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The Affects That Children Diagnosed with Autism Disorder Have on Their Siblings in the Area of Behavior Development

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Running Head: SIBLINGS AND AUTISM

The Affects That Children Diagnosed with Autism Disorder Have on Their Siblings in the Area
of Behavior Development.

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Program in Communication Disorders

Honors Thesis

May 2012

Abstract

The purpose of this study was to assess the affects that children with Autism Disorder have on their siblings in the area of behavior development specifically pertaining to: social impairment, repetitive behavior, and impaired communication. The following questions have been answered by this study: First, how extensive are the behaviors that occur in younger siblings of children with autism, next, are the same behaviors applicable to older siblings, and finally are the behaviors described simply a part of being a sibling. The participants in this study were 4 families that have a child with autism and a younger sibling, 2 families that have a child with autism and an older sibling, and a control group of 7 families that have a child that does not have autism 5 of which have an older sibling, and 5 of which have a younger sibling. Two online surveys were created, one for the test group, and one for the control group. The test group survey was sent to autism support groups via Facebook, and a list of e-mails of was compiled and the link sent to families who have a child with autism. The control group survey link was sent via email to parents in a 3-year old Sunday school class. Both survey links were posed on my personal Facebook, as well as on both of my parent's Facebook; the links were also posted on the University of Arkansas Facebook NSSLHA wall. These surveys were used to collect the data. The analysis is descriptive.

Introduction

Awareness of Autism Spectrum Disorder was raised to me after babysitting a little boy who had recently been diagnosed with Autism Spectrum Disorder. After recently being diagnosed his mother sat down with me to explain exactly what ASD was. She began to tell me how he would act up and they would try to correct the behavior in every way but nothing seemed to make a difference to him, it was as if he just didn't care. After he had tested positive for ASD there soon came many changes in his young life. His mother explained to me that many times he would not really understand what was being asked of him so when he would not understand he would use phrases that didn't always make sense. For example, if you asked him: "What's your favorite color?" His main phrase he would use is "no thank you." He would use this phrase when he was not really sure what you were asking even if it did not make sense, but if he knew if he used this phrase then he would not get in trouble because it was polite even if it was not correct. This confusion would result in his misunderstanding and behavioral issues. His mother soon put him on a new diet, and limited his television viewing and encouraged him to do more activities outside. She would use lots of pictures and visual timers to help him better understand. She told me to use shorter more direct phrases like: First bath, then movie to help him with understanding. As the months went by I saw major improvement in the little boy's understanding and behavior, however some days were always better than others.

This is what first got me interested in Autism Spectrum Disorder. The little boy has a little brother who is 2 years younger than him. His little brother looks up to him and always tries to copy everything he does from his behavior, to his vocabulary. Having babysat both little boys and watching how many characteristics of the little boy with ASD have rubbed off on his little brother is what led me to ask the question of how having an older sibling with ASD affects the development of a younger sibling who has not been diagnosed ASD.

After coming up with this question the next step was to start to research the affects of Autism Disorder on younger siblings. The research came up with some very interesting results. According to one study Levy, Goldstein, and Weinstock tested 27 kids who had siblings with autism was compared to 27 kids who did not have siblings with autism in an attempt to see how autism can affect the siblings. Their study found that the younger siblings of children with Autism disorder had lower levels of participation in extracurricular activities and also that these younger siblings seemed to be distressed by the responsibility that was placed upon them by having an older sibling with Autism (2010). This study's results were very similar to the findings that Yonder, Stone, Walden, and Malesa had in their study. In their study they examined 43 siblings of ASD who were followed from 15 to 34 months of age. This study showed that there was in fact a social affect on the younger siblings of children with ASD (2009). One other study that I found that dealt with the effects of ASD on younger siblings focused on how the younger siblings are influenced by the behavior of their older sibling with ASD. The conclusion of this study showed that the assessment of the younger siblings is necessary to identify those who may be at risk for future adjustment problems and maladaptive behaviors (Smith and Elder 2010). All three of these studies help show that younger siblings are in fact affected by their older sibling's Autism Disorder.

