Inclusion

‘I WOULD GO TO MY CAR AND JUST CRY’: PARENTS' EXPERIENCES OF REFERRAL, INTERVENTIONS AND INCLUSION AT SCHOOL

--Manuscript Draft--

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Corresponding Author:	Lydia Carter, MSc Psych Northumbria University - City Campus: Northumbria University Newcastle upon Tyne, UNITED KINGDOM
First Author:	Lydia Carter, MSc Psych
Order of Authors:	Lydia Carter, MSc Psych
	Karen McKenzie, Ph.D.
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"I would go to my car and just cry": The experiences of parents whose children require or are referred for special education needs support at school.

In 1994, the Salamanca Statement sought to achieve a worldwide consensus on the principle of inclusion and provide a recommended educational strategy for schools, with the objective of achieving, 'education for all.' Yet, thirty years on, concerns remain about the academic and socioemotional efficacy of the inclusion process and its subsequent effects on the child's wellbeing and the well-being of their family (Florian, 2014; Nilholm, 2021; Watson et al., 2011).

In Australia and many westernized countries today, government funding to provide an inclusive education experience is supplied in lump-sums, with additional funds awarded for individual students, based on severity of need (Australian Government Department of Education Schooling Resources Standard, 2024; Dudley-Marling & Burns, 2014; Nilholm, 2021). In Australia, government funding is allocated to state schools, Catholic schools and independent schools (private schools supported by tuition-paying parents), with the added complexity of both the state/territory governments and the Commonwealth distributing these funds. To further complicate matters, the majority of funding for independent schools is provided by the Australian government, with minority funding provided by state and territory governments, with the reverse process applied to state schools. This system has been described as needlessly convoluted, and despite reviews in 2011 and 2018 to consolidate the process, there have been no significant changes. Funding has been a contentious issue, with significant concerns raised over disproportionately greater funding currently provided to independent schools (Anderson & Boyle, 2019; Australian Education Union, 2024; Australian Government Department of Education Schooling Resources Standard, 2024).

Government funding in Australia, and many westernized nations, is granted to help schools hire additional support personnel and implement a number of strategies to facilitate inclusive education. Individualized Education Programs (IEP), intended to address specific needs and track progress (Dudley-Marling & Burns, 2014) for students and their parents, have been practiced since the 1970's. Other adaptive practices, such as co-teaching to support learners with additional needs, modified teaching styles, clarity of instruction and positive education are also suggested by governmental bodies as a means of tackling the enormous diversity of students in the classroom. With little accountability as policy, however, these suggestions say little about the quality of delivery, left to the discretion of individual schools, and more often than not, to the discretion of individual teachers (Banks et al., 2015; Dudley-Marling & Burns, 2014). Lack of accountability as policy has also been criticized for inadvertently incentivizing some schools to seek diagnoses as a means to access additional support (Smeets & Roeleveld, 2016).

Despite philosophical shifts in rhetoric and empirical evidence supporting many strategies identified as beneficial for children with diverse needs, literature suggests a complex interplay of social, organizational and environmental factors that have constructed barriers to establishing genuinely inclusive schools (Connor & Ferri, 2007). Little understanding of ways to successfully implement inclusion in schools that benefit *all* students (Göransson & Nilholm, 2014) has hindered attempts to successfully engage a truly inclusive policy. A continued focus on academic competitiveness and high-stakes testing, inequitable treatment by teachers, poor peer relations, exclusionary disciplinary measures (Agrawal et al., 2010), little access to free play (Ramstetter & Murray, 2017) and environments which do not consider physical differences (Hemmingson & Borell, 2001) and neurodiversity (McAllister & Hadjri, 2013) have been cited as barriers to inclusion and substantially contributing to child mental health problems.

Australian literature has raised similar concerns. Although evidence-based inclusive practices are recommended by Australian government bodies, interpretation of these practices are largely left to individual states/territories as well as between state, Catholic and independent schools. Further, a lack of clarity around the meaning of inclusion, bureaucracy, lack of departmental cohesion and a disconnect between rhetoric and implementation of policy, have been blamed on a state-by-state approach to an application of resources, categorisation of disabilities and inclusive practices. The National Assessment Program for Literacy and Numeracy (NAPLAN), intended as a means of assessing student proficiency, has brought with it a rigid, standardized curriculum to meet the demands of high-stakes testing. As limited alternatives are provided for taking the test, and access to funding reliant on testing outcomes, schools are able to exclude students with intellectual disabilities from taking the test altogether. At the same time, educators are given the responsibility of identifying children with additional needs, yet have been provided limited training to understand diversity, address entrenched negative attitudes, and acquire the skills needed to effectively support children with diverse needs (Anderson & Boyle, 2015; Mavropoulou, Mann, & Carrington, 2021).

A particular concern has been highlighted for children with developmental disabilities and delays, who require greater levels of support, who may be predisposed to anxiety disorders, and are more likely to attend mainstream schools (Ambler et al., 2015). School related stressors such as the absence of predictability and structure, flexibility demands, interruptions to interests and susceptibility to bullying and social exclusion have been suggested to contribute to the development and ongoing prevalence of anxiety in these children (Ashburner et al., 2010) and can result in challenging behaviors such as anger, emotional outbursts and withdrawal, often being misinterpreted as unintelligent, undisciplined, antisocial and delinquent behavior (Ambler et al., 2015).

Such misinterpretations can also lead to one of the greatest barriers to a truly inclusive school environment; biases and the deficit mindset (Dudley-Marling & Burns, 2014; McGrath & Bergen, 2015; Mercer & DeRosier, 2010). Once entrenched, biases are difficult to shake and can have long term and detrimental consequences for those who are seen in an unfavorable light (Lewandowsky et al., 2012). Many parents also report a deficit attitude toward atypical children that must be 'fixed' or 'cured' (Ferri, 2008), as opposed to seeing a child who learns differently (Zeitlin & Curcic, 2014). Children who require additional support in school can be seen as below the normal curve and deficient in the skills required for school success and, therefore, society at large (Dudley-Marling & Burns, 2014). This biased and deficit mindset disregards the whole child in the presumption the diagnosis or difference overrides all other factors. It assumes value lies in the ability to perform well in core subjects and ignores the fundamental value of other abilities and the positive contributions differing skills can offer to society (Berliner, 2011; Gardner, 2011). This mindset can leave many children and their parents feeling unsupported, undervalued, alone, and with little prospects (Watson et al., 2011).

