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***A hard slog road: Aboriginal and Torres Strait Islander women talk about loving and supporting their autistic children***

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**Abstract**

This article draws on the first qualitative research on lived experiences of autism in Aboriginal and Torres Strait Islander communities in Australia. Twelve women supporting 16 autistic children living in remote, regional and urban areas of Australia participated in a semi-structured interview. Through thematic analysis, we identified four focal themes in women's conceptualisation of the practical work of mothering autistic children. These are i) navigating a complex autism system to 'achieve' diagnosis and connect to culturally-safe services and supports; ii) helping children to learn to live in the big world by engaging in everyday care and enhancing capacities; iii) protecting children by keeping them safe, dealing with stigma and respecting individuality and; iv) asserting family belonging by emphasising children's strengths, encouraging extended family relationships and advocating for others. Listening to these marginalised voices is vital to establishing a participatory research agenda in a field that has received inadequate attention.

**Keywords**

autism; culture; Aboriginal and Torres Strait Islander; mothers; family; Indigenous

**Points of interest**

- This is the first research on lived experiences of autism in Aboriginal and Torres Strait Islander communities in Australia.

- Twelve women from remote, regional and urban areas spoke about their experiences of loving and supporting their autistic children.
- Women talked about the practical work of mothering their autistic children including achieving autism diagnosis, trying to access culturally safe services and supports, undertaking everyday care needs and enhancing capacities and abilities.
- Women emphasised children's strengths and their belonging in community; they were very concerned with protecting them and keeping them safe in the context of intersecting racist and ableist attitudes.
- More participatory research on autism within Aboriginal and Torres Strait Islander communities is urgently needed.

## **Introduction**

Most of the literature on maternal experiences of raising autistic children has focused on families in high income countries and contexts, especially the United States and the United Kingdom, with the vast majority of studies based on accounts of white middle-class participants (e.g. Bayat, 2007; Ekas, Pruitt and McKay, 2016; Rodrigue, Morgan and Geffken, 1990). However, there is a gradually growing interest in the experiences of families of autistic children in diverse cultural contexts (e.g. Ha et al., 2014; Kim, 2012; Zhao and Fu, 2020), including minority (e.g. Angell and Solomon, 2017; Burkett et al., 2015; Decoteau, 2017) and Indigenous populations encompassed within dominant nation states. In this study, we adopt an emic approach that 'proceeds from mothers' own understandings of themselves and their children and documents mothers' ongoing definitions and redefinitions of their experiences' (Landsman, 1998, 73) to illuminate the experiences of Australian Aboriginal and Torres Strait Islander women bringing up autistic children.

Currently, Aboriginal and Torres Strait Islander children have a higher prevalence of disability and greater socioeconomic disadvantages than other Australian children (Biddle, Yap and Gray, 2013; DiGiacomo et al., 2017). The extremely limited literature on experiences of autism in Indigenous or First Nations contexts across the globe has documented disparities in access to diagnosis and supports (e.g. Di Pietro and Illes, 2014; Lindblom, 2014) while the impact of ‘racialised legacies of colonisation’ (Salmon, 2011, 165) on patterns of service access and use is reported across a range of childhood developmental disabilities. More broadly, there continue to be wide gaps between Aboriginal and Torres Strait Islander peoples, who constitute 3.3% of the Australian population (Markham and Biddle, 2017), and non-Indigenous Australians across a wide range of economic, health and education outcomes (Commonwealth of Australia, 2020). The historical trauma of dispossession and colonisation shapes contemporary realities in myriad ways (Arabena, Panozzo and Ritte, 2016; Parkes and Zufferey, 2020), including the continuing legacy of the Stolen Generations of Aboriginal children removed by the State to institutional or foster care (Atkinson and Swain, 1999; Green et al., 2021).

A number of commentators have suggested that Indigenous peoples have fundamentally inclusive attitudes towards autistic people based on cultural values of acceptance and support of all community members (Avery, 2018; Bevan-Brown, 2013; Kapp, 2011). In a qualitative study of attitudes towards autism in Aboriginal and Torres Strait Islander communities in Australia, we have argued that socially-inclusive attitudes and autism acceptance exist alongside experiences of social isolation, shame and stigmatisation (Lilley, Sedgwick and Pellicano, 2020). While the central role of Aboriginal women as carers and advocates for people with disabilities has been previously acknowledged (Dew et al., 2018), our study was the first to document the important role these women play as advocates for autistic children and their families.

In this article, we build on our earlier analysis to address in greater depth the experiences of Aboriginal and Torres Strait Islander women supporting their autistic children and grandchildren. We acknowledge the importance of adopting a multigeneration model of Indigenous families in which it is culturally normative for multiple caregivers from different generations to contribute to children's wellbeing (Arabena, Panozzo and Ritte, 2016). At the same time, recent research focused on the experiences of families supporting Aboriginal children experiencing a range of developmental disabilities has confirmed that it is mothers, and to a lesser extent grandmothers, who are primarily responsible for accessing fragmented and complex pathways to disability diagnosis and supports (DiGiacomo et al., 2017; Green et al., 2016). Our aim is to provide a voice to Aboriginal and Torres Strait Islander women supporting autistic children who have previously been absent in the research literature, drawing out the complexities of their lived experiences.

During interviews, conducted by one Aboriginal (MS) and one non-Indigenous (RL) researcher, we heard about the intensive work women undertook to navigate the autism diagnostic and service system, assist children to survive and thrive in contexts marked by multiple social inequalities and to help others in their communities. While ethnocentric and patriarchal constructs have often positioned Aboriginal and Torres Strait Islander mothers as neglectful, unfit or deficient (McGrath and Stevenson, 1996; see Malin, Campbell and Agius, 1996; Parkes and Zufferey, 2020), with complex histories of intergenerational trauma that shape their caregiving capacities (Stanley, Tomison and Pocock, 2003), the women we spoke to saw themselves as active nurturers, advocates and supporters of their autistic children, overcoming myriad barriers. In focusing attention on their own agency and the capabilities of themselves and their children, they challenged deficit discourses of both Indigenous mothering and autistic personhood. It is time we listened to their stories.

