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The Community Foundation

Supporting Parents of Children with Autism

Findings from Verbal's research and advocacy work exploring care needs, educational access and more for parents of children with diagnosed or suspected autism

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Executive Summary

This project has been supported by the Community Foundation for Northern Ireland through the Partners for Social Care and Health Improvement Fund. We conducted a research and advocacy project to understand the experiences of parents of children with diagnosed or suspected Autism Spectrum Disorder (ASD) in relation to their child's diagnosis, care needs, educational access and their own personal wellbeing.

Recent figures suggest that parents of neurodiverse children are struggling in a range of ways. Securing an appropriate school placement can be a challenge due to high demands and lack of resources, and these placements may only be secured through a diagnosis which can have significant delays. Parents can also struggle to access care support and additional services due to factors such as travel distance and high service demand.

We conducted a mixed-methods research project, collecting both online survey data and conducting interviews, focus groups and consultations with both parents of children with diagnosed or suspected ASD and service providers. We asked questions relating to their child's diagnostic journey, care access, school access, and the parent's own wellbeing.

Over half of parents waited at least three years from referral for their child's diagnosis, with almost three quarters of parents feeling unsatisfied with this wait time. Nearly a quarter of parents paid for private assessments for their child with an average cost of over £2,000 per parent; some parents required loans to cover these costs. 81% of children with a diagnosis did not gain access to additional support following their diagnosis. Parents reported struggles with the diagnostic process such as not being referred for an assessment and parents not being listened to about their child's symptoms.

Nearly three quarters of children in mainstream school did not have a classroom assistant due to a lack of resources and funding within the school. Several parents reported how their child would struggle in school as they would sit unsupported in silence as resources were dedicated to managing disruptive behaviour. Satisfaction with school support was lowest within mainstream schools (28%) and highest within special schools (90%). Only 14% of parents could confirm that their child's teacher had completed Autism Awareness Training, with parents feeling that teachers' understanding of ASD varied too greatly. Parents described how their child was bullied and ostracised in school and how this could harm the child's mental wellbeing.

83% of parents did not have access to ASD-friendly support resources within their community and would cite distance, lack of transport and lack of childminding as barriers to accessing support. Parents would rely on charity and voluntary support, but funding cuts had reduced

the support they receive and would even lead to parents giving up their career to care for their child. The abundance of challenges experienced by parents combined with lack of support resulted in a very high percentage of parents often feeling overwhelmed, anxious and unable to take a break for themselves.

From these findings we have created a list of recommendations on how best to support children with diagnosed or suspected ASD and their parents. These recommendations include: increased use of Autism Awareness Training; improved understanding of neurodiversity in schools; support for more age groups; increased and extended support for the voluntary sector; more child-centered assessments; support and resources for parental wellbeing; improved understanding of gender differences in neurodiversity; and improved understanding of masking.

Introduction

The prevalence of children diagnosed with Autism Spectrum Disorder (ASD) in Northern Ireland has continued to rise since 2008, increasing from 1.2% in 2008 to 4.7% in 2022 (DoH, 2022). This increase has coincided with an increase in children being placed in special education. Between 2015 and 2022, the number of pupils attending special schools increased by 31%, while the number of pupils attending mainstream schools with specialist provision increased by 54% (EA, 2022).

While an increasing number of children are accessing special education, recent figures indicate that children are falling through an education gap. In 2023, nearly 400 children with a statement of Special Education Needs (SEN) did not secure a place within a school (Lynch, 2023). While over 1000 extra school placements for children with additional needs are required for the 2024-2025 academic year, over 130 mainstream schools have refused to provide specialist provision (Meredith, 2023a; Meredith, 2024). Children from rural locations may be more likely to fall through this education gap as 5% of special schools and 13% of mainstream schools with specialist provision are located within rural settings.

The school period can be challenging for parents of children with ASD. A third of parents in contact with Autism NI have children who are placed on a reduced school timetable (Graham, 2022), causing them to leave work and feel as if they are "*constantly running back and forth*" (Meredith, 2023b). Parents also reported teachers not completing Autism Awareness Training or understanding neurodiverse children, leading to their child feeling frustrated and exhausted at home. A lack of training, low support and reduced timetables have led to more parents choosing to educate their child at home (Graham, 2022).

These factors in tandem suggest that both neurodiverse children and their parents are struggling in a range of ways, including lack of support, difficulties with school and poor wellbeing. However, even the process of receiving a diagnosis of ASD can be a challenge for parents and their children due to lengthy waiting lists (Balfour, 2024).

We conducted a research and advocacy project to understand the experiences of parents of children with diagnosed or suspected ASD. This project has been supported by the Community Foundation for Northern Ireland through the Partners for Social Care and Health Improvement Fund. The aim of this project was to speak to parents of children with diagnosed or suspected ASD to understand their experiences in relation to their diagnostic journey, the level of support they have access to, their child's school experience and their own parental wellbeing. These findings were used to create evidence-based recommendations to support neurodiverse children and their parents.

Methods

Project Design

The project was a mixed-methods research project, gathering insights from parents using both quantitative and qualitative data.

We gathered quantitative data using an electronic questionnaire delivered via SurveyMonkey. This survey was designed to capture parental insights on four key subject areas:

Parents' experience of the diagnostic process for their child, including whether their child had not been referred for an ASD assessment when requested.

Sources of care and support available to the parent and their child/ren, including support specifically for neurodiverse children.

Parents' experience of seeking an appropriate school place for their child, the support available to their child at school, and the impact of factors such as reduced school timetables on the parent.

The mental health and wellbeing of parents.

To be mindful of the time of busy parents, we designed the survey in a way that funnelled parents towards the questions most relevant to them. For example, a parent of a child currently awaiting an ASD assessment would view questions relevant to the assessment process and would not be asked to answer questions for parents of children with an ASD diagnosis.

Parents were asked demographic questions such as their gender and their postcode. Postcode information was used to identify whether parents lived in an urban or rural location to gauge access to support.

Qualitative data were collected in a variety of ways. For parents, a focus group/interview schedule was designed that asked parents further questions about access to and distance from support services, their experience of securing a school placement for their child and more. To gain a range of experiences and perspectives, we also conducted consultations with service providers who deliver services for children with diagnosed or suspected ASD.

Both the survey and qualitative data collection tools were designed using coproduction, getting feedback from parents and those who have experience of the diagnostic process on the most suitable and relevant questions to ask parents. Information on parental wellbeing was collected using the Carer Well-Being and Support Questionnaire (Quirk et al., 2012), a reliable and valid data collection tool.

Procedure

This project was conducted between September 2023 to August 2024. Between September 2023 to January 2024, the initial data collection tools were designed by the research team and sent to parental support groups and those with experience of the diagnostic process for feedback. From this feedback, questions were added such as the quality of the special school, further questions on a child's reduced school timetable, further additions to sources of support and more. While testing these resources, we also took the opportunity to speak with the parents about their own personal experiences.

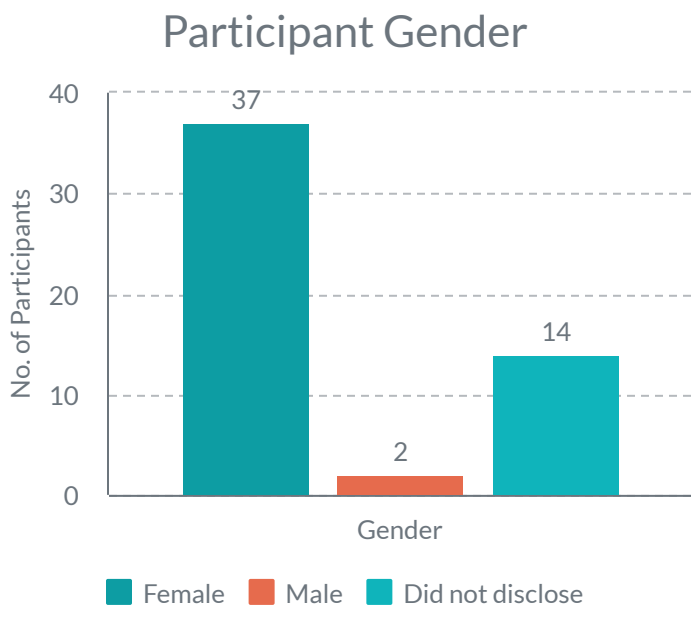
During the development of the data collection tools, the research team also conducted consultations with a wide range of service providers tailored towards neurodiversity, including special school staff and charity workers providing ASD services for young people.