The purpose of my study is to focus on the affects that children with Autism Disorder can have on their sibling(s). I plan to look at all behavioral aspects these affects have on the sibling's lives.

Review of the Literature

What is Autism Spectrum Disorder?

Autism Spectrum disorder (ASD) is defined as a group of five closely related neuro-biological disorders including: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder, and Rett's Disorder. There is still little known about ASD and what the actual cause is. Each of these disorders has their own set of specific behavioral characteristics, with some overlap.

Asperger's Disorder is commonly known as a less severe type of autism. Some of the characteristics for Asperger's include: Less impairment in cognitive function (IQ not less than 70), no significant delay in language, and language remains fixed on particular topics.

PDD-NOS is another disorder in the Autism spectrum and the behavioral symptoms of this disorder are similar to the ones that have been listed above and also includes: social impairment most noted symptom, but fewer than needed for autistic disorder diagnosis, and either communication difficulties or stereotyped actions or interests.

The next disorder listed in ASD is Childhood Disintegrative Disorder. Children diagnosed with this disorder have the following behavioral manifestations: Loss of previously acquired skills after 2 years of age, abnormal communication, abnormal social interaction, and repetitive, stereotyped behavior.

In order to be classified as having Rett's disorder the child must show the following traits: Abnormal sleep in infancy, rapid deterioration of behavior and mental status after 7–18 months of age, deceleration of normal head growth, loss of hand skills, loss of social skills, poorly coordinated gait and trunk movements, severe language impairment, and psychomotor retardation.

The main behavioral characteristics that these disorders share and which places them in the autism spectrum is that they cause the child to have impaired social interactions, repetitive behavior and interests, and some sort of impaired language and communication (Phetrasuwan, Miles, Mesibov, and Robinson 2009). ASD is often shortened to Autism, because the symptoms that classify these five disorders as ASD are the sole distinct characteristics of Autism disorder. These signs usually appear around age 3. It is reported by parents that their child is normally developing up until this point, and then the language development regresses and the behavioral characteristics often appear. Since the symptoms of autism are prevalent in all of the disorders just listed in ASD, knowing some of the indicators of these disorders helps to narrow the focus down to strictly Autism Disorder. This makes sense since Autism Disorder is the base for all of the other disorders. In theory, by studying Autism, it will help to gain knowledge about all of the other disorders in the spectrum. The main focus in the field of Speech Language Pathology and Autism Disorder is to study the behavioral and language characteristics of children diagnosed with Autism Disorder. The way this is done is by comparing diagnosed children to normal developing children within their same age range. This leads to the formal question of how do children with Autism disorder act and develop that is different from normal developing children?

Behavioral Characteristics of Children with Autism

As mentioned above, there are three main behavioral characteristics of children with Autism Disorder:

- Social Impairment
- Repetitive Behavior
- Impaired Communication

Children with autism display abnormal social qualities. They are more likely to exhibit less attention to social stimuli such as: smiling, making eye-contact, or responding to their name. These children usually react negatively to physical touch even from their caregivers. Children with Autism disorder tend to exhibit more severe forms of social impairment in terms of anticipatory postures, and tend to have less social understanding, emotional expression, and spontaneity as compared to the other children of their age. The range of behavioral characteristics can be from overly aggressive to abnormally passive when interacting with their peers. These children tend to not pay attention to the people around them, and do not reciprocate to communication, whether it is verbal or non-verbal. In the context of playing in social situations, children with autism tend to play by themselves, and with parts or pieces of toys and in a repetitive action (Manohar).

Repetitive actions are very common among children diagnosed with Autism. Their pattern of behavior and interests tends to be very restrictive and repetitive. The slightest change in these children's lives can cause major behavioral issues, because they are so resistant to even the slightest change in their normal routines which might break their repetitive tendencies. Children with autism have very low attention spans, and might be caught stemming, or doing a repetitive purposeless movement to stimulate their senses such as flapping arms, or rocking back and forth (Manohar).

