



School participation: The shared perspectives of parents and educators of primary school students on the autism spectrum[☆]



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ABSTRACT

Background: An international focus on the inclusion of students with disabilities in mainstream schools and the increased prevalence of autism spectrum disorder (ASD) has contributed to increasing numbers of students with ASD enrolling in mainstream schools. The school participation restrictions of adolescent students with ASD is widely researched, but less is known about the challenges faced by primary school students with ASD and how early in their schooling these challenges arise.

Methods: Focus groups were used to explore the perspectives of parents and educators on the school participation of primary school students with ASD. Focus group data were analysed thematically.

Results: Four themes were derived from the data: (1) more than just being there; (2) meeting in the middle; (3) consistency of supports; and (4) embrace difference.

Conclusions: Findings from this study highlight that students aged between 6 and 11 years experience school participation restrictions due to a range of intrinsic (e.g., sense of self and school belonging) and extrinsic factors (e.g., school culture, educator knowledge and skills). It is imperative school based interventions are developed and implemented in the early primary years, that not only target students' skills, but the range of environmental enablers and barriers impacting student school participation.

What this paper adds?

There is limited information about the school participation restrictions of *primary* students with ASD and as a result limited mechanisms available to support their participation in the early primary school years. This study offers unique insights into the experiences and challenges of *primary* school students with ASD from the shared perspective of parents and educators. Recommendations regarding the development of school based interventions aiming to improve school participation are also explored;

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including strategies to improve school culture and the use of evidence based intervention techniques such as peer mediation. This study emphasises the importance of intervening in the early primary years to minimise or prevent the long term implications of reduced school participation on student outcomes.

1. Introduction

An international focus on the inclusion of students with disabilities in mainstream school and the increased prevalence of autism spectrum disorder (ASD) has contributed to increasing numbers of students with ASD enrolling in mainstream schools (Australian Bureau of Statistics, 2016; Frederickson, Simmonds, Evans, & Soulsby, 2007). While there has been positive change in the last decade toward the inclusion and provision of supports for students with ASD in mainstream settings, international and Australian research suggests students with ASD continue to encounter a range of barriers to their participation in mainstream schools (Batten, Corbett, Rosenblatt, Withers, & Yuille, 2006; Lilley, 2012; McDonald, 2010).

According to the family of participation related constructs (fPRC), developed by Imms et al. (2016), participation is comprised of two essential components: “attendance, defined as ‘being there’ and measured as frequency of attending, and/or the range or diversity of activities; and involvement, the experience of participation while attending” (Imms et al., 2016, p. 18). In the context of education, this means being actively engaged in activities, tasks and routines that are typical for students of that age in a given education system, as well as a subjective feeling of belonging to, and being active in the school environment (Libbey, 2004). Merely being present in a mainstream classroom does not lead to participation and is not indicative of successful inclusion (Symes & Humphrey, 2012). Frederickson et al. (2007) found primary school students with special educational needs (SEN), including ASD, to be more likely to experience bullying and social exclusion from peers. This study highlighted that without structured supports such as peer preparation in the early years, inclusion cannot be achieved. Despite legislation that requires education systems to make reasonable adjustments to ensure students with ASD are included in mainstream settings (UNESCO, 1994), there is growing concern about the education experiences of students with ASD (Chen & Schwartz, 2012; Hebron & Humphrey, 2012; Zablotsky, Bradshaw, & Andersen, 2013). Future research is required that goes beyond the numbers of students included, but that explores the experiences of students with ASD in mainstream classrooms to better understand their social and affective outcomes (Frederickson et al., 2007).

Many studies have explored the participation experiences of adolescent students with ASD in mainstream schools (Hedges et al., 2014; Sagers, Hwang, & Mercer, 2011). Many adolescent students with ASD under achieve relative to their cognitive abilities (Ashburner, Ziviani, & Rodger, 2008); have higher rates of absenteeism, suspension and exclusion from school (Barnard, Prior, & Potter, 2000; Osler & Osler, 2002); spend less time interacting and have lower quality of interactions with peers (Sigman et al., 1999); and require a higher level of one to one assistance from aides than peers (Bauminger & Kasari, 2000). These challenges make students with ASD more vulnerable to bullying compared to typically developing peers (Jones & Frederickson, 2010), resulting in disruption to educational progress (Batten et al., 2006), reduced self-esteem (Batten et al., 2006) and mental health difficulties (Batten et al., 2006; Cappadocia, Wiess, & Pepler, 2012; Hebron & Humphrey, 2012; Penney, 2013; Zablotsky et al., 2013).

