



CENTRE FOR AUTISM  
MIDDLETOWN

# Neurodiversity



## CONTENTS

Introduction	05
Interview with Joan McDonald	07
Interview with Dr Alyssa Alcorn	09
Research Articles Summarised	
1. Annual Research Review: Shifting From ‘Normal Science’ to Neurodiversity in Autism Science	12
2. Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice	15
3. ‘Just Ask Me’: The Importance of Respectful Relationships Within Schools	17
4. To what Extent does the ‘Double Empathy Problem’ Impact on the Assessment and Grading of Autistic Students’ Creative Writing?	20
5. ‘It’s Being a Part of a Grand Tradition, a Grand Counter-Culture which Involves Communities’: A Qualitative Investigation of Autistic Community Connectedness	22
6. ‘People Should be Allowed to do what they like’: Autistic Adults’ Views and Experiences of Stimming	25
7. Neurodivergent Intersubjectivity: Distinctive Features of how Autistic People Create Shared Understanding	28
8. The Wrong Kind of Noise: Understanding and Valuing the Communication of Autistic Children in Schools	31
9. ‘Camouflaging’ by Adolescent Autistic Girls who Attend both Mainstream and Specialist Resource Classes: Perspectives of Girls, their Mothers and their Educators	34
10. I want to fit in ... but I don’t want to Change Myself Fundamentally’: A Qualitative Exploration of the Relationship Between Masking and Mental Health for Autistic Teenagers	37
Conclusion	41

## INTRODUCTION

Neurodiversity is the idea that all brains process information differently. Neurodiversity includes everyone and it highlights how each person thinks, communicates and senses the world around them in a unique way. Within this, people may be neurodivergent or neurotypical. 'Neurotypical' refers to people whose brains develop and/or process in a way similar to the majority. 'Neurodivergent' refers to people whose brains develop and/or process in a way that is categorically different to the majority. People who are described as neurodivergent include autistic, dyslexic and dyspraxic people as well as people with ADHD, DLD, fragile X syndrome, Down syndrome or Tourette syndrome. Both neurodivergent and neurotypical brains are naturally occurring.

Understanding neurodiversity is useful to help us:

- understand that everyone has different experiences and needs in relation to the physical and social environment;
- create a more inclusive world;
- fight stigma and prejudice;
- develop practical, real-world supports and accommodations; and
- support self-acceptance and self-advocacy.

This bulletin summarises both traditional participant-focused research alongside research reviews. This is so that we can fully explore topics central to neurodiversity, as well as how they can impact the lives of autistic young people and those who care about them.

Across the bulletin we will be introducing key topics related to a neurodiversity-informed understanding of autistic experience. This bulletin will focus on:

- understanding neurodiversity;
- the importance of accepting autistic behaviour;
- the negative impact when autistic behaviour is not accepted; and
- the call for non-autistic people to challenge some of their perspectives and assumptions about autistic behaviour.



## KEY DEFINITIONS:

### Double empathy

The Double Empathy Problem suggests that if people have very different experiences of the world, they will struggle to empathise with each other when they interact. This mismatch is likely to increase if they have very different ways of communicating, sensing and thinking. This theory was developed by autistic researcher and theorist Dr Damian Milton. It challenges the assumption that there is a single 'right' way to communicate.

### Masking

Masking is the suppression of behaviours associated with autism, even when they may be comforting and beneficial. It can occur as an attempt to copy the behaviours of non-autistic people. Masking usually happens when an autistic person feels unsafe being themselves and so they try to hide aspects of themselves to avoid stigma and judgement.

### Stimming

Stimming ('self-stimulatory behaviour') is a series of repetitive actions that an autistic person may do when feeling excitement, joy, distress or overwhelm. Most people stim in some way, whether that's chewing a pen, jangling keys or humming a tune, but autistic people are often more overt in their stimming. Rocking, flapping hands, tapping fingers and repeating certain words are some ways that a person may regulate themselves.

*Please note that the views represented in this document do not necessarily reflect the views of Middletown Centre for Autism.*

*The language used in this bulletin is autism-affirming and neurodiversity-informed. Some of the papers summarised use more medical and deficit-focused terminology and approaches. This bulletin is created for autistic people, family members and professionals to learn more about research being conducted. The language chosen here is intended to be as inclusive as possible to the broad autism community.*

## INTERVIEW WITH JOAN MCDONALD

Joan McDonald is an autistic teacher who provides support and training to autistic people and their families as well as schools, employers and public services. Alongside her consultancy work, she works part-time in Middletown Centre for Autism.

### What does neurodiversity mean to you?

Neurodiversity means that no two brains are exactly the same, so people perceive, create, respond, relate and learn differently to each other. This is beneficial for the world as a whole – imagine how stuck we would be if everyone thought the same and had the same skills and sensitivities!

Places such as schools, offices and shopping centres are designed around average access, sensory and social needs. This means that most people can manage there most of the time. However, these places may not suit some people whose brains differ from the average. Those people are called neurodivergent and environments need to be adapted so they can function well. These adaptations often suit other people too!

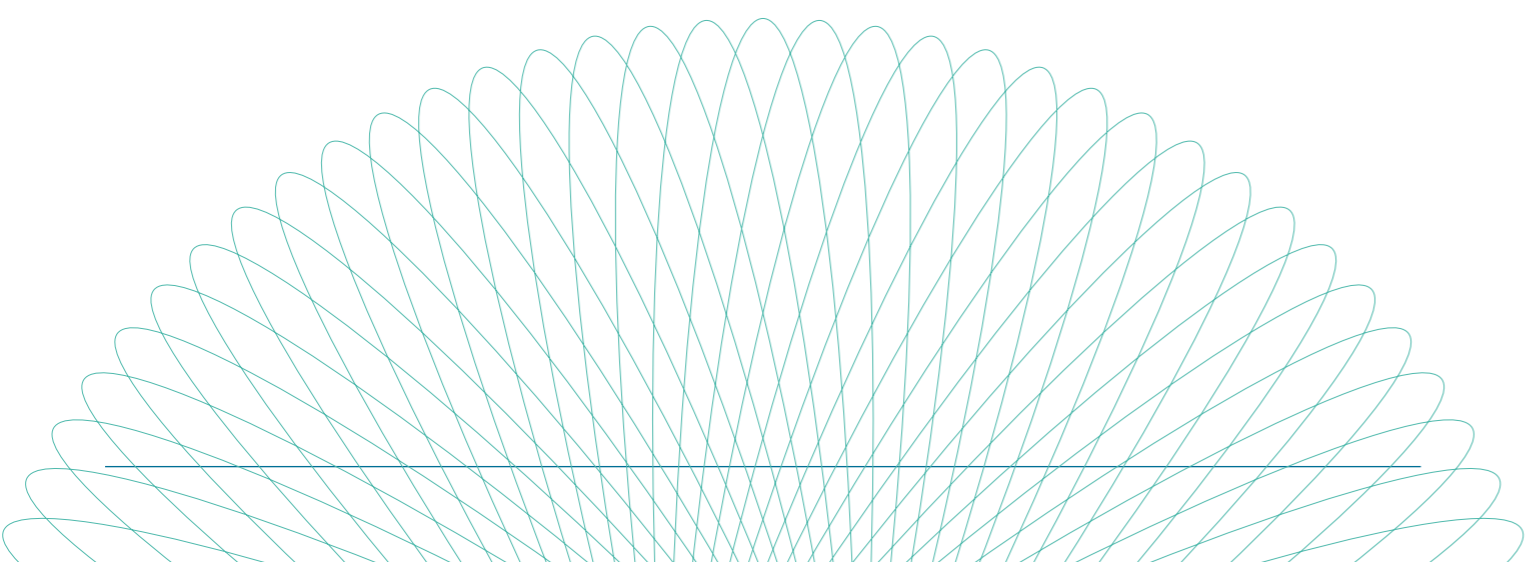
This is why the concept of neurodiversity is so helpful. It's not about isolating people who think differently. It's about appreciating that we are all different and considering what is needed so that we can include everyone. It's also about appreciating that everyone has strengths and weaknesses – that there is no 'normal'; just a society that has been set up to meet a lot of needs, but that still excludes some people.

### How does neurodiversity inform your work?

I'm an autistic teacher and trainer. Taking a neurodiversity perspective means a few things: it means I consider what I need to do my job as I know I may get overloaded by sounds or bright light. I bring my noise-cancelling headphones, my sun visor and my stimmy travel teacup with me. All these things mean I can focus on my work for longer and not get overloaded. I also try to manage my time so I don't have too much 'peopling' at a time.

By the same token, I don't make assumptions about my students or the people attending my training sessions. If they are there to learn, it's important that the environment is what their brain needs. So students may be walking around or rocking during a lesson, and as long as they are not breaking anything or disturbing others, that's fine. And if what they are doing is causing a difficulty, we try to find another way to support them to regulate themselves.

Adults in training sessions generally are not autistic. Training often happens after school and they are tired and need to fidget and move a bit. I remind them that it's okay to do that – they are adults and it's important that they meet their own needs to keep alert for the training, but generally they don't! They are encultured into believing that sitting still with their eyes on the speaker or the slides is what they must do, so they are out of the habit of looking after their own neurodiverse needs.



When training about neurodiversity, I've been asking people to complete access riders – documents that state what is 'need to have' and 'nice to have' for them to perform effectively. It's usually a powerful exercise. People, especially those in caring roles, are not used to thinking about their own needs. They may find it hard to identify what exactly they like or need, are very emotional in considering it in the first place, and it's another step again for them to share this information with their family or employer. It just shows how far we still need to go to become a neurodiversity-informed society.

### What do you wish people who support autistic young people knew about neurodiversity?

I would like support people to know that the autistic person's sensory experience, social responsiveness and mode of communication may be very different to their own, and can change frequently as their regulation changes during the day, and that this may have nothing to do with the autistic person's actual intellectual ability or potential.

They need to accept the autistic person's way of interaction, focused attention and sensory needs as being a core part of the person. It may evolve through maturing and education but there should be no attempt to make the autistic young person feel shame for who they are.

With that knowledge of the person, supporters can then create learning programmes and social supports that allow the autistic young person access to education, relaxation and to their local communities in whatever way works for them.

### What do you think the world would look like for autistic people if society embraced neurodiversity?

If difference was more accepted, autistic people would likely experience far less anxiety and be more confident about accessing the world – be it education, employment, friendships, interest groups.

A society that considers neurodiversity as important is one where people, young and old, are supported in self-understanding and in self-advocacy. These skills don't come automatically and need to be taught to all children – for example being introduced via the LEANS programme.

With the new Capacity Act in Ireland, we now assume that all adults can make their own decisions unless there is very good evidence that they can't. This makes it all the more important for autistic people to be confident in knowing who they are, how they tick and what they need so that they are more assured in making bigger decisions about their lives or in getting help to do that.

## INTERVIEW WITH DR ALYSSA ALCORN

Alyssa is the Research and Impact Lead for the Learning About Neurodiversity at School (LEANS) project, based at the University of Edinburgh's Salvesen Mindroom Research Centre (find out more about LEANS [here](#)). She is an interdisciplinary researcher with extensive experience on participatory projects and a background in psychology, education, human-computer interaction, and design. Alyssa will be speaking at the Middletown Conference this May (find out more [here](#)).

### What is the LEANS project and how do you hope learning about neurodiversity will impact students?

LEANS stands for 'Learning About Neurodiversity at School' and really tries to do exactly that – teach about the concept of neurodiversity as it relates to school contexts. It introduces pupils aged 8–11 to the concepts of neurodiversity and neurodivergence and helps them explore how these may impact their own and others' school experiences. Right now, most pupils (and many staff) won't be familiar with the concept of neurodiversity at all, and may not have a strong understanding of neurodivergent pupils' needs and school experiences. Children may be very aware of differences between people but may not know why these are there. Conversely, they may be unaware that the person sitting next to them – or even their best friend – is having a very different experience of 'the same' lesson.

