CENTRE FOR AUTISM

MIDDLETOWN

WELL-BEING

Contents

INTRODUCTION

This is the forty-first Research Bulletin produced by Middletown Centre for Autism, providing summaries of nine articles from 2019 to 2023.

There is no single definition of the concept of 'well-being', but common elements include satisfaction with life, a sense of safety, positive emotions and moods and a sense of fulfilment and achievement. In relation to autism, the concept of well-being has been largely neglected, with research and supports focusing on perceived 'deficits' and challenges.

In this Research Bulletin, we are focusing on well-being across the community: autistic people, parents, siblings, grandparents and teachers. At the heart of understanding what well-being means is taking time to listen to lived experience and hear what daily life is like. We also focus on the positive experiences across the community to better understand the factors that contribute to well-being.

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 DEIRDRE O'SHEA

Deirdre O'Shea is a specialist teacher with Middletown Centre for Autism. Part of her role involves working directly with autistic young people and the supportive adults around them to co-create a safe and comfortable environment. Considering the well-being of the child is at the heart of her work, and one element of this is to focus on the development of relational safety. This is the understanding and knowledge that we have of the young person, their environment and our own individual impact on the relationship.

What should a supportive adult ask themselves to help build relational safety?

As a supportive adult, relational safety starts with us. I cannot emphasise this enough. When we as supportive adults work towards building relational safety, it requires full acceptance of the child as they are, with no conditions attached. It is something that is sensed in a relational interaction between people and can include pets.

Too often I observe supportive adults attempting to build relational safety with an autistic child with conditions attached. For example, the autistic child is expected to behave in particular ways for the adult to fully accept them. This may appear subtle - such as a child having to work for accommodations and supports, e.g. an essential break from class, or be more obvious, such as punitive strategies being employed when a child is distressed or not engaging to the expectations of the adult.

When adults do this, we are sending indirect messages to the autistic child that they are only worthy when they show up in particular ways. The consequences of this often lead to further levels of distress or masking of true needs, which typically manifests over time as other mental health concerns.

True relational safety will involve no judgement or assumptions about a child's neurotype, abilities or their regulatory presentation on any given day. Therefore, supporting adults must firstly reflect on their own perceptions and beliefs about the child they are interacting with. Reflective practice is an essential skill to develop for anyone working with children. Questions to ask oneself could include:

- Am I honouring this child's neurology and potential differences that may exist between us?

- Am I making assumptions and judgements about this child's experience?

- Am I understanding of this child's experience of the world and being present with them?

- Am I attempting to fix or change the child's experience? If so, how can I instead stay present and attuned to them as they are and offer supports they may require?

When supportive adults notice, understand and connect with a child's inner experience and acknowledge this, then the foundation of relational safety has begun. When this is repeated consistently over time and relational safety is established, we have now opened a window of opportunity for the autistic child to thrive under our care.

How can supporting adults best address their own feelings of stress?

It is inevitable that stress will show up in our working lives from time to time. While stress can be helpful at times, the impact of persistent or toxic stress can lead to an overactive and overwhelmed nervous system (the body's command centre). This in turn has implications for how we interact with the children we support.

Keeping this in mind, it is important for supporting adults to have an appropriate plan in place to reduce stress levels and minimise the impact of stress on their relationship with a child.

Another point to consider is self-care for adults. This is also an important part of supporting autistic children, particularly for children who may present with high levels of distress. It is widely known that autistic children can experience elevated levels of stress in school, sometimes leading to externalising behaviours that can be distressing for both the child and adult. Marginalisation, sensory needs, a mismatch between the child and the environment and lack of communication supports are some of the issues that can contribute to such stress. Supporting adults should be mindful of their own physical and emotional needs and have a plan to manage these; managers should ensure that team members have sufficient CPD and support to ensure the best possible care for autistic children and young people.

To mitigate these factors the goal for supporting adults is to first tune into their own stressors or triggers.

As a supporting adult you can:

- understand that your body will shift through various states of regulation throughout the day. Appropriate hydration, nutrition and rest are essential to maintain an optimal foundation level of arousal. It is important to try to seek support if you are finding it difficult to meet these basic needs while in a caring role. Line managers and senior management teams should be supportive of the well-being of their team members.

- recognise where you feel stress in your body, try to tune into that feeling as it arises and move through it with some of the activities listed below. Too often adults get stuck in a stress response because they are tuned out to the body signals that are trying to communicate them.

- try to recognise the types of situations, activities and experiences that promote feelings of safety, connection and joy within your body. Use these to regulate and support yourself during times when stressors arise. For example, smelling a certain scent, rubbing hand cream slowly on your hands, wearing ear defenders in noisy environments, chewing gum, deep belly breathing, writing down your thoughts, a brief meditation, listening to an uplifting song, a walk in nature, a chat with a colleague and affirmations to promote feelings of safety within. This list is non-exhaustive and is unique to each individual and situation. Once you feel a shift in your nervous system state towards a feeling of calm and safety, the stress cycle has likely completed and clarity of thought will follow.
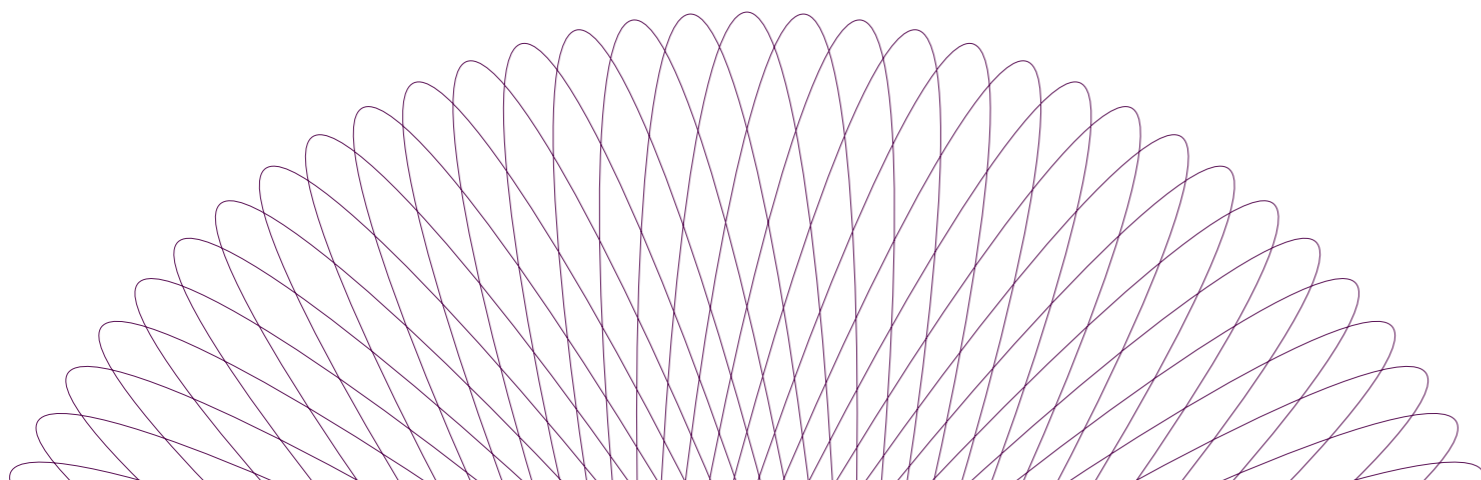
It is important to note that the above should be addressed at a whole-school level, consistently be at the top of the agenda for educators and woven into the everyday culture within the school. Appropriate self-care allows educators to be fully available and supportive to autistic children.

Do you have any tips for staying connected during a time of distress?

The most important thing for supporting adults to do is to firstly tune into their breath, tone of voice and facial expression. We must regulate ourselves to ensure we are available as a co-regulatory partner to the child. Avoid analysing the behaviour; instead look beyond it and be with the child as they are. Your presence, with a warm facial expression, regulated tone of voice, offering reassurance that you are there to support is often more than enough to maintain connection. It is extremely important that a child in distress is not ignored.

I often sit on the ground close to the child if it is safe to do so. Standing tall over a distressed child is not helpful and may further exacerbate feelings of distress.

Sometimes it can help to model or engage in a regulatory activity close to the child without the expectation to engage - rather an invitation to participate should they wish to. For some autistic children, a predictable sequence of interactions from the adult, in line with the young person's interests, can be helpful to connect and redirect during high levels of distress. It is crucial to attune this directly to the child you are supporting because for each child this will be different.

Once the stress cycle completes, stay with the child. Engage in their hobby or favourite activity as a shared connection, again being mindful that verbal conversation or communication may not be what's needed at this time.

DOES LEARNING YOU ARE AUTISTIC AT A YOUNGER AGE LEAD TO BETTER ADULT OUTCOMES? A PARTICIPATORY EXPLORATION OF THE PERSPECTIVES OF AUTISTIC UNIVERSITY STUDENTS

BACKGROUND

Lots of autistic people do not learn that they are autistic until they reach adulthood. Some parents may wait until they feel their child is 'ready' to be told of their diagnosis; others will not receive their diagnosis until adulthood. This is particularly the case for women, ethnic/racial minorities and people who have limited resources.

Receiving support that is autism-specific is associated with better outcomes for adults. While few formal supports are available, peer support has been found to have a positive impact. The diagnosis itself can offer an opportunity for self-understanding, self-compassion and coping strategies. Upon receiving a diagnosis, autistic adults report feeling relief but also report difficulty adjusting to their new identity, feelings of low self-worth, higher susceptibility to discrimination and grief at struggles experienced pre-diagnosis. One study focusing on autistic young adults found that those who were only told about their diagnosis years after it was given reported relief, shock and/or disappointment. People who gain their diagnosis in adulthood have been found to face specific barriers: years of not understanding why they were different to others, potentially trying to mask differences and having their lived experiences invalidated and overlooked by medical professionals.

Learning about autistic identity can allow people the opportunity to disclose their diagnosis and connect with other autistic people; however, research has shown that autistic university students delay identifying themselves to accessibility services.

Family members have been found to express concern over the unpredictable consequences that disclosure may bring. Given the complexities of disclosure, parents may struggle to know if or how they should discuss diagnosis with their child. Parents have expressed concern that telling their child about their diagnosis may harm the child's self-image or mental health, lower their expectations or invite stigma. For parents, sharing diagnosis was found to be a complex issue that was context-dependent and an evolving process. For young autistic adults, learning about their autistic identity helped them understand themselves, while children of parents who openly discussed their diagnosis reported more positive views of themselves and autism compared to young people who had not been voluntarily told by parents. People who were told of their diagnosis years after it was given were more likely to view it as shameful.

RESEARCH AIM

The study aimed to examine whether the age at which a person learns that they are autistic impacts their well-being, quality of life and feelings about autism.

RESEARCH METHOD

The study was designed collaboratively by a group of autistic and non-autistic researchers. They created a survey that measured quality of life (using the Autism-specific QoL), well-being (using the Warwick-Edinburgh Mental Well-being Scale) and autistic traits (RAADS-14). They were also asked open-ended questions:

- How old were you in years when you first learned you were autistic?

- How did you learn you were autistic?

- How did you feel when you learned you were autistic? Please share what you feel comfortable sharing.

- How do you feel about being autistic now? Please share what you feel comfortable sharing.