Throughout this article, we refer to Aboriginal and Torres Strait Islander peoples. These terms cover a very diverse population of over 250 distinct groups and over 700,000 people. The term First Peoples has been used when it is preferred in organisational contexts or employed by participants. The term Indigenous has also been used when quoting participants or scholars. We adopt identity-first language ('autistic children', 'autistic people') in line with the preferences of many autistic adults (Kenny et al., 2016; Mac Carthaigh, 2020) as well as research which suggests that this usage is usually perceived as less stigmatising than person-first language (Gernsbacher, 2017). However, we retain person-first language ('children with autism', 'people on the autism spectrum') when it is used by participants.

## **Research process**

### **Participants**

Participants were recruited through community contacts, including through our partner organisation, Positive Partnerships, who are funded by the Australian Government Department of Education and Training to deliver national programs and workshops supporting the families and schools of Aboriginal and Torres Strait Islander autistic children. Parents or other primary carers of Aboriginal and Torres Strait Islander autistic children were invited to take part.

Twelve women, including 11 mothers and one grandmother (age range = 30 – 63 years), agreed to participate. The grandmother and nine of the mothers identified as Aboriginal, one mother identified as Aboriginal, South Sea Islander and Native American and another mother as Torres Strait Islander. The women came from diverse parts of Australia, including New South Wales (n=3), the Northern Territory (n=3), the Australian Capital Territory (n=2), Victoria (n=2), Queensland (n=1) and the Torres Strait Islands (n=1).

Some lived in urban settings (n=4), others lived in regional settings (n=6, two of whom lived in 'outer regional' settings) and others lived in very remote regions of Australia (n=2). Two women were studying at postgraduate level, six had completed university degrees, three had post-secondary qualifications and two had completed primary but not high school. Nine mothers were in full-time employment at the time of this study, one was in part-time employment, one was not currently employed, and our grandmother participant had retired.

Among the 12 families, there were 16 children (15 boys, 1 girl) with a formal diagnosis of autism, who ranged in age from 2 to 22 years. All but two of their children had been diagnosed with additional, co-occurring medical (e.g., otitis media, epilepsy, asthma), developmental (e.g., global developmental delay, cerebral palsy) and/or psychiatric (e.g., Attention Deficit/Hyperactivity Disorder, anxiety disorder, Oppositional Defiant Disorder and Post Traumatic Stress Disorder) conditions. Six participants reported living in nuclear households with mother, father and children, three resided in multi-generational households, and three described themselves as single mothers, two of whom lived just with their autistic child. Table 1 provides selected demographic information about participants and their autistic children.



Name <sup>a</sup>	Kin relation	Place current residence <sup>b</sup>	Age in years	Level of education completed	Current employment	Number of autistic children	Name <sup>a</sup> , gender & age of autistic children	Child age at diagnosis (years)	Current education setting
Aaliyah	mother	ACT (MCA, RA1)	39	Bachelor degree	Full-time	1	Aiden: 12-year-old boy	6-7	Support class
Alexis	mother	VIC (IRA, RA2)	42	Advanced diploma	Full-time	1	Cooper: 13-year-old young man	5	Special school
Amelia	mother	NSW (MCA, RA1)	47	Year 9	Carer payment	1	Mason: 18-year-old young man	16	Special school
Ava	mother	NT (ORA, RA3)	30	Certificate level	Full-time	2	Koen: 5-year-old boy	3	Mainstream with support
Ella	mother	ACT (MCA, RA1)	39	Masters degree	Part-time	1	Oliver: 4-year-old boy	just under 2	Preschool with support; support unit in 2019
Layla	grand-mother	VIC (IRA, RA2)	63	Year 10	Retired	3	Logan: 10-year-old boy	4	Mainstream
							Hunter: 7-year-old boy	3	Special school
							Isaac: 10-year-old boy	6	Special school
Nevaeh	mother	NSW (MCA, RA1)	39	Bachelor degree	Full-time	1	Leo: 2-year-old boy	2	Aboriginal community preschool
Olivia	mother	NT (ORA, RA3)	45	Bachelor degree	Full-time	1	Scarlett: 8-year-old girl	3	Special school
Ruby	mother	Torres Strait Islands (VRA, RA5)	44	Year 12	Full-time	1	Noah: 9-year-old boy	5-6	Mainstream with support
Sienna	mother	NSW (IRA, RA2)	51	Certificate level	Full-time	1	Elijah: 22-year-old man	10-11	Living at home with no current services; previously support class
Sophie	mother	NT (VRA, RA5)	40	Bachelor degree	Full-time	2	Alex: 6-year-old boy	4	Mainstream with support
							Warrin: 8-year-old boy	6	Mainstream with support
Willow	mother	QLD (IRA, RA2)	No answer	Bachelor degree	Full-time	1	Kai: 9-year-old boy	4.5	Mainstream with support

Notes. <sup>a</sup>Pseudonyms are used to protect participant confidentiality. <sup>b</sup>The Australian Statistical Geography Standard (ASGS) Remoteness Structure is used to refer to participants' place of residence. Remoteness Areas divide Australia into 5 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; ACT = Australian Capital Territory.

**Table 1.** Background characteristics of participating families.

## Method

This research was designed and implemented, and the data analysed and interpreted, by a research team including two mothers of autistic children (RL, MS), one of whom is Aboriginal and also asked to be an interview participant (MS). RL and EP are non-Indigenous. Our research protocols were further developed in collaboration with Positive Partnerships and First Peoples Disability Network (FPDN), the national organisation of and for Australia's First Peoples with disability. The project was also approved by Positive Partnerships' Aboriginal and Torres Strait Islander National Reference Group, who provided feedback on the research information sent to families. Study information documents were revised following the Group's recommendations. Together, this experiential expertise and input ensured that our methods were respectful and supportive of families' needs and preferences.

Each participant took part in a semi-structured interview, conducted wherever they felt most comfortable and was most feasible. For some (n=5), this meant visiting Sydney to take part in a face-to-face interview with researchers, supported by Aboriginal advocates from Positive Partnerships and FPDN. For others, interviews were conducted face-to-face at their place of employment (n=1), over the phone (n=5) or via videolink (n=1). Participants were asked a series of open questions to examine their experiences of raising their child, including with regard to their child's early development and diagnosis, access and barriers to relevant supports and services, and education placements (see Appendix 1). Throughout, participants were encouraged to tell their stories in their own way and to introduce other topics reflecting their own interests and experiences.