Fostering genuine understanding and regard for the emotional wellbeing of children and their families is imperative for inclusion to be effective. Despite limited research on the referral experience within schools, medical diagnosis is frequently described by parents as a prolonged period of worry with intense levels of stress and uncertainty (Watson et al., 2011). Further, feelings of shock, loss, anger, guilt, resentment and blame (Skotko, 2005), not only effect individuals but can also impact the family dynamic (Watson, et al., 2011). Many report feeling unheard and undervalued in a diagnostic process that ignores their observations, opinions and concerns (Watson et al., 2011).

Although quantitative research may provide a broad view of participant perspectives, it may not necessarily provide context, reasons nor reveal detailed information of the inclusion process (Libarkin & Kurdziel, 2002). To date, only limited research has explored the narrative accounts of parents' personal experiences of the referral, intervention, and inclusion process (Banks et al., 2015; Göransson & Nilholm, 2014; Nilholm, 2021; Watson et al., 2011) and this can often focus on children with a specific diagnosis, such as autism (McKinlay et al., 2022) or one aspect of the intervention and inclusion experience, such as IEP meetings (Zeitlin & Curcic, 2014). Although these studies offer valuable insights into their targeted areas, school inclusion affects children with a wide spectrum of needs. The inclusive system in its entirety is not explored nor how the bidirectional interactions between students, parents and educators within the system can positively or negatively impact academic achievement, socialization and mental health (Merçon-Vargas et al., 2020).

As Tudge (2022) states: "*If early childhood educators know and appropriately use just one theory that is relevant to early childhood education, Bronfenbrenner's is the theory for them.*" Tudge goes on the explain that the value in Bioecological theory lies in its consideration of *interactions* between individuals (eg. teachers, child, parents, peers), the *activities* they engage in (curriculum, tests, inclusion process), the organization and set up of the *environment* (order, temporal nature, physical structure, accountability), and the way these things interplay to create, "developmental outcomes" (Bronfenbrenner & Morris, 2007; Tudge et al., 2022). As children spend a minimum of half of each year in school, excluding extracurricular activities (National Center for Education Statistics, 2020), experiences in the education system may significantly influence the development of self-esteem, self-efficacy, behaviors and potential outcomes of children with diverse needs.

Therefore, via rich qualitative inquiry, through the lens of the bioecological model, the aim of this study is to examine the lived experiences of parents of children in primary schools who require a broad range of additional support and their perception of the referral process, interventions and experience of inclusion. This study askes the question: what are the experiences of parents whose child has been identified as requiring special educational support in school? With the aid of thematic analysis, the objective is to identify common benefits and challenges in the system which may better inform inclusion policy and foster the wellbeing of children and their families.

Method

Design and Ethics

The study received ethical approval from the authors' university ethics committee. A qualitative research design was used, using reflexive thematic analysis (Braun and Clark, 2006, 2020) as the approach to analyse data collected from semi-structured interviews. Reflexive thematic analysis was chosen because it is flexible and allows the researchers to conduct a rigorous analysis of the subjective experiences of many participants, (Nowell et al., 2017). While the approach can incorporate a range of theoretical and epistemological stances (Braun & Clarke, 2006, 2020), it is considered to be particularly suitable for researchers with a constructivist approach because the analytic process can help uncover some of the ways in which social constructs develop (see Kiger & Varpio, 2020). The focus of the researchers in the current study was on the subjective perspective of the participants and was underpinned by a constructivist approach. In addition, as reflexive thematic analysis is not atheoretical (Brauan & Clarke, 2020), a bioecological approach to inquiry was also employed. This approach suggests child development is affected by a complex interplay between the biological and characteristic traits of an individual and their environment rather than one single factor (Bronfenbrenner & Morris 2007).

These were subsequently analyzed utilizing the six-step thematic analysis framework proposed by Braun and Clark (2006).

Participants

Eight participants were recruited with an age range of 35 – 49 years and a mean age of 45 years. Seven of the participants were mothers with one father willing to be a participant in the research. All participants were parents of a child who had been referred for assessment or required additional support in an early years school setting. All parents were professionals with a tertiary level of education.

School settings: Seven participants were based in Australia, with one of the seven describing experiences in international schools in Southeast Asia and Australia. One participant recounted experiences in America. All participants' children were enrolled in independent or catholic/independent schools at the time of the events described, with two participants later enrolling their children in state schools and one participant later opting for home-schooling.

Participants' children: One participant's child had been diagnosed at birth with a physical and developmental disability. The remaining seven participants were referred for assessment in the early years of school. Experiences of inclusion in schools first began for children in this study, aged 3 – 7 years, with a mean age of four years. Events and experiences described by parents of these children took place over approximately 5 – 6 years with children now aged between 10 - 11 years old. Four of the participants' children had not yet acquired a formal diagnosis while the other four had been formally diagnosed (see Table 1).

Recruitment process

The eligibility criteria for this research included individuals aged 18 years or older, who granted their consent, and who served as the parent of a child who required or had been referred for special needs assessment and support within the primary school setting. Recruitment of participants was conducted through two primary channels: social media and the personal contacts of the researcher. Children referred or diagnosed in a secondary school setting were not included in this study.

