frequency and age of diagnosis of autism in Australian children aged under 7 years have reported that 1,500 children or 4.7% of those accessing a federal government scheme assisting families of autistic children identified as Aboriginal and/or Torres Strait Islander (Bent et al., 2015, 2017). Responding to the clear presence of autism in Aboriginal and Torres Strait Islander communities and the extremely limited research undertaken, there have been calls for a more sustained research agenda (Bailey & Arciuli, 2020; Bennett & Hodgson, 2017; Wilson & Watson, 2011), including consideration of how culture affects understandings of autism and access to services.

Overall, Aboriginal and Torres Strait Islander people experience widespread socioeconomic disadvantage and health inequality (Australian Institute of Health and Welfare [AIHW], 2018), including being 1.8 times more likely to be living with disabilities than other Australians (ABS, 2017). Such disparity is especially evident in rates of childhood disability (DiGiacomo et al., 2013b; Green et al., 2014) with research to date largely focused on hearing loss (DiGiacomo et al., 2013a) and Foetal Alcohol Spectrum Disorder (FASD) (e.g. Bower et al., 2018; Fitzpatrick et al., 2015, 2017). Canadian research (Di Pietro & Illes, 2016) with health professionals and researchers working on the frontline with First Nation communities has raised the possibility that autistic children may sometimes be misdiagnosed with FASD due to stigmatising cultural stereotypes. We do not currently have sufficient data to assess the likelihood of diagnostic substitution with FASD occurring in the Australian context. However, Secretariat of National Aboriginal & Islander Child Care (SNAICC, 2010), the national non-government peak body in Australia representing the interests of Aboriginal and Torres Strait Islander children and their families, have commented that general knowledge about autism is low and that families face many barriers to a child being diagnosed early and receiving supports.

In general, the sociocultural factors shaping experiences of impairment and disability in Aboriginal and Torres Strait Islander communities have been under-researched (Gilroy & Emerson, 2016). Discrepancies between Aboriginal and Western biomedical conceptualisations of disability appear to contribute to low rates of participation in disability services (Ravindran et al., 2017). A qualitative study of the experiences and needs of carers of Aboriginal children with a disability in a metropolitan setting demonstrated that financial cost, mistrust of outsiders and social isolation as well as racism and lack of cultural sensitivity on the part of providers were key barriers to service access and utilisation (DiGiacomo et al., 2017; Green et al., 2018). For analytic purposes, however, no distinctions were made according to disability type, making it unclear whether these barriers apply to families of children on the autism spectrum. Certainly, in general, the legacy of the Stolen Generations of Aboriginal children forcibly removed from their families by successive Australian governments as well as the large, and growing, numbers of these children placed in out-of-home care (Australian Institute of Family Studies, 2017) can make people very wary of engagement with mainstream services (Bailey & Arciuli, 2020; O'Neill et al., 2004).

Gorman and Toombs (2009, p. 4) have eloquently remarked,

If we aspire to social justice for [Australian] Indigenous people, especially in the area of health, then we must undertake appropriate research that addresses the needs of Indigenous people as they perceive them in a way that fits within their frame of reference.

The current study, therefore, reports on Aboriginal and Torres Strait Islander experiences of autism, as described by women supporting their autistic children and grandchildren. This article explores 'key epistemic tensions' (O'Dell et al., 2016) in attitudes about autism and attitudes towards autistic children and their families in urban, regional and very remote communities, documenting how socially inclusive attitudes and autism acceptance exist alongside experiences of social isolation, shame and stigmatisation. In so doing, it provides a sociocultural perspective that is urgently required as part of the process of building a research agenda that illuminates experiences of autism among a very diverse Indigenous population, who are bound together by experiences of colonisation and marginalisation in the broader context of the Australian nation state.

Method

Participants

Families with Aboriginal and/or Torres Strait Islander children on the autism spectrum were recruited through the networks of our partner organisations (see below) and

through researcher contacts. Twelve families – including eleven mothers and one grandmother – agreed to participate in a semi-structured interview. While the research project was open to all family members and/or primary carers, only women consented to participate, which may be a reflection of broader gendered expectations in relation to caring for children in both Aboriginal and Torres Strait Islander communities and wider society. They came from diverse parts of Australia, including the Australian Capital Territory (ACT), Victoria, New South Wales (NSW), Queensland, the Northern Territory (NT) and the Torres Strait Islands. Some resided in major cities; others lived in regional or remote Australia. Table 1 shows participants' demographic information as well as details on their 16 children (female: $n=1$; male: $n=15$), who ranged in age from 2 to 22 years.

Ethics and community involvement

The research was designed in consultation with Positive Partnerships, who are funded by the Australian Government Department of Education and Training to deliver national programmes and workshops supporting the families and schools of Aboriginal and Torres Strait Islander children on the autism spectrum, and First Peoples Disability Network, the national organisation of and for Australia's First Peoples with disability. Ethical approval for the research protocol was granted by the Aboriginal Health and Medical Research Council (1433/18) and Macquarie University Human Research Ethics Committee (5201832104269). The protocol was also approved by Positive Partnerships' National Reference Group, consisting of Aboriginal and Torres Strait Islander leaders from key organisations and services across Australia.

The research team was comprised of two non-Aboriginal [Rozanna Lilley and Elizabeth Pellicano] and one Aboriginal [Mikala Sedgwick] researchers, whose disciplinary backgrounds span psychology, anthropology and Indigenous policy and health. Two of the team members [RL and MS], including the Aboriginal researcher, are mothers of autistic children, and thus contributed experiential expertise to the design, implementation of the methods and interpretation of the findings, beyond their knowledge and skills as researchers.

Procedure

Positive Partnerships were involved in the recruitment of participants using their previously established networks. The semi-structured interview schedule asked a series of open questions to examine participants' experiences of their child's early development and diagnostic pathways, access and barriers to relevant supports and services, as well as education placements and experiences (see Supplementary Material). Participants were free to introduce other topics

Table 1. Background characteristics of participating families.

