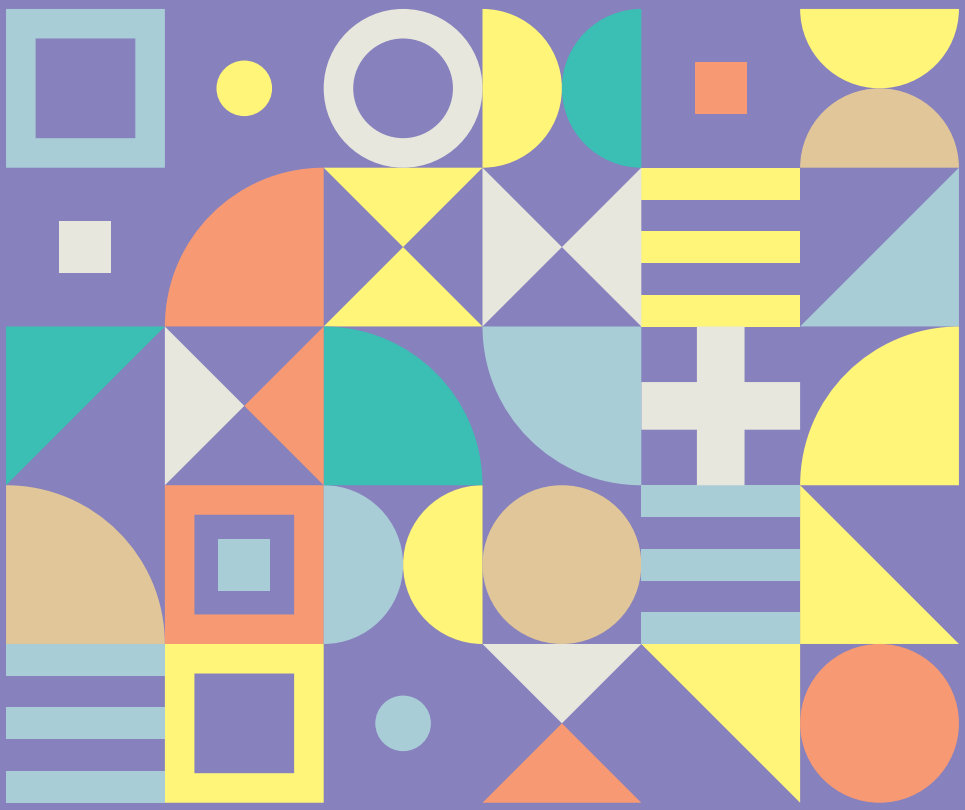
STRENGTHENING PARTNERSHIPS

Autistic Parents' Experiences with Australia's Schools

Report, March 2022



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Autistic Parents' Experiences with Australia's Schools

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EXECUTIVE SUMMARY

Schools are meant to serve all students, providing education and broader social support in a way that sets children and young people up for life. Unfortunately, and despite the best efforts of many, we know that autistic children and young people do not always enjoy the experience that they require in formal schooling in Australia.

Many autistic people report having deeply challenging times at school, with opportunities held back and even mental health suffering as a result.

These challenges have been consistently exacerbated, too, by a failure to learn from the experience of autistic people themselves. For a long time now, researchers, educators and policymakers have failed to be duly attentive to the perspectives of the autistic population; the opportunity to share their experiences in research has been limited and even where they have existed, few people have listened and fewer still have learnt.

This report seeks to change that. It presents new research about autistic parents' unique experiences of interactions with schools. The information in this report shares our understanding of educational experiences for autistic parents of autistic children and suggests ways we may be able to promote more effective partnerships between autistic parents and the educational system more broadly in the future for the benefit of all.

We conducted the research by listening directly to the first-hand experiences of 31 autistic parents of autistic children, whose experiences relating to their child's education and their part within it, have not previously been heard. Their autistic children attended preschool, primary school, and secondary schools across mainstream, disability-specific, virtual school and home-school settings. These accounts provide us with key information about current and future priorities for these families.

Our participants, who came from across Australia shared with us the importance of agency, respect for diversity, and acceptance in school settings and elsewhere. These parents wanted the very best for their children and continuously strived to communicate to schools their child's needs and the accommodations needed to help them thrive. But their interactions with schools were all too often challenging. Unconscious bias and stigma around autism continued to negatively impact families. Parents expressed the stress, trauma, and sheer magnitude and impact of negative interactions with schools, which inevitably led some to consider alternative schooling options. This dissatisfaction was often caused by a lack of knowledge, willingness and collaboration between schools and autistic families. Expertise and partnership with autistic parents were rarely sought by schools of these dissatisfied families.

Fortunately, this research also unearthed stories of successful partnerships with schools. Parents were constantly advocating for their children, gaining in confidence and a strong sense of autistic identity that formed part of a wider orientation towards social justice and as a result they helped identify some key foundations for the future. Autistic parents who had these positive experiences, that is, told us about the key ingredients that made these partnerships work: collaboration, willingness, and openness to learning from families and flexibility. It was only when teachers and schools demonstrated empathy, built a connection, and valued the parents' input, that mutual respect was formed, and parents and teachers worked together towards a common goal of improving the autistic child's experience of school. When a joint vision between home and school was embraced, autistic children together with their autistic parents experienced a positive connection to school and to education in general.

Successful and effective partnerships between schools and caregivers can have a positive impact on children and young people's experiences of school, and ultimately their outcomes. These partnerships can be especially important for autistic children. To improve our knowledge and gain a better understanding of how to promote successful home-school partnerships we have provided an opportunity for these families to share their experiences. By reading them and attending to their ideas, educators and policymakers can move a step closer toward the broader aim of improving relationships between autistic parents and schools, which can positively impact the educational experiences of autistic children and young people.

"So that's when it works, when I become part of the discussion about how my child is supported"

Single mother of 14-year-old autistic boy and 10-year-old autistic girl

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ACKNOWLEDGMENTS

Macquarie University and Positive Partnerships worked together to understand autistic parents' views and experiences of interacting with the schooling system. This work considered the effects of such interactions upon parents and their autistic child(ren) between home and school settings. The authors are extremely grateful to have the opportunity to work on such an important topic, allowing us to listen to, and learn from, autistic families.

Positive Partnerships is a national project, funded by the Australian Government Department of Education Skills and Employment (DESE) through the Helping Children with Autism package. It is delivered by Autism Spectrum Australia (Aspect), with the goal of improving the educational outcomes of school-aged autistic students.

We are enormously grateful to our Autistic Parents Advisory Group, including Kate Batty, Siobhan Lamb, Elizabeth Linklater, and Katy Reid, for their support in developing this research project and providing helpful comments throughout, particularly with communicating the outcomes. We are also grateful to Marc Stears for his comments and edits on a previous version of this report. We express our gratitude to members of the Positive Partnership Autistic Advisory Group, who initially raised the importance of understanding the experiences of autistic parents together with the Positive Partnerships team, including Vanessa Alexander, Carmel Corrigan, Emma Dresens, Narelle McCaffrey, Geraldine Robertson, Julie Storey, and Ian Ward.

Finally, we are extremely thankful to all our participants – autistic parents, their children, and teachers – who dedicated their time to sharing their experiences and knowledge, during an especially challenging time of the COVID-19 pandemic in Australia. We have learnt so much from their stories and have tried to convey them as accurately as possible. Any errors or omissions are entirely our own.

ABBREVIATIONS AND TERMINOLOGY

NDIS:	National Disability Insurance Scheme
PP:	Positive Partnerships
DESE:	Department of Education Skills and Employment
DSE:	Disability Standards Education
OT:	Occupational Therapy/Therapist
ADHD:	Attention Deficit/Hyperactivity Disorder
NSW:	New South Wales
SA:	South Australia
WA:	Western Australia
NT:	Northern Territory
TAFE:	Technical and Further Education (a type of tertiary education)

A NOTE ON TERMINOLOGY

In the autistic community, **identity-first language** ('autistic person'), is preferred to, and considered less stigmatising than, person-first language ('person with autism') [1]. It is also the terminology preferred by our autistic co-authors. We therefore use identity-first language throughout, unless participants themselves have used person-first language, which we retain in their quotes.

The term **neurodiversity** describes a natural and valuable form of human diversity in which autism is seen as one form of variation within a diversity of minds [2, 3]. **Neurotypical** describes individuals who have typical neurocognitive functioning, while **neurodivergent** describes individuals whose brain diverges from what society views as 'usual'. The **neurodiversity paradigm** encourages autism research and practice to focus on the individual *and* the social context in which they are embedded, as opposed to the medical paradigm, which focuses on the individual, seeing autism as a set of symptoms and deficits to be 'treated' [4]. In this report, we adopt a neurodiversity lens to understand autistic parents' experiences of their autistic children's education.

INTRODUCTION

SETTING THE SCENE

School should be a place in which children thrive. It should be a place that helps to set people up for the kinds of future life that they want. Yet children don't always thrive at school and for some, including autistic children and young people, school can be a challenging place to be.

It can be noisy, chaotic and socially overwhelming. And it can be easy to encounter people, including peers and school staff, who don't understand autistic students' differences or ways of being (see Box 1) or know how best to support them. It is not surprising, then, that autistic young people and their parents often report negative school experiences [5, 6], including challenges with their learning, behaviour and social connections, and are at an increased risk of developing mental health problems, all of which can have serious consequences for their futures.

One way to circumvent these challenges is to develop strong partnerships between teachers, parents, students and the broader community. These partnerships – which are based on respect for the contributions each party brings to the process of education – can substantially improve all children and young people's success in and out of school. Such home-school partnerships might be especially important in the case of autistic students [7], who benefit most from learning supports and consistent approaches across home and school contexts [8, 9].

