CENTRE FOR AUTISM

MIDDLETOWN

Autism and Siblings
Volume 2

CONTENTS

INTRODUCTION

This is the thirty-third Research Bulletin produced by Middletown Centre for Autism, providing summaries of ten articles from 2017 to 2020.

The Bulletin commences with an interview from Freya O'Horo, a Mayo native and CEO of Autism Siblings Ireland. Upon her younger brother Dian's diagnosis of autism, Freya was struck by the lack of resources for siblings of autistic children. This information gap led to the creation of Freya's Autism Siblings Ireland blog when she was sixteen years old.

Autism Siblings Ireland highlights information on autism supports and resources from Freya's experience as Dian's sister, and it serves as a platform for Freya to connect with other siblings. Topics range from interviews with occupational therapists about their profession to discussions with autistic adults. Freya keeps any work with services restricted to those she and Dian have personal experience of.

Freya studies Social Care Practice in Athlone Institute of Technology due to an interest in disability supports and hopes to one day work in the field. Her work is a testament to the network of support that emerges between families after diagnosis and the value of understanding from within the community.

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

INTERVIEW WITH
FREYA O'HORO

1. How and at what age did you learn that you had a sibling with autism?

In 2011, when I was eleven years old, I found out my youngest brother Dian had autism. I remember my mum and dad sitting me and my other brother down to tell us Dian has autism. I didn't know what that meant for him or for our family. Autism wasn't something I had heard of before, so I had a lot of questions.

2. Growing up, how did you feel about having a sibling with autism?

I always knew our family wasn't like anyone else's. We had our way of doing things, like sticking to particular dinner times and bedtimes, keeping noise down, no arguments, having things and objects in a particular order and instructions to do things all over our house. It was the norm for my family and me, and I wouldn't have wanted it any other way. Being Dian's sister has made me more mature, non-judgmental and extremely caring. Growing up with a sibling with autism made me become a better person.

3. Did having an autistic sibling impact on your social and leisure activities growing up?

Not really. I discovered that Dian wanted to do what my other brother and I were doing. I did horse riding and swimming, my other brother did football, and Dian took an interest in those activities. He started doing them with us and it was a great way for us to become closer and bond over something. As for the social aspect, we sometimes were the first people leaving family gatherings, or he came along to my friend's house to see them, but that was something I didn't mind. Seeing him happy and content was more important to me then causing an issue that would bring him distress or lead to a meltdown.

4. What would have helped support you growing up?

I felt there wasn't any kind of support for siblings out there. Everything was geared towards parents. I remember my parents being invited to events for parents, given leaflets and information, and the professionals in Dian's life were there for my parents. I wished growing up there was as much support, information and help for me and my brother.

5. What advice would you give to siblings? How can they support their autistic sibling? How can they manage their own concerns and challenges?

I would say to siblings in a similar situation as me that communication is so important. It's okay to have your own problems, fears, worries and failures. It's okay to communicate those with your family. You don't have to be the perfect mature sibling all the time. It's okay to be human and express that when you need to. Don't bottle those troubles in because you feel as the sibling you can't have any problems. Your parents, family, loved ones care and want to help you with any challenges life gives you.

I find the best way to help your sibling with autism is to find activities and common interests you can do with them. Build up your relationship with them like you would with anyone else. My brother and I love horses, the beach and going on adventures. Find those similar likes and create a positive, loving relationship with your sibling. Another way to help would be to offer to help with their occupational therapy work, their speech and language therapy work, their homework or any additional support they have that you can do with them. It's important as their sibling to be able to help them in all aspects of their life.

6. How can parents support their child who has a sibling with autism?

Parents can support their child who has a sibling with autism by reminding that child that they are just as important and matter just as much as their sibling with autism. Remind them you are always there for them, to listen to them and, most importantly, spend time with them. Support your child by always making sure they are seen and heard as an equal member of the family.

7. How can schools support siblings of children with autism?

If schools openly discussed autism, siblings of children with autism would feel like their family is less different from their peers'. Conversations around disabilities in general should be had in schools from a young age to encourage inclusion. If schools show their understanding of autism, siblings of children with autism would feel understood and supported, which could lead to them going to their school for help if they're struggling.

8. How do you think that autism is understood more now than when your sibling was diagnosed? How has our understanding impacted on the life of a sibling?
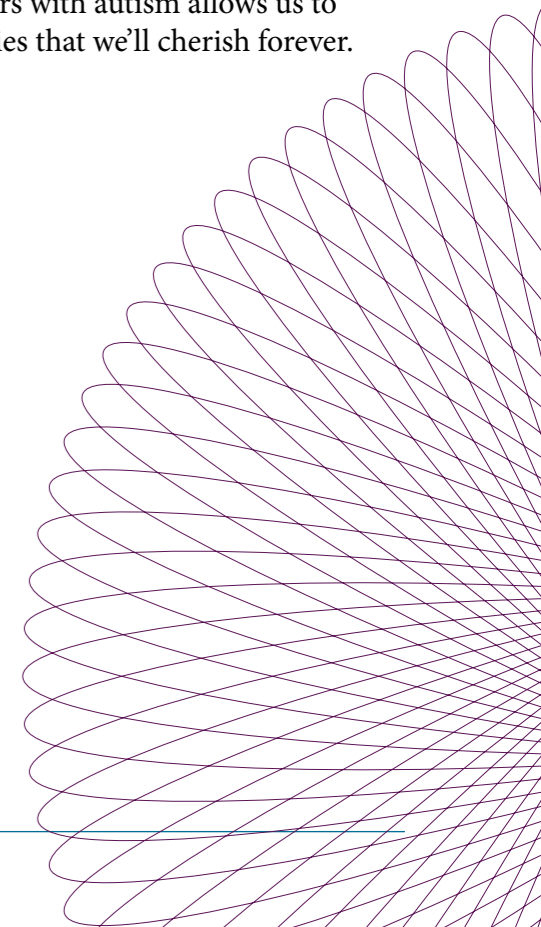
I can see autism is understood more and is more common to people by the awareness created in our communities. Autism units, autism friendly hours in supermarkets, people raising money for autism services and locals sharing support during Autism Awareness Month are the main areas where I've seen the knowledge of autism grow.

People's understanding has helped me as a sibling because I rarely have people asking me about cures for autism or asking will they ever be 'normal'. The better understanding of autism among communities means that my brother can walk on his tiptoes, wear headphones, make noises and if it happens, go through his meltdown with less people judging him and making him feel different.

9. Is the world more autism aware? How can this benefit families?

Yes, I do feel like the world has become more autism aware. I can see it in everyday life. It hugely benefits my family and others like mine because the more autism aware communities are the more it accommodates our family's needs. We can have more experiences together as a family. Having autism friendly movie screenings, theme parks having days dedicated in the year to individuals with autism and their families, accepting autism ID cards at different places and events, means that we as a family can experience new things together. Society lifting barriers for our family members with autism allows us to make new memories that we'll cherish forever.

A CHILD WITH AUTISM SPECTRUM DISORDER TEACHES SIBLINGS TO SKATEBOARD: EFFECTS ON SIBLING SKILLS AND FAMILY SOCIAL BEHAVIOR

BACKGROUND

Autism impacts a child's ability to play in many ways, including limited joint attention and interaction with others, restricted play interests, uncertainty about how to play with toys and difficulties with the motor skills required for play activities. This then affects relationships with siblings as they are less likely to play together or have shared positive experiences.

Interactions with siblings, however, can create opportunities to develop social skills that can then be generalised to the wider community. Positive relationships between siblings and a child with autism can also improve family life.

Research indicates that an autistic child is more likely to play with siblings if the activities incorporate the child's special interest, and that some autistic children may be able to teach a skill to their siblings. Some use the Behavior Skills Training (BST) approach (instructions, modelling, rehearsal and feedback), but this requires a high-level of communication skills and so activity schedules can be used to support a child when teaching a skill or activity to others. The activity schedule provides visual step-by-step instructions using words or pictures or a combination of both.

RESEARCH AIMS

This study aimed to examine the effects on skateboarding skills of two siblings without autism when taught how to skateboard by their sibling with ASD, using a written activity schedule and components of BST. The study also aimed to examine the effect on family social interaction.

RESEARCH METHOD

Tony, an eleven-year-old boy with autism, taught skateboarding to his thirteen-year-old sister, Sara, and five-year-old brother, Sami – neither Sara nor Sami have autism. Prior to this, Tony engaged in very limited positive interactions with his siblings – he was able to use verbal language to request needs and answer questions but had difficulty with two-way conversations. He also had difficulties in physical play with others, and engagement in play was also affected by his stereotyped behaviour, self-injury, aggression and screaming.

Tony had extensive experience in using activity schedules in daily activities.

Three dependent variables were measured:

1. Ability to stand correctly on the skateboard for five seconds.

2. Ability to ride or 'roll' correctly on the skateboard for five seconds.

3. Social interaction between the siblings was observed. This was measured by recording the absence or presence of any interaction (e.g. vocal statement or smiling with eye contact) at ten-second intervals over a ten-minute episode.

These variables were scored by three observers (one in vivo and two from video recordings).

A multiple baseline design was used to measure skateboarding skills, and a pre- and post-test design was used to measure social interactions.

Tony was taught how to use the activity schedule to teach his siblings prior to the first session, and was reported to be very competent in using the schedule. The schedule used the components of BST to teach skateboarding and was written in the form of a checklist. Tony followed this checklist in each training session to teach the skills to his brother and sister, and marked off each step as he completed it.

RESEARCH FINDINGS

Both siblings improved significantly in the skateboarding skill of standing. Sara also improved significantly in riding the skateboard, but Sami still had difficulty with this. This study expands previous research as the child with autism was teaching the skill, whereas in most previous studies the sibling without autism taught a skill to an autistic child.

