



APRIL
2019

INVISIBLE CHILDREN

SURVEY ON SCHOOL
ABSENCE & WITHDRAWAL
IN IRELAND'S AUTISM
COMMUNITY

AsIAM Policy Office, part of
AsIAM Community Support Department

Contents

- **Foreword** pg 1
- **Executive Summary & Key Findings** pg 3
- **Survey Analysis** pg 5
 - **Survey A: Waiting on a School Place** pg 6
 - **Survey B: Exclusion & Withdrawal from School** .. pg 13
- **Key Recommendations** pg 20

Foreword

Dear Reader,

Thank you for taking the time to consider the findings of *Invisible Children: Survey on School Absence and Withdrawal in the Autism Community*. The findings make for a grim but very necessary read.

It was Nelson Mandela who said, “*There can be no keener revelation of a society’s soul than the way in which it treats its children.*” It is the considered view of AsIAM that autistic children, who are arguably one of the most vulnerable groups in Ireland today, are not treated with the same respect and importance as their neurotypical peers. When the NCSE published policy advice on autism in 2017, it gave the following breakdown in terms of where autistic children attended school:

- 14% in special schools;
- 21% in autism classes, and;
- 65% in mainstream classes.

Unfortunately, what these figures failed to recognise is that there was and is still a significant body of children within our community who do not go to school at all. In some instances, these students have simply been failed by the State in terms of inadequate levels of autism or special class provision despite the obligations on the State under the Education for Persons with Special Educational Needs Act 2004 to provide an appropriate school place for every child.

In other instances, students have a school place in theory. They appear on the roll book and, from the point of view of the officials, all is well. However, the reality is totally removed from this. These students may be reduced to a partial school day by the school that they attend – despite the fact that this is illegal. These students may be suspended or expelled not for negative behaviour in the traditional sense but literally because they are autistic and go unsupported in school. They may irregularly or almost never attend school due to overarching anxiety or a lack of suitably trained teachers but continue to be enrolled as normal.

There is no single action or solution that will address this crisis. It comes from the Department of Education and Skills’ failure to appropriately adapt the school system to be autism-friendly and a lack of regulation around how schools treat autistic students and their families. To ensure this problem is comprehensively addressed we need more autism classes, improved infrastructure, better teacher training and an obligation placed on schools to be fully inclusive.

This report does not aim to unpick all of this. Our aim here to demonstrate beyond any doubt that there is a desperate need for the Department to recognise that there is a problem and to take decision action. In addition, broader statutory services, such

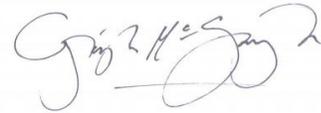
as Tusla and the HSE, have failed in their own respective roles to provide the support required to prevent students falling out of school or to help them to return.

We urge Education Minister Joe McHugh TD and his officials to immediately put in place a clear plan to ensure every autistic child will have a suitable school place by September 2019 and to request policy advice from the NCSE on the issue of school absence and withdrawal. Anything less will be to knowingly ignore the breach of the rights of our children.

Yours faithfully,



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Executive Summary & Key Findings

We commissioned two surveys among stakeholders right across school communities in the country. In doing so, we aimed to compile an informed picture of the situation facing autistic students of all ages and their families on a national level.

The questionnaires were conducted online through SurveyMonkey, whereby members of the public were asked their thoughts on a variety of issues. The first sought to explore the issues involved with securing a school place for an autistic pupil, ranging from their age group and current enrolment to what were the main obstacles encountered whilst applying for a place.

The second survey concerned itself with expulsions and extended absences, examining the complications arising for families whose children were experiencing complications in their educational and personal development. Among its questions, the survey inquired what the main reasons for pupils' exclusion were, their families' engagement with their local Special Educational Needs Coordinator (SENO) and whether or not the families were receiving support from social services.

Stakeholders identified and engaged with throughout the process were chiefly composed of autistic pupils themselves and their family members.¹

We found that:

- 54% of those families seeking a school placement said that their children were due to enrol at a primary school;
- 48% said that a mainstream school with an autism class was the recommended setting for their autistic child's education;
- 35% said that they had applied to anywhere between four and seven different schools whilst seeking a place for their child;
- 54% felt that a lack of school places was the biggest barrier for their child in accessing education, supported by a further 18% saying that their chief obstacle was a lack of nearby schools or classes in their local catchment areas;
- 80% of respondents who were seeking a school place reported engaging with their local SENO to 20% who had not; for those whose child(ren) were expelled or experiencing exclusion, this gap considerably narrowed, with 56% and 44% reporting engagement and a lack of engagement with their SENO respectively;
- A range of varying school attendance rates were reported, with 17% of families saying that their child attends school on a reduced timetable contrasting with 13% who reported as long as three years' worth of absence from school for their child;

¹ AsIAm. "NCSE Policy on Special Schools/Classes Survey." Questionnaire. February 2019.

- 54% of those families whose child(ren) were experiencing exclusion or extended absences from school were secondary school-aged, compared to 41% at primary level;
- 91% of respondents whose child(re) were experiencing exclusion or extended absence from school said they were presently receiving no support from Tusla;
- 66% reported that anxiety was the main reason why their child(ren) were experiencing exclusion or an extended absence from school, followed by 52% who believed that a lack of knowledge and understanding of autism was their main reason, as well as 34% who cited inadequate supports currently available in schools.

Common Challenges Encountered

- Absence of grounded awareness of autism or awareness-raising initiatives within existing school cultures;
- Lack of staff awareness of autism and broader understanding of neurodiverse conditions, including dyslexia, dyspraxia, etc;
- Poor communication between school staff, pupils' families and therapeutic professionals about concerned pupils' needs and supports;
- Inadequate in-school supports / poor school infrastructure in place to appropriately support autistic pupils, namely a lack of Special Needs Assistants (SNAs), misuse of resource hours, shortage of autism classes;
- Shortage of appropriate school places within the families' respective catchment areas, leading to extensive waiting lists in local schools;
- Disparate levels of engagements between families and SENOs, particularly amongst those seeking a place for their child and those whose children who had been expelled or were experiencing extended exclusion.

