



# RESEARCH JOURNAL

MIDDLETOWN CENTRE  
FOR AUTISM

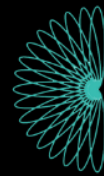


The Middletown Centre for Autism Research Journal publishes high-quality research that has the potential to impact and improve the educational outcomes, opportunities and services for autistic people across Ireland and beyond.

Volume 1

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<b>Introduction</b>	Dr Rachel Ferguson	02
<b>Interview</b>	Dr Mary Doherty	03
<b>Articles</b>		
Artwork	Niamh Taylor	06
The Hidden Autistic Voice: Exploring the Strengths of Autistic People of Marginalised Genders from lived experiences	Noelle Foley Coughlan	07
Artwork	Áine Trearty	27
Nurturing neurodivergence in schools. The crucial role of teachers in supporting autistic learners with neuro-affirming and trauma-informed practices and approaches	Sharon Grady	28
Artwork	Andrew Ryan	31
Parental Experiences of Autism Diagnostic Services in Ireland	Anna O'Brien, Lorraine O.B. Madden & David Mothersill	32
Artwork	Rebecca McFadden	46
Resilience and Wellbeing of Autistic Pupils in a Mainstream Post-Primary Setting	Julie McCullough	47
Artwork	James Murphy	52
Shaping Futures: Exploring the impact of Role Models in promoting Autistic Strengths	Noelle Foley Coughlan	53
Artwork	Keelan Doherty	61
A Systematic Review on the Effectiveness of Group Cognitive Behavioural Therapy (G-CBT) on improving anxiety outcomes for school-aged autistic children in the community context.	Madeline Dolan	62
MCA Graduate Courses		85
MCA Training		86
MCA Research Journal Description		87

# Introduction

Dr Rachel Ferguson, Middletown Centre for Autism

Welcome to the second edition of the Middletown Centre for Autism (MCA) Research Journal! We strive to present high-quality research and scholarship dedicated to improving the lives of autistic children, young people, and adults. Our mission is to publish articles that can significantly impact and enhance educational outcomes, opportunities, and services for autistic individuals across Ireland.

By focusing on evidence-based practices and research, our goal is to foster environments and support systems that reduce barriers and provide kinder life experiences. We firmly believe that through ongoing research, training, and guidance, we can create a more inclusive and supportive educational environment for all children.

Traditionally, autism has been viewed through the lens of struggles and challenges, but this Journal shifts the narrative through research from Noelle Foley Coughlan, to highlight the unique strengths and role models among autistic individuals, particularly those of marginalized genders. We also share articles focusing on supporting, accepting and understanding neurodivergence across educational settings.

Within this Journal, we share exciting news from Dr Mary Doherty, an autistic consultant anaesthetist and founder of Autistic Doctors International. Mary discusses the Autistic SPACE Framework, designed to reduce barriers and create a safer healthcare experience tailored to the needs of autistic people. This framework, built on the core needs of Sensory requirements, Predictability, Acceptance, Communication, and Empathy, is currently being adapted for educational settings as well.

Additionally, we celebrate the concept of autistic joy through art, beautifully showcased throughout the Journal and on the cover. We are proud to feature the artwork of Michael Ryan, a 9-year-old artist, who loves watching birds, painted a stunning robin using oil and canvas. We extend our heartfelt thanks to Michael and all the young artists from schools across Ireland and Northern Ireland, who shared their work for this Journal. A special thank you also goes to Clare Hughes, a Trainee Educational Psychologist in her second year of the doctorate course at Queen's University where she is focusing her research on autistic burnout. We thank Clare for her editorial talents, which have been invaluable in creating this edition.

We hope you find inspiration and valuable insights in this edition of the MCA Research Journal. Thank you for joining us on this journey to improve the educational landscape for EVERYONE!

# Interview

## Understanding the Autistic Space Framework:

### An Interview with Dr. Mary Doherty

Dr. Mary Doherty is a consultant anaesthetist and leading expert on autism and healthcare. She has published extensively on the barriers autistic individuals face in healthcare settings and is the co-developer of the Autistic Space Framework.

#### *Could you describe the Autistic Space Framework for our readers?*

Mary: Absolutely. The Autistic Space Framework was developed to help medical colleagues better meet the needs of autistic people in healthcare. I recognised that for many of my colleagues in healthcare, that autism can be very nebulous (unclear), and it's often challenging for professionals, especially those without specialized training, to understand its nuances. It's very hard for people to get their head around autism and it's very hard for people to understand what it really means to be autistic.

That was where we started.... we wanted to create a useful and easy to remember framework that highlighted important things to consider when supporting or working with autistic people. Sensory needs are core to the autistic experience, so we wanted a framework that starts with 'S' and gradually we came up with the descriptive acronym which the Autistic SPACE Framework is. It stands for (S) sensory, (P) predictability, (A) acceptance, (C) communication, and (E) empathy. The title is particularly useful because the most important thing that we all need, particularly in stressful situations, is a little bit of extra space; we think the Autistic SPACE framework does this.

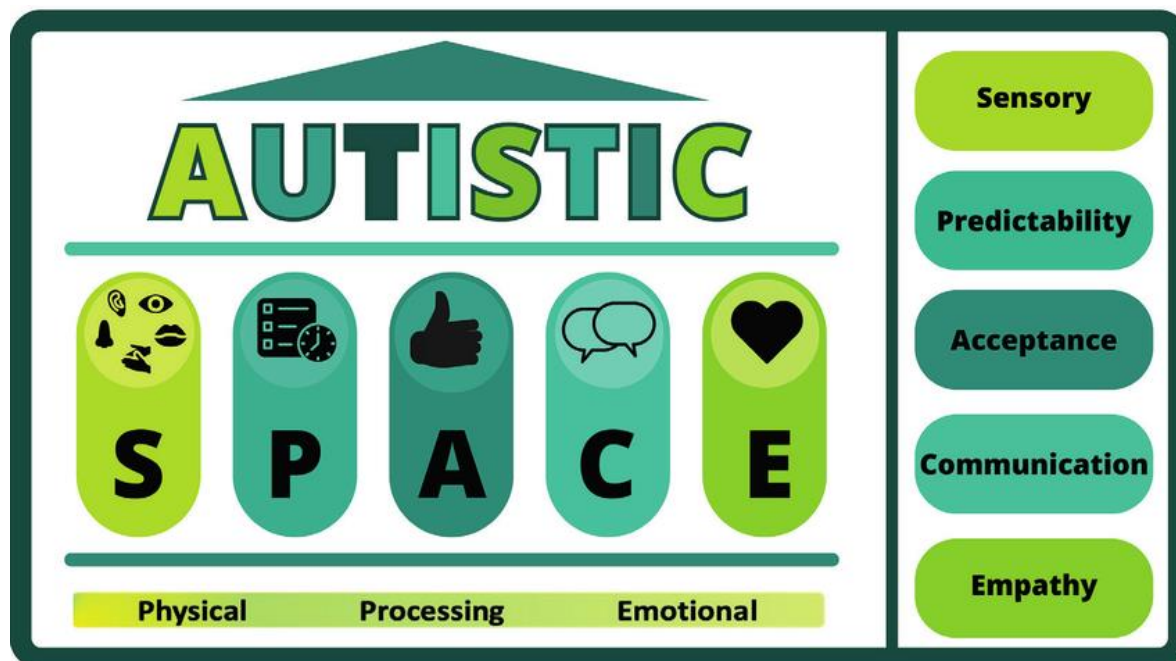
#### *What inspired you to develop the Autistic Space Framework, and how did you identify these core areas?*

Mary: My prior research highlighted barriers to healthcare for autistic individuals. Despite publishing comprehensive articles on recognizing and meeting the needs of autistic patients, I realized that busy clinicians needed something more accessible. Our colleagues are often too pressed for time to delve into lengthy papers, so we developed a memorable, easy-to-access framework. We wanted something that could easily be recalled and implemented, even by those without a deep interest in autism.

#### *You mentioned the importance of 'space' for autistic individuals. Could you elaborate on how physical, processing and emotional space can contribute to overall well-being?*

Mary: Physical space is crucial because autistic people generally need more space between themselves and others. Crowding or unexpected touch can cause significant distress. Processing space refers to the time needed to take in and respond to information. Autistic individuals may need a bit longer to process questions or make decisions, and repeated or rephrased questions can reset their processing

time. Emotional space involves understanding how autistic people experience and manage emotions, including conditions like alexithymia, which can make recognizing one's own emotions challenging. Respecting these needs can significantly reduce distress and improve interactions, which is why they are incorporated within the Autistic SPACE Framework, which was beautifully illustrated by the very talented Amanda McGuinness, who is an autistic graphic artist working with As I Am.



### *How can the Autistic Space Framework be implemented in practice?*

Mary: The article where Sue McCowan, Sebastian Shaw and I launch the framework offers specific suggestions on how to use the framework in real life scenarios, such as reducing lighting, avoiding loud areas, and minimizing sensory overload. Within the article, we suggest simple accommodations like not wearing strong perfumes which can make a big difference. Ensuring predictability by giving as much information in advance and having familiar staff also helps. Understanding how autistic people communicate and their need for detailed information can prevent misinterpretation of their behaviour.

### *Beyond healthcare, do you see potential applications for the Autistic Space Framework?*

Mary: Definitely. The framework is equally applicable in education, justice, and workplace settings. It helps educators understand the needs of autistic learners and assists in creating supportive environments. In justice settings, it can improve interactions with police and judiciary. In workplaces, it guides creating autism-friendly practices. The framework aids in conceptualizing autism and ensuring the needs of autistic individuals are met across various domains.

### *What resources or support systems would you recommend for educators looking to incorporate the Autistic Space Framework into their teaching practice?*

Mary: Our framework is Open Access, and the graphics designed by Amanda McGuinness can be downloaded, printed, and used as posters or discussion starters in staff rooms. It's intuitive and

requires no specific training to use effectively. However, I do offer advanced training sessions for those interested in a deeper understanding. A team from Middletown Centre for Autism, along with Elaine McGoldrich and Aoife Munroe are currently working on educational adaptations of the framework, which will further support its implementation in teaching practices.

It's been a pleasure discussing the framework, and I look forward to seeing its impact grow.

*End of Interview.*

You can freely access the original article online on the Autistic SPACE framework: Doherty, M., McCowan, S. and Shaw, S.C.K. (2023). Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings. *British Journal of Hospital Medicine* Vol. 84, (4).

You can find the article here: <https://www.magonlinelibrary.com/doi/full/10.12968/hmed.2023.0006>





## Niamh Taylor

Age: 9

Drawn via Procreate on the iPad

When Niamh was asked what brings her autistic joy:

“I love to draw pictures because it helps me calm down and block everything else out. My favourite pictures are anime characters and anything Japanese themed. In this picture the lady is being still and listening to the wind in the trees behind her and just taking deep breaths and everything is okay.”



# Engage, Embrace, Empower and Educate.

## The Hidden Autistic Voice: Exploring the Strengths of Autistic People of Marginalised Genders from lived experiences

### Noelle Foley Coughlan

Noelle Foley Coughlan is an autism advocate, dedicated to positive, strengths-based autism research. Her impactful work and contributions to the field were honoured by President Michael D. Higgins and his wife Sabina at the presidential garden party, "Celebrating Communities in All Their Diversities". With over 20 years of industry experience, Noelle has worked with some of Ireland's leading brands and is currently Chief Operating Officer with Career Decisions Ireland. She is passionate about lifelong learning and was one of the first four graduates across the island of Ireland to earn an MA in Autism Studies. Additionally, she holds a Master of Business (Research), a BBS (Hons) in Marketing, Diploma in High Performance Leadership, and numerous professional development qualifications.

#### Introduction

Historically, autism research has largely overlooked the autistic voice; little is known about the strengths of autistic people of marginalised genders through lived experiences. This oversight has perpetuated a male bias in autism research, resulting in a lack of research on autistic females (Meng-Chuan, et al., 2012) and even less research on autism in other marginalised genders. Moreover, research has often been conducted "on" autistic people rather than "with" them (Botha & Cage, 2022), further exacerbating the gap in understanding. To address this gap, this study aimed to explore autistic strengths through the

lived experiences of people of marginalised genders. Recognising the increasing demand for genuine involvement of autistic people in research and decision-making processes (Hobson et al., 2021), this study prioritised narratives shared directly by autistic people themselves, offering authentic insights into their personal strengths and experiences.

Goodall and Purkins believe autistic people have a greater incidence of divergent gender and gender identify differences (2018, p. 55). This study included 30 participants, meeting the inclusion criteria, including a diagnosis of autism spectrum condition, age over 18, and



identification as cisgender female, transgender, non-binary or intersex, and the ability to give informed consent to participant in the research. The sample excluded autistic cisgender males, autistic teenagers and children and non-autistic people. By focusing exclusively on marginalised genders within the autistic community, this study aimed to provide a comprehensive understanding of strengths and experiences that have historically been overlooked.

This research aims to directly benefit participants in thinking about their own strengths in a positive-affirming way leading to positive-affirming research, thereby contributing to a more positive and affirming narrative surrounding autism. By amplifying the voices of autistic people from marginalised genders, this study seeks to promote inclusivity and understanding within both research and broader societal contexts.

### **Why Marginalised Genders?**

According to Harvard University (2023), marginalised genders refer to a community of members who experience marginalization due to their genders; this includes transgender women, cisgender women, transgender men, non-binary people, among many other marginalised gender identities. Gender bias has detrimental effects on the health and wellbeing of autistic women and girls (Bargiela, et al., 2016) however, many autistic people identify as non-binary, transgender or gender-fluid (Kanfischer, et al., 2017). The connection between transgender identities and autism is increasing (Walsh, et al., 2018). According to the HSE (2019) gender identity is the internal sense of being male or female, neither or both. Kanfischer, et al. (2017) states that many autistic people identify as non-binary, transgender or gender-fluid. Autistic people are more likely to be sexual and/or gender minorities (Botha & Gillespie-Lynch, 2022) which has *'implications for*

*understanding the outcomes for autistic people'* (p. 103). According to Strang (2018), marginalised groups with insufficient support and understanding include both autistic people and transgender and gender diverse people. Crenshaw (1991, p. 96) states 'researchers must understand differences within marginalised communities if they wish to effectively engage in the type of collective identity making and advocacy that transforms an identity from a mark of stigma to a banner for collective action.'

### **Autistic Testimony - The Hidden Voice**

Research has been *'characterised by a narrowness of perspective'* and *'have failed to understand the nature of autistic people's life experiences'* (Pellicano & den Houting, 2022, p. 385); this leaves a huge gap in research. Research by Botha, et al., (2022) investigate how autistic individuals understand their own autism and the place of autism in society; their research reveals that autistic people feel they are given less room in society and carry a characterisation that society finds offensive. They suggest by depriving autistic people the freedom to be who they are and erasing their experiences widens the gap between autistics and non-autistics. They add, by telling an autistic person to use person-first language implies that autistics are secondary to neurotypical individuals, even in terms of self-identification.

Botha & Gillespie-Lynch make the point that, *'as we learn more about the twisted origins of the diagnostic category "autism" it becomes increasingly unsurprising that many autistic people have called for a fundamental shift in how autism research and practice are conducted'* (2022, p. 94). Many have criticised the overwhelming reliance on samples that are primarily male in autism research and the way that these samples defined autism, therefore less is known about autism in females and gender diverse individuals (Ratto, 2020).



Certainly, investigation is warranted on the lived experiences of autistic people of marginalised genders due to the huge gap in research. Aligned with this research study, Ratto (2020) believes by listening to the insightful and deeply knowledgeable voices of autistic people, researchers gain critical new insights which will enhance research.

This deficit model and way of thinking takes attention away from the social and environmental factors which could play a significant role in shaping autistic lives (Engel, 1977). This model is dangerous as it undermines autistic people's own understanding of autism and of their own lives (Pellicano & den Houting, 2022).

### **Autistic Strengths**

Strengths are defined as character traits or skills that are considered positive; strengths include knowledge, attributes, skills, and talents (Davis, 2022, p. 01). Given the global narrative and uncanny focus on the challenges faced by autistic people, it is not surprising that most research focuses on the challenges of autism leaving a huge gap for positive-affirming strengths-based research. Challenging the deficit-focused assumption, researchers could potentially explore double empathy and the impact it might have on how we understand autistic strengths. Double empathy refers to a *"disjuncture in reciprocity between two differently disposed social actors"* who have different customs and expectations of one another, which is common between autistic people and non-autistic people (Milton, 2012, p. 884).

*"We don't ask a blind person that we're working with to see more like me.....and we don't ask someone with cerebral palsy to walk more like me in order to be accepted but we do this, time and time again, with our autistic community where we say success means you're more like me and that is the hallmark of a medical model of*

*disability, a deficit based approach that really doesn't recognize that, a lot of what individuals that are autistic are dealing with, are related to the social model of disability and how the social context and the social world is really the most disabling condition."*

(Patten, 2020)

Growing evidence suggests that certain abilities also define autism (Nuwer, 2021). As per Pellicano and den Houting, the conventional medical paradigm focuses on deficits and impairments in autistic people and *'often has the unintended consequence of drawing away from the particular strengths of autistic people and focusing entirely on limitations, whether perceived or real'* (2022, p. 382). The term 'strength' refers to performance level in one particular type of task, it aims to reflect *"domain general"* strengths, which can be applicable to a large array of tasks (Meilleur, et al., 2015, p. 1355). Autism has been linked to certain cognitive proficiency (Russell, et al., 2019). Autistic people have recognized strengths in themselves for decades (Nuwer, 2021). The field of strengths in autism is still in its infancy stage; according to Nuwer (2021) the studies documenting strengths are still small giving prominence for the need of this study.

