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# "Individualisation is key": Autism intervention professionals' experiences of working with minority ethnic families in Australia

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#### ABSTRACT

Introduction: Early intervention (EI) professionals play an important role in supporting autistic children and their families. When families come from minority ethnic communities, the early autism journey is often more complex than for native-born families for caregivers and professionals alike. Whilst there is growing awareness about parents' experiences, we have little data from EI professionals on what can be done to improve the experiences, engagement and outcomes for these families. Here, we sought professional insights on their efforts to provide early autism supports for minority ethnic families, namely those from Chinese and South Asian backgrounds. Methods: Through a community-partnered participatory approach, we conducted semi-structured interviews with EI professionals who had experience working with autistic children and their families from Chinese and South Asian backgrounds in Australia (n=18). Data were analysed using inductive reflexive thematic analysis.

Results: Participating EI professionals described the challenge of developing a common language to talk about autism and supports with families, and often had different intervention priorities when compared to parents. They described observing parents' own unmet mental health and wellbeing needs, which they felt were compounded by shame and stigma associated with autism within their specific communities. Moreover, professionals relayed their powerlessness in effectively supporting parents' wellbeing due to a funding model focused solely on child goals. Participating professionals felt that the best way to work with families was to start by truly understanding the child, the parent and the family dynamics in order to tailor supports, as well as to encourage community connection and belonging.

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*Discussion and implications:* The insights offered by EI professionals into how early supports can be adapted to better meet the needs of minority ethnic parents and autistic children can inform more equitable policy-level decision-making for service provision.

Access to and engagement in early supports is a key factor in improving outcomes for autistic children and their families (Cheng et al., 2022; Kalorath et al., 2022; Landa, 2018). Since parents are the experts of their young children and influence early developmental trajectories (Smith et al., 2019) a key role of early intervention (EI) professionals is to facilitate parents' knowledge and confidence during the preschool years (Roberts et al., 2016). Helping parents to support their children can bring benefits for both parents and children alike (Auert et al., 2012) and so optimising outcomes for autistic children requires a collaborative and understanding relationship between parents and EI professionals (Trembath et al., 2022). Identifying active ingredients of effective parent-professional partnerships is an important avenue to explore in research.

# 1. What parents want from professionals and services

Although data on parents' involvement in early supports is currently lacking in quality (Crank et al., 2021; Trembath et al., 2022), we are aware of influences on parents' decision-making and engagement in El. Logistical factors (i.e., the availability and accessibility of supports) and family values and preferences have been found to play a role in parents' decisions about intervention approaches (Edwards et al., 2018). Parents have likewise highlighted the importance of experienced clinicians and of parent-professional partnerships which are based on respect, mutual empathy and collaboration (Auert et al., 2012; Smith et al., 2024; Wallace-Watkin et al., 2023). Parents have also reported valuing supports where clear, specific and practical goals are set for their children (Smith et al., 2024).

Critically, racial and cultural disparities exist for autistic children and families, both in terms of access to services and in outcomes following the receipt of supports (Bishop-Fitzpatrick & Kind, 2017; Broder-Fingert et al., 2020; Heneker et al., 2017; Liu et al., 2023). So, understanding experiences of and engagement in EI for Culturally and Linguistically Diverse (CALD) families is especially valuable. We know that CALD families desire culturally competent professionals and access to community-specific autism supports (Fong et al., 2022)—but can find both difficult to access (Smith et al., 2023b). Perhaps relatedly, we also know that CALD parents have reported experiencing prejudice and discrimination from professionals (Guo, 2005; Kediye et al., 2009; Smith et al., 2023b).

It is well established that caregivers of autistic children experience poorer mental health than parents of non-autistic children and parents of children with other developmental disabilities (Green et al., 2021; Ingersoll & Hambrick, 2011). Whilst poorer mental health amongst parents of autistic children has been observed across cultures (Wang et al., 2011), higher rates of autism stigma and increased social isolation within CALD communities (Kim et al., 2020; Shorey et al., 2020) are likely to exacerbate mental health outcomes for these families. Since supportive parent-professional partnerships can mitigate parental stress (Auert et al., 2012), understanding the active ingredients of effective partnerships between professionals specifically with CALD parents may bring greater gains, especially for parents as direct beneficiaries, and with implications for autistic children.

