

Understanding Parents' Experiences With Mainstream Schooling for Their Children With Autism Spectrum Disorder: A Meta-Analysis

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Importance: Children with autism spectrum disorder (ASD) face school-related occupational challenges. Attending a mainstream school offers benefits for children's learning and their development of social skills; however, parents express frustration with ensuring their child's unique needs and preferences are met.

Objective: To gain insight into parents' experiences with the mainstream preschool and primary educational system for their children with ASD.

Data Sources: Eleven electronic databases were systematically searched, and processes were followed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Study Selection and Data Collection: Study eligibility was determined through the use of selection criteria and paired independent reviewers. Critical appraisal was conducted using a qualitative research hierarchy and a modified version of the Critical Appraisal Skills Programme tool. Two reviewers synthesized the data into themes, following the Joanna Briggs Institute meta-aggregation process. Twenty-six qualitative studies, representing the voices of 397 parents, are presented in this review (spanning 2013–2021). Articles were set in Westernized and non-Westernized settings and represented culturally and linguistically diverse population groups.

Findings: Parents of children with ASD reported a lack of awareness and understanding of their children's unique learning needs in the mainstream school system at all levels.

Conclusions and Relevance: This review has various occupational therapy practice implications for supporting school-age children with ASD, their parents, and school staff. These include adopting family-centered and ecological approaches, raising awareness, influencing policy, and facilitating collaboration.

What This Article Adds: This review provides guidance for occupational therapists working in schools about their practice in working at the individual, targeted, and whole-school levels to address occupational barriers faced by children with ASD.

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Occupational therapists address students' abilities to participate in desired daily school occupations (American Occupational Therapy Association [AOTA], 2016) by means of their unique understanding of the interactions among the personal, environmental, and occupational demands that can facilitate or hinder a child's participation (Cohn & Lew, 2010). By adopting a strengths-based approach, they can support children's academic and nonacademic outcomes, including literacy, behavior management, and participation in

extracurricular activities during key transition periods (e.g., primary to high school), social skills, and more (AOTA, 2016). Their interventions have applications at the individual and population levels, including the provision of specialized intervention strategies to individual students, groups of students, whole classrooms, and whole-school initiatives (AOTA, 2016). For example, on an individual level, they can help a child develop and use an appropriate pencil grasp to support writing tasks. Group interventions can involve targeted

activities for a small group of children learning scissor skills. School-level interventions can include whole-classroom interventions and supporting teachers in designing alternate ways of performing school occupations to ensure that all children meet their learning goals (Kaelin et al., 2019). Occupational therapists work holistically within a child's environment and play a crucial role in collaborating with, supporting, and educating parents and school staff.

Occupational therapy is provided to support children with autism spectrum disorder (ASD) in schools (McDougle, 2016). ASD is a complex neurodevelopmental diagnosis, characterized by a diverse spectrum of impairments in social interaction and communication as well as restricted, repetitive patterns of behaviors, interests, and activities (American Psychiatric Association [APA], 2013). Children with ASD often attend inclusive mainstream school settings, where a focus on their well-being, dignity, and autonomy is prioritized and differences in abilities are valued (United Nations, 2016). Occupational therapists support children with ASD who often have learning experiences that differ from those of their peers; for example, they may struggle academically and find social relationships with peers difficult (McDougle, 2016).

Children with ASD often experience unique sensory preferences, including difficulty tolerating sensory environments, which can affect their occupational performance and classroom engagement (Lindsay et al., 2014). For these children, difficulty in engaging optimally at school can be attributed to difficulties adjusting as well as to the school's failure to respond to their unique needs (Brede et al., 2017). Many parents believe mainstream schooling reaps benefits for their children's learning and social skills by providing them opportunities to socially interact with neurotypical peers (Lynch & Irvine, 2009).

In supporting academic and occupational outcomes for children with ASD, family involvement and parent-teacher relationships can be instrumental (Garbacz et al., 2016). The importance of parent-teacher relationships was articulated by Clarke et al. (2009) as "child-centred connection(s) between individuals in the home and school settings who share responsibility for supporting the growth and development of children" (p. 61). In addition, foundations of trust are developed between both parties when promises and expectations are met (Stoner et al., 2005).

Parents, however, report frustration in navigating and understanding the complexities of the educational system (Garbacz et al., 2016), especially regarding supports available to their children (Fontil & Petrakos, 2015; Hutchinson et al., 2014; Starr et al., 2016). Because parents are the experts on their children's needs, wants, and behaviors, they play a key role in their learning progress. Parents' contributions should therefore be highly valued within the educational system (Connolly & Gersch, 2016).

