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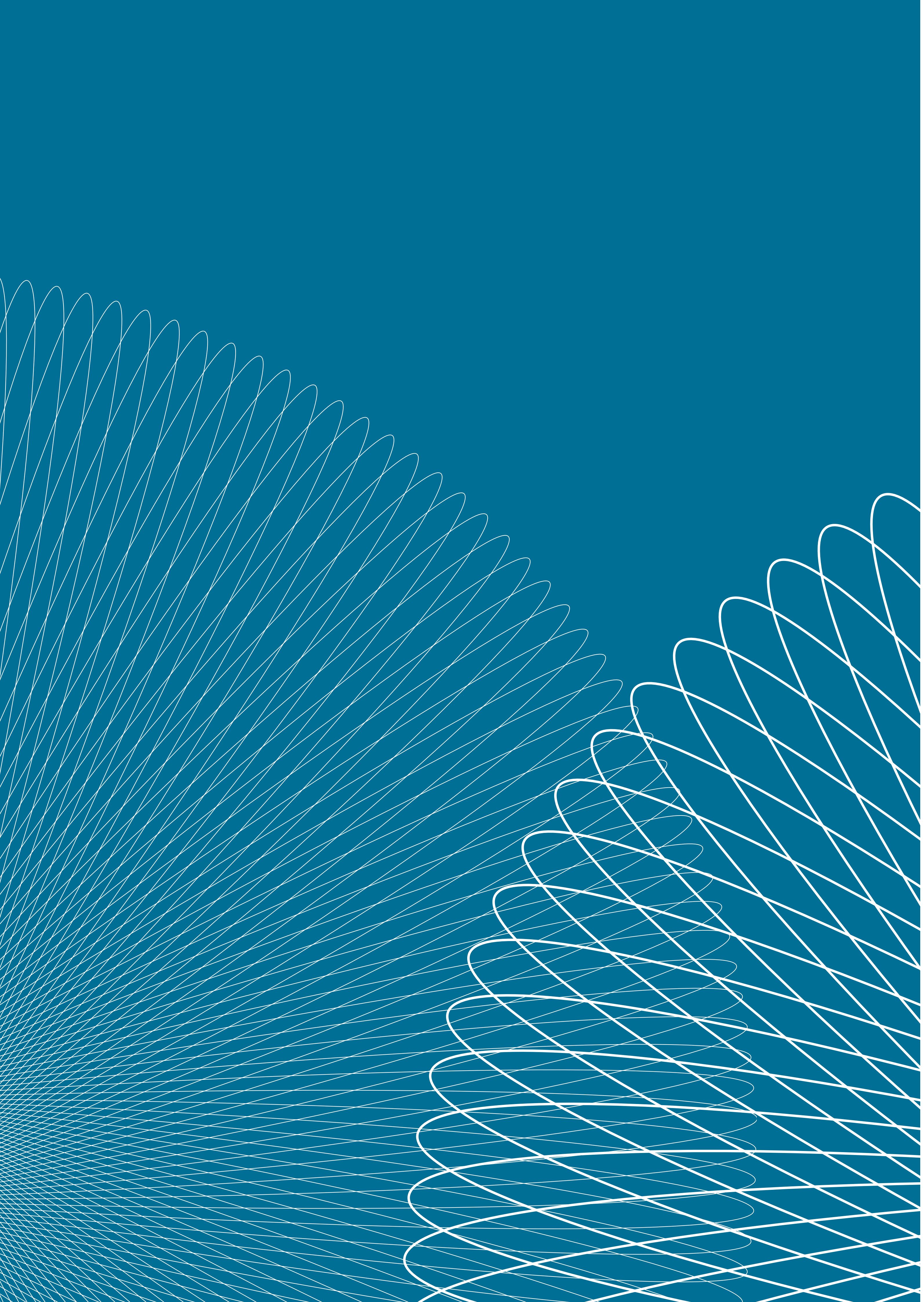


CONTENTS

INTRODUCTION

This is a special Middletown Research Bulletin comprising research summaries written by students on the Graduate Diploma in Autism Studies (GDAS) that is provided in partnership with Mary Immaculate College, Limerick. The students have summarised articles that are of interest to them living and working with autism and as such cover a broad range of issues.

The Bulletin commences with two interviews from tutors and one from a student on the GDAS course: tutors Dr Cat Hughes and Dr Laura Ambrose and Hazel Deegan, a Special Needs Assistant and GDAS student.

GDAS is a progression to the MA in Autism Studies and further details on this and the Graduate Certificate in Autism Studies can be found by following the link **https://www.mic.ul.ie/faculty-of-education/programme/graduate-certificate-diploma-autism-studies.**

Please note that the views represented in this document do not necessarily reflect the views of Middletown Centre for Autism. Reviewers have, where possible, used the original language of the article, which may differ from UK and Ireland usage and the usage of a range of terminologies for autism.

INTERVIEW WITH DR. CAT HUGHES

Brief biography and role on the GDAS course.

Dr Cat Hughes is a research officer at Middletown Centre for Autism. She previously worked as research communications manager with UK autism research charity Autistica where she supported researchers and community members to communicate about research and lived experience. She has also worked extensively in mental health research and was research manager with Pieta House. Cat is a lecturer and helped to develop modules on the Graduate Diploma in Autism Studies at Mary Immaculate College. Cat received an autism diagnosis herself while in university and she is passionate about inclusive research that improves the lives of autistic people and their families.

Cat, you deliver some of the lectures on the course. Can you tell us about some of the topics covered in the course?

I feel lucky to get the chance to deliver lectures on the course. My priority was to focus on how our understanding of autism has changed and developed, as well as looking at research into topics that are really impacting the lives of our community. I wanted all my sessions to get students thinking about why research really matters and how our understanding of autistic experience through research can teach us so much about the sorts of supports that really make a difference.

We covered modern theories of autism like neurodiversity, double empathy and monotropism, which were developed by autistic researchers. We also looked at cutting-edge research based on topics that we know are community priorities, like mental health, access to diagnosis and education supports.

We also focused on understanding what researchers should be doing in their work to fully create space for autistic experience and expertise in every step of their research.

The GDAS course is designed to support students wanting to further their expertise within the area of autism research. What are the benefits of focusing on autism research and how can research support the autism community?

An exciting part of the GDAS course is that it has a very practical focus. It's all about examining how research can be used to understand and address challenges that the autism community is facing. By looking at cutting-edge research and theory, students learn about new ideas that can be brought into practice.

The students aren't just taught about autism research, they're also taught how to evaluate it. Throughout the course they learn about good research practice and how to appreciate if the experiences of the autistic community have been considered and included. This skill can really empower students to keep challenging and examining new developments in autism research so they can better assess how useful a piece of research might be.

Learning together has also been a benefit of the course. I was delighted to share my experiences as a researcher and a late-diagnosed autistic woman. Our students have also been able to share their amazing breadth of experience in relation to the topics we've discussed. I know I learned a lot from hearing their experiences and perspectives.

The students on the GDAS course are encouraged to design and conduct their own research study. Can you tell us about that?

It has been very exciting to watch our students explore topics that they are interested in and develop their own systematic reviews. This meant that they picked a topic important to them and conducted an evaluation of research that has focused on it.

We started by helping them to appreciate good research practice and introducing them to lots of different topics in autism research. Through lectures they learned about how autism research has developed over the years and where current autism research is focusing. As an assignment, they developed a research protocol describing their area of interest and how they planned to conduct their review.

Throughout the course we emphasised the importance of community perspective and creating research that is relevant to autistic people's lives. To encourage this we gathered a review panel of autistic experts who could answer questions and offer feedback to students to support them in shaping a review that was as relevant as possible.

In the final module students conducted and wrote up their reviews. We held small group-supervision sessions so they could discuss any challenges and share their learning along the way. It has been a privilege to see so many fascinating reviews produced and to see the dedication that all the students have put into their work.

INTERVIEW WITH DR. LAURA AMBROSE

Brief biography and role on the GDAS course.

Dr Laura Ambrose is an educational psychologist and a lecturer in Educational and Developmental Psychology within the Department of Educational Psychology, Inclusive and Special Education at Mary Immaculate College, Limerick. She has worked with autistic children and young people across a range of settings: public and private schools, paediatric hospitals, an outpatient neuropsychology clinic and a child development centre. She has served on several federally funded research grants in the US. She has also worked with AsIAm to evaluate the impact of the Autism Friendly Schools Initiative. Laura joined Mary Immaculate College in 2019 and is course coordinator for the Graduate Certificate in Autism Studies and the Graduate Diploma in Autism Studies. She will also serve as course coordinator for the upcoming MA in Autism Studies that will be offered in September 2022.

Can you briefly describe the courses designed in partnership between MCA and MIC?

Both the Graduate Certificate in Autism Studies (GCAS) and the Graduate Diploma in Autism Studies (GDAS) are delivered as a partnership between Middletown Centre for Autism and Mary Immaculate College. Both programmes are offered on a part-time basis with a combination of online and face-to-face teaching.

Within the GCAS programme students engage with a range of topics: core features and individual differences within autism; the use of visual learning strategies in supporting autistic individuals; the relationship between autism and anxiety with a view to identifying appropriate supports; and sensory and behavioural needs for autistic individuals.

One of the strengths of the programme is that it is open to applicants who hold a bachelor's degree in any discipline, and so we have a very diverse student body each year. Our students include parents and siblings of autistic people, educators, healthcare providers, therapists, professionals from disability services and members of the legal profession. We encourage students to engage in discussion and collaboration with one another so that they can make the most of learning from one another's perspectives in addition to learning from the readings, lectures and assignments.

Graduates of the GCAS programme who have a particular interest in autism studies research may then pursue the GDAS programme. This programme aims to support students in exploring contemporary trends and discourse within the field of autism research and in developing the requisite skill set to engage in desk-based research. We aim to enhance student capacity to critically reflect on research developments and findings; ultimately harnessing research to enhance practices and policies relevant for autistic individuals.

How does the GDAS differ from other autism courses?

The GDAS programme begins with an introduction to trends and debates within autism research, with students being encouraged to develop critical analysis skills when engaging with research. Following this students identify a research topic that is of interest to them. They then develop a research proposal to complete a systematic literature review on their topic of interest and are supervised through completion of their systematic literature review by supervisors from both Mary Immaculate College and Middletown Centre for Autism. Students engage in lectures with experts across a range of research topics and are also given the opportunity to present their research proposal to a panel of neurodiverse researchers. In this respect students are encouraged and required to conceptualise their research from a viewpoint that considers the needs and priorities of the autism community and are prompted to consider the complexities and necessity of inclusive research. I think that this level of interaction with professionals in the field offers students a unique opportunity to ensure that their approach to research is consistent with the expressed priorities of the autism community, while also providing students with the opportunity to further develop their identities and positions as researchers in the field. As students complete their systematic review, they critically analyse research in their chosen area, all the while identifying ways in which this research can and should impact on practice in the field. This allows students to bridge research and practice in a chosen area that is relevant and meaningful for their professional or personal development.

It sounds like the students gain a lot of research knowledge and really focus on an area of autism research that is of particular interest to them and of benefit to the autism community. How do you encourage students to pursue their area of interest further?

For students who wish to further their research skills we are now offering the MA in Autism Studies. As with the GCAS and the GDAS, this programme is delivered as a partnership between Middletown Centre for Autism and Mary Immaculate College. Within this programme students will design and conduct their own primary research study with support from supervisors across both institutions. This will allow them to enhance their existing research skills, wherein they will analyse literature and policy to develop a research question that is relevant to the needs of various stakeholders in the autism community, design and conduct their study, analyse the data and reflect critically on the implications of their findings for research, practice and policy. Students will be encouraged to apply their findings to enhance their own practice, ensuring that every effort is made for research findings to be translated into real-world environments so that the benefits may be felt by all involved.

How do people find out or register interest about the courses designed in partnership between MCA and MIC?

More information about the GCAS, the GDAS and the MA in Autism Studies is available on the Mary Immaculate College website: **https://www.mic.ul.ie/faculty-of-education/programme/graduate-certificate-diploma-autism-studies**. I am always happy to meet with potential students and answer any questions they have about the programme.

INTERVIEW WITH HAZEL DEEGAN

Hazel Deegan is a special needs assistant in ArdScoil Rís, Limerick, which is a mainstream secondary school.

As a special needs assistant (SNA) in a mainstream secondary school, you have a unique perspective on the education system for our autistic students. What do you think are the main challenges for our young people in school and how can we improve them for our young people?

Starting secondary school is daunting for most students, but for the students I work with it is a type of internal anxiety they find difficult to express. Fitting in and being accepted by their peers, particularly in the first year as everything is new, is stressful. Being part of a large class and dealing with fourteen different subject teachers in the first year is overwhelming, and the time they were afforded by their teacher in primary isn't possible in secondary. How I support a student changes throughout the school year. In September, gaining their trust and building a relationship before anything else is vital as they need to be able to trust me and understand that I am there for them. From there, it's guidance with organisational skills, creating a system that works for them at their locker and promoting their independence to help themselves throughout the day while also affording them time when they need it and, most importantly, understanding.

Educating teachers on why these students may react differently would help both the teacher and the student. CPD courses as part of Croke Park hours may be an option to upskill, and having open lines of communication between teachers and SNAs to support the student should be encouraged as in most cases the SNA knows the student better than anyone. Having flexibility should a student need time out of class due to sensory sensitivities, and ideally having a place to go, such as a unit or a room where they can have some time out. Lunchtime clubs like art, chess, music, etc. work well in my school, giving students an option should they want to escape a loud and busy canteen.

What attracted you to the graduate programmes in Autism Studies offered at Mary Immaculate College?

I lived away for several years, and when we moved back in 2019 I decided to change my career as I wanted to work in an area that had more meaning for me and I had always wanted to work with children with additional needs. I have a degree in art and design and had initially thought of play therapy, so having the GCAS course was an excellent foundation for my new career path. Going back to study was a big decision, but not one I have regretted.

I enjoyed the GCAS so much that when they announced we would be the first students to start the GDAS, I jumped at the chance. As the GDAS is a very different course to the GCAS, being in control of what direction the year would take me and deciding what my systematic review would be based on both excited and terrified me. Having the course delivered online really suited my circumstances, and a mix of recorded and live lectures was an additional bonus.

Can you give us a brief description of what you learned from the courses and how your learning impacted your daily practice?

The many skills I have taken from the GCAS guided what direction I wanted my systematic review to take in the GDAS. On a personal level this course has given me so much, as unlike many of my peers who have great experience, I was very new to the world of autism. I had to learn so much that my group already knew, even down to the terminology used.

So when it came to assignments, I would read and keep reading, write and rewrite, and by doing this and researching an area of interest, it completely changed how I work, both on the course and in practice.

Researching what inclusion means allowed me to learn what daily life and its challenges are like for students through the students' words. Being assigned to one student in my role allows me a window into their world, and when researching for my systematic review, I saw that life and the challenges these students come up against daily are very similar, regardless of geographical spread. Taking the knowledge I have learned through the GDAS has given me a level of understanding in my position as an SNA that I may not have reached without completing the course.

The three modules within the postgrad diploma in Autism Studies are taught through recorded and live sessions on most Saturdays over the year-long course. How did you fit in studying around life and work?