## 1.1. Professionals' perspectives

We have a growing understanding of what parents of autistic children want and need from professionals and services; we likewise have some information from the perspective of EI professionals. Two studies—both from the United States (US)— have studied professionals' perspectives of working with diverse families in the context of parent coaching (Stewart & Applequist, 2019) and child communication disorders more broadly (Cycyk et al., 2022). More specifically, one scoping review explored healthcare providers' experiences with autism revealing professionals' limited autism knowledge, experience and training alongside the importance of collaboration and service coordination (Morris et al., 2019). Another recent US study investigated early autism intervention providers' experiences working with marginalised families—largely in the context of Hispanic families (Lee et al., 2024). The authors likewise described the value of professionals having a trusting, collaborative, culturally responsive and family-centered relationship with parents which was made easier when parents and professionals shared a cultural background. Lee et al. (2024) also noted key challenges, such as parents' and professionals' divergent expectations of EI, professionals needing to work beyond their scope of practice (i. e., interpreting, translating) and a lack of professional development. Whilst findings from past studies are valuable, we require more information from service providers working with diverse underrepresented subpopulations (i.e., broader ethnic communities) (Morris et al., 2019). Further, as supports (i.e. social and health provision) vary widely across countries (Kuo et al., 2006; Mahon et al., 2012), future studies should explore experiences in different countries.

Further research focusing on service users' and professional' experiences of autism within the context of CALD communities is important not least because a person's background shapes their views around autism (Bernier et al., 2010). So, where the neuro-diversity movement is gaining traction in Western counties (Pellicano & Heyworth, 2023), autism stigma remains widespread within CALD communities (Kim et al., 2020; Shorey et al., 2020). And, since allied health professionals (i.e., speech-language pathologists) often have low levels of CALD representation (National Disability Insurance Agency, 2022; Snyder et al., 2018) it is likely that professionals' experiences and views about autism may differ from those of CALD communities. In order to develop collaborative and effective partnerships between EI autism professionals and CALD caregivers, we must understand experiences, priorities and perspectives from both sides.

# 1.2. Current study

Behind the United Kingdom, the South Asian <sup>1</sup> region and China now provide the largest migrant communities in Australia (Australian Bureau of Statistics, 2022). This study therefore sought EI professionals' views and experiences of efforts to provide early autism supports for families from Chinese and South Asian backgrounds in Australia. We sought insight into ways in which early supports might be adapted to better meet the needs of these parents and their autistic children and to facilitate more equitable access to services and outcomes for individuals and families from these minority communities. In this study, we aimed to answer the following research question: What are EI professionals' views and experiences around provision of early supports for Australian migrant families from Chinese and South Asian backgrounds with autistic children?

## 2. Method

## 2.1. Community involvement and positionality

This study was part of a broader project on experiences of EI for Chinese and South Asian families in Australia. We have previously published accounts of Chinese (Smith et al., 2023a) and South Asian (Smith et al., 2024) parents' experiences, and here report on EI professionals' perspectives of working with families from these communities in their clinical practice. Our team for this community-partnered participatory research included members from autism and autistic communities, including parents with autistic children from Chinese and South Asian backgrounds, autistic adults, formally-trained researchers and EI professionals.

Our participatory project was informed by best-practice guidance for meaningful community involvement in research (see Fletcher-Watson et al., 2019; Nicolaidis et al., 2020). Hence, for this project, team members worked together to initially design the project and secure funding. Throughout the project, regular advisory group meetings with subgroups of team members reflecting different interests/relevant lived and professional experience took place, with group composition designed to ensure that there were equal/more community members to researchers to reduce power imbalances. Clear roles and responsibilities were discussed—an important consideration in participatory research (den Houting et al., 2021, 2022; Jose et al., 2020)—including two community members acting as interviewers for the project. During advisory groups, all aspects of the study were discussed (i.e., study design, materials and methods, participant recruitment, implementation, analysis and dissemination). Non-salaried members were paid for their time spent on the project and their lived-experience expertise, and are named co-authors of this research.

Our team members brought a range of perspectives and professional expertise to bear on this research and the qualitative analysis, including from psychology/public health (CN, CB, CC, CG, KH, SW), community engagement (EM), education (HS, KP, RW), speech-language pathology (JS, NG), behaviour analysis (KF), and engineering (RI). Some members of our research team identify as autistic (CC, HS) and/or as parents of autistic children (EM, KP, RI, HS, RW). Whilst all of our team spoke English, some also spoke other languages relevant to the context of this research including Mandarin (RW), Cantonese (EM), Urdu (RI), Hindi (KP) and Gujarati (KP). Most of our team were native-born Australians, but several had migrated here, including from the UK/Europe (JS, KH), USA (CG), China (RW), Hong Kong (EM), Pakistan (RI) and India (KP).

