

CULTURE AND CONNECTION

Building Strong Home-School Partnerships
with Culturally and Linguistically Diverse
Families of Autistic Children

Report, March 2022



Jodie Smith, Aspasia Stacey Rabba, Poulomee Datta,
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EXECUTIVE SUMMARY

Strong, effective partnerships between teachers and caregivers can substantially improve all children's success in and out of school, including autistic children and young people. Such partnerships between parents and schools may be especially important for autistic students since they can benefit from learning supports and consistent approaches across contexts.

Yet, we have little knowledge of experiences of home-school partnerships for families from Culturally and Linguistically Diverse (CALD) backgrounds who have autistic children. We need to hear from these families in order to understand how we can better foster effective home-school partnerships, with the broader aim of improving school success for autistic children and young people from all of our diverse communities.

This Study sought to bridge the gap in knowledge for CALD families of autistic children and suggests ways we may be able to promote more successful partnerships between CALD communities and kindergartens/schools in the future. We conducted the research by listening directly to the first-hand experiences of 56 parents of autistic children from different communities, namely Chinese, Vietnamese, Somali and Middle Eastern cultures. Parents told their stories in their own languages. Their autistic children attended kindergartens, primary and secondary schools across mainstream, special and selective settings. We have not heard from these parents before and their stories provide us with critical information about current and future priorities for these families.

Our participants told us how much they loved and were proud of their autistic children. They clearly had high expectations of their children and found it deeply disappointing that these high expectations were often not shared by teachers and schools. Parents were frustrated by inadequate, reactive and inconsistent communication from schools and other professionals; and this poor communication often led to an erosion of trust within relationships. Parents were similarly frustrated by what they observed was limited experience and knowledge of autism within education settings, especially within specialist provisions. Parents also found the lack of coordinated supports within schools exasperating.

Having limited spoken and written English made everything so difficult for many of these parents. Parents also often had few resources upon which to draw. They frequently did not understand Australian education or funding systems so were unaware of their own or their children's rights. They also often lacked extended family supports with many being solo parents.

It was therefore unsurprising that pandemic-related restrictions and associated school closures were enormously challenging for many of the parents to whom we spoke.

Parents reported experiencing discrimination in many forms. They told us that widespread stigma and misunderstanding about autism exists within their respective communities, including from family members. Mother-blame was especially common in all communities. Parents, and sometimes children, also faced overt discrimination from the wider community with racial profiling and prejudice reported. These cumulative experiences of discrimination, stigma and blame impacted parents' mental health, leading to isolation and exhaustion.

Many parents were respectful and deferential towards teachers and had clear role boundaries between themselves and educators. Parents were often grateful for opportunities offered to their children in Australia and sometimes felt that they should not ask for anything more from teachers or schools. Some parents also anticipated negative repercussions on their families if they addressed teachers directly.

Despite stigma, limited resources and deference, many parents felt that they had no choice but to speak up on behalf of their children and their community; and these parents demonstrated extraordinary flexibility and resilience in their advocacy. They promoted autism knowledge and acceptance within their schools and communities and they benefitted when community-specific supports were available to them, both within their schools and the broader community.

In response to the experiences shared by parents, this Report makes the following key recommendations:

1. **Schools and kindergartens should always have high expectations of all children**, from all backgrounds, in all settings. These **high expectations should be applied to all skills**, including academic, everyday life and social interaction skills.
2. **Schools should provide a checklist for all families before they start school** to understand what individual families may need as they transition into school and between schools. The checklist could include finding out:
 - a. Family's language preferences, including whether they prefer oral or written information (i.e., phone calls, emails or texts).
 - b. Whether families have reliable internet at home and whether they can access and understand the e-learning platforms and apps used by schools.
 - c. How families travel to school (i.e., whether they rely on public transport or have access to a car).
3. **Schools should expect that good communication will be different for each family**. Some parents may want to know lots about their children while others prefer a brief update or timely information on specific skills. Some parents may also want to see what their children do at school. Plan ahead with each parent about what 'good communication' looks like for them and discuss how feasible this is within each school context. Ensure parents know **who** they can contact at the school and **how** they can contact this person. Having a dedicated person within schools to communicate and coordinate with parents is advised.

4. **Schools should proactively explain school protocols** to parents to help them know what they can/cannot do at their child's school. Tell parents if specialists/support workers/family advocates are allowed into schools, including in meetings. Tell parents if and when they are allowed in the classroom. Be aware that the structure of families may mean that **more responsibility falls on one parent** than another.
5. **Schools should have regular, planned, structured communication with parents.** It can take time to develop relationships when families have had different and/or more difficult past experiences. Having frequent, proactive positive communication with parents will help to develop trust.
6. **Schools should provide training on use of e-learning platforms and apps,** ensuring parents know how to assist their children. Explainer video in different languages may be helpful. Some parents may not have the internet or have previous experience with these tools. In order to achieve equity of access, it is crucial to provide alternatives for these families. It may be helpful to use school apps to link parents in with language speaking members of staff.
7. **Schools should plan how best to prepare children to leave and return to school** and advise parents about how they can assist with these transitions, especially given that transitions, including holidays and school changes, can be difficult for families, especially CALD families. Providing new teachers and/or schools with relevant information on successful student supports and accommodations will assist **autistic children to have continuity throughout schooling.**
8. **Schools should provide balanced feedback to parents that includes communication about issues and solutions.** Different families have different expectations and preferences in relation to communication between home and school. Parents are not afraid to hear about their children's difficulties, and they want to contribute to addressing issues and have their expertise valued. Asking parents if they have any tips or strategies can often lead to improved learning or wellbeing outcomes for students.
9. **Schools should actively consider ways to increase contact and communication with parents from CALD backgrounds.** Parents should be *encouraged* to advocate for their children and be given strategies to support their advocacy.
10. **Schools should acknowledge that all parents' journeys will be different.** Be curious, interested and non-judgmental about parents and children as individuals. Be careful with language use when describing parents and children. Find out parents' language preferences when talking about their autistic children and their culture.
11. **Schools should meaningfully acknowledge parents' cultures in order to encourage a sense of cultural safety for students and their families.** This may include activities such as learning songs in different languages or celebrating key cultural dates. Including parents when planning cultural events will help to build relationships with families as well as ensure that such events are authentic. Cultural diversity provides rich student experiences and is relevant to many key learning areas in the curriculum.
12. **Teachers should benefit from additional training around autism and disability, including the intersection of autism and cultural diversity.** Specific training on effective use of interpreters and use of simple written and spoken English is recommended.



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ACKNOWLEDGMENTS

Macquarie University and Positive Partnerships worked together on this Report, which aims to understand the views and experiences of home-school partnerships for parents of autistic children from CALD backgrounds – communities on which there is remarkably little research. Positive Partnerships is a national project, funded by the Australian Government Department of Education, Skills and Employment (DESE) 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.

We are enormously grateful to Positive Partnerships for giving us the opportunity to work on such an important topic, allowing us into the lives of a group of seldom-heard parents and young autistic people. In particular, we thank the parents who joined our community-specific advisory groups (Hau T Nguyen, Phuc Nguyen, Ngoc Dang, Rena Wang, Julia Wang, Emily Ma, Ling Cong, Chong Yeow, Rami Khraim, Shano Ali, Shorsh Ahmad, Amal Ali, Khadra Ige, Naado Yusuf Ali and Helen Said), who so generously gave their time and expertise throughout the duration of this project. We would further like to thank our wonderful colleagues and interpreters, Nadia Faragaab, Patricia Lee and Kim-Van Nguyen.

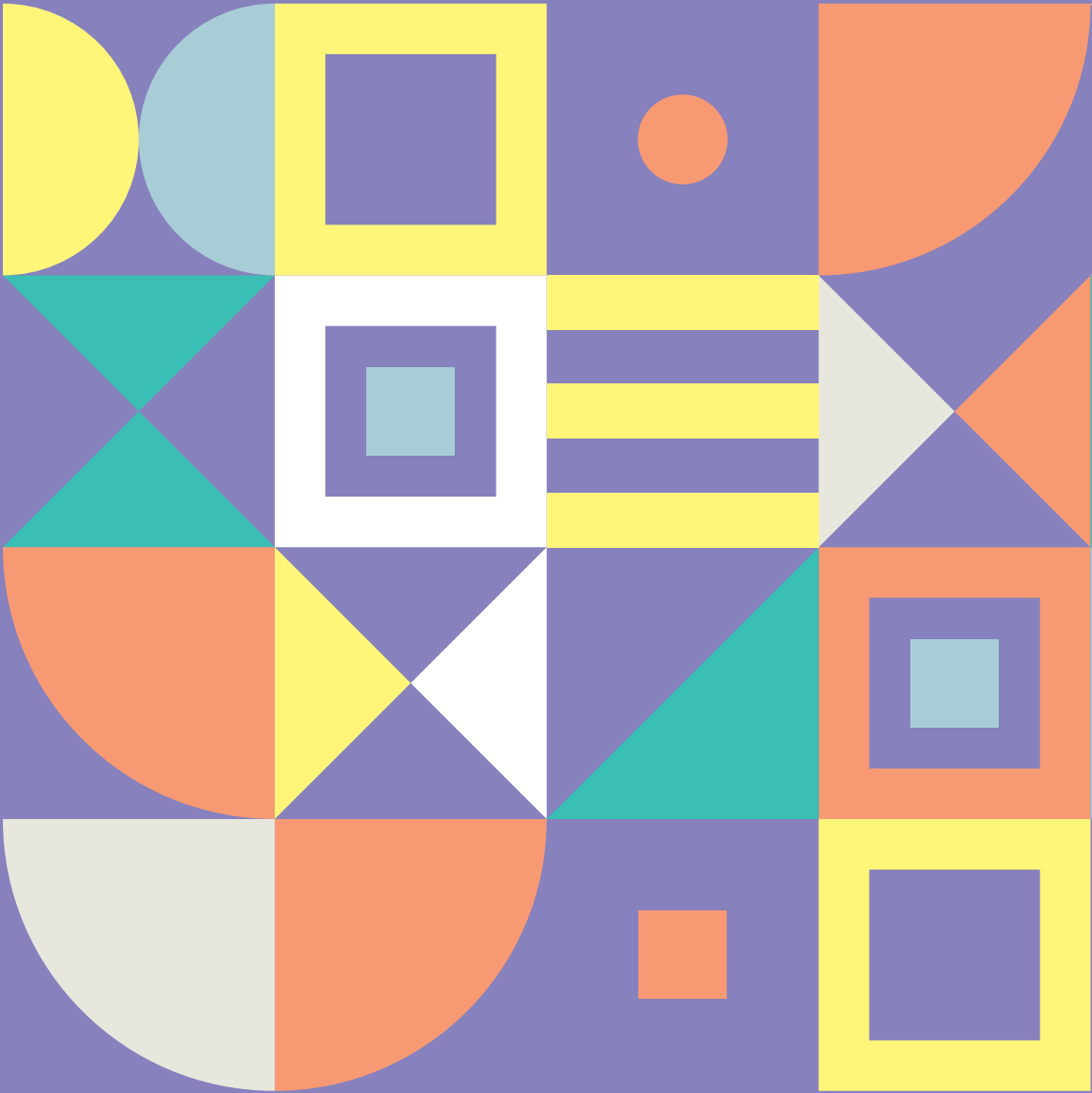
We are also indebted to all the children and young people, their parents, and teaching staff, without whom this project would not have been possible. We are extremely grateful to all who took the time to share their knowledge and experiences with us, including during a particularly unsettling time, the second wave of the COVID-19 pandemic in Australia. We were deeply moved by their stories and experiences and feel very privileged to have heard them. We have done our very best to convey these stories as accurately as possible. Any omissions or errors are entirely our own.

ABBREVIATION AND TERMINOLOGY

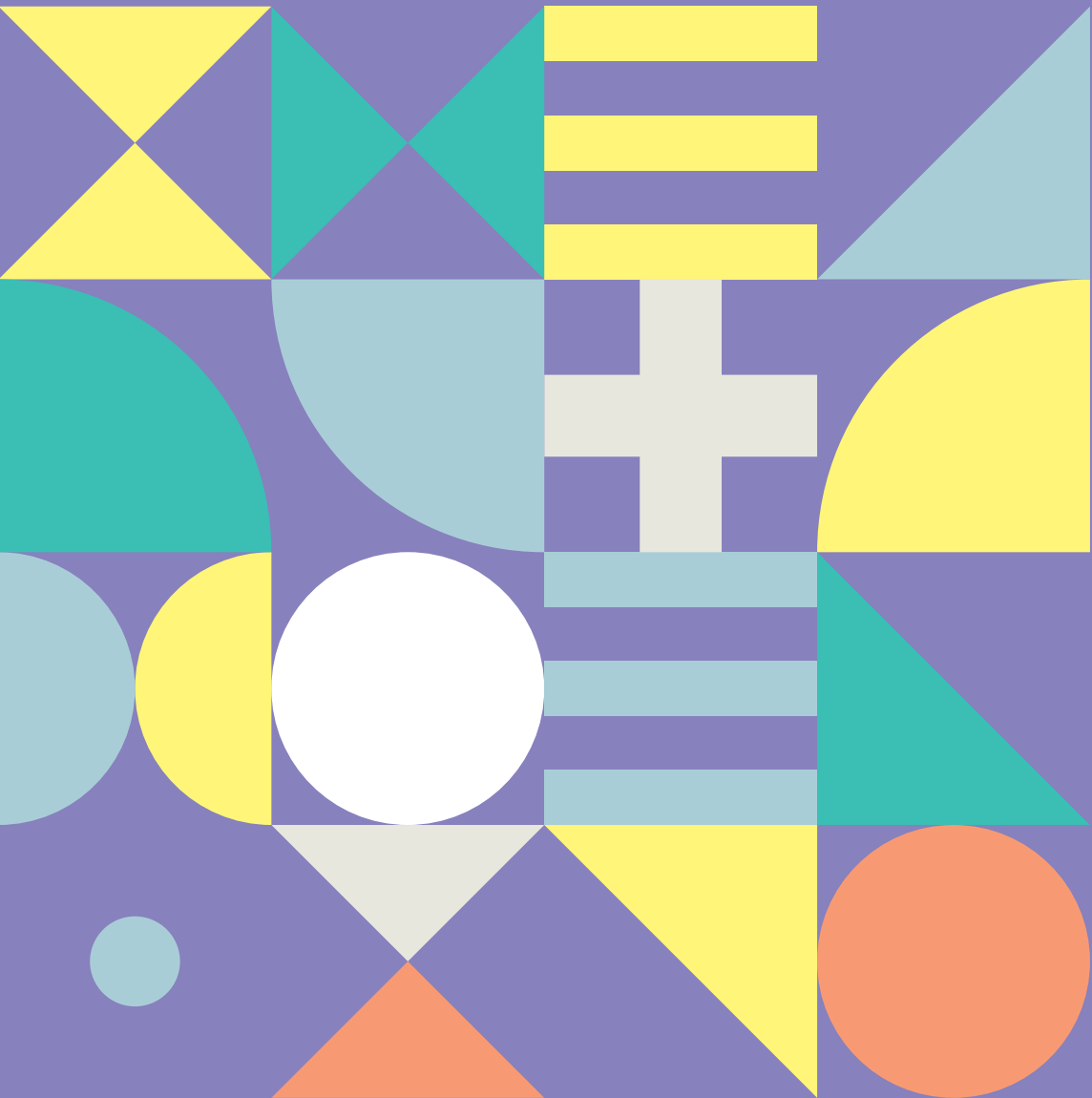
CALD:	Culturally and Linguistically Diverse
Centrelink:	A service that provide support payments
Dual schooling:	Where children split their weeks between different types of schools
NDIS:	National Disability Insurance Scheme
NSW:	New South Wales
OT:	Occupational Therapy
PP:	Positive Partnerships
PSD:	Program for Students with Disabilities
Prep:	The first year of formal schooling in Victoria, Australia
SP:	Speech Pathology
TAFE:	Technical and Further Education
VCA:	Victorian Certificate of Applied Learning

A NOTE ON TERMINOLOGY

In the autistic community, identity-first language, for example, ‘autistic person’, is often preferred to, and considered less stigmatising than, person-first language, for example, ‘person with autism’.¹ It is also the terminology preferred by our autistic co-authors. We therefore use identity-first language throughout, unless parents themselves have used person-first language, which we retain in their quotes.



1. INTRODUCTION



INTRODUCTION

SETTING THE SCENE

The Australian Education Act² and Disability Standards for Education (2005)³ advocates for strong partnerships between teachers, caregivers, and the broader community as these partnerships can substantially improve children and young people's success in and out of school for *all* children. Such partnerships between parents and schools may be especially important for autistic students⁴ who can find traditional schooling particularly challenging (see Box 1) and can benefit from learning supports and consistent approaches across home and school contexts.^{5,6}

There are no established criteria for what constitutes an effective parent-professional partnership, as all partnerships are unique.⁷ Nevertheless, there is some agreement around which features might be important for such partnerships, including fostering

effective two-way communication, developing meaningful, trusting relationships between parents and school staff, and providing inclusive opportunities for all families.^{8,9} Professional learning for school staff around the value of, and the best ways to, engage with parents has also been recommended for improving partnerships.¹⁰ Yet, family engagement in home-school partnerships is influenced by a variety of factors, which means effective partnerships will look different for individual families and schools. Family background, including cultural identity and connections,^{9,11} is an important factor, but one that is often overlooked in research, especially autism research, which is typically conducted with white, middle-class populations.¹² As such, we know remarkably little about the experiences of home-school partnerships for parents of autistic children from different cultural backgrounds.

BOX 1. WHAT IS AUTISM?

Autism is a lifelong neurodevelopmental condition or spectrum of related conditions that influences how individuals interact with others and experience the world around them. Approximately one in every 70 Australian people lie on the autism spectrum.^{13,14} We know that autism is highly heritable but, currently, we do not fully understand the causes of autism.

According to current diagnostic criteria,¹⁵ autistic people show behaviours across two main areas. The first area is showing **difficulties in social communication**, which can include challenges with turn-taking in conversations, making and keeping friends and using and understanding communication cues (i.e., eye contact, gestures and facial expressions). The second area is **restricted and repetitive**

ways of behaving and thinking, which can include enjoying the same activities and routines, being intensely interested in outwardly unusual things (i.e., animal names or train timetables), 'stimming' behaviours like hand-flapping and finger-twisting and unusual reactions to sensory sensations (i.e., the sound of hand dryers/ vacuums or the smell of perfume).

(continued next page)

Although autism has set criteria, every autistic person is different. Behaviours vary widely from person to person and also across different environments. Autistic behaviours might also look different as people grow up. Autistic people are more likely to experience mental health difficulties, including anxiety and depression.¹⁶ Some autistic people have an intellectual disability. Others have average or advanced cognitive skills. For some autistic people, learning language may also be challenging. So, some autistic people will have no apparent spoken language or very few words whereas others may have an extensive vocabulary but might struggle to use their words in social contexts when talking to others.