Survey Analysis

Our surveys were conducted on our website between 30th January and 20th February. At the outset, it is important for us to stress that despite the significant number of responses we do not believe that this is the full picture. From our experience supporting families, many have lost hope in advocacy or experience ‘survey fatigue.’ Many parents simply get not time to go online or do not fully understand their entitlements or how to go about vindicating them. What we present here is but a snapshot of a much deeper problem.

Additionally, as population and diagnosis rates increase, it is important to understand this issue as one which will only grow if we do not take decisive action now and plan provision for the decade ahead.

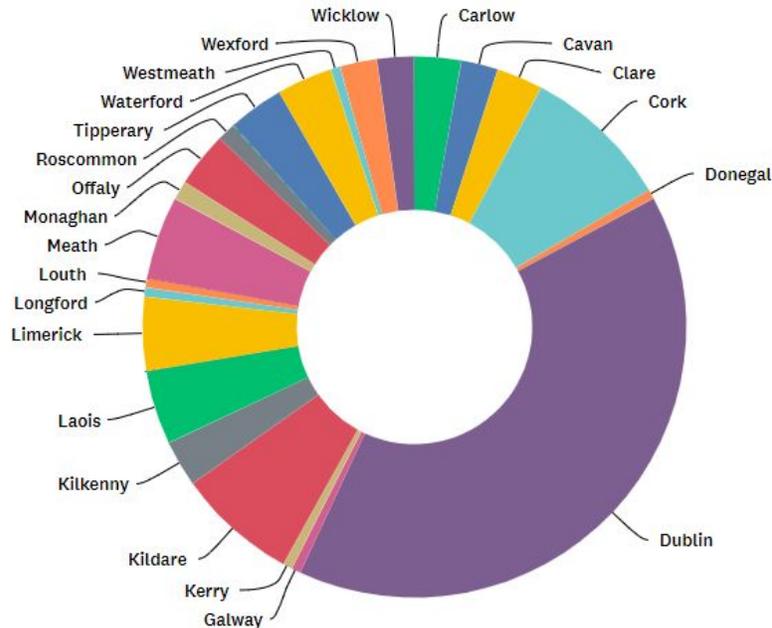
We knew that in conducting the survey that these issues were often complex and difficult to reduce to “Yes” or “No” answers therefore we had two primary objectives for this report:

- a) to demonstrate the demand for the Department of Education and Skills to comprehensively explore and address this issue, and;
- b) to provide an opportunity for families to share their stories and experiences – humanising the very real crisis.

We tried to divide the issue of autistic children missing out on school into two broad categories – those “*Waiting on a School Place*” (Survey A) and those experiencing “*Exclusion and Withdrawal from School*” (Survey B). Whilst this allows us to ask both groups key questions, it is important to understand that **the demarcation is often not clearly defined**. A parent, for example, may be waiting on a school place because their child has been expelled from or failed by another school. This nuance highlights the need for a deeper consultation and research process beyond the resources of our organisation. We hope that the Government will respond to these statistics by taking them on and interrogating them further.

Survey A: Waiting for a School Place

Which county are you currently living in?



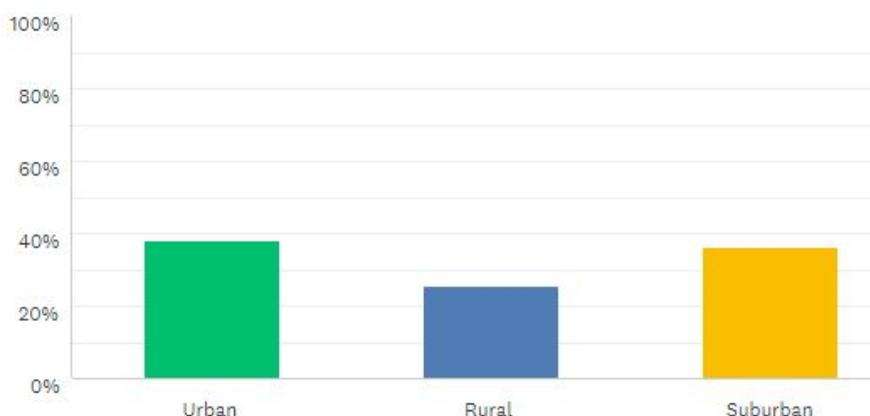
It is beyond dispute that Dublin, and indeed the Greater Dublin Area (GDA), are most acutely affected by the issue of a shortage of autism class placements.

Whilst some of this challenge may be attributed to population growth, it is important to recognise that this would not be tolerated for mainstream school children. The State has a duty to plan the effective use of its resources to the benefit of all children. In addition, the issue in the GDA goes beyond demographics. We know that whilst some schools have consistently worked to meet the demand for autism class places and support at a whole school level, others have appeared to take a step back. This is particularly true at Second Level, with vast swathes of Dublin having no autism class places available and a huge discrepancy existing between the number of class places available at primary school versus those at post-primary.

This speaks to a wider point throughout the country, which is that **many children living outside of Dublin continue to travel long distances outside of their community to attend school**. This massages the numbers in terms of a shortage of places in communities across Ireland and also undermines a key purpose of inclusive education – the opportunity to be educated in your own local community.

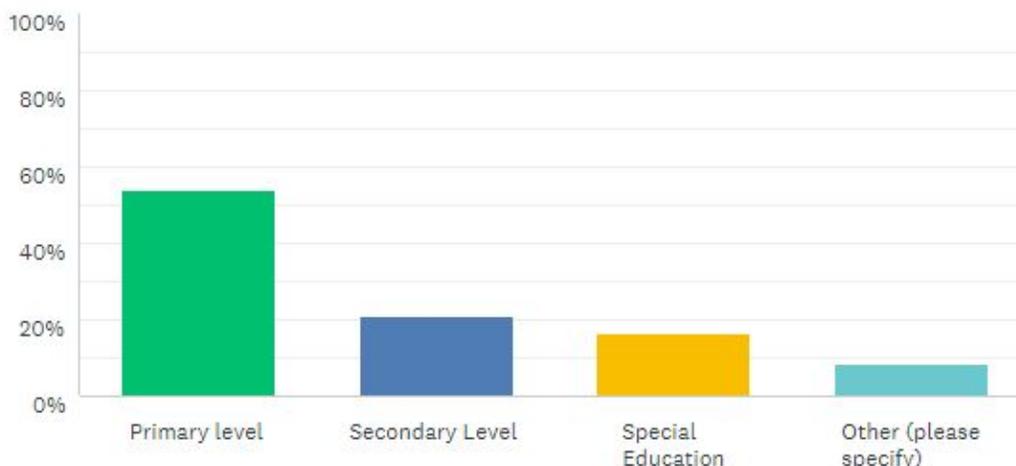
Whilst nearly 40% of respondents were from Dublin, it is important to bear in mind that 60% of respondents were from outside of Dublin and so it is not accurate to explore the issue as a topic exclusively relevant to the Capital.