## 2.2. Recruitment and participants

Following ethical approval, participants were recruited through formal and informal networks. Formal networks included providing information about the study to EI organisations associated with our research partners/professionals (i.e., Learning for Life, Autism Partnership Australia), as well as contacting professionals listed on professional organisation websites (i.e., Speech Pathology Australia, Occupational Therapy Australia). Informal networks included the research team sharing flyers with informal connections and via word of mouth. Participants needed to have a minimum of 1 years' experience supporting South Asian and/or Chinese families with autistic children. A total of 18 participants were recruited and interviewed. Most were female (n = 14; 78 %) reflecting known gender biases of these occupations (Nancarrow & Borthwick, 2021). The range of professionals interviewed included speech pathologists (n = 9, 50 %), psychologists (n = 4, 22 %), occupational therapists (n = 2, 11 %) and Applied Behaviour Analysis (ABA) providers/consultants (n = 3, 17 %). On average, participants had 13 years' experience working with autistic children (SD = 9.26) albeit with a substantial range of 1 to 35 years. Many participants identified as Australian (n = 10, 56 %) but with a range of cultural backgrounds reported. See Table 1 for demographic information.

#### 2.3. Procedure

Study recruitment was conducted between May and December 2022, with approval from the La Trobe University Human Research Ethics Committee (#HEC22170) and work was conducted in accordance with the Declaration of Helsinki. Informed consent was gained from all participants who then completed a background questionnaire hosted via REDCap (a secure web platform for hosting databases), and participated in an in-depth individual interview (mostly conducted via Zoom; 6 % in person). Interviews were conducted by members of our team who were parents of autistic children (RI and KP) and were on average 39 min duration (range 23–60).

<sup>&</sup>lt;sup>1</sup> Bangladesh, Bhutan, India, Pakistan, Nepal, and Sri Lanka.

**Table 1**Participant Demographic Characteristics.

Gender	Self-identified culture	Profession	Years of experience
Female	Australian	Psychologist	18
Female	Australian	Speech Pathologist	35
Female	Australian	Speech Pathologist	7
Female	Indian	Occupational Therapist	19
Female	Canadian	Behaviour Consultant – ABA	21
Female	Singaporean	Speech Pathologist	14
Female	European	Speech Pathologist	19
Male	Australian Cantonese	Psychologist	5
Female	Australian European	Psychologist	> 1
Female	Australian Italian/Anglo-Indian Heritage	Speech Pathologist	11
Male	Malaysian Chinese	Speech Pathologist	3
Male	Australian	Occupational Therapist	2
Female	Not Disclosed	Speech Pathologist	12
Male	Taiwanese	Speech Pathologist	1.5
Female	Australian	Speech Pathologist	20
Female	Caucasian	Psychologist	15
Female	Australian	Certified ABA Provider	24
Female	Australian	Certified ABA Provider	7

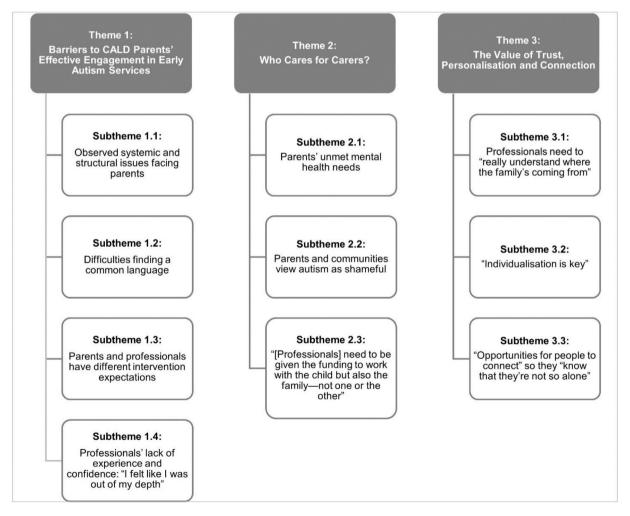


Fig. 1. Thematic map of themes and subthemes generated from analysis of professionals' interview transcripts.

Participants were asked about their interactions, involvement, and communication with Chinese and South Asian parents and their thoughts on ideal ways of working with these families. With consent, interviews were audio recorded and subsequently transcribed verbatim using Way With Words (a confidential transcription service). All participants were emailed their interview transcripts and given an opportunity to amend or add any information prior to analysis. Participants were gifted a \$25 voucher for participating.