Procedure

A research advertisement contained a link to an online survey platform (Qualtrics), which provided detailed participant information. Potential participants were asked to read this and record their consent if they wished to take part. Participants were then asked to provide a code (in case they later wished to withdraw their data), their name, and contact details. They were then directed to a separate online survey where they were asked to provide basic demographic information about themselves and their child. Recruitment ended when it was felt that data saturation had been reached i.e. participants in later interviews were discussing very similar issues to those raised in earlier interviews and it was felt that no new issues were being uncovered.

The researcher used the contact details to arrange a suitable interview time. Interviews were conducted via phone and were digitally recorded with the use of a Voicetracer recording device. The interviews lasted between 30-120 minutes, with an average of 90 minutes. Participants were asked about their experiences of the referral process, inclusion practices in the school and the impact of this on themselves and their children. During the interviews, the researcher followed a semi-structured interview schedule of open-ended questions (see Table 2).

Participants were also given a debrief sheet that explained the nature of the research, how they could find the results after the study, how to withdraw their data if they wished, and sources of support.

Name and contact information were securely stored on the Qualtrics platform and deleted at the conclusion of the study. Any personally identifying information was removed during the transcription process. All data handling procedures were in compliance with the Data Protection Act and University guidelines.

Data-analytic strategy

The data-analytic strategy followed Braun and Clarke’s (2006) 6 phase recommendation for thematic analysis. Digital recordings of interviews were transcribed. Transcriptions were checked for accuracy and emotional responses and then reviewed line by line by comparing the transcript with the original audio recordings. Interview transcripts were emailed to participants to check for accuracy or any misinterpretation of punctuation which could also impact meaning.

The agreed transcripts were read through initially to gain an overall sense of the interviews, individually, and as a whole. Coding of data extracts took place on second and third readings.

Following Braun & Clarke (2020), codes were conceptualised as: ‘an analytic unit or tool, used by researcher to develop (initial) themes. Here, codes can be thought of as entities that capture (at least) one observation, display (usually just) one facet’ (p13). Notes were made on meaningful passages and to identify codes related to the research question. This process was repeated for all eight participants and codes across all participants were organized into groups. The researchers had some pre-existing knowledge of the research literature relevant to the study topic, which shaped their approach, however further engagement with the literature was only undertaken after the initial codes had been generated in order to prioritise the participants’ subjective experiences (Burnard, 1991).

These codes were collated into four over-arching themes and associated subthemes. The themes were further refined and the researchers considered whether the themes captured ‘multiple observations or facets’ (Braun & Clarke, 2020, p13), which went beyond just a description of answers to the questions that participants had been asked. At this stage codes that did not sit within any theme or subtheme were removed. The themes were then evaluated to identify coherent patterns, and check for internal homogeneity and external heterogeneity (Patton, 1990). The former evaluates whether the information that is considered to form one theme is relevant to, and consistent and coherent within, that theme. The latter evaluates whether information that is considered to form separate themes is broadly distinct.

Finally, an analysis of each theme was conducted to identify and convey an overall narrative, supported by illustrative quotes. The final themes and associated subthemes were sent to participants to review and evaluate whether the interpretation accurately represented their perspectives. Final adjustments were then made according to participant recommendations.

Researcher position

The first author is a psychology graduate and researcher who has training and experience supporting children with developmental disabilities in school contexts in Australia. The second author is a clinical psychologist and researcher in the United Kingdom. She has over 30 years experience of both clinical practice and research with children and adults with developmental disabilities and their families.

Quality and rigour

While acknowledging the important role of researcher subjectivity in reflexive thematic analysis in shaping knowledge (Braun & Clarke, 2020), the authors also tried to ensure the robustness and credibility of their results by following recommendations for quality indicators in qualitative research (Brantlinger et al., 2005; Braun & Clarke, 2020; Trainor & Graue, 2014; Yardley, 2008).

Sensitivity to the context in which the study took place was addressed by drawing on our own knowledge and experience of the area and reviewing existing literature. This highlighted the relevance of the bioecological approach to child development. We also sought to evidence transparency in relation to our epistemological positions as researchers, our experience of the topic in question, our research and analytic processes, and the theoretical underpinning of the research. Recruitment was via purposive sampling to ensure the participants had experiences that were relevant to the topic of interest. Discussion and reflection between the researchers were used to refine the interpretation of the results, and feedback from participants was sought on the final themes and subthemes. Reflexivity was carried out throughout. The first author maintained a reflexive diary and there were regular discussions between the authors in relation to all aspects of the research process.

Results

The analysis identified 4 themes and associated subthemes as described below. Table 3 provides an overview of themes and associated subthemes and a brief description of each.

Theme 1: ‘We just see it as a red flag’

The first theme explored the implicit assumptions and biases that were held by professionals and how these impacted the children. The associated subthemes are outlined below.

‘He’s ASD, he can’t learn’ – unhelpful assumptions and comparisons made by teachers

This subtheme outlines the parental perception that some professionals made assumptions about their children that were not always accurate or helpful. All participants recalled situations in which teachers were highly focused on deficiencies, negativity and finding fault in their child*: “Never. Never had any positive feedback at all.”* (P7*).* In some cases, participants had to ask teachers to consider the positive attributes of their child: *“I asked the teacher in a meeting, where she had listed an absolute litany of [my child’s] deficits, ‘What are my child’s strengths?’ And she just looked at me blankly” (P5).*

Teachers were described as using comparisons with other children to highlight perceived difficulties with progress and capacity: “*They got [my child’s], schoolwork out, and other children's work and compared her work to their work, saying, she wasn't really up to the level she should be at*” (P7). In other cases, the abilities of the child were underestimated: *“She didn't believe that he could…was starting to read. I ended up having to take a video of him at home, demonstrating what he could do.”* (P.4)

Current behaviour, that could be viewed as developmentally appropriate was interpreted as a predictor of future difficulties for the child: *“[The teachers] were like, ‘We just noticed... out on the playground, if someone's not following direction or the rules, then he'll get really frustrated. We just see that maybe he, in the future, could get really, really frustrated. We just see it as a red flag’”* (P2). This could lead to suggesting diagnostic labels for some children that could cause distress for the family: “*She kept saying, ‘I think it's ASD and maybe ADHD,’…I was in a lot of distress at that point myself, but I just remember thinking, ‘You know, that's not for you to decide’”* (P.5).

