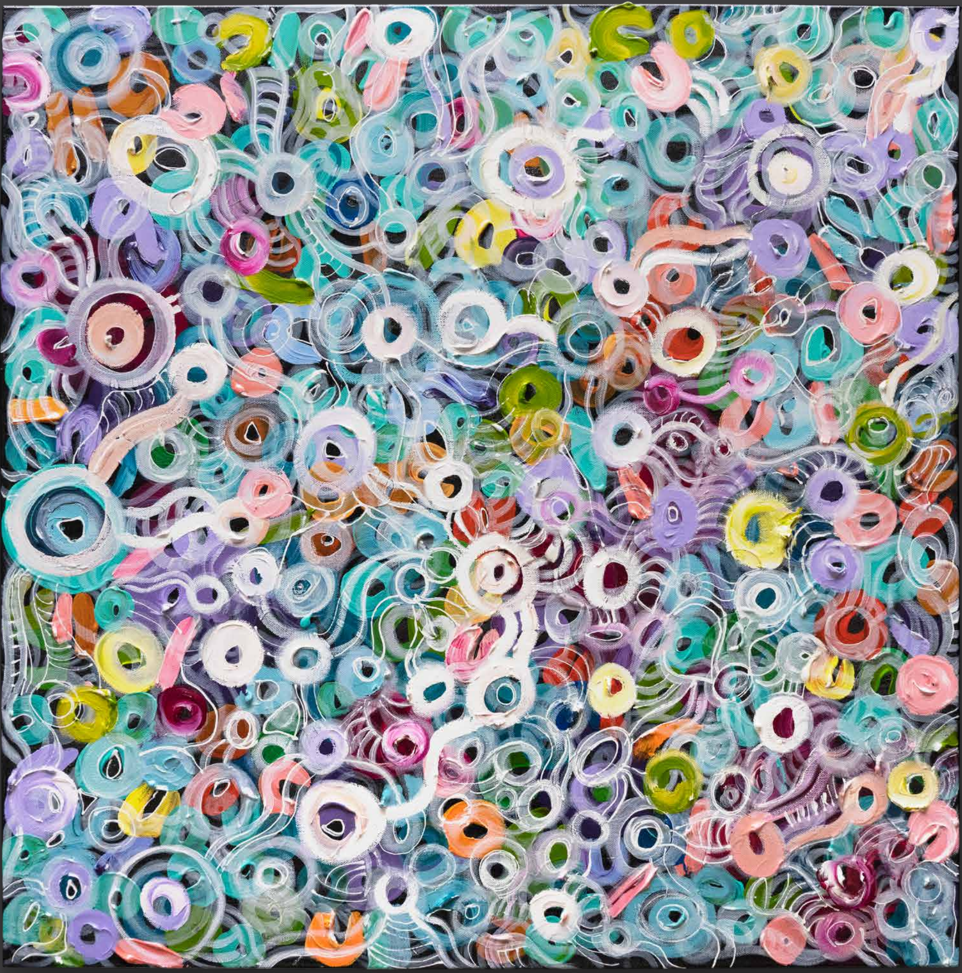
WE LOOK AFTER OUR OWN MOB

Aboriginal and Torres Strait Islander Experiences of Autism



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Aboriginal and Torres Strait Islander readers are advised that this publication may contain the voices of people who have passed away.

Aboriginal and Torres Strait Islander people are further cautioned that this research contains personal testimony and content that some people may find distressing.

COVER ARTWORK

An Optimistic Journey 2019
by Maria Watson-Trudgett, a Koori woman
of the Wiradjuri People.

To find out about the artist and her process, please refer to the inside back cover of this publication.

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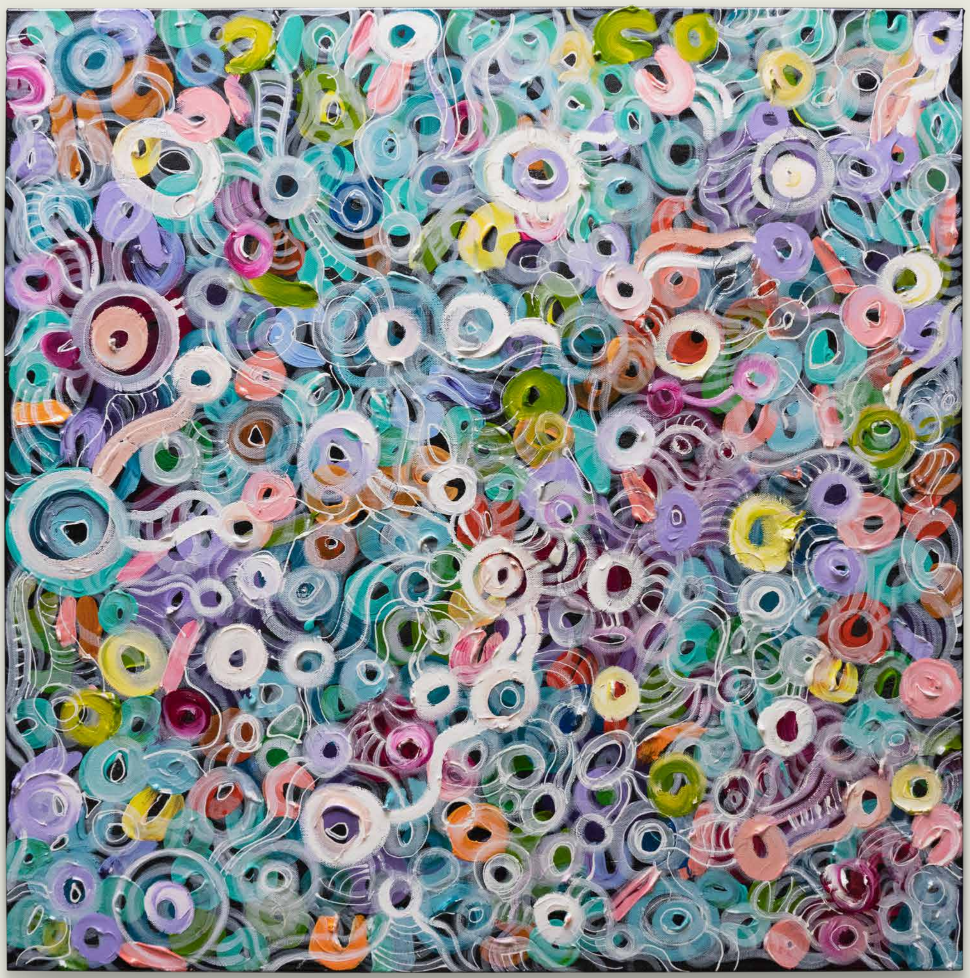

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EXECUTIVE SUMMARY

Autism directly or indirectly affects millions of people across the globe – and the impact can be substantial, on autistic individuals themselves, their families and society more broadly. Greater awareness of autism in Australian communities and the growing availability of support services is encouraging, and goes some way to ensure that autistic people lead flourishing lives.

Yet almost all of what we know and understand about autism has come from a very limited range of viewpoints. We know virtually nothing about how autism is understood by, and how autistic children, young people and adults are supported in, culturally and linguistically diverse communities. This includes Australia's own First Peoples: Aboriginal and Torres Strait Islander communities.

This absence of research leaves a lack of understanding of how these communities across Australia perceive autism, the services and supports that they are currently being offered and the services – from the early years and into adulthood – from which they might benefit the most in the future.

This Report, commissioned by Positive Partnerships and supported by First Peoples Disability Network, sought to change that. It is the first research on autism in Aboriginal and Torres Strait Islander communities. As such, it provides a vital starting point for understanding the needs of Aboriginal and Torres Strait Islander autistic children and those who care for them.

We conducted the research by listening directly to the first-hand experiences of 12 Aboriginal and Torres Strait Islander families with a child on the autism spectrum, that have previously not been heard in autism research and, critically, identify key areas for future investigation.

Our participants, from diverse parts of Australia, told us that they were deeply dissatisfied with the state of autism-related services in their communities. We frequently heard intense anxiety on their own family's behalf and, just as strongly, concern on behalf of other Aboriginal and Torres Strait Islander communities too. The specific concerns expressed included worries about the cost of diagnostic services, lengthy waiting times, limited access to diagnostic professionals, especially in regional and remote Australia, as well as to post-diagnostic services. Where families did receive government assistance, it was often seen as being insufficient to cover the costs of basic services.

Families wanted their children to feel secure, safe and supported at school. While they described many positive aspects of school life including dedicated and knowledgeable staff and a range of individualised student supports, their children nevertheless encountered many difficulties, including being bullied, isolated and excluded. Some of these students had serious mental health issues.

Participants stressed that they wanted their children to be connected to their traditional culture and for the importance of family and community ties to be recognised and strengthened. They also highlighted the lack of knowledge about autism in Aboriginal and Torres Strait Islander communities, their frequent sense of social isolation and the need for better supports and services across the lifespan.

In response to these views and concerns, the Report makes the following recommendations:

1. Production of a targeted “road map” outlining the post-diagnostic support services available to parents and caregivers of Aboriginal and Torres Strait Islander autistic children.
2. Development of a network of currently-existing Aboriginal and Torres Strait Islander parent support groups and the creation of a support process to enable further groups to be created.
3. Production of information about autism and autistic life-experience, designed specifically for Aboriginal and Torres Strait Islander communities, in a variety of accessible formats and, where possible, translated into local languages.
4. Deepening and extending existing strategic frameworks designed to enable the recruitment and retention of Aboriginal and Torres Strait Islander workers in health, education and disability services.
5. Development of autism awareness training that incorporates high-quality cultural safety for use in services and institutions, both mainstream and Aboriginal and Torres Strait Islander specific.
6. Review widely-used autism intervention and therapy guides, special school curricula and disability services to ensure they fully acknowledge Aboriginal and Torres Strait Islander cultural knowledge and practices.
7. Development of further community-based research into the identification and diagnosis of autism in Aboriginal and Torres Strait Islander families.
8. Development of a community-directed research strategy into the circumstances of Aboriginal and Torres Strait Islander autistic adults to better support their needs and aspirations.
9. Seek to secure specific additional funds for research into the needs, priorities and preferences of Aboriginal and Torres Strait Islander autistic people and their families.
10. Improved access to and greater availability of respite for parents and carers of autistic individuals, regardless of cultural background, socioeconomic status or geographic location.
11. Development of targeted support for the mental health needs of Aboriginal and Torres Strait Islander children, young people and adults on the autism spectrum.
12. Increased assistance to families of Aboriginal and Torres Strait Islander children with a diagnosis of autism to access the National Disability Insurance Scheme and plan supports.

ACKNOWLEDGMENTS

This Report was commissioned by Positive Partnerships to understand the views and experiences of families of an Aboriginal and/or Torres Strait Islander child on the autism spectrum. The authors are extremely grateful to Positive Partnerships and First Peoples Disability Network (FPDN) for giving us the opportunity to work on such an important topic, allowing us to listen to, and learn, from these families.

Positive Partnerships is a national project, funded by the Australian Government Department of Education and Training through the Helping Children with Autism package. It is delivered by Autism Spectrum Australia (Aspect), with the goal of improving the educational outcomes of school-aged students on the autism spectrum.

This project was also supported by FPDN, the national peak systemic advocacy organisation, working from a Human Rights framework, of and for Australia's First Peoples with disability, their families and communities. Their organisation is governed by First Peoples with lived experience of disability.

Although this project was conducted independently by the research team, we are indebted to Jacqui Borland, Lee Cascuscelli, Maria Watson-Trudgett and Suzanne Donnelly from Positive Partnerships, and to June Riemer from FPDN, for thoughtful discussions and help throughout the process, especially with inviting families to be part of the research and supporting them through it. We are very grateful to Positive Partnership's National Aboriginal and Torres Strait Islander Reference Group for their support and helpful comments on our ethics application.

We also thank Maria Watson-Trudgett for her beautiful artwork, Prof. Bronwyn Carlson and Tristan Kennedy for their ideas and encouragement during the initial stages of the project and Prof. Marc Stears for his ever-careful reading of the Report and constructive feedback. Thanks also to Pete Flanagan from Swell Design Group for the wonderful design and production of the Report, and to Ball & Doggett and Clarke Murphy Print for generous assistance with printing the hard copies.

Most of all, we express our sincere gratitude to the 12 families who so generously gave up their time to take part in this project and share their experiences. It has been such a privilege to hear about their lives. We have done our very best to convey their experiences as accurately as possible. Any omissions and errors are entirely our own.

ABBREVIATIONS

ACCHS: Aboriginal Community Controlled Health Services

ACT: Australian Capital Territory

ADHD: Attention Deficit Hyperactivity Disorder

FASD: Fetal Alcohol Spectrum Disorder

FPDN: First Peoples Disability Network

HCWA: Helping Children with Autism package

NDIA: National Disability Insurance Agency

NDIS: National Disability Insurance Scheme

NSW: New South Wales

NT: Northern Territory

OCD: Obsessive Compulsive Disorder

ODD: Oppositional Defiant Disorder

OT: Occupational Therapy

PTSD: Post-Traumatic Stress Disorder

WA: Western Australia

TERMINOLOGY

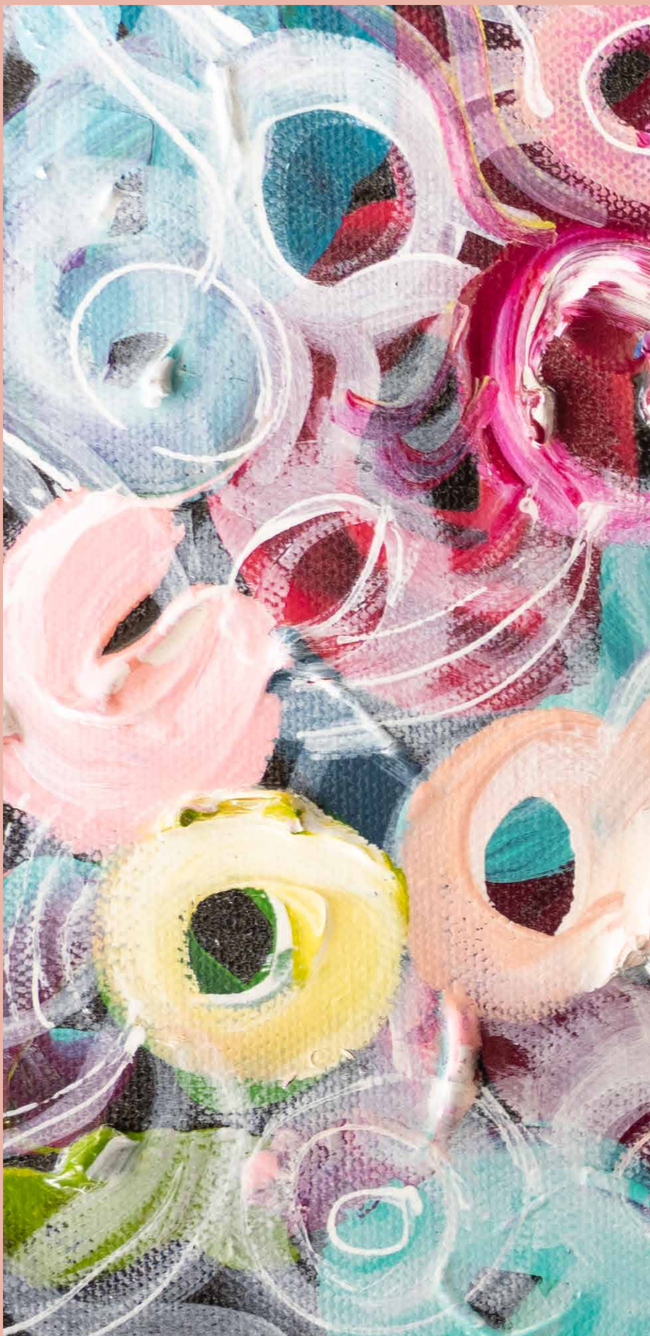
Throughout this Report we refer to Aboriginal and Torres Strait Islander peoples. We acknowledge the diversity of the over 250 distinct groups and over 700,000 people that make up Australia's Aboriginal and Torres Strait Islander population. The term First Peoples has been used when it is preferred in organisational contexts or employed by participants. The term Indigenous has been retained when used in directly quoted speech from participants.

In the autistic community, **identity-first language** (e.g., "autistic person") is often preferred to [1,2], and is less stigmatizing than [3], person-first language (e.g., "person with autism"). We therefore use identity-first language throughout this Report. The exception to this pattern is where family members themselves have specifically used person-first language.

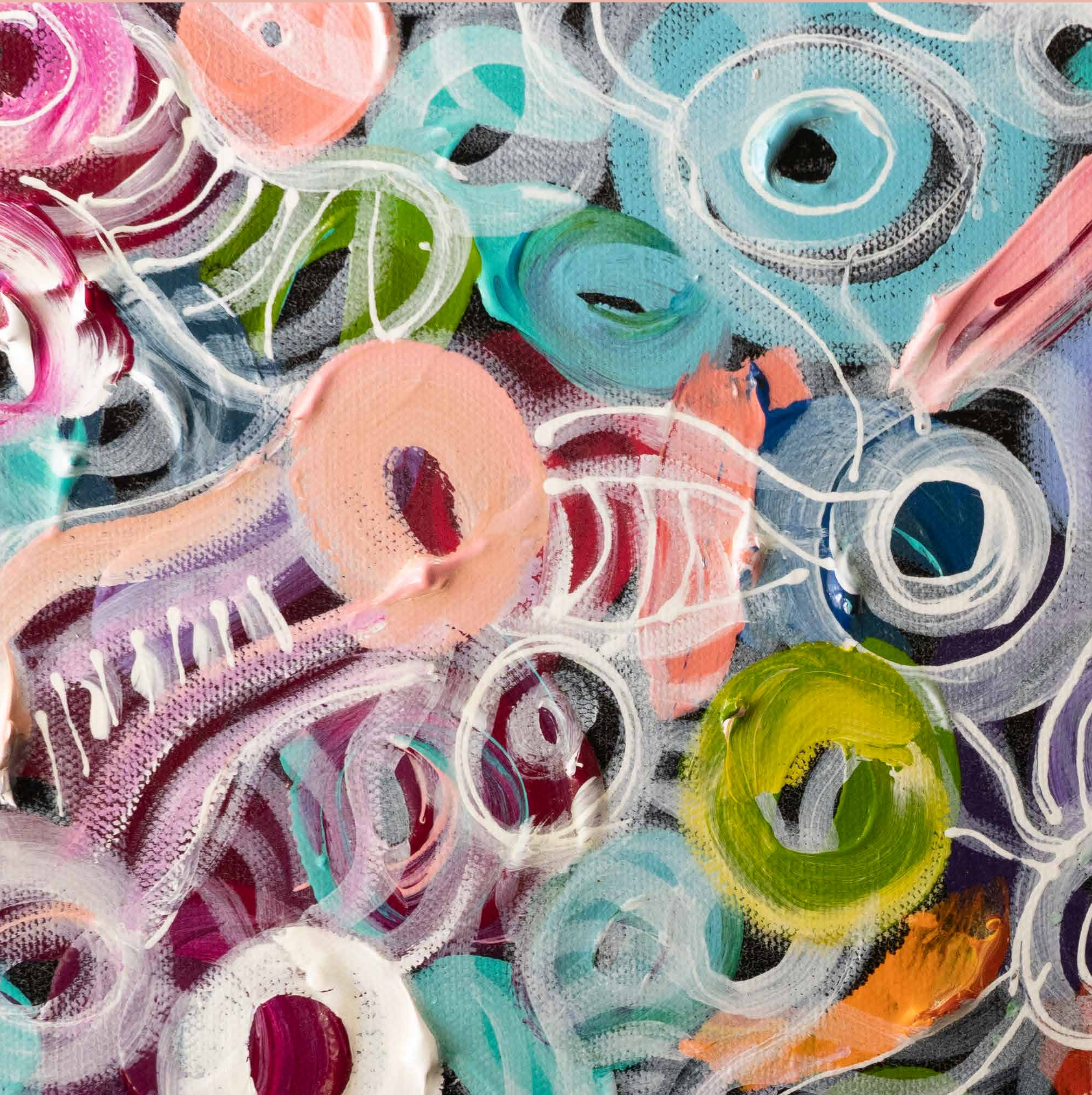
DEFINITIONS

The **Helping Children with Autism (HCWA) package** was an Australian Government initiative that provided autistic children aged under 7 years with up to AUD$12,000 in funding for early intervention services and treatments as well as additional Medicare services. It commenced in 2008 and was progressively replaced by the National Disability Insurance Scheme (NDIS).