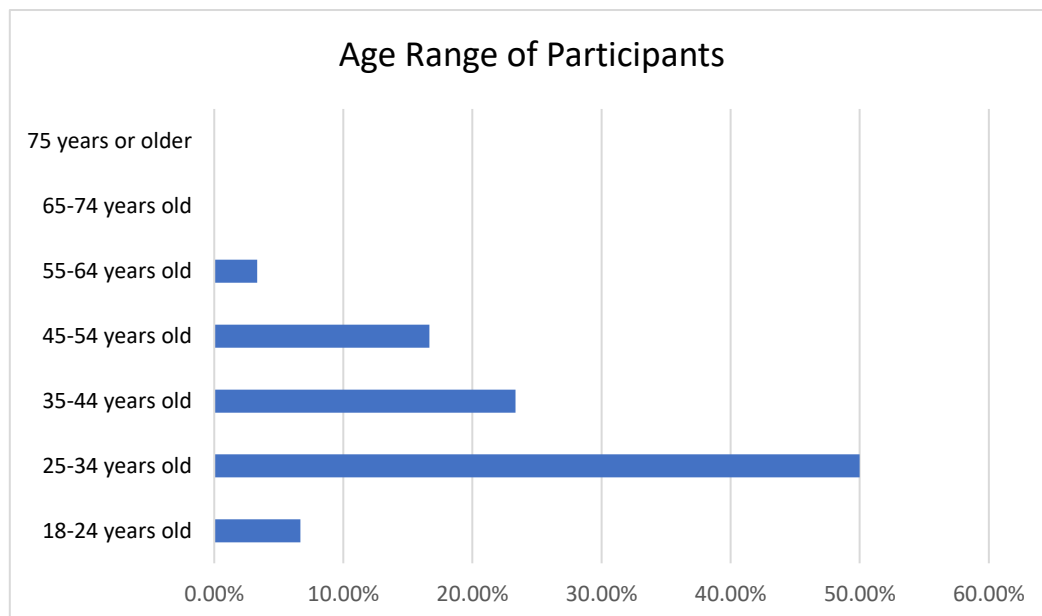
### **Methodology**

The researcher used a mixed method approach which allowed the researcher to get as close to the truth as possible. Qualitative and quantitative data enabled the researcher to understand the strengths of autistic people of marginalised genders with a hope of uncovering trends and insights for young autistic people. Methods included an anonymous online survey coupled with biographical analysis. The primarily qualitative survey focused on rich data which allowed the emergence of key themes, it also contained some quantitative questions. Biographical analysis enabled the researcher to understand

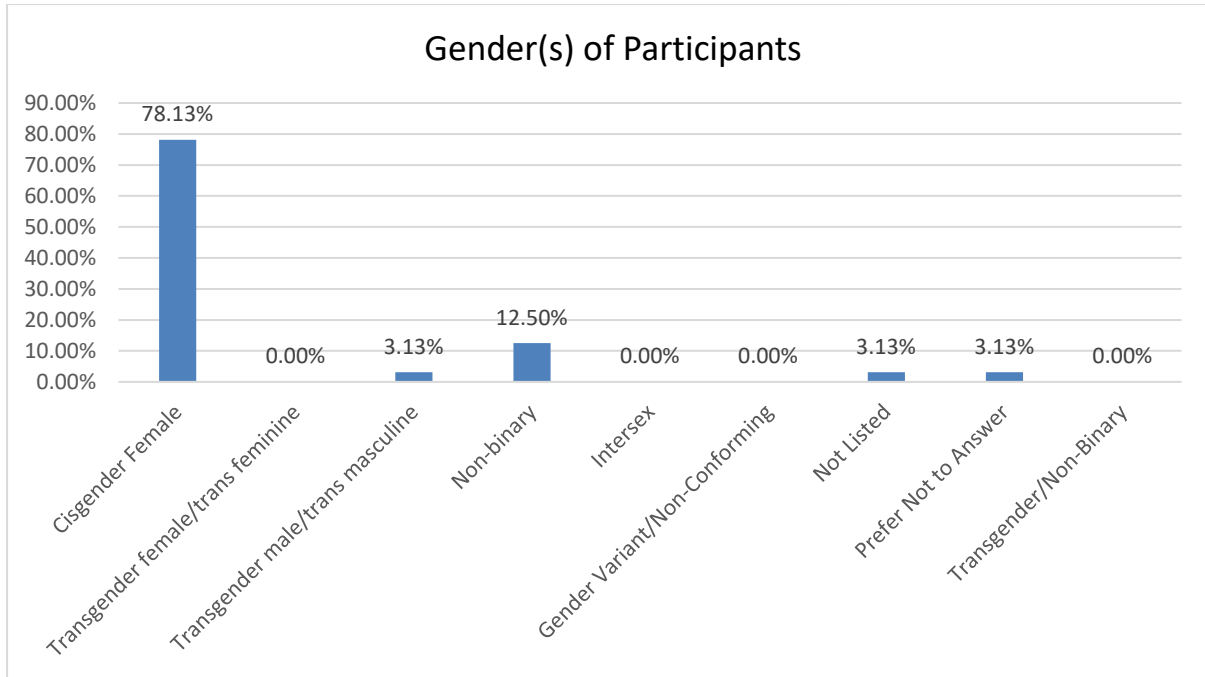
the personal strengths of autistic people of marginalised genders through their lived experiences and uncovered trends, insights and learnings for young autistic people. The researcher implemented thematic analysis using a framework by Braun & Clarke (2021) and inductive analysis, which allowed the researcher to draw conclusions and develop themes from data without the use of assumptions or preconceptions.

### Research Demographics

In total 30 people took part in this study ranging in age from 18 to 64 years of age, most of which (78%) identified as cisgender female. The majority of participants (83%) were from the Republic of Ireland, and half of the participants (50%) were aged 25-34 years of age. The average age of autism diagnosis was 32 years (range 7 – 60 years of age). Summary of participants demographics:



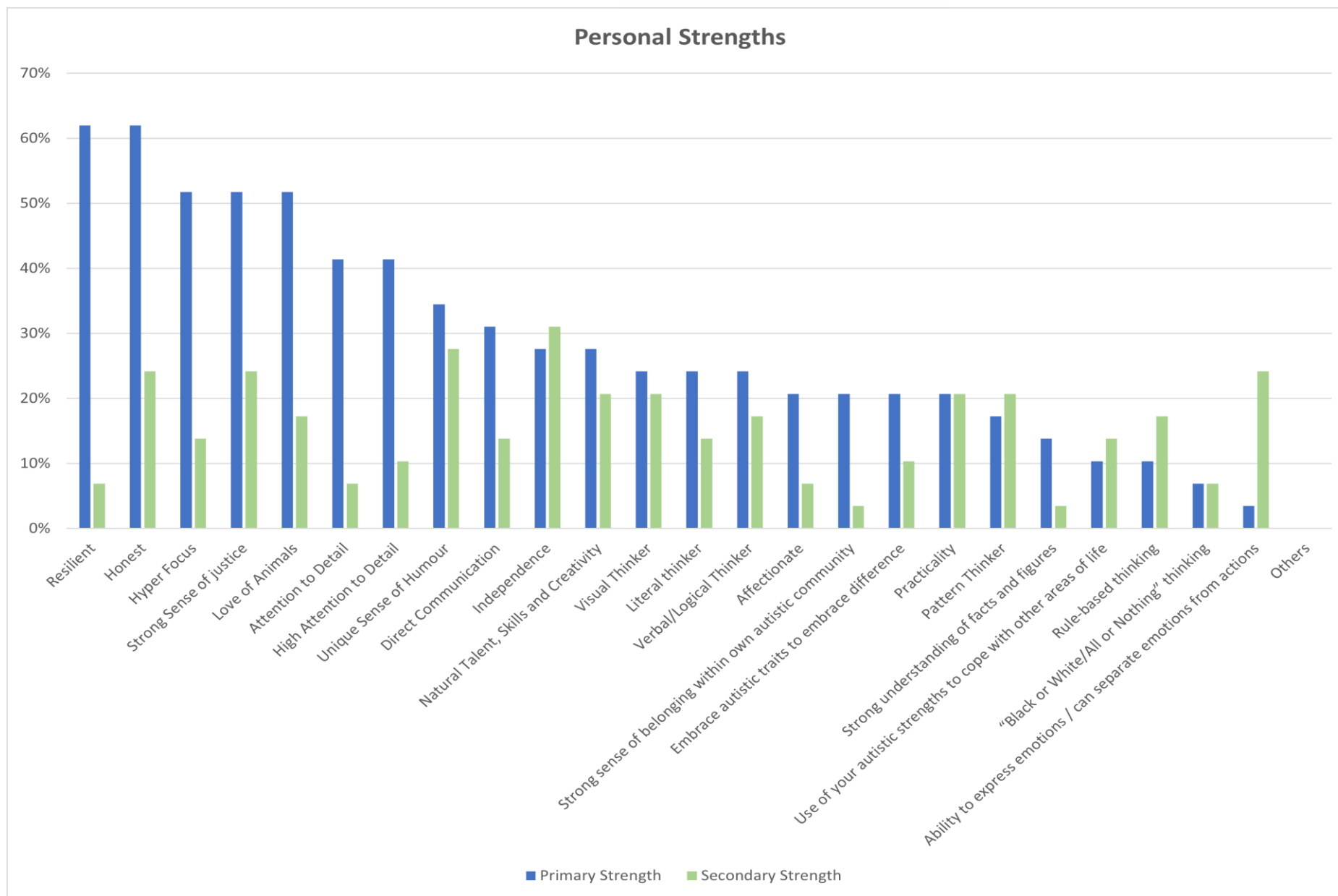
**Location of Participants:** 83% of participants resided in the Republic of Ireland, 6.67% Northern Ireland, 6.67% identified as European and 3.33% Canadian. The jurisdiction of biographical analysis was international books published in the English language.



Gender(s) of Participants

**Research Findings**

Participants ranked what they perceived as their main personal strengths, ranking them in order of primary and secondary strengths. A list of strengths was presented following biographical analysis.





The top five primary and secondary strengths are:

Primary Strengths – Top 5	Secondary Strengths – Top 5
Resilient	Independence
Honest	Unique Sense of Humour
Hyper Focus	Honest
Strong Sense of Justice	Strong Sense of Justice
Love of Animals	Ability to Express Emotion / can separate emotion from actions

**Resilience**

Resilience was a central theme that emerged from the data; the rich qualitative data from the survey demonstrated how participants' lived experiences have been positively impacted because of their resilience.

*“Resilience given me the ability to keep going even when life is awful.”*

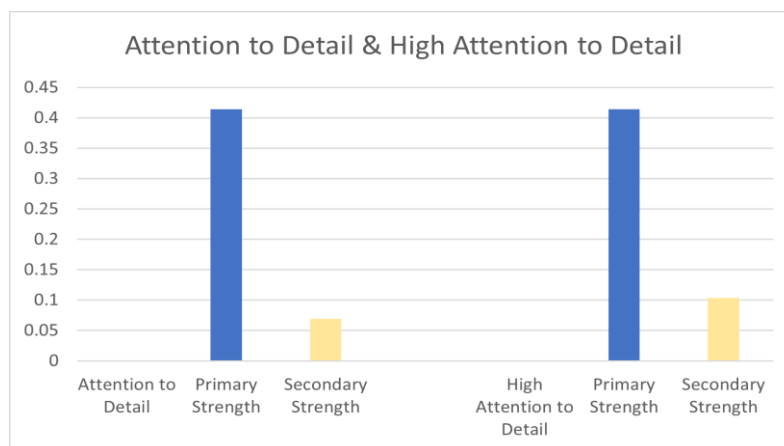
*“I am very resilient and bounce back from traumas because I just look to the next accomplishment I want to achieve.”*

Equally, resilience was very evident from biographical analysis showing the consistency of findings between primary and secondary data. Biographical analysis showed resilience being ranked within the top five strengths.

**A Note on Attention to Detail**

It's important to keep in mind that different people have different levels of attention to detail; following biographical analysis, the researcher opted to add 'attention to detail'

and 'high attention to detail' as two separate options. Even though both options relate to the ability to focus on minute or specific details in a particular situation or task, there can be variations in capacity. Attention to detail can be referred to as the ability to focus on all areas of a project or task, no matter how small (Kaplan, 2023). People who have strengths in this area tend to recognise details that others may miss. However, high attention could be defined as the ability to perform tasks with supreme accuracy and precision (Hiration, 2022). High attention to detail could suggest an exceptional ability of focus, precision, reliability, and accuracy in noticing detail and inconsistencies. This skill may be beneficial in professions that require a heightened eye for details such as research, science, forensics, data analyst etc. Interestingly, both options ranked the same in primary strength. Although neither ranked in the top 5, combining their scores emphasised the strength in this area, giving a credible reason to add attention to detail to the top 5 personal strengths.





### How Strengths Have Positively Impacted Autistic People of Marginalised Genders

Participants quoted positive-affirming descriptors to portray how their strengths have positively impacted their lived experiences. It is evident from the primary data that participants' strengths have supported them to excel in their career. A recurring theme of career success was also discovered through biographical analysis. Whilst 56.67% of people were employed/self-employed, it is important to note that not all participants were employed, 6.67% were unemployed, 10% were full time carers and 13.33% of participants were students.

*"Ability to excel in my career."*

*"Career progression."*

*"I specialize in anaesthesia for neurosurgery, including brain tumours, aneurysm clippings, and spinal fusions. I have also specialized in anaesthesia for trauma, transplants, and burns. All of these specialties require very intense concentration and skill, and I thrive on these types of cases." (Lesko, 2020, p. 167).*

Figure 1: Environments ranked in order of having the most Positive Impact in Promoting Strengths

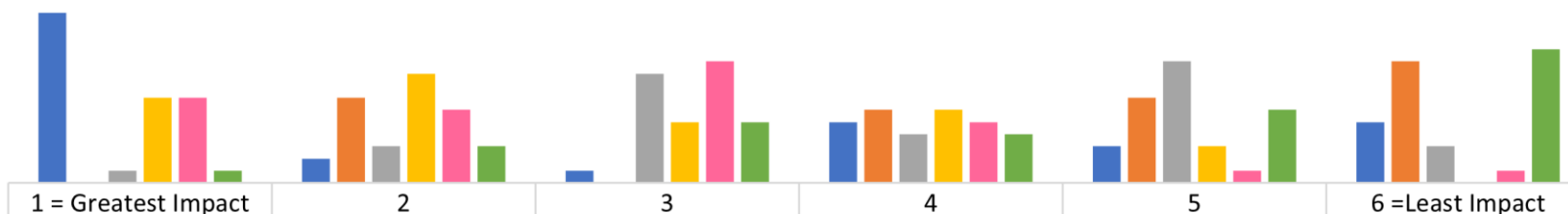
1. Home Environment (Parents, Siblings etc.)
2. Physical Environment (Animals, Nature, etc.)
3. Social Environment (Friends, Local Community, Support Groups etc.)
4. School Environment (School Principal, Teachers etc.)
5. Further Education Environment (College Lecturer, Clubs/Societies etc.)
6. Work Environment (Mentors, Managers, Work Colleagues etc.).

### Environments Having the Most Positive Impact in Promoting Strengths

Participants identified the environments which had the most positive impact on them in promoting their strengths. The findings showed, overwhelmingly, that the home environment had the greatest impact in promoting strengths (46.67%). This was followed by the physical environment (30% i.e., animals, nature etc.). This finding evidently showed a correlation between this environment and a love of animals which was ranked number five of the top five personal strengths. The social environment ranked third (33.33%).

Participants' work environment (Mentors, Managers, Work Colleagues etc) was ranked as having the least impact in promoting strengths (36.67%). Interestingly, 0% of participants ranked the school environment as the number one choice in having the greatest impact in promoting personal strengths which was a clear and definite statement, instead the school environment ranked at number 4 of 6. See figure 1 for the environments that had the most positive impact in promoting strengths, ranked in order of greatest to least.

### Environments Having the Most Positive Impact in Promoting Strengths



	1 = Greatest Impact	2	3	4	5	6 =Least Impact
■ Home Environment	46.67%	6.67%	3.33%	16.67%	10%	16.67%
■ School Environment	0%	23.33%	0%	20%	23.33%	33.33%
■ Further Education Environment	3.33%	10%	30%	13.33%	33.33%	10%
■ Physical Environment	23.33%	30%	16.67%	20%	10%	0%
■ Social Environment	23.33%	20%	33.33%	16.67%	3.33%	3.33%
■ Work Environment	3.33%	10%	16.67%	13.33%	20%	36.67%

■ Home Environment   ■ School Environment   ■ Further Education Environment   ■ Physical Environment   ■ Social Environment   ■ Work Environment

### **Supporting Young Autistic People in Embracing and Developing their Strengths.**

Participants outlined what supports they believed could assist young autistic people in embracing and developing their strengths. Participants called for a positive representation of autism using a strengths-based approach. Findings showed that positive representation can be achieved through teacher training, listening to the autistic community, visibility of autistic role models and positive language promotion. Participants outlined how they would educate society on the benefits of autism, and evidence from the data showed a strong prerequisite to provide a better understanding of autism through improvement of teacher training, awareness campaigns, education and training and inclusion.

#### **Positive Representation of Autism**

*“Training for teachers to view autism as a strength. Engage with autistic community to promote positive representation.”*

#### **1. Engage with the Autistic Community**

There was repeated opinion to show that the above strategies will only be successful if they are encompassed within the wider context of engaging with the autistic community.

*“I think the autistic community is still a bit taboo in this country, possibly even the world. People need to see the autistic community like they see the blind, or deaf community (often considered a lot more capable and like-minded to society than we are). We are often infantilised, our voices ignored due to not knowing what's good for us. But we are completely capable. We just need to be listened too. We have as much of a diversity of strengths as any of group of people and sometimes even more so. With*

*our ability to see things in a just, unbiased state, we can be fantastic assets to the community and the nation! Those of us who are detail oriented and can hyper fixate, can do so much good. But unfortunately, we are not recognised as a capable people. We need to have our voices heard (not the voices of the carers or parents of, but the actually autistic voices). Then and only then will society realise how "normal" we are, and the taboo and fear can be lifted.”*

#### **2. Focusing on the Strengths of Autism**

Participants would educate society to view autism through a strengths-focused approach.

*“Focus being paid to our strengths, literal thinking and direct communication being seen as a benefit, not a flaw. It is important to be direct and honest. Seminars on explaining more that autism is not an intellectual disability, many of us are as or more intellectually capable than our neurotypical counterparts!”*

Biographical analysis showed similar findings on the value of supporting young autistic people by listening to the autistic community and educating society about autism.

*“Parents, tell your child that their brain is beautiful. From being around neurotypicals, I have spent most of my life thinking that I wasn't enough. I felt that I had to aspire to be neurotypical most of my life. That attitude was wrong, and I was only harming myself.” (Wangelin, 2021, p. 45)*

#### **Teacher Education and Teaching School Stakeholders about Autism**

Findings suggested a need to provide a better understanding of autism through the improvement of teacher training.

*“More training for teachers.”*

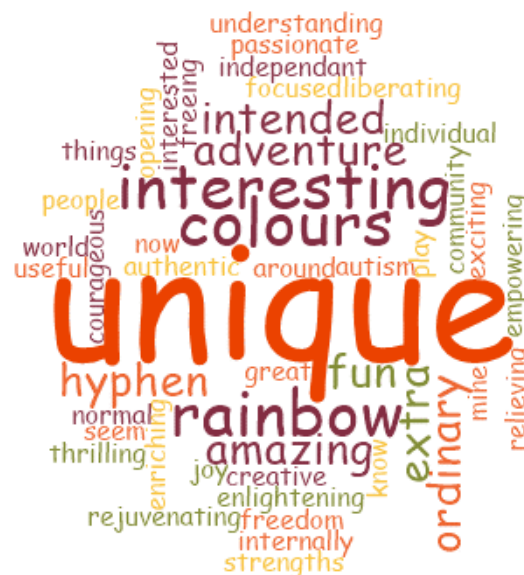


*“Make it part of the school curriculum. We learn about everything in school but why not learn something about people who are a big part of society and the world.”*

*“Positive language. Education about neurodiversity from primary school.”*

### **The Experience of Being Autistic**

Participants described their experience of being autistic and the findings yielded some intriguing results. The researcher noted a feeling of conflicted emotions arising from both positive and difficult experiences.



#### *The Experiences of Being Autistic*

Findings from secondary data mirrored a positive experience of being autistic.

*“Feeling good about yourself is one of your strengths, even though you might not have thought about it in this way [...] Autism is often thought about in terms of negative impact on our lives, but the reality is we are very focused people and can ‘hone in’ on an interest and make it a passion. [...] Unlocking your own strengths and passions could be an asset in finding your place in the world, if you haven't already....” (Purkins & Lawson, 2021, pp. 180-181)*

### **Unique and Authentic**

It was transparent from the findings that participants' lived experiences were authentic, unique, distinct and infused with a sense of freedom. The words ‘unique’ and ‘authentic’ were the most used word to describe the experience of being autistic. Other positive experiences included ‘amazing’, ‘adventure’, ‘liberating’, ‘fun’, ‘exciting’, ‘interesting’, ‘enlightening’, ‘enrichment’, ‘empowering’, ‘passionate’, ‘courageous’, ‘relieving’, ‘thrilling’ and ‘community’.

Contrary, some participants reflected on the challenges of being autistic. One must question if participants would feel the same if there was a better and more positive representation of autism in society. Their perspectives and insights are essential in providing support for fellow autistic people.