The Australian Education Act and the Disability Standards for Education [DSE; 10] both seek to ensure that disabled students have equitable access and the same sorts of educational opportunities as other students. While the Standards also have a focus on consultation and developing collaborative partnerships with families which is at the core of our research, there are no agreed criteria for what constitutes an effective parent-professional partnership [11, 12]. There is some consensus, however, on which features might be important for such partnerships. The Family-School Partnerships Framework refers to the importance of fostering effective two-way communication, developing meaningful, trusting relationships between parents and school staff, and providing inclusive opportunities for all families [13, 14].

Professional learning for school staff around the value of, and the best ways to, engage with parents has been recommended for improving partnerships [15]. Yet, family engagement in home-school partnerships is influenced by a variety of factors, which means effective partnerships will look different for individual families and schools.

BOX 1. WHAT IS AUTISM?

Autism is a neurodevelopmental condition caused by differences in the brain. We don't fully understand its causes but there are likely to be multiple factors that interact together to cause someone to be autistic.

Being autistic influences how an individual interacts with others and experiences the world around them, which means that they might behave, learn, interact and communicate differently from other people.

Approximately one in every 70 Australian people is autistic [16, 17]. Current diagnostic criteria [18] state that autistic people show characteristic behaviours in two main areas. The first area is showing difficulties in 'social communication', which can include challenges with turn-taking in conversations, making and keeping friends and using and understanding non-verbal cues. The second area is 'restricted and repetitive ways of behaving and thinking', which can include enjoying the same activities and routines, being intensely interested in ostensibly unusual things (like animal names or train timetables), 'stimming' behaviours like hand-flapping and finger-twisting and unusual reactions to sensory sensations (like the sound of hand dryers/vacuums or the smell of perfume). While the dominant view of autism tends to frame these characteristic behaviours as difficulties or 'deficits', the autistic community often prefers to frame them as *differences*, arguing that autistic ways of being and interacting are as valid as non-autistic ways of being and interacting.

Importantly, every autistic person is different. Behaviours vary widely from person to person and also vary across different environments. Autistic behaviours might also look different as people grow up. Some autistic people also have an intellectual disability, while others have average or advanced cognitive skills. Furthermore, for some autistic people, learning language may be challenging. While some autistic people have no spoken language or very few words, others may have an extensive vocabulary but struggle with words when talking to others. Unfortunately, autistic people are also more likely to experience mental health difficulties, including anxiety and depression [19]. Whether being autistic is considered disabling for an individual can depend in part on the extent and nature of support provided by others – including within schools. This support can include both helping the individual to develop skills and strategies to understand situations and communicate their needs and adapting the environment to enable the person to function and learn within it.

In Australia, the average age of diagnosis is four years [17], although this too can vary depending upon available services and other factors. Most relevant to the current report is that many more adults – including parents – are also now undergoing diagnostic evaluations for autism [20]. There is currently very little research on these late-diagnosed autistic adults, particularly those who are parents of autistic children, who are the focus of this research.

AUTISTIC PARENTS OF AUTISTIC CHILDREN

One group for whom home-school partnerships might look especially different are *autistic parents* of autistic children. There is remarkably little research with autistic parents of autistic children – in part because, historically, autistic parents were thought to be very rare [21]. Yet, the broadening of the diagnostic criteria for autism [18], and an increase in the availability of diagnostic services, has led to a rise in adult diagnoses, meaning that more and more parents of autistic children are being diagnosed or identifying as autistic, sometimes after having gone through the diagnostic process for their children [22].

Emerging research with autistic parents suggests that parenting can be a rewarding experience – one full of love and joy [23, 24]. They can also experience intense connection with their children, in part because of their experiential expertise, or unique knowledge and insight of being autistic [22–24]. But parenting can be a challenging experience, too [25–27]. The additional demands that come with parenting – doing domestic chores, getting children off to school, ferrying children to extra-curricular activities and organising playdates with their peers – can be particularly overwhelming for autistic parents [24, 25]. Interactions with professionals, including teachers, can also be a source of anxiety. Autistic parents, for example, have reported finding it more difficult than non-autistic parents to communicate with professionals about their autistic child and were also more likely to feel misunderstood during those interactions. They were also reluctant to disclose their autistic diagnosis and identity [25], for fear of being judged for being a 'bad parent' [28]. These challenges can take a toll on mental health, with autistic mothers reporting they often have few formal supports on which to draw [24].

One reason why the interactions between autistic parents and non-autistic professionals, including teachers, might be particularly challenging is because of fundamental differences in the way that each group experiences the world [29]. While it has long been thought that autistic people struggle to understand others' thoughts and feelings, it is now widely recognised that *non-autistic people* can also struggle to work out autistic people's thoughts and feelings. This has been described as the 'double empathy problem' [29] and captures the bidirectionality of potential miscommunications. These struggles can lead to breakdowns in communication – which is a two-way process – and result in often-challenging interactions [30]. We know virtually nothing, however, about the extent and nature of these communication breakdowns in the context of autistic parent and teacher interactions. This study provides the first investigation of this important issue.

ABOUT THIS STUDY

The current research sought to understand the views and experiences of autistic parents' interactions with schools for their autistic child, focusing on the impact of these interactions on themselves, their children and their family.

To address these aims, we adopted an inclusive, participatory approach – that is, where autistic researchers and community members and non-autistic researchers work in partnership on the design and development of the research. Drawing on the 'practical wisdom' of autistic people, and particularly autistic parents, serves to ensure that the research is more thoroughly relevant to autistic people, more directly tailored to the realities of their everyday lives and more consistent with their values [4].

"I think most neurotypical people haven't ever had to think the way a neurodivergent person thinks and so they're just not used to that. Whereas every single day of my life I've had to think about the way someone else is saying something… that's just what happens when you're in a minority group"

Autistic mother, Advisory Group member

"The answers just aren't there, you know. And I'm like – 'well, what can I do!' It's just important for me to learn how to be part of the process"

Autistic mother, Advisory Group member

To this end, autistic experiential expertise was incorporated at multiple levels. First, the research team itself comprised autistic scholars and advocates who were themselves also autistic parents of autistic children. All team members actively contributed from the outset of the project, making collaborative decisions regarding methodology, contributing to the analysis and interpretation of the findings and the write-up of this Report. Second, we employed one of our autistic team members, Gabrielle Hall, to interview all our autistic parent participants. In other research, autistic participants have reported that sharing their experiences was made easier when an autistic researcher was interviewing them, as it enabled them to feel heard and understood [4]. We had anticipated that some of our autistic parents' experiences with schools may not be so positive so that having a safe space in which to share these experiences was especially important. Third, we established a community Advisory Group consisting of four autistic parents of autistic children. These parents attended many meetings across the duration of the project, providing their feedback on the interview questions themselves, the interpretation of the results, and the dissemination pathways.

For the research itself, we invited autistic parents of autistic children to take part in this project and, where possible, their autistic children and their children's teachers. Given the lack of research on this topic, we were keen to include autistic parents of children across early childhood, primary school, and high school to gain an understanding of the different issues raised at different stages of children's school trajectories. We also wanted to ensure that we heard about experiences in a range of education sectors and settings, including home schooling.

In total, we spoke to 31 autistic parents – all mothers – for this project. Twenty-five mothers had received a diagnosis of autism late in life, while the remaining six self-identified as autistic. Including parents who self-identified as autistic in the absence of a formal diagnosis is important given the often-significant delays and financial costs in gaining a diagnosis. In our research, most mothers reported having completed a university degree and most were employed in some way at the time of the research. Almost all mothers were born in Australia and most identified as white. One person identified as Aboriginal. The majority of autistic parents reported one or more additional mental and physical health conditions, most commonly anxiety, depression and gastrointestinal issues.

Together, these mothers were caregivers to 59 autistic children, including 30 boys, 23 girls and three who identified as non-binary gender. Most mothers reported having more than one autistic child. Five children attended preschool, 13 attended primary school and 16 were in high school, while 21 children were engaged in home schooling (see Box 2).

"I personally really feel the difference when participating in research which has autistic input and direction versus research about autism with zero autistic input"

Autistic mother, Advisory Group member

BOX 2. EDUCATIONAL PROVISIONS FOR AUTISTIC CHILDREN AND YOUNG PEOPLE.

In Australia, autistic students are increasingly being educated in mainstream settings [31]. In 2016, around half (52%) were educated in mainstream settings, with the remaining students attending special schools or dual schooling [32]. In practice, autistic children and young people can be educated in any one of the following provisions:

- Mainstream schooling without support.
- Mainstream schooling with extra support (e.g., learning support/ teacher aides).
- Support classes/units in mainstream schools, which cater for students with moderate to high support needs, including autistic students.
- Special government and private schools specifically for children and young people on the autism spectrum.
- Special government and private schools for children with varying needs, including for those with intellectual disabilities or social, emotional and mental health difficulties.
- Tutorial centres and programs which cater for students identified as requiring intensive behavioural and educational support, typically for students in Years 5 to 12.
- Suspension centres which cater for students who are on long suspension (5-20 days) and have been identified as likely benefiting from a structured program to assist their timely, successful return to schooling.
- Distance education programs for students on the autism spectrum which allow students to learn from home by connecting them to teachers via online learning tools.
- Dual schooling where children and young people attend two different types of schools (i.e., a mainstream and special school) during their week.
- Virtual schools are an entity approved by a state or government body to offer courses through distance delivery, most commonly using the Internet.
- Home schooling, which parents might pursue if they want to follow a home-based programme, if they do not feel that they child's needs are being met in existing provision in segregated and non-segregated options available in the Government, Catholic and Independent sectors, or if their child has been permanently excluded.

During in-depth interviews, all of which were conducted over Zoom, due to COVID-19 restrictions, we asked autistic parents about their experiences of navigating the school system for their autistic children, the extent and nature of their connections with teachers and schools, and the perceived barriers and enablers to working in partnership between home and school. We also wanted to know how their autistic identity influenced home-school relationships.