As mentioned, the course being online was a big incentive to continue with the GDAS. Motivation is also a huge part of this as it is your responsibility to stay on top of things, which isn't always manageable with a full-time job and family. I joined the live lectures when they were on because I tended to ask a lot of questions, so I tried to assign time during the weekend to the lectures, and usually by Monday or Tuesday I would have completed my forum input to leave time over the following three days to work on upcoming assignments. This course has taught me that polishing my organisational skills makes it work in many ways.

I work well early morning, around 6:30 a.m., so I am first up in our house and always tried to work for a few hours before everyone else got up. The stage I was at with an assignment dictated the amount of time I required, so when it came to reading articles, I would fit it in around everything – lunch break, sitting in the car during my daughter's training or often instead of a book at night. Assignment writing is different, and I needed to commit to time blocks when I could – weekend early mornings up to lunch being my preferred time and usually the most productive.

What advice would you give parents and professionals thinking about taking part in the postgrad diploma in Autism Studies?

The course is a big commitment. There is a lot of reading, researching articles, using several databases and learning new skills as a researcher, so it was a big learning curve. The course demographic is mixed, which was great, as on a personal level I learned so much from my peers. The direction I have chosen to take with my systematic review has really broadened my knowledge to hearing the autistic voice in research. Until I started this course, I didn't realise how little there is out there in evidence-based research that includes the voice of autistic students.

Starting in September there were a lot of unknowns for me. As the GCAS was so enjoyable I just wanted to carry on. The GDAS is a very different course, though – a lot of backwards and forwards with ideas. As you decide your path through the year, it is your decision regarding the direction you want to go. Looking back, having an idea of what you want to achieve from this course will help with your decision, and for me linking it to my work gave me the scaffolding needed when digging deeper into research. I recommend linking your topic to work or home. It helped with focus and drive on the hard days and changed how I work as an SNA, giving me a far greater understanding.

USING SHAPING TO INCREASE FOODS CONSUMED BY CHILDREN WITH AUTISM

This article was reviewed by: Oates, S.

Siobhan chose to review this article because as a clinical nurse specialist (CNSp) in autism she has noticed a significant increase in the number of autistic children presenting in the resource centres with feeding behaviours ranging from food refusal to food selectivity (consuming a limited amount of foods) to mealtime behaviours. As parents often report and express their concerns and anxieties in relation to their child's feeding problems and the impact on their child's overall physical development and how these impact on family life, Siobhan wanted to extend her understanding of effective supports so she is better informed on how to support autistic children and families in her professional practice.

BACKGROUND

Parents and caregivers regularly highlight concerns in relation to feeding problems for their autistic children. Research by Ledford and Gast (2006) found that between 46–89% of autistic children experience problems with feeding. These problems can result in the risk of nutritional and /or medical issues such as malnutrition, vitamin deficiencies, weight loss or obesity. Prior research (Panerai et al. 2018) found that behavioural interventions can be effective in ameliorating these difficulties for autistic children and in supporting generalisation of behaviours to social settings and environments.

There is existing evidence that interventions based on operant conditioning can be effective for feeding difficulties in children thus avoiding the need for invasive interventions such as gastrostomy tubes (Marshall et al 2014). Whilst research on the detrimental impact feeding problems have on an autistic child's overall wellbeing and health, there remains a gap in literature on this topic which the authors of the study wanted to address.

RESEARCH AIM

The aim of the study is to examine effectiveness of shaping and differential reinforcement to increase the number of foods consumed by autistic participants.

RESEARCH METHODS

The study took place at a university-affiliated applied behaviour analysis clinic. It was conducted twice a week with approximately ten trials per one hour session. The participants were two autistic children of similar age: Ian a 7-year-old male and Ellie an 8-year-old female. Both children were selected for this study because they presented with the feeding problem food selectivity (ate only a limited amount of foods). Informed consent was obtained from the parents of both participants and approval was obtained by the participants paediatricians to rule any gastrointestinal conditions or other medical issues.

Prior to the study starting, parents engaged in a structured informal interview with the first author to determine mealtime routines and desired treatment outcomes including identifying foods they wanted their child to consume that were not currently in the child's repertoire. The foods identified were chicken (both), corn (both), carrot (Ian) green bean (Ellie) and a peanut butter cracker (both). Parents also completed a paired choice preference assessment to identify reinforcers.

Data was collected at the end of each trial at Baseline, Intervention and Maintenance level. The level of food acceptance and the number of new foods consumed was based on a hierarchical level and a clearly defined operational definition of each acceptance level. To ensure reliability, interobserver agreement (IOR) data was collected by a second person based on an agreed level of acceptance per trial that is one hundred percent of trials for Ian and ninety-six percent trials for Ellie.

At Baseline, the four targeted foods were presented simultaneously to the participant on a white muffin tin liner on a plate. The only instruction given was verbal, 'eat your snack'. Compliance was not reinforced, and inappropriate behaviours were ignored.

Intervention was identical to baseline with two exceptions: (a) targeted food acceptance resulted in reinforcement, and (b) coloured muffin tin liners were used to identify the food associated with reinforcement. Participants were taught to recognise the importance of the coloured muffin tin liners following verbal directions and reinforcement history.

Data was collected at the end of each trial based on a hierarchical level of food consumption with a clearly defined operational definition of each acceptance level. For each trial, the highest level of acceptance was recorded.

Once the study participants demonstrated consistent acceptance of each food presented individually, multiple foods were presented to target consumption of all four newly-acquired foods within one meal time session. The number of food items and time increased until all four food items were presented and consumed within 8 minutes before reinforcement was accessed.

Maintenance was conducted for 2 to 4 weeks after the participant had reached mastery. Maintenance trials were identical to Intervention trials.

RESEARCH FINDINGS

In the study the results are provided in text and graphically. They indicate that both participants consumed the four foods following implementation of the intervention, however the results were difficult to decipher.

Findings/Results for Ian:

- Baseline: refused chicken 83% of trials, refused carrot 94% of trials, refused corn 96% of trials and peanut butter crackers 89% of trials.
- After intervention was introduced, improvements in terms of the level of food acceptance were quickly demonstrated
- Mastery criterion was met for: chicken in 12 trials, for carrot in 9 trials, for corn in 9 trial and for peanut butter crackers in 9 trials
- On average, Ian met final mastery criterion for each food within 10 trials.

Findings/Results for Ellie:

- Baseline: refused chicken 100% of trials, refused green bean 95% of trials, refused corn 87% of trials and peanut butter crackers 96% of trials.
- After intervention was introduced, steady improvements were demonstrated across all food items.
- Mastery criterion was met for: chicken in 4 trials, for green bean in 9 trials, for corn in 9 trial and for peanut butter crackers in 9 trials
- On average, Ellie met final mastery criterion for each food within 17 trials.

STUDENT OPINION

While this study focused on behavioural interventions for food selectivity, follow up was not completed with the participants and families, so it is unclear if the interventions continued to be effective after completion of the programme.

The sample size of this study was small, and participants were of a similar age. Extension to a wider cohort would be beneficial to extend understanding of effectiveness of the intervention across the autistic population.

Completion of various assessments such as a sensory profile, functional behaviour analysis would provide a more comprehensive assessment and ensure an individualised approach to feeding differences in autistic children.

A limitation of the study was the small number of participants and lack of comparison group.

Sensory differences are a core feature of autism meaning autistic individuals can present with hypo and/or hyper sensitivities to sensory input, yet the authors did not complete a sensory profile assessment on participants.

Both participants of this study were familiar with Applied Behaviour Analysis therapy. The results may have been different for an autistic child not familiar with this approach.

IMPLICATIONS FOR PRACTICE

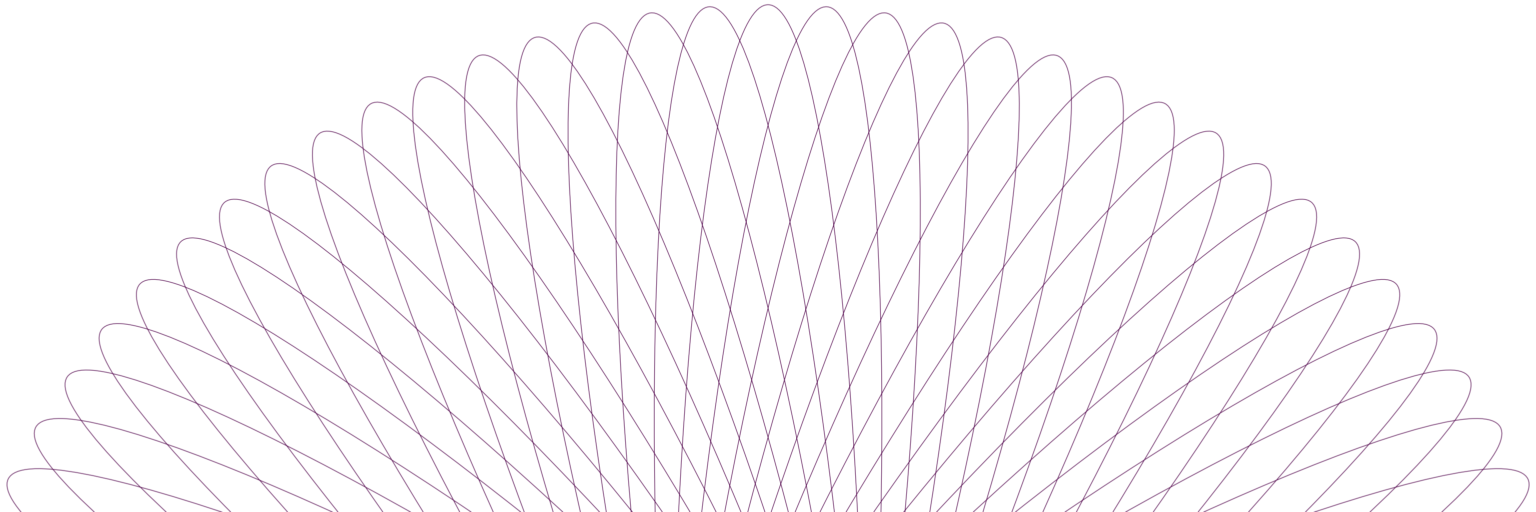
This study demonstrated the effectiveness of behavioural interventions shaping and differential reinforcement to overcome feeding inflexibility by autistic participants.

Increasing food flexibility has unique benefits for an autistic child including nutritional variety and increased social opportunities such as eating in restaurants, friend's homes, birthday parties, vacations, and field trips.

Families of children with food inflexibility may have to adjust daily routines to ensure the child has access to his or her limited food repertoire during meal-times.

The inclusion of parents and caregivers is vital for the successful implementation of this important life skill and for ensuring continuation, consistency and transferability to a wide range of environments and setting.

Whilst this study demonstrated the effectiveness of this behavioural intervention to overcome feeding inflexibility, there is still a gap in the literature. To close this gap more studies are needed to explore the effectiveness of different interventions for feeding differences in the autistic population.



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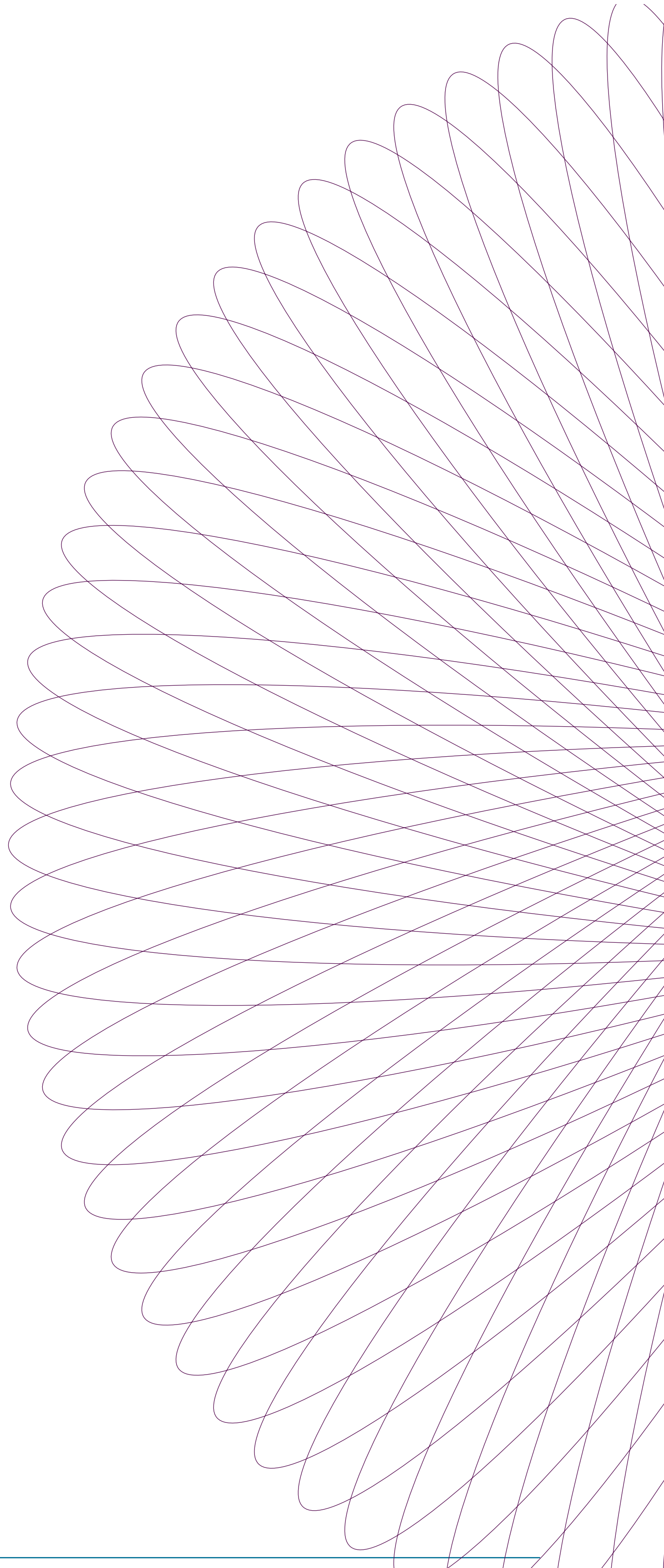

TRANSFORMING THE LIVES OF EARLY CHILDHOOD TEACHERS, AUTISTIC CHILDREN AND THEIR FAMILIES: FINDINGS AND RECOMMENDATIONS FROM AN EVALUATION OF A PROGRAMME OF CONTINUING PROFESSIONAL DEVELOPMENT

This article was reviewed by: O'Dowd, A.

Ann chose to review this article based on her experience as an early years teacher for over thirty years. She has direct experience of the importance of continued professional development for teachers within the early years education system and how this training can transform teachers, giving them confidence to work with all children in an inclusive and meaningful manner.

BACKGROUND

This study was carried out to establish the impact of an autism-specific continued professional development programme on the inclusive practices of 311 early years educators in Ireland. The literature identifies and outlines key areas of professional training that teachers require to meet the educational needs of autistic children within the early years setting. The knowledge, skills and attitudes of early years teachers are key to effective inclusion within the early years setting, which can be achieved through providing staff with continued professional development (Flynn, Shevlin and Winter, 2013). Therefore, it is believed that appropriate early education provision within early years education can improve learning outcomes for autistic children.