For occupational therapists to adequately support parent and school collaboration, an increased, in-depth understanding of parents' experiences of mainstream schooling for their children with ASD is needed. At present, no consolidated understanding exists to describe parents' experiences, and we conducted this meta-analysis to address this gap. An increased understanding may support occupational therapists working on the school-based occupational performance of preschool- and school-age children, whether in school-based, community, or clinic-based settings. Our review, therefore, aimed to answer the following question: "How do parents with a child with ASD describe their experience of the mainstream preschool and primary school system?"

Method

This study contributes to a suite of articles that have explored parent experiences in different ASD-related areas (Boshoff et al., 2016, 2018, 2019, 2021). In this study, we conducted a meta-analysis to gain an in-depth person perspective on the mainstream school experience to inform practice, as described by the Joanna Briggs Institute (JBI) authors, Munn et al. (2018). An a priori protocol was developed to meta-aggregate and analyze qualitative evidence in line with the JBI (Aromataris & Munn, 2020). Our methodology was informed by the ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research) statement (Tong et al., 2012) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Page et al., 2021). This meta-analysis is registered with the International Prospective Register of Systematic Reviews (Registration No. CRD42021241318).

Information Sources and Search Strategy

Eleven electronic databases were searched on April 20, 2021, including the Cochrane Library (1996–present), ERIC (1966–present), PsycInfo (1806–present), Ovid Embase (1974–present), Ovid Emcare (1964–present), Ovid JBI EBP, Medline (1997–present), Ovid Nursing Database, Scopus (1960–present), the ProQuest Sociology Collection (1947–present), and the Web of Science (1950–present). Search terms were adapted from a previous meta-analysis that included parent experiences in different ASD-related areas, the JBI reviewers' manual, and input from two academic librarians (Aromataris & Munn, 2020). Key word and Medical Subject Headings (i.e., MeSH) were derived from key concepts of the review question (population, interest, context). A pilot search was undertaken to determine the appropriateness and sensitivity of the search terms. The search strategy was adapted for each database and conducted within a 24-hr period to control for daily database updates (see Supplemental Appendix Table A.1, available online with this article at <https://research.aota.org/ajot>, for full search strategies). The reference lists of included

Table 1. Inclusion Criteria

Phenomenon of Interest	Parents of Children Diagnosed With ASD Who Describe the Experience of Their Children in Mainstream Preschool and Primary School
Population	<ul style="list-style-type: none"> ▪ Parents, mother, father, carer, or caregiver ▪ Children diagnosed with ASD according to <i>DSM-5</i> ▪ With mixed-diagnoses population groups, the majority of the population (50% or more) require a diagnosis of ASD ▪ With mixed preschool, primary school, and secondary school experiences, at least 50% need to be related to preschools and primary schools
Context	<ul style="list-style-type: none"> ▪ Educational system: Mainstream preschools and primary schools ▪ Preschools were defined as the formal educational setting before entry into primary school ▪ Mainstream schools with special classes were excluded
Study design	<ul style="list-style-type: none"> ▪ Qualitative research only (all designs accepted) ▪ Primary research studies ▪ Questionnaires were excluded ▪ Mixed-methods studies were included only if the qualitative component provided sufficient depth (see next point). ▪ Results needed to be presented as themes, quotes, statements, descriptions, or observations, supporting or evidencing themes.
Other criteria	<ul style="list-style-type: none"> ▪ Peer-reviewed publications ▪ Published in English ▪ Published from 2013 onward ▪ Special education and special classrooms in mainstream settings were excluded.

Note. ASD = autism spectrum disorder; *DSM-5* = *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.).

studies were used to identify any relevant papers that were not picked up in the database search.

Study Selection Process

Study screening was independently conducted at the title, abstract, and full-text levels by three primary reviewers (Pamela Carrera, Kobie Boshoff, and Louise Wiles). Each study was independently screened by two reviewers using Covidence software (Veritas Health Innovation Ltd., n.d.). Conflicts regarding studies' eligibility were discussed among all reviewers and resolved after a full consensus was achieved.

Study Eligibility

The eligibility criteria are outlined in Table 1. Reviewers included papers whose authors described the education setting as mainstream. Mainstream schools are defined by the UNESCO International Bureau of Education (n.d.) as "general educational settings or regular schools." Specialist schools that cater exclusively to children with disabilities were excluded because these settings were outside the scope of interest, providing a different parent experience. Studies published from 2013 onward were included, reflecting the most recent edition of the APA's (2013) *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*). Questionnaires were excluded because of the rich qualitative data they required.

Process of Critical Appraisal

First, we assigned each study a hierarchical level of evidence for qualitative research (Daly et al., 2007, p. 46).

We then assessed each study's methodological rigor using a modified Critical Appraisal Skills Programme (CASP; 2018) tool for qualitative studies.