LEANS is a teacher-delivered resource for the whole class. The programme is guided by three big goals: **know-think-do**. The aim is for participating pupils and staff to:

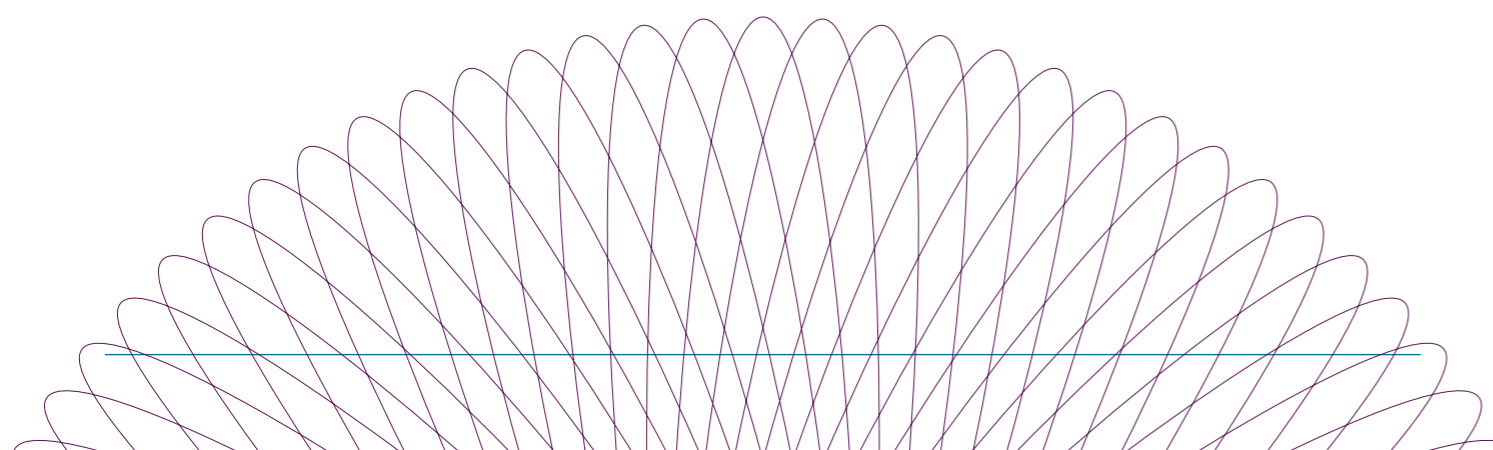
- **KNOW:** Increase their **knowledge** of neurodiversity terms and concepts.

- **THINK:** Develop more positive **attitudes** towards neurodiversity and neurodivergence.
- **DO:** Increase individuals' positive and inclusive **actions** within the school community.

All together, the big-picture goal of the programme is to try to improve school experiences for all pupils – but especially neurodivergent pupils who may be facing many concurrent challenges in school environments. Changing everyday interactions, even in small ways, can really add up. For example, if you ask a peer a question and they take a long time to respond, what might you do? Tell them the answer? Walk away? Get cross? We hope that after LEANS more children might choose to wait with patience and understanding because they know some people need more time than others to process language or plan a response, and that is okay.

We really stress that LEANS is for *the whole class* and try to persuade people that neurodiversity teaching has the greatest potential benefit that way. What **all** class members and staff know, think and do *every day* has an enormous effect on the school environment. Neurodiversity is about your classroom – not someone else, somewhere else!

The big-picture impact of all of this is trying to support well-being and positive outcomes for all children (especially neurodivergent children) by tackling negative attitudes and lack of understanding. Understanding and acceptance *are not enough* on their own but are an important place to start.





### What are the next steps for the project?

The LEANS research project has now been running for three years, and we're transitioning into what we sometimes call 'the final phase'. With LEANS now available for free, we are focusing on impact and on making those resources sustainable beyond the end of the research funding later in 2023. Many people have worked hard on them – it would be heartbreaking for the LEANS programme to gather dust on the shelf, so to speak, because people stop hearing about it or have no way to get support with delivering it. What we're trying to do is build momentum and expertise out in the community. With our charity partner, the Salvesen Mindroom Centre, we've developed companion resources for parents and carers to help them understand and propose LEANS. We've also trained our first cohorts of LEANS Champions. They are experienced education professionals around the UK and Ireland, equipped to advise others on adopting and delivering LEANS. Previously, that kind of personalised support wasn't available, so we are very excited about the Champions!

A piece that's still missing is a forum/network – or many of these – that allow people to directly meet and talk to others who are delivering LEANS or who are interested in promoting neurodiversity teaching and learning. These kinds of networks will work best if communities set up and run their own – not researchers. So this is our big challenge to the community: can you help create a way for people in your area or profession to talk about LEANS? It can be simple! If you do, please let us know and we can help promote it.

Also, a 'future plans' question I get a lot: everyone asks if we're working on a 'LEANS 2' for secondary schools or anything for other age groups. The answer is, not yet! Team members are still hoping to secure future funding to develop teaching materials for other age groups.

### Is there a way for people in Ireland and Northern Ireland to get involved?

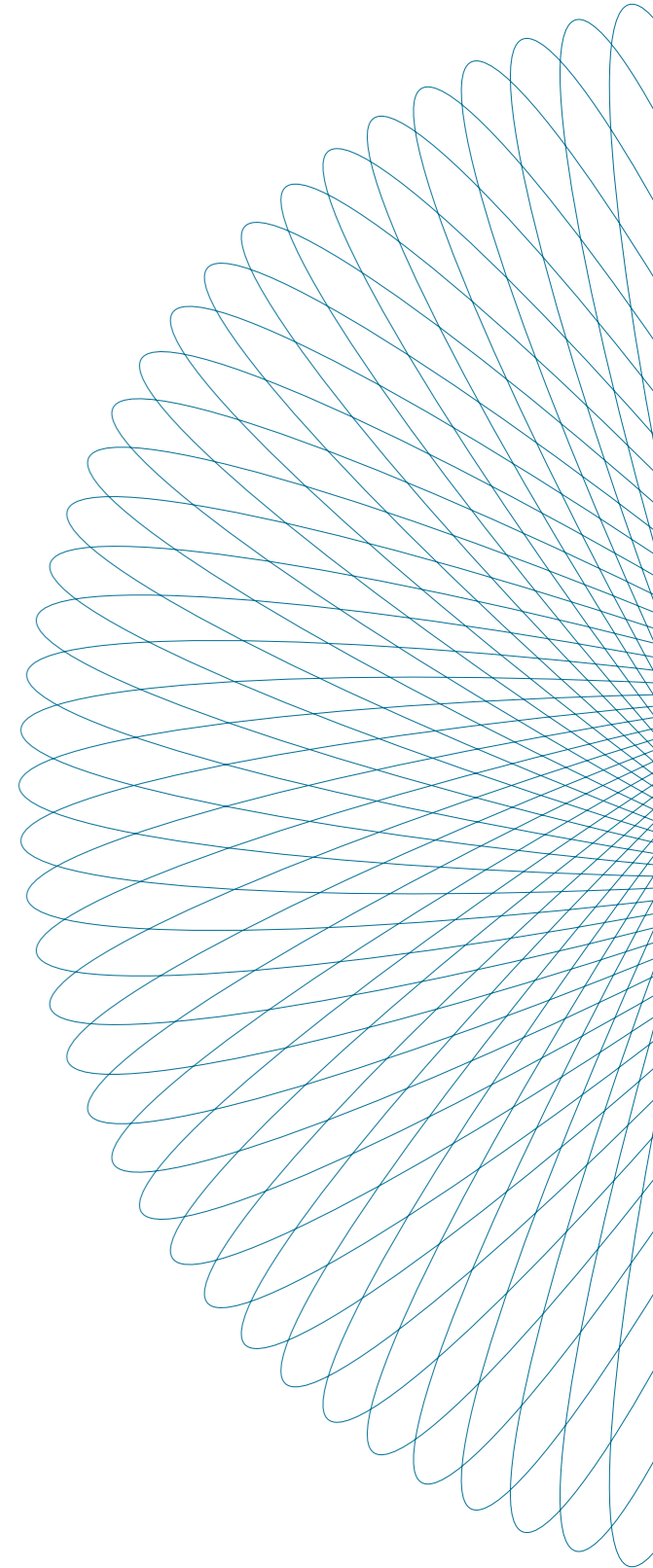
Yes, definitely! There are different types of involvement for people in different roles.

- For **people working in primary education**, the first and simplest way is to visit the LEANS website, download the resources and have a look. Might this be a good choice for your setting? Can you encourage other educators to check out LEANS – for example through a mailing list or even a staff room chat? Word of mouth is incredibly powerful.
- Interested in delivering LEANS, trying to decide, or troubleshooting? The LEANS Champions Ireland Team are experienced, trained educators who can offer you advice (including in NI). The best part is Champions support is free! Find them here: <https://salvesen-research.ed.ac.uk/leans/champions>.
- For **third-sector organisations and professionals outside schools**, such as in healthcare, you have a really valuable role in helping to explain to people what neurodiversity is and why we should be talking about it. You are trusted sources of information and can **signpost** educators and families to LEANS and other neurodiversity resources, both in conversations and online.

- For **parents and carers**, we'd encourage you to check out the [companion resources](#) to find out more about the programme, and consider proposing it to your child's school using our template letter and info booklets.

Absolutely **everyone** can help by adding to our list of community-recommended resources. It's been really popular so far and we're updating it now. If you know a great neurodiversity-related book, website, video, training course or *anything*, you can propose it for the list through our online form. You can find more info and the form at this link: <https://salvesen-research.ed.ac.uk/leans/news/recommendations2022>.

Finally, Northern Ireland is what we would consider a priority area for engagement with LEANS because our project team has comparably few professional and community connections there. This is one reason why I am so excited about the Middletown Conference. I'm hoping to meet professionals and community members who can help us spread the word about LEANS and the value of teaching and learning about neurodiversity. See you there!



# ANNUAL RESEARCH REVIEW: SHIFTING FROM 'NORMAL SCIENCE' TO NEURODIVERSITY IN AUTISM SCIENCE

## RESEARCH AIMS

Historically, autism has been discussed within a medical model of disability that focuses on perceived deficits and impairments. This review set out to examine whether how we understand and research autism needs to be rethought to create a broader model that may better capture the experiences of autistic people. This study aimed to examine three challenges to the traditional medical model of autism: an over-emphasis on deficits, a focus on the individual as opposed to a broader societal focus, and a lack of inclusion of autistic perspectives.

## RESEARCH METHOD

The researchers conducted a literature review focusing on two areas: the different arguments against the medical model and arguments for an alternative perspective to explain autistic experience. In this instance, their focus is on the neurodiversity paradigm and whether it could overcome issues within the medical model.

## RESEARCH FINDINGS

The medical model of disability focuses on a lack of ability within the individual. Under this model, treatments are focused on making the individual's behaviour more in line with the societal norm. From the first published description of autistic

traits to many current interventions, much of society's understanding of autism is based on the deficit-focused medical model. As a result of this, much of autism science has been dedicated to identifying genetic, neurobiological and cognitive mechanisms that might explain the presence of autism so that specific treatments might be developed.

The researchers suggest that a model of autism that focuses on deficits has led to a number of challenging outcomes:

- Despite research showing that there are areas in which autistic people routinely excel, strengths are rarely suggested as elements of the autistic profile.
- While many studies show that autistic people outperform non-autistic people on certain tasks, researchers have often interpreted these results negatively, actively looking for reasons why an achievement may be as a result of an 'autistic deficit'.
- Deficit-based assumptions have led to a rush for interventions and treatments that may not be as evidence-based as they should be. Further, research has found that conflict of interest or potential harms of such non-pharmacological treatments may not always be reported in studies.

- The language used to discuss autism in research may function to stigmatise by using words such as 'disorder', 'impairment' and 'deficit'.

The researchers also highlighted the impact that focusing on the individual rather than social or environmental factors may have:

- The perception that challenges rest with the individual perpetuates stigma.
- The burden of 'correcting' perceived deficits is placed on the individual, with a requirement that they change their behaviour.
- A large number of treatments focus on the autistic child becoming 'indistinguishable' from non-autistic people, which fails to acknowledge the real personal benefits that may be brought by some behaviours associated with autism, such as stimming.

The final point highlighted by the researchers as a critique of the medical model focused on the lack of inclusion of autistic people's interpretation and understanding of their own behaviours. Some researchers have suggested that autistic people lack 'theory of mind' meaning that they cannot have insight into their own mental states. The researchers of this paper suggest that these assumptions may lead to:

- development of research that excludes autistic people's opinions in preference to parents, teachers and other professionals;
- autistic people having limited say in what is researched and why it is researched;
- the majority of autism research across the world focusing on genetic causes and biology, while studies have shown that autistic people and their loved ones favour research that focuses on practical, daily living issues; and

- autistic people and their family members reporting negative experiences when taking part in research.

