

**“Somali Parents Feel Like They’re on the Outer”: Somali Mothers’  
Experiences of Parent-Teacher Relationships for their Autistic Children**

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**Abstract**

Effective parent-teacher partnerships can improve outcomes for autistic students. Yet, we know little about what effective partnerships look like for parents of autistic children from diverse backgrounds. Using participatory methods, we conducted semi-structured interviews with 15 Somali mothers of autistic children attending Australian kindergartens/schools to understand experiences of parent-teacher interactions. We used reflexive thematic analysis to identify key themes. We found that mothers were proud and accepting of their children. They had high expectations, particularly around children's independence. Mothers wished their children's differences were understood and supported by other people, including teachers. They were frustrated by low expectations of children, a lack of genuine communication from teachers and limited autism-specific knowledge, skills and experience within schools. They described racist attitudes towards their children and reported that they themselves had experienced stigma. They also had few sources of support to rely upon, although their non-autistic daughters and their faith were important foundations for resilience. Despite all of these challenges, mothers themselves were increasing community awareness and knowledge about autism in the hope that they and their children would be valued by others. Our work has implications for how teachers and schools can foster successful relationships with Somali parents of autistic children.

**“Somali Parents Feel Like They’re on the Outer”: Somali Mothers’ Experiences of Parent-Teacher Relationships for their Autistic Children**

Although definitions vary, the concept of cultural and linguistic diversity (CALD) recognises the range of cultural groups that are included within a population, with features such as ethnicity, race and language differentiating these subpopulations (Australian Government, 2006; Marcus et al., 2022). Traditionally, psychological research has focused on white, middle-class populations (Rad et al., 2018) and autism research is no different (Pierce et al., 2014; West et al., 2016). Consequently, information about participants’ backgrounds is often opaque or even omitted from the empirical literature (West et al., 2016). As an illustration, Pierce et al. (2014) examined the reporting practices of ethnicity for research participants in three major autism-related journals (2000 – 2010) with only 34% of autism-specific articles including ethnicity descriptors of samples. That participants’ ethnicities have neither been recorded nor reported reflects the relative value (or lack thereof) that has historically been placed on diversity within research studies.

Recent calls for funders to prioritise autism research within diverse communities (West et al., 2016) have led to a relative increase in these types of studies. Over the last decade, there has been a marked growth in studies focusing on Hispanic (Chaidez et al., 2012; Hickey et al., 2021) and Asian communities (Kim et al., 2020; Shorey et al., 2020; Smith et al., 2021). There has also been a smaller, but no less welcome, increase in studies within Black communities (Shaia et al., 2020; Tadesse, 2014), including Somali communities. Earlier research with Somali populations tended to focus on autism prevalence rates in native and migrant Somali populations demonstrating that autism diagnosis is higher in migrant Somali communities compared to native-born populations in Western countries, including the United Kingdom (UK) (Hassan, 2012), Europe (Barnevik-Olsson et al., 2008,

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2010) and North America (Bhagia & Kung, 2014; Hewitt et al., 2016). Moreover, co-occurring intellectual disability also appears to be greater in Somali children compared with those from other racial/ethnic groups (Esler et al., 2017; Hewitt et al., 2016).

More recent studies have sought to go beyond identifying prevalence estimates to provide a deeper understanding of Somali families' experiences of raising autistic children (Aabe et al., 2019; Fox et al., 2017; Hussein et al., 2019; Selman et al., 2018). One such co-produced qualitative research project (Fox et al., 2017; Selman et al., 2018) investigated the experiences of 15 Somali parents of autistic children living in Bristol, UK. Due to their children's diagnosis, parents – especially mothers – reported experiencing stigma, discrimination and isolation. Nonetheless, these parents were proud of their children and accepting of their diagnosis. Parents gained strength from their Islamic faith, and they developed knowledge and confidence by educating themselves and others in their community about autism. Comparable experiences have been reported in another London-based UK study where Somali parents of autistic children similarly described discrimination and stigmatisation, but also took comfort from their faith and community supports (Hussein et al., 2019).

## **Parent-Teacher Partnerships**

A critical challenge for Somali parents reported in Fox et al. (2017) was that of selecting and accessing the most appropriate educational setting for their children. Parents described a paucity of school choice and challenges transitioning between educational stages. Choosing between mainstream and specialist settings was especially fraught for these parents, largely due to stigma and misunderstanding of autism within the Somali community. Parents found that preschool educators, compared to other teachers, more often considered broader family supports beyond just education (e.g., referring them to specific programmes and

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reminding them of appointments). They also explained how trusting, effective relationships could develop with these educators, particularly when good communication existed.