What type of area are you based in?



The importance of seeing the issue of a shortage of school places as a national one is clearly demonstrated in this question. Whilst 38% of respondents were from urban areas, there were as many as 37% from suburban communities and 25% from rural areas. This shows the challenges are spread throughout the country with no community or demographic excluded.

Which type of school is your child due to attend?

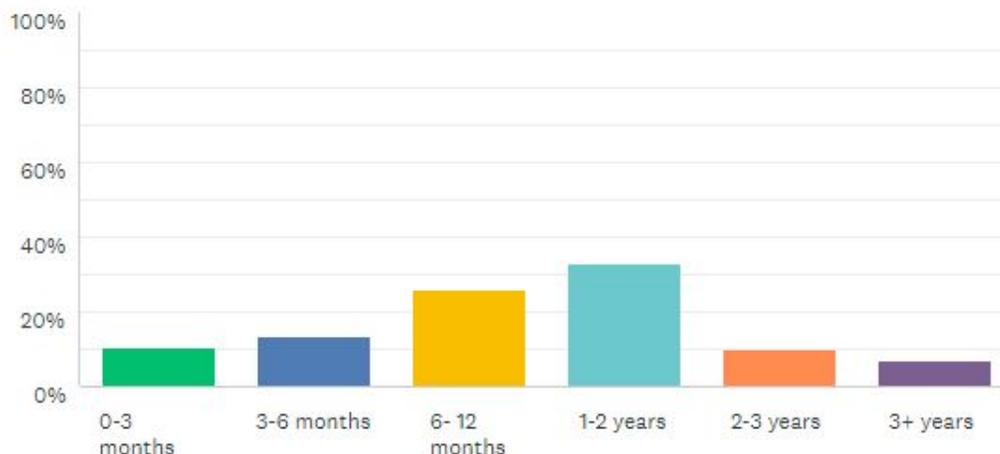


There has been a great focus on the shortage of autism class places at Second Level and this plays out with 21% of respondents waiting on a school place for their child in a secondary school. However, it is crucial to realise that this is a whole-of-system issue, with over half of respondents (54%) still waiting for a place at a national school.

Due to the major focus in recent years on inclusive education, it is easy to overlook the challenges parents who require a special school placement for their child experience. 17% of respondents fall into this category. These are often students with the most complex needs and their ongoing access to school is a key support for their personal development. Whilst it is important to continue to develop the inclusive

education agenda, it is also vital that students, like the 30 represented in this survey, who continue to require more specialist support are not overlooked or left behind.

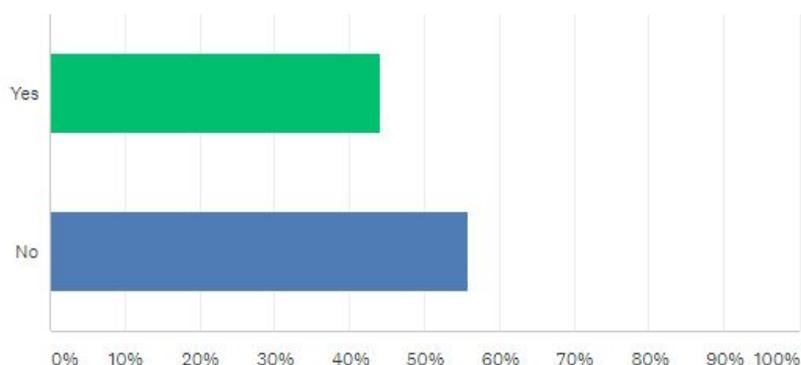
How long have you been waiting on a suitable school place to become available?



The responses to this question show a worrying trend. Only 24% of respondents are waiting less than a year for a suitable school place. The remaining 76% have been waiting anything from six months to over three years (7% or 13 children) for a place to go to school.

Missing out on this much education is devastating for any child. It is also a gross breach of the constitutional and legislative entitlements of the child. It is particularly serious, this breach, when we consider the significant body of research which shows us that the earlier an autistic child is accessing support and having an opportunity to interact with their peers, the more likely it is that the child will reach their full potential.

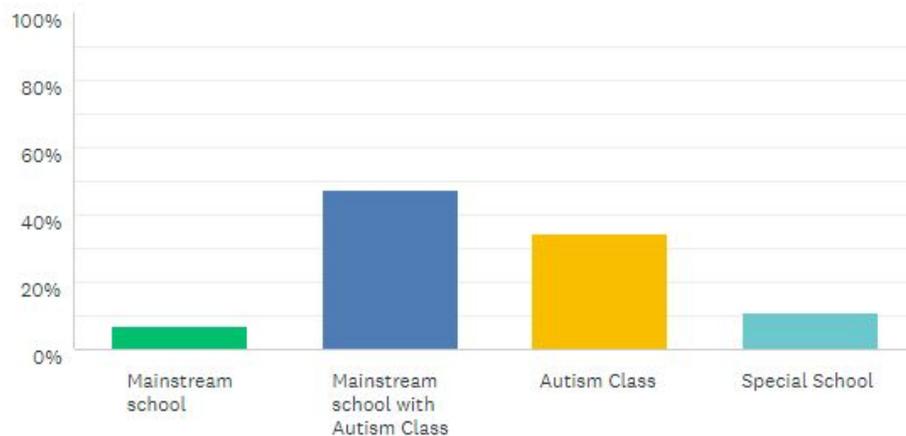
Does your child have any diagnosis in addition to their diagnosis of autism?



Whilst a majority of the respondents (56%) had a sole autism diagnosis it is worth noting the significant minority of children (44%) who had additional needs such as dyslexia, ADHD and an intellectual disability.

