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Participation in Play and Leisure Occupations in Children who have a Sibling with Autism

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Abstract

OBJECTIVE. We investigated whether having an older sibling living at home with Autism would change both a child’s opportunities for participation in play and leisure occupations and the others with whom the child engages in these occupations.

METHOD. There were two groups of 6-10 year-old children in our study. Children in our special needs (experimental) group (n= 4) had an older sibling with an Autism Spectrum Diagnosis (ASD) and children in our control group (n=6) had an older ‘typical’ sibling. Both groups of children completed the Children’s Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC) (King et al., 2004). Parents of participants completed the Parenting Stress Index (Abidin, 1995) twice, once with reference to the participant and once in reference to the older sibling.

RESULTS. In contrast to our hypothesis, none of the scores of the CAPE or the PAC reflected any differences in participation in play and leisure in the experimental population compared to the control population. In both the experimental and the control groups, stress ratings were higher when parents answered with regard to their older child. Similarly, parents in both groups indicated higher stress levels related to child adaptability in the older sibling than the participant, but this difference was even greater in the experimental group.

CONCLUSIONS. Our findings suggest that there are significant and distinct stressors associated with having a child with ASD; however, the families in our studies have absorbed these stressors such that they did not have the expected impact on the participation in play and leisure for the younger siblings. The present group of parents and siblings seemed to have adjusted well to the factors involved in raising or living with a child with ASD.
Autism

Autism is just one of many disorders known as autism spectrum disorders (ASDs). ASDs are developmental disabilities that cause extensive impairments in social interaction and communication. Children with ASDs present with unusual behaviors. They may also have unusual interests and ways of learning which can be extremely challenging though can often lead to them being gifted. It is furthermore common for children with ASDs to react to various sensations in an atypical manner. There are several criteria that must present for a formal diagnosis of autism. Some examples of diagnostic criteria according to the DSM-IV are as follows: impaired social interaction; impaired communication; activities, behaviors and interests that are repetitive, restricted, and stereotyped (Morrison, 2006). An ASD begins before the age of 3, though it is not always detected that early, and lasts throughout the lifespan (Center for Disease Control, 2007).

According to the Center for Disease Control, the only bias of Autism Spectrum Disorders is based on the gender of the child. An ASD is four times more likely to present in males than females, but is no more likely to present in differing ethnic, racial, or socioeconomic groups. ASDs were found in 1 out of every 110 children in the United States (Center for Disease Control, 2009). As such, the frequency of autism now surpasses that of all types of cancer combined according to FightingAutism.Org (2004).

Siblings

This study focused on the younger siblings of children with autism. Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev (2004) suggest that siblings of children with autism may be affected by more than genetic factors alone. They suggest that being raised in a home with a sibling with a severe disability may impact the social and emotional adjustment of the typically
developing child. This idea has been explored through research. Prosocial behavior is defined as, “positive actions that benefit others, prompted by empathy, moral values, and a sense of personal responsibility rather than a desire for personal gain” (Association for Supervision and Curriculum Development, 2006). In a 2003 study by Hastings, mothers completed the Strengths and Difficulties Questionnaire to measure sibling adjustment. The twenty-two siblings of children with autism were rated by their mothers as having an increase of behavior problems and a decrease in prosocial behaviors, when compared to a normative sample. These results were found to be especially prevalent in children that were younger than their sibling with autism. Findings also indicated more peer relationship problems and more overall adjustment problems (Hastings, 2003). Similarly, Verte, Roeyers and Buysse (2003) compared 29 siblings of children with high functioning autism and a control group in psychological adjustment along the domains of behavioral problems, social competence, and self-concept. Though there was a broader age range, they found that siblings, especially between 6 and 11 years of age, had more behavioral problems than siblings in the control group, by parent report on the Child Behavior Checklist (Verte et al., 2003).