Similar to our previous reviews (Boshoff et al., 2016, 2018, 2019, 2021), we used a modified CASP tool by incorporating an item from the critical appraisal tool "Critical Review Form: Qualitative Studies" (Letts et al., 2007). The item added ("Was a theoretical perspective identified?") aimed to capture the study's theoretical perspective. For every study, a score ranging from 1 (low) to 3 (high) was provided for each CASP item, as proposed by Duggleby et al. (2012) and Feder et al. (2006; for score explanations, see Table 2). The three primary reviewers and additional secondary reviewers (Rebecca Phillips and Deanna Gibbs) independently completed the critical appraisal, with reviewers paired to evaluate each study. Any conflicts were discussed among members of the review team, with a full consensus reached.

Data Extraction and Meta-Analysis

In accordance with the JBI manual, we used the JBI data extraction form. Meta-aggregation of data was performed, and findings were synthesized with the generation of a set of statements (Aromatarsis & Munn, 2020, p. 44). The findings were categorized on the basis of content similarity. Two primary reviewers (Carrera and Boshoff) independently conducted the meta-aggregation, followed by a discussion, with a full consensus reached on the meta-aggregation. An additional reviewer (Porter), a parent of a child with ASD, reviewed the analysis, allowing for interpretation and application of the data from a lived experience.

Table 2. Research Hierarchy Levels and CASP Scores of Included Studies

Authors	Research Hierarchical Level ^a	CASP Total Score ^b
An et al. (2020)	III	25
Bayrakli & Sucuoglu (2019)	III	25
Broadly et al. (2017)	III	25
Chen et al. (2020)	II	27
Columna et al. (2020)	III	26
Faraji-Khiavi et al. (2021)	III	18
Hebron et al. (2015)	III	24
Helkkula et al. (2020)	II	26
Hodges et al. (2020)	III	26
Hoy et al. (2018)	III	27
Johansson (2016)	III	23
Lilley (2013)	IV	21
Mahagamage et al. (2021)	III	28
Majoko (2019)	III	29
McNerney et al. (2015)	III	24
Moyse & Porter (2015)	III	27
O'Leary & Moloney (2020)	III	29
Potter (2016)	II	28
Reupert et al. (2014)	III	21
Richter et al. (2019)	III	23
Rubenstein et al. (2015)	III	29
Stack et al. (2020)	III	24
Tso & Strnadova (2017)	III	26
Valencia Medina et al. (2020)	II	27
Vlcek et al. (2020)	III	22
Yazici & Akman (2020)	III	24

Note. CASP = Critical Appraisal Skills Programme.

^aWe used Daly et al.'s (2007) hierarchy levels of evidence for practice in qualitative research. Level I generalizable studies often build on earlier studies; the sample is extended when early analysis indicates that additional conceptual categories are required. Level II conceptual studies proceed from a conceptual framework that guides sample selection. Level III descriptive studies focus on a sample selected from a specific group or setting. Level IV single-case studies focus on the views and experience of one person in a particular context.

^bMaximum score = 33. Each CASP item ($n = 11$ detailed questions) was scored as follows: 3 = deemed as providing extensive justification and explanation of the issue, 2 = deemed as addressing the issue but did not fully elaborate, 1 = deemed as offering little to no justification for a particular issue.