There was also improvement in social interactions. On average, social interactions among the siblings increased from 11.1% to 35.6%. There was positive feedback from Sara and Sami and they stated that they would like Tony to teach them more activities that he enjoys. Their mother reported that teaching the recreational skill had improved family bonding, and had increased Tony's confidence and encouraged him to attend to others.

IMPLICATIONS FOR PRACTICE
(by the authors and reviewer)

- Children with autism are more likely to interact with siblings in the context of a preferred activity. This could also be generalised to interactions with peers. When the child feels confident and happy in an activity, they are likely to interact more freely.

- Interaction may be limited when the activity or skill is being taught as the children are focusing their attention on mastery of the skill; however, once everyone is confident in the activity, social interactions can become more spontaneous and fluent.

- When an autistic child teaches a favourite activity to siblings it creates a common interest and provides them with something they can share. This then creates opportunity for more interaction and can improve bonding among siblings.

- The social skills developed in teaching a skill to siblings could be generalised to peers, further increasing interactions and creating new relationships.

- An activity schedule incorporating the steps of BST can be a useful tool for a child with autism to use when teaching a new skill to others. More specific guidance may need to be provided in how to give feedback to a sibling or peer.

- It is important to choose an activity that is achievable within the siblings' skill level as they are more likely to participate in an activity that they can master. Tony's brother did not have the motor skills to ride a skateboard, and although he persisted with it others may refuse to participate. The activity should be something that all the siblings are likely to enjoy.

- Teaching physical play to siblings is a useful context to foster improved interactions and relationships.

- When a child with autism teaches a skill to others, it is likely to have a positive effect on the development of skills such as empathy, communication and confidence.

Full Reference

Thomas, B.R., Lafasakis, M. and Spector, V., (2019). A child with autism spectrum disorder teaches siblings to skateboard: effects on sibling skills and family social behavior. Child & Family Behavior Therapy. 41(3), pp. 125–140.

THE EARLY DEVELOPMENT OF INFANT SIBLINGS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: CHARACTERISTICS OF SIBLING INTERACTIONS

BACKGROUND

During early childhood development, social relationships primarily consist of interactions with caregivers and siblings. Despite, sibling interactions playing an important role in these informative years, there are limited studies examining such exchanges between very young children with an older sibling with an autism spectrum disorder. To address this gap in research this study used a naturalistic, observational method to compare such interactions.

RESEARCH AIM

The aim of the study was to compare interactions between eighteen-month-old infants and their older sibling with autism and a control group of eighteen-month-old infants and their typically developing (TD) older sibling. Sibling role (a) symmetry and the influence of gender were also explored within the study.

RESEARCH METHOD

Fifty-one sibling pairs participated in the study. They were recruited from a follow-up study of younger siblings of children with autism who were considered to be at increased risk for developing autism and a TD control group at Ghent University.

Table 1. Sample characteristics.

	Low-risk ($n = 29$)	High-risk ($n = 22$)	
	Younger sibling		
Chronological age			
M(sd)	18.37 (.54)	18.52 (.85)	$F(1,49) = .59$
Range	17.17–19.33	17.37–20.43	
Sex ratio (M:F)	18:11	11:11	$\chi^2(1) = .74$
Developmental level (14 months)			
M(sd)	104.85 (9.29)	97.94 (11.86)	$F(1,43) = 4.78^*$
Range	92.00–126.00	79.00–120.00	
	Older sibling		
Chronological age			
M(sd)	52.61 (14.85)	89.43 (39.10)	$U = 107.50^{***}$
Range	32.97–90.30	46.00–186.07	
Sex ratio (M:F)	14:15	19:3	$\chi^2(1) = 7.95^{**}$
Social Communication Questionnaire (SCQ)			
M(sd)	3.15 (2.43)	17.23 (7.03)	$F(1,46) = 91.602^{***}$
Range	0.00–8.00	6.00–30.00	
Social Responsiveness Scale (SRS)			
M(sd)	24.96 (13.54)	102.59 (27.78)	$F(1,48) = 199.721^{***}$
Range	3.00–69.00	61.00–152.00	
	Sibling pair		
Family SES (*M(sd)*)	51.79 (6.96)	40.77 (12.28)	$U = 151.50^{**}$
Time spent together (%)			$\chi^2(1) = 5.71$
Never/seldom	3,4%	22,7%	
Sometimes	34,5%	40,9%	
Often/always	62,1%	36,3%	
Daycare attendance (%)	93%	64%	$\chi^2(1) = 6.89^*$

Note. Chronological age is reported in months
*$p<.05$
**$p<.01$
***$p<.001$

Sibling interactions were registered during a short play observation in which the children were offered a fixed set of toys: zoo-themed building blocks, a marble run and an animal-sound keyboard, with which they could play consecutively for ten, ten and five minutes respectively. Toys were chosen to elicit different types of play such as parallel play, associative play and cooperative play.

The play session took place in the familiar setting of the child's home (grandparents' home for one child). During the introduction of each toy the experimenter encouraged the children to play and gave a short verbal instruction: 'You can play together with these toys'.

The researcher watched the play from the background to observe spontaneous behaviour as much as possible. In addition, play sessions were videotaped and coded afterwards using The Observer XT (version 11.5). Interactive behaviour was coded under the following headings:

Social initiations – communicative attempts to initiate a new interaction directed towards another individual.

Responses – related to and following a previous initiation within five seconds.

No response – the absence of a response.

Mutuality – time the children spent in interaction with each other or with the parent and with the experimenter.

Non-interactive – time not spent in interaction with another person.

Hierarchical regression analyses were used to analyse the degree to which the group status (high-risk vs low-risk) predicted sibling interaction characteristics.

RESEARCH FINDINGS

Characteristics of sibling interactions were found to be similar for both the play with blocks and the marble run. As a result, data from these two play sets were combined. During play with the keyboard results differed from the other two play sets and results are therefore reported separately.

Interactive vs non-interactive behaviour: the percentage of time children spent in social interaction (mutuality) compared to non-social activities (orientation towards sibling, involvement in a purposeful activity) was assessed. Differences between the low-risk and high-risk group were not significant across all play tasks.

Characteristics of sibling interactions: the overall model was not significant; the younger and older group did not significantly predict sibling interaction characteristics during play.

Role (a)symmetry: this was based upon the number of initiations and responses of both siblings. Higher levels of initiations reflect a more dominant position, while higher levels of responses indicate a following role. Both younger and older children were compared within each group, and results for play with the marble run and play with the blocks were combined.

During the marble run and blocks and play with the keyboard, older siblings in the low-risk group took a more dominant position, which was reflected in a higher level of negative initiations.

Furthermore, while playing with marble run and blocks the younger siblings followed more frequently, with higher levels of positive responses.

In the high-risk group, older children with autism showed higher levels of negative initiations during play with the marble run and blocks while their younger high-risk siblings showed higher levels of positive responses.

The researchers compared role (a)symmetry for both groups. There was no significant difference in the dominance of the older child during play with the marble run and blocks or the keyboard task or to the degree with which the younger child followed.

Sample Characteristics: The degree to which sample characteristics influenced the association between group status (high-risk vs low-risk) and the sibling interaction was evaluated:

- Gender of the older sibling was a significant predictor for positive responses. When the older sibling was a girl, positive responses were more frequent than when the older sibling was a boy.

- The age of the older sibling significantly predicted the positive initiations and orientation to sibling of the older child. The higher the age of the older sibling, the more positive initiations during marble run and block play. In comparison, during play with the keyboard the age of the older sibling only predicted higher levels of orientation to sibling as the age of the older child increased.

- Younger siblings with a lower developmental level showed fewer negative initiations.

- During play with the marble run and blocks, a higher socio-economic status was associated with more negative initiations of the older child.

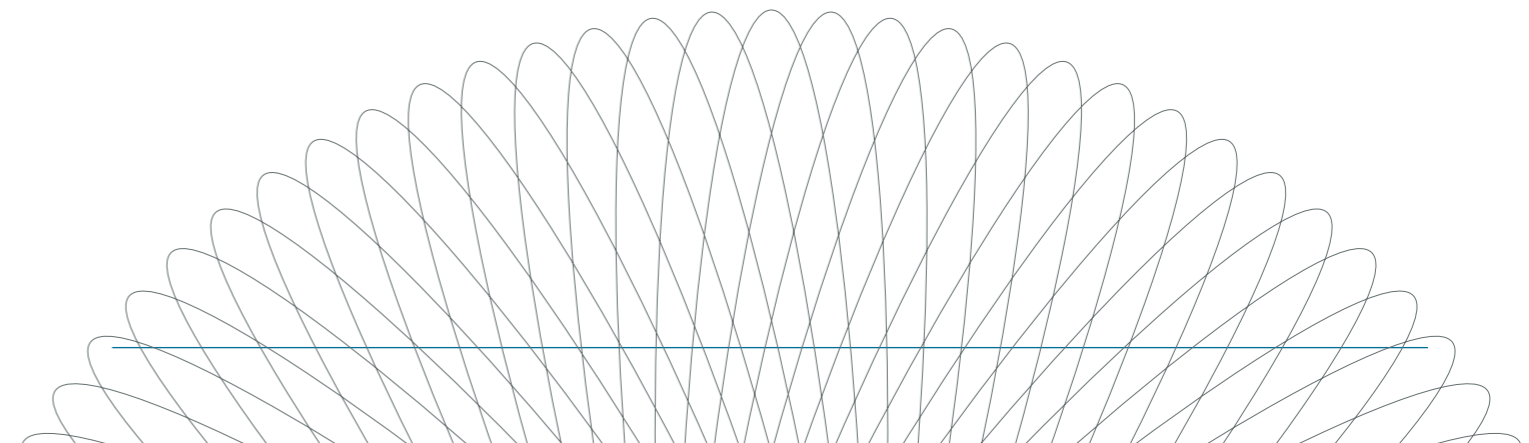## IMPLICATIONS FOR PRACTICE (by the authors)

The results of the current study raise theoretical implications.