## 2.4. Data analysis

We followed Braun and Clarke's (2006, 2019) inductive reflexive thematic analysis method. We used the 'Big Q' qualitative framework so as opposed to trying to achieve consensus codes (as per coding reliability or codebook thematic analysis approaches; see Braun & Clarke, 2019), we aimed to unearth the shared meanings and experienced reality of our participants (Byrne, 2021). Analysis was led by the lead authors (CN, JS) who immersed themselves in the complete data set, taking notes on striking and repeated observations and applying codes to each transcript (managed in NVivo). Lead authors also attended regular advisory groups to discuss transcripts from diverse participants (i.e., male vs. female, more vs. less experience, CALD vs Australian background etc.) as part of the analysis process. For these meetings, each interview transcript was first de-identified and sent to advisory group members (KH, AA, CB, CC, KF, NG. GC, RI, EM, KP, HS, RW, SW) prior to meetings to read and make notes. Meetings were then used to debrief about the transcripts and discuss patterns in participants' responses, including potential codes. Then a draft thematic map was generated showing potential themes and subthemes and shared with specific group members again with further edits made prior to finalisation. The final themes therefore arose via ongoing engagement with the data combined with an active, reflexive analytical approach (Braun & Clarke, 2006, 2019).

# 3. Results

Three main themes were generated from analysis of the EI professionals' interviews, each with several subthemes. These are shown in Fig. 1 and described below, including illustrative quotes attributed to individuals with their identification numbers in square brackets after.

# 3.1. Theme 1: barriers to CALD parents' effective engagement in early autism services

Professionals observed systemic and structural issues facing parents (subtheme 1.1). For example, they described how—due to their migration status—some CALD parents were unable to afford an autism assessment in the first instance: "Some of our families from Chinese and South Asian backgrounds may not be permanent residents and might not be eligible for government funding... they can't afford to go through the diagnostic process" [68]; "It can be really difficult for families that have come here, but they haven't got all of the visa stuff sorted out. They've got really limited options in terms of actually getting a diagnosis, because that's a really expensive process" [61].

Even when children had received an autism diagnosis and could access National Disability Insurance Scheme (NDIS) monies (Australia's disability funding body), professionals felt that CALD parents were disadvantaged regarding funds needed. Professionals felt that it was "not fair" that funding was often dependent on parents' "drive to fight" or "ability to go to tribunal with the NDIS" [68] meaning parents who "talk louder get more funding" [69]. Professionals described myriad reasons why this type of advocacy was harder for CALD parents, including a "lack of language" [57], "less access to that education" [70], less "access to information" [55], difficulties "navigating systems" [59], and not wanting to "speak out...[as] they assume that the therapist knows best" [70].

Another barrier to effective engagement, from professionals' perspectives, was difficulties finding a common language (subtheme 1.2). Professionals described the overt challenges communicating with parents who had limited spoken English skills, especially when "it's a bit offensive" to "suggest an interpreter when...[parents] feel like their language skills are good" [61] or "feel they should try to manage without [one]" [70]. One professional commented on how CALD parents and professionals often only "partially" understood one another, so neither was seeing the "whole picture" [55]. However, the communication barriers professionals described appeared more complex than simply issues around speaking different languages. Rather, they related also to parents' acceptance of autism and autism-related support, for instance:

If parents are trying to get their head around what's going on with their child or they have never even heard of autism or anything around that it can be very difficult for them to understand and to try to facilitate what the therapists are encouraging them to do at home to help the child and their situation [51]

Beyond a shared comprehension of autism, professionals also explained how hard it was to have common vocabulary to talk with "families in a way that they're understanding.... [as] there may be a lot of terminology that is more specific about EI or about development. It's not part of this regular language" [87]. Even when using interpreters or being native speakers, professionals still found it challenging to "find terminology and expressions...to explain [things] to [parents]" in ways that did not "sound very pathological or very medical [but] something that they can digest and understand" [64]. Relatedly, it was difficult to "find shared strategies with the family where we all speak different languages" [57] and hard "to get a good idea of what the family wants, and their priorities" [66]. Professionals often told of miscommunication with CALD parents too. One speech pathologist explained how families "would practice [in between sessions]... but not the way that [they had] educated them", and so would have to "explain it again" but still find "the same thing would happen" [69]. Another professional tried to account for miscommunications between professionals and parents:

It's either that they're not understanding because of the language barrier or we're not communicating the same, so then they're not able to implement. Or if they understand but don't agree but are not letting [us] know and so then they're not able or not implementing different strategies that we're recommending [87]

The idea that some parents were more deferential and less likely to speak up was mentioned by another professional who stated that some CALD parents "tend to be quieter and less comfortable and feel like the they might be wasting time by asking questions" [81].