Taken together, these studies suggest that children with a sibling with an ASD may have inherent increased risk for social and behavior problems. It is not known whether this increased risk results from genetic predisposition related to the ASD itself or from the lived experience of having a sibling with autism in the family. Dillon (1995) suggests that a child with autism will unquestionably receive a disproportionate amount of the parents’ time. Moreover, a child with autism presents endless challenges to family members, which may include aggressive and self-injurious behaviors, impulsivity, hyperactivity, and communication deficits. As a result, there may be a decrease in family outings because of the atypical behaviors displayed by the children
with autism (Gray & Holden, 1992). In a qualitative study on the past and present experiences of 14 siblings of children with autism and mental retardation, Bendrix and Sivberg (2007) found that families have less recreational time because of lack of respite care. One child stated “I don’t bring friends home when my brother is there because then Mum doesn’t have any time to help us (p. 416)”. Accordingly, siblings have also reported feelings of bitterness and resentment because of the extra attention given to the child with the disability (Powel, 1985).

Research supports both adjustment and maladjustment of siblings of children with autism. Not surprisingly, some children are very optimistic and reported satisfaction in learning to live and cope with the demands of a sibling with a disability. The typically developing children enjoy it when their sibling accomplishes something that may have been easy for them, but a challenge for their sibling (Bendrix and Sivberg, 2007). It has been reported that siblings of children with autism view their relationship more positively when there was a large age difference between siblings; when they perceived minimal parental favoritism; and when they were older than the sibling with autism (McHale et al., 1984). It is also noted that parents are unable to control some of these factors. They can, however, encourage family cohesion, open communication, positive attitudes, and use of appropriate resources for family support (McHale, et al., 1984). Family cohesion was defined in 1984 as “emotional bonding that family members have toward one another” (Olson, Russell, and Sprengkle, p. 60).

**Play**

One way parents can encourage family cohesion, open communication and positive attitudes is through play. Play has long been recognized as important, particularly in the field of occupational therapy. Parham and Fazio’s text on the topic, (2008) provides a history. In the very origins of the profession, 1922, Adolf Meyer referred to play in the same context as work,
rest, and sleep. In 1949 Norma Alessandrini said, “Play is a child’s way of learning and an outlet for his innate need of activity. It is his business or his career. In it he engages himself with the same attitude and energy that we engage ourselves in our regular work. For each child it is a serious undertaking not to be confused with diversion or idle use of time. Play is not folly. It is purposeful activity” (p. 3). For almost 100 years play has been recognized as important by prominent researchers and theoreticians in occupational therapy.

Within education, however, play come to be viewed as “educationally irrelevant and developmentally trivial” (p. 303), and it is treated as an expense--something that can be cut to help repair budgets or to leave more teaching time. (Swinth and Tanta, 2008) Yet, it is reported that children learn best through active play (Jensen, 1998). Children need to play, Parham and Fazio (2008) list the benefits of play to include sensorimotor skill development and social interaction.

**Present study**

Results from normative samples for Henry’s 2000 *Kid Play Profile*, a self-report assessment of participation in play and leisure, show that first through third grade children without disabilities did such things as: watch television, use computers, ride bikes, draw/paint, go swimming, go to the beach, and listen to music. When asking what children *liked* she found that watching television was the most liked of all of the activities, and the subsequent order in which children reported liking play occupations followed down the list presented above.

We hypothesized that having an older sibling with Autism would change both a child’s opportunities for participation in play and leisure occupations and the others with whom the child engages in these occupations. This was explored through use of a standardized, self-report of interest and engagement in play and leisure occupations, the Children’s Assessment of
Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC), an appropriate instrument for use with children from ages 6 to 21.

**Methods**

**Participants.**

We had two groups of 6-10 year-old children in our study. Children in our special needs (experimental) group (n= 4) had an older sibling with an Autism Spectrum Diagnosis (ASD) and children in our control group (n= 6) had an older ‘typical’ sibling. Inclusion criteria included having no neurological deficits between ages 6-10 with an older sibling, with ASD or typically developing, and the older sibling was required to live in the home. Other demographics collected included family size and family structure. Accordingly, some demographic information was collected via telephone when contacting the families to schedule their participation. We recruited the children from local schools, occupational therapy clinics, youth programs, and advocacy programs for children with ASD. The parents of all of our participants signed an informed consent form before any interaction took place with the children, children gave verbal assent to participate, and the families received a token of appreciation for participating in our study. Procedures were approved by the Biomedical Institutional Review Board of the University of Toledo.