The researchers presented neurodiversity as an alternative paradigm to the medical model of autism. They defined neurodiversity as 'the range of natural diversity that exists in human neurodevelopment ... including both typical and divergent neurodevelopment'. They highlighted central ideas within the paradigm:

- Neurodiversity rejects the idea that divergence from the norm should be judged as a deficit, highlighting that no form of neurodevelopment is superior or inferior to any other. As such, all people deserve to be treated with dignity and should be valued as they are.
- Neurodiversity includes all autistic and neurodivergent people, although it can be a challenge to ensure that all autistic perspectives are heard.
- The lives of all autistic people can be meaningful and rich. Quality of life may not be best judged based on limited neurotypical standards.
- Autism and other neurodivergent conditions are viewed as part of a person's identity and a central part of their experience of the world. As such, they need to be accepted.
- The social and physical environments are designed by and for neurotypical experience, as such they can often be challenging or even hostile towards autistic and other neurodivergent people. Research shows that barriers to access exist in health care, employment, mental health support and leisure pursuits. The neurodiversity paradigm suggests that these barriers need to be addressed, rather than changing the individual.



- Research shows that there are differences in the ways that autistic and non-autistic people communicate. This lack of alignment may lead to miscommunication, which makes it essential that autistic people are actively involved in decision-making around research and practice.

### IMPLICATIONS FOR PRACTICE

Researchers suggest that a shift in perspective is needed to challenge both research and interventions that focus on deficits.

Rather than place onus on the individual to change who they are to better fit into neurotypical environments, the researchers highlight the importance of examining the disabling factors within the physical and social environments.

To ensure that supports are useful and appropriate, better mechanisms need to be developed to confirm that autistic people are included as partners in autism research.

In shifting to a neurodiversity-informed approach, greater emphasis could be placed on community priorities to direct autism research towards the development of more practical supports that may impact real-world challenges.

#### Full Reference

Pellicano, E. and den Houting, J., (2022). Annual research review: shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*. 63(4), pp. 381–396. doi: 10.1111/jcpp.13534. Epub 2021 Nov 3. PMID: 34730840; PMCID: PMC9298391.

## AUTISTIC SELF-ADVOCACY AND THE NEURODIVERSITY MOVEMENT: IMPLICATIONS FOR AUTISM EARLY INTERVENTION RESEARCH AND PRACTICE

### RESEARCH AIMS

The increase in autistic self-advocacy and the growth of the neurodiversity movement have implications for theory and research, but they also have implications for real-world practice. At the heart of neurodiversity as a concept is the idea that variations in neurological development are naturally occurring and that disability arises because environment and social structures have been developed to best suit the majority. This shift in perspective has already had an impact on some theories and approaches, such as:

- our understanding of social challenges and whether they exist within the autistic individual or as shared challenges between autistic and non-autistic people;
- a change in focus to address more practical issues faced by the community, for example mental health and quality of life; and
- a better understanding of community preferences related to language and terminology of autism.

Despite these shifts in focus, little attention has been paid to implications for early intervention.

The aim of the review was to explore how the neurodiversity paradigm could impact the types of interventions commonly used with autistic children and young people. The researchers presented historic and current thinking on interventions as a basis for a neurodiversity-informed approach to interventions.

### RESEARCH METHOD

The researchers presented a perspective piece informed by a literature review focusing on research relating to neurodiversity and early childhood interventions. The team presented

a perspective based on both research and lived experience.

### RESEARCH FINDINGS/ IMPLICATIONS FOR PRACTICE

While some opposing opinions exist, a balanced approach to neurodiversity suggests that diversity brings inherent strengths, but these are often also accompanied and inextricably linked to specific challenges. Adopting a neurodiversity-informed approach to early intervention can bring valid changes to the content of interventions.

1. As it is not possible to cure any innate neurological difference, neurodiversity-informed interventions do not support attempts to 'cure' or 'normalise' autistic children, despite this historically being a focus of many autism interventions. Further, autism is pervasive, meaning that it impacts every aspect of a person's life. Interventions that target autism would require a fundamental change in the individual. Autistic advocates have described that potential change in stark terms. They suggest that an attempt to remove their autistic experience would feel like a form of death – if the individual cannot be separated from their autistic identity then removing that identity would erase the individual too.
2. More practical interventions may target the physical and socio-communication factors external to the child that are creating disadvantage. Within this framework, beneficial interventions may:
  - create understanding and acceptance in non-autistic people;
  - create opportunity for physical, sensory and emotional regulation; and



- support young autistic people to develop self-awareness and self-esteem.
3. Through a neurodiversity lens, if autism is naturally occurring, then characteristics that cause no harm or distress should not be pathologised. This can be a complex issue as people may have different thoughts in relation to what constitutes 'harm'. The researchers suggest some key principles to guide these considerations:
- Focus on the internal drive – a behaviour may be driven by a sensory or emotional experience not apparent to a non-autistic person. For example, while historically interventions have been developed to stop or minimise stimming, recent research suggests that it has beneficial functions for the autistic person.
  - Question intervention targets – many interventions have been developed with a focus on reducing 'autistic behaviour'. Research suggests that this means a child may be left without a valuable coping mechanism or at increased risk of mental health challenges. The researchers suggest that evaluation of interventions should include whether the focus is on attempting to make the child appear neurotypical.
  - Focus on well-being, pleasure and strengths – by taking a strength-based approach, interventions can focus on enhancing activities, skills and interests that naturally lead to learning, social connection and well-being. For example, research is increasingly focused on the broad benefits that encouraging passionate interests can bring for autistic children.
- Promoting autonomy – research and lived experience accounts from some autistic adults have highlighted that some early interventions removed autonomy. The researchers highlighted the potentially damaging use of techniques that exert physical control as prompts, ignore communication or remove the option of saying 'no'.
  - Tools to measure the outcome of interventions largely focus on a reduction in 'autism symptoms'. This approach often means a reduction in harmless behaviours that simply do not conform to neurotypical ways of being. Some outcome measures do fit within a neurodiversity framework, such as those that measure improvements in communication.
  - Inclusion of autistic people – historically autistic people themselves have not been meaningfully included in research focused on developing early years interventions. Increasingly researchers and funding bodies are acknowledging the need to include autistic people to share experiences. The researchers from this paper highlight a need to more creatively include the experiences of children and adults with severe communication difficulties.
- Full Reference**
- Leadbitter, K., Buckle, K.L., Ellis, C. and Dekker, M., (2021). Autistic self-advocacy and the neurodiversity movement: implications for autism early intervention research and practice. *Frontiers in Psychology*. April 12;12:635690. doi: 10.3389/fpsyg.2021.635690. PMID: 33912110; PMCID: PMC8075160.

## 'JUST ASK ME': THE IMPORTANCE OF RESPECTFUL RELATIONSHIPS WITHIN SCHOOLS

### BACKGROUND

Historically our understanding of autism has been focused on 'deficits' in relation to social and communicative behaviour. This type of deficit language is often used when behaviour diverges from the typical, and over decades autistic behaviour has been defined as a 'disadvantage' or a 'disorder'. While the economic cost of autism has regularly been discussed, rarely is there a focus on the individual, familial, social or economic impact of not appropriately supporting and including autistic people.

Although schools offer an opportunity for autistic young people to thrive socially and academically, time and again research has shown that school can be a place of bullying, discrimination and exclusion. While supports can make an important difference, establishing the right supports can be difficult. Currently, research shows that a large number of autistic children access special tuition and external support because the existing educational system may not be enough to support them to engage and succeed. Constraints such as lack of time, training and funding may be barriers to providing support. Parents and teachers have identified that the needs least supported in an education setting are primarily social and emotional.

### RESEARCH AIM

The aim of this research was to understand the school experiences of autistic young people (and adults through reflection). Underpinning the research was the assumption that autistic experience is not inferior or deficient, just as

non-autistic experience is not superior or more acceptable. The study was founded in the idea that challenges in communication between autistic and non-autistic people arise from inherent differences in neurology – with neither one being better or worse than the other.

### RESEARCH METHOD

Twenty-four participants took part in the research. They all identified as autistic, were over 16 years of age and had experience of the Australian school system. They ranged in age from 16 to 67 and they had experience of a variety of school environments, including mainstream state school, mainstream Catholic school, travelling teacher education and specialist schools. They were recruited via an advertisement circulated on social media.

To gather a range of experiences, the researchers presented a flexible route to taking part in the study. They offered the option of engaging through semi-structured interviews, written accounts or text-based individual interviews. Nineteen participants chose semi-structured interviews, while the remaining five provided written accounts.

Data from the interviews was analysed using a reflexive 'empathetic' approach. Individual researchers coded the interviews for themes that were then discussed with the whole team (who were a mixed group of autistic and non-autistic researchers). Broader themes were discussed and agreement was reached on themes to be prioritised.

## RESEARCH FINDINGS

### General observations

A number of participants discussed differences in experience between primary and secondary settings, with increased challenges in secondary school exacerbated by stigma around autism. Participants discussed attempts to manage stereotypes and stigma, with assumptions made by teachers being particularly damaging. Positive relationships were expressed as key to participation. This was centred around teachers who enquired about the participants' needs and listened and responded to their answers.

This paper focuses on three overarching themes.

- Avoiding assumptions of ability – the need for effective communication.
- The dangers of stereotypes, stigma and judgements.
- Fostering skills of advocacy.

### Avoiding assumptions of ability – the need for effective communication

Participants described instances in which teachers made assumptions about their ability based on prior experience of autistic students rather than asking the students directly. Participants emphasised the need for open communication to combat this, as one participant explained:

'So the big one was asking me. What I found out was they only did what they heard or had written and they wouldn't ask me how that made me feel or what would help me ... So there were times when it's like if you just asked me, I could clarify

things ... If the teachers and students had asked me questions of what they were unsure of, that would have helped me a lot because it meant that they were interested and they wanted to help ... So not checking on me, not asking questions and then having a belief and false facts already implemented.'

Participants found that they were informed of decisions relating to them, rather than included in the decision-making process. This left a feeling that communication was only one-way, rather than a shared exchange that allowed them to contribute.

The tone of communication was also remembered as a challenge for participants, with some describing a need for more discreet communication.

'I think that there were times when I was singled out and things were said to me in front of other kids that probably could have been saved for a quiet moment or not been bothered to be dealt with at all.'

Participants acknowledged that good communication was clear, positive and validating, while avoiding stereotypes or stigmatised judgements.

### The dangers of stereotypes, stigma and judgements

Participants noted how stereotyped ideas of autism overshadowed the strengths that they held. Assumptions were based on incorrect understanding of the individual's nature. They were also reflected in the language used by teachers.

'It's like, well, females, you can't be autistic. It was a male thing. If they ever heard of females on the spectrum, it was always they're shy, they don't talk to people. They don't like being around other people. They won't speak to you. Most of them are non-verbal. They're not outgoing, they're not boisterous. They won't be able to process things ... So it was kind of like the total opposite of what I was ... I wasn't really treated like another person. I was treated very carefully.'

The researchers highlighted that pretence of 'normality' underpinned the experiences of many participants during their school years. Several attempted to appear non-autistic, which was not sustainable, while others suffered bullying.

### Fostering skills of advocacy

While many of the participants had positively claimed their autistic identity in adulthood, some felt powerless to do this during their school years. For some, though, secondary school was where they began to take positive ownership of their identity. This was more easily achieved if the culture within the school promoted and encouraged self-advocacy, particularly through specified programmes and peer mentoring.

