Autism and Siblings
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This is the sixth Research Bulletin produced by Middletown Centre for Autism; the aim of the Centre’s Research Bulletins is to provide accessible summaries of relevant peer-reviewed research articles and literature reviews.

The current Bulletin is on the area of Autism and Siblings. It contains 12 summaries of peer reviewed articles and commences with an interview with Julia Pithouse.

Julia lives in Kent and has two children with autism. Her eldest son David has Asperger’s syndrome and is 23 and her daughter Rebecca has autism and learning difficulties and is 19. Rebecca now attends a specialist college and lives away residentially whilst David shares his time between Mum’s house and Dad’s house, depending on who is cooking the better meal that evening! David has a full-time job supporting young people with autism and is learning to live independently. Julia is the Operations Director of a group of independent schools for children with autism.

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.
1. As the mother of two children with ASD who have differing needs and personalities in addition to their autism, what strategies do you use to encourage your children to engage with each other?

By the very nature of their autism, my two children have never had the inner drive to have a lot to do with each other. However you could ask any parents of neurotypical children the same question and they would no doubt agree!

But however much my brother and I fell out, which was frequently, we did have and still share a lot of in-family jokes and silly in-games. Underneath we did like being together.

My brother and I have exactly the same age gap as my children, 4 years. David my son with Asperger’s syndrome is 23 now and Rebecca who has autism is 19. In the past when they were little, I tried everything I could to get them to play together – to no avail. When David was 6 or 7 he hated to share and God help anyone who touched his Thomas the Tank Engine trains. Rebecca was much younger of course but also very, very delayed in her development so she spent the entire day running up and down, ripping paper, pulling out all the cupboards and generally resembled a Tasmanian devil on a bad day. My efforts at a happy, shared teddy bears picnic on the lawn were ignored and worse, wrecked by the whirlwind that was Rebecca. I felt guilty and useless as a Mum and we mainly took the children out separately as they were too much to handle together. So much for shared happy family times!

But I realised that the whole play thing was not for my children and I had to take a different tack! The one thing they shared was the love of a good routine. So shared routines became shared interests where I could help them forge some sense of togetherness. This included filling the bath for bath time, an event that occurred every night. They loved water so it was one cap of bubble bath for you and one for me. We extended this to jointly counting out the chips at meal times – peas and beans give you even more shared time of course! Turn-taking during routines was seen as fair and just by David and slowed down Rebecca long enough to pay David regular attention. As they grew up these little things prevailed and it seemed to harness David’s interest in being “the big brother”. He always made sure she had her share, her turn, and she responded by paying him attention. Even as adults, this has harboured a sense of fairness and a real tolerance of each other.

2. What qualities do your children bring to each other and to your family?

Both children are very different because of the impact of their autism. David is very able in many ways whilst Rebecca has significant difficulties including limited speech. However they are in other ways very similar. They both like to please and seek the approval of others. This has always made them quite popular with other adults and I am always told what a delight they are – it is me that gets most of the flack! They are also incredibly industrious – Rebecca creating a thousand paintings a day; David working full-time and never failing to get up at 5.30 each day. We are all very proud of their achievements and they both seem to have developed a symbiotic relationship, never asking anything of each other.
3. How do you vary the approaches you use to communicate with both of your children?

Rebecca needs a lot of support with communication. She is very reliant on visual support and loves a schedule. She is a good reader and loves to create lists, mainly for her inexhaustible shopping habits! She loves to use my iPad for her schedule which she instantly learned to use and she loves to cross things out once they are done. I still talk to Rebecca in short, concise sentences and try hard to get her to understand – not always something I achieve.

David has excellent communication but like most people with Asperger’s Syndrome he can fail to pick up on inferences and gets a little confused by what people mean. He is now a learning support assistant for children with severe autism, just like his sister but finds the tough bits of the day the banter in the staff room. No different to the problems he faced socially in the playground when he was younger. So we have an end of day plenary session to work out what people meant, what he could say differently tomorrow etc. I have always felt I am both their language interpreters and suppose I always will be.

4. What are the main strengths and difficulties you find with having two children with such differing strengths and needs?

I feel the major difficulty is never feeling I do enough for them both and I feel guilty on a constant. Their needs are so different but no less time consuming. When they were younger, I always felt that David being more able and older, didn’t get any of my time and I always seemed to be asking him to watch Rebecca or to fetch something for me as I was too busy caring for his sister’s constant demands. Maybe becoming a learning support assistant was an obvious consequence for David as he was an excellent carer.

However the guilt I carry will always be enormous. I felt the worst guilt when Rebecca had to leave home to go to residential school at the age of 13, which was a very low point for us all. Sadly adolescence was a tough time for her and her aggression became too much to handle.

I have however found enormous strength in fighting for what they both need. I taught both children at home for some time through a home programme, one of the first of its type in the UK, and fought so hard to get my local authority to not only recognise it as an educational intervention but to ultimately fund it. The fights continue on a constant – benefits, getting the right level of care/education, disabled badges, doctor’s appointments...you name it and it becomes a battle! I still have plenty of fight in the tank and now try to fight for the needs of other families in my work running independent schools for children with autism.

5. Do you see any similarities and differences in the way your children react to things in their environment such as transitions and anxiety?

Rebecca finds the simplest of transitions a major trauma. Every change has to be explained with visual support and her anxiety can at times be debilitating for her. She constantly needs reassurance about what is happening next and I often find I answer the same question 1000 times over. She is very hypersensitive to noises, especially the unexpected ones like dogs or babies crying and I find myself steering away from push chairs or grassed areas on a constant!
David however does not have any particular sensory issues and copes well with the unexpected. However his anxiety manifests in different ways; not saying the right thing, not knowing how to approach someone and he has endless health and illness fears – always fearing the worst if he so much as sneezes.

My life is spent reassuring and explaining. Anxiety is the cruellest part of autism.