Name ^a	Kin relation	Place current residence ^b	Age in years	Number of autistic children	Name ^a , gender & age of autistic children	Child age at diagnosis (years)	Other conditions	Current education setting
Ruby	mother	Torres Strait Islands (VRA, RA5)	44	1	Noah: 9-year-old boy	5-6	None	Mainstream with support
Ella	mother	ACT (MCA, RA1)	39	1	Oliver: 4-year-old boy	just under 2	Mild permanent bilateral hearing loss	Preschool with support; support unit in 2019
Amelia	mother	NSW (MCA, RA1)	47	1	Mason: 18-year-old young man	16	Cerebral palsy, epilepsy (premature) & anxiety	Special school
Layla	grand-mother	VIC (IRA, RA2)	63	3	Logan: 10-year-old boy Hunter: 7-year-old boy	4 3	Prematurity	Mainstream
Ava	mother	NT (ORA, RA3)	30	2	Isaac: 10-year-old boy Koen: 5 year-old boy	6 3	None ADHD	Special school Special school
Alexis	mother	VIC (IRA, RA2)	42	1	Tyler: 4-year-old boy Cooper: 13-year-old young man	2 5	ODD	Mainstream with support Preschool
Olivia	mother	NT (ORA, RA3)	No answer	1	Scarlett: 8-year-old girl	3	PTSD, OCD, anxiety & mild hearing impairment	Special school
Nevaeh	mother	NSW (MCA, RA1)	39	1	Leo: 2-year-old boy	2	Global developmental delay & asthma	Special school
Sophie	mother	NT (VRA, RA5)	40	2	Alex: 6-year-old boy Warrin: 8-year-old boy	4 6	Epilepsy & ear infections	Aboriginal community preschool
Sienna	mother	NSW (IRA, RA2)	51	1	Elijah: 22-year-old man	10-11	Partial chromosome deletion	Mainstream with support
Willow	mother	QLD (IRA, RA2)	No answer	1	Kai: 9-year-old boy	4.5	ADHD	Living at home with no current services; previously support class
Aaliyah	mother	ACT (MCA, RA1)	39	1	Aiden: 12-year-old boy	6-7	Recurrent otitis media	Mainstream with support

Note. ^aPseudonyms are used to protect participant confidentiality. ^bThe Australian Statistical Geography Standard (ASGS) Remoteness Structure is used to refer to participants' place of residence. Remoteness Areas divide Australia into five classes of remoteness measured by relative access to services. Remoteness Area (RA) 1 is Major Cities of Australia (MCA), RA2 is Inner Regional Australia (IRA), RA3 is Outer Regional Australia (ORA), RA4 is Remote Australia (RA) and RA5 is Very Remote Australia (VRA). ACT = Australian Capital Territory, NSW = New South Wales, VIC = Victoria, NT = Northern Territory, QLD = Queensland; ADHD = Attention Deficit Hyperactivity Disorder; ODD = Oppositional Defiance Disorder; ASD = Autism Spectrum Disorder; PTSD = Post Traumatic Stress Disorder; OCD = Obsessive Compulsive Disorder.

reflecting their interests and experiences (Salmon, 2007). Throughout, the emphasis was on sharing stories in natural and casual ways (Burkett et al., 2015). Five participants told their stories face-to-face and seven were interviewed via Internet conferencing or telephone, depending on preference. Aboriginal advocates experienced in the disability sector were available for support during face-to-face interviews. Interview durations ranged from 47 to 151 minutes with an average time of 80 minutes. To preserve anonymity, pseudonyms are used (see Table 1), and identifying information has been removed following verbatim transcription of recordings. Following participatory research guidelines (Salmon, 2007), participants were given the opportunity to edit their deidentified transcripts and to comment on a summary of the research findings, which were then edited to include their suggestions. No substantive changes were suggested by participants.

Data analysis

Interview transcripts were thematically analysed using the six-step process outlined by Braun and Clarke (2006). The research team share a critical realist standpoint, acknowledging the ways in which individuals make meaning of their experiences as well as the broader social context in which those meanings are constructed and mobilised. Themes were identified using an inductive ('bottom up') approach (i.e. without integrating the themes within any preexisting coding schemes or preconceptions of the researchers), involving close reading and re-reading of transcripts.

To begin, one researcher [RL] took the lead in independently familiarising themselves with the data, reading and re-reading the transcripts, and assigning codes to data extracts. A second researcher [MS] independently coded three of the 12 transcripts. They then met and discussed the coding scheme until consensus was reached. Once all the data were coded and collated, all three researchers liaised several times to review the themes and subthemes, focusing on semantic features of the data (i.e. 'staying close' to participants' language), resolving discrepancies and deciding on the final definitions of themes and subthemes. The analysis was thus iterative and reflexive in nature and moved backwards and forwards between data and analysis. This article provides a detailed account of a group of themes related to attitudes towards autism in Aboriginal and Torres Strait Islander communities that emerged as a distinct data set within the overall data corpus.

Results

We identified four themes relating to Aboriginal and Torres Strait Islander attitudes towards autism (see Figure 1). Overall, there was a marked tension in these accounts between the growing acceptance of autism in these

communities and the continuing stigmatisation of autistic individuals and their families as well as between feeling supported, especially by family, and being socially isolated because of child preferences and shame associated with atypical behaviour.

Theme 1. Looking after each other

Subtheme A: looking after our own mob. Our participants frequently referred to the importance of looking after related others and, in turn, the expectation of children being looked after by family members, both immediate and extended. The role of the immediate family in supporting autistic children was especially salient. Participants told us that they sometimes lived in households spanning three generations and that the relationship between grandparents and grandchildren was close and supportive. For example, Nevaeh moved into her parent's home with her husband and her 2-year-old son following his autism diagnosis. She described her parents as a 'massive support . . . when we're spent, someone else is there playing more games with him and encouraging him to talk'. Layla, the only grandmother interviewed, has three autistic grandchildren. She said she helps to look after her grandchildren whenever she can: 'we look after our own mob'.

This emphasis on familial support was also apparent in accounts of the relationships between peer groups of Aboriginal children, often described as 'cousins', a term that encompasses both actual and fictive kin. Ava, who has two autistic sons, referred to the inclusivity of these peer groupings, stating that 'whenever my boys are around other Aboriginal kids, they're just them . . . There's no autism because we've not grown up with "that child has something", it's 'oh, that's your cousin''. Ava contrasted this inclusive attitude with disabling attitudes towards autistic children in wider Australian society: 'It's such a different way of thinking and it's so much more positive'. Willow, whose family includes both Māori and Aboriginal kin, described how the children in her extended family protect her autistic son, Kai:

They're like little lions . . . if anyone from outside the family comes in and says or does something in a playground with Kai, all those little cousins will come in and they enclose a circle around him and they protect him. Then they explain to the other kids that he's got autism.