- If you had a child with autism, when would you tell them about autism?

- If you had a child with autism, what would you tell them about autism?

The survey was completed by 78 autistic students from eight countries (the majority were from the US). They ranged in age from 18 to 50 years (averaging 24 years). Just over 50 per cent were male, 36 per cent were female and 10 per cent were non-binary.

RESEARCH FINDINGS

Almost 30 per cent of participants found out they were autistic in childhood, while 49 per cent found out in adolescence and 21 per cent found out in adulthood. Almost 40 per cent had been told of their diagnosis by parents, 14 per cent had found out on their own, 5 per cent had learned from an educator and 4 per cent had 'always known'.

Autistic students who had learned about their diagnosis at a younger age reported higher well-being and quality of life. Age at learning they were autistic was not linked to more positive emotions about autism in adulthood overall, but it was associated with more positive emotions (particularly relief) when first learning about the diagnosis - with higher levels shown for those who were diagnosed after childhood. Students who learned of their diagnosis in childhood were more likely to experience negative or neutral emotions when they first learned they were autistic.

After initially learning that they were autistic, participants reported a mix of emotions: 'joy' 'relief and sadness', feeling 'curious', 'broken', 'stigmatized'. While the majority of responses were positive when asked how they felt about being autistic now: 'AWESOME', 'more positive', 'proud to be autistic'. Participants highlighted the importance of support and understanding from other autistic community members.

When asked when they would tell their child that they were autistic, none said adulthood. Over 75 per cent of participants highlighted points to consider when telling a child about their diagnosis, including curiosity, personality and support needs. Almost 30 per cent stated that they would tell the child as soon as they were old enough to understand the diagnosis and themselves. The majority emphasised the importance of highlighting the positive, while not minimising the potential challenges.

IMPLICATIONS FOR PRACTICE

- **Positive impact:** the research suggests that learning you are autistic at a young age is associated with long-term positive outcomes in relation to well-being and quality of life. However, individual differences exist as to a child's readiness.

- **Initial disclosure:** the mixed findings of the study and broader research indicate that individual experiences can influence how a young person initially feels about their diagnosis. For those informed at a young age, some may not have had prior awareness of their own differences from others and may then associate their diagnosis with challenges. Others have been found to view being autistic as a natural part of who they are. Participants recommended considering the young person's developmental level, curiosity, support needs and personality.

- **Community support:** participants also emphasised the importance of community support in the disclosure process. Autistic people and other stakeholders may be useful sources of support when someone is considering telling a young person about their autism diagnosis.

FULL REFERENCE

Oredipe, T., Kofner, B., Riccio, A., Cage, E., Vincent, J., Kapp, S.K., Dwyer, P. and Gillespie-Lynch, K. (2023). Does learning you are autistic at a younger age lead to better adult outcomes? A participatory exploration of the perspectives of autistic university students. *Autism*. **27**(1), pp. 200-212. doi: 10.1177/13623613221086700.
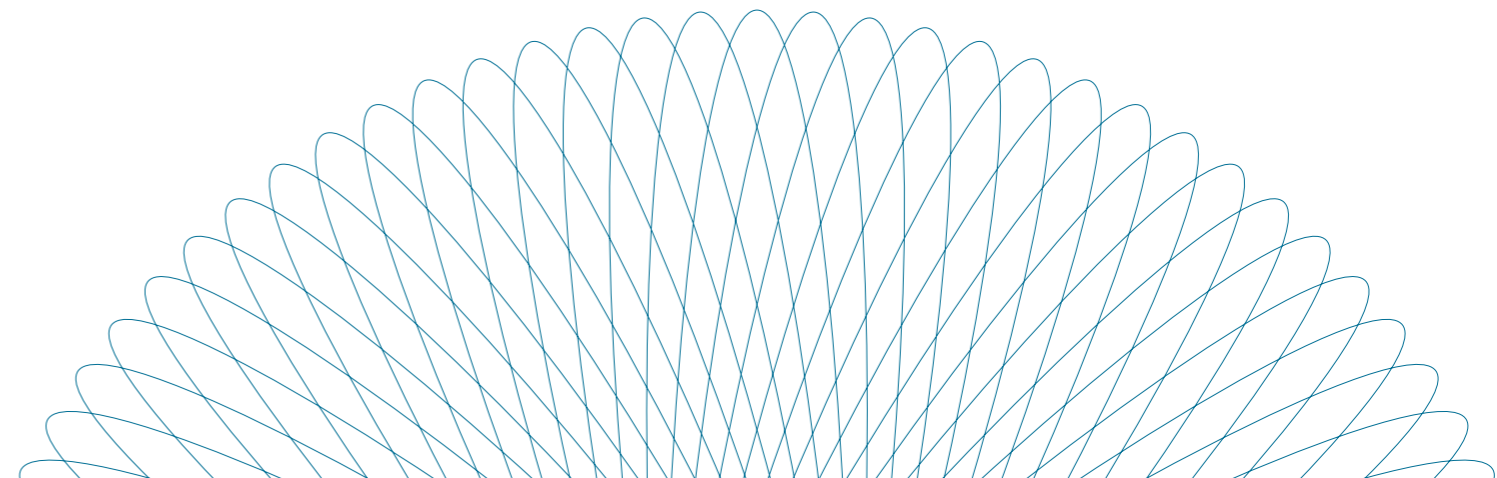
'I DON'T LIVE WITH AUTISM; I LIVE WITH MY SISTER'. SISTERS' ACCOUNTS ON GROWING UP WITH THEIR PREVERBAL AUTISTIC SIBLINGS

BACKGROUND

Child development is strongly influenced by sibling relationships, with research finding links with behaviours like sharing, cooperation and empathy. Despite this, limited research has focused on autism and sibling relationships. Historically, research that has been conducted in this area has been narrow in focus and has been informed by a medical model of autism. This has meant that many studies have focused only on the challenges of having an autistic sibling rather than taking a broader approach that fully examines the young person's experiences. Such studies have found that non-autistic siblings may experience a sense of embarrassment about their sibling's behaviour, a need for greater autonomy, anxiety due to the threat of potential violence and compassion and understanding towards their siblings. Across studies, aspects of non-autistic siblings' lives are described as atypical. The broader lived experience of siblings of autistic people is largely unknown.

RESEARCH AIM

The aim of the study was to better understand the experiences, preferences and needs of sisters who have an autistic sibling who also has a learning disability. This approach focuses on the whole, lived experience of the individual, highlighting the uniqueness of their perspective, which is informed by things like memories, joy, sadness, happiness and anger.

RESEARCH METHOD

Nine participants took part in the research. They were recruited through a community-based mental health unit for autistic young people in the UK. All were female and aged between 12 and 14 years.

They were all from lower middle class backgrounds and had one autistic sibling. Their siblings were aged between 10 and 14 years, and seven were male while two were female. All of the participants' siblings were diagnosed as autistic with a learning disability.

Semi-structured interviews

These interviews focused on the participants' experiences, feelings and beliefs. They allowed for two-way communication to explore the participants' interpretations of their own actions and the actions of others. Interviews were structured around topics: knowledge and beliefs of autism, family interactions, family routine and holidays, school life and peer relationships.

All interviews were recorded and transcribed. Interpretative phenomenological analysis was used. This takes deliberately chosen extracts to better understand meaning and lived experience.

RESEARCH FINDINGS

Four themes with associated sub-themes were identified across the interviews.

1. 'I don't live with autism; I live with my sister' (sisters' interactions with their autistic siblings).

A myriad of feelings: all sisters described a range of feelings in relation to time spent with their sibling, including love and guilt. All except one expressed a range of negative emotions in response to meltdowns: 'sad', 'bad', 'worried' and 'hard to see him biting himself'.

A sense of togetherness: sisters discussed enjoying time spent with their siblings and how that togetherness meant love for them.

'My brother and I, we stay together all the time [smiles]. Yes, we are like one. We stay together so much, we wake up at the same time, we brush our teeth at the same time. We are the kids of the house, you know … We love each other and we try to be united, this way our love grows every day …'

The data indicated that sisters attuned themselves and their behaviour to their siblings by paying attention to skills, positive attributes and the things that bring them joy.

A positive view on differences: sisters paid attention to sensory and cognitive features of autism that were perceived as strengths. While challenges were mentioned, sisters also talked of 'superpowers', 'an eye for detail' and 'good taste in music'.

2. 'Always there for us, but often asking too much' (sisters' interactions with their parents).

All sisters described feeling close to their parents and appreciating the efforts made to support their sibling. They also expressed a wish that parents would pay less attention to trying 'to fix things' and were less focused on trying to 'teach my brother how to be normal'.

Figuring out what works: sisters discussed learning how to respond to their siblings' needs and that their parents have developed knowledge around strategies that work.

Sister parentification: sisters highlighted the expectation that they take on a parental role for their sibling, which could lead to conflict with parents. This related, in particular, where fathers struggled at regulating and spending time with siblings.

'It's hard for the two of them to spend time together. They both shout and fight and get exhausted. I think they don't really know how to play together. After a point, my dad gets tired, withdraws from my brother and demands that I keep an eye on him or play with him.'

Parental expectations: parental expectations and requests impacted the sisters' experiences, with some highlighting how engagement with parents focused heavily around arguments relating to expectations.

'My parents can make things very difficult by trying hard to fix my brother the way they think he should be. My brother only eats certain foods; trying to constantly force him to eat something different creates a whole lot of tension in the house. Picture this: Mum is pushing my brother to eat something new, brother gets upset, destroying things at home, Dad gets mad with my mum, then Dad is asking me to tidy up the mess … I get mad and angry and wonder why do we have to impose our food tastes on my brother. It just does not work; it only makes things harder for all of us.'

3. 'Like a lonely fighter, tired but always on duty' (practical struggles of caring).

This theme focused on the daily struggles experienced by sisters.

Sleep difficulties: all sisters highlighted how their sleep was disrupted by their siblings' poor sleep patterns. All but two described their sleep as poor due to sharing a room with their sibling. They showed an understanding of the underlying reason why their sibling may struggle to sleep, for example if there is an unexpected event that leaves them dysregulated.

Issues with homework and study time at home: sisters showed concern relating to their homework, including fights, lack of personal space and damaged schoolwork.

Limited access to leisure activities: most of the sisters compared their experiences to those of their classmates and peers, with an awareness that they cannot have equal access to leisure activities.

'I rarely attend afterschool clubs or hang around with friends during the week. My mum will pick me up from school in a rush and we will both start planning the evening activities: shopping, cooking, bathing, etc. Not much free time really. My classmates hang around during the week. When I finally meet them, I have a feeling I missed out on some good fun while I was at home juggling with everything.'

4. 'I care about my brother and I want society to care about us' (perceived sisters' needs).

This theme focused on the perceived needs of the siblings.

Need of respite time: sisters described an awareness of the continuous and evolving needs of their autistic sibling, which they associated with phases of stress, frustration and lack of engagement in leisure activities with peers. Respite was an important strategy for some.

'It works for me to see my friends or have a chat with my cousin on a day that my brother has been out of control, hitting and breaking everything in the house. Staying home and tidying up his mess or seeing him crying makes me feel low.