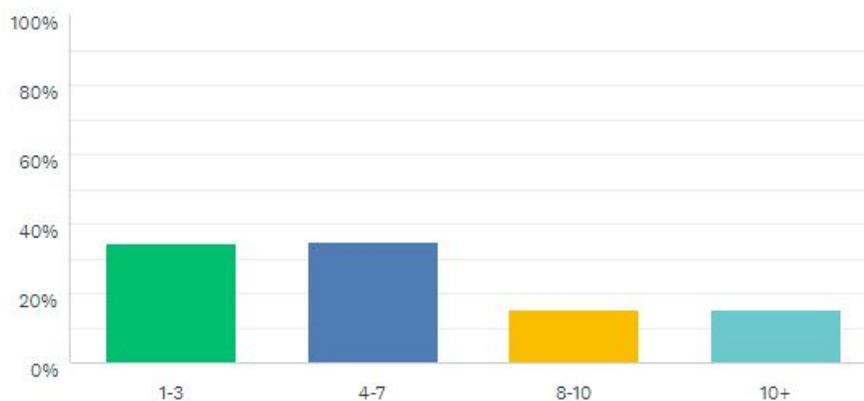
It is our view that more must be done to support schools in meeting the needs of students with the most complex needs.

What type of school place has been recommended to meet your child's needs?



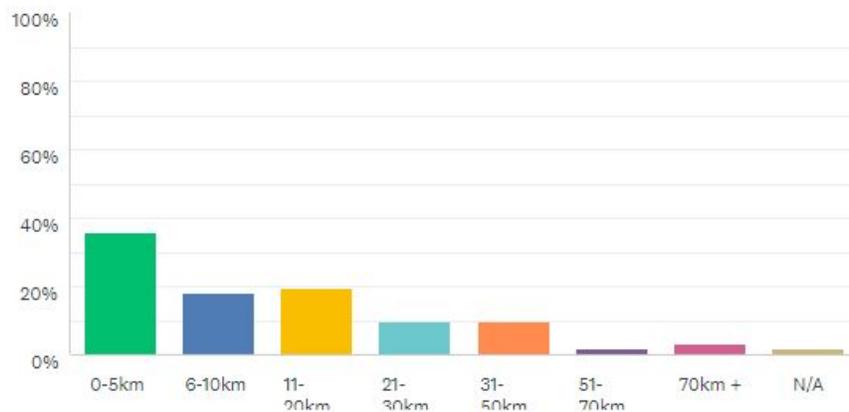
The vast majority of respondents are recommended to either access an autism class or attend a school which has an autism class. This totals around 82% of respondents and highlights the urgent need for the Department to consider where shortages exist in this area and how they can be addressed. It is however worth noting that this is a problem not limited to autism class place availability, some 13 respondents were recommended for a mainstream placement and 20 for a special school placement but are still without support.

How many schools have you applied to?



The responses to this question demonstrate that parents have been willing to apply to a wide range of schools and yet are often still not able to access a suitable school place. 66% of respondents have applied to at least four schools for a placement for their child. Most concerning some 16% of parents have applied to over ten schools to no avail.

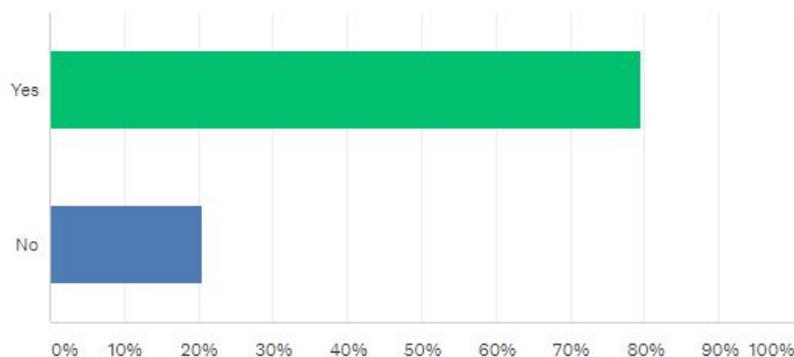
What is the distance to your nearest school place?



Travelling long distances to school is not desirable for any child but it can be particularly challenging for autistic children due to sensory processing differences, a need for routine and the reality that a school day is often a very exhausting experience for an autistic student. It is worth noting that for 46% of respondents the nearest school place was perceived to be over 11km from a person’s home, with 20% recording that it was anything between 21-50km in distance.

This highlights a challenge which is autism classes in local communities working hard to also serve a larger catchment; but in time then not being able to meet the needs of its own local community. For inclusion to succeed it is vital that every local community has a suitable number of autism class places.

Have you engagement with your Special Education Needs Officer (SENO)?



Under the EPSEN Act 2004, the SENO is charged with ensuring a child is capable of accessing the “most appropriate” school place. It is worth noting therefore that 20% of respondents (or 37 families) have had no interaction with their SENO, despite not having access to a suitable school placement.

What are the main barriers in accessing a school place for your child?

Parents consistently highlighted the issues of school places not being available in their catchment area and wider issues of school place availability.

Below are the voices of some parents on the specific barriers they have faced.

“There is a lack of places in ASD classes. We need more classes and if schools won’t open them, they should be obliged to take in x number of autistic students into mainstream.”

“There are no places available in the ASD classes. I am also running into barriers trying to enrol my son into a mainstream class with access to an SNA, as a Plan B for year 2019-2020, since we can’t put off school for another year. One local principal would not even consider it – she said I could only enrol him in the autism class and that I was unlikely to get support for him in mainstream since he’s 1) toilet trained and 2) not a flight risk. So I know he won’t manage.”

“HSE assessment hasn’t happened, it will be another 18 months.”

“No places available. Not enough spaces in the two schools in Cork that would meet her needs.”

“Only three schools suitable for our son. One informed us he is on the 2021 waiting list with no guarantee of a place that year, he will be seven then.”

“We live in Dublin 6W – one school has an autism class in the entire area – even with two schools in the area opening new extensions in the past year, no provision was made for an autism class.”