Participants also conveyed their deep concerns for other extended family members who are supporting autistic children and/or adults. Olivia said that she has 'plenty of family members who have children with autism or other disabilities' and that she informs them about how to access a diagnosis and services. For some mothers, these efforts to support other families were largely informal. But others had established more formal networks of support,

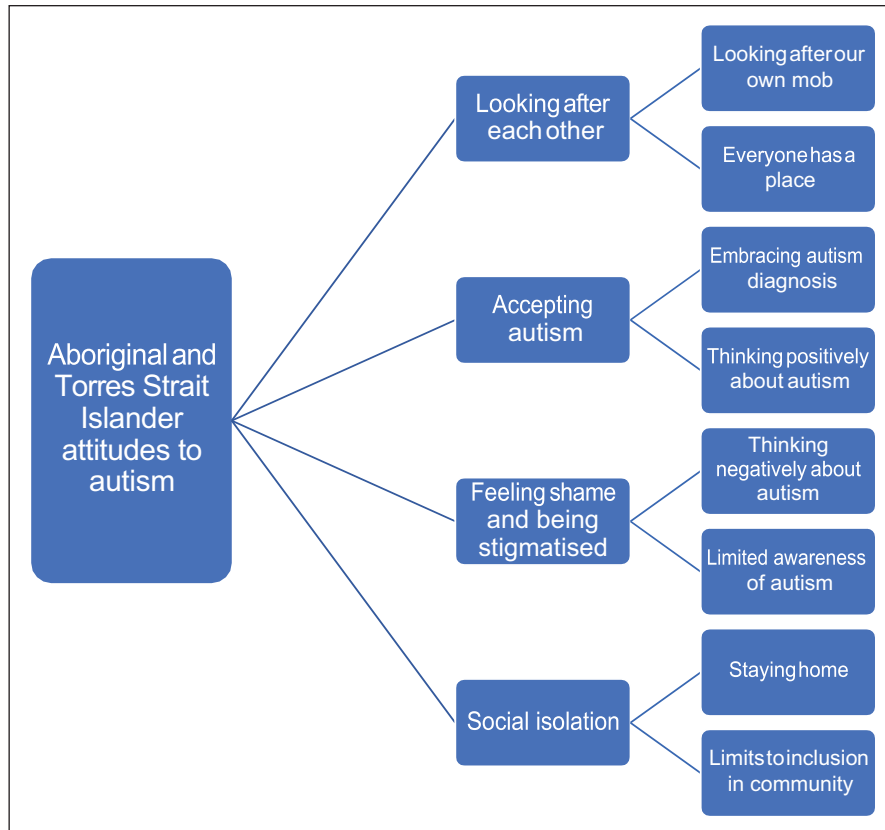


Figure 1. Aboriginal and Torres Strait Islander attitudes to autism.

including one mother, Alexis, who founded a support group for Aboriginal parents of autistic children in her regional town.

Participants also frequently expressed a preference for Aboriginal or Torres Strait Islander staff interacting with their autistic children, in childcare centres, schools and health clinics. Nevaeh sends her son to a local Aboriginal children's centre, which includes staff who are related to him and which makes the centre 'very family-orientated, he's got cousins that go there and I like that safety feel'. Olivia said that at her autistic daughter's special school 'it's nice to see another Aboriginal face, especially if it's someone you know'. Ava described how one of her autistic sons was 'looked after' at an Aboriginal health clinic, stating that the staff 'connect better with Aboriginal people'. She explained further: 'It doesn't matter if you're my colour, your colour or whatever; it's not about that. It's about the fact of understanding what it's like to be an Aboriginal person'.

Subtheme B: everyone has a place. Participants expressed the view that all individuals have a place and are entitled to a sense of belonging. Sometimes this was described as an acceptance of each individual's diverse characteristics: "in a lot of communities, it's just like 'oh that's just how so and so is' and it's accepted" [Ella]. Other mothers mentioned that all children in their (Aboriginal) communities

are loved unreservedly: 'But in communities all the kids – no matter what they're like, everyone just loves them. It's really funny, it's like there's just all acceptance of who they are' [Olivia]. Willow contributed that 'blackfellas' don't see her son as being autistic because 'he is treated as an equal'.

Alongside the idea that everybody has a place, participants expressed the strong belief that all children have a right to their culture. Layla described how she tried to encourage pride in Aboriginality with her autistic grandson, gifting him an Aboriginal flag. Willow was enthusiastic about 'going on Country' as a form of therapy for her son, telling traditional stories and imparting knowledge about local flora and fauna as a way to connect him with his heritage and to help him 'self-regulate'. Alexis said that if she won the Lotto, she would open her own Aboriginal school for autism and other disabilities, 'teaching our culture and stuff like that'.

The idea that everybody belongs in community was sometimes related to scepticism towards diagnostic labels. The 'labelling' of children was described, at times, as a Western preoccupation. In the Torres Strait Islands, one participant remarked, 'there's no label put on them . . . we don't actually have labels and in the Western world you're actually putting a label on a specific condition'. Ava concurred: 'It's only when they're put into Western standards that there's judgment'. Mothers believed there was

a positive side to not labelling children: ‘I think that we definitely grew up with people in our communities and in our families who were on the spectrum. It was just them and, in some ways, I wished it was still like that’ [Nevaeh].

Theme 2. Accepting autism

Subtheme A: embracing autism diagnosis. Although mothers expressed some scepticism towards diagnostic labels, most reported that they were ‘happy for the diagnosis’. Ava said that the diagnosis of her sons was positive because ‘I now know that I’m not mad and I now know I can get help’. For Nevaeh, the autism diagnosis ‘helped me be a better mum . . . we know what makes him tick, we know what makes him have a meltdown, we read him a lot better than we did’. This was also the case for Sienna who said that after her son was diagnosed she realised what she had to do, ‘not treat him different, but understand the way he is thinking’.

For participants, autism diagnosis often forced a re-examination of themselves and their wider families. Some reinterpreted family members as potentially autistic following the diagnosis of their child. Olivia raised the possibility of misdiagnosis, stating “digging deeper we’re finding a lot of family history where people have always just referred to family members, ‘oh no, they’re just a bit slow’”. She asserted that she now recognises ‘those people as potentially being on the spectrum’. Alexis felt that autism was a non-stigmatising explanation for the behaviour of her siblings:

I look back at my brothers now – even though they were little bastards when they were growing up, I can see why now. There was none of this autism back then. They had issues but they were just the bad kids. They’re the ones getting into trouble and all that sort of stuff. But now I know what autism is.

One participant spoke about how her children’s autism diagnoses encouraged her to re-evaluate her previous difficulties, including a history of being taken advantage of sexually, and to self-identify as autistic. ‘I started ticking some boxes for myself’, Ava explained. For this mother, the point of diagnosis is that ‘it can explain a lot; it can help me understand my life’.

Participants also spoke about their role in educating the broader community about autism. Willow said that she and her husband educated their extended families about autism: ‘They’re sort of all across it now’. Ella, too, mentioned: ‘We just try to help educate [the community] and try to help them understand that we need to do things differently so that Oliver is comfortable and can manage in this world’. Sophie said that while a ‘lot of parents and people in the community are becoming more comfortable in hearing the term autism and knowing that it’s around’, many families remain unaware of ‘what the signs and symptoms are’.

Subtheme B: thinking positively about autism. Participants expressed a range of positive views about autism. Olivia, who often travels to remote communities as part of her work, believed that autistic people had a special status in traditional Aboriginal society as ‘medicine men, or healers and things like that’. She contrasted this with contemporary discriminatory attitudes:

The perception of autistic children is that they’re damaged, they’re worthless in society, but historically I reckon Aboriginal children were probably looked at as like, wow, you’re special, in a good way.