Having a break helps me forget about it and then, in turn, when I am back home, I just act normal and fresh. I am happy to be around him again.'

Access to the ordinary activities: sisters described difficulty in accessing community spaces as a family.

'My family has to plan and think carefully every step before we visit my auntie's house, go to the playground or anywhere really. As if autistic people and their families don't belong in our community - everything in our community is made for people who know how to wait in long queues and can deal with noise or the not very discreet eyes of those who judge anyone different as less.'

Access to services and information: sisters discussed their wish to access more support services for themselves and their families.

'My brother attends a day centre for a few hours per week. I wish he could have access to more programmes there as he is learning important skills and it's the only way for him to access community stuff, like fun activities or sports. My brother loves going there with his key worker. This gives me time to study while I know he is having fun and is experiencing the world outside the house in a safe and pleasurable way for him.'

All sisters discussed a need to know more about what the future might hold. The majority discussed a wish to gain information and services related to improved communication, employability, long-term care and fun activities.

IMPLICATIONS FOR PRACTICE

By considering the sisters' broad experiences and perspectives, the research took a unique approach to understanding well-being. This approach has implications for how professionals may understand and interact with siblings of autistic people.

- There is a need to acknowledge the sisters as active agents, contributors to care and decision makers in the home, even though they may not always match parents' demands. This affirmation is important to the sisters' self-esteem and to develop the positive narrative around families with an autistic child.

- The sisters highlighted areas of well-being and struggle unrelated to their autistic sibling. This shifts the notion that families and their experiences are pathologised by the presence of an autistic family member. While still acknowledging hardships faced, this may contribute to a shift away from the very negative narrative often associated with families living with an autistic child with a learning difficulty.

- The sisters discussed both vulnerabilities (lack of leisure time and interrupted sleep) and strengths (awareness of equality and inclusion, problem-solving abilities). This offers a framework to better understand their experiences, rather than focusing solely on challenges. By acknowledging this and their experiences beyond having an autistic sibling, professionals have an opportunity to understand the uniqueness of the child's personal journey and support them to understand themselves.

FULL REFERENCE

Pavlopoulou, G. and Dimitriou, D. (2019). 'I don't live with autism; I live with my sister'. Sisters' accounts on growing up with their preverbal autistic siblings. *Research in Developmental Disabilities*. **88**, pp. 1-15. doi: 10.1016/j.ridd.2019.01.013.
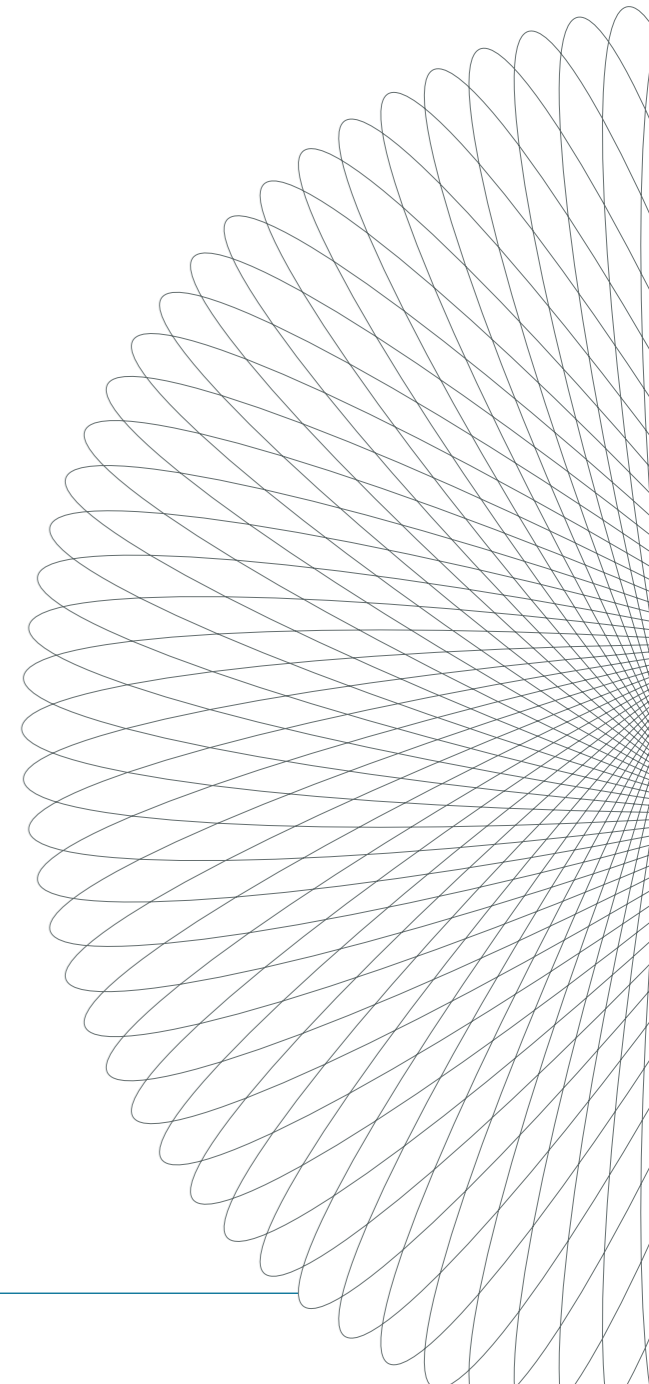
IT'S A BATTLE AND A BLESSING: THE EXPERIENCE AND NEEDS OF CUSTODIAL GRANDPARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

BACKGROUND

In the US, 2.7 million grandparents live with and provide care for over 5.7 million grandchildren. Little is known about the experiences of custodial grandparents who care for autistic grandchildren. Research suggests that parents of autistic children deal with a higher number of stressors than parents of children with other disabilities. A disproportionate amount of their time is spent navigating healthcare systems, engaging with educators and attempting to access supports. Parents report a mix of strengths and challenges associated with caring for an autistic child. Lack of support can lead to social isolation, difficulty maintaining employment and financial burden; while parents also report increased acceptance of uniqueness, enhanced spirituality, love and closeness with extended family.

Grandparents who do not live with their autistic grandchild also report facing challenges and strengths: double worry (for child and grandchild), limited systemic support, child's denial of grandchild's diagnosis and living further away, but also shared physical affection, appreciation of their adult child's skills and gratitude for positives.

Custodial grandparents of non-autistic children report significant challenges. They are more likely to live in poverty, have poor health outcomes and experience social isolation compared to traditional grandparents. They may also have experienced trauma that has led them to become custodial grandparents and hold some resentment for their role. However, they also report positives, such as using wisdom from lessons learned as parents, a warm bond with their grandchild and a renewed sense of purpose. Little is known about the experiences of custodial grandparents of autistic children.

RESEARCH AIM

The aim of the study was to find out the 'greatest challenges and joys' as a grandparent of an autistic child.

RESEARCH METHOD

Participants completed a survey that was distributed online and via email to members of support organisations. A total of 117 custodial grandparents took part (108 grandmothers and nine grandfathers). All lived in the US. Most were employed, lived in a suburban area with a spouse/partner and held an associate college degree or higher. The majority cared for their grandchild with no legal benefits such as adoption or fostering.

The survey focused on demographic questions and relationship information about the grandchild. This study focused on responses to the question: 'As a grandparent of a child on the autism spectrum, what are your greatest challenges … and joys?' A further open-ended question asked: 'Any additional thoughts, feelings or opinions?'.

RESEARCH FINDINGS

Researchers found five overarching themes that contained 16 sub-themes.

Issues with adult children

- Origins of custodial care: grandparents highlighted the issues faced by their children that, for some, led to them taking over custodial care. Issues included: substance misuse, abandonment, depression, divorce, difficulty coping with the grandchild's behaviour.

- Legal issues: many grandparents expressed frustration with the legal system and adversarial relationships with their adult child as a result.

- Conflicts during visitation: some grandparents highlighted challenges when the grandchild's parent differed in their parenting approach. 'We like to pick up toys at the end of the day, give baths at certain times [and] serve balanced meals … our daughter doesn't live this way.'

Caregiver burden

- Autism-specific concerns: grandparents expressed concerns related to coping with/supporting specific behaviours: eloping, sensory sensitivities, meltdowns, communication, social skills, toilet training and eating.

- Insufficient autism services: grandparents highlighted the challenge in accessing appropriate, individualised supports for their grandchildren. 'Getting the school administration to accept and understand the diagnosis has been a great challenge' and '[My greatest challenge is] learning to cope with all [these] people that think they have all the answers when they don't have a clue'.

- Finances: grandparents emphasised the high cost of services and supports for autistic children; some discussing the financial sacrifices they had needed to make. 'In order to provide necessary therapies for my grandson, I have almost drained my [retirement] annuity.'

- 24/7 demands: some grandparents focused on the lack of respite care that meant they were unable to rest or take a break from the constant caregiving role.

- Fear for the future: grandparents emphasised their concerns for their grandchild after they died. 'I'm concerned for [my grandson's] future. We will not always be alive to care for him or provide a home for him … I don't want him abandoned or neglected when we're not here to care for him any more.'

Coping

- Celebration of progress: grandparents highlighted that their grandchildren's accomplishments were a reason to rejoice. 'Every achievement [my grandson has] made has been a miracle and we all rejoice … When he [finally] touched his mouth to my cheek for "a kiss" [it] was the happiest day ever!'

- Unconditional love: grandparents shared their love for their grandchildren and their acceptance of them as they are. 'Each of my grandchildren is different, unique in all the universe, but my love for each of them is the same.'

- Faith/moral imperative: many grandparents discussed strong moral and/or religious beliefs. 'I thank God that he has let us be part of [my grandson's] life.'

- Focus on positive: while acknowledging challenges faced, grandparents were found to actively highlight positives instead. 'Having [my grandson] is both rewarding and challenging … but I wouldn't have it any other way.'

Wisdom

- Personal growth: grandparents emphasised how caring for their grandchild had led to personal growth. '[Our grandson with ASD] has taught us more than we could ever teach him in a lifetime.'

- Connection with village: grandparents acknowledged the importance of friends, family members, neighbours and professionals.

- Insight for others: grandparents expressed a wish to share their wisdom to improve life for autistic people. This took the form of education for the public, supporting other custodial grandparents, providing individualised supports for autistic children, developing policy change and preparing society to better support autistic people as they age.

Unique experiences

- The researchers compared the responses of grandparents in this study with previously reported experiences of other caregivers, finding that custodial grandparents of autistic children have some unique experiences. They all reported a fundamentally positive bond with their grandchild and unconditional love for them, similar to non-custodial grandparents of autistic children. They alone were found to express conflict with their adult child and they were less able to apply skills learned through their own parenting experiences. They were found to be impacted by a unique pattern of stressors that included those traditionally reported by parents of autistic children and those expressed by custodial grandparents of disabled children.

IMPLICATIONS FOR PRACTICE

- Grandparents who have not gained legal custody of their grandchild should be given specific training and assistance relating to custody issues.

- Given grandparents' fear for the future, they should be given information relating to life planning, trusts to protect the child's assets and other legal options to oversee long-term support.

- To support social connection, custodial grandparents should be provided with information about existing organisations and support groups through paediatricians, psychologists, counsellors, occupational therapists, speech therapists, school psychologists and social workers.