Less is known about the school participation of *primary* students with ASD resulting in limited supports to address their participation restrictions. Studies that have explored the participation of primary school aged children have done so primarily *outside* of the school context or have focused on the impact specific child factors such as language, cognition and adaptive functioning have on students activity participation in a range of contexts, including school (Little, Ausderau, Sideris, & Baranek, 2015; Orsmond & Kuo, 2011). In addition to student needs, there is limited knowledge and insight about the challenges faced by parents and educators working with students with ASD in mainstream primary schools (Hedges et al., 2014). There has been a call for more qualitative research in the field of ASD generally and specifically for qualitative research on educational participation to better understand how to support students with ASD to participate in mainstream settings (Falkmer, Granlund, Nilholm, & Falkmer, 2012; Humphrey & Lewis, 2008). Given the reported impact reduced school participation has in adolescence, it is imperative to understand the school participation experiences of primary school students with ASD and how early challenges arise, so that efforts can be made to intervene early to minimise or prevent the long term implications of reduced school participation on student outcomes.

The purpose of this study was to analyse parents and educators perspectives on the experiences and challenges impacting the participation of *primary* school students with ASD and if challenges exist, how early they arise in students schooling. To date, there has been limited studies that explore both parent *and* educator perspectives in view of identifying challenges and seeking solutions. Parents have an indepth understanding of their child, their ASD characteristics and how these may impact their child’s school participation. While, educators are experts in the curriculum and have insight into school factors that may impact students’ school participation. Exploring both of their perspectives was imperative in gaining a holistic understanding of the school participation of students with ASD and therefore establishing priorities for the development of school based interventions to proactively support students with ASD in the early primary years.

2. Methods

This qualitative study used focus groups to explore the perspectives of parents and educators of primary students with ASD. Focus groups are suitable when examining sensitive issues as participants may feel more relaxed about sharing their experiences when they see that others have similar views or experiences to them (Liamputtong, 2013). The group process encourages participants to identify and clarify their experiences and opinions in ways that may not be captured in individual interviews (Liamputtong, 2013, 2017). Furthermore, commonalities and differences in participants thoughts can be made more apparent in focus groups when multiple stakeholders with different perspectives are available (Liamputtong, 2011). We aimed to conduct an interactive discussion that would

Table 1
Focus Group Participant Demographics by Role.

	Parents (<i>n</i> = 15) Group 1, <i>n</i> = 7 Group 2, <i>n</i> = 8	Educators (<i>n</i> = 11) Group 1, <i>n</i> = 6 Group 2, <i>n</i> = 5
Age		
20–29 years		2 (18.2 %)
30–39 years	5 (33.3 %)	6 (54.5 %)
40–49 years	9 (60.0 %)	–
50–59 years	1 (6.7 %)	2 (18.2 %)
60 years and older		1 (9.1 %)
Gender		
Male	2 (13.3 %)	–
Female	13 (86.7 %)	11 (100.00 %)
Marital status		
Never married	1 (6.6 %)	–
Divorced	1 (6.7 %)	–
Married	12 (80.0 %)	–
Defacto	1 (6.7 %)	–
Number of children in family		
Two	12 (80.0 %)	–
Three	2 (13.3 %)	–
Four	1 (6.7 %)	–
School grade and child age		
Year 1 (6 years)	4 (26.7 %)	–
Year 3 (8 years)	2 (13.3 %)	–
Year 4 (9 years)	3 (20.0 %)	–
Year 5 (10 years)	1 (6.7 %)	–
Year 6 (11 years)	5 (33.3 %)	–
Years of experience in current role		
0–1 years	–	–
2–3 years	–	2 (18.2 %)
4–5 years	–	3 (27.3 %)
6–7 years	–	3 (27.3 %)
8–9 years	–	–
More than 10 years	–	3 (27.2 %)
Years of experience working with students with ASD		
0–1 years	–	1 (9.1 %)
2–3 years	–	2 (18.2 %)
4–5 years	–	5 (45.4 %)
6–7 years	–	1 (9.1 %)
8–9 years	–	–
More than 10 years	–	2 (18.2 %)

provide an in-depth understanding of the primary school experiences of students with ASD from the shared perspectives of parents and educators.

2.1. Participants

Parents of a child with a parent-report diagnosis of ASD as determined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) currently enrolled in a mainstream primary school and educators (e.g., teachers, learning support coordinators and/or principals) with self-reported previous experience with primary school students with ASD were eligible to participate. Participants were recruited purposively from the Perth metropolitan area using a variety of methods including: emails to parents of children with ASD attending mainstream primary school that access school aged services through the Autism Association of Western Australia (AAWA), emails to principals of Catholic Education and Association of Independent Schools Western Australia (AISWA) mainstream primary schools; advertisements on social media and snowball sampling through targeted contact with parents and educators. Participation in the study was voluntary and written informed consent was obtained from all participants prior to participation. Ethics approval for the study was obtained from the Human Research Ethics Committee of Curtin University (HREC 2016-0150) and the Catholic Education Office of Western Australia.