“They’re not enough schools within 30 minutes with special classes. There were only 10 places available for September 2019 for the whole county of Carlow and that is with a new class being open in September. The waiting lists are over 16-26 children for the next four to five places in all those schools.”

“HSE delay of Assessment of Need limited places close to home.”

“Both schools said they have a lack of resources despite the fact that I explained she doesn’t need significant support, just open-minded and supportive staff.”

Any other comments?

We were keen to keep the questions as clear as possible throughout the survey, but did want to ensure parents could share their own thoughts and experiences. Below are some representative comments on what we received.

"My son needs an autism unit. He is seven and goes to school 2.5 hours a day."

"Schools are asking for an update report on my son's Autism as it will be over 2 years since we got the original. But the Early Intervention Team says they don't do updated reports. Yet another fight..."

"My son is being discriminated against, left out, left behind, all because he has a special need and needs additional support."

"Daughter is in a mainstream class in a Secondary School that doesn't seem impressed to have to include 'them'."

"26 schools and still no appropriate place available."

"I rang a number of schools and was willing to move to a different county but there was no spaces available."

"I'm desperate at the moment. I'm battling a school who do not want my children."

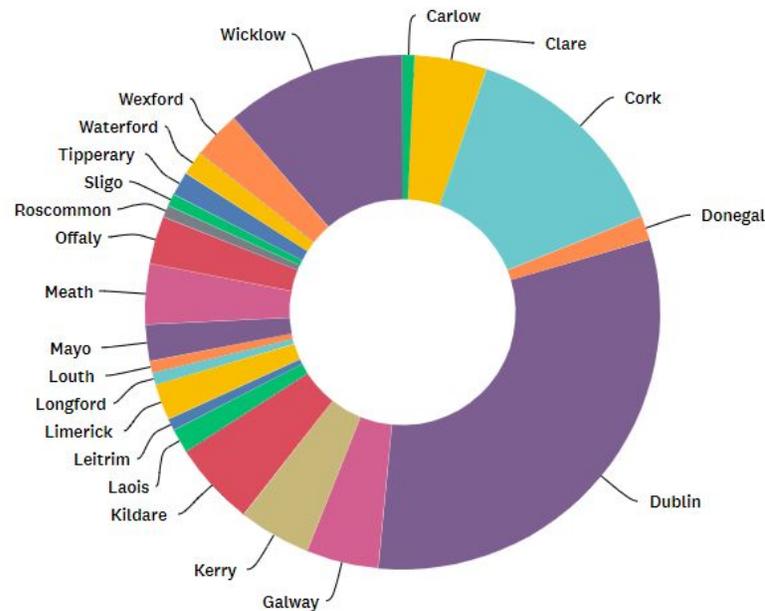
"Inclusion is not really happening."

"If I decided to not send my neurotypical children to school I'd be in trouble yet nobody cares when my ASD child won't be going to school."

"We need a place for September 2020 and have been told by 7 schools in our area that there probably won't be a place for our son when the time comes for him to move up."

Survey B: Exclusion & Withdrawal from School

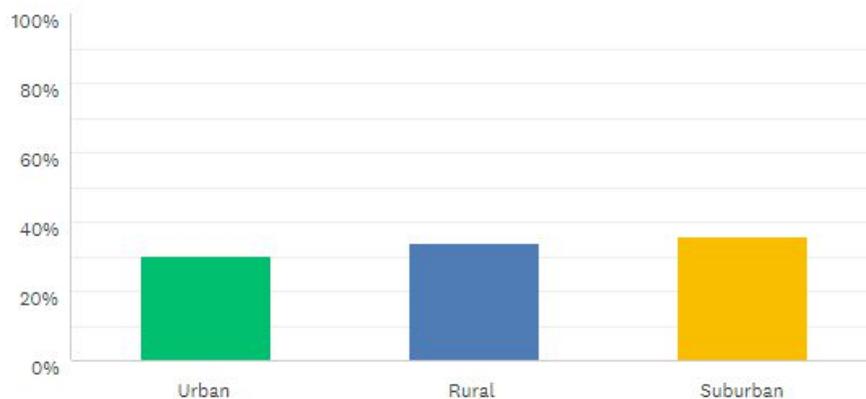
Which county are you currently living in?



As in Survey A, the greatest level of need appears to be in the GDA, with 31% respondents coming from County Dublin itself. As the issues in Survey B are not just about provision of autism classes, but broader support and school culture, this is a concerning pattern. Our organisation has noted for some time a link between schools who are competitive in academic league tables and poor levels of support for autistic students – given the high density of such schools in Dublin this needs to be taken into serious consideration.

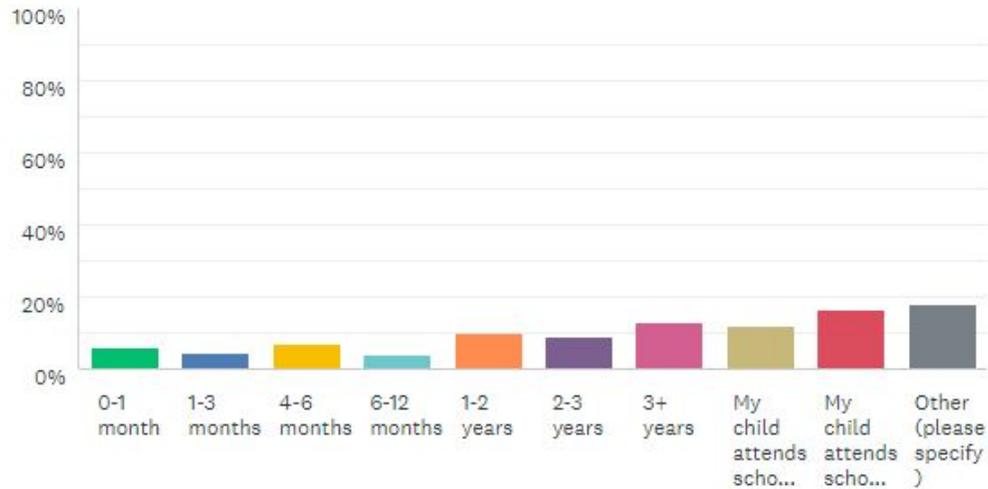
That said, there was a wide range of respondents from right across the country.

What type of area are you based in?