The interviews varied in length from 47 to 151 minutes (Mean = 80.3 mins). Pseudonyms were used to preserve participants' anonymity. Following participatory research guidelines (Salmon, 2007), participants were given the opportunity to check the accuracy of 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.

This study's procedures were granted ethical approval both by Macquarie University's Human Research Ethics Committee (3210) and by the Aboriginal Health and Medical Research Council Human Research Ethics Committee (1433/18). All participants gave written, informed consent prior to taking part in this study.

### **Analysis**

All interviews were recorded for later transcription with participants' prior permission and transcribed verbatim. The data were analysed using reflexive thematic analysis (Braun and Clarke, 2006, 2019). Our epistemological stance fits within a critical realist framework, which acknowledges the broader social context in which individual meanings are constructed

and mobilised. We adopted an inductive (bottom-up) approach (i.e., without integrating the themes within any pre-existing coding schemes or preconceptions of the researchers) to identify patterned meanings in the dataset within an essentialist framework (to report the experiences, meanings and reality of the participants).

We began by familiarising ourselves with the data, (re-)reading the transcripts, conferring to discuss preliminary codes and then assigning them to data extracts. We 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. Analysis was iterative and reflexive, moving backwards and forwards between data and analysis.

## **Results**

Overall, Aboriginal and Torres Strait Islander women described their experiences of mothering autistic children as transformative – ‘a monumental life changing event’ –, sometimes employing the metaphor of ‘the journey’. Women generally emphasised the difficulty of this maternal journey as well the personal growth it fostered. For example, Nevaeh described the impact of her son's autism diagnosis as having ‘changed our whole lives’, emphasising that it is ‘a very scary hard journey’ that has involved ‘a lot of learning’. Alexis said, ‘it's hard but I think it's going to make us stronger’. Sienna summed up her experiences of supporting her adult autistic son as ‘a long struggle to get him to where he is now... a hard slog road’.

We identified four themes relating to this maternal journey (see Figure 1), each of which we describe below.



**Figure 1.** Aboriginal and Torres Strait Islander experiences of mothering autistic children

## **Theme 1. Navigating the autism system**

### **Subtheme A: Achieving diagnosis**

Participants generally emphasised the difficulties of accessing an autism diagnosis for their children, with some stating that they had to ‘fight’ to achieve it, resulting in diagnostic delays, which they felt meant that their children ‘missed out on all these services’ [Alexis].

Some mothers commented on the financial burden of autism diagnosis:

For a single mum who wasn’t earning a whole lot, it was an expensive process. If I’d had money accessible, he would have been diagnosed a lot quicker, but sometimes I’d have to wait a month before I had the money for the next appointment. So I think he was in Year 2 by the time he was actually diagnosed and supports were put in place for him [Aaliyah].

Others spoke about travelling long distances to access a ‘gold standard’ diagnosis, which they were advised would help their children to access services. Sophie, for example, travelled more than 2,000 km from a very remote town in the Northern Territory to Adelaide, the capital of South Australia, to get diagnoses for both her sons.

Women also raised the possibility of the misdiagnosis of children in their communities with other developmental conditions, including Fetal Alcohol Syndrome Disorder [FASD].

The diagnostic process was often emotionally fraught. Women spoke about the intense initial impact of autism diagnosis, and the lengthy process of coming to terms with what it meant for their families. Nevaeh and her husband initially rejected their son’s autism diagnosis, first flagged at 18 months. In retrospect she saw this as ‘denial’ based on the hope ‘that maybe something would still shift’.

Some participants said that other members of their families resisted the label of autism as stigmatising. Aaliyah paraphrased these attitudes:

I had people saying to me, ‘You’re just trying to label the things that he’s not good at – like you keep giving him all these labels that he’s forced to live in, like you know he’s ADHD or he’s autistic and that. Don’t give him that label of being autistic, because he’ll never do anything, and he’ll never achieve anything.’

Participants referred to a lack of knowledge about autism in their communities. The sense that it is a ‘new’ diagnosis was confirmed by Layla, a grandmother supporting three autistic grandchildren, who asked: ‘Is it this generation that it’s coming out? I’ve never seen it within our community.’ Ruby commented that her son Noah is the only child diagnosed with autism in her very remote community in the Torres Strait Islands.

Participants also often spoke about the value of diagnosis in helping them to better understand and support their children. They saw the diagnosis as legitimating their concerns about their children and confirming that they are good mothers, against the negative

judgments sometimes made by others. Sienna was accused by teachers at her son's school 'of spoiling this child, having no control over him'. She underlined that diagnosis was a turning point: 'I sat there and I cried and I said "thank you, thank you very much", and now I know what to do; now I know how to deal with him.'

### **Subtheme B: Connecting to culturally safe services and supports**

Once mothers had achieved an autism diagnosis for their child(ren), usually their next step was to access suitable supports and services. Depending on the child's age, supports sought might include therapies, especially speech and occupational therapy (OT), or additional supports at school. No families in this study were engaged in intensive therapies often reported in the autism literature, such as Applied Behaviour Analysis.

Sophie gave a strong sense of the sheer hard work involved in accessing therapies and liaising between different services (speech, OT and psychology). 'There are days', she confided, 'when I feel like, man, it just seems to like never end; you know, going down and talking to therapists, doing support and you do get tired, you do get worn out'. Alexis contrasted her own experience of an abusive childhood with the kind of nurturing and supportive environment she is trying to create for her son:

I had a bad upbringing. Wasn't allowed to do anything. I got floggings. I loved school – wasn't allowed to bring my homework home. ... I swore when Cooper got his diagnosis that I wasn't going to let him fall through the gaps – got him all the supports that he needed.

Participants criticised therapies for not being culturally sensitive or appropriate. Olivia mentioned, for example, that she found the format of OT very alienating: 'sitting people in a room, the OT experience I had, I was at first going "what the hell?"'. She commented that therapy sessions, as a formal process involving a non-Aboriginal professional advising and

asking Aboriginal mothers personal questions about their children and their home life, were simply ‘culturally not really appropriate’.