Willow emphasised her son’s talent at drawing, stating that autism has ‘a lot of beautiful gifts’. Sophie, too, focused on the capacities of her children, repeatedly referring to their ‘very interesting minds’. In relation to her adult son, Sienna reported, ‘There’s nothing I would change about Elijah’. Other mothers felt that their own capacities and talents had been developed as a result of supporting their autistic children. Olivia summed this sentiment up when she said ‘it’s been, I guess, a big learning journey’.

Sophie commented on her positive approach to explaining autism to community: “Well, when I first started informing family members and friends about it, they were like, ‘Oh, I’m so sorry to hear that’. I was like ‘Why? He is not dying. He’s just a little bit different’”. Olivia, too, expressed the view that autism is a difference, not a deficit when she explained her daughter’s autism to other people: ‘I was just like, yep, she’s good, she just needs to learn a different way’. Ella also mobilised the trope of difference when explaining her son to others: ‘We would just explain that he is wired differently’. Ava went a step further in her support of what might broadly be defined as a neurodiversity viewpoint, arguing that autism is an evolutionary advance:

What if it’s actually that they’re so much more intelligent and smarter than everybody else, that it’s just evolution. That’s the next stage for everyone. Why they don’t fit in our bubble now is because we just don’t fit in theirs.

Theme 3. Feeling shame and being stigmatised

Subtheme A: thinking negatively about autism. While participants expressed a range of positive views about autism, they also reported negative views in their own communities and beyond. Nevaeh, whose son had only very recently been diagnosed, commented ‘it’s been a very scary, hard journey, and I’m only at the beginning’. The extent of her distress was evident when she recalled saying to a friend, ‘if autism had a face, I would punch it’.

Sometimes negative views of autism were related to the concept of ‘shame’, which is a concept with complex cultural salience in Aboriginal communities. Semantically,

shame is associated with a fear of disapproval or of negative consequences arising from a perceived wrongdoing. It can also simply refer to being the centre of attention. Shame is often used as a noun in Aboriginal English, as in ‘that’s a shame-job’ or ‘I’ve got shame’ (Hamilton et al., 2016). A number of mothers linked autism and shame in their observations. Alexis reported that, in her regional community, ‘a lot of the parents don’t go anywhere because the kids run amok – shame job’. Ava, too, referred to internalised feelings of shame:

Kids are getting missed, you know, slipping through because some parents are in denial or parents don’t know what help to get or parents are made to feel like they’re mad because they’re thinking it. Or, even worse, that it’s shame if you think it.

Because of shame, participants said that families may avoid disclosing their children’s autism diagnosis to family and friends. This was contrasted with more inclusive attitudes towards people with physical disabilities by Olivia, who pointed out:

But I do have cousins that have physical disabilities, and everyone’s all – no problem with that. I think it’s just the ones where you can’t see that everyone gets a bit shame about, or even shame saying anything, for fear of offence maybe.

Nevaeh corroborated this reluctance to discuss autism in her urban community: ‘Even with my cousins and stuff, even though you know that there’s a diagnosis, we’ve not really talked about it. Like everyone is kind of in their own world with it’. Ella also said that once her son was diagnosed,

that there were lots of Aboriginal and Torres Strait Islander people that I knew that had relatives or that were on the autism spectrum too . . . but it’s not really commonly talked about. I think in some communities there’s definitely still that shame factor associated with any disability.

Other mothers reported that autism was associated with negative attributions in their families. Ava explained that her mother initially had a negative response to her grandchild’s autism diagnosis: ‘When they first found out, Mum was like “eek” but that’s because her mind was still set in the fifties with the stereotypical one type of autistic child’. For Aaliyah’s relatives, ‘there was really the perception that if you’re autistic you were stupid and you didn’t have any social skills’. Sophie mentioned that some members of her community assumed that her son had FASD, which, she felt, reflected badly on her as a mother.

Participants’ starkest accounts of stigmatising interactions occurred with non-Aboriginal people and across numerous contexts, including diagnostic assessments, therapy sessions, shopping centres, schools and hospitals. Sometimes mothers felt that service providers did not sufficiently respect their family’s privacy and confidentiality. At other times, mothers felt blamed for their child’s

behaviour. Sienna said she was ‘accused of spoiling this child, having no control over him, and this was teachers that were at my school’. Sienna also spoke about how she needed to monitor her adult son’s behaviour when out shopping:

He walks normal, he talks, like he does everything normal like a normal kid, but there are some things that he does. Likes he’s six foot four and if he’s in a happy mood he will skip, like in the shopping centre, and I have to say mate, you can’t do that in the shopping centre. I said you have to walk like everybody else now because it’s not what you do, darling.

Amelia’s son, Mason, has a co-occurring diagnosis of epilepsy. She reported that a doctor in a public hospital asked her if she had caused his brain bleed by throwing him against a wall: ‘That really haunts me still’.

Subtheme B: limited awareness of autism. Participants told us that autism was a relatively new concept in their communities. Ruby reported that her son, Noah, is the only child ever diagnosed with autism in her outer island community in Torres Strait. Her support person, Mia, added:

These are the kinds of things that we never grew up with. We don’t know of autism, Asperger’s, Down Syndrome . . . this is something new for our communities and our communities are at that real rudimentary level of not absolutely knowing anything about it.

The relative novelty of autism diagnosis in communities prompted etiological reflections from some participants. Mia noted that because autism was unknown in the past, there are no traditional medicines to treat the condition: ‘it’s something new that came about because we’re living this new life in the Western world’. Layla, who is in her 60s, commented that ‘in my time and with my kids’ there was ‘nothing like this . . . is it this generation that it’s coming out?’

Sophie remarked that her traditional Aboriginal family ‘wouldn’t even be thinking of any of that at all, let alone know how to get the skills or the support to have a child diagnosed or to find out this information and then how to take care of them and support them . . . These are all big things’. Other mothers raised the issue of misdiagnosis, suggesting that some Aboriginal children who are autistic are being misdiagnosed with other disorders including Oppositional Defiance Disorder, ADHD and FASD: ‘There’s not enough understanding about what autism is’ [Ella].

A further concern raised was that autistic children may be missing out on diagnoses because of the presence of many other pressing problems and issues in Aboriginal communities. Willow, who works in the health sector, said,

I think if you have some families who have a lot of challenges or are facing a lot of other things, income and all that sort of

stuff or whatever the challenge might be, then those little kids, without that support, that's probably who will slip through the net.

Sophie raised similar concerns:

My kids are okay, but I've seen a lot of other children on the spectrum who are more impacted by other factors, whether it's a matter of a crowded house or somebody in the home with an addiction or mental illness. Some of them don't even have homes. Those other factors there are so predominant for some of these kids. Yeah, they're under the radar; they're just completely missed or they've been diagnosed and unless there's some consistent carer there or somebody that manages that, a lot of these children are actually put into the welfare system. It's a sad side of things.