6. Are you able to go on family outings together? If so, what are the implications of this?

When they were younger this became nigh on impossible. Rebecca would cry, tantrum and fall to the floor on a constant and poor David spent the entire trip just tagging along. It became too hard for me to manage and as David got older, too embarrassing for him. I admit that due to Rebecca’s unpredictable behaviour our world shrunk and a trip to the supermarket became a highlight for me! Holidays were impossible as routines were lost and new places were full of sensory hazards and unexplained transitions.

We now plump for outings with a routine flavour – so we have a fighting chance of a happy family outing! We love and can share certain cafes and restaurants, the cinema is a known favourite and both children love to shop – I have no idea where they get that from!

7. How you would explain the sibling relationship between your son and daughter?

Accepting, symbiotic, loving and gorgeous through to hateful, jealous, irritable and angry – often all in one day...isn’t that normal?

8. Has their relationship changed as they have got older? What has worked for your family?

They have both matured in their own way. David has enormous tolerance for Rebecca and is generous enough to give up his Saturdays to traipse around the same shops with her. Rebecca just accepts David and it is clear she loves him in her own way. They live apart now as any 23 and 19 year old probably would and therefore enjoy getting together at weekends.
Sibling Interaction of Children with Autism: Development over 12 Months

**RESEARCH AIMS**
In order to determine if the sibling relationship develops with age the authors compared two sessions of sibling interaction between siblings of children with Autistic Spectrum Disorder (ASD) and siblings of children with Down Syndrome (DS) over a 12 month period. The research questions were:

- Do the number of interactions increase over the 12 month period?
- Do responses to initiations change over the 12 month period?
- Is there a change in the rate of imitation over time?

**RESEARCH METHOD**
A researcher observed and scored the children across a range of 22 social behaviours, these included behaviours described as “pro social” e.g. sharing, giving approval, helping and physical affection and “agonistic” e.g. physical aggression, command, struggle and territorial claim; in addition to these the researcher also recorded incidences of imitation. The researcher would observe and record imitation and the pro social and agonistic behaviours over a 60 minute period on two sessions 12 months apart.

**RESEARCH FINDINGS**
- The pro social behaviour of children with ASD increased over the 12 months as did the pro social behaviour of the siblings of the children with ASD.
- Children with ASD responded positively to play initiations from their siblings less often than children with DS but positive responses to play initiations also increased in the 12 month period between observations.
- Siblings of the children with ASD and DS responded negatively to agonistic behaviour only 25% of the time, on other occasions either ignoring or submitting to the agonistic behaviour of their sibling.
- Siblings of the children with ASD and DS responded to pro social behaviour 52% of the time.
- Imitation rates increased in the sample of children with ASD and their siblings.

**IMPLICATIONS FOR PRACTICE**
(by the authors)
- Children with ASD will experience a development in their interest in social initiation with their siblings over time. The current research shows a clear increase in social initiations demonstrating that for some children with ASD social interest and desire to interact does develop over time.
- Siblings and class mates should be encouraged to “stage manage” or orchestrate play opportunities for the children with ASD as these play opportunities increase the amount of social interaction and initiations experienced by the children with ASD.
- Rates of imitation increased in both children with ASD and their siblings over the 12 months; Imitation is noted as an important precursor to the development of early communication so this is an important area to develop with children and their siblings.
- Siblings remain the most important playmates for children with ASD with this and other research indicating that children with ASD
will initiate more prosocial and agonistic behaviour with their siblings than their peers. The current research indicates that social initiation with siblings develops in line but at a much slower pace than in typically developing peers.

**Full Reference**
Autism Spectrum Disorders and Sibling Relationships: Research and Strategies

**RESEARCH AIM**
The author aims to review studies available on ASD and sibling relationships, address the factors that affect sibling relationships and access the impact of having a sibling with ASD compared to having a sibling with another disability. Key findings are discussed, implications identified and recommendations for improving sibling relationships are made.

**RESEARCH METHOD**
Twelve research studies on ASD and sibling relationships dated from 1987 to 2007 were reviewed. The studies used a combination of methodologies comprising parent and sibling interviews, teacher interviews, Sibling Inventory Behaviour (SIB) and Sibling Relationship Questionnaire (SRQ), completion of the Eysenck Personality Inventory plus sibling questionnaires and observations.

**RESEARCH FINDINGS**

**Factors**
Many factors affect sibling relationships these were identified as:

- Gender was identified as having an effect, i.e. girls tend to display more affection in their sibling relationships; older brothers were found to have least involvement with their siblings.
- A positive parent-child relationship was linked to positive affect and pro social behaviour of siblings.
- Culture, traditions, and environmental contexts all have an effect on sibling relationships.

**ASD: Behavioural Barriers to the Sibling Relationship**
Typically developing (TD) siblings of individuals with ASD face the overwhelming task of forming a healthy sibling bond. TD siblings found it difficult to form satisfying relationships with their sibling with ASD. Non-disabled siblings reported on a self-inventory that they were often disturbed by their sibling’s behaviours. Social deficits shown by individuals with ASD may cause their sibling relationships to be different from the relationships of other disorders such as Down Syndrome (DS) and no disorder.

**Comparison to Other Groups**
The author investigated studies comparing relationships of siblings of individuals with ASD to siblings of individuals with Down Syndrome (DS), Mental Retardation (MR), and Developmental Delay (DD), as well as siblings of typically developing individuals (TD).

**Positive relationships.** Positive experiences are reported amongst most siblings of individuals with ASD, stating they played outside, watched television and had fun with their siblings. Siblings of individuals with ASD typically “stage manage” play with their siblings and in some instances, siblings with ASD initiated play with their typically developing sibling(s). Siblings of children with ASD reported less conflict and greater warmth in their sibling relationship compared to that of TD siblings. Siblings of individuals with ASD were closer when the sibling had lower educational levels, lived closer to their brother or sister with ASD, used coping strategies and when their sibling had higher levels of independence.
More positive sibling relationships are reported when they accepted their role as a family member, perceived minimal parental favouritism, developed coping skills, understood their siblings’ disability, and were not worried about the future of their sibling with ASD. The use of effective coping strategies resulted in more positive sibling relationships between TD siblings and siblings with ASD.

