An Exploration into the Educational Experience of Children with Autism Spectrum Disorder in Mainstream Schools in Ireland from a Parents' Perspective

Áine Jane Doyle

CARL Research Project
in collaboration with
Rainbow Club Cork Centre for Autism

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What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grassroots groups, single-issue temporary groups, but also structured community and voluntary organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;

- provide their services on an affordable basis;

- promote and support public access to and influence on science and technology;

- create equitable and supportive partnerships with civil society organisations;

- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and

- enhance the transferrable skills and knowledge of students, community representatives and researchers (Living Knowledge Network).

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We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

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The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access, and the free and public dissemination of research results.

How do I reference this report?

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: https://www.ucc.ie/en/scishop/rr/ [Accessed: date].

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Áine Jane Doyle   Dissertation
Statement of Originality

I wish to confirm that the work in this dissertation "An Exploration into the Educational Experience of Children with Autism Spectrum Disorder in Mainstream Schools in Ireland from a Parents' Perspective" is my own and when I reference the work of others throughout the dissertation, I cite it accordingly using recognised academic conventions.

To ensure academic integrity I have reviewed the originality report for my dissertation on TurnItIn Feedback Studio before submitting the document and made amendments as needed to address any citation issues identified in my dissertation by the TurnItIn Feedback Studio originality report, which is in line with University College Cork Plagiarism Policy.

Áine Jane Doyle

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filling a gap for families in such an underfunded area. I am also unbelievably grateful to the six participants who took part in the interviews and who were so open, honest, and generous with their time. Without them, this project would not have been possible.

Áine Jane Doyle   Dissertation

Abstract

This primary research project was carried out in collaboration with the Rainbow Club Cork Centre for Autism and the CARL project initiative in UCC. The research investigated the experiences of autistic students in mainstream primary and secondary schools, drawing on the parents' perspective. Qualitative research was used in the form of individual semi-structured interviews, of which six participants were interviewed. Participants had to be parents of an autistic child or young person who is or has in the past attended a mainstream primary or secondary school and is a service user of the Rainbow Club Cork Centre for Autism. An epistemological approach of social constructivism was used to gain an understanding of the lived experiences of participants. Following the six interviews, thematic analysis was used to identify five key themes within the data set, which are as follows; The effects of mainstream school attendance on autistic students' mental health, Difficulty in making friends in mainstream school, Bullying and Social Exclusion, Difficulty accessing alternatives to mainstream school and Importance of a flexible approach in schools. The research findings highlight the overwhelming challenges and difficulties that autistic students face attending mainstream schools. Particular difficulties involving mental health, bullying, and making friends were highlighted by almost all participants.

Áine Jane Doyle   Dissertation

Table of Contents

Chapter 1 Introduction & Research Background

Áine Jane Doyle   Dissertation

Chapter 5 Conclusion & Recommendations

Áine Jane Doyle   Dissertation

1.0 Introduction & Research Background

1.1 Introduction

In this chapter, the researcher will give an overview of the research topic, including a description of

the research background and an introduction to the community partner, the Rainbow Club Cork Centre for Autism (RCCCA). The researcher will then detail the rationale for the research, the research title, the aims and objectives, and the research questions. The chapter will conclude will a table providing readers with an outline of the upcoming chapters.

1.2 Research Background

Having completed a preliminary literature review, the researcher became aware of the current discourse that was happening around inclusive education for students with Autism Spectrum Disorder (ASD). In Ireland and many other countries inclusive education is seen as an effective and just educational approach for all students. This was written into law in Ireland under the Education for Persons with Special Educational Needs (EPSEN) Act 2004. The Act states that children with a disability have the right to be educated, where possible, in their communities and with their non-disabled peers. However, it is important to note that some of this Act has yet to commence after 20 years. Inclusion Ireland is a very strong voice for inclusion in education across Ireland. Inclusion Ireland is concerned that the Act fails to align with the UN Convention on the Rights of Persons with a Disability (CRPD), particularly Section 2 of the Act which states that inclusive education is not an option for students with disabilities "if not in the best interests" of both the child with a disability and in the best interest of other children who will be in their classroom (Inclusion Ireland, 2023). Inclusion Ireland argues for a completely inclusive education system in Ireland. This is echoed by the National Council for Special Education (NCSE) who in January 2024 released their 'landmark' policy advise paper on special and inclusive education. Their newly published document advises for the complete inclusion of students with disabilities in their local

Áine Jane Doyle   Dissertation

schools, and for local schools to be equipped to do so. AsIAm, Ireland's leading autism charity welcomed this radical and progressive paper which promotes complete educational inclusion. However, AsIAm noted their concern that the NCSE seems to want to move away from autism-specific learning environments such as autism classes as well as concern at the accuracy and tone of the discussion of the prevalence of ASD within the document which they worry could

increase stigma (AsIAm, 2024).

A study conducted by AsIAm in 2019 found that 54% of those families whose child(ren) were experiencing exclusion or extended absences from school were secondary school-aged. Furthermore, the study reported that 66% of students who were experiencing exclusion or extended absences from school named 'anxiety' as the main reason (AsIAm, 2019). Another study conducted by Byrne and Delimata (2023), which was commissioned by AsIAm, investigated the experiences of autistic secondary school children. It was concluded that autistic students found their time in school to be a 'battle' where they felt pressure to 'mask' to fit in with their peers and to avoid bullying and harassment. In this research, it was recommended by AsIAm that schools and teachers increase their awareness of what inclusion in education looks like. From the researcher's discussions with the RCCCA, this type of

school experience is having detrimental effects on many of their service user's mental health, who have similar experiences in mainstream education as outlined in the studies.

1.3 Community Partnership – Rainbow Club Cork Centre for Autism (RCCCA)

Karen O'Mahony and her husband Jon founded the RCCCA in 2015, after seeing firsthand the insufficient number of services for children and young people with ASD. Karen and Jon's motivation to set up the organisation, and driving factor to this day are their sons who have ASD (RCCCA, 2020). The RCCCA is based in Mahon, Cork City, and offers a coordinated, holistic centre that provides services and support for families, children, and young people dealing with the challenges of ASD under one roof (RCCCA, 2020). The RCCCA provides

professional therapies and courses for children but also provides training and education for parents, carers, and professionals to raise awareness, and understanding and provide the best possible outcomes (RCCCA, 2020). In the RCCCA's own words, they 'provide a coordinated pathway of care and a thriving hub of support for every child and their family from the time they begin at the centre in early childhood until they reach young adulthood' (2020). The organisation is a one-of-a-

kind in Ireland through its innovative 'whole system approach' informed by a 'community of care and acceptance, and today has supported over 1000 children and 240 families (RCCCA, 2020). The services and resources available at the RCCCA include:

- Social groups,
- Adapted sports program
- Teen hub
- Sibling supports
- Life skills and mentoring
- Speech and Language therapy
- Art and music therapy
- Parent support
- Counselling
- Lego
- Gamer Café
- Regulation sessions
- Community Café

The Rainbow Club's overarching goal is to spread its multidisciplinary approach throughout Ireland so that no child suffers educational or social disadvantage due to a lack of service provision (RCCCA, 2020).

1.4 Rationale

The researcher met with Karen O'Mahony, the CEO of the RCCCA, and discussed different issues facing the organization and the people and their families who use their service. It was agreed that the issue of autistic young people attending mainstream schools was one of importance due to the knock-on effects seen by the staff in the RCCCA which include mental health problems, social isolation, and poor self-worth. The research project will hopefully give the RCCCA a better

understanding of what supports work well, and thus can be used to advocate for their service users

and can be used when applying for funding for more

resources. The research will also benefit social work as it will give a different perspective to

practitioners of people with ASD's opinions and will hopefully open a conversation on inclusion in

mainstream education. The research will also encompass social work principles, including social

justice, promotion of diversity, and human rights. Furthermore, conducting research is an

important part of social work and meets several CORU Proficiencies (5.2 and

5.21).