Four separate focus groups with a total of 26 participants were conducted in the Perth metropolitan area. Two of the focus groups were conducted with a total of 15 parents of children with ASD who were attending mainstream primary school. Two focus groups

Table 2
Focus Group Guide.

	Description	Minutes
1	Opening remarks and procedure	5
2	Consent and confidentiality	5
3	Participant introductions	10
4	Exploring school participation and connectedness	60
	<i>Educator:</i>	
	<ul style="list-style-type: none"> ● In your opinion, what is school participation? ● What have you noticed are the main challenges students with ASD experience in their participation at school? ● What are the key factors that contribute towards these challenges (i.e., school, classroom and individual level)? ● How do you think this impacts students' sense of connectedness at school? ● What do you think supports students with ASD to participate in the classroom and playground? 	
	<i>Parent:</i>	
	<ul style="list-style-type: none"> ● How would you define school participation? ● Describe how your child currently participates at school. ● Would you like your child's participation to change? If so, how? ● What have you found to support your child's participation? ● What does it mean for you, for your child to feel connected at school? ● Describe your child's level of school connectedness. ● Would you like their level of school connectedness to change? If so, how? ● What do you think could help to improve your child's sense of school connectedness? 	
5	Closing remarks	10

were conducted with a total of 11 educators including teachers, deputy principals and learning support coordinators who reported having experience working with primary school students with ASD in a mainstream setting. Table 1 includes demographic information about participants according to their respective roles.

2.2. Focus group procedures and data collection

Focus group guides were developed by the research team based on qualitative research guides and the literature (Liamputtong, 2013). The guides were piloted with a Consumer and Stakeholder Reference Group (CSRG), which included a parent and an educator of a primary school student with ASD. Involving consumers in the research process ensured the questions were relevant, sensitive and met the research need (Consumer & Community Health Research Network, 2017; Mathie et al., 2014). It also allowed researchers to trial the clarity and sequence of questions and develop skills in employing questions in focus groups (Liamputtong, 2011, 2013). Feedback from the CSRG was incorporated into the guide. The same guides and time allocation were used for parents and educators with minor differences in the wording of questions to reflect differences in participant roles (see Table 2).

Focus groups of approximately 90 min duration, were held over a period of two weeks in a private room at Curtin University. The focus groups were moderated by the primary author of the study who had more than 5 years' clinical experience working with parents, educators and students with ASD and had specialised training in conflict resolution and group work. The second author co-facilitated one focus group, which allowed researchers to reflect on the group and assess the efficacy of questions routes, as well as dynamics for eliciting information (Liamputtong, 2011). Participants were aware that there were multiple focus groups taking place and they were asked to not share specific details about schools or names of students or staff members to maintain confidentiality.

After initial introductions and allowing the group time to become acquainted, the moderator posed questions and allowed time for participants to respond to each other's comments; facilitating further discussion and clarifying points using probing questions and reflective statements (Liamputtong, 2011). The moderator adopted a flexible approach to allow views to be expressed and to explore issues that may not have been anticipated by the researchers (Liamputtong, 2011). Focus groups were audio-recorded and field notes were taken. Audio-recordings were transcribed verbatim by a professional transcriber and checked for accuracy by the primary author. NVivo, a qualitative software package, was used to manage and organise data electronically.

2.3. Data analysis

Focus group data were analysed thematically using Braun and Clarke (2006) framework for thematic analysis. This framework is not linked to a specific theoretical approach, which allowed flexibility in the analysis of parent and educator transcripts; providing a rich and detailed, yet complex account of data (Braun & Clarke, 2006). Individual parent and educator transcripts were analysed before moving onto analysing transcripts across groups (Braun & Clarke, 2006). The primary and secondary author read through hardcopies of transcripts multiple times to familiarise themselves with the data, before making marginal annotations that consisted of paraphrased data and preliminary interpretations. This step was repeated; further annotations were made and themes based on annotations were developed within groups. Preliminary themes derived from parent and educator focus groups were sent to participants for member checking. Following the separate analysis of parent and then educator focus groups, themes common across parent and educator focus groups were produced, prioritised, refined, collapsed and redefined until they reflected the depth and breadth of parents and educator's experiences. The process of data analysis was iterative and focused on making comparisons

Table 3
Overview of Qualitative Findings.

Theme	Description
1	More than just being there <i>Being expected to participate</i> <i>Being provided with multiple and varied opportunities to participate</i> <i>Being supported to participate</i> <i>Characteristics of ASD impacting student school participation</i>
2	Meeting in the middle
3	Consistency of supports
4	Embrace difference

between parent and educator perspectives (Braun & Clarke, 2006). Saturation is the gold standard by which sample sizes in qualitative research are determined (Guest, Namey, & McKenna, 2016). Saturation was achieved in this study as major themes in each transcript were similar and subsequent information did not present emerging themes (Starks & Brown Trinidad, 2007).