No differences. No differences were reported between sibling relationships of children with ASD compared to siblings of children with DS and no disability. Some research indicates no difference in the quality of the relationship between children with ASD or other disabilities and that of their typically developing peers. This finding has been replicated throughout other studies.

Strategies for Improving Sibling Relationships

There are a number of strategies that can be implemented to facilitate more positive relationships between TD siblings and their brother or sister with ASD. Strategies for four areas of concern are discussed below.

Teach play skills. Teaching siblings a game they can play together is one strategy for increasing positive interactions, pro social behaviours and play skills between siblings. For example begin by rolling a ball to each other or playing catch, and as the siblings become older and more skilful, gradually increase the complexity of the skill such as going for a jog or shooting baskets together. Older TD siblings might also enjoy specific teaching skills so they can be the “teacher” of play. Research has also shown that siblings of a brother or sister with ASD can effectively implement behaviour interventions.

Develop coping skills. Encouraging TD siblings to share their feelings and concerns for their sibling with ASD, can help to minimise unnecessary distress and reassure them that their feelings are natural. TD siblings often lack information or are misinformed about their sibling’s disability. Providing age appropriate information can help TD siblings cope both intrapersonally and interpersonally by dealing more effectively with their own curiosity and peers’ curiosity. When considering how to explain the disability to siblings it is important to assess the sibling’s cognitive level and then to re-present the information throughout their development.

Private special time. To reduce resentment, perceived parental favouritism, depression and increased sensitivity and intimacy of TD siblings towards their sibling with ASD, parents should set aside private special time to spend with their typically developing child when the child can be centre of attention and feel like a valued member of the family. Finding private special time may not always be easy. Parents should try to split the time between each other, spend time with the child while doing errands, ask support from other family members and use respite care for the individual with ASD.

Avoid unnecessary emotional and physical pressure. TD siblings often become second parents in the areas of care and discipline. Concerns about the future of a sibling with ASD can lead to negative sibling relationships. Parents should be conscious not to put too much responsibility on TD siblings. Parents should plan for the prospect of future residential placements. TD siblings should be involved in the process, but should not feel obligated to provide care for their disabled sibling.
IMPLICATIONS FOR PRACTICE
(by the author)

The inconsistencies e.g., negative and positive regarding the effects of ASD on sibling relationships, inevitably appear to be due to such variables as the severity of the disorder of the child with ASD and because of different family environments. A number of the studies indicated more negative than positive impacts of having a sibling with ASD compared to having a sibling with DS, DD, MR or no disability. In most instances, however, studies on siblings of individuals with ASD group together siblings spanning from childhood to adolescent years, which may obscure the differences between these life stages.

The measurement of self-reports used in most of the studies were largely reliant on the skills and development of the siblings and parents and therefore may not be reliable. Future studies are needed to take a life course approach and consider the context of life stages and to analyse the depth of the effects of factors such as those discussed below:

There are a number of considerations for areas of future research

1. **Gender of the siblings with and without ASD.** Studies reported that older sisters of a sibling with ASD had more care giving responsibilities than other siblings. Future studies should ask if the sibling relationship of an older sister is poorer than that of an older brother of an individual with ASD. It may also be interesting to look at how the relationship is affected if the siblings are of the same or opposite gender.

2. **Age of the siblings with and without ASD.** Future research should ask how the relationship is impacted if the typically developing sibling is older or younger than their sibling with ASD. Studies reported that older siblings with MR could become closer to younger typically developing siblings than if they did not have a disability. Very little research is available on whether this finding would apply to siblings with ASD.

3. **Marital relationship.** A child with ASD can put a strain on the marital relationship; does this strain carry over to siblings’ relationships?

4. **Larger family.** Studies reported that more responsibilities for the care of the disabled sibling are placed among the family members of larger families. The effects of a larger family and relationships among typically developing siblings and their sibling with ASD should be addressed.

5. **Coping strategies.** Although reported to have a positive effect on sibling relationships none of the studies addresses which strategies are most or least effective.

6. **The socio-economic status of the family.** Financially secure families may find it more difficult to meet the needs of their child with a disability because fewer resources are available to pay for services. Further research should address whether relationships are more positive in affluent families.

7. The severity of the disability, family dynamics and the cognitive and education levels of family involvement should be considered in future studies. The author also noted that most of the studies reported compared siblings with ASD to siblings with DS and used one type of assessment such as self-reports and this alone was not sufficient to draw any clear conclusions about sibling relationships.

Full Reference
Early Social and Emotional Communication in the Infant Siblings of Children with Autism Spectrum Disorders: An Examination of the Broad Phenotype

RESEARCH AIMS
Autism Spectrum Disorders (ASD) are pervasive, developmental disorders adversely affecting the social, cognitive and frequently, the intellectual functioning, of diagnosed individuals. There is evidence that a broad ASD phenotype characterises relatives of individuals diagnosed with ASD.

Autism is characterised by deficits in social and emotional functioning, communication, and sensory concerns or restricted or repetitive interests. The broad phenotype of autism involves more subtle ASD linked deficits, such as language delay, difficulties with sensory integration and potential difficulties with emotion regulation and communication.

The aim of this paper is to assist in the identification of early social and emotional deficits characteristic of the broad ASD phenotype by examining infant siblings of children with an ASD.

