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The Everyday Life of Autism: Living with Behavioral Differences

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Program in Communication Disorders

Honors Thesis Project

April 22, 2014

Abstract

The purpose of this study is to examine how family members, who have a child with autism, perceive problematic behaviors in relation to everyday activities. Parents, who have a child diagnosed with autism, were sought through social media for participation in this study. The material required for this project consisted of a parent survey created on SurveyMonkey. The link was shared online so that families who would like to participate could access the survey. Analysis will include a comparison of the themes and concerns expressed by the parents in their responses.

The Everyday Life of Autism: Living with Behavioral Differences

The American Speech-Language-Hearing Association website classifies Autism Spectrum Disorder (ASD) as a developmental disorder that interferes with three functioning components: communication, behavior, and social skills (American Speech-Language-Hearing Association, n.d.). People with autism tend to be delayed in key areas as compared to the typically developing child. The poor communication skills could consist of a multitude of problems including: limited speech, articulation errors, difficulty answering questions, repeating certain phrases (echolalia), inability to express needs, and insufficient vocabulary (American Speech-Language-Hearing Association, n.d.). There are numerous other factors with communication that can be a red flag pertaining to a developmental delay or disorder. There are also certain behavioral patterns that can serve as early indication of ASD. Some of these distinguishing behavioral differences include repetitive movements, flapping of the arms, inability to manage un-routine events, and being sensitive to overstimulation (American Speech-Language-Hearing Association, n.d.). The third identifying feature of autism is problems with social skills. This characteristic can result in disliking of affection, unstable emotions, poor pragmatic skills, and poor eye contact with people (American Speech-Language-Hearing Association, n.d.).

The autism spectrum previously consisted of four specific diagnoses: Asperger's, Autism, childhood disintegrative disorder, and Pervasive Developmental Disorder –Not Otherwise Specified (PDD-NOS). However, this classification has recently been revised. The modified Diagnostic and Statistical Manual of Mental Disorders (DSM V) includes a single diagnosis of Autism Spectrum Disorder (ASD) with variable levels of severity (Hiller, 2013). This umbrella spectrum contains many different levels of classification ranging from highly functioning verbal

children to children with no verbal communication. ASD is highly individualized with each case holding its own unique characteristics. The new diagnostic process will compensate for each individual's personal symptoms rather than a child being grouped into one of the four categories previously used for diagnosis in the DMV IV. The DSM V also included revisions to encourage early intervention for diagnosis (Hiller, 2013). The old document was geared toward diagnosing school age children, but with early intervention, actions can be taken as soon as possible to get children the services they need. The new DSM V will hopefully allow for more accurate diagnosing of ASD across clinicians.

The number of individuals diagnosed with autism has rapidly increased over the past few years. The diagnosis of ASD has increased 72% since 2007 reporting now that 1 in 50 children are diagnosed with autism (National Vaccine Information Center, 2013). It is obvious that this disorder requires increased attention for diagnosis, intervention, prognosis, and management for families. With this sort of prevalence in a developmental disability, assertive action needs to be taken by researchers. Considering ASD is becoming a more popular diagnosis, families affected by autism deserve to have information about when to expect specific characteristics of autism to emerge as well as what social interactions might result in an increased prevalence of these behaviors. Support groups and evidence-based information would be extremely beneficial for families to successfully thrive as a unit.

Children with ASD heavily rely on routines to structure their everyday life. Monotonous routines are crucial for their well being, while at the same time allowing for minor adaptability in their schedules. Dealing with a child who has autism affects the functioning of the entire family. Any simple everyday activity is much more complex for those families involving a child with

ASD. Activities like mealtime, preparing for bed, or any un-routine event can be made increasingly more stressful for these particular families.

Children who are diagnosed with ASD are susceptible to stigmatizations by others. The diagnosis of autism is a more recent disorder, so many people have not previously exposed to this issue. It is important to advocate for awareness of autism so parents can become aware of identifiable features in their children. Early intervention can make dealing with ASD a more manageable situation. It is easy to observe how a child with ASD is developmentally different from their typically developing peer, but by time the child reaches school age, the window for early intervention is lost and the child will already be delayed compared to their peers.