In Australia, the average age of diagnosis is four years¹⁴ but autistic characteristics are often observed much earlier. Due to increased awareness and changes in

services, many more adults are also now being diagnosed as autistic.¹⁷ Autism is currently much more common in males than females but, as autism may 'look' different in females, this may mean that more girls and women are overlooked or misdiagnosed.

In Australia, autistic students are increasingly being educated in mainstream settings.¹⁸ In 2016, around half (52%) of autistic children and young people were educated in mainstream settings, with the remaining students attending special schools or dual schooling.¹⁹ School staff can struggle to meet the unique needs of autistic students and their families¹⁸ which can mean that autistic young people and their parents often report negative school experiences.²⁰ These experiences can impact children's mental health and behaviour and contribute to them being excluded from schools.²⁰

BOX 2. EDUCATIONAL PROVISIONS FOR AUTISTIC CHILDREN AND YOUNG PEOPLE

- Mainstream schooling without support.
- Mainstream schooling with extra support (e.g., learning support/ teacher aides).
- Support classes/units in mainstream schools, which cater for students with moderate to high support needs, including autistic students.
- Special government and private schools specifically for children and young people on the autism spectrum.
- Special government and private schools for children with varying needs, including for those with intellectual disabilities or social, emotional and mental health difficulties.
- Tutorial centres and programs which cater for students identified as requiring intensive behavioural and educational support, typically for students in Years 5 to 12.
- Suspension centres which cater for students who are on long suspension (5-20 days) and have been identified as likely benefiting from a structured program to assist their timely, successful return to schooling.
- Distance education program for students on the autism spectrum which allow students to learn from home by connecting them to teachers via online learning tools.
- Dual schooling where children and young people attend two different types of schools (i.e., a mainstream and special school) during their week.
- Home schooling, which parents might pursue if they want to follow a home-based program, if they do not feel that their child's needs are being met in existing provisions available in the Government, Catholic and Independent sectors, or if their child has been permanently excluded.

“When I first heard [about the research], I felt excited first of all, Chinese are a small minority in Australia. Our community is being respected, especially with children with autism... we feel like we are being heard”

Mother, Chinese Advisory Group Member

THE IMPORTANCE OF CULTURE

Exploring different cultures in the context of autism is important for many reasons. Culture does not appear to contribute significantly to how many children are diagnosed as autistic in Western countries,²¹ but different social groups may understand and experience autism in distinct ways.²² Also, difficulties accessing service systems and communication barriers²³ may mean that autism presentation is perceived differently in immigrant communities. For example, one study found that, when compared to children born to white US-born mothers, children of foreign-born black, Filipino, and Vietnamese mothers had higher rates of autism diagnosis, especially with associated cognitive and language difficulties.²⁴ As autism populations, and views about autism, differ across minority and dominant culture families, and across migrant families from different backgrounds, building successful home-school partnerships is likely more challenging for families from Culturally and Linguistically Diverse (CALD) backgrounds.

We know that positive relationships and effective communication between CALD parents and teachers may be impacted by communication barriers, a mismatch in communication styles and discrimination.²⁵ A clash in cultural values about education and the division of roles may also contribute to why relationships between teachers and CALD parents may be more difficult to develop.^{25,26} For example, Asian parents have reported feeling that, as teachers are the trained experts, they should have full responsibility for children when they are at school, while parents should be solely responsible for children at home.²⁷ Successful partnerships can also be hampered by parents' discomfort in dealing with teachers, or suspicion

of authority figures,^{28,29} as well as unfamiliarity with systems and teaching approaches in their adopted country compared to their home country.^{28,30}

Teachers may also view CALD parents differently, too. As in other English-speaking countries like the United States and the United Kingdom, educators in Australia remain largely white, female and monolingual, especially in the early years and primary stages of education.^{31,32} Teachers' views about parent involvement and education likely reflect their own experiences and, as such, English-speaking teachers tend to place more value on visible aspects of parent involvement, such as through activities where they have direct contact with parents.³³ CALD parents' involvement in their child's education may be demonstrated through acts that are less visible to educators, such as showing interest and giving encouragement to their children.²⁶ There remains an ongoing dilemma around how much parents should adhere to the schools' expectations and culture versus how much parents' expectations and cultures should be taken into account.^{26,34} As such, educators can sometimes overlook the individual needs and preferences of families and expect every family to fit naturally into existing school structures and systems,³⁵ despite the array of possible provisions (see Box 2).

Despite 'on the ground' knowledge of the difficulties CALD parents of autistic children can face when interacting with teachers and schools in Australia, there is virtually no research examining their experiences. We need to hear from these families to understand how we can better foster effective home-school partnerships and, ultimately, autistic children and young people's success in school.

“Parents mostly feel ashamed and also blamed for probably something they have done wrong in their last life, or they will be blamed that they haven’t done things properly”

Mother, Chinese Advisory Group Member

“The school are usually used to English, [Chinese parents] don’t understand the talking or the teacher, so sometimes they will feel lost at the school”

Mother, Chinese Advisory Group Member

“[This research] will allow us to convey our lessons, experiences, insights to be able to benefit others”

Mother, Somali Advisory Group Member

“I’m so excited that you are looking into our backgrounds, especially the care for family, for the Vietnamese for example. I can see other cultural backgrounds in there as well... I think it’s great, as we are a multicultural country”

Mother, Vietnamese Advisory Group Member

ABOUT THIS STUDY

Our research did not aim to provide a complete picture of the experiences of home-school partnerships for all CALD parents of autistic children. Instead, we sought to provide first-hand accounts of the in-depth experiences of parents from Chinese, Vietnamese, Somali and Middle Eastern backgrounds, giving a voice to families that are all too often overlooked in autism research. We also sought to understand experiences of autistic children and their teachers. We wanted to understand what might improve home-school partnerships for these different communities.

Critically, we adopted a *participatory approach* to ensure that our research was relevant to the communities and matched up to the realities of their everyday lives. First, our team consisted of autistic and non-autistic researchers, who worked together to design and implement the project. Our autistic collaborators, who were also parents of autistic children with a range of schooling experiences, brought their lived experience and expertise to the project. They made sure that we were attentive to the needs, preferences and values of our autistic participants and families and adopted a strength-based approach throughout our work. Second, at the outset of the project, we put together four separate parent Advisory Groups, one for each of the different cultural communities, who were consulted at each stage of the research process. These parent advisors provided detailed feedback on the way that we approached communities during the recruitment process, including helping to design recruitment materials, the interview questions and the analysis of people’s interview responses.

This meant that the interview questions and the methods used were not identical across the four community groups but were appropriately tailored to each cultural community.

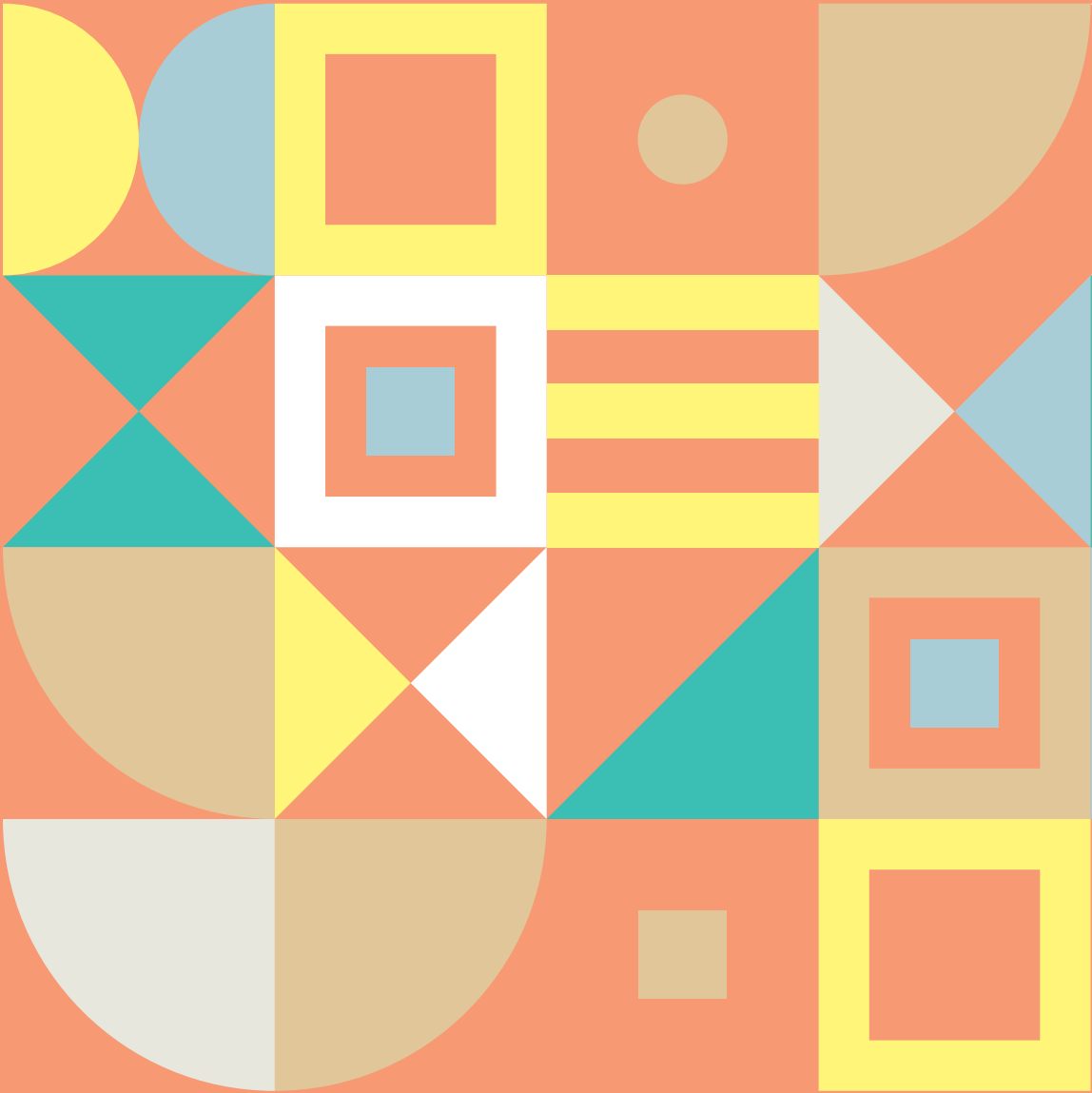
We invited parents of autistic children from Chinese, Vietnamese, Somali and Middle Eastern backgrounds living in Australia to take part in this project. Most of these communities had established relationships with Positive Partnerships. A total of 56 parents spoke with us about their experiences. Parents were aged between 23 and 65 years. We mostly interviewed mothers, but we also elicited experiences from fathers from the different communities. Most families came from Victoria, but several lived in New South Wales. Parents had 67 autistic children between them, who ranged between 2 and 18 years and attended kindergarten, primary and secondary schools across mainstream and specialist settings. As well as hearing from parents, 27 children and 11 teachers also shared their stories with us.

Each parent took part in an in-depth interview, conducted largely over Zoom (due to COVID-19-related restrictions), although some parents were interviewed face-to-face. Parents were interviewed in their preferred language, mostly by someone from their cultural background. They were asked about their experience of their child’s kindergartens/schools, communication and interactions with teachers as well as their involvement in school. Parents were also asked how they felt their community understood autism. The final question in the parent interview asked what their ideal partnership between home and school would look like.

Child and teacher interviews were also largely conducted over Zoom with a researcher, although some children were interviewed face-to-face. Children were asked what they liked and disliked about schools, including school subjects and teachers. They were also asked to draw a school they would like to go to and a school they would not like to go to. Some of these wonderful illustrations are included in the following chapters to supplement the text. Teacher interviews focused on perspectives on parental involvement in their students' schooling and teachers' partnerships with parents.

ABOUT THIS REPORT

This Report is aimed at CALD families with school-aged children on the autism spectrum, and the broader Autistic and autism communities, including autistic people, their parents and carers, and educators, clinicians and other professionals who support them. It is structured in six chapters. Each of the following chapters present results from each distinct community based on 1) Aspirations; 2) Parents' Views and Experiences and 3) Home-School Interactions. Quotations from the children themselves and teachers, as well as children's ideal/not-ideal school drawings, are included throughout to supplement and illustrate the main text. We highlight instances of successful partnerships throughout each chapter to demonstrate that such partnerships are possible. They do not, however, represent the experiences of the majority of these parents, who overwhelmingly reported ineffective and sometimes fractious relationships with schools.



CHINESE PARENTS' EXPERIENCES

We interviewed 17 Chinese parents, including 15 mothers and two fathers, for this study, including one mother and father of the same child. These parents had 19 autistic children between them, including four girls and 15 boys.

All interviews were conducted by a Diverse Communities Project Officer from Positive Partnerships. Four interviews were conducted in English, seven in Mandarin and six in Cantonese. Most parents were born in China (11 parents), four in Hong Kong and one in Malaysia. Parents began migrating from their home countries in 1988, although many arrived after 2010. They were highly educated with most having graduate or post-graduate degrees. Almost half were solo parenting in Australia.

Autistic children ranged in age between 2–17 years, with an average age of 8 years. Children also ranged in year level from preschool through to Year 11. All but one child had an NDIS plan in place. Children largely attended mainstream kindergarten and school settings, with two children in special schools and the remaining children in other settings (e.g., dual schooling or support class in a mainstream school).

ASPIRATIONS

“Children are your heart”

Chinese parents were fully devoted to their children and wanted “to actually get the best” for them. As one parent put it: “Every family has only one or two children and those children are your heart”. Parents felt that their children’s progress in school was the “responsibility of the parents”. If their children were not progressing, then they felt it was up to parents “to actually pay more attention to their child... to observe the child and find the problem”.

To support their children effectively, parents felt that they needed to take the “initiative to do things... to rely on [themselves]... and do self-learning”. This sense of parental accountability was reportedly common in China: “Chinese teachers... they won’t attribute anything to the children themselves. They would think that it’s the parents’ responsibility”. Parents’ devotion to their children and their child’s learning, meant that they “spent a lot of time” ... “just focused on [their] child”. While parents were “happy to invest a lot of time” in their children, they emphasised how it required parents to “work very hard”. As one parent told us: “I wouldn’t discount as parents how hard we have tried”.

“When I was in primary school, there was only one support teacher there. She could actually focus on me. But then in secondary school, I only have one support teacher, but she needs to look after multiple students. That’s why they cannot pay much attention to me.”

Year 8 student, Chinese background, specialist school for students with additional learning needs

PARENTS HAD HIGH EXPECTATIONS OF CHILDREN AND WISHED TEACHERS WOULD TOO

Parents reported having high expectations of their children, especially in academic achievement, and they explicitly linked those expectations to Chinese cultural values. Parents often mentioned how competitive schooling was in their home countries. One parent explained, “in China, the competition is very fierce”, while another said, “in Hong Kong, there is a lot of competition”. Parents therefore felt it was important to support their children to achieve their potential: “As parents, we know

his abilities, so we try to push hard on every single task”. They reported how school learning was regularly supplemented through learning at home: “Asians go to tuition, coaching”. One parent explained that he “sent [his son] to coaching” because they felt that Australia was “academically... too tolerant, too relaxed”. Parents often helped their children “with study or academic performance” at home, too.

Parents were grateful and appreciative of Australian teachers: “The teachers here are very kind and they’re helpful”. Another parent reflected: “In Australia, teachers are very patient with the children. And they’ll respect



Year 6 student, Chinese background, currently attending mainstream primary, Ideal and Not-ideal School drawings

the children and they try to give confidence to the children". Nevertheless, parents felt that teachers had low academic expectations of their children: "In Australia, they don't focus on academic performance". This feeling was especially apparent when parents discussed academic expectations in the context of special schools. One parent mentioned her son had not "done much academics in special school because they're only doing the behaviour correction stuff". Another parent reported being told by the teacher that "you cannot ask autistic children to do much". One parent simply said: "The teacher gave up on my son". Parents also spoke of how their children were "bored... not engaged" due not to being challenged academically at school. Parents reflected on whether expectations of their children would be higher if they were still in China:

If [child] were in China, I would have expected him to go to university. Although my child has some problems in reading and comprehension... in China, they could actually give him a lot of pressure and then he could study harder and then eventually he may have the chance of going to the university.

This view that was also highlighted in some of the children's interviews.

PARENTS' VIEWS, KNOWLEDGE AND EXPERIENCES

"I JUST LEAVE THIS TO THE SCHOOL, BECAUSE I AM NOT A PROFESSIONAL"

Chinese parents maintained distinct boundaries between home and school. This delineation was reported as being common in China: "You don't need to take the initiative; the teacher would take the initiative and talk to you". Parents firmly believed teachers were the "professionals" with "particular qualifications to be able to work in the sector" and therefore had expertise and experience that was distinct to their own. As one parent remarked: "Parents are just ordinary people, so they rely on the school to teach the parents how they educate their kids. Parents ourselves might not do the best thing as well, given our different background and levels". Accordingly, they felt that they had no "authority on what to teach at school" as schools "follow guidelines" and "have the school curriculum". As such, they felt that parents just had to "rely on the teachers". This was despite parents being quietly aware that they had expertise and experience that might be beneficial to share with teachers: "I knew very clearly what my child could do. If you ask me for experiences, I mean, I can give you a lot of examples".

"You have to build the level of trust with them first because I think with them it's not that they're ashamed of their child, but as they feel more comfortable, they will tell you more. I got the impression, 'is there a fear that we're going to be judged? This is a new teacher, she doesn't know us'. Whereas other families that I've had, they'll just come in and say it straight away. 'Yes, my child has autism and this and that, and yes, they have these', or they'll just give me everything and let it all out. But I've found [Chinese parent] was probably more reserved. But I think that's because of a cultural thing."

Female teacher, mainstream primary

“I don’t know if it’s a language thing again, families from different cultural backgrounds or maybe Chinese cultural backgrounds tend to just be like, yes, great, and happy to just do a quick check in and leave... generally they’re just happy at what you say, and then happy to go”

Male teacher, specialist school for students with additional learning needs

Parents were also profoundly “respectful” of parent and teacher roles. They were acutely aware of not wanting to come across as “overbearing” in their interactions with teachers. They often reported feeling “too shy to ask” for things, or “ask for too much” and reported “always apologising” and being careful “not to interrupt”, and not “arguing with the teacher”. They also did not want “to be impolite”. When they were unsure of the “expectations”, they worried about “doing the wrong thing”. Parents clearly felt reluctant to impose on teacher’s time or be a burden. One parent described how he was expecting an invitation to the school but, when none arrived, he decided not to follow up as he “did not want to push and add to [their] load”. Even when parents did speak out, they made sure they only “push(ed) in a respectful way”. Teachers also remarked upon parents’ reservations, noting that it was likely to be “because of a cultural thing”.

CHINESE PARENTS HAD FEW SUPPORTS TO RELY UPON

Many parents worked “full-time” and “long hours, over ten hours of work each day”, often with “both the mum and dad needing to work”. This meant parents often struggled to attend schools, especially during working hours. One

parent said: “I need to work; I don’t have much time”. Another agreed: “I’m working full-time, I can’t contribute much”. While some parents were helped by family members living in Australia – “We have work, during weekdays, they [grandparents] will come to help us” – others were not. One parent spoke about the greater level of support available in their native countries: “Normally if you have a child, you have your elderly parents, like a grandma or grandpa, who could actually look after your child, or support you”.