- Although the overall level of interactions was quite low, the interactions in the high-risk group were clearly more negative than in the low-risk group. Higher levels of negative behaviour could influence the learning environment and development of young high-risk siblings.

- Higher levels of negative initiations and responses may disturb the balance between positive and negative. This could lead to higher levels of internalising or externalising problems and lower social competence in both children.

- As a result, sibling interactions should be targeted in early interventions in autism. Interventions that can promote positive sibling relationships and individual adjustment of both siblings could improve the later outcome of both high-risk siblings and children with autism.

- Targeting sibling interactions could be part of a broader intervention or could be included in specific programmes such as home guidance.

- Although significant findings were observed, the small sample size reduced the power of the study and the likelihood of detecting significant results. After applying a Bonferroni correction, several significant results were no longer significant. This is possibly due to a decrease in power and does not necessarily mean that there are no real-world differences, but results need to be interpreted with caution.

- Future research should focus on replicating the current results in a larger sample, including a low-risk control group matched with relevant sample characteristics.

Full Reference

Bontinck, C., Warreyn, P., Van der Paelt, S., Demurie, E. and Roeyers, H., (2018). The early development of infant siblings of children with autism spectrum disorder: characteristics of sibling interactions. PloS One. 13(3), e0193367.

THE SISTERS' ADVANTAGE? BROADER AUTISM PHENOTYPE CHARACTERISTICS AND YOUNG ADULTS' SIBLING SUPPORT

BACKGROUND

Young adulthood is a unique time as it involves increasing levels of independence, autonomy and new demands. This can prove to be a particularly challenging time for young people with autism, and parents may find it difficult to provide support for young adults with autism at this time. Further support may therefore be required from siblings. Young adulthood tends to signify a time when siblings no longer reside together, and subsequently the nature of their relationship may change as interaction becomes optional.

Previous research suggests that autism characteristics, rather than the diagnosis itself, has a more significant impact on relationships with siblings, so researchers measured Broader Autism Phenotype (BAP) characteristics rather than selecting participants based on a confirmed diagnosis of autism.

Researchers hypothesised that higher BAP characteristics would be negatively linked to emotional and practical support; therefore, the higher the individual scored on BAP characteristics the less emotional and practical support they would receive from their young adult sibling. Researchers suggested that this negative relationship would be stronger for male rather than female siblings and may be less apparent when the young adult with autism and their sibling are both female. It was hypothesised that parents may be able to mediate and support sibling relationships when one of their children reside with them and so higher levels of emotional and practical support would be provided. Finally, researchers hypothesised that in families with two children, those with higher BAP scores would receive higher levels of emotional and practical support from their sibling.

RESEARCH AIM

The study aimed to examine the factors impacting support provided by young adults to their siblings who present with characteristics of autism. Researchers aimed to quantify practical and emotional support provided by young adults and examined the impact of other factors, such as autism characteristics, family size, gender and residency with a parent.

RESEARCH METHOD

Participants were identified from an existing large-scale study of individuals 18–29 years old that examined the role of siblings in young adulthood. The present study consisted of 1750 participants. The study was administered online through Amazon Mechanical Turk, which is a pool of participants who complete surveys and studies online in exchange for payment. Participants were admitted to the study if they had completed five hundred tasks to an adequate standard online. Of the young adult participants, 1.8% indicated that their sibling had a confirmed diagnosis of autism.

Young adults were asked to rate their nearest-aged sibling's BAP characteristics by responding to the fifty-item Autism Spectrum Quotient questionnaire. They were able to complete optional items relating to other siblings in exchange for further payment. Attention-checking items were included within the questionnaires administered and participants were excluded from the study if they did not respond correctly to these items. Items from the Social Support Resources measure were used to evaluate emotional and practical support.

A multi level model (Step1 and Step 2) for variables predicting practical support were examined, Factors such as biological relatedness, closeness and conflict experienced within the sibling relationship, contact with siblings, residing with their sibling, and the young adult's own BAP characteristics were controlled for.

RESEARCH FINDINGS

Results of the study indicated that BAP characteristics were negatively associated with emotional support provided by a young adult sibling: those presenting with more characteristics of autism received lower levels of emotional support from their young adult sibling.

BAP characteristics were associated positively with practical support provided by a sibling, meaning that those with more characteristics of autism received higher levels of practical support from their young adult sibling.

Residing with a parent was positively correlated with a young adult providing both emotional and practical support to their sibling presenting with characteristics of autism.

Emotional Support

Young adult participants whose father had more education, who were older and who had a brother, provided lower levels of emotional support to their sibling; whereas young adult participants who had more education themselves, whose siblings had more education, who were emotionally closer to their sibling, who had more conflict with their sibling or those who lived with their sibling provided higher levels of emotional support.

Further analysis indicated that brothers received lower levels of emotional support from their siblings irrespective of their characteristics of autism as represented by their BAP scores. Sisters received more emotional support than brothers when characteristics of autism were low, and a much larger effect size was noted when sisters presented with higher BAP scores, meaning they received much higher levels of emotional support than brothers with similar BAP scores.

Practical Support

In the first step, results indicated that older participants provided less practical support to their siblings. However, participants did provide more practical support to brothers, when they were closer to their sibling, had more conflicts with their sibling, when they lived with their sibling and when they perceived their sibling to have more characteristics of autism.

In the second step, the interaction between sibling BAP characteristics and sibling gender was significant. Brothers received consistently lower levels of practical support, irrespective of BAP characteristics, whereas sisters received higher levels of support when they presented with higher BAP scores. Sisters with lower BAP scores received less practical support than brothers; however, both sisters and brothers received similar levels of practical support when their BAP characteristics were rated as higher by their sibling.

IMPLICATIONS FOR PRACTICE (by the authors)

The authors state that previous research suggests that young adults may experience poorer relationships with siblings who have more characteristics of autism. The present study indicated that those with higher characteristics of autism received lower levels of emotional support from their siblings, but they tended to receive higher levels of practical support than those with lower BAP scores. The authors suggest that young adults may feel a sense of duty in practically supporting their siblings presenting with characteristics of autism.

Gender was found to be significant in that sisters with higher BAP characteristics received higher levels of emotional support. The authors suggest that gender differences may mean that more is expected from autistic females despite them possibly experiencing more significant challenges with social interaction and requiring higher levels of support. They also suggest that females with higher BAP scores may be seen as experiencing more challenges than males with similar scores, and therefore receive higher levels of support from their sibling. Gender was not significant in influencing the support provided by the young adult participant to their sibling presenting with BAP characteristics.

Family size was not found to impact the emotional or practical support offered; however, residing with a parent was found to increase the emotional and practical support offered. This suggests that parents are able to mediate and support sibling relationships when one of their children lived at home so that the young adult can provide higher levels of emotional and practical support.

The current study suggests that we should be particularly aware of fostering emotional support between young adults and their siblings presenting with autistic characteristics. Similarly, we should be aware that females presenting with significant characteristics of autism tend to receive higher levels of support than males presenting with similar autistic characteristics.

Full Reference

Jensen, C. A. and Orsmond, G. I., (2019). The Sisters' Advantage? Broader Autism Phenotype Characteristics and Young Adults' Sibling Support. Journal of Autism and Developmental Disorders. 49(10), pp. 4256–4267.

SEEING STRENGTHS: YOUNG ADULTS AND THEIR SIBLINGS WITH AUSTIM OR INTELLECTUAL DISABILITY

BACKGROUND

To date, research has explored intellectual and developmental disabilities in terms of deficits and differences, which shows a very narrow view. Like anyone else, individuals with intellectual and developmental disabilities possess a range of strengths and positive qualities that may be best identified by those most closely involved in their lives. Previous research has examined the views of parents and special educators, but the perspectives of siblings have been neglected. Sibling relationships are important and unique in many ways: they are among the most enduring relationships; they focus more on companionship than caregiving; and the contexts in which siblings spend time together varies greatly. These elements mean that siblings can offer a unique perspective on the strengths and positive attributes of their brother or sister.

RESEARCH AIMS

The study aimed to examine:

- how young adults view the strengths of their siblings with intellectual disability/autism.

- what individual characteristics are associated with these ratings.

RESEARCH METHOD

One hundred and sixty-three siblings (aged 18–30 years) of individuals with an intellectual disability/autism were recruited via support organisations to participate in this study. Participants completed an online questionnaire that included the Assessment Scale for Positive Character Traits – Developmental Disabilities (ASPeCT-DD) and a measure that addressed information about the siblings including shared activities, strengths, future expectations and the quality of their relationship. Data analysis included descriptive statistics and correlational and regression analyses.

RESEARCH FINDINGS

How young adults view the strengths of their siblings with intellectual disability/autism:

- Overall, participants rated their sibling very highly in terms of positive character traits. Strengths in respect of a positive outlook, positive relations, active coping and acceptance coping were rated highest. With one exception, all the siblings with disabilities were described as possessing at least one strength.

- On average, three strengths were rated particularly highly: my sibling shows kindness to others, my sibling shows caring for others and my sibling has a sense of humour.

- The three items that showed the greatest variation in responses were: my sibling does not hold a grudge against others, my sibling does not try to retaliate or get back at others who have hurt him/her and it is fairly easy for my sibling to make new friends.