1.5 Research Title

This research is titled *The Educational Experience of Children with Autism Spectrum Disorder in Mainstream Primary and Secondary Schools in Ireland.*

1.6 Research Aim and Objectives

The aim of this research is to explore the experiences of students with Autism Spectrum Disorder

in mainstream primary and secondary schools in Ireland. The objectives to meet the aim of the

research are as follows:

1. Conduct a literature review to gain a better understanding of what ASD is, investigate what the current discourse is relating to students with ASD in mainstream schools in Ireland and globally, and what the policies and legislations say on the topic.

Áine Jane Doyle   Dissertation

2. Conduct interviews with parents of students with ASD who have attended mainstream primary or secondary schools in Ireland. All interviewees will be service users of RCCCA.

3. Form relevant and detailed recommendations based on the research findings to improve the reader's knowledge of the topic and support students with ASD in education.

1.7 Research Questions

This research project will look to answer the following questions:

1. What is the experience of mainstream primary and secondary school for autistic students in Ireland as reported by parents of autistic students?

2. How effective is inclusive education for autistic people at present in Ireland?

3. Do links exist between participation in mainstream school and mental health problems for autistic students?

1.8 Dissertation Chapter Outline

Chapter One: Introduction	In this chapter, the researcher will give an overview of the research topic, including a description of the research background and an introduction to the community partner, the rationale for the research, the research title, the aims and objectives, and the research questions.
Chapter Two: Literature Review	The researcher will investigate the relevant literature that is currently available on the topic of ASD and education using resources including journal articles, books, government reports studies conducted by charities and government-funded organisations.

Chapter Three: Methodology	In this chapter, the researcher will justify their chosen research design and method as well as give the reader a clear description of how the research was conducted. The researcher will also discuss the data collection method, sampling, ethical considerations, and research limitations.
Chapter Four: Findings & Analysis	In this chapter, the researcher will highlight the key findings from the data obtained during the interviews. The data will be analysed using thematic analysis. The chapter will conclude with a discussion linking the data to relevant literature.
Chapter Five: Conclusion	The final chapter will contain recommendations and final comments from the researcher.

1.9 Conclusion

In this chapter, the researcher gave readers an overview of the research topic, as well as a description of the research background and an overview of the community partner, the RCCCA. The researcher then detailed the rationale for the research, the research title, the

aims and objectives, and the research questions. The chapter concluded with a table providing readers with an outline of the upcoming chapters.

In Chapter 2*: Literature Review*, the researcher will investigate the relevant literature that is currently available on the topic of ASD and education, including researching the history of

inclusive education and the relevant policies and legislation on the topic.

Áine Jane Doyle   Dissertation

2.0 Literature Review

2.1 Introduction

In this chapter, the researcher will explore what the current literature says about Autism and

education in Ireland. The research will give an overview of ASD followed by an investigation into

current inclusive education practices and a look at some of the challenges that autistic students can face in mainstream education, concluding with an exploration into what supports and alternatives to mainstream education are available to autistic students at a primary and post- primary level.

The areas that will be explored in this chapter are as follows: Autism Spectrum Disorder, Inclusive Education in Ireland, Inclusive Education Legislation and Policy, Challenges of Inclusive Education for Autistic Students, and What Could Help.

For this Literature Review, the researcher will use 'autism,' 'autistic' and 'ASD' interchangeably.

2.2 Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is defined by Baron-Cohen et al. (2013) as "a set of heterogeneous neurodevelopmental conditions, characterised by early-onset difficulties in social communication and unusually restricted, repetitive behaviour and interests". Furthermore, AsIAm, one of Ireland's largest autism charities, defines Autism as a "lifelong, developmental disability or difference which relates to how a person communicates and interacts with others, and how they experience the world around them" (AsIAm, 2022).

The World Health Organization (WHO) states that approximately one per cent of the world's population is autistic. ASD is more common in boys than girls, at a ratio of about three to one (WHO, 2023). However, it is believed by many in the area that autism in girls is underdiagnosed due to a 'significant implicit gender bias towards associating males with

Áine Jane Doyle   Dissertation

autistic traits and evidence suggests that autistic females are more likely to be undiagnosed or be diagnosed much later in their lives (Brickhill et al., 2023).

Some autistic people need little to no day-to-day support whereas others may need substantial levels of support and the characteristics of ASD can vary greatly from person to person, (Irish

Society for Autism, 2020). That is why Autism is known as a 'spectrum' disorder because of the wide variation in the type and severity of characteristics people experience (National Institute of Mental Health, 2023). There are many signs and characteristics of ASD, which can change throughout a person's life course. The National Autistic Society (2023) in the UK lists some common characteristics of ASD which include:

- Social communication and social interaction challenges

- Repetitive and restrictive behaviour

- Over or under-sensitivity to sensory stimuli

- Anxiety

- Meltdowns and shutdowns

Signs of ASD can begin to emerge in the first year of a child's life and can be detected between 6 and 18 months of age (Tanner & Dounavi, 2020). While a person can be diagnosed with autism at any age, Leader et al. (2021) state that the average age a child receives an ASD diagnosis in Ireland is 5 years and 5 months, however, this is dependent on waiting times to access diagnostic services. A delayed diagnosis can result in limited access to school placements and support as well as difficulties accessing programs and resources which may be beneficial such as Speech and Language and Occupational therapies (Leader et al., 2021).

2.3 Inclusive Education in Ireland

In a study conducted by the National Council for Special Education (NCSE) in 2016 regarding the education of autistic students in Ireland, it was reported that one and a half per cent of the school population has an ASD diagnosis (NCSE, 2016). The WHO (2023) states that the level of intellectual functioning ranges 'from profound impairment to superior levels', therefore autistic

students in Ireland attend both mainstream and special schools depending on the individual needs of the student.

The landscape of education for students with additional educational needs, which includes many students with autism, has changed in recent decades. Previously the vast majority of students with additional educational needs were educated in 'special schools'. There are still around 140 special schools in Ireland (Citizens Information, 2023). The NCSE (2018) states that special schools support students with more severe or complex special educational needs, not just students with ASD, in circumstances where attending a mainstream school would not be in the student's best interest.

A large number of students with ASD in Ireland are educated in 'autism classes' or 'special classes' which are attached to mainstream schools. According to Shevlin and Banks (2021), special classes have been in existence in Ireland since the 1970s, however, it was not until the late 2000s that the number of special classes began to grow and their designation changed from settings primarily for students with Mild General Learning Difficulties to classes for ASD. There are over 2,800 special classes in Primary and Secondary Schools in the 2023/24 academic year (NCSE, 2023). The NCSE (2018) explains that special classes allow students with special education needs to be educated in their local mainstream schools in smaller and supportive classroom environments.

An important benefit highlighted by many advocates of inclusive education is socialisation. There is research to suggest that without 'systematic social intervention' children and adolescents can have limited or non-existent interactions with peers (Koegel et al., 2013). In

Áine Jane Doyle   Dissertation

turn, the lack of socialisation can have a negative impact on the reported emotions of students with ASD, including difficulties with anxiety and depression (Koegel et al., 2013). Another argument for inclusive education is the concern by some advocates that without inclusive practices from an early age, individuals with disabilities are often overly protected by their community, which can harm their social development, personal autonomy, and decision- making ability (Zvoleyko et al., 2016).

2.3.1 Inclusive Education Supports

An important part of inclusive education in mainstream education is providing students with additional needs with appropriate support in school. One of these supports for students is the support from a Special Needs Assistant (SNA). An SNA is allocated to schools to work with children who have specific care needs, including autistic students (Coleman, 2023). SNAs provide non-teaching care support through a wide range of responsibilities depending on the needs of the student they are working with (Coleman, 2023). Some of an SNA's responsibilities can include supporting students with mobility and orientation difficulties as well as personal care and personal hygiene needs (NCSE, 2015). In a Dáil Eireann debate in November 2022, Minister of State with responsibility for Special Education and Inclusion, Josepha Madigan stated that in 2023 there would be over 20,000 SNAs, which would be the highest number of SNAs to be in the education system in Ireland ever before (Houses of the Oireachtas, 2022).