**Setting.**

The child assessments were administered individually at each participant’s home at a time that was most convenient for the family. We attempted to keep the testing room quiet by using a sitting room or another room in the house that was quiet but if there was a door, it was open to ensure the child’s comfort.
Assessments.

CAPE and PAC.

We explored our hypothesis through use of the Children’s Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC) (King et al., 2004). Both the CAPE and the PAC are appropriate to use with typical developing children and young adults ages 6-21. The CAPE is an assessment that uses 55 activity picture cards to assess the diversity, intensity, and enjoyment that children report with regards to play and leisure occupations. These 55 items were constructed after a longitudinal study was done with 427 children with disabilities ages 6-15 on a 49 item scale, the 6 new items that were added were activities that were commonly suggested from the participants. For each item, children are asked whether they have done the activity in the past four months. If so, they go on to respond using Likert-type scales as to how often they participate (ranging from 1, once in the past four months to 7, daily), with whom (1, alone; 2, with family; 3, with other relatives; 4, with friends; and 5, with others), where (1, at home; 2, at a relative’s home; 3, in the neighborhood; 4, at school; 5, in the community; and 6, beyond the community), and how much they enjoy it (ranging from 1, not at all to 5, love it). The results are reported as diversity (how many of the 55 activities the participant reported to have done in the 4 months prior to participating in the study) and the average scores for how often (referred to as intensity), with whom, where, and how much they enjoy it (referred to as enjoyment). Also reported is the diversity of activities done in each of 5 categories, recreational, active physical, social, skill-based, and self-improvement, which were determined by the authors of the assessment through principal component analyses (King et al., 2004).
The PAC corresponds to the CAPE uses the same 55 activity cards, but instead of being a direct measure for participation in activities it measures preference for activities (King et al., 2006). The PAC measures this by showing the participants each of the activity cards and asking them how much they would like to do such an activity, using a 3 point (ranging from 1, would not like to 3, would really like) Likert-type scale (King et al., 2004). PAC scores are reported as the average score for the items in each category of activity and the overall average score.

We collected data and reported findings for both the CAPE and the PAC. The results of the CAPE allowed us to test our primary hypothesis. The information from the PAC determines participants’ preferences which allowed us to determine if siblings of autism have different interests than siblings of typically developing children perhaps accounting for any differences in participation.

The psychometrics of these assessments are adequate, the internal consistency for the CAPE/PAC across the levels ranges from .30-.84, where the .30 is an outlier relating to the skill-based activity type of the CAPE. The test-retest reliability across levels ranges from .12-.86, where the .12 is an outlier relating to enjoyment of a physical activity (King et al., 2004). There have been extensive validity studies done on the CAPE/PAC resulting in adequate evidence of validity (King et al., 2006).

**QNST-II.**

Children with siblings who have an ASD may themselves represent an at-risk population. According to Toth, Dawson, Meltzoff, Greenson, and Fein (2007) “siblings [of children with ASD], as a group, were below average in expressive language and composite IQ” (p. 145). Given this information, we screened all of our participants for neurological impairments, using the Quick Neurological Screening Test II (QNST-II). The QNST-II consists of 15 subtest tasks
and takes about 20-30 minutes to administer. The following are some of the skills that can be observed by doing the QNST-II: balance, visual-motor integration, fine and gross motor control, and sound discrimination. In scoring the QNST-II the participant can fall into one of three categories, they are (1) Severe discrepancy (scores >50), (2) Moderate discrepancy (scores 26-50), and (3) Normal range (scores \( \leq 25 \)). The QNST-II psychometrics are acceptable across all properties, as documented in the test manual (Mutti et al., 1998). It was our original intent to exclude participants whose scores fell outside of the normal range from participating; however, this occurred in only one instance, in the experimental group, and it was apparent to the researcher that the child would be disappointed at not being able to continue participating. The child’s parents were informed of the QNST II results and encouraged to follow up with their physician. They reported that the child had no history of neurological impairment nor required any special services at school. The child was able to complete the CAPE/PAC without difficulty. The data from this child are included in the report of results.