RESEARCH AIM

The purpose of the study was to evaluate the Teach Me As I Am programme. This programme was designed by Ireland's national autism charity, AsIAm, to enhance early childhood teachers' capacity to provide an inclusive education for autistic students.

Initial consultation took place with 246 early childhood teachers through an online survey to establish their knowledge and experience in working with autistic children and further specific training they required.

The results from the survey informed the development of the Teach Me As I Am programme. The programme was delivered over two days, at sixteen locations throughout Ireland, with varied intervals between both sessions to allow participants to reflect on their learning. Following this, an evaluation sought to establish the impact of the programme on participants' experiences and knowledge regarding the provision of inclusive education for autistic children.

RESEARCH METHODS

Study participants were adult learners who completed the Teach Me As I Am programme, with data collection taking place across both days of programme delivery. The programme was evaluated via a multi-method approach. An exploring and telling methodology was used as a means of capturing the perspective of the autistic child in their education setting, wherein two children wore a small portable camera in their setting with the video data then being coded by the researchers. A pre- and post-questionnaire collected demographic data, along with information on participants' values, beliefs, attitudes, knowledge and practices in the area of inclusive education. Using Mentimeter, participants recorded a pre- and post-word cloud to share their understanding of accommodating the needs of autistic children within the early years environment. Six participants also completed a semi-structured interview to further discuss their experience of the Teach Me As I Am programme.

RESEARCH FINDINGS

The word cloud from pre-programme delivery included terms such as 'difficulty', 'social issues' and 'out of control', while the word cloud from post-programme delivery highlights terms such as 'individual', 'equality' and 'everyone is different', emphasising the conceptual shift in understanding of autism. Questionnaire data indicated that 80 per cent of participants had previous experience working with autistic children, while 60 per cent of participants did not previously participate in CPD training related to autism. Participants stated that they had gained knowledge, confidence and expertise in providing for children with autism as a result of completing the programme. A key point that emerged was that participants gained knowledge on the importance of observation, planning and listening to the child. Questionnaire results also showed a change in participant beliefs and attitudes with regard to the learning environment, showing a need to create a calm, predictable and structured physical environment to meet the child's learning.

STUDENT OPINION

- A strength of the paper was in the identification of the impact of CPD training within the early years education setting. This study provides a detailed account of participant attitudes regarding the educational benefits of CPD training, outlining via a range of methodologies the ways in which a shift in attitude can enhance teaching practice and aid in establishing an interpersonal connection with the child.
- A limitation of the study was that it did not include the age range of participants or years' experience working in the field of early years. This information could be relevant in establishing why half of the course's participants' highest qualification was Level 6 teaching.
- It must also be noted that the paper did not specify whether any of the participants were from the same early years setting, which would have allowed for a collaborative learning experience for participants.

IMPLICATIONS FOR PRACTICE

Practitioners will have the knowledge, understanding, skills and competencies to support autistic children holistically and provide the highest standard of education for autistic children. CPD opportunities are a vital link for parents, teachers and all professionals to ensure that they have the confidence to bring about positive change where every autistic child is valued as an individual in our society. Continued professional development opportunities may enable practitioners, parents and professionals to see through the child's eyes and hear their voices, which may have life-changing benefits for the autistic community; a world where autistic children can grow socially with their peers, where differences are embraced and understood and are no longer stigmatised, where all children are equal. CPD training can bring about a change within society where neurodivergence is no longer seen as a disorder.

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THE IMPACT OF SENSORY PROCESSING ON EXECUTIVE AND COGNITIVE FUNCTIONS IN CHILDREN WITH AUTISM SPECTRUM DISORDER IN THE SCHOOL CONTEXT

This article was reviewed by: Clifford, A.

Aoife chose to review this article because sensory processing in autistic children is an area of special interest to her. Aoife is currently teaching in a mainstream junior infant classroom and has an autistic boy in her class who presents with a myriad of sensory processing differences. Aoife was interested in furthering her knowledge of sensory processing and the various effects it has on the everyday lives of autistic children. She took it as an opportunity to better understand the boy in her class and gain knowledge on how best to support him.

BACKGROUND

Executive functioning encompasses higher-order cognitive processes that control goal-directed behaviour, such as working memory, planning and inhibition. Executive dysfunction can be a major obstacle for autistic people. It is associated with many challenges including communication, emotion regulation, resisting impulses and maladaptive behaviours. Some research suggests that executive functioning is influenced by sensory processing. Sensory processing refers to gathering, organising and interpreting information from the auditory, visual, tactile, gustatory and proprioceptive systems. Some researchers theorise that sensory processing may act as the first step in successful higher-order cognitive processing like executive functioning. This article explored the impact of sensory processing differences on the severity of executive functioning challenges.

RESEARCH AIM

The aim of the study was to analyse the relationship between sensory processing and executive functioning (inhibition and planning) and the cognitive functions of verbal fluency, sustained attention and short-term memory. It investigated whether sensory processing differences are predictive of executive and cognitive functioning differences in autistic children. Researchers hypothesised that the greater sensory processing difficulties are, the greater the cognitive and executive functioning challenges will be, so sensory processing challenges will predict cognitive and executive functioning difficulties. The study focused on the experiences of autistic children with moderate to high support needs as this group is less often included in research.

RESEARCH METHODS

A cross-sectional case-control design was used. There were two participating groups: a group of autistic children and a group of non-autistic children. The two groups of children were matched one-to-one on non-verbal IQ, chronological age and gender, with forty children in each group. A total of thirty-three teachers also took part in interviews to provide demographic information and complete a questionnaire focusing on sensory processing issues and social participation. Researchers also observed the children in their classroom settings. They used a broad battery of tests to evaluate each child's non-verbal IQ, verbal IQ, executive functioning and cognitive functioning. Analysis was conducted on the quantitative data produced.

RESEARCH FINDINGS

The hypothesis of the study was supported. There were statistically significant differences between the autistic group and the comparison group across all measures, with autistic children showing significantly higher levels of sensory, cognitive and executive function difficulties.

The group of autistic children demonstrated more sensory processing challenges and they obtained lower task performance scores on all executive functioning and cognitive measures. Findings suggested that sensory processing challenges were predictive of difficulties in the areas of inhibition, auditory-sustained attention and short-term verbal memory.

STUDENT OPINION

- The purpose of the study was to learn more about the impact of sensory differences on executive function by determining if there is a difference between autistic and non-autistic children. As such, the case-control cross-sectional approach was appropriate.
- A limitation of this design is the difficulty in determining cause and effect outside of the participant group; therefore, it is difficult to generalise the results to the whole autistic community.
- Invitations to participate were only sent to schools with TEACCH-integrated classrooms. This may have created a sampling bias as it is possible that only those with a strong interest in the area opted in.
- While there is benefit in focusing on children with moderate to high support needs as their experiences are under researched, this limits the generalisability of the findings.
- There was a benefit in conducting observations in the classroom. The use of a familiar setting would have been especially beneficial for the autistic children. Uncertainty caused by new places may create fear and stress that could influence performance.

IMPLICATIONS FOR PRACTICE

- By understanding the relationship between sensory processing and executive functioning, it may be possible to develop targeted interventions.
- The inclusion of the school context may offer particular benefit for understanding the potential of child-centred interventions that use playful and goal-directed activities that provide a sensory motor challenge.
- By focusing on autistic children who have moderate to severe support needs, researchers are developing our understanding of a section of the community less often included in research.

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AUTISTIC GIRLS AND SCHOOL EXCLUSION: PERSPECTIVES OF STUDENTS AND THEIR PARENTS

This article was reviewed by: Ryan, E.

Eilís chose to review this article because she currently works as a teacher in a mainstream primary school with autism spectrum disorder (ASD) classes. In recent years a lack of adequate educational placements for autistic students has been a prominent educational policy concern in Ireland. Even when students can access educational provision, school exclusion is disproportionally high for autistic students. Therefore, identifying and alleviating both existing and potential barriers to students' participation, engagement and achievement is an area of interest for Eilís. The study represents one of the few that examined exclusion experiences from the perspective of young autistic people.

BACKGROUND

School exclusion is highest among children with special educational needs, including autism. It is defined as either temporary suspension or permanent expulsion. In England, exclusions of autistic children increased by almost 60 per cent between 2011 and 2018, while in Ireland, one in three autistic children are likely to experience exclusion through reduced timetables. Despite the high rates of exclusion, there is a dearth of literature examining autistic students' experiences of it and even fewer focusing on the experiences of autistic girls, who are often overlooked in the classroom. In the move to secondary school, fewer supports may be available, time is less structured and a tendency to mask may mean that teachers miss a student's struggles. As a result, they may be at greater risk of isolation, rejection or bullying, and all these factors may place them at greater risk of school exclusion.

RESEARCH AIM

The research aimed to gain insight into experiences of school exclusion from the perspective of eight autistic girls and their parents. By capturing their voices it was hoped that insight into their experiences of secondary school education would be provided, adding to knowledge concerning this under-researched population.

RESEARCH METHODS

The study was advertised by contacting PRUs (Pupil Referral Units) and special schools across South East England. The study focused on the experiences of eight autistic girls and their parents. All participants had experienced exclusion from a second-level mainstream setting. Data was collected using semi-structured interviews. The interview schedule consisted of open-ended questioning regarding classroom environments, experiences of school exclusion, prior expectations of school provision and the experiences of mainstream settings. Given the sensitive nature of the research topic, girls were given the option to have a parent present during their interview.

Investigator triangulation was used to enhance credibility of the findings and decrease risk of bias and subjectivity in the study's results. Two of the authors analysed the data independently and developed initial themes and subthemes before reviewing these together without theorising. Once coded, the data was categorised into themes.

RESEARCH FINDINGS

Difficult school environments, tensions in school relationships and problems with staff responses were perceived to have contributed to the exclusion of the participants from their schools. Challenges within the school environment included problems with the sensory environment, difficulties when placed with inappropriate peers and general pressures of mainstream classrooms.

With regards to school relationships, both peer and staff relationships were highlighted, as well as a general lack of communication. Staff relationships were one of the most influential aspects regarding the participants' perceptions of mainstream school and their subsequent experiences of exclusion.

Problems with staff responses included a perceived lack of understanding of the girls' needs and a lack of appropriate support being provided, resulting in 'battles' between parents and schools.

STUDENT OPINION

- As the study aimed to investigate the autistic females' experiences of school exclusion, a specific subgroup of the autism population was required. The small-scale nature of the study limits the generalisation of its findings. Contacting participants through alternative placements such as PRUs ensured that participants had previous experience of school exclusion; however, generalisability of the findings is limited by the profile of the participants in the study. As seven of the participants were placed in a PRU, findings may not be reflective of autistic girls currently experiencing temporary exclusion or a reduced timetable in their mainstream setting.
- The barriers identified in this study are not gender specific. This limitation may have been addressed had there been a comparison group of autistic females, or a group of autistic males who had experienced exclusion. Without this, this study cannot distinguish between the nuanced experiences of autistic females, which would develop the understanding of the female phenotype.

IMPLICATIONS FOR PRACTICE

- The study recommended that further research identify how mainstream settings can adopt more flexibility into their practice. It also recommended that schools promote inclusive attitudes within their staff, establish positive relationships with families and develop transition plans for excluded children.
- Improving staff knowledge and awareness of autism, developing effective methods of supporting students and enabling staff to challenge the ethos and practices that cause such difficulties are of critical importance in creating an inclusive atmosphere that may limit the likelihood of school exclusion.
- The PRU model may have useful practices for schools to adopt. It was found that PRUs had smaller class sizes, accommodated different coping strategies and actively attempted to alleviate barriers. Physical and sensory environments are generally understood to promote or hinder inclusion of autistic students; however, replicating the flexible approach shown in the PRUs in mainstream classrooms would be both challenging and costly.

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FAMILY PERSPECTIVES ON EDUCATIONAL EXPERIENCES, POST-SCHOOL NEEDS, AND QUALITY OF LIFE OF YOUNG AUTISTIC ADULTS

This article was reviewed by: Rainsford, C.

Carmel chose to review this article because she is interested in exploring what is next for autistic teenagers as they transition from school. During her career, the Department of Education in Ireland formally recognised the 'distinct educational needs' of autistic pupils in 1998 and allocated additional resource teaching hours and SNA support (Daly et al., 2016). special education needs organisers were employed to allocate resources to schools for autistic and other children with special education needs following the EPSEN Act in 2004. Then publicly funded multidisciplinary assessments were introduced as part of the Assessment of Need (AON) process under the Disability Act in 2005 (Daly et al., 2016). Though these policies have improved the situation for autistic pupils, Carmel questioned if these changes have been enough and wanted to learn from the experiences of young autistic adults in Ireland who have left school and see how the transition to adulthood could be improved for future generations.

Carmel is a primary school teacher in Charleville, Cork. She has worked in education for over thirty years. In addition to mainstream teaching, she has worked towards inclusion in her former roles as principal, special education teacher and in her current job teaching in a special class for autistic children.

BACKGROUND

There has been an explosion of research into autism in the twenty-first century, with the majority focusing on childhood (Lord et al., 2020; Walsh, Dempsey and Lawler, 2021). However, very little appears to be based in Ireland (Republic), and few studies examine adolescent and adulthood life stages. As autism is a lifelong condition, research highlights the need for appropriate services to support autistic individuals throughout their lives (Boucher, 2017, p. 262).

It is important that schools support autistic students into adulthood; however, young people have reported that 'schools can be extremely bad places to learn if you are autistic' (McAnulty, 2020, p. 88). So how can we support young autistic people to develop the skills necessary to successfully transition to adulthood and obtain similar opportunities to neurotypical peers, such as employment and third-level education?

Current research into the factors that affect quality of life (QoL) of young autistic adults as they transition to third-level education and/or employment should inform current practice and guide future environmental supports.

RESEARCH AIM

This pilot study aimed to examine education, employment and availability of supports in Ireland and how they contributed to the QoL of young autistic adults. The research was through the lens of an adult family member (the participant) who could evaluate the impact.

RESEARCH METHODS

The lives of four autistic people aged 18–21 were the focus of this exploratory research. Researchers consider this group to be 'a hidden population' as involvement with state services finishes at eighteen. Participants were recruited following online advertising and direct contact with autism spectrum disorder (ASD) support groups. Clear criteria were in place for participants regarding age, level of English and the method of ASD diagnosis. Participants were all female: three mothers and a sister.

For such a small population the autistic young people varied in gender, intellectual ability and the existence of a comorbid condition.

An interpretative qualitative methodology was employed via semi-structured interviews that took place in a convenient location for participants. Open-ended lines of questioning based on literature were used in the forty-minute sessions. Responses were recorded and transcription and thematic analyses followed.

RESEARCH FINDINGS

The authors cite the delay in autism diagnosis and access to support services in Ireland as two of the main factors that impact the QoL of young autistic adults. These children's services often disappear at the age of eighteen leaving a huge void when autistic people are transitioning to independence.

Walsh, Dempsey and Lawler (2021) recommend that education staff be sufficiently trained on autism. This is supported by reference to NCSE research. Currently there is an emphasis on inclusion in Initial Teacher Education (ITE) without providing 'detailed guidance on how to enact inclusive practices' (Hick et al., 2019). This has immediate implications for ITE, SNA training and CPD.