There was a near even split between students living in rural, suburban and urban areas. As schools in these different geographical areas often vary in size, this shows the issues being experienced are throughout both the system and the country.

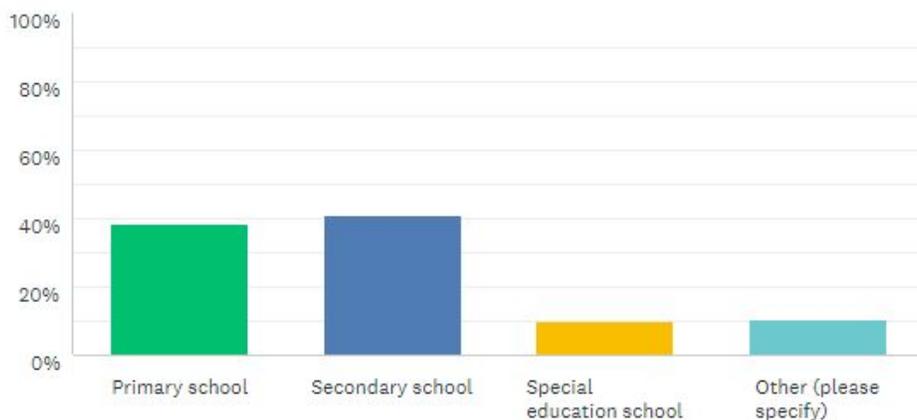
How long has your child not been attending school?



We knew from the outset that this question would not always have a straightforward answer. We had heard anecdotally of children who are enrolled in school, but regularly not attending or on reduced days for long periods of time. 17% of students were on a reduced timetable despite this practice’s illegality. A further 12% attend school “irregularly”. When this is taken into consideration, some 32% of respondents had children out of school for at least a year, with 13% out of school for over three years.

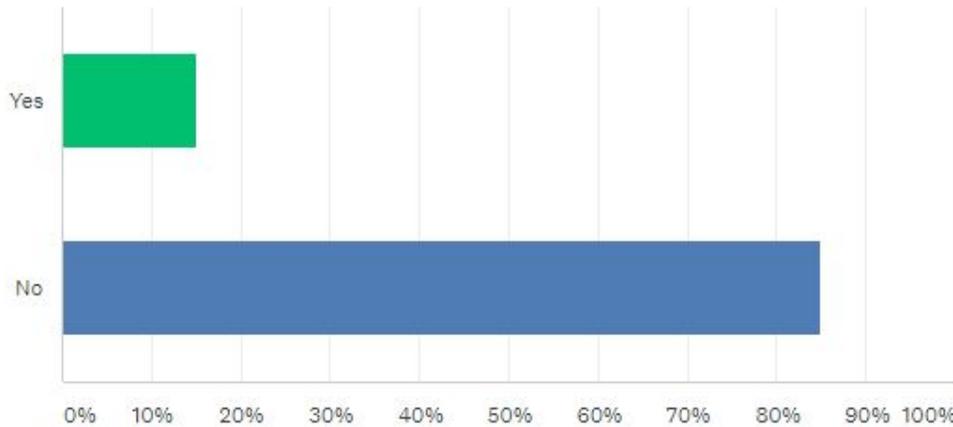
This poses serious questions about the supports being offered to families when a child begins to experience school refusal, or a school is not providing adequate support.

What type of school best applies to your child?



39% of respondents had children in primary school. This is of real concern, as a child not accessing education at Primary Level is a serious breach of the child's rights under the Constitution. The problem is even more pronounced at Second Level, with 41% of respondents falling into this category. Of real concern is the 10% of students in Special Schools who are still unable to attend.

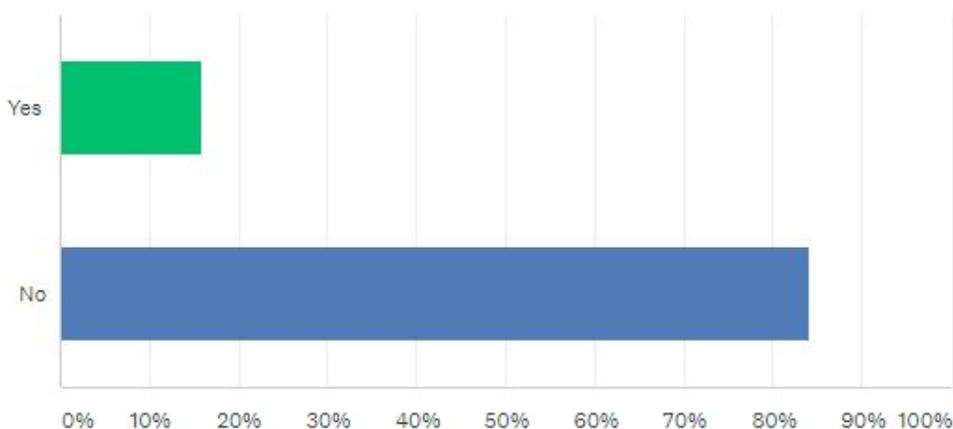
Is your child in receipt of Home Tuition?



We frequently hear from families who once the child leaves the school system, no further support follows. This is particularly true of students who are still enrolled in school on paper but are irregularly attending or regularly excluded. 85% of respondents have had no access to home tuition for their child since they began to experience school refusal or exclusion.

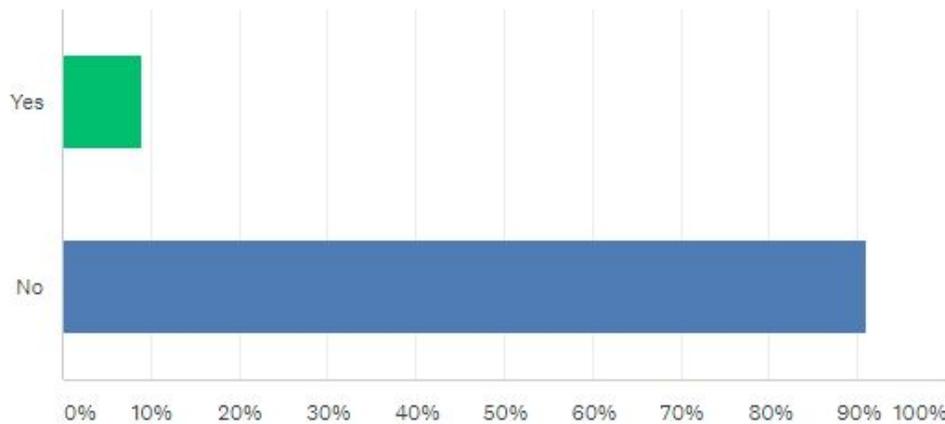
This is alarming as the cohort of young people who perhaps need the most support appear to be receiving the very least.