Where possible, we also interviewed the autistic children of these parents and their children's teachers to bring together their views and perspectives. To this end, we spoke to 20 autistic children, aged between 5 and 16 years. Half attended mainstream school with extra support accessed in the school setting, and the other half were homeschooled. Ten children identified as boys, eight as girls, one as non-binary, and one as 'other'. The students varied in grade level, ranging from preschool through to secondary school.

We asked young people to tell us about their good and their not-so-good experiences of school. To help them, we used a 'Draw an Ideal School' activity, which aimed to engage students in elaborating on their school experience, by first asking them to draw a school that they would not like to go to, followed by their 'ideal school'. Children and young people completed this activity either during the interview process or prior to their interview. Some of these drawings are featured in this Report, offering unique insights into children's perspectives.

Finally, we also spoke to seven teachers, including three female and four male teachers. Teachers' professional experience ranged from 6 to 37 years. Some teachers had limited interaction with autistic students, having taught only one to five children across their careers, while others had taught more than 30 autistic students. These teachers came from various educational settings, including government, Catholic, and virtual schools (see Box 2). In the interviews, we asked teachers about their experiences of interacting with parents, specifically autistic parents, and to reflect on the barriers and enablers to forging partnerships with parents.

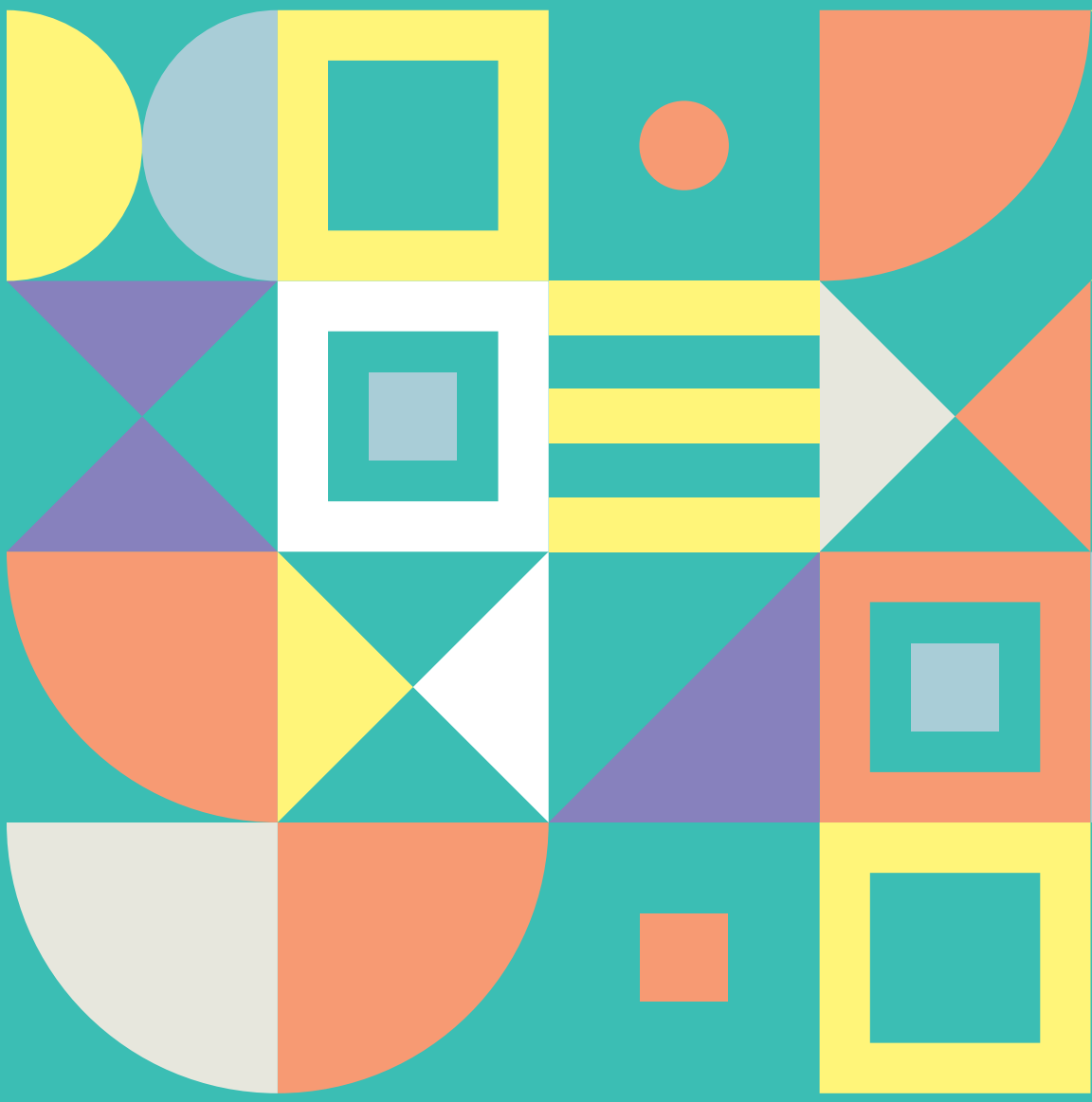
ABOUT THIS REPORT

This report is divided into an introduction, three chapters and conclusion. In Chapter 1, we begin by reporting on the autistic children's reports of their own educational experiences – both to understand what matters to them at school and to contextualise autistic parents' experiences. In Chapter 2 – which forms the bulk of this report – we recount autistic parents' experiences of interactions between home and school, which were unfortunately all too often negative, and the impact that these interactions had on them, their children and their families. In Chapter 3, we focus on the few but impactful successful home-school experiences in order to ascertain what might help to achieve greater understanding and more positive interactions between autistic parents, teachers, educators and schools in general. In the concluding chapter, we summarise the findings and offer recommendations, highlighting key strategic messages.

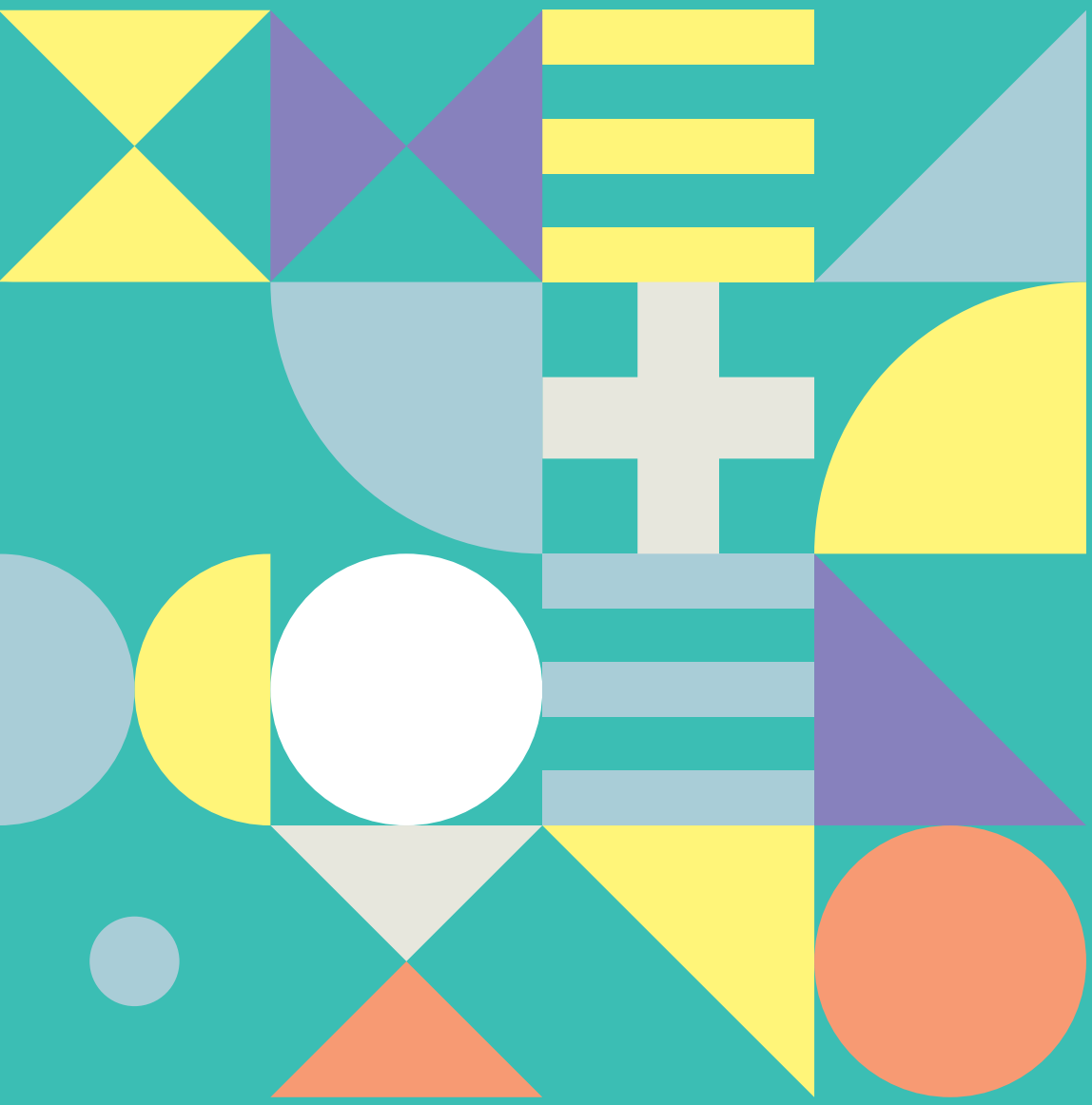
This report is aimed at the broader Autistic and autism communities, including autistic people, parents and carers, and the professionals and institutions who serve to support them. Under the Disability Standards for Education [10], autistic children and young people have the right to receive an education on the same basis as their peers and deserve the same educational and lifelong opportunities as non-autistic children and young people. Schools need to work together with autistic young people and autistic parents, who have unique insight into their children's experiences, to ensure that this is a reality.