The research suggests that third-level institutions need to be proactive in preventing obstacles to entry and success. There is an 'extra effort required by autistic students to thrive within higher education' (McLeod et al., 2018). According to Mitchell and Beresford (2014), young autistic people valued a 'practitioner' to help prepare for the move to further education. However, the second-level curriculum also needs to include independence skills in preparation for adulthood (Hume et al., 2014). Similarly, a transition plan for post-school placement should be a focus of secondary schools, which was a recommendation of Daly et al., (2016).

STUDENT OPINION

This research paper provides information on factors influencing the QoL of young autistic people who have recently left school in Ireland. A major strength is the unique Irish context, considering current practices and highlighting support limitations.

Overall rigour was employed with evidence of trustworthiness. Clear themes emerged from the qualitative inductive analysis: diagnostic process, education, services, post-school needs and family expectations. Even though there was variance within the population of autistic people, there were many common findings with implications for practice.

The authors have restricted the discussion to the results that can be supported by literature. This ensures that broad findings rather than individual viewpoints alone are taken into consideration.

The greatest limitation of this study is the small number of participants (four); however, the implication of this for generalisation of findings is accepted by the authors.

The argument for using family members for the research is logical and grounded in literature. There is recognition of neurodiversity and an acknowledgement of the need to focus on the autistic viewpoint for the next phase of the research. This will be awaited with interest.

IMPLICATIONS FOR PRACTICE

As autism is a lifelong condition, the research highlights the need for supportive services prior to and state services after the age of eighteen. It is important at government level that timely assessment combined with ongoing support into adulthood is a feature of future policy.

In order to achieve a good QoL, this study highlights:

- that autistic young people need support in school with career guidance, social skills and independent living skills.
- that professionals in secondary and third-level education should engage with training in autism and best autism practices to support autistic students to transition to third-level education placements successfully.
- parents, professionals and young autistic adults should work in partnership to plan for transition to third-level education.
- the education of employers and society about the support needs and strengths of autistic people.

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SCHOOL AGE OUTCOMES OF CHILDREN DIAGNOSED EARLY AND LATER WITH AUTISM SPECTRUM DISORDER

This article was reviewed by: Conway, D.

Denise is an educator, access and inclusion model specialist, and inclusion coordinator in an Irish Early Learning and Care setting. She has chosen to review this article as she is interested in the benefits to autistic children in receiving an early autism diagnosis and the early interventions that follow. Without an early diagnosis there are limited interventions and supports available.

BACKGROUND

The question of how soon an autism diagnosis can and should be made is an important one. Diagnosis is the predecessor to early interventions (EI) and so the validity of early diagnosis cannot be ignored (Miller et al., 2021; Aishworiya et al., 2021; Di Renzo et al., 2021).

There are benefits and drawbacks when looking at early diagnosis. An early diagnosis and access to timely supports and services may promote positive developmental gains, but when milder characteristics of autism present consideration is needed and timing of diagnosis should be: 'As soon as the benefits of diagnosis for the child and family outweigh any adverse effects of possible misdiagnosis' (Boucher, 2017, p. 194).

Therefore studies such as the one chosen for this review are important building blocks to validate or repudiate very early diagnosis. It is through analysing the differences of age of diagnosis, diagnostic criteria and benefits of early interventions that the autism community can receive the supports they need and access services in a relevant and timely manner.

RESEARCH AIM

This study investigated the school-age outcomes of children who received an early and later diagnosis of autism.

RESEARCH METHODS

The cognitive and behavioural outcomes of children aged 7-9 years who were diagnosed early were compared to children diagnosed after three years. The early diagnosis group comprised forty-eight children diagnosed with autism at or before twenty-four months of age who were identified by maternal and child health care nurses as part of a previous study (Barbaro and Dissanayake, 2010). The late diagnosis group included children diagnosed after three years of age (n=37) who were recruited via advertising on social media, university blogs and invitations sent to those on a participant registry.

Data about the children's history was collected by gathering information from parents using questionnaires and surveys. The researchers also used a broad range of diagnostic assessment tools to compare both cohorts at school age (5–7 years) looking at cognition, vocabulary, reasoning, play, social communication skills, adaptive behaviour, daily living and socialisation. These included the Wechsler Abbreviated Scale of Intelligence (WASI) (Wechsler, 2004), Verbal Intelligence Quotient (VIQ), Autism Diagnostic Observation Schedule (ADOS-2) (Lord et al., 2000) and Vineland Adaptative Behavior Scales-II (VABS) (Sparrow, Balla and Cicchetti, 2005).

All participants were from similar socio-economic backgrounds, parental incomes, levels of parental education and were living in similar communities (Clark et al., 2018).

RESEARCH FINDINGS

This study found that the children in the early diagnosis group (diagnosed at or before twenty-four months) began intervention significantly earlier than children diagnosed later (eleven months on average), and also accessed significantly more EI overall (ten months more on average). The early diagnosis group received less support at school age and had significantly higher Full-Scale Intelligence Quotient (FSIQ) than children diagnosed later (Clark et al., 2018). Additionally, children diagnosed later also demonstrated significantly more restrictive repetitive behaviours at school age (Clark et al., 2018).

A comparison of when the children in both cohorts received intervention was a critical part of the study's results. The children diagnosed earlier were wait-listed for interventions with an average waiting time of six months. Whereas the children who were diagnosed approximately two years later were immediately provided with EI. Although the age difference in diagnosis was approximately two years, the age difference at the start of EI was eleven months. The authors emphasise the need for intervention as early as possible to take advantage of early learning experiences while neuroplasticity is at its greatest (Clark et al., 2018).

The benefits of early diagnosis and early intervention as demonstrated in this study are seen in other recent studies of early autism diagnosis (Miller et al., 2021; Aishworiya et al., 2021; Di Renzo et al., 2021).

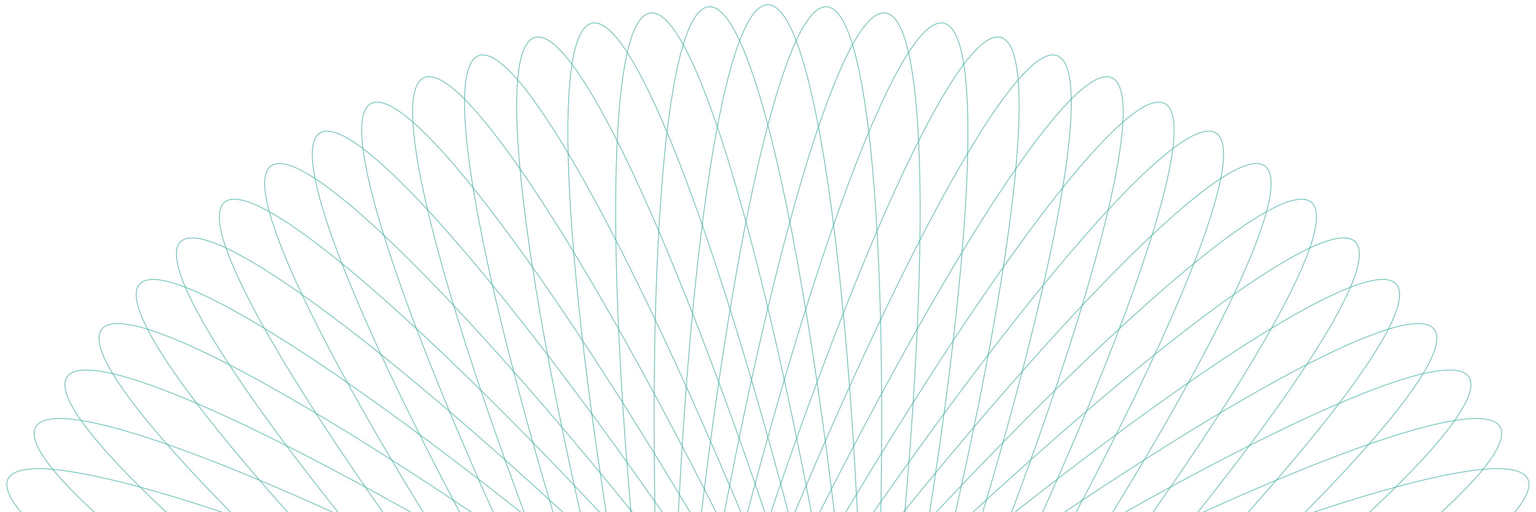
STUDENT OPINION

This study showed children diagnosed at or before twenty-four months of age were able to access more interventions, displayed greater verbal and overall cognition at school age, required less ongoing support and were more likely to attend mainstream school than children diagnosed later (Clark et al., 2018).

However, lack of baseline knowledge of the late diagnosis group was a weakness in the study. Diagnoses from different clinician types and use of a non-random control cohort also weakened the study.

The study highlighted the effects of waiting times, showing that the case cohort were advantaged by early diagnosis but would have been more advantaged if they had received immediate EI.

This study, and other studies like it, impact the autistic community. Continued research, without the weaknesses and biases shown here, will validate the benefits and drawbacks of early diagnosis and early intervention, and subsequently promote the development of clearer guidelines for early diagnosis and interventions.



IMPLICATIONS FOR PRACTICE

This study suggests that early identification and diagnosis of autism and prompt access to services and supports promotes greater developmental gains for autistic children.

Training and education could help support professionals and parents to recognise the characteristics associated with autism earlier.

Investment should be focused on early support services to afford families more timely support opportunities after diagnosis.

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INCLUSION IS A FEELING, NOT A PLACE: A QUALITATIVE STUDY EXPLORING AUTISTIC YOUNG PEOPLE'S CONCEPTUALISATIONS OF INCLUSION

This article was reviewed by: Deegan, H.

Hazel is a special needs assistant (SNA) in a mainstream secondary school. When researching mainstream school experiences for autistic teenagers, Hazel noticed that there was an abundance of research articles on teaching strategies, practice and inclusion, yet there seemed to be a lack of direct research including the autistic student. Hazel suggested that within mainstream education a range of opportunity and possibility exists, surrounded by the understanding of what inclusion means to the autistic community. Professionals can learn from the experiences of autistic students and improve services and supports provided. Working with autistic students daily, Hazel can see the effect inclusion has on these teenagers, which influenced her decision to choose a topic that included the autistic voice. Communication and understanding from their peers and teachers, and hearing their voice through lived experiences, is the foundation for inclusion within this demographic.

BACKGROUND

In the UK 70 per cent of children with autism attend mainstream school (DfE, 2021), yet the inconsistencies in teaching knowledge, teaching practice, sensory challenges and the fallacy surrounding ease of inclusion is evident in research and practice (Goodall, 2020). The evaluation encompassing the success of integration and inclusion is mainly measured through research including teachers, parents and caregivers rather than from the perspective of the autistic student (Lebenhagen, 2020).

Research that includes the autistic voice gives validity and depth, strengthening its credibility, yet participatory research is still rare (den Houting et al., 2021). An all-inclusive approach underpins qualitative evidence-based research in mainstream education that supports and optimises the right of inclusion for the student (Roberts and Webster, 2022). Such studies with a participatory approach to garnering evidence can give meaning and hope to families (Bradley, 2016).

RESEARCH AIMS

This study aims to understand how twelve autistic young people aged 11–17 coped with inclusion into mainstream school, how they were supported and their personal experiences leading to alternative means of education.

Goodall's (2020) approach puts the autistic student at the centre of the research, highlighting the daily challenges mainstream school held for them. In conclusion, a wish list of wants is clearly presented, with inclusion and understanding at the forefront.

RESEARCH METHODS

This study uses a flexible qualitative participatory approach – participatory action research (PAR) (MacDonald, 2012). Being an exploratory study that included CRAG consultation, therefore garnering trust with an inclusive appropriate method, PAR allowed participants to have more control and speak freely. This fostered an empowered methodology during one-to-one semi-structured interviews (Powers, 2017; Chown, 2019) in either a familiar location, such as the Alternative Educational Placement or the study hub in a local church.

Using purposive convenience sampling, twelve participants (ten males and two females), 11–17 years of age, took part in the study. The study focused on students who struggled with full- or part-time inclusion into mainstream.

The researcher used a range of methods: one-to-one semi-structured interviews, draw-and-write activities, a true-and-false-style activity, and ranking activities. These methods and the topics discussed (such as 'exclusion in inclusion', 'supporting me' and 'inclusion and me') were developed by an advisory group of three young people.

A thematic analysis granted ease of communication collected and flexible and accessible analytics, generating much data, yet overall not generalised within the wider autistic community due to participant demographic (Crompton et al., 2020).

RESEARCH FINDINGS

The findings have an overwhelming focus on lack of inclusion, top-down understanding from teachers through to peers in the classroom, lack of knowledge and support of autism itself, yet no singular definition was identified. In summary, inclusion as a feeling is essential, yet full integration into mainstream is not possible (Chamberlain, Kasari, and Rotheram-Fuller, 2007). These findings disagree with comprehensive, inclusive education in mainstream as a one-size-fits-all approach, but outlines inhibiters and enablers of inclusion in the eyes of the students.

The twelve students in this study identified a lack of understanding from teachers and peers, sensory challenges posed by the school environment and large class sizes as inhibitors to inclusion. They noted that inclusion was a feeling of belonging, being accepted, respected and part of the school community.

STUDENT OPINION

Goodall (2020) presents a compelling argument underpinned by the educational experience of the participants, that inclusion is a feeling rather than the historical misconception that inclusion means integration into mainstream school. The cohort of students who participated in the research outlined the limitations and offered alternative viewpoints (Anderson-Chavarria, 2021) about education and suggested change. The autistic voice is heard in this article, yet due to selection and sampling bias the reader cannot help but feel another side of this argument needs to be heard.

Extensive research was conducted, strengthening the argument surrounding inclusion. The negative undertone paints a bleak picture for the reader, but the method of information gathering is easily transferable to a more extensive, diverse participation, allowing a more balanced overall view. With 70 per cent of autistic children attending mainstream (DfE, 2021), a twelve-participant study, albeit in-depth, provides a small window into mainstream experiences for those who are challenged, rather than widening parameters to gather a more generalised comprehensive analysis.

Within mainstream education, a range of opportunity and possibility exists surrounded by the understanding of what inclusion means to the autistic community.

IMPLICATIONS FOR PRACTICE

This study highlights the challenges young autistic people face daily in the school setting and suggests that parents, professionals and school communities should consider:

- training on autism and current best autism practices.
- capacity building on double empathy and understanding a range of student perspectives.
- the importance of listening to the perspectives and lived experiences of students to improve current practice.

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THE EXPERIENCES OF MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: MANAGING FAMILY ROUTINES AND MOTHERS' HEALTH AND WELLBEING

This article was reviewed by: Sloan, L.

Louise chose to review this article to learn more about the impact of raising an autistic child on maternal health and well-being, given that there was little research exploring the experiences of raising a child with autism spectrum disorder (ASD) from the maternal perspective. Autistic individuals and their families' experiences suggest that life is getting more difficult for autistic individuals and services are failing to deliver. As a parent to an autistic child, Louise has experience of this arduous process. Research suggests that it is common for a family to grieve the loss of the 'normal' child while coming to terms with an autism diagnosis, and Louise believes families are at their most vulnerable at this time.