*“Difficult - due to poor information and accommodations.”*

*“Self-hatred as a child.”*

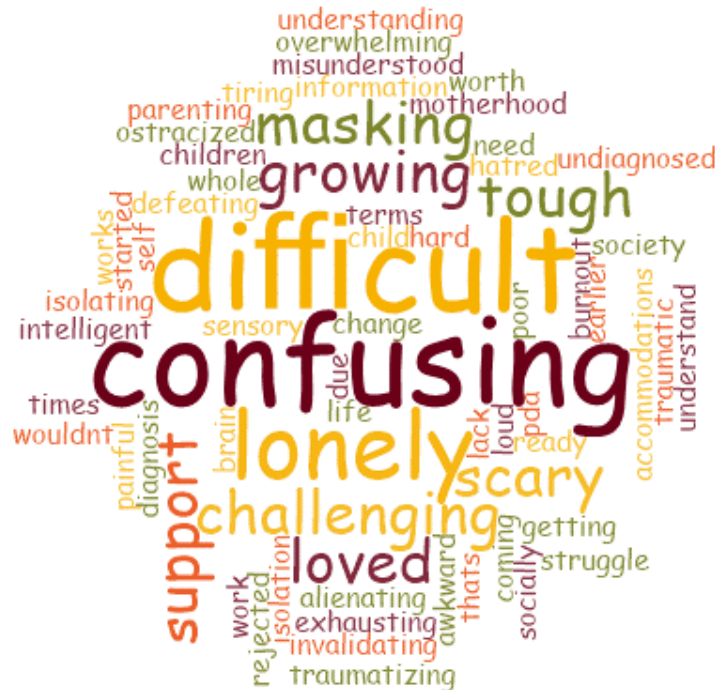




*“Confusing - I would have loved to understand how my brain works earlier in life!”*

Some of the challenges of the experience of being autistic are illustrated below.

*The Experiences of Being Autistic*



## **Learnings and Insights to Support Young Autistic People**

### ***Greatest Benefits of Being Autistic***

In total, 87 perceived benefits of being autistic were named; overwhelmingly, an understanding of self was the top benefit (26.4%, 23/87), encompassed in a strong sense of community (13%, 11/87). A shared sense of community and support for each other was evident throughout the research. This was perceived as a substantial benefit of being autistic (26.4%). Evidence from the qualitative data clearly demonstrated the importance of acceptance and belonging in supporting autistic people to discover and embrace their strengths.

### ***Advice for Young Autistic People –As Told by Autistics***

Participants documented three pieces of advice for young autistic people. The overwhelming piece of advice was ‘*Be Yourself and Celebrate You*’. Furthermore, participants asked young autistic people to embrace their ‘*uniqueness*’ and ‘*difference*’ and ‘*not to change to fit in*’. In the context of autistic people, findings could suggest that each person has an identity unique to them.

#### ***Be Yourself - Celebrate You***

*“Unashamedly be yourself.”*

*“Be yourself and celebrate your identity every day.”*

Biographical analysis presented a similar sentiment.

*“I'd been a long-life bookworm always searching for an image of myself in the novels*



*and memoirs I read, but never quite finding my reflection, until I read the words of other autistic people.” (Human, 2018, p. 14)*

### ***Find Your ‘Tribe’ and Seek Support***

Evidence of findings noticeably demonstrated the significance of the community where participants advised and reassured young autistic people to find their "tribe". There was a correlation between this finding and the benefits of being autistic where a strong sense of community was evidenced.

*“Be patient, you will find your tribe.”*

*“If you are struggling at school, you will eventually find your people, I promise.”*

*“You will find your people. People you don't have to mask around, where you won't be the odd one out, where you will just be seen as your true self, and you will be truly accepted.....You're uniquely wonderful.”*

Mirroring the qualitative survey data, ‘find your tribe’ was also a key theme developed through biographical analysis.

### ***Celebrating Autism***

Findings clearly illustrate that each person has a distinct identity and the experience of being autistic is different for everyone. Autistic people of marginalised genders contribute greatly to society thanks to their diverse range of strengths and unique lived experiences. Findings overwhelmingly present a platform to celebrate autism and embrace the uniqueness autism brings. There was a tremendous sense of self-understanding among participants, something that is perhaps misunderstood by the non-autistic population. The sense of community is very evident from the research and the sense of belonging in ‘*finding your tribe*’ cannot be underestimated. The research suggests that the autistic community provides a positive and supportive environment for fellow autistic people to embrace their autism. The benefits of such support can nurture and

encourage the promotion of individual strengths through sharing of experiences, mutual support and a shared sense of connection, something that is evident throughout this research. The social environment was the third ranked most popular environment in promoting strengths (33.33%). This finding aligns with other elements of the study, particularly the strong emphasis on community. It also challenges traditional assumptions about autistic people and their social interactions, where historical research has primarily focused on a social deficit.

### ***Resilience - Built from overcoming challenges?***

It is no surprise that resilience was the number one personal strength of autistic people of marginalised genders. This merits further granular analysis as to the intensity of the interconnection between autism and resilience and if this is related to the many challenges autistic people face and the ability to adapt and cope with such challenges. One must question if resilience is linked to the other personal strengths recorded e.g., does building resilience help develop additional strengths such as problem-solving, decision making, strong sense of justice, advocacy skills? It is evident that resilience is a skill that can be developed and grown over time, this is important in promoting strengths for young autistic people.

Given some of the findings surrounding the experiences of being autistic, there is a clear need for autistic people to be resilient. Resilience is defined as adapting positively in the face of adversity (Al-Jadiri, et al., 2021). Although there was a lot of positive experiences in this research, some were less positive referring to words such as ‘*tough*’, ‘*confusing*’, ‘*challenging*’, ‘*painful*’, ‘*invalidating*’, ‘*alienating*’. It gives merit as to why resilience is such an important skill for autistic people. Further investigation is



required as to whether we want autistic people to build resilience or to live in a world where resilience is less necessary.

Building resilience in autistic individuals can involve providing necessary supports, strengths-based education, inclusive work environments and hiring practices, and interventions that focus on strengths. That said, it is crucial to work toward a future where resilience is not as vital as it is today for autistic people of marginalised genders. This future may see barriers removed, promoting inclusion. An environment where less resilience is required may allow autistic people to thrive without continually having to overcome challenges.

### **Career Success**

Autistic people possess many unique skills that are beneficial to the workforce (Costello, et al., 2021), therefore there is a clear need for future discussion on how organisations can embrace autistic strengths and include autistic people in human resource planning. Evidence could suggest that career success is as a direct result of the impact of personal strengths. The finding implies that autistic people of marginalised genders can grow, develop and thrive in their careers thanks to their strengths. Recent research exploring the career motivations, strengths and challenges of autistic and non-autistic students found that autistic student's main reason for attending university were to advance their career prospects, followed by academic growth, interpersonal development, and personal development (Cheriyana, et al., 2021)..

This research suggests that autism is a contributor of successful career development, contrary to the 'impairment' and 'deficit-based' model. However, there is a lack of understanding from employers according to the '*Autism in the Workplace*' Report (2022), this lack of understanding *'leads many not only*

*to underutilise the talents of autistic people at work - 94% of whom believe that with the right supports, they would be an asset to any business or organisation – but to discourage autistic people from applying for roles in the first place'* which is alarming.

Participants' work environment (Mentors, Managers, Work Colleagues etc) was ranked as having the least impact in promoting strengths (36.67%) which clearly highlights a misalignment between the work environment and career success. Similarly, an employment report by AsIAM (2022) show that 84% of autistic people do not feel confident that employers, managers, colleagues and clients know enough about autism to support them in the workplace. That said, 94% believe that with the right supports, they would be an asset to any business or organisation.

Questions must be asked as to why the work environment was ranked as having the least impact in promoting strengths given the above findings relating to career development. Further research is necessary in this area; conceivably, this may be due to the lack of diversity and inclusion programmes within organisations, the lack of awareness and understanding of autism and autistic strengths and how these strengths can provide valuable human resources to any organisation. It must also be acknowledged that this could be due to the lack of disclosure about an autism diagnosis. The visibility of autistic people in the workforce and those who have achieved personal career success could serve as role models and mentors, instilling a sense of endless possibilities.

### **The School Environment & Lack of Teacher Education**

The three least impactful environments for promoting strengths include the school environment, further education, and work environment. Findings recommend the need to



adopt a strength-based approach to education, from early years, that focuses on developing autistic strengths.

The school environment being ranked at number 4 is justified due to the evidence of findings, referencing the need for teacher education on autism. It is evident from the findings that there is a strong requirement for teacher training on autism. It appears that teachers' misunderstandings of autism can suppress autistic students' strengths. The findings show convincingly that each autistic person is unique, and this uniqueness needs to be embraced by educators when developing strengths. Teacher training and curriculum development around autism should avoid generalisations and assumptions, based on limited knowledge or stereotypes of how autism presents. Research by Brownlow, et al., (2021) sought to understand the school experiences of autistic young people and adults through reflection, the results highlighted the dangers of stereotypes, stigma and judgements, participants observed how autism stereotypes obscured their personal strengths. The nature of the person was incorrectly presumed, leading to assumptions. This was also expressed in the language teachers used.

The Department of Education's Publication "*Autism Good Practice Guidance for Schools*" (2022) emphasises abilities, personal accomplishments, talents, and preferences, rather than a deficit approach which was previously adapted, to support autistic children and young people. They add that concentrating on a person's strengths and interests can lead to positive experiences, opportunities for personal growth, and future employment opportunities for autistic people. In addition, to implement a strengths-based approach, it is crucial for all education staff to have "*high aspirations*" for autistic students, including those who have complex needs. The study

demonstrates that implementing a strengths-based approach must start very early. Looking to the future, these changes will take years to embed into the educational system therefore it is vital teacher training is accessible as part of teacher college programmes before entering into the workforce formally.

### ***Importance of the Home Environment in Celebrating Autism and Promoting Strengths from a Young Age***

Findings show the home environment as the number one environment in promoting strengths. Research on the family context of autism by Smith, et al., (2014) showed the importance of the relationship between parents and autistic adolescences or adults, their research showed the family environment as important '*not only to reduce family distress but also to improve functioning for the autistic child, adolescent or adult*'. Their research sees this relationship as being an important contributor '*shaping trajectories of behavioural functioning*'. Their research shows how 'behaviour problems' and 'autism symptoms' may improve if high levels of criticism are reduced or kept low while parental warmth is increased. Research by Bayat (2007) show that a sizable number of families with autistic children display factors of resilience, reporting having become stronger as a result of their autistic children, acquiring spiritual strength; being more unified and connected as a family and discovering a greater appreciation of life in general.

### ***Educating Society on the Strengths of Autism***

Findings show the crucial need to listen to and to learn from autistic people, respect their views and lived experiences to create positive representation of autism. Listening to the autistic community will help dispel stereotypes created by society due to lack of knowledge and lack of understanding on autism and to promote a more accurate representation and understanding of autism. This is crucial when it



comes to policy development be it at national or local level, be it school policies, organisational policies or community policies. The autistic voice was incredibly strong in asking for a more inclusive society to support a positive representation of autism, reducing misconceptions and stigma. Lei, et al., (2021) speaks about the semantic choice of language used around autism, citing members of the autistic community prefer to use identity-first language (autistic person), whereas professionals were more likely to use person-first language (person with autism). They add, beyond language choice, there is a much bigger need to accurately convey each person's strengths, recognising that autism is a crucial component of an individual's identity and using language that respects the autistic community (2021, p. 1354).

***Supporting Young Autistic People to Embrace their Strengths.***

Autistic participants believe a positive representation of autism using a strength-based approach can assist young autistic people to embrace and develop their strengths. By listening to the autistic community better supports can be implemented to support autistic people. The research indicates that autistic adults can empower their younger peers by showing them it is perfectly acceptable to embrace their uniqueness and to inspire them to capitalise on their strengths to develop their true potential. A strengths-based approach to education and teacher training is crucial in promoting strengths from an early age. Curricular supports need to focus on and build upon the interests and strengths of young autistic people. Giving young autistic people a platform to explore their interests and areas of enjoyment is important and a first step to identifying one's strengths.

***Future of Autism - Positive Representation***

Evidence from the data shows a strong prerequisite to provide a better understanding of autism through improvement of teacher training, awareness campaigns, education, and training and the promotion of inclusion. There was repeated opinion to show that these strategies will only be successful if they are encompassed within the wider context of engaging with the autistic community and viewing autism through a strengths-focused approach.

Autistic people, including autistic role models, educators, professionals, mentors etc. can all educate society on the strengths of autism. By using their voice, they can highlight their accomplishments and personal strengths with a view to changing society's perception of autism and raise awareness of the strengths and abilities of autistic people of marginalised genders. Change is a slow process, but each small step is a step towards a positive representation of autism and autistic people. Through advocacy and change, autistic people can change the narrative of how non-autistic people view autism. Continuing their campaign for autism acceptance, social change, inclusion, and legislative improvements will be crucial for the future of autism in Ireland and globally. It is imperative that non-autistic people listen to autistic people, their visibility and influence can help to shape a more inclusive society that celebrates autism, a key theme which developed from this research.

Findings suggest that autistic people of marginalised genders can achieve academic and career success thanks to their diverse range of strengths. The findings highlight that autistic people may face challenges in certain areas, however, the potential for personal development and professional success within the right environment is crucial in developing strengths. However, this may not be true for all of society, autistic or otherwise. Not everyone





will have the competence or capacity to achieve academic and career success.

### ***Equality, Diversity & Inclusion***

We need to create inclusive environments that enables autistic people to use and embrace their strengths and to allow them to contribute successfully to society. In turn, society needs to develop a deeper understanding of the strength's autism presents and provide equal opportunities where autistic people can develop and grow.

To promote understanding, acceptance, and social inclusion for autistic people, schools should create inclusive and encouraging learning environments. For future generations, it is crucial the Department of Education & Skills and stakeholders engage with the autistic community to train education professionals on the strengths of autism. Additionally, it is critical that schools engage directly with the autistic community in designing professional development programmes and that such programmes are made mandatory for all staff to broaden their understanding of autism to address misconceptions society has presented.

It is critical that autistic people are afforded the same opportunities for professional advancement, academic success, and career progression as those available to the non-autistic population. To embrace inclusion and create a steady talent pipeline, organisations should ensure autistic people are involved in decision-making, giving them a platform to inform organisations diversity and inclusion strategies, training programmes and policy frameworks.

The key to career success is the identification and recognition of key strengths and the opportunity to develop such strengths. In addition, developing strengths may lead to careers that are aligned with special interests. While it must be acknowledged that career success for some autistic people may present a

challenge, findings imply that autism is not a restriction to career development and career success and that autism can present unique strengths that could advance careers and contribute to the future world of work.

This study demonstrates the value of listening to the autistic voice when it comes to career success, yet a staggering amount of autistic people are unemployed, approx. 80-85% of the autistic population (AsIAm, 2022); this clearly shows that the autistic voice is incredibly important to ensure future employability of autistic people, to promote inclusive hiring practices and to ensure that autistic people's perspectives and requirements are valued and incorporated into the design of supportive work environments.

### ***The Concept of Allyship in Autism***

Allyship is defined as *"a lifelong process of building and nurturing supportive relationships with underrepresented, marginalised or discriminated individuals or groups with the aim of advancing inclusion"* (Poornima, 2022). Poornima adds to achieve allyship, one must comprehend intersectional identities, conduct honest self-assessment acknowledging personal biases, consider privileges, embrace empathetic engagement and authentic conversations, build vulnerable interactions, and courageous responsibilities using influence to amplify the voices of those often overlooked.

Allyship signifies the importance of listening to the autistic voice, actively supporting, and advocating for autistic people. Allyship may imply a better understanding of autistic people's perspective, embracing their lived experiences, respecting their views and their way of life. Society at large could benefit from allyship in autism, be it in the community, schools, further and higher education or in the workforce. This could be achieved by engaging with autistic-led organisations, autistic



activists, autism friendly organisations, and autistic role models. We must begin to take steps to promote a world that celebrates autism and values the strengths and uniqueness that autism presents.

### Conclusion

The autistic voice and the lived experiences of autistic people of marginalised genders has been central to this research and the results have proved invaluable in the promotion of strengths. The research question, exploring the personal strengths of autistic people of marginalised genders, has been answered. While further research is required in some areas, overall, the positive-affirming findings will be instrumental across a variety of settings. The findings suggest the importance of the home environment in promoting strengths and the importance of 'the tribe' in the context of support networks. Autistic people should not be defined by a medical model or deficit model but instead defined by their unique strengths, lived experiences, and the incredible contribution their strengths play in our schools, our organisations, our communities and overall, in promoting a positive representation of autism.

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## Áine Trearty

Age: 12 years

Áine described how she made the drawing: 'My art was made by using my imagination and autistic joy. I used white art paper and my colours.'

Áine noted 'This picture is me, my self-portrait. I feel joy and happiness when the sun is shining, and I can feel it's warmth on my face. I like cool drinks and yummy ice-cream by the seaside. Away from all the noise and chaos of life.'





# Nurturing neurodivergence in schools. The crucial role of teachers in supporting autistic learners with neuro- affirming and trauma-informed practices and approaches.

## Sharon Grady

Sharon Grady is a support teacher in a primary school, focused on special education and inclusion. She currently oversees three autism classes and advocates for diverse learners. Sharon's primary focus is on championing the needs of every pupil, ensuring their needs are met, providing them with the support necessary to succeed, and ensuring equitable opportunities for them to thrive. Sharon holds a master's degree in education and is pursuing a Post Graduate Diploma in Inclusive and Special Education. She will begin her PhD studies at University College Cork (UCC) in September 2024.

In education, the experiences of autistic learners within mainstream schools unfold as a distinctive journey. This journey not only highlights the challenges they face but also provides valuable insights into the inherent opportunities and complexities of inclusive practices. The journey is significantly shaped by the educators who play a pivotal role in fostering an inclusive and supportive learning environment. It goes beyond textbooks and curriculum; it's about the students being seen, accepted, understood, and accommodated (Losh, Eisenhower and Blacher, 2022). So, what makes the difference for autistic students in schools? The answer lies in the genuine efforts of teachers who embrace neurodivergence and integrate neuro-affirming, trauma-informed practices to create an inclusive space.

At the heart of this difference is the acknowledgment that each student is an individual with distinct needs, strengths, and

challenges. Research consistently highlights the transformative impact of teachers who recognise and celebrate neurodivergence. A study by Mitchell et al. (2015) emphasises the significance of a supportive teacher-student relationship in enhancing the academic and social well-being of autistic students. This relationship fosters a sense of belonging and security crucial for their overall development.

The journey begins with being seen. Autistic students often grapple with feeling invisible or misunderstood. A teacher who takes the time to truly see their students, acknowledging their unique qualities and potential, lays the foundation for a positive learning experience. This sentiment is echoed by Molloy and Vasil (2014), who stress the importance of acknowledging and respecting the individuality of autistic students within the school community.





Acceptance follows closely. Autistic students thrive when they feel accepted for who they are, without pressure to conform to neurotypical standards. A study by Humphrey and Lewis (2008) underscores the role of acceptance in shaping positive outcomes for autistic students in educational settings. Teachers who create an inclusive atmosphere help build a sense of acceptance, empowering students to embrace their identities.

Understanding is the bridge that connects teachers with their autistic students. Educators who invest time in understanding the unique needs and communication styles of autistic individuals can tailor their teaching methods accordingly. Current research recommends teacher training programs that focus on autism awareness and effective strategies for accommodating diverse learning styles. Autism Research Institute (ARI) (n.d.).

Accommodation is not a mere courtesy; it is an essential component of supporting the education of neurodivergent students. Teachers who provide reasonable accommodations, such as sensory-friendly classrooms or personalised learning plans, create an environment conducive to the academic success of autistic students. Research by Zablotzky et al. (2012) emphasises the positive impact of individualised accommodations on the educational experiences of autistic students.

Neuro-affirming practices take this a step further. These practices involve recognising and validating neurodivergent experiences and identities, promoting a positive self-image among autistic students. By incorporating neuro-affirming language and activities into the curriculum, teachers can foster a sense of pride and self-worth among their neurodivergent students (Leadbitter, Buckle, & Ellis, 2021).

Moreover, trauma-informed practices play a crucial role in supporting autistic students. Many autistic individuals may experience heightened sensitivities, and a trauma-

informed approach considers these sensitivities to create a safe and nurturing environment. Understanding and addressing potential triggers, incorporating calming strategies, and promoting emotional regulation contribute to a trauma-informed supportive approach (Thomas, Crosby, & Vanderhaar, 2019).