The online questionnaire (along with its branching pathways) was designed in January 2024 and launched in February 2024. This survey was frequently shared on Verbal's social media pages and was generously shared by project beneficiaries such as neurodiversity services and parent support groups. After completing this survey, parents had the option to provide their email address if they would like to speak to a member of the research team about their experiences. These interviews could be conducted online or offline based on parental preference.

Including focus groups, consultations, online survey respondents and parent interviews, we captured data from a total of 125 participants, including 102 parents and 23 service providers. The findings of this data collection are detailed below.

Online Survey: Demographics

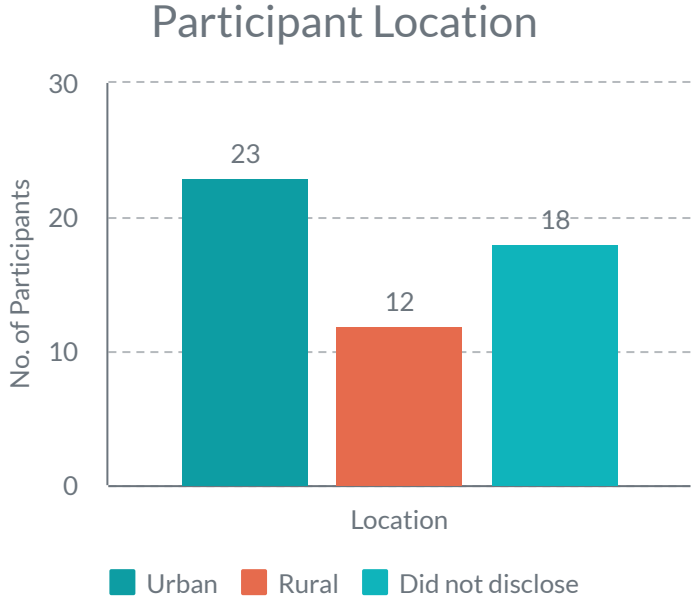
A total of 53 parents completed our online survey. Please note that as the survey showed parents the questions most relevant to their personal circumstances (i.e. parents of a child with a diagnosis and parents of a child awaiting a diagnosis receiving separate questions), not all questions were completed by all 53 parents. Parents were also reassured that they did not have to answer any questions that they did not feel comfortable answering.



The majority of parents who disclosed their gender were female (70%) with two males completing the survey (5%).

14 parents chose not to disclose their gender when completing the survey (25%).

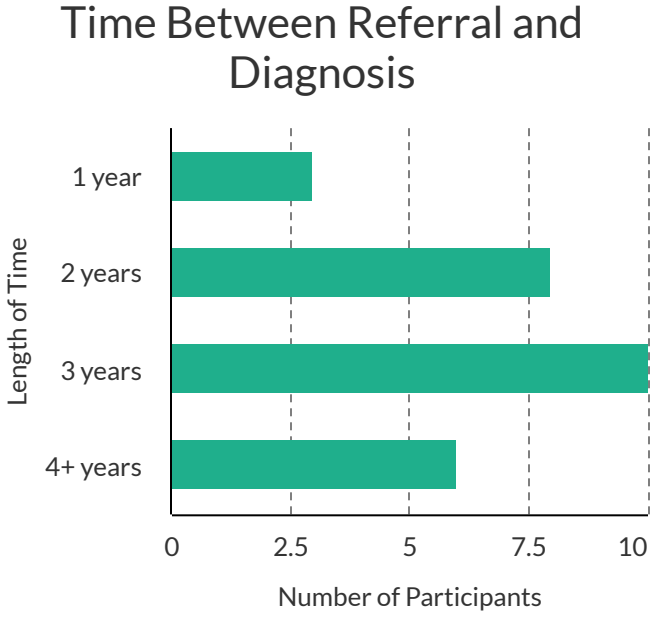
We asked parents to provide their postcodes to identify whether they lived in an urban or rural location. Of the parents who disclosed their postcode, nearly twice as many parents lived in urban locations (43%) compared to rural locations (23%); 18 parents chose not to disclose their postcode (34%).



Results: Diagnostic Process

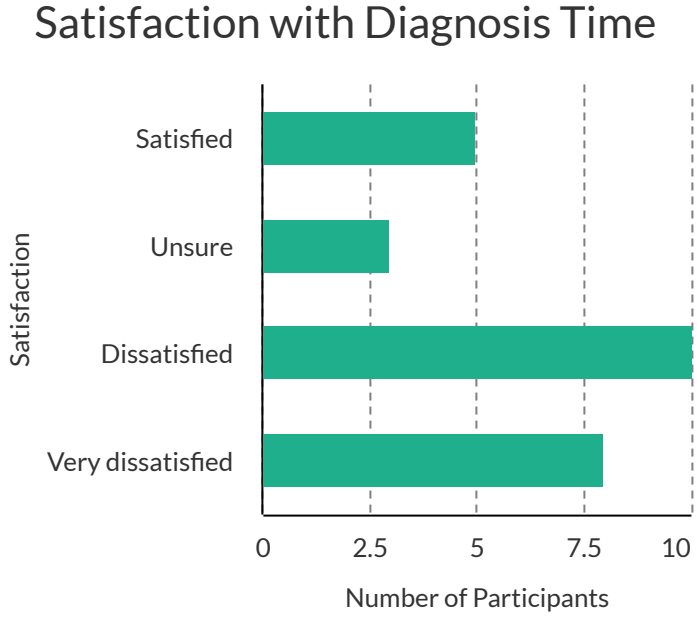
We asked parents to describe the diagnostic status of their child. 31 parents had a child that was currently diagnosed with ASD (61%), 12 parents had a child that was currently being assessed for ASD (24%), and 8 parents had a child who has not been referred for an ASD assessment (15%). Each category of parent was asked separate questions about their experiences that will be detailed separately below.

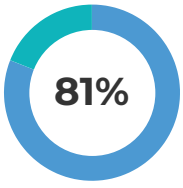
Parents of Children with ASD Diagnosis



Parents were asked to recall the length of time between their child's referral for an ASD assessment and receiving their diagnosis. **Over half of parents (59%)** reported waiting at least three years for their child's diagnosis, with **nearly a quarter (22%) of parents** waiting four or more years.

When asked how satisfied they were with the length of their child's diagnostic journey, **71% of parents** reported a degree of dissatisfaction, with **nearly a third of parents (30%)** reporting that they were **very dissatisfied.**

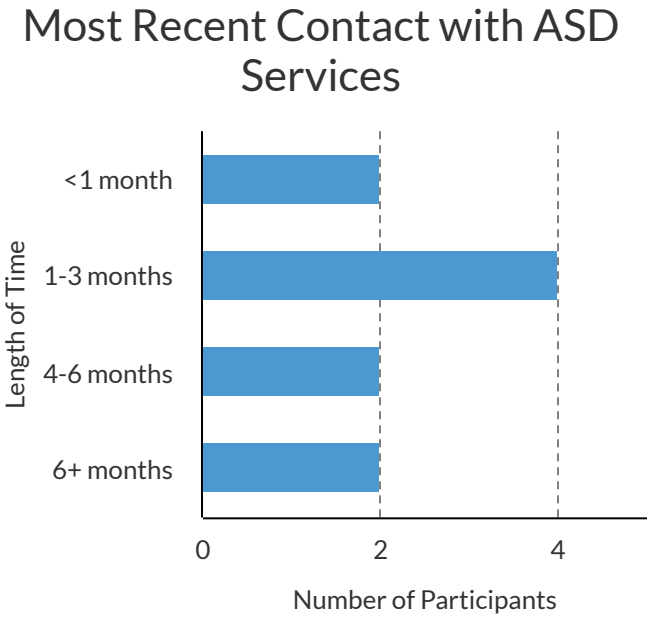




of children did not receive extra support following diagnosis

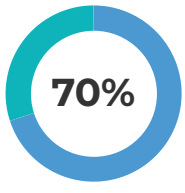
We asked parents if their child's diagnosis had provided them access to additional care and support such as art therapy or respite services. **81% of parents reported that their child's diagnosis did not provide any avenues for further help and support**. Some parents reported that their child's diagnosis allowed them to access extra support such as courses, speech therapy, occupational therapy, further appointments with CAMHS, direct payments towards a support service, and access to a school with SEN provisions.