Results

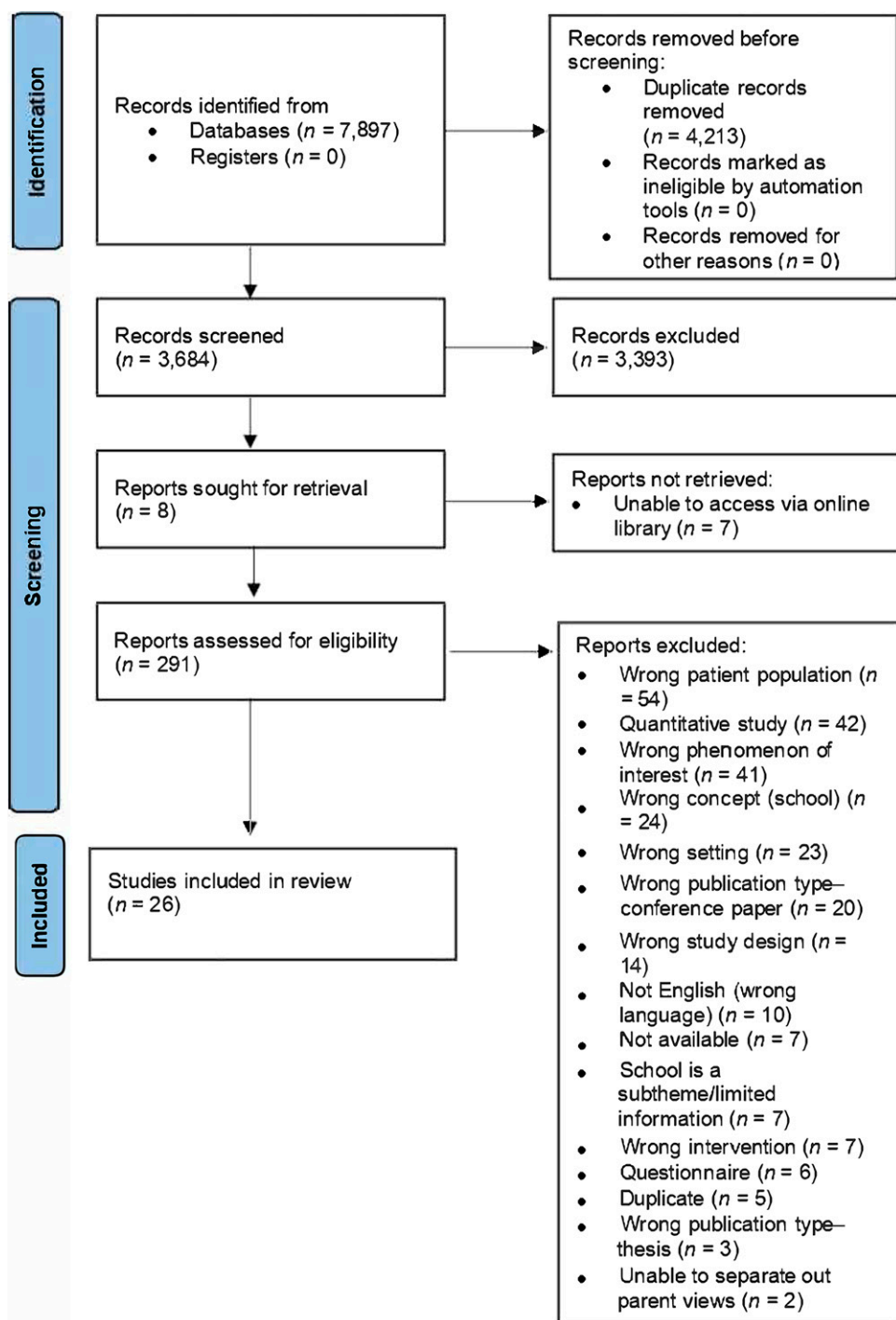
The electronic database ($n = 11$) searches yielded 7,897 results. A total of 291 studies were accessed at the full-text level, resulting in a total of 26 included studies. The main reasons for full-text ineligibility were wrong population ($n = 54$), quantitative design ($n = 42$), and wrong phenomenon of interest ($n = 41$). Figure 1 depicts the PRISMA flow diagram (Page et al., 2021).

The critical appraisal results of the included studies, including the articles' hierarchical level and CASP score, are presented in Table 2. The majority of studies ($n = 21$) were Level III (descriptive studies), 4 were Level II (conceptual studies), none were Level I (generalizable studies), and 1 was Level IV (single case study). CASP total scores ranged from 18 to 29, out of a potential

score of 33. Studies ($n = 6$) with lower CASP scores (scoring 1 on Item 6, regarding the demographic information of the sample) indicated that they did not report sufficient detail on demographic information about the population of interest (e.g., cultural background, parents' education, and socioeconomic indicators). Studies with low CASP scores ($n = 20$, scoring 1) on Item 9, addressing the researcher's role and relationships with participants, indicated potential bias in the research questions and findings.

Table A.2 provides the characteristics of the included studies. A total of 26 studies were included, describing the experiences of 397 parents of children with ASD. Parental experiences were represented across preschool ($n = 4$) and primary school ($n = 12$)

Figure 1. Flow diagram of the study selection process.



Note. Figure format from “The PRISMA 2020 statement: An updated guideline for reporting systematic reviews,” by M. J. Page, J. E. McKenzie, P. M. Bossuyt, I. Boutron, T. C. Hoffmann, C. D. Mulrow, . . . Moher, D., 2021, *British Medical Journal*, 372, n71. <https://doi.org/10.1136/bmj.n71>

settings and transitions from primary to secondary school ($n = 8$), as described by the authors of the papers. Six studies did not specify the type of educational setting; however, in the discussions of their findings (i.e., how the setting was described) they implied it to be a preschool or primary school (An et al., 2020; Broady et al., 2017; Faraji-Khiavi et al., 2021; Helkkula et al., 2020; Potter, 2016; Valencia Medina et al., 2020).

The majority of studies ($n = 17$) were set in Westernized countries such as Australia, the United Kingdom, Ireland, the United States, and France. Nine studies included Culturally and Linguistically Diverse (CALD) population groups from the United States, Kazakhstan, Iran, and India (An et al., 2020; Bayrakli & Sucuoglu, 2019; Columna et al., 2020; Faraji-Khiavi et al., 2021; Johansson, 2016; Mahagamage et al., 2021;

Majoko, 2019; Valencia Medina et al., 2020; Yazici & Akman, 2020).