Individual characteristics associated with these ratings:

- Several factors were significant in predicting how a sibling was rated including gender of sibling, frequency of challenging behaviours, whether they had a diagnosis of autism, how they communicate and whether or not they lived together.

- Higher ratings of overall strengths were reported when siblings were male, demonstrated less frequent challenging behaviours, when the sibling was not autistic, when the sibling was verbal and when the siblings were not cohabiting.

- A highly individualised and diverse range of profiles were provided by siblings of those with an intellectual disability/autism.

IMPLICATIONS FOR PRACTICE
(by the authors)

- It may be helpful to seek the views of siblings to contribute to person-centred planning meetings.

- It is beneficial to understand the interpersonal and character strengths exhibited by an individual (as well as documenting their skills and knowledge); therefore, formal planning approaches should incorporate strength-based assessments.

- To further expand the strengths of those with intellectual and learning disabilities, more investments may be required.

Full Reference

Carter, E.W., Carlton, M.E. and Travers, H.E., (2020). Seeing strengths: young adults and their siblings with autism or intellectual disability. Journal of Applied Research in Intellectual Disabilities. 33(3), pp. 574–583.

ACADEMIC SELF-CONCEPT AND SENSE OF SCHOOL BELONGING OF ADOLESCENT SIBLINGS OF AUTISTIC CHILDREN

BACKGROUND

While there is a growing body of research in the area of autism and family systems, researchers have historically focused their attention on exploring the outcomes and experiences of parents/carers. This has led to the experiences of siblings of autistic children being largely neglected as a subject for research. Studies that do focus on the experiences of siblings of autistic children centre around psychological outcomes and have yielded mixed results of social, emotional and behavioural outcomes. This study addresses the limited literature focusing on the siblings of autistic children within the context of school.

RESEARCH AIM

The purpose of this study was to develop a more comprehensive understanding of the challenges and benefits within the school context for adolescent siblings of children with autism.

RESEARCH METHOD

This study involved participants aged 11–16 years attending high school in the UK. Self-report measures were collected from sixty-five siblings of autistic children and from a comparison group of fifty-seven siblings of non-autistic children. In addition, psychological adjustment data was collected from 140 parents – 73 parents of children with siblings with autism and 67 parents of non-autistic siblings.

This study included a range of self-report measures to explore siblings' own perspectives and experiences as well as incorporating behavioural and emotional adjustment data from siblings and parents/carers to gain multiple informant perspectives and provide a more holistic picture of the sibling experience.

- Demographic questionnaire

A demographic questionnaire was constructed for the purposes of this study and completed by parents. This was used to gather information about age, gender, Multiple Deprivation Index (MDI), English as an additional language (EAL) and any known illnesses, disability or mental health diagnosis.

- Questionnaire measures

In addition to a demographic questionnaire, three questionnaires were included to measure the constructs identified: Myself-As-A Learner Scale (MALS), The Belonging Scale (TBS) and the Strengths and Difficulties Questionnaire (SDQ).

- Academic self-concept

To explore academic self-concept, the MALS was self-reported by siblings. This is a twenty-item questionnaire for children aged 8–16 years. The MALS measures children's emotional perceptions and beliefs of themselves as learners and problem-solvers within educational settings and is standardised on British school children.

- Sense of school belonging

Siblings' sense of school belonging via TBS was self-reported. This is a twelve-item questionnaire for children aged 8–14 years. TBS is adapted to be used on a British population of children from Goodenow's eighteen-item Psychological Sense of School Membership scale, which was developed for American adolescents. TBS measures psychological membership to school – the extent to which individuals feel accepted, included, respected and supported at school.

- Psychological adjustment

To explore siblings' behavioural and emotional adjustment, the SDQ was used. The SDQ is a twenty-five-item measure for use with 4–16 year olds (parent report) and 11–17 year olds (self-report). Items are separated into five subscales:

- Conduct problems

- Emotional symptoms

- Hyperactivity/inattention

- Peer relationships

- Prosocial behaviour

Participant recruitment occurred October 2017–April 2018 using an opt-in consent procedure. Participants were recruited through advertisements in specialist schools, mainstream secondary schools, charities, social media, parents who had attended an autism sibling talk for families of autistic children and through word of mouth. Questionnaires were completed and submitted online. To thank participants for their time, siblings received a £5 voucher.

RESEARCH FINDINGS

This study set out to investigate the experiences of adolescents with siblings with autism specifically within the school context. The authors found robust group differences on broader school-related outcomes even when demographic and psychological adjustment variables were accounted for. It is important, however, to note that there was large variation in the school-related and psychological adjustment outcomes for siblings of autistic children, and that many siblings of autistic children reported a strong sense of belonging and self-concept. As a group, these siblings reported experiencing higher rates of externalising and internalising problems and lower self-concept and sense of belonging.

The siblings of autistic children reported significantly lower school belonging and academic self-concept and had significantly poorer self- and parent- reported behaviour problems. When controlling for demographic variables and internalising and externalising behaviour, robust sibling group differences on academic variables remained.

The authors propose that the findings of this study suggest that siblings of children with autism are at increased risk of experiencing a lower sense of perceived relatedness and competence in a school context. In addition, they note that findings show that the siblings of autistic children self-reported significantly lower psychological adjustment scores; with significantly more siblings of autistic children with total difficulties falling in the 'atypical' category. The authors propose that this suggests that siblings of children with autism may be vulnerable to developing clinically significant difficulties.
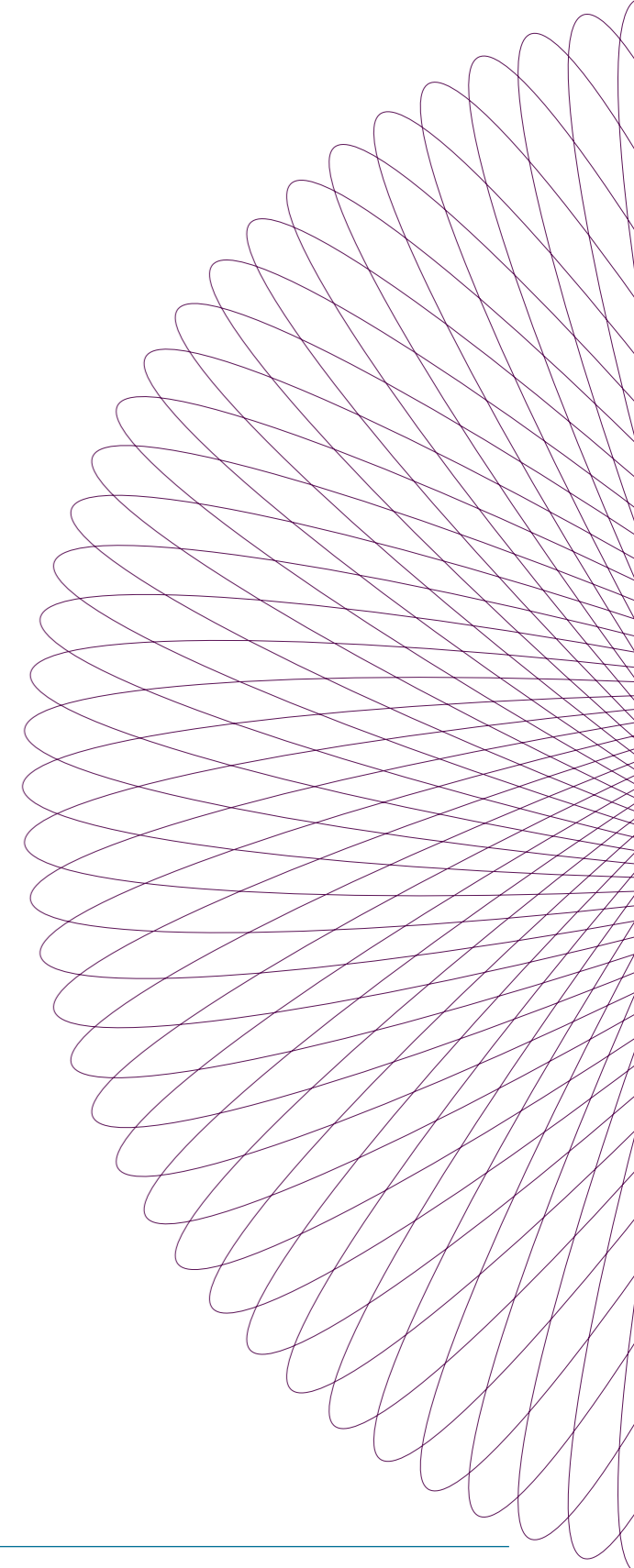
The findings show that the sibling group significantly predicted both academic self-concept and school belonging in all of the models, which suggests sibling differences that cannot be fully accounted for by the demographic variables or sibling psychological adjustment measures in this study. This also suggests that there are other factors, including those not measured in the current study (e.g. attending the same school as the sibling with autism), associated with being a sibling of someone with autism that may influence outcomes on these school-related factors.

IMPLICATIONS FOR PRACTICE (by the authors)

- It is important that practitioners are involved in school-based consultation, assessment, intervention, training and research to support siblings of children with autism with school belonging, academic, self-concept and psychological adjustment most significantly where individual, group or whole school needs are identified.

- The assumption that being the sibling of an autistic child has negative effects on an individual should not be made.

- A person-centred approach should be promoted when working with and researching siblings of autistic children to accurately reflect strengths, needs and to provide individualised support accordingly.

Full Reference

Gregory, A., Hastings, R.P. and Kovshoff, H., (2019). Academic self-concept and sense of school belonging of adolescent siblings of autistic children. Research in Developmental Disabilities. Vol 96, Article 103519.