Parents of Children Awaiting ASD Assessment



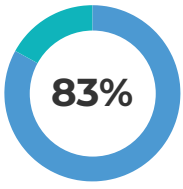
For parents whose child is still undergoing the assessment process, we asked when they had last heard from the appropriate ASD services. **40% of parents** had not received contact from ASD services in at least four months, with **20% of parents waiting at least six months** for contact or updates.

We asked parents if they currently had access to any support services while their child was being assessed. **70% of parents** told us they had no access to support, while 30% of parents told us that they currently had access to an Early Intervention Service, parent-child support sessions and CAMHS talking therapies.



of parents did not have access to support while awaiting assessment

Parents of Children Without Referral



of parents did not have access to support for their child

Parents of children who had not been referred for an ASD assessment were asked if their child currently had access to any support for their suspected neurodiversity. **83% of parents reported no**, with one parent reporting that their child had access to music therapy.

Private Consultations

All parents, irrespective of diagnostic status, were asked if they had ever sought private consultations for their child's neurodiversity.

Nearly a quarter of parents (24%) said that they had paid for private consultations and appointments for their child. We asked these parents, if comfortable, to share how much they had paid in consultation fees for their child. **All but one parent had paid fees in the thousands for their child**, for which we calculated **an average cost of £2,063 per parent**. Some parents shared in this survey their regrets for not being able to afford private consultations for their child, leaving comments such as "*if I could afford to I would*".

A parent we spoke to about their private diagnosis described how they had to take out a private loan to be able to afford the private assessment. While this was costly for them, they said how it "*was never a problem*" as they were willing to do whatever they could to support their child.

Insight from Parents: Diagnostic Process

Through a combination of interviews, focus groups, survey responses and consultations, we identified a range of insights from parents on what they are experiencing and struggling with regarding the diagnostic process for ASD. These include:

Length of Diagnostic Process

My child was on the waiting list for 3 years...we were told it would still be another 2 years before our daughter would be seen. We then decided to take her privately.

The most common concern expressed by parents was the length of the diagnostic process and how long the process was currently taking them. Parents described the waiting time for a diagnosis as "*ridiculous*", to the extent that years of waiting caused parents to seek a private diagnosis.

One aspect of the length that frustrated parents was the lack of continuity between health workers, as one parent describes: "*It takes far too long from beginning to end and you are seen by so many different people you end up explaining the same thing over and over*". While parents were frustrated at the length of the process, they were still sympathetic towards "*understaffed and overworked*" health services.

The length of the diagnostic process can also be impacted by movement between healthcare services. A parent detailed how they had waited for three years for a diagnosis in England, yet upon moving to Northern Ireland their progress could not be transferred and they had to start the process again from the beginning, leading to them feeling "*neglected*".

I've just been like a dog with a bone. I've just constantly been calling, and they probably absolutely hate me, but I don't care. It's your child.

Lack of Information and Support

I believed [an ASD referral] would happen through the school system and have just been informed it is only available through the GP.

I felt unsupported as where to reach out for advice.

Parents expressed concerns about the level of information and support they received at different stages of the diagnostic journey. Parents whose child has not yet been referred to ASD services described a lack of clarity on who was responsible for the referral process. A parent described how they had waited a year for school support only to be told to seek a GP referral, while another parent described how the "*GP said they couldn't refer and school said [the] waiting list is too long so no one will take responsibility*".

Parents whose child received a diagnosis described how "*there is very little opportunity for further in-depth discussion*" about their child's diagnosis and how "*you are left to get on with it*". While awaiting a diagnosis for ASD, it can be "*very frustrating and hard to know who to talk to*" for information and support.

The wait time and follow up care are both entirely unfit for purpose and a massive disservice to our children.

The Fear of 'Labelling'

I was delayed by CAMHS for years as they did not want to 'put a label' on my daughter and by the time they decided that they did want to, she had already suffered heavily.

Multiple parents described how health services either delayed or were hesitant to begin the referral process for an ASD assessment due to fears surrounding 'labelling' the child. When a parent spoke to a social worker about seeking a diagnosis of ASD, they were asked "*Why do you want to label [your child]?*". A parent whose child was diagnosed with ASD described how "*she had already suffered heavily*" between the period of fears surrounding 'labelling' and her referral for assessment.

While a diagnosis of ASD can provide avenues for extra support, the label was also described by parents as something that could validate children and help them to understand their neurodiversity.

[The lack of referral is] impacting her mental health and education. My child needs validation on why she feels different and struggles to fit in the world.

Gender Differences

> **My son's referral and diagnosis happened very quickly...whereas for my daughter we have been on the waiting list for 4 years. We have lots of problems but as she has masked, we haven't had our first appointment yet.**

Several parents we spoke to told us about their experiences taking more than one child through the diagnostic process. In these conversations, parents would share how they "*don't feel [the process] is tailored to girls as much as it is boys*". Parents would describe how their daughter was "*completely overlooked*" and on waiting lists far longer than their son/s. One parent attributed this to how their daughter is good at 'masking' their neurodiversity, referring to the act of masking neurodivergent traits by mirroring the behaviour of others. Another parent described how private assessments were "*more thorough and in-depth*" when it came to exploring the ASD assessment for their daughter.

The Role of 'Masking'

> **When they're outside of their familiar environment, you're seeing the masked child. [My child] is unrecognisable when you see him at those appointments, like he's a totally different child. When he comes home, that's him.**

As described in the previous theme, neurodiverse children may 'mask' their true feelings or behaviours in a situation by mimicking the behaviours of those around them. Parents were concerned that the combination of their child masking and the structure of ASD assessments either would or had made the diagnostic process more challenging for them. A parent of a child who had not been referred for an ASD assessment described the range of symptoms their child exhibits, including "*very strict routines and ways of doing things*", "*[getting] very upset if there are any changes*", "*repetitive motions, echolalia and uncontrollable emotions*" and more. However, the child was not referred for an assessment as they were "*verbal, sociable and not showing any significant delays*". Parents during a focus group expressed their worries about assessments taking place outside of the child's familiar environment as that was when assessors were most likely to see "*the masked child*" who is "*totally different*".

The Role of the Parent

I wasn't being listened to. I thought "I'm being so stupid here".