It is well-established that good communication, together with trust, respect and advocacy, are foundational for effective parent-professional partnerships (Turnbull et al., 2015). Successful parent-teacher partnerships can support autistic children and young people to succeed both inside and outside of school (Azad & Mandell, 2016; Lilley, 2019; Simonoff et al., 2012). These partnerships can likewise foster positive parent expectations for their children's school year (Bush et al., 2017). Yet, aside from 'good communication' (Fox et al., 2017), we know little of what constitutes an effective partnership for migrant Somali families with autistic children. This knowledge is essential to developing strategies to encourage more effective partnerships for these families.

The lack of knowledge about how to promote effective parent-teacher partnerships is especially concerning in the context of Somali migrant parents of autistic children since they are likely to be confronted by multiple challenges; challenges which can lead to poor collaboration between home and school and a lack of confidence and trust in teachers (Azad et al., 2021; Lilley, 2019; McNerney et al., 2015). Some of these challenges are related to those faced by all migrant parents, such as language barriers, fewer social supports and unfamiliarity with education systems and teaching approaches (Haines et al., 2018; Jegathessan, 2009; Lai & Ishyama, 2004; Wang & Casillas, 2012). Somali parents are also likely to face barriers reported by other Black communities, and especially Black African communities, in largely white societies, including racism, stigmatisation and discrimination (Kediye et al., 2009). Furthermore, since autism is often viewed negatively by the Australian Somali community, these parents will also likely face discrimination from their own community (Abdullahi et al., 2017) These challenges may be further intensified for Somali mothers (Crenshaw, 1991), who face gendered racism (i.e., where biases around gender and

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race intersect; Celeste Walley-Jean, 2009), and their children 'adultification' (i.e., whereby Black children are seen as less innocent and more mature than they are; Goff et al., 2014). These challenges and discriminatory attitudes make it vital that we investigate the actual experiences of Somali migrant parents as they interact with schools on behalf of their autistic children.

### **Current Study**

The current study sought to examine the experiences of Somali migrant parents of autistic children within an Australian context. While the Somali community is relatively established in the UK (Abdullahi & Wei, 2021) and the United States (US) (Hall-Lande et al., 2018), in Australia this more recently established community is growing, with a 31.8% increase in Somalia-born people recorded between 2006 and 2011 (Department of Home Affairs, 2018). Around 2% of all migrants arriving in Australia in 2016 were from Somali backgrounds (Harvey et al., 2020). It is therefore important that we understand more about how best to support these families, including in their interactions with predominantly Western-educated teachers (Baker & Kim, 2018). This study provides first-hand accounts of Somali mothers living in Australia as they navigated education for their autistic children. Specifically, we asked these mothers about their experiences of their children's education, including interactions and involvement with kindergartens/schools, parent-teacher communication and ideal parent-teacher partnerships.

### **Method**

#### **Community Involvement**

This study adopted a participatory approach, operating at several levels. To begin, autistic scholars and advocates who were also autistic parents of autistic children (GH, MH, WL) worked collaboratively with non-autistic researchers (JS, SR, PD, RL and EP) to secure

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the research funding for this project and design the initial study. Next, the team – and JS in particular – worked together with ED and NF (a Somali mother of an autistic son, interpreter and advocate) to assemble a Somali-specific parent Advisory Group, consisting of four Somali mothers of autistic children (including NF), researchers and professionals. NF facilitated all Advisory Group meetings in Somali. Meetings were subsequently scribed in English and JS regularly shared the Advisory Group's feedback with the broader research team. The Group met four times over the duration of the project and oversaw all aspects of the study, including study design, participant recruitment, implementation and dissemination.

### **Recruitment and Participants**

Participating parents had to be  $\geq 18$  years and self-describe as being from a Somali background. Children of participating parents had received a clinical diagnosis of autism and were engaged in education (early education, primary or high school, or home-schooling). Participants were recruited through informal networks (e.g., word of mouth). All recruitment and interview material was available in English and Somali. Parents were reimbursed AUD\$56 for participating in the study.

Table 1 presents parent characteristics. Fifteen mothers were recruited and interviewed. Most were born in Somalia ( $n=12$ ; 80%), with the US and Algeria other countries of birth ( $n=1$  each;  $n=1$  missing). Mothers began immigrating to Australia from 1990 onwards, with the majority arriving between 2000-2009 ( $n=6$ ; 40%), reflecting the general trend of Somali migration to Australia (Harvey et al., 2020). A wide range of education levels was reported, from no formal education through to university degrees.