Theme 4. Social isolation

Subtheme A: staying home. Participants frequently mentioned that their autistic children or grandchildren preferred to stay home, which meant that they were 'stuck in a house'. Aaliyah felt that getting her son out of the house was like 'pulling teeth'. Sienna noted that Elijah 'doesn't like big crowds, doesn't like lots of people, hates shopping', and even exempts himself from socialising at home: 'Like even if I have family come over, when the mob comes, he just goes in his room'. In relation to her son, Neveah remarked,

I could deal with a lot of that other stuff. I just want to really see that shift in his ability to socialise. If I had to choose something that I could fix, it would be that little bit, socialising with other humans.

Participants also mentioned that sometimes families are reluctant to take autistic children out because they want to avoid stigmatising encounters. Layla's grandson Hunter has diagnoses of autism and intellectual disability, which made it very difficult for her daughter to travel with him, even to the nearest capital city:

They stay in a motel or whatever but she tries to get somewhere where it's not a lot of other people. Because he runs around playing and he screams out, in circles and stuff, because he can't talk. He laughs loud, and stuff like that.

Subtheme B: limits to inclusion in community. While many participants stressed the inclusivity of their communities and the support offered by their families, they also told us about limits to inclusion. Ruby mentioned that it was very difficult to include her son in traditional cultural activities and family events in the Torres Strait Islands: 'It's hard to go. If we have family gatherings, whether it's a birthday party or tombstone opening,¹ sometimes we don't go because they can't connect with Noah or communicate with Noah'.

Other participants spoke about the limits to family support in their communities, related to the age and health of the grandparents of autistic children, and/or living so far away from their families: 'We lived in Queensland with my Mum and my sister, but no we don't have any family or connections down here' [Aaliyah]. Sienna preferred not to ask others for help, choosing to care for her adult son and her mother without assistance: 'Like I've got mob here, but I'm too proud to ask for help, and I know I'm stubborn'.

Sophie stressed that although she could ask family for assistance, she also wanted access to formal respite services:

My family is spread out all over the Northern Territory and all along the east coast of Australia. But you want to be able to function as a family and not always have to rely on your family, you know what I mean? So it's nice to be able to access that carers support as well and that way when you're with family, you can just be with family and enjoy them too. It's not about putting the pressure back on them. I'm sure they accept it and they tell me that I'm being stupid otherwise, but it doesn't matter. It's full-on.

Discussion

This is the first study to report on perceived attitudes towards autism in Aboriginal and Torres Strait Islander communities. Alongside an emphasis on inclusion, there were accounts of isolation. As well as an acceptance of autism, there was a questioning of the value of diagnostic categories. Some participants believed autism had always existed in their cultures while others thought it is newly introduced. Shame and stigma were widely reported but so, too, were, positive attitudes emphasising neurodiversity and autism's gifts. This diversity in attitudes partly reflects the great diversity of Aboriginal and Torres Strait Islander cultures. It also reflects the diversity of attitudes towards autism that exist in the broader Australian society in which those cultures are now embedded. The complexity of attitudes towards autism reported in this study is typical of the range of views, sometimes paradoxical, held in many societies (Frith, 2003; Hebert & Koulouglioti, 2010; Lilley, 2011; Myers et al., 2009), including a wide variety of beliefs about autism causation, varying views on likely future outcomes for diagnosed individuals, scepticism regarding the increasing numbers of autism diagnoses as well as the coexistence of stigmatising and inclusive attitudes. Nevertheless, the analysis presented here illuminates specific aspects of the current experience of supporting Aboriginal and Torres Strait Islander autistic children.

Our findings show that while participants' experiences varied, an inclusive ethos, expressed as an expectation that people look after each other, characterised attitudes towards autistic children and their families. Participants emphasised that they looked after family and, in turn, family looked

after them. Everybody has a place in Aboriginal and Torres Strait Islander communities because relationships of mutual care are prioritised, enacted within the framework of kinship obligations (Ariotti, 1999). This inclusivity has been noted by other scholars (Gilroy & Emerson, 2016; O'Neill et al., 2004). Avery (2018), for example, has described a widespread Aboriginal 'culture of inclusion' in relation to people with disabilities. An inclusive ethos towards autistic people has also been reported in other indigenous contexts, including among Māori (Bevan-Brown, 2013) and Navajo (Kapp, 2011) peoples.

This inclusive ethos extended to interactions between families and services. Respondents in this study clearly stated that they prefer to access services provided by Aboriginal and Torres Strait Islander professionals, in part because they provide a sense of cultural safety. Previous studies on childhood disability (DiGiacomo et al., 2013b) and disability in general in Indigenous communities (Dew et al., 2018; Gething, 1994; O'Neill et al., 2004) have echoed this finding.

One novel finding of this study is that the peer group interactions of Aboriginal children, often described as 'cousins', provide a supportive environment for autistic children, in which they are encouraged to participate in play-based activities and protected from potentially negative interactions with other children. This is because the primary social learning environment for many Aboriginal children is their peers (Eickelkamp, 2010) and children, who have considerable autonomy from adults, are encouraged to be compassionate and generous towards each other (Heath et al., 2011).

Although inclusion was salient, participants also reported the social isolation of their own and other families. There was considerable variation in the degree to which participants either received or wanted the support of their extended families. The social isolation of some Indigenous families supporting children with disabilities has previously been documented (DiGiacomo et al., 2017) but this is the first available data specific to autistic children.

Gilroy and Emerson (2016) have reported that Indigenous children with low cognitive ability may be at a higher risk of social exclusion than their peers. This finding is concerning because research has suggested that cultural experiences play an integral role in positive health and wellbeing outcomes for Australian Indigenous peoples (MacLean et al., 2017). One mother in our study reported that in her Torres Strait Island community it was difficult to include her son in valued cultural activities, suggesting that while an inclusive ethos may be predominant, it is important to remain aware of the possibility of exclusion.

The acceptance of autism reported in this study, including embracing diagnosis as a pathway to better management and support as well as a source of understanding, is reported in other studies (e.g. Fernell et al., 2013). Our participants were concerned about the situation of other

families and a number reported advocating on their behalf. While the central role of Aboriginal women as carers and advocates for people with disabilities has been acknowledged (Dew et al., 2018), this is the first study to document the importance of mothers as advocates for autistic children and their families in Aboriginal and Torres Strait Islander communities.