Having one's voice heard is a powerful aspect of fostering inclusivity. Teachers who actively seek input from their autistic students create a sense of agency and empowerment. A study by Ashburner et al. (2014) highlights the positive correlation between self-advocacy and well-being in autistic students. Encouraging self-expression and incorporating student perspectives into the learning process contribute to a more enriching educational journey.

So, what makes some teachers go the extra mile for their autistic students? It boils down to a genuine commitment to inclusivity, a willingness to learn, and an openness to understanding and accommodating neurodivergence through neuro-affirming and trauma-informed practices. As educators embrace these principles, they become not just teachers but allies in the journey of autistic students toward realising their full potential.

At the core of creating a truly inclusive educational environment is a teacher's genuine desire to know the autistic student, recognising and valuing their worth as an individual. Before imparting academic knowledge, the emphasis is on forming a deep connection and understanding the authentic self of each student. This approach goes beyond the classroom, seeking to build meaningful relationships that prioritise the well-being and emotional growth of the autistic learner. Research by Kluth and Chandler-Olcott (2008) highlights the transformative impact of educators who prioritise building connections with neurodivergent students. By fostering a sense of connection and acceptance, teachers not only lay the groundwork for effective



learning but also create an environment where the authentic voice of the autistic student can be heard and valued.

In conclusion, the success of autistic students in schools is intricately linked to the attitudes and actions of their teachers. By being seen, accepted, understood, and accommodated with neuro-affirming and trauma-informed practices, autistic students can thrive in mainstream educational settings. It is the responsibility of educators to foster an inclusive environment that celebrates neurodiversity, ensuring that every student's voice is not just heard but valued. Ultimately, it is the genuine connections forged in the classroom that become the cornerstone of empowering autistic students to reach their full potential.

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## Andrew Ryan

Age: 11 years

Drawn using pen and crayons.

Andrew loves going places to see animals of all kinds and it makes him very happy. Andrew would draw about them all day.

# Parental Experiences of Autism Diagnostic Services in Ireland

**Anna O'Brien, Lorraine O.B. Madden & David Mothersill**

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## **Abstract**

Limited research on parents' experiences in Ireland with autism diagnostic services prompted this study, examining five factors (information, parental stress, professional manner, post-diagnostic support, and time/child's age at diagnosis) and their impact on overall satisfaction. With 211 participants, non-probability convenience sampling, and hierarchical multiple regression, the study explored differences in satisfaction levels between private and public providers. Key findings highlight that higher parental ratings for information quality, professional manner, and post-diagnosis support, alongside low parental stress, correlate with higher overall satisfaction with autism diagnostic service experience. This research informs service delivery, potentially enhancing parents' experiences and satisfaction and service improvement.

## **Background and Literature Review**

This current study explores parental experiences of autism diagnostic services in Ireland. A dearth in available research on this topic in Ireland necessitates investigation due to the rising need to support the autistic community (House of the Oireachtas, 2023). A review of the available literature was conducted to examine factors influencing parental experiences during the diagnostic process.

### ***Parental Stress:***

Higher autism diagnosis rates (American Psychiatric Association, 2013; Roddy & O'Neill, 2020; World Health Organization, 2019), and delayed processes contribute to prolonged waiting lists (Department of Health, 2018), affecting overall satisfaction (Crane *et al.*, 2016; Rogers, 2016). Parents may at times experience periods of higher stress levels (Keenan *et al.*, 2010), which is heightened by societal stigma (Farrugia, 2009), consequently impacting self-esteem (Recio *et al.*, 2020). This can negatively impact a parent's ability to



nurture an autistic child's social development in a meaningful way (Templeman, 2019). In particular, it can impact parent's emotional availability to respond in a compassionate manner to children's distress (Bekhet et al., 2012). As a result, evaluating stress-inducing factors related to the diagnostic experience, including professional manner and information provision, is crucial for enhancing service provision (Crane et al., 2016; Moh & Magiati, 2016; Rogers, 2016).

**Professional Manner:**

Effective communication and collaboration between parents and health professionals plays a vital role (Straus et al., 2019). Difficulty navigating autism services can leave parents feeling isolated (Legg & Tickle, 2019), which highlights the importance of the development of a positive parent – professional relationship. Research indicates that a satisfactory partnership positively correlates with higher prosocial behaviours, and fewer behavioural problems in children, emphasising the responsibility of the clinician to foster a positive parent-professional working relationship (Templeman, 2019; Casagrande & Ingersoll, 2017; Coussens et al., 2020).

**Information Provided:**

Ensuring parents receive sufficient and quality information during the diagnostic process also positively influences overall satisfaction (Mansell & Morris, 2004). Challenges have been reported in accessing knowledgeable professionals in Ireland and the US, whereby parents have struggled to find appropriate support (Finnegan et al., 2014; Silva & Schalock, 2012). Providing appropriate information may ease parental stress and enhance understanding of autism and the diagnostic process (Crane et al., 2016; Silva & Schalock, 2012).

**Post-diagnostic Support:**

Support for parents, post-diagnosis, is crucial as they often struggle to find, manage, and balance autism services (Ludlow, 2012; Nealy et al., 2012). Families can also struggle to determine which services and supports they require, and how to access them after their diagnosis (McLennan et al., 2003). Raising awareness and informing parents about available post-diagnostic support is essential for mitigating stress and improving satisfaction with the diagnostic process (Crane et al., 2018; Zablotzky et al., 2010). Therefore, it is essential that post-diagnostic healthcare supports are available to parents (Crane et al., 2018). This can help mitigate the negative effects that stress can have on the health of parents (Zablotzky et al., 2010) and greatly impact their satisfaction with diagnostic processes (Doherty et al., 2000), as well as improving prosocial behaviour in autistic children (Templeman, 2019).

**Experiences of Parents:**

Assessing parents' experiences is critical for service improvement (Raina, 2005). Ensuring parent have had an opportunity to provide feedback regarding their experience may reduce stress, anxiety, and improve overall life satisfaction (Ryan & O'Connor, 2017; Resch, 2010) as well as improving the families' overall experience (Resch, 2010). Limited research exists on the lived experiences of Irish parents navigating autism diagnoses, highlighting potentially unmet needs (Bromley et al., 2004; Chiri & Warfield, 2012; Lindly et al., 2019). Examining parental satisfaction is vital for reducing stress and optimising positive development for autistic children (Plant & Sanders, 2007; Siklos & Kerns, 2007).

**Private vs Public Healthcare:**

Service user experiences can differ between public and private healthcare, with private healthcare often receiving higher satisfaction





ratings (Owusu-Frimpong *et al.*, 2010). Public healthcare users may find it harder to access services (Miller *et al.*, 2014). This study addresses a literature gap in comparing parental experiences between private and public healthcare services within autism diagnostic services in Ireland.

#### **Previous Research:**

This study builds on Crane *et al.*'s (2016) survey on UK parents' autism diagnostic experiences, utilising a validated questionnaire. Crane *et al.*'s methodology, focusing on parental experiences during and after diagnosis, serves as a model for best practice. Adapting their approach to the Irish context provides a strong foundation for the current study (Crane *et al.*, 2016; Brogan and Knussen, 2003; Siklos and Kerns, 2007).

#### **Aims of the Current Study:**

Adapting Crane *et al.*'s (2016) questionnaire and analyses, this study explores autism diagnostic experiences in the Irish context. An additional analysis compares private and public healthcare providers. Limited research highlights the emotional nature of diagnostic processes in Ireland, with parents often experiencing high stress levels and susceptibility to psychological difficulties (Doherty *et al.*, 2000). Research suggests that efforts to identify and alleviate stress during the diagnostic process would enhance service satisfaction and parental optimism for their child's future (Myers, 2009). Providing support services and education improves diagnostic process satisfaction (Renty & Roeyers, 2006).

#### **Community Involvement Statement**

This research showed a commitment to valuing community involvement as an integral component of autism research and wants to credit the contributions made by parents of autistic children as integral components of the autism community. Lived experience is

instrumental in shedding light on key factors influencing overall satisfaction levels with the autism diagnostic process. Parental collaboration and willingness to share their experiences were central to the study's success and relevance. By presenting their insights, the research aims to contribute to improving diagnostic services and enhance the overall experience for parents and children within the autistic community.

#### **Hypotheses Based on Previous Research:**

Building upon findings from research conducted by Owusu-Frimpong *et al.* (2010) and Miller *et al.* (2014), it is hypothesised that the following factors lower levels of parental stress, and correlate with higher ratings of overall parental satisfaction:

- 1) A shorter time frame between first seeking help and receiving a diagnosis, as well as age at diagnosis.
- 2) Appropriate information received at the time of diagnosis.
- 3) High ratings for professional conduct in delivering the diagnosis.
- 4) The presence of post-diagnostic support.

In line with previous research, it is further hypothesised that a difference may emerge between parental experience in private versus public service in Ireland.

#### **Methods**

##### **Participants**

This study, conducted by the National College of Ireland in collaboration with EPT Clinic employed non-probability convenience sampling through various recruitment methods. Participants were recruited from a database of parents who had previously accessed autism diagnostic services, either publicly or privately, and who had provided





written consent to EPT Clinic and psychology students on placement with the clinic to be contacted for research purposes. In addition, social media platforms were used to recruit participants, with recruitments posts published by the Autism Special Interest Group of the Psychological Society of Ireland (PSI) and by EPT Clinic. The diverse recruitment platforms provided an opportunity for a diverse range of participants to participate. Participants had to meet a set of inclusion criteria. A total of 225 responses were gathered, with 14 excluded due to questionnaire non-compliance.

### **Outcome Measures**

This study utilised a questionnaire adapted from Crane *et al.*'s 2016 UK research, tailored for the Irish context. The questionnaire ensured a highly reliable measurement (Cronbach's alpha of .74) for satisfaction and stress rating questions. Demographic data on parents and children, diagnostic processes, referrals, disclosure, and post-diagnosis support were collected. Parents rated satisfaction and stress levels on Likert scales.

### **Study Design and Data Analysis**

The current study adopted a cross-sectional quantitative approach to assess satisfaction scores by analysing the collected data through inferential statistics. A previously established and validated questionnaire was used (Crane *et al.*, 2016). The *dependent variable* for the hypotheses was parental satisfaction with the diagnostic process, while the *predictor variables* were as follows:

- 1) Time period between first seeking help and receiving a diagnosis, and child's age at diagnosis.
- 2) Ratings of appropriateness of information received at diagnosis.
- 3) Ratings of the manner of the professional delivering diagnosis.
- 4) Ratings of post-diagnostic support.

5) Level of parental stress.

6) Public versus private service providers.

Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. Hierarchical multiple regression was used to analyse the quantitative data.

## **Results**

### **Demographics**

The current study consisted of a research sample of 211 participants with a mean age of 41 years. All participants being female with the exception of one male. Participants' children showed a higher number of males (73%) than females (25.1%). The mean age of participants' children at the time the questionnaire was 10.04 years, with a range of 2.17 to 25 years (SD= 5 years). The diagnosis of the participants' children had been completed a mean of 4.17 years previous to the study being conducted, with a standard deviation of 3.8 years and a range of 0 to 20.7 years (SD= 3.82). The mean age of children at diagnosis was 5.86 years (SD= 3.49), ranging from 1.17 to 17 years.

From the time of their first appointment with a professional about their concerns, it took parents a mean of 2.9 years to obtain a diagnosis, with a range from 0 to 17 years, and a standard deviation of 2.6 years. It took female children longer to get diagnosed (M=3.4 years, SD= 2.9) compared to males (M=2.7 years, SD= 2.22). Parents first noted their concerns around the average age of 3.02 years, this ranged from 8 months to 19 years (SD= 3.04). Parents sought their first appointment with a professional for these concerns at an average child age of 3.39 years. This ranged from 2 to 14 years (SD= 2.51).

### **Support Services**

53.1% of parents reported that they were *not offered* any follow-up appointment with their diagnosing professional. After the diagnosis of

their child, 21.8% reported that they received direct help or support. 37% stated that they were only signposted towards help, and 37.9% stated that they were offered no help or support from at all from their diagnosing professional.

### ***Predictors of Satisfaction with Diagnostic Process***

A hierarchical multiple regression was performed to investigate the six predictor variables for satisfaction with the overall diagnostic process. Additionally, the correlations amongst the predictor variables were examined and these are presented in Table 1. Correlations ranged between  $r = -.185$  to  $.650$ .



Table 1

*Correlations between variables included in the model.*

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.
1. Satisfaction/whole diagnostic process	-													
2. Child gender	.048	-												
3. Child age at present	-.185**	.149*	-											
4. Parent Support group	.004	-.066	-.046	-										
5. Parent age Location	-.109	.168**	.640***	-.051	-									
6. Munster	.027	.018	.102	.046	-.049	-								
7. Ulster	.072	-.094	-.077	-.113**	-.098	-.171**	-							
8. Connaught	.005	-.011	-.050	.015	.073	-.248***	-.080	-						
9. Quality of information	.513***	-.083	-.154	-.032	-.044	-.038	.089	.055	-					
10. Professional manner	.510***	-.012	-.078	-.012	.001	-.070	.043	.052	.632***	-				
11. Support post-diagnosis	.339***	-.007	-.087	.011	.042	.026	-.033	.016	.271***	.308***	-			
12. Levels of stress	.390***	.004	-.077	.013	-.093	.119*	-	.025	.151	.202**	.217**	-		
13. Diagnosis time period	-.103	.170**	.380***	-.016	.227***	.005	.112*	.032	-.079	-.003	.022	-.011	-.042	-
14. Child age at diag	-.074	.293***	.650***	-.051	.401***	.091	-.035	-.018	.010	.062	-.006	.010	.655***	-
15. Public vs private	-.169*	.167*	.306***	-.009	.321***	-.082	.052	.097	-.129	-.049	-.097	-	.263***	.133*
														.154**

Note: Note: \*p < .05; \*\*p < .01; \*\*\*p < .001



The first step of the regression (child gender, parental education level, child age at the time of the questionnaire, if parents attended a support group, parents' age, and location), was not statistically significant  $F(7, 169) = 1.220$ ;  $p = .295$  and explained 4.8% of the variance in satisfaction levels with the diagnostic process (see Table 2).

Step two of the regression included an evaluation of the time frame between first seeking help and receiving a diagnosis, ratings of information received at diagnosis, ratings of the manner of the professional delivering diagnosis, and ratings of post-diagnostic support, levels of stress, and public vs private. The total variance explained by the model was 45% ( $F(7, 162) = 9.543$ ;  $p < .001$ ). This

explained an additional 40.4% variance in satisfaction levels with the diagnostic process, after controlling for parent and child demographics; the change was statistically significant ( $R^2$  Change = .404;  $F(7, 162) = 9.543$ ;  $p < .001$ ).

In the final model, five predictor variables uniquely predicted satisfaction levels with the diagnostic process to a statistically significant degree, all of which were positive predictors. Quality of the information received ( $\beta = .28$ ,  $p < .001$ ) and levels of stress ( $\beta = .26$ ,  $p < .001$ ) were the strongest predictors (see Table 2), followed by ratings of professional manner ( $\beta = .24$ ,  $p = .002$ ), and ratings of post-diagnostic support ( $\beta = .13$ ,  $p = .04$ ), and finally, child gender ( $\beta = .13$ ,  $p = .04$ ).



Table 2

Hierarchical multiple regression for analysis of hypothesised predictor variables for satisfaction levels of the overall diagnostic process.

Variable	<i>R</i>	<i>R</i> <sup>2</sup>	<i>R</i> <sup>2</sup> Change	<i>B</i>	<i>SE</i>	<i>β</i>	<i>T</i>
<b>Step 1</b>	<b>.219</b>	<b>.048</b>					
Child gender				.24	.22	.08	1.08
Age at present				-.06	.03	-.21*	-2.11
Parent Support group				.02	.25	.01	.09
Age				.004	.02	.02	.21
Location							
Munster				.19	.24	.07	.82
Ulster				.49	.49	.08	1.02
Connaught				.08	.36	.02	.21
<b>Step Two</b>	<b>.672</b>	<b>.452</b>	<b>.404</b>				
Child gender				.37	.18	.13*	2.06
Child age at present				-.001	.03	-.003	-.03
Parent Support group				.07	.19	.02	.37
Parent Age				-.004	.02	-.02	-.29
Location							
Munster				.09	.19	.03	.49
Ulster				.55	.39	.09	1.43
Connaught				-.06	.28	-.01	-.22
Quality of information				.32	.09	.28***	3.66
Professional manner				.25	.08	.24**	3.12
Support post-diag				.15	.07	.13*	2.03
Stress				.49	.12	.26***	4.26
Time period for diag				-.02	.04	-.05	-.55
Age-diag				-.03	.04	-.08	-.80

Note: Statistical significance: \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$



## Discussion

### **Key Findings**

This research study provides important information for healthcare services in Ireland and internationally. The study evaluated parents' experiences of the autism diagnostic process in Ireland, across both private and public service providers. The aim of the research was to build upon existing research, such as that carried out by Crane *et al.* (2016), Silva & Schalock (2012) and Mansell & Morris (2004) to identify what is important for parents in order to optimise their experience with professionals who provide diagnostic services for children and young people. The key findings reveal that the *quality of the information received* by parents during the diagnostic process, alongside parental perception of *professional manner* and *post-diagnostic support* were indicators associated with how the parent experienced diagnostic services, correlating to higher ratings for overall satisfaction with service provision. In addition, the degree to which a parent experienced *stress* was also predictive to how they rated their experience of diagnostic services, with higher levels of stress associated with lower levels of satisfaction. These findings are now discussed in more detail, comparing current results with previous research in this area.

In terms of the quality of information received during the diagnosis, the findings for this variable align with previous findings from Crane *et al.*'s (2016) study, as well as with older studies (Mansell & Morris, 2004; Silva & Schalock, 2012). This highlights that receiving appropriate and quality information is an area of great importance for parents (Mitchell & Sloper, 2002). This has direct implications for healthcare professionals, providing simple guidance on how to improve service provision – by providing good quality and appropriate information to families during the diagnostic process.

In terms of the manner of the professional, findings from this study align with those of Crane *et al.* (2016), wherein high positive ratings for professional manner was a predictive relationship for parental satisfaction of the diagnostic process. This is similar to previous research which has highlighted the importance of the parent-professional relationship as an important factor required in order for parents to have a positive experience while engaged with autism diagnostic services (Casagrande & Ingersoll, 2017; Coussens, *et al.*, 2020; Straus *et al.*, 2019). Similarly, post diagnostic support has consistently been found to present as a significant factor in predicting higher levels of satisfaction with the diagnostic process. Findings in this study align with those from previous studies (Crane *et al.*, 2016; Doherty, Fitzgerald, & Matthews, 2000).

In terms of parental stress, the current study replicates the relationship produced by Crane *et al.* (2016) between parental stress and satisfaction, whereby stress is a prominent factor associated with parental satisfaction when going through the diagnostic process for autism (Keenan *et al.*, 2010; Moh & Magiati, 2016).

The current study found that the age of the child at the time of diagnosis and the time period taken to receive a diagnosis did not significantly predict satisfaction levels for the overall diagnostic process. This is in contrast with Crane *et al.*'s findings (2016). However, when comparing this study's results to those of Crane *et al.*, it must be noted that the current study found the wait time to receive a diagnosis was lower (2.6 years) than that of Crane *et al.* (3.5 years), highlighting shorter wait times in Ireland for autism diagnoses compared to the UK. This could be a contributing factor to the difference in results between the two studies. Lengthy wait times





can negatively impact parental experiences of the diagnostic process (Chiri & Warfield, 2012).

Contrary to the findings of Owusu-Frimpong *et al.* (2010), which found higher levels of parental satisfaction and lower levels of parental stress with private services, this study did not find a significant difference between the type of service provider used (public or private). This may indicate that Irish services are non-discriminatory towards parents who seek their services privately or through public providers.