## IMPLICATIONS FOR PRACTICE

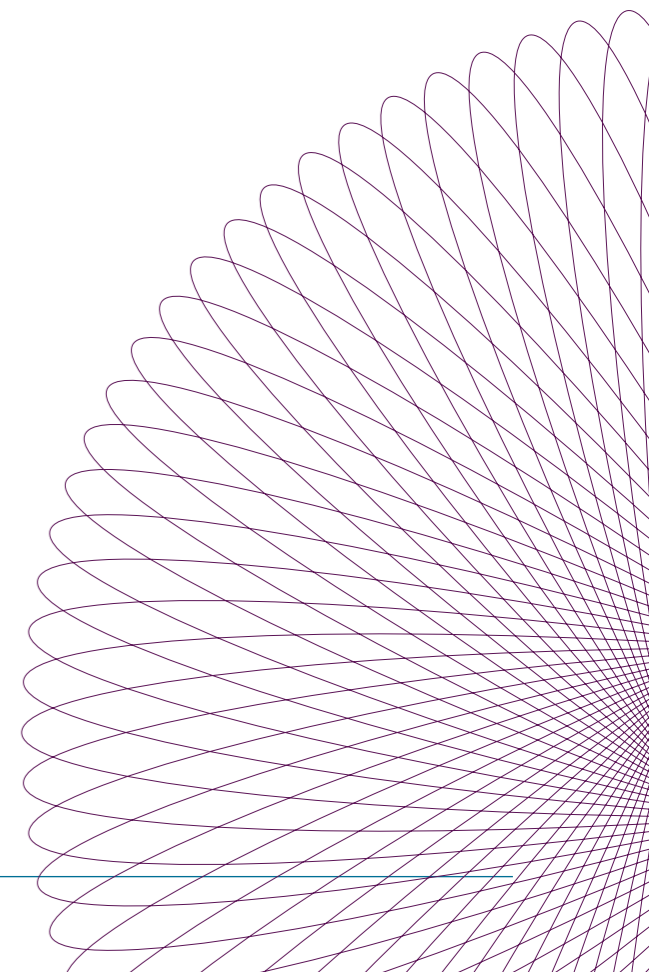
The researchers developed a list of positive strategies for schools based on the key themes presented by participants:

- All autistic students are different – avoid assumptions based on labels or experience based on previous students.
- Presume competence.

- Build an environment that facilitates discussion and understanding of student needs and allows meaningful choice.
- Deliberately ask, listen and respond to autistic students in relation to their experiences.
- Prioritise relationships with autistic students.

### Full Reference

Brownlow, C., Lawson, W., Pillay, Y., Mahony, J. and Abawi, D., (2021). 'Just ask me': the importance of respectful relationships within schools. *Frontiers in Psychology*. June 15;12:678264. doi: 10.3389/fpsyg.2021.678264. PMID: 34211427; PMCID: PMC8239345.





# TO WHAT EXTENT DOES THE 'DOUBLE EMPATHY PROBLEM' IMPACT ON THE ASSESSMENT AND GRADING OF AUTISTIC STUDENTS' CREATIVE WRITING?

## BACKGROUND

Research suggests that autistic people may face inequalities in relation to exam success. Historically, barriers to achievement have been thought to stem from the autistic person themselves, with suggestions that issues with theory of mind, executive functioning or central coherence may impact success. More modern theorising has focused on the 'normative' structure of education processes. With standard practices developed to support non-autistic people, efforts to address the challenges faced by autistic people have often focused on challenges and perceived deficits rather than the strengths that autistic people naturally exhibit. This approach may risk normalising non-autistic behaviour, with autistic young people only rewarded if they can adapt themselves to non-autistic ways of being.

Research examining writing by autistic students and non-autistic students has produced inconsistent findings. Some studies have found differences in preferred content, grammar, vocabulary and sample length, while others have found no difference when children are given support. Few studies of creative writing examined more artistic elements of expression; however, autistic university students have been found to value creativity and self-expression in their work. For school children, though, these features are rarely emphasised, with a greater focus on marked elements such as vocabulary, structure, clarity and purpose. GCSE examiners have been found to express difficulty in marking creative writing tasks due to the variety in submitted exam scripts.

## RESEARCH AIM

The study aimed to examine differences in grades awarded for creative writing to autistic students and cognitively matched non-autistic students.

## RESEARCH METHOD

Eleven autistic and 11 non-autistic students aged between 12 and 16 contributed at least one piece of creative writing. They were produced as standard coursework for each age group. Scripts were read and marked by participants' English teachers or GCSE AQA examiners. None of the adults identified as autistic themselves.

Each piece of creative writing was marked based on standard GCSE marking schemes, with an additional rubric designed to focus on broader creative writing strengths.

Students' scripts were analysed by researchers over three stages.

- Stage One focused on 'autistic features', which have been developed based on analysis of writing by acclaimed authors thought to be autistic. These included themes of:
  - difference/assimilation;
  - sensory processing/cognition; and
  - empowerment/disempowerment.

They also included structural features such as:

- unusual, unexpected elements; and
- a preference for detailed description over global 'big-picture' focus such as plot.
- In Stage Two, scripts were assessed based on the AQA GCSE marking scheme.

- In Stage Three, scripts were marked based on broad measures: social and psychological complexity, structure and the effectiveness of language used.

## RESEARCH FINDINGS

Stage One revealed a greater number of 'autistic themes' in the creative writing of autistic students. These included a gifted protagonist overcoming challenges and themes relating to sensory or cognitive differences. Autistic students' writing was found to feature more 'unexpected' events and had a more detailed, descriptive focus over overall plot.

Stage Two, marking against GCSE criteria, saw non-autistic students more highly rewarded. Disparities were greater among older students. This was interpreted as evidence that either GCSE marking schemes do not support the rewarding of this type of content or assessors respond less positively to it.

Stage Three data suggested that autistic students produced content that was more psychologically and socially complex as compared to non-autistic students. Autistic students presented complex representations of protagonists' thoughts and feelings but they were less rewarded for this than their non-autistic peers. The researcher suggested that this may indicate that scripts were more complex and required a higher degree of time and 'cognitive commitment' from the marker, which may have impacted on the marks given.

Overall structure was broadly similar between autistic and non-autistic scripts, although autistic writers used more dialogue and switching narratives. Autistic students were also more likely to use humour and extended metaphors, but these elements were not rewarded.

## IMPLICATIONS FOR PRACTICE

- By providing a wider range of curriculum fiction and non-fiction that includes neurodivergent authors, both students and teachers may gain greater familiarity with material created through a range of perspectives.
- Focusing on coursework alongside exams would allow teachers to gain a gradual understanding of their students' perspective, thinking and creative approach.
- If exam scripts from neurodivergent students were flagged for marking, examiners would have the opportunity to consciously address any potential bias.
- Training examiners to better understand autism may help to minimise bias, particularly if training is provided by autistic professionals.
- Broadening the marking rubric to include a fuller definition of creativity may lead to the awarding of higher marks for autistic students as more of their areas of strength are included.

## Full Reference

Finn-Kelcey, I., (2021). To what extent does the 'double empathy problem' impact on the assessment and grading of autistic students' creative writing? *Good Autism Practice*. **22**(1), pp. 24–37.

# 'IT'S BEING A PART OF A GRAND TRADITION, A GRAND COUNTER-CULTURE WHICH INVOLVES COMMUNITIES': A QUALITATIVE INVESTIGATION OF AUTISTIC COMMUNITY CONNECTEDNESS

## BACKGROUND

A vibrant autistic community exists, thriving online since the eighties and, more recently, in real life. Autistic people report comfort and ease of communication when with other autistic community members. However, a stereotype persists that autistic people are not interested in social connection or friendship. The idea of autistic people making connections and supporting one another runs counter to the deficit-based 'theory of mind' explanation of autism. Emerging research has shown that increased identification with other autistic people is protective of mental health, but the concept of autistic community has never been formally analysed.

## RESEARCH AIM

This study of 20 autistic adults aimed to discover and understand adults' experiences of autistic community connectedness. In other minority communities, connections with similar people are known to promote good mental health and well-being. The researchers wished to see if a similar effect occurred with autistic people.

## RESEARCH METHODS

Participants were all autistic (15 assessed, five self-diagnosed), over 18 years of age, and communicated in English. Speaking, non-speaking and selectively mute people took part. The lead researcher conducted all interviews either in-person, online, via text messaging or via email according to participant preference. Participants were of mixed nationality, location, gender and age.

A framework for questioning was used including broad questions on diagnosis, autistic identity and community connectedness. To be guided purely by the participants' experience, this framework was adapted and adjusted as the data was gathered from each interview. Indeed, the literature review took place after data collection was complete in order for the researchers to remain open-minded.

## RESEARCH FINDINGS

The research found that most participants did belong to autistic communities, and three common categories of connection emerged from their interviews:

### A sense of belonging

Participants reported connecting to 'tribe' and being accepted by other autistic or otherwise neurodivergent people. They found it easier than being with non-autistic people. They felt accepted with their quirks rather than in spite of them, and often had an instant connection with each other.

### Social connectedness

Within autistic communities, participants reported making specific friendships. In face-to-face meetings, this was mediated by the accessibility of venues that considered autistic sensibilities and so were not overwhelming or stressful. However, the main place for interaction was the internet. Being with people who understood their challenges meant that giving and receiving advice was part of such friendships, which assisted people to understand their own autistic identity. Common subjects discussed included sensory issues, interactions with others and raising children. These interchanges included both speaking and non-speaking autistic adults.

### Political connectedness

Most participants who engaged in this type of community were also part of the more socially oriented communities. They were largely engaged in campaigning around rights-based issues such as campaigning for:

- a ban on fake 'cures' for autism, e.g. MMS;
- suitable education provision for autistic children;
- access to autism assessment;
- an end to stigma against autism;
- an end to 'normalising' autistic people; and
- research that is relevant to autistic people.

These participants also valued the neurodiversity perspective and connected with other minorities in relation to, for example, race and gender to promote common issues of social justice.

Benefits associated with these three forms of community connectedness included:

- feeling a sense of purpose and joy with reduced social isolation;
- learning about oneself in a safe, validating space; and
- creating friendships.

Political connectedness also gave participants a sense of purpose and of identity with a network working towards a common cause.

However, three participants experienced disconnection from autistic community. Three main factors seemed to influence this.

- They did not consider autism to be a core part of their identity, especially those who discovered they were autistic later in life.
- There had been a mixed response from their parents to their diagnosis, which made them question their autism.
- An internalised sense of stigma created a fear of those who might be 'more autistic' due to maintaining negative stereotypes about autism. This resulted in a desire to distance themselves from autistic people. This could also have led to a sense of superiority, with ingrained ideas that certain levels of intelligence or ways of being useful to society make a person intrinsically of greater value.

Just one participant was distant from both autistic and non-autistic communities and so was completely socially isolated, even from their family.

Overall there was an inverse relationship between acceptance of autistic identity, or lack of stigma towards it, and association with the benefits of autistic community.

## IMPLICATIONS FOR PRACTICE

- The positive effects of belonging to autistic communities show the need to provide opportunities for autistic people to connect with others.
- Further research is needed to understand and challenge internalised and externalised stigma and how it may impact an autistic person's desire to connect with their community.
- More research is required focusing on the joy, happiness and improvement in well-being caused by being part of an autistic community.



- There is a need for greater exploration on how to make physical environments accessible so autistic people can meet in real life and not only online.
- Autistic people need to be fully involved in all aspects of research to better represent their reality, interests and concerns.
- Accessibility needs to be considered to support autistic people with co-occurring learning disabilities and those from other marginalised groups to better access their community.
- Further research is needed to understand community connectedness in relation to formal/self-diagnosis, minority stress and the factors that encourage autistic community development.

#### Full Reference

Botha, M., Dibb, B. and Frost, D.M., (2002). 'It's being a part of a grand tradition, a grand counter-culture which involves communities': a qualitative investigation of autistic community connectedness. *Autism*. 26(8), pp. 2151–2164. PMID: 35318862 PMCID: PMC9597163 doi: 10.1177/13623613221080248.

## 'PEOPLE SHOULD BE ALLOWED TO DO WHAT THEY LIKE': AUTISTIC ADULTS' VIEWS AND EXPERIENCES OF STIMMING

### BACKGROUND

'Repetitive motor movements' are included as a core diagnostic feature of autism. Many autistic people describe this behaviour as 'stimming'. Research looking at the perspectives of non-autistic people has found that stimming is considered by many to be a problematic behaviour thought to contribute to socio-communicative challenges. Historically, this behaviour has been viewed as a form of self-stimulation that shut out external stimuli and impacted on attention and focus. Many 'treatments' have been developed and are still used in an effort to control, change or eliminate stimming behaviour by autistic children and adults.

The language used to talk about stimming has also been largely negative. Many researchers discuss stimming as something that is under voluntary control, ascribing asocial or antisocial motivations to it. Research has found that parents may opt for interventions that target stimming because it is a noticeable and stigmatised behaviour. Therapies are still being suggested to 'treat' stimming despite limited evidence relating to efficacy or appropriateness.