Some mainstream primary and secondary schools have 'autism classes', or 'autism units' which are separate areas from the mainstream school. These classes are comprised of a small number of students (AsIAm, 2022). The idea of these classes is to promote inclusive education while also allowing autistic students to receive additional support to meet their needs (AsIAm, 2020). AsIAm (2022) explains that some students may spend most of their day in these classes learning from an individualised curriculum, while other students may need to be in the class for a short period during the day, and can participate in the mainstream

classes. Speaking in Dáil Eireann in October 2023, Minister of State at the Department of Education Josepha Madigan stated that there are a total of 2,919 special classes in Ireland, 2,475 of which are autism classes. Furthermore, there are autism classes in 1,345 mainstream schools nationwide (Houses of the Oireachtas, 2023).

2.4 Inclusive Education Legislation and Policy

Over the years there has been new and emerging legislation and policies which concern inclusive education and children with ASD. Two of the most influential in Ireland include the Education for

Persons with Special Educational Needs Act (EPSEN) 2004 and the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD). While there is no legislation in Ireland specifically for autistic students, the EPSEN Act and the UNCRPD Act include autistic students under the broad definition of 'special educational needs.' The EPSEN Act defines 'special educational needs' as "a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition" (NCSE, 2014).

2.4.1 Education for Persons with Special Educational Needs Act (EPSEN) Act 2004

EPSEN Act states that where possible, children with special educational needs should be educated in an inclusive environment, with their peers who do not have special educational needs (Banks & McCoy, 2017). A goal of the EPSEN Act is to ensure students with additional educational needs still receive a level of education that matches their peers while also building skills necessary to participate in society and live independent and fulfilled lives (Banks & McCoy, 2017).

2.4.2 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006)

Article 24 for the UNCRPD covers the area of education for people with disabilities. The Act states that people with disabilities have the right to equal opportunity to access the general

education system and should not be excluded based on having a disability (National Disability Authority, 2022). The Act also states that the state must provide reasonable accommodations and support so that a person with a disability can take part in the general education system (National Disability Authority, 2022).

2.5 Challenges of Inclusive Education for Autistic Students

While the concept of inclusive education may seem ideal and aspirational for many, it is not without its challenges (Haug, 2017). This section will discuss what the literature says about four

common challenges experienced by students with ASD who attend mainstream school.

2.5.1 Difficulty in getting a place in an Autism Unit or Class

Despite possessing the right to an education and equal opportunities in education under the

EPSEN Act and the UNCRPD, there are barriers facing autistic students who try to access autism

classes or units. Despite the growing number of special classes in Ireland, every school year

students are left with no school placement, or in a school placement that is not suitable for their

needs. In October 2023 it was reported that there were 55 children with additional needs still

without a suitable school placement for that school year, 44 of which were primary school age while

the remaining 11 were secondary school age (White, 2023). However, as the report stated this

number only includes the students who are known to the NCSE. In May

2022, AsIAm concluded that 270 autistic students were without an appropriate school place for the

upcoming school year. The majority of children in the survey had been assessed and deemed to

require a place in a special school or special class attached to a mainstream school, however, due to

a lack of places they were unsuccessful in their applications (O'Brien, 2022). The total number of

students without a suitable school placement published by AsIAm suggests that the lack of school

places is larger than the official numbers (O'Brien, 2022).

Furthermore, in 2022 AsIAm published a study which stated that 28% of participants believed that

their child does not have a suitable school place. The autism charity also argued in the

study that the Government's 'adversarial approach' when providing educational support to

people with additional needs is one of the first barriers to inclusion (AsIAm, 2022).

2.5.2 Bullying

A common trait of autism, and a diagnostic criterion under the DSM-5, is a difficulty or

inability to develop and maintain peer relationships and difficulty reading social situations, as a

result, students with ASD are far more likely to experience bullying than their peers

(Rowley et al., 2012), which can make participating in mainstream education increasingly difficult.

When speaking to the Oireachtas Committee on Education in 2021, Inclusion Ireland stated that children with disabilities are 'three times more likely to be bullied than their peers' (Inclusion Ireland, 2021). Furthermore, Inclusion Ireland also quoted research from the United Nations that children with disabilities are four times more likely to experience violence than their peers without a disability (UN, 2012). According to Patchin and Hinduja (2016), bullying can be defined as the deliberate, repeated harm inflicted by one or more people against another person who is deemed to be unable to effectively defend themselves. Research that backs up this statement on bullying of autistic students was conducted in Manchester, England. Humphrey & Symes (2011) state that integrating students with ASD into mainstream schools has an increased risk of experiencing negative outcomes such as bullying and emotional distress. Autistic students who attend mainstream schools are more at risk of being the victims of bullying (Humphrey & Hebron., 2014).

It can be argued that a lot of bullying takes place because of a lack of knowledge and understanding of autism (Humphery & Symes, 2011). This point however does not help or ease the upset and additional stress that attending a mainstream school can cause autistic students. The effects of bullying have long been identified and studied. According to Wolke and Lereya (2015), young people who are the victims of bullying are more likely to develop

Áine Jane Doyle   Dissertation

anxiety and depression disorders, as well as experience physical symptoms such as headaches and stomach problems. At the adolescence stage, people who have experienced bullying are at a greater risk of engaging in self-harm and having suicidal ideation (Wolke & Lereya, 2015). Bullying, even if stopped during school age, is also shown to have negative effects on self- worth, self-esteem, and quality of life (Wolke & Lereya, 2015). The effect of bullying is long and vast and can be detrimental to someone with or without autism. However, for autistic people, the effects may play an even more detrimental role in a vicious cycle of mental health difficulties.

2.5.3 Mental Health Difficulties

Both autistic children and adults experience mental health difficulties such as anxiety and depression on a much greater level than the general population (Dickerson Mayes et al., 2011). A study by Simonoff et al. (2008, as cited in Rodgers, 2018) states that fifty per cent of autistic people experience anxiety which 'significantly affects their everyday life'. Another study, conducted by Dickerson Mayes et al., (2011) concludes that eighty-eight to eighty-nice per cent of autistic people across the spectrum experience symptoms of anxiety. Anxiety particularly can have a negative impact on academic performance and school functioning. School demands such as social, cognitive, and behavioural challenges can increase the levels of anxiety of students with ASD (Hillman et al., 2020).

Research conducted on the topic suggests that autistic people may experience some aspects of anxiety in a unique way to 'neuro-typical' people (Kerns et al., 2014). Rodgers (2018) outlines the four key areas that may be seen as the major triggers of anxiety for autistic people which are issues recognising emotions of self and others, sensory sensitivities, difficulty with uncertainty, and performance anxiety. Hull et al. (2021) suggest that 'camouflaging' or 'masking' behaviours may be another factor associated with greater symptoms of generalised anxiety as well as depression. In the study conducted by Dickerson Mayes et al. (2011), it was concluded that between fifty-eight and seventy-two per cent of autistic people experience

symptoms of depression. Little is known about the causes of depression in autistic people, although it has been linked to experiencing prolonged anxiety, bullying, low self-esteem, and social isolation (National Autistic Society, 2023.).

2.5.4 School Avoidance

School avoidance, often referred to as 'school refusal,' refers to children and young people experiencing great distress at going to school or remaining in school for the full duration of the day. While school avoidance is not exclusive to autistic people, it is unfortunately a common experience for many students on the autistic spectrum. In a discussion with the Autistic Centre Middletown, based in Northern Ireland, Dr Philip Tyndal, a Consultant Psychiatrist, explains that

school avoidance can happen because of several factors, including problems at school such as bullying or difficulties at home (Middletown Centre For Autism, 2020). Dr Tyndal further explains that for autistic students, social skill difficulties or being isolated socially by their peer group can exacerbate school refusal (Middletown Centre For Autism, 2020). AsIAm (2019) adds that issues surrounding sensory overload, environmental factors, workload, and exam stress can be a factor in school avoidance. Furthermore, according to a Norwegian study carried out by Havik and Ingul (2021) school refusal is defined as "child-motivated non-attendance related to emotional distress experienced in connection with academic or social situations in school." Similarly, Elliott and Place (2019) explain that school refusal is often due to emotional distress such as general, social, and separation anxiety, sadness, and worry.