A further reported barrier was that *parents and professionals have different intervention expectations* (subtheme 1.3). Whilst professionals typically described viewing EI as "collaborative" [68] with "the parent and the therapist being equal partners, and both having an active role" [61], they felt that CALD parents viewed intervention differently. One psychologist felt parents assumed: "You take my child, and you spend three hours with my child and you give them back, there is no crossover [between professionals and parents]" [59]. It was thought that CALD parents "follow much more of a medical model, so a lot of them think that they go to therapy to fix the child" [52] with the main intervention question being "how long does it take to fix this?" [55].

Since some parents were described as seeking a "cure", it could be challenging for parents and professionals to develop shared goals for children. Some parents were reported to want "their kid to be perfect" [57] or "to be normal" [61]. Accordingly, professionals described finding it challenging to set more realistic goals with parents: "If their goal is right up here, it's how we then bring them down to what is agreeable, [reducing] that massive disparity between the two perspectives" [50]. As one professional reflected: "We have to manage the expectations a bit...we might have to say, okay I don't know if we'll be able to do that straight away" [70]. Developing shared goals was also described as complicated by families struggling to "talk about things that were hard for their child" [54] or understand that "their [autistic] child and the way that they presented [was] unique and different from that child's sibling [with] different strengths and different challenges" [96].

Another barrier to effectively engaging CALD parents in EI services was *professionals' lack of experience and confidence: "I felt like I was out of my depth" [55]* (subtheme 1.4). Professionals described having "imposter syndrome with not feeling comfortable in dealing with families with complex children" [66]. Many professionals felt that their clinical education had not effectively taught them to work with children on the spectrum in general: "I was feeling really out of depth working with autistic kids because of the limited [autism] training in my Masters program" [55]. One speech pathologist explained:

The first time we learn about autism, you learn that it's a disorder of the social understanding communication difficulties and then the lecturers used to give you a prototypical case in your mind. And you used to think, okay, all kids look like this, or they all look like that. I didn't understand how complicated that could be and how different children on the spectrum could look [57]

Consequently, professionals felt *even less equipped* when complexity increased due to working with autistic children from CALD backgrounds. One speech pathologist described how "working with families is a bit of an artform" where "working with a child is one thing, but working with their parents, in a way that is effective because it respects their preferences and their family... is not necessarily easy to do" [70]. Despite almost 20 years' experience, one speech pathologist said: "I feel like I need, maybe, more direction, training, support" to learn "how I can do things differently to better support [CALD parents]" [56].

# 3.2. Theme 2: who cares for carers?

Professionals described being concerned about CALD parents' unmet mental health needs (subtheme 2.1). One speech pathologist stated: "Several families...were under a lot of stress, and were mentally quite unwell, but not getting any help for that" [70]. Professionals felt that whilst "some [parents] have no idea" about their perceived mental health challenges, for others, "it's the elephant in the room that you don't necessarily talk about explicitly" [50]. Some believed that there were "cultural expectations or cultural norms around not talking about feelings" [59]. Professionals also believed that CALD parents in general are "so selfless in that they would be literally doing anything for their child" [62] so "don't have time to spend on themselves" [50].

Professionals described witnessing parents' isolation: "I think a lot of them I found were quite alone. They felt quite lonely in their journey" [55]; "Families, I think, can feel very isolated" [70]. Professionals felt that mothers in particular experienced loneliness since they were less likely to work and more likely to provide caregiving: "Most of the time [mothers] are with this child 24/7, and they don't get any social outings and they don't get any other social activities. Some of them don't even have any friends" [53]. It was not just the perceived poorer wellbeing of parents that concerned professionals, but what they saw was the knock-on impact of CALD parents "being able to engage with any supports for their child" [70]. As one professional said: "I really would love to think about a way that we can remind [parents] that actually caring for themselves, that is one of the best things they can do for their child" [61].