Willow had given a great deal of thought to ‘how you can use culture and integrate it into autism therapy’. One strategy she adopted was to take her son ‘out on Country’ and ‘do the cultural stuff a lot’.

Mothers expressed concerns that Aboriginal culture was not sufficiently incorporated into the school curriculum or understood by staff. For example, Amelia said that her son was thought to be speaking nonsense at his Special School when he was actually using words from his Aboriginal language, Wiradjuri.

Mothers spoke about the importance of interacting with Aboriginal and Torres Strait Islander professionals. Sometimes, these professionals were, literally, family. Neveah, for instance, sent her son to a local Aboriginal preschool where she felt he was well looked after by her Aunty, who manages it, and her niece, who is a childcare worker there.

Ava recalled a number of stigmatising encounters with non-Indigenous autism professionals. She contrasted these with affirming interactions with Aboriginal professionals: ‘We grow up differently; there’s no judgment’. She strongly supported the view that there need to be ‘more Aboriginal people working’ as therapy providers and in schools ‘who can understand Aboriginal ways’.

All of the mothers emphasised the tremendous effort they put into achieving diagnosis, and accessing supports and services, seeing it as their responsibility to navigate the autism system on behalf of their children. As one mother said: ‘I don’t have a choice’. However, Sienna, whose son is a young adult, indicated that her family had disengaged from services over time. As the primary carer for both her adult son and her chronically ill mother, Sienna necessarily limited her activities: ‘I just go about, do my stuff, go to work, come home, yeah, cook, clean, feed – that’s it.’

## **Theme 2: Learning to live in the big world**

### **Subtheme A: Engaging in everyday care**

Participants described the myriad ways in which they assist their children with daily activities – which depended on their children’s age and developmental level – as well as some of the restrictions on their everyday lives.

Women often mentioned assisting their children, including adolescents and adults, with toileting, restricted food preferences and the need for regular prompting to undertake tasks. Children were described as only eating ‘certain foods and colours’, having very narrow food preferences or refusing to eat in certain settings, such as school. The difficulties of keeping children on task was also mentioned. For example, a mother described her teenage son as ‘a bugger of a thing to get up in the morning’, as she had to constantly remind him to shower – ‘you’ve got to go in there about 20 times to tell him to get out’ – and get dressed.

Mothers also described the impact of their children’s communication differences. Ella said that her son’s main difficulty was ‘just not being able to communicate his needs and being frustrated when he can’t tell us what he wants’. Sienna indicated that interactions with her adult son tended to be one-sided: ‘You can have a conversation with him, but it’s more based around what he’s interested in’.

Children’s preference for routine and the distress caused by change was also perceived to impact their everyday lives. Sienna ruefully remarked: ‘There was points – it’s like even where his laces couldn’t touch the ground, his socks had to be the same length, everything in the morning was a routine, everything had to be done at the same time every day... if them socks weren’t the same height, I was in trouble’. Speaking about her grandson Logan, Layla provided a very touching example of dislike of change: ‘He doesn’t like change – even with his mum, especially, and so she says, “Oh, I’ll have to lose some weight” and he said, “No, you’re not to lose it; you’re beautiful as you are”’.



Difficulties with or a dislike of socialising were also described. Indeed, mothers mentioned that these differences in socialisation preferences could lead to intense feelings of isolation. Aaliyah said her son prefers ‘to stay home and play video games’, adding ‘it’s like pulling teeth sometimes to get him out and about’. Mothers generally attributed their children’s preference for home-based activities to anxiety.

### **Subtheme B: Enhancing children’s capacities**

Participants talked about the many ways in which they support their autistic children to develop their capacities. Neveah emphasised the difference between mothering her typically developing older son and her younger autistic son: ‘Our big boy was just really easy kind of stock-standard, grew up kind of kid, and this little fellow is just a whole other learning space for us’.

Women talked about teaching their children. Layla, for example, was very proud of the ways her eldest daughter teaches her autistic son, describing ‘his Mum doing stuff with him all the time ... showing him cards and teaching him all sorts of different things not to do and what’s good and what’s not’. Olivia stressed the importance of learning skills from therapists, stating ‘we are the teachers at home’. She described this as ‘a mind switch’ explaining ‘we can’t just go take her to these people and they’ll fix her; no, actually we’ve got to change to do the things that help her to learn, because she learns in a different way’.

Some mothers mentioned the importance of attending professional autism events and workshops to expand their knowledge. Alexis spoke of how such training had helped her to ‘break things down’ for her son. This had transformed her attitude towards other mothers struggling with their children, making her more less judgmental:

I’ve been to the supermarket and you see a kid crying and you think, ‘Oh dear, he needs a smack on the bum’, but then you do all this training and you think what that mother’s had to do to get that child out of the car, to get her in just to grab a

few groceries. You need to go up and commend her because of what they've got to deal with. I don't know whether that child's autistic or not.

Other mothers used strategies they learned from psychologists to influence their children's behaviour. Ava learned how to manage Koen's meltdowns, making it possible to take him shopping. 'It was hard', she confided. 'It was like months, years, of hard work and lots of screaming', she continued. But for her family 'it's definitely paid off'. Neveah, too, said that she had become better at dealing with meltdowns. She summarised the influence of parent training workshops: 'We know what makes him tick, we know what makes him have a meltdown, we read him a lot better than we did'. In addition, Neveah said that this training had a positive impact on her own capacities as an educator, saying 'it helped me in my job'. In particular, she stated that she now had a less stereotypical view, having developed an understanding of 'how different [autism] looks for everybody'.

Ruby summed up women's views of their active responsibility to care for and to teach their children when she remarked, 'I've got to learn him to live in this big world'.

### **Theme 3: Protecting children**

#### **Subtheme A: Keeping children safe**

Women expressed numerous concerns about keeping their autistic children safe at home, at school and in public settings, such as neighbourhood streets and hospitals. Their strategies included both risk minimisation and building up 'confidence and capabilities'.

