

# Exploring the school experiences of Autistic Children and Young People

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## List of Abbreviations

Abbreviation	Definition
<b>AslAm</b>	Ireland's National Autism Charity
<b>CAMHS</b>	Child and Adolescent Mental Health Services
<b>CDNT</b>	Children's Disability Network Team
<b>C/YP</b>	Children / Young People
<b>EPSEN</b>	Education for Persons with Special Educational Needs
<b>EWO</b>	Education Welfare Officer
<b>GoI</b>	Government of Ireland
<b>IEP</b>	Individual Education Plans
<b>IHREC</b>	Irish Human Rights and Equality Commission
<b>IP</b>	Interview Participant
<b>ISB</b>	Irish Statute Book
<b>NCSE</b>	National Council for Special Education
<b>NDA</b>	National Disability Authority
<b>NEPS</b>	National Educational Psychology Service
<b>PCT</b>	Primary Care Team
<b>P/G</b>	Parent / Guardian
<b>SENO</b>	Special Educational Needs Organiser
<b>SET</b>	Special Educational Teacher
<b>SP</b>	Survey Participant
<b>UD</b>	Universal Design
<b>UDL</b>	Universal Design for Learning
<b>UN</b>	United Nations
<b>UNCRC</b>	United Nations Convention on the Rights of the Child
<b>UNCRPD</b>	United Nations Convention on the Rights of Persons with Disabilities

## Executive Summary of Findings

### Voice of the Autistic Young Person - Executive Summary

- Young people reported feeling like they had to mask their autistic characteristics to at best make friends and at worst, prevent themselves from being bullied or excluded, which led to feeling they were ceasing to be themselves. To protect herself from stigma one young person chose not to disclose her Autistic diagnosis during school, but then had to endure listening to her friends making *"fun of other people's Autistic traits"* in front of her, which was deeply hurtful.
- Young people described the psychological and emotional burden of masking *"to be liked and respected."* Young people described having to force themselves to behave in a different way to fit in. *"Going into school... I was acting like everything was alright, in fact, when I was kind of crumbling inside and it was all too much, I felt as if everything was going too fast"*.
- While school policies claim to promote equality, diversity and inclusion, young people felt there was minimal understanding of what this means in practice. As one young person suggested: *"saying one word [in the school policy] about inclusion is not going to work, there needs to be ... more detail about what inclusion is"*.
- Young people repeatedly highlighted the absence of their voice in the decisions that are made for them, for example in the design of their individual support plan.
- While schools officially welcomed Autistic students, participants felt there was a lack of awareness and understanding of Autism and that it was not integrated into everyday life of the school. According to one young person, *"it's not openly talked about outside of Autism week"*, but Autism *"exists 365 days of the year."*
- Young people described experiencing school as a battle, where they found themselves *"having to fight so hard to get accommodations"* such as regular breaks.
- Young people highlighted the requirement to adhere to a strict school uniforms policy as being in opposition to claims of inclusion as well as being a significant source of tactile discomfort.
- Numerous young people received their diagnosis late in their schooling, which they described as seriously impacting the level of support they received and the reasonable accommodations they could request.



## Voice of the Parent/Guardian - Executive Summary

- The Autistic child's experience was reported to be more negative in mainstream post-primary schools than at mainstream primary school.
- A significant number of parents/guardians noted their child's social experience as negative, with several parents/guardians describing their child as excluded because of being Autistic or stimming in the school environment.
- A high volume of parents/guardians reported to receive no support following a request to the EWO, HSE CAMHS, NEPS, Primary Care Teams, CDNTS, and SENOs.
- Parents/Guardians reported a lack or insufficiency of school supports and resources as the most frequent reason for their child to have a negative experience of school.
- Parents/Guardians expressed significant frustration by what they described as a lack of school commitment to obtain resources to support their child, which included confused or inconsistent messaging as to where and how they can be obtained.
- Parents/Guardians also described some school provisioning as inappropriate to their child's needs, for example "*using toilets as a sensory room*".
- Across the findings, the extent to which some children feel the need to mask their autistic identity at school is highlighted, with some children refusing support, to lower the risk of being seen as different.
- Homework in many cases was described as "*difficult*" and "*stressful*", with just under half of the parents/guardians surveyed expressing a negative sentiment on this.
- Parents/Guardians described their child receiving inappropriate and unfair 'punishments' for simply displaying Autistic characteristics and actions (e.g., stimming)
- On two occasions, Parents/Guardians described how their child's reasonable accommodations were permitted or withdrawn as part of a reward / punishment system used to control the child's actions.
- Parents/Guardians described their child as feeling "*unsafe*", "*scared*" or "*fearful*", while others mentioned their child returning home with an "*unexplained injury*" or referred to excessive force used on their child causing bruising.
- Parents/guardians identified a lack of understanding amongst teaching staff as a major cause for concern and frustration.

- Parents/Guardians were often keen to stress that their child's non-attendance was not related to disinterest in education but to the inaccessibility of the physical and social environment of schools in Ireland.
- Some Parents/Guardians felt that reduced timetables were used instead of providing the required supports.





# Introduction

## Research Aim

The aim of this research is to explore the extent to which education practices in Irish schools are inclusive of Autistic young people, in line with the United Nations Convention on the Rights of Persons with Disabilities [UNCRPD].

## Research Rationale

The rationale for this research comes from the work of the AslAm Community Support Team who identified several issues and barriers around education practices within Irish schools. Through AslAm's casework and engagement with community members, the team recognised these as having an exclusionary effect on Autistic students. Nationally and internationally, there is an increasing tendency towards inclusion of Autistic children and young people in mainstream schools, despite gaps in academic research and professional practice on how best to support Autistic students in mainstream education<sup>1</sup>. In light of this, AslAm sought funding from the Irish Human Rights and Equality Commission [IHREC] to explore education practices in the Irish school system (mainstream, mainstream with Autism class and special schools) and how they impact Autistic school age children and young people. This project was funded under the IHREC Grant - Scheme Supporting compliance with the Public Sector Equality and Human Rights Duty.

It is intended that this research will inform our advocacy around education as Ireland seeks to build a holistic, inclusive education system in line with our international obligations. The findings and recommendations of this project will be shared with the key relevant public bodies involved in developing inclusive policy and practices with the intention of supporting their implementation of Section 42 of IHREC ACT 2014 - The Public Sector Equality and Human Rights Duty.

This research explored the perspectives of Autistic young people and parents / guardians regarding the educational experiences of Autistic children and young people. In order to gain a firsthand understanding of the educational experiences of young people, five participants from diverse contexts were interviewed who were either attending or recently finished school. Parents / guardians participated in a survey which sought to provide both quantitative and qualitative information relating to their child's or young person's educational experience.

## Research Framework

This research is a qualitative exploration of Autistic children's and young people's experience of education from a human rights perspective, complimented by parents/guardians' perspective of their child's/young person's experience.

## Background

### Policy emphasis

In recent decades there has been a shift in educational policy nationally and internationally. Internationally, the United Nations Convention on the Rights of the Child (UNCRC)<sup>2</sup> became a significant driver for policy change in educational provision for children with additional learning needs and/or disabilities. Ireland ratified the UNCRC in 1990. The UNCRC treaty outlines a multitude of children's rights including the right to an education (Article 28). In ensuring this right the UNCRC requires the State to "ensure that the disabled child has effective access to [...] education, [...] and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development" (Article 23). In February 2023, the UNCRC published its combined 5<sup>th</sup> and 6<sup>th</sup> periodic report on the Irish State's implementation of the UNCRC treaty. The review acknowledged multiple improvements, but it was also critical of the Irish State's response to several children's rights requirements, which recognised the need to:

- Update legislation in line with a human rights-based approach to disability;
- Reduce the waiting times for assessments and diagnoses, particularly relating to mental health;
- Improve social integration and individual development for children with disabilities;
- Combat discrimination against children with disabilities and promote a positive image of them as rights-holders through awareness-raising campaigns;
- Ensure the right of children with disabilities to be heard in all decisions that affect them;
- Invest in suicide prevention measures and allocate resources for mental health advocacy for children<sup>3</sup>.

### The Education Act 1998

In Ireland the right to an education is protected under both the Irish Constitution and a range of other Acts and Treaties. Of particular interest are the Education Act 1998 objectives which state:

- (a)** to give practical effect to the constitutional rights of children, including children who have a disability or who have other special educational needs, as they relate to education;
- (b)** to provide that, as far as is practicable and having regard to the resources available, there is made available to people resident in the State a level and quality of education appropriate to meeting the needs and abilities of those people;
- (c)** to promote equality of access to and participation in education and to promote the means whereby students may benefit from education.<sup>4</sup>

## The Education for Persons with Special Educational Needs [EPSEN] Act 2004

The Education for Persons with Special Educational Needs [EPSEN] Act 2004<sup>5</sup> is a piece of Irish legislation that provides for the educational needs of children. It aims to ensure that children with additional educational needs receive an education that is appropriate to their needs and abilities, and to promote equality of access to education for these children. The act requires that schools make reasonable accommodations for students with needs and mandates the creation of a national database of educational resources for students with disabilities (reasonable accommodation within a mainstream setting can be understood to mean that children with needs will be educated in mainstream schools providing it is consistent with their best interests and does not affect the educational provision of other children)<sup>6</sup>. Through the establishment of the National Council for Special Education [NCSE], the EPSEN act initiates a process for the assessment of the educational needs of children with disabilities and provides for the creation of Individual Education Plans (IEPs) to support their education<sup>7</sup>.

### Individual Education Plans (IEPs)

IEPs are the mechanism for addressing the additional education needs of children. An IEP “provides evidence of the agreed additional educational interventions and other supports to be provided for the child together with recording parent, student and teachers’ views. An IEP also records the strategies that need to be used to enable a child to progress in the education system”<sup>8</sup>. While the EPSEN Act was received as a ground-breaking initiative in addressing children’s educational needs, it is almost two decades since it was passed and Inclusion Ireland highlight much has yet to be implemented, meaning:

- a child with a special education need does not have a legal right to an assessment of their education needs and have these identified needs addressed through an IEP. Parents have no legal right to have an input into the IEP. Because the Act has not been implemented, children’s rights are at the whim of policy makers, changes in government, funding priorities and other factors<sup>9</sup>.

Teachers and other professionals view IEPs as a valuable for ensuring that students individual needs are maintained and addressed<sup>10</sup>. However, several national and international criticisms of IEPs have emerged, including: having too many purposes ascribed to them (a single IEP is often also an educational, legal, planning, accountability, and resource allocation document); there can be a heavy emphasis on behavioural psychology (i.e. observing the students behaviour rather than understanding the student’s experience); there is an over-emphasis on the individual (as opposed to the school environment or resources); and they are not proven to be effective in addressing the special educational needs of children<sup>11</sup>.

## United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities [UNCRPD] 2006 focuses on promoting, protecting, and ensuring 'the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities' (Article 1). The UNCRPD identifies measures viewed as facilitating this purpose, namely:

Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others<sup>12</sup>.

Here we see a shift from the medical model of disability, which focuses on addressing the person's individual impairments, to the social model, which recognises that societies are often structured in ways that facilitate the enabling inclusion of some and leads to the disabling exclusion of others. In forwarding a more social model of understanding and addressing disability the UNCRPD promotes use of the principle of Universal Design defined as:

- the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design (Article 2<sup>13</sup>).

The UNCRPD was not ratified by Ireland until 2018. This treaty requires the State 'to undertake or promote research and development of universally designed goods, services, equipment and facilities' to be inclusive of and accessible to everyone without the need of 'special' accommodations. Therefore, services such as education and environments such as schools should be incorporating both the social model and the principle of universal design emphasised by the UNCRPD as well as the requirement to directly consult disabled people on anything and everything that will affect them, as stated in the disability rights mantra 'nothing about us, without us'.

Every two years the UNCRPD Committee produces a report reviewing and updating the UNCRPD instrument. In 2016 the Committee included the right to an inclusive education in General Comment no. 4, of their report. Here the Committee emphasised the right of persons with disabilities to education, without discrimination and based on equal opportunity, as enshrined in Article 24 of the UNCRPD. They recognised that despite the progress achieved they remained concerned that many persons with disabilities were still being denied the right to education. General Comment no. 4 focuses on full and effective participation, accessibility, attendance and achievement of all students.

Ensuring the right to inclusive education entails a transformation in culture, policy and practice in all formal and informal educational environments to accommodate the differing requirements and identities of individual students, together with a commitment to removing the barriers that impede that possibility<sup>14</sup>.

Ireland is perceived to be world leaders in the development of Universal Design [UD] and Universal Design for Learning [UDL]. In 2007 the National Disability Authority [NDA] established the first statutory Centre of Excellence in Universal Design founded under the Disability Act 2005, which remains the only centre of its kind in the world. The centre is informed by a diverse range of stakeholders in seeking to:

- develop and promote standards in universal design;
- integrate UD and UDL into the education system;
- raise awareness of the benefits of the UD approach;
- make society easy to use and easy to understand for all without modification<sup>15</sup>.

The recent Joint Committee on Autism recommends that funding and guidelines are provided to all schools constructing new premises to ensure that they are built in line with the principles of Universal Design<sup>16</sup>.

## IHREC – Public Sector Equality & Human Rights Duty

The Irish Human Rights and Equality Commission [IHREC], was established through the Irish Human Rights and Equality Commission Act 2014<sup>17</sup> and has a mandate to protect and promote human rights and equality in Ireland<sup>18</sup>. The Public Sector Equality and Human Rights Duty ('the Duty') is contained in Section 42 of the Irish Human Rights and Equality Commission Act 2014 known as the "The Duty". "The Duty" is a legal obligation on public bodies to have regard to the need to eliminate discrimination, promote equality of opportunity and protect the human rights of all public sector staff and service users. The concepts of discrimination, equality of opportunity, and human rights are central to the Irish Human Rights and Equality Commission Act 2014.

**The concept of discrimination** is defined in the Irish Human Rights and Equality Commission Act 2014 in terms of the definitions provided in the Employment Equality Acts 1998-2015 and the Equal Status Acts 2000-2015. The nine protected grounds are: gender, civil status, family status, sexual orientation, disability, age, race, religion and membership of the Traveller community.

**The concept of equality of opportunity** under the Duty should be understood as requiring more than the elimination of discrimination but also a basis for positive action to address inequality.

**The concept of human rights** in the requirement under the Duty to protect human rights, is defined in the 2014 Act as the rights, liberties and freedoms that are conferred on, or guaranteed to persons, by the Irish Constitution.

The Duty applies to all public bodies including the Department of Education, Higher Education Institutes, Education and Training Boards and state organisations such as the National Council for Special Education. However, the Duty does not currently apply to schools.

The Equal Status Acts (2000-2018) do apply to primary and second-level schools. These Acts together with the education legislation are used to ensure that schools are inclusive, and respect and accommodate diversity. The aim of the Acts are to promote equality of opportunity, prohibit discrimination on the nine protected grounds, prohibit harassment and sexual harassment, require reasonable accommodation of people with disabilities, and allow for positive action.

A recent Public Consultation on the Autism Innovation Strategy<sup>19</sup> recorded insufficient specialist places/classes for Autistic children in primary and post primary schools, insufficient specialist Autism-specific training available to primary and secondary school staff, and a lack of access to appropriate supports. In June 2023 the Final Report of the Oireachtas Joint Committee on Autism<sup>20</sup> was published containing 109 recommendations to improve the lives of Autistic people in Ireland. In all 31 of the recommendations were to improve education.



## The Autistic Voice

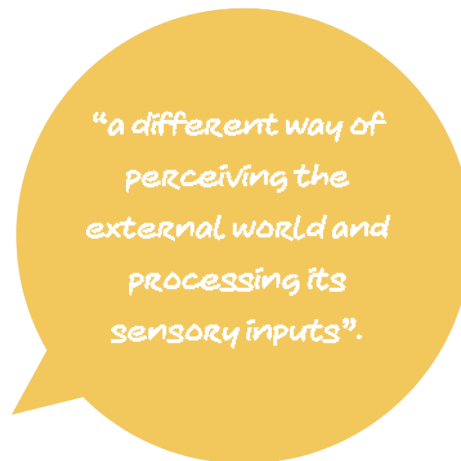
The term Autism has existed for over 100 years but in that time has referred to a wide range of often contradictory psychological and behavioural characteristics<sup>21</sup>. While widely researched, there is growing concern that much of the knowledge produced has been from the perspective of an outsider looking in<sup>22</sup>. Harvey states: “in our science-driven world, academic and professional knowledge [...] have become paramount over personal or lived / embodied knowledge”<sup>23</sup>. Up until recently Autism was objectively defined by clinicians and researchers as a collection of behaviours or psychological characteristics which were often pathologised through the application of terms like ‘disorder’<sup>24</sup>. Such use of pathologising and stigmatising language justifies a view of Autism that emphasises deficits over strengths, which leads to inaccurate and unjust impressions of Autism<sup>25</sup>. Viewing Autism as a ‘disorder’ presupposes that Autism is something that ought to be ‘fixed’, which has led to funding being diverted towards the identification of biological or cognitive causes and treatments. Significantly, the Autistic community has not sought this research. The issues of day-to-day living and societal access are concerns for the Autistic community, but these are rarely subjects of research. As one UK study highlights only 27% of research funding on Autism was spent on what the Autism community identified as their top ten priorities, raising the question - who is Autism research designed to benefit?<sup>26</sup>.