Some mothers felt that they lacked support from their immediate family. Some said their partners had “initially, just rejected the idea” of their child’s diagnosis. One mother commented, “my husband did not think that it was a good idea to have a diagnosis”. Many parents (mainly mothers but also some fathers) were also solo parenting in Australia so were more affected by lack of extended family support. The pandemic further decreased access to supports as people – including family members – could not easily enter Australia: “We came to Australia about two years ago. My husband is still in Hong Kong, so it’s just three of us here”.

“We have got Indians, we have got Chinese backgrounds and Somali backgrounds. But once again, those are the parents who ask for the least help.”

Female teacher, special education setting

“And then another time, [the teacher] pronounced a name wrong. She pronounced a name that wasn’t correct, and she pronounced another person’s name differently. She said it differently, and then everyone [other students] started saying it’s supposed to be this name”

Year 5 student, Chinese background, mainstream primary

PARENTS’ EXPERIENCES OF STIGMA

Stigma was reported to be commonly experienced by parents and their children. When one parent tried to advocate for her son during a school enrolment interview, she described being racially stereotyped by the school coordinator: “So, at the beginning, when I dealt with him, they were saying that I was a ‘typical Chinese mum’... what he said and what he did was kind of making me upset”. Another mother described being judged about her single parent status:

They told me that they were happy to apply for some benefits, but then they told me that because I was a single parent, even if you took these benefits, the child would not have a father to enjoy. This made me quite angry... I don’t know why they discriminate against us.

PARENTS HAD LIMITED KNOWLEDGE OF EDUCATION, FUNDING SYSTEMS AND AUTISM

Parents’ limited understanding of how to navigate the Australian education system – including knowing their own and their children’s rights – meant they had difficulties being proactive advocates: “Sometimes I don’t know what to advocate for and we don’t know the pathway”. One parent mentioned that she did not know how to “enroll [her child] in a [mainstream government] school” so by the time she did enroll, the school “was full”. Another parent had her child’s school enrolment rejected and “so he stayed at home for the whole entire month” since she “didn’t know [she] had a right to ask for public school”.

This limited understanding about the Australian school system was further compounded by limited knowledge about autism and being

autistic. One parent explained that in Chinese “autism is a literal meaning of the phrase itself — it means isolated from the external world and not communicating with other people”. They felt this contributed to a narrow perception of autism within their community. Another parent commented that some Chinese community members perceive autistic children as those unable to “control themselves in a public area, screaming, or running around”.

Parents also described different beliefs that they, their family or their community held about the causes of autism. Some felt that “autism is kind of like a genetic problem, and then if your child has autism, maybe one of your parents has some extent of autism as well”. Others felt that autism was caused by post-natal injury. One mother spoke of how her “husband believes that because they used forceps (in labour), it might have caused brain damage to my child; that’s why my son has this autism”. Another parent stated that “autism is caused by different causes – 60-70% from environmental causes and the rest, 30%, is natural causes”. They also reported a widely-held belief within their communities that autism “will get better naturally by itself”, that it is something the child will “outgrow” and will “go away when [the] child grows up”.

PARENTS FELT GUILT AND SHAME ABOUT THEIR CHILD’S DIAGNOSIS

Parents reported wanting to “save face” and were “afraid to see [their] friends (in China) because [they] don’t want to get embarrassed”. They felt “guilty” and “ashamed”. This shame was sometimes reinforced by the feeling of being ostracised by others in their community because of their child’s diagnosis: “I can feel parents, once they know my son’s condition, they try to stay away from us, which is very

“And then it got to the point where I actually said to her, you know, ‘You are aware that he is eligible to be onsite?’ [during Covid-related school closures]. So, she goes, ‘I didn’t know’. And I said, ‘We’ve always said that. You know, he’s funded. All children who are funded, PSD students, are allowed to be onsite’”

Female teacher, mainstream primary

heart-breaking”. In response to being asked what specific factors might influence a Chinese parent not seeking or accepting a diagnosis, one parent simply answered “pride”.

PARENTS WERE APPRECIATIVE OF AUSTRALIAN OPPORTUNITIES

Parents were thankful for the financial support provided, that they felt would otherwise not have been available to them: “If I were in China, I would have gone bankrupt because I just couldn’t afford to look after a child like this. I’m so lucky that I’m in Australia”. Parents were also sympathetic to the fact that “teaching is very stressful”. They expressed gratitude for teachers’ care and compassion: “We want to show our appreciation for how good they have treated my child” (see also Box 3).

Parents also felt that there were more options for their children in Australia, as they moved into adulthood: “In Hong Kong I just cannot see our future, I cannot see my child’s future, but here, in Australia, I hope that my child can find a job and I can see her future”. They referred to a greater acceptance of difference: “The Australian community is more tolerant and welcoming to different diversity”. Parents were further encouraged that Australia allowed them a sense of agency in this process: “You feel like you make a choice of your own”.

“We had a student, who has left this year, but he had some quite significant issues, he’d come from Asia, and Dad was not upfront about the behavioural issues that he had had, and Dad was saying, ‘No, he doesn’t do that’. But over the course of the four years that he was here, it came out that, well, yes, this was a known thing, and things were quite bad at home, and Dad was quite ashamed of what was happening at home, because he was getting hurt. So, I think that makes it harder to develop [partnerships] with families.”

Female teacher, school for intellectual disabilities and complex learning needs

“And it is hard for them, and they are non-English speaking background, they don’t know how to access the help, they don’t know what is NDIS. They don’t speak English”

Female teacher, special developmental school

PARENTS APPRECIATE THE FOSTERING OF ‘SOFT SKILLS’ IN SCHOOLS

Although low academic expectations were a source of frustration for parents, they were grateful that schools focused on “kids’ personal ability, personal development, and that they encourage them to cook, to live independently... for kids with disability, it’s very important for them to grasp these practical skills”. Parents liked that Australian teaching was well rounded: “They try to develop all abilities for the children... what they teach children, the value, the ethics, is way more than academics can measure, which is better”. Moreover, some parents felt that non-academic skills should be more of a focus as children move through school: “For my child, he needs to develop academically but then he’s now a teenager and he has different psychological or mental needs... they need to provide more support in this respect, especially for the autistic children”.

HOME-SCHOOL INTERACTIONS

PARENTS LACKED CONFIDENCE AND TRUST IN TEACHERS

Despite their respect for clearly defined roles, parents often reported frustration that being assigned a ‘good’ teacher “all depends on luck” and effective leadership. The idea of good fortune in relation to good teachers was common: “I was lucky. I got one teacher... she’s got 20-years’ experience”; “If you have a good teacher then you are lucky, and if you have a bad teacher, you are unlucky”. Parents valued effective leadership but, again, this was perceived to be largely a matter of chance: “I spoke to the headmaster; I spoke to the person who was responsible for allocating teaching aides and I was lucky”. Although variability across teachers’ experience and skills is somewhat unavoidable, parents found it frustrating that schools appeared aware of differing teacher quality: “I talked to the Vice-Principal, and the Principal told me that, don’t worry about it because next year he will give me a better teacher”. Of most frustration to parents was their observation that teacher quality had a knock-on impact on children’s engagement in education: “For the mainstream school, I found that she’s reluctant. She’s finding excuses of not going to this school”; “He loved going to (previous) school but... I feel like he is less keen. If he has a choice, he would choose not to go to school”.

“I think what families really appreciate is when they can tell that you’ve got to know their child. And when you’re talking about them, you’re like, they really like this, or they can do that, that’s when you can start to work together well, when you start to understand the idiosyncrasies of the student, and then that’s when you can really try and support them. So I think that’s one thing that goes well in those discussions.”

Male teacher, specialist school for students with additional learning needs

BOX 3: THE IMPORTANCE OF ATTENDING TO CHILDREN’S INTERESTS

During our conversations with Chinese parents, the importance of educators and professionals paying attention to the interests of children was a prominent theme.

Noticing children and young peoples’ interests not only laid the foundation for scaffolding interactions with them and building their skills but also demonstrated to parents that their children were being listened to and valued as individuals.

One mother Hui* spoke of how critical it was to be attentive to children’s passions and talents.

Hui is the mother of an autistic 17-year-old, named Jian. Jian is coming towards the end of his school career (Year 11) in a school for students with mild intellectual disability. He has additional support through an NDIS plan. Hui is a single mother who moved from China in 1996. The family speak Mandarin at home. She mentioned that Jian attended a cooking class with another child who had a tutor. The tutor asked her “for some pictures and information that related to [Jian]”. The tutor then “wrote a book, an article about [her] son, and it was

called Master Chef”. Hui mentioned this to Jian’s teacher who was interested and asked for the story. The teacher then “read aloud it in the class, in front of all of the students” which made Jian “quite happy and very proud”. Hui subsequently had “another meeting with the vice-principals, and the Vice Principal told [her] that, in this class, there used to be an open class. It was attended by vice-principals. But then they observed that [her] son began to speak, and this was the first time that they saw [her] son actually speak loudly, and they were quite impressed... I mean, they were happy about it”. She reported that after this incident the school staff knew her “son could actually talk, and he could speak, talk, and he could talk and speak confidently”. Hui “kept talking to this teacher all the time, because he’s so attentive and patient”.

*All names have been changed

ALL PARENTS “HEAR FROM SCHOOL IS THE GOOD NEWS”

While Chinese parents wanted “positive feedback”, they also felt that “Australia[n] teachers don’t want to talk about the bad things”. They contrasted this with their experience of schooling in China, where they reflected that Chinese teachers would “tell you your kids are doing good in school, but they then would also tell you your kids may not be doing quite well”. With teachers avoiding telling them “any negative things”, they felt they were not getting a “a true reflection of how [their] kids are doing in school”. Parents also described “inconsistency” across teacher feedback, pointing out, for instance, that while the “generic report is generally very positive”, “individualised feedback” made it clear that their child “didn’t do as well as [they] had thought”. One parent explicitly requested the teacher “give [her] some negative things” about her child.

The incomplete picture parents’ had of their child’s education was compounded by having “zero idea” about what their child learns at school and no “clue how to find out”. This experience was distinctly different to their experiences of Chinese kindergartens and schools, where they reported having many more opportunities to learn first-hand information about their children – either through direct communication with parents and teachers – “we have this WeChat group... so the teachers can post updates any time, and the parents can discuss issues more frequently” – or through “technical things like apps” or “live cameras so that the parents can monitor what’s going on in the classroom”. One parent even said: “It is quite common” for caregivers in China to

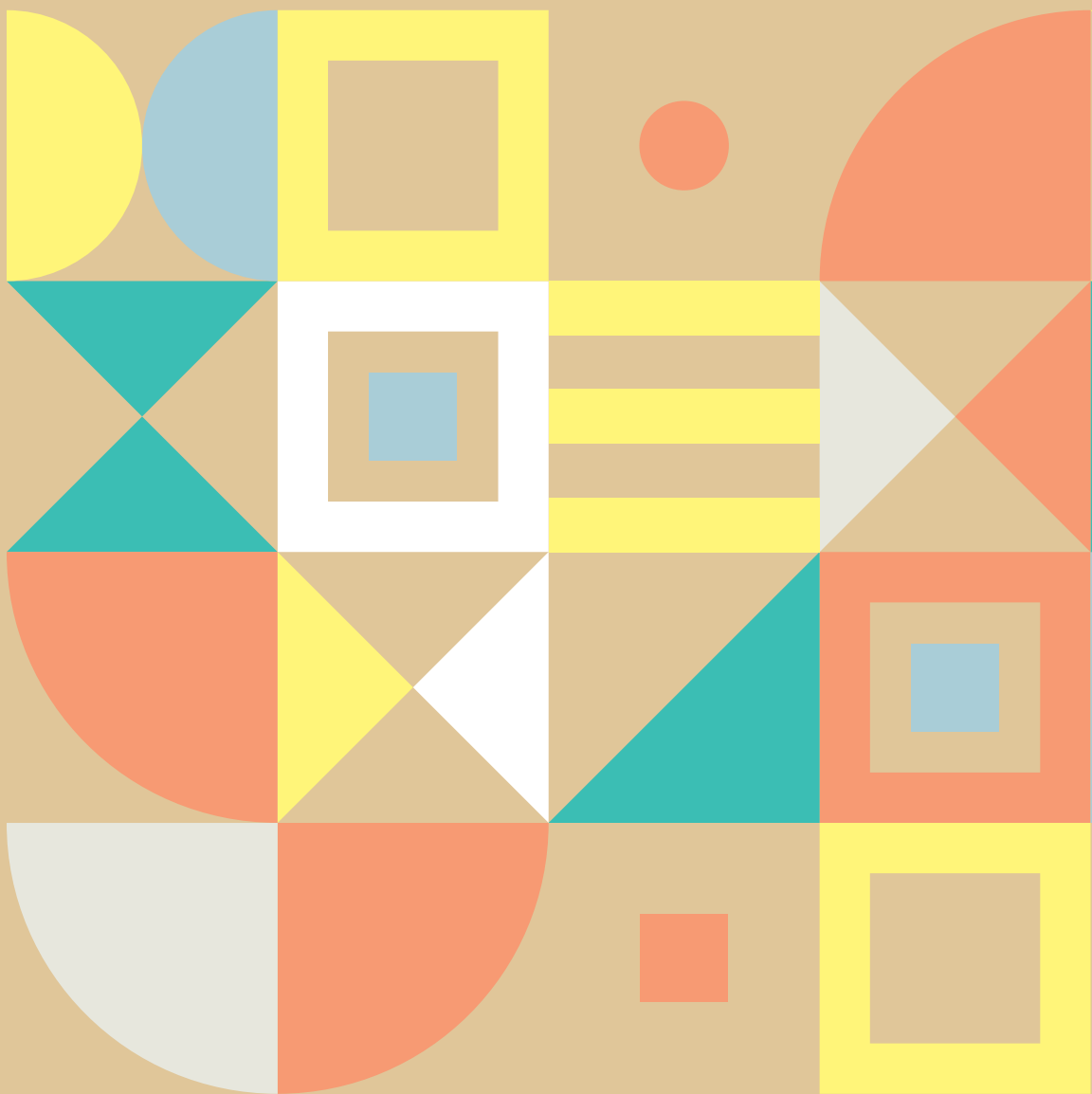
stay with their children at school all day. Yet, parents actually felt discouraged from attending Australian schools: “They [teachers] just tell you that that the classroom is not for you; it’s for the students and the teacher”. In an Australian context, parents said they are told by the teacher “okay, go home, mum”.

It was not just the limited interaction between parents and teachers that was challenging, parents also found that the home-school “communication channel was very frustrating”. When some parents “asked for [school] contact details” they were told that they “need to speak to the office”. Parents stressed the importance of their own “privacy” and their “child’s privacy”, so using generic communication channels was sometimes felt to be problematic. One parent reflected: “You can’t e-mail the teacher, you have to send an e-mail to the reception” so “with the psychologist report and everything, I have to send it to the reception and it’s exposed to everyone”, adding “Oh my God, I want to keep that private”.

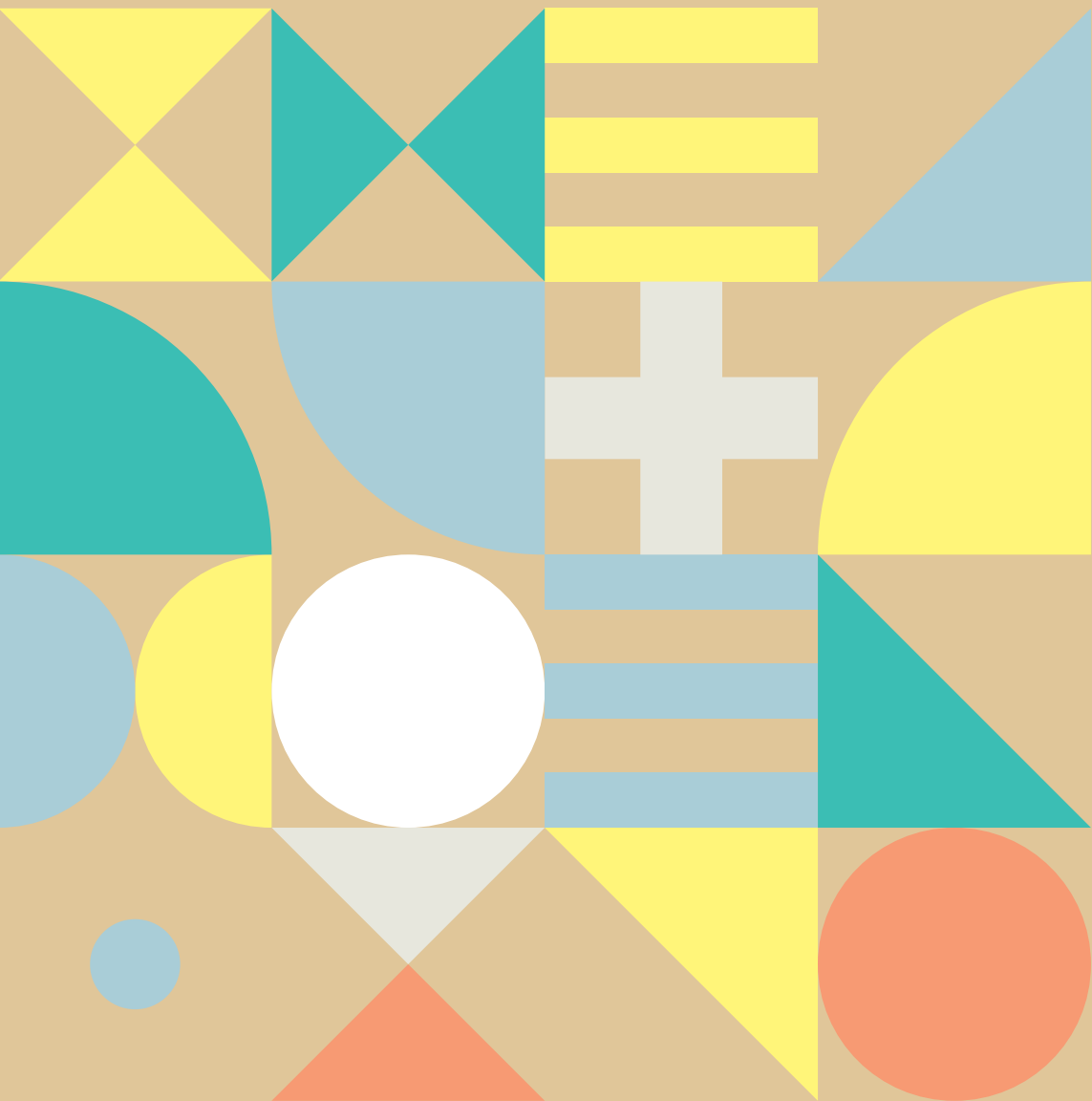
Since parents felt they were neither given open and honest feedback about their children nor encouraged to attend school in person, one alternative way for them to gather information was to “volunteer in the school” where: “I can observe and find out how she’s doing in school”. As one parent described: “I actually took a very active role in taking part in the school’s parent helper program... I have the chance to see how my kid is going with the school’s life”. Parents were especially keen to observe how their children managed “maintaining relationships”: “I want to find out whether she can make friends with other classmates”.