Alongside an acceptance of autism diagnosis, participants reported widespread scepticism towards diagnostic labels, including autism. A variety of factors contributed to this scepticism. First, Aboriginal and Torres Strait Islander notions of developmental typicality and atypicality as well as cognitive normality and abnormality may not conform to Eurocentric perceptions (Vicary & Westerman, 2004). Second, in general, people from socioeconomically disadvantaged backgrounds are less likely to access services for children with disabilities, in part because poor health is normalised within their communities (Green et al., 2016; Hollinsworth, 2013). Our participants were concerned that children may be missing out on diagnoses because of the coexistence of multiple intersecting disadvantages. Third, extensive and traumatic experiences of child removal by government agencies, both past and present, affect attitudes towards autism diagnosis. Mistrust of government and of official organisations may inhibit families from accessing disability supports (Green et al., 2016; Ussher et al., 2016).

Given scientific uncertainty about the specific causes of autism, it is unsurprising that lay theories attribute autism to different causes. Our participants variously interpreted autism as either having always existed, and as conferring religious status, or as a novel disease entity caused by colonisation and the effects of Westernised modes of living and diet. This is the first report of beliefs about autism causality in Aboriginal and Torres Strait Islander communities.

Some researchers have remarked on the association between childhood disabilities and stigma or 'shame' in Aboriginal communities (DiGiacomo et al., 2013a; O'Neill et al., 2004), with concerns that FASD, in particular, feeds into stereotypical assumptions of substance abuse in Indigenous families. Stigma and shame about mental illness have also previously been reported in Aboriginal communities (Vicary & Westerman, 2004). Some participants reported that 'shame' about autism was widespread leading to the social isolation of autistic children and their families. They also reported that people often avoided talking about autism, relating this to an attempt to protect the feelings of interlocutors from shame. This finding is consistent with autism stigma being also widely reported in Australia (Broady et al., 2017; Gray, 1993, 2002; Lilley, 2013a, 2013b) as well as other countries (e.g. Kinnear et al., 2016; Veroni, 2019).

When describing their children, mothers often drew on ideas about children with disabilities that have broader

social currency. This included the idea of autistic children both as having special gifts and as conferring the gift of teaching mothers how to be better people. The notion that disabled children transform those around them is common to many cultures (Altiere & von Kluge, 2009; Landsman, 1999). It has also been specifically noted among families of autistic children (Fleischmann, 2005; Huws et al., 2001; Jegatheesan et al., 2010; Myers et al., 2009; Tait & Mundia, 2012). Some of our participants also drew on discourses of neurodiversity to assert that their children's brains are 'wired differently' and that they should be conceptualised as different rather than impaired (see den Houting, 2019; Tan, 2018). Cascio (2012) has documented the neurodiverse sentiments of mothers (predominantly White Anglo women) in the United States. Our research suggests that these sentiments are also adopted by parents in other cultural contexts.

The findings of this study demonstrate that there are multiple attitudes towards autism in Aboriginal and Torres Strait Islander communities. On the one hand, some of these attitudes potentially point towards under-identification or misdiagnosis. Misdiagnosis may be related to a number of factors, including stereotyping and prejudice, and the use of inappropriate diagnostic tools that have not been culturally adapted or socially validated (Soto et al., 2015). Furthermore, where people experience widespread poverty, chronic poor health, marginalisation and racism, autistic children may not be diagnosed, may be diagnosed later and/or may not always receive the kinds of supports, at home or at school, that could benefit them (Norbury & Sparks, 2013). On the other hand, we also found a widespread ethos of 'looking after each other' and of embracing individual differences. In this respect, Aboriginal and Torres Strait Islander attitudes towards autism provide a positive model of support for and acceptance of autistic children and their families.

Limitations

There are some limitations to this research. While our participants came from city, regional and remote locations in different states and territories of Australia, the small and self-selecting nature of the sample mean that the findings of this study cannot be generalised as representing the views of all Aboriginal and Torres Strait Islander peoples supporting autistic family members. Further, all of the participants in this research are women. More research is needed to elicit the views and perspectives of larger numbers of Aboriginal and Torres Strait Islander peoples about autism, including fathers and grandfathers, living in diverse circumstances across Australia. No studies have been undertaken on autism service provision, including diagnostic practices, in these communities. Such studies would shed light on how best to support autistic individuals and their families in Aboriginal and Torres Strait Islander communities

and provide a starting point for genuine dialogue on these issues.

Conclusion

This is the first research to explicate attitudes towards autism in Aboriginal and Torres Strait Islander communities in Australia. The underrepresentation of Aboriginal and Torres Strait Islander people in autism research impedes access to culturally-appropriate supports and services and the building of a sound knowledge base on which to construct culturally-safe policies and practices. Quality research that can inform future services, programmes and policies and which is based on participatory principles that recognise Aboriginal and Torres Strait Islanders as the experts on their own lives is urgently needed. This research, highlighting the complexity of attitudes towards autism and the realities of social isolation and stigma, is the first step towards that goal.

Acknowledgements

The authors are enormously grateful to the 12 families who so generously gave up their time to take part in this project and share their experiences. We are also indebted to Jacqui Borland, Lee Cascuscelli, Suzanne Donnelly, and Maria Watson-Trudgett from Positive Partnerships, and to June Riemer from First Peoples Disability Network, for thoughtful discussions and assistance throughout the research process. We also thank Bronwyn Carlson and Tristan Kennedy for their ideas and encouragement during the initial stages of the project, Angelica Ojinnaka for help during data collection and Marc Stears for his comments on a previous version of this manuscript.

Author contributions

E.P., R.L. and M.S. secured funding for the project, and designed the interview content and procedures. R.L. and M.S. recruited and interviewed participants. R.L. led the analysis, and E.P. and M.S. contributed to it. R.L. drafted the manuscript. All authors commented on and edited the manuscript prior to submission.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research project received financial support from Positive Partnerships, who are funded by the Australian Government's Department of Education. Positive Partnerships had no involvement in the analysis, interpretation, or write-up of this project.

Ethical approval

Ethical approval for this project was granted by the Aboriginal Health and Medical Research Council (AH&MRC) (1433/18) and Macquarie University Human Research Ethics Committee (5201832104269).

ORCID iDs

Rozanna Lilley  <https://orcid.org/0000-0001-6143-8805>

Elizabeth Pellicano  <https://orcid.org/0000-0002-7246-8003>

Supplemental material

Supplemental material for this article is available online.

Note

1. Tombstone openings are a traditionally valued cultural practice commemorating the deceased through the unveiling of headstones, accompanied by communal feasting and singing.