"I'm really interested to see what it's all about and how we can share knowledge"

Autistic mother, Advisory Group member



1. WHAT MATTERS TO AUTISTIC CHILDREN



WHAT MATTERS TO AUTISTIC CHILDREN

To build a picture of the school experiences of autistic children, we begin by reporting the views and experiences of the children and young people themselves, for whose best interests parents and teachers come together.

What we discovered was sometimes unsettling: many children described intensely negative experiences of being at school, in particular, of feeling misunderstood and unwanted in schools, and described the impact that these experiences had on them. From their stories, however, we were also able to glean what matters to them at school and, importantly, what factors influenced a successful school experience for them. We describe these in detail below.

CHALLENGING EXPERIENCES OF SCHOOL

Most children and young people described having started their schooling career in mainstream schools. While they reported some positive experiences, including "feeling pretty safe" and "being encouraged to help each other", it was more common for young people to speak of these initial experiences as "terrible" or even "traumatic".

Young people explained that they would often either "just sit for hours doing nothing" or "sit in the corner of the classroom every day" because "I was just so mentally overwhelmed". Some young people "would keep it inside until I got home, and usually had a meltdown then". Sometimes they felt they had teachers they could turn to if they were feeling worried or stressed, but often this support was not forthcoming: "I thought this was going to be a good school, but my help has left me; I need help".

Young people felt that "there were just too many kids", especially those who were "not really like me", and they often didn't "feel safe because you never know what someone's going to do". In general, they didn't feel well treated by their peers – "they're quite bad to me, the people in my class", and that, as a result, "a few kids… really triggered me and made me struggle".

"It was like if you were trying to learn, but what you're learning was at the bottom of a muddy river, and you couldn't learn because of the muddy river. And that was partly being overwhelmed"

12-year-old male autistic student

Exclusion and bullying were, unfortunately, reported to be a common problem: "sometimes kids can be mean". Some children were targeted by bullies: "there was this one kid, he didn't bully me by insulting me or anything, he just punched me and stuff a lot". This made them feel "so insecure", especially when "the teachers didn't do anything". Others ended up being bullied by people who they thought were their friends: "It helped that I was doing pretty well with friendships… but then my best friend turned out to be a bully". One young man bravely reported having been sexual assaulted on multiple occasions in upper primary school by someone who he previously considered to be a friend: "before we weren't friends anymore, he sexually assaulted me two or three times… I made a report [to the school] and the only thing he got at the end was a telling off". The assault led to school refusal and difficulties transitioning into high school, including "really impacting my mental health… I said 'I'm just fed up' and I'd just given up".

One young person, who was diagnosed later in primary school, felt that some of his challenges came down to his teachers not knowing he was autistic: "I guess for an autistic person, one of the hardest times in their life is before they are diagnosed as autistic. Before that, everyone expects you to pull the weight of any normal person even though you might not be capable of it and then people just think you are lazy or dumb". Another young person, however, described feeling socially excluded precisely because people knew he was autistic: "[school] had a satellite class but it wasn't like there was a satellite class even near other kids. There was physical distancing. And mental distancing. They never ever got anyone, any neurotypical person, to come into their room".

For some children, their schooling experiences were so "horrible" that they didn't "want to go to school". A student described how "during my prep year, I school-refused, and during most of my Grade 1 year… because I had separation anxiety and because my anxiety in general had just gone haywire". Ultimately, this meant that some autistic students had only lasted in mainstream "up to about mid-Grade 1" and, as a result, had been to "all the different kinds of schools". Such change "was hard", they described, because "you are thrown into a different school, a different location, different people. To be honest, you are like I know no one here". But they nevertheless persisted with the challenges of new schools, because their previous schools had been so difficult for them: "I really hated my first school, it was awful, I hated everything about it".

Some children and young people left conventional schooling altogether and began home schooling instead. Some young people described the initial transition of "going from mainstream to home schooling" as somewhat challenging "because I find that I work well amongst others". But they described this particular shift as having a positive impact on their learning – "I probably learnt more in that first year [of homeschooling] than I have learnt over the entirety of my life beforehand" – and their wellbeing: "so at home, I have felt much better, because I'm able to express who I actually am".

BOX 3. AUTISTIC YOUNG PEOPLE'S VARIED SCHOOL INTERESTS

Children and young people described enjoying a range of subjects, including reading, art, writing, different language (German, Russian), maths, history, science, humanities, English, engineering, history, food technology, design technology (because "I like to make and create things"), as well as physical education, which as one young person put it, "you might find unusual for an autistic person".

There were other subjects, of course, that they didn't find so enjoyable, including spelling ("because I find it hard to spell a lot"), information technology ("I'm just not good at all of that"), English ("I had a very hard time understanding the concept") and writing ("I can't really hold a pen well, not in the correct way, and that makes my hand get quite tired fast"). Some subjects were simply not enjoyable because young people felt that they weren't being sufficiently challenged: "it's a bit too easy so it gets boring for me".

WHAT WORKED BEST AT SCHOOL

Despite these severe challenges, some children and young people also talked about enjoying aspects of school, especially particular subjects (see Box 3), and identified various ways in which school worked best for them and their learning, including when they had (1) sufficient time and space; (2) some control over the rhythm of the day; and (3) people who showed concern for them.

i. TIME AND SPACE

Children and young people were clear that they learned at their best when the classroom and school setting was unobtrusive – that is, when it was quiet, and when they had "fresh air" and space.

They described how the classroom is often "very loud, noisy and distracting", which "makes it a lot harder to learn". Some subjects were noisier than others ("music is just the loudness") – and some teachers were, too ("one teacher, he shouts a lot") – which often meant that the environment "just didn't work for me". Instead, they wanted "lots of quiet places to sit", particularly a setting that "feels breathable", with "fresh air, as I get headaches a lot, when it's too hot", and is spacious, that "hasn't got chairs and desks bumping against each other". One young person recounted that he "can handle [physical education] because it's in a really open space no matter where we are, so I can be okay".

Young people felt they needed this space – *and* the time – in which to de-stress "and get that negative energy out, going down the oval and playing football with your mates". Some reported having "teachers that actually let me go to lunch earlier so that I didn't have the rush of everybody getting their lunch and then it was more relaxing", and some were able to "go into the space in between the two classrooms, called the bubble, and just do my work there or something like that, just have a break". Others were able to take refuge in the library: "I found this perfect little nook that's sandwiched between one of those turning book things, so no one can really disturb me there".

Yet, such recovery time from the stresses and strains of formal schooling wasn't always possible: "our lessons are 80 minutes long and we don't really have break time, so it's just sit down for 80 minutes, get up, sit down for 80 minutes, recess. It's very long and tiring". As a result, they often "struggled with subjects", which could be "exhausting": "I don't join any of the lunchtime or before-school clubs because I'll be way too tired to do any of my lessons if I have to do something".

ii. THE RHYTHM OF THE DAY

Young people also reported wanting a school that "is very flexible with its way of learning", especially when they had more choice and control over that learning. Some young people, particularly those in high school, felt that they "get choices a lot", including getting "to choose what subjects I want to do" and "having a choice about having my [Teaching Aide] with me or not – but most of the time I say no". More often than not, however, young people felt constrained by the "specific timetables that repeat every single week". Consequently, young people often felt "usually quite restricted at school", where they "don't really get much time and just feel rushed a lot". They described "not working well" under pressure, including "time limits", "short deadlines" or "a reward for doing good at something – that would make me feel like I had to do really good, but that would make me start stressing out and make me feel really bad".

This issue was particularly highlighted by those who had experienced an alternative to the traditional mainstream school setting. One such setting was learning-from-home during the COVID-19 lockdowns. As one young person described, "at home, every time I get down whilst I'm doing my homework, I just go outside, do some exercise and then come back and do

"Well, when I get home from school, I'm always exhausted so I'm always a lot quieter after school ends and at home because I feel comfortable just being quiet"

14-year-old autistic student

"I like that I can do my work independently without anyone needing to give me a timetable so that I can choose what subjects I want to do when"

11-year-old autistic student

it and smash it. Unfortunately, at school I just can't do that". Other young people who were now engaged in home schooling also valued feeling less beholden to externally regulated timetables and described having more influence over their learning. One said, "I can basically choose what I want to learn at any time", while another reported liking "doing it at my own pace and having all the breaks". As one young person put it, "it allows me to do things that I want. So, if I'm not feeling up to Maths today, then I could go and do something like Chemistry".

iii. CARE AND CONCERN

Friends. Young people spoke a lot about their friends and how things were at their best when they were "doing pretty well with friendships". Their friends often "like the same stuff as I like, well, *all* the same stuff", including "just hanging out and chatting, pretty much", "playing tag or whatever", and "climbing trees and playing sport". They often saw their friends as a source of strength, "especially for my mental health". One young person, who had left a conventional school to be home schooled, explained: "I had many friends back at [mainstream] school and that's not the reason why I left. It's completely the opposite; it's one of the reasons why I wanted to stay. Having loads of friends there really helped me". Some young people had such strong friendships that "we just feel like we are family – we just talk together, we play together and we laugh together". Importantly, these were friendships in which they felt respected for who they are: "they treat me like I'm able-bodied, they treat me equal compared to everybody… like we are best mates and we all stick together".

They also saw their friends as like-minded people – "usually we just talked about how unfair the world is, basically" – that they could draw on for support if needed: "if you have any issues or concerns, I could just speak to them at any time". One young person described her best friendship:

> *This year, I have a best friend in most of my classes so we can do all our work together and send each other our notes because I know that she takes really good notes in class but sometimes struggles to understand them, and I take no notes in class but understand the content. So, it's just a nice system.*

Teachers and teaching assistants. Ultimately, young people felt safe and secure in their schools when they felt their teachers and other school staff "care about them". They spoke highly of teachers who were "really nice to you", "patient and kind" and "fun and easy-going". They often mentioned liking teachers who were "kind of strict" but not "really strict… as it's hard for me to concentrate without getting scared".