Expressive Communication is area that is most affected by Autism. Children with autism have trouble expressing their wants/ needs appropriately. All areas of language morphology, syntax, semantics, and pragmatics with the exception phonology are severely impaired. They use unusual gestures that might not always be correctly understood by the person they are trying to communicate with. These children tend to have a monotonous intonation and speak in the same

voice in all social situations. As mentioned earlier, eye-contact is usually not maintained by children suffering from this disorder. One of their biggest problems is that they have trouble understanding social cues and using expressive communication to respond appropriately (Manohar). With all of these behavioral impairments, the next question is asked how do these impairments impact the development of siblings of children diagnosed with Autism Disorder?

Impact of Autism Disorder on Siblings

Autism not only affects the child that is diagnosed with it, but it also affects the families of the children with this disorder. According to one study found in the *Journal of Family Studies*, there was a study done in which 27 children who had siblings with autism and between the ages of 6 and 18 were compared to the control group, 27 children who did not have a sibling with autism. Twelve of the siblings were male and fifteen were female. All parents of the children with autism completed a two part questionnaire, also known as the child behavior check list. The parents of the control group answered the open ended questions on the first part of the questionnaire and were also used for the validation of the WAI (Weinberger Adjustment Inventory). The WAI is a “is a 62-item self-report questionnaire, used for the assessment of social and emotional adjustment over a long term of external pressures.” The purpose of the first part of the questionnaire was to measure the children’s competency. It consisted of twenty items rated on a four point scale encompassing three categories of competency: child activities, social relations, and school performance. The first part of the questionnaire contained two open ended questions for the parents to answer. The first question was: “What troubles you most about your child.” The second question was: “Describe the good qualities of your child.” After calculating the scores of the questionnaire, they were compared to the norms of child behavior check list. The range of the scores was from normal to clinically borderline, to clinical. The lower scores

showed more behavioral difficulties. The second part of the questionnaire was to measure the children's behavior and emotional problems. It consisted of 118 items with a focus on various syndromes and behavior problems in general. This part had nine subscales that included: "anxiety/depression, withdrawal/depression, somatic complaints, social problems, cognitive problems, attention problems, rule breaking, aggressive behavior and other problems." These questions were scored on a scale of: 0 doesn't apply to the child, 1 sometimes applies to the child, and 2 always applies to the child. Scores were once again compared to the norm. All data was reviewed and themes were drawn between the two research groups. The results focused on part 1 of the child behavior check list and the WAI. The researchers found 2 main things. First those siblings have markedly lower levels of participation in extracurricular activities and second those parents and siblings defined the attributes 'helpfulness/responsibility' in an almost dichotomous manner. Whereas parents considered these to be positive attributes of their healthy child, self-reports suggest that for siblings these same attributes may be a source of distress. Findings suggest that counselors and parents may assist siblings to lessen possible emotional distress by lowering expectations of assistance and by facilitating their participation in activities outside the home. This study was done in an attempt to see if autism disorder not only affects the children with the actual disorder but also siblings of the children who have the disorder (Barak-Levy, Goldstein, and Weinstock 2010). This study showed that the behavior of the children, who do have autism disorder, does in fact have an impact on their siblings. After reading this study is made me ask the question; to what degree do Children with ASD impact their younger siblings?

A study I found that helps to answer this question was done by Yonder, Stone, Walden, and Malesa. The study attempts to show that Later-born siblings of children with autism spectrum disorder at elevated risk for social impairments. This study includes 43 siblings of

children with ASD who were followed from 15 to 34 months of age. The two predictor variables (Responding Joint Attention, RJA; and Weighted Triadic Communication, WTC) were measured at 4 time points, each separated by approximately 4 months. ASD diagnosis and the three social outcome variables were measured at Time 5: RJA, WTC, and Social Behavior Checklist score. There were several tests given to the participants including: *Mullens Scales of Early Learning*, *Screening Tools for Autism in Two Year Olds*, *Responding to Joint Attention*, *Social Behavior Checklist*, and *Diagnostic Measures*. After all these tests, 6 of the siblings were diagnosed with ASD. Results revealed that initial level of responding to joint attention and growth rate of weighted triadic communication predicted the degree of social impairment at the final measurement period. Additionally, both predictors were associated with later ASD diagnosis. This study showed that there was in fact a social affect on the younger siblings of children with ASD but it could not predict later social impairment (2009). This experiment helps to gain knowledge to the idea children with ASD have a great impact on their younger siblings. When I read this study, I learned that Children with ASD significantly affect their siblings. My next question became in what specific areas do children with Autism affect their siblings?