RESEARCH METHOD
Twelve infant siblings of children with ASD (ASD-sibs) and nineteen infant siblings of typically developing children (TD-sibs) participated in the research. Infants were included in the ASD siblings group if their older sibling was diagnosed with autism, Asperger’s Syndrome or Pervasive Developmental Disorder-Not Otherwise Specified. All infants were assessed using the Face-to-Face / Still Face (FFSF) protocol which assesses positive and negative emotional expressivity, and the Early Social Communication Scales (ESCS) which assess early communicative behaviour in young children who do not yet use language as their primary mode of communication. Initiations of Joint Attention (IJA) are precursors to language and refer to the use of gestures and gaze to proto-declaratively or declaratively communicate about an object or events in the environment. Responding to Joint Attention (RJA) refers to the child’s ability to follow the joint attention behaviour (i.e. pointing) of the examiner. Initiating Behavioural Requests (IBR) refer to requests for help or an object.

RESEARCH FINDINGS
Evidence of some differences between ASD-sibs and TD-sibs were found as early as six months old. ASD-sibs smiled for a significantly lower proportion of time with parents. They engaged in significantly lower rates of IJA, RJA and IBR than TD-siblings. However differences in abilities were inconsistent.

ASD siblings seemed to show a range of inconsistent but potentially related difficulties with referential communication. These include subtle differences in initiating joint attention, later developing difficulties in responding to these joint attention bids, and deficits in requesting, particularly in conventional requests. These deficits in referential communication all occurred in the second year of life. A likely explanation is that such complex referential skills involving the intentional use of comprehension and gaze and its coordination with more conventional gestures are developing in this period. Only as TD-sibs
integrate these behaviours into their repertoires at stable levels in the second year of life are differences with ASD-sibs likely to emerge.

**IMPLICATIONS FOR PRACTICE**
(by the authors)
This paper contributes to a growing body of research suggesting subtle, communicative deficits for ASD-sibs in the first two years. Determining the links between the characteristics of the broad phenotype in the first 18 months of life and diagnosable ASD that can benefit from intervention remains a topic for continued research.

**Full Reference**

**RESEARCH AIM**
Children with autism have been found to sustain attention, but appear overly focussed and impaired in the ability to disengage and shift their attention which may underlie difficulties in coordinating communication behaviours. This is reflected in the statistic that over 60% of parents retrospectively report that their children with autism “looked through or past people” in the first year of life (Gomez and Baird, 2005, p.113).

The purpose of this study is to identify possible disengagement deficits associated with the broader autism phenotype (BAP) and potential later Autism Spectrum Disorders (ASD) classification within the first year of life by examining the at-risk infant siblings of children with an ASD. The researchers hypothesised that siblings of children with ASD would shift their gaze to and from their parents’ faces less frequently than comparison siblings; they also considered the impact of parent behaviours, such as tickling, touching and positive affect on infants’ gaze patterns.

**RESEARCH METHOD**
The present study included a sample of 34 infant-parent dyads. All infants were approximately six months old, both siblings of children with and without ASD and were comparable on gestational age, ethnicity and parent education. All siblings participated in the Face-to-Face/Still-Face Protocol which is a measurement consisting of three episodes: the face-to-face episode, the still face episode and the reunion episode. The interactions were recorded by video camera. Infants were coded as either gazing directly at the parent’s face or not gazing at the parent’s face. The behaviours of parents that were coded included smiling, tickling and touching.

**RESEARCH FINDINGS**
Compared to comparison siblings, siblings of children with ASD had longer mean durations of gazing away from their parents’ faces. This suggests that while siblings of children with ASD are more interested in non-social stimuli than comparison siblings, both groups are equally interested in and engaged by the parent’s face, a significant social stimulus. It may be the case that the siblings of children with ASD are delayed in their ability to shift attention and engage with social stimuli but once engaged in social stimuli like their parents’ faces, may do so for a typical amount of time. There may be a neurological basis for disengagement deficits given that delayed attentional orienting has been associated with severity of cerebellar hypoplasia in autistic children between two and six years old.

**IMPLICATIONS FOR PRACTICE**
Atypical patterns of disengagement may have adverse implications for emotional regulation, orienting, joint attention and other abilities directly associated with socio-emotional functioning.

Children with autism may be unable to disengage from a disconcerting interaction resulting in increased anxiety levels and emotional dysregulation. Therefore, this group of children may need a specific programme in order to teach skills related to socio-emotional functioning.

**Full Reference**
The Adjustment of Non-Disabled Siblings of Children with Autism

**RESEARCH AIMS**
The researchers set out to compare the psychosocial and emotional development of siblings of children with autism and siblings of non-disabled children. Additionally, differences between self and parent reports as well as a number of demographic characteristics were examined.

**RESEARCH METHOD**
Fifty one siblings of children with autism and 35 siblings of non-disabled children between the ages of 7 and 17, along with one parent of each sibling participated. The siblings completed the Children's Depression Inventory and Piers-Harris Children's Self Concept Scale and parents completed the Behaviour Assessment System for Children.

The researchers hypothesised that non-disabled siblings from the control and experimental group would score higher on the Children's Depression Inventory and Piers-Harris Children's Self Concept Scale if they were male, had more than one sibling, were younger than the child with autism and came from a family with high SES level.

**RESEARCH FINDINGS**
Siblings of children with autism appeared to have a more positive self-concept than did siblings of non-disabled children. Furthermore, they were more likely to have a more positive view of their behaviour, intelligence, scholastic performance and anxiety than were siblings of non-disabled children. These siblings also had a more positive view of their overall personal characteristics in comparison to siblings of non-disabled children.

These results may be due to the non-disabled child comparing themselves to their sibling in which case it would be intuitive to assume they compared themselves favourably. Contrastingly, these results may be due to increased maturity levels of siblings of children with autism which results in improved behaviour, better social skills and improved academic performance, thereby increasing their overall self-concept. However, it must be noted that siblings of non-disabled children still scored in the average range on these measures.

Interestingly, parents of children with autism viewed the siblings’ social and emotional adjustment somewhat more negatively than did parents who did not have any children with autism. This may be because parents spend so much time attending to the needs of their child with autism that they do not have an accurate view of the sibling’s social and emotional functioning. It is also possible that parents may project any frustrations that they may have because of their child with autism on to their non-disabled child. Nevertheless, when multiple demographic risk factors are present it becomes more difficult for the non-disabled sibling to cope with the child with autism emotionally and psychologically.