Children were often defined by, and blamed for, their differences. This mechanism was seen as a way to absolve professionals from their responsibility to support and teach the children in appropriate ways: “*His prep teacher… pretty much took the attitude that [my child] had a disability and therefore was unteachable”* (P4). Some teachers were also perceived as using a diagnostic label as an excuse for failing to help a child progress: “*Not learning? Not my fault, he’s ASD, he can’t learn.”* (P5). This could cause parents to be reluctant to seek a formal diagnosis for their children:

> I was adamant we wouldn't do a diagnosis. Because as soon as we do a label, a diagnosis, then there's a whole set of categories and ways of approaching that which then compartmentalizes and constrains [my child’s] ability to grow and flourish. (P6)

‘It’s unconsciously baked in there now’ – the impact of negative bias on children

Negative labelling and blame had a detrimental impact on children and their families. Being perceived and labelled as ‘naughty’ caused distress for the child and potentially influenced how they were perceived by their peers: “*…he was getting upset that it was being said that he was naughty… And I know how kids can be pigeonholed and how it can be quite cruel.”* (P3). This, in turn, could influence how classmates behaved towards the ‘naughty’ child, such as trying to provoke them to behave badly: “*They would poke the bear and call [my child] a loose unit* “ (P6). In other cases, the labelling influenced both how the children perceived themselves: *“…the other children were saying, ‘well [my child] was naughty.’ So, he was starting to become this naughty child.”* (P3) and how they behaved, such as withdrawing: “*…at school he wouldn't talk, he would only meow*” (P5) or running away: “*It got to the point that he kept running away [from the school] and then start to not talk…”*(P8).

Negative labelling and perceptions could also have a detrimental impact on the child’s self-esteem: *“His confidence, just bottomed that year… he's a perceptive little boy. He was very aware that, she thought he wasn't up to it.”* (P4). For some of the children, school became a place associated with failure: *“School is still stressful for him. And he's got all these compounded negative experiences that we need to try to wind back.”* (P5). This led to ongoing consequences for young children who were developing their sense of self-esteem and self-efficacy: “*…we had to work a lot with [my child] about the way he talked himself: ‘I’m the stupid one. I'm hopeless. I'm just dumb.*

Why am I so stupid? Unconsciously, I think that still plays out…the negative self-talk. It's unconsciously baked in there now; that he's not going to be able do it any better. So why bother?' (P6).

Theme 2: 'It was just *them against me*'

The second theme examined the approaches taken by school staff in their interactions with parents and how this impacted parents and families.

'You can jump or you can be pushed'

Parents described feeling that school staff often used intimidation and blame to push a parent toward a desired result or out of the school:

> …problems keep coming up for these poor children, and it's allowed to get to a point where you're told you're on your last chance, you can jump or you can be pushed. What do you want to do? (P.5)

Parents felt they were faced with a barrage of complaints: *"I felt [the teacher] was always just at pains to point out his deficiencies…*" (P4) and *"…they were constantly calling me to go to see the teacher."* (P1). This was often in the context of parents feeling that their child was not being appropriately supported: *"… [I said] you're continuing to berate us about what we're not doing, yet you are fundamentally not working with my child."* (P6).

Some parents described shock tactics, where issues were raised suddenly: "*I wasn't expecting anything to be wrong, because I hadn't heard from the teachers for half the school year. But then…they start going over all these so called red flags regarding my child*" (P2) or multiple staff members attending meetings with one parent, giving parents the feeling, they were being ganged up on: *"…it was just them against me, kind of thing."* (P2) and "*…when I arrived, there was always a meeting with the teacher, the principal, and the head of the school"* (P1).

Parents described feeling blamed; that they were perceived as bad parents and that any issues with their children were their fault: "*So, I said, 'you tell me the interventions that you'll do, and we'll support them. Not this, we need to do better as parents.*" (P6). A condescending approach was often employed, particularly toward mothers, who regularly dealt with the majority of issues with schools. Despite the mothers interviewed being professionals themselves, many perceived a difference in response when their husband joined meetings:

> I often came out with the feeling that being a female, it didn’t matter how educated or intelligent I was or how carefully researched and considered my position on something was, I was only a mum…. But my husband was in the same meeting, and when he makes a suggestion…the response is, ‘Well, that's a good idea, that's worth a try.’ (P5)

As a result, potentially effective strategies were not considered: “*They have such insightful things to say about what goes on in schools and what doesn't go on in schools that should, and no one's listening… just a mum*.” (P4).

‘Deliberately hamstrung’

Some parents were met with unreasonable delays in securing a place for their child at school: “*it was the best part of 12 months for them even to say, ‘yes, we'll have [your child]*” (P4). Bureaucracy and an inflexible approach were seen as undermining effective strategies to support children and was seen at times as a way to frustrate parents into removing their children from the school: *“It's a deliberate policy of faffing around and making it difficult for people in the hope that you'll go somewhere else.”* (P4). Many parents felt consistently frustrated by an unwillingness on the part of schools to accommodate the needs of their children, try different strategies or listen to advice from parents’ personal experiences with their child: *“As far as my suggestions, that wasn't really flowing. They weren't gonna change their classrooms style.”* (P2) or even act on advice from specialists:

> …the advice wasn't coming from me, it was coming from professionals and she didn't want to take it on board. And really, I came away thinking, ‘You just don't like my child… you don't want him to succeed, because he's hard work.’ (P5)

Some schools required formal diagnostic assessment before allowing a child in school or offering support: *“We got our family therapist to talk to the school about the possibility of maybe allowing our son back to school and we got an immediate, ‘No. No, he needs an assessment’”* (P8).