One area recognised as being particularly under-researched is the experience of education from the perspective of Autistic school-aged children and young people (C/YP), both nationally and internationally<sup>27</sup>. As highlighted by McDougal, et al., (2020)<sup>28</sup> research exploring Autistic children’s and young people’s educational achievement often focuses on objective observation and evaluation of behaviours rather than attempting to subjectively understand children’s and young people’s experiences. It should be noted that the UNCRC. Article 12 emphasises the importance of respecting the views of children and their right to express them. Article 12 also recognises that persons with disabilities have legal capacity on an equal basis with others and recognises that some persons with disabilities require support to exercise this capacity.

Though the EPSEN Act sought to address the special educational needs of Autistic children, there are growing concerns that these are not being met and that their voices are not being heard<sup>29</sup>. Some studies have highlighted that even where Autistic voices are sought the very mechanisms used to gather information are exclusionary, for example, the emphasis on text and speech immediately limits or excludes the participation of visual and non-speaking contributors, with the result that research reflects the perspectives of only a small cohort<sup>30</sup>. While participatory research methods were recognised as an ideal mechanism for identifying inclusive modes of participation, the majority of research on Autism in education was “conducted ‘to’ the participants and not ‘with’ them”<sup>31</sup>.

## Autism and Education

While some Autistic C/YP flourish at school, difficulties with social engagement, sensory distress, anxiety, and depression can make the experience of school challenging for others<sup>32</sup>. While it has been suggested that online learning may suit Autistic students better, recent research suggests that though their experiences may differ, Autistic students also encounter difficulties with this mode of learning<sup>33</sup>. Additionally, online learning does not facilitate social participation, which is important for social development and emotional well-being<sup>34</sup>. Autism advocate, educator and author Dr Catherine Harvey defines Autism as



As she notes, difference implies a need for alternatives particularly with regard to education. In the absence of appropriate alternatives, education becomes inaccessible and disabling. After three decades of advocating for the inclusion of Autistic children in mainstream schools, Harvey says she has concluded that the reductive 'one-size-fits-all' approach to schools and classrooms does not work for everyone, "especially those with Autism"<sup>35</sup>. She argues that this approach does not develop the "flexible, empathetic response and a celebration of difference"<sup>36</sup> necessary to adapt classrooms to a diversity of students. In her book *Difference not Disorder*<sup>37</sup> Harvey sets out the necessary elements for a successful schooling experience designed around what she recognises as the strengths of the Autistic mind. While focusing on the needs of Autistic students, Harvey is keen to point out what she is proposing is not segregation but adaption, "adaption that is not of the child to the classroom, but of the classroom to the child"<sup>38</sup>. Some of the essential elements Harvey identifies include, finding methods to address sensory and physical needs, using visual images as educational and communication tools, and the development of appropriate mechanisms for, what she terms, managing challenging behaviours Harvey concludes:

Creative and reflective teaching practices are necessary if teachers are to adapt their individual classrooms to the different strengths and needs of each year's students<sup>39</sup>

One feature of modern schools which Harvey believes is particularly difficult for Autistic children is discipline. While school discipline policies are becoming more detailed, the varied interpretations of these by teaching and non-teaching staff means students may be reprimanded for a behaviour in one classroom, while it is greeted with amusement in another. Navigating these inconsistencies can be particularly difficult for many Autistic students. Instead, Harvey advises that rules should be few but consistently applied.



She recommends against implementing rules that are likely to be subject to change or interpretation and emphasises use of positive rather than negative rules, i.e., students are *encouraged* for doing... rather than *punished* for doing...<sup>40</sup>.

In her book *Inclusive Education for Autistic Children* Rebecca Wood (2019)<sup>41</sup> argues that in many instances these difficulties experienced by C/YP are not the fault of the C/YP's perceptual difference but emerge as a result of the way the education system is structured. When exploring biological states described as 'disability' social scientists often employ a distinction between the medical model – the idea that the disorder is innate – and the social model – the idea that the disorder is socially constructed, meaning that the way society has structured institutions like education can make participation in those institutions difficult for some people. To raise awareness of these exclusionary social structures Wood emphasises the socially constructed barriers to education, but also to oppose the stigmatising assumptions that Autistic people are intrinsically 'disabled'. In posing the question; '[i]s Autism a disability?', Wood answers:

Well, yes, if you fail to understand and accommodate Autistic people, if you expect them to slot into the status quo, regardless of their needs, wishes and particular dispositions. If children spend their educational life being essentially told, one way or another, that they are flawed, damaged goods, then this may well result in a disabling lack of self-confidence, or serious mental health issues in later life<sup>42</sup>.

Regarding the provision of education,

Wood highlights an important distinction between 'needs' and 'rights'. A 'needs-based' perspective on educating Autistic students situates the disability within the child or young person, whereas a 'rights-based' perspective suggests that we do not regard some children as having 'additional needs' or 'special needs' but that all children have a "right to a fully accessible and inclusive education in which 'unique differences' are accommodated and integrated"<sup>43</sup>.

In a section entitled "The Inclusion Delusion", Wood (2019)<sup>44</sup> highlights how the very provision offered to students to ensure inclusion – Statements of Special Educational Need – are signifiers of exclusion, with these students being three times more likely to be permanently excluded from school. Focusing on Autistic students the situation is even worse where they were found to be four times more likely to be permanently excluded. In addition to temporary and permanent school exclusions, many Autistic students experienced exclusions from extracurricular activities such as sports or hobby classes due to lack of availability of teaching assistants and many were told they could not go on school trips unless accompanied by a parent. Further, Wood describes in addition to school exclusions, Autistic students are subjected to micro-exclusions where they are seated separately or not included in class activities. While it might be argued that these school exclusions are due to the different needs of Autistic students which cannot be accommodated in a mainstream school, 'the rate of fixed-period exclusions of pupils in special schools is higher than for state [UK] primary and secondary schools'<sup>45</sup>.

The problem as she sees it is not how to include Autistic students in the current mainstream schooling system but how the mainstream schooling system must change if it is to be

successful in meeting the legal and educational requirements of making education accessible to all at all levels<sup>46</sup>. Evoking the principles of universal design Wood argues that this does not mean “bolting on adaptations and accommodations once all the core structures and programmes are in place”<sup>47</sup> but suggests if inclusion is to be meaningful it “must incorporate the curriculum, extra-curricular activities and design of the school building from the earliest planning stages”<sup>48</sup>.

Wood highlights how the principle of universal design as outlined by the UNCRPD emphasises the importance of attitudes in inclusion and how these can be significant barriers to full participation. Wood argues that from an educational perspective this requires that all stakeholders, including a diversity of learners, must have a voice in the design and creation of the education system at all stages and levels, where learners are recognised as experts in identifying their own needs and strengths. While outlining the above scenario she is also aware that satisfying all the needs of all students in all educational circumstances is not without challenges but insists that if the education system is to be inclusive it must assume a core principle of “having the same expectations for Autistic children as for any others”<sup>49</sup>.

### **Autism, Prevalence and Gender**

Since estimates began, the number of Autism diagnoses have been increasing. In 1966 the number of Autistic people within the (US) population was estimated to be 1 in 2200<sup>50</sup>; by 2022 the US Centre for Disease Control estimated the rate to be 1 in 44<sup>51</sup>. Many reasons for increasing numbers of Autism diagnoses have been suggested including environmental toxins<sup>52</sup> and population migration<sup>53</sup>. More recently increases have been attributed to growing awareness, public health responses, broader definitions, and identification of Autism in previously under-recognised populations, for example women and girls<sup>54</sup>.

As discussed above, over the last century Autism has meant very different things at different times. As descriptions of Autism have evolved, more and more people have been recognised as Autistic. In 2002 Baron-Cohen described Autism as an instance of ‘extreme male brain’ development<sup>55</sup>. This now somewhat outdated theory of Autism has been subject to considerable criticism for a variety of reasons including the generation of male bias in recognition and diagnosis of autism<sup>56</sup>. It suggests that human brains develop along a sex differentiated continuum where in one direction we have the empathising brain (typically female) and in the other we have the systemising brain (typically male). Baron-Cohen used this to argue that males are more likely to be Autistic because the shift along the continuum from systemising (male brain) to extreme systemising (Autistic brain) is small, whereas the shift from empathising (female brain) to extreme systemising (Autistic brain) is much larger, thus women and girls are less likely to be Autistic than men and boys. While the literature on Autism consistently suggests a male to female Autism ratio of 4:1, several recent papers that correct for sex bias suggests that far more girls and women may be Autistic than first estimated<sup>57</sup> with a ratio of 2-3:1 girls to boys now regarded as more accurate<sup>58</sup>. Decades of male bias has meant that sex difference in Autism has been profoundly under researched resulting in a limited understanding regarding the particular needs and experiences of Autistic girls and women. In their paper Rynkiewicz et al. (2019) highlight how Autism identification is based almost entirely on observations and research on males. As a result girls and women with Autism are often undiagnosed, misdiagnosed or receive a diagnosis of Autism at later age. This can result in

adverse outcomes in their well-being, mental health, education, employment, and independence<sup>59</sup>.

Rynkiewicz et al's research shows that Autism in girls and women manifests differently to boys and men, often being associated with increased compensatory behaviours such as masking. They argue that the lack of social awareness and clinical recognition of female Autism is leading to delays in girls and women getting supports which is impacting their access to health, education, leisure, social relationships, and employment and needs to be addressed. Not surprisingly then, Autism in females is also associated with poorer mental health, particularly during adolescence which can include high incidences of suicide, depression, anxiety, and eating disorders.

In her 2020 PhD research on Autistic girls' absence from mainstream secondary schools, Ruth Moyle highlights how Autistic girls are now more likely than Autistic boys to be missing from school and the problem is worsening for a variety of reasons, most notably the lack of recognition of Autism in girls and the consequent lack of recognition of their needs. While it is already known that schools refer girls for an Autism assessment later than boys, Moyle found that of those likely to make a referral, schools were the least likely to refer girls, with teachers often citing other reasons for girls' classroom behaviours. Rather than being recognised as evidence of unmet need, Autism in girls was often viewed as deviant, leading girls to feel marginalised and unwelcome:

The apparent lack of awareness that girls can be Autistic is significant. A further implication is that teachers may not, as a result, support a parental request for their child to be assessed. In addition, they may not provide the appropriate support for a potentially Autistic girl pre-diagnosis or, as evidenced by this research, not accept an Autism diagnosis as valid nor understand that a pupil with a neurological condition may not visibly demonstrate their needs in class<sup>60</sup>.

Moyle argues that if schools are to meet their legal obligations in meeting the needs and supporting the strengths of students, they must ensure the voices of all students are heard. However, her research found that Autistic girls were not asked about their needs, were not believed or their requests were not acted on, meaning their needs were often left unmet and their strengths unrecognised. This has led to profoundly negative experiences of school, poor mental health, and consequently reduced levels of school attendance. Contrary to claims of inclusivity, Moyle argues, schools continue to be deeply conservative institutions where a heavy emphasis on conformity and uniformity makes responding to individual needs difficult for teachers and support staff. While schools may argue this is in part fuelled by a combination of limited resources and pressure to produce the best results, the participants in Moyle's research repeatedly conveyed the message that while very keen to learn, girls are far more interested being part of an educational system that cares for their overall wellbeing than one that prioritises grades.

Ultimately, Moyle arrives at very similar conclusion as those of Harvey and Wood above, namely that despite reams of legislation, the school system is failing Autistic students in general and girls in particular. She highlights the need to make C/YP's voices central in understanding their needs.

Particular teachers who encouraged, believed and formed a strong relationship with the girls had a profound impact on their school experience. Acknowledging this Moyses recommends that “schools should recognise the value to Autistic [young people] YP of an adult they can trust to be their ally and understand that this adult must be chosen by the YP, and not the school”<sup>61</sup>. Many of the participants in Moyses’s research found that the impact on their mental health of continued unmet needs left them with no alternative other than school absence. Moyses recognises a need for a major shift in education where schools offer a broader curriculum and high academic teaching along with a nurturing environment that address everyone’s needs, for example allowing students to watch online classes – if it was acceptable during the pandemic why not now? Finally, Moyses recommends that all teachers and teaching assistants undergo training to better understand what it means to be Autistic as many teachers seemed to have little or no knowledge of Autism, particularly in relation to girls, which leads to delayed assessment and lack of supports.

## Methodology

### Introduction

This project involves a comprehensive review of education practices for Autistic school-aged children in Ireland. A literature review explored barriers to education for Autistic C/YP nationally and internationally. (To capture first-hand the educational experiences of Autistic school-aged children from the young people and parent/guardian(P/G) perspectives the research team used a mixed methods approach. An online survey was developed for P/G of Autistic school-aged children and semi-structured interviews were conducted with Autistic young people.

### Parent/Guardian Survey

The impetus for this research came from a growing body of anecdotal evidence gathered by AsIAM suggesting that there may be a variety of issues in schools that may be exerting an exclusionary effect on Autistic schoolchildren. An important function of this research was to identify whether this anecdotal evidence reflects a national picture that could be indicative of, for example, state policy or broad educational practices in general, or alternatively, reflective of the more particular concerns of a localised but vocal minority. To achieve this the researchers needed to gain a broad and general picture of P/G perspectives on their Autistic children’s experience of school. Where more than one member of the household was an Autistic school-aged child the researchers asked, if possible, to complete a separate survey for each. The online survey was distributed to P/Gs of Autistic school-aged children who were members of the Autism community in Ireland . In all n=383 people responded but after initial screening the final number of completed surveys was n=353. The sample is representative of the variety of contexts in which children are schooled and reflective of the diversity of P/G perspectives. The survey was designed with a large qualitative component<sup>62</sup> and a thematic approach was used to analyse the data.

## Interviews with Autistic young people

To understand the subjective experiences and perspectives of the participants the research team employed an interpretivist methodology using qualitative and inductive methods. As this project was time-sensitive certain desired methods were outside its remit, i.e., participatory research. However, the research team were informed by an advisory group made up of Autistic and non-Autistic experts from AsIAM including an occupational therapist, speech and language therapist, and the Accessibility Officer. Together the research team and the AsIAM Advisory Group developed specific strategies to ensure engaging in this research was as Autism-friendly as possible, for example use of visual communication methods to ensure fully informed consent and how best to adapt the interview environment to the young person's sensory and communication preferences.<sup>63</sup> The research team and the AsIAM advisory group agreed that a maximum of eight interviews would be conducted to ensure an in-depth interview took place with participants.

An invitation for Autistic young people to take part in the research project was shared on AsIAM's social media platforms, newsletter and website. Sent with the invitation was a short survey form that included an 'Expression of Interest' section, inclusion criteria, and a request for demographic information to ensure a broad sample. To be eligible a young person had to be Autistic (diagnosed or self-declared), aged 16 or over, attending school, fluent in English and able to articulate their experiences (verbal or written). Participants who were aged 16 or 17 needed to have their P/G give informed consent on their behalf, to have the capacity to assent on their own behalf and had to be accompanied during the interview by a parent or familiar adult. Participants aged 18 or over needed to have the capacity to give informed consent and they were invited to have a parent, guardian, or familiar adult to accompany them during the interview. All participants, parents, guardians or accompanying adults had to be able to travel to an agreed public enabling environment where the interview would take place.

The initial response was n=19 and after checking against the inclusion criteria n=16 young people were eligible to take part. The research team selected n=8 young people that represented the broadest sample - age, gender, school class type, location, member of ethnic minority and preferred communication method. This group was contacted and invited to join the project and n=3 completed the consent/assent forms and agreed to be interviewed. The remaining n=8 were also contacted and invited to remain on a reserve list and n=4 agreed. The reserve group were contacted and n=2 completed the consent/assent forms and agreed to be interviewed. While the researchers had tried to include as broad a range as possible in total n=5 young people were interviewed n=4 girls and n=1 boy. The age range was n=1, 16, n=2, 17 and n=2, 18 or over.

Participant information, consent and assent forms, as well as the interview questions, were emailed to the participants when they were invited to take part. The interview questions were sent so that the participants would be familiar with the questions and could select the questions that they would like to answer. In keeping with the qualitative / inductive methodology interviewing, questions were general. Interview participants were also invited to write a question they would like to be asked during the interview.