GROWING OLDER WITH AUTISM - THE EXPERIENCES OF ADULT SIBLINGS OF INDIVIDUALS WITH AUTISM

BACKGROUND

Previous studies that have explored the experiences of individuals with autism have mostly centred around children or adolescents, and findings have been mixed as to whether siblings of a child with autism are exposed to higher risks of emotional, behavioural and relationship difficulties compared to other children. In recent times it has been evident that there is considerable variation in findings.

The following research is part of a long-term family genetic study of ninety-nine individuals with autism and their families. The cognitive, linguistic and behavioural profiles of siblings of children with autism, who were of at least average cognitive ability (i.e. IQ level of > 70), were assessed. None of the siblings who took part in the study had autism themselves.

RESEARCH AIMS

This study explored the experiences of adults with a brother or sister with autism with the aim of:

- providing a descriptive account of older siblings' reported experiences of growing up with a brother or sister with autism.

- summarising their concerns for the future.

- exploring the relationship between the extent of negative experiences/emotions reported and factors noted as significant in child sibling studies: gender, sibling ages and the age gap between siblings, number of siblings in family, ability level of autism sibling, mental health and social outcome of non-ASD sibling.

RESEARCH METHOD

Forming part of a larger scale study, there were a number of restrictions that impacted the follow-up with participants, including non-contact with families who had a family member who had passed away since the research team last contacted them. In families that had three or more siblings, only the two siblings closest in age to the individual with autism were invited to participate. A total of 56 adult siblings (37 females and 19 males with a mean age of 40 years and who were of at least average IQ) participated.

Initial contacts with siblings were made through their parents, all of who had agreed to be re-contacted for future research studies. Ethical approval was obtained from the Joint South London and Maudsley and the Institute of Psychiatry Research Ethics Committee. In addition to participating in direct assessments, including cognitive assessment, assessments of social outcome were based on a modified version of The Family History Schedule (FHS), a semi-structured interview developed for family studies of autism. This assessment provided information on residential status, employment, friendships and intimate relationship with outcomes within each domain rated from 0 (no difficulties) to 3 (severely impaired) with a composite outcome rating generated from the total score across all four domains. The FHS also provided information to assess mental health difficulties with each area of psychiatric difficulty rated again from 0 (none) to 3 (severe/needing inpatient treatment). Siblings also completed the General Health Questionnaire (GHQ-12), a widely used psychiatric screening tool.

The most recent level of employment and GHQ-12 scores were also compared with data for a similar age group of adults that was provided by The National Child Development Survey: Sweep Six 1999–2000 (NCDS).

To assess the experiences of having a sibling with autism, additional questions were asked about their overall experiences of growing up with a sibling with autism and any future worries they had. Each adult was asked one general question: How does it feel to grow up with a sibling with autism? and three specific questions: (1) What were the positive aspects of growing up with a sibling with autism? (2) What were the negative aspects? (3) Do you have any worries about the future?

All answers to questions were recorded in writing during the process of the interview and then transcribed in SPSS by two researchers. A research assistant coded the emotion/experience associated with each answer or part of an answer. Ratings were then checked by another researcher. This was followed by joint discussion with disagreements resolved and composite codes generated to encompass the various individual categories.

RESEARCH FINDINGS

Results revealed that over three-quarters (77%) of adult siblings described having positive benefits that often impacted their own life or personality (e.g. making them more tolerant and caring) as well as the positive characteristics of their siblings with autism.

Social outcomes such as independence, work and social relationships were rated as either good or very good across all participants. All participants were employed with most in managerial/

professional positions in comparison to the general population. Of siblings, 91% were living independently with 90% also reporting that they had long-term intimate relationships. In total 76% had been or were married or cohabiting with a partner. Despite this the study found that many had mental health difficulties. Although the median score indicated that many siblings were of good mental health, 42% were experiencing significant or had experienced mental health difficulties. Furthermore, the median score on the GHQ-12 indicated that scores were above the NCDS sample (11.0 vs 9.0) and 47% had scores at or above the suggested clinical level.

When asked how it felt to grow up with a sibling with autism, most (93%) siblings reported some negative experiences or emotions with 7% expressing strong negative feelings. Most problems were related to feelings of guilt and sadness towards their siblings or parents, restrictions on family or social life (e.g. restriction of activities because of not being able to take trips or holidays, 'missing out on normal life'), confusion, embarrassment or difficulties caused directly by their siblings behaviour (e.g. aggression/unpredictability) or the characteristics of their autism (rituals/rigidity). Overall, 41% of siblings commented that they had grown up accepting the situation, with a further 5% stating that it was difficult when they were young but they grew to accept the situation. Around 13% of siblings reported positive emotions/experiences because of their own personal development or because of the positive attributes of their sibling (e.g. sibling had a 'fantastic personality', or they became more tolerant or felt empowered).

Questions about the positive aspects of growing up with a sibling with autism were initially asked prior to asking about negative aspects of growing

up with a sibling with autism. Over three-quarters (77%) of siblings reported some positive effects with 55% expressing positive effects on their own lives and experiences, 32% focusing on agreeable characteristics of their sibling with autism and 7% feeling that their family had been brought closer together.

When asked if they had any worries for the future, 9% had no particular worries; however, most siblings worried about the long-term future for their sibling with autism. Many (43%) worried about the impact on their sibling with autism when their parents became debilitated or died.

Overall, findings from this study indicated that being an adult sibling of someone with autism has both negative and positive effects. The study also suggests that there is little or no direct association between functioning in adulthood and the experiences of having a sibling with autism. Anecdotally, while several siblings reported negative experiences these had reduced or disappeared in adulthood.

IMPLICATIONS FOR PRACTICE (by the authors)

The authors of this study highlighted that despite many siblings eventually taking on the role of caring for their autistic sibling, they often did not have any contact with services until well into adulthood. Professionals responsible for the welfare of individuals with autism should be much more involved with adult siblings at an earlier stage.

Siblings are also in need of information and support around future care options. In addition, advice and information about bereavement support for their autistic sibling should also be borne in mind when working with individuals with autism and their families.

Full Reference

Moss, P., Eirinaki, V., Savage, S. and Howlin, P., (2019). Growing older with autism – the experiences of adult siblings of individuals with autism. Research in Autism Spectrum Disorders. 63, pp. 42–51.

A NATURALISTIC BEHAVIORAL INTERVENTION TO INCREASE INTERACTION BETWEEN SIBLINGS WITH AND WITHOUT AUTISM

BACKGROUND

Social difficulties associated with autism come in many forms including difficulties with social interactions, sharing interests and maintaining relationships with peers. Research suggests that incorporating siblings into social skill interventions may be beneficial to both the child with autism and the typically developing sibling; however, previous studies have predominantly involved only participants with mild symptoms of autism and have not also reported outcomes for the typically developing sibling.

RESEARCH AIMS

The purpose of this study was to investigate the effects of a naturalistic behavioural intervention on social interaction between typically developing siblings and siblings with autism. The authors aimed to find out if:

- the intervention could be carried out by siblings.

- social interaction behaviours improved for children with varied characteristics of autism and their typically developing siblings.

- the intervention demonstrated a sufficient level of social validity to support its use.

RESEARCH METHOD

Two sibling dyads consisting of one sibling with autism (hereafter referred to as 'participants') and one typically developing sibling (hereafter referred to as 'siblings') participated in the study. English was the primary home and school language of both sibling dyads.

The first dyad included Julia and Lily. Julia was a Chinese Mexican American female and was six years old. She scored a fifty on the Childhood Autism Rating Scale – second edition (CARS2),

indicating severe symptoms of autism. Julia did not demonstrate functional verbal speech, rarely initiated interaction and could respond to initiations after prompting. She could use picture symbols to make requests (e.g. listen to a song). Julia's sister Lily was five years old and demonstrated developmentally appropriate language and social skills for a child her age and did not receive special education services.

The second dyad included Seth and Talia. Seth was an Indian American male and was nine years old. He scored thirty-three on the CARS2, indicating mild to moderate symptoms of autism. He also had diagnoses of speech impairment and a blood disorder that resulted in anaemia. Seth was verbal and able to communicate functionally in short sentences or phrases of three to five words. Seth preferred solitary, exploratory play. He demonstrated some functional play skills but tended to perseverate on preferred television episodes or movies during play by reciting lines from the shows. Seth's sister Talia was twelve years old and demonstrated developmentally appropriate language and social skills for a child her age and did not receive special education services.

An ABAB reversal design was used to evaluate the effects of the intervention package on initiations and responses within each sibling dyad. Phases included baseline unstructured free play, interest-based intervention package and, for Seth and Talia, generalisation in a novel setting.

Baseline sessions were ten minutes in duration and consisted of 'business as usual' play time in the home.

The intervention package involved an age and developmentally appropriate play-based activity mutually appealing to the siblings and was designed around each participant's preferred or restricted interest, e.g. Julia liked arts and

crafts and her sibling liked Disney princesses, so activities combined both children's preferences and resulted in colouring in an image of a Disney princess. The intervention package activities were ten minutes in duration and involved the facilitator introducing the activity to the dyad. The facilitator was responsible for the organisation of the materials and providing a brief demonstration of the preferred play activity to the sibling dyad through modelling and verbal explanation that lasted approximately 2–3 minutes prior to beginning the sibling play session.

Dependent variables included frequency of participant initiations directed to a sibling and frequency of participant responses. Initiations were operationally defined as any verbal, non-verbal or motor behaviours directed toward a sibling such as greetings, asking questions, commenting, sharing materials or helping behaviours. Sibling initiations and responses were measured in the same manner described above.

All play sessions were video recorded. Special education graduate students trained in collecting direct observation data performed data collection from the video recorded sessions.