**IMPLICATIONS FOR PRACTICE**
(by the authors)
Education professionals should be aware that having a family member with any illness or disability may be challenging, however, the unique combinations of impairments associated with autism and related disorders may place
family members at an increased risk of psychological difficulties.

Education professionals should be aware that the presence of a child with autism appears to have an increasingly negative effect on the non-disabled sibling’s emotional and psychological well-being where there are multiple demographic risk factors.

Full Reference
Mealtime Problems in Children with Autism Spectrum Disorder and their Typically Developing Siblings: A Comparison Study

RESEARCH AIMS

The term “selective eating” is used to describe eating problems defined by eating a limited variety of foods and refusal to eat or taste new foods. These behaviours may interfere or limit a child’s integration in the social environment. Whether some of these problems are secondary to associated medical problems in Autism Spectrum Disorders (ASD) is still poorly defined. The aims of the research are:

- To determine whether children with ASD have more mealtime problems than their typically developing siblings.
- To describe the nature of these problems in children with ASD and their siblings.
- To explore whether age and sex are associated with eating problems.

RESEARCH METHOD

A cross sectional study of children with a diagnosis of autism, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) or Asperger’s Syndrome aged 3-12. The sibling without ASD nearest in age to each child was also included. An eating profile questionnaire was developed and completed by the parents for the child with ASD and his/her sibling. Eleven domains were covered: 1) dietary history, 2) child health, 3) family dietary history, 4) mealtime oral motor behaviours of the child, 5) food preferences, 6) autonomy with respect to eating, 7) behaviours outside mealtimes, 8) impact of mealtimes on daily life, 9) strategies used to resolve difficulties, 10) communication abilities of the child and 11) socio-economic family factors.

RESEARCH FINDINGS

1. Children with ASD had at least one associated medical condition compared to siblings, including attention deficit disorder, hyperactivity and intellectual impairment. They also took significantly more medication, including medications which may have suppressed food intake.

2. Older children tended to have fewer eating problems than younger children in both groups, children with ASD had more problems than siblings. Transition from thin purees to textured food during the first year of life was more difficult for children with ASD.

3. More children with ASD ate fewer foods, needed supervision and did not stay seated during meals. None of the siblings had oral motor difficulties, where children with ASD had more problems with gagging, drooling, chewing, swallowing, vomiting, and choking.

4. Eating problems had significant impact on family routine with mealtimes considered stressful. Numerous strategies were used by parents to resolve mealtime difficulties for both children with ASD and siblings, particularly the use of rewards.

IMPLICATIONS FOR PRACTICE (by the authors)

1. Results demonstrate that problems relating to mealtimes and eating are significantly more common in children with ASD than in typically developing siblings, even when adjusted for age and sex. However, none of the problems were exclusive to children with ASD.
aside from oral-motor difficulties. Sensory-motor problems in children with ASD may need more careful evaluation in respect to their impact on developmental motor skills.

2. The nature of the eating and mealtime problems seems multidimensional. The study points to the importance of screening for mealtime problems in children with ASD using a psychometrically sound screening tool. A better understanding of the mealtime issues may lead to the development of more effective interventions for this group of children.

**Full Reference**
Factors Influencing Adjustment in Siblings of Children with Autism Spectrum Disorders

RESEARCH AIMS
Previously researchers have proposed that siblings of children with autism may be at increased risk of adjustment problems, however, findings have been inconsistent. Given these contradictory findings, it is important to consider factors that may influence the relationship between having a sibling with ASD and adjustment problems.

One factor that may affect sibling development is the level of impairment of the child with ASD, as symptom severity and behaviour problems in the child with ASD have been found to be positively associated with adjustment difficulties in typically developing siblings both concurrently and over time.

Additionally, a number of mediating variables have been identified including the impact that the child with ASD has on the non-disabled sibling, the presence or absence of maternal depression and the presence of the Broader Autism Phenotype (BAP includes a group of personality traits and social, cognitive and language deficits often found in family members that are thought to represent a familiarity or genetic liability). The current study sought to examine whether child autism severity and sibling BAP predicted adjustment problems in siblings, and whether maternal depression mediated or moderated the effect of child autism severity on sibling adjustment.

RESEARCH METHOD
Participants included 70 mothers who had at least one biological child aged 2-18 with ASD and at least one typically developing child aged 6-18. Child autism severity was measured by the Autism Behaviour Checklist (ABC); impact on siblings was measured by the Family Impact Questionnaire (FIQ); maternal depressive symptoms were measured on the Centre for Epidemiological Studies-Depression Scale (CES-D), sibling broader autism phenotype was measured on the Social Responsiveness Scale (SRS); and sibling behaviour adjustment was measured by the Strengths and Difficulties Questionnaire (SDQ).

RESEARCH FINDINGS
Results indicate that siblings of children with ASD exhibited higher rates of adjustment problems than children in the normative sample and mothers of children with ASD report significantly higher rates of depressive symptoms than the normative sample, both these findings are consistent with the findings of existing studies.

IMPLICATIONS FOR PRACTICE
The authors suggest that there are two possible mechanisms by which siblings of children with autism may be at heightened risk for adjustment difficulties:

- Siblings of children with more severe autism symptoms were more likely to exhibit adjustment difficulties. This is consistent with other studies, however, they also found that this relationship was fully mediated by maternal depressive symptoms. Thus, this study does not support the premise that child autism severity affects sibling adjustment directly and highlights the theory that a depressed parent may model less effective coping styles that are then adopted by their
typically developing children, as well as being less adept at balancing the needs of developmentally differing children.