BACKGROUND

The current expectation of full-time 'professional' autism parenting is rooted in a discourse of mother blaming persistently woven into the history of autism (Waltz, 2015) due to stigmatisation and the unjustifiable term 'refrigerator mother' (Kanner, cited in Boucher, 2017). In a study by Papadopoulos (2021) about mothers' experiences and challenges raising a child with ASD, the results revealed that families parenting a child with ASD experience several consequences across many aspects. Mothers reported their children's behaviour and their parenting role as the primary source of their caregiving burden stress, with intense feelings of autism stigma perceived from their community. These issues had a considerable and broad impact on their own lives. In a similar study by Halstead et al. (2018), it was discovered that maternal resilience had a significant independent main-effect relationship with well-being outcomes in mothers of children with ASD.

RESEARCH AIM

The chosen study was aimed at understanding the experiences of mothers of autistic children, how they dealt with their family routines and the effect this had on the mother's health and well-being. Many studies have examined the entire family experience (Bagatell et al. cited in McAuliffe et al., 2019), and the impact of autism on family routines has been investigated commonly through mothers' perspectives (Bagatell et al. cited in McAuliffe et al., 2019), but there is limited research in this specific area. This study used interpretative phenomenological analysis (IPA) to understand individual participants' experiences. IPA allows researchers to explore the experiences of participants, and not only describe them but also develop meanings in a thematic form (Larkin, Watts and Clifton, cited in McAuliffe et al., 2019).

RESEARCH METHODS

A qualitative approach was used when exploring the experiences of mothers of children with ASD. A phenomenological approach allowed the researchers to explore the experiences of participants. Purposive sampling methods were used to enlist twenty mothers of children with ASD aged 2–19 years. Semi-structured interviews were used. These were conducted face-to-face at participants' homes or by phone. Five main open-ended questions were developed. The interviews ranged from 60–90 minutes. Each interview was audio recorded digitally and transcribed verbatim. Two researchers analysed the data for triangulation (Altrichter, Posch and Somekh, 1996). The first and second authors separately read and reread one interview transcript first, while making notes of points that were then discussed between the two authors. This process enabled the author to obtain a holistic overview of the participants' thoughts and feelings (Papadopoulos, 2021).

RESEARCH FINDINGS

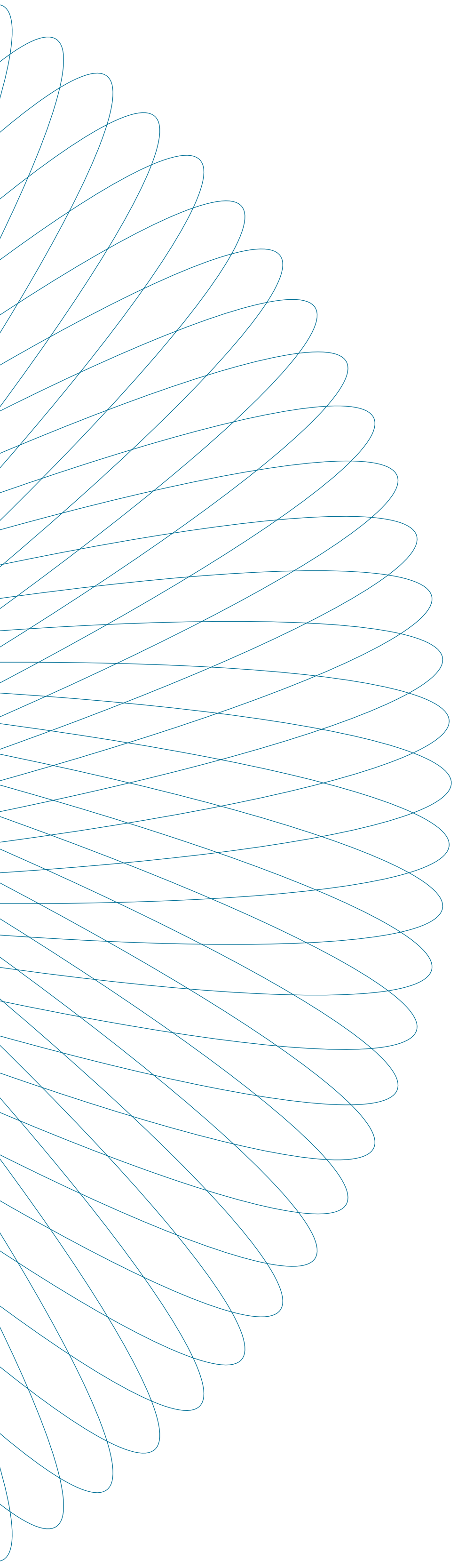
Five themes emerged from the analysis: 1) Keeping on track keeping healthy; 2) My life is busy because I do everything for everyone else; 3) Keeping on track all the time is tiring or frustrating; 4) Looking after my family by looking after myself; and 5) I am not perfect and it's OK. These findings are significant as they highlight the vital role that mothers play. The study demonstrates that the mother's responsibility for managing family routines is a potential risk to their own health and well-being (Bagatell et al. cited in McAuliffe et al., 2019). These themes suggest a need to consider an appropriate support to be provided for mothers in managing family routines, not only for their own benefits, but also for their families. The study concludes that mothers are crucial in managing family routines and without them, their families would struggle.

STUDENT OPINION

- Strengths of this study were that the authors engaged in reflexivity, thus minimising research bias. Additionally, demographics of the participants are quite specific, resulting in low transferability but very rich data.
- Although the researchers were able to explore the experiences of this specific group of mothers, this study uses a small sample and is a reflection of specific participants' experiences in a particular setting. The age range of the participants' children is quite varied and they are all from one geographic location.
- A further potential limitation is that it is unknown if participants were aware of the questions prior to the interview. The interviewer only met each participant prior to the interview, so there may have been limited disclosure of information due to lack of rapport.

IMPLICATIONS FOR PRACTICE

- This research paper uncovered five main themes. These themes suggest a need to consider an appropriate support to be provided for mothers in managing family routines, not only for their own benefits but also for their families.
- This study concludes with an emphasis on the importance of me time to promote the health and well-being of mothers with autistic children. These activities should be encouraged to enable mothers to fulfil their mothering role in managing family routines that, in turn, support their families. Going forward, family routines as well as the health and well-being of these mothers should be the focus of research for health professionals.



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A RANDOMIZED CONTROLLED TRIAL OF A PLAY-BASED, PEER-MEDIATED PRAGMATIC LANGUAGE INTERVENTION FOR CHILDREN WITH AUTISM

This article was reviewed by: Dolan, M.

Madeleine is a primary school teacher who is passionate about special education teaching and providing evidence-based interventions to support the development of students with autism. Based on current research and writings of the lived experience of autism, Madeleine was intrigued by the impact pragmatic language skills (i.e. verbal and non-verbal communication skills) have on social understanding skills and developing healthy relationships. Pragmatic language skills are important for communicating thoughts, ideas and feelings and understanding other peoples' communicative intent. Challenges with these communicative skills are known to be a core feature of autism (APA, 2013). Madeleine is also very passionate about well-being and resilience building. Educators are interested in learning new ways to promote well-being in schools in line with the Wellbeing Policy Statement and Framework for Practice (2018–2023). Developing pragmatic language skills will enable children to form meaningful friendships that bolster a sense of self-worth and resilience (Gifford-Smith and Brownell, 2003). This topic could be very useful for parents or teachers working with autistic children to develop their pragmatic language skills and social understanding in an effective way.

BACKGROUND

Roche, Adams and Clark (2021) conducted a systematic review of key stakeholder perspectives on research priorities of the autism community. The review suggested that key priorities included mental health, well-being and meaningful research that will improve quality of life. Pragmatic language skills are extremely important for communicating needs and feelings to have a good quality of life. They are also important for developing essential relationships. Autistic children have voiced their feelings of loneliness and difficulty with maintaining positive friendships (Bauminger and Kasari, 2000).

The presence and degree of psychological difficulties in childhood has been linked to friendships and social engagement (Laird et al., 2001; Gaertner, Fite and Colder, 2010). In addition, it is also suggested that childhood friendships may have consequences for adult psychological well-being (Sakyi et al., 2015). Gifford-Smith and Brownell (2003) note that childhood resilience and positive feelings such as self-worth are developed through quality friendships. Facilitating the development of healthy relationships by improving pragmatic language skills would enhance children's mental health and well-being (Parsons et al., 2019).

RESEARCH AIM

This randomised controlled trial aimed to evaluate the effectiveness of a new play-based pragmatic language intervention for autistic children (aged 6–11 years) during social play with peers. A variety of techniques were used in the intervention over a ten-week period to ameliorate pragmatics including self-modelling through video feedback and feedforward, and modelling by a peer and therapist during child-led play activities.

The researchers wanted to find out if the play-based, peer-mediated pragmatic language intervention improved pragmatic language skills for a group of autistic children and whether these gains were maintained and generalisable to other environments.

RESEARCH METHODS

A randomised controlled trial (RCT) was conducted. Convenience sampling was used to recruit seventy-one children aged 6–11 years with a diagnosis of autism or Asperger syndrome without an intellectual disability with an accompanying neurotypical playmate to either the intervention or wait-list (control) group.

In total sixty-six children completed the study, of which N=54 were male. The study was set in a clinic playroom that contained various toys and equipment to encourage social-play activities.

A speech pathologist and an occupational therapist who had received training delivered the intervention over eight sessions between pre- and post-assessment (Sessions 1 and 10 respectively). Each session followed the same format including: 1) 15-minute therapist-led video feedback; 2) 20-minute child-led play with therapist modelling; and 3) 15 minutes of therapist–parent discussion while children continued playing.

Intervention goals were encouraged by therapists by modelling pragmatic language skills and by prompting neurotypical playmates to support the development of such skills by asking questions, for example. Parents were trained by therapists during Session 1 to deliver the home components of the intervention. This included following a manual at home to deliver one module a week by viewing a video at home. Parents were also required to provide feedback before, during and after playdates organised outside of therapy sessions.

Data were collected using the Pragmatics Observational Measure (POM-2) (Cordier et al., 2014) and the Social Emotional Evaluation (SEE) (Wiig, 2008). Outcomes were measured pre- and post-assessment as well as at a 3-month follow-up.

RESEARCH FINDINGS

This research has positive implications for practice and the autism community. It confirms that it is possible for psychosocial interventions to positively impact pragmatic language skills during peer-mediated play (Parsons et al., 2019). Results of the study confirmed that the intervention was effective for improving pragmatic language in children with autism aged 6–11 years.

There was a statistically significant result (p=0.05) for the change in overall pragmatic performance in children with autism over the 10-week intervention when compared to the wait-list group. Similarly, changes in non-verbal communication skills were significantly greater for the children receiving intervention. The 3-month follow-up also confirmed that improvements in pragmatic language performance were maintained.

This study also examined generalisation effects proving that pragmatic language performance was consistent across both clinic and home environments.

STUDENT OPINION

While this study has made great progress towards identifying the effectiveness of certain tools such as video feedback, feedforward, peer and therapist modelling, and parent mediation within the context of child-led free play, it is not yet clear what ingredients are most responsible for the improvement in performance. There are some limitations, including using siblings for playmates, the difference in the occupations of trained therapists and the reliance on parents to deliver home components with consistency. There is still room for future research to identify long-term effects, such as a 6-month follow-up, and further generalisation effects such as in the school environment.

IMPLICATIONS FOR PRACTICE

This research has positive implications for practice and the autism community. The results suggest that:

- it is possible for peer-mediated play sessions to positively impact pragmatic language skills in a relatively short period of time.
- parents and professionals should work together and share skills and knowledge to provide a continuity of support across environments to encourage skill development.
- peers and siblings can positively impact social experiences. Parents and professionals should consider how to include peers in supportive programmes. Such inclusion could enhance the understanding and rapport between neurotypical peers and autistic young people.

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EVIDENCE OF INCREASED PTSD SYMPTOMS IN AUTISTICS EXPOSED TO APPLIED BEHAVIOR ANALYSIS

This article was reviewed by: Lawlor, G.

Gina's first-hand lived experience of classic autism and ABA made evaluation of Kupferstein's (2018) research compelling.

BACKGROUND

GL outlines that Applied Behaviour Analysis (ABA) was designed to eliminate the self-destructive, self-mutilating behaviours of institutionalised children (Chance, 1974). It is a behaviourally focused comprehensive programme for teaching skills across all domains from linguistics, to cognitive, to social, to mundane task such as getting dressed, brushing one's teeth and so on. Numerous studies have demonstrated its effectiveness and two meta studies support this.

The neurodiversity movement, including intelligent, articulate autistics who embrace their autism as part of their neurological diversity, describe ABA as abusive and support a common theory proposed, that is ABA "survivors" suffer Post Traumatic Stress Disorder (PTSD).

Exposure to potentially traumatic events (PTEs) is often associated with significant psychological and emotional distress, causing post-traumatic stress symptoms (PTSS). Using DSM-5 criteria, a specific cluster of PTSS can be diagnosed as a post-traumatic stress disorder (PTSD) with moderate, severe, or extreme levels.

Autistic individuals have a sensitivity to the way any situation is initially appraised, and a benign situation which was perceived as harmful or threatening to the individual can become a PTE which could trigger PTSS due to their underlying vulnerability.

The impact of traumatic events during childhood can adversely affect the child's development and cause the child to suffer even when the child has healed from the trauma. This is why Kupferstein focused on exposure to early childhood ABA interventions for autistic children.

RESEARCH AIMS

The purpose of this study was to:

- examine the prevalence of post- traumatic stress symptoms (PTSS) in autistics exposed to ABA autism early childhood intervention.
- investigate whether severity of symptoms increase with length of exposure time.

Research Methods: This quantitative study was designed to incorporate the lived experiences of adult autistics, and the experiences of autistics through their caregivers. It was carried out by an independent researcher living in San Diego, California, USA.

Participants were recruited through social media networks, adult gatherings, social skills groups, and autism support groups nationwide. The inclusion criteria was age 18 years or older and either diagnosed or self-diagnosed with autism. 460 respondents completed the survey compromising of autistic adults (n=243) and caregivers of autistic children (n=217).

The survey was based on participatory action research using an online survey directed at focus groups and demographically similar individuals. Participants completed an online survey which opened with a consent section alerting respondents of their rights to withdraw at any time and that confidentiality would be maintained. The online survey progressed to collect data about basic demographics, the type of autism childhood intervention received, and the length of time the intervention was applied. The survey was created specifically for this study and included questions that were an amalgam of both autism-specific and intervention-related questions modelled on the PCL-5 Psychopathy Checklist self-report measure, which assesses the twenty symptoms of PTSD. The authors modified the questions to assess whether the intervention itself was the stressor. Participants were instructed to answer "as it pertains to the present, in the last four weeks". Participants could omit answering a question which was denoted as a null value.