The 4 Level II conceptual (highest ranking) studies were from Westernized countries, namely, 2 from the United States (Helkkula et al., 2020; Valencia Medina et al., 2020), 1 from the United Kingdom (Potter, 2016), and 1 from Australia (Chen et al., 2020). Three of these studies (Chen et al., 2020; Potter, 2016; Valencia Medina et al., 2020) scored moderate and high (scores of 2 and 3) regarding addressing the CASP item related to the researcher's role and relationship with participants. A study conducted by O'Leary and Moloney (2020) from Ireland also scored high (3) on the demographic details provided. These critical appraisal results indicate confidence in the results of these studies. The Level IV case study was from an Australian context, and the findings from this study were confirmed by the other higher-level studies.

In studies that specified parents' gender ($n = 18$), males were underrepresented, with the majority being female (a total of 191 female voices captured overall). Of note is that 1 study focused specifically on fathers' perspectives, capturing 25 voices (Potter, 2016). Six studies included children with additional diagnoses, including attention deficit hyperactivity disorder, learning delay, dyspraxia, dyslexia, intellectual disability, and anxiety (Hebron et al., 2015; Lilley, 2013; McNerney et al., 2015; Reupert et al., 2014; Tso & Strnadova, 2017; Valencia Medina et al., 2020).

Five studies reported indicators of parents' educational attainment, with the majority having higher educational attainment ($n = 3$), and 2 studies included mixed educational attainment ranging from "some primary school" to a college degree (Bayrakli & Sucuoglu, 2019; Columba et al., 2020; Majoko, 2019; Valencia Medina et al., 2020; Yazici & Akman, 2020). Six studies reported on parents' employment status, which ranged from part time to full time (Faraji-Khiavi et al., 2021; Helkkula et al., 2020; Johansson, 2016; Mahagamage et al., 2021; Potter, 2016; Tso & Strnadova, 2017).

Findings: Categories

Our synthesized findings are divided into five categories, which emerged from the themes of the original studies (see Table A.3). The findings of studies set in non-Westernized countries with lower CASP scores were reinforced by the findings of studies in Westernized countries with higher CASP scores. The five categories were as follows: (1) When Engaging With the Education System, Parents Describe a Range of Intense Psychological and Behavioral Responses, (2) Parents Experience Difficulty With Access to and Entry Into Mainstream Schools for Their Children With ASD, (3) Parents Experience a Lack of Understanding and Awareness of ASD at School, (4) Parents' Experiences of Collaboration, Communication, and Relationships With Educational Staff, and (5) Parents' Experiences of the School Accommodating Their Child's Needs.

Category 1: When Engaging With the Education System, Parents Describe a Range of Intense Psychological and Behavioral Responses

Parents described emotional and behavioral responses when engaging with and navigating the educational system for their children with ASD. For example, parents reported "feeling fear, sad, frustrated and stressed in regard to their child's behavior" (Valencia Medina et al., 2020, p. 126). One parent detailed the stress of interactions with the school: "And you know, it was like the stress level. . . . There was always something else you would think about" (Valencia Medina et al., 2020, p. 128). Moreover, parents felt burdened with the responsibility of providing additional educational support at home: "You know the parents have enough on their hands without having to be a teacher at home" (Potter, 2016, p. 497).

Potter (2016, p. 498), uncovered unique experiences of fathers. One father described empathy with their child's experience:

He was struggling with school, he was struggling with friends. . . . It was heartbreaking for me and. . . . The more I saw what was happening to Simon. . . . It was my childhood. It was me being repeated. And I kept saying to [my wife] "This isn't right; I'm not going to have this for him."

Another father saw benefit in his lived experience, taking initiative in educating and coaching their child's teacher (Potter, 2016).

Parents adopting an advocacy role for their children with ASD also were portrayed (Johansson, 2016; Rubenstein et al., 2015; Valencia Medina et al., 2020). One parent stated,

It's normal to think as a parent, "Oh, my child is very important because he's my son." Right? But schools, unfortunately don't; he's just another child in need of services. So that's why it's so important for parents to be their voice, that we are always demanding what our children deserve by law. (Valencia Medina et al., 2020, p. 128)

Advocacy did not always result in desired outcomes, as parents experienced difficult relations with educational staff and the continuation of inadequate services.

In contrast, parents in Johansson's (2016) study described their experience of a mutually beneficial relationship: "Actually, whatever the school says, I try to cooperate with it. They have said she [the daughter] needs an attendant, so we will find one as the school has given her a lot of support" (p. 107). However, this was not the experience of all parents. A CALD parent described feeling intimidated by educated individuals:

You have no idea how it feels to be surrounded by this army of educators and educated people . . . especially with my son, Emilio, [who] was behaving so badly and you feel that you just stop. You stop listening at one point. (Valencia Medina et al., 2020, p. 128)

Category 2: Parents Experience Difficulty With Access to and Entry Into Mainstream Schools for Their Children With ASD

A strong category emerged of parents describing difficulty gaining access to and navigating mainstream schools, with many facing informal school exclusion. Sourcing information on suitable schools was challenging: “I wanted someone to say to me, ‘Where do the [autistic kids] go in the borough? What’s the best school for the autistic kids?’ But no one will talk to you” (McNerney et al., 2015, p. 1104). Some parents were required to travel long distances to access appropriate schooling (Mahagamage et al., 2021).