Review of the Literature

The establishment of a maintainable routine is a common theme for most families with a child. When a family contains a child diagnosed with ASD, this routine becomes increasingly crucial for structure and order in that child's life. A study was conducted that examined the dinnertime and bedtime routines of families with an autistic child. Mothers were recruited through different autism related programs to participate in an open-ended interview about their family's routines. The researchers conducted interviews via telephone or direct contact inside the families' home. Of those interviewed, 14 mothers met the following conditions and were interviewed. The conditions required to participate were that each family had a child with ASD based on the DSM-IV criteria, said child was between the ages of two and five years, did not attend a full time formal school, and was demographically located in Queensland, Australia. The mothers described their routine for mealtime similar to the basic structure one would think of for mealtime including the setting of the table, cooking of the food, and serving the food. The results

concluded that mothers focused more on attending to their child with ASD and their peculiar behaviors rather than the actual task associated with normal mealtime routines. The most common behaviors the children with autism exhibited included irrational food selectivity, assertive using of only one utensil, and insisting on a usual seat. Whenever these mealtime routine activities were disrupted, 82% of mothers reported behavioral challenges that affected the family as a whole (Marquenie, Rodger, Mangohig, & Cronin, 2011). The researchers also found that dinnertime was thought of as a time of turmoil with a complete lack of structure. Most likely the child with ASD often got excused from the standard rules set for the rest of the family (Marquenie, Rodger, Mangohig, & Cronin, 2011). The structure for bedtime also consisted of routine typical behaviors. As with mealtime, the child with ASD was excused from the family rules when problematic behaviors were exposed. However, bedtime was not described quite as chaotic considering the child desired consistency with the activities and objects needed to induce sleep (Marquenie, Rodger, Mangohig, & Cronin, 2011). The study concluded that based on the mother's descriptions of these two routine daily events, the child diagnosed with ASD greatly affects how the family functions during mealtime and bedtime (Marquenie, Rodger, Mangohig, & Cronin, 2011).

Early identification is a critical factor with the prevalence of autism in today's world. Being able to recognize characteristics associated with the disorder would allow parents or primary care physicians to seek the appropriate intervention at an early age for the child. The earlier intervention is sought, the faster the child can be enrolled in services that will benefit many aspects of their life. Although many conspicuous facial features identify certain disorders at birth, children with autism look just like the typically developing child. A study was conducted to evaluate characteristics associated with autism, such as early development and

behavioral factors that were identified in Indian context, and then compared to a larger population of children with autism. The study recruited 54 mothers of children diagnosed with autism to be interviewed. The interview probed questions regarding the initial concerning behaviors of their child. The four characteristics that the study analyzed were: language delay/regression, repetitive behavior, poor eye contact, and squatting/oddities with toileting (Kishore, & Basu, 2014). If the mother expressed her concern for one or more of these behaviors, more thorough questions were asked pertaining to the age in which they first noticed them. Research concluded the average age that the mothers generally identified these autistic characteristics was 2.2 years (Kishore, & Basu 2014). There was one main outlier in the data in which one mother became overly concerned when her child at eight months developed issues with maintaining proper eye contact. Fifty of the mothers reported that their child portrayed at least one of the early identification characteristics. The top three identifying features were language delay/regression, problems with eye contact, and repetitive behaviors (Kishore, & Basu 2014). Some limitations to this study were that all the mothers interviewed were educated and above twenty years of age. Because these women were educated, they were aware their child exhibited developmental delays, whereas some mothers from a lower socioeconomic class may not be aware of these characterized autistic behaviors.

Sibling relationships are a crucial component of the family dynamic that is often affected by a member diagnosed with a developmental disability. The psychosocial outcome of a typically developing child can be influenced by their perception of the relationship they have with a sibling with either ASD or Down Syndrome (DS). The most discernible psychosocial difficulty is internal problems including anxiety (Pollard, Barry, Freedman, & Kotchick, 2013). A study was conducted to examine the perceived relationship that typically developing siblings