Credibility was enhanced through researcher triangulation, peer debriefing and member checking to test findings and interpretations with participants (Bryman, 2016). Transferability was met through the provision of detailed descriptions of participants and of results (Nowell, Norris, White, & Moules, 2017; Padgett, 2008). Dependability was achieved through use of an audit trail, field notes and reflexive journal throughout the research process (Lysak, Luborsky, & Dillaway, 2006) and confirmability through a description of the specific approach used to analyse, organise, describe and report on themes within the data set (Bryman, 2016; Curtin & Fossey, 2007; Fossey, Harvey, McDermott, & Davidson, 2002; Liamputtong, 2013; Nowell et al., 2017). Pseudonyms were used to maintain confidentiality of participants in results.

3. Results

Four core themes were derived from the data and summarised in Table 3. Themes are reported collectively for both participant groups given the shared themes that resulted from separate analyses. However, where differences were noted between participant groups, these are reported in the results. See Figs. 1 and 2 for examples of how parent and educator themes converged to develop themes, ‘meeting in the middle’ and ‘more than just being there’, using thematic networks (Attride-Stirling, 2001). These findings provide unique insights into parent and educators understanding of student school participation and factors that support or hinder participation of students with ASD in the early school years.

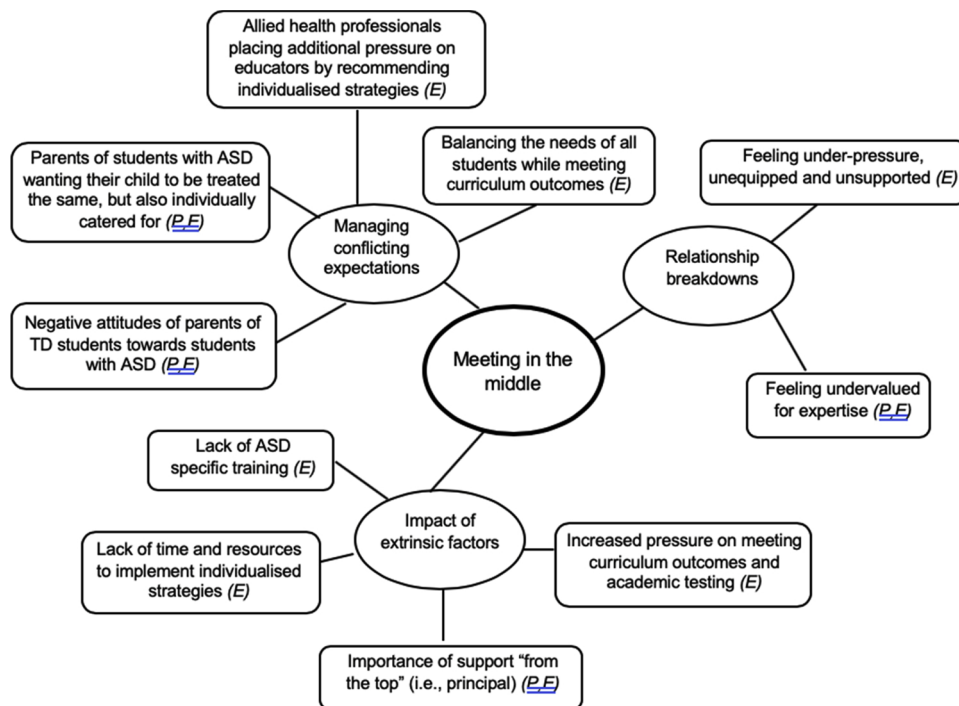


Fig. 1. ‘Meeting in the middle’ thematic network illustrating convergence between parent and educator themes derived from textual data. TD refers to typically developing; P refers to parents and E, educators.

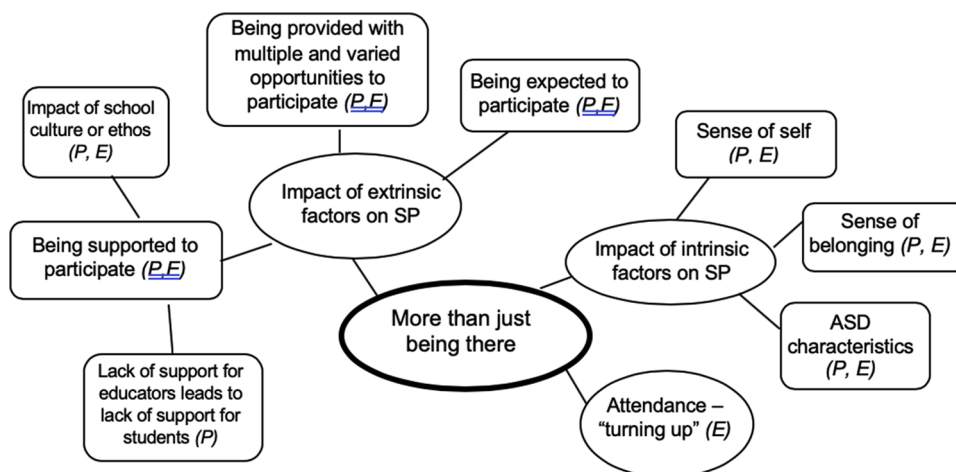


Fig. 2. ‘More than just being there’ thematic network illustrating convergence between parent and educator themes derived from textual data. P refers to parents; E, educators and SP, school participation.