Table 2 presents child and family characteristics. The 15 mothers together had 20 autistic children ( $n=17$  males,  $n=3$  females). The total number of children per household (including autistic and non-autistic children) ranged between 1 and 9, with most families



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having 4 or 5 children. At the time of interview, autistic children were an average of 11 years (SD = 4.90, range = 3 – 17). Children ranged in education levels from kindergarten to having completed school, with all mothers having at least one autistic child still engaged in formal education. Children were fairly evenly split between primary and secondary settings, including mainstream, autism-specific, disability-specific and independent schools.

[insert Tables 1 and 2 about here]

## Procedure

Ethical approval was obtained for this study (Macquarie University HREC Ref No: 5202196412836). This study was conducted between January to December 2021, coinciding with the second wave of the COVID-19 pandemic in Australia. Informed verbal consent was gained by our Somali-speaking interpreter (NF) who, aside from one interview conducted by JS, also conducted the interviews. Following consent, each parent then took part in an in-depth interview, mostly via Zoom. Prior to the formal interview, parents verbally provided brief demographic information about themselves and their family. In the interview, parents were asked about their experience of their child's kindergartens/schools, interactions and involvement with teachers and ideal parent-teacher partnerships (see Supplementary Table 1 for full interview schedule). Interviews were conducted in preferred languages (Somali,  $n=12$ ; English,  $n=3$ ). All interviews were audio-recorded, with Somali interviews subsequently transcribed by NF and English interview recordings transcribed verbatim using a transcription service.

## Data Analysis

We followed Braun and Clarke's (2006) method for reflexive thematic analysis using an inductive (bottom-up) approach to identify patterned meanings within the data set. Once all interviews had been transcribed, one senior researcher (JS) immersed themselves in the

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data, taking notes on striking and recurring observations and applying codes to each transcript (managed in NVivo, version 12). To begin, JS developed and applied codes in detailed discussion with EP, NF and ED. Next, JS generated a draft thematic map showing potential themes and subthemes. This map along with all relevant quotes was revised during multiple discussions with EP. Finally, the revised thematic map was reviewed by the broader team (SR, PD, GH, MH, WL, RL and NS), as well as members of the parent AG (AA, ED, NF, KI, and NY), during which changes were made to the thematic structure, as well as the theme and subtheme labels themselves (for emphasis and transparency), prior to being finalised.

[insert Figure 1 about here]

## Results

Figure 1 presents key themes and associated subthemes. Illustrative quotes (with participant IDs) are provided throughout.

### **Theme 1: Proud Mothers with High Expectations for Their Children**

Mothers wanted their children to be “treated well and nurtured” [P56] and to be proud of being “Somali, Black, Australian, all of these things” [P37]. They often spoke affectionately about their children. One mother stated: “I’m very proud of him. I love him and I love supporting him” [P56]. Another echoed: “I have so much love for him and I only want the best for him” [P11]. They also expressed an enormous amount of pride in their children, as one woman said: “*I would never hide [them]*” [P56] (subtheme 1.1). 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” [P3] and that, while some admitted initially trying to “keep it on the low”, they soon realised “okay, there’s nothing wrong with it” [P54]. There was also a strong desire for other parents to “bring their kids out in the open” because, as one mother metaphorically

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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” [P22].

In addition to the deep affection interviewees expressed for their children, they also had “high expectations” of children and felt that *children should “be challenged”* [P37], (subtheme 1.2). 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” [P3]. They likewise felt it was important for children to not be “talk(ed) down” and to be held “accountable for [their] actions” [P22].

Mothers particularly *encouraged children to get “ready for life”* [P22] (subtheme 1.3). They wanted their children to “learn to be independent” [P8], “equipping [children] as early and young as possible so that they are able to participate in society, and are able to contribute to society” [P38]. Mothers saw teaching basic adaptive skills as the first step towards achieving independence. Accordingly, they prioritised life skills like how to learn to “use the toilet” [P22] and “to get [themselves] to school, get dressed... have a shower, those sort of things” [P37]. Self-sufficiency in community contexts was also a priority. Mothers taught their children specific adaptive skills like “how to use money” to “learn to buy things” [P26], “to walk by themselves”, to “go shopping” [P63], to “orient” them to where they “live” [P22].

Mothers valued the collaboration of professionals in these day-to-day activities: “I’m teaching him how to have a shower with the guidance from the OT (occupational therapist)” [P8]. They also reported, however, that it was disappointing 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... I haven’t seen how they’ve taught him anything” [P11]. In addition to valuing hands-on support,

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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 [non-government service provider]” [P35].

### **Theme 2: A Deep Mistrust of Schools**

Many factors contributed to mistrust of schools. Interviewees spoke of how schools failed to properly gain informed consent from parents, especially those with limited English. One mother explained how there was no “due diligence” [P58] regarding a psychology referral for her son. Another parent likewise found it “very upsetting” when her child’s school “did a referral or talk(ed) to someone without [her] permission” [P63]. Concerns about their child’s safety also played a role in creating a sense of mistrust: “I don’t feel that my son is safe at this school” [P26]. 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” [P56].