The unwillingness of some schools to support their child had a negative effect on families: “*It was very stressful. You know, I'd drop her off and she'd have to get pulled off me to go to school. And I would go into the car and just cry.”* (P7). Many parents described being in a state of anxiety: “*I was very anxious… sending him to school and thinking what was going to happen today?”* (P.1), stress: “*We were stressed. We didn't know what to do…Even the grandparents were very stressed by it…So, all of this was affecting us, affecting him and affecting his older brother*” (P8) and despondent about their child’s future: *“My husband and I came out of that meeting absolutely slumping and just thinking, ‘Is he even going to finish primary school? What are his prospects? What is his future?’ …we were just exhausted, overwhelmed.”* (P.5)

Theme 3: ‘Like moving the Titanic around the iceberg’

Rather than adapting to the needs of their children, most parents experienced inclusion in mainstream schools as seeking to standardize all children, failing to recognize individual abilities and learning styles, and emphasizing academic attainment over other skills. They felt that the structures and processes were confusing and disorganized and that there was a lack of collaboration within schools and between schools and specialist services. Overall, there was a sense that schools were not properly prepared to support children with developmental disabilities: *“…they’re so unprepared for children who are different. And I just want to say to them, there are more children like [my child] coming…Get ready….and they're just not. It’s like moving the Titanic around the iceberg.”* (P5).

‘Individuals en masse’ – a contradictory concept

The competitive approach to assessments and a one-size fits all approach to learning rather than viewing each child as an individual was seen as being at odds with the goals of inclusion:

> We celebrate them as individuals, but then when we put them all together, en masse, in big classrooms, without any reference to their likes, dislikes, sensory problems, abilities… It's just kind of an extraordinary mismatch of priorities and needs. (P5)

Children who did not conform to expectations could cause discomfort for schools*: "…he wasn't fitting into their classroom structure mold or whatever. And so that was bothering them."* (P2) and lead to pathologizing differences: "*I think she just wanted to have children do certain things and if they weren't doing that, then there's something wrong with you*" (P7). The pressures of being forced to conform to a one-size-fits-all approach could instill the belief in some children that they aren't good enough: "…*because he has not been able to find a way to fit in…he is internalizing that as yet another failing on his part, as not being enough, just the way he is*." (P5). Rigid policies and inflexible teaching styles were also seen as leaving little room for differences: "*I think she was capable of teaching, probably about the average 20% of students… every kid got the same list of spelling words every week*" (P4).

All parents spoke about an emphasis on academic achievement at school. This could be at the expense of physical activity and play: *"They come to class and there's no outside activities where boys can run around and jump up and down. Everything's catered for subdued, quiet time."* (P6). In all cases this was felt to have had a negative impact on their child's learning and introduced rigid views of appropriate behavior: "*they took away all the play equipment…And then [my child's] use of sticks and stuff was inappropriate*." (P3). Inappropriate academic expectations could cause distress, anxiety and low self-esteem for children and their parents:

> He said, 'Look mum, I can do Mathletics.' And he went click click click click on various responses without pausing to think or even to look at the questions, got them all wrong, failed the test. The program came up with a message that you've been re-levelled and you're back at level one…He was devastated. He said, 'I'm going to kill myself. I hate myself; I can never go back to school.' [voice breaks] And just to see your tiny little bit of a child just so distressed over something so minor was just really awful. (P5)

‘No clear center of power’: Management and co-ordination

All participants described the co-ordination and management across the school and with specialists as challenging:

> I find it frustrating. I find it multi layered to the point where it’s absolutely bewildering, just so confusing. It’s as if there is no clear center of power. You're not sure who’s in charge of information passing and processing. And you're not sure who has authority over whom. (P5).

There was a perceived lack of collaboration, coordination and information sharing across the school:

> They would come to me and say, ‘What's [your child] going to need in prep?’ And I'm like, ‘Talk to your preschool director, who's been looking after [my child] for *three years*… who would have a much better sense… of what he will actually need in the classroom or in a school environment, than what I would.’ (P4)

Schools and teachers were described as often being unclear about what they want or why parents are being approached about issues concerning their child: *“…it was so vague and unclear… I didn't understand”* (P2). When schools requested the child be assessed, parents spoke of feeling unsupported, overwhelmed, and confused: “*I think that for me, I was feeling… lost on this journey. I didn’t feel that as educators they were guiding well*.” (P1). This caused stress and distress for parents:

> …there was no information or support, nothing. It was entirely up to me to find the assessment team and everything. So, I was pretty much alone. In a sense, it did feel quite lonely and very stressful. (P8)

Many parents described a limited number of specialists: “*I found that it's not easy because… not enough health care professionals*.” (P8) and long delays in accessing them: *“[it was] almost 6 months of seeing the psychologist until the assessment.”* (P8). Many times, multiple specialists were described as working with their child: *“…we had him in therapy, ABA, CBT, you name it, everything…* (P8) but not coordinating their approach:

> There needs to be a cross disciplinary understanding, or something. It's not just who they see but it's how that information is synthesized into a more integrated picture of this child. (P6).

This could sometimes result in multiple or conflicting diagnoses: "*We had two diagnoses on the opposite ends of each other*." (P8).

There was a perceived gap between specialist advice, its implementation: "*I don't think that teachers actually were advised on ways to help her within the classroom."* (P7) and monitoring: "*And given that [the learning support coordinator] is not on campus I have no idea how she would begin to monitor whether they're executing it effectively*" (P5). This could result in inconsistent and therefore, ineffective interventions: "*because this teacher does this, and the next one, the next year does something completely differently."* (P4). One parent, who was also a teacher, spoke of improvements to the system with a 'dedicated department' for inclusion available at her school. This offered additional support to the teachers, children and their families. It also supplied continuity and a greater understanding of the individual child and their needs while providing a level of accountability and transparency: "*They're all calibrated together for what might be going on for a kid… there is a mechanism where the different lenses of a child get brought together to be understood as a whole*" (P6). This was, however, still teacher dependent: "*The infrastructure is there. But the teacher still needs to utilize it*." (P6).