The **NDIS** provides Australians aged under 65 who have permanent and significant disability with funding for supports and services. Piloting of the NDIS was undertaken from 2014 and the full national rollout began in 2016. NDIS marks a shift to person-centred services based on the principle of individualized funding. Autistic individuals currently comprise approximately 30 per cent of the scheme's participants. The NDIS is implemented by the National Disability Insurance Agency (NDIA).



1. INTRODUCTION



INTRODUCTION

Autistic people – in Australia or wherever they may live – deserve the same sorts of chances in life as non-autistic people: to be able to enjoy trusting, nurturing relationships with family and close friends, to feel safe, secure and valued at school, at workplaces and in communities, and to develop their skills and talents to the maximum possible extent.

Unfortunately, this is not yet the reality for many autistic people. Although there is recognition of their rights, needs, and preferences, there is much we don't know with regard to the most effective ways to support autistic people to lead the lives they wish to lead. Listening to, and learning from, the experiences of autistic children, young people and adults and their families is essential to this process in part because people's experiences of being autistic, or of supporting someone who is autistic, can be so different from one another.

This is especially true for people of different cultural backgrounds, whose values, beliefs and traditions will shape ways of understanding autism and of supporting autistic people in families and communities.

Until recently, however, researchers have largely overlooked the relevance of culture with regard to autism [4-6]. Nowhere is this truer than in Australia, where virtually nothing is known about Aboriginal and Torres Strait Islanders experiences of autism. This Report seeks to change that.

Here, we document the perspectives of 12 Aboriginal and Torres Strait Islander families on their experiences of caring for an autistic child, both the joys and the struggles. We have also sought to identify their views on the best and most respectful ways to support their children and families to lead long, happy and fulfilling lives.

> *“I think this is really important. Because often Aboriginal and Torres Strait Islander people aren’t given an opportunity to talk about these things or they aren’t given a voice to say what might work for them or what are the barriers for them.”*

SETTING THE SCENE

Autism is a common, lifelong neurodevelopmental condition that affects the way that a person interacts with and experiences the world around them. In nations like Australia, the United Kingdom and the United States, autism is the most commonly diagnosed neurodevelopmental condition, with current research suggesting that 1–2 in every 100 children and adults are autistic [7].

Despite the high prevalence of autism, the opportunities and life-chances for autistic people remain often severely limited in comparison with the non-autistic population. Autistic children are far more likely to be bullied and underachieve at school compared with non-autistic children [8-10]. They are also at increased risk of being excluded from so-called inclusive settings [11-13]. Once they leave school, they are far less likely than non-autistic adults to have a job, live independently or to have friends outside their immediate family [14,15]. Many also have ongoing struggles with their health and their financial and emotional wellbeing [16-19].

In Australia, two recent national initiatives have promised to improve this picture.

The first is the National Disability Insurance Scheme (NDIS), which came into effect in 2013 and began its national rollout in July 2016. The Scheme aims to provide all Australians with permanent and significant disabilities who are under the age of 65 with funding for supports and services [20]. It is underpinned by a person-centred model of service delivery in which people are directly involved in the decision-making processes that affect them. This model should allow individuals more choice and control over the design of the supports and services they receive. Autistic Australians constitute approximately one third of all NDIS participants [21]. In 2018 an Autism Advisory Group (AAG) was established to provide a strong voice for autistic people participating in the NDIS.

The second development relates to the newly-launched *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia* [22]. Currently, the way that Australian health professionals diagnose autism varies considerably between states and territories, especially in regional and remote settings [23]. This can have huge implications for families and individuals, including delays in diagnosis, misdiagnosis and inequity in access to services, and the added stress of trying to navigate a complex system to get the help needed for themselves or their child. This National Guideline promises to provide greater consistency in the processes for how an individual is assessed for a diagnosis of autism, wherever the person lives.

These initiatives are encouraging. Yet they rest on the assumption that we know what autism “looks like”, and how it is understood and experienced by people from different cultural and linguistic backgrounds. The lack of research into culturally-specific understandings of autism, especially among Aboriginal and Torres Strait Islanders, has potentially far-reaching implications for how autism is assessed by health professionals and how children, adults and families are supported within health, education and social care systems, as well as in communities.

ABORIGINAL AND TORRES STRAIT ISLANDER EXPERIENCES OF DISABILITY

In Australia, the health outcomes of Aboriginal and Torres Strait Islanders lag significantly behind the rest of the population. Aboriginal and Torres Strait Islanders are, in many respects, Australia's most disadvantaged group. They are 1.8 times more likely than other Australians to be living with a disability [24]. Elevated rates of disability in childhood form part of this picture [25,26], with most research focusing on hearing loss, intellectual disability and Fetal Alcohol Spectrum Disorder (FASD).

Once diagnosed, Aboriginal and Torres Strait Islander peoples are less likely to access services than other Australians [25-27]. There are many reasons for this inequity. One major barrier is the lack – or very limited availability – of disability support services, including lengthy waiting lists, especially in, but not limited to, remote areas [28]. Another is the deep-seated lack of trust in government. The legacy of the Stolen Generations [29], the large, and growing, numbers of Aboriginal and Torres Strait Islander children placed in out-of-home care [30], and experiences of racism in mainstream services [31] can make people extremely wary of seeking help from such services. Poverty and marginalisation can also impede access to services: even for free-to-access services, difficulties getting to such services can be a disincentive [28].

Aboriginal researcher Scott Avery has highlighted this point in *Culture is Inclusion* [32], in which he reported on interviews with 47 people experiencing disability in diverse Aboriginal communities. His work demonstrates how multiple forms of discrimination can interact and combine to reduce the life possibilities for many Aboriginal and Torres Strait Islanders. He argues that a culture of inclusion helps to lessen the impact of this widespread discrimination in Aboriginal and Torres Strait Islander communities [32].

AUTISM IN ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

Despite growing knowledge of experiences of disability within Aboriginal and Torres Strait Islander communities, there is almost no published research specifically about autism in these communities.

The handful of studies that do exist suggest that Aboriginal and Torres Strait Islander children, young people and adults are often being misdiagnosed or missing out on a diagnosis altogether. For example, two studies focused on the scale of intellectual disability in Western Australia (WA) reported that Aboriginal mothers show an increased likelihood of having an intellectually-disabled child and a *decreased* likelihood of having an autistic child, compared with non-Aboriginal mothers. Living in a remote area further decreased the likelihood of an autism diagnosis. Aboriginal children in WA may be missing out on an autism diagnosis because they have less access to diagnostic services than non-Aboriginal children, especially in remote areas; when they do have such access, they tend to receive a diagnosis of intellectual disability rather than autism [33,34].

This phenomenon, known as "diagnostic substitution" was also reported by a diagnostic review of 14 adult Aboriginal psychiatric patients previously identified with schizophrenia in the Kimberley region of WA. Almost all of these patients were rediagnosed as autistic when a developmental history was taken [35].

These studies suggest that Aboriginal and Torres Strait Islander people might be missing out on a diagnosis of autism or being misdiagnosed with another condition partly as a result of cultural and language factors. For example, differences in the use of eye contact is often a key sign of autism, particularly in early childhood, but the Aboriginal and Torres Strait Islander cultural norm of avoiding eye contact may contribute to diagnostic uncertainty.

Two more recent studies investigated trends in the frequency and age of diagnosis of autism in Australian children aged under 7 years using data from the Helping Children with Autism (HCWA) package [36,37]. The authors reported that 1,500 children or 4.7% of the 32,199 children accessing the scheme identified as Aboriginal and/or Torres Strait Islander. While no differences in the age at diagnosis were found, Aboriginal and Torres Strait Islander children with a less severe clinical presentation were under-represented suggesting, once again, that they might be missing out on a diagnosis.

Overall, the absence of research on autism in Aboriginal and Torres Strait Islander communities is concerning. It means that we lack an understanding of how these communities – urban, regional and remote – perceive and experience autism, the services and supports that they are currently being offered and the services from which these children and families might benefit the most in the future.

This project sought to address these issues.

BOX 1. WHAT IS AUTISM?

Autism is a lifelong neurodevelopmental condition or spectrum of related conditions that affects the way a person interacts with others and experiences the world around them. One in every 70 Australian people lie on the autism spectrum [7,38].

According to current diagnostic criteria [39], autistic people show behaviours or characteristics in two key areas. The first is **difficulties in social communication**, which can include difficulties interpreting one's own or other people's emotions, responding to social cues like taking turns in a conversation, and making and keeping friends. The second area is **restricted and repetitive ways of thinking and behaving**, which can include a preference for particular routines like taking the same route to school each day, intense interests in seemingly unusual areas (e.g., prime numbers, train timetables, drain pipes), "stimming" behaviours like hand-flapping and finger-twisting, and unusual reactions to some sensations (such as the feel of clothes or the smell of perfume).

These features, however, can vary enormously from person to person. They can also change with age, waxing and waning as the person develops. Some individuals may also have an additional intellectual disability, while others will have average or advanced intellectual abilities. For some people, spoken language is limited or absent altogether while for others, speech can be fluent, but their use of language to communicate with others can seem awkward and often one-sided to non-autistic people. Autistic people can also experience additional mental health problems, including anxiety, depression and attentional difficulties [40].

Autism can usually be diagnosed well before the age of 5 years, although this too can vary depending upon available services and other factors [41,42]. Some individuals, especially those with good language skills and of average or above-average intellectual ability, might not be identified as autistic until much later in life. Autism is more common in boys and men, than in girls and women [43], but autism in girls and women might well "look" different, which can lead to many girls and women being misdiagnosed or missing out on a diagnosis altogether [44].

Research has not yet identified genetic or biological signatures for autism. We know that autism is a strongly genetic condition, which can consist of both heritable and sporadic (non-inherited) forms. In some cases, autism might be caused by nongenetic factors, but such instances probably account for only a small minority of cases [45,46].

Although there are many services, interventions and supports available for autistic children and to a much lesser extent, young people and adults, the reality is that many of these approaches have not been rigorously tried-and-tested and, even in those that have, we do not know which approach works best for any individual [47,48]. That said, whether being autistic is considered disabling for an individual can depend in part on the extent and nature of support provided by others – within families, schools, workplaces and communities. This support can include both helping the individual to develop skills and strategies to understand situations and communicate their needs and adapting the environment to enable the person to function and learn within it.

ABOUT THIS STUDY

Our research did not aim to provide a complete picture of the experiences of families with an Aboriginal and/or Torres Strait Islander child on the autism spectrum. Instead, it sought to provide the first account of the in-depth experiences of these families, giving a voice to families that have previously not been heard in autism research. We also sought to identify key areas for future research and practice to support autistic children, young people and adults and their families within Aboriginal and Torres Strait Islander communities.

We invited families with Aboriginal and Torres Strait Islander children on the autism spectrum, who had an established relationship with Positive Partnerships, to take part in the project. Twelve families – including 11 mothers and one grandmother – agreed to tell their stories in the hope of making things better for their children and for other Aboriginal and Torres Strait families.

The 12 families 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. Their autistic children ranged in age from 2 to 22 years (see Table 1).

Each participant took part in a semi-structured interview, conducted wherever they felt most comfortable and was most feasible. For some, this meant coming to Sydney for a few days to speak to researchers, supported by Positive Partnerships and FPDN. For others, it meant speaking to researchers via Internet conferencing or telephone.

During the interviews, we asked people to tell their stories in their own way, focused on their child's early development, their journey to diagnosis, and their experiences of education as well as of other services and supports. We also asked about their hopes and dreams for their child and family and their priorities for future research.

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).

ABOUT THE REPORT

This Report is aimed at Aboriginal and Torres Strait Islander families with a child(ren) on the autism spectrum, and the broader Autistic and autism communities, including autistic people, their parents and carers, and the educators, clinicians and other professionals who support them. It is structured into four chapters and a conclusion.

The chapters present the results from the interviews with family members. In Chapter Two, we report on women's experiences of getting support in the early years for their children on the spectrum, including their varied routes to autism diagnosis. In Chapter Three, we present their experiences of school. Chapter Four describes families' experiences of autism in communities. Chapter Five focuses on families' positive stories about autism and on their aspirations for their children and communities. The concluding chapter summarises the findings and offers recommendations, highlighting key strategic messages.

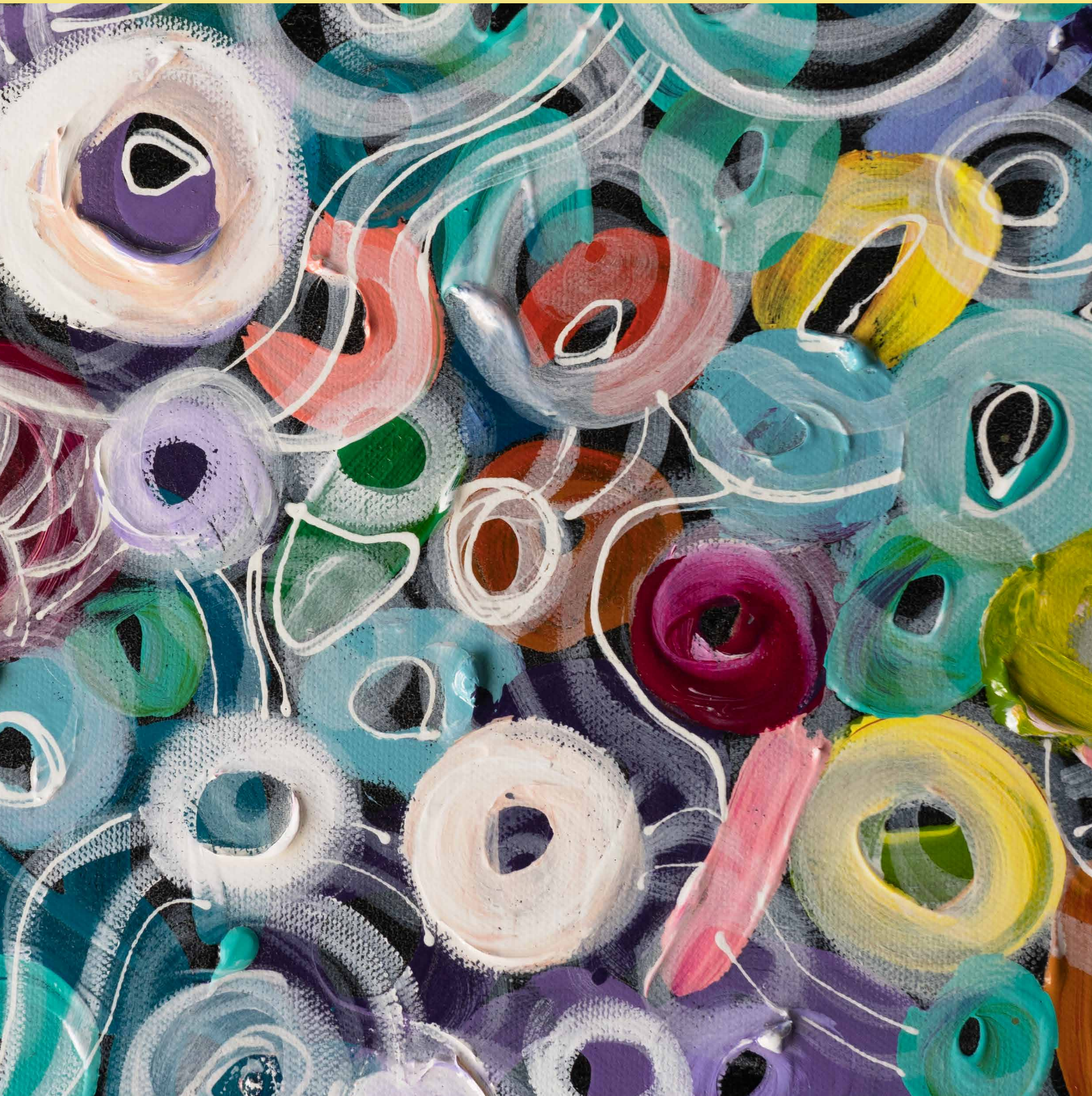
Table 1: Background characteristics of families who took part

NAME†	KIN RELATION	PLACE CURRENT RESIDENCE‡	AGE IN YEARS	NUMBER AUTISTIC CHILDREN	NAME†, GENDER & AGE OF CHILDREN	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	4	Prematurity	Mainstream
					Hunter: 7-year-old boy	3		Special school
					Isaac: 10-year-old boy	6	ADHD	Special school
Ava	mother	NT (ORA, RA3)	30	2	Koen: 5-year-old boy	3	ODD	Mainstream with support
					Tyler: 4-year-old boy	2		Preschool
Alexis	mother	VIC (IRA, RA2)	32	1	Cooper: 13-year-old young man	5	PTSD, OCD, anxiety & mild hearing impairment	Special school
Olivia	mother	NT (ORA, RA3)	45	1	Scarlett: 8-year-old girl	3	Global developmental delay & asthma	Special school
Nevaeh	mother	NSW (MCA, RA1)	39	1	Leo: 2-year-old boy	2	Epilepsy & ear infections	Aboriginal community preschool
Sophie	mother	NT (VRA, RA5)	40	2	Alex: 6-year-old boy	4	Partial chromosome deletion	Mainstream with support
					Warrin: 8-year-old boy	6		Mainstream with support
Sienna	mother	NSW (IRA, RA2)	51	1	Elijah: 22-year-old man	10–11	ADHD	Living at home with no current services; previously support class
Willow	mother	QLD (IRA, RA2)		1	Kai: 9-year-old boy	4.5	Recurrent otitis media	Mainstream with support
Aaliyah	mother	ACT (MCA, RA1)	39	1	Aiden: 12-year-old boy	6–7	Anxiety, ADHD & ear infections	Support class

† Real names are not used in order to protect families' anonymity.

‡ 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) [49].

2. GETTING SUPPORT IN THE EARLY YEARS



GETTING SUPPORT IN THE EARLY YEARS

SUMMARY

Overall, women painted a picture of unmet need, both for diagnostic and post-diagnostic services and support for their autistic child(ren) and families.

