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To cite this article: Michelle Cleary, Sancia West, Loyola McLean, Colleen Johnston-Devin, Rachel Kornhaber & Catherine Hungerford (2024) When the Education System and Autism Collide: An Australian Qualitative Study Exploring School Exclusion and the Impact on Parent Mental Health, *Issues in Mental Health Nursing*, 45:5, 468-476, DOI: [10.1080/01612840.2024.2328251](https://doi.org/10.1080/01612840.2024.2328251)

To link to this article: <https://doi.org/10.1080/01612840.2024.2328251>



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Published online: 09 Apr 2024.



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When the Education System and Autism Collide: An Australian Qualitative Study Exploring School Exclusion and the Impact on Parent Mental Health

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ABSTRACT

Autistic students experience elevated rates of school exclusion, whether this be through expulsion, suspension, informal suspension, refusal of enrolment, or school refusal. This exclusion can come about from a range of factors, including sensory or cognitive overload, a lack of training in neurodiversity for teachers, an absent sense of safety by the student at school, or poor attitudes towards the inclusion of autistic students in schools. The impacts of this exclusion on parents can be logistical, financial, and psychological, with a range of mental health outcomes. This Australian qualitative study presents case studies of seven parents of autistic students, as well as four themes that capture the recommendations of parents to address school exclusion. The findings demonstrate that parents experience stress in finding a suitable school for their child, working with staff to meet the needs of the child, and attempting to maintain employment and other commitments when the child experiences exclusion. Parents recommend greater acceptance of autism by education systems, better communication and use of neuro-affirming language, the option for flexible learning, and individualised support by the school for the student.

Introduction

School exclusion defines the experience of a child being removed, or self-removal, from a school setting. School exclusion can come in multiple forms: temporary exclusion or suspension; permanent exclusion or expulsion; informal exclusion where the student is relocated from their usual school setting and moved to a different room; and refusal by the child to attend school or by the parent to send the child to school, as outlined in a recent discursive paper that scoped the issue of school exclusion of autistic students (Cleary et al., 2024).

Research has found that young children with disabilities are more at risk of temporary or permanent school exclusion than those without disabilities (Zeng et al., 2021). For those on the autism spectrum, the risk of non-attendance of any type is three times higher than for neurotypical peers (Adams, 2022) while the risk of permanent school exclusion for autistic children is higher than that of children with other forms of disability (Zeng et al., 2021).

This risk of school exclusion begins early, with pre-school-aged autistic children being 10 times more likely to be

permanently excluded from childcare than neurotypical children (Blacher & Eisenhower, 2023). However, despite the increase in the number of school exclusions of autistic children, the process of exclusion for over half of the children does not adhere to legal requirements (Martin-Denham, 2022). For example, children with special educational needs, which includes many autistic children, cannot by law be excluded from school because of those needs in most countries, with few exceptions (United Nations Educational, Scientific and Cultural Organisation, 2020). Yet approximately 70% of permanent exclusions in the United Kingdom come from those involved in special education (Sproston et al., 2017). Additionally, rates of school refusal by the child are significantly higher among neurodiverse groups compared to neurotypical (Munkhaugen et al., 2017).

The causes of these increased school exclusion rates for autistic children are numerous, including extrinsic causes such as teachers believing alternative disciplinary measures, for example time out, are not understood by autistic children. Other reasons include perceptions of disruptive behaviours or behaviours that compromise the health and well-being of other people; the teacher being unable to

effectively teach the other students due to the behaviour of the autistic child (An & Horn, 2022); (mis)interpretation of autistic traits as non-compliance; the student not being toilet trained (Blacher & Eisenhower, 2023); lack of teacher training in supporting autistic children (Martin-Denham, 2022); and inflexible, 'zero tolerance' school policies (Miller & Meyers, 2015). Causes also include those intrinsic to the autistic child, such as traits of lower social reciprocity, poorer communication skills (Adams et al., 2019); the need for sameness (Blacher & Eisenhower, 2023; Brede et al., 2017); higher rates of anxiety that can manifest as a behavioural outburst or 'temper tantrums' (Franz et al., 2013); aggressive outbursts and co-occurring intellectual disabilities (Ambler et al., 2015); lack of school readiness, such as attention deficits, (Blacher & Eisenhower, 2023); bullying by other students and the ensuing isolation and rejection (Sproston et al., 2017).