To answer my question, I found an article in the *Journal of Autism & Developmental Disorders*. This article describes a study that consisted of 25 children from which 17 were boys and 8 were girls. The group was divided in 3 groups: 8 children with ASD, 8 untested younger siblings of children with ASD, and finally 9 typically developing children from families without ASD. All children participated in a videotaped, structured interactional procedure called the Early Social Communication Scales. Very young siblings were compared to young children with a diagnosed autism spectrum disorder and to a group of young typically developing children. Results indicated that, on three of four of the ESCS subscales, the social communicative

behaviors of the younger siblings differed from those of the typically developing children but not from the behaviors displayed by the ASD group (Goldberg, Jarvis, and Osaan 2005). This study shows that Siblings of Children with Autism are affected in the area of social behaviors.

Summary

As can be seen from this review of the literature, younger siblings are impacted by an older child with Autism. There are two unanswered questions that emerge from the literature. First, it is not clear how widespread such differences are and secondly, there is little data on the impact of autism on oldest siblings. This study seen is going to address both of these.

Questions of the Study

- How extensive are the behaviors that occur in younger siblings of children with Autism?
- Are the same behaviors applicable to older siblings?
- Are the behaviors a part of just being a sibling?

Methodology

Participants

The following participants were used to complete this study: 4 families that have a child with autism and a younger sibling, 2 families that have a child with autism and an older sibling, and a control group of 7 families that have a child that does not have autism 5 of which have an older sibling, and 5 of which have a younger sibling.

Materials

Two electronic surveys were compiled from the review of the literature.

Procedure

Two online surveys were built using survey monkey, one will be for the test group, and one will be for the control group. The test group survey will be sent to an autism support group to

distribute the link to their members. The test group survey was sent to autism support groups via Facebook, and a list of e-mails of was compiled and the link sent to families who have a child with autism. The control group survey link was sent via email to parents in a 3-year old Sunday school class. Both survey links were posed on my personal Facebook, as well as on both of my parent's Facebook; the links were also posted on the University of Arkansas Facebook NSSLHA wall.

Analysis

The Analysis done was descriptive.

Demographics:

Men and Women who have children; there was not an age range set on the children in order for the parents to participate in the survey. The age range of the children of the participants was 3 years old to 32 years old. If parents had adult children, then they reflected back to previous years when the children were growing up.

Results of Study

1. How extensive are the behaviors that occur in younger siblings of children with autism?

In the behavioral characteristic area of social impairment, there was no correlation. When answering the questions for the younger sibling related to this area none of the answers were marked.

The behavioral characteristic area of repetitive behavior as a whole has the greatest prevalence when compared to the other two behavioral areas in the younger sibling. In this area, the child diagnosed with autism displayed more repetitious behaviors than the younger siblings, but the younger siblings did display some of the same behaviors just not as strongly. In reference to the younger sibling, the two most frequent

specific behaviors observed in this area was the child getting upset when the schedule is disrupted and the child being resistant to change were more prevalent in this specific area. However, low attention span and stemming were also observed, but just not as often. Table 1 visually represents the prevalence and extensiveness of the individual behaviors in the area of repetitive behavior when comparing children with autism and their younger siblings.

Repetitive Behavior (Table 1)

Questions	Child With Autism		Younger Sibling	
	Response Count	Response %	Response Count	Response %
Child prefers set schedule everyday	3	75%	0	0%
Child gets upset when schedule is disrupted	4	100%	2	66.7%
Child tends to be resistant to change	3	75%	2	66.7%
Child displays a low attention span	4	100%	1	33.3%
Child has been observed stemming	2	50%	1	33.3%

In the behavioral characteristic area of impaired communication, the only similar behaviors the younger sibling displayed when compared to their older sibling was autism was that other children find it hard to understand the child and that the child doesn't always understand social cues. Although these behaviors were identified in the younger sibling, the prevalence is much weaker than in the child diagnosed with autism. Table 2 visually represents the correlation in the behavioral area of impaired communication between the child diagnosed with autism and their younger sibling.