The time period parents waited for a diagnosis, along with their child's age at the time of diagnosis did not have a significant effect on satisfaction levels with the diagnostic process. Furthermore, whether parents obtained their services through private and public service providers did not predict levels of satisfaction for the diagnostic process in this research study.

A child's gender had a significant effect on satisfaction levels. Parents of male children reported higher levels of satisfaction than female children. This relationship aligns the emerging theories in literature around gender differences in autism diagnostic services, identifying that parents of female children have less satisfaction with services (Zamora *et al.*, 2014). This could be the result of gender differences in core characteristics of autism (Rivet & Matson, 2011), and the delayed formal identification of females with autism (Begeer *et al.*, 2013).

### **Strengths and Limitations**

This study relied on a self-selecting sample of survey participants, making it unclear if the sample accurately represent non-respondents. While building on Crane *et al.*'s (2016) research, some discrepancies could be attributed to jurisdictional or sample size

differences—Crane *et al.* had 1,000 participants compared to this study's 211 participants. The majority of participants were from Leinster, limiting generalisability. Regional service equality cannot be determined, as participants may have sought services elsewhere. Notably, the study has an under-representation of private service users. Additionally, the majority of participants were female (mothers), and it is unknown if they had multiple children with autism, potentially affecting satisfaction levels. Future studies should address these limitations, incorporating questions to explore these factors. Crane *et al.*'s use of categorical variables posed challenges for inferential statistics in this study; future research may benefit from gathering continuous data. Despite limitations, this study obtained a diverse participant sample, using reliable measures and covering a broad range of children's ages and diagnostic timelines. Further research, with a broader sample size and addressing limitations, could enhance understanding and reliability.

### **Implications for Practice**

This research yields reliable results, offering valuable insights into parental experiences, with wide applicability in the field of autism. Professionals can use these findings to enhance awareness of factors impacting parents, ultimately improving family outcomes. Targeting specific areas of the diagnostic process, professionals can implement cost-effective strategies to address parents' concerns and provide ample information, positively influencing their satisfaction. Clinicians would benefit from future research into parental stress during autism diagnoses, aiming to reduce stress levels for improved satisfaction. The findings indicate that psychologists can enhance parents' experiences by guiding them toward post-diagnostic supports following diagnostic assessment. This finding has an important



implication for clinical practice, emphasising the importance of developing support programs for parents, addressing a key factor in determining overall parental satisfaction during diagnostics. Multi-disciplinary teams in healthcare clinics, incorporating various professionals, offer valuable resources for both clinicians and parents, positively impacting children's outcomes in the autism journey (Strunk *et al.*, 2017).

### Conclusion

This study amplifies parents' perspectives on the autism diagnostic process in Ireland, revealing crucial aspects influencing overall

satisfaction. Results indicate that when parents perceive that they receive high quality information during the process, whereby clinicians behave in a professional manner, and offer post-diagnosis support they perceive a more positive service experience. In terms of factors to mitigate for, high levels of parental stress correlates with diminished satisfaction. A child's gender emerged as a significant predictor in terms of parental satisfaction, with parents of boys reporting higher levels of parental satisfaction than parents of girls. Again, this has implications for clinicians and requires further investigation.

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## Rebecca McFadden

Age: 16+

Photograph titled 'Joy in Progress'

Eliabeth Tulsie McFadden took this photograph of her daughter Rebecca enjoying equine therapy at Caring Capall in Falcarragh. This photograph depicts the connection that Rebecca has with both the horse (Midnight) and the therapeutic riding coach (Katie Coyle) displaying both interest and immense joy. Even though Rebecca did not take this photo it would not be here without the triangle of connection and bond between her, Katie and Midnight.





# Resilience and Wellbeing of Autistic Pupils in a Mainstream Post-Primary Setting

## Julie McCullough

Julie McCullough has taught in post-primary education for thirty years. She has an autistic daughter who is her inspiration on her journey of understanding and advocating for autistic young people. She has developed and led the autism support in Parkhall Integrated College in Antrim over the past eight years. In 2022 she completed a Master of Education at Stranmillis College, focusing her dissertation on the resilience and wellbeing of autistic pupils in the mainstream post-primary environment.

## Abstract

There has been a significant growth in the number of autistic pupils attending mainstream post-primary schools in Northern Ireland. The challenges facing autistic pupils within this environment are well documented with high rates of school absenteeism and mental health issues. Within the current article, I discuss my reflections based on my experience as an autism support teacher, primarily focusing on the view that an autism-friendly environment must be rich in both supporting social and emotional learning as well as supporting the overall approach to raising awareness and engagement from a pastoral, home, and whole-school perspective.

## Social and Emotional Learning

Social and Emotional Learning includes recognising, understanding, and managing emotions in a positive way. Developing emotional intelligence is a key factor that promotes resilience (McCarthy et al. 2020) and is essential to support autistic pupils to thrive in school. This can be achieved by supporting pupils in small groups outside of the busy classroom to explore strategies and emotional regulation skills in a safe environment (Konning et al. 2013; Mackay, Shocbet et al. 2017).

In addition, being in a group with other autistic pupils may decrease the sense of isolation many pupils feel in school. This connects to findings in Williams et al. (2019) where the need for schools to provide alternative social

settings, outside of the classroom in small groups, for autistic pupils was highlighted as beneficial. These small groups may provide a fun and engaging environment where pupils feel understood and therefore secure enough to express their views and build friendships (Gates et al., 2017).

Social and emotional learning can empower pupils, infusing them with greater confidence and can be a contributing factor in academic engagement and achievement. Consequently, this will make school more enjoyable and lower stress and anxiety levels. Strategies that support social and emotional learning should be introduced as early as possible before the cycle of anxiety, low self-esteem and isolation begins (Wood and Gadow 2010). Furthermore,



it fosters the development of a positive pastoral relationship between support teacher and pupil.

### **Pastoral Care Needs**

Due to differences in communication styles between non-autistic and autistic people (Crompton et al., 2020), the views of autistic young people are often not heard in the largely non-autistic school environment. By taking the time to listen and adapting how we interact, this hurdle can be overcome (Harrington et al., 2014). Acker et al. (2018) concluded that educational professionals supporting autistic pupils:

*'may benefit from 'digging deeper' to learn about the depth of their worries and upset; for example, it may not be enough to accept that a young person with autism is concerned about routine change, without finding out more about the possible relational and social anxieties hidden beneath the surface.'*

Acker et al. (2018, p17)

This benefit of having an individual who is willing to spend time and give the pupil a platform to air their views and feelings was reflected by one of the participants in Bolic Baric et al.(2018):

*'I think that it is important just knowing that there is somebody who cares. Just knowing that somebody cares, just a little bit by asking "why," "why did you not do your homework," or "why are you quiet during the lessons?" Just asking "why" makes you feel a little inspired, and then you may feel that you can get to grips with schoolwork.'*

Bolic Baric et al.(2016, p190)

High anxiety levels experienced by some autistic pupils can often lead to anger and physical aggression or self-harm (Ambler et al. 2015). This is often misunderstood by staff who focus on the behaviour rather than the reasons behind the behaviour. This is discussed in Koegel et al. (2012) and Sansosti & Sansosti

(2012) who suggest offering other ways to communicate distress or anxiety are effective strategies for improving relationships.

For these young people who often feel isolated and misunderstood, the ability to explore understanding themselves and others is indispensable. If this intensive pastoral care can be given early in the pupil's time at post-primary, it allows strong relationships to be built and creates the positive perception of school as 'a safe place'. This is described in Brownlow et al.(2021):

*'A core facilitator for enabling positive educational experiences was the establishment of positive relationships and respectful communication between teachers and students . Effective communication was considered a two-way process, with the need for teachers and others to suspend some of their previous assumptions concerning the capabilities of autistic people, and listen and respond to students as individuals according to the needs for support articulated by them'*

Brownlow et al. (2021, p6)

Having a key adult who takes time to understand and know the pupil can provide a context where the pupil can freely express themselves, ask questions and talk through difficulties. This key adult then could support the young person in the development of individualised strategies which can be disseminated to relevant staff. This may help the pupils to feel as though their needs are heard and understood and may in turn alleviate some anxiety and provide access to new areas of school life.

### **Whole School Engagement**

A school needs to examine the bigger picture of where they are now and what direction their autism provision should take. Pratt (2005) stated:

*'Principals who take ownership for all students and who consider any challenge*



*affecting an individual student as a challenge for the entire school team, are most effective in working on behalf of these (autistic) children.'*

Pratt (2005, p1)

Similarly, Morewood (2011) discussed a whole-school saturation model where autism understanding and awareness is always high on the agenda and a culture of individual worth and value is encouraged.

*'Helping the young person to know themselves better and understand what*

*autism means to them, gives them the tools to manage themselves in a much more productive way, making them feel valued as a person rather than a social outcast*

*or someone who doesn't fit in anywhere.'*

Morewood et al. (2011, p67)

Whilst mandatory training for staff is welcomed and valued (Osborne and Reid 2011; Lindsay et al. 2013), there may be a need for more focused support for teachers. As some teachers in Lindsay et al (2013) stated:

*'although training is available on understanding the basics of autism, it is not helpful for learning specific teaching methods to work with students.'*

Lindsay et al. (2013, p356)

Staff often value having a specialist teacher whom they can approach to gain advice on wellbeing or strategies that could be used in the classroom. This allows teachers to seek individualised advice. If this is combined with this same specialist delivering emotional learning groups and providing individual pastoral sessions a very clear picture of the pupil's particular needs can be obtained and communicated. The autism specialist can act as an advocate to help staff understand the pupil and interpreter to help the pupil understand others.

In Sansosti and Sansosti (2012) teachers indicated responsiveness to pupil needs was essential for effective inclusion and yet Rodriguez et al. (2012) highlighted teachers are likely to have a more positive attitude towards including autistic pupils if they are supported by specialists.

### **Home School Communication**

There is much value in regular contact with parents and this is more poignant in parents of autistic pupils. In McKinlay et al. (2021) parents described how they felt unheard and even made to feel like they were a problem by staff. These difficulties can be diffused by regular and effective communication.

Educators must build a strong relationship with parents and be willing to step back and listen. Prizant (quoted in Murray and Law 2016) comments on conflict with parents:

*'Parents do not want professionals to "sugar-coat" autism, nor do they want to hear only about the negatives. They want balanced, honest and accurate information, but presented with compassion and understanding. And they also want to be respected and heard.'*

Prizant (quoted in Murray and Law 2016, p53)

Additionally, in Hsiao et al. (2017) and Pfeiffer et al. (2017) the benefit of strong family-teacher relationships was highlighted as a factor in improving the quality of life for families. It is recommended educators develop open and effective communication, trust and shared decision making. Having a key individual on the school staff who serves as a point of contact throughout the pupil's whole time at school is important. Moreover, a specialist in autism is beneficial to discuss and share strategies with parents as a consistent, synergic approach. If the specialist teacher can build a relationship of trust with the parents where the needs of the child are to the forefront, then this should reduce conflict and foster strong collaboration.



## Summary

It remains the case that the post-primary mainstream school environment can be difficult for autistic pupils, and it is essential educators consider ways to develop resilience and wellbeing to support the young person to thrive in school. Schools should seek to develop a climate which supports social and emotional regulation learning and opportunities to develop friendships so autistic pupils can enjoy school, feel valued, safe and secure and grow in confidence.

Supportive practices for autistic pupils are often suggested or implemented when the pupil is already experiencing significant difficulties or distress in the school environment. The effectiveness of this 'quick fix' is questionable (Leadbitter et al. 2021).

Developing a school culture that aims to promote the social inclusion, wellbeing, and resilience of autistic pupils will require a sustained vision and commitment if it is to be effective. Guldberg et al. (2020) describes this whole school mindset:

*'Changing outcomes for vulnerable groups is unlikely to be achieved unless there are changes in the understanding, attitudes and actions of adults. Consequently, the starting point must be with staff members: in effect, increasing their capacity to imagine what might be achieved and enhancing their sense of accountability for bringing this about. It is the responsibility of leadership and management to embed such change within settings.'*

Guldberg et al. (2020, p45)

This can be unintentionally neglected in a busy school environment. Morewood (2011) talks of having 'an agent of change', a central figure that would co-ordinate a whole school response. Hence, it would seem prudent for post-primary schools to create the role of a specialised autism support teacher with a passion to enhance provision for autistic pupils.

This is often overlooked due to cost and allocation of resources. However, in a large school setting, the expertise of an autism specialist can be invaluable to a busy Special Needs and Pastoral Department, meeting needs and providing support that is currently not being met. This need for extra provision cannot be ignored.

Certainly, the model suggested here is time intensive and will require school management teams to commit to the vision of making post-primary mainstream a better, more nurturing environment for all young people. Nevertheless, great opportunities exist within the education system to have a positive, far-reaching effect on the mental health and self-perception of our ever-growing numbers of autistic pupils.

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# James Murphy

Age: 6 years.

Drawn using pencil and felt tip.

James gets joy from Lego, loves Science and robotics. James is always drawing almost every day. This artwork shows his joy for Lego and for science.



# Shaping Futures: Exploring the impact of Role Models in promoting Autistic Strengths

## Noelle Foley Coughlan

Noelle Foley Coughlan is an autism advocate, dedicated to positive, strengths-based autism research. With over 20 years of industry experience, Noelle has worked with some of Ireland's leading brands and is currently Chief Operating Officer with Career Decisions Ireland. She is passionate about lifelong learning and was one of the first four graduates across the island of Ireland to earn an MA in Autism Studies. Additionally, she holds a Master of Business (Research), a BBS (Hons) in Marketing, Diploma in High Performance Leadership, and numerous professional development qualifications.

### Introduction

*"Can you bring to mind a positive female role model? I bet you can, easily. Can you bring to mind a positive female autistic role model? I'll wait.....hmmm, not so easy huh?"*

Sam Warner (Warner, 2020)

This research endeavoured to discover, explore and understand the impact of role models in promoting the strengths of autistic individuals, encompassed in the context of gender. Autistic role models can provide representation and visibility for fellow autistic peers. Seeing people who share similar experiences and challenges can be profoundly encouraging, offering a counterbalance to the negative experiences often encountered by autistic people. Moreover, autistic role models hold the transformative potential to break stereotypes and challenge stigma surrounding autism. They can showcase that it is possible to achieve success, both professionally and personally, and being autistic is not a barrier to achievements.

### Methodology

The research aligned to a post-positivism paradigm; mixed methods included an anonymous and confidential online survey and biographical analysis. 30 autistic people of marginalised genders were surveyed, the criteria included having a diagnosis of Autism Spectrum Condition, over 18, identify as cisgender female, transgender, non-binary or intersex, the ability to give informed consent to participate in the research. As studies to date have largely focused on the experiences of autistic males, the sample excluded autistic cisgender males, autistic teenagers, autistic children and non-autistic people. In addition, 97 biographical accounts were recorded from books written by autistic people of marginalised genders.

### Literature Review

Gauntlett defines a role model as *"someone to look up to and base your character, values and aspirations on"* (Gauntlett, 2022, p. 211). Paice, et al., believe *"excellent role models will*



*always inspire, teach by example, and excite admiration and emulation” (2002, p. 707)*

Autistic adults tend to experience a sense of not being understood and recognised by others (Rodogno, et al., 2019). Most research to date has focused on a deficit model and the challenges of autism, leaving a huge gap in research. Nuwer (2021) believes this research may lead doctors, teachers and others to pathologize and overlook useful traits in autistic people.

*“What if positive representation of autistic people was more common? Would there be more autistic people in work right now? Would people have been so quick to write me off? Would I have had an easier time getting my first job?.....I will never know the answer to these questions because I didn’t have any autistic role models growing up. Autistic representation was not common in the 90s.”*

Zeinab Ali, Digital Marketing and Membership Administrator, Inclusive Employers  
(Ali, n.d.)

Autistic people report greater comfort socialising and easier communication with each other; a sense of being connected to other autistic people have been reported anecdotally according to Botha, et. al (2022, p. 2151). Botha & Gillespie-Lynch add that *‘autistic culture provides spaces for autistic people to grow, role models, social support, ways to stigmatized identity positively, and opportunities to develop and empowered collective identity’* (2022, p. 107). Warner (2020) refers to Greta Thunberg as being a positive role model for all young autistic people *‘who are constantly told to sit down, stop fidgeting (quiet hands), close their mouth, and do as they are told’*.

*“People are more likely to seek (and emulate) role models they can identify with, so for teens with ASD, just like any other group of people, a certain threshold of being able to identify with someone must be reached before they feel that they can achieve similar experiences and outcomes. Decades of research have established that the likelihood of learning increases if the role model is of the same sex, ethnicity, or skill level, therefore making it so important for teenage girls with ASD to have role models also with ASD.”*

Julie Robinson, Director of Behaviour and Learning at Dreams with Wings.  
(Fellingham, 2020).

Active research underway in Australia entitled *“Autistic Role Models: Positive Pedagogy for Youth on the Autism Spectrum”* aims to support autistic individuals to gain more self-confidence and become more hopeful adults who can lead a life that they find fulfilling (Rodogno, et al., 2019). Their research aims to suggest that exposure to the right role models will facilitate the positive identification of autistic individuals. A study carried out by Webster and Garvis (2016) suggests success may look different for autistic woman compared to non-autistic women; participants recalled how having people around them who believed in them contributed to the promotion of their success.

Autistic mentors are crucial to provide young autistic people with positive role models (Hotez, et al., 2018). Speaking with regards to higher education, Capozzi, et al., (2019) believes including autistic peer mentors in college transition programmes achieves much more than just giving autistic people a voice and an opportunity. Her research highlights the potential advantages of autistic role models and mentors. In a separate study, Hotez, et al.,



(2018) noted it has taken years for a culmination of autistic students to feel confident taking on leadership roles as mentors and researchers, therefore one has to ask is this due to the lack of visibility of autistic role models? Or perhaps people being afraid to disclose their diagnosis due to stigma following years of deficit-focused research?

*“The need to change the deficit narrative and redefine autistic strengths by autistic people themselves, to legitimise and normalise autistic ways of functioning and adjust the managerial provisions, criteria and practices accordingly. Coaching autistic leaders to be the public role models would also help.”*

(Djela, 2021, p. 86)

### **Are Role Models Inapplicable, or Is the Lack of Autistic Role Models the Issue?**

Intriguingly, of the 30 participants surveyed, 50% believed they did not have any role model, nor believed in role models or name any.

*“I didn't know I was autistic as a child so didn't have autistic role models.”*

*“I do not have role models. I have had people I like or enjoy specific aspirational aspects of e.g., they're always dressed well or they're queer and have a partner and a degree, but that is for short times and not as intense as role models seem, it's more just an 'oh that's nice' thing?”*

*“At 46 years old and having went through severe trauma, I am at a stage in my life where I am feeling isolated vulnerable and unsafe. I have been reflecting over my life and working through a variety of feelings and emotions, resentment, hurt, regret. I cannot think of any healthy role models I had.”*

Secondary data was also mixed, with some autistic people acknowledging the support of role models while more documented the lack of positive role models.

*“So much of what society told me about being gay, trans or having autism painted a terrible picture of my future..... I had nothing in the way of positive autistic, gay or trans role models in my life at the time....”*  
(Dale, 2019, p. 64)

### **Positive Role Models - Sense of Belonging and Shared Experiences**

Contrary, the remaining 50% of participants experienced the benefits of having role models, citing a sense of belonging and a sense of shared experiences.

*“They've also taught me to feel proud of my strengths and to not feel ashamed of them whether other people think my strengths are strange or not.”*

*“They made me realise that being Autistic isn't a bad thing, I just experience the world differently and that's okay.”*

*“They help me feel connected to the world when I feel like so much of my world is small.”*

Biographical analysis concurred, highlighting the sense of support.