The impacts of autistic children being excluded from school are significant and often long-term. School exclusion is a form of disempowerment that further increases the risk of social isolation, as posited in a theoretical framework proposal (Annamma et al., 2013). The removal of autistic children from the school environment separates them from the linguistic and social enrichment that comes with schooling and is integral to their development (Blacher & Eisenhower, 2023). Removal, as reported in a public policy research report, can lead to higher rates of school drop-out and even incarceration (Adamu & Hogan, 2015). Progress made towards the ideals of inclusiveness can be harmed (Ambler et al., 2015), and educational outcomes are impeded (Martin-Denham, 2022).

However, the effect of school exclusion on parents and carers can be equally as impactful. Parents can be engaged in a stressful and seemingly endless battle with the education system that they feel is 'letting their children down' and failing to provide adequate and appropriate support (Brede et al., 2017; Sproston et al., 2017). They experience frustration and guilt as they watch their children respond negatively to school exclusion, such as self-harm or a heightened stress response (Martin-Denham, 2022). Parents can also expend considerable time and mental energy sourcing a suitable replacement to mainstream schooling and even go as far as home-schooling their children, bringing a whole new layer of complexity and difficulty to the parent and child. Likewise, home-schooling ends or halts some parents' careers as they forego employment to ensure a safe environment for their child to learn. Additionally, parents identify a detrimental impact on their mental health from the emotional toll of trying to find support for their children's educational needs but witnessing their child being impacted by the social isolation that follows school exclusion, as well as their own isolation (Altiere & Von Kluge, 2009a).

While there is a growing research base that identifies the causes and impacts of school exclusion on the autistic child, a recent review of existing literature identified that there is limited research focussing specifically on the impacts of school exclusion on parents' mental health or psychological well-being (Cleary et al., 2024). Therefore, a fuller understanding of how school exclusion and refusal impact parents' mental health is lacking in the current knowledge base.

With multiple impediments to normal cognitive, intellectual, and social developments already attached to autism, and with parents already leading the way as the primary support for the autistic child (Ang & Loh, 2019), the additional stress load brought about by school exclusion and refusal simply compounds mental health risks for parents.

This qualitative study explores parents of autistic children in Australia who have experienced school exclusion, through actions taken by the education system, including teachers, principals and school administrators, or by the refusal of the child or parent to attend. Findings include recommendations made by these parents and carers on how they and their children can be supported to engage in inclusive education. By understanding how parents or other carers are affected, including psychological impacts, this research contributes to the evidence upon which to build interventions. This evidence base will, in turn, help mitigate harm to parental psychological well-being and enable more appropriate and effective support for parents during periods of psychological distress.

Methods

The qualitative study was approved by the Central Queensland University Human Research Ethics Committee Research Division (Application reference: 0000024153) and conducted in Australia. Recruitment of participants occurred mainly through posts on social media in autism-related groups and fora. With permission from group administrators, the research team posted information about the research project on Facebook groups. Additionally, some members of the team approached their own networks to advertise the study. The recruitment posts provided an overview of the project and included contact details for further information on the project, an email to request further information or register interest. Inclusion criteria for recruitment were being a parent or full-time carer of a child on the autism spectrum who has experienced one or more forms of school exclusion. No time limit was given on the recency of experiences.

Interviews were held via video conferencing (July-August 2023), at a time convenient to the participant. These semi-structured interviews were conducted one-on-one (by trained, experienced interviewer MC) with seven parents and lasted between 50 min to 1.5 h (average 73 min). All aspects of the study were explained, and consent obtained from participants. Topics (based on the literature, and professional and 'lived experience') covered interviewee demographics, and those of their child, schooling and whether their child had ever been child excluded from school, including suspension, expulsion, removal from the classroom or if they had ever been denied enrolment in a school. Experiences of self-exclusion were also explored (where refusal means the child refused and did not attend school as a result) as well as the parent being the one to refuse sending their child to school. Finally, recommendations were sought as to what could be done by the schools to reduce the likelihood of autistic children being excluded.

The number of interviews conducted was based on the quality of the interview data and the achievement of

theoretical saturation of ideas (Cleary et al., 2014). Interviews were audio-recorded, transcribed, checked against the digital recording to ensure accuracy, and de-identified to ensure confidentiality. This occurred before the transcriptions were read, coded, reviewed and categorised into elements of the parents' experiences to allow for a comparison or contrast of their stories and meaning drawn from their experiences.