- Our participants described varied routes to autism diagnosis for their children or grandchildren. Sometimes mothers became concerned about their child's loss of skills; at other times, women were advised by family members, childcare providers or school staff that their child may be on the spectrum.
- Their accounts of the diagnostic process repeatedly raised concerns about the cost of diagnosis, lengthy waiting times for diagnostic services, limited access to diagnostic professionals, especially in regional and remote Australia, the need to travel long distances for a diagnosis and perceived stigmatisation during encounters with health professionals.
- These factors sometimes led to delayed diagnosis and also increased the likelihood of underdiagnosis of autism in Aboriginal and Torres Strait Islander communities.
- Various concerns arose once children received a diagnosis. Many mothers reported having received very little or confusing advice about post-diagnostic support. They were concerned about long waiting lists for early intervention, the high cost of therapies, and limited availability of therapy services, especially in regional and remote Australia. We also heard about how supports tapered off altogether as their children grew older.
- They acknowledged the important role of federal government support to assist with the high cost of resources, therapies and other services but felt that government funds, including the NDIS, do not fully meet children's support needs.

We began our interviews by asking women about their child and how they came to receive a diagnosis. At the time of interviews in late 2018, our participants' children (16 in total) varied widely in age. One was an adult (aged 22), and two were teenagers (aged 18 and 13). The rest ranged in age from 2 to 12 years. For some mothers, the experience of their child's diagnosis and the emotional effort to come to terms with it was very recent and still quite raw. For others, many years had passed since their child was first identified as autistic.

VARIED ROUTES TO DIAGNOSIS

Women shared valuable insights into their children's varied routes to autism diagnosis.

Two mothers told us that they initially felt concerned when their children lost skills or regressed. Ella said she was the first "to think there might be something going on". Her son Oliver started talking very early and then his speech dropped off after his first birthday. A hearing check revealed he had mild permanent hearing loss and Ella thought this was the likely explanation for his apparent loss of speech. However, she began to think "it could be something else". Oliver had some unusual characteristics such as being absorbed by spinning objects. Ella's partner and her parents were convinced he was just "a late developer". Ella went back to her paediatrician and was then referred to a developmental psychologist. Oliver was diagnosed with autism at 22 months.

“What I found in my journey I guess, in learning about helping or assisting a child who has been diagnosed with a disability, is that nobody actually has a real clear picture of what you need to do. So all of these things I’ve found out myself. … It’s all piecemeal.”

Ava also told us that, of her two young autistic children, her eldest son, Koen’s skills had regressed: “When he turned one, he was saying ‘Mum’. One of his first words was Mum on his first birthday and then about a month later he no longer said it”. An Occupational Therapist saw him and decided to refer Koen to a multidisciplinary assessment team at a public hospital. After waiting six weeks, Ava phoned the assessment team. A psychologist asked her to describe her son. Ava told her about Koen’s frequent “meltdowns” and “how he struggled with change, going into a shop, struggled to leave the shops”. Ava was told she was just not coping well with being a mum and that the assessment team would not review her child. Following that experience, she went to a private diagnostic service.

Other mothers reported that family members initially raised concerns about their children. Sophie has a large family and was concerned about her son Warrin’s lack of speech at 18 months. He seemed different to her other children. These concerns were cemented when a cousin visited whose son had an autism diagnosis. After observing Warrin, her cousin suggested that Warrin reminded her of her own son at the same age. Following that conversation, Sophie sought professional advice about Warrin’s development, which eventually led to an autism diagnosis.

Ruby and her son Noah are Torres Strait Islanders. Ruby took Noah to a hospital on the Australian mainland to have his tonsils removed. There she met with her sister, a school teacher. Her sister was direct with her, saying “Ruby, you need to refer Noah to a specialist because I think he has autism”. Initially, Ruby was “freaked out a little bit” but she sought a diagnosis after her sister explained autism to her.

Concerns were first raised about Olivia’s daughter at family day-care. “She was probably about two when the family day-care provider started mentioning that she might need to be just checked for hearing or something like that, because she wasn’t talking”, Olivia explained. “She was also doing those typical autistic type of traits, so lining things up, playing with her hands”, she added. Olivia had also “observed difference” but “didn’t really want to go there”. After more conversations and observations, Olivia took her daughter to a paediatrician.

A number of other mothers reported that their child’s route to diagnosis was through the school system. Two children were identified as being potentially on the spectrum by their teachers in their first year of school. Alexis and her husband were shocked when their son was identified on his first day. When Alexis talked to the teacher she was told, “I think there’s something wrong with your child; have you thought of autism because I could just see he doesn’t listen; he’s just – no eye contact; he’s none of this, none of that”. Alexis reported feeling devastated. Employed in the health care system, she made an emergency appointment with a developmental paediatrician, who confirmed the teacher’s observations.

Sienna’s son Elijah was not diagnosed until he was in Year 5. Over the years, she had been told he had Attention Deficit Hyperactivity Disorder (ADHD) and Oppositional Defiant Disorder (ODD). Yet, she felt that “there was something else wrong with him”. The family paediatrician disagreed. Sienna then heard a talk on autism at her son’s school. “I sat there and I almost cried”, she recalled, “because I went that’s my boy – that’s what my baby does”. The woman giving the talk suggested that Sienna make an appointment with a different paediatrician in her regional town. Sienna did so and soon Elijah was diagnosed.

Amelia’s son Mason has primary diagnoses of cerebral palsy and epilepsy. He was not diagnosed with autism until he was 16. Amelia explained that she “just left it for years and year and years” because “we were dealing with everything else”. For this family, getting an autism diagnosis has helped to make sense of some of his preferences, including a reluctance to leave the family home.

THE DIAGNOSTIC PROCESS

Our participants also raised a number of issues and concerns about the diagnostic process, which is well known to vary widely depending on where in Australia people live.

The first issue raised was the **cost of diagnosis**. While some families had their children diagnosed through the public health system at no or minimal cost, others indicated that getting an autism diagnosis for their child was expensive and a hardship for families already struggling financially. Due to long waiting-lists of more than 12 months in the public system, Ava, a single mother living in Outer Regional Australia, decided to have private autism assessments done for her two boys. She reported that they cost “a shit tonne of money” – the first was $2,000 and the second $1,300. “It was expensive going private”, she explained, “but we got it done in a timely manner”. Aaliyah took her son to a child psychologist when he was in Year One. The psychologist suggested he had ADHD and Asperger’s syndrome, later confirmed by a paediatrician. She remarked, “for a single mum who wasn’t earning a whole lot, it was an expensive process. You know a couple of hundred dollars for every appointment and then $700 for them to do these specific tests”.

Many women described **lengthy waiting times** for a diagnostic assessment for autism. Nevaeh’s son was identified by a paediatrician. Her family lives in urban NSW but she still had to wait 12 months for a multidisciplinary assessment team to confirm the diagnosis. Other families described having to **travel long distances** to get a diagnosis. Sophie’s family lives in a very remote region of the NT. She was advised that if she wanted a “gold standard” diagnostic assessment, her family needed to travel to Sydney, Melbourne or Adelaide. She opted for Adelaide. The process of getting her eldest son diagnosed took two years. Her younger son was fast tracked because the family was already “in the system”. His diagnosis took one year. Willow commented that her family faced challenges “living in a rural area and having limited access to services or developmental paediatricians”. Her son, Kai, was eventually diagnosed when he was four-and-a-half-years-old – although that could have been much earlier because “he would have met pretty much every criteria”. Willow also expressed concern for other Aboriginal and Torres Strait Islander families in Queensland whose children have not been diagnosed until they are 8 or 9 years old due to **limited access to services and diagnostic professionals in regional and remote Australia**.

Some of the women we spoke to experienced regrets about the relatively **delayed diagnosis** of their children. Willow, for example, wished in hindsight that she had taken the time off work from her job in a regional Queensland town to travel to Brisbane to achieve a quicker diagnosis for her son. Sienna believed that “things would have been different” if her son had been diagnosed earlier, in that he would have received intervention earlier. She described herself as “fighting his paediatrician to diagnose him with something”. When he was finally diagnosed by a different paediatrician, aged 10, it explained many of the everyday struggles she was experiencing at home:

> *Like I knew that there was something else … Like I’d say to him, “Oh, can you help pack the groceries away” and if there was no spot – if there was already a carton of milk in the fridge and it took up that spot in the fridge – he couldn’t understand that the milk could go somewhere else in the fridge. So then he’d just have a meltdown.*

When Sienna finally learned about autism at the talk at her son’s school she felt empowered to act: “I sat there and I cried and I said, ‘thank you, thank you very much’, and now I know what to do”. This sense of empowerment was also confirmed by Ella. She described her son’s diagnosis as “a really scary time” when she felt “a bit panicked”. But then she thought “Okay, no, we just have to do what we can to help him”.

Mothers also sometimes raised concerns about how the diagnosis was communicated to them. Ava was upset that other people had walked into the room while the psychologist delivered her son's autism diagnosis. Ava recalled:

> *She's like, "Oh, they're just my next clients, they're a bit early". Anyway, she keeps talking to me. I was like – like I'm crying and I'm upset and I'm overwhelmed and I can't understand what's going on so I let her just keep talking. When I left there, I was like that's a massive breach of confidentiality. I just couldn't believe it. Yeah, so that was a shock. I didn't go back to her.*

Alexis felt that the paediatrician she saw regarding her son Cooper's autism diagnosis made unwarranted assumptions about her life. After explaining that Cooper had older siblings, the paediatrician assumed they were "half brothers and sisters". When she explained that they all have the same father, he remarked "that's rare these days". Alexis felt that her moral reputation had been called into question.

The mothers and grandmother we interviewed all confirmed the importance of autism diagnosis for their families.

While they often found the process included numerous pragmatic challenges and could also be emotionally gruelling, they saw diagnosis as the first fundamental step in helping their child. Sienna felt diagnosis helped her to understand the way her son thinks. Ava stressed that diagnosis is important for a child's sense of self-identity: "If your kid ever wonders why they were different, why they were teased, why they were bullied, you have an answer for them". Having recognised the importance of diagnosis, some participants were also concerned about **underdiagnosis** in Aboriginal and Torres Strait Islander communities. Sophie, whose work often takes her to remote communities, cautioned:

> *For other families, well they're remote. They literally live out in communities and they may not get seen to or counted – they may not even get assessed. They're completely flying under the radar.*

POST-DIAGNOSTIC SUPPORT

Following the identification of their children with developmental differences, mothers embarked on the process of accessing suitable therapies. As Alexis expressed it, "You name it, we did it and we've been doing it ever since he was diagnosed". Some mothers were advised about what they should do next by the paediatrician or a psychologist who diagnosed their child. Olivia, for instance, reported that their paediatrician placed her in contact with a range of local support providers. Others received somewhat **minimal advice**. The paediatrician who diagnosed Sienna's son gave her two photocopied pages from a book about autism and told her to do her own research. At her subsequent appointment, "we went back, and I said to him, 'Right, I've read this, I've done that, what do I do?' And he said 'There's no manual that comes with kids like this.' He said 'Everything will be a learning curve; it will be a learning curve for you, it'll be a learning curve for him'".

Worryingly, a number of mothers reported that they felt they had received **insufficient or confusing post-diagnostic advice and support**. Olivia summed this up:

> *What I found in my journey I guess, in learning about helping or assisting a child who has been diagnosed with a disability, is that nobody actually has a real clear picture of what you need to do. So all of these things I've found out myself. It's never been handed to – like, here you go, here's some people that can help you. It's all piecemeal.*

Aaliyah commented on the deficit-based approach required by the diagnostic process and also confirmed a lack of post-diagnostic support: "I kind of felt they sort of said okay these are all the things that are wrong with him, now good luck in your journey".

Others pointed to the irony of being told how important it is to do early intervention and then finding that there are **long waiting lists** for therapy services. Nevaeh remarked, "I think my issue is if we're going to talk about early intervention let's have services that don't have people on waiting lists, because to me it's not early intervention if you've got to wait six months".

Some mothers felt entirely unsupported following the diagnosis of their child. Ava commented, “When we got diagnosed, we got given our piece of paper that said he has autism and that was it. And I went what now? What do I do with this piece of paper? So it’s hard, where do we go, what do we do?”

Alexis, too, felt at a loss following her son’s diagnosis and pointed to the challenges of navigating the complex disability system. She described her online research as a source of distress, which stressed the probability of lifelong impairments for her son and provided her with little hope for the future:

> *I walked out of there; I had no one. I had no information, no nothing, so I turned to Google and then you think oh – I was upset because my kid’s never going to have a life, never going to be able to talk and never going to be able to do this or that.*

Sienna gave a sense of the impact of that **lack of ongoing post-diagnostic support** on her own mental health over many years: “Yeah, it took me a long, long time to get there, it took me a long time – there were nights where I would just cry my eyes out because I had no idea what to do with him, because nobody would help”. The negative impact of lack of support on primary carers was corroborated by Evie, an Aboriginal disability advocate with many decades of experience who was supporting Amelia during her interview. Evie expressed concern that there is limited support for Aboriginal and Torres Strait Islander families looking after children with disabilities: “I see a lot of mothers particularly because they’re the main caregivers in this area with what I would call post-traumatic stress. We see that all the time and I can name a thousand families from Wilcannia to the Territories to anywhere”.

THERAPIES

Anecdotally, many Australian autistic children receive far more **limited therapy support** than suggested in research, with speech and occupational therapy (OT) being the most commonly accessed services. This pattern was no different for the families we interviewed.

Some recently-diagnosed children saw psychologists on a regular basis, most often in relation to behaviour support. Only one of the mothers reported undertaking an Applied Behaviour Analysis program, a form of intensive therapy. Layla said that two of her grandchildren, diagnosed with autism at ages 6 and 4, received no therapies at all. She explained that Isaac, diagnosed with Asperger’s syndrome, “wouldn’t participate in it anyway, because of his behaviour and the way he was” while Logan “could talk and stuff, so that was okay with him”. Sienna, whose 22-year-old son is living at home with her and her mother, whom she also cares for, receives no services at all. In fact, none of the family receives any support with Sienna juggling full-time employment and substantial caring responsibilities across family generations. The general picture provided was that all types of **therapy and other types of professional support tended to drop off** as children become older.

A number of women commented on the **high cost of therapies**. Many accessed the HCWA package, introduced by the Australian Government in 2008 to provide support for children aged 0-6 years, to assist with the costs of therapies and resources. HCWA funding was capped at a lifetime total of $12,000 for each child, with a maximum of $6,000 payable in one financial year. Because of these requirements, children who received a later diagnosis of autism sometimes had access to fewer therapies than children diagnosed earlier. Alexis’ son Cooper, for example, was diagnosed just before he turned 6. Approved for HCWA funding, the family only spent $5,000 before he turned 7, making him ineligible for further funding under that system.

While mothers told us that access to HCWA funding was very helpful, they also indicated that it did not cover the full cost of therapies and that they either tried to cover the shortfall themselves or limited the amount of therapy their child received because of those financial considerations.

HCWA clients are now transitioning to the NDIS, which is designed to provide support across the lifespan [50]. Five families in this research were enrolled in NDIS. Others were waiting to apply because the scheme had not yet reached their area or, in one case, had decided not to access the scheme because they did not wish to receive financial help from the government.

The five families receiving NDIS funding gave numerous examples of the scheme **not fully meeting support needs**. Ella said that her son's NDIS funding "only goes so far" and that the family had used their own money to cover the remainder of his speech and behaviour therapy costs: "Whenever we run out, we just pay for it ourselves". She further explained that even though Oliver is non-verbal and requires substantial support, his allocated funding had actually been reduced across two consecutive NDIS plans. Aaliyah, too, reported a pattern of decreased NDIS funding across consecutive plans. Her son Aiden has autism and an anxiety disorder. He has difficulty leaving the house. Aaliyah also has a diagnosed mental health condition. She commented, "We use NDIS, and I have a carer come – it used to be weekly, just spent a couple of hours with him and take him out and do stuff, because I have social anxieties myself. But they've just really truly cut my funding to practically nothing, so I've had to stretch it out to fortnightly now".

Sophie has two children receiving NDIS funding. She reported numerous hurdles accessing advice and funding, partly attributable to "teething problems" with the new scheme in the very remote area in which her family live. Even though her children had funding allocated to them, they were unable to use the funds for a 12-month period because "they couldn't get their system working properly. They had problems with their system for so long that it was just because it was a new organisation, it was a new Department still getting their heads around it. Even when you went into the office, they were like 'can you come back tomorrow?'" She now provides advice to other families of children with disabilities in her very remote town about how to access the NDIS and self-manage their funding.

Amelia mentioned that her 18-year-old son, who has diagnoses of cerebral palsy and autism and also suffers from intense anxiety, has not seen a psychologist in the past year because the NDIS declined to provide funds for that service. Sienna's adult son Elijah briefly attended an NDIS-funded transition to work program in his regional Australian town. But he refused to continue attending because he felt it did not meet his needs, complaining to his mother, "they're boring – they don't do anything new, it's the same thing all the time".

Some participants told us that basic **therapies are simply unavailable** in their areas.

This was especially the case in remote Australia. Sophie travelled 1,000 kilometres every six months to take her boys to therapy services (speech, OT and psychology) in Darwin. She is now planning to move there so that her children can have access to more regular therapeutic support. Ruby flies from Thursday Island in the Torres Strait to Cairns to access support from Autism Queensland. Her son is visited once a term by therapists from the mainland at his Catholic school. Mia, her support person during the interview, who works in the Catholic Education system, explained the situation for Torres Strait Islander families:

> *We don't have much support at home in the community. There's nobody actually here in the region. All services need to be accessed through whoever gets on the plane and that's in dribs and drabs. There's not a person constant here. There's been nobody come into her home. Nobody's been inside her house to sit with family. It's mostly her flying out.*

Concerns about lack of access to therapy services were also voiced by some participants in relation to regional Australia. Sienna said that she "had to do OT with him at home, because there was no OT that would come out to the town that would do anything for him". Willow, who works in the health sector, summed up the **systemic nature of these limitations on the availability of therapy services, especially in regional and remote Australia**:

> *I think with rural and remote this stuff is a massive challenge, whether you're Indigenous or not Indigenous. People are still screaming out for stuff in rural and remote areas. We have a gap. I'm trying to work out what we can do locally here in our community to fill that gap.*

She also pointed to the importance of broader issues when thinking about how to improve access to therapies for families: "It's still about the resourcing and the unemployment and all those other issues going on, the broader issues as well, I think, because if you don't have money, you can't pay to go do your speech once a week or twice a week. You can't take the time off work because you are so busy working".

Mothers told us that bringing up autistic children is often "a hard slog road". Sometimes this was because of the characteristics of the child. But frequently the effort of engaging with bureaucracies or being the child's "case manager" was the source of their exhaustion. Sophie confided, "There are days when I feel like, man, it just seems to like never end; you know going down and talking to therapists and you do get tired". Reflecting back on life with her 22-year-old son, Sienna said: "It was so hard to the point, you know like I'd never give him up, but some days I thought about it and I just thought no, I can't, this is my baby, I can't walk away from him". Olivia complained, "It's like you've got to jump through 20,000 hoops to get the support you need".