*A lack of “genuine communication” from teachers* (subtheme 2.1) was another contributor to mothers’ mistrust. They 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” [P8]. Others similarly commented that schools “don’t tell you that much” [P63]; they “can’t do the information, the education at the same time” [P35]. Where there was positive communication between homes and schools, mothers sometimes expressed scepticism: “The teachers always tell you, ‘they’re doing good and all that’ but they’re not doing [it] at home” [P61]. At worst, parents thought of schools as openly dishonest: “I don’t like the lies” [P8].

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Mothers sometimes spoke positively about Australian education: "Look, everything I've said about the school and teachers is true, they're wonderful" [P56]. But oftentimes mothers *expressed the view that schools "don't have experience or don't understand autism"* [P54] (subtheme 2.2): "They had very little understanding of additional needs" [P61]. Mothers felt "teaching professionals" put their children in "the too hard basket" [P37]. They were frustrated by teachers' "ignorance... their unfair judgement of [their child's] disability" [P56]. Mothers often recollected how teachers "had no patience" [P61] with their children, forgot that their children did not "really like loud voices" [P7] 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" [P35] 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" [P7]. 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'" [P35].

Mothers were increasingly frustrated when even specialist provisions lacked autism-specific knowledge, skills and experience. Many mothers had made the decision to send their children to specialist provisions so they "can get more help" [P3] and be taught by teachers with specific "training in this field" [P26]. 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?" [P54]; "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" [P26].

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Mothers felt that teachers had *low expectations of students* (subtheme 2.2), which further added to their mistrust. They reported feeling frustrated “knowing that so little is expected” [P37] of their children. One parent lamented: “They [teachers] tell me, ‘his level is low. It’s too low’. They demoralised him. They discouraged him” [P3]. One mother recounted how her child had been excluded from a school outing because staff were “afraid that he would run onto the road” to which she responded: “‘Who says he would run onto the road? I would’ve told you if he did that’” [P56]. Another child had been putting his clothes into the toilets at school and kept 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” [P22]. 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” [P3]. 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” [P37]. 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” [P3].

Mistrust was further fomented when mothers felt that school staff (implicitly or explicitly) demonstrated *racist attitudes towards children* (subtheme 2.3). Prejudice came in several forms, including a focus on the physical size of Somali students. 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” [P37]. 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” [P35]. Worryingly, mothers also emphasised that their adolescent sons were unnecessarily feared because of their size: “The school said, ‘no, this

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boy is too big... he's too tall, he is going to hit people” [P26]; “Teachers saying, if [child] comes to school, we're not going to come” [P63]. As a result, they felt that their children were “ascribed [a] larger portion of the blame” [P58] compared to their peers. Racist attitudes were also experienced by other parents. One mother similarly 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” [P37].

Paradoxically, these same children were also reported to be infantilised. 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]” [P22]. Another mother commented how her son “didn't want to have a staff member constantly hovering near him. He became self-conscious” [P3]. 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” [P37] them.

### **Theme 3: Strength in the Face of Limited Supports**

Mothers emphasised that their “priority was [their] children” [P61]. When talking about her son, one mother said: “I sit with him. I teach him, I learn with him. I'm always striving to give him the best that I can give him” [P11]. Another parent similarly dedicated extra time to her son, describing how she “would take advantage while the other kids were asleep” and “in the morning for an hour [she] would sit with [child]... have conversations, read books together” [P3]. Yet, these *mothers often managed with little help, except from their non-autistic daughters* (subtheme 3.1). One mother described how her child's father “left [them] when [her] son was diagnosed with autism” [P26]. Another mother said: “Look, if I am honest, my husband has no idea what autism is. He doesn't understand it” [P8]. Many felt “like there isn't any [respite]” [P26] and that they feel “lonely and isolated and

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abandoned" [P26] and that "no one helps" [P11]. Within this potentially isolating context, non-autistic daughters were seen as a source of support, "actively helping [her autistic children] when they need assistance" [P58]; "My eldest daughter helps quite a lot" [P61]; My daughter who is older than [her son] is the person who helps him the most" [P26].