**PSI.**

Raising a child is a stressful job in itself, but current research suggests that the level of stress for a parent of a child with Autism is greater than for parents raising typically developing children. In a recent article, Bendrix, Norstrom, and Sivberg (2006) state “The parents were suffering from severe symptoms of stress, such as exhaustion, feelings of being depressed, the experience of losing control, and cognitive deterioration, not only in the family but also at work” (p. 6). This finding suggests that parental stress may be a crucial factor affecting a child’s play and leisure participation. To explore this possibility, we utilized the Parent Stress Index (PSI) (Abidin, 1995).
The PSI is a measure of the degree of stress in given parent-child interactions. Parents are given a booklet of 120 test items, 19 of which are optional Life Stress items that we included in our study. Items cover a variety of areas such as the marital relationship, parental depression, parental attachment to the child, various aspects of the child’s temperament, and the degree to which the child is reinforcing to the parent. The parents rate the 101 items on a 5-point scale, and scores are summed to form 13 subscale scores in two broad domains: stress that results from characteristics of the parent and stress that results from characteristics of the child. The last 19 Life Stress items are yes or no questions relating to recent stress in the family (e.g., During the last 12 months has divorce occurred in your immediate family?). These results were calculated into the final score. The psychometrics of the PSI have been established by several studies with in varying populations. They are very satisfactory and are documented in the PSI manual (Abidin, 1995).

We asked each family to complete the PSI separately with regards to each of their two children who are relevant to our study (e.g. both the participant child and the older sibling who had ASD in the experimental group and was typical in the control group). The order in which the responses related to each of the two children were randomized and counterbalanced across participants. To accomplish this, the first PSI was mailed to each family’s house one to two weeks before we visited with instructions to the parent to answer the items as they relate to 1 of their 2 children. When we later visited the family’s home, we collected the completed PSI and then requested they complete a second questionnaire answering items as they relate to the other child. Alternatively, when families requested to schedule participation with less than one week’s notice, we administered the first PSI, with instructions to answer the questions as they relate to 1 of the 2 children, at the beginning of the visit and mailed the second PSI, with instructions to
answer the questions as they relate to the other child, to the home with a stamped return envelop one to two weeks after the home visit.

Finally, we assessed the families’ socioeconomic status using the Hollingshead Four Factor Social Index of Social Status (Hollingshead, 1975). We did this because finances may have been a factor involved in children’s play and leisure occupations and it was important data to include in our study. This involved asking parents questions that relate to marital status, education, and occupation using an in-house questionnaire that was mailed to the family’s house two weeks before we visited (see Appendix A). It should be noted that gender was be determined by direct observation as directed in the manual. Responses were scored, weighted, and summed according to the Hollingshead formula, with the total scores for this test ranging from a low of 8 to a high of 60.

**Design/Analysis.**

This study employed a cross sectional design. After collecting the results of the CAPE/PAC, the scores were demonstrated normal distribution (skew and kurtosis); therefore, parametric tests were used. Comparisons were made using unpaired t-tests and 2X2 mixed model ANOVA. Significance was considered at the $p \leq .05$ level. To determine if other factors beyond having a sibling with ASD accounted for any observed differences, we tested for differences between our groups in the Parenting Stress Index and the Hollingshead Four Factor Social Index of Social Status, after testing each for normalcy. We used correlation of CAPE scores and PSI scores to identify whether the scores account for any of the variance observed in play and leisure participation. Data are presented as mean ± standard error, unless otherwise indicated.
Results