The study wanted to measure the following criterion:

- Criterion A focused on type and length of time of intervention was applied. Following DSM-5 criteria, one of four exposure types were needed for adults and older children, and three exposure types were needed for children aged 6 and younger. The survey provided two opportunities to meet the moderate threshold for both groups.
- In order to meet Criterion B (experience one or more intrusion symptom), respondents were provided with seven opportunities to meet the moderate threshold for both groups.
- Criterion C (persistent avoidance of stimuli related to the trauma) in adults this entailed one or both of the avoidance of thoughts or feelings associated with distressing memory, and the avoidance of external reminders of the event. Caregivers of children were provided with 13 opportunities for these to be met. Adults were provided with 6 opportunities for it to be met.
- Criterion D (for children-negative alterations in cognition and mood associated with the trauma) which must be evidenced by two or more of seven possible alterations.
- Criterion E (for adults-marked alterations in arousal and reactivity associated with the trauma) required two of six possible hyperarousal types to meet the moderate threshold, and four of six arousal types represented in a total of six questions.

The Clinician Administered PTSD Scale (CAPS-5) age-adjusted severity conventions were used to score survey responses with reference to thresholds of moderate, severe, or extreme.

Binary classification of PTSS was determined by the cumulative scores exceeding a PTSD diagnostic threshold of 2= moderate.

A 1-5 Likert scale was used for responses concerning symptom frequency, with 1 denoting never and 5 denoting always. Participants had the option of entering free-response textual comments before directly submitting the survey via a software system. Participants were advised that responses would be stored securely on a central server.

RESEARCH FINDINGS

50% of the adult respondents answered all of the survey questions compared to 61% of caregivers.

Nearly half (46%) of the ABA-exposed respondents met the diagnostic threshold for PTSD.

Extreme levels of severity were recorded in 47% of the affected subgroup.

Respondents of all ages who were exposed to ABA were 86% more likely to meet the PTSD criteria than respondents who were not exposed to ABA.

ABA correlated with the highest ratings of PTSS in both children and adults. By comparison, individuals who did not receive ABA remained without PTSS and reported excellent daily functioning.

Those exposed to ABA had heightened severity symptoms upon initial exposure.

There was no significant correlation between PTSS and length of exposure to ABA as reported by caregivers.

There was a significant correlation between PTSS and length of exposure to ABA as self-reported by adults.

Survey responses of adults who answered questions to Criterion D and E pertaining to self-esteem, negative perceptions of self, aggression, self-harm, and shame were investigated. The study found that ABA-exposed adult respondents scored themselves with an average 68% higher severity rating when compared to non-exposed adults.

STUDENT OPINION

Caregivers' opinions useful on some questions but not on others as they are not in a position to say conclusively whether those in their care suffered flashbacks, nightmares or trauma.

Participants of this study were not required to have a confirmed autism diagnosis.

Autism diagnoses need to be clearly established by a multidisciplinary team/ clinical psychologist. Self-diagnosis does not meet inclusion criteria for scientific studies (Leaf et al. 2018).

Limitations exist when using a survey as the main source of data collection. Respondent's risked being lead by study design, questions asked and the sampling method employed. Data acquired from this survey does not prove causal relations.

The respondent selection created sample/ selection bias. The autistic respondents are not representative of the whole autistic community.

The methodology is flawed, attempting to prove correlations between ABA and PTSD. To justify the findings, more research is needed. The research needs to be replicated by researchers independent of organisations associated with ABA or those with strong neurodiversity views. This study hypothesised a link between PTSD and ABA, not proven it.

GL feels as surveys use self-report they allow for loose correlations which do not prove causation. Results of survey data should be treated with caution if not eliminated from research.

This survey was designed to prove the hypothesis therefore the findings are affected by bias. Safeguards should have been included to ameliorate bias.

The ABA interventions/type of ABA was not clearly established. More information about ABA providers, their training and teaching was needed in this study. Assessment for ABA should be made in conjunction with medical professionals to ensure it is the right intervention for a child and their particular needs.

ABA may be a risk factor for PTSD, but more research is needed to find out what kind of ABA, under what conditions, in what environment, with which type of people.

The adult autistic voice should be included in future research and intervention design.

IMPLICATIONS FOR PRACTICE

Kupferstein concluded that respondents exposed to ABA interventions had a 46% likelihood of succumbing to PTSS than other interventions and were almost twice as likely to meet the PTSD diagnostic criteria.

Those exposed to ABA had heightened severity symptoms upon initial exposure.

ABA intervention was more positively viewed by caregivers than adult autistics. Kupferstein reported discrepancies in reporting bias between caregivers and autistic adults.

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EFFECTS OF PECS ON THE EMERGENCE OF VOCAL MANDS AND THE REDUCTION OF AGGRESSIVE BEHAVIOR ACROSS SETTINGS FOR A CHILD WITH AUTISM

This article was reviewed by: Sweeney, C.

Ciara chose to review this article because she has observed the Picture Exchange Communication System (PECS) in use in her professional setting and was interested in the factors that enhance PECS use and the potential effects of PECS use on behaviour. This article was chosen due to the effort made to generalise effects through the implementation of PECS in a range of settings. PECS was implemented in the participant's therapy room, playground and home. This illustrated the researcher's commitment to providing a range of communication opportunities and contexts for the child in question.

BACKGROUND

PECS is an alternative and augmentative communication (AAC) system used by many autistic individuals. PECS relies primarily on direct reinforcement, similar to the direct reinforcement that occurs during typical language development. PECS adopts a lifespan approach with potential use from two years of age into adulthood. Few prerequisite skills or behaviours are required (for example, oral skills and eye contact) making PECS an accessible method of communication for a large community of people who may require extra support. Research indicates that PECS can positively impact communicative repertoires, but the ways in which PECS may impact other behaviour is still unclear.

Research suggests that teaching people to make verbal requests (vocal mands) can reduce problem behaviour such as aggression. Limited research has looked at whether PECS may be useful in reducing aggressive behaviour. PECS is a reasonably easy intervention to implement. If it were possible to use it to increase requests, it may offer autistic people a way to communicate their needs, thus reducing potential frustration and resultant aggression.

RESEARCH AIM

The aim of the study was to examine the effects of PECS on the emergence of vocal mands and the reduction of problem behaviour for a single autistic child in China. Researchers trained teachers and parents to implement PECS, which is less commonly used as an intervention in China. They also wanted to examine whether vocal mands and reductions in aggressive behaviour were maintained for the child one week after the PECS intervention.

RESEARCH METHODS

One four-year-old Chinese boy took part in the study, which was conducted in Mandarin. During the study he attended an early intervention centre for three hours per day, five days per week. The study employed a multiple baseline design across three settings familiar to the boy: the therapy room, the playground and at home.

The child's use of PECS pictures as an exchange for a preferred item was recorded as a PECS exchange. If the child requested a preferred item using a spoken word approximation, this was recorded as a vocal mand. Aggressive behaviour was defined as one push, hit, kick, bite or throwing objects toward others.

They established baseline behaviours during 15-minute natural observation sessions within each of the three settings. PECS sessions took the form of 15 minutes of training followed by a 15-minute 'probe' session in which the boy could practise by requesting preferred items. During each session one adult acted as a teacher and another as a prompter to encourage requests from the boy.

RESEARCH FINDINGS

In keeping with the researchers' hypothesis, results indicated that the PECS intervention did effectively increase vocal mands and decreased aggressive behaviour from the young boy. These effects were maintained with access to the boy's preferred items in all three settings assessed. One week following the completion of the intervention, the child maintained the PECS exchanges at a high level and continued to use an increased level of vocal mands. His aggressive behaviour remained at almost zero occurrences.

STUDENT OPINION

- This study was conducted across three settings: the participant's therapy room, playground and home. A critical component of the PECS training protocol is the active restructuring of the child's natural environments. This aims to create many communicative opportunities throughout the day to practise and develop fluent communication skills. The inclusion of a range of settings aids generalised use and promotes social validity through functional use of the skill. Furthermore, these settings were selected as they were the locations in which the participant spent the most time and wherein aggressive behaviour was frequently displayed, allowing the intervention effects to be demonstrated.
- The autistic voice of the participant in question was considered when designing and carrying out this study. This study acknowledges that aggressive behaviour serves a function. The researchers identified the function of the participant's behaviour as him being unable to communicate needs verbally. Through natural observations and anecdotal reports it was deemed that the participant's aggressive behaviour was associated with his limited verbal repertoire and inability to communicate desires and needs. Formal observations with descriptive data, such as identifying the behaviour's antecedent, the behaviour and the consequence, also indicated that the aggressive behaviour was related to obtaining preferred items.

IMPLICATIONS FOR PRACTICE

- The research highlights the importance of understanding the function of behaviour to fully address the needs and wishes of the autistic child. Added communication options like PECS can help people to more fully communicate their needs, reducing frustration and limiting potential aggression.
- The study appears to show that for the young boy PECS learning could be generalised across settings and across learning partners. This may suggest that PECS could be used in collaboration across an individual's school and home life.

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SELF-REPORTED CAMOUFLAGING BEHAVIOURS USED BY AUTISTIC ADULTS DURING EVERYDAY SOCIAL INTERACTIONS

This article was reviewed by: Vernon, T.

Tara chose to review this article due to its importance to the autistic community at large. While camouflaging or masking may appear to be of benefit and can provide autistic individuals with a method by which to successfully navigate what is often an overwhelming non-autistic world, being unable to simply be yourself has a long-term negative impact on self-worth, mental health and access to supports. In the reviewer's opinion, it is in the best interest of society that its members are valued and respected for who they are.

BACKGROUND

Camouflaging is a developing area of research in autism (Pearson and Rose, 2021; Libsack et al., 2021) and one that warrants formal attention due to the negative impact that camouflaging has on autistic well-being (Cage et al., 2018; Cassidy et al., 2019; Fletcher-Watson and Happé, 2019). Autistic individuals report that camouflaging is mentally and physically exhausting (Cage and Troxell-Whitman, 2019). Camouflaging may lead to a late or missed diagnosis of autism, impact on romantic and work relationships, and may lead to burnout (Hull et al., 2017; Pearson and Rose, 2021). Research on this topic is a priority for the autistic community so that both the autistic and non-autistic community may understand how the neurotypical social world contributes to autistic masking, why autistic people mask and how it impacts on mental health (Cage et al., 2018; Hull et al., 2017; Pearson and Rose, 2021; McQuaid et al., 2021).

RESEARCH AIM

This article examined camouflaging behaviours used by autistic people in their daily social interactions. It sought to expand the current understanding of camouflaging through identifying behaviours that are self-reported to be avoided, displayed or changed by autistic adults when camouflaging. This study used Interpersonal Process Recall (IPR), wherein participants took part in a short conversation with the researcher that was recorded. Participants then completed a semi-structured interview immediately afterwards while viewing the recording, during which they identified camouflaging attempts observed in the recording. The study authors used this methodology with the aim of supporting autistic individuals to directly identify and describe camouflaging behaviours immediately following a camouflaging experience.

RESEARCH METHODS

This study adopted a qualitative design and sought to follow AASPIRE guidelines, which are specific to research conducted with autistic participants and as such limit ethical concerns through their very construction (Nicolaidis et al., 2019, cited in Cook et al., 2021). A convenience sample of seventeen autistic adults were recruited for this study. Participants were required to be over eighteen years of age, have a formal diagnosis of autism and an IQ in the average or above average range. Participants were required to engage in a ten-minute open-ended conversation with a non-autistic female researcher who had been trained in IPR. The conversation was recorded on video and replayed while the experimenter carried out a semi-structured IPR interview with the participant. This allowed for the participant to observe their behaviour in real time and identify personal camouflaging behaviours. This is a significant addition to a body of research that has typically relied on participants retrospectively recalling experiences of camouflaging.

RESEARCH FINDINGS

Findings identified four primary categories of camouflaging behaviours: masking, innocuous engagement, modelling neurotypical communication and active self-preservation. Within the masking category participants described efforts to conceal personal information or to suppress autistic behaviours. Within the category of innocuous engagement participants outlined efforts to use passive or cautious social behaviours, to centre their conversation on their social partner, engage deferentially with their social partner, and avoid social risks, e.g. sticking to small talk. Within the modelling neurotypical communication category participants identified efforts to use communicative behaviours that aligned with neurotypical norms, e.g. altering gestures or body language. The category of active self-preservation saw participants use reciprocal social behaviours such as asking questions, using more risky social behaviours like asking jokes or choosing conversation topics that were comfortable or familiar.

STUDENT OPINION

- A main strength of the study is the use of IPR as it potentially allowed for participants to recall their camouflaging behaviours clearly (Larsen et al., 2008). The use of IPR also allowed for the inclusion of behaviours that function within conscious awareness that have not been stated in previous camouflaging research (Cook et al., 2021).
- This study may have been limited by the lack of real diversity of the participants included and as such may not be generalisable across the autistic population (Cage et al., 2018; Cook et al., 2021). It should be noted also that the design and analysis of this study is limited due to the absence of input from autistic individuals; inclusive research would advocate for the inclusion of the autistic voice at all levels of a research study (Pearson and Rose, 2021; Pelicano et al., 2014).

IMPLICATIONS FOR PRACTICE

- This study details how camouflaging behaviours manifest in real-life social interactions. The findings of this study are supported by research by Hull et al., (2017), who also highlight the personal consequences of camouflaging, and by previous studies in the area of autistic masking that concur that camouflaging behaviours are multifaceted and can be difficult for clinicians and researchers to correctly identify without direct interpretation from the autistic person and an understanding of the autistic person's lived experience (Cage and Troxell-Whitman, 2019; Hull et al., 2019).
- Studies such as this one are of real value to the autistic community as they examine and seek to understand issues that are of ongoing importance to the community, e.g. a more comprehensive understanding of masking could positively impact a reduction in autistic burnout (Higgins et al., 2021).

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PARENT PERCEPTIONS OF BARRIERS TO FRIENDSHIP DEVELOPMENT FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

This article was reviewed by: Drohan, E.

Elle chose to review this article because of the importance of developing friendship skills across the lifespan, and the positive impact of friendship and social connections on well-being.

BACKGROUND

Friendship is defined as stable, interconnected interactions facilitating companionship, intimacy and closeness (Bauminger et al., 2008). Childhood friendships enable practice of social skills and experience of societal norms within secure environments (Calder, Hill and Pellicano, 2013). As they occur within contexts of participation and acceptance in wider social networks (Calder, Hill and Pellicano, 2013), friendships act as a protective factor against bullying and foster a sense of belonging (Bauminger et al., 2008). Humphrey and Lewis (2008) reinforce that friendship is central to development in autistic children.

Cook, Ogden and Winstone (2018) propose that motivation exists to develop friendships, although many autistic individuals appear to prefer fewer friends and seek different characteristics in friendships to their non-autistic peers (Mendelson, Gates and Lerner, 2016; Ryan et al., 2021). Mendelson, Gates and Lerner (2016) found that the majority of autistic individuals have at least one reciprocal friendship; moreover, autistic children report reasonable satisfaction in friendships (Calder, Hill and Pellicano, 2013). However, evidence also exists of autistic children experiencing lower quality friendships and fewer reciprocal friendship nominations (Feldman, 2021). In addition, some discrepancies can exist between children's own stipulations of satisfaction and parents' perceptions of lack of reciprocity, stability and responsiveness in friendships (Ryan et al., 2021).

RESEARCH AIMS

This study uses qualitative methods to explore barriers to friendship experienced by autistic children from parents' perspectives. It highlights that research often focuses on innate characteristics of autism as barriers to friendship, with lack of consideration for environmental factors. This study proposes that homophily, or likeness between individuals, and propinquity, or geographical distance, may act as obstacles in friendship formation for autistic individuals. Given the significance of friendship throughout the lifespan, the researcher aims to use insights gained to propose recommendations for interventions and programmes to support autistic individuals and their families in forming social connections.