2.6 What could help?

Despite the popular opinion of some advocates, educators, and professionals on inclusive education, many autistic people have found that education in a mainstream school is a negative experience (Goodall, 2018). Goodall (2018) suggests that more supports are needed for autistic students to flourish in mainstream education such as smaller classrooms and flexible timetables. Other alternative schooling offers these accommodations to autistic

learners, such as home tutoring, Youthreach, iScoil, and Education and Training Board centres, although these alternative options might not fall under 'inclusive education.'

In an interesting study carried out by Crompton et al. (2022), they found that autistic students found having peer support in mainstream education from another autistic student as being a positive prospect. Research also suggests there are benefits for young people to engage in 'autistic culture' and spend time with other autistic people (Crompton et al., 2022). An interesting perspective from an academic researcher San Sun Wong (2018), who is also autistic, argues that it is 'unproductive' to try and get autistic people to fit in all the time, both in school and the workplace, which can be detrimental to an autistic's persons mental and general wellbeing. Concerns that arise around the quality of life of an autistic person would lead to struggling to 'fit

in' in society. In a study carried out by AsIAm and IrishJobs.ie in

2021, it found that approximately 85 per cent of autistic people in Ireland are un- or under-employed, which in turn can lead to a whole range of negative outcomes, including poor quality of life, mental health difficulties, homelessness, poverty, and social isolation (AsIAm & IrishJobs.ie, 2021).

Mac (2021) argues that such narratives about overcoming negative aspects that attending a mainstream school can have on some autistic students place responsibility on the student. It could be viewed as the autistic person having a problem with the mainstream classroom, so they need to find a solution to cope in such environments. Mac (2021) argues that this does not allow for the questioning of 'structural inequalities'. Furthermore, Mac (2021) states that for many students with disabilities in mainstream education to be successful, the student had to adapt to the curriculum rather than the curriculum being adapted to the individual student's needs. While the goal of inclusive education is to ensure that students with additional needs are receiving an education that equals their peers, it is argued by Kozelski and Waitoller (2013) that physical placement in a mainstream classroom is not a fix for inequity in

education. Waitoller and Super (2017) argue that for an educational institute to be fully inclusive, the institute's norms of belonging must be altered.

2.7 Conclusion

In this literature review, the researcher investigated what the current literature says about Autism and education in Ireland. The chapter began with an overview of ASD, which was followed by an investigation into inclusive practices in education, and a look into some of the challenges that autistic students can face in mainstream education. The chapter concluded with an investigation into what supports and alternatives to mainstream education are available to autistic students at a post-primary level in Ireland.

In Chapter 3: *Methodology,* the researcher will provide an overview and justification of the chosen research methods.

Áine Jane Doyle   Dissertation

3.0 Methodology

3.1 Introduction

In this chapter, the researcher will justify their chosen research design by exploring the areas that were given significant consideration when researching the lived experiences of young autistic adults with experience in mainstream schools in Ireland. A research design is described by Khanday and Khanam (2019, p.367) as a "framework of methods and techniques chosen by a researcher to combine various components of research in a reasonably logical manner so that the research problem is effectively handled."

The areas that will be explored in this chapter are as follows: epistemology and theoretical

perspective, community-based participatory research, research methodology and methods for data collection, sampling of participants, data analysis, ethical considerations, research limitations, and researcher reflexivity.

3.2 Epistemology and Theoretical Perspective

Epistemology in research deals with the study of knowledge and describes how knowledge about reality is acquired, understood, and utilised (Alele & Malau-Aduli, 2023). The researcher will investigate the varying opinions which are informed by the lived experiences of the participants by using an epistemological approach of social constructivism.

Boyland (2019, p.30) explains social constructivism as a paradigm of thinking "whereby the researcher journeys with participants into a space of interpreted reality that is as personal and individual as each person in the collective sampling and as diverse as the multiplicity of lived experiences that are profiled." Social constructivists argue that people look for an understanding of the world around them and social constructivist research is conducted by the investigation of the human experience, attitude, and feelings (Creswell, 2014).

A view of knowledge based on social constructionism leads to a theoretical position of interpretivism. Interpretivism is the assumption that "social reality is not singular or objective", it is however "shaped by human experiences and social contexts" (Bhattacherjee, 2012, p.103). Therefore, using interpretivism, researchers use a "sense-making" process rather than a hypothesis-testing process (Bhattacherjee, 2012, p.103).

However, a limitation of this theoretical perspective is that it tends to focus less on the overall structural problems in an individual's environment (Ormston, 2014). As highlighted in the previous chapter, this topic cannot be researched without the acknowledgement of structural issues within the educational system that autistic people experience. The researcher worked to

overcome this theoretical limitation by asking specific questions that look to answer what structural disadvantages autistic students face in mainstream schools.

3.3 Community-Based Participatory Research (CBPR)

This research was done as part of the Community-Academic Research Links initiative (CARL) at University College Cork (UCC). The community partner has a long-established relationship with UCC and CARL and has worked closely with previous students of the MSW program on research projects. The CARL initiative facilitates non-profit voluntary or community organisations to participate in research with the aim of addressing exclusion, and promoting equality (University College Cork, 2022). CARL projects fall under the category of CARL community-based participatory research (CBPR). For years, higher educational institutes (HEIs) were seen as only catering to the elite in society, however, all citizens and organisations should have the right to benefit from higher education, regardless of their financial status (Bates & Burns, 2012). CBPR looks to bridge this gap which still exists for many in society. CBPR connects communities and civil society organisations with HEIs through student, and staff, research projects (Mcllrath et al., 2014).

A designated liaison person was selected as the coordinator for the community partner and the researcher. The community partner had shared decision-making power throughout the research project due to the nature of CBPR (Bates & Burns, 2012). There was a continual stream of communication between the researcher and the community partner, and consultations were had concerning the selection of the research method, recruitment of suitable participants, and the creation of an interview schedule.

3.4 Research Methodology and Methods for Data Collection

3.4.1 Research Methodology

As the researcher's objective was to gain a better understanding of the lived experiences of

autistic people in mainstream schools in Ireland, a primary, qualitative research approach was

determined to be the most appropriate as it would allow participants to tell their stories and not have

their lived experiences represented by numerical data alone. Keating (2019) argues that there has

been an increasing disconnect between researchers and the autism community, which may be

partially due to the lack of involvement of autistic people in research. Keating (2019) suggests

participatory research which focuses on voices from within the autism community as a solution to

bridging this disconnect.

Qualitative research helps researchers develop explanations of social phenomena by helping us to

understand the social world in which we live and why things are the way they are (Hancock et al.,

2007). Furthermore, Austin and Sutton (2014) state that qualitative research involves asking

participants about their experiences of things in their lives, therefore enabling researchers

to gain an understanding of the world from their perspective. Using qualitative methods to

collect data involves emerging questions and procedures, data collection, data analysis, and data

interpretation (Creswell, 2014).

3.4.2 Research Methods

There are three main methods used in qualitative research, namely interviews, focus groups, and

observation. The researcher and the community partner decided that the use of individual semi-

structured interviews to collect data would be the most appropriate for this research project.

There are several benefits to interviewing participants as part of the research. One of these

benefits is that it allows participants to give in-depth answers to questions allowing for greater,

richer data collection (Austin & Sutton, 2014). Furthermore, semi-structured interviews allow for a

more flexible approach to interviewing while also creating a structure to provide participants

with knowledge of the proposed questions before the interview. As Denny and Weckesser (2022)

explain, semi-structured interviews contain pre-set, open-ended questions, with further questions emerging from the discussion.

3.5 Sampling of Participants

Sampling is the process of choosing a group of people from a larger population for measurement or analysis (Bineham, 2006). Purposive sampling was used for this research project. Purposive sampling, groups participants according to preselected criteria relevant to the research question

(Mack et al., 2005). Purposive sampling hand-picks participants who can provide the most relevant and insightful information (Burns, 2000) The criteria that participants had to meet to be involved in this research was that they had to be an autistic individual or a parent of an autistic individual who has experience of mainstream education in Ireland.