They noted, however, that their efforts were not in vain: "Then you see something within your children, whether it's something that they do or say or even reach a milestone, and it's just a reminder to how worth it that all of that effort really is. It is worth it to see your child successful and to reach things". Indeed, all of the women we interviewed saw therapies as crucial for their child's development. As Ella put it, "He would not be where he is today without doing all of the therapies". But they wanted **better post-diagnostic advice**: "If there was something that sort of gave indicators to okay, start here and go to this one and then you've got to go to this one it would help people go, okay that's the process" [Sophie]. Many believed their children needed **more or better access to therapeutic supports**. Ruby wanted more early intervention for her son Noah; Ella believed that "just doing more" therapy would help her son Oliver; Amelia said that her son Mason "needs a little bit more of everything".

INTERACTING WITH HEALTH SERVICES

Many of the children had co-occurring conditions, most commonly hearing impairments. ADHD, anxiety and epilepsy were among the other conditions reported (see Table 1). All of the families accessed varied health services, including Aboriginal Community Controlled clinics. For some children, these conditions necessitated time in hospitals. In the following, we report on some of their experiences with these hospitals and clinics.

Amelia's son Mason, who has cerebral palsy and spent a lot of time in hospitals when he was younger because he had frequent seizures. She described the following stigmatising encounter:

> *One doctor came to me and had a look at his brain. He's got this gap from where he had the bleed on the brain. He asked me – and I put in a complaint given everything he'd done – did I throw him up against a wall?*

Amelia explained that, in a later hospital visit with Mason, she took him to the casualty department with a suspected broken arm. She said the hospital staff "had no idea how to handle him". He was visibly distressed and was crying and swearing. They were sent home with no treatment. Later, it emerged that Mason actually had three breaks in his arm. "When I took him in there, I was the worst mother and he was the worst child", Amelia recalled. Following these experiences, she has become reluctant to take Mason to hospital because she fears a repeat of the same discriminatory attitudes.

Layla agreed: "Once there's been bad experiences, it's very hard to get them back".

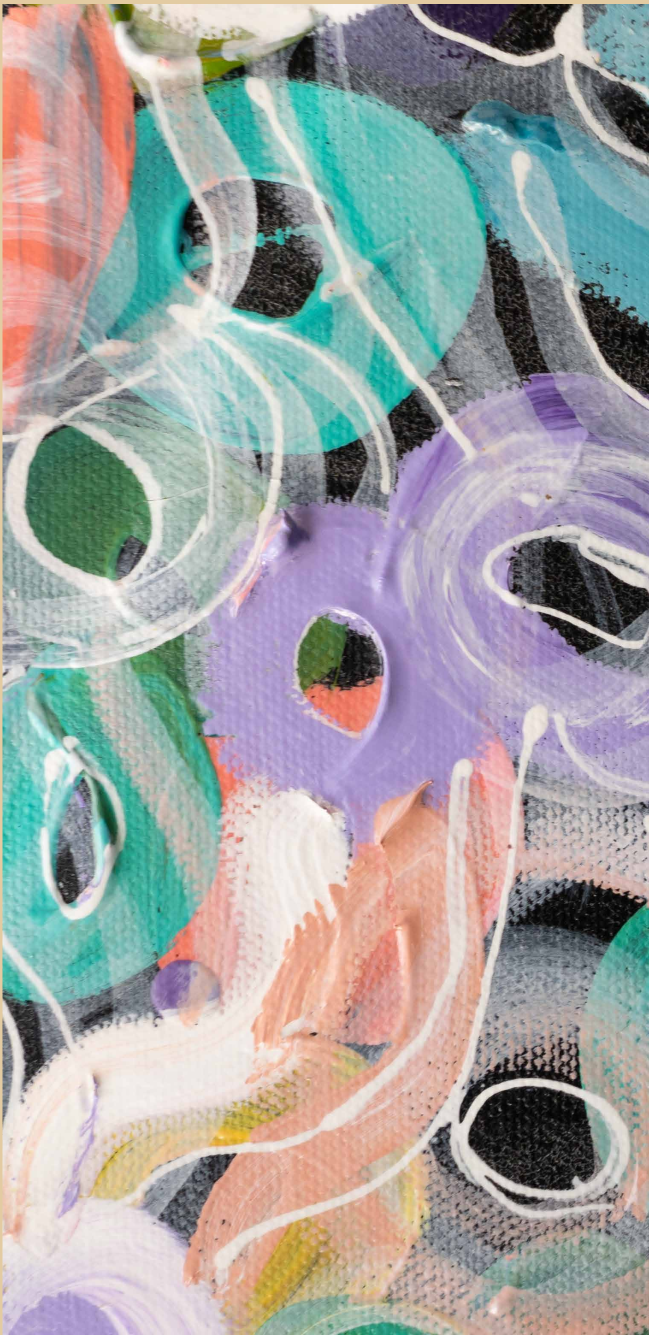
ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES

Aboriginal Community Controlled Health Services (ACCHS) were clearly preferred by the families with whom we spoke. This model of care was developed to better meet the needs of Aboriginal and Torres Strait Islander peoples by delivering holistic and culturally appropriate health care to the community which controls it.

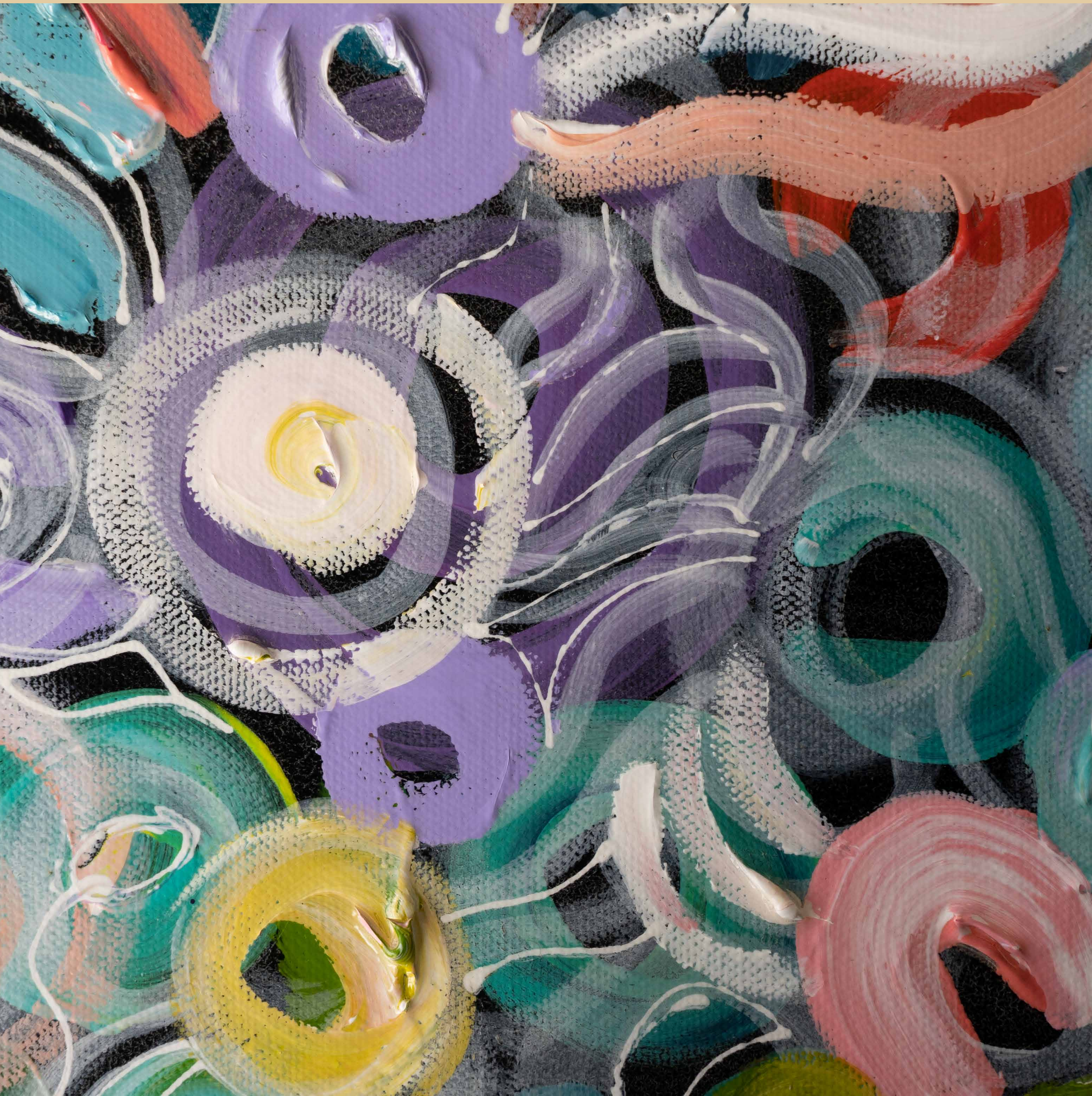
Nevertheless, our participants also suggested that **ACCHS could provide a greater focus on disabilities**. Nevaeh put forward this view:

> *I know that there are services that are around but I don't know about them and I think, well, if I'm a mum of a little Koori fella with a disability and my local Aboriginal Medical Service, which is just around the corner, doesn't have any access for disabilities, I think, what's wrong there?*

Alexis described an incident in her local ACCHS where a child with a disability was told to be quiet by a nurse. She suggested that the clinic needed to make accommodations such a sensory room for children to wait in. She further cautioned that when parents encounter stigma, they can become reluctant to access services as "in our community they're just too ashamed to take their kids anywhere because they run amuck".



3. BEING SAFE, SECURE AND SUPPORTED AT SCHOOL



BEING SAFE, SECURE AND SUPPORTED AT SCHOOL

SUMMARY

In this chapter, we report on women's perceptions of the school experiences of their children.

- Overall, mothers indicated that they had limited choice in their child's school placement. Many of their children had experienced one or more school changes, in which they transitioned from mainstream into more specialised or segregated placements.
- The mothers and grandmother who shared their stories told us about many negative aspects of school life, including bullying, behaviour mismanagement, school exclusion, removal and refusal, mental health concerns and poor home-school relationships.
- Families also reported positive aspects of school life, including the provision of therapies at school, trusted staff (teachers, education support staff and principals) who had experience of autism and worked in partnership with communities, and a range of student supports such as individual plans, withdrawal spaces and small class sizes allowing for intensive instruction.
- Women expressed pride in their children's diverse achievements and wanted schools that keep students safe, respect Aboriginal and Torres Strait Islander cultures and recognise, encourage and enrich student potential.

"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."

BOX 2. EDUCATING AUTISTIC STUDENTS

Australian policy has followed broader international shifts in the education of children with disabilities, promoting inclusive education. All students have the right to receive an education and to be included in their local school.

Students experiencing disabilities, including autistic students, may be enrolled in 1) regular classes in mainstream schools (with or without additional assistance), 2) support classes in a mainstream school, or 3) special schools. When students attend specialised education settings such as support classes or special schools this is sometimes referred to as a segregated placement. These varied options exist in the government, Catholic and independent education sectors. Only local government schools, however, are legally obliged to accept enrolments from students living in their catchment areas.

While all education providers in Australia are committed to inclusion, many autistic students attend either special schools or support classes [51] as do students with other disabilities. Indeed, government statistics indicate that the percentage of students with disabilities attending special schools rather than mainstream schools is actually increasing in Australia [52]. Deciding on the "best" or "least restrictive" placement for particular students is not straightforward [53,54]; it depends on many factors. These include the options available in a local area, professional advice given, student characteristics, as well as family preferences and financial capacity.

In this chapter, family members describe a number of concerning incidents at schools. These issues are not confined to Aboriginal and Torres Strait Islander students. Bullying, suicidality and school refusal, for instance, have all been described in the wider literature on the experience of autistic students in Australia [55]. Further research is urgently needed to assess the full extent of these issues amongst Aboriginal and Torres Strait Islander autistic students.

SCHOOL “CHOICE” AND CHANGE

The children of our participants were enrolled in a variety of school settings in which they reported both positive and negative experiences. Of their 16 children, three were enrolled in childcare or preschool, 12 were currently attending school (nine in primary; three in secondary) and one had completed school. Of the 12 children in school, six were attending mainstream settings with varying levels of support, while the remaining six were enrolled in specialist settings.

Overall, **mothers indicated that they did not feel they had much “choice” in what schools their children attended**. Most children in this study were enrolled in their local government school, either in mainstream or specialist provision. They felt constrained by where they lived (the “postcode lottery”), by financial circumstances and by the decisions of education professionals, which they largely accepted. Ava, for example, told us that the local government primary school her son attends is “a very good public school”. Her children were able to go there because their father lives in the area:

> *We were fortunate enough they accepted us to go there because he’s there. It’s very strictly zoned. But if we were to have put them where we live in a low socioeconomic area, I can’t say we would have had the same results, but that’s the options that we would have been left with.*

Mothers were advised as to whether their children should attend mainstream or specialist settings (“we had the lady come out that said that our children were suited to mainstream”), effectively, as one participant pointed out, “triaging all the children into where they can go”. Another mother described the experience of secondary school transition:

> *Because the schools I know, especially the government schools, like the funding that comes along with the children, and it’s just like well we’re going to put him in here and this is what we’re going to do. There wasn’t a great deal of consultation in regards to what might fit best for him.*

Often mothers felt unable to influence placement decisions. One, for example, was very interested in a newly offered model in her city of mixed enrolment in an autism-specific placement and a mainstream school with students gradually transitioning to full-time mainstream enrolment. But she simply had to wait and see whether her child would be invited to participate: “The woman who visited us, she says what boxes are ticked and whatever else and she probably puts it through and then they look over and they decide”.

Seven of the students currently enrolled had moved schools. While one school change took place to be closer to a mother’s place of work, the remaining six were attributed to either difficulties at a particular school and/or a need for more support. The majority of school changes were from regular classes in mainstream schools to either support classes or, more frequently, special schools. Nearly all were from **more inclusive to more segregated placements**. Mason, for example, initially attended a support class in a mainstream school but then moved to a special school. His mother briefly described the reasons for this change: “Like the school he first started at was hopeless, they were terrible. Couldn’t deal with his behavioural problems at the start because he was a real handful. So we made the decision to send him to a special needs school”. Isaac first went to a regular class in a mainstream school but by the age of 10 had been moved to a government special school followed by a Catholic school followed by an Independent special school. As described by his grandmother, a substantial history of school refusal and other behavioural issues prompted these multiple moves.

Cooper originally attended his local government primary school. His mother, Alexis, said that “the education system failed him”. After numerous difficulties, including discovering that he was frequently excluded from class and sent to sit in the Principal’s office for much of the day, Alexis asked for a second psychometric assessment for her son. Following that assessment, he was enrolled in a special school.

Not all of the children who changed schools moved to a more segregated placement. Kai’s parents moved from regional Queensland to Brisbane so that he could access an early intervention program. After a few years they returned to their home town. As a result of these moves and of unsatisfactory school placements, Kai attended two different government primary schools, was enrolled in a distance education program provided by an Independent Christian school and, at the time of interview, was going to a small rural government primary, which allowed a partial enrolment.

The mothers and grandmother we spoke with did not express any strong commitment to either mainstream or specialist schooling. They were mainly concerned that their children were **safe,**

secure and supported at school and were prepared to try a range of settings to achieve those goals. Alexis explained that when her son initially transitioned to primary school, she "wanted him to be around normal kids; pick up on normal things". "After seeing him every month, every term struggling, he was just too far behind", she decided to enrol him in a special school.

Willow said that she was aware that "people advocate for mainstreaming" but that after some negative experiences in mainstream schools, including finding bruises on her son's arm from being roughly handled by adults, she takes "a different view" and supports the provision of a range of education placements. Aaliyah's son, Aiden, initially went to a regular class in a mainstream school. Now in secondary school, he attends an autism-specific support class. Although the school has encouraged him to transition back to a regular class and his mother thinks he may not be achieving to his academic potential, Aiden has opted to remain in the support unit because "he didn't have the confidence to go". Aaliyah supported her son's decision: "I said you're just going to throw him in the deep end because he's going to sink to the bottom of the pool when he's up against normal children". She explained:

> *I just want him to be a happy, confident young man and just be comfortable with trying things. You know I honestly don't even look at his grades on his report cards. I've said to the teachers that his wellbeing counts for far more than any kind of academic skills.*

This **parental focus on wellbeing** emerged in concerns over whether children were safe as well as adequately supported and genuinely included at school and, conversely, in discussions about danger, inadequate supports and exclusions.

AREAS OF SCHOOL CONCERN

Women raised many negative aspects of their children's and grandchildren's school experiences. We discuss these in turn.

BULLYING

We heard a number of accounts of the bullying of autistic students at school. Some mothers saw bullying as simply part of school life. Sophie remarked: "They've had some bullying but never too bad. But I've always thought that it is important that they learn how to take care of themselves". Alexis said that other primary school students "used to really pick" on her son Cooper: "they bullied him, kicked him and did all of that sort of stuff". She enrolled him in boxing lessons so he could learn self-defence. Layla, too, told us that her grandson Logan was bullied at his primary school by older non-Aboriginal children who would hit him and pull his pants down. His sister, who attended the same school, would try to defend him: "She'd go back at the teacher and say, 'Well, you're walking around the yard here, and you see them, what they're doing to my brother'". Following these incidents, she would be in trouble for her outspokenness. Layla explained that Logan's peers bullied him "because he acted different and he didn't play football or run around like the other kids". Logan "would wait till he got home to actually cry and stuff and say what happened to him at school". For Logan, this meant that he sometimes refused to attend school. According to Layla, the problem of non-Aboriginal children bullying Aboriginal children was widespread in this school and as a result a number of Aboriginal parents had removed their children.

BEHAVIOUR (MIS)MANAGEMENT

Some mothers were concerned that their children had been labelled as having "challenging" or difficult behaviours. This was sometimes the case even when they had never displayed any aggressive behaviour. One of the teachers in Aiden's autism-specific secondary school support unit said to his mother, "We don't know how far we can push Aiden before he will get aggressive". Aaliyah said she "stewed on it because he's never shown an aggressive bone in his body ever. So it was almost like anyone who was in that learning support unit had the potential to display this range of behaviours, which autistic children would demonstrate. And it was just basically an assumption made that if he's on that spectrum then that must be what he is".

Amelia reported that over the course of her son Mason's attendance at a special school she had been constantly telephoned to pick him up because the school could not mange his behaviour. At one point, school staff locked him in the tennis court. There, "he stripped off because he was stressed". When Mason's father arrived and saw his naked son he told the staff, "Don't you ever do that; he's not an animal". Amelia acknowledged that her son could be difficult to manage: "I'm not saying it's easy. I couldn't imagine like four, five boys the same as mine just thrown in together". Nevertheless, Amelia also felt the school had taken little effort to understand Mason's triggers or to implement strategies to calm him down: "Mason loves blankies and if you just go right he's so easy to turn around". For Amelia and her husband, it was this lack of understanding that led to the unacceptable isolation and mistreatment of their son.

SCHOOL EXCLUSION, REMOVAL AND REFUSAL

A number of mothers told us that their children had missed out on significant amounts of schooling due to a combination of school-initiated exclusions, student anxiety, maternal concerns about the impact of school on their child and student school refusal. As Amelia put it, "I kept him home a lot and he did get suspended a lot". Sienna's son locked her out of her car one day because he did not want to go to class.