- Given the difficulty that grandparents expressed in leaving their grandchild, support groups should be available online.

- To minimise conflict with children during visitation, a strengths-based approach should be used in which professionals identify and build upon the family's existing strengths to foster shared competence between parents and grandparents.

- Grandparents discussed the use of positive coping strategies throughout the survey: downward social comparison, focusing on the positive, celebrating progress. Professionals should encourage and highlight the positive mental health benefits of these and other strategies.

- Given the expressed wish to increase public understanding and improve supports, professionals should actively engage with custodial grandparents to share their expertise to shape change.

FULL REFERENCE

Hillman, J.L. and Anderson, C.M. (2019). It's a battle and a blessing: the experience and needs of custodial grandparents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. **49**, pp. 260-269. https://doi.org/10.1007/s10803-018-3761-0.

THE LIVED EXPERIENCE OF AUTISTIC TEACHERS: A REVIEW OF THE LITERATURE

BACKGROUND

The discussion around autism in the classroom tends to focus on students, but there is a lot to be learned from the lived experience and insight of autistic teachers; a more prevalent group than once thought. Autistic teachers should make up approximately 1 per cent of teachers as a reflection of the general population, but many choose not to disclose their autism due to negative stereotypes and discrimination. While autistic teachers can experience challenges, their strengths and insight may be beneficial to accommodating a range of needs and improving inclusion within the classroom.

RESEARCH AIM

The aim of this research was to review the literature concerning the lived experiences of autistic teachers in education settings (from early childhood to high school) to explore the barriers to success that autistic teachers experience and how these can be overcome.

The review addressed the following questions:

(1) What strengths can autistic teachers bring to education settings?

(2) What barriers hinder the success of autistic people working in education?

(3) Are there similarities of experience that can inform inclusive practices?

RESEARCH METHODS

The literature review followed a framework for inclusive autism research that highlights the necessity of the autistic voice in research, examining the experiences of autistic people. As such, the research was conducted through an autistic lens, using identity-first language ('autistic teacher/person/individual') to reflect the terminology most preferred by the autistic community, in accordance with the social model rather than the deficits-based model of disability.

The review included research published until the end of 2020 investigating the lived experiences of autistic teachers and pre-service teachers in early childhood, primary, secondary and special education settings from around the world. Multiple online databases and search terms were used to encompass as much of the literature as possible. All papers reviewed were in the English language.

Once the search was complete, the quality of the relevant literature was appraised using the Critical Appraisal Skills Programme (CASP) (2018) Qualitative Studies Checklist and reviewed in detail. Papers were coded thematically and details and findings were recorded and categorised. All data were then collated and thematic analysis conducted using interpretative phenomenological analysis methods that are deemed suitable for autism research.

RESEARCH FINDINGS

Five documents met the inclusion criteria for the literature review.

The first, a book chapter, outlined the lived experience of an autistic individual with multiple disabilities as she progressed through her career to become a special education teacher. While it was not applicable to appraise its quality using the CASP Qualitative Studies Checklist, it qualified for inclusion because of its value as a first-hand account. The experiences outlined in the chapter include childhood trauma, social ostracism, bullying, home schooling, mental health, low expectations, education accommodations and negative stereotypes around autism.

The second document was a case study that showed how low expectations and negative stereotypes can impact teacher training for autistic individuals using the example of African-American pre-service teacher CJ, whose racial identity and autism diagnosis created a complex set of barriers to his success that he was able to overcome by accessing accommodations and supports from his family and university. The study identified CJ's initial lack of disclosure of his autism diagnosis as greatly impacting his ability to access academic supports.

In another case study Greg, an autistic pre-service teacher from the UK, discussed his positive experience with the education system. He planned to disclose his autism in the classroom and believed that it would be an asset to his teaching, particularly with regards to inclusive education. Greg identified his own challenges relating to executive function, bullying and a lack of understanding among senior management.

The fourth document was a case study examining pre-service secondary English teacher Celia's experience as an autistic teacher engaging with literature and her attitudes towards facilitating literature studies for autistic students, particularly relating to theory of mind, language awareness and empathic regulation. Celia viewed autistic perspectives of literature as making valuable contributions in the English classroom.

The final document was a qualitative research project examining the lived experience of autistic teachers in the UK (n=149) using an online survey. The study identified seven main themes: lack of understanding and support; environment; mental health issues; poor treatment of autistic pupils by teaching staff; problems with revealing diagnosis; positive experiences of revealing autism diagnosis; and facilitating inclusion.

The following themes emerged from the five documents:

(1) identity and disclosure

(2) strengths and challenges

(3) pedagogical practices

(4) lived experience/autistic voice

IMPLICATIONS FOR PRACTICE

(by the authors)

The author recommends further qualitative research exploring the lived experience of autistic teachers from countries other than the UK, following the principles of inclusive autism research.

They also recommend that the expertise of autistic teachers is actively sought to provide consultation and training in education settings, including inclusive pedagogy, school management and communication and the physical environment.

FULL REFERENCE

StEvens, C. (2022). The lived experience of autistic teachers: a review of the literature. *International Journal of Inclusive Education*. doi: 10.1080/13603116.2022.2041738.

AUTISM VOICES: PERSPECTIVES OF THE NEEDS, CHALLENGES, AND HOPES FOR THE FUTURE OF AUTISTIC YOUTH

BACKGROUND

Historically, our understanding of the experiences of autistic adolescents has been gathered through non-autistic researchers, parents, teachers and clinicians. These accounts have not always aligned with experiences expressed by autistic youth, and rarely have we heard directly from the young people themselves. To better support autistic young people as they approach adulthood, it is useful to understand how autistic young people themselves perceive their motivations, their hopes, the things that make them happy and the barriers that may impact them.

When autistic adolescents are actively involved in post-school transition planning they are found to be happier, more involved in their community and more successful in their post-school environment. Inclusion of autistic people in research is associated with greater empowerment and a sense of community belonging. It has also seen an increase in studies focusing on lived experience. However, the majority of studies still favour the inclusion of autistic people who use spoken communication and who do not have an intellectual disability.

RESEARCH AIM

The aim of the study was to gain insight into the experiences and perspectives of autistic adolescents of varying communication and intellectual abilities. The study focused on the perceived facilitators and barriers that the young people experienced, as well as their hopes for the future.

RESEARCH METHODS

Thirty-one autistic young people (26 male, six female) aged 11-18 years took part in semi-structured interviews. Researchers used the Autism Voices protocol, which was specifically designed to engage autistic young people with differing language and intellectual abilities. Researchers tailored the interviews in advance based on pre-interview phone calls with a primary carer. This allowed researchers to develop individual interviews built around the young person's preferred method of communication (writing, texting, using pictures, talking, typing, etc.), as well as their interests, preferred language, knowledge about their diagnosis and their living situation.

Interviews were conducted in the young person's preferred setting (home or a familiar lab/hospital setting). The interviews were based around a set of predetermined topics (family, friends, future, school and leisure). Participants who were aware of their autism diagnosis were also encouraged to discuss their experience and opinions of autism. To close the interview, participants were asked reflective questions (e.g. what three things they would change in their life if they had the power to do so? What would be involved in their 'best day' ever?). All participants were provided with picture prompts to help them understand potential responses.

Interviews were then transcribed and coded, with team members regularly checking coding choices and confirming consensus across interviews as they were coded.

RESEARCH FINDINGS

Six overarching themes were identified from the interviews:

1. Autistic identities

The young people described autism in complex and nuanced ways. Their responses were neither overwhelmingly positive nor negative, with many describing autism as a human variation stemming from differences in brain function. They did identify challenges, but emphasised that being autistic was a part of their identity. Rather than change who they are as autistic people, they wished for external barriers to be removed. As the researchers described it 'they were OK with their autism diagnosis, but they wanted being autistic to be easier'.

They described challenges such as social difficulties but the majority of challenges described were not linked to autistic traits but rather co-occurring conditions or stigma and mistreatment.

'Ahh, mainly lots of people can misjudge me sometimes' and 'I'm like "dude, I'm a regular person" and a few people are like "you'll never get a girlfriend because you're autistic" and I'm like "wow, that's a little prejudice, there". Probably. I don't know if, I don't know what they would call it when people don't like people under the spectrum …' (Participant 28, Male, 17 years old).

Some positives listed were directly linked to autism (such as focus on interests) but others were external to autism, such as cognitive abilities.

2. Thinking about the future

The participants ranked their future as the second biggest worry. Two did not discuss the future because it made them uncomfortable or sad. Of those who did respond, many highlighted the responsibilities they would need to fulfil as independent adults: financial security, housing duties and job requirements. They also focused on practical obstacles that they may encounter in the pursuit of their goals, e.g. driving.

Many of the young people emphasised a need for stability in their hopes for the future with a focus on staying at home or pursuing employment roles similar to their parents. Participants who spoke few words were often quick to highlight that they wanted to stay in their current living situation.

Interviewer: OK. Where would you live, do you think, when you are an adult?

Participant: Here. I like here. Here is a very here place. (Participant 8, Female, 11 years old.)

Many of the young people identified that they would like to pursue future jobs or plans based on their current interests.

Participant: I want to live in a cinema.

Interviewer: You want to live in a house, or you want to live in a cinema?

Participant: Cineplex.

Interviewer: You want to live in Cineplex so you can watch all the movies! … What do you want to do?

Participant: Building a cinema.

Interviewer: You want to build a cinema.

Participant: Yes.

Interviewer: Oh, cool. What would you put in the cinema? How many theatres would you have?

Participant: Nine screens, featuring UltraAVX. (Participant 30, Male, 17 years old.)

3. Seeking social connections on their own terms

Many participants highlighted a need to connect with more people, with most participants wanting to engage in meaningful relationships, emphasising quality over quantity. For those who spoke few words, this focus was shared verbally, using picture cards or through repetition of the names of specific people close to the participants. Some participants indicated that they would like to have romantic relationships later in life.

4. Seeking autonomy

Many young people focused on gaining autonomy through independent decision-making about matters important to them. Some thought that this was possible, while others were aware that they may need long-term support.

5. School as both a stressor and social facilitator

School was the primary stressor for the majority of young people. The school environment was described as unwelcoming, detrimental to well-being and a barrier to future hopes.

Interviewer: What do you dislike about school?

Participant: [points to letters on an alphabet display board; parent speaks out loud] I H-A-T-E-D I-T B-E-CA-U-S-E T-H-E-Y T-R-E-A-T-E-D M-E L-I-K-E A-N I-D-I-O-T (I hated it because they treated me like an idiot). (Participant 29, Male, 16 years old.)

Participants highlighted specific stressors within school, including: lack of rapport with teachers, overwhelming sensory environment, bullying and stigmatisation. Many did highlight school as an enjoyable environment as it was the primary way to make friends and interact with peers. Despite apparent barriers, some students expressed excitement about learning new academic subjects.

6. Experiences of stress and anxiety

Anxiety and stress were raised consistently and in relation to each of the topics in the study. Participants who spoke few or no words appeared to express the anxiety that they felt through changes in communication, such as getting up or refusing to answer. Participants expressed that they did not have strategies to cope with their anxiety and those who had received professional support did not find it helpful. A subset of both speaking and minimally speaking participants stated that creative expression (such as music, cinema, YouTube, imagination and drawing) were a source of comfort.