Parents' perceived isolation was compounded by *parents and communities viewing autism as shameful* (subtheme 2.2): "I think [Chinese and South Asian] groups have an idea of shame when it comes to mental disorders" [57]; "Being on the spectrum is viewed quite negatively by parents of these backgrounds" [69]. Professionals described how some parents had "difficulty understanding some different behaviours that are sometimes displayed by people on the spectrum...they often want to stop that because it's not seen as socially appropriate" [68]. It was also reported that parents "haven't wanted to disclose the autism to those family members" [61] as "once their friends and family know that their child has a difference, a disability, then they just think that child is never going to be part of the community or part of society" [70]. Unfortunately, professionals explained how parents "stop going to their friend's house because the child has autism" and "is making problems, or they are not comfortable and the people around them are talking bad[ly] about them" [53].

As parents often appeared to have their own unmet needs, "[professionals] need to be given the funding to work with the child but also the family—not one or the other" [81] (subtheme 2.3): One occupational therapist said: "Sometimes [parents] come and want to discuss

[their personal issues]...they just break out and say that today I just want to talk to you because I don't have anyone else to talk to" [53]. There was a feeling that intervention "was very focused on the child and their skills, which is important" but that ignored those "families who wanted more help themselves" [70]. Funding needed to be "allocated to support the parents... to help them understand the diagnosis, [provide] workshops...support groups" [64]. Professionals felt that "a really important part of the process for families" was having "someone that they can ask questions to or just express what they're feeling" [59]. Another mentioned how although their organisation focused on "doing behavioural intervention [with children]" there were "also a team of many, many psychologists" [50] so have the skills to assist with parent wellbeing. However, professionals explained how supporting parents more holistically was not factored into how the NDIS currently funds early supports:

While things like [the] NDIS have been amazing and given families access to money they didn't previously have access to, there are really strict limits about what they can do.... Stuff [i.e., conversations with parents] that is not directly related to the child is often the stuff that doesn't get funded [81]

A common criticism was that NDIS funding does not "consider each family situation" [53] nor does it reflect that "therapy isn't just for the child; it is for the support of the parents as well" [66].

# 3.3. Theme 3. The value of trust, personalisation and connection

It was emphasised how *professionals need to "really understand where the family's coming from" [59]* (subtheme 3.1). For effective engagement with families, spending time "talking with the families" [56] and "finding out about what their life looks like is really important" [68]. Devoting time to learn about a family was valuable to not only "establish trust" [70] but to "have the buy-in [so parents] want to come to their therapy and find it useful" [68]. Also, without learning about "struggles at home... it's harder for [professionals] to give [parents] the best information or the best advice" [51]. Although professionals acknowledged that they had their own priorities for children, it was important not to be "forcing the conversation" [59]. As one professional said:

It's all about having those discussions together and moving along when the time is right. Because we can't work on things if the family is not ready for that yet because they're the ones that are following through with all of that when we're not there, so [what is being worked on] needs to be meaningful. [87]

Part of learning about where a family was coming from was understanding "family dynamics because... all families are very different, so you have to know what is important to them and what they value" [52]. Learning "a bit of information about relationship dynamics within the family system" was also important as "it can impact communication and emotional regulation" [68]. Understanding family dynamics seemed vital when working with CALD communities—especially within the current NDIS funding model. Professionals discussed how in CALD families "roles... tend to be more traditional" which can mean that "often the father gets involved with financial decision... which is tricky because that financial conversation is also really about the goals" [70] so both parents were needed at funding meetings to set meaningful and achievable goals for children.

Understanding both parents' views was also seen as essential as "there are fathers that won't accept [support] and mum is pushing everything, or vice versa" [50] or sometimes "mum doesn't speak English and the dad does" [81]. So, dynamics between parents influenced how professionals needed to approach working with families. Moreover, in CALD families, it was common for extended families to be involved and so professionals had to "balance working directly with the parents and communicating with them, but also if there are other people who are involved in the caregiving and those routines, extend[ing] the support to, say, the grandparents as well" [87]. Further, professionals needed to consider whether parents have "other family members telling them they shouldn't be [seeking supports] and that their child is fine" [70].

For professionals, "individualisation is key" [87] (subtheme 3.2) to effective early supports for CALD families. As one professional stated: "I guess what I've learned over the years is just the individualisation of it. So, every child is different. And every family is different. And it's really about meeting everybody in the middle" [54]. For professionals, "guiding principles" included supports being "individualised depending on the characteristics of the child… the family goals and preferences and also their values" [61]. It was vital to talk "about the child as an individual and what do they need support with" [59]. It was also imperative that professionals considered all stakeholders to ensure that "everybody's getting what they want and what they need out of that relationship" with an example of "creating behaviour plans that suit the school but also suit the family" [96]. Although individualisation was seen as paramount, there was an understanding that it was a skill which came with experience: "I've become much more open and more able to adapt to a families' preferences and priorities than I was earlier in my career" [70].