When the participants agreed by email that they wanted to proceed the researchers offered a choice of venues and all the participants selected private meeting rooms in hotels close to their location. Signed consent and assent forms were collected by researchers before the interviews commenced. They were invited to bring along anything that would make them feel comfortable and asked if there were any sensory/environmental issues that the research team should be aware of. The research team brought (Figure 1), tactile and auditory supports and 'Break' 'Continue' 'Pass' and 'Finish' cards. The participants were invited to move around when they wanted to.

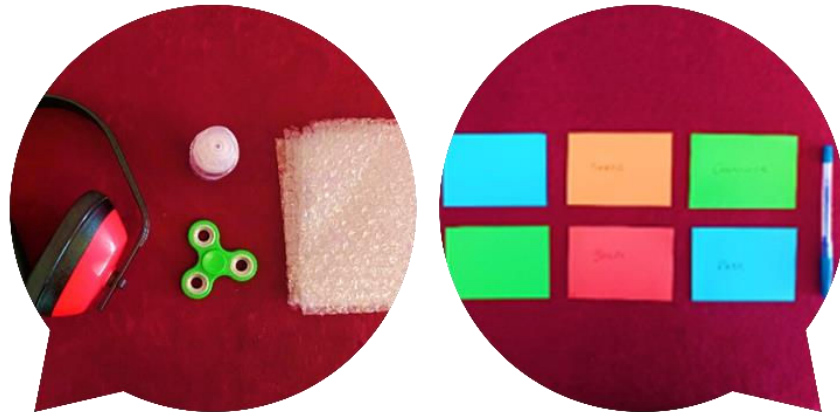


Figure 1: Interview

## Ethics

The project was given ethical approval by the Research Ethics Committee at Atlantic Technological University Sligo in February 2023. In writing the ethics application the researchers consulted a wide range of legal and ethics texts<sup>64</sup>, professional research ethics guidelines<sup>65</sup>, UN Commission articles<sup>66</sup> and legislative acts<sup>67</sup> to draw up an ethics framework for best ethics practice from a general and perspective. By general we mean relating to the kind of research – interpretivist social science – which is a research perspective carrying specific methodological and ontological presuppositions:

- **The aim of research is to understand the participant's world from their perspective.**
  
- **The research outcome reflects the expressed interests and concerns of the participants.**

From a particular perspective this research aims to qualitatively explore the experiences of Autistic C/YP aged 16 years and over in Irish secondary schools. When conducting research with C/YPs there are several additional considerations, particularly around capacity to comprehend what they are agreeing to participate in and their associated capacity to consent. When dealing with young people 16 and 17 years old who have considerable autonomous capacity but are not yet legally adults, the task is to identify to what extent they can assent / consent to participate in the research and to what extent is P/G consent required. In addition to being children or young adults the participants of this research are Autistic. Whether or not Autism is viewed as conferring additional vulnerability depends largely on how Autism is understood. The researchers of this study regard Autism to be a spectrum of neurological variations that mean Autistic people perceive the world differently. Autism can be, but is not necessarily, associated with particular characteristics, benefits and disabilities. In order to understand the world from an Autistic participant's perspective researchers must facilitate effective communication by addressing the needs and preferences of participants and ensuring that the research process is safe and accessible.

## Limitations

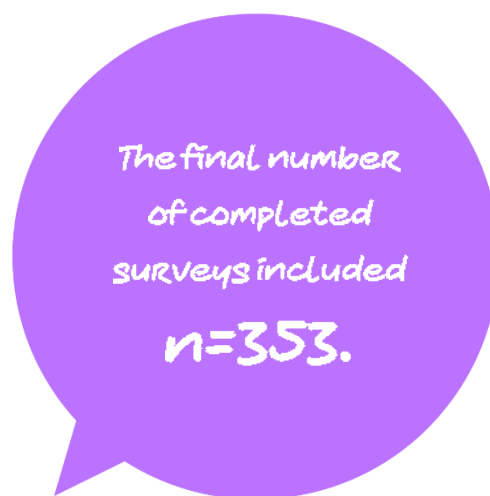
This research project has produced an extensive dataset that exceeded the researchers' anticipations. The data collected warrants further analysis to address aspects raised by the research participants. As stated at the outset this project had to be completed within a restricted timeframe. A primary aim of the research was to provide an opportunity for the Autistic community to express their experiences of school. The parent / guardian survey yielded a high response but the call for interviews coincided with Leaving and Junior exams resulting in a limited response. Planning research with school children needs to reflect the curricular demands they are under. The final sample for the young people's interviews did not reflect the expected gender balance and further research would benefit from a representative gender balance. Further research that was beyond the remit of this project but also needed is for example: an exploration of Autism in schools from teachers and support staff perspectives and also children and young people under the age of 16 years should be given the opportunity to voice their experiences of school. Finally given the historical sex bias associated with autism, a study on sex differences in educational experience could examine the extent to which the relative needs of males and females are recognised and supported in schools.



## Findings Section 1: Descriptive Analysis

### Parent/Guardian Survey

The survey was designed to explore school experiences of Autistic children and young people [C/YP] from a parent/guardian [P/G] perspective. The aim was to produce a snapshot of the current situation and was limited to P/Gs of Autistic school-aged children who had been enrolled in a mainstream or an Autism class in a primary or post primary mainstream or special school in the past two years. The survey was distributed through AsIAM social media networks. In all n=383 people responded but after initial screening.



The final number  
of completed  
surveys included  
n=353.

The results of the survey were organised in two ways: firstly, through a careful reading of each answer P/G descriptions of the C/YP's school experiences were broadly identified and colour coded using a traffic light system: green for positive; red for negative; and orange for mixed. The following is an example of the words or phrases used by parents/guardians to categorise C/YP's experience:

**Positive** - 'Good', 'brilliant', 'positive', 'enjoys', 'excellent', 'loves school', 'great', 'getting on really well', 'happy', 'fantastic', 'school is the only thing he has', 'pleasant', 'satisfactory', 'content', 'I thank God every day he got such an understanding school', 'much happier and engaged', 'loves routine of school' 'school is wonderful', 'doing well academically'.

**Negative** - 'terrible', 'poor', 'awful', 'sad', 'disappointing', 'bad', 'difficult', 'challenging', 'tough', 'hard going', 'a struggle', 'traumatic', 'horrendous', 'horrible', 'harrowing', 'threatening', 'damaging', 'simply surviving', 'not good', 'very negative'.

**Mixed** - 'bearable', 'ok', 'mixed', 'good but...', 'good days and bad days', 'challenging at times', 'generally positive but...', 'lots of ups and downs', 'improving', 'mostly good but...', 'some good days, some bad days'.

This colour coding allowed the researchers to broadly compare respondents' answers with demographic information, for example whether girls were more likely to have positive experiences than boys or whether rural schools were more often experienced as negative than urban schools. In addition to demographic/descriptive analysis a more detailed and thematic analysis of the broadest question, which asked participants to describe their C/YP overall school experience was undertaken and is presented in section 2.

## Profile of respondents

The background information was gathered to show the range of participants completing the survey and the questions centred on the school C/YP. **The survey was completed in 25 of the 26 counties and the full range of ages was represented** (see Figure 2). The majority of respondents were from Dublin (n=103) and 25 of the 26 counties were represented with 23% of the respondents from urban, 39% were suburban and 39% rural areas.

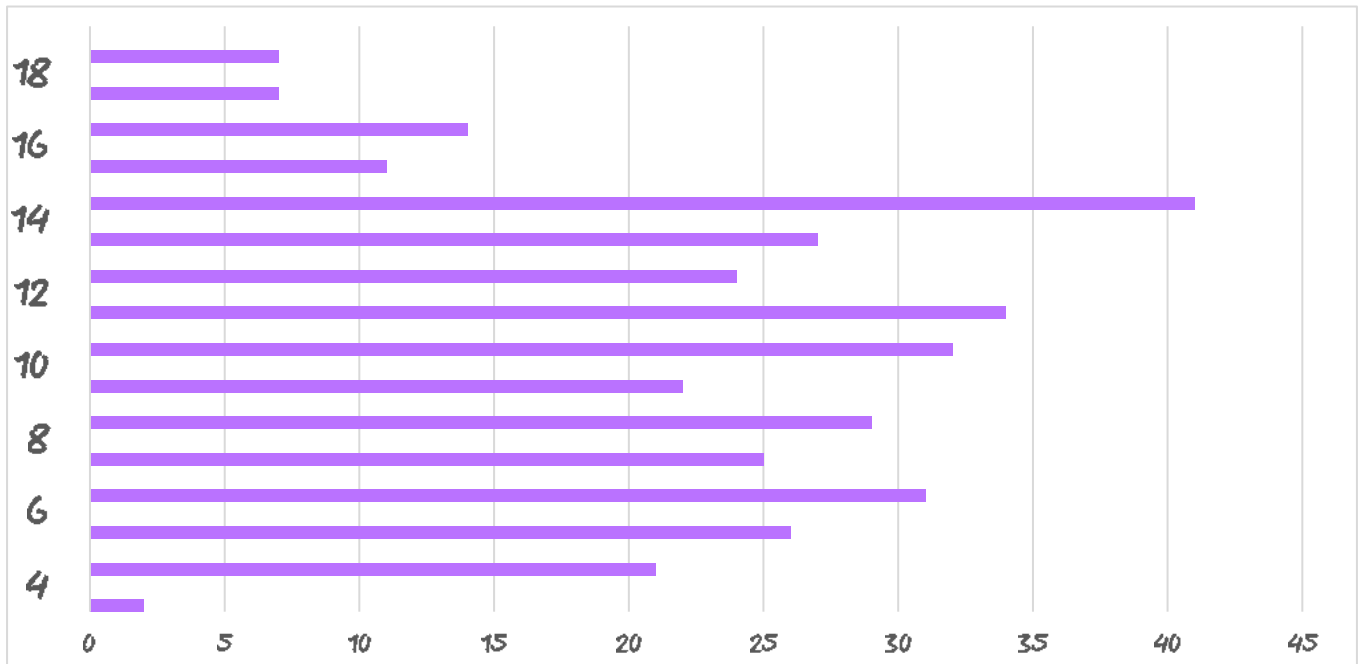


Figure 2: Age range of school aged C/YP

## Gender

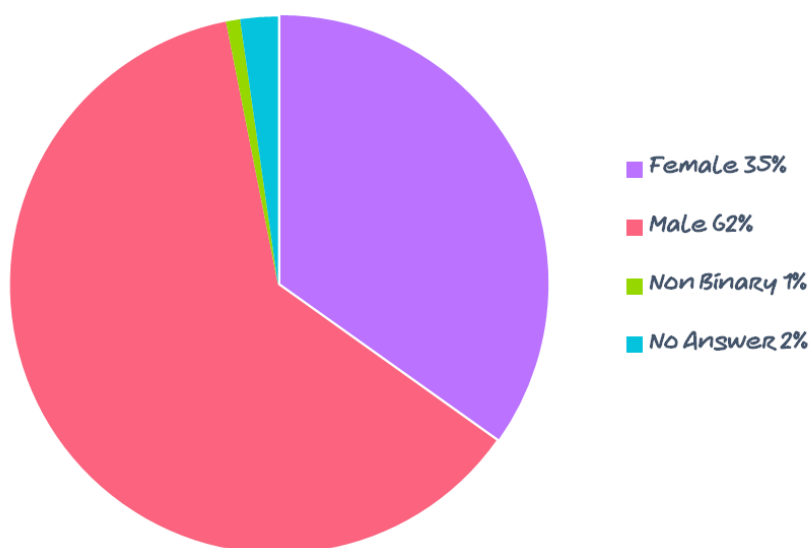


Figure 3: Gender of school aged C/YP

The majority of Autistic C/YP were male (n=219) and over half that number were female (n=123). This supports recent research that shows the prevalence ratio of autism in males to females is closer to 2:1. and in this instance the ratio is less than 2:1. Only n=3 participants selected non-binary options and n=8 chose not to answer this question (see Figure 3).

The researchers compared the responses on general school experience by gender and as shown (Figure 4) boys' general experience of school was quite evenly distributed across the traffic light system; girls were recorded as having more negative experiences (55%) and C/YP identified as non-binary and LGBTQIA+ were most likely to have a negative general experience at school (78%).

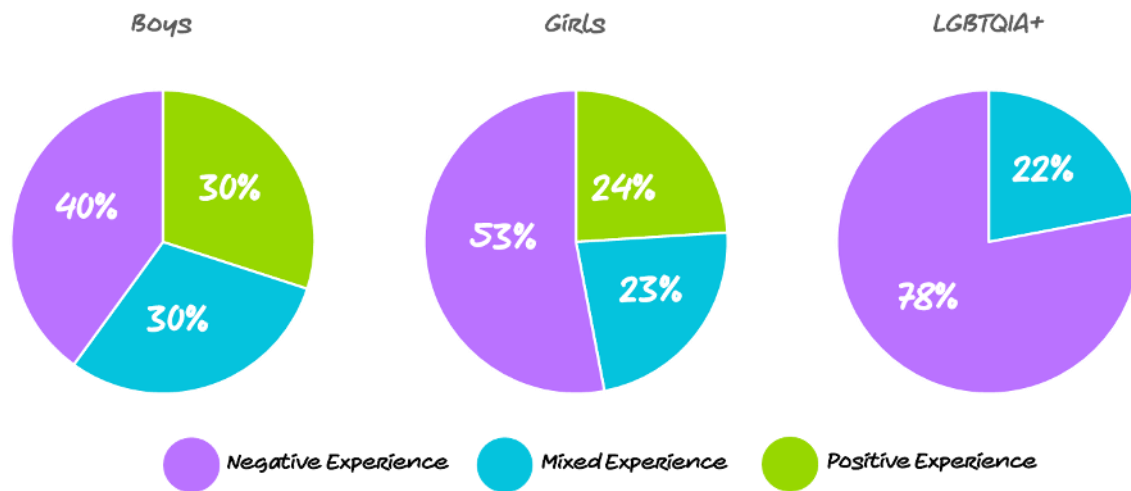


Figure 4: Experience of school by gender

The majority, just under 67%, of Autistic C/YP were attending mainstream class in mainstream primary (n=160) or mainstream post primary (n=76) schools, and 26% were attending an Autism class at mainstream primary (n=60) or mainstream post primary (n=31) school. Only 3.5% P/Gs said their C/YP was attending a special primary or post primary (n=14) school. For the remaining 3.5% who selected "Other" n=5 said their C/YP attended a combination of classes of whom n=1 said their C/YP was on a reduced timetable, n=2 were being home-schooled, n=4 said their C/YP was currently not attending school, and n=2 had recently left school. In Figure 5 the gender of Autistic school C/YP is shown in relation to class types. The numbers reflect the 2:1 boy to girl ratio in mainstream primary but are almost 1:1 in mainstream post primary and are similar in Special Education classes.

	M	F	NB	NA
Mainstream class in a mainstream primary school	104	52	1	3
Autism class in a mainstream primary school	43	17		
Mainstream class in a mainstream post primary school	40	34	1	1
Autism class in a mainstream post primary school	19	8	1	3
A class in a special primary/post primary school	7	6		1
Not in school (not attending or left recently)	1	5		
Mixed (Home school and attending part-time)	3	1		1
Home schooled	2			

M - Male, F - Female, NB - Non-Binary, NA - Not answered

Figure 5: Type of school class by gender

The increased ratio of girls to boys at post primary level may reflect Rynkiewicz et al.,<sup>68</sup> proposal that lack of social awareness of Autistic women or girls is leading to later diagnosis and delays in girls getting the support they need in schools. A very small number of Travellers (0.3%), ethnic minorities (0.8%) and others (1.4%) responded to the survey.

Geographical area was found to exert only minimal differences to the general school experiences of the Autistic children and young people as shown in Figure 6 where urban areas ranged from 28% positive to 49% negative, suburban areas ranged from 26% positive to 45% negative, and rural areas ranged from 31% positive to 41% negative.

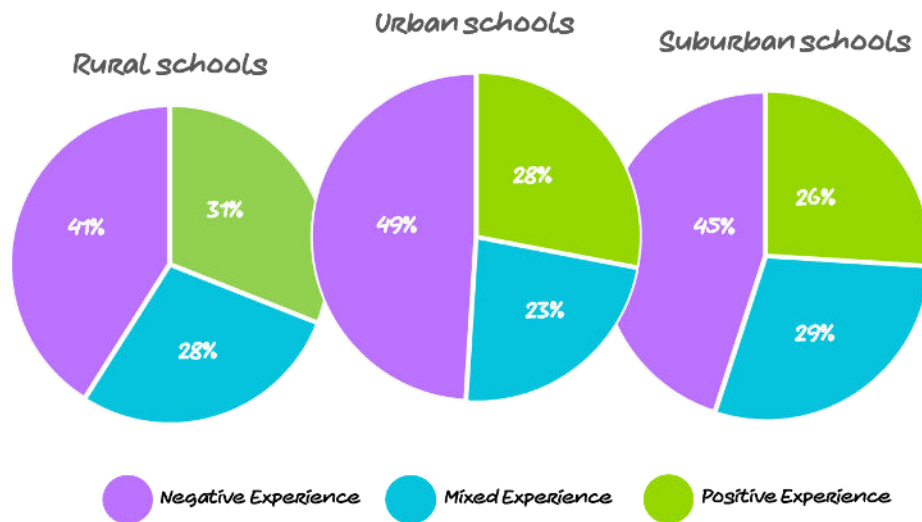


Figure 6: General school experience by area

The data from the question 'what type of class?' was compared with the general school experience question and the results (see Figure 7) show that more C/YP (n=31) attending an Autism class at mainstream primary schools were recorded as having a generally positive experience and the figure drops (n=7) for Autism class in mainstream post primary. Students in mainstream classes in mainstream post primary recorded having the most negative experiences at school (n=72). This finding is in line with the call for increased academic research and the development of professional practice on how best to support Autistic students in mainstream education<sup>69</sup>.