Impaired Communication (Table 2)

Questions	Child With Autism		Younger Sibling	
	Response Count	Response %	Response Count	Response %
Child has trouble finding words/gestures to	2	50%	0	0%

express needs/wants				
Adults find it hard to understand child	2	50%	0	0%
Other children find it hard to understand child	3	75%	1	100%
Child tends to speak in monotone voice	2	50%	0	0%
Child displays little eye contact when speaking	2	50%	0	0%
Child doesn't always understand social cues	4	100%	1	100%
Child tends to use a single word phrase to respond to multiple social situations even if the word or phrase doesn't make sense in context	1	25%	0	0%

Table 3 is representative of the extensiveness of all of the individual behavioral characteristics observed across all 3 areas as seen in the younger sibling when comparing them to their older sibling with autism.

All Behavioral Characteristic Areas (social impairment, repetitive behavior, and impaired communication) Prevalent Table 3

Questions	Child With Autism		Younger Sibling	
	Response Count	Response %	Response Count	Response %
Child gets upset when schedule is disrupted	4	100%	2	66.7%
Child tends to be resistant to change	3	75%	2	66.7%
Child displays a low attention span	4	100%	1	33.3%
Child has been observed stemming	2	50%	1	33.3%
Other children find it hard to understand child	3	75%	1	100%
Child doesn't always understand social cues	4	100%	1	100%

2. Are the same behaviors applicable to older siblings?

Yes, some of the same behavioral characteristics were observed in the older sibling group were also observed in the younger sibling group. However, even of the behavioral characteristics that were the same, there was an overall stronger occurrence of these behavioral features in the younger siblings than in the older siblings.

Just as seen with the younger sibling of the child with autism, the older sibling also did not share any behavioral characteristics with their younger sibling with autism in the area of social impairment.

In the behavioral characteristic area of repetitive behavior, both the younger siblings group and the older siblings group share features of getting upset when schedule is disrupted, being resistant to change, and having been observed stemming.

Pertaining to the behavioral characteristic area of impaired communication, the younger siblings group and older siblings group shared characteristics in equal occurrence in other children finding it hard to understand the child, and the child not always understanding social cues.

Table 4 visually represents the comparison of all 3 groups (child with autism, younger siblings, and older siblings) in the behavioral characteristic areas of repetitive behavior and impaired communication. The area of social impairment was left out of the table since neither the younger siblings nor older siblings showed any behaviors from this part.

Table 4

	Child With Autism		Younger Sibling		Older Sibling	
Questions	Response Count	Response %	Response Count	Response %	Response Count	Response %
Repetitive Behavior						
Child prefers set schedule everyday	3	75%	0	0%	0	0%
Child gets upset when schedule is disrupted	4	100%	2	66.7%	1	100%
Child tends to be resistant to change	3	75%	2	66.7%	1	100%
Child displays a low attention span	4	100%	1	33.3%	0	0%
Child has been observed stemming	2	50%	1	33.3%	1	100%
Impaired Communication						
Child has trouble finding words/gestures to	2	50%	0	0%	0	0%

express needs/wants						
Adults find it hard to understand child	2	50%	0	0%	0	0%
Other children find it hard to understand child	3	75%	1	100%	1	100%
Child tends to speak in monotone voice	2	50%	0	0%	0	0%
Child displays little eye contact when speaking	2	50%	0	0%	0	0%
Child doesn't always understand social cues	4	100%	1	100%	1	100%
Child tends to use a single word phrase to respond to multiple social situations even if the word or phrase doesn't make sense in context	1	25%	0	0%	0	0%

3. *Are the behaviors a part of just being a sibling?*

No. In Table 5, I compared the results to both the test survey and the control survey. In order to do this, I looked at the questions in all 3 behavioral characteristic areas in both surveys to compare the siblings of the child with autism, and the siblings who are all normally developing.