In recent years, autistic people have started to be included in discussions about stimming. Autism activists have suggested that stimming may act as a type of coping mechanism leading them to oppose attempts to stop non-injurious stimming. They have also questioned the impact that preventing stimming may have in relation to bodily autonomy.

At time of publication, only one previous study had sought to directly find the opinions that autistic adults held about stimming. That survey study found a wide range of reasons for stimming including reduction of anxiety and

overstimulation, as well as a method to calm down. The majority surveyed said that they generally or sometimes enjoyed stimming but most had been told not to do it.

### RESEARCH AIMS

The study aimed to extend the previous research focusing on the opinions of autistic adults through in-depth semi-structured interviews and focus groups. The specific aims were to examine autistic adults' understanding of stimming, their thoughts on the purpose of stimming and their views on the worth of stimming. A central feature of the study is that it was co-produced by autistic and non-autistic researchers, adding a unique and important perspective to the designing, conducting, analysing and interpreting process.

### RESEARCH METHODS

Thirty-one autistic adults (20 male, ten female, one non-binary) participated in the study. They were aged between 21 and 56 years. Interviews were conducted with 19 participants, while a further 12 took part in focus groups. All participants were based in England and were recruited through residential homes, training centres and the research teams' networks. It was hoped that this would allow for a sample with wide-ranging support needs. All were diagnosed as autistic, with 21 receiving their diagnosis in adulthood and ten in childhood.

Interviews were structured around four key questions: 1) Do you have any stims or repetitive movements? 2) What triggers your stim? 3) Is it helpful/useful? 4) What would happen if you could not stim? Participants were offered a range of communication options to take part in interviews, which resulted in 17 in-person, one email and one email/instant messenger interview structure. Participants had the option to have a

parent/carer present during the interview, with five choosing to do so.

Focus groups took place after the interviews. There were two in-person sessions held, with six participants in each group. They were facilitated by members of the research team, who focused on encouraging all participants to share. Sticky notes were used to enable contributions from participants who preferred a non-verbal method of sharing and to enable further discussion once collated and presented to the group. The focus groups were structured around the question schedule used in the interviews.

## RESEARCH FINDINGS

The research uncovered two central themes:

### Theme One: **stimming as a self-regulatory mechanism**

Participants defined stimming as a repetitive, usually rhythmic behaviour expressed through body movements and also vocalisations. Many participants said that they experienced stimming as voluntary and unconscious, at least at the beginning of the behaviour. No participants stated that they consistently or inherently disliked their stims (as separate to the social consequences in response to stims). Most suggested that stimming was comfortable or calming, with some stating that it played a regulatory function.

Researchers found four interconnected situations that participants linked to stimming: overwhelming environments, sensory overload, noisy thoughts and uncontrollable emotion. When external environment was impacting internal thoughts and emotions, stimming served to create a single point of focus to regulate by stopping or minimising excessive input.

‘It helps you talk to yourself at a rhythmical pace, so when I’m doing this I can sort of think in the rhythm that I’m moving my hand ... Which is very helpful because it means like when you’ve got your internal monologue it doesn’t all come in at once and you find yourself sort of shouting at yourself in your head to get everything done.’

Most participants stated that an emotional state was consistently linked to the need to stim. Some discussed stimming in response to a negative emotional state such as anxiety, while others described stimming in response to a positive emotional state such as excitement. While stimming was associated with positive or negative emotions, the strength of the emotion was consistently strong. This suggests that stimming is a method to minimise hyperarousal.

Some participants highlighted that they use different stims in response to different emotions, meaning that the stims themselves may serve a communicative function in indicating the person’s emotions. For some participants, stimming could sometimes be held under conscious control, allowing them to actively prevent emotional dysregulation by stimming to soothe their emotions.

### Theme Two: **(de)stigmatisation of stimming**

Participants expressed an awareness of the negative reactions that observers have in response to stimming. They suggested that responses to stimming had made them feel anger, nervousness, frustration, belittlement, shame and confusion. Many participants stated that they wished to avoid negative attention and sought to suppress or conceal stims in public. Some concealed their stims from view as much as possible, while others shared that they had felt the need to adapt stims into more socially acceptable behaviours that

provided them with similar physical feedback. The choice to suppress, minimise or conceal stims was largely based on how much stimming behaviour was understood by those who might view it. A number of participants reported internalised stigmatisation, meaning that they had negative feelings about being seen to stim even though they were aware of the utility of their stims.

Participants expressed no desire to engage in stims that were self-injurious, but they did discuss stimming behaviour that resulted in accidental and unintended physical harm. These stims were regarded as unhelpful. Participants also discussed the impact of age in relation to the stigmatisation of stimming. A number shared that as they entered secondary school they felt the need to minimise or hide their stims because they were aware of negative judgements. Some reflected that this may be due to increased self-awareness in adolescents, while others suggested that stimming may be stigmatised by some as a childish behaviour.

Understanding was highlighted as the key to combating stigmatisation of stimming. One participant discussed how sharing information about autism and stimming with his workplace had allowed him to increase his productivity as he worried less about stimming.

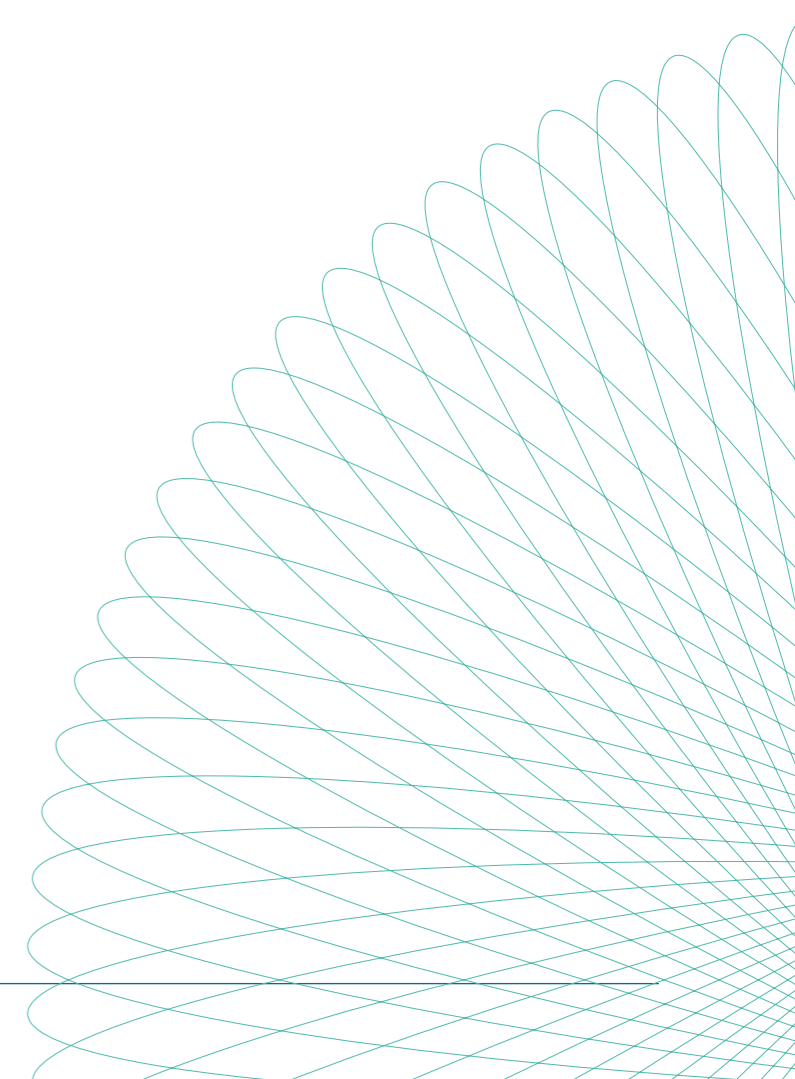
## IMPLICATIONS FOR PRACTICE

The authors note that none of the participants reported their non-injurious stimming to be detrimental, aside from the negative social judgements that made them question stimming around others. By suppressing or minimising stims due to feeling self-conscious, autistic people may miss out on the suggested benefits of stimming such as self-regulation and contained

emotions. The authors highlight participants’ calls for more understanding and acceptance of stimming.

### Full Reference

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E. and Russell, G., (2019). ‘People should be allowed to do what they like’: autistic adults’ views and experiences of stimming. *Autism*. **23**(7), pp. 1782–1792. PMID: 30818970 PMCID: PMC6728747 doi: 10.1177/1362361319829628.





# NEURODIVERGENT INTERSUBJECTIVITY: DISTINCTIVE FEATURES OF HOW AUTISTIC PEOPLE CREATE SHARED UNDERSTANDING

## BACKGROUND

Autistic people are neurologically divergent, yet approaches to studying autism are traditionally framed by neurotypical definitions of the particular characteristic under scrutiny. This has resulted in autistic people being compared to non-autistic people and being measured against non-autistic norms and expectations. As such, research has predominantly identified differences between both neurotypes, which has negatively impacted how autistic behaviour has been viewed both in research and in real-life scenarios.

For a long time research has highlighted the difference between how autistic and non-autistic people socially interact. Most of these studies use neurotypical, or non-autistic, definitions and standardised norms of social interaction to measure autistic people's social ability. More recently, researchers, like the authors of this study, have identified that there is a two-way misunderstanding between non-autistic and autistic people that impacts on the success of social interaction measured across neurotypes.

## RESEARCH AIM

The aim of this study was to understand the features of social interactions between a group of autistic people. This study used the term 'neurodivergent intersubjectivity' to describe how autistic people build shared understanding.

- Neurodivergent: someone who behaves, thinks and learns differently compared to those who are neurotypical.
- Intersubjectivity: something that is shared between people, e.g. shared communication, thoughts, feelings and understanding. It covers the variety of ways of socially relating to another.

## RESEARCH METHODS

The study took place at a charity that supports autistic adults. A total of 30 autistic adults aged 16–34 years were recruited to take part in the study. The participants were videorecorded during three sessions of a social activity they enjoyed, namely collaborative video gaming.

During each video-game session, participants played either multiplayer or single-player games (for single-player games, the participants shared the console without intervention from the researcher). In total, 20 sessions were recorded involving 30 participants, with ten participants taking part in more than one session. No session involved a duplicated set of participants. The researcher was present in the interactions to assist with any equipment issues and contributed to the conversation at the beginning (during set-up) and at the end (concluding the session).

The researchers observed the video recordings of participants and measured three core aspects of intersubjectivity.

- Coherence, focused on the logical alignment from one conversational turn to the next.
- Affect, focused on the emotional harmony between participants, e.g. laughing.
- Symmetry, focused on the alignment of conversational turns in terms of assertiveness/submissiveness, e.g. both speakers were quiet or both were animated.

Inter-rater reliability checks with an autistic researcher were conducted as a means of questioning neurotypical assumptions that may be embedded within the research.

## RESEARCH FINDINGS

While autistic interactions have been described as overtly logical, the researchers found that displays of positive affect were common, with encouragement, joking and laughter widespread throughout the interactions.

This study found two features of neurodivergent intersubjectivity:

### 1. Generous assumption of common ground

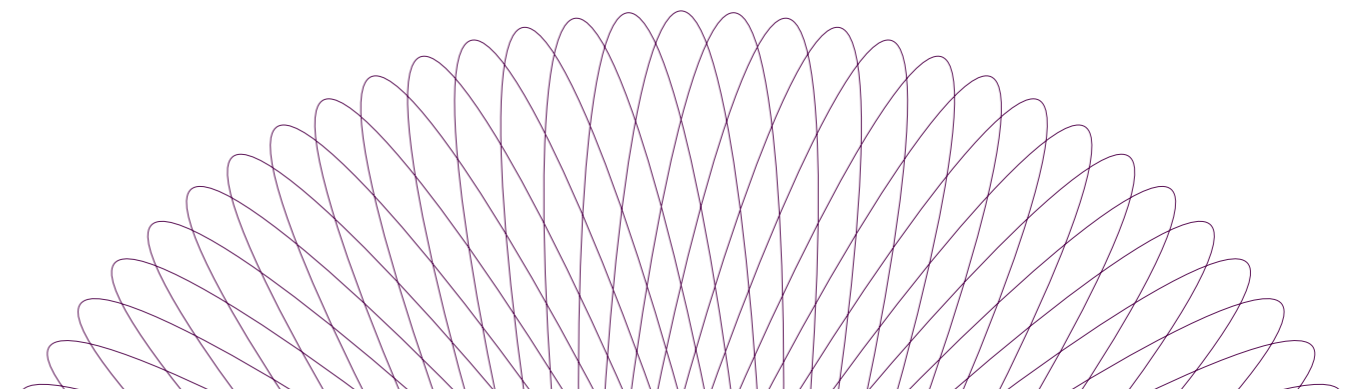
- Previous research states that social exchanges take place upon a foundation of assumed common ground. Assumptions of common ground made by the autistic participants led to the rapid construction of shared understanding, rapport and humour. This shared common ground can lead to increased affect, symmetry and coherence, creating a rich intersubjective space for shared understanding.
- While previous research has noted autistic difficulties in maintaining interaction trajectories and staying on topic, the present study found that a shared assumption of common ground allowed participants to rapidly switch conversation, often without any difficulty, and allowed creative and productive shifts in topic.