3.1. More than just being there

Both parents and educators found the concept of school participation difficult to define, however, more than half of participants described school participation as “more than just being there”. “I think school participation is your child feeling a part of the school. You know, that they feel a sense of belonging I guess. At least, that’s what I hope for anyway” (Jessica, parent).

Educators tended to focus more on observable or behavioural aspects of school participation such as “turning up”, following classroom routines and following teacher instructions. Whereas parents tended to focus more on the affective or psychological aspects of school participation, such as feelings of being included. Both parents and educators emphasised the profound influence students’ sense of self including their confidence, motivation and self-esteem had on their school participation.

One of my boys, he’s involved and he puts his hand up on the mat, he’s engaged and he functions really well in the classroom. Because I think because he’s had a degree of success. He feels like he “fits in” and he’s successful – he goes to drama, special subjects. . . (Trish, educator).

Parents and educators described multiple environmental factors they felt contributed towards the successful participation of students with ASD in the early school years. These included: being expected to participate; being provided multiple and varied opportunities to participate; and being supported to participate.

3.1.1. Being expected to participate

Both parents and educators reported feeling that there was less expectation on students with ASD to participate at school, than typically developing peers. “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?” (Phoebe, parent).

I’ve found in my experience that a lot of the time its “oh they’re not going to go on the excursion because it’s too hard” or “leave them out of that assembly because it’s too hard”. There needs to be an expectation that they will be involved in some capacity – whatever the student can cope with (Isabel, educator).

Parents attributed minimal expectations of students with ASD to school staff not knowing the student with ASD well enough to know what they are capable of and how hard to push. Parents also felt educators minimised demands placed on students with ASD in an attempt to prevent behaviour that may disrupt the class. Parents also acknowledged limited support for educators in individualising the curriculum to support the participation of students with ASD.

3.1.2. Being provided with multiple and varied opportunities to participate

Parents and educators spoke of the importance of students having access to multiple and varied participation opportunities that considered the students’ unique strengths, interests and learning needs. “A lot of schools get so focused on what they’ve always done that they provide this sporting activity or say we do ‘that’ at this school. Rather than finding out what the kids are really into. . .” (Melissa, educator).

My girl is a Lego nut and all we had to do was say “look she will participate with other kids if they are doing what she likes doing as well”. So the Lego comes out at lunchtime instead of her being forced to play ball where she has seizures and hits her head because she doesn’t see the ball coming. I mean that’s not participating. You’ve got to provide other opportunities. It’s not a one size fits all thing (Kate, parent).

Examples of varied ways parents and educators felt students with ASD could be provided with opportunities to participate included: providing access to a range of school organised extra-curricular activities that cater for varied interests; having access to structured activities during break times for students who find free play challenging; and having access to varied options in the way work can be completed in class.

Parent's shared positive experiences where school events had been adapted, enabling students to demonstrate their knowledge and skills in varied ways. Paula (parent) says:

So this year, he went [to the sports carnival] and he wore headphones the whole time and didn't have to do the running races. But he did get involved in the team stuff. It was such a big thing. . . He's much more comfortable with that sort of thing now (Rebecca, parent).

Parents and educators reflected that when given opportunities, students with ASD were more likely to participate and therefore more likely to develop skills and demonstrate their unique abilities.

3.1.3. *Being supported to participate*

Finally, parents and educators emphasised the importance of students having access to appropriate supports to maximise their school participation so that they were 'not left behind'. "If you set them up for success and have them participating when they're all good – then they're going to grow from that. But to try and push them, beyond their capabilities, without support then more people suffer" (Rebecca, educator).

Parents and educators acknowledged, however, that for educators to be able to support the participation of students with ASD, they need to have access to adequate support themselves, which is often determined by the culture or ethos of the school. Parents and educators agreed that 'without support from the top', it is often very difficult to implement strategies and support the participation of students with ASD on the ground.