Participants in the experimental category had older siblings with Autism Spectrum Disorder (ASD). Participants in the control category had older siblings who are typically developing. There were 4 experimental participants (1 boy, 3 girls) and 6 control participants (3 girls, 3 boys). The two groups were similar in age. The average age (± standard deviation) was 8±1.4 and 8.5±1.2 for experimental participants and control participants respectively (p>0.05). Results from the QNST-II indicated one participant in the experimental group scored higher than typical results but had no history of neurological diagnoses or reported disability. Scores for the experimental group were 16±2.8 and 22.5±3.2 in the control group, not statistically different (p>0.05). The average age (± standard deviation) was 12.5±1.7 years old for older siblings with ASD and 12.4±1.5 years old for older typical siblings, not significantly different (p>0.05) The Hollingshead Index for the experimental group was 41.5±9.3 and 51.0±2.7 for the control group. There was no difference between the groups (p>0.05).

Both groups of participants completed the CAPE to self-report their participation in and enjoyment of play and leisure occupations. In contrast to our hypothesis, none of the scores of the CAPE reflected any differences in participation in play and leisure in the experimental population compared to the control population. The diversity of participation did not differ between the two groups. The experimental group reported participating in 34.8±3.6 of the 55 activities, and the control group reported participating in 33.2±1.7 of the 55 activities (p>0.05). Similarly, there were no differences in the other measures of the CAPE, including intensity (2.8±0.1, 2.9±0.2, for experimental and control, respectively, p>0.05), with whom (2.4±0.1, 2.6±0.2, for experimental and control, respectively, p>0.05), where (2.6±0.1, 2.8±0.2, for experimental and control, respectively, p>0.05), and enjoyment (3.6±0.2, 3.8±0.2, for
experimental and control, respectively, p>0.05). The proportion of occupations done in each category of activity was similar across the two groups, also (recreational, 0.88±0.05, 0.88±0.06; physical 0.36±0.05, 0.4±0.1; 0.78±0.06, 0.84±0.11; skill-based 0.28±0.05, 0.36±0.1; and self improvement, 0.75±0.06, 0.7±0.07, for experimental and control, respectively, p>0.05). The measures of with whom and where are reported as average ratings across occupations on their respective Likert scales (of 1-5 and 1-6, respectively). Conceptually, both of these scales move from isolated participation at home to participation with broad groups within or beyond a child’s own community. Our aim was to specifically test whether the participation patterns of children with a sibling who has ASD are similar, in terms of participation with their own families and their own communities, to children whose siblings are typically developing. Therefore, we also examined the frequency distribution of Likert scores in the “with whom” and “where” response categories. There were no differences in the distributions indicating that in our sample, the children whose siblings have ASD participate to an equal extent with their own families and in their own communities. Figure 1 graphically depicts the results of the CAPE.

Allowing us to explore any differences in interests, participants also reported their preferences for participating in play and leisure occupations using the PAC. The average Likert rating on the 1-3 scale for the 55 activities was 2.0±0.1 for experimental subjects and 2.2±0.1 for control subjects, with no statistical difference (p>0.05). The Likert scales in each category of activity demonstrate similar patterns across groups as well. This suggests that both groups of participants have similar interests in play and leisure occupations. The results of the PAC are presented in Figure 2.

We had anticipated that the stress parents face in raising a child with an ASD may have an impact on the participation in play and leisure of younger siblings. We did not find any
differences in participation; nonetheless, the results of the PSI shed light on the lived experience of the families with a child with ASD. Parents of participants completed the Parenting Stress Index (Abidin, 1995) twice, once with reference to the participant and once in reference to the older sibling. These were completed in random order. To test if there were differences between the stress ratings according to group (experimental, control) or child in the family (participating younger sibling or older sibling) we utilized a 2X2 mixed-model ANOVA to compare the total PSI scores (child and parent domains combined). In both the experimental and the control groups, stress ratings were higher when parents answered with regard to their older child, as demonstrated by a within subject effect (F(1,7)=7.423, p<0.05, partial $\eta^2 = 0.515$ (medium effect)). Similarly, parents in both groups indicated higher stress levels related to child adaptability in the older sibling than the participant, but this difference was even greater in the experimental group as demonstrated in both a significant main effect (child, p<0.01, F(1,7)=18.415, partial $\eta^2 = 0.725$ (medium effect)) and a significant interaction effect (group X child, F(1,7)=13.935, p<0.01, partial $\eta^2 = 0.666$ (medium effect)). Finally, parents in both groups indicated higher stress levels related to the mood of their older child, as compared to the participant as evidenced by the main effect finding (child, F(1,7)=6.48, p<0.05, partial $\eta^2 = 0.481$ (small effect)). However, parents in the experimental group indicated higher stress levels related to mood in both the older child and the participant compared to parents in the control group as seen in the main effect finding (group, F(1,7)=14.475, p<0.01, partial $\eta^2 = 0.674$ (medium effect)). Figure 3 displays the findings of the PSI graphically.