### 2. Low demand for coordination

- Past research has highlighted disconnect in autistic interactions in relation to coherence and awareness of sociocultural cues. In the present study, while there were many small misunderstandings and misinterpretations between participants, they were not problematic because participants had a low demand for coordination and could move on quickly from this disconnect.

The generous assumption of shared common ground can complement a low demand for coordination and can have enabling outcomes within an interaction. The two elements can fit together to allow rich forms of social relating. It can allow space for autistic people to continually experiment with different ways of relating to their situation with minimal negative impact if references are not shared.

The findings mirror previous research that highlighted the largely unrecognised abilities of autistic people to be motivated and skilled at managing interactions together.



These findings suggest that neurodivergent intersubjectivity reveals potential for unique forms of social relating and that the research procedures and methodology used by the researchers were a useful way of exploring autistic communication.

Ultimately, the study makes two claims based on findings:

1. That neurodivergent people are able to come up with alternative ways of socially relating outside of what is conventionally recognised.
2. That this can be investigated if we take their own interaction as the baseline norm.

## IMPLICATIONS FOR PRACTICE

Though understanding neurodivergent intersubjectivity is still a relatively new subject, this study highlights the following:

- Researchers should question traditional perceptions and measures of behaviours and work in partnership with the neurodivergent community to understand, explore and re-evaluate traditional assumptions.

- Educational professionals and parents should consider the Double Empathy Problem by Damian Milton when reviewing social differences and challenges with an autistic young person. As evidenced by this study and a growing body of research, differences or challenges experienced socially may be experienced more often between different neurotypes.
- Educational professionals and parents should consider introducing and supporting natural social opportunities for neurodivergent students to develop friendships.
- Future research should explore ways of enhancing social understanding between autistic and non-autistic people to reduce difficulties and challenges being experienced.

### Full Reference

Heasman, B. and Gillespie, A., (2019). Neurodivergent intersubjectivity: distinctive features of how autistic people create shared understanding. *Autism*. 23(4), pp. 910–921. <https://doi.org/10.1177/1362361318785172>.

# THE WRONG KIND OF NOISE: UNDERSTANDING AND VALUING THE COMMUNICATION OF AUTISTIC CHILDREN IN SCHOOLS

## BACKGROUND

As the diagnostic criteria of autism currently stand, challenges in social communication and social interaction are central to these descriptions. Research has long focused on perceived communication ‘deficits’, emphasising challenges in areas such as comprehension, pronoun use, narrative delivery and intonation. Autistic people are routinely divided based on language-use (e.g. verbal or non-verbal) and selective mutism is more common within the autistic community. In such a context, it is often assumed that for any autistic person communication challenges will be present and that communication will be in some way ‘disordered’. Within an educational context, interventions that target communication and language have been emphasised, with over 150 available interventions for children identified. With communication impairment implied through diagnosis, targeted interventions are often perceived as a priority for autistic children and young people.

In conjunction with these communication interventions, a growing interest in behaviour has developed in schools, with a focus on achieving a ‘quiet’ or silent classroom. Research has shown that a large number of pupils find that there is ‘noise and disorder’ in the classroom, with many noticing it hard to work because of the noise. Evidence suggests that this can be a particular challenge for young people who struggle to process language. In this context, autistic children may be stuck in a particularly difficult situation: it is assumed that they will have communication impairments, they may face targeted interventions that ask them to alter their natural modes of expression and modulate their ‘noises’, while at the same time teachers are under pressure to maintain an ordered, quiet classroom in which only certain kinds of noise are acceptable.

## RESEARCH AIM

Based in five primary schools in England, with ten autistic children, ten autistic adults, 36 school staff and ten parents as participants, the aim of the study was to identify what sort of communication support the children were provided with and why this was deemed necessary. The broader context of the study was the nature of inclusion of the autistic children in those schools.

## RESEARCH METHOD

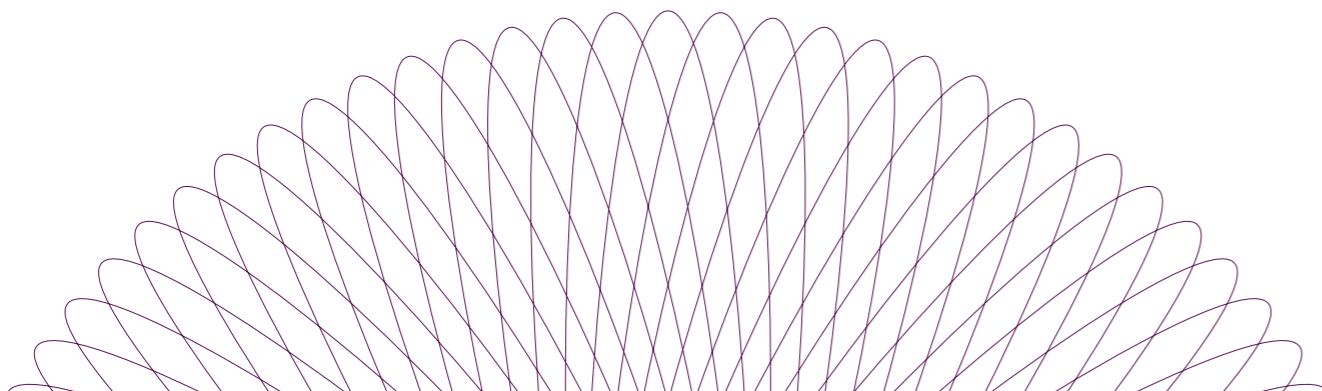
The researcher spent five months collecting data. All schools were located in a densely populated, multicultural local authority. The researcher used interviews, questionnaires, structured and unstructured observations.

## RESEARCH FINDINGS

### Speech difficulties and communication support

All children involved experienced difficulties with speech to some extent. The youngest two were described as ‘non-verbal’ (although this was not the case). Some school staff described additional communication support, such as speech and language therapists, as essential to development. Within observations TAs (teaching assistants) also provided support which, when effective, was shaped by their knowledge of the child, gentle encouragement and offering choice to the child.

In some contexts providing support could be overwhelming for both staff member and child. The researcher discussed one four-year-old boy, Piotr (not his real name), who had been described as ‘non-verbal’. Staff had developed a large amount of support paraphernalia to work with him: a choosing board, now and next sheet, work trays and pictures.





Staff were also focused on encouraging the boy to say 'good morning', 'please' and 'thank you' via Makaton, a simplified form of sign language. In these situations the focus was on his social compliance rather than his actual communication needs.

While the focus of communication interventions may also have been to build the boy's independence through these learnings, staff may have been missing important natural communication in favour of coercing communication that they deemed acceptable. In one observed task Piotr showed an array of verbal and non-verbal forms of communication:

TA3 and Piotr are at the visual timetable. Piotr picks the 'outside' card. TA3: 'No, we're not choosing' (...) TA3 takes him to the 'now and next' board. (...) Piotr shakes his head and throws the tray work card onto the floor. (...) TA3 is holding Piotr in front of her. Piotr tries to stop her from putting the card onto the board, and to wriggle out of her arms.

(...)

Piotr exclaims 'No!' (...). Hear what sounds like 'I don't wanna do this' from Piotr, but TA3 either doesn't hear or ignores.

The boy communicated through speech, sounds, gestures and actions. He attempted to communicate in the way that he chose naturally and also through the language supports provided by staff (the 'outside' card), yet his wishes were not acknowledged or accepted.

Such examples highlight that clear verbal and non-verbal communication from autistic children may be ignored if it is not 'on message' with the task devised by staff. They also suggest that a child

with the label of 'non-verbal' might not be heard, even when speaking.

### The complexities of noise

The researcher noted that all the schools involved in the study were noisy, which may be of particular concern to children who experience noise sensitivity. One autistic boy was not able to take part in PE, go to assembly or have lunch in the dining hall as he could not tolerate the noise levels. Some staff encouraged autistic children to leave the classroom if it became noisy. In effect, noise can be a barrier to full participation for autistic children.

In interviews with staff and parents, the researcher found a particular negative focus on the noises that autistic children made. These conversations uncovered a dislike of the 'American accent' that one child spoke in, as well as numerous mentions of issues with 'screaming'. The researcher noted that in one instance where the screaming by an autistic child was being discussed negatively, non-autistic children were screaming outside in the school yard. Further, noises produced by autistic children were more often considered meaningless or dismissed as 'babble'.

Some of the autistic adults in the study also reported that noise had been an issue for them when they were in school, making it difficult to concentrate.

### Silence

When focused on a strong interest, a number of the children showed an ability to silently engage with a task. Piotr, mentioned above, engaged in a self-directed reading activity for four minutes and 20 seconds, acting with skill spontaneously and

on request. This highlights how non-speaking can communicate clear messages about engagement and well-being. However, the researcher observed silent engagement being used as an opportunity to work on communication, with TAs attempting to focus on vocabulary development while the child quietly focused. Equally, general engagement with the class was also observed to be accompanied by supplementary questions whispered by a TA for an autistic child. In these instances, children already labelled with communication challenges may be overloaded with requests for responses from adults when their engaged silence was not taken into account or viewed as sufficient. Further, some staff assumed that autistic students could not follow rules on silence, even though their own needs for silence were not always respected.

## IMPLICATIONS FOR PRACTICE

By focusing on the shared exchange of meaning in an interaction between adult and child, greater agency may be felt by the child. Children were found to regularly demonstrate a range of communicative modes and skills but they were not acknowledged if they did not match the wishes of the adult interacting. This could result in frustration for the child because they learn that their attempts to communicate are not acknowledged or endorsed.

A greater consistency relating to the sorts of noise and silence that are acceptable may remove value judgements from the classroom. Currently, an autistic child may feel that whether speaking, screaming or remaining silent they are in danger of making the wrong sort of noise.

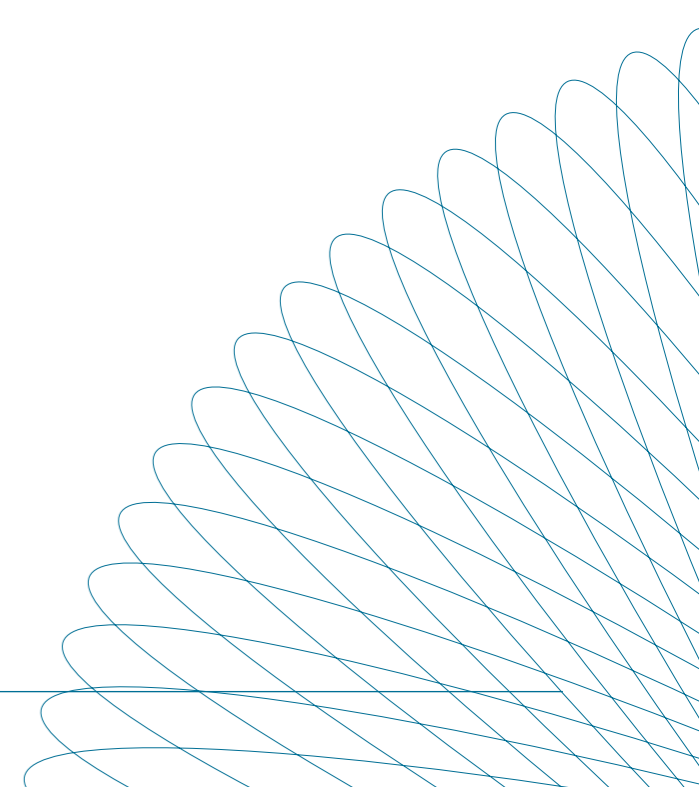
By shifting focus from the 'normative ideal' of non-autistic communication established through authoritarian intervention, staff may be able to create more opportunities for autistic children to communicate. By following the child's preferred modes of communication and focusing on what they want to communicate about, a more natural shared rhythm of communication may be established. It is important to support children to communicate what matters to them, even if it is not what the adult wants to hear.