Mothers also had *few other resources to draw upon* (subtheme 3.2). They often had "big families", which meant "time is limited" [P8]: "I am busy, I have five kids. That one-on-one time is hard" [P28]; "I'm dealing with four children, single mother, and also alone" [P63]. Limited time influenced their broader involvement in their children's schools. They commented that although schools did not "acknowledge or celebrate" their culture, they did not "have time for" [P61] supporting schools with these issues, even if they wanted to. Mothers also had limited "language and the lack of understanding of how the education system works" [P37]. They reported not knowing that they could ask for interpreters and, even when parents were aware that they could "talk to teachers", they did not "want to overwhelm [them]" [P35]. Parents also did not "know what [their] rights are as a family, what their rights are as children on the spectrum" [P61]. Children were also often born in different countries and states: "Three (born) in New Zealand, and six in Australia" [P8]; "I have four kids... born in Kenya, New Zealand, Brisbane, Melbourne" [P56]. These multiple relocations presented another challenge as mothers were often unable to access services for autistic children born outside of Australia.

These women also *experienced stigma* (subtheme 3.3). Mothers experienced stigma within the Somali community towards autism: "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" [P26]. Another mother described "the unfavourable attitude in the community" towards autism, explaining how "people will say 'oh, she is the mother with the sick children'" [P58]. Another mother similarly reported that "when you tell



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a Somali person, 'my child has autism', they say 'are they mentally disturbed or something?'" [P11].

These mothers also experienced racial discrimination and felt that there was a general "prejudice against Somali families" [P37]. 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 [P56]

Mothers reported feeling that schools "bullied [them] as a family" and "accused [them] of being a bad parent" [P61]. 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" [P26]. Due to extant 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" [P37] to others.

Despite the pressures of limited resources and felt stigma, these mothers drew upon many *sources of resilience* (subtheme 3.4) to support their children. Parents were well aware that they needed to advocate: "If you don't go in to bat for him, who will?" [P37]. They described themselves as having "to push, to agitate" [P35], and "actively challenge the teachers" [P58]. One parent stated: "I don't sleep until I come up with solutions to their problems" [P61]. 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" [P22]. Parents took strength from their religion, especially after their child's diagnosis: "You come to accept what Allah

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has given you” [P26]; “God’s given us autistic children and people” [P56]. 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” [P22]; “I went to [friend’s name] and I took a notebook and I wrote down advice, tips and tricks” [P3].

### **Theme 4: Becoming Community Advocates**

Mothers often stated that they “don’t really know other Somali people with children who have autism” [P11]. 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” [P26]. There were also not “many Somali students at school”, perhaps “only, like, two Somalis” [P8], and when they joined autism information sessions, “there were no Somali people attending” [P26]. As these mothers could not find existing Somali supports, they were forging ahead to *build their own community* (subtheme 4.1) “that gets on with things and is not tied down by the baggage of taboo” [P56] and “shame” [P28]. Mothers felt that, despite the growing number of autism diagnoses in their communities, autism knowledge remained limited: “Well, you know, we have a lot of people with autism, but our understanding is limited” [P26]. These mothers shared their own stories in the hope of fostering others’ autism knowledge and acceptance, including with parents who already had children on the spectrum: “I’ve become a racehorse point for my community, where I’m like, that sounds difficult, have you tried this and this and this” [P37].

As it was often “hard to feel that you belong in the school” [P61], mothers spoke about the importance of *being valued* (subtheme 4.2). “Oftentimes, Somali parents feel like they’re on the outer” so 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” [P28]. Mothers saw the value in having a Somali speaker who “can facilitate how parents and the kinder can work together for

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the success of the child”, and that they “would really benefit” from someone who “could explain everything, interpret, help with translating school notices” [P58]. 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’” [P56].

## Discussion

This research provides first-hand accounts of Somali mothers' experiences of navigating education for their autistic children in Australia. Our interviewees clearly had high expectations of their children and found it deeply disappointing that expectations were not shared by teachers. Instead, they were often confronted by perceived low expectations of children, a lack of genuine communication from teachers, little autism-specific knowledge within schools, as well as striking instances of racism and discrimination toward themselves and/or their children – all of which ultimately led to an erosion of trust within parent-teacher relationships. These challenges were further compounded by experiences of stigma within their own community. Despite all of this, they drew support from their non-autistic daughters, their faith and their determination to advocate for their autistic children, and for greater community awareness about autism.

### **Marginalisation of Somali Mothers and Children**

Echoing past research with Somali-Australian communities (Abdullahi et al., 2017), our interviewees experienced a worrying degree of autism stigma and discrimination within their communities. As with Somali-Canadian mothers of autistic children (Kediye et al., 2009), our interviewees and children experienced stigmatisation in educational settings too – with this stigma related to intersecting aspects of their identities (i.e., race, gender and disability; Baker & Kim, 2018; Crenshaw, 1991). Mothers experienced gendered racism (Celeste Walley-Jean, 2009), whereby their advocacy efforts were perceived as aggressive.