As there were higher stress scores in parents of children with ASD, we investigated if they may be have a subtle effect on participation in play and leisure in the younger sibling. We
preformed linear correlation analysis of CAPE scores and PSI scores. There were no significant findings.

Discussion

We explored whether children with an older sibling with ASD living at home had differences in participation in play and leisure, as compared to a control population. With our assessment instrument (CAPE), no differences were detected in the diversity, frequency, participation parameters (with whom and where), or enjoyment. Similarly, the children in the experimental group reported similar preferences for play and leisure, as measured by the PAC. Though we do not demonstrate significant differences in the play and leisure participation in children with older siblings with ASD, we did have interesting findings with regards to parenting stress. Parents in both groups reported higher stress levels in regards to the older siblings, whose average age was 12.4, than in regards to the younger sibling. This suggests that raising early adolescents is in and of itself stressful. It is possible that parents may have answered differently knowing that the younger sibling was the subject of the study at hand, however, future studies could explore whether parenting an early adolescent is as stressful when there are not younger siblings present in the home. This would provide insight into the challenges of balance the needs of children who are at different stages of development.

In terms of stress perceived with regard to the older sibling, there were differences between the experimental and control families. Stress resulting from the adaptability of the older sibling, compared to the younger sibling, was greater in both groups; however, the difference was larger for families in the experimental group. This indicates that in the older siblings with ASD, adaptability was a notable stressor. Decreased adaptability is consistent with the symptoms of ASD, and here we see that challenges this presents result in increased perception of stress for
Participation in Play

parents. An example of a question referring to adaptability on the PSI is, “Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house” (Abidin, 1995). Another example is, “My child easily notices and overreacts to loud sounds and bright lights” (Abidin, 1995). Furthermore, the mood of both children in the experimental (ASD) group was a significant stressor for parents, as compared responses given by the parents in the control group. An example relating to mood in the PSI booklet is, “When playing, my child doesn’t often giggle or laugh” (Abidin, 1995). Another example is, “I feel that my child is very moody and easily upset” (Abidin, 1995). This suggests that there is a negative impact on children who have an older sibling with ASD, as reported by their parents. Our results are similar to the recent findings of Rao and Beidel (2009) who also used the Parenting Stress Index (Abidin, 1995) and found parents of children ages 8 to 14 years old with high functioning autism had higher stress levels than normal controls.

Taken together, our findings suggest that there are significant and distinct stressors associated with having a child with ASD; however, the families in our studies have absorbed these stressors such that they did not have the expected impact on the participation in play and leisure for our participants. The socioeconomic status of our groups were similar to one another and in the moderate range of Hollingshead’s 60-point scale (41.5 and 50 for the experimental and control groups, respectively). Perhaps the families with children with ASD utilize their financial resources to provide play and leisure opportunities for their children. Additionally, in the region of this study, there are several organizations which offer services for parents and siblings of children with ASD, such as support groups, education, and social events. These resources may aide in buffering the stress these families perceive. Future studies are needed to explore the sources of resiliency in families with children with ASD.
This research has implications for occupational therapy practice. If families are not able to adapt to the challenges having a child with ASD can bring, practitioners need to be able to assess the impact of the stress and provide services to improve occupational performance for all members of the family.