have with their sibling diagnosed with ASD or DS. Research has found that sibling relationships are one of the most personal enduring relationships a person can have in their lifetime (Brody, 2004). However, research is sparse when comparing sibling relationships of those involving a sibling with a developmental disorder. To conduct this study, 119 participants were recruited from different organizations involving families with a developmentally disabled child. To qualify for participation the subject must have been diagnosed with ASD or DS, be between the ages 11 through 17, and have a normally developing sibling. Each family involved was required to fill out a parent survey as well as a separate child survey. The sibling that was closest in age to the child with the ASD or DS was asked to complete the child survey. The results found that the siblings of a child diagnosed with ASD reported less provision from social support qualities, more negative interactions between siblings, and lower relationship quality than those described by the siblings of children with DS (Pollard, Barry, Freedman, & Kotchick, 2013). This result could be due to the stigmatizations associated with ASD as compared to DS. The typically developing siblings that reported more negative interchanges also reported higher levels of anxiety overall. More research needs to be conducted in order to elaborate on the relationship of siblings with a diagnosed ASD or DS. The normally developing children deserve more options for support groups and resources to help them learn how to have more positive interactions with their affected sibling and reduce the levels of anxiety. Families that have a child with autism do face adversity in their day-to-day life. Therefore these families must be compliant to make the appropriate adaptations.

Summary and Questions of the Study

As can be seen, the literature on ASD concerning behavioral problems and family interaction is extensive. However, the everyday experiences of living with autistic behaviors are not effectively documented. An insider's perspective on living with the autistic behaviors associated with ASD could benefit the numerous families affected by this disorder. It is also important to inquire the specific behavior as well as what activities promote these behaviors to be displayed.

The specific questions of this study are as follows:

1. What daily or social activities promote the behaviors associated with autism?
2. What behaviors initially concerned the parent about their child's development and at what age did these behaviors first appear?
3. According to the perception of the parents, what is the sibling relationship like between the child with autism and the typically developing child? How does the parent adapt their disciplinary actions to accommodate for the child with autism?

Methodology

Participants

The participants included 27 families, each involving a child diagnosed with autism. The ASD children were not restricted by age or gender, and consisted of both males and females of all ages. The ideal families who completed the survey also had an unaffected child as well as both parents present. However, the presence of both parents and siblings was not required. The families all used English as their primary language. There was no control for socioeconomic or cultural differences.

Materials

The materials consisted of a brief parent online survey. The survey contained questions regarding the autistic behaviors of their child. It also touched on parents' perception of the sibling relationship between the child with autism and the typically developing child.

Procedures and Analysis

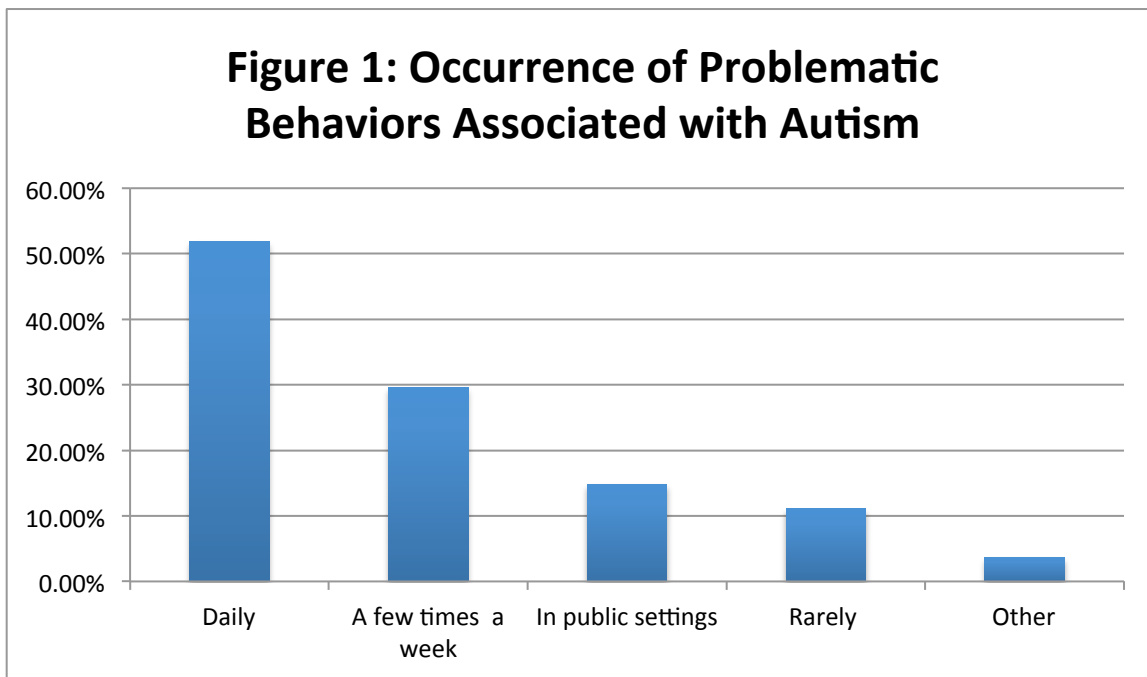
Permission to conduct this research was granted by the Institutional Review Board of the University of Arkansas. Once this research was approved, a parent survey was constructed. The parent survey titled "Behaviors in Autism" was posted on SurveyMonkey and included information about the study. The survey link was also posted on social media by the primary researcher. Families, who had a child with ASD and were interested in the study, voluntarily completed the online survey. By submitting the survey, they gave consent for their answers to be used in the analysis. Themes and concerns expressed by the various family members were then computed and compared as results.