Participants noted that little consideration was given in schools to the impact of the physical environment on children with differing needs: "*very quickly became apparent to me that [my child] could not have coped with that environment. There were all sorts of big open plan learning areas; the noise was phenomenal*" (P4). Unwillingness to consider the physical space can also impact a child's behavior, sense of safety and ability to learn:

> There were suggestions for modifications to the classroom that might make [my child] more comfortable and at ease and [the teacher] didn't want to hear about them. Really simple things like a tepee in the classroom. So, [my child] as an alternative, kept climbing under

> tables and into the bag rack. All he wanted was to be tucked out of sight and, in fact, I think even more than that he just wanted to know a safe space was available to him. (P5)

Theme 4: 'Let's hit the ground running'

This theme reviews parent thoughts on positive experiences and how the system can be improved.

'I'll always be so grateful' – making a positive difference

Parents showed great appreciation for educators who considered the whole child and could see their child's positive attributes: *"…the other teacher met him and within half an hour said [our child] is kind and he's curious, and we can do so much with a curious kid … That was wonderful…"* (P5) and sought to meet their child at their own level: *"There was a deep curiosity about what a child needed. The whole child… a particular curiosity about the whole person, which is kind of meeting [my child] where he is…"* (P6) This approach helped children feel competent in their learning and grow in confidence: "*She's confident, she'll just go off to school. She's confident to get up in front of the whole school and do performances… she's just really excelling*" (P7).

Educators and school staff who showed empathy and compassion toward children had a positive impact on the child's well-being: *"He liked my child, and he was kind to my child. And my child started to blossom as a result."* (P5) and fostered a sense of belonging in the school environment: "*She actually worked with him to make him feel that he was safe at school"* (P8).

When teachers were proactive and encouraging, parents described marked improvements in their child's self-esteem: "*She just was so positive and so encouraging. I picked him up a different child at the end of the first day of grade one.*" (P4) as well as academic achievement: "*He was meeting all of the benchmarks, that he should have met, and he was enjoying school*" (P3).

Educators who were willing to be flexible, listen to parents, collaborate, and implement strategies, not only supported the child but also provided relief for parents, who felt their child was being cared for and appropriately supported:

> [The year one teacher's] attitude was, 'Yes, let's hit the ground running. Let's have the classroom space set up in a way that will help this child.' …the teacher actually requested that any therapists who were available should be present, and also the Inclusive Learning teacher, if we were comfortable with that. That was brilliant. We had the psychologist present and it just meant we felt we were hitting the ground running. We spent the summer feeling like there was communication in place, and there was a plan in place… It was just so *generous* in comparison to what we had encountered and I'll always be so grateful for that. (P5)

'Who's got ASD here?... Sometimes I think it's the school'

This subtheme explores parental thoughts on improving the education system by creating a truly inclusive environment that fosters a foundation of confidence and self-efficacy: "...*little kids, they need to be… content, and they need to feel safe to be able to learn."* (P4).

Parents expressed the need for collaboration, emphasizing the need to *"partner with parents," (*P2) and *'teachers…therapists and a learning support person'* (P5). Participants stressed the importance of early collaboration, where current and future teachers, parents, therapists, and support staff work together "*with a staff member… in a position to track the child through several years of their schooling, be a source of support and comfort and conduit of information in all directions"* (P5) to provide stability and consistency for the child.

Acknowledging individuality emerged as a key factor, emphasizing the necessity to meet children *"where they are"* (P4) developmentally and consider their unique needs. Participants highlighted the significance of proactive approaches to prevent problems arising: *"We can see with [my child] that a proactive approach pays dividends. When we're reacting to problems were already in trouble,"* (P5). Participants also underscored the need for increased training and support for teachers. Parents emphasized, *"there's no same diagnosis for any child"* (P8) and, therefore, providing specialized *"expertise that they can draw on readily"* (P4) was essential within the school environment.

Furthermore, participants emphasized the need for emotional support for parents, advocating for support groups and counselling services to assist families navigating the challenges faced by children with varying needs so *“they're not totally alienated or isolated.”* (P8) They called for practical information and support to be readily available to parents: *“… a little black notebook filled with potential therapists, potential programs that might assist the child, possible sources of funding support,”* (P5) to help alleviate stress and confusion in navigating the system.

They also underscored the need for policy makers to comprehensively *“review their strategy”* (P1) of the curriculum and assessments to better align with the developmental stages and individual learning styles of young children, *“so that they can then feel that they are making gains in their own learning,”* (P3), thereby fostering a system that accommodates diverse abilities and styles of learning. Participants emphasized the importance of accountability and transparency within a comprehensive framework incorporating *“transparent statements of who's responsible for what [and] where responsibilities begin and end,”* and including a *“system of reporting back and accountability; tracking that child and how they are managing across their whole academic program but more importantly across their development as a whole person, their wellbeing.”* (P5)

Finally, parents sought an inclusive environment that fosters empathy, flexibility and creative thinkers, with one parent also eloquently describing the paradox of inclusive education:

> I would want my department to be filled with creative problem-solvers…I would want to employ people who are compassionate front and center and have the flexibility and agility and theory of mind that we expect of our children. Because I look at [my child] and I think, you are far more flexible and compassionate than this institution. So, who's got ASD here? And sometimes I think it's the school. (P5)

Discussion

This study aimed to explore the perceptions of parents about the referral process, interventions, and experience of inclusion for their children with additional support needs. Consistent with previous literature (McGrath & Bergen, 2015; Mercer & DeRosier, 2010), the results demonstrated that the parents felt bias and a deficit mindset acted as major contributors to problems with inclusivity in the education system. As has been noted by previous researchers, participants described teachers who focused on the perceived inadequacies of their children, made unfavorable comparisons, and placed the blame on children for their differences or inability to meet academic benchmarks within allotted timeframes (Causton-Theoharis et al., 2011; Dudley-Marling & Burns, 2014; Ferri, 2008; Zeitlin & Curcic, 2014).