Post intervention, two types of social validation measures were used in this study:

- Caregiver, participant and sibling feedback of intervention procedures through interview.

- Observer ratings (that involved teachers viewing a sample of the recordings) of participant social behaviour during baseline and intervention.

RESEARCH FINDINGS

This study successfully replicated findings from a school-based peer interaction study and demonstrated that a treatment package consisting of interest-based play activities involving adult instruction, modelling and response to child questions resulted in a significant increase in social interaction between children with autism and their typically developing siblings.

In addition, results generalised across settings for one sibling dyad and multiple social validity indicators revealed that the intervention was feasible to caregivers, viewed favourably by all stakeholders and resulted in socially significant behaviour change as indicated by observers.

IMPLICATIONS FOR PRACTICE
(by the authors)

This study highlights the importance of:

- utilising and combining the young person with autism's area of interest and the sibling or peer's area of interest/preferred play activities for encouraging social skills and shared play experiences.

- modelling, teaching and explaining a play/social-based activity and the preferred social behaviours associated with that activity to both the young person with autism and the sibling/peer.

Full Reference

Watkins, L., Tomeny, T., O'Reilly, M., Sillis, K. and Zamora, C., (2020). A Naturalistic Behavioral Intervention to Increase Interaction between Siblings with and without Autism. Behavior Modification. pp. 1–24. doi: 10.1177/0145445520920813

SOCIAL CONNECTIONS AMONG SIBLINGS WITH AND WITHOUT INTELLECTUAL DISABILITY OR AUTISM

BACKGROUND

Having a sibling has a profound and lasting effect on your life and can influence development and life choices. The sibling relationship provides opportunities for social interaction, sharing, rivalry and companionship. When a sibling has a diagnosis of autism or intellectual disability (ID) the relationship may also involve a caring role, particularly as the sibling gets older. To date there has been limited research into the nature of sibling relationships when one member has an ID or autism.

RESEARCH AIMS

The study aimed to explore siblings' perspectives of their relationship with their sibling with autism or ID.

The study explored several research questions including:

- How do young adult siblings (18–30 years) spend the time with their brother or sister with a disability?

- What influences the number and variety of activities that are completed together?

- How do siblings perceive the quality of their relationship?

- What future expectations do siblings hold for their brother or sister with disabilities?

RESEARCH METHOD

There were 155 siblings of those with ID or autism who took part in the study. Participants were recruited through organisations passing the study's information to relevant families and sharing via social media. The study involved an online questionnaire in which participants provided information about their sibling and their relationship. Demographic information obtained indicated that the majority of individuals with ID or autism used speech to communicate (77.4%), 13.5% used limited words, 1.9% used a communication device and 7.1% were non-verbal.

RESEARCH FINDINGS

How do young adult siblings spend the time with their brother or sister with a disability?

The most common activities were watching television (94.9%), talking on the phone (82%) and taking part in hobbies (71.6%). More common community activities included going to the cinema, shopping centre or a concert. Less common hobbies, most of which were not completed in the last year, were taking a class, volunteering together or visiting a library.

What influences the number and variety of activities that are completed together?

There were several factors that influenced the frequency and variety of activities completed together. Having a sibling who was able to communicate via speech related to a significantly higher total of activities with their siblings. Female siblings also spent more time with their brother or sister with a disability. As the age difference increased between siblings the number of activities decreased. Siblings with a disability who exhibited more challenging behaviour participated in less activities with their sibling.

How do siblings perceive the quality of their relationship?

Overall respondents were positive about their relationships with their sibling with 79.1% reporting that they were 'pretty much' to 'extremely' close. Siblings who spent more time

together reported more positive relationships in all seven areas of the quality-of-relationship survey items (respect, affection, fairness, understanding, trust, closeness, overall positivity about the relationship).

Respondents whose brother or sister engaged in challenging behaviour reported less positive-quality relationships. Those whose siblings had ID reported more positive relationships than siblings who had autism.

What future expectations do siblings hold for their brother or sister with disabilities?

For siblings with autism or ID, over 20.8% were in paid employment. Over half of participants (56.1%) reported that they expected their sibling to have a job in the community and 51% reported that they expected their sibling to volunteer in the future. With regards to education, 3.9% were attending college and 22% expected that their sibling would attend college in the future.

Around half of siblings with disabilities lived with family members, and 32.2% expected this would continue in the future. A fifth of participants (20.7%) expected their sibling to live independently, while a further 25.8% expected that their sibling would live in a group home.

IMPLICATIONS FOR PRACTICE (by the authors)

- Overall, siblings spent a substantial amount of time together completing a wide range of activities, indicating the important role of siblings. At present siblings are not routinely engaged in planning for their sibling with disability. Given the knowledge and closeness they share with their sibling this might be important to consider in the future. This would be particularly valuable where siblings may play a greater caring role in the future.

- When the sibling with autism or ID had limited speech or engaged in challenging behaviour it was less likely they would take part in activities in the community. In these circumstances, siblings may not feel equipped to support their brother and sister in the community. This highlights that siblings require support in this area.

- Siblings could benefit from receiving information on activities and supports available in the community to increase the number and variety of activities completed. This is particularly important as the number of activities completed together was correlated with the quality of the relationship.

Full Reference

Travers, H.E., Carlton, M.E. and Carter, E.W., (2020). Social connections among siblings with and without intellectual disability or autism. Intellectual and Developmental Disabilities. 58(1), pp. 19–33.

SIBLING SELF-MANAGEMENT: PROGRAMMING FOR GENERALIZATION TO IMPROVE INTERACTIONS BETWEEN TYPICALLY DEVELOPING SIBLINGS AND CHILDREN WITH AUTISM SPECTRUM DISORDERS

BACKGROUND

The relationship between siblings, regardless of the presence of a disability, is significant. It is often long-lasting, providing friendship and support throughout each other's lives. When one sibling has autism the relationship may be characterised by less intimacy and nurturance, as well as fewer positive responses, prosocial behaviours and social initiations.

The authors wanted to find out if explicitly teaching self-management strategies to a neurotypical sibling would positively impact on the sibling relationship between a neurotypical child and a child diagnosed with autism. To the authors' knowledge, this was the first study that focused on using Behavior Skills Training (BST) to teach neurotypical siblings self-management response skills for the purpose of improving the relationship with a sibling diagnosed with autism.

According to the authors, self-management is when behaviour change responses are independently used rather than prompted by a practitioner. Independent self-management responses increase the likelihood of generalisation and maintenance in naturally occurring sibling interactions.

To evaluate the effectiveness of explicitly teaching self-management strategies to the neurotypical sibling, the authors used the social skills programme called Stay-Play-Talk (SPT). The original SPT curriculum was for neurotypical preschool-aged peers but it was found to be effective for older children. The programme progressively shapes social interactions by teaching children to stay within proximity of each other, to engage in cooperative play and to initiate and respond to verbalisations from their peers. The first author of this paper created a modified SPT curriculum for use with individual children rather than the intended large class group of children.

BST involved the author introducing, teaching and modelling an SPT skill to the neurotypical sibling. The neurotypical sibling rehearsed the SPT skill and received feedback from the author before proceeding to a play session with their sibling with autism.

RESEARCH AIMS

1. To find out if BST resulted in improvements in neurotypical siblings' self-management of the SPT curriculum during intervention.

2. If improvements were generalised across settings and maintained over time.

3. If improved responses were associated with improvement in sibling reciprocal interactions.

RESEARCH METHOD

Participants were recruited through verbal advertisement by the authors. Inclusion criteria included parents reporting an autism diagnosis for one child and the absence of autism for another child. Four neurotypical children and four siblings diagnosed with autism participated in this study. All children were aged 6–12 years and all four children diagnosed with autism were verbal.

The first author administered the Autism Diagnostic Observation Schedule–Generic confirming autism diagnosis. The neurotypical sibling achieved average performance on the Stanford–Binet Intelligence Scales (fifth edition) and non-clinical scores on the parent-completed Child Behavior Checklist.

The authors administered the full-scale Stanford–Binet to gauge the neurotypical siblings' ability to understand instructions and to ensure

intervention efficacy. It was not completed with the sibling with autism as they were not the direct consumer of the intervention. All siblings with autism had a repertoire of play skills enabling them to take turns and follow directions as they played with their neurotypical sibling. A variety of play resources found in each family's home were used for play sessions.

Baseline, intervention and maintenance sessions took place in the siblings' homes (e.g. in a common play area such as the living room). Generalisation sessions also took place in the siblings' home but in secondary locations (e.g. the bedroom of the sibling with autism) in addition to a play location outside of the physical home (i.e. backyard).

Prior to collecting baseline data, the authors determined that the targeted response goals would be for siblings to progressively play together for a maximum of ten minutes without adult involvement and to:

- Stay – within 1.5 metres of each other.
- Play – both siblings engaging with the same toys by taking turns, moving items on the same materials or using the same materials.
- Talk (ten comments) – the neurotypical sibling engaging in intelligible verbalisations directed toward their sibling with autism.

Intervention sessions involved the neurotypical sibling participating in weekly BST where they received instruction, observed modelling, rehearsed and received feedback about self-management and an SPT topic. Immediately following the BST, the sibling dyad engaged in play sessions similar to baseline. Once the targeted response criteria was met across three consecutive sessions, generalisation and maintenance sessions began.

For generalisation and maintenance sessions, the author observed the neurotypical siblings' interactions during play at weeks two, six, and fourteen post intervention. If self-management responses fell below mastery criteria, a booster training session was delivered immediately following the play session with the neurotypical child.

A pre-agreed reward system was in place for all sessions. All sessions were video recorded and subsequently reviewed and coded by trained research assistants for integrity.