References

- Altiere, M., & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual and Developmental Disability, 34*(2), 142–152.
- American Psychiatric Association. (2013.). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Publishing.
- Ariotti, L. (1999). Social construction of Anangu disability. *Australian Journal of Rural Health, 7*(4), 216–222.
- Australian Bureau of Statistics. (2017). *Aboriginal and Torres Strait Islander people with disability*. <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features802015?OpenDocument>
- Australian Bureau of Statistics. (2019). *Estimates and projections, Aboriginal and Torres Strait Islander Australians, 2006 to 2031*. <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/3238.0Main%20Features402006%20to%202031?opendocument&tabname=Summary&prodno=3238.0&issue=2006%20to%202031&num=&view=>
- Australian Institute of Family Studies. (2017). *Children in care. Child family community Australia resource sheet*. <https://aifs.gov.au/cfca/publications/children-care>
- Australian Institute of Health and Welfare. (2018). *Australia's health: In brief. Cat. no. AUS 222*. <https://www.aihw.gov.au/reports/australias-health/australias-health-2018-in-brief/contents/all-is-not-equal>
- Avery, S. (2018). *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*. First Peoples Disability Network.
- Bailey, B., & Arciuli, J. (2020). Indigenous Australians with autism: A scoping review. *Autism*. Advance online publication. <https://doi.org/10.1177/1362361319894829>
- Barrio, B., Hsiao, Y. J., Prishker, N., & Terry, C. (2019). The impact of culture on parental perceptions about Autism Spectrum Disorders: Striving for culturally competent practices. *Multicultural Learning and Teaching, 14*(1), 1–9.
- Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine, 45*(3), 601–613.
- Bennett, M., & Hodgson, V. (2017). The missing voices of Indigenous Australians with autism in research. *Autism, 21*(1), 122–123.
- Bent, C., Barbaro, J., & Dissanayake, C. (2017). Change in autism diagnoses prior to and following the introduction of DSM-5. *Journal of Autism and Developmental Disorders, 47*(1), 163–171.
- Bent, C., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *The Medical Journal of Australia, 202*(6), 317–320.
- Bevan-Brown, J. (2013). Including people with disabilities: An Indigenous perspective. *International Journal of Inclusive Education, 17*(6), 571–583.
- Bower, C., Watkins, R., Mutch, R., Marriott, R., Freeman, J., Kippin, N., . . . Tarratt, L. (2018). Fetal alcohol spectrum disorder and youth justice: A prevalence study among young people sentenced to detention in Western Australia. *BMJ Open, 8*(2), Article e019605.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.
- Broadly, T., Stoyles, G., & Morse, C. (2017). Understanding carers' lived experience of stigma: The voice of families with a child on the autism spectrum. *Health & Social Care in the Community, 25*(1), 224–233.
- Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders, 45*(10), 3244–3254.
- Cascio, M. (2012). Neurodiversity: Autism pride among mothers of children with autism spectrum disorders. *Intellectual and Developmental Disabilities, 50*(3), 273–283.
- den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism, 23*(2), 271–273.
- Dew, A., McEntyre, E., Vaughan, P., Cooney, E., Dillon Savage, I., & Dowse, L. (2018). *No more waiting: A guide for organisations to plan with Aboriginal people with disability*. University of New South Wales.
- DiGiacomo, M., Davidson, P. M., Abbott, P., Delaney, P., Dharmendra, T., McGrath, S. J., . . . Vincent, F. (2013a). Childhood disability in Aboriginal and Torres Strait Islander peoples: A literature review. *International Journal for Equity in Health, 12*(1), 7.
- DiGiacomo, M., Delaney, P., Abbott, P., Davidson, P. M., Delaney, J., & Vincent, F. (2013b). 'Doing the hard yards': Carer and provider focus group perspectives of accessing Aboriginal childhood disability services. *BMC Health Services Research, 13*(1), Article 326.
- DiGiacomo, M., Green, A., Delaney, P., Delaney, J., Patradoon-Ho, P., Davidson, P., & Abbott, P. (2017). Experiences and needs of carers of Aboriginal children with a disability: A qualitative study. *BMC Family Practice, 18*(1), Article 96.
- Di Pietro, N., & Illes, J. (2014). Disparities in Canadian Indigenous health research on neurodevelopmental disorders. *Journal of Developmental & Behavioral Pediatrics, 35*(1), 74–81.
- Di Pietro, N., & Illes, J. (2016). Closing gaps: Strength-based approaches to research with Aboriginal children with neurodevelopmental disorders. *Neuroethics, 9*(3), 243–252.
- Dyches, T., Wilder, L., Sudweeks, R., Obiakor, F., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders, 34*(2), 211–222.
- Eickelkamp, U. (2010). Children and youth in Aboriginal Australia: An overview of the literature. *Anthropological Forum, 20*(2), 147–166.
- Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., . . . Yasamy, M. T. (2012). Global prevalence of