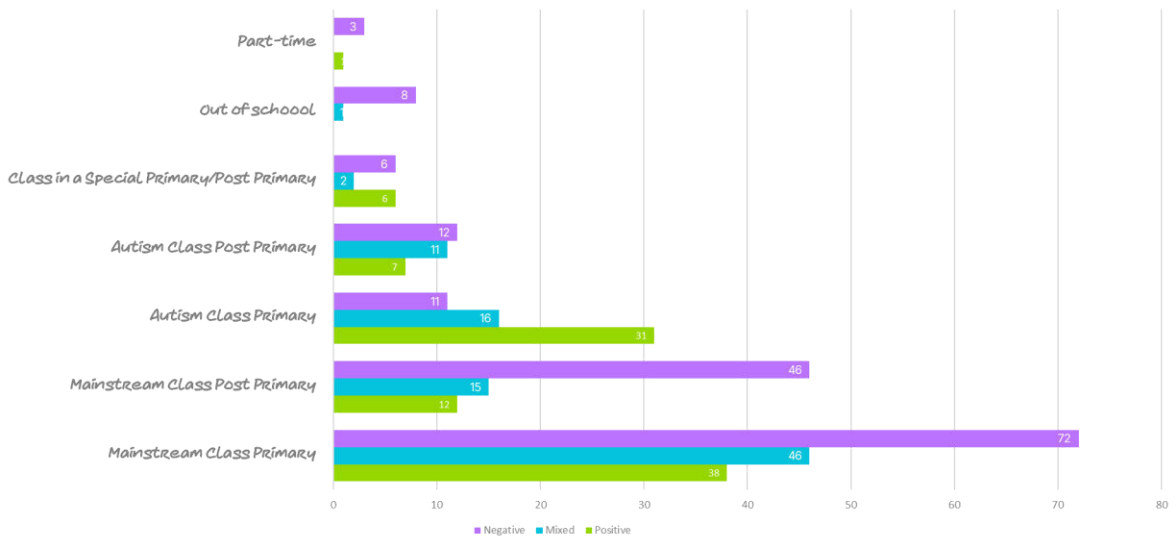


Figure 7: Class type by general school experience

## Academic Experience

When asked to describe their child's experience of academic tasks including homework, in-house exams, in-class tests, groupwork and/or project work using again the traffic light system (see Figure 8) the majority of responses were negative (n=145) or mixed (n=112). P/Gs describing their child's positive academic experience (n=86) used terms such as "good, excellent, doing well, enjoys, loves". The most used negative words were "difficult, stress, hates, poor, bad". Homework in many cases was described as difficult and stressful. As discussed, several P/Gs referred to their C/YP being too exhausted after managing the school day. "He was never able for homework; it was always a hugely stressful part of the day" many also referred to homework as a battle: "she dreads homework, it causes such stress, she's so exhausted at the end of the day; homework is a bridge too far" and "we have given up the homework battle, as the meltdowns are too intense".

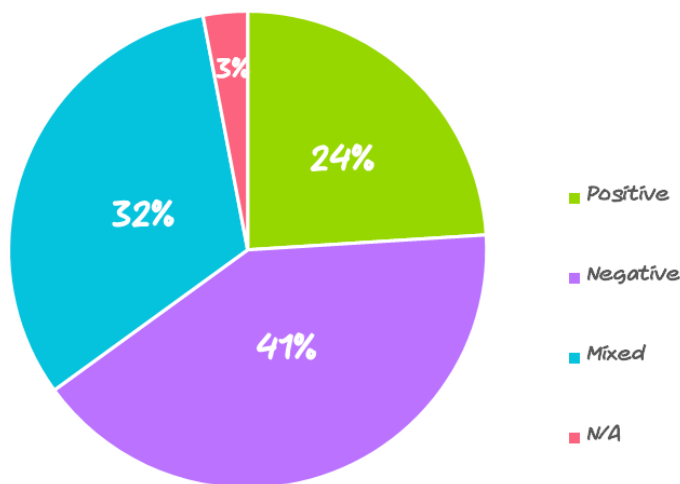


Figure 8: Academic experience

Group work was another area of concern. The P/Gs referred to their child being unable to cope with group work due to communication barriers or increased stress and anxiety. "She is left out of group work, not necessarily by the teachers but the girls do not include her in discussions or ask her opinions...". "He enjoys group work but finds it very difficult when there is any type of challenge in the group".

Others noted that their child needed to do things in a specific manner, and this was difficult to manage in a group situation. Exams in class as well as Junior Cycle and Leaving Certificate was mainly referred to as causing additional stress and anxiety and the need for exam accommodations such as smaller rooms, assistive technology, scribes, completing exams online, spelling/grammar waivers, extra time, and movement breaks.

## Social Experience

As Figure 9 shows the Autistic C/YP experience of social engagement at school was fairly evenly spread across the traffic light assessment. Positive responses included: *"has friends, is very sociable, and included"*. P/Gs recognised that their child's social engagement had been a concern: *"I always worry as a parent that he would be left out for being "different", but he has some great friends. Gets invited to birthday parties."*

However not being invited to parties was more often mentioned: *"He has a small circle of friends that he interacts with at school but still is not invited to any birthday parties."* The mixed responses mostly referred to their child coping with social engagement but struggling with some aspects such as rules in games or unclear communication.

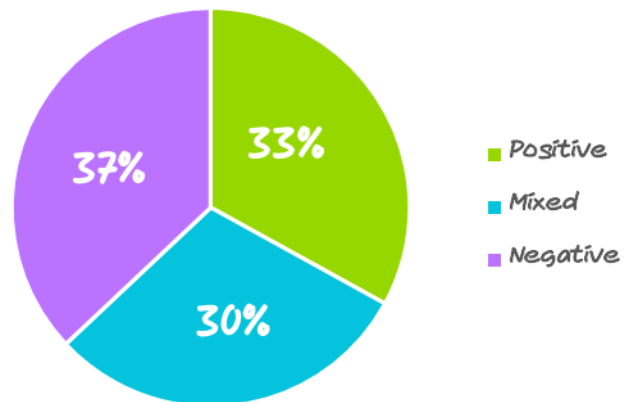


Figure 9: Social engagement

Mixed statements for example were: *"he loves other kids, but also finds it difficult, he has some good friends, but can be very negatively impacted by teasing as he just doesn't get that it's meant to be a bit of fun,"* and *"he struggles to make friends but is included in everything. He finds it hard to make proper connections with other children."* The negative responses were mostly: *"No friends, isolated, lonely, excluded, struggles, not understood, picked on, and bullied."* Several P/Gs said their child felt excluded because of their Autism and self-stimulatory behaviours or *"stimming"* – *"She stims in a very obvious way which some kids find frustrating and confusing - the older she gets, the more people comment, and she feels like 'a weirdo' in her words."*

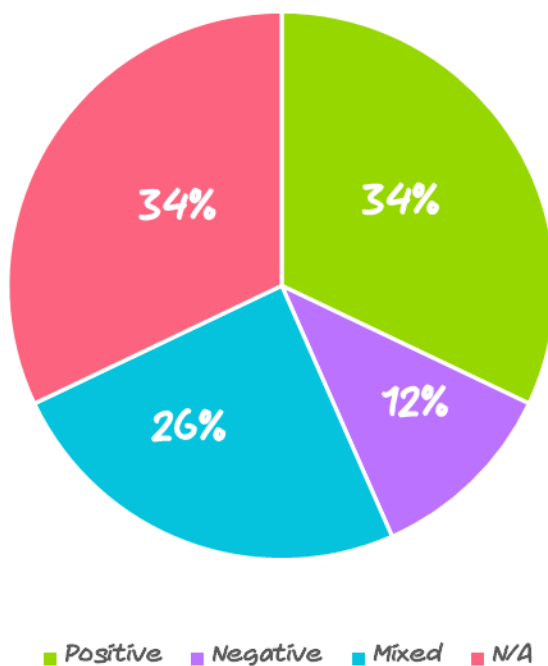
A number of P/Gs referred to their Autistic child being teased or bullied. In some cases, the school was aware that a child had been bullied and had handled the situation well, and some P/Gs expressed disappointment in how the bullying had been handled by the school. Students in mainstream classes in mainstream primary schools were bullied or being picked on most often. Students in post primary schools in mainstream classes and Autism classes were also bullied. No P/Gs with a child in an Autism class in a mainstream primary school or in a special education class referred to bullying.

## Experience of travelling to and from school

The majority of P/Gs said that their child's transport to school was not State-funded (n=274) and just over 20% travelled to school on State-funded transport. The P/Gs were asked to describe their child's experience of getting to and from school and n=233 responded positively. Positive terms such as "good, fine, no issues" were used. Several C/YP were happy to walk and lived close enough to the school. Other P/Gs said their child was happy to be driven to school by them and that the journey was a pleasant and stress-free time. For some C/YP taking the bus to school was also viewed as a positive experience – "My son loves the bus, the escort and driver always go above and beyond with all the kids on the bus".

Routine was referred to across the transport answers and changes could lead to stress and anxiety for both P/Gs and their child – "no issues once we stick to routine" and "he doesn't like any change to this routine or it upsets the whole day, we have to leave at a certain time, take a certain route". Other issues that added stress to Autistic C/YP's transport experience included "heavy traffic, time pressures, unpredictable behaviour of others on public transport".

## Experience of School Discipline



The majority of P/Gs said that their C/YP had no experience of school discipline (see Figure 10). There were also several references to not understanding when rules were not adhered to and teachers bending the rules: "She rigidly stuck to school rules and behaviours but really struggled when others didn't especially when teachers bent the rules as there was no predictability." Harvey (2018) also found navigating inconsistencies in rules can be difficult for many Autistic C/YP. Negative experiences referred to were being disciplined unfairly and the need for an adapted code of behaviour for Autistic students.

Figure 10: Experience of school discipline

The responses ranged from "he loves rules and follows them very rigidly," to "follows every rule to the letter to their own detriment and is so afraid of getting in trouble." Autistic C/YP being afraid of breaking rules and getting disciplined was a recurring theme. The majority of negative responses referred to being on reduced timetables where the school limits the amount of time a child spends in school and may only attend for a shorter day or only a few days a week. Some



P/Gs felt that reduced timetables were used instead of providing the required supports. They were also asked if they had engagement with the school's Board of Management.

The vast majority (n=320) had not. Only three P/Gs were on the school's board. For those that had engaged with the board they were either in the process of requesting support or had been refused support. A number of P/Gs had initiated complaint procedures and some expressed concern that principal being on the school's board made it difficult to make a complaint.

### Experience of Unstructured Time

When asked to describe break-time/lunch-time experiences (see Figure 11) **eating at school was a significant source of sensory discomfort with P/Gs describing canteens as difficult places for their C/YP due to being busy with too much noise and too many smells.** The range of concerns included having a quiet place to eat, having enough time to eat and not being able to eat with others. With reference to the school yard the positive responses described how their C/YP enjoyed break-times with their friends. Some P/Gs recognised that their C/YP preferred to spend time alone but for many a concern was loneliness and belonging. Several P/Gs described how their C/YP found break-time to be stressful and overwhelming "she hides in the toilet at lunchtime".

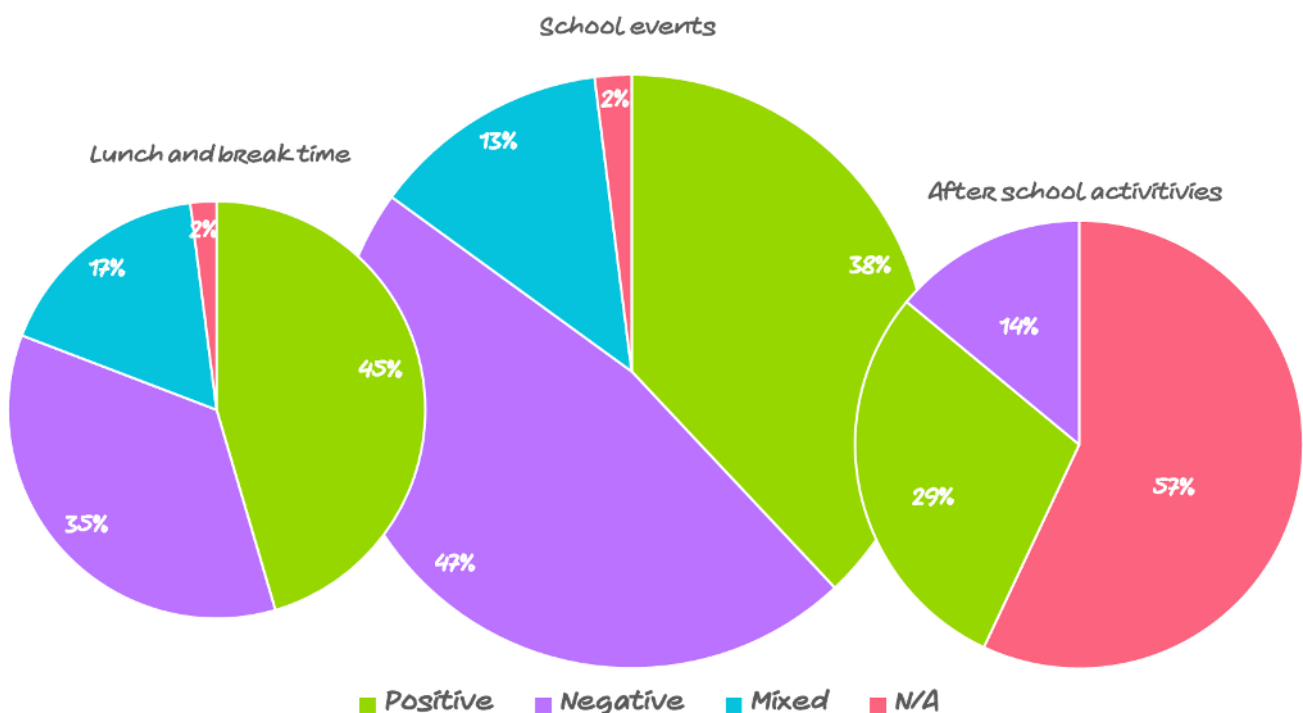
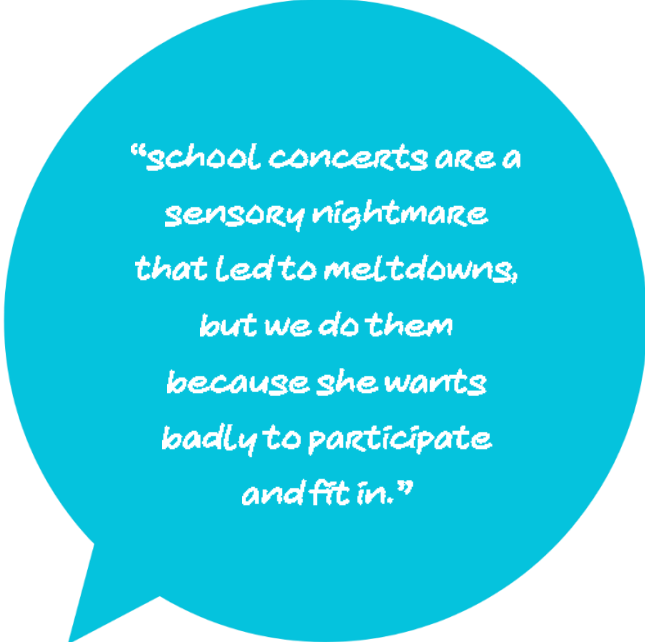


Figure 11: Experience of unstructured time

School events such as assembly, plays and trips were often described as stressful, overwhelming and when possible, avoided by some C/YP

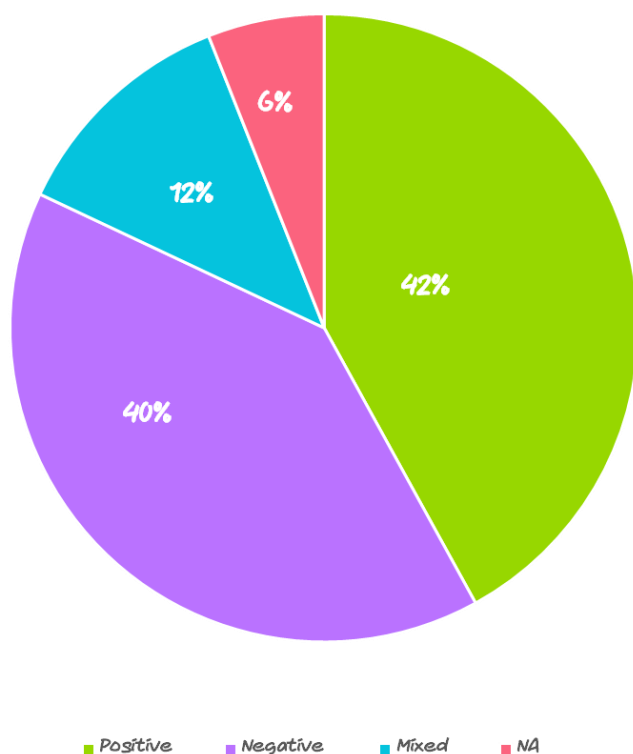


*“school concerts are a sensory nightmare that led to meltdowns, but we do them because she wants badly to participate and fit in.”*

Many of the P/Gs said their C/YP was not involved in after-school activities either because the C/YP was not interested, was too exhausted after the school day or there were no suitable activities available for Autistic C/YP.