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Mothers also described how their children were simultaneously patronised *and* treated more like adults (i.e., the “adulthood bias”; Goff et al., 2014). Whilst views of disability are often conflated with being childlike (Robey et al., 2006), infantilisation juxtaposed with adulthood here seem a double disadvantage for these Somali children and young people. Whether these patterns stem from views of disability, unconscious bias or both, biases may be mitigated by cultural and disability competency training, as Australian teachers report this to be a key knowledge gap (Syeda & Dresens, 2020).

Unfortunately, experiences of stigmatisation and discrimination in educational settings led to our interviewees feeling “bullied”, with other CALD parents likewise relating feeling unwelcome, intimidated and/or unconfident in educational settings (Guo, 2005; Lowe et al., 2009). Although teachers of autistic children have reported *wanting* access to professional development around culture (Syeda & Dresens, 2020), our interviewees' frustration went beyond teachers' cultural incompetence. Our interviewees, akin to CALD (Lai & Ishyama, 2004) *and* non-CALD parents (Hodges et al., 2020; Lilley, 2013; Lilley, 2014; McNerney et al., 2015), repeatedly reported inconsistencies in teachers' experience in, and knowledge of, how best to support autistic children in school. Professional development for teachers cannot, therefore, be delivered in a siloed way; educators need training on autism *and* cultural competency, and the interplay between the two.

### **Perceptions vs. Actualities of Parental Involvement**

Western teachers' views of parent involvement in children's education often reflect *visible* involvement, such as attending events, listening to children read and volunteering at school (Bakker et al., 2007; Bromley & Yazdanpanah, 2021). The Somali mothers with whom we spoke clearly felt they were less visible at schools and/or viewed as less involved in their children's education. For example, mothers felt that teachers did not gain informed consent for their children to be referred to other professionals, they had little knowledge of

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what happened at school for their children or of their own/child's educational rights. These types of concerns have also been expressed by other immigrant parents of children with disabilities (Alsharaydeh et al., 2019; Fox et al., 2017) and may reflect the possibility that teachers perceive CALD parents' differential engagement in education in a negative way (Bromley & Yazdanpanah, 2021).

It is also possible that Somali parents – for various reasons – may prefer to be less visible or involved at schools. Other CALD parents of autistic and non-autistic children have reported being less engaged in their child's education citing various reasons for this including: deference towards teachers; discomfort in dealing with teachers; feeling that education is not their responsibility; limited English, and a lack of time (Guo, 2005; Jegathessan, 2009; Lai & Ishyama, 2004; Smith et al., 2022). Our interviewees similarly mentioned their time limitations and a reluctance to overwhelm teachers as reasons for not engaging as much in their children's education. For supports to be culturally sensitive and effective, a greater understanding of how cultural values and experiences shape attitudes towards, and expectations of, education settings is needed. Further research on the experiences of ethnically diverse families supporting autistic students will deepen understandings of this complex issue.

Despite feeling less visible at school, our interviewees provided substantial support for their autistic children in the home context, such as reading and having conversations with them. These home-based activities and supports have been previously described by other CALD parents (Denessen et al., 2007). Since Somali culture emphasises the contribution of all family members (Kediye et al., 2009), mothers often taught children skills they valued, namely adaptive and independence skills. They had high expectations of their children and were frustrated that skills they taught were not reinforced, or indeed even expected, at school. Importantly, our study highlights how Somali/CALD parents may show their involvement in

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their child's education in different ways to non-Somali/non-CALD parents. Consequently this involvement may go unrecognised or be undervalued by teachers. The route to teachers' appreciating parents' differential involvement in their autistic children's education is by developing trusting, open relationships between parents and teachers. By fostering shared understanding between home and school, autistic students should benefit from more consistent supports across contexts.

The mothers with whom we spoke were also involved in advocacy more broadly. Independent of schools/kindergartens, they were trying to build their own communities that accepted them and their children. The promotion of autism knowledge and acceptance was one mechanism through which they were trying to develop supportive, tolerant communities where they and their children felt like they belonged. Previous studies have also found that Somali parents advocated for autism acceptance within their communities (Fox et al., 2017; Hussein et al., 2019; Selman et al., 2018). This type of activism reflects earlier experiences of Western mothers of autistic children who made efforts to promote change within the wider community, not just their immediate family context (Ryan & Runswick Cole, 2009). Mothers in our study were trying to promote broader autism acceptance in the face of significant barriers. Understanding the most effective ways to support mothers to advocate for themselves and their children, in collaboration with these mothers, is an important avenue for future research and practice.