This research further illustrated how such biases depersonalized children and their families (Watson et al., 2011). Despite having educated and professional backgrounds, parents, and particularly mothers, faced condescending attitudes and marginalization and often left meetings feeling unheard and undervalued; positioned as an additional burden rather than an integral part of the solution (Watson et al., 2011). The unwillingness to adapt or listen to parents' input hindered progress for the child.

Consistent with previous findings (Zeitlin & Curcic, 2014), parents in the current study described educators as having little understanding and compassion concerning the impacts that the inclusion process had on their families. Parents reported feeling bombarded with complaints and criticisms from school staff and pressure to fix issues perceived within the school environment. Lengthy waits for diagnostic assessments, multiple assessments, multiple specialist interventions, school exclusion without diagnostic assessment and ongoing pressure by schools to obtain assessments or higher tier assessments, put enormous strain on children and their families (Watson et al., 2011). Parents expressed feelings of intimidation, shock, distress, anxiety, confusion, sadness, depression, isolation, anger, guilt, self-doubt and resentment with extended periods of uncertainty for months and sometimes years, with little reprieve. Yet, despite such a heavy emotional toll, they felt they received little to no practical or emotional support for themselves or their children (Skotko, 2005; Watson et al., 2011).

Although previous literature highlights concerns regarding the quality and effectiveness of the inclusion process, this study provides a detailed account of the extent of the problem across eight parents whose children had differing needs and attended different schools. They describe bureaucracy, disorganization and an inflexible approach which stifled progress and effective communication between parents, specialists and schools (Zeitlin & Curcic, 2014). Barriers to effective inclusion, noted in previous research, were found to still be in evidence, including the inconsistency of support offered to children, which often relies on individual teachers. Many teachers lack sufficient training or understanding of how to effectively support children with diverse needs (Connor & Ferri, 2007; Hsien et al., 2009). Parents described resistance to professional and parental advice, instances where effective strategies were ignored or neglected, and a lack of collaboration and information sharing across school departments (McKinlay et al., 2022; Scruggs et al., 2007; Zeitlin & Curcic, 2014). This led to missed opportunities for providing appropriate support and often resulted in reactive measures to issues rather than proactive interventions, further escalating problems (Rae et al., 2011). Despite a few instances of improvement with dedicated departments for inclusion, the results suggested that many systems of inclusion remained teacher dependent, showcasing that infrastructural support alone isn’t sufficient without policy that requires consistent implementation school-wide (Banks et al., 2015).

Consistent with previous literature, parents described inclusion in schools as being marked by standardization, a disregard for individual abilities and learning styles and an excessive emphasis on academics and competitive assessments over personal and holistic development (Connar & Ferri, 2007; Ramstetter & Murray, 2017). Parents expressed dismay at the education system’s struggle to accommodate and appreciate differences and its tendency to pathologize the child unable to fit in. This approach led to children feeling immense pressure to conform to a one-size fits all curriculum, causing high levels of distress, anxiety, and feelings of inadequacy. Further, physical environments not conducive to physical and sensory requirements, limited the number of schools children with differing needs were able to attend. Some educators’ resistance to minor classroom modifications, such as the provision of safe, quiet spaces within the classroom for children to retreat to (Barrett et al., 2013; McAllister & Hadjri, 2013), had significant negative impacts on the child's ability to learn, sense of safety and anxiety.

Negative tactics such as labelling the child as 'naughty,' and exclusive practices were identified as a way to deal with children presenting with challenging behaviors (De Boer et al., 2011). These negative perceptions and reactions by educators effected peer perceptions of these children, exacerbating instances of stigmatization and intensifying poor self-perception (McGrath & Bergen, 2015; Mercer & DeRosier, 2010). By contrast, parents showed great appreciation for some educators and specialists who recognized and celebrated each child's unique strengths, acknowledged their potential, showed understanding and compassion and were proactive and supportive. These qualities not only helped children navigate their anxieties and fears but also led to significant positive improvements in the child's self-perception, behaviors and academic achievements. In turn, this increased feelings of relational safety, comfort and confidence in the school environment and fostered a genuine sense of belonging for children.

Implications for practice

The study highlights that, for some children with additional needs, the inclusive education structure is failing to properly meet their educational, physical and social needs, with detrimental impacts to academic attainment and socio-emotional well-being. The results suggest the need for improvements in teacher training. This includes reinforcing the use of effective, positive, and proactive behavior management strategies to target bias and the deficit mindset. This can be tackled through training in positive and strengths-based pedagogy (Bolte et al., 2003; Fredrickson & Branigan, 2005) as well as personal interaction through engaging activities with children of differing needs (Martiny et al., 2022), which have been shown to be particularly effective in combating unhelpful biases. In some cases, an examination of the physical structure of schools and classrooms may be needed to ensure they meet the needs of diverse students (Barrett et al., 2013; McAllister & Hadjri, 2013). Shaping the content and delivery of the curriculum so that it has a greater focus on multiple-intelligences (Berliner, 2011; Gardner, 2011), places value on free play as a subject that significantly contributes to the cognitive, socio-emotional and physical development of children (Ramstetter & Murray, 2017), and promotes collaborative learning as opposed to competition-based models (Holmes et al., 2023), may help promote a learning environment that is better for all children. In terms of policy, the results suggest a need to target the organizational structures and require whole-school, parent and inter-professional collaboration, in order to create more effective and transparent systems of accountability for the inclusion process (Banks et al., 2015). Finally, this study advances further by demonstrating the far-reaching mental health impacts on families and a need to provide more practical and emotional support for parents and children.