Young people also valued teachers who "check in on how my wellbeing is" and who "always respond in a respectful way, always giving up their time for me". One young person described this in depth:

> *Every time I have meltdowns or every time I struggle, my favourite teacher, Mr X, always sits next to me, and helps me out and gets me through this because he knows I could do better than just giving up and sitting around doing nothing. He just sits with me and says, 'just do it with me and we'll get this over with'. And then, we work well together, and we make up stories, and we make up ideas. He helps me with all that and I think that just makes it better.*

Young people wanted "more understanding [from teachers] of how people learn". They spoke of how it felt "helpful and reassuring" when their teachers noticed when they weren't learning at their best – "at my old schools, I could do no work and people wouldn't really make a big deal out of it. But here, people care, which is nice". They also referred to the positive impact of educators – who believed in their capabilities and challenged them: "All [teacher's] questions make me feel really proud to answer them, because they're so difficult, but in a good way". Above all, their favourite teachers were those who were "really, really understanding": "I just feel like she understood me, and she knew what I needed".

Unfortunately, not all young people experienced teachers as understanding and encouraging. Some described having teachers who failed to explain things "really easily and clearly", but instead used "really big language, and who don't even explain what it means, just expect". The impact of not explaining things "too well" was highlighted by one high school student:

> *Giving me too much information… I know it sounds a bit silly, but if you give me ten ideas or you're saying it all at once and not breaking it down, I get a headache. I just can't handle that much information and also that stress. And that makes it hard for me to pick one of them or pick your idea, and then I end up just storm[ing] off and walking out of the class. I just feel like I'm going to pass out.*

Other young people reported having teachers that were just "really mean; they didn't understand anything". Some felt misunderstood, reporting that teachers perceived them "as being cheeky, but when I'm actually just being literal". Teachers were also not always accommodating, "always asking us to write notes and study in certain ways that doesn't work for me, and if I don't do it, they get me in trouble". Some still were fearful of teachers who "always shout a lot": "it always scares me because I'm not sure who he's yelling at. Sometimes it feels like he's yelling at me even though I know he's not".

Family. Finally, children and young people also described having close connections with their families. They deeply valued the love and support they received from their families, especially from their mothers, who one described as "the best person ever". They felt that they could "talk to my Mum openly about it, so I've had her as a bit of a support". Some young people were also aware – and appreciative – of the continued support of their mothers for ensuring their success in school: "without Mum advocating for me, I think I would still be school-refusing". As one homeschooled young person put it: "this is my ideal school; I'm happy learning with Mum".

"I think [teacher] notices my strengths. And my weaknesses. And she tried to build more on my strengths and buffer out what my weaknesses are"

11-year-old autistic student

NOT-IDEAL

IDEAL

The 'worst school' shows a playground with nothing but grass and sand. There is lots of writing on the board, unhappy teachers, and students all bunched together on one desk. In contrast, the 'best school' illustrates a playground with lots of equipment, students with adequate space at their desks, and a smiling teacher.

Not-ideal and ideal school drawings from a 9-year-old autistic student

2. WHAT MATTERS TO AUTISTIC PARENTS

WHAT MATTERS TO AUTISTIC PARENTS

In Chapter 1, we heard the many challenging aspects of school for autistic children and young people. Their autistic parents witnessed first-hand these challenges, empathised with them and were committed to addressing them. They had high aspirations for their children and wanted others to have the same. Below we describe their views and experiences – including what they wanted for their autistic children and how they sought to ensure that their autistic children enjoyed, and flourished in, their learning.

CONFIDENCE, VOICE, CONNECTION AND INCLUSION

The autistic parents to whom we spoke often reported having negative school experiences as a child – experiences that often contributed to their concerns for their children: "I went to a very academic school, that was very, very, very square peg, round hole, and there's probably a layer of my worry, more than it's maybe, actually happening right now, but I feel like I can see it happening already". They often described having little-to-no opportunity to express their needs at school, only to learn this later in life when their own diagnosis helped them to develop "a confidence that comes with self-acceptance". It was this self-acceptance and sense of confidence in themselves that autistic parents reported wanting particularly to instill in their autistic children. They wanted their children to "have a really positive sense of who they are" and to have the confidence to "make connections with other people that understand them and accept them". As one mother put it: "The most important skills that I teach my kids are self-awareness and self-advocacy, the learning to know yourself and then the learning to advocate for what you need".

Autistic parents were focused on helping their autistic children express what is important to them – sometimes successfully and other times unsuccessfully. One parent recounted a school meeting in which there was a total lack of acknowledgment of her autistic child's preferences, "I asked, I wanted her voice to be included, but we sat there, she and I, at a meeting, not being heard and not being asked what she wanted or what would help her as an autistic student".

"Being really confident in themselves to go out into the world not feeling like they're wrong or broken or stupid or the odd ones out. Have a really positive sense of who they are."

Autistic mother of a 9-year-old autistic boy and a 6-year-old autistic girl

Autistic parents also yearned for their children to feel safe, secure, and connected at school. They wanted schools to be a "safe space", which embodied, at least for one parent, "lots of little, tiny incidental conversations that show respect. As soon as that happens, students feel safer, and the minute they feel safer you will get as much participation as you will get from them". Having the option to use a "safe place" was also perceived as making a very positive difference to autistic students, providing a sense of security and making learning easier.

Autistic parents also wanted teachers to develop deep and sustained relationships with their children. Like their autistic children (see Chapter One), autistic parents felt that the connection between the student and teacher was critical for their autistic children to thrive. As one parent put it: "if she doesn't feel connected to someone, it just does not work, and she feels really uncomfortable". They felt that the ideal partnership between school and home would therefore be centred on "values, respect, agency, flexibility. They'd [school] value difference. They'd value diversity".

Finally, autistic parents hoped for a future where "every single person embraced difference around them". To achieve this goal, the changes that many parents wanted to see for their autistic children in school were a "no brainer". In fact, they were convinced that the changes would benefit *all* children. One mother of two autistic daughters said, "there would be other kids in that grade that would be finding the noise level too high… and there would be other kids that need to graze and eat – if you did these things for them, the whole class would benefit".

"For me personally, it's just working with the students to build a relationship or build rapport and have those things you can connect over, because there are going to be times when things don't go exactly as you want them to go. If you haven't built that connection with them, it's really hard to steer them in a certain direction that's going to help them."

Primary School Teacher of an 11-year-old autistic boy

BOX 4. WHAT IS THE 'RIGHT' SCHOOL FOR AUTISTIC CHILDREN?

Many of the parents with whom we spoke had tried a range of schooling options, including in the government, Catholic and Independent sectors as well as virtual or home-schooling, with varying success. One mother, *Elle spoke of how crucial it was to think carefully and critically about choosing schools for her autistic children.

A mother of five children, four of whom were formally diagnosed as autistic, and one who is undiagnosed, but "has some neurodevelopmental differences and potentially ADHD", Elle described having gone through many ups and downs with her children's school journey. She spoke of her children's individuality ("they're all very unique even though there's lots of similarities") so selecting one school that all her children could attend, was never going to be an option. She shared her thinking of "a very firm understanding that whatever is best for the child, and however that may be, is how we should proceed. So, unlike all of the neighbourhood families, for us it was needing to educate the child in whatever setting, wherever that may be, that is best for them". This approach helped create options and flexibility for the family, allowing "us to constantly always have our eyes open, and constantly having a reflective mindset rather than a 'that's our family neighbourhood school, and that's what's going to happen'".

Within the family, all children went through different experiences with the educational system. Elle's youngest left school in Grade 4 after expressing her frustrations to the school principal in a letter stating how she was "not learning", "going to be sick" and "needed out". She now attends virtual school online. Another child currently attends Year 8 in a mainstream secondary school and that option works for him – "he is learning, and he is engaged – so far so good". Another "finished high school towards the end of Year 11 through absolute burnout, breakdown, and trauma". Another still left school in Year 8 and never went back, which has meant that Elle and her partner "had to find a whole different way of educating and helping him into adulthood". Although Elle and her family have been "down all sorts of different pathways in educational settings, with various levels of degrees and challenges or failures", they felt resoundingly that "it's all part of the learning journey, and we would hope to think that in the end, even through those failures, we've found a way to succeed the best that we could with what we have."

* Names have been changed to respect the privacy of our participants.

CONFRONTING OPPOSITION

Although autistic parents hoped for empathetic and supportive interactions with teachers and school staff, these relationships were not always – or easily – achieved. Instead, parents reported that they often felt that they were "the problem… even though we were so polite and so gentle and so proactive".

These damaging perceptions began with their children being blamed for being different "even just in terms of him being able to cope with the day-to-day school life, it was always that he was a problem". Such perceptions extended to autistic parents themselves – "I was a convenient excuse for every failure" – which had a detrimental impact on children's engagement with school. Parents reported that both they and their children were sometimes exhausted by school, resulting in reduced attendance: "I ended up pulling them out of school, just for the last three days of term, because I was like, I'm exhausted, they were both exhausted".

Parents felt that these negative perceptions resulted from fundamental misunderstandings of autism: "I realised pretty quickly from the staff and the principal that [according to them] that's what autism is, it's this extreme behaviour, and these are naughty kids". Parents were perplexed how their parenting expertise and intimate knowledge of their own child was neither appreciated nor utilised by teachers and other school staff: "it's difficult when school staff only ever see you as a parent, you deliver the same message that a professional would deliver, but they don't see any value in what you say because you're there as a parent and not a professional".