SUMMARY

- Chinese parents were devoted to their children and felt responsible for their child's progress at school. These parents had high expectations of their children – especially around academics – and found it frustrating that teachers did not appear to share their expectations.
- Limited knowledge of autism, education and funding systems made it challenging for parents to navigate the Australian education system – including knowing their own and their child's rights. Parents also often worked during school hours which made physically attending school during this time difficult, especially since they often lacked extended family supports in Australia.
- Chinese parents maintained distinct boundaries between home and school believing that teachers were the professionals. Parents were profoundly respectful of parent and teacher roles and were deferential, polite and respectful in their interactions with teachers. Parents were reluctant to impose upon teachers and actively seek out information. Parents also felt discouraged from attending schools. Sometimes they sought other channels, especially through volunteering, to get first-hand information about their children.
- Chinese parents felt that they were not always given open, honest and consistent feedback about their children. Parents described often hearing only positive feedback but not being told of areas their children were struggling with. Parents found this frustrating because they wanted to know what their children would benefit from being supported with at home.



3. VIETNAMESE PARENTS' EXPERIENCES



VIETNAMESE PARENTS' EXPERIENCES

We interviewed 15 Vietnamese parents, including 14 mothers and one father, for this study. They had 19 autistic children between them, including six girls and 13 boys.

Two interviews were conducted in English by a Macquarie University researcher. The remaining interviews were conducted in Vietnamese by an experienced interpreter affiliated with Positive Partnerships. All parents were born in Vietnam. Parents began immigrating to Australia from 1987 onwards, some as refugees. Most parents arrived in Australia between 1990-1999 and 2000-2009. Parents had a wide range of education levels, with one parent having started primary school, four having finished high school and seven having completed a university degree.

Autistic children ranged in age between 3–18 years, with an average age of 10 years. Children likewise ranged in education levels from preschool to Year 12, with children fairly evenly split between primary and secondary settings. All children had an NDIS plan in place. Most children attended mainstream kindergarten and school settings, with three children attending special schools and the remaining children in other settings (e.g., dual schooling or a support class in a mainstream school).

“This is probably the worst thing about my school, but a lot of the classrooms are open, it’s very weird to me. When I say open, I mean, walls in between classes, but there’s no doors... [It’s] very annoying because you can hear other teachers. If another teacher’s mad in another classroom, you can hear them”

Year 11 student, Vietnamese background, selective-entry high school

ASPIRATIONS

“VIETNAMESE PARENTS ONLY WANT THE BEST FOR THEIR CHILDREN”

Parents clearly wanted to support their autistic children to have the best future they could. One parent said her “whole and sole purpose” was to help her child “integrate into society” and that she was “dedicated wholly to [her] son’s development”. As part of supporting children, caregiving was the priority whereby parents consistently put their children’s needs above their own. Parents, especially mothers, often did not seek employment to ensure they could be available for their children: “I’m very much on stand-by, 24/7. If the school calls, I have to be there... I can’t do any more work”. Another parent echoed: “I can’t imagine if I was still working during the day to be able to organise all of this; I cannot do that”.

Parents were “willing to go” to any and all “activities for disabled children”, “regardless of how far”. Part of prioritising caregiving meant that activities needed to focus explicitly on supporting children, not on themselves. One parent stated that she “can’t afford to have the meeting just to have a chit chat and have tea” (referring to a more informal, monthly parent support group); she would only participate in “more productive or more purposeful meetings” including “hints and tips” to “help [her] children”. Mothers spoke about spending substantial time at their child’s school, especially when they were initially transitioning to formal education. One parent described how she would “have to sit in front of the kinder with a chair so she [her daughter] can see the back of my head; six hours for her to just be in the classroom”.

PARENTS WANTED THE BEST EDUCATION FOR CHILDREN BECAUSE “STUDYING IS THE TREASURE”

As one parent put it: “All Vietnamese parents are very focused on their [children’s] education and achievements”. For these parents “studying meant doing work on the paper, doing maths, doing English... you read the book, that means you’re studying”. Some parents therefore “prefer(ed) the Vietnamese educational system” because they saw Australian teachers as “more relaxed, more lenient, more open than the teachers in Vietnam” – to the extent, as

suggested by one mother, that children “would tend to play all the time and not study or learn”. On the other hand, they also valued Australian teachers: “They [teachers] show respect to the parents, they show respect, are sympathetic to the parents and the school children”. Another commented on how teachers “even kneel down to get the [children’s] eye level accordingly, look at the eyes of the students, make them feel good, make them feel comfortable”.

As parents both prized education and had specific views about what their child’s education should look like, choosing the right school was critical. Nonetheless, parents “didn’t [know] how to start, where to begin, how to find a school”. Transitions between settings were similarly challenging since parents “didn’t have that knowledge” when moving into “kindergarten, and then from kindergarten to primary school”. Parents weighed up many factors when choosing a school, including educational philosophy and faith orientation. They had to compare the “structure” and “understanding in morals” afforded by Catholic schools with secular schools that might better suit “[their child’s] level”.

Choosing between a mainstream and a special school was especially complex. Parents had high expectations of their children and felt that specialist disability provisions may not maximise their child’s capacities: “I would choose a school for disabilities. However, I feel that he’s got potential, so I put him in mainstream”. Indeed, some parents moved their children from special into mainstream schools since they perceived that teaching at special schools was “dependent on the lowest level of the class” yet their children were “not at a low level”. Parents were also concerned that their own child would be negatively impacted by meeting other children in disability-specific schools who were “more serious”: “It’s like if you’ve been surrounded by people that are screaming all the time, or people that melt down all the time, people having disorder all the time, then of course your kid will learn from those examples”. Anticipation of stigmatisation similarly played a role in parents’ decision-making here because if parents put “their son or their kids into a special school they [their children] will get labelled”. School choice was therefore both “extremely important” and “very difficult” for parents.

“When they turn 16, I always have a plan in place, an action plan. I tell the parents what they need to do. And you tell them, okay now the child is turning 16, you’ve got to remember Centrelink. Think about Royal Children’s Hospital. They may not be children any more, you’ve got to start looking for other hospitals that may not cater to your child... Start looking for adult day programs... What do you want us to work on your child when your child leaves school? What are you looking for? So I think when we have those really good, solid action plans in place, we really see success. You really see the parents also getting empowered. They’re on that journey... So by the end, when their child is ready for graduation, they are well informed”

Female teacher, special education school

PARENTS’ VIEWS, KNOWLEDGE AND EXPERIENCES

“I HAVE TO BE HER VOICE”

Since there was often no one else advocating, parents had to speak up on behalf of their children and their community: “It’s a battle we have to pick, which is a very tricky battle that we are forced to pick”. They had to “go the extra mile” to “help the child”. Parents felt that they must “speak out and fight for everything” – even parents who had limited English and felt “scared”, “not confident” and “very hesitant” would still “speak up on their behalf straight away...if the teacher’s done something not good for my children”. As one parent put it: “I myself will not be scared, but I would stand up and advocate for my kid”. Parents – especially those with more spoken English – similarly felt compelled to speak up to advocate for their wider community: “I want to speak up, I can speak up about all of the experience and other observations that I see in other parents, but because of their language barriers and their suffering, I want to speak up for other parents as well”.

“WE BEHAVE. WE DON’T MAKE TROUBLE”

It was commonplace for Vietnamese parents to defer to teachers. As one parent said, even when “Vietnamese people really want to say something to the school, to raise any concerns, they are hesitant to talk, unlike Western people”. Some of the deference was due to respect for professionals: “They [Vietnamese parents] never ask questions because it’s disrespectful if you ask the teacher anything”. Anticipated negative repercussions of speaking up also contributed to parents’ deference: “Vietnamese people are very reluctant to say or to give feedback to the schoolteachers or to the class teachers in case they formed a bad impression against the children”. On the one hand, parents’ beliefs, expectations and experiences of Australian education meant they often “lost the trust with the school”. Yet, on the other hand, parents were also aware that they needed to “have a degree of trust in [teachers]” if they were to be informed about their child’s education.

“Well, some of the girls are kind of racist and stuff, but that’s about it, I haven’t had any bullying or anything”

Year 8 student, Vietnamese background, Catholic secondary school

Part of parents’ deference was also because they were grateful and felt they deserved no more. It was stressed that Vietnamese parents “never speak up because we appreciate that we’re here. We are migrants. We’re here. We’re happy that we’ve got a place to stay, food on the table”. Compared to Vietnam, parents felt they were fortunate to be parenting their children in Australia; it’s “very lucky that all of those children get attention from society... a lot of attention and a lot of support”. Parents clearly appreciated the encouragement, care and respect their children received from Australian teachers. Their perceived fortune was especially mentioned in relation to the funding and supports available: “In Australia, there’s a lot of services, there’s a lot of agencies, there’s a lot of help”. Yet, this sense of gratitude for the comparative level of supports received in Australia compared to Vietnam made parents reluctant to seek additional funding or services: “I’ve already got the NDIS, then I don’t need [other programs] because I don’t want to put my finger into too many things”.

PARENTS, ESPECIALLY MOTHERS, EXPERIENCED STIGMA

Some Vietnamese parents spoke of previous experiences of stigmatisation, including overt racism, which affected their existing views and behaviour: “As a refugee, we always get told to send us back, or go on the boat and go back”. Parents also mentioned discrimination based on stereotyping at their child’s current school: “I feel very upset because they [teachers] showed some discrimination with Vietnamese parents... if there is anything, they would blame it on being Asian; they have racial discrimination against Asians”. Mothers spoke about mother-blame in the context of community beliefs about autism. One parent said: “It was [a] culture thing where lots of parents knew it but don’t want to accept it because they’re afraid that if they accept it, the family, or in-laws, or things, [think] they must’ve done something wrong as a mother”. When talking about understanding of autism in Vietnam, another parent echoed: “The relatives just throw the comment in the room and say, ‘because of the way the mother raised him... this is because of the mother’”.

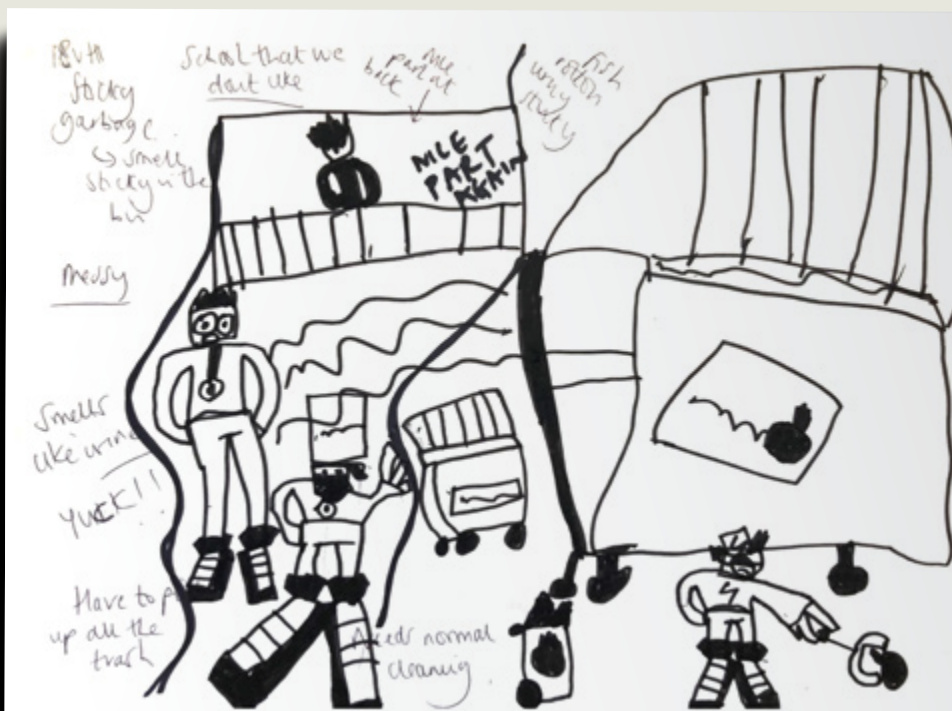
“I think generally, there’s just more of not wanting to rock the boat, kind of get that sense a little bit. Yes, we’re happy with everything that’s going on here. But if you could really, really ask them, maybe they would want something, but they’re not saying it. Just say what you want, it’s fine... When I was speaking, I was actually thinking about a Vietnamese family, when I was thinking of the not rocking the boat bit.”

Male teacher, specialist school for students with additional learning needs

IDEAL



NOT-IDEAL



Year 3 student, Vietnamese background, mainstream primary, Ideal/Not-ideal School drawings

IT WAS STRESSFUL AND ISOLATING TO HAVE TO “FIGHT FOR EVERYTHING”

As one Vietnamese parent stated: “It’s exhausting to the point that having to organise all the therapists, OT, speech, behavioural therapists, to sit in meetings”. Another parent said: “I can’t put my hand in anything else other than my kid.... I’m worrying all the time about her”. The burden of responsibility seemed disproportionately to fall on mothers: “My husband has got no idea about the autism... the Vietnamese husbands say, ‘I don’t care to raise children. It’s the job of women’”. Another mother mentioned that her “husband doesn’t give a lot of support”. Feelings of isolation were commonly reported by parents: “Nobody understands me... nobody helps me”, “I feel like I’m doing all this by myself”. Parents’ experience of isolation was further compounded when there was no extended family in Australia: “I live here all by myself, I don’t have anyone to help me”. Isolation was similarly amplified when parents found it difficult to make social connections within their child’s school: “I’m really upset that I haven’t known any parents of my children’s friends”.

The COVID-19 lockdowns also added to parental stress: “It’s such a stressful time for everybody... so, I’m just trying to keep track and making sure they are finishing their work... I don’t know what work they are doing. I can’t keep up”. Supports that parents typically relied upon were unavailable during the pandemic, including, for example, allied health:

“with regards to psychologists, you don’t have enough resource because of the COVID-19 pandemic effects because they’re too flat out with so much demand”. They were unable to have community group meetings face-to-face “now because of COVID” or even meetings with teachers: “because of the pandemic, I cannot proactively make an appointment”.

HOME-SCHOOL INTERACTIONS

HAVING LIMITED SPOKEN AND WRITTEN ENGLISH MADE EVERYTHING SO DIFFICULT

As one parent said: “I don’t know a lot about English... I’m not able to tell the teacher what I really want to say”. These parents also reported receiving less attention from educators: “Often, if you’re not good in English, then they [teachers] don’t share with you much... they don’t pay attention to your comments or your questions”. Parents who spoke more English expressed empathy towards other Vietnamese parents: “I can’t imagine how much struggle other parents would have, just to communicate their needs, to voice themselves for the goals they wish their children would have”.

Limited written English language was identified as a particular hurdle in the school context: “There’s a lot of newsletters or letters from school, bulletins, more of the newsletters or some information, but the parents cannot read”.

“The language barrier. They don’t know where to go. And I think they have got quite a few parents from diverse backgrounds who just don’t know where to go. They don’t even have a network because they feel a bit conscious because they can’t speak English very well. And I think that for them it’s like, I don’t fit into that social network of other English-speaking parents. They dress differently, they look different.”

Female teacher, special education school

“I guess, if I’m in a country where I’m not fantastic at the language, and I might be embarrassed that I can’t read, and I’m going to be asked a lot of questions, and I feel like I’m on trial, well, potentially, I don’t really want to go either.”

Female teacher, schools for intellectual disabilities and complex learning needs

Limited written English language was especially problematic during the COVID-19 pandemic since teachers largely relied on emails and apps to communicate with parents: “A lot of them [Vietnamese parents] just don’t know how to send emails. Even reading, even interpretation, they don’t have that skill”. Parents who were unable to use the school’s apps or e-learning platforms during the pandemic missed out on key information related to their child’s education: “Every week, they would give the calendar and send through the app to give the consent or notice form for the parent to say yes or no”. Parents were also unable to support their child’s education because they needed to go online to check their child’s progress: “So, last time she [the teacher] gave some homework to [child], but he didn’t do it because he didn’t understand, and I didn’t know either... the teacher didn’t let me know that he didn’t go online”.

PARENTS WORKED SO HARD TO ENSURE EVERYONE WAS ON THE SAME PAGE

Parents understood the value of “teamwork” in helping children achieve their goals. Parents wished that their school had “someone like a social worker who specialises in the connection or the communication between the school and the parents” as they were often the main person coordinating supports for their children: “I have to connect between the therapist and the school... I have to be the bridge between the therapist and the school” (see Box 4 for an example of successful coordination). Moreover, parents’ coordination role was required throughout their children’s school trajectory as, at the beginning of each school year, parents would often have to “explain [themselves] over again to all the teachers”. Parents reflected that “it would be nice just to have the teachers on the same page” instead of having to “go through all that process again”. Many parents discussed how coordination was so difficult because schools were not “very accommodating with

“So, staff at school, we don’t necessarily have access to the health professionals, whatever information they gather based on the student so it’s left up to the parents to give that to us. And obviously, that doesn’t happen all the time. And a lot of times, we may find ourselves doing completely different to what the health professional believes should be happening”

Male teacher, selective entry school

therapists coming into school” and their “wish” was that schools “should allow [therapists] to observe how kids are taught at the school... and to work in cooperation with each other to develop the same goal”.

Parents believed that effective collaboration was easier when the school’s leadership team was meaningfully engaged: “The principal there was very supportive. I sent my son there to start with and I was very happy because everyone was very supportive and encouraging and they supported us a lot”.

Without effective leadership, parents found it challenging to navigate school systems and work collaboratively with schools, even if their child’s class teacher was helpful: “Even though there was a very supportive teacher there, the system there is different. The managers or the principal were not very supportive”. Collaboration was also easier when there was someone “in the school to be the voice of Vietnamese parents”, to “convey the concerns, the frustration, to translate or to interpret into English”.

BOX 4. GOOD HOME-SCHOOL COORDINATION MAKES A BIG DIFFERENCE

Throughout our interviews with all Vietnamese parents, it became clear how important it was to have a dedicated person in schools to coordinate supports for autistic children.

Having a dedicated contact was beneficial for students, in consolidating and streamlining their goals, but also reduced the organisational burden on parents. One Vietnamese parent, Nghi*, of three autistic daughters, aged 3, 8 and 9 years, recounted an excellent example of good coordination between parents and schools and its positive effects.