Limitations

The research has limitations which need to be considered. The use of a qualitative approach offered the opportunity to obtain rich descriptions of parental experiences and their impacts. However, these experiences were limited to eight participants, primarily mothers, in relation to independent schools, predominantly in Australia. Despite unique challenges in the Australian system, many of the results were consistent with those found in previous research in the United States (Zeitlin & Curcic, 2014) and the United Kingdom (McKinlay et al., 2022). This suggests overarching international issues with the implementation of inclusive education in schools. Greater research into the experiences of both mothers and fathers, across state and independent schools, is imperative in Australia and internationally, to fully understand and evaluate the current systems. The analysis was also limited to the school context, whereas multiple contexts can shape individual outcomes (Bronfenbrenner & Morris, 2007). As such, further research in diverse settings is required.

Conclusion

This research highlighted how the inclusion process had a profound impact on how children viewed themselves and their capabilities, as well as how they were perceived and treated by their peers. For parents, the simple act of taking their child to school became emotionally draining, leaving some parents in tears or in a constant state of worry. Battling the school for support strained family relationships and left parents questioning their child's future prospects. Such narratives of distress highlight the extensive reach negative misconceptions and poor policy in inclusive education can have on children and their families. Although parents reported some educators exhibiting qualities conducive to inclusion, these educators faced significant barriers with other passive or resistant staff members, school organizational issues, access to resources and lack of cross-school accountability, further highlighting the importance of effective policies school-wide.

Parental experiences recounted in this study are consistent with decades of research pointing to extensive problems with the learning efficacy and socio-emotional effectiveness of inclusive practices. The results describe a process whereby educators adopt a deficit perspective. This can allow schools to place failure in the hands of atypical children and their parents while absolving educational bodies from critically evaluating policies and making changes to their own system.

Further qualitative research is imperative to understand the socio-emotional and academic impacts of the inclusion process in schools. However, research into reshaping the academic model, curriculum approach, philosophy and physical school environment is also crucial for successfully establishing a truly inclusive educational system that benefits *all* students. If we genuinely wish to create inclusive schools that ‘include everybody, celebrate differences, support learning and respond to individual needs,’ as stated in the Salamanca Statement, a greater understanding of the needs of diverse children in educational settings is vital to effectively implement the practical infrastructures and strategies that promote integration.

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Table 1

Participant Demographic Characteristics

Baseline Characteristic	
Participant Gender	
Female	7
Male	1
Child's Gender	
Female	1
Male	7
Child's age at referral	
3yrs	1
4-5yrs	6
7yrs	1
Year level at referral	
Preschool	3
Prep/Kindergarten	4
Year 2	1
Child's current age	
10yrs	5
11yrs	3
Location	
Australia	6
America	1
Southeast Asia/Australia	1
School type	
Independent	6
Catholic	2
Formal Diagnosis	
ASD; Severe Anxiety	1
Generalized Anxiety	1
PDA Autism	1
Prader-Willi Syndrome	1
No diagnosis acquired	4

Note. N=8. Participants were on average 45 years old.

Table 2

Overview of semi-structured interview questions

Semi-structured interview schedule of open-ended questions
Why and when was your child referred for assessment and support?
How were you approached about the recommendation for referral?
Were any considerations made with concern to the decision to refer if referral was school led? (e.g. context of situations causing concern/change in environment, teaching style differences from pre-school)
What kind of information and support was made available to you/your child through this process?
What was the process? (e.g. child behaviour checklist, parent teacher report forms, psychologist/psychiatrist/school counsellor/GP/paediatrician/ other specialists?)
How did this process impact you/your child/family dynamic?
What (if anything) changed for you/your child as a result of the process?
Were any interventions employed? What were they? Which were/weren't successful? Why? How?
How did this process impact the outcome for you/your child/others?
What were the benefits of the process?
What were the disadvantages of the process?
How could the process have been improved for you/your child?
If you could help other parents, what would help support them better through the referral process?

Table 3

Overview of themes and associated subthemes, with a brief description of each

Theme	Associated Subthemes and Brief Description
Theme 1: 'We just see it as a red flag.'	
Exploring the implicit assumptions and biases that were held by professionals and how these impacted the children.	Subtheme 1: 'Not my fault, he's ASD, he can't learn' – the role of blame. This subtheme explored the ways in which bias and assumptions often led to children being defined by, blamed for and at times erroneously categorized for their differences. Subtheme 2: 'It's unconsciously baked in there now' – the impact of negative bias on children. This subtheme examines the effects negative labelling and blame can have on children and the ongoing consequences.
Theme 2: 'It was just *them against me*.'	
Examining the approaches taken by school staff in their interaction with parents and impacts on families.	Subtheme 1: 'You can jump or you can be pushed' – using coercion. This explores the parental experiences of some school staff using intimidation tactics and blame to push a parent toward a desired result or to get the child out of the school. Subtheme 2: 'Deliberately hamstrung': restricting effectiveness and efficiency This reviews the way bureaucracy and an inflexible approach restricts

Table 3

	effectiveness and efficiency and the negative affect of this on the family.
Theme 3: 'Like moving the Titanic around the iceberg.' Exploring the current environment of inclusion that seeks to standardise all children, does not recognise individual abilities and learning styles, emphasises academics over other skills, and is often embroiled in confusion, disorganisation and a lack of collaboration.	Subtheme 1: 'Individuals en masse' – a contradictory concept. This outlines the contradictory nature of inclusion within the current structure of the school curriculum.
	Subtheme 2: 'No clear centre of power' - Management and co-ordination This explores participants' experiences of the co-ordination and management across the school and with specialists as disorganised, confusing, reactive, uncollaborative, teacher dependent and without accountability.
Theme 4 'Let's hit the ground running.' Reviews parent thoughts on positive experiences and how the system can be improved.	Subtheme 1: 'I'll always be so grateful' – making a positive difference. This explores the positive experiences parents have had with particular teachers and school staff and the positive impact it had on parents and their children.
	Subtheme 2: 'Who's got ASD here?... Sometimes I think it's the school' – parent thoughts on improving the system. This outlines parent thoughts on improving the system by creating an environment that fosters a foundation of confidence and self-efficacy.