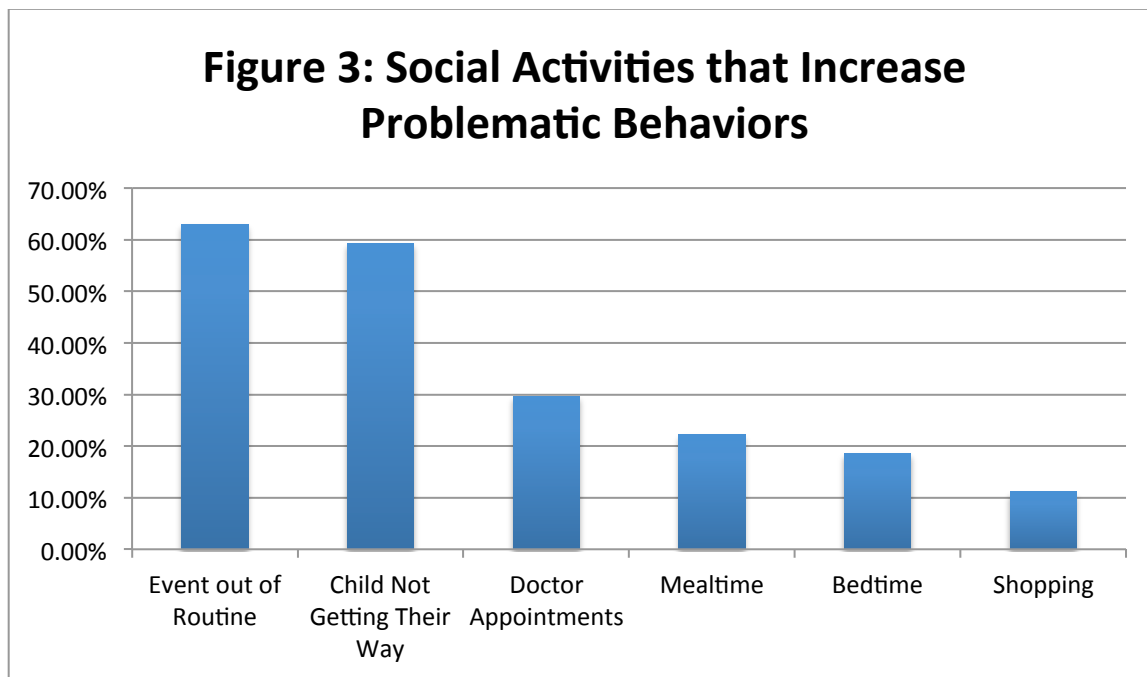
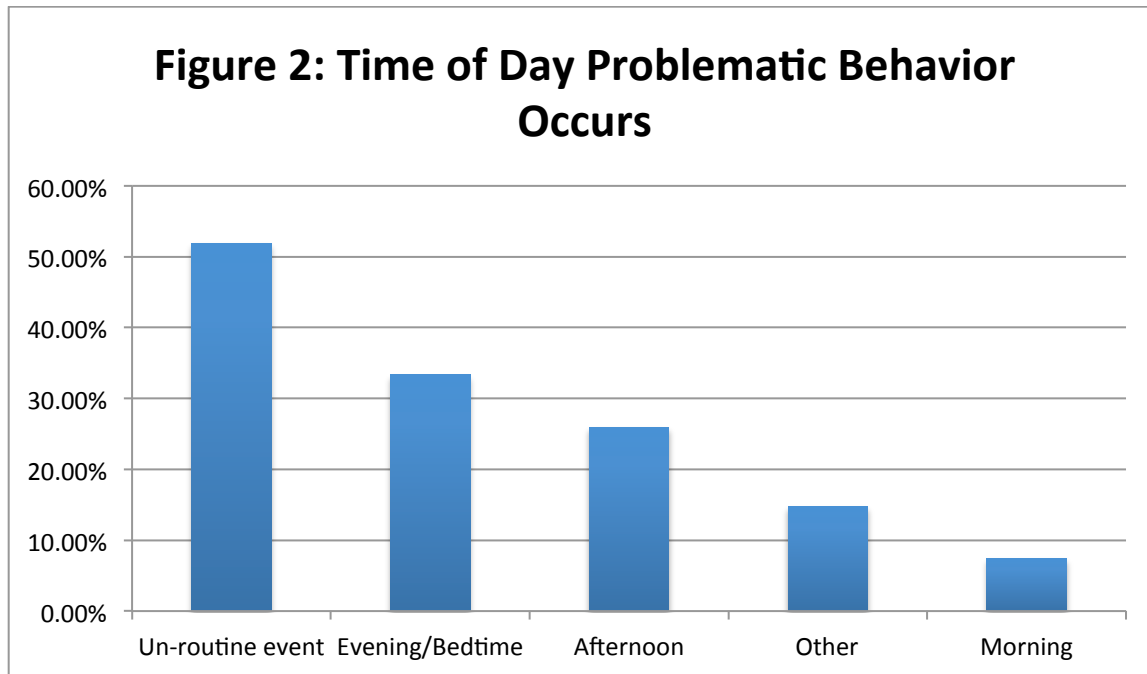
Results