### **Promoting Belonging**

Fostering a sense of belonging and strong community relationships is important for CALD parents of autistic children, including Somali parents (Schweitzer et al., 2021; Selman et al., 2018). Nurturing school belonging is similarly valuable for CALD students' social connections and mental health (Due et al., 2016). Parents are more likely to feel a part of their child's school when teachers are responsive towards their home language and culture and

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where diversity and family strengths are leveraged (Denessen et al., 2007; Emerson et al., 2012). In consultation with parents, schools should explore how they can meaningfully acknowledge parents' cultures *within* educational settings, as well as connect community members to appropriate services and supports *outside* of these settings (Schultz et al., 2016). Since, as noted in previous research (Fox et al., 2017; Hussein et al., 2019; Selman et al., 2018), faith was a source of support for parents, it is imperative that schools/kindergartens consider how they support parents to practice their religion (e.g., being aware of the dates of Ramadan each year and scheduling meetings around prayer times).

Schools should also be encouraged to identify and support family language preferences (including whether they prefer oral or written information) (Schweitzer et al., 2021). Parents with limited English skills would benefit from availability of competent and knowledgeable interpreters and/or bilingual staff (Schweitzer et al., 2021). Ensuring child goals are jointly discussed and shared across home and school/kindergarten is important for consistency of supports across contexts (Lilley, 2019). Some parents may feel less comfortable in educational environments (Lowe et al., 2009), so educators need to work towards reducing power imbalances to promote equitable parent-teacher relationships (Bromley & Yazdanpanah, 2021; Schweitzer et al., 2021). Equitable partnerships will be further fostered by parents being informed about school policies and procedures, especially children's educational rights (Lilley, 2019). Future research should investigate the most effective ways to share this type of information with CALD parents.

## Limitations

Our participatory approach was a clear strength of the study and ensured that methods used to recruit families were culturally sensitive and engaged parents who had never before participated in research, including our Advisory Group members. There are, however, several

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limitations of our study. First, we only report perspectives from mothers here. While childrearing is the primary responsibility of mothers in Somali culture (Guerin et al., 2004), gathering fathers' perspectives would add depth to our understanding. Second, we report solely on parental views and experiences, not teachers. Gaining teachers' views and experiences will be critical to understanding precisely what kind of support would assist in developing positive school partnerships with Somali families. Finally, the self-selecting nature of our sample meant that our findings are unlikely to be representative of all Somali migrant parents of autistic children. Future participatory research will need to identify ways to elicit the views and experiences of a broader range of Somali families and of how teachers/schools can develop relationships with these families (see Galpin et al., 2018).

## **Conclusion**

Our findings contribute to an understanding of how Somali mothers experience education for their autistic children and how we might better foster parent-teacher partnerships for these families. We hope this study contributes to the provision of targeted supports for these parents in order to strengthen family-school partnerships.



**Table 1: Demographics of participating parents**

	<b>N (%) / M (range, SD)</b>
<b>Gender</b>	
Female	15 (100.0)
<b>Age (years)</b>	39 (23 – 51, 7.9)
<b>Education Level</b>	
No formal education	1 (6.7)
Year 8	1 (6.7)
Year 11	1 (6.7)
School level	5 (33.3)
Post school (i.e., diploma, certificate)	5 (33.3)
University Degree	2 (13.3)
<b>Country of Birth</b>	
Somalia	12 (80.0)
Algeria	1 (6.7)
USA	1 (6.7)
Missing	1 (6.7)
<b>Identified Culture</b>	
Somali	14 (93.3)
Missing	1 (6.7)
<b>Year moved to Australia</b>	
1990-1999	5 (33.3)
2000-2009	6 (40.0)
2010-	2 (13.3)
Missing/unknown	2 (13.3)

**Table 2: Demographics of participating children and families**

	<b>N (%) / M (range, SD)</b>
<b>Child Characteristics</b>	
<b>Gender</b>	
Female	3 (15.0)
Male	17 (85.0)
<b>Age</b>	11 (3 – 17, 4.9)
<b>Average age of diagnosis (years)</b>	3.7 (1.5 – 14, 2.6)
<b>Type of Education Setting</b>	
Kindergarten	2 (10.0)
Mainstream/Government	3 (15.0)
Autism specific	4 (20.0)
Disability specific	3 (15.0)
Other (i.e., faith school)	1 (5.0)
Completed School	1 (5.0)
Missing	6 (30.0)
<b>Grade</b>	
Kinder/preschool	3 (15.0)
1	3 (15.0)
3	1 (5.0)
5	1 (5.0)
7	3 (15.0)
9	3 (15.0)
10	2 (10.0)

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	<b>N (%) / M (range, SD)</b>
11	2 (10.0)
12	1 (5.0)
Completed	1 (5.0)
<b>NDIS<sup>a</sup> plan in place</b>	
Yes	18 (90.0)
Pending approval	1 (5.0)
Deemed ineligible	1 (5.0)
<b>Family Characteristics</b>	
<b>Number of autistic children</b>	
1	11 (73.3%)
2	3 (20.0%)
3	1 (6.7%)
Total number of children <sup>b</sup>	4 or 5 (1 – 9, 2.2)
<b>Languages Spoken at Home</b>	
Somali	7 (46.7)
English and Somali	3 (20.0)
English	1 (6.7)
English, Somali & German	1 (6.7)
Italian	1 (6.7)
Missing	1 (6.7)