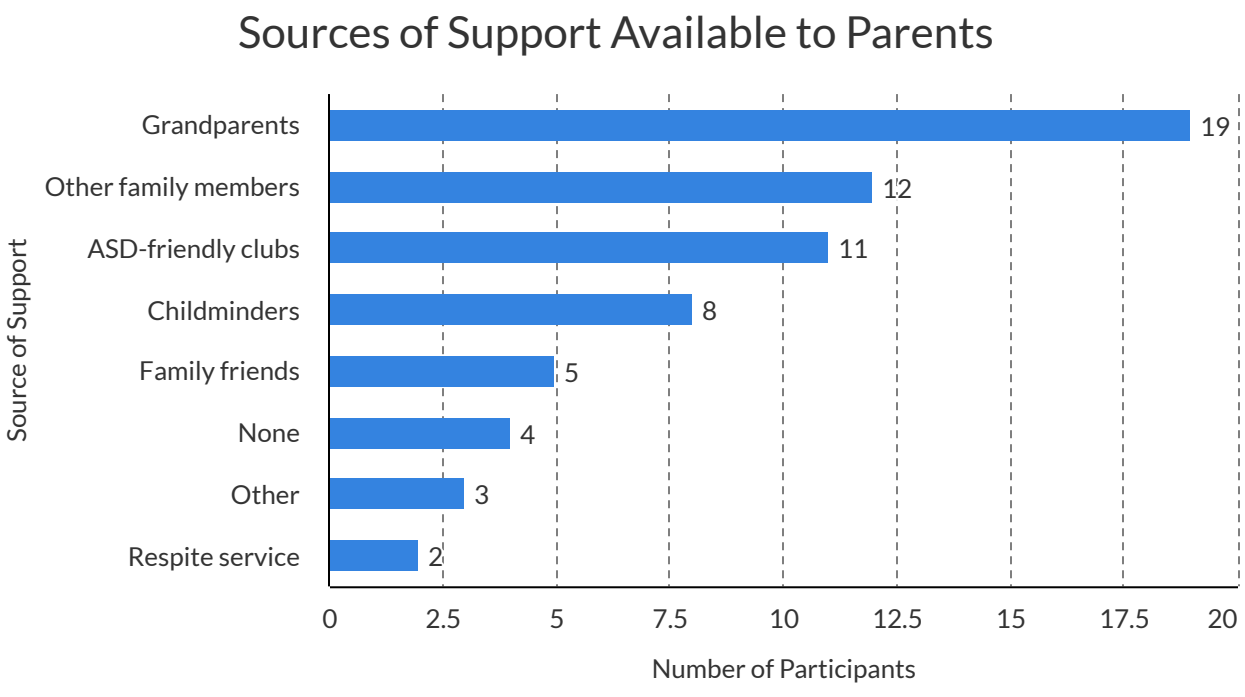
An additional theme that emerged from talking to parents was how symptoms of neurodiversity were being attributed to the parents themselves. This could happen in a range of ways, such as how a parent speaking to a health visitor about suspected symptoms of ASD in their child led to the health visitor suggesting that she was experiencing postnatal depression. The parent doubted themselves and felt "*so stupid*" as a result, yet the child later went on to be diagnosed with ASD.

Parents also felt that their concerns were being misattributed to COVID lockdowns, despite parents feeling that "*there was a lot more with [their child] going on than just social anxiety or social disconnect*". One parent detailed how multiple attempts to get support for their child would lead to suggestions such as "*Do a parenting programme*" or to take a class on bedtime routines; this child has since been diagnosed with ASD.

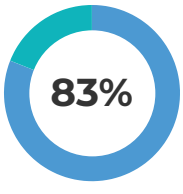
You go to your GP and you try to access CAMHS and these other services, but on every occasion they said "Do a parenting programme".

Results: Care Needs & Support

Parents were asked to share the range of support available for their child with diagnosed or suspected ASD. The responses are available below; please note that these responses are not mutually exclusive as parents could tick more than one source of support.



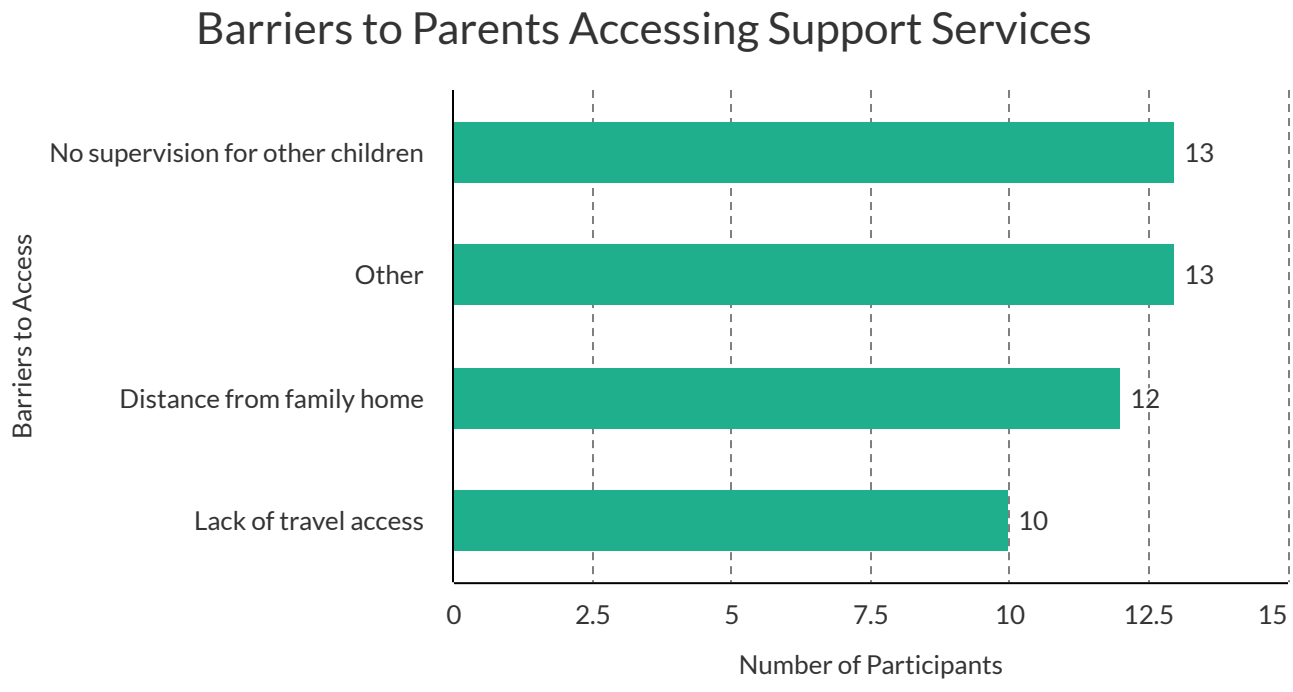
Family members such as grandparents were often the most likely source of support when helping to take care of the child. **Nearly a third of parents (30%)** had access to ASD-friendly clubs that they could take their child to. It was also noted that **over one in ten parents (11%)** reported having no additional sources of help or support available for them and their child.



of parents did not have local access to ASD support for their child

We asked parents if they had any support within their area for children with ASD. **83% of parents reported no**, suggesting that parents must travel to access the ASD-friendly clubs and services mentioned above.

The theory of travel and distance being a barrier to parents accessing services was supported in a follow-up question on barriers to service access:



When parents were asked which barriers prevented them from accessing support services, **nearly half of participants (46%) mentioned either distance from the child's home or lack of access to transport**. The single largest barrier identified was a lack of supervision for the parent's other child/ren when trying to access support for their neurodiverse child. Examples of barriers included under 'Other' include a lack of knowledge of support services and the child's difficulties with leaving home and meeting new people.

Insight from Parents: Care Needs and Support

Through a combination of interviews, focus groups, survey responses and consultations, we identified a range of insights from parents on what they are experiencing and struggling with regarding care and support for their child. These include:

Lack of Knowledge and Support

I'm sure there are lots of different types of support available, some families seem to fall through the cracks as they are not told what is available to them.

When speaking to parents about sources of help and support that they could access, parents told us they were "*unaware of what's available*" and were "*unsure of what support*" they could avail of. Alternatively, parents told us they are "*not told what is available to them*" and are "*never given anything*" or "*told about other options or services*".