Nghi came to Australia as a refugee in 1987. She is a single mother, who speaks English at home. Her eldest two children attend a mainstream government primary school, which had just created a new health and well-being coordinator role “to support the parents who needed that extra support”. The coordinator was once a teacher at the school and therefore well versed in the school’s systems and processes. Nghi is able to email the coordinator directly, who responds quickly and, when their main teacher is absent, passes on information about her children to supply staff, who “won’t have that time to look through all the child’s notes, things like that”. When her children “didn’t want to go into class” because unfamiliar teachers were present, the coordinator was able to “go and have a look to see what’s wrong and speak to

the emergency teacher”. The coordinator organised all the meetings: “they send the agenda either a day or a few days before so [she] can have a route to see that’s a goal, the strategies”. The coordinator always emails Nghi “option days and times” and is aware that she has two children so tries to “actually book appointments close together”. The coordinator is “in the meeting and takes the minutes”, and always sends the minutes on to the mother so that she “can use this and forward on to the OT, the psychologist and see what they can do with [child] this term to help her achieve those goals; so, that’s very helpful”. Nghi also described how she is allowed to bring other professionals to meetings at school so “the teachers are aware of the child’s needs more”. She summed up the benefits of having experienced good home-school coordination: “I think that role is just so important that she understands, and she understands parents’ culture and their needs as well... the parents have better communication with not just the teacher but the whole school itself and the whole curriculum systems as well”.

* All names have been changed

“They’ve [the school] also opened, what they call, a community hub, because of the demographic. They do sessions up there, where they get outside people in, and do either educational sessions or they were doing a little playgroup. And it was mainly so that parents could be in the company of other parents that have similar situations, because, potentially, they can’t go to an average outing with other parents and have common experiences, feel comfortable discussing what’s happening at home.”

Female teacher, school for intellectual disabilities and complex learning needs

One parent mentioned how her child’s previous schools had parent meetings for Vietnamese parents which were “very important and very useful for the mothers that do not speak a lot of English... because they’re able to speak in Vietnamese, they can give more comprehensive and meaningful feedback, and they can say all they had to”. Being “on the same page for parents” was not only in the context of their children but also their community. Parents reported wanting the Vietnamese community to understand more about autism because greater awareness benefited everyone, including their own children: “You need to educate the communities, it’s about my own kid”.

SUPPORT FROM THE COMMUNITY AND OTHER PARENTS WAS CRUCIAL

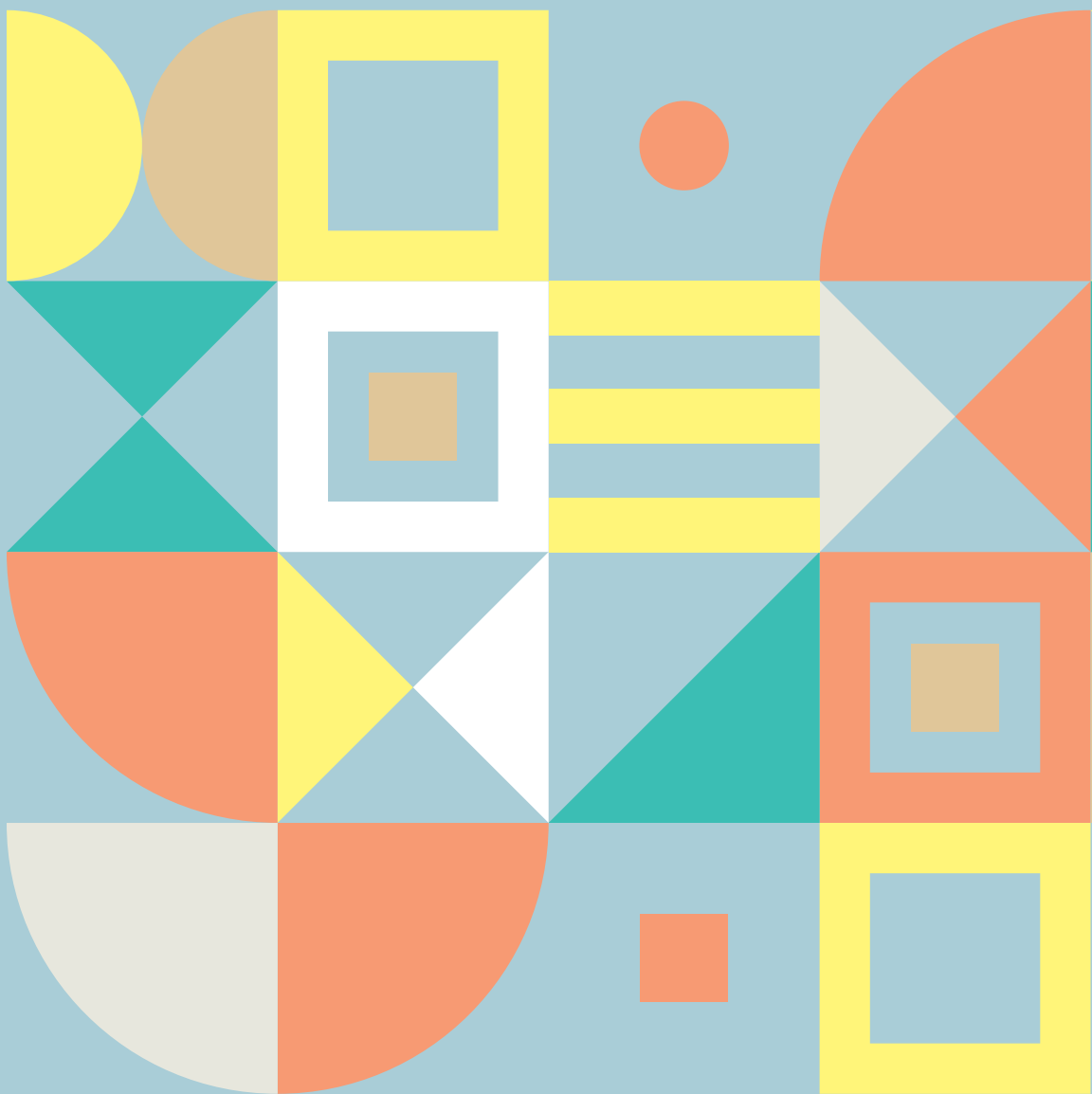
As “it’s really hard for any parents who are new who don’t have the English... or family, or friends”, Vietnamese parents felt that it was: “very important that the community is there and they know that we are here, also here. Other parents are here to support them as well”. One parent said how “in early days, like every two weeks, [she] would meet others on Thursday, and share all of the concerns, the anxious feeling, or some other feedback about cultural or ethnic communities”. Parents who spoke more English mentioned how sometimes when they go shopping “midway” they will “come across one of them [parents]” who will say “please help me, can you read this newsletter for information; I have no idea what these are”. Assistance from others often came in the form of sharing knowledge to both support and upskill parents. One parent reflected how parents often feel their “autistic kid’s behaviour will give a lot of discomfort to strangers and other people... make them feel embarrassed” so when parents “go into the [Vietnamese] association”, parents can “share” and listen to “speeches from the presenters” so “they learn more”.

“I get emails from parents saying, ‘my child is in year six, I don’t know what to do next year. I don’t know where to go’. I help them”

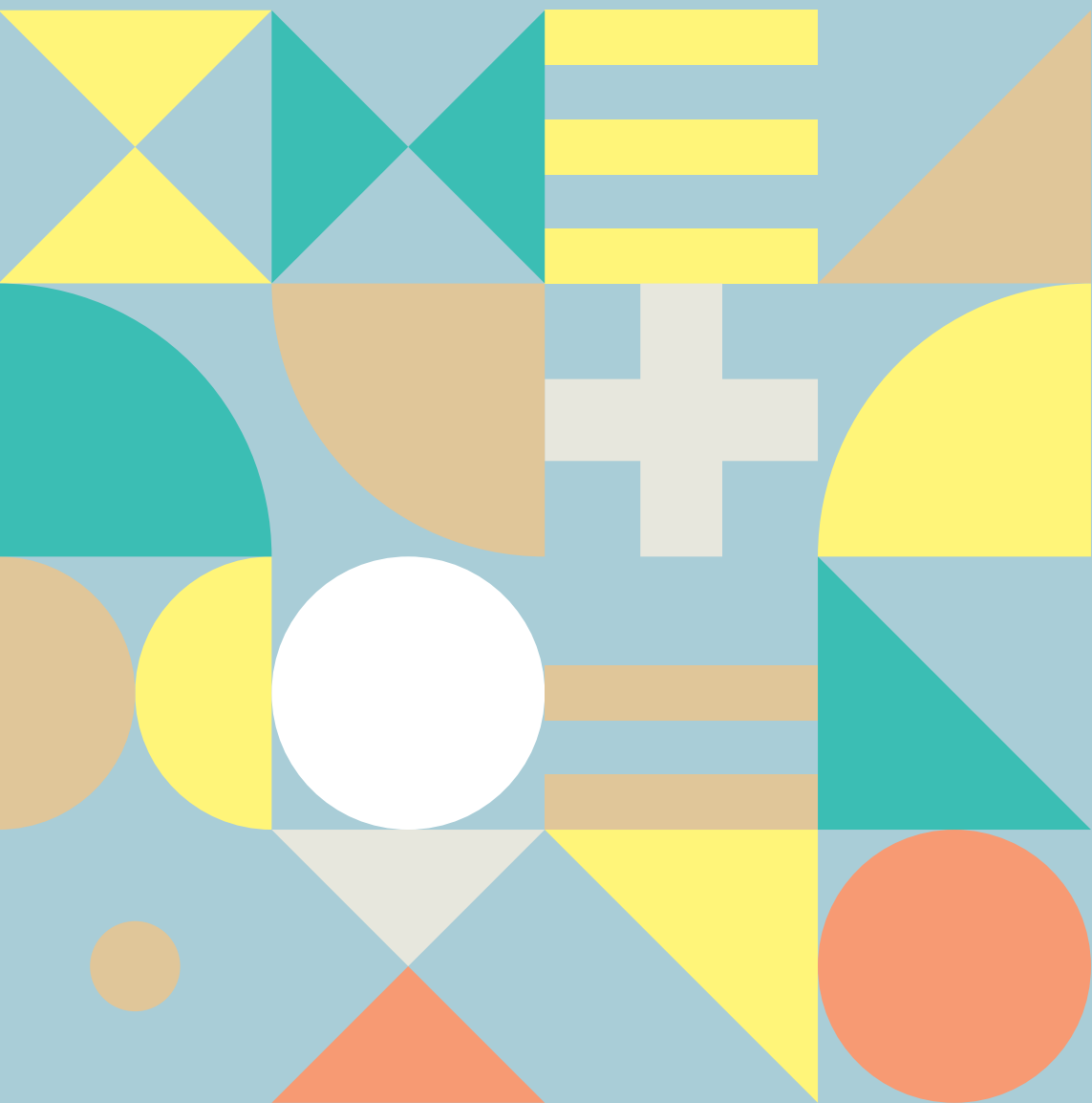
Female teacher, special education school

SUMMARY

- Caregiving was the priority for Vietnamese parents. Many parents, especially mothers, did not work because they felt they needed to be available for their children throughout the day. These parents wanted to support their autistic children to have the best future they could. Consequently, choosing the right school was critical. However, parents found school choice challenging since they did not know the Australian education system and had to weigh up factors including the school’s educational philosophy and faith orientation.
- Vietnamese parents were deferential towards teachers for several reasons. Parents were grateful for Australian opportunities and felt that they should not ask for anything more from schools. Parents were likewise respectful of the professional role of teachers. They also anticipated negative repercussions on themselves and their children if they addressed teachers directly.
- Having limited spoken and written English made everything so difficult for these parents. Limited spoken English made it difficult to talk to teachers and to advocate for their children. Limited written English language was identified as a particular hurdle in the school context due to frequent use of written communication such as flyers and newsletters. This was especially true during the pandemic with teachers largely relied on emails, apps and e-learning systems to communicate with parents and to set work for their students.
- Parents experienced autism and disability stigmatisation from their own community, as well as racial discrimination within their schools and the broader community. Mothers in particular spoke about mother-blame in the context of community beliefs about autism.
- Despite their deference, parents often felt compelled to speak up on behalf of their children and their community; they felt they had no other choice. They were able to overcome their tendency to be deferential, as well as language barriers and stigma. Yet, these experiences were exhausting for parents, especially mothers who largely took on the caregiving role. Feelings of isolation were commonly reported by parents too. COVID-19 lockdowns and limited extended family in Australia exacerbated these difficulties for these parents.



4. SOMALI PARENTS' EXPERIENCES



SOMALI PARENTS' EXPERIENCES

We interviewed 15 Somali mothers for this study. These mothers had 20 autistic children between them, including three girls and 17 boys. Aside from one interview conducted by a Macquarie University researcher, all interviews were conducted by an experienced interpreter affiliated with Positive Partnerships, largely in Somali.

Most parents were born in Somalia, with the remaining parents born either in the USA or Algeria. Parents moved from their home country from 1991 onwards with most parents arriving between 1990-1999 and 2000-2009. Parents had a wide range of education levels from no formal education to completing university degrees. Most parents were Muslim.

Autistic children ranged in age between 3–17 years, with an average age of 11 years. Almost all children had an NDIS plan in place. Many children attended special schools, with two children in kindergarten, three children in

mainstream school and the remaining children in other settings (e.g., Independent settings or had completed school). Children ranged from preschool to Year 12, and were fairly evenly split between primary and secondary settings. Families were often large, with most having four or five children.

ASPIRATIONS

PROUD AND LOVING MOTHERS

Mothers often spoke affectionately about their children. One mother stated: “I’m very proud of him. I love him and I love supporting him”. Another echoed: “I have so much love for him and I only want the best for him”. They also expressed an enormous amount of pride in their children. As one woman said, “I would never hide [them]”. But these opinions were not shared by everyone in the Somali community. Mothers noted how they had witnessed other Somali “parents and children around Australia... hiding that their children have autism” and that, while some admitted initially trying to “keep it on the low”, they soon realised “okay, there’s nothing wrong with it”. They were emphatic that they did not “want to be insulted” for having an autistic child; rather, they wanted to “talk about the fact that [their children are] on the spectrum”. There was also a strong desire for other parents to “bring their kids out in the open” because, as one mother metaphorically stated: “Somalis say, *‘waxaad qarsatit way ku qurmiyaan’* (‘if you hide something it will smell and make you smell’). The more you take your children out, the more healthy and happy that they’ll be”.



Year 7 student, Somali background, mainstream secondary, Ideal/Not-ideal School drawings



Year 7 student, Somali background, mainstream secondary, Ideal/Not-ideal School drawings

“When they try to put lots of detail. For example, in English my English teacher, we were doing this essay, and she made it clear enough for us to understand and make the essay, but not too easy that it’s a very bad essay by being lazy and not putting effort into it.”

Year 7 student, Somali background, mainstream secondary, describing what teachers do that makes it easier for him to learn

MOTHERS HAD “HIGH EXPECTATIONS” OF CHILDREN

Mothers consistently reported having high expectations for their children. One mother stated: “I would say to Somali parents to encourage their children on the spectrum to be their best and to reach their potential”. Indeed, supporting children to ‘reach their potential’ was a common refrain from mothers: “Early intervention is very important so that children have a chance of reaching their potential”. They likewise felt it was important for children “to be challenged”, not to be “talk(ed) down”, and to be held “accountable for [their] actions”. Mothers especially had high expectations about what their child should be able to do independently. They wanted their children to “learn to be independent” and get “ready for life”, “equipping [children] as early and young as possible so that they are able to participate in society, and are able to contribute to society”. Mothers saw teaching children basic adaptive skills as the first step towards achieving independence. Accordingly, mothers prioritised teaching children to “learn how to use the toilet” and “to get [themselves] to school, get dressed... have a shower, those sort of things”. Self-sufficiency in community contexts was also a priority. Mothers taught their children “how to use money” to “learn to buy things”, “to walk by themselves”, to “go shopping”, to “orient” them to where they “live”.

Mothers spoke of how they appreciated it when professionals worked together with them on these day-to-day activities: “I’m teaching him how to have a shower with the guidance from the OT”. They also reported, however, that it was frustrating when these skills were not being reinforced in the school context: “Sometimes [teachers] will say that they’re going to teach him something and they don’t, for example, toileting, or putting on his clothes. Unless, you know, I help him learn these things, I haven’t seen how they’ve taught him anything”. In addition to valuing hands-on support, mothers also found it “really incredibly helpful” when they received information about strategies and services that assist with activities of daily living, for example, learning “about incontinence” or having “people coming in from Carers Victoria, people coming in from Centrelink”.

PARENTS' VIEWS, KNOWLEDGE AND EXPERIENCES

MOTHERS WISHED SCHOOLS WOULD UNDERSTAND AND SUPPORT DIFFERENCE

Some parents had really positive experiences with schools: "Look, everything I've said about the school and teachers is true, they're wonderful... I often ask myself because I don't know how to thank the school. To show my gratitude for how they've helped my son". However, most mothers were concerned that schools did not sufficiently understand and support difference. They wanted their children to be "treated well and nurtured" and to be proud of being "Somali, black, Australian, all of these things". This desire for schools to appreciate difference extended to the broader Somali community too: "Somali parents need to be made to feel welcome in the school. Somali parents often feel like they're on the outer". Mothers sometimes spoke positively about Australian education: "Look, everything I've said about the school and teachers is true, they're wonderful". Yet they also felt that "teaching professionals" often put their children in "the too hard basket". They were frustrated by others' "ignorance... their unfair judgement of [their child's] disability". This ignorance often meant that their child's needs were neither accepted nor accommodated. In the school context, mothers felt that teachers just "focus on neurotypical children, neurotypical everything" (mainstream secondary).

Mothers recollected how teachers "had no patience" [mainstream secondary] with their children, forgot that their children did not "really like loud voices" [kindergarten] and, rather than understanding that bus trips to school may be "too long, too noisy" for some, teachers just say "put [them] on the bus, it's good for [them], [they'll] get used to it", even when their children

are "on the bus... crying, screaming" [disability-specific setting] each day. Mothers wanted schools to "recognise that not all students are going to do things in the same way, understand things in the same way, speak in the same way or even speak at all". They further reported this lack of appropriate adaptations extended beyond education settings. As one mother stated: "There has never been a place where they've said, 'bring your child here and they'll be safe, and we can accommodate them'".

Interviewer: "What makes a good teacher, do you think?"

Young person: "That's respectful. That helps you to get your goal."

Interviewer: "And what makes a bad teacher do you think?"

Young person: "That doesn't care about you, about your schooling"

Year 11 student, Somali background, mainstream secondary school

PERSISTENT LOW EXPECTATIONS OF STUDENTS

Mothers reported feeling frustrated "knowing that so little is expected" of their children. One parent lamented: "They [teachers] tell me, 'his level is low; it's too low'. They demoralised him. They discouraged him". Similarly, another parent stated: "If a child doesn't cause trouble but they're not doing great, there's a tendency to just let them do whatever". Such perceived low expectations were inclusive of behaviour, character, communication, and academics. One mother recounted how her child had been excluded from a school excursion because staff were "afraid that he would run onto the road". She replied: "Who says he would run onto the road? I would've told you if he did that".

"It [the special school] was bad... I kept learning the same thing... I mean there's no fun repeating the same things I know already... I want to do something that is challenging for me"

Year 11 student, Somali background, describing why he moved to a mainstream school

Another child had been putting his clothes into the toilets at school and coming home with them all wet in his schoolbag. When his mother eventually found out, she quickly informed teachers that this behaviour was unusual: "At home, he goes to the toilet, he's dressed nice, he's very clean".