IMPLICATIONS FOR PRACTICE

- Many barriers identified by autistic young people do not differ dramatically from those experienced by non-autistic young people, such as stressful school environments and mental health challenges. Supports need to be adapted to meet autism-specific needs.

- Autistic young people should be considered active decision makers in planning their future. Many are aware of the factors that may influence their future and where they may need support.

- To create an environment where young people may have more autonomy, parents, teachers and other stakeholders may need training and support to facilitate this transition.

- Many of the young people expressed a desire to form friendships but stigma and misconceptions about autism presented a barrier. Clearly this stigma needs to be formally addressed through training and supports. Also, formal peer support with other autistic young people may allow for sharing of experiences and developing friendships without stigma or misunderstanding of autistic experience.

- Young people need to be actively listened to and involved in making their school environment safe and comfortable for them. Equally, school staff need to be provided with resources (training, staff, time, etc.) to be able to fully support students and address stigma within the school setting.

- To create a sense of belonging and reduce anxiety, stigma and misconceptions need to be actively addressed. Simultaneously, autistic young people need support in developing healthy coping strategies. Promising avenues include drawing on current interests and also allowing room for creative activities.

FULL REFERENCE

Tesfaye, R., Courchesne, V., Mirenda, P., Mitchell, W., Nicholas, D., Singh, I., Zwaigenbaum, L. and Elsabbagh, M. (2023). Autism voices: perspectives of the needs, challenges and hopes for the future of autistic youth. *Autism*. **27**(4), pp. 1142-1156. https://doi.org/10.1177/13623613221132108.
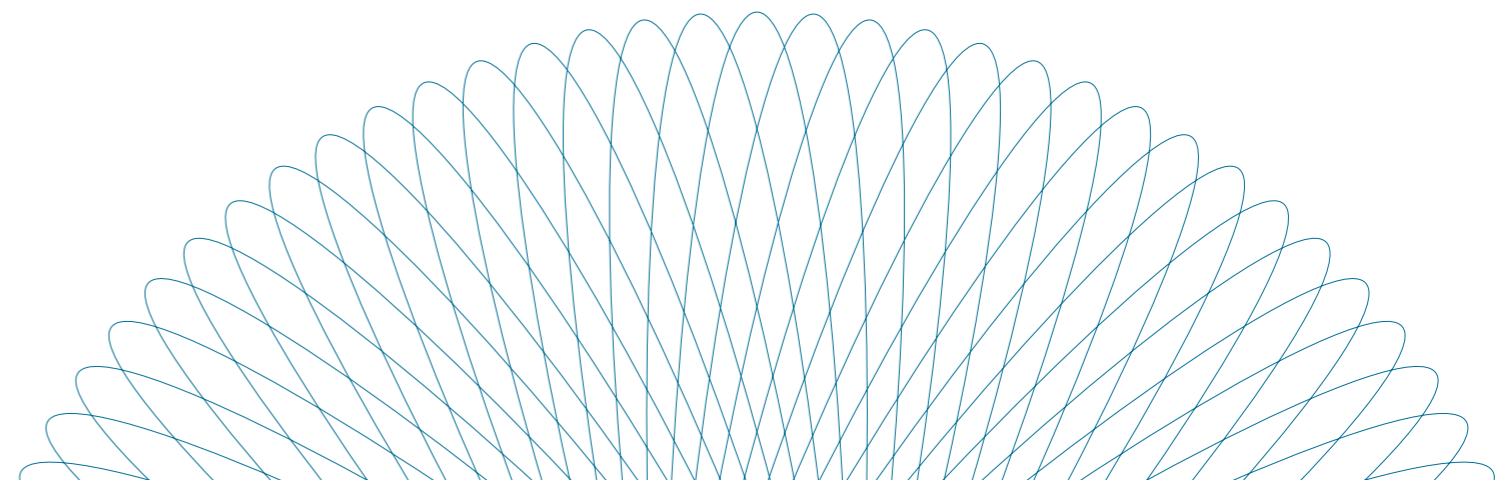
EDUCATORS DESCRIBE THE 'BEST THINGS' ABOUT STUDENTS WITH AUTISM AT SCHOOL

BACKGROUND

Historically autism has been described based on deficits. A diagnosis requires the presence of 'persistent deficits'. Equally, research into autism has been deficit-focused. Even when researchers are studying a positive concept like well-being, over 50 per cent of studies are found to be deficit-focused, while only 11.4 per cent focused on strengths. Highlighting strengths can have a positive impact.

- It can create a 'general sense of hope' that encourages school staff to set goals beyond perceived deficits.

- It may cause change in attitudes of parents and teachers that could lead to improved working relationships.

- It could lead to the identification of specific interests and talents held by autistic students, which could boost self-esteem.

When parents were asked to identify strengths of their autistic children aged 3-19, 25 per cent included loving/caring/affectionate, happy and sociable/friendly. In a separate study, parents of children aged 3-8 most frequently highlighted five strengths: loving/caring/affectionate, various academic skills (e.g. good reader, good at math), good memory, intelligent/smart and various recreational skills.

Some research has focused on teachers' perceptions of autistic children's characteristics. While many focused on deficits, teachers did highlight students as loveable, charming and observant. A teacher's ability to recognise and support positive character traits in their autistic students could be protective for the student. It may be the foundation of a warm and close student-teacher relationship, which, in turn, could provide a secure base that allows the students to feel safe and explore the physical and social environment. This is particularly useful for students who may struggle with transitions to new states or challenging sensory environments.

When researchers asked autistic students about their student-teacher relationship, the majority reported positive experiences, but between 14.7 per cent and 31.6 per cent reported negative experiences. Indeed, the majority of research looking at autistic student-teacher relationships has focused on negative experiences.

RESEARCH AIMS

1. Examine the character traits identified by educators of autistic students at ages 7-8 and 10-11.

2. Examine whether traits identified by educators varied by education setting (mainstream school or special education school) or curriculum type (general mainstream curriculum or modified/life-skills curriculum).

3. Examine whether traits associated with autism (communication challenges, focused interests, stimming, etc.) or distressed behaviour* were linked to trait endorsement by teachers.

RESEARCH METHODS

Participants were sourced as part of a longitudinal Canadian study. Teachers were asked to fill out the question 'Please describe the best thing about this pupil' as part of a broader questionnaire. Children that they were answering about were aged 7-8 (130, 89 per cent male) or 10-11 (177, 84 per cent male). For teachers, 94 per cent of those teaching 7-8 year olds were female, 89 per cent were mainstream teachers and 9 per cent were special education teachers. Of those teaching 10-11 year olds, 84 per cent were female, 83 per cent were mainstream teachers and 14 per cent were special education teachers.

RESEARCH FINDINGS

Across both age groups, educators identified kindness, self-regulation, specific skills and perseverance among the top five positive characteristics of students. Kindness was the number one trait reported by educators at both ages. Over 25 per cent of educators highlighted strengths that were coded under the umbrella term 'self-regulation' ('easy-going', 'compliant', 'works quietly and independently', 'adaptable to most changes in schedule', 'obedient', 'tolerant', 'cooperative' and 'well-behaved'). In research looking at positive traits mentioned by parents, these self-regulation traits were less often highlighted. The current researchers suggest that this may reflect the high value that educators place on students' abilities to follow directions and self-regulate in the classroom.

A small but notable number of educators felt the need to qualify their descriptions of students' positive traits, with researchers suggesting that they seemed to struggle to find something positive to say (e.g. 'She's a sweet girl when happy and can be very affectionate') or to be precise (e.g. 'usually polite').

Only two significant differences were found between education settings - both for students aged 10-11 years. Traits associated with courage (predominantly perseverance) were endorsed more often for students in mainstream schools. Wisdom and knowledge (predominantly intelligence) were endorsed for students in mainstream and/or adapted curriculum. These students were engaged in course work that required considerable literacy and mathematical skill, and as such it is unsurprising that educators highlighted strengths linked to academic skills.

In relation to traits associated with autism and distressed behaviour, at aged 7-8 years students who showed higher levels of autism traits or distressed behaviour were less likely to be endorsed courage (primarily perseverance), suggesting that educators were less likely to perceive students as 'finishing what they started'. This may not be surprising as higher traits of autism were associated with lower levels of attentiveness. Similarly, if students are experiencing distress, they are less likely to stay on task. Again, unsurprisingly, students who showed more distressed behaviour were less likely to be endorsed for happiness.
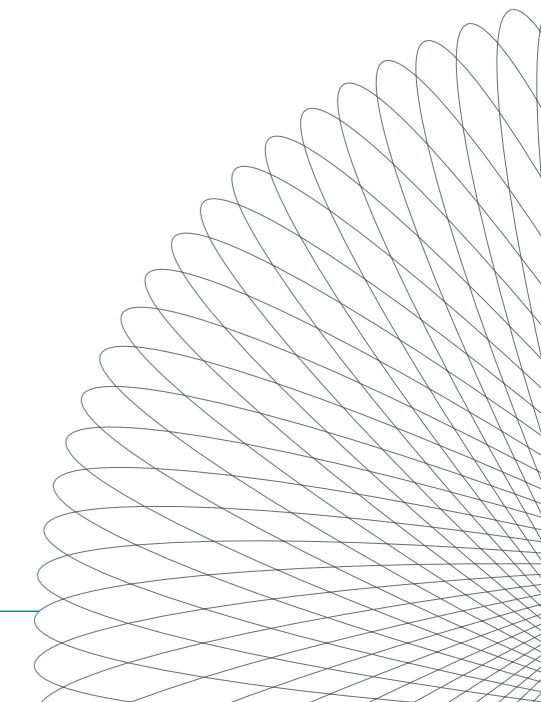
IMPLICATIONS FOR PRACTICE

The researchers highlight a number of areas where focusing on strengths could benefit autistic children - both immediately and long-term.

- They highlight the potential benefit of beginning IEP meetings with a discussion that allows both parents and educators to share anecdotes about student strengths.

- They imagine a situation in which psychoeducational reports focus on a student's academic, social and character strengths in equal measure to challenges.

- They suggest a case for a class-wide exercise in which educators identify a positive character trait each week (e.g. curiosity, fairness) and all students then track their ability to engage in activities that exemplify the traits.

The researchers suggest that by incorporating a focus on student strengths into a school setting there is potential to positively impact student outcomes, the student-teacher relationship and the broader classroom culture.

*Within the original paper, the researchers refer to this as 'challenging behaviour'. We have switched it here to focus on the child's perspective and motivation for the behaviour rather than focus solely on the external impact of the behaviour on others.

FULL REFERENCE

Mirenda, P., Zaidman-Zait, A., Cost, K.T., Smith, I.M., Zwaigenbaum, L., Duku, E., Kerns, C., Georgiades, S., Vaillancourt, T., Elsabbagh, M., Bennett, T. and Szatmari, P. (2022). Educators describe the 'best things' about students with autism at school. *Journal of Autism and Developmental Disorders*. doi: 10.1007/s10803-022-05761-2.