## Accommodations

Schools can provide accommodations to support Autistic children/young people that can include sensory, academic and additional supports. Sensory accommodations included: uniform rules being relaxed, movement breaks, being allowed to leave the classroom, wearing ear defenders, using fidget spinners, access to a sensory room and small exam centres. Academic accommodations included: a homework allowance, using laptops in class, Irish and other language exemptions, spelling and grammar waivers, resource hours and the Summer Education Programme. Additional supports included: IEP, SET, Autism Hub, dedicated or shared SNA. When asked if the P/Gs thought the current accommodations were meeting their C/YP's needs (Figure 12) the responses were rather polarised. Several P/Gs felt that the social aspect of the C/YP's development was being neglected and many felt that their C/YP needed more support at school.



*"I don't know what would help. It's the noise and sensory overload she struggles with but how can you avoid that in a school setting."*

*"I sound incredibly negative, and I really don't want to be as my son has the most gorgeous teacher and SNAs who are turning themselves inside out for my boy to try make this work. They are just up against so many barriers on his behalf and it is horrible to watch."*

Figure 12: Accommodations

The P/Gs were asked who had provided support for their child's participation in school. As shown (Figure 13) a large percentage of participants were not being provided with any support despite having requested it.

## Who has supported your child's participation in school?

Education Welfare Officer (EWO)	21
HSE CAMHS Team	49
National Educational Psychology Service (NEPS)	55
HSE Primary Care Team (PCT)	56
HSE Childrens' Disability Network Team (CDNT)	94
Special Educational Needs Organiser (SENO)	109
None of the above-although support was requested	122

Figure 13: Who has supported your child's participation in school.

## Parent / Guardian Recommendations

The last two questions in the survey asked for recommendations that would improve C/YP's experience of school and if they had anything else they would like to add. In all n=215 P/Gs offered recommendations. Again, these questions elicited a broad range of responses but many reiterated previous comments. The answers were organised into the following themes and shown in Figure 14:

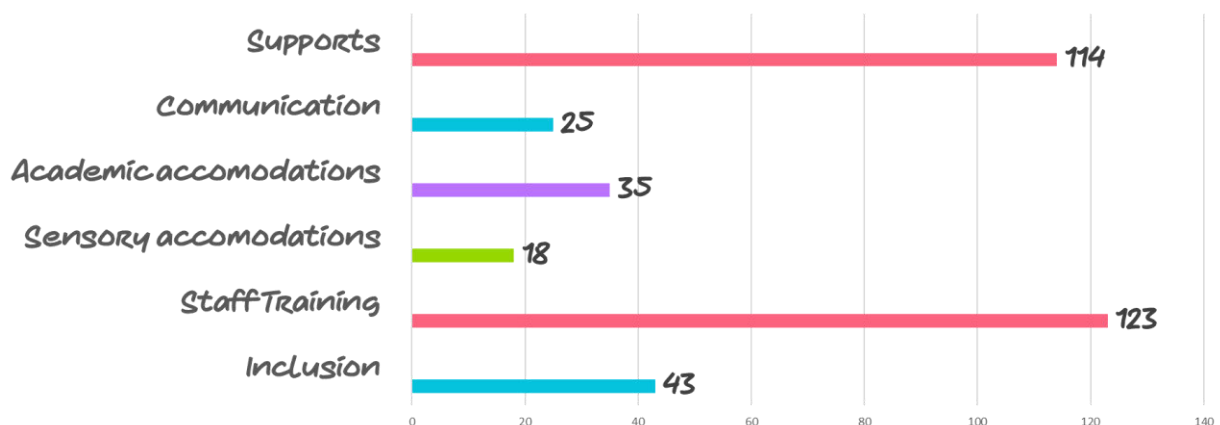


Figure 14: Parent / Guardian Recommendations

<b>Staff Training</b>	Proper and mandatory training for all school staff on Autism and neuro-affirmative awareness, preferably provided by Autistic-led organisations and informed by Autistic people themselves. All staff includes all who interact with Autistic students - teachers, support staff, administration, catering, caretakers and bus drivers. Particular attention should be given to staff training in understanding of Autism in girls.
<b>Supports</b>	People in the Autism community should not have to fight for the supports that are needed for their children and young people's right to an education.
<b>Inclusion</b>	Inclusion and acceptance of Autistic children and young people by their peers needs to be improved. Social skills and Autism awareness should be embedded into the curriculum across primary and post primary schools.
<b>Academic accommodations</b>	A recurring theme was that an exemption from Irish language was one of the few areas where flexibility was offered within the curriculum. Academic accommodations are needed for exams, homework, group work, online learning, access to using assistive technology. There also needs to be a discussion started on alternative curriculum content and the national exam structure so that Autistic children are not being excluded from completing their education.
<b>Communication</b>	Regular two-way communication between schools and parents/guardians needs to be established. A link-worker between school, family and other relevant professionals should be considered.
<b>Sensory accommodations</b>	The classroom environment has not changed for decades and not all children are suited to sit behind a desk all day. More hands-on learning and outdoor experiences should be considered for all children, not just those with additional needs. There also needs to be alternative uniform options available.

## Findings Section 2:

### Thematic Analysis of Parent / Guardian Survey

#### Introduction

As discussed above a qualitative survey was distributed to parents / guardians through AsIAM's social media networks, newsletter, and website. Anticipating a response rate of between n= 60-80 the intention was to conduct a thematic analysis of all questions. After initial screening the final number of completed surveys included n=353. This number far exceeded the researchers' anticipated response. Correspondingly, the time required to conduct a thematic of all questions represented many multiples of the scheduled timeframe of the project. Often in this situation researchers might select a small sample that would allow for a representative group of respondents to be fully analysed. However, conducting a first sweep of survey answers, it was clear that there was a massive diversity of perspectives and a deep desire from P/Gs to voice their C/YP's school experiences and to have that voice heard. Given the diversity of perspectives it would have been impossible to identify a representative sample, as the perspectives were so different. The second option was to narrow the focus to a key question but include the maximum number of respondent perspectives in the thematic analysis. We chose the second option.

#### General School Experience

The question we selected to focus on for thematic analysis was question 12: **"How would you describe your child's school experience?"** Recognising that some respondents might focus solely on the classroom, the question-phrasing highlighted that participants could include all aspects of schooling including playground, lunchroom etc. We chose to focus on this question for several reasons. Firstly, it was answered by nearly all the respondents (N=350). Secondly, it was the least prescriptive of all the question which allowed for the greatest breadth and diversity of answers. Thirdly, this was the first long question of the survey, meaning respondents, being fresh to the survey were more likely to invest time and consideration into their answers, which was borne out by it garnering more written data than any of the other questions. While we recognise that there is much more to be learned through a fuller analysis of the survey data, through focusing our analysis in this way we have sought to provide an overview of C/YP's experiences of school as described by P/Gs from the broadest possible perspectives, while keeping within the scheduled timeframe. These findings have been organised into themes and are presented below. It should be stated that organising what people say into themes is not an exact science, thus on occasion themes and subthemes ascribed may not conform exactly to what participants describe.

## Identified Themes

### School Support and Resources

#### Positive experiences of supports and/or resources

Support and resources (n=107) were closely linked as themes where a commitment by school staff to obtain resources was frequently identified as evidence of support or where there was a lack of commitment as evidence of the reverse. Thus, the two themes will be taken together.

Where C/YP were described as having a positive experience of school, P/G's most cited reason broadly related to their being sufficient resources to meet the C/YP's particular need(s). The kinds of resources P/Gs identified as making a difference to their C/YP's experience included: use of a range of technologies, quiet Autism Hub for eating lunch or have breaks, having access to SNA or Resource Teacher, being allowed movement breaks, small class sizes, time with a therapy dog, access to an educational psychologist, training for parents, enjoying being outside where there is more space and less people.

**P/Gs repeatedly acknowledged the positive impact of supportive and understanding staff, where a single supportive and understanding teacher was enough to make a significant difference to a C/YP's school experience.** This support seems to be very closely linked to staff having a good comprehensive understanding of Autism and the needs of Autistic C/YP, particularly where specific Autistic traits can signify an unmet need rather than disruptive behaviour. This level of understanding was occasionally linked by P/Gs to staff having personal experience of Autism. P/Gs were also particularly appreciative of good, clear and consistent communication which allowed them to gain a deeper understanding of their C/YP's experience and support them better with homework, school issues and experiences. Similarly, P/Gs also identified good collaboration in relation to how best to support their C/YP as very beneficial. Positive school experiences were also linked to high level of principals, teachers, SNA and Resource Teacher enthusiasm in engaging with the Autistic C/YP to address their needs and support their learning, which involved exploring innovative approaches and a willingness to engage in training.

With regard to supports and resources not all P/G accounts neatly fall into one or other side of the positive / negative divide. Occasionally P/Gs acknowledged that despite considerable efforts by the school, principal or teacher, their C/YP was still having difficulties, was experiencing loneliness or isolation, or could not get the necessary resources. Despite these ongoing difficulties P/Gs were keen to acknowledge the ongoing support of school staff.

## Negative experience of support and/or resources

Conversely, where C/YP were described as having a **negative experience of school (n=121), P/G's most cited reason broadly related to a lack of school support and their being insufficient resources to meet the child's particular need.** In addition to frustration with an absence of resources, P/Gs also felt frustrated by what they described as a lack of school commitment to obtain resources, which included confused or inconsistent messaging as to where and how they can be obtained. P/Gs also described some school provisioning as inappropriate to their child's needs, for example "using toilets as a sensory room". P/Gs also expressed frustration with inconsistent supports and resources, e.g., due to frequent changes to teaching staff. Though their child was assigned an SNA several P/Gs were dissatisfied citing lack of communication as an issue, or concern that the SNA's role seemed to be to more focused on perceived 'normalising' of their child's autistic characteristics and assisting the teacher than addressing their child's needs. Several P/Gs mentioned a lack of willingness on the part of teachers to adapt to their C/YP's needs, for example fidgeting or denied identified supports, such as movement or sensory breaks. P/Gs described situations where C/YP who were not seen as "*problem students*" or were regarded as "*too capable to be Autistic*", found as a result that their needs went disregarded. Similarly, P/Gs describe how their C/YP liked school and was doing well academically but their other needs were not met. Other P/Gs described how their C/YP were not academically challenged in class and as a result were "bored" by school. P/Gs also felt there was a lack of academic support resulting in their C/YP struggling academically. While many P/Gs were grateful of additional resources, several highlighted that these only came following an official diagnosis, which in some cases was late in their C/YP's schooling.

With regard to responsibility for support and resourcing some P/Gs felt there was a sense of blaming P/Gs for their child's or young person's educational issues, leading them to feel there was an expectation that *they* ought to pay for additional supports and resources. In communication with teaching staff and SNAs, some P/Gs also mention the prevalence of ongoing negative feedback in relation to their C/YP. Another felt that some teachers were anxious about their own liability in relation to dealing with Autistic students.

## Belonging and Loneliness

### Positive experiences of belonging and loneliness

With regard to belonging and loneliness (n=84) their C/YP's positive experiences of school P/Gs frequently cited having a sense of belonging as very important. Of P/Gs who regarded their child's experience of school as positive, several described the school as "very inclusive", while others referred to their C/YP as having school friends as significant.



## Negative experiences of belonging and loneliness

Where P/Gs described their C/YP's experience of school as negative one of the most consistent themes was loneliness and not belonging. Many P/Gs expressed concern regarding their C/YP's social difficulties which were described as leading to loneliness and feelings of isolation. These feelings were described by P/Gs relating to their C/YP as having "no friends", being "ignored", were "slow to make friends", "does not get on with peers", of "feeling different" or being "the odd one out." Several P/Gs describe their C/YP's discomfort with being in the yard/playground or other communal areas such as corridors or locker rooms. One P/G suggested non-participation in playground activities was due to finding "rule free games difficult to follow."

With regard to the school's role in their C/YP's sense of not belonging, some P/Gs expressed frustration with the lack of activities for Autistic students, particularly in relation to the limited number of team sports on offer. Other P/Gs referred to difficulties their C/YP experienced with working in groups or "with the teacher." Several P/Gs mentioned their child having communication differences or being non-speaking leading to loneliness and isolation, meaning their C/YP was misunderstood or did not have a communication system in place to interact with peers or teaching staff. For example, one P/G described how their C/YP would interpret a passing comment by the teacher relating to the entire class as a personal criticism.

## Feeling Excluded, Humiliated or Bullied

One of the more concerning themes identified in the data relates to exclusion or humiliation in response to Autistic characteristics and the pressure Autistic students put themselves under to hide these to conform or become "invisible", even to the extent of refusing their accommodations (n=66). Many P/Gs described how their C/YP engaged in masking or repressing actions such as stimming, or masking emotions to fit in. In some cases, this was described as undertaken to avoid reprimand by teachers. Many P/Gs felt that their C/YP was repressing their need for self-regulation such as stimming or movement breaks, to avoid been seen as different and therefore socially excluded. P/Gs described how masking leads to

exhaustion, meltdowns and withdrawal when the C/YP arrived home. A

significant number of P/Gs described their C/YP being subjected to

"condescending", "patronising" or "disabling treatment" by teachers and SNAs, for example "being asked to wear nappies" or told they are "being too dramatic." P/Gs described their child as being "stigmatised", "singled out", "made to feel different or stupid", "watched", "viewed as a difficult student", or how teachers unfavourably compared Autistic students with their peers and were "found wanting". While not described in detail several P/Gs stated that their C/YP experienced "bullying" while at school.



"patronising"

"stigmatised"

"singled out"

A number of P/Gs described difficulties with discipline where their C/YP received inappropriate or unfair punishments. Reflecting Harvey<sup>70</sup> these P/Gs often commented on confusing reward and punishment structures that were inconsistently applied which depended on who was applying the rule and to whom.

**Some P/Gs also mentioned that their C/YP's meltdowns or expressions of distress were occasionally viewed as "bold or spoilt."** Several P/Gs felt that despite claims of inclusivity schools were "not inclusive", or that inclusivity was "tokenistic", for example one P/G felt that though Autism classes were on the grounds of mainstream schools, there was "no integration" of Autistic students into the mainstream school. A few P/Gs commented on their school's limited understanding of inclusion which was described as "being allowed to do what everyone else does", rather than be your Autistic self. Occasionally more official forms of exclusion were described where C/YP were permanently excluded from their school or formally excluded from activities.

Rather concerningly two P/G's described how **their C/YP's accommodations were permitted or withdrawn as part of a reward / punishment system used to control the C/YP's actions, but only exacerbated the C/YP's difficult situation.** One P/G described how their C/YP's "confidential information" was disclosed to other students. Another P/G referred to parents of non- Autistic students as not inclusive, as their child was never invited to parties or playdates. A P/G described how their child worked hard and "loved to learn" but hated the school environment.

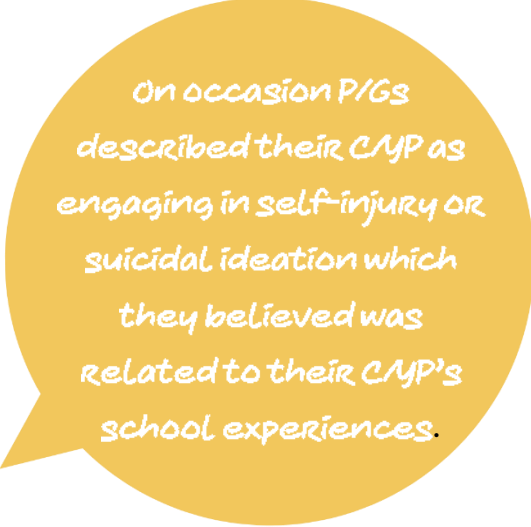
### Sensory Discomfort

Many P/Gs (n=58) referred to sensory discomfort or sensory unsafety as a significant reason for their child having difficulties in school and finding school a negative experience. P/Gs described their C/YP's school or classroom environment as overstimulating and causing varying degrees of sensory discomfort and not feeling safe for a variety of reasons, including being too bright or too noisy, which resulted in their C/YP having difficulty with focusing on tasks, sitting still, maintaining attention, being unable to relax and requiring frequent movement/regulation breaks. Several P/Gs described their child as frequently feeling overwhelmed in school resulting in their C/YP having a meltdown or shutdown, or frequently crying. In an effort to address feeling overwhelmed some C/YP sought out places to hide in school.