Finally, professionals wanted "opportunities for people to connect" so they "know that they're not so alone" [61] (subtheme 3.3). Professionals felt that it would be beneficial for parents to access "some parent groups" where there are other parents "supporting a child with disability... who they can bounce ideas off" [64], especially as "some of these families often don't have much family support" [68]. Professionals highlighted the value of having culturally-specific groups—"maybe a South Asian parent group or a playgroup" [53]—where others will understand their unique situation, as "they might also have those additional cultural things that they're facing; for example, that idea of the shame of disability" [61]. As one professional stated:

I guess it was quite difficult sometimes for these families to find like-minded mums and dads that they feel like they could connect with on a cultural level, and then on a language level, and then finding other parents of autistic kids who were similar as well [55]

# 4. Discussion

This research provided first-hand accounts of the experiences of EI professionals working with autistic children and their families from South Asian and Chinese communities. This is a vital area of study, for insights into how services could be improved to enhance engagement and outcomes for families who likely face additional challenges when caring for an autistic child. Indeed, professionals described numerous barriers to working with CALD autism communities, but also identified effective ways of working together. Findings are discussed in detail below.

# 4.1. Early challenges facing CALD parents and professionals

Similar to past research highlighting limited autism awareness in non-Western countries (Durkin et al., 2015) professionals we interviewed about their efforts to provide EI for autistic children in CALD families in Australia reported initial challenges just talking about autism and early supports with parents. Some of the challenge was due to limited English proficiency, consistent with previous accounts from CALD parents themselves highlighting language barriers as a factor impacting working with professionals (Shorey et al., 2020; Smith et al., 2023b). However—since the professionals we spoke to were working with families at the beginning of their autism journey—part of the challenge they shared was also around supporting parents to understand autism and appreciate that their child was developing differently. This extra 'processing time' for CALD families has also been described in previous research, and likely arises from myriad factors including limited education about autism, and cultural stigma around disabilities (de Leeuw et al., 2020; Smith et al., 2023b). Given autism presentations may be more complex in non-native versus native-born children (Abdullahi et al., 2019), extra processing time may also be required since co-occurring cognitive and language difficulties are more common here (Becerra et al., 2014). Incorporating ways to support parental understanding—and hopefully acceptance—of broader neuro-developmental differences among CALD families, should be considered by professionals and organisations working with this group in the post-diagnostic period. Yet, this can only be achieved if funding bodies, organisations and professionals dedicate time and money to autism and neurodiversity education for caregivers, as well as traditional therapeutic supports.

Professionals here described how CALD families anticipated more traditional 'medical models' of practice, in contrast with the more collaborative, social model of autism support increasingly adopted in Western countries, reflecting previous research (Alsharaydeh et al., 2019; Khatri & Assefa, 2022). Relatedly, EI professionals in the current study reported how CALD parents' goals were often aimed at 'fixing' their child, with mismatched goals between parents and professionals similarly reported in a recent US study exploring early autism professionals working with marginalised families (Lee et al., 2024). Many factors likely contribute to different attitudes towards intervention approaches and goals—not least the aforementioned stigma around autism within CALD communities (de Leeuw et al., 2020; Smith et al., 2023b). Perceived power imbalances between parents and professionals also likely plays a role since CALD parents are more likely to show their respect for role boundaries through deference towards professionals (Lai & Ishyama, 2004; Liu & Fisher, 2017; Smith et al., 2023c). Parents' lack of clarity around the benefit and rationale of the social (vs. medical) model of support may also contribute here. Intensive, behavioural-based interventions with clear, practical goals have been prioritised by some CALD parents of autistic children (Smith et al., 2024) and so when supports are less intensive and embedded within naturalistic social contexts, their value may be less clear to parents. Accordingly, professionals should have transparent discussions with parents about different intervention approaches and, where possible, ensure everyone understands and agrees upon chosen approach, activities and goals.