Alexis removed Cooper from his mainstream primary school at the advice of their paediatrician. He was suffering from intense anxiety and had lost a lot of weight. Before she pursued a special school enrolment for her son, they tried gradually transitioning him back to school with a part-time enrolment. Alexis was informed that Cooper had been absent for 159 days out of 200 in the last school year. This is a complicated case because it emerged that Cooper was the victim of sustained sexual assault over many years by a family friend. This student was also diagnosed with post-traumatic stress disorder as a result of these experiences.

Willow's son Kai was also enrolled on a part-time basis at his local government primary school. His family suggested that he take a break every Wednesday to better cope with the school week. Part-day and part-week attendance arrangements are sometimes perceived to be useful for students with disabilities; mothers sometimes refer to these as "mental health days". Aaliyah also said that her son Aiden benefited from days off "just to sort of recuperate at home".

MENTAL HEALTH ISSUES

There were many accounts of student anxiety impacting on school attendance and overall mental health issues threaded throughout women's stories.

There were some accounts of good whole-school approaches to mental health. Sophie told us that at the school her sons attend in very remote Australia, which has a reputation for being "rough", some of the teachers use meditation, tai chi and aromatherapy to help students focus and keep calm. They also use an OT-developed program called "Zones of Regulation" designed to foster self-regulation and emotional control. This was initially introduced for Sophie's children and then rolled out by the Principal across the entire school.

Disturbingly, we also heard stories about suicidality amongst young Aboriginal students on the autism spectrum. One participant gave a heart-wrenching account of her son's suicidal thoughts:

> *He was at school one time and he wanted to commit suicide – he was, yeah, he was that sad that I had no idea why. But he just said "I want to jump in front of the bus". His teacher rang me; I had to go and pick him up.*

Alexis confided that Cooper recently attempted an overdose using prescription medications. She also spoke at length about the attempted suicide of one of his Aboriginal peers, also autistic, at his mainstream primary school. She said that this child was unsupervised in the playground and attempted to hang himself with a skipping rope. Police were called in and questioned children who witnessed this event, including Cooper, but parents were not informed about this until the close of the school day.

FAMILY-SCHOOL RELATIONSHIPS

Collaboration between schools and families is vital for ensuring the best outcomes possible for all students. Some mothers, such as Ruby in the Torres Strait Islands, reported excellent trusting relationships with their children's schools. Aaliyah, too, mentioned that her son's support class teachers are "pretty good – they email me and tell me how he's going and that sort of stuff". Sophie said she had "a really close rapport" with her son's mainstream primary. Other mothers felt, however, that schools did not listen to them or respect their expertise about their child. For a few, there was a strong sense of poor home-school relationships. This was especially the case when schools contacted external agencies, such as Child Protection, without first consulting with families.

Layla attended some school meetings with her daughter, Hunter's mother. She complained that the meetings were conducted in open areas in front of people walking past, pointing out that this lack of confidentiality contributed to a sense of distrust in school processes and perceived stigmatisation. Amelia felt that school staff did not listen to her often enough in relation to the behavioural management of her son at his special school. Although she identified triggers and calming strategies, staff did not necessarily follow her suggestions. Alexis pulled Cooper out of his mainstream school following the incident of his peer's suicide attempt. In particular, it was the school's lack of communication over the incident, which she felt was traumatising for her son, that upset her: "There was no communication; there was just nothing. They didn't give a shit about us".

POSITIVE ASPECTS OF SCHOOL EXPERIENCES

While participants reported many negative school experiences, they also acknowledged the successes and hard work of many educators supporting their children and grandchildren.

Some mothers indicated that schools were an important resource for their children and their families. In some cases, schools were the only contexts in which children received **therapy services**. Ruby's son, Noah, was visited once a term by speech and occupational therapists from the Australian mainland at his Catholic school on Thursday Island in the Torres Strait. In other cases, private therapists and school-based therapists were described as having good collaborative working relationships. Sophie described how her son's mainstream school and private therapists successfully worked together to create **common goals across home and school environments**. Olivia said that her daughter's special school "brought in a lot of therapies and give me recommendations of things that are working at school too, so that's been really handy". Sharing information across home and school settings and adopting consistent approaches was seen by a number of mothers as leading to better outcomes for their children.

Many participants mentioned the importance of particular school staff in supporting their children. The pivotal role of **classroom teachers** was recognised by numerous families. "If you've got a good teacher, you'll be all right", Sienna told us. Sophie nominated her children's classroom teacher for an award and gave a picture of the diverse needs of the student population at their local government primary school in very remote Australia:

> *She has Alex, but she also has two other children who are further along the spectrum and another child that's in a wheelchair. She is unreal. There's people in the school that know their stuff and they're good at it. They've kept children like my boys quite safe.*

The most commonly mentioned characteristic that distinguished a successful classroom teacher was "lots of **experience** working with kids with autism".

Parents also spoke about the importance of **stability in staffing** arrangements. Having the same classroom teacher over an extended period of time was seen as helping children to learn and to thrive. Amelia said that Mason had the same teacher for the past three years at his special school. She described this teacher as "really good", partly because he treats her son with respect: "He kind of talks to him like he's grown up and tells him about personal space and how he should be a gentleman". By contrast, Sophie's eldest son had four different teachers in one year, which was disruptive to all the students' learning. Maintaining school staff in remote regions was mentioned as a particular challenge.

Ava spoke about the importance of **education support staff** in supporting all of the students in her children's classrooms at their government primary school. She was impressed that they "help everyone in the class" and "will just keep an eye out on them and make sure they're happy and comfortable".

Other mothers discussed the essential role of **principals** in providing leadership and setting the tone for schools. Sophie said that her children's school had a poor reputation but that a new principal was turning that situation around. "School has definitely gotten better", she observed. "It's got a principal now who is putting a lot into the school personally, but into the community as well". This ability to work with the community was seen as essential in this remote region of the Northern Territory.

The positive effects of **individualised plans and specialised supports**, such as sensory rooms and withdrawal areas where students could receive one-on-one teaching, were also mentioned. Alexis believed that Cooper's transition from a mainstream to a special school was in his best interests for a number of reasons. One of these is the **individualised curriculum**:

> *They're all on the same topic but you might have one kid who's brilliant on the computer who can't write; someone might be a brilliant writer; one who can only use a whiteboard. They're all at different levels but they all learn the same topic. I thought how good is that.*

Class size was a common topic of discussion with smaller schools and smaller classes being seen as better for these students. Willow enrolled her son in a small mainstream school and believed the attention he receives in this environment makes a huge difference to his outcomes: “The children are absolutely amazing compared to a larger school. I believe it’s because they’ve got smaller numbers and they can invest that time”. Olivia said her daughter has been “doing great” at her special school “because of the small classroom sizes”. She explained: “The size of the room is about five kids, and the children have lots of different needs, but there’s a teacher and a support officer in all her classes, so that’s really good too because the kids get a bit of one-on-one specialist support”. Alexis, however, said that her decision to enrol Cooper in a small mainstream primary school had not worked. He was still subject to frequent bullying there. Reflecting back on her adult son’s schooling, Sienna mentioned that the support unit he attended in a secondary school was a “small class of probably ten kids at most”. Nevertheless, she believed that students would benefit from having more staff in support classes, especially in managing behaviour.

Although participants often described how their children struggled with the academic demands of school, they also expressed great **pride in their diverse achievements**. These achievements were most frequently mentioned in the context of specialised education settings. Amelia’s son Mason had “ups and downs” at his special school. But she was very pleased that he was now school captain. Hunter’s grandmother, Layla, reported that he was doing well at his special school: “He’s going in leaps and bounds with them, he’s getting awards and everything”. Alexis proudly said that, “All the other kids actually look up to Cooper for help”. Aaliyah was concerned about the behaviours of some of the other students in her son’s autism-specific support class, saying that one student in particular “just sort of goes bananas and swears and throws things and that sort of stuff”. Yet, she, too, was happy that her son has a reputation for being “quite helpful with the other kids”.

Willow summed up the feelings of a number of mothers when she said that the most important factor in contributing to a positive school experience was school attitude, not school affluence. A genuine sense of partnership between educators and families and the development of a school culture where everyone is respected are vital aspects of welcoming and inclusive school communities. She described this as “the people factor”.

WHAT ABORIGINAL AND TORRES STRAIT ISLANDER FAMILIES WANT FROM SCHOOLS

Different families had diverse ideas about education and about the kinds of settings and programs they thought would best benefit their children on the autism spectrum. Nevertheless, there was strong agreement on three issues. The first was the fundamental importance of safety. The second was the importance of respecting Aboriginal and Torres Strait Islander cultures. The third was the role of schools in recognising, encouraging and enriching the potential of Aboriginal and Torres Strait Islander students on the autism spectrum.

KEEPING CHILDREN SAFE AT SCHOOL

Participants shared many concerns about the safety of their children at school. Some students had experienced bullying. Some also wandered or deliberately absconded from school. Sienna was frequently called by her son’s school when they could not find him: “I’d say to my boss, I’ve got to go; he’s done the bolt”. Often, she would find Elijah hiding within the school grounds. When her son finished school, Sienna was relieved because “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”.

Sometimes the desire for safer environments pushed parents in the direction of specialised education placements. For Alexis, one of the attractions of a special school was the much closer supervision of students: “The kids are actually physically locked in their room so they can’t really go anywhere anyway and they’ve always got somebody with them. At his primary school it was open; they could do whatever they liked”.

Aboriginal and Torres Strait Islander students live in communities that may experience high rates of disadvantage and discrimination, which inevitably has an impact on students, autistic or not. As Sophie described, “We had children coming to school, some of them with some extreme and significant physical injuries and others were coming with some very emotional ones. There were kids who were just doing what they wanted pretty much”. In this environment, Sophie is very focused on safety: “I mean it’s not always a good idea or it’s not always safe when the teacher has to lock the door to keep the class safe”. She also pointed out that in her community the needs of autistic children may not receive priority over a raft of other pressing issues, including homelessness, poverty and substance abuse.

Women did not expect schools to address all of these issues. Yet, those that were perceived as working in partnership with communities and as supporting the socioemotional wellbeing of students were felt to be relatively safe environments. That sense of safety was very important to families.

RESPECTING ABORIGINAL AND TORRES STRAIT ISLANDER CULTURES

Women highlighted the importance of understanding and appreciating Aboriginal and Torres Strait Islander cultures, and of respecting their values, beliefs and ways of knowing. Amelia gave a very straightforward example of how ignorance about Aboriginal culture can negatively impact students. Mason was speaking some of his local language, Wiradjuri, at school. His intentional communication was mistaken for "blibbering" because staff could not understand him. Amelia and her support person mentioned that they would like to see Aboriginal culture better incorporated into the special school curriculum, especially when a number of Aboriginal students were attending.

These women also mentioned that schools needed to develop a better understanding of Aboriginal families, especially the role of extended kin in looking after children. Some students have multiple caregivers in extended families. Grandparents may play a major role or even become primary carers. Older siblings, too, often support their brothers or sisters on the spectrum. Women felt that effective family-school relationships are strengthened when family diversity is both respected and valued and efforts are made to engage with and support all family members.

Ava, who lived in the Northern Territory, said it was important that schools could "bend to Aboriginal ways" and understand that "families would drop anything for their culture". Having worked as an education support officer for an Aboriginal autistic student, Ava strongly supported the recruitment of more Aboriginal people into diverse roles at school. As she expressed it: "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".

Olivia, too, mentioned the important role of Aboriginal education support staff and said that school is a less intimidating environment when there are other Aboriginal families there: "It's nice to see another Aboriginal face, especially if it's someone you know, that helps. Yeah. I think it's very intimidating if you don't have people of a similar background because it's all very overwhelming".

Nevaeh's son Leo attends an Aboriginal community children's centre. She stressed the importance of family connections in making the decision to send Leo there:

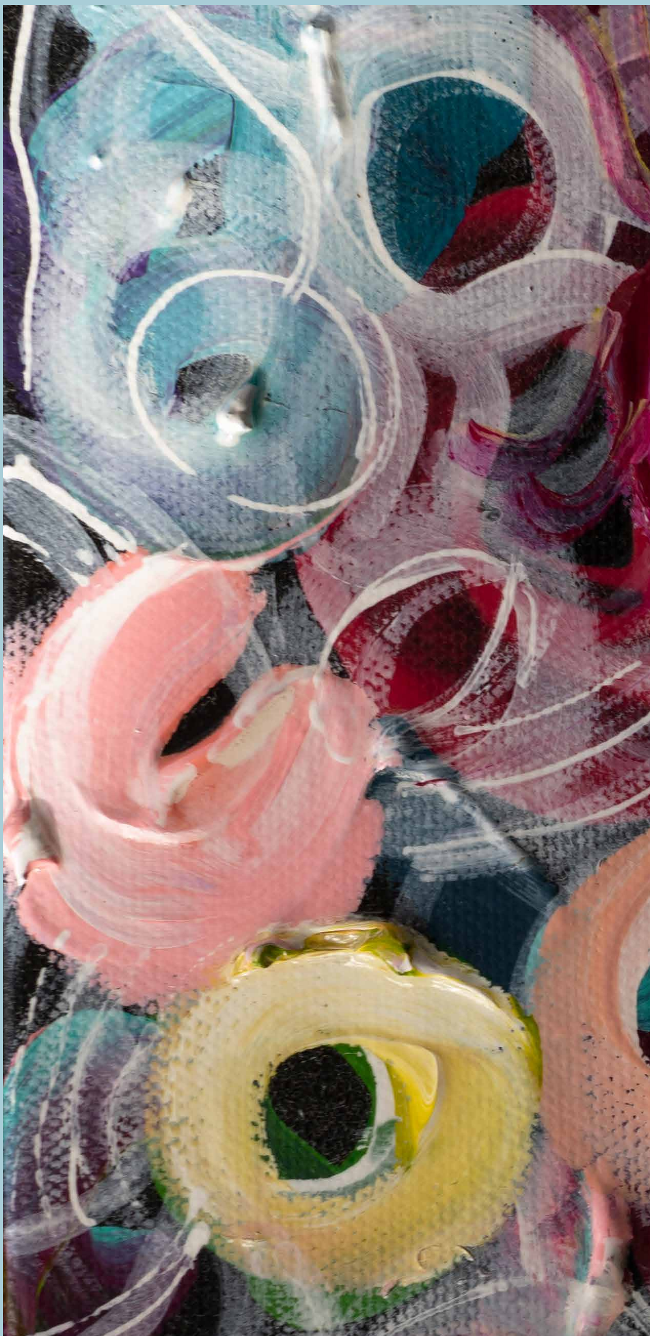
> *My Aunty actually runs it and my niece was the child care worker there so it was a great spot for him to start. So it's very family-orientated; he's got cousins that go there and I like that safety feel. Just the fact that we know them on a real personal front, sending him somewhere like that really made the difference for me.*

RECOGNISING, ENCOURAGING AND ENRICHING STUDENT POTENTIAL

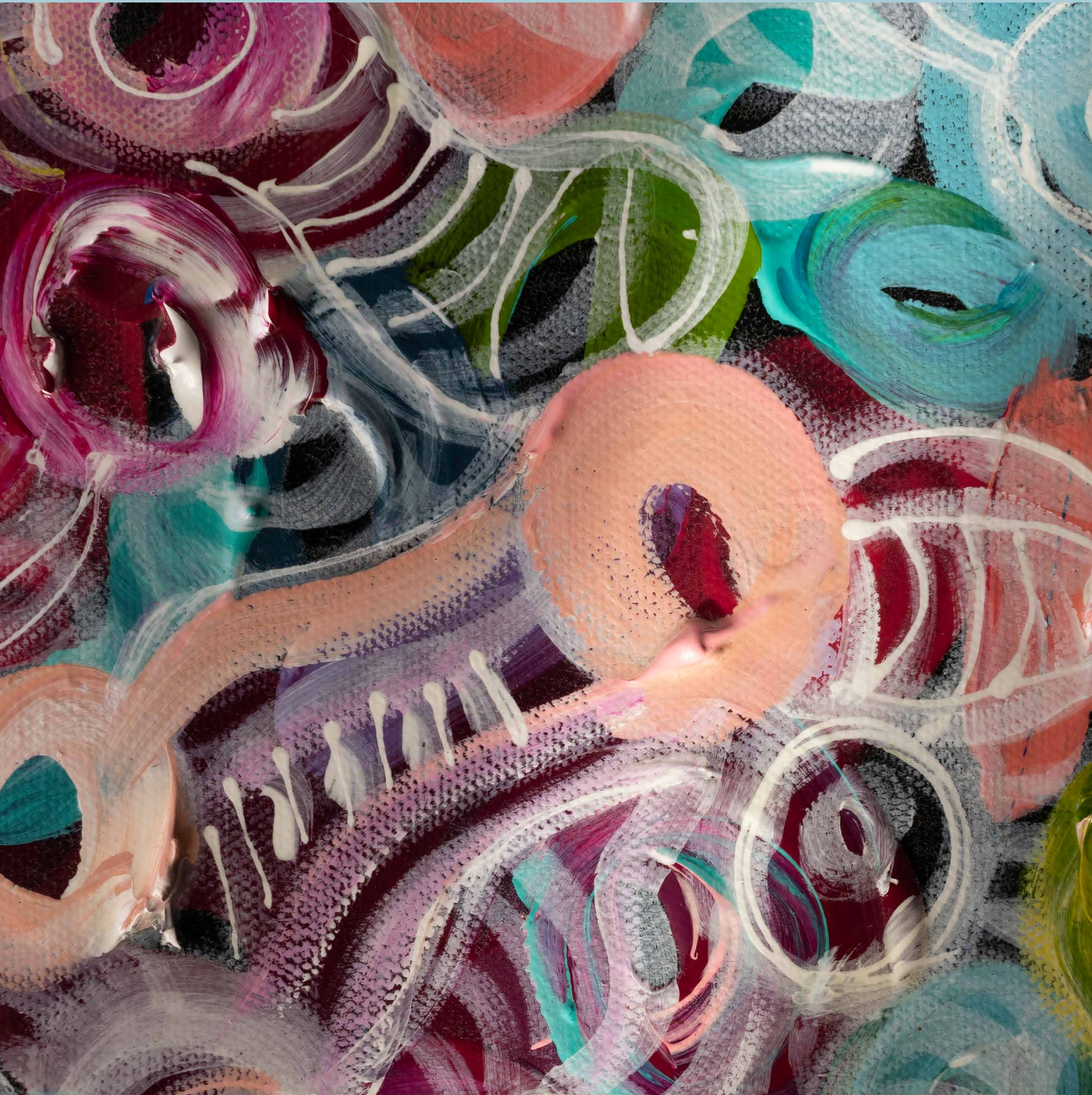
Aaliyah believed her son was capable of more than teachers assumed and that he was being underestimated because of his autism diagnosis. She moved him from his first school because she "felt like they'd labelled him and just put a limit on what his learning would be". Alexis too was very worried that her son had missed out on a lot of education when she found out that his mainstream school had been excluding him from class.

Olivia spoke about her daughter's ambitions to be "either a mum or an airline hostess, or a shopkeeper". She stressed that she thought workplace recruitment and practices would become less discriminatory towards people with disabilities in the future. What is important right now is that her daughter is helped "to grow and develop so that she can live the happiest life she can have". Sophie echoed these sentiments: "I would like for my boys to go as far as they want to with their education".

That optimism was perhaps strongest amongst women caring for younger children. Sienna indicated that she thought it would be unlikely that her adult son would seek employment. Nevertheless, she pointed to his vast general knowledge and increasing everyday living skills with pride: "He's come a long way, a long, long way".