Sometimes keeping children safe meant restricting their activities. Sienna, for example, does not allow Elijah to cook 'because he doesn't comprehend hot things'. She described Elijah's transition from secondary school as a movement away from danger and towards safety: 'I think I was like when he finished Year 12, it was like okay, I know where he is now, I know he's home, he's safe, no-one can get to him, no-one's going to touch him'.

Sophie was concerned about her children leaving the house and ‘wandering’ or doing ‘runners’, describing herself as ‘vigilant’ about safety. She uses surveillance technology to keep track of her children; they wear GPS watches and an alarm rings on her phone if they exceed set perimeters. Sophie balanced these risk minimisation strategies with proactive efforts to teach safety skills including swimming, reinforcing road rules and self-defence.

Being outside the home often presented risks. Especially with younger children, these risks were repeatedly related to children having ‘no fear’ ‘of heights or speed or anything else’ [Sophie]. Speaking about her 2-year-old son, Neveah repeated, ‘he doesn’t have no fear, this kid has no fear’. Ava, too, said that her four-year-old son Tyler loved to chase birds so ‘he’ll chase them wherever they go, even if that means in front of a car’. ‘It’s scary as shit’, she confided.

Schools were sometimes described as unsafe places. Layla, for example, reported that one of her autistic grandson’s was bullied at school because ‘he acted different and he didn’t play football’. Alexis’ son Cooper was also bullied at school and was frequently absent due to severe anxiety and mental health issues. Alexis saw her son as a hero because he intervened when another Aboriginal student at his school attempted to hang himself: ‘Cooper picked him up, grabbed him, put him on the table and ran and got help’.

Amelia’s son Mason was refused treatment at a hospital. Because he was anxious and in pain, he was crying and swearing ‘like a trooper’. Hospital staff said there was nothing wrong with him but he actually had several breaks in his arm. Mason was finally admitted after his psychologist attended the hospital with the family. Amelia’s friend and interview support, Evie, commented that the attitude of hospital staff was ‘Here’s a bad Aboriginal mother with a bad Aboriginal child’.

### **Subtheme B: Dealing with stigma**

Mothers often described autism as a stigmatising condition. They reacted to autism stigmatisation in a number of ways, including rejecting stigma, encouraging more normative behaviour in their children and avoiding stigma by isolating their family. Women also said that they felt stigmatised as bad or inadequate mothers.

Aaliyah removed her son Aiden from the school he was attending because she 'felt like they'd labelled him and just put a limit on what his learning would be'. Rejecting these attitudes, Aaliyah explained 'they didn't sort of get that he learns differently, and that he can be just as clever'. She saw herself as 'trying to protect him from that'.

Sienna rejected stigmatising attitudes when out shopping with Elijah: 'And I just ignore people that look at him, because I'm short-tempered. If I say something, I will gun them and I will go at them. So I've learnt to zip my lips and just keep walking'. She specifically suggested that her rejection of stigmatisation was bound up with protecting her son and that both attitudes are characteristically Aboriginal or 'Koori', explaining 'that comes from being Koori I suppose... yeah I'm very protective of my kids'.

Nevertheless, Sienna also reported encouraging Elijah to behave in ways that will not attract unwanted attention. She commented that her son can 'pass' as non-autistic: 'If you walked past Elijah in the street you wouldn't even think he had autism – like you wouldn't think there was anything wrong with him. He walks normal, he talks, like he does everything normal like a normal kid'.

Women also reported being stigmatised as mothers of autistic children. Ava said that she had been blamed for causing or contributing to her children being autistic, with people asking, 'Is it because of how you raised them?' She referred to the emotional impact of that mother blame, saying, 'It's hard because it breaks you down as a mum, as a parent'. She added: 'I've never been judged more than becoming a mum and a mum of autism'. Alexis conveyed a strong sense of the internalisation of mother blame that can accompany an autism

diagnosis: ‘Then you hear about autism and then it’s like you blame yourself – I should have done this or hubby should have done that... I thought I failed him’.

### **Subtheme C: Respecting each individual**

Although mothers sometimes tried to direct their children’s behaviour towards perceived norms, at other times they strongly defended their right to express themselves in public however they chose to. For Ava, it is important that her children can ‘just do things they love’: ‘If we go shopping and a song comes on the radio through the bloody shops, he’ll want to start dancing, like “dance with me, Mum”. I’m like, “Okay, let’s dance off”. They’re kids, they deserve to be kids.’

Other mothers spoke about respecting their child’s preferences at home. Olivia said that her daughter Scarlett can find family events stressful – ‘if it’s too loud she will want to leave... I’m not going to force her because it’s just going to make her get really scared and unhappy’. Olivia went on to explain that her daughter’s preferences limit her own socialising:

Yeah, there are a lot of things that as a first-time mum you thought, oh we’re going to go out and get coffees, do the playdates, all that kind of stuff – no. Didn’t do none of those. It was more like, just giving her space and making sure she was happy.

In general, mothers tried to convey a positive view of autism to others, explaining it as a neurological difference rather than a deficit. Sophie told family and friends that her son ‘learns differently and he sees the world differently; it’s nothing to be sad about’. Ella has explained to family that her son is ‘wired differently’. Ava, who self-identifies as Asperger’s, asserted that autistic people are ‘so much more intelligent and smarter than everyone else’.

Other mothers stressed that Aboriginal and Torres Strait Islander worldviews are inherently accepting of all forms of difference. For Nevaeh, this marked a distinction between an Aboriginal sense of personhood as fundamentally individual and non-Indigenous forms of

categorical thinking, based around diagnostic constructs. She said: ‘They [autistic children] have their little ways and stuff like that and no one really thought too much more about it, more than it was like personality traits of someone rather than it’s attached to this whole spectrum of autism’. Olivia, who works in remote Aboriginal communities, contributed that ‘there’s lots of people with autistic children’. She said that autistic children in these communities are ‘teased a little bit but they’re taken, and you’re all still family, doesn’t matter about that, so it’s good’. She contrasted this ethos of kin-based belonging with ‘children in Western society’ who are ‘picked on’.