- Siblings of children with autism who exhibit a greater number of BAP characteristics may be more likely to have adjustment difficulties and this relationship appears to be moderated by autism severity in the child with autism. Consequently teachers may need to pay particular attention to these children as they may be less likely to seek social support when needed and more likely to react negatively to the stress of having a sibling with autism or other stressful life event; contrastingly, siblings with fewer autism traits may be able to relate to and empathise with a sibling at any functioning level.

In general, it is recommended that autism practitioners understand the need for a family level approach when supporting those with autism and their relatives in order to make appropriate referrals if necessary.

**Full Reference**
Play and Developmental Outcomes in Infant Siblings of Children with Autism

RESEARCH AIMS
To ascertain whether children with Autism Spectrum Disorders (ASD) displayed functional, symbolic and repeated play actions during free-play sessions, when they were 18 months old. Two questions were raised:

- Were the differences in symbolic, functional and repeated play between children later diagnosed with ASD and typically developing children present at 18 months of age?
- Was the play of siblings of children with ASD who do not meet criteria for ASD similar to that of children who are later diagnosed with ASD and different from typically developing controls?

RESEARCH METHOD
Three groups of children were identified for the research:

- Infant siblings later diagnosed with Autism Spectrum Disorder (ASD).
- Infant siblings with difficulties in cognition, language and social behaviour (others).
- The comparison group consisted of typically developing (TD) children who did not have a family history of ASD.

The authors note that no research has previously looked at all three domains of play:

- Sensorimotor manipulation.
- Functional.
- Symbolic/imaginary.

Typically, a child progresses through each of the domains when mastery of one leads directly to the next stage, a development from physical to representational play. Previous research has shown that children with ASD:

- Tend not to engage in symbolic play spontaneously and do not produce as many symbolic play actions as typically developing children.
- May engage in symbolic play that is stereotyped and repetitive.
- Show difficulties concerning functional play by performing fewer functional play actions and integrated sequences of functional acts.
- Spend less time engaging in functional play than children with Down Syndrome and typically developing children.

Each child was afforded a four-minute free-play assessment involving the presentation of a standard set of toys the child had not yet seen and was administered in the middle of the full assessment protocol after the Mullen Scales of Early Learning (MSEL) and before the Autism Diagnostic Observation Schedule (ADOS). During the administration of the assessment, the child was allowed to play with the toys with little intrusion from the test administrator or the child’s guardian.

RESEARCH FINDINGS

- The ASD group engaged in fewer new and improvised functional play acts than the TD group.
- The ASD group demonstrated fewer self-directed and other-directed play behaviours than the TD group.
- The ASD group displayed more non-functional repeated play than the TD group.
The findings in the others group echoes much of what has already been stated of the ASD group, including decreased self-directed play; this may indicate that some children experience a similar difficulty in understanding social partners and/or sharing attention, which in turn may affect social development.

The groups did not differ significantly in functional repeated play suggesting that all of the groups, regardless of their later developmental status, engage in some form of repetition. Symbolic play did not differ among the groups with few participants in any of the groups displaying symbolic play behaviours.

**IMPLICATIONS FOR PRACTICE**  
* (by the authors)

Parents and professionals working with the early years should be aware that the difficulties in functional play for children with ASD are observable by 18 months indicating that it is advisable to introduce strategies as early as possible through the medium of play.

Children with ASD portrayed fewer self or other directed play behaviours; it could be suggested that they do not see others as potential recipients of play and they may not be motivated to interact through directing play behaviours to others.

With respect to symbolic play, previous studies have shown that children at 18 months have not yet reached the play maturity needed to engage in this type of play, thus reminding professionals that where absence is perceived, developmental norms must be addressed rather than seeing this as an indicator of any difficulty.

As the ASD group in the current research appeared to engage in non-functional repeated play at the expense of performing new play ideas, this suggests that repetitive and stereotyped behaviours are observable in the second year of life. This indicates that children with ASD may not be benefiting from exploratory play, which in turn may affect their cognitive and language development. The authors remind us that as all children engage in repetitive play, it is the content or what is being repeated rather than the presence of repetition of actions that is predictive of atypical development.

One limitation of this study is that the four-minute play assessment was too short, meaning that measures of observed play may have underestimated participants’ true abilities.

To verify the accuracy of these results, future investigators might observe play for a longer period and thus obtain a more representative sampling of participants’ play.

**Full Reference**

Review of Literature Related to the Social, Emotional and Behavioural Adjustment of Siblings of Individuals with Autistic Spectrum Disorder

RESEARCH AIMS
This article provides a comprehensive review of the literature relating to the social, emotional and behavioural adjustments of siblings of individuals with autistic spectrum disorder (ASD). Family systems theory contends that it is necessary for professionals to understand the impact of ASD on all the subsystems of the family, including the siblings, to support and provide effective services to the entire family. Six themes relating to the challenges of studying siblings of individuals with disabilities are described in relation to the reviewed studies:

a) methodological challenges
b) measurement
c) developmental and life-course perspectives
d) mediators and moderators
e) cultural and sub-cultural issues and
f) balanced views of both positive and negative aspects.

RESEARCH METHOD
Articles related to siblings of individuals with ASD were identified by conducting electronic and ancestral searches and included research focused on the social, emotional and/or behavioural adjustment of typically developing siblings of individuals with ASD. 12 studies were selected for inclusion in the review.

RESEARCH FINDINGS
The 12 studies represented a wide range of research questions, research methodologies, assessment instruments and tools and age range of participating siblings. Since ASD represents a diverse array of disorders in terms of severity of symptoms and level of social and intellectual functioning it is difficult to generalise the information from the reviewed studies to all siblings of individuals with ASD. The review revealed mixed results on outcomes for adjustment of typically developing siblings of individuals with ASD. While some variables such as age, gender, socio-economic status, family size, coping style and available support are important and could relate to sibling adjustment, the findings of potential predictor variables were also found to be mixed. Overall studies showed that some siblings are positively affected by having a sibling with ASD, demonstrating high levels of self-concept and social competence; other studies found that siblings experience negative effects such as antisocial behaviour, increased internalising and externalising problem behaviour, loneliness and delays in the acquisition of socialization skills.