3.1.4. *Characteristics of ASD impacting student school participation*

As well as environmental factors, parents and educators acknowledged student specific factors such as characteristics of ASD they felt significantly impact students capacity to participate at school. Particularly, students ability to: remain calm and in a state for learning in the classroom, build and maintain relationships, adapt and respond to change and transition throughout the school day, manage conflict in play, work in groups and engage in classroom activities and routines. Parents identified fine motor skills as a significant challenge impacting their child's participation in classroom activities involving handwriting. Overwhelmingly, participants agreed that school participation was a unique experience and highly dependent on the student's skills and support needs, as well as the characteristics of their learning environment.

3.2. *Meeting in the middle*

Educators reported facing challenges in meeting the varying and often conflicting expectations of parents of students with ASD, parents of typically developing students and visiting allied health professionals. More than 80 % of parents of students with ASD expressed a desire for their child to be treated the same as their typically developing peers, while at the same time, emphasised the importance of schools individualising supports to cater to the specific needs of their child. Educators recognised this, Barbara (educator) explains:

That's actually what a lot of the parents want – for their child to be treated the same. But they still want their child supported but just sort of under the radar I suppose. So that not everyone else knows that their child is being supported ... They don't want them treated any different. So you've got to support them without it being obvious.

Parents reported they wanted their children to participate in as much as possible at school, but not if their participation caused more harm than good. Belinda (parent) explained:

He really struggles in assemblies and to this day he has not sat through an assembly. He can't handle it, he runs out every time and they keep putting more supports and structures in place, giving him headphones and something to play with in his hands or do and I kind of think it's two assemblies a term – does it really matter if he doesn't go?

Parents and educators agreed that parents of typically developing students often had negative attitudes towards students with ASD and, as a result, expectations that conflicted with those of parents of students with ASD. These attitudes included: that their children may be negatively impacted by the student with ASD, for example, they may copy their behaviour, or they may not get as much support because the teacher's efforts were being directed towards the student with ASD. Educators reported that parents of typically developing students often did not want whole class strategies implemented if they did not see a direct benefit to their child; placing additional pressure on educators to rationalise curriculum adjustments for students with ASD on top of their busy workload.

In addition to parents' expectations, educators reported being faced with additional expectations from visiting allied health professionals who entered the classroom for short periods of time and made specific recommendations for the student with ASD. Educators expressed frustration when they had a limited understanding of the educational environment and how these strategies could be feasibly incorporated into the busy school day. They admitted the strategies were often not implemented due to a lack of time and resources. Parents reported the value of input from external professionals, because they often validated their concerns and reiterated the strategies they had been advocating.

With multiple stakeholders with varying and often conflicting expectations, schools, and particularly classroom teachers were left stuck in the middle. Educators described feeling torn – dividing their time between students with ASD and the rest of the students in their class as well as meeting necessary curriculum and reporting requirements. Educators also reported feeling at times unequipped to manage the complex needs of students with ASD; attributing this to a lack of time and resources to adequately prepare and a lack of knowledge and skills to support the student with ASD. Elise (educator) explained – “over the five years [I’ve been teaching], I’ve had five or more children [with ASD] in my class – but I’ve never really had any specific training at all. It’s just kind of here you go and good luck.” While parents acknowledged the challenges that educators faced, they also acknowledged the schools’ responsibility in ensuring teachers had adequate knowledge, skills and supports to make adjustments to support their child with ASD.

3.3. Consistency of supports

Parents and educators reported the use of several strategies to support the school participation of primary school students with ASD including but not limited to: incorporating the students interests and strengths into classroom activities and routines wherever possible; using visual supports such as schedules and social stories; explicitly teaching skills such as emotional regulation and social skills and providing access to regular breaks that meet sensory needs. Both parents and educators acknowledged the benefits of structure, predictability and routine in promoting the participation of students with ASD. Educators acknowledged, however, the challenges in providing structure and predictability in what was often an unpredictable and chaotic environment, where last minute changes to daily routines were unavoidable and sometimes difficult to manage. Educators acknowledged that many of the strategies utilised for students with ASD were also beneficial for other students in the class and described situations where strategies had been utilised as a whole class with positive outcomes for peers. For example, presenting the daily routine using a visual schedule at the beginning of the day and having it visible at the front of the class for all students. Educators acknowledged that there were often multiple students with additional learning needs in the classroom and through use of whole class approaches they could not only address the needs of multiple students, but also minimise burden for themselves.

While parents and educators identified many strategies effective in promoting the participation of students with ASD, they also spoke of the arduous process and often cyclical nature of establishing, implementing and maintaining supports for students with ASD. Sue highlighted parents’ frustration over the lack of consistency of supports:

One of the key things that happens yearly is that at the beginning of the year they start with the education supports ... schedules, pictures on the desk and then they are achieving so well due to this structure. Somewhere during the middle of the year, they get taken away. Then week by week, slowly things start happening. It happens every year, things go missing and then by the end of the year we’re bringing it all back again (Sue, parent).