RESEARCH METHODS

This study uses a qualitative design involving semi-structured interviews and thematic analysis. The article did not detail the sampling process; however, it was noted that all participants were parents of autistic children placed in general education classrooms within the Los Angeles Unified School District (Daughrity, 2019). Children ranged in age from 5–12 years, thus reflecting the researcher's understanding of the pivotal role of friendship at this developmental stage (Mendelson, Gates and Lerner, 2016).

Data were collected through semi-structured interviews. Interviewers used discussion guides containing open-ended and probing questions relating to parents' perceptions of their children's friendships. Interviews were audio recorded, transcribed and edited for accuracy with live notes to ensure descriptive validity. Transcripts were analysed and coded by two individuals to ensure analyst triangulation and increase methodological rigour. Both coders compared codes for consensus and high inter-rater reliability of >90% was achieved. Coding of data through thematic analysis was based on grounded theory.

RESEARCH FINDINGS

Twenty codes were extracted and categorised into five primary themes of barriers to friendship development: propinquity, attempts at social exposure, social deficits in autism, siblings as a protective factor and parent networks.

Challenges facing autistic children in friendships were evident as parents noted engagement in age-appropriate activities but not with peers.

It emerged that children wanted to make friends but lacked social skills. Despite motivation, due to social and communication differences, autistic individuals experience challenges responding to subtleties in non-verbal communication and understanding relational behaviour. Parents remarked that children experienced difficulties following social rules and maintaining conversation with peers.

Propinquity appears to be a barrier to friendship development for autistic children; parents reported children attending schools or activities outside their locality due to a dearth of autism-specific programmes, thus diminishing opportunities to socialise with peers.

Consistent with extant research, parents and siblings act as a protective factor against bullying and social isolation of autistic children by providing direct support and facilitating social interaction. The findings confirmed the initial proposal that both internal and external barriers exist for autistic children and young people in making and keeping friends.

STUDENT OPINION

- The study satisfied ethical considerations including informed consent and participant confidentiality.
- Participants were culturally and racially diverse and interviews were facilitated in Spanish for one participant.
- Some negative language relating to autism is used, including terms such as 'deficit' and 'disorder', which are not reflective of contemporary moves towards the Neurodiversity Paradigm.
- The voice of the autistic person could be further amplified by including children's perspectives.

IMPLICATIONS FOR PRACTICE

Future research should focus on comparing within-neuro-type friendships with cross neuro-type friendships. Herein, interventions may benefit from reframing focus on reducing atypicalities in social interactions and instead celebrating different ways of thinking and communicating, as advocated by the Neurodiversity Paradigm (Granieri et al., 2020). Emphasis should also be placed on increasing understanding of autistic communication styles within non-autistic populations (Crompton et al., 2020).

Finally, given their active role in friendship development, it is important to create support networks for families to enable parents to provide peer engagement opportunities for their children (Daughrity, 2019), although constant expectations to socialise with others can be overwhelming (Calder, Hill and Pellicano, 2013). This highlights the importance of respecting autistic individuals' preferences regarding the type and degree of social interaction they desire.

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PROMOTING PEER INTERACTION FOR PRESCHOOL CHILDREN WITH COMPLEX COMMUNICATION NEEDS AND AUTISM SPECTRUM DISORDER

This article was reviewed by: Ahern, D.

Denise chose to review this article because the UK charity Autistica, in consultation with the autism community, has created a top ten list of questions for autism research. Number two on this list is: which interventions are effective in the development of communication/language skills in autism? (Autistica, 2021). It is with this question in mind and a specific interest in how to encourage and support communication using alternative and augmentative communication (AAC) that this article was chosen for review.

BACKGROUND

Many autistic individuals are non-speaking and require an alternative means to communicate. AAC is used to describe the range of alternative mechanisms available. AAC can be unaided, such as gesturing or sign language, or aided, such as low-tech communication books or high-tech devices running a range of software options. Typical language acquisition happens when learners are immersed in communicative experiences where spoken language is part of that experience. Children with complex communication needs (CCN) who are learning to communicate with AAC also benefit from being in an immersive environment (Sennot, Light and McNaughton, 2016). Aided AAC modelling is a mechanism whereby communicative partners pair the spoken word with a visual representation during communicative exchange. The AAC device becomes a shared medium of communication between the autistic individual and their partner.

RESEARCH AIM

The purpose of this study was to investigate the impact of a multicomponent intervention in facilitating improved social communication and engagement between young autistic children with CCN and their neurotypical peers (Therrien and Light, 2018). The intervention consisted of two components – a turn-taking training component coupled with access to a shared AAC device. An Apple iPad Air 2 with the AAC app GoTalk NOW was used. This app was chosen because it supports visual scene displays (VSD) functionality. This allows target vocabulary to be programmed as hotspots within a single picture. VSD scenes were created from picture books based on identified shared interests of the children. Creating a shared experience helps to ensure a more equitable basis on which to develop a social relationship. The authors consciously embraced the concept of Universal Design by creating an environmental support equally relevant to both parties. The study measured the impact of the specified intervention on the frequency of symbolic communicative turns, together with the balance of turn taking and the level of joint engagement (Therrien and Light, 2018).

RESEARCH METHODS

The mixed methods study consisted of a sample of five children with CCN and ASD as well as five neurotypical peers (M=9; F=1). A mixture of parent interviews, checklists and diagnostic tests were used to create a profile for each child. The children all attended the same preschool, although were not all in the same class.

Data were collected over a three-month period with an average of one to three sessions per week for each dyad. All interactions took place within the preschool setting. A separate room was used for both the baseline and intervention phases, with some generalisation activities taking place in the main classroom. It is noted that due to time constraints (primarily) the generalisation phase did not happen for all children, which does limit our ability to infer how well the targeted skills would transfer to another environment. A maintenance phase was planned but not implemented, so there is no data to show whether the positive effect noted was maintained beyond the intervention period. The first author and another colleague conducted all sessions. Sessions were videoed and analysed by a third party for procedural integrity (Therrien and Light, 2018).

RESEARCH FINDINGS

The outcome of this study supports the authors' hypothesis that for children with CCN and ASD, their social communication competence can be enhanced by AAC in shared communicative exchanges with peers. Of particular interest to the present discussion is the role of peers in aided AAC modelling where the goal is to support children in their increased use of symbolic communication. A key strength of the current study is that the AAC support is embedded within the social activity itself and this becomes an object of equal desire and relevance to both parties. It creates an equality within the communicative exchange that may be missing in a situation where one child assumes the role of teacher/helper.

The generalisation phase was not completed for all participants, so there is insufficient evidence to support how well this intervention would transfer to other settings. However, it is likely that the activity as described would transfer well to a classroom setting. What is likely to be more challenging is the generalisation of the concept to activities other than book sharing, e.g. pretend play, Lego.

STUDENT OPINION

- The sample size was small, although this is not unusual for a single subject experimental design (SSED) study.
- All children participating in the research were Caucasian and all bar one was male. A more balanced gender and ethnic mix of participants would have been preferable given the predominance of male representation in autism research generally.
- A maintenance phase was planned but not implemented, so there is no measurable data to show whether the positive effect noted was maintained beyond the intervention period.
- One participant did not experience gains even after a change was made to include more of his special interests in a bid to increase engagement. Further research would be required to determine whether his combination of strengths and challenges requires a different approach.

IMPLICATIONS FOR PRACTICE

- By embedding AAC within an activity this research has shown that this can be a powerful mechanism for encouraging symbolic communication. It removes the potential difficulty where children may struggle to engage in an activity while simultaneously trying to navigate their AAC device.
- Further research is required to determine if this had a positive impact on the use of AAC for other aspects of communication, in particular transitioning from the specialised language of the VSD to the more generic grid vocabulary typical of AAC devices.
- Creating an immersive AAC environment in this way would allow for the celebration of the many different ways we communicate; accepting and championing difference rather than seeking to change it. In listening to the voices of the autistic community (Autistica, 2021), communication has been highlighted as a discussion topic for further research. All autistic voices must be part of that discussion.

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FIRST-HAND ACCOUNTS OF INTEROCEPTIVE DIFFICULTIES IN AUTISTIC ADULTS

This article was reviewed by: Atkinson, V.

Valerie chose to review this article because research into mental health is an identified priority for the autism community. One of the benefits of research into interoception deficiencies in autistic adults is to help mental health concerns for all members of the autism community.

BACKGROUND

Promotion of positive mental health is a key priority among the autistic community and clinicians. It is also highlighted that people with autism are at increased risk of developing mental health problems. According to Autistica's research approach strategy (2021) over 70 per cent of autistic people have had a mental health problem. Understanding why and finding treatments that work for autistic people is a priority.

It is well known that anxiety is a key feature of autism, but emerging research is showing us that this could be due to an impairment in interoception. According to Hample, Mahler and Amspacher (2020) the ability to notice internal sensations such as tense muscles, a rumbling stomach or heavy eyelids and translate these internal sensations into emotional meaning such as anger, hunger and fatigue is an important skill called interoceptive awareness. Deficits in interoception have been identified in autism.

RESEARCH AIM

The research sought to determine the relationship, if any, between interoception differences and the experience of anxiety for autistic people.

RESEARCH METHODS

The qualitative research analysed texts from the discussion forums on wrongplanet.net, an online community of over 80,000 registered users self-identifying with ASD. The researchers searched for key terms in the online discussions. Some of the key terms used were 'bodily feelings', 'interoception', 'body sensations', 'interoceptive' and 'internal signals'.

They found the following themes:

- Hypo-sensitivity– this was broken down into four further subthemes:
    - limited awareness of hunger, satiation and thirst;
    - disordered eating behaviour;
    - limited awareness of pain, injury, illness or exhaustion; and
    - incontinence.
- Hyper-sensitivity hypochondria – defined by over sensitivity to internal body signals.
- Poor interoceptive accuracy/confusion – where individuals can detect interoceptive cues but fail to accurately interpret them.
- Alexithymia – defined by having difficulties identifying and describing one's emotions.

RESEARCH FINDINGS

The researchers report that the qualitative analysis of these online accounts agreed with their hypothesis that many people with autism have difficulty perceiving internal body signals and that these findings are consistent with other studies carried out on interoception and ASD. The researchers believed that this interoceptive dysfunction may help explain higher levels of alexithymia in ASD in comparison to other groups, contributing to higher levels of emotion dysregulation and mood disorders like depression and anxiety. The study suggests that further research in this area is required and that researchers should develop methods for assessing interoceptive dysfunction that is not totally reliant on reports from people with autism to give a better understanding of it in children and other people who may not be able to communicate their interoceptive awareness.

STUDENT OPINION

- The research team sought and obtained permission to conduct their qualitative study from the owner of the website but did not seek or gain permission from the users of the online forum. It could therefore be argued that Trevisan, Parker and McPartland (2021), while being aware of the need to incorporate the perspectives of people with ASD, did not give them the option to willingly participate in a study of their choosing.
- The reported data maintained the anonymity of all sources and was deemed minimal risk. There was no way of truly knowing if in fact any of the users of the site were autistic.
- The overall rigour of the research does not meet the four components of trustworthiness. While the main aim of the study was to get a better understanding of interoception deficiencies in adults with autism, to lend weight to the credibility of the study there should have been representation from other sources and not just the online forum.

IMPLICATIONS FOR PRACTICE

- The researchers set out to investigate an interesting and necessary area; however, their research does not support any robust implications.
- The research highlights the need for high-quality participatory research in autism.

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INCLUSION IS A FEELING, NOT A PLACE: A QUALITATIVE STUDY EXPLORING AUTISTIC YOUNG PEOPLE'S CONCEPTUALISATIONS OF INCLUSION

This article was reviewed by: O'Brien, E.

Elaine chose to review this article because she has a particular interest in the area of inclusion of young autistic students in mainstream schools having worked as a special needs assistant for the last nine years. She has witnessed how challenging it can be for some autistic students to feel included and how this can impact their behaviour and overall well-being.

BACKGROUND

The starting point for developing an inclusive and equitable approach into autism research is to listen to the voices of autistic individuals. Researchers are beginning to understand the importance of engaging members of the autism community and listening to their views and perspectives in decision-making processes that shape their lives. Autistic individuals frequently report that their experiences are minimised or reinterpreted by well-intended non-autistic parents, researchers, educators and allies (Lebenhagen, 2020). In particular, there is a lack of research focusing on the educational experiences of autistic students and their perspectives on inclusion.

The topic of inclusive education is complex – as evidenced by varying definitions available in policy and literature, alongside the challenges for educators in identifying and implementing inclusive education practices. To date, the debates in inclusive education have been defined and driven by adult voices, with little opportunities for children or young people to share their perspectives.

RESEARCH AIM

Research until now highlights that autistic students can experience bullying, isolation and anxiety in mainstream schools. Despite such challenges, autistic students express a desire to have opportunities to develop friendships and feel included. This study aimed to investigate the educational experiences of autistic young people and elicit their perspectives of mainstream education, alongside defining and conceptualising inclusion. More specifically, perspectives were sought from students who had experienced challenges in mainstream education. This study aimed to employ a range of inclusive methodologies in eliciting these views.

A children's research advisory group (CRAG) of three young autistic people advised on the methods used and topics to be discussed. This allowed the author to develop research methods and tools that were appropriate, authentic, engaging and able to support the research aim and questions.

RESEARCH METHODS

Twelve young people aged 11–17 years participated in this study (ten boys and two girls). Seven of the participants attended the Alternative Education Placement (having come from mainstream schools), and five of the participants were homeschooled. A flexible qualitative and participatory approach was used that incorporated a range of methods, including draw-and-tell activities and a beans-and-pots activity to allow the participants to respond to seventeen statements. Participants were asked to place a polystyrene ball into a pot to indicate if the statement was 'true', 'not true' or 'unsure'. A ranking activity was used to explore the barriers to inclusion and focused on ranking nine aspects of school from most to least worrying and most to least important. Semi-structured interviews incorporated activities such as selecting emotions to help visually support the discussion. Participants were given two generic outlines of a figure and were asked to draw and add feelings and descriptions to describe the characteristics of a good teacher and a bad teacher. They were also asked to draw a picture of themselves at school. They were asked to add written descriptors and were asked to orally describe the drawing.

RESEARCH FINDINGS

Three themes were identified: 'exclusion in inclusion', 'supporting me' and 'inclusion and me'. The twelve young people shared a variety of mostly negative experiences.

Some of the individuals spoke about how they had feelings of dread before and during school, impacting their well-being. Many felt unsupported and misunderstood by teachers and felt socially, emotionally and physically isolated from their peers. Participants suggested having more breaks to de-stress, smaller class sizes, less homework, instructions broken down into smaller pieces of information and safe places to use when feeling anxious. They defined inclusion as 'belonging, being valued, and wanted as a person by teachers, of fairness, and of being afforded the necessary support to access and thrive in education'. The participants suggested that being academically able for mainstream should not be the only thing considered when deciding on whether a mainstream setting is suitable or not.