The school canteen and eating were a significant source of sensory discomfort with P/Gs describing canteens as difficult places for their C/YP due to being crowded, noisy and filled with the "unpleasant" smells of different foods. P/Gs highlighted a range of concerns including how their C/YP "*can't eat in school*", "*eats alone*", "*can't use canteen*", "*excluded during lunch*", "*is on a restricted diet*", "*hates smells of food*", and in an effort to find a comfortable place, "*eats in toilet*." Other difficulties related to classroom size, either too big or too small and school uniforms being uncomfortable and itchy. Several P/Gs mentioned their C/YP's disorientation or anxiety when confronted with unexpected change, for example timetable, teacher or classroom changes.

## Mental and Physical Health and Safety

The most concerning theme that emerged from the data relates to mental and physical health and safety. As outlined above many P/Gs (n=49) described their C/YP's experiences of school as involving sensory discomfort, loneliness, exclusion, and masking. While meltdowns, shutdowns and feeling overwhelmed have already been identified as transient responses to aspects of school experience, many P/Gs described their C/YP's more prolonged or ongoing mental health concerns such as "anxiety", "panic attacks", "stress", "loss of confidence" and "loss of self-esteem." Occasionally P/Gs described their C/YP's school experience as traumatising and that their C/YP was "intimidated" or "terrified" of school.



*On occasion P/Gs described their C/YP as engaging in self-injury or suicidal ideation which they believed was related to their C/YP's school experiences.*

Regarding safety, some P/Gs described their C/YP as feeling "unsafe", "scared" or "fearful", while others mentioned their C/YP returning home with an "unexplained injury" or refer to excessive force used on their C/YP causing bruising. Another issue relating to safety identified by P/Gs was "absconding" particularly where the school gates "open to a busy road". **Finally, with regard to 'managing pupil behaviour' one P/G described feeling pressured to consider use of medication for their C/YP.**

## Understanding Autism

**A major source of concern and frustration for many other P/Gs (n=53) related to school staff's lack or limited knowledge or understanding of what it means to be Autistic**, for example a lack of understanding of sensory processing, a lack of knowledge regarding diverse learning styles. In some cases, P/Gs felt this resulted from a lack of interest or engagement with their C/YP resulting in a lack of understanding of their needs. For several P/Gs this lack of knowledge and understanding of Autism led to varying degrees of ableism by teachers and other school staff. Where school staff exhibited a high level of understanding this was often attributed to their connection with an Autistic relative or close acquaintance, rather than due to formal training.

In addition, several P/Gs expressed concerns relating to what might be described as teachers' and school staff's interpretation of 'behaviour'. On one hand 'good' or 'normal behaviour' was interpreted as an indication that the C/YP was not really Autistic and therefore did not really require sought-for accommodations. P/Gs felt in these circumstances teachers and other school staff had minimal understanding of masking and the cost of C/YP's exhausting efforts to appear 'normal', and that appearing 'normal' should not be used as a reason by teachers and other school staff to forgo accommodation requests. On the other hand, when C/YP exhibited Autistic characteristics, lack of knowledge and understanding relating to Autism resulted in teachers and other school staff interpreting actions such as stimming as misbehaving.

## School Attendance

For many P/Gs (n=45) the issue of their C/YP's school attendance was described both as a source of concern and frustration. P/Gs were often keen to stress that their C/YP's non-attendance was not related to disinterest in education but to many other often complex reasons, many of which are cited above. Periods of non-attendance could be for hours, days, weeks or permanent, meaning a C/YP was being "home schooled" or "self-educating" at home where P/Gs felt their child was able to be "their Autistic self". In response to non-attendance many P/Gs endeavoured to find a more suitable school with several P/Gs describing moving their C/YP to a new school hoping they would have a better understanding of their C/YP's needs. While some C/YP were fortunate in finding a better alternative, others attended multiple schools in a short time before finding a better school or withdrawing their child from school altogether. Another group of P/Gs said they would move their C/YP if they had the option. Several P/Gs described their C/YP as not wanting to be at school because they "dislike" or "hate" school. Occasionally the State supports home tuition, but as one P/G noted it can be "difficult to find a tutor." Several P/Gs referred to their C/YP moving to a "better school."

## Autism Class

### Positive experiences of Autism class

A significant number of P/Gs (n=21) referred to the impact of the school's Autism classes. While mostly positive there were some P/Gs who felt the move to an Autism class had not been the best choice for their child. Those P/Gs who felt the Autism class was beneficial, regarded it as providing their child with the "best of both worlds" i.e., the opportunity to experience a mainstream school while having access to a more supportive environment. Some P/Gs described their child as happier in the Autism Class because supports and resources were more readily available, while others said their child found it easier to make friends. Having had negative school experiences in primary and/or secondary school, several P/Gs described their C/YP's transition to an Autism class as positive.

### Negative experiences of Autism class

Not all P/Gs accounts of Autism classes were entirely positive (n=6). One P/G while describing the Autism class as "great", also felt Autistic students from the Autism class were "not included in mainstream school". Another described how their C/YP loves the Autism class but does not engage with the mainstream school for fear of non-acceptance. Other concerns P/Gs had in relation to Autism classes include: the move from mainstream class to Autism class was a bad choice for their C/YP; that as a result of being in the Autism class their child was "regressing"; that the school's decision to place Autistic children in the Autism class was informed more by school requirements than student need, that their C/YP had "outgrown" the Autism class; or that they could not access the Autism class.



## Findings Section 3:

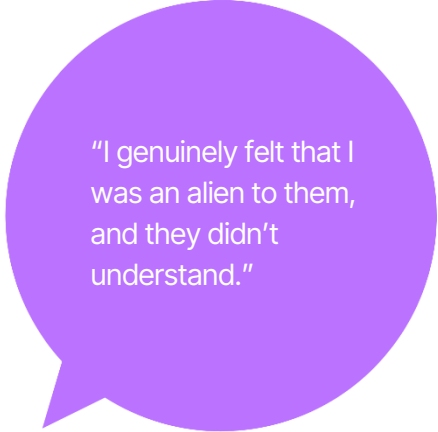
### Interviews with young people

The five students or recent past students who participated in the interviews provided an insightful perspective on school experiences of Autistic children and young people. The participants provided extraordinarily articulate accounts of school life born out of a critical capacity to reflect on and describe the difficulties they encountered, but also to provide innovative and creative solutions, which if implemented could benefit the school community as a whole. Outlined below are the themes that emerged from the participants' interviews. The solutions suggested by participants have been listed as recommendations at the end of the section.

#### Exclusion and Isolation

The impact of exclusion through stigmatisation and prejudice were described by participants as particularly hurtful and damaging. One participant described how from early primary school she felt *"really disrespected"* and that her peers were talking to her like she *"was a dog"* or *"an animal"*. She described how efforts by the school to provide her with a room to regulate resulted in her being peered at through the windows or teased through constant door-knocking. She suggested that her Autistic characteristics meant that she was viewed as a vulnerable person by her peers, *"so they think they can do [or] say whatever they like."* The issue for this participant was that room required special permission to use, other students were not allowed to use this room which singled her out as different and segregated her from other students. What she was looking for was for the school to provide universal spaces that are less frenetic, spaces where all students can go that are quieter, not 'special' spaces for 'special' students.

Another participant who described being bullied a lot in primary school expressed frustration that "there was no person there to put the [antibullying] rules in place" meaning, **"there's nothing really done about it because you are seen as different and there's nothing that can be done about that."** As she put it: "I genuinely felt that I was an alien to them, and they didn't understand." To protect herself from stigma one participant chose not to disclose her Autistic diagnosis, but then had to endure listening to her friends making **"fun of other people's Autistic traits"** in front of her, which was deeply hurtful. On the theme of isolation another participant described her peers as "not the most understanding", were "making assumptions" about her, where she was "treated like a child", and that she felt **"left out and lost."** Another participant who was very anxious around people described how her fear of talking to others meant **"I'm left on my own."** The only time she fully interacted with other students in school was when a particular circumstance emerged where she and a small group of students had to spend time together once a week.



"I genuinely felt that I was an alien to them, and they didn't understand."

The participant described the experience, "I can talk to them, and they're nice to me", "that's been the best part of [school this year, I think]."

Several participants described the experience of being stared at, in the words of one participant her flapping was "*stared at judgingly by students*" and instead of diverting the students' attention elsewhere, the teacher told her to "*sit on your hands*". Another participant described how her fear of being overwhelmed in front of other students influenced her decisions not to attend school. She described how some teachers become impatient with Autistic students' use of supports like ear-defenders and fidget toys, and how Autistic students using ear-defenders were mistakenly reprimanded for listening to music when they were trying to block out excess noise. This resulted in her choosing not to use her supports for fear of "*how other people would see me*" and when attempting to regulate through surreptitiously fidgeting with pens, she "*got them taken off*" her. She also highlighted how her teachers were not sympathetic to her missing class despite being aware of her circumstances. Though usually allowed to go to a quiet room to self-regulate, permission varied between teachers. Some less familiar insisted that she sat where she could be monitored, but this was in full view of staff, students and visitors which the participant described as "*mortifying*." Another participant described how Autistic traits can be viewed as disruptive. Sometimes when there is too much sensory stimuli, she "*explodes*", which has been interpreted as "*bad behaviour*", but "*I just need extra support, movement breaks or advanced notice of changes*."

While school policies claim to promote equality, diversity and inclusion, participants felt there was minimal understanding of what this means in practice.

As one participant suggested:



*"Saying one word [in the school policy] about inclusion is not going to work, there needs to be ... more detail about what inclusion is."*

While schools officially welcomed Autistic students, participants felt there was a lack of awareness of Autism and that it was not integrated into everyday life of the school. According to one participant, "*it's not openly talked about outside of Autism week*", but Autism "*exists 365 days of the year*." In describing the transition to secondary school, a participant remembered her primary school experience as very positive: she was in a small class, in a small school

everyone knew each other very well, and *"when you know someone well you don't judge them, or you don't prejudge them"*. *"In my primary school everyone knew everything about me, they didn't care about anything I said or did different ... it was a very comfortable experience, so it was quite shocking going into secondary school, where people can shut you out."*

In a discussion relating to the enormous diversity of skills, abilities, attributes and talents of Autistic people the duplicity around social values was highlighted as a source of frustration and isolation. As one participant described: *"I'm good at some things."* Among the things she identified as being particularly good at are organising information, researching subjects, being honest and having a great sense of social justice. Consequently, she finds it hard to understand that when she calls people out for lying or being unjust, *she* is regarded as the problem when everyone claims it is good to be truthful and fair. She described dealing with this duplicity as *"too exhausting"*, stating *"I'm never going to have the social awareness...so I'm not going to fit in, in that regard either."*

## Support Worker

A common theme from the interviews was a need for a dedicated support person for Autistic people whose responsibilities would include educating staff and students about Autism; provide training on how to be inclusive; meeting Autistic students to see how best to address needs e.g., timetables; evaluate the effectiveness of current supports; address issues like mental health or bullying; and provide ongoing emotional support *"if I'm not feeling ok."* This emotional support would involve checking in with the student periodically; providing a space where Autistic students can discuss how they're feeling or plan for events to reduce anxiety e.g., exams. In the words of one participant *"there's learning support teachers, but often they only focus on having maths or something like that. But I think there needs to be like emotional support [teachers] there as well."*

## Consultation and communication

The well-known disability rights phrase 'nothing about us without us' was used several times during interviews where participants expressed frustration with the lack of consultation. Participants insisted that if there are plans being designed that affect Autistic students, they must be part of the discussion regardless of age and modes of communication. While participants were in favour of support plans because they allowed for more targeted supports one participant pointed out that they are often designed by non-Autistic people. **Participants felt there should be greater equality here and that Autistic students should be included in writing their support plan, not only so they can contribute but that they know what's happening – "because it was actually me who knows my needs better than anyone else"**. Further, it was felt that the hierarchical structure in most schools leads to teachers who may have limited understanding of Autism making decisions on how best to address the needs of Autistic students, while the opinions of Autistic students are not really considered. Finally, participants described how teachers make decisions relating to supports without consulting the student e.g., when a student shows signs of improvement removing the support without consultation.



## Supports

In relation to supports participants had a broad range of experiences, criticisms and suggestions. Several interview participants were critical of *"having to fight so hard to get accommodations"* such as regular breaks. While it was acknowledged that there are often a range of general supports, Autistic students also need more specific person-centred supports, for example through an individual support plan. As one participant states, ***"I think it kind of comes down to what the student themselves and what they need. I don't think that there should be any kind resistance to that."***

Following years of struggling in school one participant was eventually promised supports only after an official diagnosis. However, many of these supports depended on staff availability and in the case of occupational therapy, speech and language therapy and psychological support, these never materialised. This participant suggested that these and other supports such as disability services, CAMHs, mental health services, National Educational Psychology Service [NEPS] should be linked in with the school and made available during school hours so that students can access the therapies they need. This participant stated: *"if something is going to be mandatory then it should be made accessible"*, thus if school is mandatory for Autistic children, then they must get the necessary supports. Another participant argued that Autistic students need to be supported by all teachers, rather than being viewed as the responsibility of a few SNAs and support teachers.

One of the issues raised by participants was how Autism supports can become co-opted for school requirements, leaving Autistic students without much needed supports. A concern for one participant was that her school was restructuring and that the sensory room might change. She had *"a lot of difficulty accessing the sensory room"* because it was being used as a meeting place; she insisted *"the sensory room isn't a hang out space."* She described it as necessary space for Autistic students to regulate, gather thoughts, recover from distress or feeling overwhelmed; *"it's a life support"*, that should be kept *"solely for Autistic people."* She also opposed the idea that once they've reached the senior programme Autistic students grow out of needing the sensory room: *"I needed it more than ever."* Other participants referred to having a quiet room, which *"was very important to me"*, a *"break from regular school"*, *"a safety net"* where they take some quiet time to recover from the stresses of school life.

While not officially supports, participants referred to a range of features about school that made their school experience easier or more pleasant and are worth a mention. Participants were grateful they had supportive teachers *"most of them anyway"* and *"really enjoyed the routine"* and structure of school. *"I like how it was the same thing every day and I knew where I was going and what I was doing."* Participants also liked the separation of subjects and increased choice of subjects in secondary school (though would like more). Another participant described how being allowed to use her phone gave her something interesting to do during the times she spent on her own in the quiet room. One participant was particularly grateful that he could use his laptop which is easier to take notes on, but not so good at taking maths notes because it doesn't have the correct symbols on the keypad. Participants also liked the social side of school and playing games (but not the crowds). Participants enjoyed the more project-based work and enjoyed Transition Year for this reason.

Another participant particularly liked her small *"more comfortable"* primary school where everyone knew each other. She described it as a place where *"the teachers, the principal and staff, were really looking out for the students and that was good."* This participant also described a variety of methods to assist with organisation such as colour coding subject files. Finally, several participants described how having something to do and somewhere to go during breaks was very beneficial: *"I don't like the unstructured time"*, *"I don't really know what to do with myself"*, which *"is exhausting."*

## Masking and fitting In

Participants described the psychological and emotional burden of masking *"to be liked and respected."* Participants described having to force themselves to behave in a different way to fit in. ***"Going into school... I was acting like everything was alright, in fact, when I was kind of crumbling inside and it was all too much, I felt as if everything was going too fast."***

Participants described the efforts they would go to conform to social norms. *"I would ... make a kind of scripts in my head that if somebody came over and said something that I would know to say, 'Oh hello. How are you?'"*, *"I would have it kind of rehearsed in my head ... different social situations ... which was exhausting."*

Participants told how masking in an effort to make friends also meant ceasing to be themselves. *"I try to be a different version of myself and say if somebody in my class then was into horse riding, I will try having an interest in horse riding, even if I didn't have an interest in horse riding, so that maybe people would like me or that people would be friends with me."* When asked if she thought masking was different for boys one participant answered, *"I think so. I think most girls, are a little bit better at hiding it"*, she goes on to suggest that girls are more insecure about being seen as "weird."