Parents would also tell us about the lack of help and support available within their area and how it would impact their quality of life. Parents described how "*there is very little available for special needs children in my area*" and how there are "*online Zoom courses for families*" but little to support the child themselves. Not only could this extend to clubs and support groups, but also neurodiversity-friendly childminders. Parents spoke of how childminders would refuse to supervise their child with ASD, insisting that the child would have to be separated from the parent's other children. This lack of support culminated in a parent giving up their career to take care of their child which has impacted their mental wellbeing.

Have had to give up a career to look after my child because of the lack of childcare for children with additional needs. It makes life extremely hard for parents. We basically have no life at all.

Lack of Age Ranges

Support is very limited in our area. Mostly aimed at young children. Nothing for teenagers.

16+ services are nonexistent. There is NO support. No ASD-led social groups. Nothing.

Several parents raised concerns about the lack of support available for their child's current age range. It was noted that a large focus was placed on supporting younger children, with services for teenagers being "*nonexistent*".

Parents felt that for their teenage child, groups with a social component that helped neurodiverse teenagers to meet each other would be particularly helpful.

The Quality of Family Support

I have a brother as well that actually is hoping to move over to Northern Ireland, which is really exciting.

With a lack of available or age-appropriate support, parents would discuss the role of their wider family and the support that they could offer the child. However, the quality of this support could vary widely. Parents would describe how they moved to be closer to wider family as "*it definitely works in our favour to have grandparents down the road*", and wider family members such as aunts and uncles would move themselves to be closer to the family.

Nobody understands it unless they have a child like that. Your family don't understand it either, they just go "Wise up".

While some parents had family close by, they were not always a suitable source of support due to lack of understanding and patience towards those with ASD. Extended family members would be "*unwilling to stick to routines*" if they were to help with childminding, while parents have described how they often have to avoid family events "*because I don't want to deal with so-and-so [not understanding my child]*".

The Role of Voluntary Support

Parents praised the role of the voluntary sector in providing help and support to their child, describing voluntary help groups as "*your best bet*". However, praise for these organisations was often paired with discussions on how these voluntary groups "*don't have the staff and the resources to provide [children] with what [they] need*". Examples were provided of cutting support hours for their child, but parents were sympathetic towards this as "*the playgroup he's in is charity run*" and they "*understand the pressures and challenges of this economy*".

Seeking voluntary help groups are your best bet.

They cut his hours to an hour and a half, so he's only in from 9:00-10:30am which is just so disheartening.

We spoke with staff members from voluntary organisations who provide services to young people with ASD. They described how fears surrounding "*looming budget cuts every financial year*" would lead to staff leaving the organisation for more secure employment as they "*need to pay their mortgage and keep a roof over their heads*". This is challenging for both the organisation and the young people they support as they need to "*start all over again*" in finding a suitable person for such a sensitive role and to build a secure attachment with the young people in the group.

High Demand

There are no resources close by or that aren't already fully booked.

Support services for children with ASD were shown to be in high demand, with parents describing how services they were interested in attending were "*already fully booked*" or "*have a big waitlist*" due to their demand.

A staff member of an ASD support service told us how turning away referrals due to lack of space "*breaks my heart*". The staff member also shared how an additional source of hurt to them was just how accustomed parents had become to rejection and being turned away from services. The demand for support services for neurodiversity is so high that a new service they had launched almost two weeks ago at the time of speaking had already met its capacity.

I know this service has a big waitlist because it's very needed in the town.

Barriers to Access

There is little to no support until you actually have your statement for your child.

By the time we would travel to things after school, it would be too late.

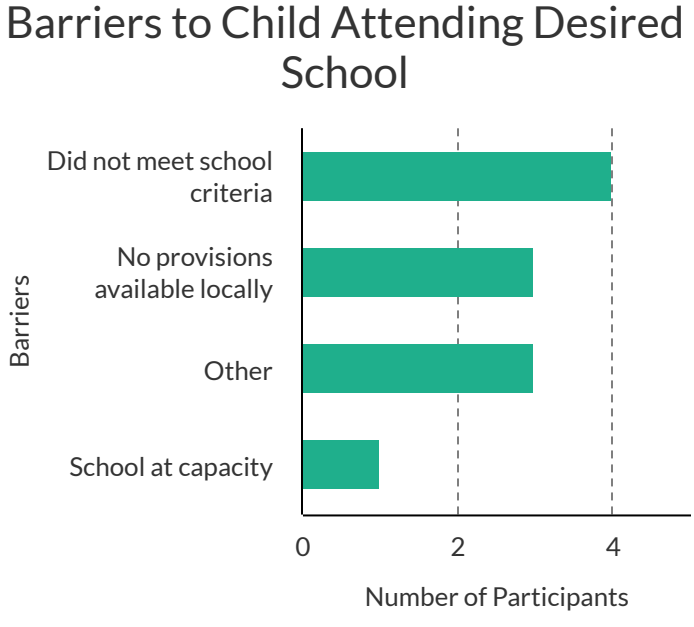
Our conversations with parents identified several miscellaneous barriers to accessing support services. Firstly, parents couldn't avail of outside services for children with heightened social anxiety and for those who "*refuse to leave home*". Secondly, parents struggled to gain access to appropriate services while they were awaiting a diagnosis for their child. Finally, distance and travel time was mentioned as a significant barrier, particularly within rural locations. For example, a parent described how getting to sources of support wasn't possible after school as "*it would be too late*" by the time they arrive.

Results: School Access & Support

We asked parents to describe the type of school that their child attended. 15 parents had a child that attended a mainstream school (37%), 10 parents had a child that attended a mainstream school with specialist provisions (24%), 10 parents had a child that attended a special school (12%) and one parent homeschooled their child (2%). Five parents stated that their child was not yet of school age (12%). Each category of parent was asked separate questions about their experiences that will be detailed separately below.

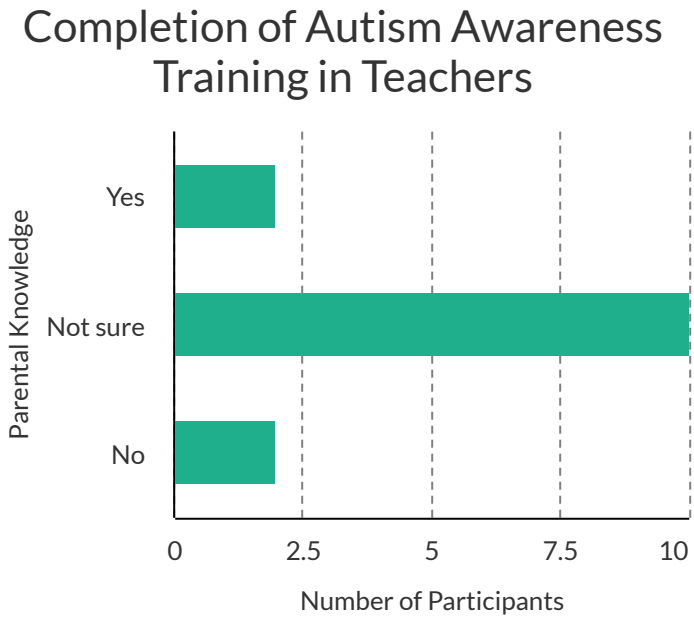
Mainstream School

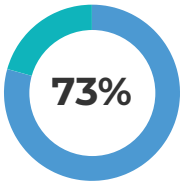
When asked if they would like their child to attend a special school or a mainstream school with specialist provisions, **40% of parents said yes**. For the parents of children who wished for a special school or a specialist provision school placement, we provided a list of barriers to this school placement and asked them to select as many barriers as they felt applied to them:



The most common barriers were not meeting the school's criteria for a placement, the lack of schools offering this placement type where they live, and 'other' barriers such as lacking a severe learning disability.

We asked parents of children in mainstream school if they knew whether their child's teacher/form teacher had completed Autism Awareness Training. **Nearly three quarters of parents (72%) said that they were unsure,** with the remaining parents confirming yes or no equally. This meant that **only 14% of parents could confirm** whether their child's teacher had completed Autism Awareness Training.