Parents articulated instances of immediate rejection after disclosing to the school that their child had ASD (Broady et al., 2017; Faraji-Khiavi et al., 2021; Lilley, 2013; Mahagamage et al., 2021). As one parent illustrated, “She said straight up to me, ‘No; we don’t take special needs children.’ I said, ‘But you haven’t seen my child; you haven’t asked what the special need is’” (Lilley, 2013, p. 523).

Another parent described exclusion that was based on judgment and a lack of understanding of ASD: “Once I took him to the kindergarten, the staff didn’t let him in. They said ‘Your child has stereotypical behaviours. Other children may learn negative behaviours from him’” (Faraji-Khiavi et al., 2021, p. 3). The importance of finding the right school was emphasized:

Find a good school that’s prepared to actually help your child and see that. . . . Schools need to be open to the fact that they’re not just going to fit in and act like all the other cookie cutters. (Tso & Strnadova, 2017, p. 395)

Category 3: Parents Experience a Lack of Understanding and Awareness of ASD at School

A large proportion of parents described experiences that demonstrated a lack of understanding and awareness of ASD on the part of educational staff, their children’s neurotypical peers, and other parents: “Other parents don’t understand. Basically they are just ignorant” (Broady et al., 2017, p. 228). One father described the impact of others passing judgments:

It is a huge issue and it’s very, very typical of how an awful lot of people approach seeing a family with a child with ASD in it. They look from a distance . . . at a snapshot, and they make assumptions. . . . They make judgments on the basis of those assumptions, and then when you object they blame you for being difficult. (Potter, 2016, p. 499)

Parents described how a lack of understanding from peers led to incidents of bullying and exclusion: “[Other pupils] will tease Samuel about something really small, not even significant in his life, you know, they will start saying something and he will flip out and next thing you know, Samuel is in trouble” (Hebron et al., 2015,

pp. 188–189). Another parent emphasized their child’s vulnerability to bullying: “With the passage of time, slowly the difference with her peers is getting wider. Naturally, when there is a gathering, they are teasing her” (Johansson, 2016, p. 108).

A lack of expertise on the part of educational staff was evident as parents described instances when staff lacked an understanding of the unique characteristics of their children:

We would get calls from teachers or administrators telling us that my son was blurting out in class or waving his hands in his face or stacking books up in class and could we get him to stop! Typical behaviour from an autistic child. They expected him to behave just as a non-autistic child. (Helkkula et al., 2020, p. 1024–1025)

Parents articulated schools’ reduced expectations and belief in the children’s capabilities: “He has been excluded from so much in the past because they just say, ‘He won’t be able to handle that.’ But they didn’t even try—you know?” (Hodges et al., 2020, p. 6).

Category 4: Parents’ Experiences of Collaboration, Communication, and Relationships With Educational Staff

Parents described varying experiences when collaborating and communicating with educational staff. Stack et al. (2020) mentioned how parents described not “feeling heard” or “believed,” and as a result “they often no longer reported issues to the school as they did not expect their problems to be addressed” (p. 9). A CALD mother exemplified a tenuous relationship with her child’s teacher:

I do not know what activities are being done at the school, if my son participates in the activities. . . . Neither teachers mentioned nor [did I ask]. . . . I just go, pick him up and leave the school. “How was he?” “He was good.” That’s all. (Bayrakli & Sucuoglu, 2019, p. 129)

Parents highlighted a need and desire for multilevel support with greater involvement of school leadership to enable strategies that support the participation of students with ASD in the school environment (Hodges et al., 2020; Vlcek et al., 2020).

In Columna et al.’s (2020) study, mothers articulated a desire for increased collaboration and information-sharing with educational staff. Fathers in particular mentioned the timing of school meetings as an obstacle to collaborating with educational staff because fathers who were employed full time could not attend daytime meetings (Potter, 2016, p. 498). Moreover, mothers were often considered “the first point of call during the day due to fathers’ employment status” (Potter, 2016, p. 499).

Parents described strong relationships with teachers characterized by collaborative communication and teachers demonstrating responsiveness to their child’s needs (Chen et al., 2020; Majoko, 2019; Reupert et al.,

2014; Rubenstein et al., 2015). One parent stated, “If I have an issue I’ll go up and deal with it and then I’ll get a report back to say, ‘This is what we’ve done about this issue’” (Reupert et al., 2014, p. 91).