Data were analysed using narrative inquiry for the stories shared by the seven participants (SW, MC). Narrative inquiry uses small numbers of participants to provide an in-depth exploration of the human experience as expressed in textual form (Josselson, 2010). This allows the meaning that participants attach to their experiences to be expressed by telling their stories and for this to be analysed through interview transcripts. Additionally, narrative research enables the person at the centre of the experience to tell listeners about their sense of identity within these experiences (Overcash, 2003). This is particularly powerful when considering policy changes or person-focused interventions in promoting mental health care. Quotes are used every time a participant made a statement that could be connected to their mental health or psychological well-being so that their words might clearly illustrate their own view of the mental health impacts of their experiences.

The recommendations were compiled and analysed thematically (by SW, MC), as outlined by Braun and Clarke (2006). The thematic analysis involved reading and re-reading the transcripts, grouping the recommendations made by all participants into overarching themes and discussing these holistically. This allowed the analysts to gain a sense of the recommendations that were common among participants.

Narrative inquiry and thematic analysis are strengthened by reflexivity and rigour. Reflective practice encourages the interviewer to consider their own position within the data collection process (Pessoa et al., 2019). By acknowledging these potential interviewer-led impacts on the research process, rigour is promoted. Likewise, it is important for the interviewers and those undertaking the analysis to reflect on the assumptions or beliefs they may take for granted when interpreting words and experiences, grouping emerging themes or designing approaches (Macqueen & Patterson, 2021). In this research study, rigour was promoted by clear role delineation. An experienced interviewer, well-versed in reflexivity and minimising interviewer bias, conducted the participant interviews. In addition, the interviewer had no lived experience with autism or similar conditions or as a carer of such, minimising the use of assumptions that might impact the data collection process. During the data analysis and development of themes, additional researchers, both with and without lived experience, were brought in to ensure that data analysis was free from bias, correctly categorised, and sensitive to the experiences of the participants and the autistic community.

Findings

Characteristics of the participants

To protect the participants' privacy and identity, the characteristics of the participants are grouped and not presented in

a table format. Of the seven parents who consented to an interview, all were the biological mothers of a child who had experienced school exclusion, and all parents identified as female. Their ages ranged from 35 to 57 years. Five were married, and two were separated. Three worked part-time, three chose not to work and one worked full-time. Five stated that they lived in a metropolitan area, one in a regional area and one did not state their location. Two participants stated that they had depression, two had diagnosed anxiety, one had a previous diagnosis of anxiety, and one believed they had anxiety but no formal diagnosis. Two stated they had neurodiversity themselves, one previously had obsessive compulsive disorder (OCD), one had post-traumatic stress disorder (PTSD), and two had no mental health conditions or neurodiverse diagnoses.

Regarding their children, six participants had a son with an autism diagnosis, and one had a daughter with an autism diagnosis. Three participants had one additional son each, one had an additional daughter, one had two additional daughters and one had one additional son and one additional daughter. Only one participant had one child. The children with a diagnosis of autism ranged in age between seven and 20 years, with an age at diagnosis ranging from three to 15 years. Only one child was an adult at the time of the interviews but had only graduated from school 2 years prior and was still engaged in formal education. Four of the autistic children were diagnosed as Level 2-2 as per the DSM-5 (American Psychiatric Association, 2013) (the first score being for social communication and the second score for restrictive, repetitive behaviours). One was diagnosed as having Level 3-3, and two were diagnosed as Level 2-3. No child had a Level 1 diagnosis. Two of the children had a formal additional diagnosis of attention deficit hyperactivity disorder (ADHD), a further two had symptoms of ADHD but no formal diagnosis, two had sensory processing disorder, two had anxiety, one had OCD, one had oppositional defiance disorder, and one had an intellectual disability. One child identified as non-binary but was described by the mother as being their daughter. Two children had a total of three sisters who were also autistic, one had a sister who was possibly autistic but undiagnosed, and one had a brother who was autistic.

Participant 1 – when the education system 'just won't listen'

Participant 1 told the story of her teenage son who had been attending school in a limited capacity since early primary school, having been to a mix of mainstream public and specialist schools. Participant 1 reflected on her son's experience at school, describing him as having "hated" it, largely due to anxiety, an inability to concentrate for extended periods, and social difficulties. School holidays were seen to break his routine, resulting in having to "go right back to the beginning" in rebuilding trust and stability in routine. Peer relationships were complicated by issues socialising in age-appropriate ways. From Grade 1, her son exhibited school refusal as well as being suspended frequently. When at school he was not engaging in, nor required to engage in,

class activities, which essentially acted as a form of soft or informal exclusion. A period of stability in early high school was disrupted by a medication change that resulted in “the wheels falling off”. Participant 1 expressed frustration at continual suspensions, which were counterproductive as her son did not wish to attend school and therefore welcomed suspensions as an opportunity to avoid attending. COVID-19 related lockdowns were likewise a positive experience for her son, with no requirement to attend school.