#### **Theme 4: We’re all family**

##### **Subtheme A: Emphasising children’s strengths**

Mothers consistently emphasised the strengths of their autistic children, highlighting their capacities and interests. For younger children, mothers spoke about their child’s sensory involvement in the natural world and their capacity for enjoyment. Ella described her son as ‘a nature boy’, stating that he loves ‘going to parks’ and is ‘a water baby’. Neveah said her son ‘just loves the outdoors’ including ‘swinging in trees’ and ‘digging and dirt’. Other mothers emphasised their child’s particular talents such as their ‘amazing artwork’ [Willow] and drawing [Ruby]. Sienna is proud of Elijah’s general knowledge, especially of how good he is at quiz shows – ‘He knows 95 per cent of them answers’. Amelia also expressed admiration for Mason’s general knowledge, stating ‘Because of that autism he just knows exactly everything’.

Mothers sometimes described behaviour that clinicians would most likely interpret as evidence of restricted and repetitive behaviours (a core diagnostic feature of autism) in positive ways. Thus, Layla described her grandson’s repeated viewing of the same small

segments of video clips – ‘he’ll just backwards and forwards there’ – as ‘cluey’, while Ella described her son’s placement of toys in patterns as ‘creative paths’.

When mothers summed up the character of their autistic child(ren), they used overwhelmingly positive characterisations, describing them as ‘affectionate’ [Alexis], ‘charming and friendly’ [Amelia], ‘very caring and happy’ [Ella], ‘very super special’ [Nevaeh] and ‘very lovable’ [Sienna].

Mothers of autistic adults emphasised their progress over time as part of a narrative of overcoming impairment. Amelia said that her 18-year-old son Mason ‘walked before he was two where they said he wouldn’t walk’. She further highlighted how inaccurate his initial prognosis was, adding ‘said he wouldn’t talk and he can talk, talk, talk’. Sienna commented, ‘There’s nothing I would change about Elijah’, adding ‘He’s come a long way, a long, long way’.

### **Subtheme B: Family belonging**

Participants consistently stressed that their autistic children are valued family members, noting the particularly positive relationships between grandparents and autistic grandchildren. Olivia said that her mother ‘doesn’t treat them all any different at all, they’re all still her grannies’. Sienna’s mother has lived with her and her children for the past 20 years. She laughed as she told the story of how her mother favours her autistic grandson: ‘Elijah is the Golden Child – whatever Elijah wants, Elijah gets off Nan. She spoils him rotten.’

The importance of relationships between autistic children and their cousins was also often mentioned, especially the role of cousins in teaching play skills. Ava gave a concrete example:

I always find whenever they’re with their cousins, or other Aboriginal kids, there’s no such thing as ‘you can’t do it’. It’s ‘let me show you’. I want to kick

the footie with you so you better learn to kick this football so we can kick it together.

Olivia said that her daughter ‘Scarlett’s social group is all her cousins, which there are many’. Willow, too, remarked that even though her son, Kai, ‘might not be able to understand’, his cousins ‘take him and they do stuff with him’. She added that Kai’s cousins ‘protect him’ if ‘anyone from outside the family comes in’. Layla also highlighted her autistic grandson Hunter’s connection with his cousins, saying ‘he’ll follow them around and want to do stuff’.

### **Subtheme C: Helping other families in community**

Participants often voiced concerns for other families in their communities supporting autistic children and adults. As Amelia said: ‘there is some parents out there who does need help’. For some, concerns were focused on the difficulty of navigating the autism system: ‘So I’m there advocating, “Oh, you need to apply for this”, or “you need to go and get a paediatrician’s diagnosis”. But it’s such a muck around to do all this stuff’ [Olivia]. Participants suggested that some families are reluctant to access services. Sophie, for example, said that she has a late diagnosed 33-year-old autistic nephew with high support needs who receives no formal services. When she spoke with her relatives about this, they replied, ‘we just look after him as a family’.

Alexis, too, said that there were many Aboriginal families in her regional community who ‘had nothing in place’ for their autistic children: ‘In our community, they’re just too ashamed to take their kids anywhere because they run amuck; they’re bad kids’. Alexis was determined to help other families in her community through education about autism and disability services. To this end, she started a regular support group for Aboriginal parents of autistic children in her regional area. Willow, too, set up an informal network for Aboriginal



parents of autistic children in her regional area where she offered support and advice via telephone.

## **Discussion**

This is the first research to explore the experiences of Aboriginal and Torres Strait Islander women supporting their autistic children. We identified four themes – ‘navigating the autism system’, ‘learning to live in the big world’, ‘protecting children’ and ‘we’re all family’ – that were linked together by participants through the metaphor of ‘the journey’. The journey was perceived as both difficult – ‘a hard slog road’ – and rewarding, providing knowledge that led to transformations in understandings of self and others. The salience of the metaphor of a journey through which individuals search for meaning has been extensively theorised in illness narratives (Frank, 1995). Numerous studies have reported that parents emphasise the transformative impact (personal, relational and perspectival) of caring for children experiencing disabilities (Landsman, 2005; Scorgie, Wilgosh and Sobsey, 2004), including autism (Myers, Mackintosh and Goin-Kochel 2009; Russell and Norwich, 2012). In the Aboriginal and Torres Strait Islander context, the journey is an especially apt potent metaphor because travel is a constitutive element of cultural practices bound up with knowledge transmission and looking after Country (Green et al., 2016; Ross, Ulm and Tobane, 2013).

**Navigating the autism system** encompassed achieving an autism diagnosis and connecting to culturally-safe services and supports in a costly and complex autism service landscape. Participants outlined numerous barriers to **achieving an autism diagnosis** for their children, including affordability, availability and geographical accessibility. These barriers to autism diagnosis are widely reported in the literature (e.g. Ebert, Lorenzini and da Silva, 2015; de Leeuw, Happé and Hoekstra, 2020) and have been specifically documented in

Australia, including the limited availability of diagnostic assessments in regional, rural and remote areas, longer waiting times for public assessments and considerable variability in costs (Taylor et al., 2016; Whitehouse et al., 2018).