'BEST THINGS': PARENTS DESCRIBE THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER OVER TIME

BACKGROUND

Over time, parents, autistic individuals, researchers, practitioners and educators have moved away from a negative focus, debate and discussion of autism to one that identifies, embraces and celebrates a positive approach while recognising that specific needs must be addressed to ensure respect, inclusion, acceptance and appreciation of neurodiversity in a neurodiverse world. As a community, we must seek out, hear and understand the autistic person's perspective that allows the adult, student or child to live in a society where their well-being, satisfaction, hopes, optimism and happiness are valued and honoured, where strengths and potential are highlighted rather than differences emphasised. Children need supportive adults to accept and appreciate who they are at this time, that they are developing, following their pathway, if we take the time to get to know them.

RESEARCH AIMS

This research aims to examine the character traits identified by 153 parents of autistic children at ages 3-4 years, 7-8 years and 10-11 years, to appreciate these strengths and recognise that positive character traits follow a developmental time framework. This insight will subsequently inform education practitioners of how best to support the maturation of the children. The focus will not be if the child has strengths but when the optimal time is for us to expect them.

RESEARCH METHODS

Researchers used a mixed methods approach - a quantitative, longitudinal system, with results accrued from 153 parents derived from questionnaires based primarily on the Child Behavior Checklist, and a qualitative aspect whereby each parent was asked to complete a particular section with no limits set on length or content: 'Please describe the best things about your child'. This methodology spanned the development and acquisition of skills of the autistic children from an average age of 3.4 years until they were 10.6 years, a time frame of 7.2 years. A time frame when we would expect to see similarities, development and changes for each child.
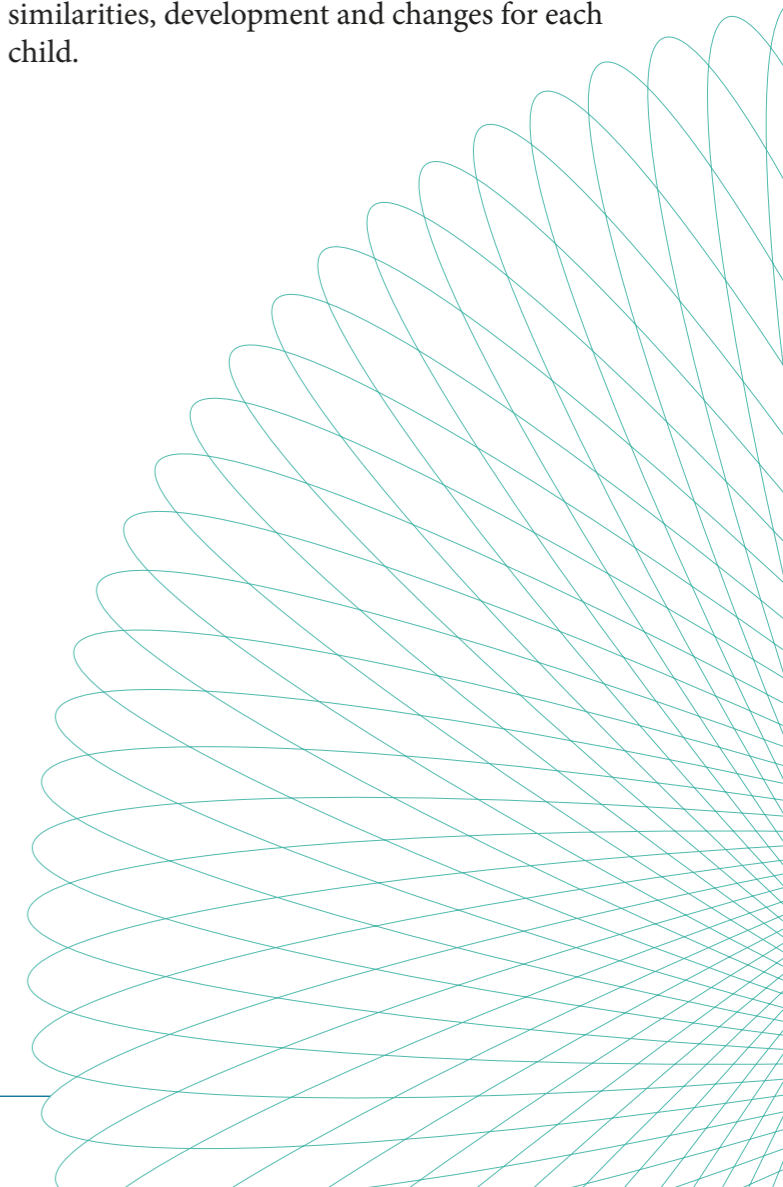
RESEARCH FINDINGS

As expected with such a group of parents and children, a variety of results was found across the groupings.

Wisdom and knowledge: with intelligence developing over the time period due to greater number of opportunities and experiences in a range of settings.	Temperance, forgiveness, humility, prudence and self-regulation: ability to self-regulate appears to be consistent across the time but temperance is an area where greater adult support may be required.	Appearance: consistent throughout. Parents may see kindness and happiness in terms of appearance too: 'a smile that would melt your heart', probably as only a parent can say.
Courage: perseverance and zest developed across the three time periods. Historically this may have been seen in negative terms, but instead this determination is respected.	Transcendence: with sense of humour developing and changing as the child gets older. Forgiveness is another developing skill that increases with age and experience.	Specific skills: identification and development of skills in the areas of memory: 'remembers everything'; gross motor: 'co-ordinated, great gross motor skills'; others: 'great reader, knows letters, numbers'.
Humanity: love, kindness and friendliness consistent throughout.	Happiness: although more prevalent during the earlier time frame, mean age 3.4 years, incredibly high throughout.	Miscellaneous: again, development and an increase in the acquisition of skills noted. This section was dependent on the individual response of the parents based on knowing their child.
Justice: teamwork and fairness remained consistent, yet very low, thus recognition must be that these are areas where further input, support and work from supportive adults is required.	Interests: continued to play a vital role across all age groups, both passive and active interests, but parents may not have noted this as a 'best thing' as the child got older.	

The largest proportion of responses fell into two categories.

1. Humanity, including love, kindness, social intelligence and friendliness; and

2. Happiness, ranging from very happy, always wakes up happy, always in a good mood, cheerful.

The older children displayed examples of gratitude, humility, forgiveness, hope, appreciation of beauty and perspective. Thereby indicating that such qualities follow a developmental pathway that may be dependent on cognitive and social development, yet the opportunities offered and expectations held by the supportive adults were also key to the children reaching their potential.

IMPLICATIONS FOR PRACTICE

(by the authors)

- In the past, diagnosis of autism appeared to focus solely on the aspects with which a child experienced difficulty. Parents and educators are reminded that their first thought should be to look at the skills, talents and strengths the child already has before designing an educational programme - a strengths-based approach.

- Educators, to create a strong parent-professional relationship, remind parents of the many positives of their child's character rather than focusing on perceived problems and deficits. Ask parents:

  - What can the child do?

  - What skills have already been amassed?

  - Who is this child?

  - What are their positive personality and character traits?

  - What does the child enjoy?

  - What are the child's interests?

- Autistic children will follow a pathway of development much like their non-autistic peers. Parents and educators must be cognisant of such development when offering opportunities and activities to the children. Unsurprisingly, wisdom and knowledge were dependent on experience and opportunity; the older the child, the greater the number of activities and variety of experiences.
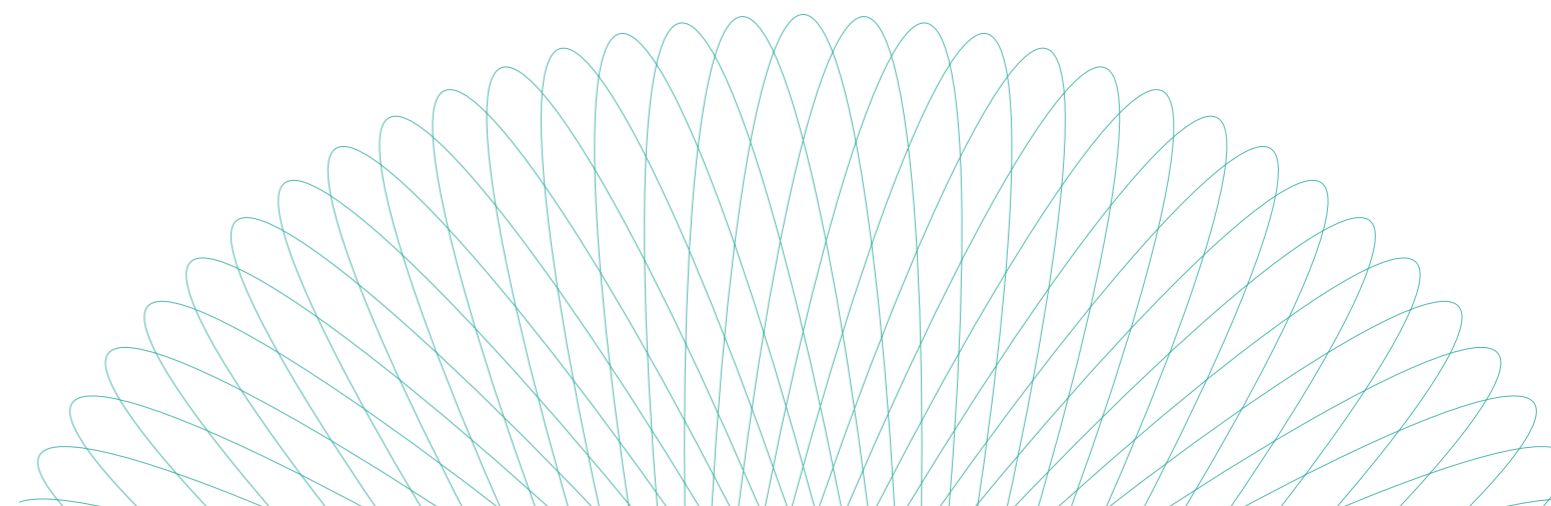
- Perseverance, once seen as a difficulty experienced by many autistic children, was found to be seen as a strength and fell within the category of Courage. Do we see perseverance, finishing a task, taking pleasure in completion, being resourceful, as an attribute? Do the supportive adults, educators and parents need a change of mindset?

- Knowing the child's interests can be the first step in planning educational experiences. Knowing an effective means of motivation and engaging the child with and in the activities and opportunities presented can allow for greater inclusion and respect.

- We need to embrace neurodiversity having a positive impact on the child's overall well-being, self-esteem, resilience and, ultimately, development and maturation.

- Love, kindness and humour are distinct characteristics of being a child whether that child is autistic or not.

FULL REFERENCE

Cost, K.T., Zaidman-Zait, A., Mirenda, P., Duku, E., Zwaigenbaum, L., Smith, I.M., Ungar, W. J., Kerns, C., Bennett, T., Szatmari, P., Georgiades, S., Waddell, C., Elsabbagh, M. and Vaillancourt, T. (2021). 'Best things': parents describe their children with autism spectrum disorder over time. *Journal of Autism and Developmental Disorders*. **51**(12), pp. 4575-4576.