## Impatience with, or Misinterpretation of Autistic Traits

While many of the participants were very grateful for the contributions of teachers to their life and education, for example, *"one of the reasons I don't really want to move schools, all the teachers are very nice"*, there were also accounts where certain teachers or other school staff were less supportive. A common theme among participants was instances where teachers were unsympathetic with Autistic traits or suspicious that they were being exaggerated to get out of class. One participant stated,

*"Teachers and students often see, say if I for example have meltdown or sensory overload, they would see that as misbehaving, when it's actually my needs not being accommodated."*

Participants described that due to smells or sounds some classes were more likely to cause sensory overload than other, meaning that students were more likely to show signs of sensory overload (e.g., covering ears) in these classes. One participant suggested that when teachers witnessed this difference, they interpreted it as evidence that these behaviours were deliberate, rather than caused by different triggers in different environments. One participant who needed to take frequent breaks from class due to feeling overwhelmed stated, *"teachers will get annoyed at me about not being in class, but I can't really do a whole lot about that."*

Another participant who often experienced difficulties in understanding tasks would *"get in trouble for not following directions"*, but the teacher's instructions were followed literally, and when the student would genuinely respond by saying *"but you said to..."* would get into more trouble. Some participants described how staff were *"becoming impatient"* with addressing the needs of Autistic students who were seen as *"too demanding"*. One participant who was confused by her teacher's apparent disregard for her Autism diagnosis stated, *"I don't even know if they were told about my Autism or not, or they just don't remember."*

## Diversity

One of the most consistent themes from interviewing participants related the prevalence of subject choices and extracurricular activities on offer in schools that reflect the preferences and interests of a particular school cohort. Participants were critical of the *"focus on sport in school."* As one participant put it, *"a lot of Autistic people have motor skill and fine motor skills issues, and sport doesn't really cater for that."* The emphasis on sport while suiting some non-Autistic students was described as having a significant exclusionary impact on Autistic students where they witnessed teams heading off on training days and away-matches, often supported by the school, but no equivalent mechanism existed to encourage or celebrate the achievements of other students including many Autistic students. Even where Autistic C/YP achieved things on their own, these were either not acknowledged or only recognised in passing by the school because they did not form part of the body of celebrated school activities. To address this, participants suggested that schools establish clubs that reflect the diversity of student interests. Some suggestions forwarded included music, drama, research [doing research projects on areas of interest], politics, literature, reading and gaming. Participants suggested that in the same way high achievers in sport are recognised with school award ceremonies, high achievers in clubs should be rewarded and celebrated too. Further in the same way that schools fund sports away-days, they should fund away-days for clubs, for example a drama club's trip to the theatre. By not recognising diversity participants felt they were viewed as worthless, having no purpose in the school and nothing to offer. As one participant put it, *"for the Autistic person in school" they're seeing us as "Ohh, that's the student that needs extra support ... our achievements are not always seen ... I think awards should be given to Autistic people ... to help them to see that yes, they are wanted and yes, they have a purpose in school, and they are making a difference in the school community."* Participants were frustrated by the presumption that certain activities like sport was viewed as an essential and worthy expense, but their areas of interest were viewed as an extra burden on school resources.

Another feature of school identified as exclusionary or disadvantaging of Autistic students was ***“the education system itself. It's not accommodating, not just for Autistic people, but to a lot of different people with different issues.”*** The state exams [Leaving and Junior Certificates] were particularly identified as ***“not very accommodating.”*** While officially there are accommodations to support diverse students, these were found to be “difficult to actually get” and “aren't great.” One participant stated that the Leaving Cert is “a difficult course and not everyone can do it, but there aren't any other options if you want to finish school.”

In exploring her options, a participant was attracted to the structure of the Leaving Cert Applied (LCA) but given the 90% attendance requirement and that she often missed days due to her mental health, she felt this would not suit her. Further, as the LCA is not the usual option, many schools have limited subject choice and some of the subjects on offer like cooking could be very challenging due to extreme sensitivity to smells. That participant was also critical of the subject choice for the ‘mainstream’ Leaving Certificate. She was interested in studying economics and politics, but these were not offered at her school, or any of the schools in her area and doing it outside of school was not permitted. Given how big a motivator interest in a subject is for Autistic students, she felt not having access to subjects that interested her was disadvantaging and suggested that more specialist interest subjects could be offered by schools through a centralised / online teaching system. The same participant makes the point that online teaching worked during Covid, so why not use it to provide more diverse subject choices and learning opportunities. Ultimately participants described how attempting to complete their State education in an environment that did not reflect their needs, doing subjects that were not of interest, which were communicated in ways that were difficult and confusing and examined through a method that was excessively stressful, collectively acted as a barrier to educational success and impacted opportunities for further education and future employment.

One participant highlighted how ‘supports’ designed to modify Autistic behaviours to bring them more in line with the ‘social norm’ have been experienced as prejudiced and exclusionary. This participant refers to how various programmes, such as Zones of Regulation<sup>71</sup> designed to help Autistic students integrate into school life through regulation can come across as wanting to change the Autistic person or erase fundamental aspects of their identities. In a similar vein another participant draws attention to school ‘wellbeing’ programmes which often focus on ‘wellbeing’ from the perspective of non-Autistic people. She makes the point that *“the Autistic person’s wellbeing may not be supported because what works for neurotypical’s wellbeing may not support Autistics people’s wellbeing.”*

## Single-Sexed Schools

An issue relating to lack of diversity was the participants’ experience of being in single-sexed schools. Several participants described how their preferred subject choice corresponded to what has traditionally been regarded as stereotypically ‘male’ subjects which were not offered in several of the all-girls school, thereby requiring participants to commute to the local boys’ schools to avail of these subjects. One participant who found it difficult to integrate with the students in a single-sexed girls school described her difficulties. She spent the first part of her education in a mixed primary school where she was “more friends with the boys” but moved to

an all-girls secondary which "was kind of weird" as she had difficulty connecting with the girls around her. She stated: *"I don't really like all girls' schools. I feel like it's not a good environment for mental health", they're "very cliquey, so it's hard to talk to people and make friends."* She described going over to the boys' school for some subjects where she felt *"more comfortable."*

## Sensory Sensitivity

Participants described many different elements of school life that were designed for neurotypical sensory profiles. These included the sheer size of schools and corridors, canteens and classrooms being too crowded, noisy or smelly due to food and chemicals etc. While distressing sensory experiences were an ongoing issue for all participants, one participant was keen to highlight how *"I do benefit from sensory input in different ways like the sensory room."* Participants described distressing sensory experiences as greatly contributing to meltdowns or feeling overwhelmed requiring more breaks from class to *"ward off dysregulation."*

The requirement to adhere to a strict school uniform's policy was recognised as being in opposition to claims of diversity but also a significant source of tactile discomfort. Several participants described how the types of fabric used in school uniforms are a major cause of itching and overheating, which greatly impact students' concentration and increase the likelihood of feeling overwhelmed. As one participant states:




*"I don't like the uniform. I don't like the feel of it"*

and another described having to mask her discomfort *"with the uniform but it came to the point that my jumper was too much"* resulting in the participant having a meltdown in class. Another participant described how as a result of the uniform she *"struggles with temperature regulation."* She described her efforts to find acceptable alternatives through purchasing similar cotton garments to the uniform synthetic fabrics *"but school not happy."*

The combination of hungry crowds of students, food smells, clattering noise and raised voices were recognised as making lunchtime, and the canteen in particular, a place of considerable sensory discomfort for many Autistic students. One participant described how *"I was going straight out of class into this overwhelming environment", "everyone's talking", "I would dread the lunchtime"* and would *"zone out"* and *"heavily mask"* in the canteen.

Another participant commented:



*"I really don't like  
lunchtime... I don't  
like the open [space]  
... it's a very big hall,  
people all speaking  
together."*

Another stated *"lunch is one thing that would really not make me want to go to school"*, *"I'd rather not have lunch to be honest or I'd rather lunch, would be like two minutes and then go back to class."* On the positive side, another participant described his small lunchroom which is specifically for Autistic students which he likes because *"there is less mess, less people, less noise"* and a variety of appliances they can use to make sandwiches or heat food.

## Diagnosis and gender

The majority of interview participants received their diagnosis late in their schooling, which they described as seriously impacting the level of support they received and the accommodations they could request. Not surprisingly then, an issue these participants wanted to highlight and have addressed was the need for timely diagnosis. One participant described how despite exhibiting a lot of Autistic traits and signs *"it was never picked up that I was Autistic."* This participant felt that teachers are in a position to play a vital role in identifying Autistic children and should be educated in identifying the signs in girls and boys. It is perhaps worth noting that late diagnosis was mentioned as an issue for three of the four female participants but not by the male participant.

Concerned about the loss of supports where diagnoses are missed one of the participants recommended *"mandatory screening so everybody would be tested or assessed, not just for Autism but for dyslexia, to help get supports put in place."* This participant described her experience where she and several of her female friends had clear signs of being Autistic but *"we weren't able to get supports because [we] didn't have the diagnosis."* Another participant described late diagnosis as *"quite hard"*, she stated, there *"wasn't as much understanding about female Autism"* as *"there is now, still lots of women and girls coming out as Autistic."* The participant described the relief the diagnosis brought: *"when I got my diagnosis, I realised that there was nothing wrong with me, in terms ... of trying to fit in ... it was never going to happen because my brain was wired differently."* When asked why she felt her diagnosis was late one female participant answered: *"I think it kind of came down to my teachers in primary school not*

knowing the signs for young girls and even my parents they had no idea." Recognising the struggle caused by late diagnosis she suggested "teachers in both primary and secondary school should be educated a bit more on Autism and the struggles the students might feel."

With regard to disclosing their diagnosis to teachers and peers, participants had mixed feelings. One participant felt adults are more understanding once they know you're Autistic but *"I haven't told many people in my year, they definitely know something is up but they don't know I have Autism."* Family advised her *"be careful about who I told"*, which she says, *"got me scared about it"*, she then mentioned *"and I hear the way they speak sometimes"*, *"they use Autistic as an insult"*, *"I don't want them ... shutting me [out] ... not giving me a chance ... to be friends."* However, she does say that as she is getting older, she is *"becoming more inclined to tell"*, *"I feel like if I'm comfortable with having Autism myself, they won't care either"*, *"so I need to get a bit more comfortable in myself."* Another participant described how since she has been *"publicly open"* about her Autism diagnosis it has made a small difference around acceptance.

## Change and Uncertainty

The issue of change and how to manage it was a significant theme for all participants. Discomfort relating to change applied to all aspects of school, macro to micro, from changing school or classroom, to changing teacher and seat. Highlighting how discomfort with change relates to not being able to anticipate, one participant says, *"I don't like the uncertainty ... there might be an assembly, or the teacher off and I don't be told most of the time until it happens."* Another stated *"I don't like moving classrooms at all ... it was kind of exhausting"*, *"I don't like moving seat"* and *"get bothered by other people moving, the different layout of the classroom was a bit upsetting"*; another participant suggested *"the change to secondary school is quite a big one."*

Participants identified the start of the school year as particularly stressful. In the words of one participant, *"every year when you go back, there's obviously a new timetable ... change of rooms, change of teachers, maybe new people in your class and then maybe changing your head [principal], changing school rules and getting used to the classrooms again."* She also mentioned how in secondary school there are different teachers, in different subjects which may change from year to year and moving from higher to lower subjects also means a change in teacher. She recognised this as particularly worrying for Autistic students because they don't know how these new teachers will respond to them: *"some teachers are very equipped and very interested and accepting, but then other ones are not."* Several participants highlighted seat-change as challenging, one participant described being asked to move seat and how she *"couldn't understand what she'd done wrong, took it personally"* resulting in *"a meltdown [and] crying."* Though the situation was explained to the teacher, and she was allowed to stay in her seat, she felt judged for being difficult or spoilt by the other students, which was *"really hard."* Several students referred to the continuity brought about by the Covid pandemic, *"so Covid was nice. It really helped because we stayed in the same classroom the whole time."* The ideal scenario for one of the participants was to be in the same seat, in the same place, in the same class, all day, every day.

## Young People's Recommendations

As discussed in the methodology the primary purpose of this research project was to provide a means by which the school experiences of children and young people could be expressed from their perspective. During the course of these interviews, participants not only provided great insights into the ups and downs of their school life, but where they identified problems or difficult experiences they proffered a wide range of recommendations, solutions and preferences. These recommendations fall within similar themes identified by the P/G survey. What is presented below comes straight from the participants themselves and reflects many of the issues outlined in the themes above.

### Increased training of school staff

1. That teachers and SNA continue to upskill and engage in Autism training.

### Inclusion and acceptance

2. That the school policy refers specifically to inclusion and acceptance of Autistic people, in a similar way schools are accepting of LGBTQI + people.
3. That students seeing someone having a meltdown would not stare but know to inform a teacher or offer to go for a walk with them.
4. That inclusion is recognised as a whole-school effort including canteen, admin and teaching staff and not just falling to one support teacher.
5. That students sign a contract on entering the school that they will behave in a way that supports diversity and participate in educational programmes on diversity.
6. That schools integrate a diversity policy that is permanent and ongoing, not just for Autism awareness week.
7. That Autistic students can create material about what it's like to be Autistic for non-Autistic students.
8. That schools adapt their behaviour policies to reflect the behavioural traits of Autistic people.

### Access to services and supports

9. That schools provide increased access to assistive technology and other types of reasonable accommodations.



- 10.** If there is an Autistic student starting at the school, they should be allowed visit the school before the start of term, so they become familiar with the school, where the classrooms are, the canteen, meet the teachers and possibly have taster classes. This could be done every year, but particularly for big changes during school such as moving into Transition Year and the Leaving Cert cycle.
- 11.** That the teachers and SNA stay the same each year, to reduce disclosure and repetition of personal information "especially the SNA because I talked to them more than the teachers."

### Sensory accommodations

- 12.** Participants expressed a strong preference for schools with fewer students, smaller classes and working in small groups.
- 13.** That schools have one or more dedicated sensory rooms for Autistic students.
- 14.** That there is a quieter and less busy area where Autistic people can have their lunch.
- 15.** That the school day is structured with regular breaks.
- 16.** To alleviate sensory discomfort schools could support a quiet class transition e.g. Autistic students could leave class early to get to the next class.
- 17.** To minimise sensory discomfort and facilitate regulation schools could have several quiet areas and low sensory areas with dim light, no noise or smells and beanbags: "I like sitting on the ground more than on a chair."
- 18.** To avoid changing environments and crowded canteens Autistic students could eat lunch in class.
- 19.** To avoid change, sensory discomfort and crowds, Autistic students could stay in the same classroom with the same people (though with secondary school subject choices this was recognised as difficult).

### Academic accommodations

- 20.** To alleviate uncertainty teachers could write a class plan for each class which would be shared in advance.
- 21.** To provide clarity and facilitate organisation, year-heads could provide a plan for the day, what classes, assemblies, extracurricular stuff and advanced notice of any changes, for example if the teachers will be in "that makes it easy."

22. To avoid being taken out of scheduled classes, Autism support classes such as "life skills" are embedded into their timetables.
23. That schools continue to provide individual exam centres: *"it really helped."*
24. That assessments were less exam-based and more based on projects/extracurricular activities, for example, classroom-based assessment focused on presentation skills where the student picks the topic.
25. That assessments were broken down into smaller elements at the end of each topic, rather than one final exam.
26. That schools offered more subject choice including theatre, photography, politics, economics, media, social studies, and more language choice.
27. Where schools cannot offer a wide range of subjects on campus, subjects are offered online, or students are transported to other schools, or have a local base for each subject.
28. That students studying non-school subjects can sit these subjects in their school State Exam Centres [many schools do not accommodate this].
29. That teachers show understanding if homework is not done or completed; doing five identical questions may not be necessary, one or two may be enough.
30. That teachers would assess students' abilities by taking a note of how people are working: are they quick or slow.
31. To avoid boredom, students who complete tasks quickly could be given a research project in that subject that they can work on while they wait.
32. That there is an option to learn from home - would help during periods of poor mental health – if it worked during Covid why not all the time.

#### Better communication

33. That teachers would use different methods of communicating information, not just the board.
34. That teachers use plenty of visuals, that topics are broken into stages visually, e.g., science experiments.
35. That teachers use more video so students can re-watch classes.
36. That teachers give handouts / notes for each class – "that worked for me".

- 37.** That teachers would provide a list of expected learning outcomes / intentions at the start of the class so students can anticipate what's coming and prepare.
- 38.** That teachers would provide a list of necessary materials / books etc before each class.
- 39.** That teachers would write homework on the board in time to take it down.
- 40.** That a Home School Liaison Worker would be assigned to see how the student was getting on.
- 41.** When planning an Autistic person's day, keep to the schedule / routine, give them advance notice of change, if there are changes to seat plans etc. explain why this is happening so the person knows and does not think it's due to something they've done wrong.