The designated liaison person for the community partner recruited the participants based on the participant's interest in being involved in the research project and the relevant criteria. The liaison person recruited 6 suitable participants for the research project.

3.6 Data Analysis

In this research project, the research used thematic analysis to analyse the collected data. This approach to data analysis provides the researcher with a practical way of identifying, analysing, organising, describing, and reporting themes found within a data set (Braun & Clarke, 2006). The thematic analysis aims to not only identify important themes and patterns within the data but to also interpret and make sense of it (Delahunt & Maguire, 2017).

3.7 Ethical Considerations

Researchers must conduct research responsibly, making ethical decisions from the inception of the research idea and throughout the research process to protect participants and uphold the values of Social Work (Wester, 2011).

3.7.1 Ethical Approval

The research took several steps throughout the research procedure to ensure that the process

was ethical. The researcher received ethical approval from the University College Corks MSW

Social Research Ethics Committee prior to commencing their research (See Appendix 1).

3.7.2 Data collection and storage

The researcher conducted the interviews in person or on MS Teams depending on the

preferences and availability of participants. The researcher used their UCC credentials to log onto

the MS Teams application. Interviews were recorded for the purpose of transcribing. The interview

recordings and transcriptions were stored on the researcher's UCC OneDrive account using their

UCC credentials.

Throughout the research process, the researcher made sure to respect GDPR and follow UCC's

guidelines involving the correct storage and collection of data.

3.7.3 Informed Consent

Informed consent is the process of protecting research participants by having ongoing

communication between research participants and the research to ensure participants' comfort

Áine Jane Doyle   Dissertation

(Owens, 2010). Informed consent allows potential research participants to volunteer their

participation freely, without duress while also being provided with information before their

potential participation to allow for an educated decision to be made (Owens, 2010).

The participants were given a consent form and information letter before participating in the

research study. The information letter and consent form gave participants an outline of what the study

entails (see Appendix 2 & 3).

The researcher made the signed consent forms into digital copies and transferred the digital files

onto UCC's official encrypted Microsoft OneDrive. The researcher then destroyed the physical

copies in UCC confidential shredding.

3.7.4 Pre-Interview Preparation

Research participants were given the semi-structured interview schedule with the proposed

questions (see Appendix 4). Participants were made aware that if they were uncomfortable with any

of the questions the question could be omitted from their interview. Participants were also given the

contact information of the researcher's academic supervisor if they needed to make contact due to

any concerns or issues that may have arisen.

3.7.5 Debriefing Process

Due to the sensitive nature of the research topic, the researcher with support from the

community partner and academic supervisor took great care in ensuring that a robust debriefing

process was put in place to protect participants. The researcher made sure to ask participants direct

questions about how they found the interview process. Participants also received the researcher's

UCC email and the email of their academic supervisor if any concerns arose as a result of their

participation in the research. The designated liaison person from the community partner was a

contact person for participants if they felt that they needed further help or support following the

interview process.

Áine Jane Doyle   Dissertation

3.7.6 Confidentiality and Anonymity

The study included interview questions involving individuals most vulnerable in society,

therefore confidentiality and anonymity for the participants were of the utmost importance.

To ensure anonymity, the researcher removed all identifying information when transcribing the

interviews and replaced that information with letters, as shown in the table below. The

researcher did not ask any questions during the interviews which required identifiable data such as the

names or geographical locations.

Participant A	Parent
Participant B	Parent

Participant C	Parent
Participant D	Parent
Participant E	Parent
Participant F	Parent

3.8 Research Limitations

As the study only included a total of 6 participants, the research is limited due to the small population sample. There was also a short time frame in which the data had to be collected, therefore the findings are an outcome of cross-sectional research and consequently, only give a finite view of the research topic. Another limitation of the research was the restraints of the geographical scope of the research project due to working with a community partner who is only based in one location in Ireland. Further research on this topic could expand to include parents whose children have experience in mainstream schools and are located in a different geographical locations around Ireland.

3.9 Researcher Reflexivity

Reflexivity is an important quality control strategy in qualitative research (Berger, 2013). Berger (2013, p.2) continues to explain that reflexivity is the process of "continual internal

dialogue and critical self-evaluation of the researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome."

The researcher has a background in social care before studying on the MSW program at UCC. From working in social care, the researcher has worked with many autistic individuals in community and residential settings for several years. In this line of work, the researcher used a strengths-based approach when working with autistic clients which is something they have carried into their social work studies. A strengths-based approach focuses on an individual's strengths, resources, and self-determination while focusing on an individual's capacity rather than their deficiency

(Caiels et al., 2023). The researcher has seen firsthand the structural issues that autistic individuals and their families face on a day-to-day basis. Furthermore, the researcher's thesis for their undergraduate program was titled "An Investigation into the Educational Experience of Students with Autism Spectrum Disorder in Mainstream Primary Schools in Ireland, from the Perspective of Teachers and Special Needs Assistants." This project has given the researcher prior knowledge and insight into mainstream education for autistic students, albeit from the perspective of primary school staff.

The researcher focused on gaining 'empathic neutrality' (Ritchie et al., 2013, p.22) throughout the research process by engaging in research supervision with their academic supervisor and liaising with the community partner

3.10 Conclusion

In this chapter, the researcher wrote about the research design, plans, and considerations that were carried out during the research process. An overview of the epistemology and theoretical perspective, community-based participatory research, research methodology and methods for data collection, sampling of participants, data analysis, ethical considerations, research limitations, and researcher reflexivity.

Áine Jane Doyle   Dissertation
In Chapter 4*: Results & Discussions*, the researcher will examine the results from the data collection and analysis that was carried out by the researcher.

Áine Jane Doyle   Dissertation

4.0 Results & Discussions

4.1 Introduction

The results and discussions from the data gathered during the interviews with the six participants

will be highlighted in this chapter. The participants spoke of their personal experiences of having

an autistic son or daughter in mainstream primary or secondary school. The researcher used the

method of thematic analysis to analyse the data. Subsequently, five main themes emerged:

Theme 1	*The effects of mainstream school attendance on autistic students' mental health*

Theme 2   *Bullying and Social*

Theme 2	*Difficulty in making friends in mainstream school*
Theme 4	*Difficulty accessing alternatives to mainstream school*
Theme 5	*Importance of a flexible approach in schools*

Furthermore, a discussion will be provided at the end of each theme comparing the results with the literature which was outlined in Chapter 2: *Literature Review* of this dissertation.

4.2 Theme 1: The effects of mainstream school attendance on autistic students' mental health

Five out of the six participants stated that mainstream school had affected their son or daughter's mental health. Participant C spoke about their son experiencing mental health difficulties in primary school, especially towards the end of 6th class. They explained that:

"The whole experience of primary school, especially coming towards the end, he was so down, you know, he was so low in himself. The friendships that he thought were there weren't really. So yeah, like we were worried about him at the time. I would say it was affecting his mental health and emotionally, feeling very left out" (Participant C).

Similarly, Participant D spoke of how her daughter has had her mental health greatly affected by mainstream secondary school. One particular event was highlighted as causing "the biggest damage to her" (Participant D). Participant D described how her daughter's class laughed at her while she was presenting a piece of work to her peers. Participant D spoke of the upsetting effects experiences such as this have had on her daughter, explaining that:

"It's really hard. I would say that different things, so many things have come and they've knocked her confidence, they've chipped away at her. Then she's like I hate being autistic, I don't want to be autistic. She has a lot of that conflict going on" (Participant D).

School avoidance was a common issue spoken about by some participants relating to mental health difficulties, particularly feelings of anxiety. Participant E spoke of the severe anxiety her daughter experiences around school, which results in long periods of absence. Participant E spoke about trying to encourage her daughter to attend school, stating that:

"we'll see tomorrow morning what will happen, and the following morning comes, and I know it's not, school isn't going to happen. Like the last few weeks now, I said, we'll try again now in the morning, we'll try to go and she told me she was going to drink bleach" (Participant E).