All of our participants saw autism diagnosis as valuable in both helping them to understand and manage their children and as a gateway to further services and supports, including therapies. However, some reported that either they or other family members were initially resistant to their child's identification as autistic. Gilroy and Emerson (2016, 118) have pointed out that disability constructs and diagnostic categories are 'Western concepts' that are 'imposed on Indigenous peoples in Australia'. Given the broader context of racism (Larson et al., 2007; Priest et al., 2011) as well as autism stigmatisation in the wider Australian community (Broady, Stoyles and Morse, 2017; Gray 1993, 2002; Lilley 2013a), family members may resist diagnosis, believing it could lead to limiting preconceptions of children and negatively impact their self-esteem.

Respondents in this study clearly articulated a preference for **connecting to culturally-safe services and supports**. Some mothers felt that therapies were delivered in culturally inappropriate ways, echoing concerns that the uninterrogated tacit standards and ideals of early intervention may have limited cross-cultural resonance (Iwama, Thomson and Macdonald, 2011). Other mothers said that they and their children strongly preferred interacting with Aboriginal and Torres Strait Islander professionals. Participants suggested that there would be benefits both to making Aboriginal Community Controlled Health Services more autism literate and to improving the culturally competency of mainstream autism services. They also gave examples of the ways in which they encourage children to prioritise and maintain their cultural identity, reworking therapeutic goals to incorporate valued practices of connecting with Country. This is consonant with research identifying the

ongoing task of reclaiming and preserving cultural traditions as a salient aspect of Aboriginal mothering (Brant, 2020; Heath et al., 2011).

Teaching their autistic children about **learning to live in the big world** was perceived as an essential component of their mothering role by our participants. This task included **engaging in everyday care** and enhancing children's capacities. While the types of activities undertaken and supports offered varied across time, women's responsibilities for intensive mothering (Hays, 1998) in order to meet the additional needs of their autistic children extended from early childhood to adulthood. As Joosten and Safe (2014) have argued in the wider Australian context, many of the daily caregiving tasks reported, such as assistance with toileting or getting children dressed for school, do not vary from typical mothering tasks. However, the complexity of supports required and the number of years over which this continues make the experience of mothering autistic children qualitatively different from that of mothering typically developing children.

Women also spent considerable time and energy **enhancing children's capacities**. In doing so, they often took on an explicitly pedagogical role as their child's main teacher and therapist. Taking expert advice from autism professionals, such as psychologists, speech and occupational therapists, as well as undertaking their own training in autism was seen as an integral part of this responsibility. The emphasis on developing children's capacities is, as Sousa (2011, 239) points out, 'a continuation of a historical typification of maternal responsibility for children's outcomes'.

As well as engaging in everyday care and enhancing children's capacities, our participants also saw themselves as responsible for **protecting children**. This involved **keeping children safe** and dealing with stigma. While keeping children safe was often related to child characteristics, such as limited road safety sense, it was also frequently related to the behaviour of others in the community. Women sometimes felt that schools were

unsafe because of bullying and mental health issues. They also reported that the intersection of ableism and racism, for example in healthcare settings, led to inadequate treatment of their children.

Children's preference for routine combined with felt and enacted stigma (Link and Phelan, 2001) in community settings also meant that mothers often experienced feelings of social isolation (Lilley, Sedgwick and Pellicano, 2020) finding it difficult to maintain valued social connectedness in their communities. Women described **dealing with stigma** in varied ways, including isolating their families, encouraging normative behaviours and rejecting stigma. They reported that felt attributions of mother blame were very upsetting. The continuing stigmatisation of mothers and their autistic children has been documented both in Australia (Broady, Stoyles and Morse, 2017; Gray, 1993, 2002; Lilley, 2013a, 2013b) and elsewhere (e.g. Selman et al., 2018; see Papadopoulos, 2019). Some mothers in our study suggested that being very protective of children is perceived as an integral part of Aboriginal parenting. Pervasive social inequalities and systemic racism towards Aboriginal and Torres Strait Islander peoples, as well as continuing practices of child removal that target their families, provides a strong impetus for these protective attitudes (Hollinsworth, 2013; Green et al., 2021).

Women described **respecting each individual** child. This attitude of respect encompassed a sensitivity to children's preferences and conveying a positive view of autism, based on a construct of neurological difference, to others. Our participants specifically connected this respect for individuality to an acceptance of many forms of difference in Aboriginal and Torres Strait Islander communities, sometimes described in the literature as an inclusive ethos common to First Peoples (Avery, 2018; Bevan-Brown, 2013, Kapp, 2011). More specifically, Vicary and Westerman (2004) have argued that Aboriginal beliefs about mental health do not conform to Eurocentric perceptions because differences are viewed as

part of someone's innate character rather than as pathological conditions that require treatment.

An important component of this acceptance of difference is a strong sense of family belonging – ‘**we're all family**’ – that encouraged an **emphasis on children's strengths** and a reworking of medical models of impairment to focus, instead, on positive characteristics, including intelligence and creativity. Maternal validation of children's personhood is a salient theme in the childhood disability literature (Landsman 1998, 2003). Mothers of autistic children in varied contexts, including Australia, have been described as creating counter-narratives to a clinical diagnosis necessarily based on impairments (Lilley, 2011; Singh, 2016; Sousa, 2011). The continuing importance of kinship as a framework for structuring social relations in Aboriginal and Torres Strait Islander communities means that ideally all children grow up with a strong sense of **family belonging** (Heath et al., 2011). In particular, our participants highlighted the positive relationships between autistic children and their grandparents as well as their cousins. While some of the mothers in our study reported limited support from family members, others stressed the role of immediate and extended family in looking after autistic children.

Mothers also often saw themselves as having a responsibility for **helping other families in community**. The pivotal role played by mothers as advocates for their own autistic children's welfare is widely documented (Silverman and Brosco, 2007). This role sometimes develops into forms of systemic advocacy and activism (Ryan and Runswick-Cole, 2009). Because autism is a relatively new concept in Aboriginal and Torres Strait Islander communities (Lilley, Sedgwick and Pellicano, 2020), mothers in our study reported engaging in numerous forms of advocacy, including educating others about autism, creating informal networks of support and advice and establishing formal support groups for other Aboriginal families. In doing so, they enacted relationships of care based on a shared cultural

and historical identity becoming valuable community members by helping and looking after others.