RESEARCH FINDINGS

The neurotypical siblings demonstrated no self-management responses during baseline; however, once intervention began self-management responses increased to one hundred per cent for all by the second session.

After intervention, all neurotypical siblings achieved generalisation goals.

For maintenance goals, two participants received booster sessions at the second and six-week stages. At week fourteen post intervention all neurotypical siblings demonstrated generalisation and maintenance of both self-management and SPT responses.

Reciprocal interactions to ascertain if improved responses caused improvement in sibling interactions were analysed separately for neurotypical siblings and for the siblings diagnosed with autism:

- Of the four neurotypical responses, one sibling's improvement was as anticipated, another's initially improved just slightly but by the final maintenance session had exceeded expectation. The remaining two showed high levels of improvement at completion of the sessions.

- Of the four children diagnosed with autism, one showed high levels of improvement, another showed a steady level of improvement but below what was anticipated. Two initially showed improvement but for one by week fourteen the improvement was comparable to baseline and for the fourth improvement was average.

IMPLICATIONS FOR PRACTICE (by the authors)

There are two consumers in each sibling dyad. Only targeting the behaviour of the neurotypical sibling may not sufficiently address the barriers in their interactions. Given the effectiveness of this intervention with neurotypical siblings, this study could be expanded to include targeting the siblings with autism.
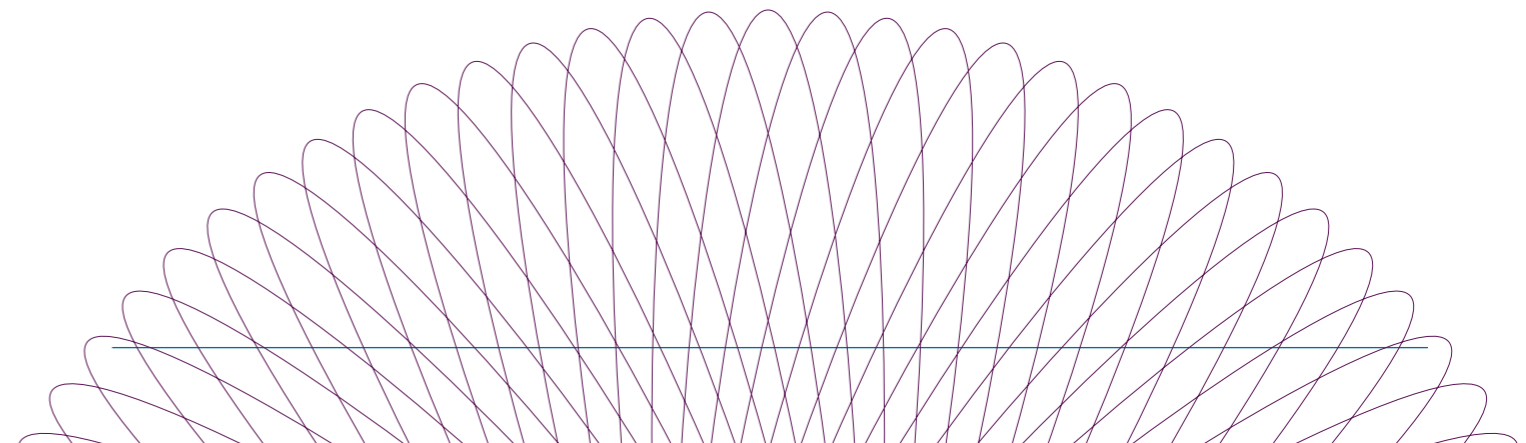
A challenge to teaching skills to improve interactions between this sibling dyad is that delivering instructions during these interactions is unnatural. Also, siblings have more opportunities to interact when the practitioner is absent. However, this should not deter the practitioner as teaching self-management skills to the neurotypical sibling should still result in the desired outcome.

Further investigation is needed to ascertain if generalisation can be maintained in locations outside the home, for example in the community.

Booster sessions will be necessary, but other factors such as age, birth order, play interests and needs of siblings should be considered. Practitioners also need to consider ways of providing natural support to facilitate generalisation and maintenance. For example, facilitating parent training to support and enable them to help their children develop self-management skills as the siblings' mature would be important as this improves interactions and sibling relationships for neurotypical siblings and their sibling with autism.

Full Reference

Kryzak, L.A. and Jones, E.A., (2017). Sibling self-management: programming for generalization to improve interactions between typically developing siblings and children with autism spectrum disorders. Developmental neurorehabilitation, 20(8), pp. 525–537.

A THEMATIC SYNTHESIS OF SIBLINGS' LIVED EXPERIENCES OF AUTISM: DISTRESS, RESPONSIBILITIES, COMPASSION AND CONNECTION

BACKGROUND

When a family member receives a diagnosis of autism spectrum condition (ASC) the implication can reverberate throughout the full family circle, having an impact on everyone concerned. In particular the parents as they negotiate the implications of parenting, understanding the needs of their child, working with a range of external agencies, juggling family life and relationships, financial repercussions, associated stress management; as well as amassing the positive outcomes of the development of strength, resilience, the ability to make adjustments and the acquisition of advocate skills. Although the researchers maintain that knowledge and understanding of familial impact when a member has been diagnosed with ASC has grown and developed, consideration and understanding of neurotypical siblings' (NS) lived experiences is in its infancy in research. Thus, this thematic synthesis has been designed to identify, appraise and review the lived experiences from the available qualitative literature.

RESEARCH AIMS

The research recognised that there were additional factors to be faced by a sibling when their sibling was diagnosed with ASC. Through analysis of qualitative research, this allowed the NS to clearly illustrate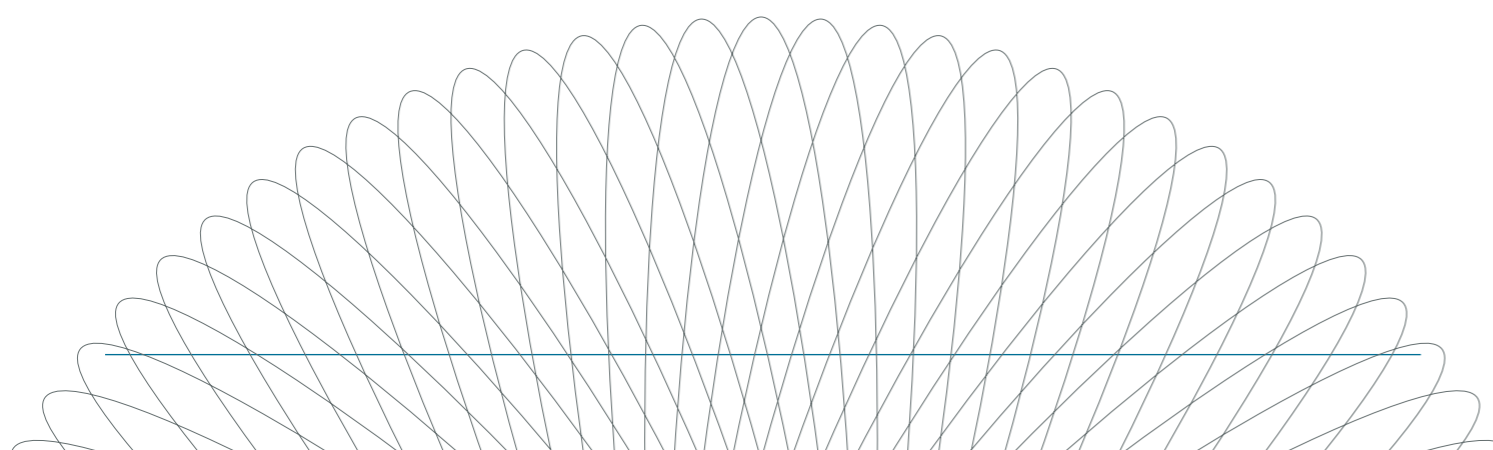 and vocalise emotions and feelings from individual rather than collective experience; therefore, this study aimed to include personal influences for the NS, mental health issues, pressures to adopt a more active caring role, the occurrence and being on the end of aggressive behaviours, all-consuming family difficulties and feeling that others fail to notice their individual needs. It was also noted that the NS experienced the positive impact of sibling connectedness and a growth of their interpersonal and intrapersonal skills of love and empathy.

Thus, in relation to the lived experience of NS of autistic people, this research aims to identify and appraise the current research and through this describe and analyse recurring themes.

RESEARCH METHOD

This review involved the use of the PICo (Population, Phenomenon of Interest, Context) mnemonic to develop the question and search strategy. Web of Science, PsycINFO, PsycARTICLES, MEDLINE (all via OvidSP), Scopus and CINAHL (via EBSCO) were systematically searched using a combination of relevant terms. Terms identified numbered 417, yet after rigorous screening, data extraction and quality appraisal, eighteen studies met the criteria for inclusion.

Theme	Sub-theme	Findings
Roles and responsibilities	Caregiving and parenting	• NS role differed considerably from that of their peers; motivated by an inherent responsibility for sibling development and protection and based on affection but also a sense of duty. • Supported parents to relieve pressure. • Provided insight to teachers and peer group. • Understood the need for their involvement in various environments. • Felt deprived of opportunities to manage own life, yet such emotions resulted in feelings of guilt.
	A protective role	• Protected sibling from both emotional and physical harm driven by love but a sense of appreciating vulnerability. • Feeling in a state of constant alert as to how others would perceive and interact with sibling. • Sense of accomplishment and pride when this support and protection was provided. • Sense of frustration when sibling did not see the aim of the protection.
	Future concerns	• Interactions and support proved easier as both got older. • Continuity and constancy of care were looming worries, but others enjoyed, even relished, the role. • Mixed emotions: wanting to retain their input while also accomplishing some individual independence. • What services would be available in the future.