Sally (parent) explained:

It’s about reminding the teacher that I’ve got a calendar and I write my appointments on there, but I don’t necessarily need to look at that to know that I’ve got a doctor’s appointment next week. But I wouldn’t throw the calendar off the wall ... Because sometimes just seeing the calendar, not necessarily reading it helps me to remember. I feel that it’s the same with all of the schedules and visuals on their desk.

3.4. Embrace difference

The final theme illustrates the impact failure to accept difference can have, not only on the school participation of primary school students with ASD, but on participation of *all* students with diverse learning needs (e.g., students with Attention Deficit Hyperactivity Disorder (ADHD) or dyslexia). Parents and educators described stigma often associated with a diagnosis of ASD – a preconceived idea that students with ASD were likely to behave or learn in particular ways – without considering the varied and unique ways in which characteristics of ASD influenced students’ participation.

The perceived lack of understanding and awareness of ASD was portrayed by Ebony (parent) who said, “an education assistant once said to me – I didn’t think he has autism because he has manners.” While parents and educators acknowledged that students with ASD often had unique learning needs compared to typically developing students and students with other disabilities, parents and educators also acknowledged that all students had unique strengths and differences that should be recognised and embraced. Parents and educators agreed that the aim should not be to “fix the student” or “try and make them like everyone else”. Louise (parent) stated: “It’s that empowerment to understand that you are perfect and you are fine. You do things differently but that doesn’t mean that you are wrong”.

There was a perception among parents and educators that schools often expected students to fit a particular mold, rather than recognising individual student differences and considering innovative ways in which tasks and/or the environment could be adapted to maximise the participation of all students. Educators, in particular, described how peers were often aware of student differences and still tended to label students negatively, if they were not supported to do otherwise. Parents and educators suggested that by being open and transparent about differences; supporting students to recognise their own differences and take on the perspective of others, students may be more accepting of difference and more able to proactively support students in the classroom and playground.

4. Discussion

This study offers unique insights into the experiences and participation restrictions of *primary* school students with ASD in mainstream schools from the shared perspective of parents and educators and provides greater understanding about factors that support and hinder school participation in this population of students. Highlighted student factors impacting school participation included students' sense of self, sense of school belonging and individual characteristics of the student with ASD. Attitudes of educators, parents of typically developing students and peers towards students with ASD; educators' level of knowledge and skills; school culture; and the availability of resources were identified as environmental factors impacting the school participation of primary students with ASD. This study reinforces and extends findings from [Frederickson et al. \(2007\)](#), to students with ASD; highlighting that students' sense of belonging is integral to their school participation and the importance of school-based interventions in the early years to prevent intolerance to difference and maximise school participation.

Parent and educator perspectives of the definition of school participation was consistent with the literature; defining school participation as not only being there, but the students subjective experience while participating ([Falkmer et al., 2012](#); [Imms et al., 2016](#)). Participants agreed that merely being present in the classroom was not enough – students needed to feel confident and satisfied, as well as a sense of belonging to their school. Yet again, the importance of social and affective outcomes of inclusion are highlighted; however, as [Frederickson et al. \(2007\)](#) emphasises, the assessment of these outcomes is lagging behind academic performance and as a result students are not adequately supported in these areas. Without early positive participation experiences, primary school students with ASD are at risk of increased absenteeism, reduced self-esteem and academic performance in adolescence ([Barnard et al., 2000](#); [Batten et al., 2006](#); [Osler & Osler, 2002](#)). Meaningful school participation should, therefore, be an essential intervention goal ([Imms et al., 2016](#)) enabling us to focus on what really matters at school, such as if a student is able to engage with their peers and feel a sense of belonging, rather than how they scored in a test or if they were merely present in the classroom. Efforts focused on promoting students sense of self and belonging and a positive school culture via whole class and school intervention programs are crucial in early primary school to prevent a cycle of restricted participation, particularly for students with ASD and SEN included in mainstream classrooms ([Frederickson et al., 2007](#)).

The complex nature of managing the varying, and often, conflicting expectations of stakeholders in the primary school context is a key finding of this study. Educators were confronted with the impossible task of meeting parents unrealistic expectations to make adjustments to support the participation of students with ASD. Parents were overly critical of educators, and educators, defensive. The importance of collaborative parent and educator relationships is well documented ([Schultz, Sreckovic, Able, & White, 2016](#)). What is not so clear, are the factors that contribute to relationship breakdowns and how to address these from the perspective of parents and educators. Without support, relationship breakdowns have the potential to impact future interactions and therefore parent and educators capacity to support student school participation in a proactive and collaborative way. Based on the findings of this study, building an understanding of each others expertise, capabilities and limitations may help to build the foundations for a positive relationship. Future research should engage parents and educators in participatory action research to identify feasible and appropriate strategies to promote positive, and repair strained relationships, so that efforts to support student school participation are not futile ([Consumer & Community Health Research Network, 2017](#); [Wallerstein & Duran, 2010](#)).