Is your child being home schooled?



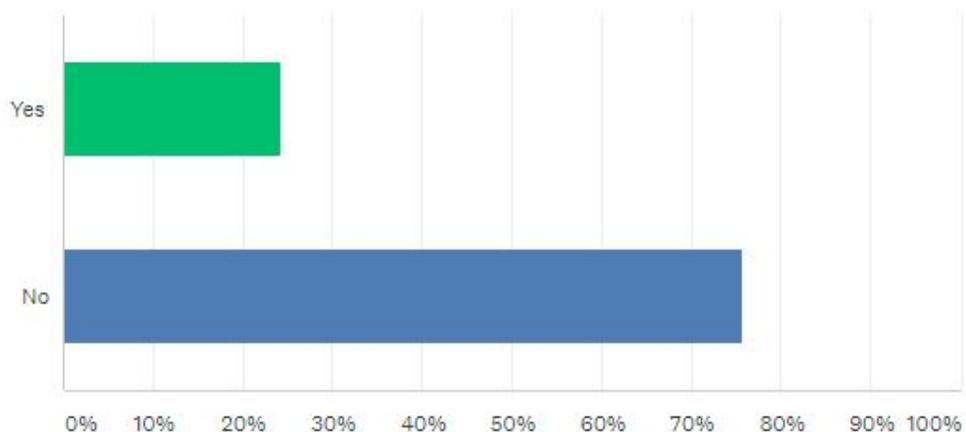
In keeping with the trend of little to no support for children outside of school, it is worth noting that 84% of students who are not attending school are not being home schooled. Therefore, this is not simply a parental choice but a failure of the system to provide a suitable education.

Are you receiving support from Tusla?



Tusla is not fulfilling its role in ensuring students on the autism spectrum receive their education. 91% of families affected by this issue are receiving not support from the Child and Family Agency. Whilst Tusla do not need to play an enforcement role with the families affected by this issue, it is clear more could be done to support families in dealing with schools, identifying possible supports and ensuring the child's right to an education is vindicated.

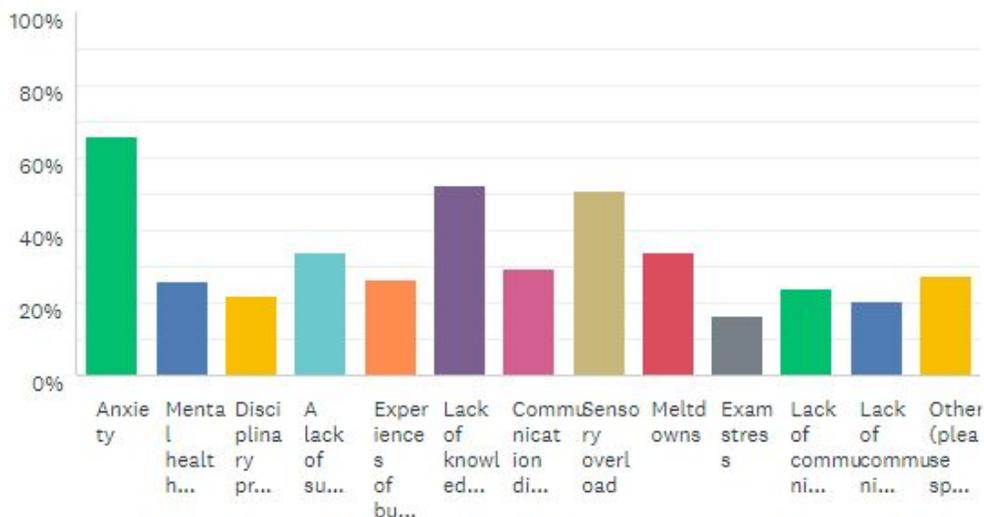
Are you currently seeking a school place?



The long term impact of school refusal or withdrawal is clear from the survey findings and should increase our concern for the children waiting on a school place in Survey A. Presently, 76% of respondents simply have given up on the system after repeated failures – perhaps their child is too long out of the system to transition back in or perhaps significant trauma was experienced during the person's time in

education. This cohort of young people desperately need alternative packages of support and a real urgency is required to ensure other children do not end up in this position.

What are the reasons for your child's absence / exclusion from school?

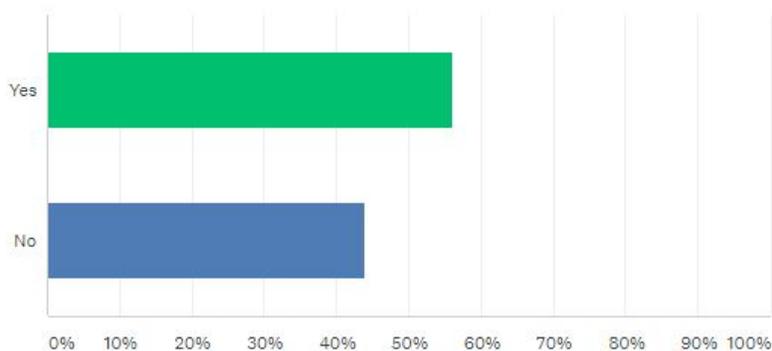


The complexity of the issues surrounding school refusal and withdrawal are captured in our survey findings. 66% of students are experiencing anxiety to a point which is preventing them from attending school. The suitability of support and school placement must come into question for these young people.

A broad range of issues ranging from school disciplinary processes (22%) and experiences of bullying/isolation (27%) can be attributed to other reasons for a child not attending school.

This highlights the need to recognise that inclusion is about more than a school place – it is about a supportive, adapted and understanding environment which meets the needs of a child. More must be done to ‘autism-proof’ our school system to reduce school absence.

Have you had engagement with your Special Education Needs Officer (SENO)?