The whole school community should be involved in decisions about noise impacts in school, allowing all community members to participate.

### Full Reference

Wood, R., (2018). The wrong kind of noise: understanding and valuing the communication of autistic children in schools. *Educational Review*. 72(1), pp. 111–130. <https://www.tandfonline.com/doi/full/10.1080/00131911.2019.1566213>.

The author's accepted version can be accessed here: <https://eprints.gla.ac.uk/273226/>.



# 'CAMOUFLAGING' BY ADOLESCENT AUTISTIC GIRLS WHO ATTEND BOTH MAINSTREAM AND SPECIALIST RESOURCE CLASSES: PERSPECTIVES OF GIRLS, THEIR MOTHERS AND THEIR EDUCATORS

## BACKGROUND

For autistic girls the challenge of social demands during adolescence can be overwhelming. This can be amplified by the school setting, particularly once the transition has been made to a mainstream secondary environment. Autistic girls' heightened social motivation and range of coping strategies can help them to manage the expectations of school life, meaning they fall under the radar in terms of receiving appropriate support. One common strategy is camouflaging, which involves masking autistic behaviours to fit in with neurotypical peers. Research has shown that autistic women and girls are particularly vulnerable to camouflaging their autistic characteristics, which is increasingly associated with significant negative impacts including exhaustion and anxiety, and missed opportunities for support and intervention in school.

Parental reports indicate that camouflaging among girls is more common in mainstream settings. Resource bases attached to mainstream schools provide a middle ground between mainstream and specialist settings, which aim to alleviate pressures and promote social inclusion for autistic pupils.

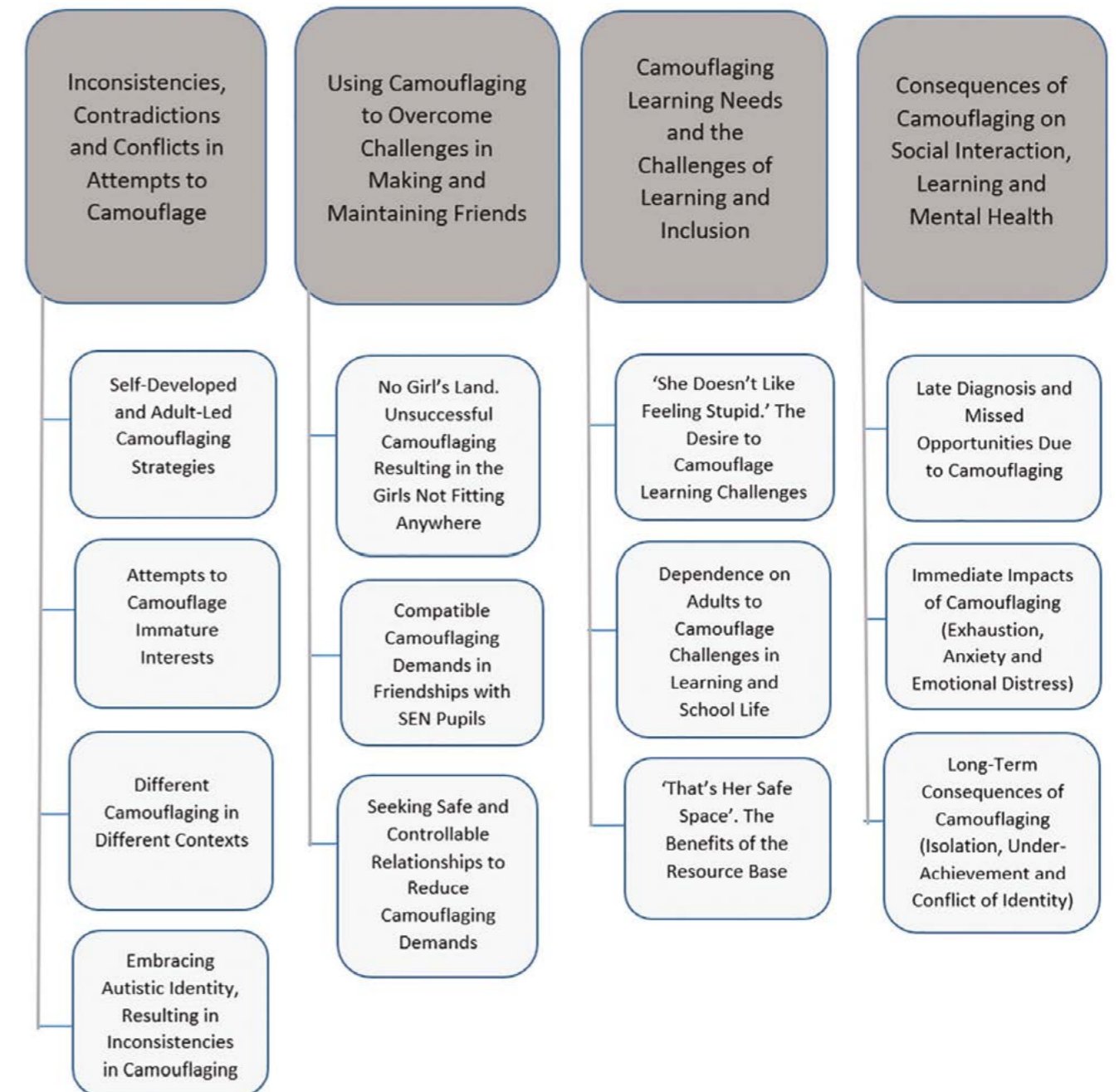
## RESEARCH AIM

The research aimed to give a multi-perspective overview of the camouflaging experiences of autistic girls attending a resource base within a mainstream setting, including the motivations and consequences of using camouflaging strategies.

## RESEARCH METHODS

Semi-structured interviews were conducted with eight adolescent girls, their parents (eight mothers) and their educators (six teaching assistants and one senior staff member) about the girls' camouflaging experiences. The girls were aged 12–15 years, and were selected through purposive sampling due to the small number of autistic girls attending resource bases. All participants gave informed written consent, and the data collection materials were piloted with autistic pupils attending a different resource base attached to a mainstream school in order to inform and amend them for use.

The girls' interviews used inclusive approaches to support them to communicate their experiences. These interviews consisted of three parts: 1) interests and friendships 2) camouflaging and 3) school views and experiences. After answering initial open-ended questions about their interests and friendships, the girls completed a visual scaling activity developed from the self-report Camouflaging Autistic Traits Questionnaire (CAT-Q) adapted to suit the girls' different developmental profiles (e.g. simplified wording and the use of cartoons to support understanding). Responses were rated on a 4-point scale (never, sometimes, often, always) and were used as prompts to further discuss their uses of camouflaging. The girls were finally asked to describe their ideal school, including other pupils and staff, activities and physical features.



(Figure 1. Thematic map)



Parent interviews were derived from the literature around girls' camouflaging and questions were divided into four sections: 1) diagnosis and the impact of autism on their lives 2) relationships before and since joining the resource base 3) camouflaging skills, including differences between presentations in different contexts and 4) positive and negative impacts of camouflaging.

The educator interviews were similarly developed from the literature around girls' camouflaging, specifically within the school context. The questions were also divided into four sections: 1) girls' involvement in class-based learning and their camouflaging skills 2) girls' relationships and camouflaging 3) girls' experiences and camouflaging in different contexts (resource base classes, mainstream classes, home) and 4) positive and negative impacts of camouflaging.

## RESEARCH FINDINGS

The results were thematically analysed using a social constructionist perspective, and four themes (incorporating 13 sub-themes) were identified (see Figure 1). Results showed that the girls tried to use camouflaging strategies to hide their autism and learning needs, especially within mainstream classrooms. This included attempts to disguise learning challenges so as not to 'feel stupid' and interests that might be considered immature by peers. Attempts to camouflage were often unsuccessful with immediate (exhaustion, anxiety and emotional distress) and longer-term negative effects (isolation, under-achievement and conflict of identity) identified as impacting on the girls' relationships, learning and mental health.

## IMPLICATIONS FOR PRACTICE (by the authors)

The findings highlight the need for increased awareness of how camouflaging presents across the autism spectrum and suggests that individualised, evidence-based support will be essential for enabling autistic girls to flourish in school. While previous research has primarily focused on the autistic individual changing their behaviour to fit in, future research should examine how to develop a culture within schools (and wider society) that celebrates diversity and explicitly promotes acceptance of difference. This will reduce the requirement for autistic girls to camouflage and the negative consequences associated with this.

### Full Reference

Halsall, J., Clarke, C. and Crane, L., (2021). 'Camouflaging' by adolescent autistic girls who attend both mainstream and specialist resource classes: perspectives of girls, their mothers and their educators. *Autism*. 25(7), pp. 2074–2086.

# 'I WANT TO FIT IN ... BUT I DON'T WANT TO CHANGE MYSELF FUNDAMENTALLY': A QUALITATIVE EXPLORATION OF THE RELATIONSHIP BETWEEN MASKING AND MENTAL HEALTH FOR AUTISTIC TEENAGERS

## BACKGROUND

Autistic people are more likely to experience co-occurring mental health conditions than non-autistic people, with 70 per cent of autistic adolescents aged 10–14 experiencing at least one mental health condition. Research shows an association between masking and mental health; however, the direction and causality of this relationship is less understood. This study defines masking as the 'experience of changing oneself in order to fit in with the expectation of others, specifically within the context of hiding or changing autistic characteristics'. Masking for autistic people includes suppressing their autistic selves and deliberately and consciously using self-monitoring to change own body language, facial expressions or forcing eye contact to present oneself as neurotypical. Existing research suggests those who mask experience higher levels of anxiety and there is a correlation between masking and depression, but the direction of causality is not yet established. It is possible that the association between masking and mental health may not be unidirectional, as mental health issues may drive masking and be present during masking experiences.

## RESEARCH AIM

This study aimed to explore the interaction between masking and mental health from the experiences of autistic children and young people. It used a qualitative approach to investigate autistic teenagers' social experiences. Key research questions included: how do autistic teenagers describe their experiences of masking? And how do autistic teenagers describe the relationship between their experiences of masking and mental health?

## RESEARCH METHOD

Twenty autistic teenagers aged 13–19 took part in the study. Ten participants identified as male and ten identified as female. Twelve attended a specialist school or college for autistic young people, seven attended a mainstream school or college and one was home-educated. The study used a semi-structured interview that was analysed using reflexive thematic analysis. The analysis generated seven themes listed in the table below.

## RESEARCH FINDINGS

### Theme 1 – Keeping it inside

Participants all reported keeping things hidden from other people. Some participants gave examples of hiding or suppressing parts of themselves or their experience. They described suppressing and hiding emotions, sensations, stims, reactions, opinions or interests.

### Theme 2 – Being myself

All participants described experiences of feeling or knowing that they were not masking and reported situations where they were able to be themselves. One participant did not describe any experiences of masking and several others felt they did not relate to a sense of 'masking' or 'putting on an act'.

### Theme 3 – How others treat me

Many participants described how masking developed as a response to other people's behaviour towards them. They described how experiences of other people valuing, supporting and accepting their social differences reduced or prevented the need to mask in certain contexts: 'Because I'd spent so much of my life not fitting in and being ostracised, I thought that [masking] was the only way to be liked.' Participants made direct links between past social experience and the development of masking.

#### Theme 3.1 – Responses to social differences

This sub-theme describes the development of masking by teenagers as a gradual response to criticisms and discouragement from others, particularly important people in their lives. One participant said, 'People have this expectation that we have to look each other in the eyes. And if you don't, you're shady or you're lying or you're a bit dodge. So I trained myself to look here ... so many times I've had teachers [say] look me in the eye when I'm talking to you, look me in the eye when I'm talking to you.' Teenagers also reported others' misconceptions or prejudices impacted on what they shared with people. These misconceptions included compliments for appearing non-autistic, pity when disclosing autism, and holding prejudiced views. Others described times when their differences were valued, accepted and supported by people, and how they felt these experiences had either prevented or limited the development of masking.