IMPLICATIONS FOR PRACTICE
(by the authors)
Currently there are more questions than definitive answers as to the best way to support siblings of children with ASD. The overall mixed findings emphasise the need to continue research in this area. Future studies should be large-scale, use multiple outcome measures and informants, investigate life-course perspectives, examine the influence of genetic versus environmental factors and investigate the influence of culture and other predictor factors. Research should be focused on
hearing the voices of siblings of children with ASD by asking directly for their perspective, by attempting to understand their adjustment and by having them identify areas of needed support. Developing a support system based on this information may affect, and hopefully enhance, quality of life for all family members of children with ASD.

Full Reference
Siblings of Individuals with an Autistic Spectrum Disorder: Sibling Relationships and Well-being in Adolescence and Adulthood

RESEARCH AIMS
Sibling interaction is a unique relationship which lasts a lifetime. It must be realised however that such relationships are transient. Age, level of independence and striving to mature are factors, which can impact this relationship irrespective of the ability of each member.

Previous research, with less rigidity to variables, and attempting to encompass a wide age range of siblings, thus ignoring typical sibling relationship development and trajectory, found the typically developing siblings experienced:
- Admiration for their brother/sister.
- Moving to regarding him/her as a burden thus decreasing the number of interactions leading to a less intimate familial relationship.
- Feeling isolated and lonely with limited interactive familial activities.

However, it must be noted that the knowledge base of these groups and their development and changes in relationships is limited.

This research therefore aims to investigate if there is a contrasting relationships and sense of well-being between adolescents (12 – 18 years) and adults (19 years +), when one sibling has a diagnosis of Autism Spectrum Disorder (ASD).

RESEARCH METHOD
This ongoing 18-month study, focusing on the two specific maturation life stages, adolescence and adulthood, included reports from at the outset 406 individuals, to 198, due to availability, all with a sibling with ASD; adolescents provided qualitative feedback from interviews while the adults completed questionnaires with the focus being:
- Engagement in shared sibling relationships.
- Positive affect in the sibling relationship: their feelings towards their sibling with ASD and their perception of their sibling with ASD’s feelings towards them.
- Siblings’ psychological well-being.
- Diversity and maturation of coping strategies assisting with stressful events, both problem and emotion based.
- Availability and acceptance of social support; with adolescents this was derived from parents and friends, while with adults this came from romantic partners through social events such as:
  1. Going out for a meal.
  2. Going shopping.
  3. Going to recreational activity.
  4. Visiting a friend/relative.
  5. Accompanying sibling on medical appointments.
  6. Going on holiday.

Each family had to meet an agreed criteria: a) the family member with an ASD was age 10 or older, b) he or she had received a diagnosis on the autism spectrum from a medical, a psychological, or an educational professional, as reported by the parents, and c) administration of the Autism Diagnostic Interview–Revised.
The authors claimed that difficulties surrounding social interaction, communication and behaviour experienced by those with ASD appeared to lessen with age and although they may continue to cause difficulty for the sibling, this lessening of severity may improve relationships as both siblings age, develop and accrue a wider range of mature coping strategies.

**RESEARCH FINDINGS**

- As predicted in their hypothesis, the authors found that adolescents engaged more frequently in shared activities than their adult counterparts.
- Also as expected by the authors, adolescents reported using more emotionally focused supportive techniques whilst the adults tended towards problem focused coping.
- However, it was also found that the age difference between the siblings was important in terms of emotional well-being of the sibling who did not have ASD. The closest in age, irrespective of whether he or she was an adolescent or an adult, displayed greater characteristics associated with depression.
- The gender issue was also raised with female-to-female relationships being the most positive, sharing the greatest number of interactions, while male-to-female the least, yet not negatively influencing positive affect.
- Behaviour issues were regarded as impediments to a successful relationship as was age of sibling, with adults reporting a direct correlation between the frequencies, diversity and challenging nature of the behaviour and the quality and regularity of the interactions. However, adults were able to engage their problem-focused coping strategies when significant behavioural issues arose, a series of strategies, which adolescents had still to accrue.
- Both adolescents and adults reported the need for and dependency on social support from whomever was available, claiming that this support influenced positive affect and desire to, and ease of interacting with their sibling.

**IMPLICATIONS FOR PRACTICE**

(by the authors)

1. There is a difference in sibling relationships when one sibling has ASD to other familial relationships. Both adults and adolescents reported the same degree of positive affect leading the authors to suggest that there might be stability over time in the closeness of the siblings, therefore not displaying the typical sibling relationship progression of decrease in closeness during adolescence to a resurfacing and increase during middle to later adulthood. This information may be reassuring to parents that the relationship does not decline over time.

2. Care must be taken when siblings are close in age. Although it was expected that adolescents display greater depressive characteristics, this was not borne out. However, the fact that adolescents from larger families experienced greater positive affect in their sibling relationship is noteworthy. The meting out of the care role appears to better support everyone in the family.

3. Adolescents did, as predicted, utilise problem solving based strategies while adults focused attention on the use of emotion based
interventions. This may be merely a result of experience and age and can be seen in typical development.

4. Women with ASD may encounter isolation if their only sibling is male, therefore plans for support must be introduced early and reviewed often to assist. Parental support and guidance may be crucial to supporting both the brother and the sister, in adolescence and through to adulthood.

5. Behaviour management and modification techniques may need to be an integral aspect of family development, as inappropriate and challenging behaviour may influence the frequency of whole family excursions, thus limiting the number of opportunities for and desire to partake in sibling engagement.