STUDENT OPINION

- A strength of this study was the inclusive methodologies used. They were appropriate as they gave the autistic students a voice to share their perspectives on their educational experiences and their understanding of inclusion. The visual methods used helped support communication and enhance their understanding of what was being asked of them and served the participants who process information primarily through visuals.
- One of the limitations was that the sample size was small and there was a gender imbalance. A more diverse and larger sample may provide nuanced insights and be more reflective of the wider autism community in mainstream school settings.
- This study would have benefited from autistic individuals for whom mainstream was less challenging and could have added further richness to the data.

IMPLICATIONS FOR PRACTICE

- This study provided an insight into the varied educational experiences of twelve young autistic people who had attended mainstream schools. For them inclusion is a feeling (a sense of belonging), not a place (mainstream or otherwise). The participants suggested that attempts at inclusion in mainstream resulted in exclusion, feelings of dread and isolation and for some participants, impacted their well-being.
- Although research has accelerated in the last number of decades, it is particularly important that we consult with autistic individuals so that society can understand them and support them in every aspect of their social, emotional, physical and mental development in mainstream school and other settings. They are the narrators of their own experiences and without their voice, educators and policymakers will always try to judge what is best for them. This can result in autistic individuals feeling excluded and disempowered.

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EXPLORING SLEEP QUALITY OF YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDER AND DISRUPTIVE BEHAVIORS

This article was reviewed by: Pearson, D.

Deirdre chose to review this article because sleep difficulties present numerous behavioural daytime issues and the author felt it was necessary to explore this further. According to Mindell and Meltzer (2008), more than 40–80 per cent of children with ASD experience sleep problems compared with 25–40 per cent in neurotypical children.

The author liked that all three aims of the study are shown clearly in the introduction: examination of the link between age and IQ in sleep disturbance, testing if poor sleep influences daytime behaviour, and if parental stress is higher in the poor sleep group compared with the better sleep control group. The article cites eighty individual references linking to previous research in the area, though most are before 2015. The article lays it out clearly for a non-clinical person to understand what is being investigated.

BACKGROUND

Sleep quality is a constant issue for autistic children and young people, and there is a causal link between sleeping and disruptive daytime behaviours as shown in this study. Within the autism community, sleep issues affect children greatly. Priority should be given to developing a greater understanding of the sleep issues in autism and how these impact on the autistic person and their families.

RESEARCH AIMS

The research set out to explore the relationship, if any, between sleep quality and disruptive behaviour in a sample of 177 autistic children. The upper quartile of 'good' sleepers was matched against the lower quartile of 'poor' sleepers using a range of standardised tests, including the Aberrant Behavior Checklist, Children's Sleep Habits Questionnaire and a measure of parental stress. There was an expectation within the researchers that poor sleep would correlate with more reported incidents of disruptive behaviour.

RESEARCH METHODS

The study takes a quantitative RCT approach: 177/180 children with autism were sampled and divided into two groupings – good sleepers and poor sleepers. The upper quartile of good sleepers was matched against the lower quartile of poor sleepers. The study chose participants who had no medication or who were stable for six weeks on medication. The poor sleepers and good sleepers were compared across a range of standardised measures with an expectation that poor sleep would impact on behaviour as reported in the standardised measures.

RESEARCH FINDINGS

Results indicated that children in the poor sleeping group had significantly higher daytime behavioural problems including irritability, hyperactivity, social withdrawal and stereotypical behaviours. Parents in this group also reported significantly higher levels of stress.

The good and poor sleeping groups did not differ on measures of age or IQ; however, poor sleepers presented with more disruptive behaviours and irritability, with a consequent impact on the child and their family.

The results will allow parental stress to be addressed, further sleep studies completed and the reasoning behind disruptive behaviours found and further assisted with for a better quality of life for the autistic child and their family.

STUDENT OPINION

- There is no mention of informed consent and ethically this should have been confirmed prior to the study, although parental consent should have been received prior to the parents completing any measures.
- This study sample size is quite small (177/180) compared with other studies in the area.

IMPLICATIONS FOR PRACTICE

- The research provides the basis for further investigation into the important areas of sleep, behaviour and mental health. The initial findings indicate that sleep should be taken into consideration when assessing behaviour.
- Staff could consider accessing specialist sleep training to provide comprehensive supports for families.
- Parents of poor sleepers also need to be supported.

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RANDOMIZED CONTROLLED TRIAL OF A SIBLING SUPPORT GROUP: MENTAL HEALTH OUTCOMES FOR SIBLINGS OF CHILDREN WITH AUTISM

This article was reviewed by: Teahan, E.

Emma chose to review this article to seek and explore the benefits of support groups for siblings of autistic children. In her professional practice Emma observes many implications of autism for siblings, both positive and negative. The purpose of this review was to seek information on the benefits of siblings meeting in support groups with other siblings who have autistic brothers and sisters to engage in discussions and activities about the nature of autism and to share how it feels to live with an autistic sibling.

BACKGROUND

Research identifies that all family members influence each other reciprocally; therefore, the well-being of one family member is likely to affect that of other family members. The presence of an autism diagnosis in a family may affect the mental health and adjustment of all family members, including neurotypical siblings. Often the longest relationship an autistic person has is with siblings, and siblings are commonly the first friend and role model an autistic child has. Sibling relationships also provide opportunity for social, emotional, behavioural and psychological development for the autistic child, but they can cause the siblings to be at increased risk of mental health difficulties compared with siblings in general. As this important relationship is often ignored in autism research, this provides an important rationale for the significance of the study, which seeks to explore the effect of a sibling support group on the mental health of siblings of autistic children.

RESEARCH AIMS

The study had two research questions:

1. What are the effects of support groups on siblings' mental health? [Based on sibling and parent report measures.]
2. Does sibling with autism symptomatology or externalising behaviour moderate the effects of the support group?

The authors hypothesised that the support group would be associated with improvements in siblings' mental health and that siblings of autistic children showing more severe symptomatology or problem behaviour would benefit more from the support group.

RESEARCH METHODS

Participants for this study were recruited from a family programme for autistic children and their siblings. To be eligible to take part in the programme a family needed to have a child with an autism diagnosis and a TD sibling (no autism diagnosis). A total of ninety-eight children (forty-four diagnosed with autism and fifty-four TD) attended a ten-week programme lasting two hours each week in Queens College, New York, between 2014 and 2016. As this study focused on siblings of autistic children, the participants of this study were the fifty-four siblings (mean age 8.31 years) who attended the family programme.

The fifty-four siblings were randomly assigned to either a sibling support group or a control group by the coordinator of the programme. For the first hour the sibling support group participated in activities focusing on experiences and characteristics of autism. The control group participated in similar activities, but there was no focus on any experiences of autism. The autistic children participated in a social skills group for the first hour. During the second hour, all children came together for recreational activities. The groups were led by graduate and advanced undergraduate psychology students who were skilled and experienced in implementing social skills groups for children with additional needs.

Data were collected from parents and siblings prior to the start of the programme (pre) and again on the last week (post) of the programme. A mixed analysis of variance (ANOVA) for group (sibling support vs control) and within-subjects factors (pre- vs post-intervention) were computed separately using IBM SPSS Statistics for Windows, Version 24.0, for the following variables: depression, anxiety, support, coping skills and siblings' externalising and internalising behaviours.

The assistant leader in each group rated treatment fidelity and completed a checklist of the steps of the curriculum. Fidelity mean was 95 per cent for the support group and 96 per cent for the control group. Attendance for seven or more of the sessions was 88 per cent for the support group and 96 per cent for the control group.

RESEARCH FINDINGS

The results showed that there were no significant differences in scores between the groups on most variables measured; the exceptions being siblings who participated in the support group showed significant improvements in both externalising behaviour and coping skills.

There were no significant differences between groups on any of the post-intervention measures.

Across all siblings (in both the support and control groups):

- coping skills increased;
- self-reported anxiety symptoms increased;
- self-reported depressive symptoms decreased; and
- parents reported a decrease in externalising behaviour.

When the autistic siblings showed more severe characteristics of autism, the support group provided a buffer against symptoms of both anxiety and depression.

STUDENT OPINION

The autistic community was at the heart of this research as it directly involved autistic individuals and their families.

Not all measures were fully sampled because some siblings were outside the appropriate age range for the chosen measure. Also, some data were missing due to families not returning it. Considering the limitations identified, the results should be viewed with a degree of caution.

The improvements in externalising behaviour and coping skills for siblings in the support group are consistent with a similar study conducted by Brouzos, Vassilopoulos and Tassi (2017) that demonstrated a significant reduction in sibling emotional and behavioural problems following support group participation.

The family programme used ideas from the SibShops curriculum; however, an Irish study was conducted to evaluate the effectiveness of SibShops and showed no statistical significance in children's self-esteem after engaging with the curriculum (D'Arcy et al., 2005). While the aforementioned study stated that children enjoyed the programme, the lack of evidence-based findings in support of the SibShops curriculum undermines the reliability of the support group used in the current study.

IMPLICATIONS FOR PRACTICE

This study demonstrates the positive impact of support groups for siblings of autistic children. They learned about autism as well as learning coping skills and discussing their feelings.

Siblings who participated in the support group showed statistically significant improvements in behaviours that led to more positive sibling and familial relations. While this is hugely beneficial for families, it is possible that the individualised instruction, attention and opportunities for siblings to play together during the second hour of the programme could have influenced sibling interaction regardless of whether the TD sibling was in the control or support group.

The results also showed that for siblings with a brother or sister with more severe autism characteristics, the support group acted as a buffer against self-reported depression and anxiety.

The results of the study did not show clinical significance in all measures of mental health, which may mean that not all siblings need a support group, yet equally it could be the most suitable intervention for other siblings. It is also possible that siblings who show clinically significant levels of mental health difficulties may benefit more from individual therapy.

Future research with a larger sample size would allow for further exploration into the various types of interventions that support siblings of autistic children.

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PARENTS' STRATEGIES TO SUPPORT MEALTIME PARTICIPATION OF THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER

This article was reviewed by: Hickey, K.

Karen chose to review this article because through her work with autistic children and their families, feeding problems are highlighted regularly as an area of concern that have an impact on both the child and family's everyday functioning. Understanding the importance of the mealtime experience for the family, in addition to supporting the autistic child's individual feeding needs (e.g. trying new food), will help develop interventions that are holistic in nature and meaningful to the family.

BACKGROUND

Research studies highlight the incidence of paediatric feeding problems in the general population, with autistic children five times more likely to present with significant feeding challenges. In addition to impacting on the autistic children's growth and nutrition, feeding behaviours influence the mealtime experience of the family with the family's focus oriented around the child's feeding requirements. Mealtimes are an important social and emotional routine with parents reporting dissatisfaction in mealtimes and the stress involved in managing their child's behaviours. By understanding the strategies that parents use, it may be possible to develop effective interventions that are meaningful for the autistic population and employ a strengths-based approach.

RESEARCH AIMS

The importance of parent-mediated interventions for feeding challenges has been highlighted in recent reviews with the emphasis on the need to provide families with the opportunity to help shape intervention strategies. Studies have evaluated parent training interventions, but there is a lack of information on what strategies parents of autistic children currently employ in real-life settings. The aim of the current study was to identify, describe and understand these real-world strategies.

RESEARCH METHODS

This was a qualitative observational study. Twelve families of autistic children aged 2–7 years were video recorded during mealtimes and a qualitative content analysis was employed to identify specific parental strategies employed. A parental strategy was 'any technique that a parent or caregiver used, regardless of success, to encourage a child's participation in eating and mealtime'. This study provided detailed information in relation to its data analysis and procedures with analysis of the videos occurring over time and in a systematic way that included all trained researchers. Following completion of the analytic procedures, the parent strategies were condensed and organised into final categories, based on a coding scheme, with the employment of a software programme (Observer XT). Both triangulation and inter-rater reliability measures were employed to increase the credibility and validity of the research findings.

RESEARCH FINDINGS

Six main categories were outlined: (1) Parent Intervening and Ignoring; (2) Meal Preparation and Adaptability; (3) Play and Imagination; (4) Distractions; (5) Positive Reinforcements; and (6) Modelling. The videos reflected the heterogeneity of family mealtimes with autistic children, which fits within the literature in relation to the heterogeneric nature of autism. However, parental vigilance emerged as a key component of all mealtimes, as was the use of props to support participation. Multiple strategies were employed both within and across mealtimes that emphasised the complex nature of feeding challenges.

A common theme was a sense of 'constant vigilance' with mealtimes revolving around the autistic child, which is consistent with the literature, e.g. parents monitor and alter the physical environment to support the child during mealtimes. The parent strategies described, e.g. Reinforcement, had a wide range of goals to encourage participation and eating. While assessment of these strategies was beyond the scope of the study, data indicated that in the presence of the parental strategies, children stayed longer at the table, engaged with family members and/or ate a greater quantity of a preferred food rather than eat or try non-preferred food. This information is significant as often the target of intervention is increasing the repertoire of new foods or tasting a non-preferred food rather than focusing on the mealtime behaviours/mealtime experience of the family.

STUDENT OPINION

- Limitations of the study include the possibility of the Hawthorne effect as the researcher videotaped the family. The Hawthorne effect occurs if individuals modify an aspect of their behaviour in response to their awareness of being observed. Efforts to minimise this effect were introduced.
- There was no mention in this study that there was any consultation with the families about the results of this study, which may have provided additional insights.
- There was a lack of detail provided in relation to the child's presentation, e.g. language skills or degree of feeding challenges experienced, which would have added to the depth of the data analysis.

IMPLICATIONS FOR PRACTICE

The main implication for practice is the increased understanding of parental strategies to manage their autistic child's feeding challenges and develop family-mediated interventions that increase participation and eating behaviours. The complexity of the strategies employed demonstrates the need for holistic interventions that address multiple components of mealtime participation and family characteristics.

Families of autistic children are often identified in terms of their challenges rather than their strengths and this study adds to recent research with a resilience lens. A resilience lens shifts the focus from deficits and pathology towards capacity and strength, which also fits in line with the neurodiversity movement. Families of autistic children with feeding challenges show creativity in their ability to support their autistic child to participate in family mealtimes.

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CONCLUSION

This Bulletin does not have an overall theme and in this is different from the Centre's usual publication. The students chose their own research publications to summarise and these are articles that impact on work and family lives. In this way the articles summarised can provide a snapshot of the issues that are most pertinent to parents and professionals in Ireland. Three students summarised articles on feeding and mealtimes; support for families and siblings was also a popular choice, as was issues around inclusion. Salient issues emerging from the articles are:

- Families should be included and consulted, where possible, in all aspects of the planning and delivery of supports.
- Peers and siblings create an important supportive community and with some support they can make a difference in the lives of autistic students.
- Communication is a critical area of early support and professionals should consider a range of programmes to support the development of a communication system that suits the child and family.
- Finally, inclusion matters, and schools and learning communities form the foundations for the fostering of inclusive communities for autistic students.

The Centre wishes to thank the GDAS class of 2021 for their contributions to this special edition research Bulletin and wishes them all the best for their post-graduation futures living and working in the field of autism.

Special thanks also to Dr Cat, Dr Laura and Hazel for giving so generously of their time in providing an interview for this Bulletin.

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The Centre's Research and Information Service welcomes any correspondence including suggestions for future Bulletins to: research@middletownautism.com.

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