Notes. <sup>a</sup>The NDIS, funded by the Australian Government, provides no fault insurance cover for Australians (aged <65 years), who are born with or acquire a permanent and significant disability. It provides disability funding for support and services directly to individuals and is designed to give them more choice and control over their care. Those not in receipt of the NDIS funding accessed services and supports through other means, including government, charitable, and private provision. <sup>b</sup>Mode

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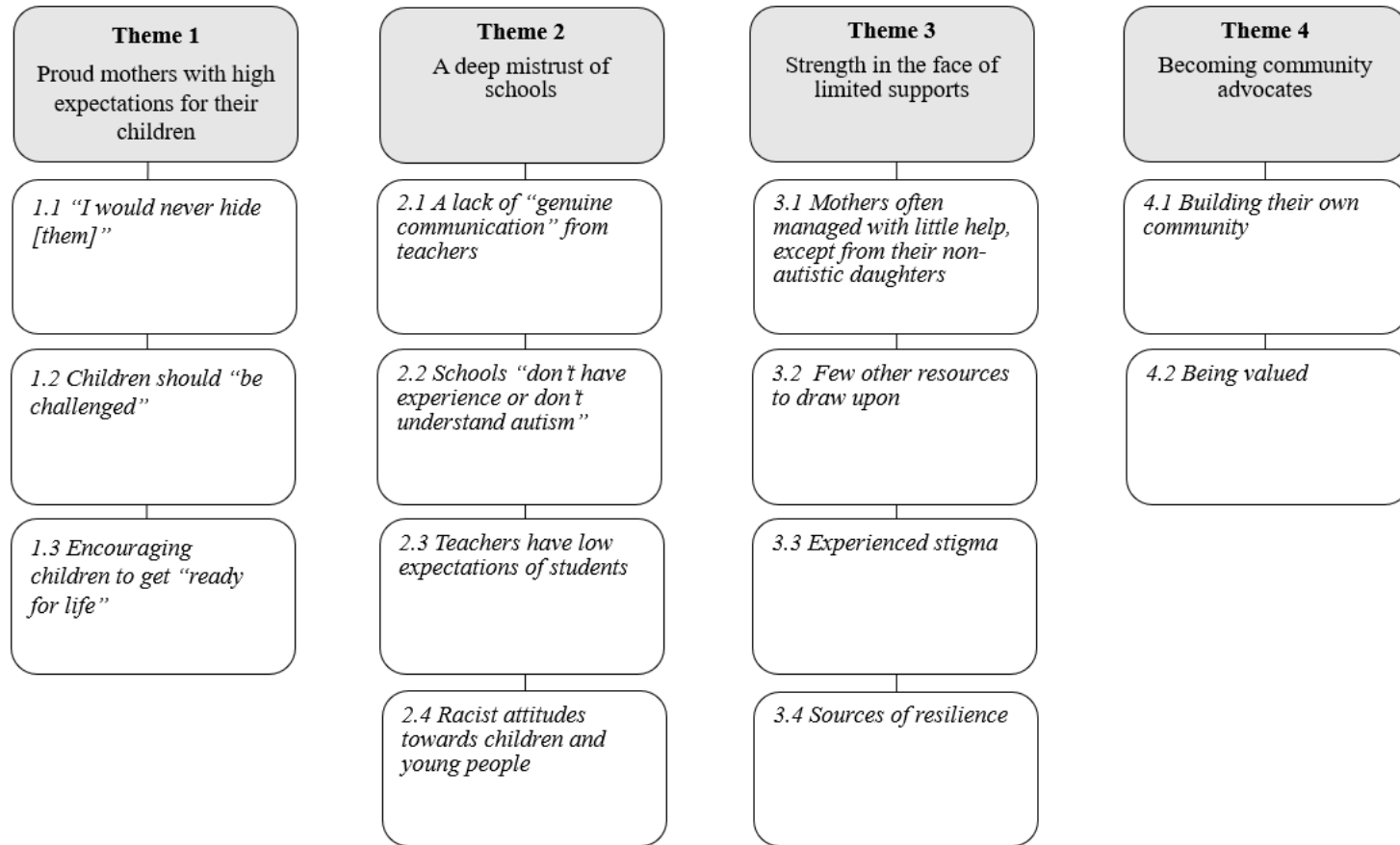


Figure 1. Themes and subthemes

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