Another mother was baffled that she needed to tell teachers that they could "expect [her son] to be kind – that should be a given". Low expectations of communication were also common. One mother said her son's teachers "seemed really surprised" when they "realised that [her] son communicates well with [her]", telling them: "I know you think he has limited language, but he does actually talk to me". These low expectations extended to academics. One mother was told by her son's teacher that he "doesn't try to read in class" and she had to clarify: "Yes, he can read... he reads with the speech therapist". The breadth of low expectations led one mother to comment on the "tendency to low-ball or have low expectations of children of colour and boys especially". Similarly, another mother felt that low expectations of children of colour was "common across all schools" and she had even "spoken to other parents, culturally diverse women, including Somali parents" who "shared the same issue".

RACIST ATTITUDES

Prejudice was reported in several forms. Mothers felt that "Black children are made into adults, way before they're adults... there's just all the expectation on this child because they're tall". Another mother spoke of how her son was "pushed more quickly" and "transitioned early" because "the facility was just not for him" because he was "very tall". Worryingly, mothers also emphasised that their adolescent sons were unnecessarily feared because of their size. One mother said, "The school said, 'no, this boy is too big... he's too tall, he is going to hit people'", while another reported that a teacher had said, "if [child] comes to school, we're not going to come". As a result, they felt that greater accountability was placed on their children compared to their same-aged peers: "There are two children who both engage in misbehaviour but it is my child that is always ascribed the larger portion of the blame". Racist attitudes on the part of other parents were also reported. One mother described an occasion when a parent from her son's school said to her that her own child had "been rough on the children today" to which she responded "no, [her son] is a child also and he's the same age as them".

Ironically, these same children were also described as being infantilized by school staff. Mothers had to emphasise to teachers that their children were "actually quite smart" and teachers needed "to speak to [them] directly and explicitly... don't baby [them]".

"And, at the minute (during Covid-related home schooling), I'm calling every week, to put things in place, where students have quite challenging behaviours, sometimes and some parents are just trying to get to the end of the day. And so, then, sometimes it feels like you're adding pressure, even though, potentially, in the long run, it would make life easier. But to push through, and go through that really difficult time, I think, is really challenging for some parents, so try not ever to be judgy."

Female teacher, school for intellectual disabilities and complex learning needs

Another mother commented how her son “didn’t want to have a staff member constantly hovering near him; he became self-conscious”. Overall, they felt that, for autistic Somali boys, “there’s the disability element but there’s also the race element”, they have “so much working against” them.

MOTHERS OFTEN MANAGED WITH LITTLE HELP

One mother described how her child’s father “left [them] when [her] son was diagnosed with autism”. Another mother said: “Look, if I am honest, my husband has no idea what autism is. He doesn’t understand it”. Many felt “like there isn’t any [respite]” and that they feel “lonely and isolated and abandoned” and that “no one helps”. However, their daughters were a source of support, “actively helping [her autistic children] when they need assistance”. Another parent mentioned that her “daughter who is older than [her son] is the person who helps him the most, but the boys, they don’t help me”.

Mothers had few other resources to draw upon. They often had “big families”, which meant “time is limited”: “I am busy, I have five kids – that one-on-one time is hard”; “I’m dealing with four children, single mother, and also alone”. Mothers also had limited “language and the lack of understanding of how the education system works”. They reported not knowing that they could ask for interpreters. They also did not “know what [their] rights are as a family, what their rights are as children on the spectrum”. Multiple relocations also presented a challenge for these mothers. Children were born in different countries and states: “Three (born) in New Zealand, and six in Australia”; “I have four kids... born in Kenya, New Zealand,

Brisbane, Melbourne”. This lack of stability meant mothers were often unable to access services for their autistic children – “We found out we weren’t eligible because we’re from New Zealand” – and/or they were unfamiliar with services – “There was an organisation in Perth, when we were there, for a period. But in Sydney, when we moved here, there wasn’t any I knew of”. With so few resources on which to draw, pandemic-related restrictions and associated school closures were enormously challenging for many: “Since lockdown, it’s been really hard”.

SCHOOLS HAVE LIMITED AUTISM KNOWLEDGE AND EXPERIENCE

Mothers expressed the view that schools “don’t have experience or don’t understand autism”: “They had very little understanding of additional needs”. Remarkably, this was felt to be the case even in specialist disability settings. Many mothers had made the decision to send their children to specialist schools so they “can get more help” and be taught by teachers with specific “training in this field”. So, when these schools failed, in their view, to effectively support their children, bewilderment was coupled with frustration: “I don’t think they understood how you cope with someone that’s banging their head on the cement kind of thing? Do you know what I mean?”; “They’re always telling me, ‘he pushed this, he touched that, he took his clothes off’. And I’m thinking yes, he has additional needs. He’s not a child who can express himself”. Parents wanted “educational settings where there’s adequate staffing and staff that are trained with working with children on the spectrum”. They also just wanted schools to “accept that children with additional needs have additional needs”.

“And when there’s so many people in the bus, it was so awkward...”

And there was bigger boys... And I saw so many guys here. It was just a little difficult”

Year 1 student, Somali background, specialist school for students with additional learning needs

“To be honest, I felt overwhelmed, I felt like, well, I have to somehow fit in [child’s] needs amongst 25 other kids in that classroom. . . it just sounded like I couldn’t give everything that he needs.”

Female teacher, mainstream secondary school

MOTHERS EXPERIENCED STIGMA

Mothers often commented how “Somali parents don’t want to acknowledge each other because they’re ashamed they have children on the spectrum, so they just avoid each other – everyone dodges each other”. They also felt that there was a general “prejudice against Somali families”. One mother described an occasion when she was racially profiled:

I was driving my sons and their friends, and a man saw me telling the boys off for something while the boys were in their school uniform. He called the police and told them a woman who looked like me (and obviously it’s Brisbane and I’m a black woman) was verbally abusing children. The police then came to the school and told the Principal that they were worried about my children and their friends.

Mothers reported feeling that schools “bullied [them] as a family” and “accused [them] of being a bad parent”. One mother reflected: “I started to wonder whether this was the way they treated everyone or they treated my family like this because we were different”. Due to such prejudice, some felt that advocacy for their children may have a “racialised element” to it in that they come “across like an angry black woman” to others.

“I haven’t had experience where the families aren’t open or willing. . . Where they don’t see an issue, or they don’t think there might be something going on. I know there is a younger child who’s Grade 1, Somali family. I taught the sister. I don’t know for certain if the child has been diagnosed yet, but there are some significant behaviours, and the family were sort of in denial about it. And that has made it hard for that teacher.”

Female teacher, mainstream primary school

MOTHERS WERE STRONG IN THE FACE OF ADVERSITY

Parents were well aware that they needed to advocate for their children: “If you don’t go into bat for him, who will?” Consequently, they managed “to push, to agitate”, and “actively challenge the teachers”. One parent stated: “I don’t sleep until I come up with solutions to their problems”. Another parent echoed: “Even with all of my limitations... I ask around, I talk to people, I know there are ways to get around barriers”. Parents took strength from their religion, especially after their child’s diagnosis: “You come to accept what Allah has given you”; “God’s given us autistic children and people”. Religion also instilled other qualities in them: “In my religion, and in Somalia, I was raised with the knowledge that waking up early in the morning is a good time to learn and your mind is more capable of learning”. This meant that this mother would wake her son up each morning at 6am and “put a lot of concentrated time into him for that hour”. These mothers also sought out practical advice from others around them whom they trusted: “It’s been this one cousin who has been a godsend. She’s shared the things she knew, shared the services that worked for her”. Another mentioned that she “went to [friend’s name] and I took a notebook and I wrote down advice, tips and tricks”.

BECOMING COMMUNITY ADVOCATES

Mothers often stated that they “don’t really know other Somali people with children who have autism”. When they asked professionals if there were Somali families they could talk to about autism, they were told: “No, I don’t know of anyone I could link you up with”. There were also not “many Somali students at school”, perhaps “only, like, two Somalis”, and when they joined autism information sessions, “there were no Somali people attending”. As these mothers could not find existing Somali supports, they were forging ahead to build their own strong community “that gets on with things and is not tied down by the baggage of taboo” and “shame”. Mothers were aware that knowledge of autism in their communities was not reflective of autism diagnoses in their communities: “Well, you know, funnily enough we have a lot of people with autism, but our understanding is limited”. These mothers shared their own stories in the hope of fostering others’ autism knowledge and acceptance, including parents who already had children on the spectrum: “I’ve become an [information] point for my community, where I’m like, oh, well, okay, that sounds difficult, have you tried this and this and this”. Another mother recounted:

I said to them, ‘you should access this service, read these books to them, go on holidays, ask your children what they enjoy and give them access to those things’. That’s the advice that I give to other mums about having children on the spectrum... In fact, I want to write a book about this.

These mothers also shared information about autism with other parents who did not have diagnosed children, especially when they had concerns – “I find myself talking to people... I tell them about the stereotypical signs to tell if their child is on the spectrum” – even when such advice was unsolicited: “I’ve had four [mothers] who absolutely lost it at me but I don’t care”. This willingness to face backlash was because of the belief that wider acceptance would *only* be achieved by increased community awareness about autism: “The whole community needs [training]. Because they just don’t have any knowledge about autism... The one who doesn’t have the child with autism will talk ill of the person with the child that has autism. But if those people were also educated, they wouldn’t say such things”.

BOX 5: GOOD RELATIONSHIP-BUILDING

Throughout our interviews, it was clear that parents found it difficult to trust schools, making positive home-school relationships more challenging. One Somali mother, Yasmiin*, described how her son's school had worked very hard to build a trusting, open relationship with her.

Yasmiin is a Somali mother of four children. Her third child, Asad, is aged 6 years and autistic. Yasmiin speaks Somali at home. She fled the war in Somali, moving first to Kenya then New Zealand. Yasmiin arrived in Australia in 2006. She lived by herself with her two youngest children. Asad was attending Year 1 of an autism-specific school. When Asad started school, Yasmiin "was so afraid that no-one would care for Asad that [she] would park outside the school... just wait in case he wasn't being taken care of....was still imagining the worst". She "was vigilant of all the children's movements... would call often, would always be [at school] early and would linger". On recalling this, it brought "back the feelings of wanting to cry and of feeling powerless to help".

But the school "were always very patient" and never made Yasmiin feel like she was "bothering them" or that she "was making their job harder". She felt that they were there to "comfort" her and not "make [her] feel bad about the fact that [she] was acting crazy". To support her, the school would "sometimes get in touch after hours, send pictures of [her] son and his activities. They would follow up on everything. They understand every child's needs, their characteristics. They

showed compassion and warmth toward the children". Eventually, Yasmiin came to "accept that the school was there to support [her] and [her] family". She talked about how the school earned her trust. Small gestures helped to foster this trust, such as when teachers would "gently come and get [Asad] from me and hold his hand in the way that [she] would". She felt that all staff treated Asad well, not "necessarily [just] his classroom teachers".

Yasmiin reported that the school "communicates with [her] like there's no tomorrow... as if we're neighbours". She was overwhelmed at the depth of teachers' dedication, saying that sometimes "they email [her] from their homes at 8pm" and tell her "how his day was, how he ate, even if he's gone to the toilet - every single thing". Yasmiin recalled an incident of being racially profiled by the police where she was supported by the school. She said: "The police came to the school and told the Principal that they were worried about my children and their friends". The principal told Yasmiin about this incident saying: 'I just had to laugh at the police'" telling them 'That's ridiculous [that Yasmiin was a risk to the children]. Get out of here"'.

* All names have been changed

“There’s this little motto thingamajig where it says all teachers have the right to teach and all students have the right to learn and everyone has the right to feel safe. The teachers try and make the students feel safe and happy and make them feel happiness in the environment at school.”

Year 9 student, Somali background, mainstream secondary school

HOME-SCHOOL INTERACTIONS

INADEQUATE SCHOOL COMMUNICATION

Mothers felt that teachers did not keep them updated about their children. When one mother was asked if she knew how her child was doing at school, she simply replied, “Nope, no idea”. Others similarly commented that schools “don’t tell you that much”; they “can’t do the information, the education at the same time”. Where there was positive communication between homes and schools, mothers sometimes expressed skepticism: “The teachers always tell you, ‘they’re doing good and all that’, but ...I don’t know how they’re doing all these positive things. They’re not doing them at home”. At worst, parents thought of schools as openly dishonest: “I don’t like the lies”.

MISTRUSTING SCHOOLS

Somali mothers conveyed a deep mistrust of schools and school staff. Many factors, including inadequate communication, contributed to this mistrust. Mothers spoke of how schools failed to properly gain informed consent from parents, especially those with limited English. One mother found it “very upsetting” when her child’s school “did a referral or talk(ed) to someone without [her] permission”. Another mother explained:

I would like the process of schools referring children... to be a more informed process for the parent. Particularly, if there are language barriers present, the school should be more considerate of that. Beforehand, they should send out letters that are in Somali. When that assessment is happening with that psychologist, they should book an interpreter for the parent. The school needs to take their due diligence in making sure that they explain in a language that is understood by the parent throughout the entire process. It’s not enough to just get a form, explain to them in a language that isn’t their first “you have to sign this form to consent to a child psychologist”. That isn’t the best way to go about it, which I felt was what happened to me. And in fact, some people may not even understand what psychologists do, which can cause worry.

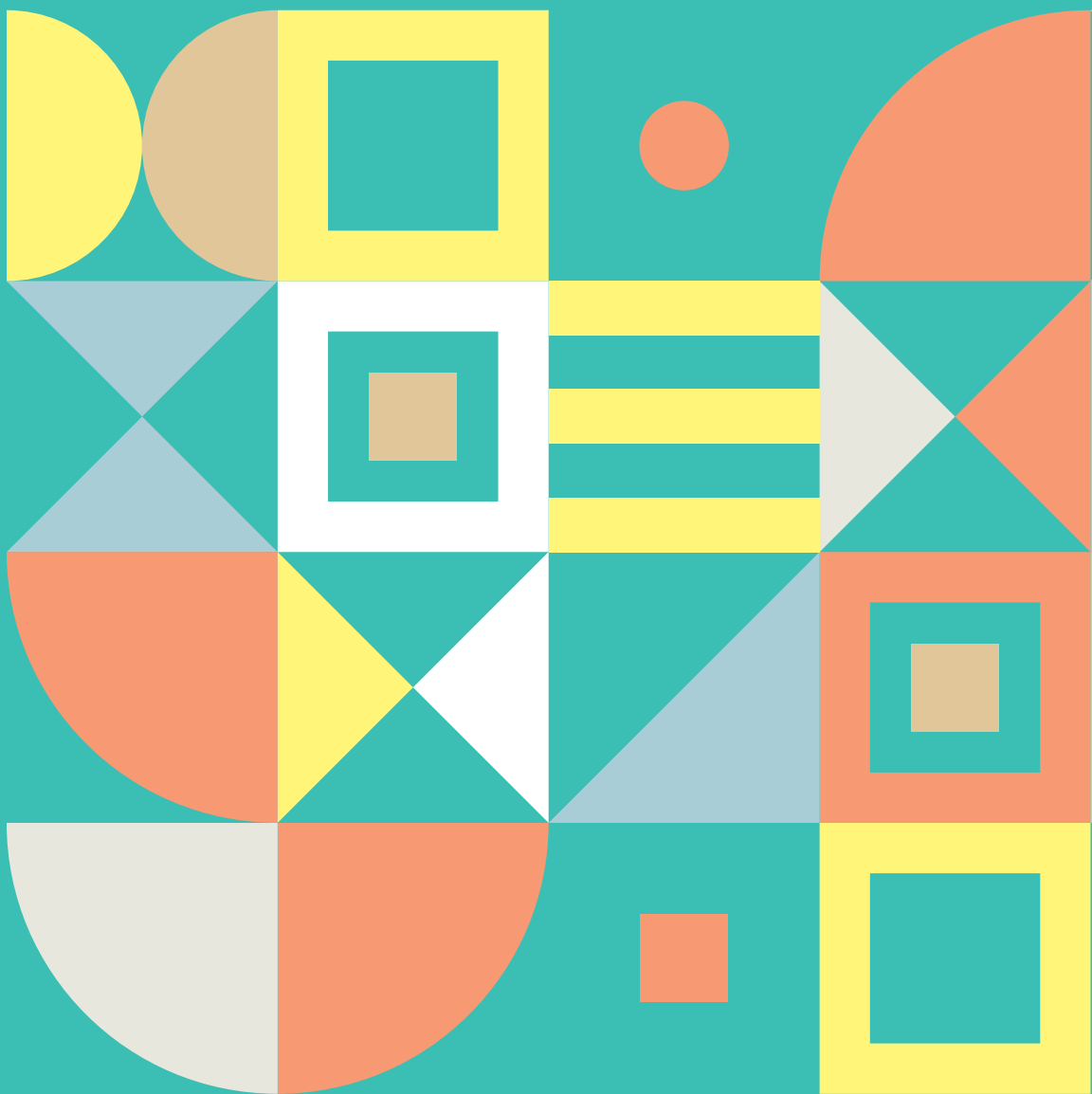
Concerns about their child's safety also played a role in fostering mistrust: "I don't feel that my son is safe at this school". As a result, some would tell teachers that they "would feel more comfortable" if they could accompany their children on school outings. One mother even described how she was "so afraid that no-one would care for [her child]" when he started school that, after she dropped him off each morning, she would "park three buildings down from the school on stand-by [like] a guard". That said, because of the consistency and support shown by the school, this mother eventually learnt to trust the school and they developed an effective partnership (see Box 5 for more details about this experience).