An episode of behavioural dysregulation at school was the catalyst for the most recent period of school refusal. One episode of physical approach and contact by staff was in breach of the Behaviour Support Plan in place for her son, and his response was to threaten staff physically. His behaviour was deemed by the school to break “school values and rules”. The fallout was her son being excluded from the school camp, being given another suspension, and his renewed refusal to attend school. Participant 1 expressed her frustration at the school’s decision to issue another suspension as “[they are] not listening to what I am saying”.

Participant 1 summarised her own experience as being one of frustration with both “his behavior and the responses from the school”. She engaged in constant negotiation and persuasion each day to get her son to attend school and, when he had incidents at school, she experienced a level of discomfort when collecting him as “usually he rages and carries on in the car”. De-escalating him could take several hours. Simultaneously, she was experiencing poor communication with her son’s school. The school’s use of suspension was done without “acknowledgement or concern” for her commitments and instead she was required to “change my schedule to fit this”. This had effectively derailed her ability to return to work and reduced her household to a single income which had financial implications. When he was suspended, she received little to no contact or support from the school and experiences ongoing “worry, frustration or concern” about the inevitability of another suspension occurring.

Participant 2 – when the education system collaborates constructively

Participant 2’s experience with school exclusion began early. Her son began by absconding from class at times. Additionally, there were occasional instances of the after-school care program contacting Participant 2 and asking her to collect her son early when he was experiencing dysregulation. This had since progressed to her son refusing to attend school.

In the 2 years since, her son had progressed to refusing school attendance at least a few times each term. Participant 2 allowed this at times for a period of 2–3 days to allow a “reset” of his behaviour. However, her son was now engaged in a prolonged period of school refusal (multiple weeks). This recent episode was not preceded by any particular catalyst but rather lots of little things that “kept filling up his bucket”.

Despite this longer-than-usual period of school refusal, Participant 2 is positive in her view of the response by her son’s school. Communication has been open and constructive, with the school suggesting a range of different options

to trial, including a step-by-step approach to returning to school. Participant 2 summed up this constructive relationship between parent and school when she said: “I haven’t felt like they’ve been passing judgment or blame on me as a parent for my child not going to school...they’ve been open to collaborating and working together to figure out ways and asking what supports would be helpful.”

Even in the context of the largely supportive role the school has played, however, Participant 2 still experiences negative psychological impacts from her son’s reluctance to attend school. She expressed this impact when asked about how the prolonged school refusal, as well as the demands of having a child at home while working from home, was affecting her: “Stressed is the easy answer...It is having a negative effect on my own mental health...decreased mood....it’s definitely making my sleep worse...there’s a lot of anxiety around it...Frustration and worry about how to support my child and what this means long-term.” Participant 2 went further when reflecting on the overall experience of raising an autistic child and attempting to navigate the educational experience: “I find it very isolating and a very lonely experience because even if people are supportive and empathetic, I don’t know anyone else....who has experienced something like this.”

Participant 3 – when the education system says it’s ‘all your fault’

Participant 3’s experience of school exclusion was situated within a complicated home life. Having removed her family from a domestic violence situation, Participant 3 also had to contend with a son who exhibited violent behaviour at home, towards himself and his mother. She recalled her son attempted to refuse school from an early age, a stressful daily experience for Participant 3. Moreover, he was removed from the class on occasions, which Participant 3 described as counterproductive given her son’s desire to not be in class. Participant 3’s son went without diagnosis until a crisis as a teenager. This crisis led to ongoing school refusal—her son had not attended school for several years.

Participant 3 recalls her son’s school indicating that her son’s behaviour was “all her fault”, compounded by family who continually questioned her actions and choices regarding her son. The school held limited meetings with Participant 3, and when such meetings were arranged, her estranged husband was invited. Such invitations were extended by the school despite their knowledge of her experience of domestic violence, triggering a trauma response: “what happens then to me is tears just start pouring down my face and I can’t talk”. Additionally, the school made the unilateral decision without consulting the mother to hold her son back a year, which she saw as a tactic to place pressure on her to remove her son from the school. She ultimately decided to do so, with the school happily signing paperwork for him to move to online, distance education. Since then, Participant 3 has attempted to utilise the funding she has for a tutor, but is unable to find one, resulting in her son doing no schoolwork for a prolonged period.