Interactions with schools on behalf of their children were described by parents as a challenge, a never-ending battle: "it feels like you're constantly in a war zone". Some autistic parents reported that school staff made them "feel guilty for having to beg for the smallest accommodations, which really weren't very much at all". Parents just "couldn't understand" why it had to be so complicated and surprisingly "rigid" in a classroom setting, "especially when we're trying to teach our children flexibility and adaptability and yet their very own school makes this difficult". Another parent said, "They're little people with big feelings and emotions that can be managed in an environment that is suited to them quite easily". Their attempts to include their autistic children in decisions around schooling were also thwarted: "not being heard and not being asked what she wanted".

Our conversations with parents repeatedly revealed that it often took so much effort to help schools and teachers understand the importance of adopting a flexible approach.

Instead, they recounted being "stonewalled… every time I would try and step over another hurdle of bureaucracy or funding… it was shaming and othering and really, and again, it makes you feel powerless and hopeless". Another parent said: "It's not fair to ask parents to have to do that, and to feel that they're fighting, when we are, ourselves, such a vulnerable population". They reported having to fight for schools to acknowledge "my child's needs and advocate" for the right support, but they often felt treated "like the enemy". Parents felt blamed for their child being autistic, "that was always put back onto us and always put back onto our child". Autistic parents' parenting was at the forefront, and their "parenting was called into question", further stigmatising and ostracising these already vulnerable families. Many parents found that being autistic is frequently highly stigmatised. Nonetheless, they had rich suggestions on how to change this: "You need to just accept that difference is not a bad thing, it's just difference. And if we are flexible and able to move and see the positive and negatives of difference, everyone will be embraced".

Autistic parents were well aware that "being an invisible neurodivergent person is not an easy path in the school environment". This was made more challenging due to prevailing narrow views of education, in which "everyone needs to fit into a box and get out the other end in a certain way". Their children often learned in different ways ("half of his day, from my understanding, sitting under his desk, doing schoolwork"), which meant that teachers and school staff should have "to think outside that box, and work with what works for [child]". Unfortunately, this did not always happen: "they just didn't get her".

Autistic parents felt that their individual schools' normative "mindset" reflected "a broader problem", an education system that focuses "on the outcome and the comparison, not the nourishing and development of a person". Some described seeing this mindset play out with other parents trying to navigate school with autistic children, commenting: "They're trying to make their kids fit in and trying to make their kids be normal. And I find it really hard to watch it and not be like, it doesn't have to be like this".

One parent summed it up: "being autistic is just like having brown eyes, it's just a part of you, and it has benefits, and it has things that sometimes make things a little extra tricky for you, and unfortunately, the world isn't always set up to really support that".

Although persistent advocacy was seen as the only way to get through to schools, parents suggested that interactions with schools did not always need to be adversarial in nature. As one mother highlighted, "advocacy doesn't always have to be combative, it doesn't always have to be that way, but it seems like school's set us up to be a really aggressive kind of power struggle, and parents are always that imbalance, in that we don't have the power". Ultimately, autistic parents did not feel listened to by schools. One reason put forth for "why parents are not listened to more" was that "teachers and principals feel that they know better than parents, and therefore that, as a parent, you have very little to offer… ultimately, your views and your insight and your experiential knowledge is ignored". When this occurs, they felt that schools not only miss an opportunity to develop trust by working collaboratively with families. They also fail to benefit from the vital knowledge and experience autistic parents have about their autistic children. As one mother put it: "I have a little bit more of insight than the average normal mother might do, with an autistic kid".

ALL OF THIS TAKES ITS TOLL

The effects of these negative interactions with school were far-reaching – just as their children had described – taking their toll on themselves, on their children and on their family (see Box 5). Parents conveyed how "[child's] mental health was so, so bad", with some children contemplating suicide: "she was talking about killing herself at eight". Another autistic parent recounted how her autistic child "at one point actually told me that he'd rather die than go to school". This same parent described the sense of compassion that everyone in the school showed her son when he was suicidal, which disappeared when he became aggressive, his "big behaviours" overshadowing everything else.

Parents repeatedly described how "traumatic" and "incredibly stressful" advocating for their child/ren can be and how the cumulative stress of dealing with schools meant that their "own mental health was suffering". Even the mere thought of interactions with teachers and schools was reported to be stressful, with some parents experiencing "full blown heart palpitations at the thought of having to deal with teaching staff and school and the whole system". These negative experiences often impacted the entire family. Some autistic parents reported that family relationships were damaged "between me and my child, between his dad and I, because we were sending him to school when he was telling us he wasn't safe. And we were saying, well, it's really important you go to school". Families were also significantly affected financially, with mothers reporting having to give up their employment, just so they could support their child's education.

I've given up my whole teaching career because I'm so traumatised by the way I was dealt with, the way I was handled, the way I was ridiculed, the way my parenting was called into question. The people that are supposed to be understanding and supportive and a community, a school is supposed to be a community, completely not understanding not showing any compassion, and the lack of communication.