'I'M PROUD TO BE A LITTLE BIT DIFFERENT': THE EFFECTS OF AUTISTIC INDIVIDUALS' PERCEPTIONS OF AUTISM AND AUTISM SOCIAL IDENTITY ON THEIR COLLECTIVE SELF ESTEEM

BACKGROUND

Societal attitudes towards autism have begun to shift from a focus on the challenges and difficulties encountered by autistic people to an acceptance of difference and acknowledgement of strengths. Research has shown that this focus on strengths and a positive feeling towards the autistic community is likely to have a positive outcome for autistic people. While the recognition of strengths is imperative, there are challenges associated with being autistic in a social world that caters for the neurotypical population. Research indicates the need to acknowledge these difficulties, including those experienced by people with intellectual disability, as part of the neurodiversity movement.

How autistic people feel about and relate to their diagnosis is also central to debates around terminology used to describe autism and whether people feel autism is a core aspect of their identity ('autistic') or whether they prefer to distance themselves from their diagnosis ('person with autism'). Generating a positive sense of self is further complicated due to society's stigma against autism, with many autistic people often facing bullying and social isolation. This can present challenges for autistic people deriving a sense of self-worth, resulting in negative outcomes for emotional well-being such as anxiety and depression.

There is evidence suggesting that some autistic people prefer to view their autism as central to their identity, with a positive sense of autism identity associated with positive outcomes. Conversely, some autistic people see their diagnosis in a negative light. The authors of this study, therefore, identified a need for a systematic investigation to help improve the understanding of how autistic people themselves conceptualise autism, and how this affects how they feel about themselves.

RESEARCH AIMS

This study aimed to determine the specific attributes relating to autism that autistic people identify as positive. It also examined the relationship between autism social identification and collective self-esteem and the number of positive or negative attributes that a person links to their autistic identity.
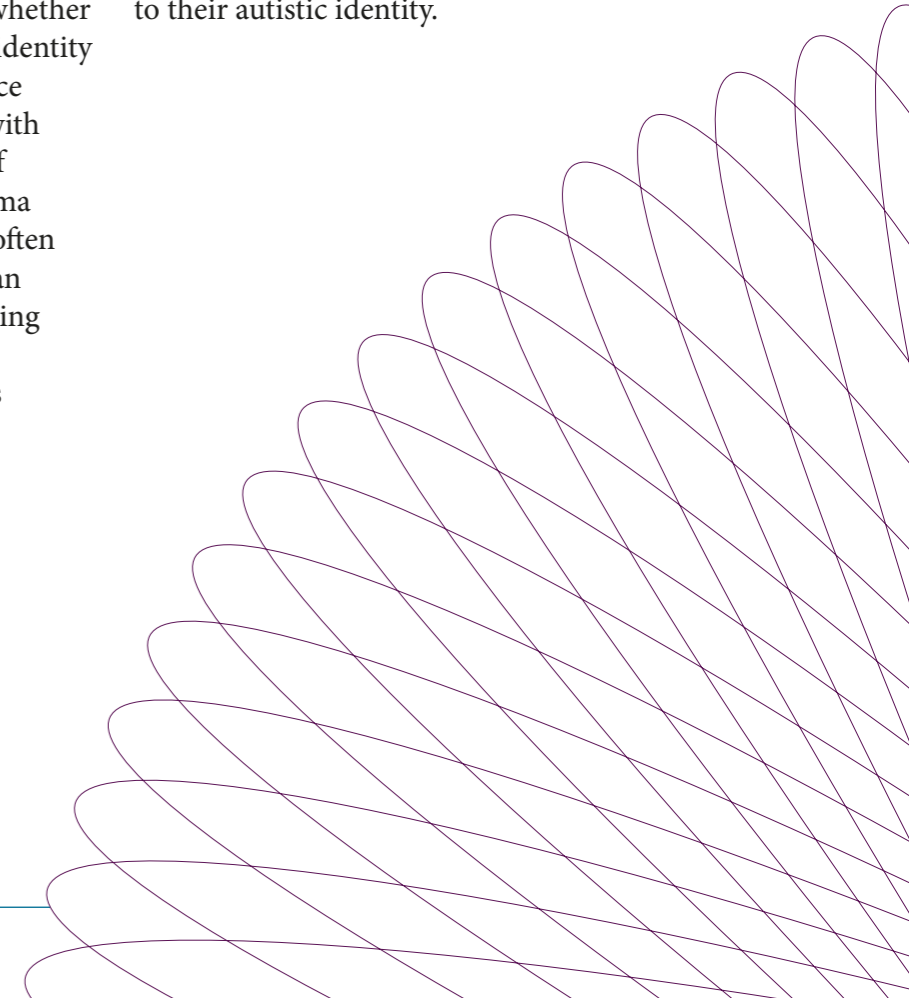
RESEARCH METHODS

This research included two studies, with analysis integrating the results of both. Study 1 involved the recruitment of 140 autistic participants, over the age of 16, who participated in an online survey by completing autism social identification and collective self-esteem measures and by listing attributes they associated with autism. Following these, basic demographic information was collected, including age, ethnicity, gender and information regarding autism diagnosis. Participants were recruited via online forums, the National Autistic Society (NAS) research network and social media advertisements.

In Study 2, four focus groups were employed whereby 15 autistic participants rated the autism attributes collected in Study 1 according to how positively they perceived the attributes of autism in relation to their own individual experiences and identity. In Study 2, participants were recruited from a university transition programme for autistic students and a community social group for autistic adults. None of the participants in Study 2 had taken part in Study 1.

Within the integrative analysis stage, the researchers applied the positive and negative valence ratings to the Study 1 data to explore the associations between attribute valence, autism social identification and collective self-esteem.

Ethical approval was gained by University of Bath Ethics Committee. Prior to commencing the study, all study materials were reviewed by autistic people. Participants were informed of their right to withdraw, gave fully informed consent and all data was anonymised.

RESEARCH FINDINGS

A range of autistic attributes were put forward by participants. The attributes identified most by 10 or more participants were reported. Social skills difficulties were listed by 43 per cent of respondents as the main challenge they encountered. This was followed by: loneliness (36 per cent); sensory issues (31 per cent); emotional difficulties (25 per cent); difference (21 per cent); cognitive differences (21 per cent); anxiety (21 per cent); communication issues (20 per cent); gifted (17 per cent); unique (16 per cent); special interests (16 per cent); caring (16 per cent); bullied (14 per cent); routines (12 per cent); focused (11 per cent); stimming (9 per cent); attention to detail (8 per cent); rational (7 per cent); and introversion (7 per cent).

Forty-three attributes were mentioned by more than one participant and there were 55 idiosyncratic attributes stated by individual participants that were not categorised, including attributes such as 'freedom' and 'trivia'.

While the core characteristics of autism were included in the list of attributes, broader issues such as emotional difficulties (anxiety and depression) were regarded by many participants as key features of autism. This finding suggests that autistic people may view emotional difficulties as central to their autism rather than as a co-occurring condition with separate aetiology. Alternatively, findings may reflect emotional and psychological processes that are transdiagnostic and common across a range of neurodevelopmental conditions. Some of the attributes focused on strengths such as 'gifted' and 'unique', in line with the increasing focus on positive aspects of the autism diagnosis and identity.

A noteworthy finding reported that a significant proportion of attributes listed were idiosyncratic, i.e. mentioned by individual participants. This highlighted the diversity of perceptions of autism in the autistic community.

In Study 2 researchers identified four overarching themes from the focus groups. These included:

Challenges due to autism

This theme referred to the difficulties participants experienced due to the features they associated with autism and responses of others to their autism. The *intrinsic difficulties* sub-theme depicted challenges (e.g. anxiety, social and sensory challenges) due to being autistic. These challenges could lead to anger and frustration. *Rejection by others* emerged as another sub-theme indicating that students in particular were in receipt of negative treatment. *Lack of understanding from others* described how stereotypical views of autism revealed a lack of understanding of the autistic person beyond their diagnosis.

Diversity and adaptation

This theme described how autism is experienced differently by every individual, and that the features of autism are affected by context such as environment, age or time since autism diagnosis. The sub-theme autism as a spectrum highlighted the uniqueness of everyone, with individual strengths and challenges emphasised. The *effect of the environment* sub-theme indicated how autistic attributes can be affected positively and negatively by the environment such as social situations, sensory factors and external stimuli. The *improvements over time* sub-theme described how with understanding and self-acceptance, several challenges experienced by the participants improved as they grew older. Others associated this with an increase in their personal skills, such as time management.
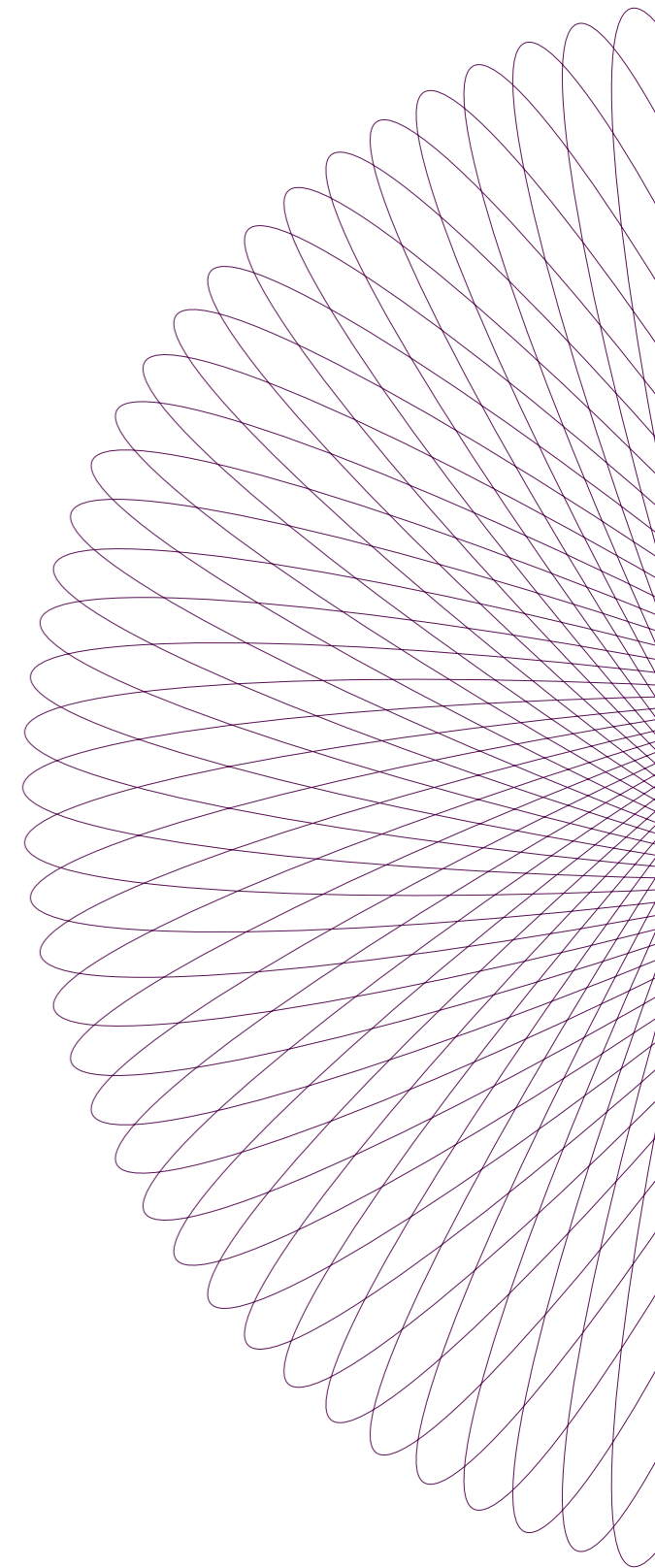
Navigating difference

This attribute captured participants' strategies for managing their autism, having an identity that differed from the 'norm' and living in a world designed for non-autistic people. Sub-theme *self-acceptance* referred to an understanding of oneself and their autism, which was viewed as an important method to improve well-being. *Resilience* highlighted how participants tend to draw on positive aspects of demanding situations and adaptations when required.