Participant 3 articulated several impacts from this experience with her son's school, including her health: "It's definitely had a huge effect on my health. It's been going on for so long that it's hard to tell what it was like before", as well as her financial circumstances. She had been unable to work for a year when her son was considered unsafe to be left unsupervised, is unable to engage in full-time work, and is therefore unable to secure a home loan. Her son's lack of school participation was also causing issues with her financial support from the government agency. The experience was described as "isolating" where "nobody understands", "financially stressful" and feeling as though "there's something wrong with you". One saving grace had been her introduction to an online group for parents in similar circumstances. "The group, it's really lovely. It's very supportive most of the time and it's great... I think when I first got in there, it really did save my life."

Participant 4 – when the education support changes

The schooling experience began as a relatively positive one for Participant 4 and her son. He attended the early school years every day, albeit for part of the day at the request of the teacher as he was not managing the demands of a full day at school. When he started full-time, Participant 4 remembers the school psychologist being integral in helping them secure funding for a teacher's aide. Curiously, funding was said to be unavailable if issues were attributed to autism and instead the psychologist advised the right wording to use to trigger funding for challenging behaviours. Her son had a good relationship with his aide, teacher and even the principal, who would take him for a walk around the school if he was overwhelmed.

Grade 1 was a turning point in the school experience, however. The mental health service [MHS] withdrew support as he was "doing really well". Then, shortly after, his school principal, teacher and aides were replaced, and Participant 4's son struggled to build relationships with their replacements. This sudden change to the key relationships he had at school, and the loss of MHS support, resulted in behavioural changes, which led to the school sending him home on multiple occasions or using in-school suspension where he was moved to the library or another area away from the class. Participant 4 was told to make the home more boring for her son so he did not enjoy being sent home, and to have her husband collect their son from school as she was too much "of a reward" for her son. The impact of this was significant: "It really, I think, undermined my view of myself as a parent that they started to treat me this way...am I somehow complicit in these difficulties that my child was having? And the school's basically telling me I'm too nice to my son."

Participant 4 looked at other schooling options but was told by a local specialist school that they did not think her son would "be a good fit", while another public school nearby refused his enrolment due to insufficient places. Participant 4 finally considered home schooling, which her son has now done for several years. Participant 4 reflects on the whole experience as one which made her "very

distressed" as her son was not being given an education and was missing out on social connections.

Participant 5 – when the education system shoulders some of the burden

Participant 5 was the only parent with a non-binary child; one who was a teenager before they were formally diagnosed as autistic (Participant 5 referred to her child as female and used she/her pronouns which are replicated here to reflect her words accurately). Before the autism diagnosis, Participant 5's child had already been diagnosed with a mental disorder.

Early in life, Participant 5's child had an experience similar to school expulsion when they were expelled from a dance school: "I was pretty angry, to be honest. I thought that's pretty pathetic. She wasn't yelling and screaming. She wasn't punching kids. She was a little kid dancing in front of the mirror. But at the time, it upset me." Participant 5 noted the attitude of other parents of dance students as contributing to this expulsion.

The schooling experience for Participant 5's child was marred by ongoing issues of bullying and poor relationships with female peers. From an early age, they attempted (unsuccessfully) to avoid attending school on an almost daily basis by verbalising a range of physical symptoms that were consistent with illness, but in a manner that Participant 5 referred to as "hilarious". Despite this, Participant 5 still described the overall experience as "traumatizing...it was actually quite anguish-producing...because I was worried about her the whole time. Because I knew I was making her go to school where she was having to deal with this, but you can't not have her go to school either."

Participant 5 described the schools that her child attended as being "great". When her child was diagnosed the school said they were going to take the task of tutoring off her (Participant 5), which she had been doing all through school to keep her child up with their peers. This was "a huge relief" to Participant 5, as the tutoring "was too much. And it did contribute, I think to my poor mental health for a while, my anxiety for a while."

Participant 6 – when the education system breaks the sense of safety

The experience of Participant 6 began as one of separation anxiety, exhibited by her autistic son and borne from a lack of a sense of safety in his school environment, and progressed to one of irreparably broken trust between her, her husband, her son, and the school he attended. Participant 6 likened her son's need for her or her husband to be nearby and the school's dismissiveness of this to someone being told to "leave your wheelchair at the door and you just crawl in." Participant 6 persisted and would wait outside her son's classroom until he was ready for her to leave, which could mean staying there for the entire duration.