Full Reference
The Impact of Children with High Functioning Autism on Parental Stress, Sibling Adjustment and Family Functioning

RESEARCH AIMS
This investigation assessed the impact of children with high functioning autism (HFA) on parental stress, sibling adjustment and family functioning. Children with autistic spectrum disorders (ASD) face developmental challenges that can significantly affect parental and family functioning. Social and communication deficits and the problem behaviours associated with ASD can create significant stress for all family members. Parents of children with ASD report elevated levels of stress, depression and emotional exhaustion. Parenting stress resulted in lack of time for family activities, lack of spontaneity or flexibility, stress in marital relationships and restrictions in career progression. Stress appears to be most exacerbated when children exhibit problematic or aberrant behaviour and families may become socially reclusive rather than risk embarrassment from their child’s problem behaviour. Studies of the effect of children with ASD on siblings show mixed results, some siblings demonstrated increased positive self-concept while others showed increased levels of loneliness, depression and behavioural problems.

The differing clinical presentation of HFA may be qualitatively and quantitatively different from “classic” autism. Given the increasing number of children meeting diagnostic criteria for HFA it is imperative to identify the stressors within these families. Interventions directed only at the child may be ineffective without adequate attention to family factors that may attenuate treatment outcome.

RESEARCH METHOD
Subjects were recruited from families seeking treatment for their child for autism and developmental delay at a behavioural health outpatient clinic and from the families of patients and employees at a medical centre. Children had to meet diagnostic criteria for autism, have developmental delay before the age of 36 months and have intelligence within the normal range. Typically developing children for the control group were screened for autism and to determine that they were free from psychopathology. Parents completed self-report assessment questionnaires to measure parental stress, family functioning, psychological problems and psychopathology, general physical and mental health and child behaviour problems.

RESEARCH FINDINGS
Results indicate that higher intellectual functioning does not appear to compensate for or ameliorate the behavioural problems associated with ASD. Parents identified child behavioural factors such as hyperactivity, demandingness and disturbed mood as contributing to stress in the family. Findings also showed a significantly elevated level of internalising problem behaviours among children with HFA and their siblings. Internalising behaviours are more related to mood and anxiety disorders. Children with HFA may be more aware of social difficulties and difference and may be more anxious about their abilities to fit in with peers. Families with a child with HFA report less independence
among family members in terms of assertiveness, self-reliance and decision making, and may participate in fewer social and recreational activities than families with children who have no disorder.

**IMPLICATIONS FOR PRACTICE**  
(by the authors)

Parental stress in families with a child with HFA may be mediated through child characteristics. Child behaviour problems are associated with internalising problem behaviours both in the child with ASD and in siblings. Interventions need to address the internalising and externalising child behaviour problems that contribute to parental stress and family functioning.

**Full Reference**
Adolescent Siblings of Individuals with an Autism Spectrum Disorder: Testing a Diathesis Stress Model of Sibling Well-Being

RESEARCH AIMS
The authors aimed to determine if diathesis (genetic vulnerability) and stress played a part in the development of mental health difficulties in the siblings of children and young people with ASD.

Background
Analysis of the interaction between possible genetic vulnerability and environmental stress has been employed in previous research to explore the experiences of children and young people across a range of circumstances. An analysis of these important influences on a child or young person should provide the researcher with an indication of how genetic and environmental influences can impact on an individual’s vulnerability or resilience to the development of difficulties. Analysis of diathesis stress has not been previously conducted with the siblings of children and young people with ASD prior to the current research.

RESEARCH METHOD
57 siblings of children with ASD completed two self report measures on depressive symptoms and anxiety symptoms. Parents also completed two measures on features of ASD in the siblings and also participated in an interview addressing family history of ASD. Researchers conducted analysis on the responses in order to determine if there was a relationship between the siblings’ responses on measures of depression and anxiety and the parents’ reports of features of ASD in the siblings.

RESEARCH FINDINGS
There were clear gender differences in self report measures of anxiety and depression with brothers reporting less depression and anxiety than sisters. The findings did provide some support for the diathesis stress model of anxiety and depression. The siblings identified as having higher traits of ASD according to the parental reports did also report higher levels of anxiety and depression but only in the presence of stressful life events. The parents who identified themselves as having traits of ASD also recorded higher levels of anxiety and depression. Higher levels of depression were found in those siblings that had a significant family history of ASD; the researchers note that this is not the case for anxiety symptoms.

IMPLICATIONS FOR PRACTICE
(by the reviewer)

The mental health needs of siblings of children and young people with ASD are a complex area; siblings may be affected not only by the stress of life of having a brother or sister with ASD but also by possible genetic vulnerabilities. This diathesis stress relationship has not been firmly established in the current research but some tentative evidence has emerged indicating that this is an area requiring further exploration. Parents and practitioners should be mindful that the issues affecting siblings can be multiple and complex.

The differing experience of sisters in the current research is also notable. Parents and practitioners should be mindful of the potential additional support needs of sisters and consider this when developing supports for siblings.

Full Reference
CONCLUSION

It has been suggested that sibling relationships last the longest of all human relationships. Typical sibling relationships provide experiences that encourage the development of emotional understanding, self-regulation and a sense of belonging.

Sibling relationships can have a significant influence on the child’s understanding of others’ emotions and thoughts. Research has found the interplay between siblings can affect a child’s personality, social and intellectual development.

The articles included in the current Bulletin provide a range of practice related points that should be considered in relation to siblings of children with autism.

The salient points in relation to practice are:

- The social abilities of some children with autism will improve and develop over time; siblings are the most important playmates that the child with ASD will have;
- Play opportunities with siblings should be stage managed and orchestrated if they do not occur spontaneously;
- The development of coping skills, including the provision of age appropriate information about autism are important to promote positive sibling relationships;
- The age and gender of the sibling is important as are other demographic factors that impact on the family and these should be taken into consideration;
- Having a sibling with autism can be a positive and enriching experience for brothers and sisters.

The Centre extends a special thank you to Juliet Turner, a Speech & Language Therapist, who voluntarily gave her time and expertise to contribute to this and other Research Bulletins. Anyone wishing to provide input into Middletown’s Research Bulletin series should email research@middletownautism.com.
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.

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