*“I look for characters on TV and in movies who might be autistic. Not the typical, geeky males, but subtler female types. I think we all need to see ourselves represented.”* (James, 2017, p. 154)

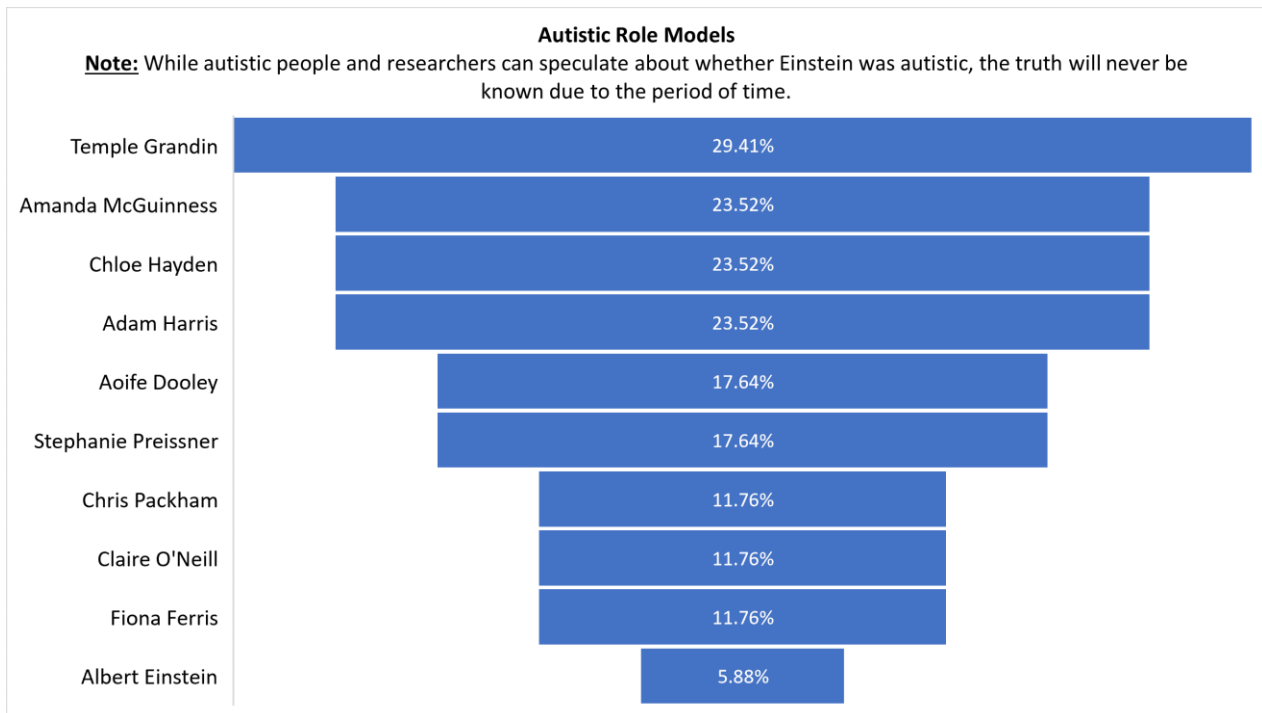
*“Children today have more role models to encourage them than ever before. From rock stars to actresses, YouTube stars to professional gamers, there are idols out*

*there that kids can look up to.” (Dale, 2019, p. 18)*

### **Autistic Role Models**

Participants were asked if they were aware of any autistic role models and the findings yielded some interesting results with 56.66% of people being able to name at least one

autistic role model and 29.4% naming up to 5 autistic role models. Not surprisingly Temple Grandin was named as the number one autistic role model. The full list of role models is outlined below, with the following named as the top ten:



Other autistic role models named included: *Anne Hegerty; Blessing Dada; Blind Boy; Creator of Pokemon; Damien Milton; Dara McNulty; Elle McNicoll; EM Rusciano; Greta Thunberg; Jessica K Doyle; Jude Morrow; Kate Foster; Kirsty Forbes; Laura Crowley; Luke Beardon; Lyric; Maisie Hill; Mary Doherty; Mia Duffy; Pete Wharmby; Sarah Hendrickx; Simon Harris; Sonny Wise; Steve Coogan*; all representing 5.88% (some of the mentioned role models may or may not be autistic. The researcher questioned whether Simon Harris may have been mistaken for his brother Adam Harris who is a prominent autism advocate).

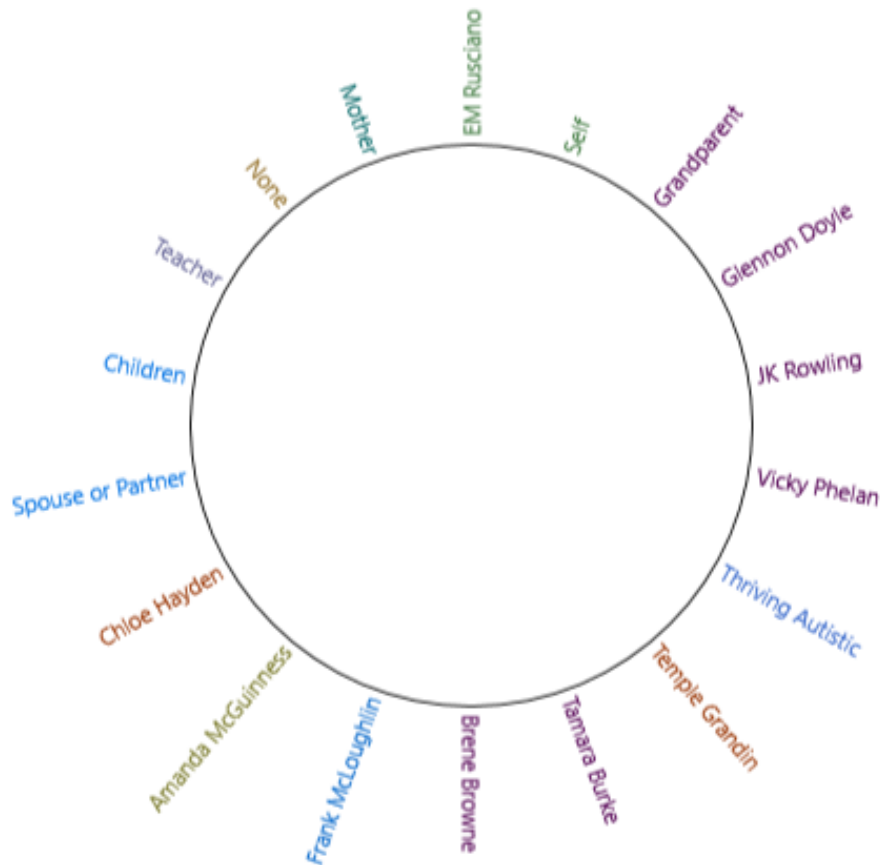
Through biographical analysis, some autistic people viewed themselves as positive role models.

*“I have been able to position myself as a safe and reliable person for the pupils within what can be a bewildering system for them in school. I have boosted their confidence while also supporting their learning. I also feel that as a mixed-race, autistic woman, I have been a role model for them. They can see that being a woman, being mixed-race and having a disability are not barriers to progression true life and achieving goals.” (Ponnudurai, 2022, p. 89)*



### **Greatest Role Model (Autistic or Non-Autistic)**

Participants were asked to name their greatest role model, autistic or non-autistic. 46.66% of participants were unable to name any role model, while 53.33% could. The following showcases the role models named, some autistic role models and some non-autistic:



### **Mothers – The Greatest Role Models in Promoting Strengths**

Among the 53.33% of participants who acknowledged they had role models, 31% named their mother as their greatest role model. The findings could suggest that mothers are the most popular role model in promoting strengths.

*“My mother always told me to play to my strengths. I sometimes thought negatively, and she constantly reminded me I was good enough and to embrace who I am.”*

*“My Mammór showed me the kindness and beauty in the world and helped shaped me as a person. I always wanted to emulate her and her compassion for people and animals around her. She also accepted me as me and allowed me to develop naturally without expectations. It gave me the opportunity to grow as I saw fit and trust myself. She cared for so many people and was so strong for so long. She was a leader in her time, and always had a calm, powerful yet caring demeanour about her. I always strived to be a good person because of her.”*



This finding was also evident from biographical analysis.

*“My mother has always been my greatest ally. She is always there for me, even when the world seems to be against me.”*  
(Rankowski, 2021, p. 12)

*“My mom knew I was different, which she believed I was different in the best of ways.”*  
(Devnet, 2020, p. 10)

Research findings by Foley-Coughlan (2023) show the home environment as the number one environment in promoting strengths, therefore, it is not surprising that mothers (31%) are viewed as significant role models by the autistic participants. The results suggest mothers provided unconditional love and solid support to participants. Clearly, mothers provided a nurturing and safe environment for participants that encouraged the development of their strengths. This was followed by participants spouses/children adding strength to the importance of family and the role of family in promoting strengths and celebrating autism. Possibly, family influence and family values may also be linked to the high degree of self-understanding and self-respect mentioned by participants.

Looking at resilience, cited as the number one personal strength of autistic people of marginalised genders (Foley Coughlan, 2023), one has to ask if mothers, and indeed the home environment, are contributors to the development of resilience due to the ability to support autistic children overcome the many challenges they are faced and the lack of understanding around autism. Research by Bayat (2007) show that a sizable number of families with autistic children display factors of resilience, reporting having become stronger as a result of their autistic children, acquiring spiritual strength; being more unified and

connected as a family and discovering a greater appreciation of life in general.

Furthermore, looking at independence which was named as the top secondary strength of autistic people of marginalised genders (Foley Coughlan, 2023), it would be fascinating to see if there was a connection between that independence and mothers; assuming mothers play a crucial role in teaching and promoting independence, from core life skills to more learnt skills such as coping strategies, problem-solving skills, and decision-making. It is important to note that not every participant answered this question, and while the findings are incredibly strong citing mothers as the primary role model of autistic people of marginalised genders, the concept of role models require further research.

Research on the family context of autism by Smith, et al., (2014) showed the importance of the relationship between parents and autistic adolescences or adults, their research showed the family environment as an important one for intervention *‘not only to reduce family distress but also to improve functioning for the autistic child, adolescent or adult’*. Their research sees this relationship as being an important contributor *‘shaping trajectories of behavioural functioning’*. Their research shows how *‘behaviour problems’* and *‘autism symptoms’* may improve if high levels of criticism are reduced or kept low while parental warmth is increased. Contrary, according to Ricles (2017) autistic children experience significantly more adverse childhood experiences than their peers, likely due to the stress that autistic parents and caregivers experience as parents.





### **Supports Gained Through Role Models**

Even though it is acknowledged that more research is warranted on the impact of role models and their influence in promoting strengths, many participants spoke of the support they received from having a positive role model.

*“Mine taught me the importance of being myself. Not conforming. They also taught me the importance of relationships. Role models are important. Especially when you're disadvantaged in some way, and they shine a light on the path to personal growth.”*

*“It [Role Models] creates an opportunity for shared experiences but also is important for young people to see themselves in others to see autistic people as part of the population that teaches self-esteem and creates self-value...”*

Research findings show the supports received from role models include

1. Acceptance of Self
2. Encouragement
3. Belief In Own Ability
4. Compassion
5. Inspiration
6. Advocacy
7. Leadership

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### **Promotion of Strengths through Role Models**

While some participants acknowledge the support of role models giving a shared sense of experience and sense of belonging, further research is warranted on the impact of role models versus the impact of emulating certain behaviours and traits. One must question if the findings relate to the lack of visibility of autistic role models. One also must question the meaning of role models. Further research is necessary on the assumption about the meaning of role models that may not apply to or be fully demonstrative of the actual experience of all autistic people. Some participants highlighted that autistic individuals can be quite literal therefore would not identify with any role model as they may not possess all their desired traits, adding that a non-autistic person may chose a role model due to one desired trait. Other participants noted they do not model themselves against any character or person nor have they ever understood this concept, however noted that positive behaviours, such as kindness, can be respected and emulated.

Autistic people, including autistic role models, educators, professionals, mentors etc. can all educate society on the strengths of autism. By using their voice, they can highlight their accomplishments and personal strengths with a view to changing society's perception of autism and raise awareness of the strengths and abilities of autistic people of marginalised genders.



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## Keelan Doherty

Age: 14 years

Drawn using felt tip.

Keelan reflected 'Art is my escapism and happy place. I draw from memory and from happy episodes of my favourite T.V. and YouTube videos. It makes me happy, keeps me focussed, calm and quiet and helps me to regulate. I can spend hours drawing when I am feeling "together". Everybody comments on my artwork and my fantastic abilities and memory for detail.'

# A Systematic Review on the Effectiveness of Group Cognitive Behavioural Therapy (G-CBT) on improving anxiety outcomes for school-aged autistic children in the community context.

## Madeline Dolan

Madeline Dolan is currently undertaking a Doctorate in Educational and Child Psychology, Educational Psychology at Mary Immaculate College, Ireland. After working as a teacher in mainstream schools, Madeline pursued further training through the Graduate Certificate and Graduate Diploma in Autism Studies provided in partnership by Middletown Centre for Autism and Mary Immaculate College. Madeline would like to acknowledge the support of Dr Lainey Keane and Dr Laura Ambrose from Mary Immaculate College, for their support and guidance throughout Madeline's studies and their contributions to creating this review.

## Abstract

Autistic children are more likely to experience high levels of anxiety symptoms which can have a significant impact on their development and daily functioning. Recent evidence suggests that Group CBT (G-CBT) may be effective in reducing anxiety levels. In order to increase accessibility and transferability, this review identifies studies that utilise Group CBT across a range of community contexts to ascertain its effectiveness. This review focuses on primary school aged children, incorporating studies with a mean age less than 12 years old. Findings from the review suggest that Group CBT can be successful. However, there are some caveats to the success of its delivery, including factors such as challenges with accessibility, modifications required for individual differences in the group, staffing required for implementation, and the context or setting in which it is delivered. Implications for the autistic community and for policy and practice are discussed.

## Introduction

### ***Autism and Anxiety***

Autism is a lifelong, neurodevelopmental condition associated with differences in social interaction, communication and repetitive patterns of behaviour (APA 2013). However, co-

occurring mental health conditions are experienced by as much as 70% of the autistic population (Lai et al 2019). Recent research developments have unveiled anxiety as the most common psychiatric condition among autistic children (Mutluer et al 2022; Salazar et



al 2015). In fact, meta-analysis shows co-occurring anxiety conditions are found in over 40% of autistic children (Van Steensel et al 2011). Autism and anxiety have a complex relationship whereby higher levels of anxiety appears to increase the risk of more social communication differences over time in autistic children. This underlines the importance of working to alleviate anxiety symptoms to improve both social and emotional functioning (Duvekot et al 2018). Furthermore, research indicates that anxiety poses a greater challenge than other co-occurring conditions, making it a key research priority (Adams et al 2019; Smith et al 2019).

Research confirms that the prevalence of anxiety disorders is higher in the autistic population than the general population (Ghandour et al 2019; Remes et al 2016). It is estimated that 9.4% of neurotypical children aged 3-17 years, had a diagnosis of anxiety between 2016-19 (CDC 2022), whereas it is reported that overall prevalence rates for anxiety in autistic children range between 42% and 79% (Kent & Siminoff 2018). Anxiety can negatively impact the holistic development of the autistic child, affecting social, emotional, and academic ability (Fujii et al 2012 ; Reaven et al 2011 ; Wood et al 2015 ). Saggars et al (2016) concur, reporting that anxiety impedes school participation and impacts classroom support needs, highlighting the significant impact on children's development. Furthermore, family life and parental wellbeing can suffer due to poor socialisation, sleeping, eating and general health for the parent as a result of the lack of support in managing their child's anxiety (Dabrowska & Pisula 2010). Therefore, successful anxiety supports which are suited to neurodivergent individuals are a key priority for families (Reaven et al 2011).

### ***Cognitive Behavioural Therapy (CBT)***

Cognitive Behavioural Therapy (CBT) has been extensively researched and proven effective in managing anxiety (James et al 2006; Seligman & Ollendick 2012). CBT integrates cognitive, behavioural, and emotional skill development

(Bauminger, 2007; Wood et al 2009), targeting unhelpful thoughts and behaviours (Beck 1970; Higgins et al 2019). It equips children with coping mechanisms to deal with anxiety-inducing situations (Rapee et al 2009), often employing strategies like cognitive reframing and problem-solving (Perihan et al 2019)

### ***CBT for Anxiety in Autistic Children***

While research on CBT for anxiety has predominantly focused on non-autistic children, several studies with autistic children show promising outcomes, including reduced anxiety levels (Chalfant et al 2006; White et al 2012; Wood et al 2020). Adaptations such as using visual stimuli and structured delivery have proven effective (Moree & Davis 2010; Reaven 2011), with additional modifications like Functional Behaviour Assessment and parental involvement enhancing efficacy (Stack & Lucyshyn 2019; Sofronoff et al 2005).

### ***Individual vs. Group Cognitive Behavioural Therapy***

CBT can be delivered individually or in groups, each with its advantages. Group CBT (G-CBT) offers opportunities to share feelings of anxiety experienced, peer modelling, and social interaction (Rodgers & Dunsmuir 2015). On the other hand, Individual CBT (I-CBT) provides tailored programme approaches targeting specific needs (Hedman et al 2013), especially in complex cases (Guo et al 2021). While individual therapy may offer more personalised sessions, group therapy may entail longer wait times and scheduling challenges (Stangier et al 2003; Guo et al 2021). Further research is needed to confirm the efficacy of G-CBT for autistic children (Guo et al 2021), aligning with the autistic community's call for meaningful, individualized research (Roche et al 2021; Autistica 2016). Therefore, this systematic review aims to evaluate the effectiveness of group CBT in reducing anxiety for autistic children.

### ***Double Empathy Theory***

Double Empathy Theory suggests that communication challenges between autistic





and non-autistic individuals arise from a mutual lack of understanding rather than a one-sided deficit (Milton 2012). A study conducted by Crompton et al (2020) found that autistic people communicated effectively with one another, suggesting that the challenges occur in communication between different neurotypes. This suggests that both neurodivergent and neurotypical people communicate more effectively with the same neurotype. Therefore, it is important to consider Double Empathy Theory in the context of group therapy. This perspective can enhance therapeutic outcomes by fostering a more inclusive environment where autistic individuals feel validated and understood. Drawing on shared experiences of the autistic identity offers an opportunity for young autistic people to exist in a more comfortable space and reduce feelings of isolation and frustration. By acknowledging the bidirectional nature of empathy gaps, group therapy can focus on bridging these divides, promoting mutual respect, and improving social connectedness among participants. However, it is important to highlight that there will be times when CBT is not an acceptable approach for anxiety experienced by autistic people. Challenges experienced by autistic individuals such as sensory differences or social anxiety may render the group setting an unsuitable match for some autistic individuals. Often anxiety is potentially a very reasonable response to painful stimuli and unpredictability in the environment. Equally, anxiety in social settings can be very real and protective if other people in the environment are not accepting of the individual. Therefore, it is important to take careful consideration of potential environmental changes which could lead to alleviation of anxiety.

### ***Current Policy and Practice***

Recent years has witnessed an increase in new guidelines regarding mental health with the EU strategy the "Joint Action Mental Health and Wellbeing" (2013-2016) emphasising the importance of mental health in education. In Ireland, the importance of wellbeing is highlighted through the Social Personal Health Education (DES 1999) curricular policy, the Draft Primary Curriculum Framework (NCCA 2020), and the Wellbeing Policy Statement and Framework for Practice (2018-2023). Wellbeing is also a key focus in the revised 'Looking at Our Schools' self-evaluation process at primary and post-primary level (DES 2022). Additionally, research which has heard the voices of those in the autistic community has found that there is a demand for meaningful research which will result in real-world changes for autistic individuals (Roche et al., 2021) and research which focuses on combating mental health problems and tailoring practices to suit the individual's needs (Autistica, 2021). Therefore, in line with policy suggestions, it is necessary to determine ways to support wellbeing, such as an increased understanding of effective group practices for anxiety in autistic individuals.