**Limitations**

Broad generalization of the findings in this study are limited by the small sample size, a specific birth order, and a limited age group. There was not enough power to be certain that our failure to confirm our hypothesis did not result from a false negative. Therefore, we strongly caution against drawing the conclusion that there is no impact of having a sibling with ASD on a child’s participation in play and leisure. Several factors may have contributed to limited participation in this study. The hectic life of families with a child with ASD may make it difficult for them to find time to participate in research. As we have noted, the families who did participate demonstrated resiliency to the stress induced by having a child with ASD such that their younger child reported sufficient opportunities for play and leisure participation. On their parts, this may have also provided the means to allow time for research participation. Perhaps the families who did not participate are not as adept in managing the stress of having a child with ASD. On the other hand, it could have been the perception of eligible families that research efforts should be focused on the needs of the child with ASD, not their typically developing siblings. Finding assessment measures that require less time to complete may allow further investigations with increased sample size. Another suggestion for further research is exploring a larger age range of children who have a sibling with ASD, as well as including those whose sibling is younger. This would give researchers the ability to increase participation as well as test to see if birth order affects siblings.
Conclusion

In conclusion, the present study enhances understanding regarding play and leisure participation, as well as, parental stress in families that have a child with ASD. The results of the study need to be considered cautiously and further investigation is needed. However, the present group of parents and siblings seemed to have adjusted well to the factors involved in raising or living with a child with ASD.
Acknowledgments

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References


Participation in play and leisure was measured through self-report using the CAPE. The participants whose older sibling had ASD (experimental) were not different from the participants whose older sibling is typically developing (control) on any measure using unpaired t-tests, p>0.05. Children report on 55 activity cards whether they have done the depicted occupation in the last four months resulting in scores for A. Diversity, number done out of 55, B. Intensity, With Whom, Where, and Enjoyment, each on their own Likert Scales, and C. Proportion of activities done in each category. We separately analyzed the frequency distribution of Likert ratings for D. With whom and E. Where. Bar charts represent average ± sem.
Figure 2. Preferences for participation in play and leisure, as measured by the PAC.

Preferences for participation in play and leisure were measured through self report using the PAC. The preferences for participants whose older sibling had ASD (experimental) were not different from those of the participants whose older sibling is typically developing (control) using unpaired t-tests, p=0.05. Children report on 55 activity cards how much they would like doing the depicted occupation on a 1-3 scale. Bar charts represent average ±sem.
Figure 3. Parenting stress, as measured by the PSI

A. Combined total: Parent domain and Child domain

- Typical Sibling
- Sibling with ASD

Stress parents perceive with regard to their two children relevant to the study, the younger participating child and the older sibling (who, in the experimental group, had ASD and in the control group, was typically developing) was measured using the PSI which consists of a child domain and a parent domain. A. The domains are summed for a combined total. B. Items related to the adaptability of the child revealed that both sets of parents find the older child more stress-inducing. However, this was more pronounced in the experimental group, creating an interaction effect in addition to the main effect. C. On items relating to mood, both sets of parents found the older child to be more stressful; however, the ratings for both children was greater in the experimental group.

Connected symbols represent average ±SEM for each group, experimental and control, with reference to the two children relevant to the study, the younger participating sibling and the older sibling. Differences were tested using mixed model 2X2 ANOVA. See text for statistical results. *p<0.05. **p<0.01.
Appendix A

Marital Status, select one

1. Married/Committed Partnership
2. Single/Divorced/Widowed

If Married and living with spouse, are one or both of you employed?

One [ ] Both [ ]

Level of School Completed

1. Less that seventh grade
2. Junior high school (9th Grade)
3. Partial high school (10th or 11th grade)
4. High school graduate (whether private preparatory, parochial, trade or public school)
5. Partial College (at least one year) or specialized training
6. Standard college or university graduate
7. Graduate professional training (graduate degree)

If employed, please lists your current job title below

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Thank You for Your Time