# 4.2. The support needs of CALD parents

The professionals we spoke to were clearly concerned for the wellbeing of CALD parents themselves, as also highlighted in earlier research (Kambouri et al., 2022; Kulasinghe et al., 2022). They believed that stigma around disabilities and autism within CALD communities contributed to parents' self-isolating from important community supports (Papoudi et al., 2020) and explained that the absence of formal mental health supports led them to work beyond the scope of their EI practice in attempt to meet parents' mental health needs. Since its inception, a reported limitation of the NDIS—Australia's funding mechanism specific for disability-related supports—has been the focus solely on the child (or person) with an identified disability rather than holistically considering the needs of the family system (Gavidia-Payne, 2020). This oversight in supporting parents is compounded in the case of CALD parents' additional challenges related to stigma, social isolation and limited familial supports, meaning that professionals working with CALD communities have a larger void of support need to fill. Consideration of how funding models can better support the family unit would be welcomed. Moreover, since professionals interviewed for the current study, and samples of CALD parents we have also interviewed (Smith et al., 2024; Smith et al., 2023a) have converged in their reports on the lack of autism expertise and experience among professionals working in the early support sector, there is also a vital need to understand how to train professionals to holistically meet the needs of families with complex socio-cultural circumstances.

# 4.3. Benefits of individual partnership and community supports

The EI professionals we interviewed felt that when they took the time to understand a family's situation and build a collaborative relationship with parents, there were better child outcomes—an insight supported by results from other research with CALD (Lee et al., 2024; Smith et al., 2024) and non-CALD communities (Kambouri et al., 2022; Trembath et al., 2019). Knowing a family's circumstances allowed EI professionals to tailor supports to better meet the unique needs of child and family alike, consistent with research

indicating that if the entire family is supported, better child outcomes follow (Auert et al., 2012; Durkin et al., 2015). When working with all families, professionals should always try and build a trusting, collaborative relationship with caregivers and develop shared goals for children which are realistic but also foster a sense of personal hope for CALD parents with autistic children (Kambouri et al., 2022). Positive outcomes may also be supported by helping CALD parents to foster community connections, which may not only help to educate wider CALD communities about autism and reduce the social isolation experienced by families (Shorey et al., 2020), but also help CALD families with autistic children to navigate the NDIS system (Carey et al., 2021). Professionals should learn about local community-based organisations which may be suitable for different CALD families and develop resources in community languages which can be shared with caregivers.

## 4.4. Strengths, limitations and future directions

The community-partnered participatory approach, with research co-designed and produced with the autism/autistic and CALD communities, was a clear strength of this study. A co-produced approach allowed greater insights into diverse professional and familial lived experience perspectives on the research topic, giving confidence in the validity of our findings. Whilst we sought out and engaged participants who represented a range of professional backgrounds and years of experience working with autistic children, we acknowledge the limitations that the group was, on average, highly experienced (M=13 years) and also more diverse than typical for these professions (as described by Nancarrow & Borthwick, 2021). Thus, we may not have captured additional challenges faced by those newer to their professions. Future studies could investigate perspectives of those professionals with limited experience to gain further insights into training requirements and evaluation of training on effectively working with autism and CALD communities. Studies could also explore in more detail the potential benefits for children and caregivers when professionals providing supports share their cultural and/or linguistic background. Further, we cannot know whether these findings would generalise to other regions with different CALD representation and service provision models. While we might imagine there are generalisable themes, future research in other countries would be warranted.

# CRediT authorship contribution statement

Rabia Ijaz: Conceptualization, Writing – review & editing. Emily Ma: Conceptualization, Writing – review & editing. Kanisha Patel: Writing – review & editing, Conceptualization. Christos Constantine: Writing – review & editing. Kathleen Franks: Writing – review & editing, Methodology, Nilushi Goonetilleke: Methodology, Writing – review & editing. Cherie Green: Writing – review & editing. Helen Said: Writing – review & editing, Conceptualization. Corinna Newton: Writing – review & editing, Validation, Methodology, Visualization, Writing – original draft, Formal analysis, Conceptualization, Project administration, Investigation, Data curation. Kristelle Hudry: Writing – review & editing, Validation, Methodology, Writing – original draft, Supervision, Conceptualization. Sarah Wood: Conceptualization, Writing – review & editing. Alexandra Aulich: Writing – review & editing. Rena Wang: Conceptualization, Writing – review & editing. Jodie Smith: Writing – original draft, Validation, Methodology, Writing – review & editing, Supervision, Conceptualization, Visualization, Project administration, Investigation, Data curation. Catherine Bent: Writing – review & editing.

# **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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# Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at 10.1016/j.reia.2025.202655.

# **Data Availability**

The data that has been used is confidential.

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