### **Objectives**

The goal of the current systematic review is to evaluate the moderators of Group Cognitive Behaviour Therapy (G-CBT) and community delivery. Specific research questions posed were:

1. To what extent can G-CBT reduce anxiety related outcomes in autistic children?
2. What are the advantages and disadvantages of G-CBT?
3. Can G-CBT be delivered effectively across a variety of community contexts?





## Methodology

**Table 1 Inclusion/Exclusion criteria**

	<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
<b>1. Type of Publication</b>	Peer-reviewed journal	Material in a non-peer reviewed journal
<b>2. Language</b>	Article written in English	Article is not written in English
<b>3. Eligible study design</b>	Empirical study that involved the collection and analysis of primary data	The study does not contain primary empirical data
<b>4. Focus of programme</b>	Programme must focus on changes to anxiety levels as a result of CBT as primary focus	Programme is not specifically targeting anxiety or using CBT
<b>5. Type of programme/setting</b>	Programme is group based CBT carried out in the community context (e.g community disability service, hospital, health-care centre)	Programme is not group based CBT carried out in the community context
<b>6. Population of Interest</b>	Primary-school aged children (study with a mean age less than 12) who have a diagnosis of autism	Studies with a mean age over 12 years who have no autism diagnosis
<b>7. Year of dissemination</b>	Studies published in the last 10 years	Studies not published within the last 10 years

### **Information sources and search strategy.**

The following electronic databases were searched on 29th January 2023 and again on 19th October 2023: PsycINFO, PsycARTICLES and ERIC (EBSCO). Databases were chosen as they are relevant to the current topic and publish studies in the fields of psychology and education. The search strategy included terms pertaining to autism, anxiety and group-based CBT to systematically identify potential literature (see table 2). The initial search yielded 38 studies (PsycINFO: 23, ERIC: 7, PsycARTICLES: 6). Following removal of duplicates, the electronic search resulted in 30

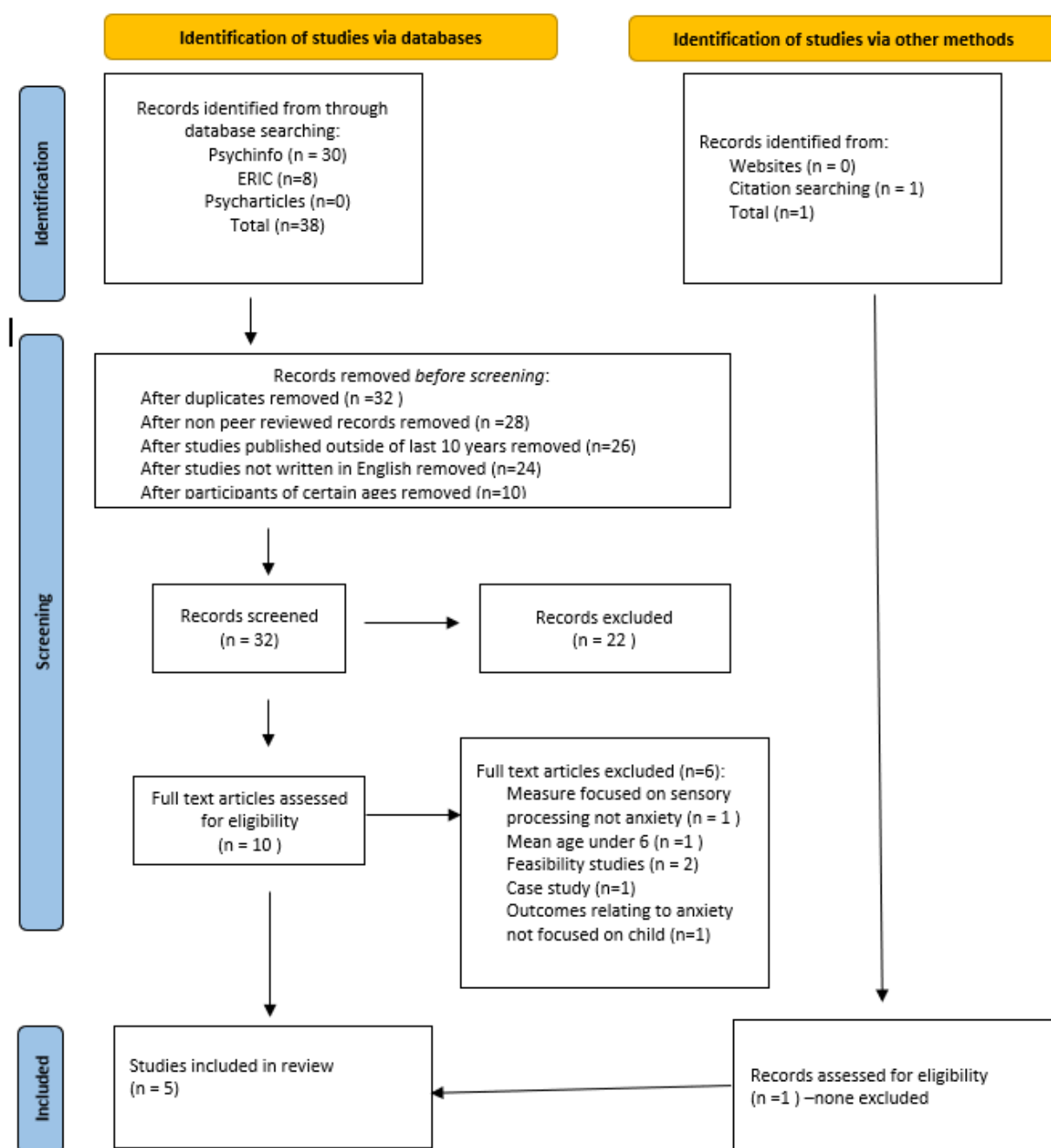
studies. Filters were applied using database tools to align the results of the search with inclusion criteria. The studies were filtered to limit the search to peer reviewed journals (N=26), studies published in the last 10 years (N=24), written in English language (N=22) and participants of school age (N=10). One additional record was identified through lateral search techniques such as hand searching the references of papers for related articles and using Google Scholar to carry out key word searches.


**Table 2. Search Strategy**

Population	Programme	Type	Outcome/Measure
autism OR asd OR "autism spectrum disorder" OR autis*	cbt OR "cognitive behavioral therapy" OR "cognitive behavior therapy" OR "cognitive behavio*"	"group therapy" OR "group based" OR "group programme"	anxi* OR anxiety

\*search strings were connected by the Boolean operator "AND"

\* was used to denote all variations of that word for example 'anxi\*' could be 'anxiety' or 'anxious'

**Table 3. PRISMA Flowchart (2020)**


Results

Table 4. Overview of articles included in the review

Study	Population/ Participants	Focus/Aim	Measures/ Data collection	Research Type and Study design	Findings
<b>Study 1</b>  <b>Kilburn et al (2020)</b>	49 children  aged 8–14 years (M = 11.34, SD = 1.77)  A waitlist controlled study in a general child psychiatric hospital setting.  a small majority of males (57%)	To investigate the efficacy of the manualised CBT programme Cool Kids Anxiety Programme: Autism Spectrum Disorder Adaptation (Cool Kids ASD), 2nd Edition (Lyneham <i>et al</i> 2018 (unpublished)) in a randomized controlled trial (RCT) in a non- English-speaking, general child psychiatric hospital setting.	Primary Outcome Measure: Anxiety Disorders Interview Schedule for DSM-IV: Parent and Child interview schedule (ADIS C/P)  Secondary outcome measures: -Spence Children’s Anxiety Scale (SCAS) (Spence 1998 ) -Children’s Anxiety Life Inference Scale (CALIS) -Children’s Automatic Thoughts Scale (CATS) (Schniering and Rapee 2002 ) -Demographic data -The Experience of Service Questionnaire (Attride-Sterling 2002 ; Brown <i>et al</i> 2014 )	Quantitative – a randomised control trial. Random allocation to treatment or waitlist conditions.  Groups of 5 families,  10 group sessions lasting 2hrs	Post-programme 30% of the children were free of their primary anxiety diagnoses and 5% were free of all anxiety diagnoses. While primary outcomes showed no statistically significant difference between trial conditions, significant differences on secondary outcomes suggested clinically meaningful programme responses. High program satisfaction underscores the feasibility and potential effectiveness of the CBT program for treating anxiety in autistic children within a general child psychiatric hospital setting.

<p><b>Study 2</b></p> <p><b>Solish et al (2020)</b></p>	<p>105 children aged 6-15 years (M=10.47, SD=1.75).</p> <p>Data were collected over six years in various community settings.</p> <p>76 males, 29 females;</p>	<p>The current community effectiveness study investigated the effectiveness of a modified group CBT programme (Facing Your Fears) delivered in a tertiary care hospital and across six community-based agencies providing services for autistic children.</p>	<p>-SCARED Screen for Child Anxiety Related Emotional Disorders, total score</p> <p>-SCAS Spence Children’s Anxiety Scale, total score</p> <p>-BASC-2 Behaviour Assessment System for Children, Second Edition;</p> <p>-Parent and Child Questionnaires</p>	<p>Quantitative- Exploratory single-case design (no control)</p> <p>Twenty-six groups (12 main sites; 14 community) of 3 to 5 child/parent dyads each, took place over a six-year period. Groups involved 14 weekly 1.5-h sessions</p>	<p>Results indicated significant improvements in anxiety levels from baseline to post-programme across measures, with medium effect sizes. An attempt to uncover individual characteristics that predict response to programme was unsuccessful.</p>
<p><b>Study 3</b></p> <p><b>Higgins et al (2019)</b></p>	<p>12 children aged 9-12 years (M= 10.25 years; SD = 1.26).</p> <p>participated in an exploratory investigation</p> <p>2 females, 10 males</p>	<p>This study conducted an exploratory investigation into the impact of a specifically tailored CBT group programme “Special FRIENDS” , delivered in a school age disability service in Ireland, on “ overall anxiety” levels in young autistic individuals</p>	<p>Quantitative- “Spence Children ’s Anxiety Scale ” (SCAS) and SCAS parent version (Spence, 1997).</p> <p>Qualitative- semi-structured interviews with parents, parent comments on a researcher designed feedback form, and weekly session summaries compiled by the researchers.</p>	<p>Quantitative-Single case design (no control) embedded mixed methods design was utilised and inferences were drawn by collecting and analysing quantitative and qualitative data separately.</p> <p>12 group sessions, lasting 1 hour</p>	<p>Findings indicate CBT can be delivered successfully to a group of autistic children. As is the nature of an embedded design, quantitative findings are reported as supportive evidence for the qualitative findings of this study.</p>

<p><b>Study 4</b> <b>Reaven et al (2015)</b></p>	<p>16 children aged 8-14 years (<math>M=10.4</math>, <math>SD=1.5</math>).  85.7% male.</p>	<p>Study aims were to (a) train clinicians to deliver "Facing Your Fears (FYF): Group Therapy for Managing Anxiety in autistic children." to fidelity and (b) examine feasibility of the programme for novel settings. A secondary aim was to examine preliminary youth programme outcome.</p>	<p>-The ADIS-P was the primary outcome measure and was administered pre- and post-programme.</p>	<p>Quantitative - Quasi-experimental design  The FYF programme is delivered in multifamily groups over 14 weekly sessions, each lasting 1.5 hours.</p>	<p>Meaningful reductions in anxiety were reported post programme for 53% of children. Results support the initial effectiveness and transportability of FYF Therapy in new clinical settings.</p>
<p><b>Study 5</b> <b>Reaven et al (2012)</b></p>	<p>50 children Aged 7-14 (<math>M = 10.4</math>)  48 males, 2 females 96% male</p>	<p>The study aims to examine the efficacy of family-focused group CBT programme developed specifically for autistic children. It aims to increase the generalisability of findings by addressing limitations in previous study which were lack of random assignment and independent evaluation.</p>	<p>The ADIS-P was the primary outcome measure and was administered pre- and post-programme.  SCARED completed by FYF group at pre, post programme and follow up at 3 and 6 months.</p>	<p>A randomised trial  12 multi-family group sessions for 1 and half hours, group size 3-6 children, mode-4F</p>	<p>Findings indicate markedly better outcomes for the CBT group. 50% of CBT group had positive programme response compared to 8.7% in the TAU group.</p>



### **Quality Assessment of individual studies**

The quality of the studies included in the systematic review were assessed using a myriad of tools which were carefully selected to align with the study design. The Critical Appraisal Skills Programme (CASP) tool (CASP 2009) was utilised to assess the quality of quantitative randomised trials. Quality

appraisal of single-subject studies was completed using the Quality Indicators for Single Subject Research Design (Horner et al 2005). The Mixed Methods Appraisal Tool (MMAT) was also used to assess the quality of studies which had a mixed method design (Nha Hong et al 2018).

Study	Quality Assessment Tool	Overall Score
Study 1 Kilburn <i>et al</i> (2020)	CASP tool (2019)	12/13 92.3%
Study 5 Reaven <i>et al</i> (2012)		11/13 84.6%
Study 2 Solish <i>et al</i> (2020)	<i>Quality Indicators for Single Subject Research Design</i> (Horner <i>et al</i> 2005)	9/12 75%
Study 4 Reaven <i>et al</i> (2015)		8/12 66.6%
Study 3 Higgins <i>et al</i> (2019)	<i>Mixed Methods Appraisal Tool</i> (Hong <i>et al</i> 2018)	4/5 80%

### **Participant characteristics.**

Selected studies investigated the effectiveness of group CBT programmes for anxiety levels of school aged autistic children. In total, 232 children aged 6-15 years participated in the five studies included in this review. The sample size ranged from N=12 (Higgins et al 2019) to N=105 (Solish et al 2020). It is important to note that results of quantitative group studies with small sample sizes, such as a sample size of 12 (Higgins et al 2019), should be interpreted cautiously (Law et al 1998). Percentage of males in each study were as follows: 57% males (Kilburn et al 2020), 83% males (Higgins et al 2019), 72% males (Solish et al 2020), 85.7% male. (Reaven et al 2015) and 96% males (Reaven et al 2012). Parental involvement was a feature of all five studies (Kilburn et al 2020, Solish et al 2020, Higgins et al 2019, Reaven et al 2015, Reaven et al 2012). This is positive as research suggests that parental involvement can enhance the generalizability of skills post-programme (Perihan et al 2019). Parents were involved in

group sessions and spent time working with their child or in separate parent/child groups for all studies. Parents were also required to follow up at home with homework tasks, however this was not monitored in any study. Eligible participants required a formal diagnosis of Autism and screening for anxiety symptoms in all studies, except for the study conducted by Higgins et al (2019) where participants were referred by parents or a member of a multi-disciplinary team for anxiety management programme. Some studies had more rigorous eligibility screening processes and inclusion criteria. This created a clear picture of the participants at baseline. Some examples of participant requirements include Average intellectual ability on Wechsler Intelligence Scale for Children® Fifth Edition (WISC®-V) (Kilburn et al 2020; Solish et al 2020), and Average intellectual ability on the Wechsler Abbreviated Scale of Intelligence (2nd Edition) (WASI-II) (Reaven et al 2015; Reaven et al 2012). Other specific requirements included no significant behavioural differences that preclude group





participation (Solish et al 2020) or reduced language ability, untreated ADHD or psychosis (Kilburn et al 2020). Higgins et al (2019) requirements were not as refined. Participants ranged in intellectual ability and had a diagnosis of autism in line with Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria.

### ***Study designs and methodology.***

This review aimed to include quantitative studies with pre- and post-programme measures. One study also included a qualitative aspect and the researcher decided to include this data as it adds great insight to the review (Higgins et al 2019). This review only includes studies which analyse the effect of group-CBT as opposed to individual CBT. Two studies were randomised trials and measured participant outcomes for both programme and control/programme as usual (TAU) (Kilburn et al 2020; Reaven et al 2012). Sampling biases are eliminated by this randomisation of allocation. The use of more than one group strengthened the rigor of these studies and provided a robust method for ascertaining the effectiveness of group CBT on anxiety levels, in line with the systematic review question. This study design may result in more insightful findings as well as mitigating any participant, examiner or expectancy bias or regression to the mean (Ehrenreich-May et al 2014; Thomson et al 2015). Furthermore, it controls for confounding variables and allows for statistically controlled effect sizes (Carlson & Schmidt 1999). Hence, one should interpret results of non-controlled studies cautiously.

Three studies incorporated a single-subject design which allows the individual to serve as their own control (Solish et al 2020; Higgins et al 2020; Reaven et al 2015). Single-subject designs are particularly appropriate for use in special education research as they focus on the individual, allow in-depth analysis of participant responses, offer a practical approach and are more cost-effective (Horner et al 2005). However, there can be challenges with this design type as it is hard to control for

confounding variables, other factors outside of the programme which may impact anxiety levels. Nevertheless, it is useful for evaluation purposes and the flexibility of this design adds to its appropriateness for conducting research in clinical settings (Law et al 1998). Higgins et al (2019) also incorporated an embedded mixed methods design which highlighted the success of CBT programmes, such as enjoyment, feelings of group belonging and development of CBT and social skills.

### ***The Setting.***

Two studies were conducted in Canada (Solish et al 2020; Reaven et al 2015), one in USA (Reaven et al 2015), one in Ireland (Higgins et al 2019), and one in Denmark (Kilburn et al 2020). All studies were delivered in a community setting, albeit varying contexts within the community, such as a general child psychiatric hospital (Kilburn et al 2020), tertiary hospital and community based Autism service setting (Solish et al 2020), a school-age disability service (Higgins et al 2019), tertiary paediatric health centre (Reaven et al 2015) and a research clinic (Reaven et al 2012).

### ***CBT Group Programme***

All studies reviewed used a group CBT framework to reduce anxiety symptoms for autistic children. A range of programmes were used including "Cool Kids ASD" (Kilburn et al 2020), "Facing Your Fears" (Solish et al 2020; Reaven et al 2015; Reaven et al 2012) and "Special Friends" programme (Higgins et al 2019). All programmes included modifications such as increased visual aids, highly structured activities, simplified cognitive restructuring tasks, relaxation techniques and graded exposure tasks. The programme delivery was well described for studies including detail of therapists' training, programme manuals and group sizes. All studies required three adults for delivery, namely one main therapist and two co-therapists. Only one study did not describe in detail the number of therapists delivering the programme (Solish et al 2020). Programme length ranged from 10 sessions (Kilburn et al 2020) to 14 sessions (Solish et al



2020; Reaven et al 2015). However, when analysed in terms of hours of contact all studies had similar hours of contact of 18 hours or higher, except for one study that had 12 hours (Higgins et al 2019).

### ***Programme Fidelity.***

Programme fidelity is important to establish whether programmes adhere to the original model and the quality of delivery (Mihalic 2004). Three studies carried out video-based fidelity monitoring to ensure adherence to programme delivery and all exceeded the minimum standard of over 80% adherence for acceptable programme fidelity which is a significant strength (Kilburn et al 2020; Solish et al 2020; Reaven et al 2015). Higgins et al (2019) adhered firmly to the programme manual which outlines sessions clearly to ensure programme fidelity. While programme fidelity was not measured by Reaven et al (2012), alternative approaches were used to ensure adequate training for programme delivery by providing ongoing supervision for new group facilitators who recently received training. However, video-based monitoring of programme fidelity may further strengthen the quality of these studies (Higgins et al 2019; Reaven et al 2012). Two studies also completed pilot sessions before the programme began to examine feasibility and any further modifications required (Kilburn et al 2020; Reaven et al 2015).

### ***Data Collection.***

All five studies used appropriate measures to collect data on anxiety outcomes. Outcome measures also varied between studies. Some studies utilised only one or two measures while others incorporated multiple types of measures to ascertain the accuracy of their findings. A detailed list of outcome measures can be seen in Table 8.