- autism and other pervasive developmental disorders. *Autism Research*, 5(3), 160–179.
- Fernell, E., Eriksson, M., & Gillberg, C. (2013). Early diagnosis of autism and impact on prognosis: A narrative review. *Clinical Epidemiology*, 5, 33–43.
- Fitzpatrick, J. P., Latimer, J., Carter, M., Oscar, J., Ferreira, M., Carmichael Olson, H., . . . Hawkes, G. (2015). Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan Project. *Journal of Paediatrics and Child Health*, 51(4), 450–457.
- Fitzpatrick, J. P., Latimer, J., Olson, H., Carter, M., Oscar, J., Lucas, B. R., . . . Fitzpatrick, E. (2017). Prevalence and profile of neurodevelopment and fetal alcohol spectrum disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Research in Developmental Disabilities*, 65, 114–126.
- Fleischmann, A. (2005). The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism*, 9(3), 299–316.
- Frith, U. (2003). *Autism: Explaining the enigma* (2nd ed.). Blackwell.
- Gething, L. (1994). Aboriginality & disability. *Aboriginal and Islander Health Worker Journal*, 18(3), 29–34.
- Gilroy, J., & Emerson, E. (2016). Australian Indigenous children with low cognitive ability: Family and cultural participation. *Research in Developmental Disabilities*, 56, 117–127.
- Gorman, D., & Toombs, M. (2009). Matching research methodology with Australian Indigenous culture. *Aboriginal and Islander Health Worker Journal*, 33(3), 4–7.
- Gray, D. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness*, 15(1), 102–120.
- Gray, D. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24(6), 734–749.
- Green, A., Abbott, P., Davidson, P. M., Delaney, P., Delaney, J., Patradoon-Ho, P., & DiGiacomo, M. (2018). Interacting with providers: An intersectional exploration of the experiences of carers of Aboriginal children with a disability. *Qualitative Health Research*, 28(12), 1923–1932.
- Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: A qualitative study of carers' interface with services. *BMC Health Services Research*, 16(1), 680.
- Green, A., DiGiacomo, M., Lockett, T., Abbott, P., Davidson, P. M., Delaney, J., & Delaney, P. (2014). Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: A systematic integrative review and theory-based synthesis. *International Journal for Equity in Health*, 13(1), 126.
- Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. Basic Books.
- Grinker, R. R. (2015). Reframing the science and anthropology of autism. *Culture, Medicine, and Psychiatry*, 39(2), 345–350.
- Hahler, E. M., & Elsabbagh, M. (2015). Autism: A global perspective. *Current Developmental Disorders Reports*, 2(1), 58–64.
- Hamilton, G., Brubacher, S. P., & Powell, M. B. (2016). Expressions of shame in investigative interviews with Australian Aboriginal children. *Child Abuse & Neglect*, 51, 64–71.
- Heath, F., Bor, W., Thompson, J., & Cox, L. (2011). Diversity, disruption, continuity: Parenting and social and emotional wellbeing amongst Aboriginal peoples and Torres Strait Islanders. *Australian and New Zealand Journal of Family Therapy*, 32(4), 300–313.
- Hebert, E. B., & Koulouglioti, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in Comprehensive Pediatric Nursing*, 33(3), 149–163.
- Hollinsworth, D. (2013). Decolonizing Indigenous disability in Australia. *Disability & Society*, 28(5), 601–615.
- Huws, J., Jones, R., & Ingledew, D. (2001). Parents of children with autism using an email group: A grounded theory study. *Journal of Health Psychology*, 6(5), 569–584.
- Jegatheesan, B., Miller, P., & Fowler, S. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on Autism and Other Developmental Disabilities*, 25(2), 98–109.
- Kapp, S. (2011). Navajo and autism: The beauty of harmony. *Disability & Society*, 26(5), 583–595.
- Kim, H. U. (2012). Autism across cultures: Rethinking autism. *Disability & Society*, 27(4), 535–545.
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942–953.
- Landsman, G. (1999). Does God give special kids to special parents? Personhood and the child with disabilities as gift and as giver. In L. Layne (Ed.), *Transformative motherhood: On giving and getting in a consumer culture* (pp. 133–165). New York University Press.
- Leonard, H., Glasson, E., Nassar, N., Whitehouse, A., Bebbington, A., Bourke, J., . . . Stanley, F. (2011). Autism and intellectual disability are differentially related to sociodemographic background at birth. *PLOS ONE*, 6(3), Article e17875.
- Leonard, H., Petterson, B., De Klerk, N., Zubrick, S., Glasson, E., Sanders, R., & Bower, C. (2005). Association of sociodemographic characteristics of children with intellectual disability in Western Australia. *Social Science & Medicine*, 60(7), 1499–1513.
- Lilley, R. (2011). The ABCs of autism: Aspects of maternal pedagogy in Australia. *Social Analysis*, 55(1), 134–159.
- Lilley, R. (2013a). Crying in the park: Autism stigma, school entry and maternal subjectivity. *Studies in the Maternal*, 5(2), 1–28.
- Lilley, R. (2013b). It's an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia. *Disability & Society*, 28(4), 514–526.
- Lindblom, A. (2014). Under-detection of autism among First Nations children in British Columbia, Canada. *Disability & Society*, 29(8), 1248–1259.
- MacLean, S., Ritte, R., Thorpe, A., Ewen, S., & Arabena, K. (2017). Health and wellbeing outcomes of programs for Indigenous Australians that include strategies to enable the expression of cultural identities: A systematic review. *Australian Journal of Primary Health*, 23(4), 309–318.

- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). 'My greatest joy and my greatest heart ache': Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3(3), 670–684.
- Norbury, C. F., & Sparks, A. (2013). Difference or disorder? Cultural issues in understanding neurodevelopmental disorders. *Developmental Psychology*, 49(1), 45–58.
- Ochs, E., Kremer-Sadlik, T., Sirota, K., & Solomon, O. (2004). Autism and the social world: An anthropological perspective. *Discourse Studies*, 6(2), 147–183.
- O'Dell, L., Bertilsdotter Rosqvist, H., Ortega, F., Brownlow, C., & Orsini, M. (2016). Critical autism studies: Exploring epistemic dialogues and intersections, challenging dominant understandings of autism. *Disability & Society*, 31(2), 166–179.
- O'Neill, M., Kirov, E., & Thomson, N. (2004). A review of the literature on disability services for Aboriginal and Torres Strait Islander peoples. *Australian Indigenous Health Bulletin*, 4(4), 1–26.
- Parker, R., Balaratnasingam, S., Roy, M., Huntley, J., & Mageean, A. (2014). Intellectual disability in Aboriginal and Torres Strait Islander people. In P. Dudgeon, H. Milroy, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (2nd ed., pp. 373–382). Commonwealth of Australia.
- Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, 21(2), 311–319.
- Ravindran, S., Brentnall, J., & Gilroy, J. (2017). Conceptualising disability: A critical comparison between Indigenous people in Australia and New South Wales disability service agencies. *Australian Journal of Social Issues*, 52(4), 367–387.
- Roy, M., & Balaratnasingam, S. (2010). Missed diagnosis of autism in an Australian Indigenous psychiatric population. *Australasian Psychiatry*, 18(6), 534–537.
- Salmon, A. (2007). Walking the talk: How participatory interview methods can democratize research. *Qualitative Health Research*, 17(7), 982–993.
- Secretariat of National Aboriginal & Islander Child Care. (2010, May 15). SNAICC early days project on autism spectrum disorder. *SNAICC Newsletter*. <https://www.snaicc.org.au/wp-content/uploads/2016/01/02542.pdf>
- Soto, S., Linas, K., Jacobstein, D., Biel, M., Migdal, T., & Anthony, B. J. (2015). A review of cultural adaptations of screening tools for autism spectrum disorders. *Autism*, 19(6), 646–661.
- Tait, K., & Mundia, L. (2012). The impact of a child with autism on the Bruneian family system. *International Journal of Special Education*, 27(3), 199–212.
- Tan, C. (2018). 'I'm a normal autistic person, not an abnormal neurotypical': Autism spectrum disorder diagnosis as biographical illumination. *Social Science & Medicine*, 197, 161–167.
- Tobler, R., Rohrlach, A., Soubrier, J., Bover, P., Llamas, B., Tuke, J., . . . O'Loughlin, I. (2017). Aboriginal mitogenomes reveal 50,000 years of regionalism in Australia. *Nature*, 544, 180–184.
- Ussher, J., Charter, R., Parton, C., & Perz, J. (2016). Constructions and experiences of motherhood in the context of an early intervention for Aboriginal mothers and their children: Mother and healthcare worker perspectives. *BMC Public Health*, 16(1), Article 620.
- Veroni, E. (2019). The social stigma and the challenges of raising a child with autism spectrum disorders (ASD) in Greece. *Exchanges: The Interdisciplinary Research Journal*, 6(2), 1–29.
- Vicary, D., & Westerman, T. (2004). 'That's just the way he is': Some implications of Aboriginal mental health beliefs. *Australian e-Journal for the Advancement of Mental Health*, 3(3), 103–112.
- Wilson, K., & Watson, L. (2011). Autism spectrum disorder in Australian Indigenous families: Issues of diagnosis, support and funding. *Aboriginal and Islander Health Worker Journal*, 35(5), 17–18.