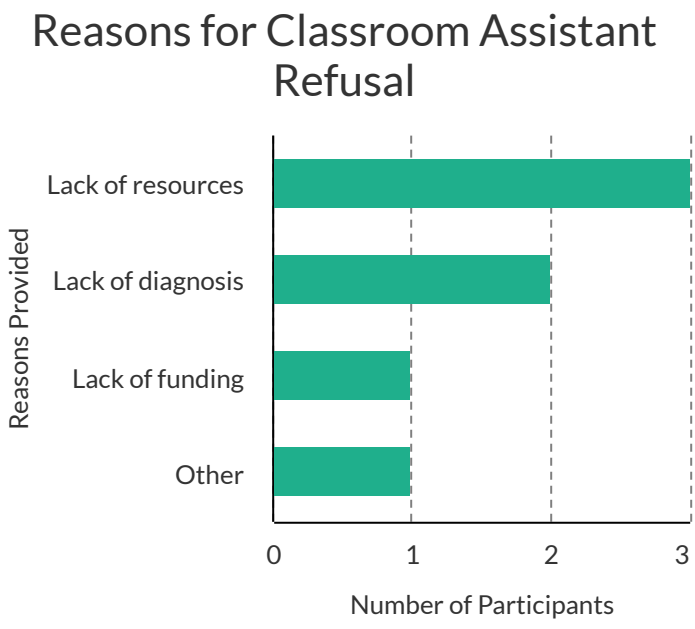


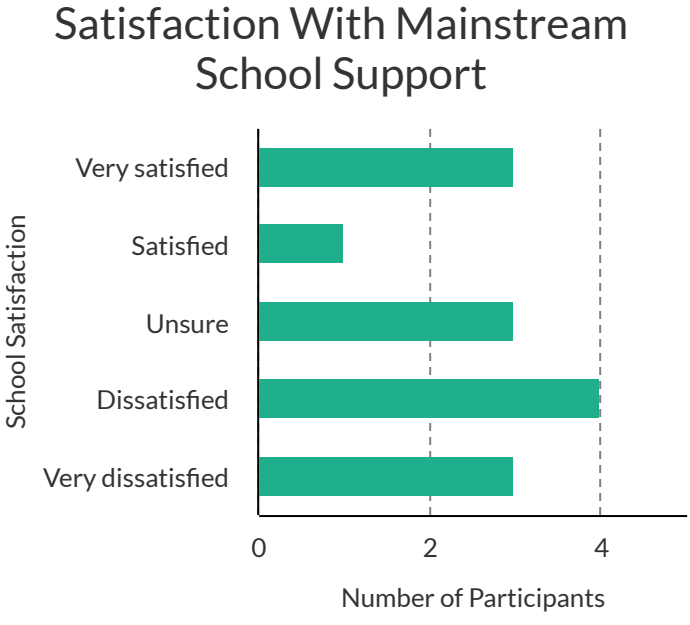
of children did not have a classroom assistant

Several questions were asked about children's current and previous experiences of having a classroom assistant. **Almost three quarters of parents (73%)** shared that their child did not have a classroom assistant. For the parents who said yes, 75% currently had a diagnosis of ASD while 25% were awaiting a diagnosis. Of the parents whose child currently did not have a classroom assistant, one (9%) shared that their child had previously had a classroom assistant but had lost this support due to resources being directed towards "*children with much more disruptive behaviour*".

36% of parents whose child did not have a classroom assistant had asked for their child to receive classroom support. Parents were provided with a list of possible reasons for rejection and were asked to tick as many as they felt applied:

The most common reason for not receiving a classroom assistant was a lack of resources and funding within the school, followed by the child not having received a diagnosis of ASD at that point. One parent described how the school was adopting a 'wait-and-see' approach to whether their child would need more support in the classroom environment.

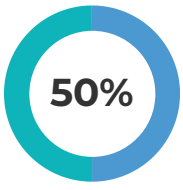




Parents were asked how satisfied they were with the level of support their child received in mainstream school. A total of **50% of parents reported a degree of dissatisfaction** with this level of support, with **28% of parents feeling satisfied** with this support.

Mainstream School with Specialist Provisions

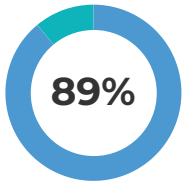
Parents of children attending mainstream with specialist provisions schools were asked about provisions they avail of such as reduced school timetables and additional support.



of children were on a reduced school timetable

50% of parents we spoke with reported that their child was on a reduced school timetable. 40% of these parents said that they had other children on full school timetables, with the traveling and scheduling associated with this leading to parents feeling that they had "*no time to myself*".

As anticipated in specialist provisions schools, nearly all parents reported that **their child had access to a classroom assistant (89%).**



of children had a classroom assistant

Parents were asked how satisfied they were with the level of support their child received at a mainstream school with specialist provisions. **55% of parents reported a degree of satisfaction** with their child's level of support. **No parent overtly reported feelings of dissatisfaction**, in contrast with mainstream school which saw parental dissatisfaction rates of 50%.

Special School

Parents of children attending special schools were asked questions regarding school availability in their area, school transport and satisfaction.

Parents of children attending a special school were asked how long they travelled from home to reach the child's school. School distance ranged across parents, with **30% of parents travelling 16-20 miles** to attend their child's special school. However, **60% of parents** whose child attended a special school noted that their child is taken to school via school transport.

Parents were asked how satisfied they were with the level of support their child receives at special school. **90% of parents reported a degree of satisfaction with their child's level of support**, with 'very satisfied' being the most common response.

Insight from Parents: School Access and Support

Through a combination of interviews, focus groups, survey responses and consultations, we identified a range of insights from parents on what they are experiencing and struggling with regarding school access and support for their child. These include:

The Role of The Diagnosis

[My child's] struggling to cope in his current school setting, and as he doesn't have a diagnosis of autism he isn't eligible to access the autism support class in the school.

Parents reported mixed experiences for their child at school that were influenced by whether the child had received a diagnosis of ASD. Multiple parents described how a lack of a diagnosis prevented children from accessing support within their school such as an "*autism support class*". This left parents feeling "*lost*" and "*unsure how to navigate the hurdles*" without a diagnosis.

Alternatively, parents whose child had received a diagnosis still felt a "*lack of support*" in schools and had received "*no support since the diagnosis*". A parent whose child is currently awaiting a diagnosis described how they were able to access support for their child through a Statement of Educational Needs rather than solely relying on the ASD assessment.

She is struggling in school and cannot receive the appropriate support as she does not have an official diagnosis. I feel lost as a parent and unsure how to navigate the hurdles.

Disruption As A Priority

He is really struggling [in school] and told me that he hadn't been to the learning support unit...I then learned at a school meeting that the unit was currently being used as a place to bring kids out of class that had behavioural issues.

Similar to how masking could impact the diagnostic process for children, masking in schools can impact the quality of education and support that they receive. Several parents shared examples of how their child was not being supported in school due to disruption being a staff priority. A parent chose their child's secondary school "*based on the open day and having been shown around the learning support class*" and feeling "*reassured that my child would have support*". When their child was struggling at school, they later found out that the unit had been repurposed for children with behavioural difficulties.

Other parents shared how their child had not been reaching their academic potential as they were being left to sit quietly while teachers managed disruptive behaviour. The priority placed on disruption was further supported by a testimonial from a parent, sharing how access to a school with more support for their child "*took a very long time and only seemed to be prompted when it started to affect other school children*".

One of my children got nothing because he would sit quietly and not talk, therefore they just left him as there were children with much more disruptive behaviour... he academically hasn't been able to fill his potential.

Teacher Training

It is a small school but they have a great understanding from a personal level and have all had training.

Teachers and school management are woefully ignorant of everything to do with ASD – they have no training.