4. COMMUNITY CONNECTIONS AND DISCONNECTIONS



COMMUNITY CONNECTIONS AND DISCONNECTIONS

SUMMARY

In this chapter, we report on women's views and experiences of family and community connections and disconnections in relation to their autistic children.

- Participants told us that autism is seen as something new in Aboriginal and Torres Strait Islander communities. They also told us that traditionally their communities are inclusive, supporting and caring for people with a range of abilities and impairments, and that these inclusive attitudes are common to all Aboriginal and Torres Strait Islander cultures.
- Mothers wanted their autistic children to be connected to their traditional culture and thought that this connection improved the wellbeing of all family members.
- Women described the fundamental importance of family, especially grandparents, in providing emotional and practical support. They mentioned Aboriginal and Torres Strait Islander peer groups, particularly cousins, as providing safe and inclusive relationships in which autistic children are accepted and encouraged to learn. Overall, families were associated with an ethos of mutual care.
- Women were often responsible for explaining autism diagnosis to immediate and extended family members, as well as to other members of their communities. They often expressed concern for the wellbeing of other families of autistic children in their communities. They gave examples of advocacy including establishing informal and formal support networks.
- Participants also gave many examples of disconnection from their communities. They repeatedly pointed to a lack of knowledge about autism in Aboriginal and Torres Strait Islander communities and the implications of this for misdiagnosis and underdiagnosis.
- They also told us about their strong sense of social isolation. Some women said that they found it difficult to talk about autism in their families and communities because of shame and stigma.
- While families are often supportive, mothers did not want to have to rely on them all the time. They also wanted professional support and services for their autistic children and their families.

“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’. There’s no autism because we’ve not grown up with ‘that child has something’. It’s ‘oh, that’s your cousin’.”

MAKING CONNECTIONS

UNDERSTANDING AUTISM

A number of participants described autism as something new in Aboriginal and Torres Strait Islander communities. Ruby’s son Noah, for example, is the only child with a diagnosis of autism in their outer island community in Torres Strait. He is also the only student identified as autistic at his school on the main settlement, Thursday Island. Mia, a local education officer who was supporting Ruby during her interview, explained that developmental disabilities commonly diagnosed in mainland Australia were unheard of until recently in this very remote part of Australia:

> *Ruby and I both grew up in the outer island community. These are the kinds of things that we never grew up with. We don’t know of autism, Asperger’s, Down syndrome. We didn’t see that during our childhood. We actually don’t recall any child having those behaviours. So this is something new for our communities and our communities are at that real rudimentary level of not knowing anything about it.*

Mia reasoned that because there are no traditional medicines for autism, “it’s something new that came about because we’re living this new life in the Western world”.

Layla is a respected elder in her regional Victorian community. Thinking about her three autistic grandchildren, she reflected:

> *We lived in the bush and in a tin shed. There was seven of us living there, with Mum and Dad, at a riverbank. Then we moved into the outskirts, and Mum had twins, and then into town, but we didn’t have much schooling back then. Growing up around there and then moving to this town when I got married and stuff and had my own children – nothing. Nothing like this. Is it this generation that it’s coming out? I’ve never seen it within our community. In my time, and with my kids, never.*

Participants also told us that Aboriginal and Torres Strait Islander cultures are traditionally inclusive. Mia, for example, said that Noah is recognised as “different” in his community. But “we don’t actually have labels and in the Western world you’re actually putting a label on a specific condition”. Ava made a similar point: “It’s only when they’re put into Western standards that there’s judgment – school settings or sporting settings where there’s other people dictating it or you need to be at this level, you need to be able to do this and that”. Disabling attitudes, Ava suggested, are tied to institutions such as schools that operate on the basis of standardised ideas of typical childhood development.

Other participants believed that autism is part of a long tradition of accepting and valuing developmental difference in Aboriginal communities. Olivia's work takes her to remote settlements in the Northern Territory. Talking to people in remote settlements about her daughter's diagnosis led her to the following conclusions:

> *I've heard little stories from community members about people that they felt that were autistic were actually like medicine men, or healers and things like that, and I'm like, wow, so people used to look at autistic children kind of like seers. Really interesting stuff I've heard. 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.*

Olivia believes these remote communities provide a positive model of inclusion from which mainstream Australian society could learn: "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".

Nevaeh, who lives in urban New South Wales, confirmed this idea of traditional Aboriginal communities as inclusive as well as recognising that the labelling and medicalisation of difference can be stigmatising:

> *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 wish it was still like that. They have their little ways and stuff like that and no one really thought too much more about it – more that it was like personality traits of someone rather than it's attached to this whole spectrum of autism.*

Aaliyah mentioned that members of her extended family in Queensland questioned her son's diagnosis, highlighting the negative consequences of being labelled autistic:

> *You know 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".*

CONNECTING WITH CULTURE

Willow gave an interesting account of how her family creates a bridge between autism diagnosis and Aboriginal culture by incorporating cultural elements into her son's therapy: "we use our culture with Kai to do autism therapy". One example she gave was of "getting out on Country" with her son and telling traditional stories, which she described as "healing". Willow categorised this as OT because it calms her son down and helps him to self-regulate. Because Willow's son also has Māori heritage, he learns aspects of cultural practices of the First Peoples of Aotearoa/New Zealand as well, including the ceremonial dance, the haka. Willow mentioned the recently coined Māori term for autism, Takiwātanga, (tōku/tōna anō takiwā) 'my/his/her own time and space' [56], as an example of how core Māori values support inclusive attitudes and practices towards individuals on the autism spectrum [57]. She suggested that these inclusive attitudes to autism are fundamentally similar among First Peoples in Australia and New Zealand: "The people – with my husband and with Kai – the Māori people are very similar to blackfellas in that the kids still do all of the cultural stuff. It's very inclusive, very supportive".

Other participants also stressed the importance of connecting autistic children to their culture. Layla described how she encouraged a sense of Aboriginal identity in her grandson, giving him books about Aboriginal culture and his own Aboriginal flag. Alexis had previously been involved with a Homework Club that taught the local Yorta Yorta language to students at her son's mainstream primary school. She said that if she ever won Lotto she would establish an Aboriginal school for students with disabilities to "teach our culture".

FAMILY CONNECTIONS – “WE LOOK AFTER OUR OWN MOB”

Participants often mentioned the importance of family in providing them with practical and emotional support. They also sometimes described family members as developing special bonds with their autistic children. Nevaeh, her partner and child moved back in with her parents following her son’s diagnosis. She said both of her parents are a “massive” support. She also outlined the close supportive relationship between her father and her son, Leo:

> *My Dad is one of Leo’s favourite people in the world. They just play games all day. So after my partner and I are finished with him for the day and we’re spent, someone else is there playing more games with him and encouraging him to talk and all of those kinds of things.*

Sienna has been living with her mother for decades. During that period, her mother developed cancer and Sienna now looks after her. Sienna affectionately described the way her mother cares for her son, Elijah, including the extra attention he receives compared to his siblings:

> *My Mum spoils him rotten. Well, actually, his middle name is the Golden Child because he just gets everything he wants. Mum makes sure of that. Yeah, like he’ll go “Nanny”, and she goes “What do you want my darling?” “I’m hungry”. So she’ll jump up – this was before she got really sick – she’d jump up and she’d cook him bacon and eggs. Yeah, and the other pair would come along, “Nan we’re hungry”. “Yeah, you know where things are”.*

Sometimes grandparents were described as having struggled to accept the validity of autism diagnosis; this was interpreted as part of a loving orientation towards their grandchildren. Olivia said: “My mother is pretty old-school, and she’s like, ‘Nuh, they’re right’. She doesn’t care, like as in she doesn’t treat them all any different at all; they’re all still her grannies”. Ava lives in an extended family with her mother, her three children and her sister. Her mother was initially very worried by the diagnosis of two of her grandchildren but became more accepting as she learned more about the diversity of autism: “When they first found out, Mum was like ‘eek’ but that’s because she was still set in her mind on the 1950s with the stereotypical type of an autistic child. Then she learned that there was levels and a spectrum. Now she understands it and she gets it”.

Peer groups of cousins were repeatedly singled out as providing supportive, inclusive environments for play and learning for children. Layla said her grandson Hunter “loves coming around and playing with the other kids”. She described how he “cuddles and grabs and hugs” the other children and “follows them around and wants to do stuff, so there’s that connection”. Amongst Layla’s kin, these peer groups usually included more than one autistic child who were related to one another.

Ava explicitly contrasted the way children are negatively labelled at school as “different” or “weird” with the inclusiveness of peer groups of Aboriginal children:

> *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. It’s such a different way of thinking and it’s so much more positive. 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”.*

Olivia offered some insight into the ways in which adults encourage their children to be both protective of and inclusive towards other Aboriginal children:

> *They’re very good with their kids too, ensuring their children are really accepting and supportive of Scarlett too. So Scarlett’s social group is all her cousins, of which there are many. All the children have this patience with her. I think it’s because the parents have been really accepting, and are you going to look after her, she’s your cousin, blah, blah, blah. I think the kids have all taken on that look after Scarlett approach. Does that make sense?*

Willow described similar peer group dynamics, focused on protection and inclusiveness, in the context of school, in relation to her son, Kai:

> *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. He might not be able to understand, but it’s really interesting that actually they take him and they do stuff with him.*

Participants also repeatedly described how their children were looked after by other Aboriginal or Torres Strait Islander students at school. Although Ruby was worried that her son isolated himself from other students, partly due to his sensitivities to noise, she also said that at his school on Thursday Island "they all take care of him in his class". Sophie, too, described her son's peers at their local school in very remote Australia as "quite protective". Ava was pleased that her child was one of a handful of children in his class invited to a birthday party, remarking: "So I think it's the same goal as any other parent – you want your kids to be happy; you want them not so much to fit in but to find their friends and to find their little people, their little crew".

Layla reflected on the importance of family and of an ethos of mutual care. "It's very hard to know" whether autism had existed in the past in traditional Aboriginal communities, she said, "because our elders and family from generations have all gone now". She continued: "There's never been any history kept or stuff like that. All we were told is, we look after our own mob".

Seven of the 12 participants in this research reported multiple diagnoses of autism in their extended families. "A number of my first cousins have children who have autism on various scales", Olivia told us. For some, this provided a sense of connection. Nevaeh has cousins on both sides of her family who have autistic children. One of these cousins recently confided that the school thinks her son is autistic. Because they are "in this real similar spot", Nevaeh now messages her every second week or so to ask how the family are doing. "It's good to be able to share something with people about it and she shares the same fears for him. It's cultural, like connecting with people, but it's just a human thing as well".

COMMUNITY CONNECTIONS

Once their children were diagnosed, mothers usually took on the task of explaining the diagnosis to immediate and extended family members, as well as to other community members. Ruby finds it better to disclose her son's diagnosis to people he comes into contact with and to explain that he has a delay in his communication skills so that they can make any adjustments and understand his preferences. When Noah stays with his grandmother or aunties and uncles, Ruby writes down "what he can and can't do, what he likes and his dislikes" so that they can look after him better. Ella, too, said that she had to explain autism to family members, some of whom were sceptical about her son's diagnosis, saying that "it's just a phase" or "he'll grow out of it". She and her partner do their best to educate others about autism by explaining that he is "wired differently and that he has a speech and language delay and he needs to do things to help keep him kind of calm and deal with all this outside stuff in the world". They also explain that everyone on the autism spectrum has different capacities and challenges.

Ava also mentioned that many relatives told her that her children would "grow out of it". She said she was tired of "dealing with the stupidity that will come from their mouths" but that she was "fine with people that don't understand it, as long as they want to" and that she tries to teach them. When Sophie first started informing family members and friends about her child's autism diagnosis, they invariably told her they were very sorry. She would reply to them: "Why? He's not dying; he's just a little bit different. He learns differently and he sees the world differently; it's nothing to be sad about".

Listening to these women, we were very struck by the strength of their concern for other families of autistic children in their communities. Some were worried about their own extended family members. Olivia, for example, said that she has "plenty of family members who have children with autism" who are unaware of their entitlements to services and supports: "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".

Others became concerned for other families in their own communities. Sophie reported that once she had "figured a lot of it out myself" she then "tried to help some of the other parents in town". Emphasising that "there isn't a lot of education or understanding or awareness, particularly with Aboriginal families about autism", Sophie told us that she has a 33-year-old nephew who is "quite far along the spectrum". When she was growing up, she explained, "we never knew what was going on with him". She was in touch with his family again recently and found out that he had an adult diagnosis of autism. Even though he is unable to live independently, the family has no formal supports. "We just look after him as a family", she was told. Sophie encouraged them to apply for services.

Alexis' concern that other families of autistic children in her region had "nothing in place" and "no supports or anything like that" made her take action. Alexis did not want other families to face the same lack of basic information that she had when her son was diagnosed. She has collected resources about autism that she distributes in her community. She also started a local autism support group for parents that now has more than 30 Aboriginal families as members. Alexis described her advocacy efforts like this: "We're trying to get it out there to the community this is what it's about. Our kids aren't naughty kids". Willow also pointed to the limited support available to parents in her region. In response, she has set up a small informal telephone network to help families.

DEALING WITH DISCONNECTIONS

Participants repeatedly told us that there is a lack of knowledge about autism in Aboriginal and Torres Strait Islander communities. As Sophie put it, "there's a lot of parents and people in the community becoming more comfortable in hearing the term autism and knowing that it's around, but what it is, what the signs and symptoms are, they'd have no idea".

Some women pointed out that this lack of knowledge may lead to misdiagnosis with other conditions such as ADHD, ODD or FASD. Others raised the issue of underdiagnosis of autism, especially in remote communities. Sophie said: "I think about my own family – my own traditional family. They wouldn't 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". She was especially concerned about families who live in remote communities.

We also repeatedly heard stories about the ongoing social isolation of Aboriginal and Torres Strait Islander families supporting autistic children. That isolation occurred for a number of reasons. Some women mentioned that their family found it very difficult to go out because their child preferred not to leave the house. Layla, for instance, said that her grandson Logan simply "won't leave the house". Alexis summarised what she sees as the prevailing attitude of parents of Aboriginal autistic children in her area: "They don't take their kids anywhere. They leave them home because they run amuck".

Layla also said that her other grandson Hunter "never goes out to the shops or nothing". This was related to both difficulties in managing him in unfamiliar environments but also because of the family's fear of what others might think. If Hunter's mother takes him to the city, "she tries to get somewhere where it's not a lot of other people" as she is concerned about how people will respond to his behaviour. "He runs around playing and he screams out, in circles and stuff, because he can't talk; he laughs loud, and stuff like that", Layla explained. Ruby discussed some of her family's difficulties participating in Torres Strait Islander social life, especially culturally important Tombstone Openings in which engraved headstones are unveiled, accompanied by feasting and traditional dancing. She simply said "It's hard to go. If we have family gatherings, whether it's a birthday party or Tombstone Opening, sometimes we don't go because people can't connect with Noah or communicate with him".

This sense of having limited options for social contact and support was especially strong for women looking after their adult children. Amelia's son Mason is 18. She told us that his preference is not to leave the house. This has led to a situation where Amelia and her husband "can't go anywhere together". As her support person, Evie, said, this leaves all of them "stuck in a house". Sienna is supporting her 22-year-old son. After school finished he briefly attended some transition to work programs but he then withdrew from them. He now spends his days at home with his grandmother while his mother works full-time. Juggling multiple caring responsibilities and work, Sienna offered a vivid picture of a socially restricted life: "I have no idea like what they offer out there, like out in the town, because I'm not into everything. I just go about doing my stuff, go to work, come home, yeah, cook, clean, feed, that's it".

Some women described experiences of difficulty and discomfort in talking about or acknowledging autism in their communities. They frequently used the word "shame" to describe these feelings.

One of the consequences of shame is silence or just a reluctance to discuss other people's difficulties. Ella gave an account of how the connection between shame and reticence became apparent to her after her son's diagnosis:

> *Then when I did kind of start talking to my friends, I was finding out 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.*

Alexis explained that parents are sometimes reluctant to take their autistic children out because they will be perceived by other members of their community as "bad kids". She described this as a "shame job".

Olivia gave a lengthy account of the emotional dynamics that can inform shame around disability in general and autism in particular. She said she "knew something was up" with her young cousin, later diagnosed with autism, because when she walked into her uncle's home the entire house was covered in texta scribbles at eye level:

> *So I was like, there's something wrong here, but I never said anything, and he never said anything. We never said anything, nobody said anything. … So we sort of just pretended it wasn't happening. I think that's what it is, no one wants to make you feel like there's something wrong with your child, and then you don't want to say anything. So I think it is a bit of shame job.*

Olivia told us that amongst her family people have "no problem" with physical disabilities. Shame, she suggested, is confined to invisible disabilities, like autism.

Neveah, on the other hand, explicitly rejected any connection between autism and shame in her community. She asserted, "As Kooris, I don't think that we ever look at anybody who is not doing good and feel ill or bad or shame about them". She also added, "But then maybe still in that sense we don't talk enough about what we're supposed to do to help either".

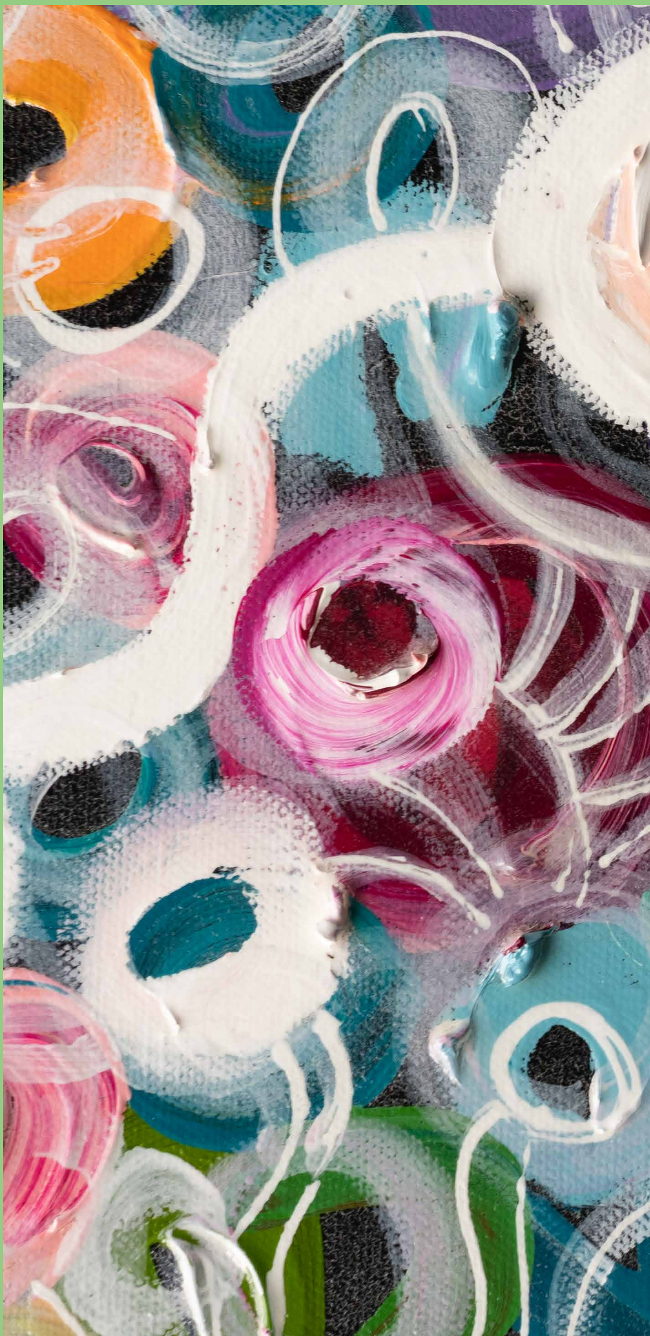
These women clearly had varying experiences in their communities. Nevertheless, a strong picture emerged of a reluctance to openly discuss autism or acknowledge that family members have autism diagnoses. One of the difficulties in encouraging a conversation about autism is that autism is sometimes perceived in very stigmatising and negative ways. Aaliyah referred to this everyday stigmatisation of her son when she said that amongst her relatives, "there was really the perception that if you're autistic you were stupid and you didn't have any social skills. They didn't sort of get that he learns differently and that he can be just as clever".