## Discussion & Conclusion

The aim of this research was to explore the extent to which education practices in Irish schools are inclusive of Autistic young people in response to AsIAM's Community Support Team who identified several issues and barriers around education practices within Irish schools. This research set out to understand the experiences of Autistic students from the perspective of Autistic children and young people themselves, and their parents / guardians. In achieving this, two research projects were undertaken: the first surveyed parents and guardians (n=353) asking them to provide a detailed description of their child's or young person's school experience, and the second interviewed Autistic students (n=5) regarding their school experiences. This research project adopted a human rights approach and was informed by the following legislation, acts and treaties.

*“Our children are not being given their human rights” (SP).*

As outlined in the literature review Ireland has an abundance of legislation emphasising the rights of all children to an education, regardless of learning abilities. This includes Ireland's ratification of the UNCRC which recognises education as more than mere academic skill but something conducive to “achieving the fullest possible social integration and individual development” (Article 23). There is also the Education Act 1998 and the EPSEN Act 2004 both of which emphasise equality of access to and participation in education, and that schools make reasonable accommodations for students with additional needs. In 2005 the National Council for Special Education [NCSE] was established to achieve the aims set out in these acts through the provision of Individual Education Plans [IEP]. While in 2023 Ireland was recognised by the UNCRC periodic report (PR) as making improvements, the report identifies many gaps in the provision of rights for children, in particular children with disabilities<sup>72</sup>. The finding from this study reiterates their concerns.

*“Everyone with an Autistic child has already had a battle to get assessed, waiting lists, red tape, more forms and then when you finally get a diagnosis you commence the battle to obtain the supports your child needs to progress” (SP).*

The UNCRC Periodic Report<sup>73</sup> identifies unacceptable waiting times for diagnosis and assessment, particularly relating to mental health. Reflecting this, many of our participants describe how delays in Autism diagnoses greatly impacted their access to resources and supports. The Irish State was also instructed to improve social integration and individual development for children with disabilities. Many participants described feelings of isolation and exclusion and how the emphasis in schools on academic achievement over social integration provided little support for C/YP who experience difficulties with social connection.

*“People are very clicky, so it's hard to, you know, talk to people and make friends” (IP).*

The Irish State was also found to be failing to recognise and empower children as rights-holders and having insufficient regard for their opinion and perspectives. Similarly, the participants highlight many instances where C/YP and their P/G describe not being taken seriously, having to fight for resources, not being communicated with and in many cases feeling that necessary supports were viewed as tentative additional extras for which they ought to be grateful. With regard to awareness-raising, many felt that “understanding Autism” was something done during “Autism week” and viewed more as an imposition for the remainder of the school year. Many participants described how lack of understanding in relation to Autism led not only to insufficient or inappropriate resourcing but in many cases an interpretation of Autistic students’ behaviour as tricky or self-indulgent.

In many instances Autistic students frustrated with how they were perceived organised awareness-raising campaigns themselves, and while experienced as very empowering, they felt this shouldn't be something they have to undertake in order to feel more accepted and included within their schools. Finally, the UNCRC PR highlighted the State's lack of resourcing for child mental health. It is well known that mental health is an issue for many Autistic C/YP<sup>74</sup>, particularly for girls and young women. Many participants, in particular girls described the intense pressure to fit in which required heavily masking Autistic traits and behaviours. Despite these attempts at inclusion participants continued to feel that they were viewed as weird, suffering intense loneliness and loss of self-esteem through a relentless feeling of exclusion. These experiences not surprisingly led many Autistic students to have feelings of intense and overwhelming anxiety in relation to school leading many to choose to stay at home "where they can be their Autistic self."

*"I try to be a different version of myself... so that maybe people would like me or that people would be friends with me" (IP).*

While the medical model of disability focuses on addressing the needs of the individual, the UNCRPD adopted a more holistic, social model-led interpretation of disability. This involved recognising the primary role of disabling social attitudes and the physical environment which act as barriers to participation. Thus, in attempting to create a more inclusive society the UNCRPD shifted emphasis from individual interventions to Universal Design, which requires that to the greatest extent possible all aspects of an environment must be usable by all people without special modification and that people are encouraged to examine their biases through equality and diversity training. Throughout this research participants have identified instances where student and teacher attitudes, and the school environment are experienced as stigmatising and disabling.

*“I think there is a general feeling that we should be lucky our children have a school place. Sometimes we don't want to rock the boat with schools in case it will affect our children's school experience or place” (SP).*

With regard to teacher and peer attitude many participants described how when they were experiencing a sensory overload and feeling overwhelmed, attempts at self-regulation through stimming caused them to be stared at and viewed as weird. Occasionally teachers were described as unsympathetic and not modelling good behaviour but also staring at the student themselves. Participants described in some cases a lack of understanding where requests to leave the class to self-regulate were denied causing intense distress and in some cases total meltdown, leading to stigmatisation and exclusion. Despite claiming to celebrate diversity many participants felt that schools were more likely to reward conformity, focusing attention on academic success, prescribed sports and adherence to the school uniform, while the more unique achievements of Autistic students were largely ignored or not given the same prestige. The celebration of conformity over diversity was experienced by many Autistic students as a deeply oppressive pressure to hide Autistic traits and characteristics. As a result, accommodations were often experienced as stigmatising, singling out Autistic students as odd or needy, and resulting in some students forgoing supports to fit in. Others described how programmes designed to help Autistic students with integration, felt more like attempts to eliminate Autistic traits and identities.

*“I think there needs to be more ... making them feel wanted in the school environment ... helping them to have purpose, like not basing it all on academics” (IP).*

Participants described finding many aspects of the school environment difficult and exclusionary most notably the yard or playground and the canteen or lunch hall. Participants described how the hustle and bustle in corridors, changing class, or rushing to lunch was a source of stress, while the noise and smells of crowded canteens often made them difficult places to be. While schools were described as attempting to support students' needs through provision of private spaces, these were presented as 'special' accommodations and resented by others leading to further isolation. While participants often described liking learning and finding class time enjoyable, many found unstructured time difficult. Some described not knowing how to interact with other students and therefore waiting around the yard or school grounds on their own, waiting for class to start again. Many parents and guardians described their younger children standing at the edge of the playground trying not to draw attention to themselves and finding unstructured games like chasing difficult to follow. Many expressed a desire for more structured activities during breaks that would allow for social interaction through shared interests such as a games room, and provide opportunities to make friends through activities which match their interests.

*“I don't like the unstructured time ... I don't really know what to do with myself” (IP).*

While there were many accounts of positive experiences of school where students felt included and supported in their education, these were often attributed to a particularly supportive and committed staff member(s) rather than being attributed to the educational system. On the whole participants' experiences of education were negative for a broad range of reasons. The presence or absence of supports or a supportive attitude was identified as a key factor in whether parents and guardians, and children and young people found school engagement pleasant or stressful. The requirement to obtain a diagnosis was recognised as a significant barrier is obtaining timely supports particularly in the case of girls who were often described as receiving a late diagnosis.



*“We got diagnosed when we were in our later teens even though we had the signs and weren't able to get supports and stuff in school because of that” (IP).*

Many other factors were identified as contributing to participants' experience of school as positive or negative. Positive experiences often related to managing academically and having a cohort of friends. Negative experiences were more complex and included feelings of isolation and loneliness; feeling excluded particularly during breaks leading to masking in an effort to fit-in and make friends; experiencing poor mental health, especially anxiety and low self-esteem; experiencing overwhelming sensory overload, most notably at lunchtime or during class changes; feeling stigmatised due to peer and staff lack of understanding Autism; feeling disoriented and anxious due to poorly-communicated or unanticipated change; and limited choice regarding curricular subjects and extra-curricular/free time activities. While large numbers of participants had a generally positive experience of school, the majority described their general experience of school as negative, with Autistic girls' experiences being significantly more negative than Autistic boys'.

*“Girls tend to hide it (Autism) better than boys” (IP).*

*“I don't want them ... shutting me (out) ... not giving me a chance ... to be friends” (IP).*

The question is how to address these issues so that Autistic children and young people have a more inclusive and pleasant experience of school? While some parents and guardians may be able to home-school their child this is not an option for all, nor should it be necessary.

Without an education it is very difficult to succeed within today's society, thus it is with good reason that school attendance is a legal requirement. However, the many difficulties faced by Autistic children and young people is having a profound effect on their educational experience, their capacity to succeed educationally, and to progress on to other stages in life such as university or employment<sup>75</sup>.

*"I feel very fortunate that he got a place where he did. Lots of families are so desperate to get an appropriate school place for their child but to also get an environment that is so welcoming and nurturing feels like winning the Lotto" (SP).*

Harvey<sup>76</sup> argued that teachers must be given the skills to adapt classrooms to the diverse strengths and needs of students as opposed to expecting all students to conform to a deeply reductive and exclusionary interpretation of education. Harvey views this 'one-size-fits-all' approach to education as deeply disabling to many students, in particular Autistic children and young people. In exploring whether Autism is a disability, Wood answers:

'Well yes, if you fail to understand and accommodate Autistic people, if you expect them to slot into the status quo, regardless of their needs, wishes and particular dispositions. If children spend their educational life being essentially told, one way or another, that they are flawed, damaged goods, then this may well result in a disabling lack of self-confidence, or serious mental health issues in later life'<sup>77</sup>.

The problem as she sees it is not how to address the individual needs of Autistic students so they can be integrated into mainstream schools but how mainstream schooling can be made more inclusive for everyone. Evoking the principle of Universal Design, Wood argues if inclusion is to be meaningful it "must incorporate the curriculum, extra-curricular activities and design of the school building from the earliest planning stages"<sup>78</sup> in consultation with all stakeholders, including Autistic people. Finally, Moyse highlights how the perception of Autism as male is leading to a later diagnosis of girls and young women resulting in delayed supports. Further, the social pressure on girls to conform to gender stereotypes is exerting an additional exclusionary impact on autistic girls and young women who feel under enormous pressure to mask their Autistic traits.

*“So that resulted in me heavily masking and trying to fit in, when it [fitting in] was never going to happen” (IP).*

While Harvey, Wood and Moyse all take a slightly different approach collectively what they are calling for is a new model of education that accommodates diversity through a variety of measures including Universal Design and a more inclusive attitude. Firstly, this requires that educators and policy makers provide mechanisms whereby all stakeholders' voices are heard. Secondly, this requires flexibility and a willingness to adapt to the evident strengths and expressed interests of all students. To do this, educators need to be provided with ongoing training on diversity and inclusion and what this means within an educational context, in particular how to acknowledge and celebrate the strengths, skills, and talents of all students. As outlined in the findings, participants shared numerous and often ingenious recommendations that could contribute in various ways to the development of a new model of education, including: the provision of an emotional & social support teacher; ongoing diversity training for staff and students; more self-directed project based learning; broader choice of subjects which could be shared between schools or online; access to multiple quiet spaces; greater diversity of extracurricular school activities that could also be accessed during breaks, prize days that recognise more than sporting or academic prowess, to name a few. While some participants felt their school went to considerable efforts to consider these, many felt they were not listened to or had no mechanism whereby these ideas would be treated with due regard. While not a legal requirement of schools, the Public Sector Equality and Human Rights Duty provides an ideal consultative framework for schools to address and promote inclusion through engaging with all stakeholders.

*“Children’s voices should be at the centre of supports” (SP).*

IHREC regard the implementing of the Duty as involving a three-step approach, to assess, address and report on the obligation to eliminate discrimination, promote equality, and protect the human rights. From a school's perspective this three-step approach might involve:

- **Assess** – here schools could outline in their policy a means of assessing equality and human rights issues relevant to their broad social and educational obligations.
- **Address** – the policy could also set out the plan and actions to be used in addressing any issues raised during the assessment process.
- **Report** – developments and actions undertaken would then be gathered in an annual report shared with the whole school community, including students, parents, and staff<sup>79</sup>.

In addition to providing its own guidance documentation on how to implement the Duty, IHREC advises institutions to draw on other sources such as The Equal Status Act, which prohibits discrimination in the provision of education on any of the following nine grounds: gender, marital status, family status, age, disability, sexual orientation, race, religion, and membership of the Traveller community. However, schools are exempt from elements of the Equal Status Act in that they are allowed to discriminate on the grounds of gender (single-sexed schools) and religion (single-denomination schools). It is easy to see how these exemptions could weaken the perception of equality and human rights from schools' perspectives. Several parents and guardians commented on how conservative schools were with regard to diversity of teaching practices and inclusion of students, that little had changed since their time. As suggested by Moyses, diversity and inclusion tend not to mix well with schools' adherence to tradition and conformity. While implementation of the Duty has brought about improvements in inclusionary practice within universities, county councils and prisons, schools and most importantly students, are unlikely to see these benefits while schools are exempt from fully acknowledging equality and human rights.

*“So, it was kind of weird going into an all-girls’ school” (IP).*

While it is clear from this research that many schools, teachers, SNAs and support staff are doing their utmost to support the needs of Autistic students, it is still the case that the majority of Autistic students describe their school experience as negative for a wide variety of reasons. What is truly optimistic is that these students and their parents have a very clear idea of what modifications are necessary to make their school far closer to their ideal and are keen to voice this. While schools may feel resource limitations make this impossible, there is an abundance of freely available expertise that schools can call upon and many of the ideas proposed by participants require nothing more than a willingness to listen and a degree of flexibility.

In addition, if the Irish State is serious about the rights of Autistic children and young people it must support schools' implementation of universal design by funding the necessary changes to school environments, teaching styles and curricula as outlined by the Oireachtas Joint Committee<sup>80</sup>. These changes will make schools more inclusive to all.

It is common at this point in a report to make several recommendations. In keeping with the aims and objectives of this research we have only one: to read the recommendations of the participants above – and listen to Autistic students. They know what they need and want.

*“I have done so many surveys and so many third level students ... have done projects on our son, but sadly they all only gather dust and I never see them and nobody else does either. My wish is that your research actually does something, like changes people's lives!!!”*

In the hope for this change to manifest itself, there is an onus on the Department of Education and the National Council for Special Education to ensure it provides the appropriate supports and resources to our schools. AsIAM is taking the opportunity with this research to provide evidence-based information from this study on “Exploring the school experience of Autistic Children and Young People” to support the Department of Education and the National Council for Special Education to implement the three recommended steps of the Public Sector Duty. The template below presents the **issues/barriers** to education identified by the participants of the research, we believe these issues can inform an assessment of equality and human rights issues relevant to the public bodies listed above. The template also includes potential actions/solutions to remove these barriers to education, that can inform the development of actions/plans to address equality and human rights issues relevant to the public bodies listed above). We have also taken the opportunity to present the potential impact for Autistic children in education if these issues are addressed.

<i>Identified themes</i>	<i>Recommendations</i>	<i>Impact/Outcome</i>
<p>Understanding Autism</p> <p>A major source of concern and frustration for many Parents/Guardians (n=53) related to school staff's lack or limited knowledge or understanding of what it means to be Autistic, for example a lack of understanding of sensory sensitivity processing, a lack of knowledge regarding diverse learning styles e.g., visual, or a disregard for the need to stim</p>	<p>Increased training of school staff</p> <p>That teachers and SNA continue to upskill and engage in Autism training on an ongoing basis.</p>	<p>Mandatory training?</p> <p>A teaching staff which understands, respects and is open to increasing their knowledge of the Autistic experience can have a deeply positive impact on a child's/young person's educational experience.</p>
<p>Resources</p> <p>Lack of supports in place for some students. Providing the necessary supports for a child/young person to engage with the educational system. Parents/Guardians should not have to face a battle for appropriate resourcing.</p>	<p>Increased resources for schools</p> <p>Additional SNAs supplied to schools along with additional teacher resource hours.</p>	<p>Increase in the budget for special education</p> <p>Retention of key personnel in our schooling system and ensuring there are appropriate school places for autistic children and young people.</p>
<p>Accessible curriculum</p> <p>A recurring theme within the research was that an exemption from the Irish language was one of the few areas where flexibility was offered within the curriculum.</p>	<p>Additional Accommodations</p> <p>Academic accommodations are needed for exams, homework, group work, online learning, access to using assistive technology.</p> <p>There also needs to be a discussion started on alternative curriculum content and the national exam structure so that Autistic children are not being excluded from completing their education.</p> <p>Access to reasonable accommodations in mainstream classrooms, and different ways of learning or accessing curriculum materials should also form part of what is offered, and schools should be resourced to support students to have their support needs accommodated and to learn in ways that is intuitive and accessible to their way of thinking.</p>	<p>Supported Students</p> <p>Increased positive outcomes for autistic students transitioning out of school.</p>

Inter-departmental/agency coordination/communication

Coordinated supports between relevant state agencies such as the NCSE/CAMHS/NEPS/Children's Disability Network Teams & /Primary Care Teams

Positive schooling experience with appropriate supports in place.

The P/Gs were asked who had provided support for their child's/young person's participation in school. As shown (Figure 13) a large percentage of participants were not being provided with any support despite having requested it.

Better communication between each team in these categories where applicable to a child's/young person's support needs.

Coordinated effort to support a child's/young person's needs as they journey through school. Creating less stress at home for child/young person and families. Such practices would make the education system more equitable and accessible for autistic children/young people.

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