The results show that when compared, the siblings of the child with autism have more shared behavioral characteristics in all 3 areas (social impairment, repetitive behavior, and impaired communication) than the siblings who don't have autism in their family. The siblings in the normally developing families didn't share any of the same behavioral characteristics. These results reflect that the behaviors are not just a part of being a sibling and that autism can in fact impact the behavioral development of siblings.

Table 5

	Control Survey				Test Survey			
	Youngest Sibling		Next Youngest Sibling		Younger Sibling of Child with Autism		Older Sibling of Child with Autism	
Questions	Response Count	Response %	Response Count	Response %	Response Count	Response %	Response Count	Response %
Social Impairment								
Child displays lack of eye-contact	2	100%	0	0%	0	0%	0	0%
Child doesn't smile frequently	0	0%	0	0%	0	0%	0	0%
Child often times	2	100%	0	0%	0	0%	0	0%

fails to respond to his/her name when being addressed								
Child displays little emotional expression	0	0%	0	0%	0	0%	0	0%
Child is rarely spontaneous	0	0%	0	0%	0	0%	0	0%
Child prefers to play by self versus playing with other children	1	50%	0	0%	0	0%	0	0%
Child displays repetitive behavior	0	0%	0	0%	0	0%	0	0%
Repetitive Behavior								
Child prefers set schedule everyday	0	0%	1	100%	0	0%	0	0%
Child gets upset when schedule is disrupted	0	0%	0	0%	2	66.7%	1	100%
Child tends to be resistant to change	0	0%	0	0%	2	66.7%	1	100%
Child displays a low attention span	3	100%	0	0%	1	33.3%	0	0%
Child has been observed stemming	0	0%	0	0%	1	33.3%	1	100%
Impaired Communication								
Child has trouble finding words/gestures to express needs/wants	1	50%	0	0%	0	0%	0	0%
Adults find it hard to understand child	1	50%	0	0%	0	0%	0	0%
Other children find it hard to understand child	1	50%	0	0%	1	100%	1	100%
Child tends to speak in monotone voice	0	0%	0	0%	0	0%	0	0%
Child displays little eye contact when speaking	2	100%	0	0%	0	0%	0	0%
Child doesn't always understand social cues	1	50%	0	0%	1	100%	1	100%

Child tends to use a single word phrase to respond to multiple social situations even if the word or phrase doesn't make sense in context	0	0%	0	0%	0	0%	0	0%
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Discussion

The purpose of this study was so assess the affects that children with Autism Disorder have on their siblings in the area of behavior development, specifically pertaining to: social impairment, repetitive behavior, and impaired communication.

The results concluded that children with autism do have some effect on their siblings in the area of behavior development, with the exception in the area of social impairment. It also refuted the argument that the impact was simply just a normal sibling thing. The study showed that it doesn't matter if the sibling of the child with autism was older or younger, although the younger siblings seemed to be impacted more.

When comparing the review of the literature and the results of my study, the complement each other. The lit review stated that the behavior of children, who do have autism disorder, does have an impact on their siblings; I found this concept to be accurate after reviewing the results of my study. The review of the literature showed that children with ASD significantly affect their younger siblings but not so much their older siblings. The results of my study support part of this statement, but I found that although the younger siblings are impacted more, the difference between the impact on the younger siblings and older siblings isn't as vast the literature states. I took away that siblings are impacted by autism disorder but the degree of the impact between younger siblings and older siblings is still unknown.

Limitations

The limitations of the study include that this study had a limited number of participants so the data collected doesn't represent a large population as a whole. Another limitation is that all participants in the study live in Arkansas; the results might be different if the participant population extended to across the United States.

Future Directions

I plan on continuing this study, and trying to reduce some of the previously listed limitations. The more research that comes out about ASD and the more children who are diagnosed would make it interesting to compare the results of this study to a replicated study a year from now and compare the findings.

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