Participant E explained how anxiety before school would manifest itself in her daughter *"slapping her face, pulling her hair, just all kind of pent-up anxiety."* Participant E continued to explain how weekends are negatively affected by the prospect of school on Monday by stating:

"I mean, our weekend ends at lunchtime on a Saturday because she does activities on a Saturday morning. So once that's over, she knows that Monday is around the corner. So Sunday is a right-off" (Participant E).

4.2.1 Discussion

The negative effects of attending mainstream education on autistic students were evident throughout the research process, with 5 out of the total 6 participants telling the researcher of the difficult scenarios they have faced or are currently facing. It is widely accepted that autistic people experience greater levels of anxiety than their neurotypical peers (Lugnegård et al., 2011). A study by Dickerson Mayes et al. (2011) conclude that between eighty-eight and eighty-nice per cent of autistic people across the spectrum experience symptoms of anxiety.

Due to the specific challenges that mainstream schools present, autistic students also experience anxiety around school at a greater level (Hillman et al., 2020). While the research varies on the trigger of anxiety in autistic students, it is suggested by Hillman et al. (2020) that school demands such as social, cognitive, and behavioural challenges can increase the levels of anxiety of autistic students. Hull et al. (2021) suggest that 'camouflaging' or

'masking' behaviours may be another trigger that leads to higher rates of generalised anxiety and depression in autistic people. This is something that resonated with Participant D who stated "*My daughter masked so much…..and it really is in short that masking equals mental health issues.*"

4.3 Theme 2: Difficulty in making friends in mainstream school

All six participants spoke of the difficulties that their son or daughter faced in mainstream schools. Participant F believed that the school their daughter attends "could do better" in facilitating potential friendships. Participant F explained that her daughter is taken out of non- academic classes such as SPHE for resource support, which Participant F argues could be an opportunity for her daughter "to seek out or be sought out by like-minded girls" due to the more relaxed and interactive nature of these classes.

Similarly, participants spoke of the difficulties her daughter experienced making friends in school due to the fear of being judged by their classmates and wanting to be like their peers. Participant D spoke about their daughters' experience of this stating that:

> *"She was very conscious of what others would think and afraid to get things wrong. So I mean, again, she got resources, you know. Although there was hesitancy from her because she didn't want to be different. She was a bit older and very conscious of attention, drawn to her being different to her peers. I mean that has been her biggest hang-up and still is"* (Participant D).

Similarly, Participant B shared that while her daughter had two or three friends in primary school, her daughter wanted to go to a different secondary school because she wanted a 'fresh start'. Participant B explained that:

> *"She didn't want people to know she had autism. She wanted to go in there with a fresh start and be as she said herself normal"...... "So she walked in there not knowing anybody which she thought was going to be amazing"*
> (Participant B)

Despite the hope for a new start in secondary school, Participant B stated that secondary school has been difficult for her due to not knowing anyone. Participant B explained that her

Áine Jane Doyle   Dissertation

daughter is 'shy' and struggles to manage a group of friends, preferring to have one friend at a time.

Participant A spoke of how her son's classmates were friendly and would look out for him, however since they have all moved on from primary school the friendships have not continued. When asked if establishing friendships in mainstream primary school was difficult for her son, she explained that:

> *"Yeah massively (difficult). I mean like we wouldn't see those kids anymore, so it's not that it was a long-lasting friendship, but like that's what. But they certainly were friends and very friendly towards him and very caring"*
> *(Participant A).*

4.3.1 Discussion

As evidenced in the literature, an important benefit of autistic students attending mainstream education is that they have access to peers, and thus will benefit from socialisation. However, Koegel et al. (2013) argue that without 'systematic social intervention' autistic children and adolescents can have limited or non-existent interactions with peers (Koegel et al., 2013). This suggests that autistic students need to be supported to promote interaction and integration with their peers. Participant A praised the primary school her son was in as she felt that the teachers worked hard to include her son in the school activities. In turn, her son also received support from his peers in school, albeit not long-standing friendships.

This is in contrast to Participant F who felt that her daughter's school wasn't support friendship building by removing her from non-academic subjects. Furthermore, Koegal et al. (2013) concluded from their research that the lack of socialisation can have a negative impact on the emotions of autistic students, such as anxiety and depression. Unfortunately, Participants B to F have experienced their sons or daughters experiencing negative emotions

due to difficulty relating to peers and making friends.

Áine Jane Doyle   Dissertation

4.4 Theme 3: Bullying and Social Isolation

Bullying and social isolation were other issues that appeared frequently throughout the interview process. Participant F spoke about the detrimental effects that bullying in school has had on her daughter, who was diagnosed with Post Traumatic Stress Disorder (PTSD) as a result of the bullying she faced in secondary school. Participant F spoke about the social exclusion her daughter faces from her peers.

"Say at midterm, the girls then will start talking about their plans. She asks to do something with them. They'll say, oh no, we're busy. I'm going to my granny's or whatever because that's an easier thing to say rather than you can't come because we don't want you there. But then, she will see it on social media that they met up" (Participant F).

Participant B had a similar experience and spoke of the exclusion her daughter experienced in secondary school, which caused feelings of loneliness and isolation.

> *"She had no friends in school. She would say that she would be walking around all day with headphones in and listening to music. She was very lonely, very isolated. She found it really difficult but then became friends with a couple of girls. She went downtown with them one day, which was a major thing, you know. But then after that, they just kind of ignored her and moved on"* (Participant B).

Participant D told the researcher that her daughter struggled with the social side of school since attending mainstream primary school. Despite teachers trying to integrate her with her classmates, Participant D reflects that it was too stressful for her daughter. Reflecting on a difficult moment during her daughters' school Participant D recalled her last day of primary school stating that:

Áine Jane Doyle   Dissertation

> *"I'll always remember her last day……But for her last year in primary school, they were all walking out, and she was on her own. It just hit me like, you know. I was thinking you know, secondary school is a new thing, new people, but she struggled there as well"* (Participant D).

Another form of isolation that was discussed during the research process was schools isolating autistic students from their peers. Participant E spoke about the difficulty she had when her daughter's school took her out of class to attend a 'socialising class' with other students who were often much younger than she was. This decision was made without consultation and led to her daughter experiencing further difficulty relating to her peers.

> *"She was brought into this socialising class with children that were in junior*

infants, first class, you know. So, then she'd arrive back into the class and all the craic would have been happening while she was gone, she'd have missed out on the interaction and they'd all, at break time then, they'd be discussing what a great time they had in school and what craic it was when such one said something, but she would have missed all that"
 (Participant E).

4.4.1 Discussion

Five out of the six participants spoke of their experiences of their sons or

daughters being intentionally isolated or bullied in school by their peers. Bullying is a

common experience for autistic students, who Rowley et al. (2012) states are far more

likely than their peers to be bullied. In 2021 Inclusion Ireland stated that children with

disabilities are three times more likely to experience bullying than their peers (Inclusion

Ireland, 2021). Furthermore, the United Nations published research in 2012 which

stated that children with disabilities are four times more likely to experience violence

than their peers without a disability (UN, 2012).

Áine Jane Doyle   Dissertation

Several participants spoke of the difficulties of encouraging their sons and daughters

to go to and stay in school. School avoidance is a common experience for some

autistic students. Difficulties with_____social skills and being isolated by their

peers can exacerbate school avoidance claims a Consultant Psychiatrist Dr Philip

Tyndal (Middletown Centre For Autism, 2020). This was Participant E's experience

with her daughter explaining that:

"In first year she settled in quite well but then, by the end of first year, it was very difficult to interact and now the present day she is finding it very hard to actually go to school because she doesn't have friends, she hasn't been to school in a month now at this point" (Participant E).

4.5 Theme 4: Difficulty accessing alternatives to mainstream school

Speaking about the negative effects that mainstream school has had on their daughter's mental health, Participant F stated *"If there was another option, 1 would have done it."* Participant F researched home tuition, however, they stated that:

> *"it just seems so flimsy and nearly inaccessible. 1 had started to look into it in the last 12 months but it didn't seem very clear to me. There seemed to be a lot of kind of confusion about it"* (Participant F).