#### Theme 3.2 – Bullying, ostracism and victimisation

Participants described experiences of bullying as frightening, overwhelming and impacting on their mental health. They started developing

a mask to protect themselves from further victimisation.

### Theme 4 – Self-image

Participants described feelings of shame, inferiority and low self-confidence and how these feelings influenced the development of masking. Participants described times when their sensory reactions to an environment, a period of high energy or hyperactivity, or strong emotional expression had caused them to feel guilty for the impact on someone close to them. A negative self-image drove and reinforced masking. Some shared strong convictions about acceptance between autistic and non-autistic people needing to work both ways and a positive narrative of being autistic directly reducing or preventing the need for masking.

### Theme 5 – Immediate environmental context

Participants described masking as contextually driven.

#### Theme 5.1 – Familiarity of context

Participants identified unfamiliar situations as a trigger for masking, and often related this to higher levels of anxiety and lower self-confidence. In comparison for some participants, masking became impossible in emotionally overwhelming unfamiliar contexts.

#### Theme 5.2 – Characteristics of other people

Most commonly participants felt more authentic in their interactions with other autistic people, close friends and family members; people who knew they were autistic and people who they shared interests with. They reported feeling less anxious and more relaxed in the company of these people. One participant said, 'and they will be more understanding but also it's just because

I think there's also something a bit because of, the same sort of ethereal sense of being different is less so you're less on guard so you're less managing your expressions, your voice, your actions'. Some participants reported masking most commonly with neurotypical people their own age.

#### Theme 5.3 – Environmental characteristics

Some participants described how masking was elicited by specific places or situations. Teenagers noticed that they masked more in busy public places, where their anxiety was higher, and they experienced specific fears that other people would respond negatively to them or make negative judgements.

#### Theme 5.4 – Intersecting identities

Teenagers suggested masking became more necessary in environments when other people's norms, expectations or prejudices relating to gender and class were activated.

### Theme 6 – Internal experiences drive masking

Participants described how their mental health and internal emotional and sensory experiences were involved in the development of masking.

#### Theme 6.1 – Anxiety and worry

Some participants described worrying about others noticing they were anxious or upset and developing an 'emotional mask' to hide feelings of anxiety. Teenagers named specific fears relating to coming across as rude or 'weird', or doing something 'wrong', and noticed feeling tense and nervous in these situations.

### Theme 6.2 – Depression and low mood

For some participants masking was motivated by a desire to hide their low mood from others. Participants described how long-term experiences of bullying and ostracism, alongside being distressing, led to experiences of depression and low mood, which contributed to the development of masking.

### Theme 6.3 – Sensory and cognitive overload

A number of participants described how masking itself could be physically uncomfortable and this challenge increased if dealing with sensory or cognitive demands.

### Theme 7 – A self-fulfilling prophecy

Participants discussed how masking had direct consequences for their mental health and areas related to mental health.

#### Theme 7.1 – Anxiety

Participants described anxiety before and while they were masking. They also discussed how anxiety could be maintained long-term through masking by suppressing stims, emotions and natural responses. Situations where participants could be themselves, particularly around other autistic people, were found to reduce anxiety.

#### Theme 7.2 – Mood

Participants discussed how masking lowered their mood and made some have feelings of hopelessness about the future. Mood became more positive if participants were in situations where they could be themselves.



### Theme 7.3 – Self-image

Teenagers highlighted the impact that masking can have on self-esteem and self-image as it reinforces feelings of shame, difference and low confidence. Some highlighted that experiencing positive responses when they were not masking could have a positive impact on self-image.

### Theme 7.4 – Connection

Participants described how masking can increase feelings of disconnection from people, which can impact mental health. They felt as though hiding their authentic selves created a barrier between them and others. They discussed feeling most connected when they were not masking.

### Theme 7.5 – Exhaustion

Teenagers described how emotionally, physically and mentally draining masking can be. They described how masking all day in school could cause everything to ‘come out’ once at home, impacting relationships with their family.

### Theme 7.6 – Sensory and cognitive overload

Some of the participants discussed how stimming is essential for regulating emotions and sensory sensitivities, and, as such, suppressing stims through masking can remove an essential coping mechanism. When able to stim freely, participants discussed feeling huge emotional, sensory and cognitive release.

### Theme 7.7 – Suicidality

One participant described how the exhaustion and impact of masking took a toll on their mental health and led to thoughts of suicide.

### Theme 7.8 – Protection from bullying and ostracism

Participants discussed how masking may protect against further bullying or ostracism. They highlighted the negative impact of bullying and how masking may bring some relief if it helped to avoid this.

## IMPLICATIONS FOR PRACTICE (by the authors)

- Therapeutic support provided to autistic young people experiencing mental health challenges should consider their access to environments in which they can be their authentic selves and where their natural expression and interaction is supported.
- In safe contexts, therapeutic support should consider encouraging autistic young people to explore their authentic selves and consider dropping their mask when they feel comfortable doing so.
- Given the emotional, cognitive and physical toll that masking can take, consideration should be given to the long-term consequences of social skills training interventions that encourage autistic young people to mask their authentic selves.

### Full Reference

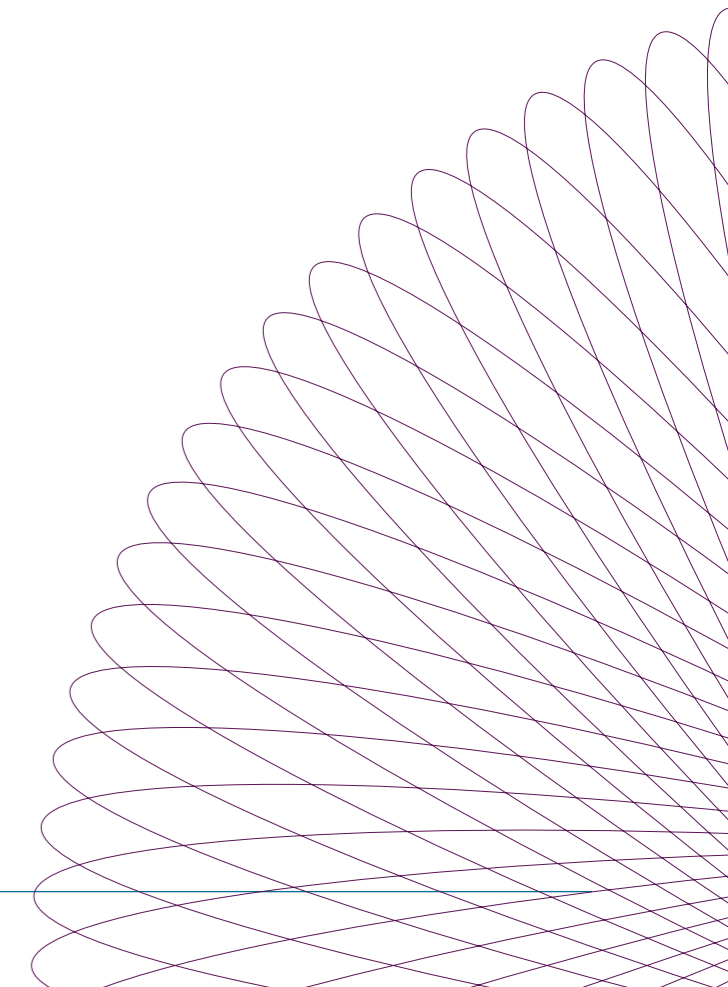
Chapman, L., Rose, K., Hull, L. and Mandy, W., (2022). ‘I want to fit in ... but I don’t want to change myself fundamentally’: a qualitative exploration of the relationship between masking and mental health for autistic teenagers. *Research in Autism Spectrum Disorders*. 99, 102069.

## CONCLUSION

The concept of neurodiversity focuses on accepting difference and creating space and support for each person to thrive as the best version of themselves. The articles summarised offer some key takeaways to help all of us create inclusive, autism-affirming practices.

- Challenge assumptions – examine whether our perspective on behaviour is informed by an assumption that neurotypical behaviour is preferable. If there is a mismatch in communication between autistic and non-autistic people, is the onus being unfairly placed on autistic community members to change?
- Address stigma – throughout the summarised articles, autistic community members highlighted the negative impact that stigma and a lack of understanding can have. Whether it’s impacting someone’s ability to stim, shaping their exam scores or forcing someone to mask their true selves, a lack of understanding can have drastic impact on personal achievement and mental health.
- Allow people to be themselves – historically, all behaviour linked to autism has been pathologised to some extent. As the summarised papers show, there are many autistic ways of being that may differ from non-autistic experiences but they are not harmful to well-being. Indeed, they may be essential to well-being. By making an effort to accept and understand autistic ways of being, practitioners give space to young people to be themselves and learn how to self-advocate.

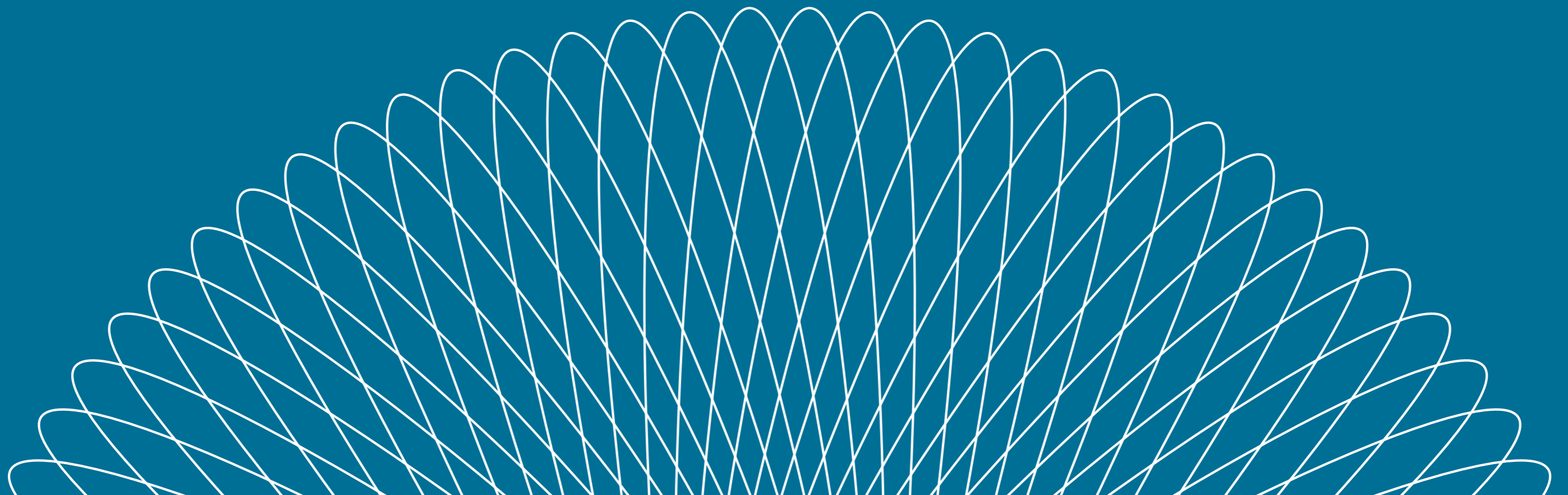
- Build community – a number of the papers summarised highlight the important role that shared experience can play for autistic people. By building a sense of belonging, developing friendships and allowing natural communication, time spent with other autistic people has the potential of a positive impact for autistic people of any age.



## YOUR OPINION

The Centre trusts that you have found this Research Bulletin informative. It would be appreciated if you would take a few minutes to provide the Centre with feedback in relation to this bulletin by clicking on the survey link below.

### **Research Bulletin Feedback Neurodiversity**







CENTRE FOR AUTISM  
MIDDLETOWN

The Centre's Research and Information Service welcomes any correspondence including suggestions for future bulletins to: [research@middletownautism.com](mailto:research@middletownautism.com).

To reference this bulletin please cite the following: Middletown Centre for Autism (April 2023). *Bulletin 40: Neurodiversity*. Co. Armagh: Middletown Centre for Autism.

Middletown Centre For Autism  
35 Church Street, Middletown, Co. Armagh BT60 4HZ  
T +44 (0)28 3751 5750 E: [research@middletownautism.com](mailto:research@middletownautism.com) W: [www.middletownautism.com](http://www.middletownautism.com)  
Fiona McCaffrey: Interim Chief Executive. Registered in Northern Ireland, No. NI063661