The sense of being dismissed continued through her son's early primary schooling. Instances of dysregulation at school were not relayed to Participant 6, despite her insistence that

they could contact her if there was an issue. Instead, “they just really dismissed that” like “we know what we’re doing.”

The breakdown in her son’s sense of safety at school occurred when a teacher physically restrained him, insisting Participant 6 leave and resulting in a physical altercation. Participant 6 described the school’s response as being “very judgemental and basically treating his behaviour as being naughty because we didn’t have any rules at home. They just said awful things...We chose to view that as distress, not naughtiness.” The experience increased her son’s need for her or her husband to be present outside the classroom. However, having to be present at the school and trying to slowly transition him back into the classroom “just became too much of a burden on my mental health” and was compounded by a lack of engagement by the school in aiding the transition. The separation anxiety at school became school refusal, which ultimately led to Participant 6 choosing to remove him from school and homeschool him. Participant 6 did not see this as a choice, but rather a forced decision. When Participant 6 described the overall experience with the school, her language is unequivocal: “I would say harrowing. Really, really traumatic...They were absolutely terrible.”

Participant 7 – when the education system exhibits malicious inclusion

Participant 7 had an early diagnosis of autism for her son, in addition to global developmental delay. When lodging paperwork online for enrolment in the local public school, Participant 7 provided the array of reports that detailed her son’s various support needs. The response she received left her feeling “devastated”. She recalled the school advising her, “we’ve looked at his results and he’s so severe with his needs, he’s not going to be able to come here.” Instead, they insisted that they facilitate his access into a special education school. Participant 7 did not believe her son needed, nor did she want him to be enrolled in, a special education school. Instead, she was required to force the issue with the school, leading to the school permitting her to visit, but without her son.

What Participant 7 experienced during this visit had a profound effect on her. She was taken on a tour and the staff member conducting the tour pointed to a special needs child sitting at the back of a classroom playing on their own, unnoticed by the students or the teacher. Participant 7 was told “That’s what your son will get at this school if you send him here.’ And I was just like, that’s malicious inclusion, right? They were showing off how neglectful they could be to try and intimidate you and coerce you into making a decision.” Participant 7 stated how the application process and the provision of the detailed reports about her son had already made her feel “vulnerable and exposed”, but the ensuing behaviour of the public school made her feel “dismissed, minimised, shamed, intimidated, and coerced” by a school that was obliged to accept her son and support his educational needs.

Ultimately, Participant 7 placed her son in an autism-specific school, where he eventually moved to a

satellite class situated within a mainstream school. While there had been issues with bullying by some mainstream students, Participant 7 felt supported by the school’s response to such matters. Despite this feeling of support, her experience of school exclusion continued. The long commute to school and his mental fatigue at engaging in age-appropriate educational tasks impacted negatively on him. Her son would attempt to refuse school and sometimes absconded when his community transport would collect him before school. The impact of this on Participant 7 was that she was late for work “almost every day” and had to work reduced hours.

Recommendations by parents. As parents engaged in the discussion about their experiences with school exclusion, they all turned to the things, both large and small, that can be done to make autism and education come together more effectively, rather than colliding and resulting in psychological harm to the child and parent alike. Parents discussed recommendations that centred around four core themes: acceptance of autism; communication and language; flexible learning; and support provided by the school and in the school.

Acceptance. Most of the participants referred to the need for greater acceptance and understanding of autism and the need for a “more neuro affirming approach” (Participant 2) as well as “trauma-informed models of education” (Participant 4). Some participants saw the education system as designed to operate in ways that failed to consider autistic students, working to their detriment. This includes rewards-based systems in classrooms that encouraged preferred (neurotypical) behaviours, thereby “rewarding children who can already meet those expectations and punishing those who can’t” (Participant 2). Where acceptance is integrated into the education setting, there follows a better understanding of why some children have difficulty attending and the focus can shift from punitive measures to supportive measures. For participants, acceptance by school staff and other parents looked like: an absence of judgement; collaboration; using alternatives to suspension and informal exclusion; understanding the far-reaching effects of school exclusion on students and parents; a respectful approach to difference; and removing or sharing the burden of parents and carers where possible.