Whilst in Survey A the vast majority of families had dealings with their SENO, this number declines significantly when it comes to students who are struggling to attend school or fall out of the system. 44% of respondents have had no assistance from their SENO with this issue. Considering the broader findings in terms of the barriers to inclusion for autistic students, these matters relate directly to the suitability of school places and the NCSE must do more to ensure SENOs are fully engaged with families experiencing these challenges.

How do you feel your child could be better supported in accessing education?

A key learning we wanted to glean from families is how did they feel their child could have been better supported in attending school. Below are a representative sample of the comments we received.

“Better input from SENO would have helped, also better input from CAMHS.”

“If we had received help when we asked for it, that would’ve helped. We paid for counselling ourselves. In the end, he got to the top of a few waiting lists once he’d left school, but that was too late. I doubt he’ll return.”

“There are no places in local autism classes therefore my son is left on a reduced timetable as school does not have provision to meet his needs.”

“School to provide honest information to SENO and NCSE about how they allocate their staff.”

“More understanding that his behaviour is sometimes caused by the way staff deal with situations and his anxiety.”

“More training for teachers about autism.”

“Improve training for teachers, modified curriculum / pathway based on interest areas and child’s strengths. Improving psychological support for student and school. Easier way to communicate on a regular basis with school.”

“Better resources in school. Better communication skills e.g. Lámh Training should be compulsory as should PECS.”

“If the teacher would attend the meetings and implement the recommendations from the ASD team and NEPS, then it may be possible for my child to return to the classroom.”

“Less curriculum more focus on life and social skills.”

“An autism-friendly environment without pressure to behave as though he is not autistic.”

It is worth noting that numerous comments called for more autism classes as the key factor which could have made a difference. This links the issues in Survey A and B. Furthermore, what is clear from parental commentary, is that increased resources is only half of the solution – improved school culture and regulation are equally vital. In addition, an alarming trend raised by parents is the number of staff teaching in autism specific classes with no additional training whatsoever.

Further Comments

We also allowed parents the opportunity to more broadly share their thoughts on the system and their own experiences. Some examples are shared below.

“My lad got a late ASD diagnosis. I think teachers need more training in picking up on it, so more kids don't fall through the cracks.”

“NCSE have a duty of care to all autistic students to not turn a blind eye to disingenuous schools.”

“Something needs to drastically change.”

“He's down to 3 hours a day and they knock him back for everything.”

“The fact that teachers are working in autism classes without training.”

“Schools are badly informed about school avoidant kids with autism and treat them with the same standards.”

“Enrolled in a secondary school but does not attend. Home tuition is seen as temporary so would worry about future support.”

“I'm very concerned about the future of Irish society if children are so excluded now where will they be in 20 years' time.”

“Not every child is suited to a large classroom but not every child is suited to an Autism class either.”

“It's very difficult when a child is only diagnosed in teenage years, even though they have had previous assessments as a younger child. Hard to get the child to engage with support and therapy at this age.”

Key Recommendations

The Department of Education and Skills should . . .

- Issue clear guidelines and examples of evidence-based best practices for local schools on providing individualised education for autistic pupils across primary and post-primary school settings, in mainstream as well as special settings;
- Obligate primary and post-primary schools to develop and implement Student Support Files (SSFs) for their autistic pupils;
- Commence the collection, analysis and regular publication of data relating to the rate of expulsions, suspensions and absences of pupils enrolled across all levels and streams of schools;
- Collaborate with the NCSE, school management bodies and teaching unions to develop a national training programme on best practices for autism inclusion and engagement to be made available to all educators throughout their respective careers;
- Establish a working group, in close collaboration with the NCSE, Tusla and affected families, to examine what reform of home-schooling provisions is necessary and which further supports are needed;
- Increase funding for the School Transport Scheme for Children with Special Educational Needs with a clear focus to widen the Scheme's outreach for more pupils and families in need.

The Teaching Council of Ireland should . . .

- Instill a culture of responsibility from initial teacher training's (ITE's) outset, ensuring that student teachers are aware of what procedures are in place for reporting exclusion and what bodies are responsible for holding schools to account in educating and supporting autistic pupils;
- Ensure that at least one placement during ITE is conducted within either a special school or a special class attached to a mainstream environment, obligating hosts to provide the necessary tools for student teachers to meaningfully engage with pupils, receive practical advice from experienced educators working there, and self-evaluate.

The NCSE should . . .

- Build on the model of inclusion set out in the *NCSE Guidelines for Educating Autistic Pupils* (2016), along with wider ambitions to involve families and wider stakeholders;
- Place an onus on local SENOs to help provide a school placement within a set timeframe, incurring possible penalties if an appropriate place is not found within a reasonable space of time;
- Establish local 'hubs' or best practice associations through the NCSE Special Education Support Service, whereby educators, regardless of their specialty or

tenure, may practically learn from and support one another through exchange of ideas and training;

- Conduct research into school absences and exclusions in the interests of formulating explicit policies and guidelines for teachers to act on if an autistic pupil of theirs is experiencing disruptions in their education.

The Teachers' Trade Unions should . . .

- Actively collaborate with autism-focused charities and advocacy groups in developing autism-specific CDP courses for knowledge-building and best practices in inclusive education;
- Encourage their members to make use of existing resources on autism, including AsIAM's *AsYouCan* guides and School Workshops Programme, as well as training courses delivered by organisations such as the Middletown Centre for Autism.

The Schools' Boards of Management should . . .

- Explore all options available to them before recommending that autistic pupils sitting in a mainstream setting with overly complex needs should be expelled, suspended or transferred to a special school;
- Provide transition training during Sixth Class, explaining the differences between the two levels in terms of routine, curriculum, workload, what supports are available and possible sensory challenges;
- Embed transition and integration as core benchmarks within a School Support Plan's checklist for First Year pupils, with a long-term view on tackling areas of personal development among stakeholders;
- Actively engage with families at regular intervals throughout First Year, providing up-to-date information on what supports the school offers and what entitlements are available in terms of assistive technology and support schemes;
- Engage in awareness-raising campaigns for autism and other forms of neurodiversity within schools, inviting local groups and advocates to actively engage with pupils and encourage greater discussion.