One parent emphasized the importance of valuing parents’ expertise: “I would suggest that people be more aware that the parents may not have a degree but we know our children better than anyone else” (Vlcek et al., 2020, p. 109). Another parent said,

In school development and whole-school meetings, our ideas are considered in the same way as those of parents of children without ASD, teachers, the headmaster, deputy headmaster, counsellors, the Member of Parliament, religious leaders, and village headmen. (Majoko, 2019, p. 914)

Category 5: Parents’ Experiences of the School Accommodating Their Child’s Needs

Parents recounted positive examples of schools tailoring situations according to their children’s individual needs and interests. One parent offered,

My girl is a LEGO nut and all we had to do was say “Look she will participate with other kids if they’re doing what she likes doing as well.” So the LEGO comes out at lunchtime instead of her being forced to play ball. . . . You’ve got to provide other opportunities. It’s not a one-size-fits-all thing. (Hodges et al., 2020, p. 6)

However, parents reported that the availability of adaptations to educational curriculum to better meet the needs of their children was varied (Johansson, 2016).

Providing safe spaces within school environments for children with ASD to regulate their emotions was reported by some parents (Majoko, 2019; Reupert et al., 2014; Stack et al., 2020). This included the use of spaces to accommodate children’s sensory needs that they could access when they needed to decompress and regulate (Reupert et al., 2014).

Parents articulated the benefit of teaching assistants providing individualized support, describing them as an “enabler[s] and confidence-builder[s] in accessing the mainstream curriculum” (Hebron et al., 2015, p. 190). Similarly, the temporary absence of teaching assistants could affect the teacher’s ability to “cope” and “control” the students with ASD and their neurotypical peers (Majoko, 2019, p. 915).

Parents described their children’s experience with transitions, which ranged from minor transitions within the classroom to progression to a new academic year level and the transition to high school. One parent illustrated the need for predictability of a schedule for their child:

I think our main difficulty . . . is transitioning from one thing to the other. . . . It still causes a lot of anxiety within them. . . . You need a lot of prewarning and a lot of visuals of time to let them know that there’s going to be a planned activity coming up. (Chen et al., 2020, p. 95)

Parents discussed attendance at school tours, chances to meet staff before the school year commenced, integration days, and meetings as effective strategies for smooth transitions from primary school to high school (Hoy et al., 2018; Reupert et al., 2014; Richter et al., 2019; Tso & Strnadova, 2017). Some of them exemplified the role of primary schools during transition: “[They] would free up a member of staff that [my child] was familiar with so they could come with him, which helped a lot as it was not a completely unfamiliar environment” (Hoy et al., 2018, p. 191). Another parent described the use of the same aide from primary school and the creation of a “passport from Grade 6 to 7” that detailed their child’s strengths and challenges in the classroom (Reupert et al., 2014, p. 90).

Discussion

This is the first meta-analysis to synthesize the perspectives of parents’ experiences accessing and utilizing mainstream preschools and primary schools for their children with ASD. The results indicate that parents’ experiences are often affected by a lack of awareness of their child’s unique behaviors and learning needs on the part of educational staff, other parents, and the child’s neurotypical peers. Increased awareness among educational staff, parents, and peers is needed to understand the unique learning needs of children with ASD within the mainstream school system at all levels, including access to appropriate educational settings and the use of educational services, including during transition periods.

A lack of understanding of the need for accommodations for their children resulted in one of two parental behavioral responses: compliance or advocacy. Moreover, it is evident that the increased educational responsibility taken on by the parents serves to increase their stress levels as they provide additional educational support at home to compensate for the lack of support and awareness from the school (Roberts & Simpson, 2016). School-based occupational therapists are ideally placed to facilitate educational staff awareness and understanding of the learning needs of children with ASD. Community- and clinic-based therapists are also instrumental in supporting educational staff and thereby facilitating the children’s optimal performance at school. Examples include conducting presentations, knowledge-sharing during individualized education program meetings, and attending school management meetings.

Parents described difficulty locating and accessing appropriate educational settings, often resulting in instances of school exclusion, whereby children were denied their universal right to attend mainstream schools. Occupational therapists can support parents in accessing appropriate educational placements through adopting an advocacy role as well as by providing emotional and educational support.

Transitional periods were found to be points of vulnerability, with both children and parents requiring additional support during these critical periods. Occupational therapy practice lends itself to addressing this need at entry points, as a part of specialized teams to facilitate smooth progression within early intervention services, from rehabilitation to a school setting, and transitions from school to the workforce and adulthood (de Oliveira Borba, et al., 2020, p. 6). It is essential that occupational therapists reflect on how they can work effectively and closely with schools to support key transitional periods.