Theme	Sub-theme	Findings
Impact of behaviours	Aggressive, idiosyncratic behaviours and unpredictability	• Stressful, upsetting and anxiety provoking when the behaviours were unpredictable and aggressive. • Repetitive behaviours had a contrasting outcome – for some irritating while others found them understandable.
	Embarrassment and being 'different'	• Some felt embarrassed when others formed an opinion on their sibling based solely on behaviours seen outside the home. • They compartmentalised life – in our house and outside the home, and the two would not meet. • Did not want others to judge their sibling but did not want everyone to know of the relationship.
Process of adjustment	Acceptance, empathy and learning	• Varied response: total acceptance, love, pride, appreciation of skills and positive qualities through to not wanting their sibling to be autistic as this would make the sibling's life easier. • NS developed resilience, compassion, empathy, patience, a sense of unconditional love and appreciation of difference. • Recognised that need for societal education into the needs of autistic people.
	Strategies and support	• Development of coping skills: time alone, being with peers, exercise, teaching their sibling. • Used external supports: network of others in same position, have fun with those who are not autistic, therapeutic support. • Sense of agency: that feeling of control over actions and consequences through learning about supportive strategies for their sibling. • Guilt for being away from sibling and family. • Stress derived from accessing appropriate services at an appropriate time. • Being left out when professionals discussed their sibling and their needs and future.

Theme	Sub-theme	Findings
Interpersonal experiences	Negotiating 'outside' relationships	• Again, the response differed. Some felt the need to spend time away from their sibling while others met up with peers and their siblings forming a support group. • Friendship building was difficult as the number of opportunities was limited. • Younger NS felt that parents needed all their time for their sibling. • In addition, younger NS did not think anyone would have time should they wish to invite a friend home, so chose not to. • Mixed response to introducing sibling to partners. Some simply explained their sibling's needs but others were worried about behavioural issues. • Some were concerned that unenlightened peers would offer sympathy or pity, which they would see as devaluing of or patronising to their brother or sister.
	Fitting in the family and being seen	• Some wanted their feelings and aspirations to have the same precedence or level of importance as their sibling – then felt guilty for experiencing this emotion. • Some felt overlooked, so masked their feelings to not overburden their parents. • Others were jealous of the attention the sibling received.
	Sibling connections	• Many wanted a robust relationship with their sibling but found it difficult to construct due to difficulties with communication, aggression and their sibling not having the same need for interaction. • Sharing their sibling's interest to help with their connectedness actually proved enjoyable and fulfilling. • Many expressed admiration for the skills of their sibling, claiming the sibling is 'one of the coolest people I know'. • Many delighted that they had forged an incredibly strong attachment and a relationship where the NS could interpret and facilitate the needs of the sibling.

IMPLICATIONS FOR PRACTICE (by the authors)

- NS need opportunities to be provided where their needs are seen as paramount and valid, where they can be children without the, at times, self-imposed support and protection of their sibling.

- Times may, when and where possible, be provided for the NS to be central whether that be with parents, peers in the same situation, peers with similar interests or with outside agencies.

- It was also felt that parents need support so that they can offer this valuable time to the NS. This may include forging and offering some form of psycho-education for parents and allowing opportunities for dedicated parent–NS time, where all interests could be accommodated.

- Development of opportunities to increase a sense of agency: the NS needs the chance to voice their feelings in a supportive environment where they can say openly how their sibling and their ASC is negatively impacting them.

- The NS also wanted the chance for their voice to be heard and to offer their opinion to both peers and professionals on the positive effect on their lives of having a sibling with ASC. The NS felt a need for their deepening empathy to not only be recognised but also utilised.

- Greater understanding of ASC:

  o Reiteration that ASC is lifelong and that the role of carer may transfer from parent to sibling at a time in the future. The NS may feel a sense of obligation to care for their ASC sibling due to societal and cultural constraints.

  o However, as the NS have grown older, they see the development of this caring, supportive role as a natural progression in the maturation of their relationship with their sibling; the need to protect as well as be proud of their sibling increases.

  o Wider community understanding of ASC and all the associated implications to increase public comprehension.

  o Greater appreciation of the individuality of autism, dispelling the fallacy that 'one-size-fits-all' and how they wanted their sibling to be seen as warm, affectionate, loving and admirable.

- Positive mental health opportunities and initiatives must be offered, even formal therapy, to afford the NS respite from behavioural issues or even to discuss the potential behavioural implications on them, their family relationships and their sibling.

- The overriding conclusion from all the studies, however, was that of love, affection, empathy and compassion from the NS to their sibling with suggestions that this could increase if the needs of the NS are perceived to be important too.

Full Reference

Leedham, A. T., Thompson, A. R. and Freeth, M., (2020). A thematic synthesis of siblings' lived experiences of autism: distress, responsibilities, compassion and connection. Research in Developmental Disabilities. 97, pp. 1–18.

CONCLUSION

Siblings report that growing up with a sibling with autism can be both a challenge and an enriching experience.
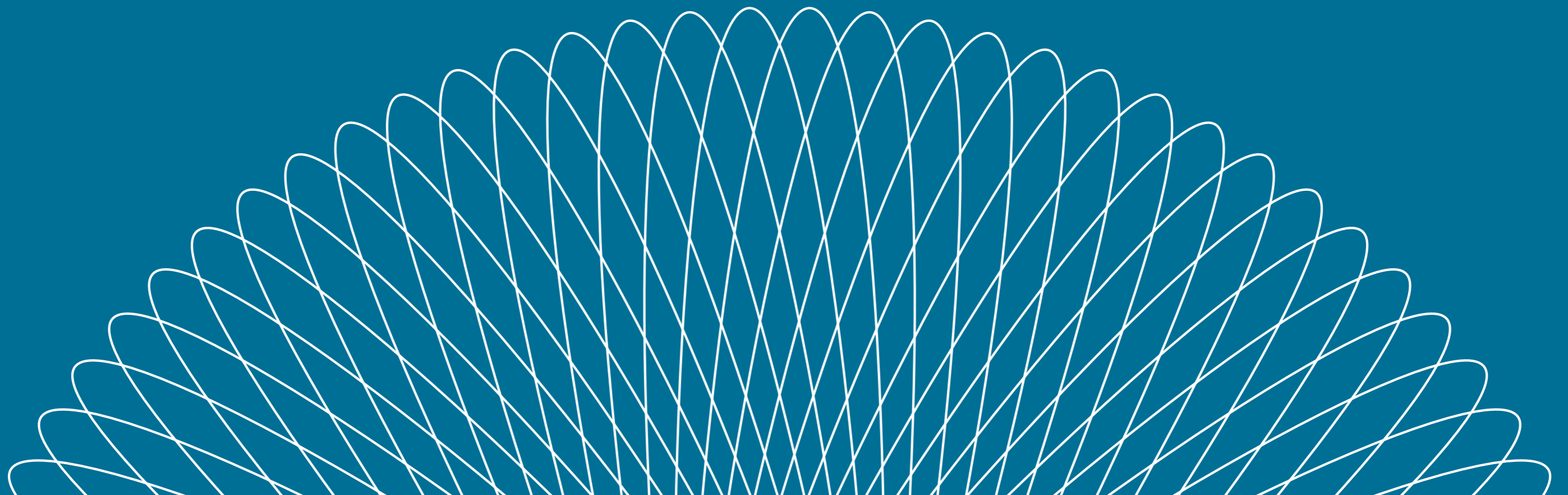
Some key points extracted from the articles included within this Bulletin are listed below, providing practical advice in relation to siblings of children and young people with autism.

- Assumptions should never be made that being the sibling of an autistic child has a negative effect on an individual. Providing siblings with opportunities to share their experiences and voice their views and opinions to both peers and professionals on the positive effect of having a sibling with autism should be encouraged.

- Consideration should be given to targeting sibling interactions early in autism interventions. This could form part of a broader intervention or could be included in specific home-guidance programmes. It is therefore important that practitioners are involved in school-based consultations, assessment, intervention, training and research to support siblings of children with autism.

- A person-centred approach should be promoted when working with and researching siblings of autistic children to accurately reflect strengths, needs and to provide individualised support accordingly.

- Permitting children with autism to interact with siblings in the context of a preferred activity can help strengthen their relationships and provide opportunities to develop their social interactions skills which in turn can then be taught across environments. For example, teaching physical play to siblings can be a useful context for fostering improved interactions and relationships among siblings. Siblings could also be supported by building their awareness on the number of and variety of activities they can avail of within their community.

- Providing an autistic child or young person with opportunities to teach their favourite activity or share their interests with siblings can create a common interest, providing siblings with something which they can share and engage in creating further opportunities for more interaction and bonding. Sharing of an interest could also be extended to peers within the school and wider environments helping them to understand autism and the unique strengths and abilities of those with autism, which can allow siblings to feel less different than their peers and their families.

- The relationship between siblings, regardless of an autism diagnosis, is significant. It is often long-lasting, providing friendship and support throughout each other's lives. Siblings should, therefore, be involved in the planning of care and support for their autistic siblings given the knowledge and closeness they have. This is particularly important in the long-term whereby the role of carer may transfer from parent to sibling. Siblings should be provided with information, advice and support around the topics of future care and bereavement.

- Most importantly, NS need to feel supported. Specific opportunities should be provided for their needs, which are as important as those of their autistic sibling. They should be given time to be children without experiencing a self-imposed feeling of having to support and protect their autistic sibling. Spending time with peers who have similar interests or share similar experiences at home or school may prove comforting and helpful.

The Centre would like to extend a special thank you to Freya O'Horo for sharing her personal experiences of living with a sibling with autism.

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.

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Autism and Siblings (Volume 2)

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