Parents readily spoke about the role of teacher training, both its presence and its absence. Parents shared warm feedback about their child's school and would quickly point out how the teachers "*have all had training*" and how they are "*very good and clearly trained to do the job*". Alternatively, parents would express their frustrations at lack of teacher training, describing how teachers "*were trained to do all kinds of jobs at school except look after [my child with ASD]*" and how "*they have no training*".

Leaving or Staying in Mainstream

Parents of children in mainstream schools were asked if they would like their child to attend a special school or a specialist provisions in mainstream school. Parental feedback on this was mixed. Some parents said they would like their child to attend a special school as "*mainstream school can't provide the level of support needed so we feel quite helpless in our current situation*", with parents describing mainstream schools as placing ASD pupils "*in danger*". When speaking to a support worker about school placements, they said "*Families wish their child was in [local special school] when they're in mainstream schools*".

Far too many ASD pupils are being placed in danger being sent into a school environment that can't provide reasonable adjustments to meet their needs.

> **I hand-on-heart believe that my son will thrive in a mainstream environment...I just think that he needs that help just to focus and get some of the things that he needs to get done at school.**

Several parents we spoke to felt that their child would thrive in a mainstream environment, with the condition that they receive some sort of support in school. Parents described how their child is "*very social*" and how they want their child "*in [a] school with the right supports*" to allow them to thrive. However, parents could also acknowledge the role of budget cuts in offering support in a mainstream environment as parents had lost their in-school Arts Therapist due to funding programmes such as Healthy Happy Minds ending. A suggestion was made for mainstream schools to have a "*peer support group where [children] talk about their emotions and share coping strategies*" as a way of helping children with ASD to feel less alone while also helping them to understand their emotions.

Child Wellbeing

School was described as "*by far and away the biggest cause of pain and distress in the lives of young people with ASD*". Parents detailed how they had made the decision to remove their child from mainstream school due to the overwhelming pressure it was putting on their mental wellbeing, leading to "*a complete mental breakdown*". When asked what more could be done to support the child's wellbeing at school, the parent described how the child needs "*a safe place where people understand him...because he gets bullied and targeted because he's different*".

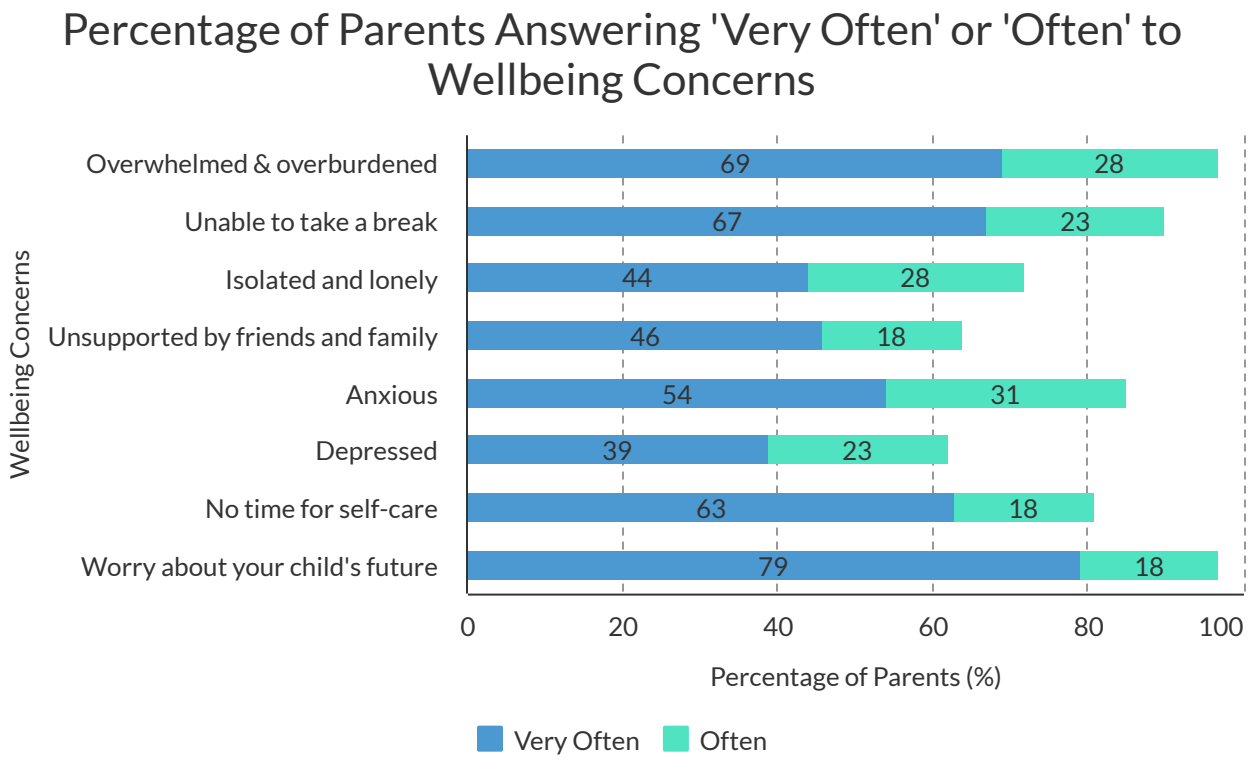
> **He had a complete mental breakdown [going to school] and he's never ever recovered.**

> **They try so hard all day at school that by the time they come home, they're ready to explode.**

Bullying at school was referenced by several parents as something that had led to poor self-esteem and anxiety in their child. Children would reportedly say things like "*I can't do that, people don't like me*" when it came to invitations and attending parties. Along with being bullied, they can also be blamed for things going missing in the classroom and are left alone at play time. Parents felt that poor classroom experiences were causing children to act out at home as they struggle with processing their emotions; one child reportedly said to their Arts Therapist "*I can't be good all the time*".

Results: Parental Wellbeing

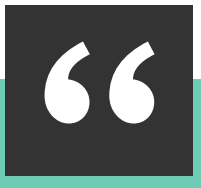
To conclude the survey, we asked parents to answer questions about their own personal wellbeing from the Carer Well-Being and Support Questionnaire. Parents answered how often, ranging from 'Very Often' to 'Never', they felt a range of wellbeing concerns. For brevity, only 'Very Often' and 'Often' responses are shown below:



97% of parents not only often felt overwhelmed and overburdened, but often worried about the future of their child. Lack of self-care and heightened anxiety were prominent wellbeing concerns for parents as **90% of parents** often felt unable to take a break for themselves and **85% of parents** often felt anxious. Factors such as lack of family and ASD-focused support may have influenced the support felt by parents as **72% of parents** often felt isolated and lonely, while **64% of parents** felt unsupported by friends and family regarding their child's neurodiversity. These factors culminated in **62% of parents** often feeling depressed.

Wellbeing Testimonials from Parents

I think depression is actually very common in parents of people with additional needs. I have depression, I'm on medication...it definitely just helps to take the edge off some feelings.



You feel like you're on your own.

I'll get an hour before bed and then it starts all over again the next day.

I can't wind down, I get about three hours of sleep a night.

It's very easy to judge parents. I feel very much like I've been judged, especially when we're out and about with [my child].

It's really affected me massively...you don't know what's going on in someone's life.

Discussion & Recommendations

We spoke with a total of 125 participants about the challenges experienced by children with diagnosed or suspected ASD and their parents, particularly in relation to the diagnostic process, the support available to them, their educational experiences, and the mental wellbeing of parents.

Over half of parents we spoke with waited at least three years from their first referral to receive a diagnosis for their child. A diagnosis of ASD offered surprisingly little additional support for children and their parents, with only 19% of parents reporting that they gained access to support such as courses and direct payments. Nearly a quarter of parents surveyed had paid for private appointments for their child, leading to an average cost per parent of over £2,000; loans were sometimes needed to afford these costs. We identified a range of concerns from speaking with parents about the diagnostic process, including lack of information and support, and parents not being listened to during appointments.