Communication and language. Some participants’ experience had been marred or exacerbated by poor communication by, with or from the school. For those who experienced open communication, they cited this as something that helped them to feel supported and that they “haven’t felt like they’ve been passing judgement or blame” (Participant 2). An openness to collaborate, asking what parents would find helpful and providing suggestions as to what the school might be able to offer were all mentioned as examples of preferred aspects of open communication.

There were also comments around the need to change the language often used when describing school refusal and engaging with autistic students, and to “stop using euphemisms” (Participant 5) so as to work in with the literal interpretation of words by many autistic students. Several participants emphasised that the use of the term ‘school refusal’ gave an inaccurate representation of the issue and that the term ‘school can’t’ should be the correct term—“It makes it sound like a choice when you say refusing” (Participant 6). Other participants referred to the ‘attendance matters’ narratives that cast a subtle but negative view on parents and their role in ensuring their children attend school. Further, participants spoke of the need for teachers to understand how language can be interpreted by some autistic students, citing the need for teachers to stop the use of euphemisms and provide students with clear, literal instructions.

Flexible learning. Most of the participants pointed to the need for the education setting to be more flexible in response to the needs of autistic students. A one-size-fits-all approach and an attendance mentality did not work to support autistic students, who need a flexible and tailored approach to learning. Instead, the education system needs to “work with where the child is [mentally or behaviorally] that day” (Participant 1). This might involve acceptance of the need to not push students who are refusing as this refusal is simply a stress response to some aspect of the education setting. The kinds of alterations that parents suggested included “some flexibility around schools where kids don’t have to go to school every day, where they can do some days from home” (Participant 3), more activity or project-based learning that allowed students to be physically engaged with learning, and even supporting the decision by parents to home school or even un-school their child (learning through self-directed exploration and play, as opposed to a structured curriculum), with un-schooling being an option in some jurisdictions.

Support by the education system. Following on from the recognition that school refusal is primarily a stress response, many of the participants talked about the need for the education system to start with an internal reflection upon “preventing them [the student] to feel safe at school” (Participant 3) and how these might be mitigated to accommodate the student. This might include the classroom setup or a lack of sensory spaces. Where students do attend school, participants emphasised the need for the school to support their children through such measures as teacher aides, individualised support, peer relationship and social skills training, access to a school counsellor, and training in neurodivergence for all teachers. Participants also pointed to the importance of “asking families what support they need, but also being able to offer examples of supports that they could provide” (Participant 2) and changing the power relationship so the school is “contacting me to talk about how they can support my [child’s] needs” (Participant 7) rather than what they cannot provide.

Discussion

The seven case studies of parents with autistic children who had experienced some form of school exclusion demonstrate that each story is unique, and each experience is complex. Additionally, the case studies demonstrate that each parent experienced a negative psychological impact from these instances of school exclusion. This negative psychological impact was analysed alongside any identified, pre-existing mental health disorders. The presence of any mental illness is important to consider largely because of the role it can play in responding to stressful experiences, such as school exclusion, and also due to the increased likelihood of similar diagnoses in their children (Johnson et al., 2018) that may impact their schooling experience. Four participants made explicit mention of the negative impact on their mental health, while most participants referred to stress, worry, anxiety, or concern. Some went further, using terms such as ‘harrowing’ and ‘traumatizing’. The experiences of stress by parents raising autistic children when attempting to engage with the education system is evident in similar studies, albeit mentioned anecdotally (Connolly & Gersch, 2016; Lilley, 2013; Martin-Denham, 2022). Stress is not just evident in their interactions with the education system, but also derived from societal stigma (Altiere & Von Kluge, 2009a), marital disharmony and divorce (Hill-Chapman et al., 2013), challenging behaviours by the child at home (Sikora et al., 2013), and poor experiences with healthcare professionals (Read & Schofield, 2010).

For some of the participants, much of the negative impacts were felt at the initial response of the school to the prospect of enrolling an autistic student. Different tactics were employed to dissuade the parent, such as the ‘malicious inclusion’ described by one participant. Such was the findings of a previous study, where four parents were discouraged from enrolling their child (Lilley, 2013). As with Participant 7’s experience, the school did not say ‘no’ outright, but instead attempted to lead the parent to this decision by emphasising the lack of resources and the impact this would have on the child. Another parent in the same study did experience outright refusal from the local zoned public school (Lilley, 2013). While the term ‘malicious inclusion’ is novel, it is suggestive of schools attempting to dissuade an enrolment and it creates a challenging dynamic for parents, where their own best interests for their child are used to achieve the school’s aim, and thus, parents feel unable to push back against what was essentially their own decision. The dismantling of such practices is made all the harder because of this.