Parents reported that educational staff lacked expertise, with limited collaboration and acknowledgment of their parental contributions. The importance of building educational staff's knowledge and understanding of ASD has been recommended in the literature (Anaby et al., 2019; Falkmer et al., 2015; Lindsay et al., 2014; Roberts & Simpson, 2016; Roberts & Webster, 2020). Structural barriers (e.g., funding, availability of resources and support for educational staff) limit staff's ability to effectively create inclusive and supportive environments (Roberts & Simpson, 2016). Challenges specifically related to fathers, such as difficulty with contributing to and accessing the collaborative relationship because of gender-based cultural expectations, as well as full-time work commitments, have not been explored in depth in the literature.

Parents reported strong collaboration, communication, and relationships with educational staff when teachers demonstrated responsiveness to the children's needs through curriculum or environmental changes, as well as when the parents' contributions were valued. In addition, strong relationships existed when multilevel support in schools, including support from educational staff in leadership, was incorporated.

Schools should create inclusive environments for children with ASD to develop and learn. Adoption of a family-centered and individualized approach is imperative for accommodating the individual needs of children with ASD, in accordance with the United Nations' (2006) Convention on the Rights of Persons With Disabilities, in which it is stated that "individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion" (p. 3).

Occupational therapists need to support parent-school collaboration in a family-centered approach in inclusive school settings. Family-centeredness should be participatory, which involves being "individualized, flexible and responsive to family concerns and priorities," providing opportunities for families to drive decisions and choices (Dunst, 2002, p. 141). Examples include supporting parent advocacy, direct advocacy, translating language, and acting as a bridge between parents and the school setting.

In the literature, whole-school approaches are recommended to create inclusive environments, with the universal implementation of structured

environments and modifications in classrooms and general school environments (Roberts & Webster, 2020). The presence of strong school leadership can be a means of fostering inclusive environments, influencing and facilitating school practices, and reinforcing positive attitudes regarding inclusion among students and staff (Falkmer et al., 2015; Roberts & Webster, 2020). School-based therapist roles are well placed to address practice and policy at higher levels, although therapists in community and clinic roles should aim to support parental advocacy and seek ways to influence the system, for example, undertaking school committee roles.

The findings of this meta-analysis provide occupational therapists with guidance to create inclusive environments. A relevant theory to support the findings of this analysis is Bronfenbrenner's ecological systems theory, which supports therapists in taking a contextual view of child development and performance (Bronfenbrenner & Ceci, 1994). This theory provides a framework to conceptualize children's contextual environments (comprising important stakeholders and physical environments), which have direct and indirect influences on their development and trajectory (Bronfenbrenner & Ceci, 1994). The theory emphasizes the need for occupational therapists to stay true to their holistic approach when working with children with ASD and their families and not to be limited by funding bodies and organization constraints.

Limitations


This meta-analysis focused on qualitative research published in English. Of note is that it involved a rigorous, well-established process of critical appraisal. Our review focused on capturing studies from 2013 onward in an attempt to provide consistency in how ASD was diagnosed through the *DSM-5*; however, some studies may have been included on the basis of *DSM-IV* (APA, 1994) criteria because of insufficient descriptions of the diagnostic details in the articles. A limitation of the currently available evidence is that the majority of studies, and the highest ranking studies, were conducted in Westernized countries with educated parents, and only 9 studies included CALD populations; therefore, future studies that focus on a broader variety of population groups are encouraged in the hopes of understanding a broader variety of perspectives. Moreover, 12 of the studies had limited details regarding demographic information, posing concerns regarding their overall generalizability. This meta-analysis focused on experiences in preschool and primary school settings, with high school as another viable review setting for future research studies. The findings demonstrate the vulnerability of children with ASD during transition periods; therefore, a focus on transition periods in future research would be beneficial. A review focusing on the perspectives of educational staff would further strengthen the existing literature.

Implications for Occupational Therapy Practice

This meta-analysis provides guidance for occupational therapists working at the individual, targeted, and whole-school level. Occupational therapists are ideally placed to

- facilitate educational staff awareness, understanding, and support of the learning needs of children with ASD, at all levels within schools;
- influence practice and policy at higher system levels to allow for inclusive education;
- support parents' access to appropriate educational placements, providing emotional and educational support and advocacy for children and families;
- support children, parents, and educational staff during transition periods at school;
- facilitate collaboration between parents and schools, at all levels, from school leaders to on-the-ground educational staff; and
- facilitate the adoption of the principles of Bronfenbrenner's theory (Bronfenbrenner & Ceci, 1994) and the family-centered approach within school settings.

Conclusion

Our meta-analysis synthesized findings from 26 studies and 397 parent voices to explore and understand how parents of children with ASD describe their experiences of utilizing the mainstream preschool and primary educational system. The main implication of this meta-analysis is that parents perceive a lack of awareness and understanding of their children's unique learning needs in mainstream schools at all levels. Various recommendations arise from this review to support occupational therapy practice in facilitating the school-related occupational engagement of school-age children with ASD, their parents, and school staff. 

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*Indicates studies included in the meta-analysis.

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