Problematic Behavior Occurrences

One question of this study was to investigate the number of occurrences of problematic behaviors associated with ASD as well as what time of days these behaviors were most likely to peak. 52% of parents reported that problematic behaviors occur on a daily basis, while only 11% of parents said problematic behaviors are a rare issue. One parent described that the prevalence of problematic behaviors was higher when their child was younger, but has diminished since the child has gotten older. Public setting accounted for 15% of the times the child exhibited behavioral issues. The study also found that problematic behaviors for children with autism are

highest during an un-routine event. Parents reported that other peak times for problematic behaviors were during an evening/bedtime routine, afternoon, morning, and when tired or over stimulated, in that order. Particular social activities that triggered behavioral challenges were found to be various non-routine events, such as attending a doctor’s appointment, mealtime, bedtime, and shopping. 60% of parents described their child not getting their way as a major factor resulting in increased behavioral issues.

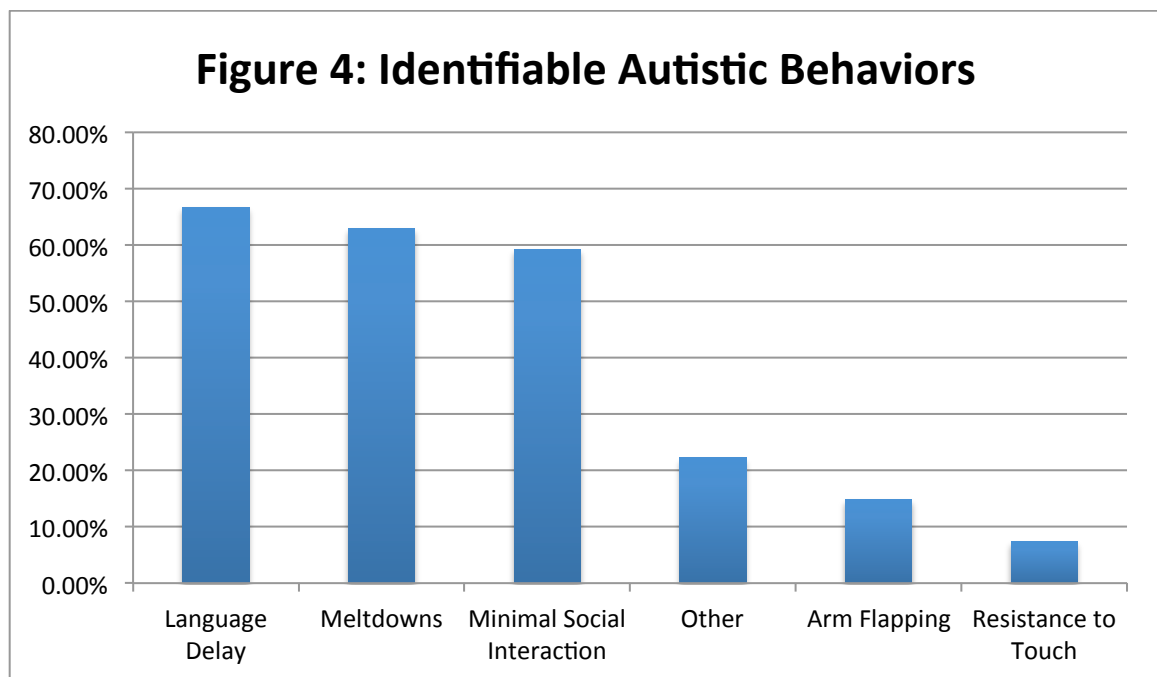


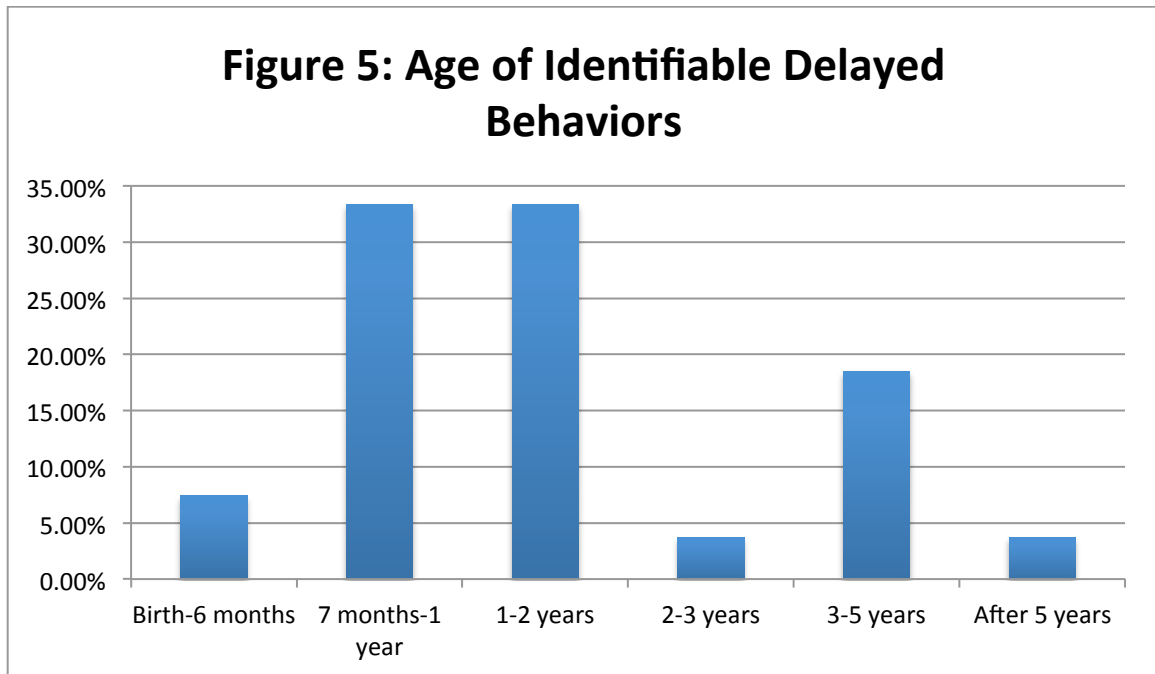


Identifiable Behavioral Characteristics of Autism

The second question of this study examined what autistic behaviors parents first noticed in their child as well as what age they became concerned with these behaviors. The number one

behavior that 67% of parents first grew apprehensive of was language delay. This was followed by meltdowns at 63% and minimal social interaction at 59%. Parents also reported on the survey in the section labeled other, that sensory issues and stimming of objects were characteristics that were alarming. The ages, in which these autistic behaviors first appeared, ranged from birth through after five years. However, 66% of parents said they noticed these behaviors between seven months and two years (33% noticed between 7 months and a year, and another 33% noticed between one and two years). Two parents who completed the survey were able to observe characteristics of autism between birth and six months. One person noticed developmental issues after five years of age.