The experience of school refusal also brought up feelings of isolation for some participants, an experience that was already exacerbated by the experience of raising an autistic child and only amplified by their interactions with the education system. Isolation remains problematic for parents, even those who receive social support (Dunn et al., 2001). It can come about from a lack of family support, limited child-care options, a lack of respite, limited finances (Hall & Graff, 2010), or, as demonstrated in this study, being caught in a stressful experience not commonly experienced by other

parents. Additionally, isolation is problematic as it can be used by many parents as a coping strategy against the stigma attached to their autistic child (Hall & Graff, 2010).

Some participants directly felt financial impacts because of their child not being at school, which impeded full-time employment. This impact on employment had extended effects, such as the inability to secure a housing loan and, therefore, keeping that family trapped in a position of housing insecurity. Negative psychological impacts are often tied to financial concerns and limited employment (Knapp et al., 2009). Parents end long-standing careers to homeschool their children (Martin-Denham, 2022) and where they cannot afford to do this, many experience feelings of inadequacy as a parent for being unable to provide this extra level of care (Altiere & von Kluge, 2009b). Parents are unable to accumulate savings due to additional expenses related to their child's special needs and/or a reduction to part-time employment (Nealy et al., 2012).

The experiences of these seven parents demonstrate that poor interactions with the education system provide just yet another example of negative psychological impacts on parents and carers of autistic children, and therefore a clear opportunity to mitigate these stressors through understanding and appropriate interventions. While the recommendations made by the parents were largely directed at the actions of schools, there is still much that the mental health nursing collegium can do. Mental health nurses, by virtue of the high co-morbidity of mental health and autism, are in a unique position to identify the experience of poor mental health by parents and carers and to provide appropriate support or referral to assist. Additionally, wherever mental health nurses come in contact with the education system, there is an opportunity to teach school staff about neurodiversity, acceptance, and neuro-affirming language and strategies. Where understanding and practical measures are raised and taught at each opportunity, change can be collectively achieved for the benefit of the school, the autistic student, and their parents or carers.

This study and its findings provide both strengths and limitations when expanding our collective understanding of the mental health impacts of school exclusion on parents and carers. Its key strength was the specific, and under-explored, focus on the mental health of parents and carers, rather than negative psychological impacts being raised as part of a more general discussion of their experiences with the education system. The study was further strengthened by employing narrative inquiry, allowing the full story of each participant to be presented, highlighted the individuality of their experiences. These experiences reached across a wide range of types of school exclusion, including expulsion, suspensions, informal or soft suspensions, refusal of enrolment, and school refusal.

The study was limited, however, in the breadth of experiences. While narrative inquiry allowed for the depth of their experiences to be captured, the study was limited by the recruitment of only seven participants despite achieving saturation. Despite seven participants being within the original recruitment target, the study would have been enhanced

by recruitment closer to the upper target range, being 15 participants. The study would have been further strengthened by the recruitment of fathers, with all participants being mothers, the recruitment of parents with autistic daughters, with only one subject being a daughter, and the recruitment of parents whose experiences involved more instances of expulsion or suspension, with the majority being focused on school refusal.

Outside the scope of this study were multiple factors that warrant future research. For example, capturing the perspectives of teachers, aides, and principals from a range of school types (public, private, special needs) would provide a more balanced view of school exclusion, but would be unable to capture mental health impacts as directly. Interviewing those who are equipped with the knowledge and skills to make or implement recommendations, such as mental health nurses, school counsellors, and Education Department policy makers, would also enhance the collective understanding of this issue and would allow for recommendations that might not be identified by parents.

In conclusion, this study has used the words and experiences of parents to fill a niche gap in our current understanding of school exclusion of autistic students. By focusing specifically on mental health impacts on parents, the actions that triggered or exacerbated these, and the recommendations made by parents to address these, we empower parents to acknowledge their experiences as real, their responses as legitimate, and their viewpoints as coming from a lived expertise that cannot be replicated by those external to the experience. The way forward now is to use these findings and the understanding we derive from them to consider ways the mental health nursing collegium can assist to promote and protect the good mental health of parents of autistic students.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

Partially funded by the 2022 CQUniversity School of Nursing, Midwifery and Social Sciences (SNMSS) Research Stimulus Scheme, project title: *When Education and Autism Collide: School Exclusion and the Impact on Parent Mental Health*

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