A history of racist representations of Aboriginal and Torres Strait Islander families has led to a focus on dysfunction and the interpretation of cultural differences in parenting and child care as evidence of neglect and instability (Hollinsworth, 2013; see Macdonald and Boulton, 2011). As noted by our participants, Aboriginal women are often stigmatised as bad mothers. Our participants refused this derogatory stereotype. They saw themselves as good competent mothers of valued children. They told us about the considerable work they undertook to secure a diagnosis and services for their autistic children, their intensive everyday care and nurturance of children's capacities, their efforts to keep children safe from physical harm and from stigmatising interactions, their children's strengths and belonging in family and, finally, their efforts to advocate on behalf of other families supporting autistic children in their communities.

The use of the term 'loving' in our title references the intense emotions often expressed by the mothers and grandmother who told their stories to us—the profound sense they conveyed of both the richness of their relationships with their autistic (grand)children as well as some of the challenging aspects of parenting (see Silverman, 2012). As Douglas (2013, 169) has remarked, 'Autism and mothering are lived in a deeply affective register'. The challenges these women experienced were sometimes related to the characteristics of their children. But, more often than not, they had their source in the stigmatising attitudes of others and in the bureaucratic difficulties of accessing diagnosis and supports. These women are mothering in the context of intersecting inequalities; every day they and their children face the risks of discrimination based on structural racism and/or ableism (see Avery, 2018). In the midst of this challenging context, women emphasised the pragmatic work they did as

mothers, demonstrating both resilience and resourcefulness as they mobilised resources and made many positive changes in their own families and on behalf of others (see Bayat, 2007).

### **Limitations**

There are a number of limitations to this research. Due to the small and self-selecting nature of the sample our findings cannot be generalised to represent the views of all Aboriginal and Torres Strait Islander peoples supporting autistic family members. These communities are extremely culturally diverse and sampling strategies designed for mainstream populations may not be effective or appropriate (Lee, 2020), especially when investigating potentially sensitive topics. We hope that this research will encourage others to conduct further studies that attempt to recruit harder-to-reach populations, including families not currently accessing services or supports. Eliciting the views of other family members, including fathers and grandfathers, would also provide additional perspectives and may be especially important in cultures where caregiving roles are shared amongst immediate and extended family (Gilroy and Emerson, 2016). Further, research with autistic children and young people themselves is vital to understanding their perspectives and preferences. The use of other methods, such as participant-observation of daily life in different settings or longitudinal studies that allow a sense of changes over time, would provide valuable additional understandings about autism as experienced in Aboriginal and Torres Strait Islander communities.

### **Conclusion**

We hope this study encourages further research exploring experiences of living with autism in Aboriginal and Torres Strait Islander communities. As noted by Bailey and Arciuli (2020), most of the available research on childhood disabilities in these communities has, to date, focused on barriers to service utilisation. Much remains to be learnt about how autism is

conceptualised in diverse communities and what kinds of support are culturally appropriate and valued by families. Understanding how best to support these families and autistic individuals will require a sustained research agenda led by Aboriginal and Torres Strait Islander researchers in consultation with local communities. Respectfully listening to women talk about loving and supporting their autistic children and understanding the complexity of the tasks they undertake to navigate the autism system as well as their resilience in walking this ‘hard slog road’ is the first step on this shared journey.

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## Appendix 1

### Interview Schedule Prompt Sheet for Researchers

#### **1. Tell me a bit about your child**

#### **2. Tell me about your journey to getting your child diagnosed with autism**

Probe questions: When did you or other people first become concerned about your child's development? When was your child diagnosed with autism and who diagnosed him/her? Has your child had any other major health difficulties or diagnoses? Was it difficult to get an autism diagnosis? Did you have to travel far? Was it expensive? Did you have to wait a long time for the diagnosis? At the time of diagnosis how was autism explained to you? Did you tell your family and local community about the diagnosis? If so, how did they react? How do you explain autism to them?

#### **3. Tell me about the support you or your child has received**

Probe questions: After your child was diagnosed, were you offered any therapies or other supports? [Example: speech therapy.] If so, can you tell me about them.

Do you feel that you have been given much information about how to help your child? And who has helped the most? [Examples: other family members, local health workers, teachers etc.]

Did you seek any services or supports on your own? [Example: the internet.] If so, what were they? Were you able to access these?

Are there any services or supports that you think your child or family would benefit from that you have not been able to access? If so, what are they? Why do you think you haven't been able to access them? What services and supports are your family receiving right now? Is it enough?

What kinds of changes have you seen in your child since diagnosis? To what extent do you attribute those changes to services provided?

How could things be better? Who do you turn to for support? What helps you to cope now?

#### **4. Tell me about your child at school**

Probe questions: Did your child attend early childhood education? If so, what type of settings did they attend (e.g. play groups, preschool)? How often did they go to these early education settings? Did your child receive any therapies (e.g. speech therapy) at these settings? If so, please provide details about the type(s) and duration of therapy (e.g. once a week; for how long)? How did you find out about these early education settings? Do you think enough was done to help your child at this time?

What school does/did your child attend? What kinds of advice have you been given about the best sort of school for your child? Do you feel you had a choice of schooling options?

What kinds of educational services and resources does your child get? How adequate are these? [Examples: Individual Education Plans including Behaviour Plans; Learning Support Officer; curriculum adjustments.] What kinds of support would you like your child to receive at school?

How does your child feel about going to school? Is s/he happy there? How does s/he get along with the other children? And what about the teachers? Do you have many interactions with his/her teachers?

Have you had any changes of school? If so, what have these been and what prompted these moves? Do you feel that your child is in the best educational setting available for them?

What do you hope your child will achieve in the next year? What are your hopes and dreams for your child in the future?

#### **5. What kinds of research about autism do you think would benefit your child and your family the most?**

Probe questions: Are you aware of much research on autism? If so, what have you heard about?

There has been almost no published research on autism in Indigenous Australian communities. Why do you think this is?

What sort of research do you think would be most useful for your family and for other Indigenous families with kids on the autism spectrum?

Do you think there are any areas that might be difficult to research in Indigenous communities? Why?

**6. Is there anything else you would like to say or to talk about?**

Once these core topics have been discussed, participants will be asked if they would like to talk about or raise any other issues around the support of individuals on the autism spectrum in Indigenous communities.