However, Participant F was also concerned that if they were to homeschool their daughter, she would have no access to peers at all. Participant B spoke of how during the COVID-19 lockdowns, their daughter enjoyed doing school work from home. Participant B thought that it would be a good option going forward.

Áine Jane Doyle   Dissertation

> *"When they were doing the homeschooling through Covid, it suited her was spoken the background noise was all taken away. She could to out and go of tea whenever she wanted. So I would think it make all suited a cup very well. You know, she'd be in there and her laptop, and she's doing the work she didn't have to mix with anyone. She only had to speak when she her very well"* (Participant B).

However, their daughter wanted to be in school like her peers, and be, as their daughter states, "normal". Similarly, Participant C looked at other options for their son, including attending a dedicated school for additional needs, as their son would say "he doesn't want anything to make him stand out." Participant C continued to discuss the importance of balance, as their son is "quiet academic", which raised concern that the dedicated school wouldn't provide enough of an academic

challenge. Home schooling was also considered.

> *"We also talked about the home tuition, you know, at one stage I said, am I going to give up work and teach at home? But I think that will be counteractive to him, making friends socialising, and dealing with the world like it does kind of give him the option of hiding away. So I think the best of both worlds is a mainstream school with a unit that has understanding and awareness"* *(Participant C).*

4.5.1 Discussion

While some of the participants believed that home tuition would be a good option for the son or daughter, the unclear and unstructured nature was off-putting and felt "inaccessible" to Participant F. Participant B felt that remote schooling worked well for her daughter during the COVID-19 pandemic. This was a common experience for autistic people during the pandemic. In a study by Heyworth et al. (2021), they concluded that overall autistic students flourished engaging in remote schooling during the pandemic, namely due to the flexibility.

However, the same study by Heyworth et al. (2021) stated that a downside to remote schooling was that autistic students and little to no support from their schools to help establish and maintain friendships. Heyworth et al. (2021) sight the improved academic outcomes of students as a result of peer interactions. This was a concern expressed by Participant C who believed that homeschooling would negatively affect her son's chance and ability to socialise with peers.

4.6 Theme 5: Importance of a flexible approach in schools

Despite the numerous challenges and difficulties that face autistic students and their parents, some positives were highlighted by the participants to the researcher. Mainstream schools have been able to support autistic students by being flexible in their approaches and treating students as

individuals. Participant C stated that her son's school for the most part makes her feel heard when she is advocating for her son, and they take her suggestions on board. One example Participant C gave was in relation to the weekly fire drill that was causing her son distress due to the loud alarm. Participant C worked with her son to support him manage his distress to take part in the fire drill, but the school also put in place a fire drill for the whole school which was tailored to her son's needs without singling him out.

> *"His school…..actually at one stage put an evacuation plan in place that would suit him, but it was put in place for the whole school. I just thought, yes, they're taking it seriously, but they're also trying their best to accommodate without singling him out"* (Participant C).

Participant D spoke of the great support her daughters' primary school provided during her time attending the school. Participant D told the researcher that even before her daughter received her official diagnosis of autism, the primary school was proactive with their support.

Áine Jane Doyle   Dissertation

> *"They were very, very good, you know, even without an official diagnosis. Once they identified there were issues there, they worked obviously within the constraints that they had"* (Participant D).

Participant A was also satisfied with how her son's mainstream primary school supported her son. Participant A highlighted that her son struggled academically, and was later diagnosed as having a mild intellectual disability. Despite this, his teachers always tried to integrate him into the classroom, especially when it came to more social activities such as PE.

> *"He was well able to participate in class kind of fun games, the academics wouldn't have been there. The mainstream local school that we were in was fantastic, the kids especially. So for us, it was an ideal*

option" (Participant A).

4.6.1 Discussion

It can be argued that the responsibility for overcoming negative and challenging aspects of

attending a mainstream school is placed on the student rather than analysing the structural

inequalities within the education system (Mac, 2021). Furthermore, Mac (2021) states that for many

students to be successful in mainstream education they had to adapt to the curriculum, rather than a

curriculum being adapted to the individual student. However, several

participants had positive experiences, particularly of primary schools, for how they adapted their

approach to support autistic students. This led to a more positive experience of mainstream school

for the student and their parents.

The overall negative experiences expressed by the parents of autistic students in this study could be

attributed to the mainstream school's inability or unwillingness to adapt or be

flexible for a more individualised approach. Kozelski and Waitoller (2013) state that physical

placement in a mainstream classroom is not a fix for inequity in education. For an educational

Áine Jane Doyle   Dissertation

institute to be fully inclusive, the institute's norms of belonging must be altered (Waitoller and

Super, 2017).

4.7 Conclusion

The results from the data gathered during the interviews with the six participants were presented in

this chapter. The participants spoke of their personal experiences of having an autistic son or

daughter in mainstream primary or secondary school, which resulted in the five themes. Subsequent

discussions were had after each theme, which related the results to the literature discussed in

Chapter 2: *Literature Review*.

In the following chapter, Chapter 5: *Conclusion and Recommendations* the researcher will

conclude the research and provide recommendations based on the findings discussed in this

chapter.

Áine Jane Doyle   Dissertation

5.0 Conclusion & Recommendations

5.1 Introduction

In this fifth and final chapter, the researcher will offer a conclusion to the research project and will outline recommendations for practice and further research. A research statement will then be provided, highlighting what the researcher has learned from conducting this project.

5.2 Conclusion

The rationale for this research was to investigate the educational experiences of autistic students in mainstream primary and secondary schools, from a parent's perspective. The project was a collaborative endeavour with the Rainbow Club Cork Centre for Autism facilitated by the CARL

initiative in UCC. The research project looked to answer the following three questions: What is the experience of mainstream primary and secondary

school for autistic students in Ireland as reported by parents of autistic students, how effective is inclusive education for autistic people at present in Ireland, and do links exist between participation in mainstream school and mental health problems for autistic students? Information was gathered using a qualitative approach in the form of individual semi- structured interviews. To participate in the research, participants had to have a son or daughter currently attending, or who did attend a mainstream primary or secondary school. Their son or daughter also had to be a service user of the RCCCA. The six participants spoke very openly throughout the interviews, highlighting the many challenges their children face attending a mainstream school as well as the effective supports that have been put in place by the school. Despite the openness and willingness of participants to share the experience of their children in mainstream school, the study is limited due to the small number of participants that could be interviewed due to time constraints. The research illustrates that overall parents spoke negatively of their children's experiences of attending mainstream schools.

Áine Jane Doyle   Dissertation

One of the findings of the research found that autistic students' mental health is negatively affected by attending mainstream school, with five out of six participants speaking about the experiences of their son or daughter. Another finding was the great challenges that autistic students face in establishing friendships with their peers in school, with 100 per cent of participants highlighting this difficulty for the son or daughter. Another common theme that branches off of the previous finding is the common experience of bullying and social exclusion of autistic students. Four out of six participants had experience of their son or daughter being excluded or bullied by their peers, with one participant stating that her daughter had been diagnosed with PTSD as a result of severe bullying. Another interesting finding was that several participants found that during the COVID-19 pandemic, remote schooling suited their son or daughter. However, access to remote schooling post-COVID-19 is found to be challenging for participants, while there are also concerns about the negative effects homeschooling could have on their socialisation. While the results of the study

were overwhelmingly negative about autistic students' experiences, there were some examples of schools being flexible and putting supports in place that work. An example of helpful approaches that emerged from the research was teachers working to ensure that autistic students are included in social activities in the classroom to support their peer interaction. This study shows the great challenges that many autistic students have to overcome to get an education. It is clear from the research that more has to be done to support autistic students through the education system.

5.3 Recommendations

Considering the key findings of this research, the following recommendations are provided to improve the experience of autistic students in mainstream schools and offer ideas for further research on the topic.

5.3.1 Recommendations for Practice

- The research suggests that many autistic students are experiencing mental health difficulties, often around attending mainstream school. Greater access to mental health support services for autistic students is needed to support their attendance and overall experience of mainstream school. Currently, there are huge waiting lists for mental health services in Ireland.