83% of parents surveyed described how they did not have access to ASD-friendly support services in their area. While family members were the most common source of support parents turned to, they also acknowledged the lack of understanding that family could have towards their child's neurodiversity. This lack of support and understanding would culminate in parents giving up their career to take care of their child full-time. The themes surrounding care access we identified include the role of voluntary support services, but also the exceedingly high demand for these services within the community.

Nearly three quarters of children in mainstream school did not have a classroom assistant; this was attributed to a lack of available resources within the school. This lack of resources was exacerbated by schools seemingly prioritising disruptive behaviour over supporting quiet students who may be masking their feelings, leading to their child struggling academically. Satisfaction with school support was lowest within mainstream schools (28%) and was highest within special schools (90%). Only 14% of parents could confirm that their child’s teacher had completed Autism Awareness Training, with parents feeling that teachers’ understanding of ASD varied too greatly. From speaking with parents, we identified school concerns such as the negative impact school was having on their child's wellbeing and the additional support needed in mainstream school environments.

The challenges and limitations described above have understandably impacted parental wellbeing, with 97% of parents often feeling overwhelmed and worrying about their child's future. Navigating these challenges could harm the parent's own quality of life, with parents often feeling anxious, unsupported, and unable to take time for themselves.

Discussions with parents and service providers granted the research team insight into potential solutions and recommendations that could support both neurodiverse children and their parents. These recommendations include:

Increased Use of Autism Awareness Training

Only 14% of parents we spoke to were aware that their child's teacher/form teacher had completed Autism Awareness Training. There is currently no requirement for teachers to complete this training, and its lack of uptake in mainstream schools has previously been noted as a stressor for parents (Graham, 2022). As several parents in our project commented that teachers' understanding of ASD varies too greatly, increasing the number of teachers in schools completing Autism Awareness Training could ensure a standardised quality of understanding towards children with ASD within schools.

Improved Understanding of Neurodiversity in Schools

While a lack of teacher training was acknowledged as a stressor for parents, they would also share how their child was bullied or targeted in school for being 'different'. This could lead to the child being isolated in the classroom and blamed for problems that arose there. To foster a more supportive and understanding peer environment, resources should be dedicated towards educating children in mainstream schools about neurodiversity from a young age.

Support for More Age Groups

Several parents commented on how the support available for neurodiverse youth focused on younger age groups, particularly nursery-aged children. Not only did parents share that there was a lack of resources available for their preteen or teenage child, but they expressed fear and apprehension towards their child having to leave their current support group when they became too old. Further resources should be dedicated to supporting young people with ASD through a wider range of development stages. This is supported by testimonials from service providers who describe how their service for neurodiverse teenagers has met its capacity less than two weeks after launching.

Increased and Extended Support for the Voluntary Sector

The role of the voluntary sector was praised in supporting both children and their parents. However, parents expressed frustration for - yet an understanding of - the limitations of this support, including lack of staff and the need to reduce support hours. When speaking with service providers about this, funding was described as a barrier to staff recruitment and retention. For example, one service provider described how well-trained staff could leave to pursue more secure employment, once again kickstarting the process of

recruitment and training to support vulnerable young children. Due to the support and comfort that these organisations provide to families, it is imperative for more secure funding opportunities to be available for staff security and retention.

Child-Centered, Not Parent-Focused Assessment

Multiple parents we spoke to described how when requesting an ASD assessment for their child, concerns were minimised and argued to be parental projection. Examples of this include parents being told that their concerns were symptoms of postnatal depression and/or a result of COVID-19 lockdowns. After requesting an ASD assessment, parents could be recommended parenting skills classes instead. It is important to note that all parents with these experiences eventually received a diagnosis of ASD for their child, including through paying privately for assessments. To minimise further delays to the diagnostic process and to avoid a lack of support for neurodiverse children, requests for assessments should take a child-centered approach, focusing on the symptoms of the child rather than focusing on the parent.

Support and Resources for Parental Wellbeing

97% of parents surveyed often felt overwhelmed and worried about the future of their child. We also found that parents often reported feeling anxious, unsupported, and unable to take time for themselves. These findings suggest that more needs to be done to support the wellbeing of parents while also being mindful of their busy schedules. We conducted consultations in parent support groups and found them to be warm and open spaces for parents to gather and support each other. Resources should be dedicated to improving the wellbeing of parents with neurodiverse children, such as parent support groups in various modalities (e.g. online platforms) that can help parents to feel supported and understood.

Improved Understanding of Gender Differences in Neurodiversity

Several parents we spoke to had more than one child with an ASD diagnosis. A pattern that emerged from speaking with these parents was their experiences of the assessment process for both sons and daughters. While parents felt that the diagnostic process was more straightforward for their son/s, their daughter with suspected ASD was experiencing more challenges within the diagnostic process. These problems could be exacerbated by an increased likelihood of neurodiverse girls 'masking', referring to hiding true feelings or behaviours by mimicking the behaviour of others. As this was a common experience among parents of girls, clinicians should be more aware of gender differences that can happen regarding the presentation of ASD symptoms during assessments.

Improved Understanding of Masking

As mentioned in the previous recommendation, neurodiverse children may mask their true feelings in unfamiliar situations by mimicking the behaviour of others. Parents detailed how a variety of factors, including the diagnostic process itself and the level of support children receive in school, could be impacted by a child masking outside of the home environment. However, masking outside of the home environment could impact the child once they come home, leading to them "exploding" and acting out towards the parent. This frustration could be exacerbated by children being ignored and left to sit quietly in class while resources were dedicated to disruptive behaviour. As these parents felt that doing this led to their child suffering academically, it is important to be mindful of masking in the school environment and continue to support neurodiverse children when they are mimicking the behaviour of their peers.

We would like to thank all of the parents and service providers we spoke to for generously giving us their time; this project was only made possible by your insights and experiences. We would also like to thank those who shared our online survey on social media platforms and helped us to reach even more parents. Finally, we would like to thank the Community Foundation for Northern Ireland for supporting this project through the Partners for Social Care and Health Improvement Fund.

References

Balfour, A. (2024). 'Heartbreaking': Autism diagnosis delays forcing families to find money for private assessments warn Derry & Strabane reps. Retrieved July 6, 2024 from https://www.derryjournal.com/news/people/heartbreaking-autism-diagnosis-delays-forcing-families-to-find-money-for-private-assessments-warn-derry-strabane-reps-4605950

Department of Health (DoH). (2022). Prevalence of Autism (including Asperger Syndrome) in School Age Children in Northern Ireland. *Department of Health: Belfast.*

Education Authority (EA). (2022). Planning for Special Education Provision: Strategic Area Plan 2022-27. *Education Authority: Belfast.*

Graham, S. (2022). Autistic children in North homeschooled due to lack of services. Retrieved March 19, 2023 from https://www.irishtimes.com/ireland/education/2022/06/29/autistic-children-in-north-homeschooled-due-to-lack-of-services/

Lynch, C. (2023). Education Authority issues statement on SEN school places as 93% are confirmed. Retrieved April 21, 2023 from https://www.belfastlive.co.uk/news/northern-ireland/education-authority-issues-statement-sen-27262444

Meredith, R. (2024). NI education: More than 100 schools refuse new SEN classes. Retrieved August 9, 2024 from https://www.bbc.co.uk/news/uk-northern-ireland-68784756

Meredith, R. (2023a). NI Education: Almost 400 children with special needs waiting on school place. Retrieved August 2, 2023 from https://www.bbc.co.uk/news/uk-northern-ireland-66114519

Meredith, R. (2023b). Moira special school pupils left without bus transport. Retrieved November 9, 2023 from https://www.bbc.co.uk/news/uk-northern-ireland-66790111

Quirk, A., Smith, S., Hamilton, S., Lamping, D., Lelliott, P., Stahl, D., ... & Andiappan, M. (2012). Development of the carer well-being and support (CWS) questionnaire. *Mental Health Review Journal, 17*(3), 128-138.

Thank you

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