FEELING VALUED

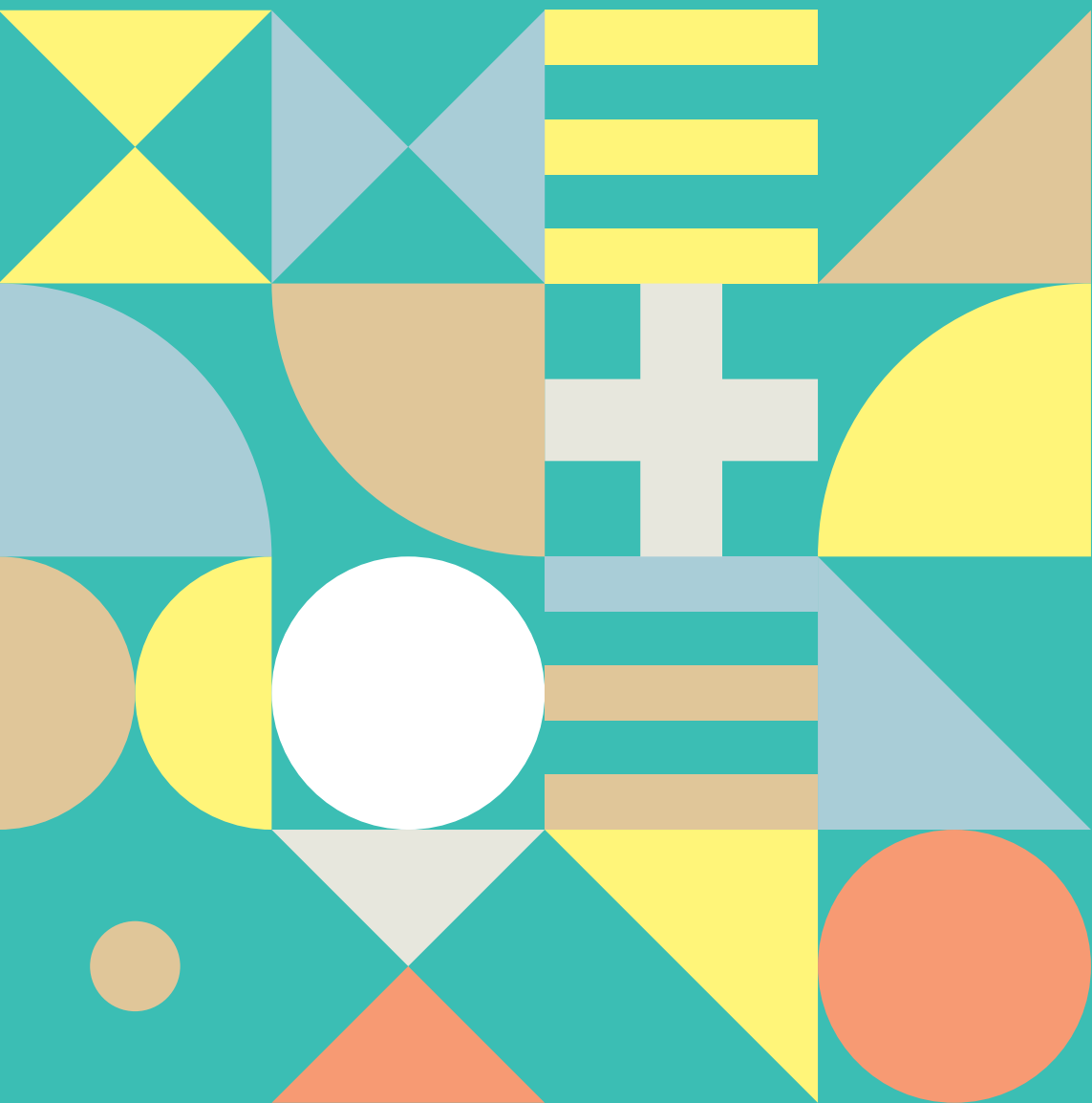
As it was often "hard to feel that you belong in the school", mothers spoke about the importance of being valued. They wanted Somali parents "to be made to feel welcome in the school" and for there to be "an acknowledgement of culture", "a small gesture that the school and teachers can offer to make Somali parents feel welcome". Mothers saw the value in having a Somali speaker who "can facilitate how parents and the kinder can work together for the success of the child", and that they "would really benefit" from someone who "could explain everything, interpret, help with translating school notices". But, more than anything, these mothers wanted their child to go to a school that was there to "support them and their family", where "the staff say, 'we appreciate you as much as you appreciate us'".

SUMMARY

- Somali mothers expressed a great deal of pride in their autistic children. They had high expectations of their children, especially around independent and adaptive skills (e.g., toileting, washing, dressing etc.). Mother often felt that schools did not share similarly high expectations and failed to reinforce children's skills in the school context.
- Somali mothers conveyed a deep mistrust of schools and school staff. This mistrust was attributable to many factors including: inadequate communication; inadequate informed consent processes (e.g., for referrals to other professionals); concerns about children's safety; and, limited experience and knowledge of autism, even in specialist settings.
- Somali mothers and their children experienced prejudice in several forms. Mothers felt stigmatised by the Somali community for having autistic children. They also felt that there was a general prejudice towards Somali families from the wider community. Mothers reported that their children experienced prejudice due to their disability, colour and physical size.
- Somali mothers had few resources to draw upon. They often had big families and received little support from their children's fathers. They also did not know their own rights or their children's rights and, due to frequent relocations, were sometimes ineligible or unfamiliar with local services. With so few resources on which to draw, pandemic-related restrictions and associated school closures were enormously challenging for many mothers.
- Despite few resources, these mothers were fierce advocates for their children and their community. They were flexible and inventive in coming up with solutions to problems. They also took strength from their religion and from others in their community who bravely shared their stories. These mothers wanted to increase community awareness about autism within their community by sharing their own stories with others.



5. MIDDLE EASTERN PARENTS' EXPERIENCES



MIDDLE EASTERN PARENTS' EXPERIENCES

Nine parents, including seven mothers and two fathers, from Middle Eastern backgrounds were interviewed for this study, including one mother and father of the same child. These parents had eight autistic children between them, including one girl and seven boys.

Interpreters were offered but declined so all interviews were conducted in English by a Macquarie University researcher. Three parents were born in Lebanon, one in Turkey, one in Iraq, one in Bulgaria (who culturally identified as Turkish) and three in Australia (all culturally identified as Lebanese). Parents moved from their home country from 1970 onwards with a wide spread of years of migration (up to 2012). Most parents had a post-school qualification, including five with a TAFE or diploma, three with a graduate degree and one with post-graduate degree. Four were solo parenting. Most were Muslim, with almost all stating their religion was very important to them.

Autistic children ranged in age between 5 and 18 years, with an average age of nine years. Most children had an NDIS plan in place. Children attended a range of settings, including one in kindergarten, one in a mainstream setting, three in special schools and the remaining in other settings (e.g., selective settings or VCAL). Two thirds of children were in early years or primary settings.

ASPIRATIONS

PARENTS WERE “NEVER GOING TO GIVE UP” TRYING THE BEST FOR THEIR CHILDREN

Middle Eastern parents described being intensively engaged in all aspects of their children's lives: “I wake him, I make sure he goes online, I check on him while he's online, I check with his tutors if he's done his work, if he understood it. I make sure with his tutor outside of school that he's doing what he's supposed to do”. Another parent echoed this sentiment: “I am very involved. I do everything for him, basically”. Parents were always “full on watching, listening, observing, connecting”. For some parents, supporting their children included overstepping boundaries: “I want so much for my son... sometimes I don't really care what boundaries I'm crossing”. This commitment to intensive support meant parents sacrificed many things: “I had to sell my house to help my kids”. One parent even described how he relocated his family from Turkey following his son's autism diagnosis:

There wasn't much in Turkey to help children who have autism. So, what I thought, I said look, let's get [in] contact with Australian officials and let's see what we can do for our son. If it's necessary, take my son, go to Australia, and start whatever curing or therapy or whatever and I'll come and join you as soon as I can. And this was a very radical idea because we had to sacrifice many things. My son has siblings and things, they're going to school, we had a house and things in Turkey. I had a good job and position. But she [his wife] accepted... And I sold my car and I sold many things, household things and we gathered the money and I sent my wife with my son to Australia and they started doing something here.

BOX 6. THE VALUE OF HOLISTIC SUPPORT

Many parents felt frustrated by siloed services and by a lack of coordination across supports and settings. Zaina, a 24-year-old single mother of Lebanese background, born in Australia, described a positive experience of a kindergarten working hard to coordinate across settings, including trying to successfully transition her son to school.

Zaina speaks Arabic and English at home. She has two children, one 5-year-old boy diagnosed with autism (Ahmed) and another younger child going through the diagnostic process. Her children's father (who does not live with them) was born in Lebanon. Ahmed is currently attending a mainstream kindergarten. Zaina had a negative experience with Ahmed's previous childcare when "he came home with a very big bite mark on his arm that no one informed [her] about" and who "brushed it off" when she complained. Ahmed was now in a new kindergarten that she was "really happy with". The teacher communicated well with "phone calls, they have an app, where they write down observations and they take photos and they say what they've done during the day". They "always constantly ask [Zaina] how the speech and the OT's been going, want to hear how his morning was, is he okay, is he settled, what can we do?"

Zaina feels that "the kindergarten that he's in now are like a family and they really actually genuinely care about the children". She said

that the new kindergarten is "always involving him in activities, whereas the other childcare was just like they're just there to make sure that he's okay kind of thing". Ahmed "tends to repeat things, or sometimes he tends to lose interest" so they ask her to tell them "about what does [she] think Ahmed would like to learn about this week". They "would sit down and talk about it... what [they're] doing differently at home or at the childcare, what can make him more happy and more settled in the mornings, stuff like that". They ensured all staff were aware of Ahmed's needs so "even when there's a new educator the other head educators would inform them [of] everything about [him]. They would give them the file and let them know that this is his condition, he's got autism, this is what he likes, this is what helps him calm down when he's upset, stuff like that". They were also trying to ensure Ahmed's transition to an appropriate setting for Year 1 so have "recommended a school that they think that [her son] would thrive in".

* All names have been changed

When it came to supporting and advocating for their children, parents said they "won't shut up". "I'm very vocal with my son [regarding his education]. If my son's got concerns, I make sure that I investigate it". Another parent similarly commented: "If the first one doesn't work, we're going to find a different solution. I'm never going to give up". One parent described how her son had initially been refused enrolment to his local Islamic school, which

his older sister attended. When she heard her son had not been accepted, she put her "foot down and said to them, 'I'm not going to accept being pushed away because I want him within our community'. You understand very plainly, bluntly, that I'm not going to take a step back?". She explained that she had told them that she was "not going to accept it" and "they knew [she] wasn't joking". Her son was accepted into the school his sister attended.

PARENTS JUST WANTED THEIR CHILD TO BE ACCEPTED

Several parents who described initial difficulties enrolling their children in their chosen school subsequently had really positive experiences with the same school: “That was the first hurdle and the only hurdle I had with them, because when he got into the school, their support has been phenomenal”. Another parent who recalled “begging [the school] to accept her son detailed how in “just [a] few weeks” “everyone started knowing [his name], everyone in the school calling [child’s name], ‘hey, how are you doing?’”. Similarly, one parent who moved her son to a different kindergarten following a negative experience found the new kindergarten to be “very welcoming and warm” where they had “other children that are also special needs, so they knew what to do and are always prepared”. There was a feeling that schools “just feared that [children] would be more challenging” but, once their children had transitioned schools could be “astonished at how beautiful” and “smart” they were.

PARENTS’ VIEWS, KNOWLEDGE AND EXPERIENCES

PARENTS FELT SCHOOLS WERE NOT FLEXIBLE ENOUGH

Parents felt that “each (autistic) child has their own learning journey” so “the curriculum should change for [children], rather than [them] fitting into the curriculum”. Lack of flexibility was more frustrating for parents who opted for specialist education settings for their children: “Maybe for the special developmental school, they might have some flexibility to contact families out of the box”. In particular, parents felt that there were no allowances for their children’s behaviour in specialist settings: “I always get a call because he’s doing something bad. I did tell them. He’s in this school for a reason, he’s autistic”. One parent described her bewilderment when her son’s school “started to suspend him” because of his challenging behaviours: “I’m saying, well, this is a special school. You guys have to find the solution for that”.

Parents expressed the view that school inflexibility was in part because “there’s not a great understanding of autism in the school environment”. They described how some individual teachers were very knowledgeable and experienced and able to “manage many things – like if some child is going to throw

“A good school, I would say... you can do stuff like that. You can talk about a joke. You can talk to others. The teachers are not too lenient on the rules like they don’t give a care. But they allow students to do what they want. But in exchange, they’ll be getting benefits as well. Students will be good.”

VCAL student, Lebanese Background

“Apparently I’m separated from everyone else and everyone else is allowed to sit with each other and I’m separated... It’s not fair.”

Year 2 student, Lebanese background, Islamic school

“If you know a bit about the culture, you can draw or point to a knowledge of that. For example, a Middle Eastern background, knowing the stereotypes within that lifestyle in this country and then in another country, you understand the thinking of a student without necessarily knowing the language.”

Male teacher, school for mild intellectual disability

“I think it is the hardest barrier for parents, and we, being teachers, also it is hard. I think in some families it is a denial, like I have experience with some families who still think that it [autism] is curable.”

Female teacher, special disability school

some toy in someone's face, they'll say no, no, no, don't do it... they know each child's hobby and triggers and warning". In general, though, parents wished teachers had more training and knowledge about autism: "If the government gave more power and more education to teachers to flag these children, they would be able to receive more help earlier".

“I THINK THE WAY I LOOK IS THE BARRIER”

Parents recounted facing overt discrimination during their interactions with schools: For example, one parent (who wears a hijab) described how she was treated differently by teachers when speaking to them over the phone when compared to in person interactions:

When they see me, I feel like their reaction's a little bit different. Whereas when I'm on the phone they're very, I don't know, like we go back and forth, we talk and there's a lot of information. But then as soon as they see me... I don't know, I felt like I really don't understand so she's just going to give me minimal information.

Her husband validated her impression, contributing it “sounded like racism and disrespect; that's how it was”. Another parent also described historical racism she had experienced: “It was a bit hard because we were [the] only [students with a] Lebanese cultural background

there... We used to get bullied a lot. And I think that took a toll on us because at one point my Mum was like, that's it, she removed us from school and we just, we ended up doing a bit of homeschooling”.

COMMUNITY STIGMA AND MISUNDERSTANDING ABOUT AUTISM

These negative experiences included a lack of understanding about autism within communities: “I feel like when it comes to autism in the community of Lebanese people, they're mainly in denial and they don't understand that it's actually something that you need to get your hands on”. One parent described “false cure or things in Turkey”, like parents being told “if you use this, autism will go away”. Parents also worried that a diagnosis would impact their child's ability to get into selective schools: “There is a very big fear that no, no, no, I don't want to label my child, they'll reject him from this private school, or he won't be accepted here”. Overt stigma from family members was particularly confronting. One Lebanese parent explained how she had given her autistic son the same name as his grandfather “and when his grandfather knew he had autism when he was older, he said, I wish I didn't give the okay to you back then, I don't want a dumb person having my name”.

Stigma was reported as being worse for mothers: “So mum always gets blamed”. Another parent said: “It’s like the fathers are immune to sicknesses, it’s only the mothers. Oh, you did something wrong while you were pregnant, or it’s from your side of the family”. Mothers also felt they received little validation from fathers when they raised concerns about their children: “He thought I was over-reacting in a way, he was, what are you talking about? My son’s fine, he’s saying two words. I was, okay, but at this time he’s supposed to be speaking sentences”. As a result, these mothers took on greater caregiving responsibility for their autistic children, in addition to trying to shield them from stigma: “His own father said to me, what is that boy doing? He will never be a dad, like a daddy, or normal, he will not be anyone, he’s a burden on me. And that’s how he saw him, and I will never forget his words”.

“I DON’T HAVE ANYTHING MORE LEFT”

These cumulative experiences of discrimination, stigma and blame – coupled with disproportionate caregiving responsibilities – meant parents often felt depleted of all their resources. One parent said: “I’m always on my feet, always. It’s non-stop. The minute I wake up until I go back to sleep... Sometimes it hectic, it’s so bad the situation, that I start crying”. One parent described reaching her “limit” and being on “the edge”. Some were so drained from having to say, “I’m sorry my son’s autistic”, that they had chosen to “isolate [themselves] from others”, to “keep away from all of them”. Consequently, for many of these parents, “the hardest part” was “dealing with all that stuff alone”, with “no support from anyone else”.

“THE THINGS I GET IN THIS COUNTRY, I COULDN’T GET IN MY COUNTRY”

Many parents felt that the sacrifices they made for their children were worthwhile. A parent who sold her house to support her children’s therapy needs said: “It’s better than walls. I have now, kids that are educated, well-mannered, and they’re going to have a better chance in life”. Parents were incredibly appreciative of Australian opportunities: “I’m so grateful and I owe a lot to this country. Whenever, wherever or wherever I knocked the door [was] wide open and gave me information and help and aid”. Another echoed: “First of all, I’m very happy with the school. They are gorgeous. I’m grateful. All the team. And I know how they’ve been working really hard and really

with passion”. One parent stated how “each child can have a chance to thrive at their own passion even at the most basic... Even in Year 12, you’ve got the arts, you’ve got the sciences, you’ve got everything”, reflecting that “in Lebanon, it’s not like that”.

AUTISM ACCEPTANCE IS GROWING

These parents actively promoted understanding of autism within their local communities, often adopting a neurodiverse lens. They were “talkative”, “not embarrassed” or “ashamed” as it [autism] “has to be spoken”. There was an indication that fathers in the community were becoming more accepting. One mother described how she “sat there with [her] husband and tried to explain [autism] to him”, recalling that “after a while he kind of understood that it wasn’t something to be ashamed of, it’s actually we’re the ones that are wrong, it’s not them”. Another father reflected on his own changing perceptions: “Even myself when it first happened, I used to tell my wife that’s stupid, he’s just a kid. I never used to understand it” but now, “it’s a bit different”. Another father detailed his own advocacy; he “prepared Turkish translated pamphlets... made flyers and organised a hub (for Turkish men)”. Similarly, there was evidence that all schools – including faith schools – were becoming more accepting of autism. One mother described how she raised the possibility of having a neurodiversity week at her son’s (Islamic) school meeting commenting that “the school was very positive when [she] spoke to them”.

PARENTS WERE “PROUD OF THE MIX” OF BOTH CULTURES

These parents were aware that they were “living in a different country, different culture” and so had “to adapt... be open-minded”. As one parent put it: “Religion’s really dear to us and our culture’s dear to us, but we have a lot of Australian values, too”. Consequently, parents made their “rules a bit flexible” when it came to their culture and religion. One parent described this flexibility regarding her expectations about her autistic son learning Arabic: “I just wanted him to learn five chapters of prayers and they’re not big, they’re very small... He doesn’t say it perfectly, but he says it and he prays with it, and that’s all I wanted”. Parents felt that “maybe both parents and the teachers need to learn about each other’s cultures” as this would encourage “a mutual understanding of what we might expect”.

HOME-SCHOOL INTERACTIONS

PARENTS WERE OFTEN FRUSTRATED BY POOR COMMUNICATION FROM SCHOOLS

Some parents reported feeling “very comfortable with their communication” and felt that “there [was] a good line of communication between [them] and schools”. Nevertheless, many of these parents found communication between home and school inadequate. According to parents, part of the problem was that they had “very minimum contact with the teachers” and were unable to contact educators directly because “teachers don’t have a personal email”. Yet, it was the lack of proactive communication that was most commonly cited as the cause of parents’ frustration: “I mean, why didn’t you tell me from the beginning?” Rather than being regularly informed about their children, parents were often belatedly told about their challenges and difficulties, either during meetings – “by the end of the term, when we had our parent-teacher interview meeting, it was, ‘Oh, [child’s] not able to continue this way’” – or through

written reports – “There’s things in the reports that have never been told to me, or never been spoken about”. This communication gap was intensely frustrating as parents felt that only by being “told what [their child] is doing” at school could they “work on it at home”. Parents wanted more frequent home-school interaction, to “be summoned to that school, have a meeting, have a chat” in order to proactively support their children (see Box 6 for one parent’s account of a positive home-school interaction experience).