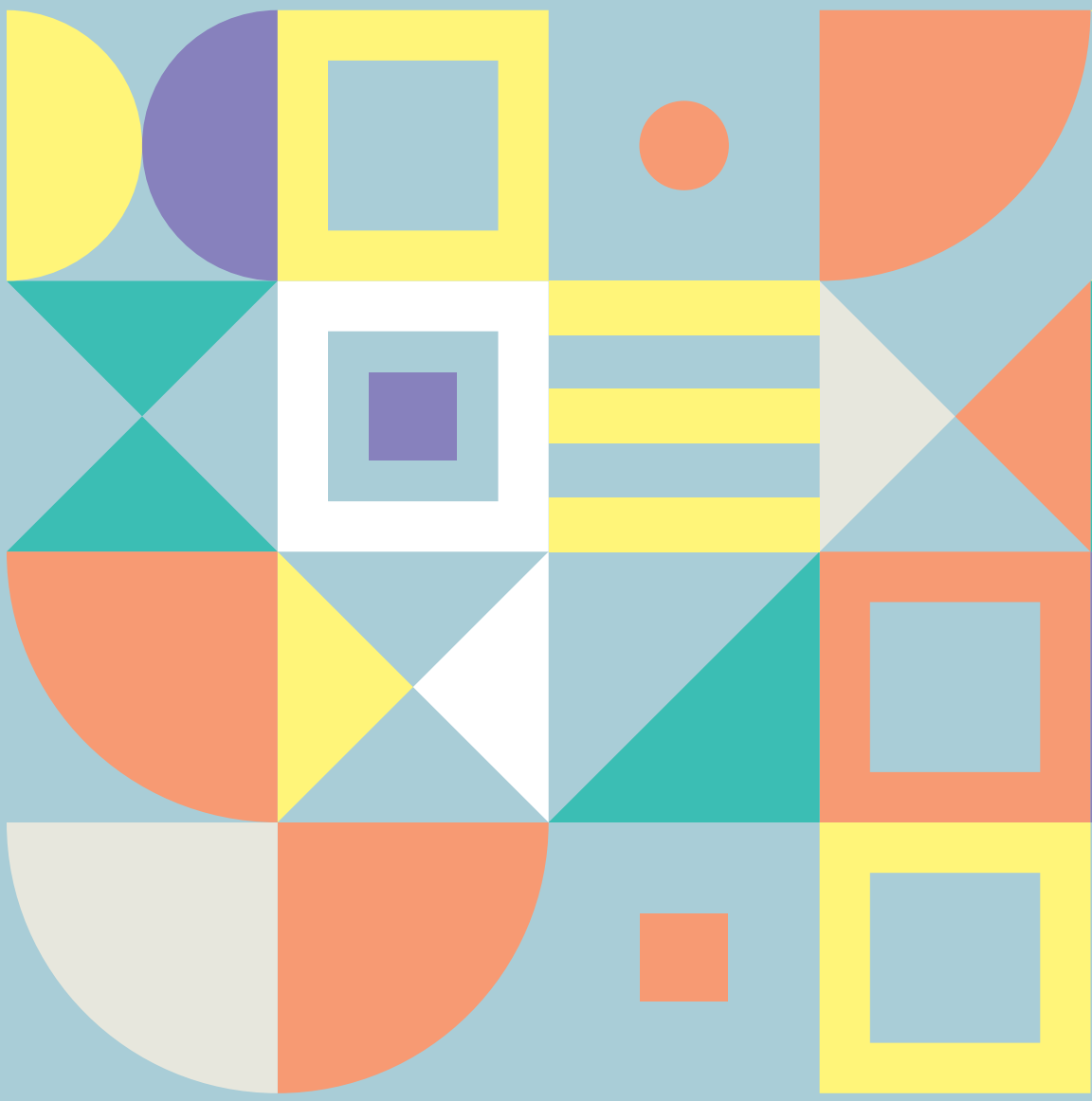
Autistic mother to two autistic girls

BOX 5. NEGATIVE SCHOOL EXPERIENCES IMPACT THE WHOLE FAMILY

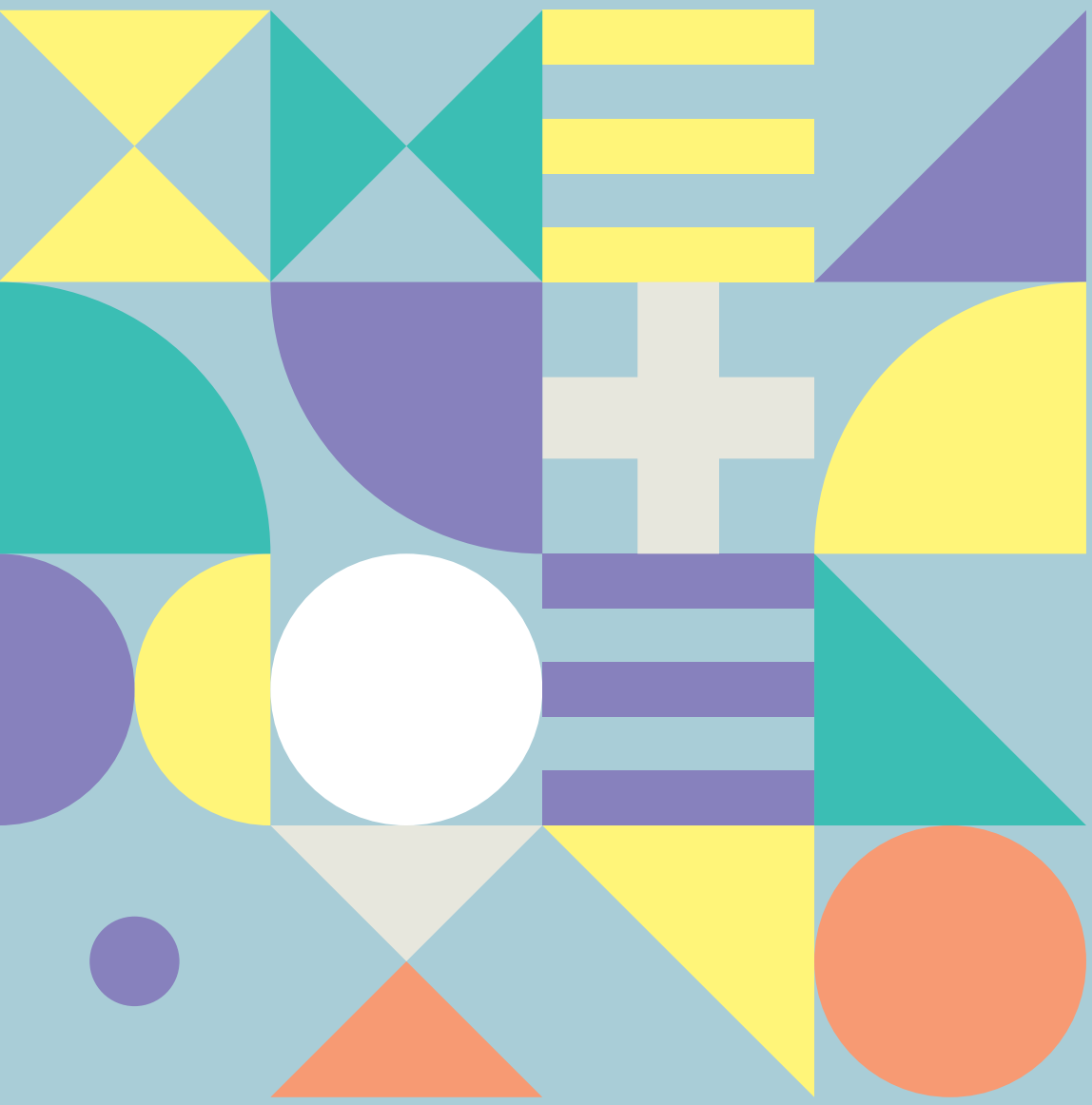
Parents sometimes reported experiencing blame and discrimination, which subsequently left them feeling broken and traumatised by the school system.

The trauma was so deeply embedded in some parents that the thought of just entering school grounds would trigger an array of negative emotions and physical sensations. Autistic mother *Cherie who has two autistic daughters, Addison (14 years old, Year 7) and Grace (11 years old, Grade 5), explained the challenges and pitfalls that led to home-schooling for her family. Cherie's experience was coloured by the fact that she was a trained teacher: "I'm a teacher myself which I think is why it's been such a traumatic experience. Because I couldn't understand why teachers wouldn't listen to me as a parent and as a colleague". The difficulties with the school setting were not immediately evident but Cherie felt things change in Addison's first year of school: "I've always said, the day my daughter went to school was the day I lost my daughter. Her personality completely changed. She became exceptionally withdrawn. She was a very happy, bubbly, outgoing little girl who would run up to people on the playground, grab their hand and just start playing with them." Cherie went on to explain: "But that all changed in school. So, she became very withdrawn. A lot of sensory stuff." Challenges came to the surface in Grade 2, when "they put her in with some exceptionally volatile kids in an open classroom. Oh, yes, that's really good for a kid on the spectrum [sarcasm]. And her sensory needs went through [the roof]. And then she started to school refuse". This was a period of significant change for the family. Cherie had to make life-changing decisions: "I'd given up my job. I'd quit due to mental health. Because I couldn't cope with Addison school refusing". Cherie's husband was often away for work during this period, which made it even "harder". The relationship with the classroom teacher also added further stress, "she yelled at Addison within the first week [of Grade 2] because she didn't understand something. Addison shut down, full on shut down". When Cherie went into the school after this episode, the teacher claimed she knew about autism, stating she'd "done the autism conference" and "courses". But what Cherie could see was that she knew little about the diversity of autism. She said to the teacher: "If you know one person with autism, you know one person. I said, we're all individuals". The school then "started to accuse me [Cherie] about my parenting. That they knew Addison better than me". Cherie felt that she wasn't being heard and her experiential expertise as an autistic parent wasn't valued. As she put it, "the school just didn't know how to manage with compassion". So, she made the decision to home-school both girls when Addison was towards the end of Grade 3 because she was school refusing again and falling behind, and similar issues were starting to surface with Grace. These challenging school experiences have left Cherie with "full blown heart palpitations at the thought of having to deal with teaching staff and school and the whole system" ever again.

* Names have been changed to respect the privacy of our participants.



3. FOUNDATIONS FOR THE FUTURE



FOUNDATIONS FOR THE FUTURE

The autistic parent participants in this study highlighted the often-challenging interactions they faced with schools and school staff. Fortunately, however, parents also reported some instances of positive home-school partnerships.

Such partnerships were perceived to be successful when autistic parents were listened to – and heard: "when it's going well, it's because they've listened to me, so then I feel like I have a say in what happens when my child is not with me".

Successful home-school partnerships went beyond being heard by school professionals. Autistic parents reported feeling most validated when schools acknowledged their knowledge and insight and valued their experiential expertise: "when they [schools] actually see me as a viable expert on my child, not the helicopter mother who is annoying everyone". Parents who felt a sense of inclusion and appreciation from the school, had far richer and more nurturing experiences overall: "that's when it works, when I become part of the discussion about how my child is supported". This sense of inclusion was also reportedly felt by their autistic children: "He felt like he was listened to, it was an environment that enabled him to be successful" (see also Box 6).

"He's supposed to be there full-time. So, technically, he is there full-time, but we have a bit of a working arrangement with the school, that if he's not coping, that he comes home before things escalate too much. And a lot of the rationale behind that being that we want school to be a positive environment for him, so we'd rather not leave him there distressed".

Autistic mother of 7-year-old autistic son and 5-year-old autistic daughter

Autistic parents further described the importance of flexibility and how it can come in many forms – from flexibility in learning and teaching approaches to flexibility in settings. Our participants' autistic children were attending school in various forms, ranging from attending for half days, a combination of home-schooling and traditional school settings, to part-time attendance. Parents expressed the view that this flexibility was important, and schools that offered flexible arrangements were perceived also to develop better relationships with parents.

Autistic parents also emphasised that positive partnerships between home and schools are built on reciprocity, sharing of knowledge, expertise and problem solving together.

One autistic parent recounted that the response from the school principal, that "we will always make it work, we will always find a way" had a positive impact on her trust and relationship with the school: "I feel that, at the school, there's always a path forward no matter what". Encouragingly, they described how "even through failures, we've found a way to succeed", demonstrating perseverance, determination, and resilience. They reported often feeling that their confidence had grown over time, although such growth was not easily won: "it takes a long time to learn to be your child's best advocate and to learn how you can speak up".

BOX 6. THE IMPORTANCE OF FORMING TRUE CONNECTIONS

For our autistic parents who reported positive school experiences, these were synonymous with caring relationships between autistic parents, their children and their teachers.

One autistic parent, *Chrissy, who is mother to 6-year-old Jessie, explained the importance of connection between her daughter and her teacher. Jessie attends a small independent school. Chrissy spoke to us about what led to positive experiences with her daughter's school. As a school "they obviously still follow the education framework, but that is not the priority, in terms of reporting and one size fits all and sticking to that. They're so focussed on connection". She described how the teaching staff are "genuinely warm" but also "they are really flexible" and willing to listen to the parent. Chrissy explained how she "just had to help them in seeing that it was better to just have her [Jessie] wanting to come here, and knowing that she could leave, than trying to encourage her to come all the time, and that leading to burning out and her not wanting to go at all". Forming connections and positive relationships was also built on open and authentic communication. This school was doing that right from the beginning: "They are great at communicating straight away. Like, I knew if she [Jessie] was upset or something had happened because I'd see the principal's number come up and she'd just talk me through what happened and how they supported her". And if the school didn't know what to do, they asked, and were willing to listen. Chrissy said she just had to "say what we need, which they're very open to". Ultimately, she felt that successful home-school partnerships are built on mutual respect and compassion. When "you know how much they [schools/ teachers] care about the children", it makes the parent's life and their journey with schools so much easier.

* Names have been changed to respect the privacy of our participants.

SUMMARY AND RECOMMENDATIONS

Reflecting on these ideas and the foundations for the future, our participants, together with our Autistic Parent Advisory Group members, made many suggestions about how life could be improved for their children, themselves, and other families. These can be summarised as follows.