An emphasis on family solidarity and mutual support helps to ease some of the isolation and stigma experienced by the women with whom we spoke. Families were often seen as supportive. Nevaeh, for example, said "We don't let him go outside the family very often because everyone knows him in the family and knows his triggers and stuff like that". At the same time, there are limitations to this family support. Aaliyah, for example, moved interstate with her son after accepting a job offer. They have no family or connections where they currently live. Amelia is partly reliant on her eldest daughter to provide support, especially when she is hospitalised for epilepsy. However, she anticipates that her daughter may find full-time employment soon and be unable to care for her brother while her mother is in hospital. Ella lives close to her parents who have been "really great" but indicated that due to age and health issues "there's only so much they can do".

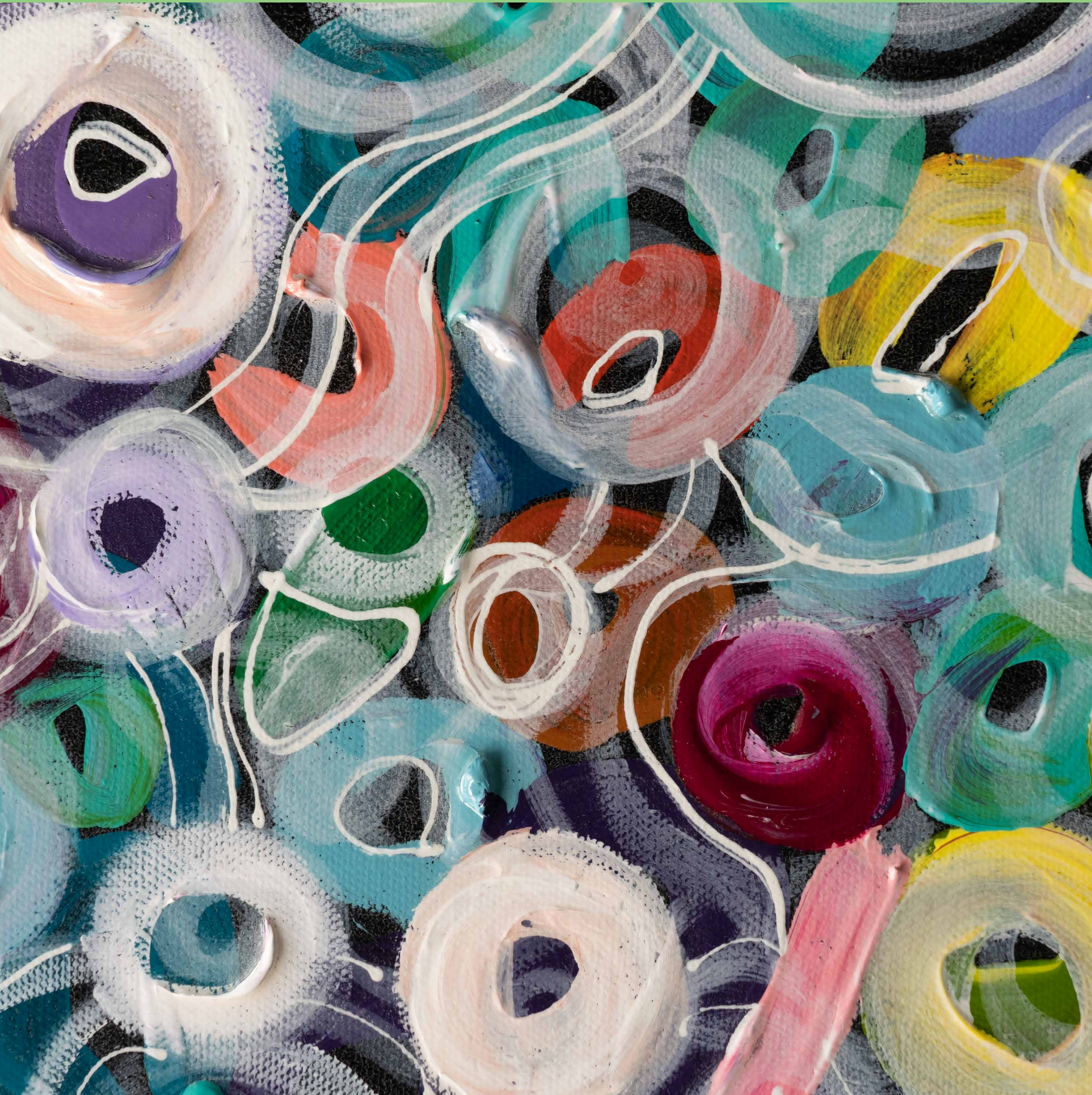
Sophie summed up many of the issues surrounding reliance on family support:

> *My family is spread out all over the Northern Territory and all along the east coast of Australia. It's the same with their Dad. So we've still got a lot of family around us. But the thing is, you don't want to always have to rely on your family. 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.*

A number of women mentioned that without sufficient support, they feared autistic children might end up in out-of-home care or, eventually, in the criminal justice system.



5. CELEBRATING CHILDREN, FORGING POSITIVE FUTURES



CELEBRATING CHILDREN, FORGING POSITIVE FUTURES

SUMMARY

- Women were proud of their children’s progress and the positive impact that their capacities and talents had on their and their families’ lives.
- While women told us about how challenging it can be caring for an autistic child, these challenges were most often caused by others’ lack of understanding of autism.
- Forging positive futures for their children and families required health professionals, service providers, educators and policymakers working together, in partnership, with communities.
- The kinds of research and practice that they prioritised for their children and families, included:
    - more information about autism in Aboriginal and Torres Strait Islander communities
    - better support for parents and carers
    - improved access to flexible supports and services across the lifespan
    - more Aboriginal and Torres Strait Islander personnel in health, education and disability services
    - enhancing children’s right to their cultural identity
    - feeling safe and respected when interacting with services and institutions
    - hearing more Aboriginal and Torres Strait Islander voices and experiences in autism research.

Our participants made many suggestions as to how life could be improved for their children, themselves and other families. This final chapter is oriented towards the future. It details the concerns and hopes of participants about their children’s and families’ futures.

CELEBRATING CHILDREN

The women we interviewed were often very positive about their children, focusing on their capacities and abilities. They celebrated their children’s unique personalities, describing them as “happy and bubbly and adventurous”, “charming and friendly” or “very caring”. Often, they were surprised by their talents, including “the way they pull apart things and put them back together without any help” or answer 95 percent of quiz show questions accurately.

They were also proud of their child’s progress. Amelia commented that her son defied the prognosis of doctors: “They said he wouldn’t talk and he can talk, talk, talk, talk”. Willow, whose son excels at art, remarked, “Autism has really a lot of beautiful gifts”. Sophie stressed that her sons “do see the world differently” and she finds that difference a source of great pleasure.

While women told us about the many everyday challenges they face, such as toileting or picky eating or meltdowns in public places, most of the difficulties and stresses they spoke about were caused by their interactions with other people, services or institutions, not by their children. Even in the face of repeated difficulties and hardship, these mothers demonstrated remarkable resilience. As Ava put it: “People will ask me ‘how do you do it, how do you get by?’ and my answer is normally ‘I don’t have a choice’. It’s just what we do”. They also demonstrated a determination to help and support their children. Alexis spoke for all the women we interviewed: “I’m trying to give my kids the best life”.

“I’m trying to give my kids the best life.”

We asked participants what their hopes are for the future. Some concentrated on immediate objectives, such as that their child who currently doesn’t speak might one day say a few words. Others focused on wellbeing, on their child’s participation in and enjoyment of life. Some imagined a future in which their child was driving a car or living entirely independently. Others anticipated that their child would find employment, as long as their skills are identified and channelled, and opportunities are made available. Whatever their aspirations, every participant was concerned as to whether their child would be supported and looked after when they were no longer able to take care of them. As Ella confided, “It keeps me up at night”. Layla described having “something in place” for when “we’re not around” as “the big dilemma” that all families of children with disabilities face.

FORGING POSITIVE FUTURES

Participants had different ideas about how to create positive futures for their children. All agreed that anyone who wants to contribute to that vision of a positive future for Aboriginal and Torres Strait Islander autistic children needs to work in partnership with communities. Mia spoke about this in the context of Torres Strait Islander communities. She complained that, “They come, they dump their information but there’s nobody here to carry it on and then they go away again. It can’t be somebody coming in and telling us; it’s got to be somebody working with us”.

Families felt that much work remains to be done to foster genuine partnerships with Aboriginal and Torres Strait Islander organisations, community leaders, families and autistic people, with broader and more sustained consultation required to identify areas of greatest need and community priorities.

Nevertheless, families did share examples of good practice. These included the efforts of **state and territory-based autism organisations** to provide information, advocacy and advice, as well as diagnostic and early intervention services. This was especially the case for families living in very remote Australia who often relied on these organisations for help and support. Ruby, who lives in the Torres Strait Islands, accessed Autism Queensland by flying to Cairns; Sophie, who lives in a remote part of the Northern Territory, has been supported by Autism South Australia. Families in regional and urban Australia also used the services of state and territory autism organisations. Willow, for example, enrolled her son Kai in Autism Queensland’s Early Intervention Program, even moving her family from a regional to an urban area in order to access an extra year of this support.

In the context of schooling, women also mentioned the national programs and workshops supporting Aboriginal and Torres Strait Islander autistic children offered, since 2008, by Positive Partnerships.

BOX 3. POSITIVE PARTNERSHIPS

Positive Partnerships is a national project funded by the Australian Government Department of Education and Training. Their goal is to improve the educational outcomes of school-aged students on the autism spectrum.

Positive Partnerships works with schools, communities and families across Australia providing workshops, webinars and online learning. Their programs and resources are delivered by Autism Spectrum Australia (Aspect).

Positive Partnerships has a strong track record of working respectfully and appropriately with people from diverse backgrounds. In particular, they have focused on establishing relationships with Aboriginal and Torres Strait Islander communities. In partnership with various organisations, including First Peoples Disability Network, they have developed resources about autism designed specifically for these communities. These resources include a range of information sheets or ‘talking points’, a series of storytelling animations, a storybook for younger children as well as a booklet featuring the stories of ten Aboriginal and Torres Strait Islander families with children on the autism spectrum.

All resources can be accessed via their website.

PRIORITY AREAS

As part of our research, we asked families what they wanted and what might help their autistic children. The responses we received were grouped into the following seven priority areas:

More information about autism in Aboriginal and Torres Strait Islander communities

Participants repeatedly pointed to a lack of knowledge about autism in Aboriginal and Torres Strait Islander communities. They were concerned about the lack of clear, accessible information available about autism in their communities and believed that this contributed to the stigmatisation of autistic people and their families. As Ella said, “there’s not enough understanding about what autism is”. Layla, too, spoke of the urgent need to “put awareness out there”. Ava confirmed, “even in schools, in childcare, there’s just no information anywhere. Kids are getting missed, you know, slipping through because some parents are in denial or parents don’t know what help to get”. Referring to the increase in autism diagnoses, she continued:

> *If people knew there’s more things out there for parents and stuff and what’s available it would be good because we’re not told about enough and there’s not enough education. Even for people that don’t have autistic family members, there’s still just not enough awareness that this is becoming a very normal thing.*

Ava further suggested that pamphlets and flyers about a range of developmental issues available in varied locations such as health services and schools would be helpful. Alexis also strongly supported the need for better autism information in her community as well as a televised public health campaign:

> *So our families should be given – here you go, here’s a booklet. Have a read; you’re not alone; contact your centre; contact this one; there’s supports out there, all that sort of stuff. When it comes to autism there needs to be more. You have stuff on TV about smoking and stuff like that, heart attacks. What about – get some stuff on TV about autism.*

Some participants also mentioned the need to translate information into local languages. Mia, for example, told us that school children in the Torres Strait Islands primarily use English in the classroom and Torres Strait Creole in the playground. In this situation, she pointed out, there is no point in someone coming from outside and delivering content in standard Australian English: "You're not going to engage the community in that way". Olivia expressed a concern with access to National Disability Insurance Agency (NDIA) information and processes in remote communities:

> *Even going through NDIA process, a lot of the community members who don't speak English as a first language just struggle if they don't have support. If nobody helps you to get the information, if you don't know how to get the information, then it's really hard. So there's a lot more that's required for people with English as a second language. A lot of the remote mob definitely need more help.*

While some participants mentioned the importance of printed or televised information, others suggested that information delivered verbally is the most culturally appropriate option. "Probably you need to sit down and have a yarn", Willow said. She also suggested recruiting respected senior women as advocates for families supporting autistic children in local communities, as a way of leveraging greater acceptance and community ownership of the issues.

Better support for parents and carers

Participants told us that they wanted more dedicated support for parents, particularly the establishment of Aboriginal and Torres Strait Islander parent support groups and improved access to respite services. As Sophie said, "What's important that doesn't always get acknowledged or mentioned and brought up by parents is that they need support too".

Nevaeh saw a need in her local urban community for a support group so that people would know they are "not alone with autism" and that lots of people are dealing with the diagnosis of their children: "For the most part those stories aren't in community and they certainly aren't spoken about enough". Sienna thought it would be good "to have a group with parents of kids with autism, and just say 'well, this is what I've been doing, this might work or that might work'". On a more formal note, Willow suggested establishing a national Aboriginal and Torres Strait Islander parent support network to help empower parents to be effective advocates for their children. As discussed in Chapter Four, Alexis had already established a parent support group in her community, hoping to address the feelings of shame and isolation some families were experiencing and to advise them about therapy options and government entitlements.

Returning to Sophie, she emphasised that she needs to take a break from her sons sometimes, without which, there is a risk of "burning out":

> *I know as a mum, I've often just gone no, this is just part of my job as being a mum. It is, I still say that, but I've started to recognise my role. I need a break too and in order to be able to keep giving my sons support and be consistent, I need to take a break. There are some families – I'm not sure do they get that break? Because where we are here, we don't have carers respite.*

Improved access to flexible supports and services across the lifespan

The women we spoke to described their lives as a constant struggle as they sought supports and services for their children at different points in time. We spoke to mothers whose children had just been diagnosed with autism. We spoke to mothers who were trying to figure out their options for early intervention. We talked with people about their experiences of their children's education. We heard about one autistic adult who received no professional supports or services. All of the participants expressed a desire for improved access to flexible supports and services across the lifespan.

Sophie summarised the experiences of a number of women when she said, "nobody had any ideas on how to go about getting a diagnosis". She suggested a more streamlined diagnostic process and also argued for more widely available genetic screening after one of her children was identified with a chromosome deletion that contributed to his autistic traits.

Willow, herself a health professional, identified General Practitioners as the first point of contact for many families. She said that children in her region were often not diagnosed until the age of 4 or 5 when they could have been identified much earlier. Willow thought that providing training about autism to all GPs and health workers would improve this situation. "I think the diagnosis is where we are falling down", she commented. "There are health checks", she added "but if the people doing the health checks don't know what they're looking for, they don't know how to flag it".

Women also asked for better post-diagnostic advice as well as more and better access to post-diagnostic supports. Ella, who lives in a major city, described being in "a little limbo where you've got the diagnosis, you want to start doing all these therapies or helping your child but you can't get access to the people or the services you need". Ava provided a sense of the extent of the problem in her region, remarking, "There's so many children that need stuff; there's just no facilities.".

Olivia was concerned that "there are tonnes of Aboriginal people in remote areas that would not know and would not be told that they have these opportunities to get assistance and funding, and potentially help".

Willow commented on the difficulties accessing post-diagnostic support and services for Aboriginal and Torres Strait Islander families:

> *Once they're diagnosed, the families are still lost. They don't know where to go. They don't know who to talk to and they want to know how to do stuff at home with their kids. But they don't know how to. They don't know what program to do. These are the struggles that families find being Indigenous and trying to access the system because most of them don't have money to do that.*

Evie explained that she had worked in disability advocacy for decades. Over that time, she has seen some children in regional and remote areas obtain an early diagnosis and thought "thank God". "But", she cautioned, "they've had no support so it didn't matter whether it was early or late".

This sentiment was especially true for the only two Aboriginal autistic adults in this sample. One, Mason, was 18 and in his last year of school; the other, Elijah, was 22 years-old and living with his mother and grandmother. Elijah's story is concerning because, after spending much of his schooling in a support class, he is living in a regional town with no supports or services. As documented in Chapter Two, Elijah attended an NDIS-funded transition to work program. But he did not find it stimulating and refused to continue attending. His mother, Sienna, said that he mainly stays at home every day, sometimes assisting with housework. We cannot know whether Elijah's story is typical of the experiences of Aboriginal and Torres Strait Islander autistic adults because there has been no research on this topic.

Participants also offered varied accounts of their experiences with NDIS. The scheme was still being implemented in some areas at the time of interview and was newly established in other areas. Nevertheless, the fact that multiple mothers reported declining funding across successive years is worrying. Certainly, they did not think that their children's support needs had declined; in fact, they reported being unable to fund basic services such as fortnightly speech therapy. Mothers also said that they found the scheme difficult to understand, were uncertain if their child was eligible and felt overwhelmed by the necessary paperwork. Ruby, for example, told us that in the Torres Strait Islands there is very limited awareness or understanding of the NDIS.

More Aboriginal and Torres Strait Islander personnel in health, education and disability services

Women repeatedly told us that they and their children valued interacting with Aboriginal and Torres Strait Islander personnel in the health, education and disability sectors. Ava told us that "There needs to be more Aboriginal speech therapists, OTs, psychologists, who can understand Aboriginal ways". She also spoke about the importance of Aboriginal education support staff in connecting with students, stating, "I can see the kids do better when they're around other Aboriginal people and with their family and stuff".

Mia, too, emphasised the importance of training "people on the ground" to work with Torres Strait Islander autistic students "so that when we go away, something remains". Alexis spoke positively about the impact of Koorie Engagement Support Officers, employed by the Victorian Department of Education and Training, on her son's schooling. Nevaeh talked about why she decided to send her young son to her local Aboriginal children's centre, explaining that she likes "that cultural safety feel".

The sense of cultural safety provided by these services is pivotal in creating relationships of trust. Developing and supporting an Aboriginal and Torres Strait Islander disability workforce has been identified by FPDN as a foundational pillar for reducing disability inequity [58]. One of the women we interviewed, Layla, stressed that families should have a choice between using Aboriginal community controlled services and mainstream providers, arguing for flexibility in service provision to meet varied needs. Most women, however, expressed a preference for interacting with Aboriginal and/or Torres Strait Islander workers where possible.