Failure to accept difference was identified as not only impacting the participation of primary school students with ASD, but that of *all* students. There was an overwhelming sense that students needed to fit the classroom or the school, rather than thinking about innovative ways students' potential could be harnessed and their school participation maximised. Lack of understanding and negative attitudes towards learning differences is common in other populations of students including students with ADHD, according to [Moldavsky and Sayal \(2013\)](#). It is concerning, however, how early parents and educators in this study reported resistance to difference, given that this is the period of time students perceptions and tolerance towards difference are most amenable to change ([Vaz et al., 2015](#)). Regardless of students skills, students placed in an environment that stifles creativity and rejects diversity cannot reach their full potential. With more students with diverse learning needs in mainstream settings than ever before, there is no better time to promote understanding and awareness of neuro-diversity, normalise the use of supports for learning, and adapt the way classrooms and schools support the participation of students with diverse learning needs.

4.1. Implications for practice

The inter-relationship between student and environmental factors impacting school participation are complex and multifaceted. While student factors were identified by parents and educators to impact the school participation of students with ASD, environmental factors significantly impacted on student's capacity to participate and feel like they belonged at school. Students spend more time at school than any other setting in their formative years, therefore the school environment and the availability of supports, has the potential to significantly impact student participation trajectories. Despite the importance of the interaction between the student, their environment and participation outcomes being emphasised in the literature, the limited interventions currently available for primary school students with ASD continue to be directed at the student with an expectation there will be flow-on effects to their participation ([Hammel et al., 2008](#); [Imms et al., 2016](#)). Findings from this study emphasise the need to develop and implement holistic school based interventions in the early primary school years that not only target student skills but address the range of environmental barriers impacting student school participation. Without peer preparation and peer group inclusion, inclusion cannot be achieved for students with ASD and other SEN ([Frederickson et al., 2007](#)). Provision of professional learning and support to educators to increase their understanding of ASD and effective classroom management strategies may help to create a positive learning environment and provide students with increased participation opportunities that cater to their needs ([Black, 1995](#); [Centers](#)

for Disease Control & Prevention, 2009). Supporting the development of positive relationships between parents and educators is also important to ensure stakeholders can adopt a united and proactive approach to support participation from the commencement of students schooling (John-Akinola & Gabhainn, 2013; Parsons, Lewis, & Ellins, 2009). Furthermore, incorporation of peer mediated intervention techniques to promote student interpersonal empathy and use of prosocial behaviours at a whole class level, may help students to practice skills limiting their participation and feel supported and included by peers (Bene, Banda, & Brown, 2014; Watkins et al., 2015). It is imperative efforts are made to intervene early through incorporation of evidence-based, school based interventions to break the cycle of restricted participation for primary school students with ASD and minimise the long term implications of reduced school participation on student outcomes.

5. Limitations and future research

The findings need to be interpreted in light of the limitations of the study. This study had a sample that was limited geographically to the Perth metropolitan area. As education is managed at a state government level, there may be differences in the experiences and perceptions of parents and educators across nationally and internationally. The aim of this study was not to generalise to a broader population but to increase understanding of perspectives of a particular group of people, as with most qualitative research (Brantlinger et al. 2005). Furthermore, participation in focus groups was voluntary and therefore participants who agreed to participate may have chosen to do so because they wanted to share particularly positive or negative experiences, which may have limited the diversity of opinions or ideas expressed. Some participants may have been hesitant to share their thoughts if they felt they did not align with the thoughts of other participants in the group. The use of an individual questionnaire prior to focus groups may have helped to seek out views that were divergent from the collective opinion and assist the moderator in facilitating group discussion.

Future research should address the shared concerns of parents and educators using participatory action research to develop school based interventions to improve the school participation of students with ASD (Wallerstein & Duran, 2010). For example, using the Delphi technique to identify feasible and appropriate school based intervention techniques or consulting with key stakeholders throughout the research process using a consumer reference group (Consumer & Community Health Research Network, 2017). The perspectives of primary students with ASD should also be explored, to better understand their school participation experiences and identify ways students feel participation restrictions should be addressed in the school environment. By actively working together to analyse challenges and generate actions, we have the potential to minimise the long term documented implications of reduced school participation on student outcomes.

6. Conclusion

This study explored the experiences and challenges impacting the school participation of primary school students with ASD from the shared perspective of parents and educators. Findings from this study highlight that students aged between 6 and 11 years experience participation restrictions due to a range of intrinsic and extrinsic factors. It is imperative school based interventions are developed and implemented in the early primary school years, that not only target students' skills, but the range of environmental barriers impacting student school participation.

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Declaration of Competing Interest

The authors have no conflicts of interest to declare.

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