To foster successful partnerships between home and school environments, we believe that schools, families, educators, and policymakers should commit to a range of key ways forward:

1. **Developing shared goals:** The foundation of empathetic and respectful communication and collaboration between parents, students, and schools lies in having a common goal, and accepting that each party can bring valuable contributions to fulfil that common goal. As one respondent put it: "If you're a teacher, you come to teaching, because you have the best interests of children at heart. If you rise up in the ranks and you're a principal, you come because you've the best interests of kids at heart, and if you're a parent, I think it's a worthy position to think that most parents have the best interests of their children at heart. So, we all have a common goal".
2. **Fostering empathy and valuing individual expertise:** Valuing individual expertise requires developing the skills and habits of empathy. Parents should aim to understand the stresses and difficulties confronting teachers but, critically, teachers must reflect this same empathy and compassion.
3. **Learning to communicate effectively with mutual respect:** Parents also wanted teachers to get to know their children and recommended the use of technology and other communications aids to assist this process. One parent suggested keeping "an electronic record of my children's experience at school, so a teacher could easily access it and I could access it. It would be a one stop shop rather than some arbitrary folder in some arbitrary desk. There'd be some really strengths-based information about my children and their capacities and their challenges, and the strategies that were involved in how that was managed. And if that was done every year, there'd actually be a really beautiful record of how my child has developed their own capacity over time, and there'd be knowledge about what had worked that someone can use".
4. **Appreciating diversity:** While everyone recognises that it may not always be possible to cater to individual students, it is also clear that many of the best strategies designed to support autistic children can benefit many students. At the same time, an acceptance of diversity is also crucial, including acknowledging that standard approaches to education are often an inappropriate way of helping autistic students thrive in the classroom as "round pegs don't fit in square holes". Teaching an understanding of autism, utilising lived experience in teacher training, where autistic adults promote further knowledge and awareness could assist this process.

Helping schools identify what they are already doing well, and then examining what can be done differently by looking through an autism lens will help to forge more effective partnerships between home and school that contribute to the successes of autistic students. Early years education is considered especially important in setting autistic families on a path to success.

5. **Flexibility:** Responding to diversity involves developing more flexible approaches to teaching and learning: "I would love it if there was just more flexibility in how things are done". As another parent described: "My ideal partnership between a school would be responsive to change and accepting of change. And being agile enough to accept that change has happened, and we need to do something different, and then have the resources to respond to that new need."

6. **Equipping parents with the skills required for self-advocacy:** Given the critical role of advocacy, supporting autistic parents to develop the skills and the confidence required to "speak up" when needed could be a vital addition to broader programmes designed to support parents.

7. **Creating a sense of agency for autistic children:** In accordance with much of the feedback from families, autistic parents want their children to be able to communicate their needs and desires and stand up for what they believe in. However, children's thoughts are all too often missed in school policymaking and planning. Providing autistic students with the opportunity to express their needs in a safe and secure environment is crucial. Parents suggested asking the child what they want and what would help them and offering a space, such as a forum/Q&A, to discuss this in more detail.

8. **Supporting smaller settings, classrooms, and schools:** Children and parents both emphasised the importance of smaller communities. One said: "I would say that we've got the ideal partnership with my children's school, the primary school that both kids went to in the end. It's a really small community. I think that helps. Everyone knows everyone." The physical atmosphere can have a profound effect on autistic students' ability to engage and learn.

9. **Generating greater awareness of sensory differences:** Similarly, more consideration needs to be given to the sensory elements of classrooms and other teaching and learning spaces: "I think schools overall should be smaller. More like a bit of a village atmosphere. I don't think that huge… If you speak to any OT, they will tell you schools are overly bright. It's visually overstimulating. It's too loud. An OT will say that and that's for the so-called normal child. And they're dirty and they're very cluttered. The physical learning environment is not helping anyone".

10. **Supporting a neurodiverse workforce:** Having access to neurodivergent teachers, whether this be a pool of teachers or individual staff members, so that education about diversity and autism happens from within the school setting can be vital. Developing a neurodiverse workforce where the expertise of autistic parents and teachers is utilised is a crucial next step in creating an education environment in which autistic students are more likely to flourish.

11. **Celebrating the role of student wellbeing:** Student wellbeing can act as a conduit between parents and school and students, therefore a positive partnership between parents and the wellbeing team will be beneficial.

12. **Being inclusive:** All parties should be included when problem solving and developing solutions and strategies rather than working in isolation. Include teachers in the solution when educating about neurodiversity. Develop a greater understanding in schools that "What works well for autistic people and other people with learning disabilities works well for everyone. And I think we need to shift the narrative to that. Instead of making these accommodations they should just be the standard because they work well for everyone". Practising inclusion, promoting the feeling of being included, and creating a sense of belonging for students will be critical [33, 34].
13. **Increasing the ratio of support staff and psychologists to students:** Given the impact of poor relationships and negative school experiences on autistic students and autistic parents' mental health it is critical that supports are available in schools to promote wellbeing and support during difficult times. Unfortunately, when ratios in schools increase and resources do not match these increases, the education system "buckles under the weight" and schools resort to compliance and meeting students' basic needs rather than striving to meet individual needs and to develop meaningful and respectful relationships. Therefore more equity across education settings is necessary in staff to student ratio, particularly in supports such as psychology [35].

Based on these ways forward, we make the following five concrete recommendations for schools and education departments:

1. **Education settings must foster a sense of belonging** for all families, regardless of diversity including disability. Mutual respect is essential to forming effective partnerships. Schools need to create a community which values and accepts diversity acknowledging and celebrating it. Each school must develop strategies of inclusion and belonging which should be made publicly available and evaluated in collaboration with representatives of disabled parents and students at regular intervals.
2. **Educators should demonstrate a willingness and openness to learning** while acknowledging what they do and don't know and valuing the input of families and autistic students. They need to be comfortable exploring both their strengths and weaknesses. This openness is fundamental to any relationship, especially in a learning environment such as school. This should be an integral part of teacher training and continuing professional learning.
3. **Providing agreed-upon flexibility in timetabling and other related expectations where possible** can have a positive effect on autistic families' engagement, wellbeing and importantly the ability for autistic children to transition into a successful school setting. Asking questions of the family around what would help is vital, but it is also vital for school leaders to accommodate autistic students by adopting flexible and inclusive practices in relation to a range of issues including small group learning, the provision of quiet spaces, uniform options, and flexible attendance.
4. **Fostering a safe and secure school environment** is essential for all students but especially autistic ones. A safe environment can take many forms, but for autistic children and their families, this includes a non-judgemental setting. A setting where children's confidence is developed, and incidental conversations occur frequently to build respect and promote empathy between teachers and students and between parents and teachers.
5. By regularly asking autistic parents to share their insights with teachers and school leaders, **educators should begin to value the experiential expertise of autistic parents** while at the same time learning about what helps their individual autistic students. Autistic parents often "have a little bit more insight than the average mother might, with an autistic kid" and this knowledge needs to be harnessed.

These concrete recommendations should help educators and policymakers move a step closer towards improving relationships between autistic parents and schools and, ultimately, to enhancing the educational experiences of the autistic children and young people they serve.

APPENDIX

Demographics of Autistic Families involved in the Study (n=31 parents, n=59 children)

	N (%)/M (range, SD)
PARENT CHARACTERISTICS	
Gender	
Female	31 (100%)
Male	0
Age (years)	44.6 (34-59, 6.1)
Average age at diagnosis (years)	41.2 (34-50, 5.4)
Self-identified	6 (19.4%)
Number of autistic children	
1	10 (32.3%)
2	15 (48.4%)
3	5 (16.1%)
4	1 (3.2%)
Other diagnosed conditions	
Mental health/Neurodevelopmental conditions	
Depression	22 (71.0%)
Anxiety Disorder	20 (64.5%)
Post-Traumatic Stress Disorder	7 (22.6%)
ADHD/ADD	6 (19.4%)
Eating Disorder	6 (19.4%)
Physical health conditions	
Gastrointestinal issues	12 (38.7%)
Chronic pain	8 (25.8%)
Sleep issues	8 (25.8%)
Obesity	7 (22.6%)
Autoimmune condition	7 (22.6%)
Regular medication	
Yes	28 (90.3%)
No	3 (9.7%)
Employment Status	
Part-time employment	10 (32.3%)
Self-employed	7 (22.6%)
Homemaker/full-time parent	7 (22.6%)
Full-time employment	4 (12.9%)
Unable to work due to disability	2 (6.5%)
Studying full-time	1 (3.2%)
Education Level	
University Degree	20 (64.5%)
TAFE Certificate/Diploma	8 (25.8%)
Trade/Technical Certificate	1 (3.2%)
Completed High School	1 (3.2%)
Started High School	1 (3.2%)

	N (%)/M (range, SD)
NDIS plan in place	
No	21 (67.7%)
Yes	9 (29%)
Pending approval	1 (3.2%)
Household Income	
$1 to $25,000 per year ($1-381 per week)	6 (19.4%)
$25,001 to $50,000 per year ($482-962 per week)	7 (22.6%)
$50,001 to $78,000 per year ($963-1,500 per week)	3 (9.7%)
$78,001 to $104,000 per year ($1,501-2,000 per week)	6 (19.4%)
$104,001 or more per year (more than $2,001 per week)	2 (6.5%)
Missing	7 (22.6%)
Country of Birth	
Australia	27 (87.1%)
UK	3 (9.7%)
Norway	1 (3.2%)
Identified Culture	
White	20 (64.4%)
Mixed background	2 (6.5%)
None	2 (6.5%)
Missing	7 (22.6%)
Languages Spoken at Home	
English	29 (93.5%)
English and Norwegian	1 (3.2%)
English and Fijian	1 (3.2%)
CHILD CHARACTERISTICS	
Gender	
Male	30
Female	23
Non-Binary	3
Missing	3
Age	12 (5-30, 4.4)
NDIS plan in place	
Yes	46 (78%)
No	13 (22%)
Type of Education Setting	
Home-schooling	26 (44.0%)
Mainstream – with extra support	21 (35.6%)
Mainstream – with no extra support	7 (11.9%)
Virtual school/online school	3 (5.1%)
Disability specific	1 (1.7%)
Other	1 (1.7%)
Educational Level	
Preschool	5 (8.5%)
Primary school	13 (22.0%)
Secondary school	16 (27.1%
Home-schooling	21 (35.6%)
Missing	4 (6.8%)

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