- Access to flexible home school options may be helpful for some autistic students. Several participants spoke of the benefits of remote schooling during the COVID-19 pandemic. However, currently, participants find it challenging to access remote schooling. Remote schooling would be a helpful option for autistic students who are struggling to attend school full-time in particular.

- This study suggests that bullying is a common challenge for autistic students in mainstream schools. While bullying may be seen as a difficult issue to tackle, teachers should engage in awareness training in relation to autistic students and their vulnerability to bullying. The

research also suggests social isolation is another

problem faced by autistic students. Similarly, teachers need to be aware of this challenge

and support autistic students and their peers to engage where possible.

- In an effort to combat bullying and social exclusion of autistic students, autism

  awareness training should be provided in mainstream schools for all students.

  Similarly, a bullying awareness program should be run in all schools.

- This study shows that when mainstream schools are open to a flexible approach to support

  autistic students, it can be very beneficial. School staff need to be available to work

  alongside autistic students and their parents to implement support that will improve the

  educational experience of autistic students.

5.3.2 Recommendations for further research

- This study which researched the educational experiences of autistic students in

  mainstream schools, from the perspective of parents should be replicated on a larger scale

  including interviewing more participants and participants based in different geographical

  locations around Ireland.

- This study focused on parents' perspectives of their son or daughter's educational

  experience. Future research should focus on the first-hand experiences and viewpoints of

  autistic young people who have attended mainstream schools.

- More research needs to be undertaken to investigate the specific mental health

  difficulties that autistic people face throughout their life course, broadening the

  educational focus of this research project.

- A study should be carried out to investigate the experiences of teachers and SNAs

  supporting autistic students in mainstream schools. Do they feel they have adequate

  resources to support autistic students?

- A similar study should focus on autistic college students' experience of navigating third-level education in Ireland.

5.4 Researcher Statement

From completing this research project my eyes have been opened to the challenges faced by autistic students attending mainstream schools. While I had an understanding of the difficulties faced by autistic people in many aspects of their lives due to personal and professional experiences, I was struck by how similar a lot of the challenges participants spoke about during the interviews. The prevalence of mental health problems among autistic students for one was staggering, as well as the great challenges autistic students face in making friends with their peers. Another upsetting finding was the levels of bullying and social exclusion that autistic students face in mainstream schools. All the participants spoke openly and honestly with me, delving deep into difficulties and upsetting experiences that

Áine Jane Doyle   Dissertation

their sons or daughters have gone through or are currently going through. I was struck by the resilience of the participants and their sons or daughters. More resources are needed to support autistic students in mainstream schools, as my research suggests that overall the current experience of autistic students is overwhelmingly negative and full of difficulties that autistic students and their parents feel that they must overcome themselves.

Áine Jane Doyle   Dissertation

Personal Reflection

Reflecting on my social work research experience I am pleased with how my research went. I was able to meet my research aims and I answered the research questions. If I were to do the research again, however, I would approach certain aspects differently. For example, I would try to interview autistic young people over the age of 18 who have attended mainstream education to get their perspective. At the beginning of my research, I planned to speak to parents and autistic young people, however, I found it challenging to engage with young people and due to the limited time I had to complete this research, Karen O'Mahony of the RCCCA and I decided to focus just on parents.

My research study was focused on the area of education and the experiences autistic students go through while attending mainstream schools. A future research area that I would like to gain an understanding of is what a social work practitioner's role is or could be in relation to supporting autistic students experiencing difficulties in school. Furthermore, arising from this study, I have a greater understanding of the challenges many autistic young people and their parents have to

manage. I will carry this new, deeper understanding into my social work practice when working with members of the autistic community and their families.

From undertaking my social work research project, I have a greater understanding of the importance of using research to inform future practice in social work. I learned the importance of letting people tell their own stories. The participants I interviewed for this study were very forthcoming and went into detail describing their lived experiences. As a practitioner, I should never forget that my clients are the experts in their own lives. Therefore, research that speaks to individuals directly is very powerful and as a social worker, I need to pay attention and listen to individuals and their lived experiences to inform and continuously improve my practice.

Áine Jane Doyle   Dissertation

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58

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Áine Jane Doyle   Dissertation

Appendices

Appendix 1: Ethical Approval

MSW Research Ethics Committee
School of Applied Social Studies

Applicant:	Aine Doyle, MSW2, 2023/2024
Committee Date:	16th January 2024
Tutor(s):	Sara Kelleher
Reference:	2023-7

Dear Aine,
Thank you for your submission to the MSW research ethics committee.

Your application is **approved, with minor changes**. The committee made the following observations below: you need to discuss these with your tutor, but you do not need to resubmit. You need to send one email to k.burns@ucc.ie by Friday 19th January to say that you accept the recommended changes and that you will work on these changes with your tutor.

We wish you all the best with your research project. If you have questions, please contact your MSW tutor.

Best wishes,

Dr Kenneth Burns
On behalf of the MSW Research Ethics Committee

Áine Jane Doyle   Dissertation
<u>Appendix 2: Information Letter</u>

Dear Participant,

My name is Áine Doyle and I am currently in my final year of college at University College Cork completing my Masters in Social Work.

As part of my final year, I am required to complete a research dissertation. My chosen topic for research is 'The Educational Experience of Children with Autism Spectrum Disorder in Mainstream Primary and Secondary Schools" which I am doing with the Rainbow Club as part of The Community-Academic Research Links initiative (CARL). I would be extremely grateful if you were available to participate in an online or in-person interview when you are available. The interview will take approximately 30 minutes to conduct.

Involvement in this study is completely voluntary and you may withdraw at any stage without consequences. All information will be fully confidential and ID codes will be used throughout the study for the full protection of you and your students. Any identifying features, such as names of geographical locations, will be changed to protect anonymity.
This study aims to investigate the educational experiences of children in mainstream secondary and primary schools who have Autism Spectrum Disorder. To do this I will interview several participants, 6-8 parents who currently have or had in the past a child in mainstream secondary or primary school.

If you require any further information about this research, please do not hesitate to contact me via email at 121101349@umail.ucc.ie. Furthermore, you can also contact my academic supervisor Sara Kelleher at sarakelleher@ucc.ie. If you are willing to participate in this study, please read and sign the attached consent form.

Kindest Regards, Áine

Doyle

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Appendix 3: Consent Form

I, _____have agreed to take part in the above research project.

- I understand that I will take part in a 30-60 minute interview with the researcher Áine Doyle which will be conducted in person or on MS Teams. For the purpose of the research, the interview will be recorded.

- I understand that my consent will be sought before the recording commences.

- All information collected as part of the study will be confidential, stored securely in line with UCC standards, and used only for the purpose of this study.

- My participation in the study is fully voluntary.

- I understand that I have the right to withdraw from this process at any time up until the 31st of March 2024.

- I understand that I have the right to withdraw or alter statements given throughout the interviewing process at any time up until the 31st of March 2024.

- I understand that if I withdraw from the study there will be no negative consequences.

- I am aware that I have the right to decide not to answer any question for whatever reason.

- I am aware that I am permitted to view all research, recordings and transcripts that have taken place concerning my involvement. I can request a copy of the report from the researcher once completed.

- I understand that the names of people and places will be changed to protect my anonymity and confidentiality and that quotations from my answers may be used for the purpose of the research.

Signed: _____

Date: _____

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Appendix 4: Interview Questions

1. What was mainstream primary and/or secondary school like for your son or daughter?

2. Did your son or daughter get help from teachers while in primary and/or secondary school?

3. Did your son or daughter have support from an SNA or use supports like a sensory room or ASD unit?

4. Do you think that primary and/or secondary school had an effect on your son or daughter emotionally or impacted their mental health?

5. Has your son or daughter tried an alternative to mainstream secondary school such as Youthreach or home tuition? Or would it be something that could be considered in the future?

6. What was it like for your son or daughter to make friends in school?

7. Looking into the future, is the prospect of further education an area of interest for your son or daughter?

Áine Jane Doyle

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