### ***Integrating findings***

In order to address the specific review questions, the author focused only on measures which relate to the effectiveness of CBT programmes on anxiety outcomes. A

summary of findings are provided above in Table 4. Overall, findings across all studies reported positive outcomes for group CBT programmes. Three studies reported the percentage of participants with meaningful reductions in anxiety post-programme with 30% of participants (Kilburn et al 2020), 53% of participants (Reaven et al 2015), and 50% of participants (Reaven et al 2012) experiencing reduced anxiety symptoms. Similarly, Higgins et al (2019) also reports that CBT can be delivered successfully to a group of autistic children. Qualitative findings from this study contribute to the evident success of this programme indicating overall programme satisfaction, CBT skill development, social connectedness, and a sense of acceptance amongst the group. Furthermore, Solish et al (2020) reported significant improvements post-programme on 11 out of 13 measures of anxiety and behaviour. Moreover, this study analysed the difference between programme-delivery in main site (clinical setting) versus a community-based setting. Results yielded significant effects on both sites, apart from the child-reported measure (SCAS).

A summary of effect sizes are provided below in Table 8. Cohen's (1992) descriptors were used to judge the effect size reported (Small = 0.2; Moderate = 0.5; Large = 0.8). Kilburn et al (2020) reported statistically significant results on the Anxiety Disorders Interview Schedule (ADIS) and Clinical Severity Ratings (CSR), with a large effect size from pre- to post-programme on the primary anxiety diagnoses ( $d = 1.05$ ). Reaven et al (2012) reported a moderate effect size of the same measure ( $d = .71$ ). Solish et al (2020) reported moderate effect size ( $d = .67$ ) on the SCARED parent report. Similarly, Reaven et al (2015) yielded moderate effect sizes for SCARED anxiety reductions and reported three primary anxiety diagnoses separately: Social Anxiety Disorder (SOC) ( $d = .61$ ), Separation Anxiety Disorder (SEP) ( $d = .53$ ) and Generalised Anxiety Disorder (GAD) ( $d = .76$ ). The authors note that these results are highly consistent with previous programme trial



(Reaven et al 2012). This strengthens the certainty of evidence for this programme.

Reaven et al (2015) and Kilburn et al (2020) also reported similar findings on the significant reductions in overall number of anxiety diagnoses ( $d = .70$  and  $d = .59$  respectively). Three studies obtained similar results on the SCAS parent version with all reporting moderate effect sizes (Kilburn et al 2020; Solish et al 2020; Higgins et al 2019). Interestingly, Higgins et al (2019) reported a small effect size for T1 to T2, which would have been directly post-programme ( $d = .22$ ). However, a 4 month follow up was conducted and a moderate effect size was reported at this time from T1 to T3 ( $d = .38$ ). This may be due to practice effects and parental follow-up at home after the programme (Higgins et al 2019). Children self-reports were utilised in three studies and found an overall reduction in children's anxiety symptoms. Two studies yielded moderate effect sizes on the SCAS-C (Kilburn et al 2020; Solish et al 2020) while one yielded large effect sizes (Higgins et al 2019).

Maintenance effects and overall programme effectiveness can be ascertained using follow up procedures (Boland et al 2017). Three studies in this review examined maintenance effects. Reaven et al (2012) measured at four time points which were pre-programme post-programme, 3 month and 6 month follow up.

Parent and child report of total anxiety symptoms on the SCARED measure both show that reductions were not only maintained, but significant reductions continued to occur post programme. Kilburn et al (2020) and Higgins et al (2019) had three points of measure; pre-programme, post-programme and 3 months follow up. As mentioned above Higgins et al (2019) yielded even more significant results and large effect size at follow up, consistent with Reaven et al (2012) research experience. In contrast, Kilburn et al (2020) found a small non-significant trend towards improvement from post-programme to follow up in both the children's ( $d = .08$ ,  $p = .753$ ) and the parents' answers to the questionnaire ( $d = .16$ ,  $p = .083$ ). Yet, Kilburn et al (2020) had some positive findings at follow up with 52.8% of children no longer meeting criteria for a primary anxiety diagnosis and 50% no longer meeting criteria for a social anxiety diagnosis. Solish et al (2020) study may have been a stronger design if it had incorporated a third data collection point such as a three month follow up to examine maintenance effects. Since this study was examining efficacy of programme in different settings (clinical v community), it would be interesting to determine if positive programme outcomes were maintained for both settings.

Table 8.

*Effect Sizes for anxiety outcome measures*

Study	Source of evidence/outcome	Pre-vs-post programme effect size
<b>Kilburn <i>et al</i> (2020)</b>	ADIS CSR (primary diagnoses)	1.05
	ADIS (no. of anxiety diagnoses)	.59
	SCAS parent report	.56
	SCAS child self-report	.33
	CALIS P –interference parent life	.52
	CALIS P – interference child life	.47
	CALIS C	.11
	CATS – social threat	.40
	CATS – physical threat	.40
<b>Solish <i>et al</i> (2020)</b>	<b>Parent Report</b>	
	SCARED	.67
	SCAS	.52
	<b>Child report</b>	
	SCARED	.36
	SCAS	.37
	<b>Parent questionnaire</b>	
	Effective	-1.14
	Avoidance	.48
	Interference	.59
	Family impact	.53
	<b>Child questionnaire</b>	
	Amount of worry	.05
Interference/distress	.12	

<b>Higgins <i>et al</i> (2019)</b>	<b>SCAS child report</b> T1 to T2 T1 to T3 T2 to T3  <b>SCAS parent report</b> T1 to T2 T1 to T3 T2 to T3	         
<b>Reaven <i>et al</i> (2015)</b>	<b>ADIS-P CSR (primary diagnoses)</b> SOC SEP GAD <b>CSR (number of anxiety diagnoses)</b>	     
<b>Reaven <i>et al</i> (2012)</b>	<b>ADIS-P CSR</b> SEP SOC SpP GAD Principal Anxiety Diagnoses	      



### ***Certainty of evidence.***

As outlined in the quality appraisal above, the studies in this review are of high quality and rigorously designed for the most part. Several consistencies within the findings are outlined above which increases the confidence in the findings. Across the studies in this review, a myriad of outcome measures are utilised which adds to the certainty of evidence. However, there are some caveats to interpreting these findings with certainty. While Higgins et al (2019) provide preliminary evidence for the positive impact of the group CBT programme, it is difficult to determine the significance of this impact with certainty due to the small sample size, lack of control group, the use of only one measure (SCAS) and possible participant/examiner bias through waitlist recruitment. Kilburn et al (2020) was a very well-designed and rigorous study which scored highly on the quality assessment tool, so certainty of evidence is strong here. However, caution is still required as the study had a small number of participants, no active control group, and no monitoring of homework assignments. Solish et al (2020) was also a study of sound design which fulfilled many criteria outlined by the quality assessment tool (Horner et al 2005). Moreover, confidence in the findings of this study is supported by the consistency in outcomes across studies. However, the addition of a control group and more demographic characteristics to create a stronger baseline may have increased the certainty of evidence. Although, the aim of the study was to identify the real-world effect or transportability of the programme to community settings. Results noted that the child-reported anxiety (SCAS) had no significant change in the community group. This creates a certain level of uncertainty around the results for community settings, however, concerns have been raised about the psychometric strength and validity of self-report measures for autistic children with anxiety in the past (Wood et al 2009). Reaven et al (2015) also commented on child report measures as authors question the additive

value of the ADIS-C in the autistic population. Storch et al (2013) suggests researchers tend to rely more on parent reports as autistic children tend to under-report. This creates uncertainty about the use of child report measures and as such these findings may not be interpreted with as much confidence.

## **Discussion**

### ***Interpretation of key findings***

The objectives of this systematic review were twofold. Firstly, the review aimed to investigate the effectiveness of group CBT programmes in reducing anxiety levels for autistic children across various contexts. Secondly, the review aimed to evaluate the strength of the evidence reported in studies examining this research area, using critical appraisal tools (CASP 2020; Horner et al 2005; Hong et al 2018). In conclusion, as outlined above, all five studies reported findings which support the use of group CBT programmes in various contexts. Studies outline numerous advantages to Group CBT. These include interacting with others, social learning opportunities, normalising feelings of anxiety experienced, thus reducing isolation and management of long waiting lists, thus increasing access to therapies (Rodgers and Dunsmuir, 2015; Reaven et al 2009).

However, there are some caveats to offering group therapy to autistic children. There are numerous factors which make the delivery and accessibility of group CBT for autistic children more complex. Factors which limit accessibility include social, cognitive and linguistic differences of autistic children (Reaven et al 2009). Other differences include the presence of restrictive thinking patterns making restructuring of thoughts difficult. Moreover, self-regulation differences and difficulty with generalisation of skills across different environments pose challenges for G-CBT (Ozsivadjian & Knott 2011). Many of the studies involved in this review have attempted to increase the accessibility of CBT and tailor it to suit autistic children. Often individual differences occur between autistic children and their needs may be diverse. This increases the





complexity of delivering a group session that is tailored to individual requirements. One-to-one conferencing during sessions to address specific concerns may prove beneficial. Alternatively, if appropriate, identifying children with similar needs and pairing them up or creating stations to target specific concerns could be a worthwhile modification.

The delivery of effective group CBT, such as the Facing Your Fears (FYF) programme required a minimum of three clinician facilitators which may not be feasible in all environments (Reaven et al 2015). Furthermore, many studies reported withdrawal from therapy because of the group aspect. This type of group CBT may not suit all learning or social styles. It could be suggested that these children trial individual CBT first and then follow up with group therapy. Completing the programme individually first may allow the child to learn new strategies, gain confidence and increase predictability of the therapeutic process. This may increase familiarity and make them more comfortable with engaging with group CBT going forward. Repeating the programme in group format will offer the added benefits outlined above as well as reinforcing and consolidating what has already been learned in individual therapy. However, further research is required to examine this.

Many of the studies included in this review incorporated modifications to CBT delivery suitable for autistic children's preferences. The Facing Your Fears programme includes core components of CBT for anxiety. Psychoeducation requires reframing of thoughts and coping mechanisms for physical symptoms of anxiety such as breathing and relaxation techniques. The other core component entails graded exposure or facing fears in a step-by-step manner (Reaven et al 2012; Reaven et al 2015). However, acceptability of CBT components is an area that has not been widely researched. Acceptability refers to beliefs about programme efficacy and satisfaction with delivery. Research indicates that parents and youth value and accept

exposure sessions more than psychoeducation sessions. Furthermore, a higher level of programme acceptability predicted better programme outcomes (Walsh et al 2018). In response to the autistic communities' views on CBT programme, other programmes should aim to incorporate more graded exposure activities.

It is also evident from the literature that CBT is efficacious when implemented in highly controlled clinical environments with heavy reliance upon programme developers (Sukhodolsky et al 2013; Kreslins et al 2015). However, despite the growing body of evidence, it remains to be determined whether this therapeutic approach is feasible and effective across various community settings, in a real-world context. To address this gap in the research and increase the accessibility of CBT, it is important to ascertain the level of transportability or transferability of such approaches to the community setting (Drahota et al 2017). All studies in this review that were conducted in community settings reported positive findings which suggests that group CBT can be delivered effectively in the community context with the correct resources and approaches.

### **Strengths and Limitations.**

The current review has several limitations that should be considered when interpreting the results. It omits unpublished literature and dissertations, studies reported in languages other than English, or those published prior to 2012; therefore, some relevant studies may have been excluded. Moreover, there is a variety of CBT programmes included in the review. Variations in delivery methods, applications, target skills and outcome measures were evident. This can be viewed as a strength as it allows for analysis of similarities and differences in modifications to CBT for autism. On the other hand, it may be a weakness as the use of different approaches or programmes make it difficult to establish causal relationships. This highlights the necessity of unpacking the core components of



successful supportive practice. As the body of research exploring modified group CBT evolves, further insight may be offered through multilevel meta-analysis and meta-regression studies.

The quality of studies in this review were appraised using a variety of appraisal tools most suited to the study type including the CASP tool, Single Subject Quality Indicators (Horner et al 2005) and the Mixed Method Appraisal Tool (MMAT) (Hong et al 2018). The review may have been stronger had it only included more rigorous studies such as randomised control trials or else studies of same research design. However, unfortunately there is a dearth of research conducted on this topic, rendering it difficult to identify studies which meet narrow inclusion criteria. Nevertheless, the researcher took great care to assess the chosen studies using the most appropriate critical appraisal tools.

#### **Implications for practice, policy and future research.**

The need for evidence-based practices to improve anxiety outcomes has become a pressing matter in the Irish educational system and educational psychology context, with high-levels of anxiety disorders reported in Ireland (Cannon et al 2013). Moreover, the autistic community requires supports which are suitable for autistic children to tackle the rise in mental health problems (Autistica 2016). Furthermore, the recent introduction of 'Well-being Practice and Policy Framework' has brought wellbeing to the forefront of education (DES 2018). As described, anxiety management is a critical component of well-being, and if not managed efficiently it can act as a barrier to school success and participation (Wood & Gadow 2010; Saggars et al 2016). The systematic review illustrates the myriad of CBT modifications required to make it accessible to autistic children. The necessity of such modifications to traditional CBT programmes and the targeting of core autistic features when working with autistic children are explored. Therefore, this will have implication for real-

world practice which Psychologists will need to consider when making recommendations. Aspects such as the emotional, social, cognitive and language abilities of an individual will need to be considered when selecting a suitable CBT program.

Further research should attempt to conduct more rigorous group studies, such as randomised control trials, especially in the Irish and European context. Recently, in Ireland a new model of service known as 'Progressing Disability Services' (PDS) has been rolled out for children and their families in the community (HSE 2010). PDS values a family-centred approach to service delivery, hence parent participation in Group CBT would align well with this delivery style. Furthermore, PDS strongly advocates for group therapies as a preferred style of delivery, thus the need for more research to ensure evidence-based practice (HSE 2010). As discussed above, programme acceptability impacts outcomes (Walsh et al 2018). Future research must analyse acceptability ratings in group CBT to ascertain if differences exist. This would add to the existing literature by procuring views and opinions from the wider autistic community, thus encompassing all voices. Moreover, future research must endeavour to include the voice of the autistic child. Qualitative evidence was gathered from parents in studies but where possible including children's opinions and experiences would add further value to the research. Feedback from children could be sought via visually supported communications to obtain their own personal perceptions (Higgins et al 2019).

Additionally, follow-up research is required to establish the longitudinal effects of CBT. Identifying the lasting effects and transferability of skills would further guide and inform policy and practice. This review has highlighted the benefits and social importance of group-based CBT. Moving forward, research must garner ways to encourage and include all autistic children in group therapies. Researchers must also continue to update and



adapt self-report measures of anxiety to make them specific to the autistic cohort. This will increase reliability and validity of such measures for this community, thus enhancing findings (Van Steensel et al 2011). Future systematic reviews will be needed to examine the effectiveness should such additional outcome measures be developed, as well as monitoring the evolution of effective group-based CBT practices in the community context.

### Conclusion

In summary, evidence from the current review provides promising and beneficial results for the autistic community. Much progress has been made to date in the delivery of Group CBT for autistic children. As this body of literature grows, it gives further insight into features of successful CBT delivery for this community. Moreover, it raises awareness of barriers to CBT for autistic children, thus highlighting areas for development. Further modifications and approaches may be required which will increase accessibility and inclusion for all autistic children with anxiety.

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## Graduate Courses

Institution	Qualifications	Duration/credit	Assessment Methods	Entry Requirements	Contact Details
Mary Immaculate College, Limerick	Post Graduate Certificate in Autism Studies	Four part time modules over 1 year  30 ECTS at level 9	Four assignments over the year (including written assignments and presentations)	A level 8 qualification or equivalent in any discipline OR a Bachelor's degree at Level 7 or 8 is required for entry to this programme.	Kim Maguire Email: <a href="mailto:Kim.Maguire@mic.ul.ie">Kim.Maguire@mic.ul.ie</a>  Majella Nugent Email: <a href="mailto:GCAS@middletownautism.com">GCAS@middletownautism.com</a>
Mary Immaculate College, Limerick	Post Graduate Diploma in Autism Studies	Three part time modules over 1 year  30 ECTS at level 9	Three written assignments over the year	A Bachelor's Degree at Level 7 or 8 in any discipline AND a post-graduate qualification in Autism Studies.	Kim Maguire Email: <a href="mailto:Kim.Maguire@mic.ul.ie">Kim.Maguire@mic.ul.ie</a>  Dr Rachel Ferguson Email: <a href="mailto:Rachel.ferguson@middletownautism.com">Rachel.ferguson@middletownautism.com</a>
Mary Immaculate College, Limerick	Masters in Autism Studies	Three part time modules over 1 year  30 ECTS at level 9	Three written assignments over the year (Including a dissertation)	This programme is designed to build on both the existing GCAS and GDAS programmes.	Kim Maguire Email: <a href="mailto:Kim.Maguire@mic.ul.ie">Kim.Maguire@mic.ul.ie</a>  Dr Rachel Ferguson Email: <a href="mailto:Rachel.ferguson@middletownautism.com">Rachel.ferguson@middletownautism.com</a>
Stranmillis University College, Belfast	Post Graduate Certificate in Education: Autism Studies	Three part time modules each worth 20 CAT points	Three written assignments over the year	2:2 Hons Degree and preferably a professional teaching qualification	Email: <a href="mailto:info@stran.ac.uk">info@stran.ac.uk</a>

All courses are delivered using online blended learning through virtual learning environments and face to face weekend lectures.



# MCA Training Courses

<https://www.middletonautism.com/training>



# MCA Research Journal Description

## Submission Guidelines

The aim of the MCA Research Journal is to publish examples of good practice in working with or supporting autistic people. We want to share the novel and interesting research studies that are carried out (primarily across Ireland) to positively impact the lives of autistic people.

Research exploring how environments and people around the autistic person can change and adapt to better suit the needs and promote the strengths of autistic people are welcomed by the journal.

## Types of Papers/ Manuscripts

MCA Research Journal welcomes the submission of:

- Research articles (maximum 3000 words)
  - Data-based manuscripts reporting original research that aims to improve the educational outcomes, opportunities and services for autistic people (primarily across Ireland).
- Executive Summary of Literature Reviews (maximum 3000 words)
  - Selected on the content's importance to the field of autism and good autism practice, executive summaries should report the main elements of the review in a condensed format which emphasizes the implications for practice.
- A Special Series or Section (Contact Editorial Board in the first instance)
  - Contains several different articles by various authors on a given topic. A lead author with extensive experience and expertise in a specific area conceptualizes and coordinates it with support from the Editorial Board. Individuals who wish to guest edit a special series should first contact the journal editorial office to ascertain interest in the topic.
- Letters to the editor (maximum 300 words)
  - Involving reaction to material appearing in the MCA Research Journal or to an issue in the field of autism are encouraged and are published as space permits.
- Perspective Article (maximum 2000 words)
  - Perspective articles are intended to provide a forum for authors to discuss models and ideas from a personal viewpoint. They are more forward looking and/or speculative than Reviews and may take a narrower field of view. They may be opinionated but should remain balanced and are intended to stimulate discussion.
- Notices of Recruitment for Research (maximum 200 words)
  - Short synopsis of research study, ethical approval and who to contact if interested in participating. Only studies meeting the aims of the journal and with ethical approval will be considered for 'Notices of Recruitment for Research' section.

## Criteria

Initial consideration of a manuscript will depend upon:

- Content relevance and usefulness to the readership
- How it compares to other articles dealing with similar content on pertinent variables (e.g., sample size, research design, research quality, literature review)
- Clarity of writing style

- Use of strengths based, autism affirming language and terminology i.e. identity first (e.g. autistic people).
- Autistic co – production / inclusion in research e.g. design, methodology, results & interpretation of finding
- Adherence to Harvard Style referencing guidelines (see here for details: <https://www.citethisforme.com/uk/referencing-generator/harvard> )
- Adherence to the journal formatting guide

### Publication

MCA publish the MCA Research Journal on a bi-annual basis. This means we publish two journals a year. All publications are available via the MCA Website.

### For more information

Please contact the below email address for a copy of the Journal description and formatting guide:

[MCAResearchJournal@middletownautism.com](mailto:MCAResearchJournal@middletownautism.com)