Positive autism identity

This theme highlighted the positive sense of identity many autistic participants experienced. Examples of benefits included creative thinking, thinking outside the box and not being constrained by social norms. *Pride in difference* focused on participants' views that their differences from non-autistic people were a positive part of their identity. Focus group participants disclosed pride in their autism and described experiencing their autism differently over time and dependent on context, as well as experiencing challenges relating to autism.

In support of the researchers' hypothesis, a mediation analysis found that autistic participants who associated positive attributes with autism had improved collective self-esteem, to the extent that they had a strong affiliation with their autism identity.

A primary finding from the integrative analysis was a positive relationship between the number of positive attributes participants associated with autism and participants' collective self-esteem, to the extent that they identified with other autistic people.

In summary, having a more positive view of autism, as determined by other members of the autistic community, correlated with a stronger sense of affiliation to the autistic community and more positive autism collective self-esteem. These findings suggest that the autistic community benefits from focusing on strengths and positives associated with autism and that focusing on strengths is something that older people are more likely to do than younger people.

IMPLICATIONS FOR PRACTICE

(by the authors)

Researchers suggest that developing a balanced view of autism, which places emphasis on autistic strengths, can have a positive effect for the collective self-esteem of autistic people and encourage a sense of connection with others within the autistic community. Although it is recognised that this may occur 'naturally' over time, efforts by educational settings and support services may help speed up this process and reduce the length of time spent living with a negative view of autism. This may be especially important for early intervention with younger people post-diagnosis.

The researchers are highly supportive of programmes like PEGASUS (psychoeducation group for autism spectrum understanding and support), a group psychoeducational programme that aims to enhance the self-awareness of young autistic people by teaching them about their diagnosis. Developing such groups for newly diagnosed adults, particularly when led by autistic people, would prove beneficial to well-being. Such interventions can be delivered in educational or clinical settings following diagnostic assessment.

The development of online or community groups are recognised as beneficial for the psychological well-being of autistic people, given the links between social identification and mental health and the isolation that autistic people can struggle with. Such groups can foster a sense of positive autism identity.

A wider societal awareness of the strengths of autism would further assist the autism community so that the obligation is not placed entirely on autistic people to raise awareness about the benefits of autism.

Within this study the participants voiced more about their challenges than strengths, and that the reality for many autistic individuals involves struggles and hardships. Often these struggles were conveyed as emotional difficulties such as disabling anxiety and depression, which was seen as integral to their autism identity. Assessment of emotional difficulties is often cited within the context of a co-occurring or co-morbid condition. While the authors were not arguing for a revision of the diagnostic criteria, they highlighted that recognition of such distressing emotional difficulties is an important part of the autism experience and for which appropriately tailored, evidence-based support should be made available.

FULL REFERENCE

Cooper, R., Cooper, K., Russell, A.J. and Smith, L.G. (2021). 'I'm proud to be a little bit different': the effects of autistic individuals' perceptions of autism and autism social identity on their collective self-esteem. *Journal of Autism and Developmental Disorders*. **51**, pp.704-714.
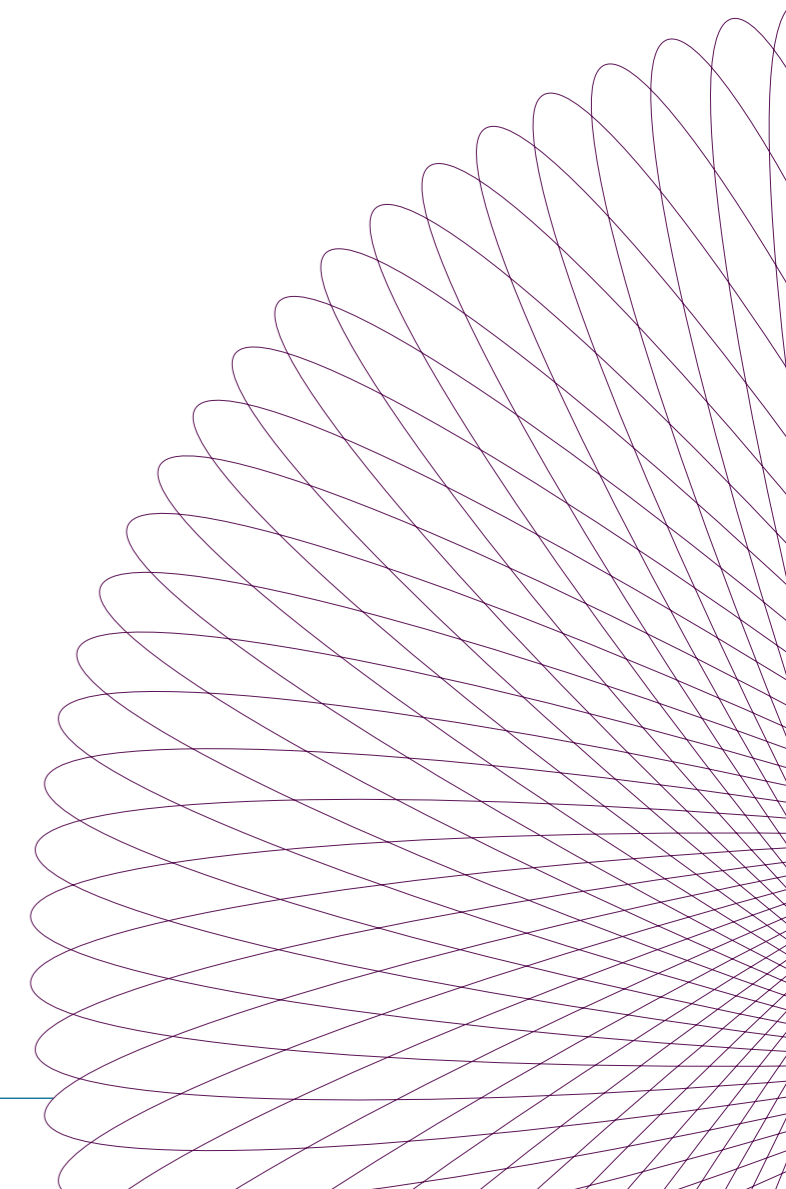
A CONCEPTUAL MODEL OF RISK AND PROTECTIVE FACTORS FOR AUTISTIC BURNOUT

BACKGROUND

Burnout is a state in which an individual's ability to cope with stress is overwhelmed. 'Autistic burnout' is a term used by the autistic community to describe the negative consequences of living in a non-autistic world. It is characterised by long-term mental, physical and emotional exhaustion that accumulates over time, often reoccurring after stressful events or transitions. The features of autistic burnout can include impaired cognitive function, loss of previously acquired skills, social and sensory withdrawal and an increase in observable autistic traits.

It is thought that masking autistic traits, stressful events, alexithymia, stigma and discrimination contribute to autistic burnout, while energy management, social support, stimming and self-awareness can be protective factors. Autistic burnout can significantly impact the mental health, quality of life and well-being of autistic individuals, highlighting the need to understand risk and protective factors in greater depth.

RESEARCH AIM

The researchers present a conceptual model to better understand the factors underlying and preventing autistic burnout.

RESEARCH METHODS

The researchers present a conceptual model of autistic burnout (CMAB) based on current literature and four well-known theories. These include two disability theories: the social-relational model of disability and the neurodiversity paradigm, and two theories of burnout and stress: the job demands-resources model and conservation of resources theory. In addition, an advisory group of four autistic adults with lived experience of autistic burnout reviewed the model and endorsed the relevance of the chosen variables and hypothesised relationships.

RESEARCH FINDINGS

The researchers report that factors associated with being autistic and the widespread lack of autism awareness and acceptance within society contribute to the onset and recurrence of autistic burnout.

The researchers present a CMAB that explores the direct and indirect relationships among various factors and measurable variables including demands and resources, mental strain and well-being, demographics and social and environmental factors, and their potential influence on autistic burnout (Table 1).

The CMAB identifies how various factors, for example personal resources such as having good social support, could have a positive impact on an individual by increasing their feelings of well-being and decreasing their likelihood of experiencing mental strain and autistic burnout. Similarly, the model highlights how various factors, for example personal demands such as masking, may have a negative impact on an individual and increase their likelihood of experiencing mental strain and contribute to autistic burnout.

Table 1 represents the CMAB developed and described by the researchers

CMAB factors	Measurable variable	Negative impact	Positive impact
Personal demands	Masking or camouflaging Sensory sensitivities Autistic traits	Will directly increase the risk of autistic burnout: By increasing mental strain May either increase or decrease personal resources Will decrease well-being	
Personal resources	Stimming Special interests Self-awareness Social support	May either increase or decrease personal demands	Will directly decrease the risk of autistic burnout Will indirectly decrease the risk of autistic burnout by increasing well-being Will decrease mental strain
Mental strain	Depression Anxiety Stress	Will increase the risk of autistic burnout Will decrease well-being	
Well-being	Satisfaction with life Community		Will decrease the risk of autistic burnout Will decrease mental strain
Additional variables	Stigma Discrimination Gender Age	Gender and age may influence the risk of autistic burnout Social and environmental factors will influence the risk of autistic burnout	

IMPLICATIONS FOR PRACTICE

This research and the CMAB:

- offer a holistic perspective for understanding individual, social and environmental factors that can influence autistic burnout via various direct and indirect pathways.

- provide information on a range of factors that may protect or prevent autistic people from experiencing burnout. These factors should be explored more to develop useful and practical methods to reduce the likelihood of experiencing burnout.

- provide supporting adults with information about signs someone might be experiencing burnout, in the hope that strategies can be implemented before the negative consequences of burnout are experienced.

FULL REFERENCE

Mantzalas, J., Richdale, A. L. and Dissanayake, C. (2022). A conceptual model of risk and protective factors for autistic burnout. *Autism Research*. **15**(6), pp. 976-987. https://doi.org/10.1002/aur.2722.

CONCLUSION

'Well-being' is a broad term, but as research shows, a starting point to understanding well-being lies in actively listening to community members and involving them in decisions about their lives. Further, by focusing on strengths and positive experiences, a more inclusive and rounded understanding of each person's experiences can develop. Both autistic people and those providing support navigate their own personal vulnerabilities and strengths, but all can contribute as active agents and decision makers.

The broader community can also contribute strongly to individual well-being, with training and education needed to reduce stigma and misunderstanding of autistic experience. Equally, community can provide a strong sense of support and shared meaning for both autistic people and their allies. Individual well-being is nuanced, but central to it is acknowledging each person as fully rounded, active agents with important strengths to share.

NOTES

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