Unfortunately, inadequate communication from schools eroded trust between schools and parents. For one parent, a lack of school communication raised issues about informed consent. She recalled how her son’s teachers “don’t tell [her] until after they try” new strategies; but this mother felt that trying new strategies without her permission was akin to trying new “medication” without her explicit consent. Consequently, this parent reported intensely mistrusting new approaches implemented by teachers: “If I don’t know what is in it, why would you try it on my son? Maybe, it will have a bad outcome”.

“There’s, it’s like a short tree next to a table and every time we climb up the table then we jump onto the tree, and just sit there, and talk about stuff... It’s not that crowded as the playground where everyone is screaming in my ears.”

Year 2 student, Lebanese background, Islamic school

“For me, because I hadn’t had experience with autistic children, I’ve heard stories and I’ve seen from other classroom, but not so much in detail and in depth. It was moreso that her Mum who had approached me... for me to receive that information, I was actually quite surprised. So, I don’t really have much knowledge in it, but my understanding is it’s somewhat of a learning disability, should I say? Yes. That’s all I’ve got for now.”

Female teacher, Islamic school

“WHICH ONE DO I HAVE TO LISTEN TO?”

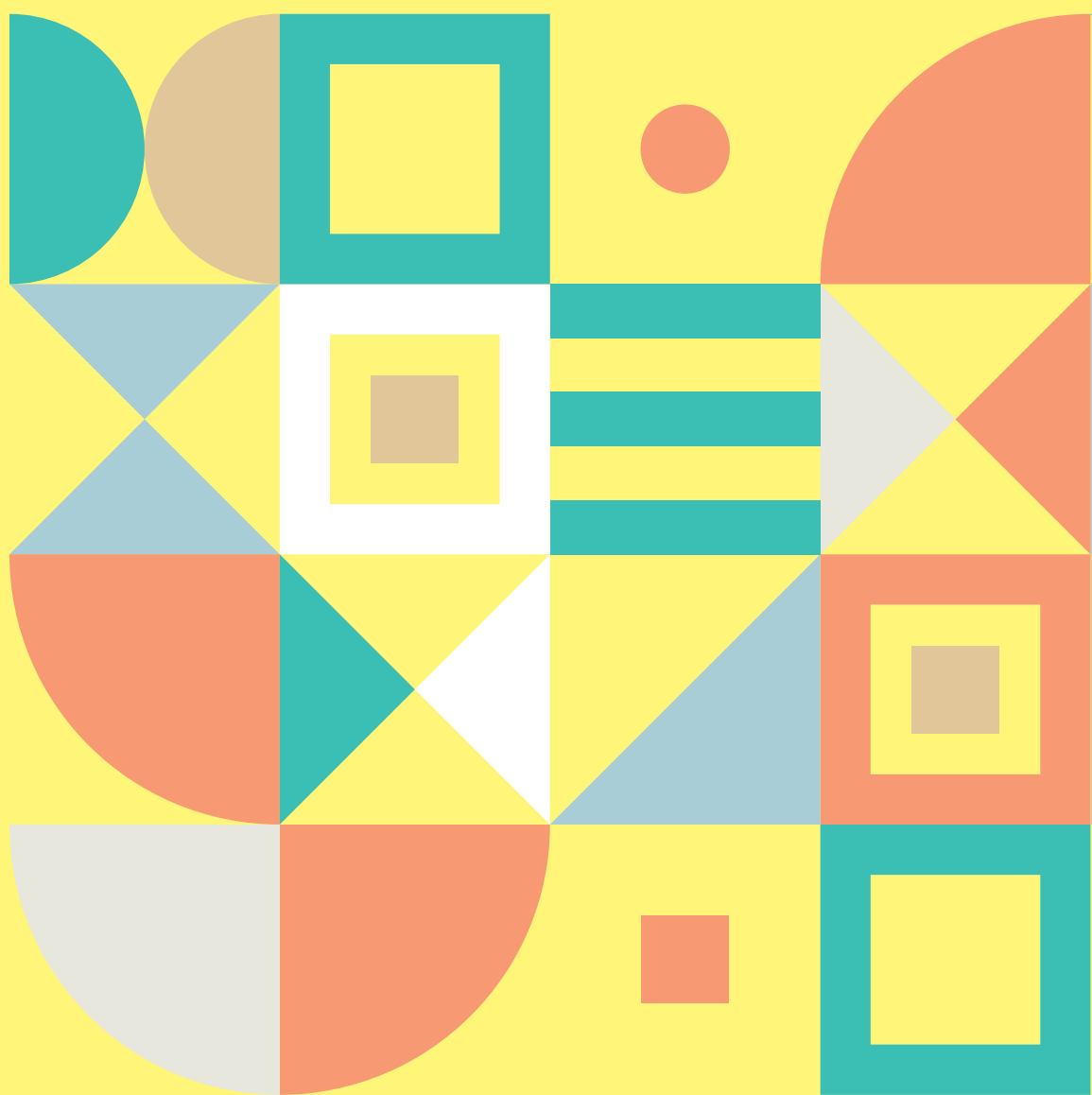
Parents' frustrations were compounded when they received inconsistent advice from professionals. Parents reported receiving conflicting advice from education professionals “about sending [their children] to mainstream, not sending [them] to mainstream”. They also received conflicting advice from medical professionals: “Between the GP and the pediatrician they're saying [the medication's] not quite right. ... Which one do I have to listen to?”. Even when parents were given consistent advice, it was often insufficient for them to meaningfully act upon: “And then they said, oh you know, maybe he should see a psychologist. How do I find a psychologist? Where do I find one?” Since parents were aware that effectively supporting their child “really is a team effort”, the lack of a comprehensive and cohesive “plan at home, school, therapy” was intensely frustrating.

COMMUNICATION IS MORE THAN JUST WORDS

Communication between parents and schools was obviously more difficult when parents' “first language isn't English”. As one parent explained: “Someone from the Middle Eastern community, if English is her second language, she's going to be very slow, very thoughtful” and worried about using “the correct word”. For some parents, however, it was pragmatics more than spoken words that complicated interactions: “It doesn't have to be the language, it might just be behaviour, the way we speak. I might do something they don't like, for example, gestures or body language”. Parents felt everything in Australia is “organised by a Westernised mind, by a Westernised criteria and logic”. In order to minimise misinterpretations and confusion, parents wanted communication from schools to be “simple[r]”, “more punctual” and further felt that schools should not be “afraid if parents get offended” by what they are told about their child.

SUMMARY

- Middle Eastern parents described being wholeheartedly engaged in all aspects of their children's lives and were unafraid to speak up on behalf of their autistic children to teachers and schools.
- Parents were frustrated by the inflexibility of schools, especially parents who opted for special schools for their children. Parents felt that school inflexibility was partly due to limited experience and understanding of autism.
- Lack of proactive communication was also commonly cited as a cause of parents' frustration. Rather than being regularly informed about their children, parents were often belatedly told what their children had been struggling with at school. Inconsistent and conflicting advice from professionals was also a source of frustration. This inadequate and inconsistent communication from schools eroded trust between schools and parents.
- Communication between parents and schools was more difficult when parents' first language was not English; yet this difficulty was not just due to spoken language. Parents reflected on how cultural differences in language use in social interactions led to misinterpretations and confusion between parents and schools. Parents wanted communication from schools to be more direct and straightforward.
- Parents reported overt discrimination from schools related to their appearance (e.g., wearing a hijab). Parents also reported widespread stigma and misunderstanding about autism within their own communities, including from family members. Stigma was described as being worse for mothers, with mother-blame common. These cumulative experiences of discriminative, stigma and blame impacted parents' mental health, often leading to isolation and exhaustion.
- Parents were proud of their mixed cultural backgrounds and experiences. They saw themselves as open-minded and flexible, incorporating values from their home culture with Australian values. Parents were grateful for opportunities afforded within Australia for both themselves and their autistic children. They also actively promoted understanding of autism and neurodiversity within their local communities.



6. CONCLUSIONS & RECOMMENDATIONS



CONCLUSIONS & RECOMMENDATIONS

This aim of this research was to understand what might improve home-school partnerships for parents of autistic children from Chinese, Vietnamese, Somali and Middle Eastern communities, giving a voice to families that are all too often overlooked in autism research.

In this Report, we have described the first-hand accounts of these parents' experiences. We adopted a participatory approach to ensure that our research was relevant to these communities and reflected the realities of their everyday lives. Our team consisted of autistic and non-autistic researchers, who worked together to design and implement the project. We also assembled four community-specific parent Advisory Groups, who drew on their own experiences to inform our research at each stage of the process.

Despite the differences between each of the four communities, parents nevertheless shared a range of experiences as they attempted to navigate the schooling system for their autistic children (see Figure 1). Overall, parents told us how much they loved and were proud of their autistic children. They had high expectations of their children and found it deeply disappointing that these high expectations were often not shared by teachers and schools. Parents were frustrated by inadequate, reactive and inconsistent communication from schools and

other professionals. In order to be able to support their children's skills at home, they wanted to receive timely, transparent and consistent feedback about their children's progress at school. Moreover, poor communication between homes and schools often led to an erosion of trust in parent-teacher relationships. Parents were also frustrated by the limited experience and knowledge of autism they observed in education settings, especially special schools and support classes. Parents were often exasperated by the lack of coordinated supports within schools.

Having limited spoken and written English made interactions difficult for many of these parents. Limited written communication, including few digital literacy skills, was especially challenging during the pandemic since teachers largely relied on emails, apps and e-learning platforms to communicate with parents and to set work for children. In addition to limited English language, parents also often had few resources to draw upon. They frequently did not understand aspects of the Australian education or funding systems and so were unaware of their own rights, or of the rights of their children. They often lacked extended family supports, and many were solo parenting. With so few resources on which to draw, pandemic-related restrictions and associated school closures were enormously challenging for many of these parents.

Parents also experienced discrimination in many forms. They reported widespread stigma and misunderstanding about autism within their communities, including from family members. Mother-blame was especially common in all of these communities. Parents, and sometimes children, also faced overt discrimination from the wider community, including within schools, with racial profiling and prejudice reported. These cumulative experiences of discrimination, stigma and blame impacted parents' mental health with parents describing feeling isolated and exhausted.

Many parents were respectful and deferential towards teachers, acknowledging teachers as professionals and describing clear role boundaries between themselves and educators. Parents often expressed gratitude for Australian opportunities and felt that they should not ask for anything more from teachers or schools. Some parents also anticipated negative repercussions on themselves and their children if they directly addressed their concerns to teachers.

Despite stigma, limited resources and deference, parents frequently felt that they had no choice but to speak up on behalf of their children and their community. These parents demonstrated flexibility and resilience in their advocacy, often trying to promote autism knowledge and acceptance within their schools and communities. They benefitted when community-specific supports (i.e., translated documents, interpreters, culturally-specific parent support groups etc.) were available to them, both within their schools and the broader community – and teachers saw the value in these supports, too (see Box 7).

FIGURE 1. COMMON THEMES ACROSS ALL COMMUNITY GROUPS.



BOX 7. TEACHERS' VIEWS ON WORKING WITH CALD FAMILIES

Teachers agreed that having time and space to consider parent and family wellbeing and parental mental health is important:

- *"I think it's important to allow us more time with them. We catch them after school, before school, those sorts of times, but really allowing us time. Yes, it's time and money, paying someone to take my class so I can show her what we're doing, so I can explain to her what we're doing with her little boy and how that fits in with our program. And yes, I suppose just allowing me more time with them because we just don't get it. We don't get time to talk to them."* [Female teacher, special developmental school]
- *"If I find that the parent is really struggling with their mental health, I connect them, I talk with the principal and say, hey, you need to get social services involved. Talk to the parent and see how they can support the parent because this parent seems to be at breaking point"* [Female teacher, special education school]
- *Family wellbeing, that's, it, you are their family wellbeing. You are staying connected, you are there, you get information from the teachers, then you go ahead to help them."* [Female teacher, special developmental school]

Teachers also agreed that more **training** would be beneficial:

Teachers also saw the value in a **dedicated role within schools to communicate and coordinate with parents**

- *"Maybe, a person, a couple of teachers, or a couple of department people, they will be there, just for the family, just to stay connected with the family. You are there to let them know this is things happening, you are there to go visit them if you can. I think that would be great"* [Female teacher, autism-specific school]
- *"I don't think we've been given explicit training at school to communicate with CALD background parents... But there was no explicit training. Or even at uni actually. Not that I can remember. We learnt about educating CALD students but not communicating with parents from CALD communities"* [Male teacher, selective-entry school]
- *"I think, as a teacher, we should all have access to that training ... there's almost always at least one autistic child in our classes, so as teachers we need a better understanding of their needs."* [Female teacher, mainstream secondary school]
- *"Because the thing is, I'm not an autism specialist. I'm a classroom teacher, I work with a range of disabilities. So as much as I would like to say what I know about autism, I'm not going to pretend I know everything, and maybe the parents know more."* [Male teacher, specialist school for students with additional learning needs]

Despite the challenges these parents often faced, they were deeply appreciative for what Australia offered themselves and their children. They were also thankful for how teachers treated their children describing Australian teachers as respectful, tolerant and caring. Parents were also grateful for the holistic education children received in Australia, with attention given to students' personal and academic development. Many parents reflected that the opportunities Australia afforded themselves and their autistic children would not be available in their home countries.

That said, the parental testimonies in this Report clearly show that we need to do more to improve the possibilities for their autistic children and for all students requiring more support. Below, we outline a series of recommendations for schools, parents and communities, co-developed with our parent participants and our parent Advisory Group members. We trust that these recommendations will promote positive home-school partnerships, which help to secure positive futures for all autistic children, young people and adults in culturally and linguistically diverse communities.

SUPPORTING EFFECTIVE COMMUNICATION

with CALD parents:

1. **What good communication looks like will be different for each family.** Some parents may want to know a lot about their children, others will be happy with a brief communication or an update on specific skills. Some parents may also want to actually see what their children do at school. Plan ahead with each parent about what 'good communication' looks like for them and discuss how feasible this is in your school context. Ensure parents **know who they can contact** at the school and **how they can contact this person**. It would be preferable, if possible, that this key contact speaks their home language. We endorse having a dedicated role within schools to communicate and coordinate with parents.
2. **Find out how interpreters are accessed at your school.** Ensure parents are aware that they can access interpreters and know that they are provided *at no cost to parents*. If interpreters are used, consider **extending the length of meetings with parents** to allow for the time taken to translate. Tell parents about the extra time allowed so they feel that they can use an interpreter without being disadvantaged.
3. "Different schools use different tools". **Provide training on the use of apps and e-learning platforms**, ensuring parents know how to use these. Explainer videos in different languages may be helpful. Some parents may not have the internet or skills in this area. It is important to provide alternatives for these parents. It may be helpful to use school apps to **link parents with members of staff who speak their community language**.
4. **Avoid using acronyms where possible.** Explain any acronyms used and/or provide parents with a list of key acronyms they may come across in the education context.

DEVELOPING POSITIVE RELATIONSHIPS

with CALD parents:

1. **Teachers and schools should have high expectations of all children**, from all backgrounds, in all settings, including academic, adaptive and social interaction skills.
2. Use a **checklist for all families before they start school** to understand what individual families may need ahead of time. The checklist could include finding out:
 - Family's language preferences, including whether they prefer oral or written information (e.g., phone calls, emails or texts).
 - Whether families have reliable internet at home and whether they can access and understand the apps and e-learning platforms used by schools.
 - How families travel to school (e.g., whether they rely on public transport or have access to a car).
3. Have **regular, planned, structured communication with parents**. It takes time to develop relationships when families have had different and/or more difficult past experiences. Having frequent, proactive communication with parents will help to develop trust.
4. **Proactively explain school protocols** to parents to help them know what they can/cannot do at school. Tell parents if specialists/support workers/family advocates are allowed into schools, including in meetings. Tell parents if and when they themselves are allowed in the classroom. Be aware that the structure of families may mean that **more responsibility falls on one parent** than another.

5. There may be **differences in expectations about what children** should learn and how; discuss this with parents. Think together about important skills that parents can focus on at home and that schools can reinforce. The more teachers can share with parents, the more consistent support can be provided for the child. Where possible, share learning plans and the curriculum with parents.
6. Transitions, including holidays and school changes, can be difficult for families, especially CALD families. **Think about ways in which you can prepare children to leave and return to school.** Think about whether there are any activities parents can do with their children during the holidays. Also think about how information about children is passed on to new teachers and schools to **support children to have continuity throughout schooling.**
7. Check **inclusion policies are up-to-date** (e.g., for virtual platforms, support for different exams etc.). Think explicitly about what inclusion looks like for students on the spectrum from CALD backgrounds. Ensure explicit teaching around inclusion for all – including teachers, students and families – starts as early as possible.
8. **Different families have different expectations and preferences in relation to communication between home and school.** Balanced feedback that includes communication about issues and solutions is often preferred. Parents are not afraid to hear about their children's difficulties and they want to contribute to addressing issues and have their expertise valued. **Asking parents if they have any tips or strategies can often lead to improved learning or wellbeing outcomes for students.**
9. **Parents should be encouraged to advocate** for their children and be **given strategies** to support their advocacy (i.e., information about their child's educational rights). Make extra efforts with families who are less visible at school and/or for whom English is a second language, offering regular opportunities for connection.
10. All parents' journeys will be different. Be curious, interested and non-judgemental about parents and children as individuals. Be careful with language use when describing parents and children. **Find out parents' language preference when talking about their autistic children and their culture.**

11. CALD parents may be experiencing increased stress and isolation. Enquire about the wellbeing of the whole family and **be aware of services you can refer families to, if required.**

MAKING PARENTS FROM ALL CULTURES FEEL WELCOME at kindergartens and schools:

1. Consider how to **promote the inclusion of students experiencing disability from CALD backgrounds across the whole school**, in all settings (i.e., classrooms, recreation areas) and activities (i.e., enrolment, classroom-based and playground-based, staff meetings).
2. **Find out how you can meaningfully acknowledge parents' cultures.** Do this in consultation with parents. This may include small gestures, such as playing songs, having phrases on the walls in different languages or showing cultural pictures.
3. **Find out key cultural dates that might be important for families.** Remember that some change dates every year (i.e., Ramadan). Also, remember that important dates may vary across cultures, for example Lunar New Year falls on different dates for Vietnamese and Chinese communities. Acknowledge these occasions, for example, in the school newsletter or in the school assembly.
4. **Schools should meaningfully acknowledge parents' cultures in order to encourage a sense of cultural safety for students and their families.** This may include activities such as learning songs in different languages or **celebrating key cultural dates.** Having a focus for **book week on different languages and characters** from different cultures (including having autistic characters) is also recommended (e.g., The Trung sisters, Hai Bà Trưng, Mulan, With the Light).
5. **Including parents when planning cultural events** will help to build relationships with families as well as ensure that such events are authentic. Cultural diversity provides rich student experiences and is relevant to many key learning areas in the curriculum.
6. Teachers would benefit from additional training around **autism and disability**, including the intersection of autism and cultural diversity. Specific training on **effective use of interpreters** and **use of simple written and spoken English** is recommended.

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