Enhancing children's right to their cultural identity

Participants commented that there is very little consideration given to the fundamental importance of cultural identity to Aboriginal and Torres Strait Islander autistic children. They highlighted the lack of Aboriginal and Torres Strait Islander cultural content in autism therapies, in specialised schooling curricula and in NDIS planning. As we saw in Chapter 4, mothers wanted their autistic children to be connected to their traditional culture and believed that this connection improved the wellbeing of all family members.

Ella observed, "there's nothing out there around autism about culturally-appropriate services or therapies". Willow talked at length about how going out on Country is "healing for the kids". She explicitly suggested using culture and integrating it into therapies as a way of engaging Aboriginal and Torres Strait Islander families: "That's where they're going to get their support and also the inclusion". Alexis and Amelia were concerned that their sons' special schools had a number of Aboriginal students but did not incorporate culture in any sustained way into the curriculum. Amelia explained that, with Evie's help, she was trying to incorporate culture into Mason's NDIS planning. Evie summarised the situation saying: "You know, he may live in the inner city but he comes from such a strong cultural background. But there's been no culture in his journey".

Feeling safe and respected when interacting with services and institutions

Throughout this Report, we have quoted instances of participants feeling unsafe and often stigmatised when they take their autistic children into environments outside the family home. Those environments have included shopping centres, hospitals, schools and even, in one instance, an Aboriginal Community Controlled Health service.

In the majority of these environments, their sense of being unsafe was due to a combination of negative attitudes towards people with disability (ableism) and towards Aboriginal and Torres Strait Islanders (racism) combining to form intersectional discrimination. Where participants reported stigmatisation in their own communities this was due to a lack of accommodations for and understandings of autistic children, revolving around misguided assumptions that behaviour perceived as challenging reflects bad parenting. In all of these public contexts, participants stressed that they want their confidentiality respected.

Cultural safety involves a willingness to recognise discrimination and to try genuinely to address challenges arising from intersecting vulnerabilities. Those challenges are twofold in the case of Aboriginal and Torres Strait Islander autistic children. First, they may be subject to bias and discrimination arising from racism, both conscious and unconscious. Second, they may be stigmatised because of their disability. Disability stigmatisation can occur in both mainstream and Aboriginal and Torres Strait Islander contexts.

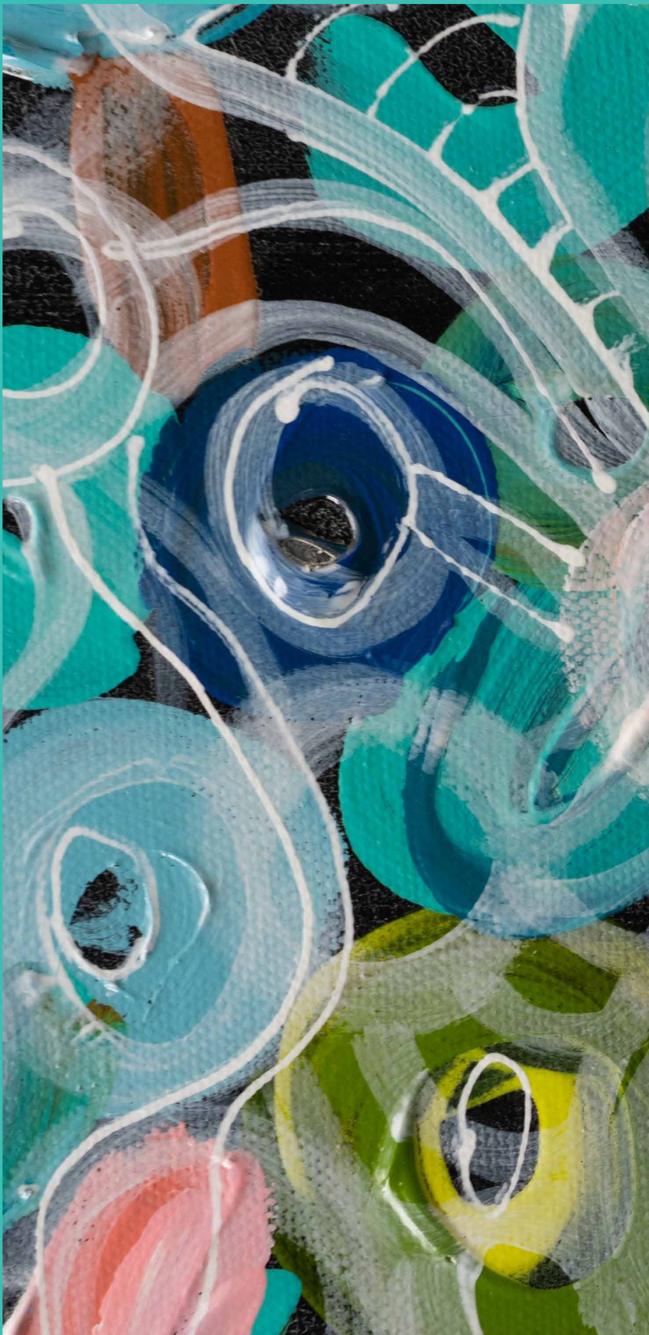
Addressing these issues requires deep attitudinal change. There is a need for service providers and institutions to become more culturally competent. There is also a need for many services and institutions, mainstream and Aboriginal, to achieve greater awareness – and acceptance – of autism.

Hearing more Aboriginal and Torres Strait Islander voices and experiences in autism research

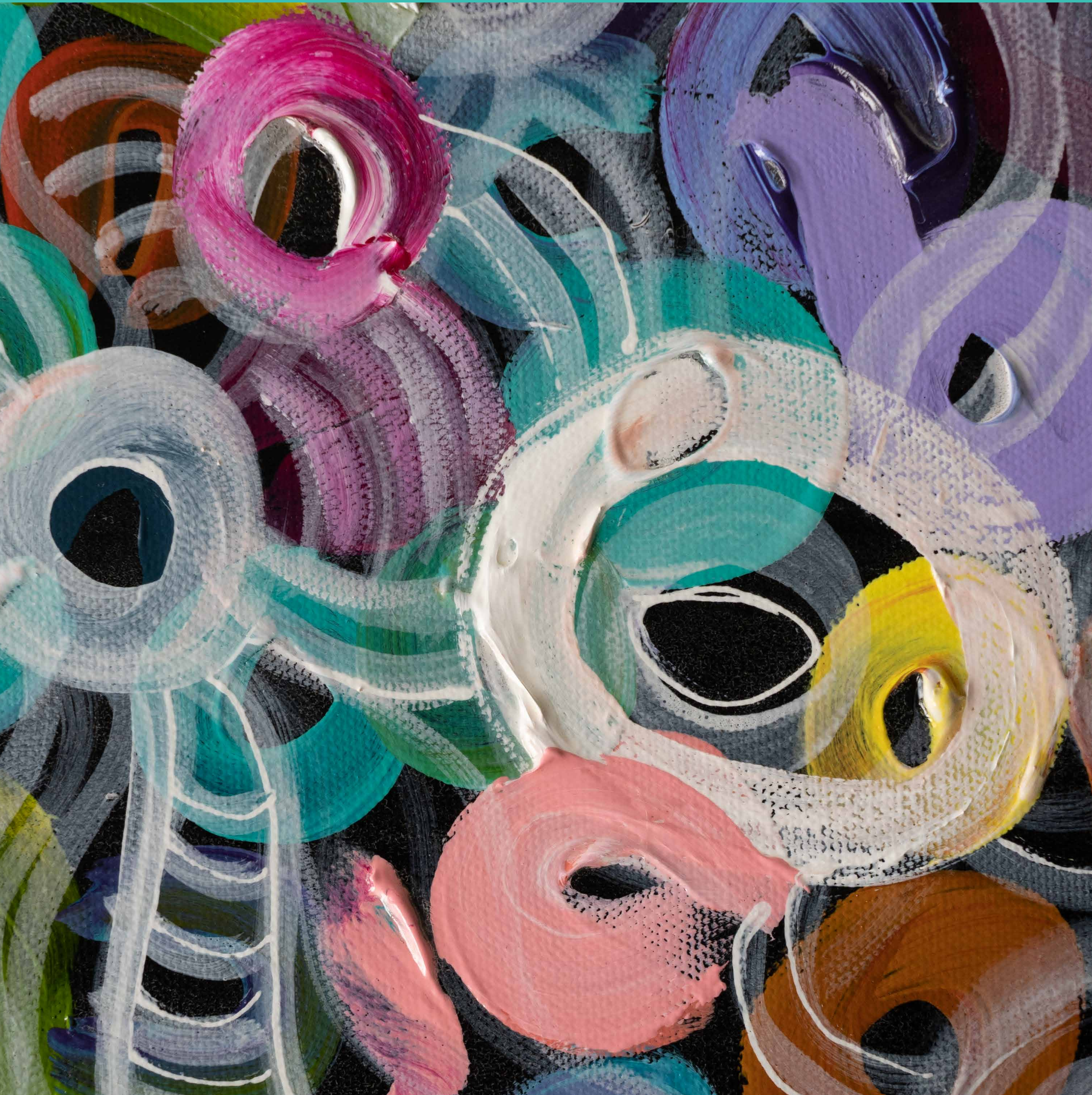
This is the first research undertaken specifically on the experiences of families supporting Aboriginal and Torres Strait Islander children on the autism spectrum. The 12 women who generously shared their stories with us were very aware of the lack of research and literature available on Aboriginal and Torres Strait Islander experiences of autism. Many knew multiple family members with autism across extended kin networks but commented that no information was available that addressed their specific circumstances and their needs.

Ella remarked that "there seems to be a real gap in the research". She suggested that "just hearing more experiences from other Aboriginal and Torres Strait Islander families would be helpful. We know it's a big issue but there's nothing out there". Layla, who provides support to three grandchildren on the autism spectrum, said she would like to see a lot more research into what would help families and communities. Nevaeh told us that it was hard to connect with "Anglo based stories" because there are "stark contrasts" between Aboriginal and Anglo Australian families. She pointed out that "as a people we like to share stories and yarns" and that learning from other families and not feeling alone in your community are important.

This research is a first step. While the findings provide some insights into the experiences of Aboriginal and Torres Strait Islander families caring for autistic children, much more research is needed, with larger samples, in different parts of Australia and led by Aboriginal and Torres Strait Islander scholars.



6. RECOMMENDATIONS AND CONCLUSION



RECOMMENDATIONS AND CONCLUSION

RECOMMENDATIONS

We recommend the following actions be initiated by self-advocacy and advocacy organisations and family support groups:

1. Production of a targeted “road map” outlining the post-diagnostic support services available to parents and caregivers of Aboriginal and Torres Strait Islander autistic children.
2. Development of a network of currently-existing Aboriginal and Torres Strait Islander parent support groups and the creation of a support process to enable further groups to be created.
3. Production of information about autism and autistic life-experience, designed specifically for Aboriginal and Torres Strait Islander communities, in a variety of accessible formats and, where possible, translated into local languages.

We recommend the following actions be initiated by service providers, civil society organisations including peak bodies and government-funded support programs:

4. Deepening and extending existing strategic frameworks designed to enable the recruitment and retention of Aboriginal and Torres Strait Islander workers in health, education and disability services.
5. Development of autism awareness training that incorporates high-quality cultural safety for use in services and institutions, both mainstream and Aboriginal and Torres Strait Islander specific.
6. Review widely-used autism intervention and therapy guides, special school curricula and disability services to ensure they fully acknowledge Aboriginal and Torres Strait Islander cultural knowledge and practices.

We recommend the following actions be initiated by institutions of research and education:

7. Development of further community-based research into the identification and diagnosis of autism in Aboriginal and Torres Strait Islander families.
8. Development of a community-directed research strategy into the circumstances of Aboriginal and Torres Strait Islander autistic adults to better support their needs and aspirations.
9. Seek to secure specific additional funds for research into the needs, priorities and preferences of Aboriginal and Torres Strait Islander autistic people and their families.

We recommend the following actions be initiated by state and federal policy-makers:

10. Improved access to and greater availability of respite for parents and carers of autistic individuals, regardless of cultural background, socioeconomic status or geographic location.
11. Development of targeted support for the mental health needs of Aboriginal and Torres Strait Islander children, young people and adults on the autism spectrum.
12. Increased assistance to families of Aboriginal and Torres Strait Islander children with a diagnosis of autism to access the National Disability Insurance Scheme and plan supports.

CONCLUSION

Children and young people on the autism spectrum already risk disadvantage in adulthood, including unemployment and poor mental health, by virtue of being autistic [10,59-61]. This Report focused on one group among those children and their families, those who are Aboriginal and/or Torres Strait Islander.

This research provides only a snapshot of the experiences of mothers and one grandmother supporting children with a diagnosis of autism in diverse Aboriginal and Torres Strait Islander communities across Australia.

Some of the issues raised by our participants – the varied routes to diagnosis, the little-to-no post-diagnostic support, the challenges dealing with bureaucracy, the all-too-often negative school experiences and the poor mental health of autistic children, young people and adults – are common to many families in Australia [62,63] and across the world [64-68], regardless of their cultural origin or identification. Yet the major health disparities that continue to exist between Aboriginal and Torres Strait Islander peoples and other segments of the Australian population [69] make these issues all the more concerning.

The importance of culture, community and Country was highlighted in all of the families' accounts. Women wanted better understanding of autism within their communities, interactions with professionals who understood, and were responsive to, Aboriginal and Torres Strait Islander cultures, and therapies, school curricula and disability services that incorporated those cultural understandings and practices. Under the United Nations Convention on the Rights of the Child [70], children – including autistic children – have the right to a cultural identity, including being connected to culture, community, Country and language. Protecting these rights for Aboriginal and Torres Strait Islander autistic children and young people and fostering a sense of identity and belonging was a key priority for the families we interviewed.

The families involved in this study have already demonstrated how much can be achieved, even in extremely challenging circumstances. They have often overcome great obstacles to ensure that their children have a good start in life. Listening to experiences like theirs is the first step we need to take towards improving the possibilities for all the children that come after them. If, after we have listened, we also work together to act on the priorities they have revealed – ensuring access to better information and services and demonstrating a real commitment to building local expertise in autism – then the future can indeed be positive for all autistic children, young people and adults in Aboriginal and Torres Strait Islander communities.

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ABOUT US

Rozanna Lilley is a social anthropologist and autism researcher with a particular interest in family experiences of education. She received her first PhD in social anthropology in 1994 from the Australian National University and the other in early childhood in 2015 from Macquarie University. After working for Autism Spectrum Australia and the Australian Human Rights Commission, she has returned to Macquarie University as a Postdoctoral Research Fellow in autism. She has published numerous sole-authored journal articles and book chapters on autism and education. Her most recent book is a memoir focused on her experiences with her autistic son, *Do Oysters Get Bored? A Curious Life* (UWA Publishing, 2018).

Mikala Sedgwick is an Aboriginal researcher from the Gamilaraay nation specialising in Aboriginal and Torres Strait Islander Health and Wellbeing. Mikala has a background in Anthropology with a particular research interest in advocating for the rights of Aboriginal and Torres Strait Islander people with disabilities. Mikala completed a Bachelor of Arts (Health, Medicine and the Body, Anthropology and Indigenous Australians studies), and a Master of Applied Anthropology and Participatory Development (Indigenous Policy Research) both at the Australian National University. Mikala is currently a postdoctoral fellow in the Aboriginal and Torres Strait Islander Health Program, Research School of Population Health, National Centre for Epidemiology & Population Health at ANU. She is also a mother of a young boy on the autism spectrum.

Elizabeth Pellicano is a developmental and educational psychologist, committed to understanding the distinctive opportunities and challenges faced by autistic children, young people and adults and tracing their impact on everyday life. She completed her PhD on the cognitive profile of autistic children in 2005 at the University of Western Australia, before moving to the UK, to the Universities of Oxford and Bristol. She was Professor of Autism Education and Director of the Centre for Research in Autism and Education (CRAE) at University College London until she joined the Department of Educational Studies at Macquarie University in October 2017. She has published over 130 peer-reviewed journal articles, book chapters, commentaries and major reports to government departments and charities. Her ambition is to conduct world-class scientific research on autism that makes a real, immediate difference to the lives of autistic people, particularly those in seldom-heard groups, ideally designed in partnership with autistic people themselves.

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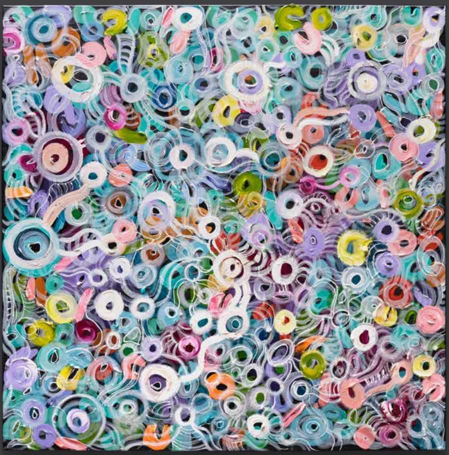
ABOUT THE ARTWORK

Maria Watson-Trudgett, a Koori woman of the Wiradjuri People, has kindly offered her artwork, titled *An Optimistic Journey*, for the cover of this Report. Here, she tells the story of her art as it relates to this research:



INSPIRATION

The inspiration for the artwork comes from the voices of the Indigenous parents who shared their stories to support this project. The main theme I drew encouragement from was that all parents agreed upon the need for organisations to work together in partnership with Aboriginal and Torres Strait Islanders families and communities, such as health professionals, educators, service providers and policymakers, to contribute to their vision of creating a positive future for their children on the autism spectrum.

ARTWORK

- Bright colours represent the diversity of autism, Aboriginal and Torres Strait Islander families and communities, cultural knowledge and Identity.
- White circles, connecting and flowing lines, represent a vision of working together and sharing in creating a positive and bright future for Indigenous children.

ABOUT THE ARTIST

Maria is a respected artist and advocate for Aboriginal and Torres Strait Islander arts, culture, education and social equality.

Maria has illustrated a number of publications which have been designed to support families to gain a better understanding of autism along with providing a connection to other parents in a similar situation. Maria has exhibited her art at NSW Parliament House as well as other galleries across Australia. As well as painting for national private collections, including Colorado USA, Maria's artworks embellish Positive Partnerships work shirt, proudly worn nationally.

Maria has donated her artwork to raise funds to support Indigenous educational scholarships, remote Indigenous eye care projects, disability services, and school programs.

Maria is also passionately involved in supporting Aboriginal and Torres Strait Islander families, carers and communities to gain a greater understanding of autism through her positon as National Team Leader for Aboriginal and Torres Strait Islander Family and Community Programs, funded by the Australian Government Department of Education and Training through the Helping Children with Autism package.

Maria states;

> *My painting style is contemporary and I paint in my own unique way, which reflects my Aboriginal culture and experiences, that express my connections to country, family and contemporary culture. Knowing that I have such a strong and lasting lineage with the oldest race of people on earth as my heritage, and knowing that until recently, Australian First Peoples culture lasted unchanged for tens of thousands of years is sometimes overwhelming when I contemplate this. These feelings influence my artistic expressions; contemporary expressions of now, inextricably linked to an ancient past.*

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