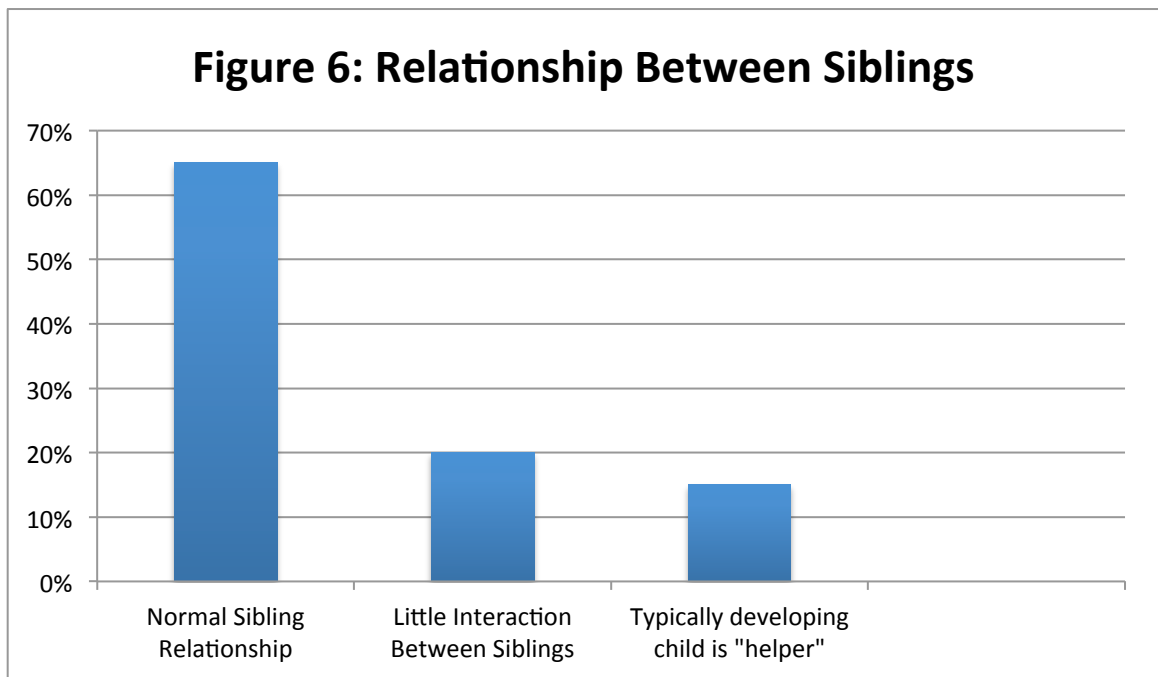


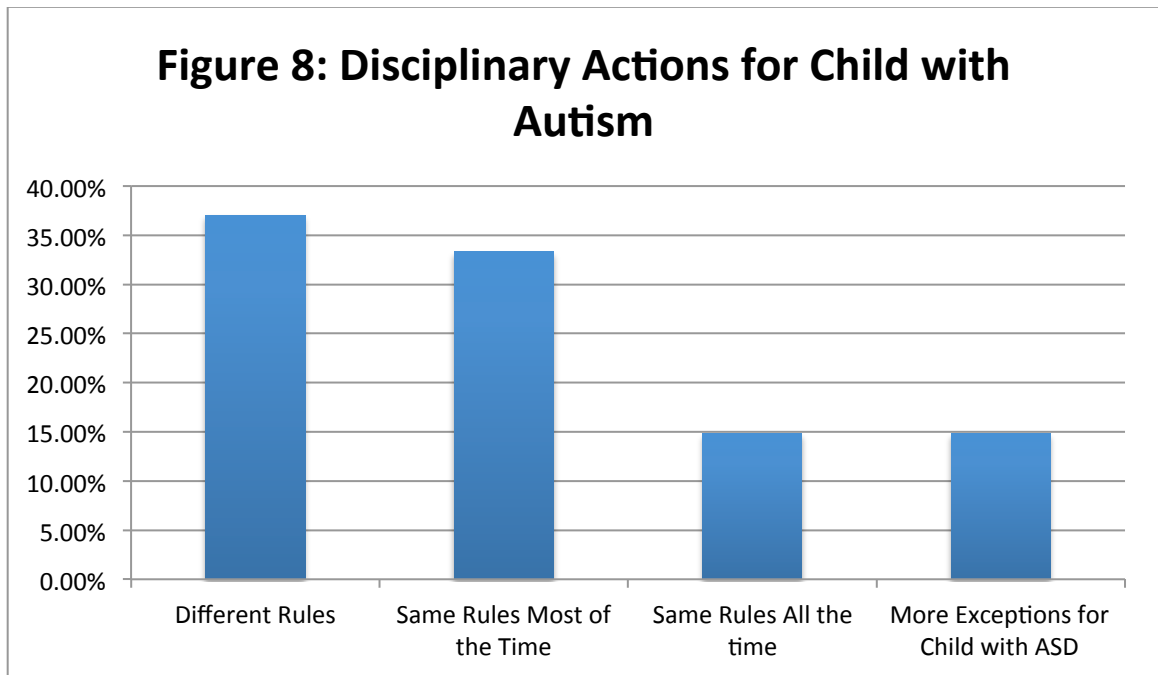
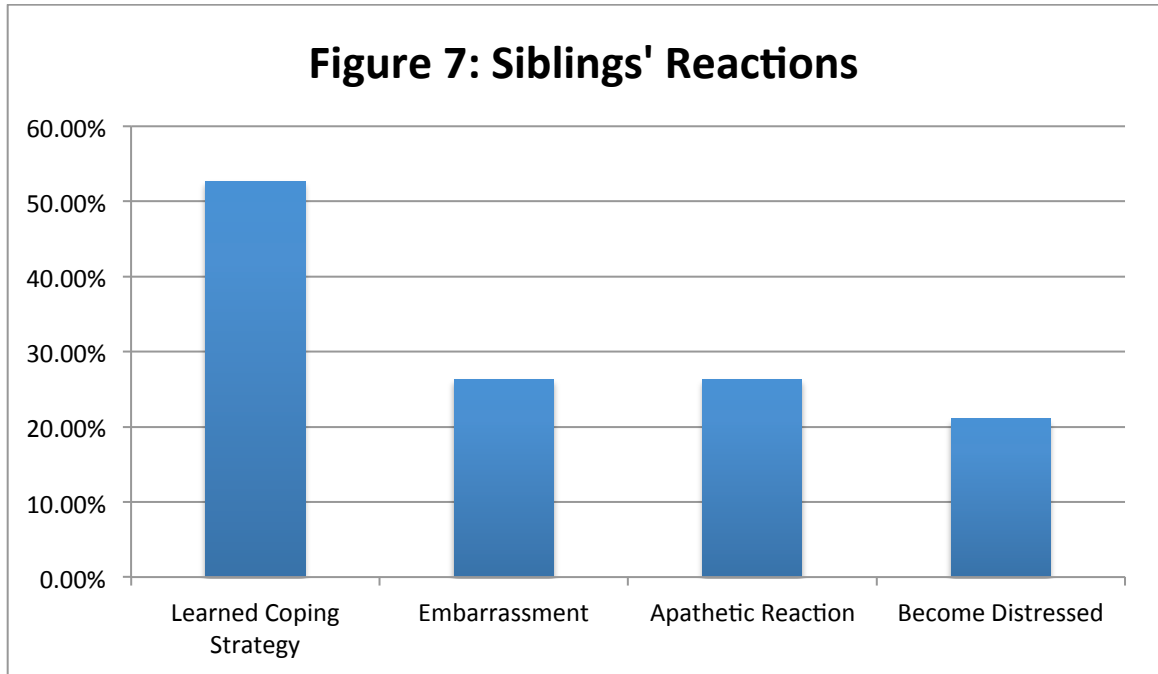


Sibling Relationships

Siblings share a bond that is unique to any relationship formed with any other human being. This study found that according to the parents' perception, the relationship between the child with autism and their sibling(s) is comparable to that of a normal sibling relationship. This was true for 65% of the parents who completed the portion of the survey inquiring about sibling relationships. 20% of the parents reported that there was little interaction between the child with autism and the typically developing child, while 15% said the typically developing child often acts as a "helper" for the child with autism. This study also conveyed, over half of the parents, 53%, said the typically developing child has learned coping strategies on how to help their sibling when they display characteristics associated with autism. Other reactions the typically developing child had when their sibling with ASD portrayed these autistic behaviors were embarrassment, distress, and apathetic. 37% of parents who completed the sibling questions of the survey reported they had have different disciplinary actions for the child with autism compared to their typically developing child. 33% said they tend to discipline the child with

ASD the same as their other children in most situations, but not all. One parent commented in the description box that they do not discipline the same because their child cannot comprehend what she did wrong, but have strict disciplinary actions when she is being purposely defiant. 15% promote equal disciplinary actions for the child with autism regardless of the situation. Another 15% reported they make more exceptions for their child who is diagnosed with ASD.





Discussion

Problematic Behavior Occurrences

This research conducted analyzed the time of day and what social activities increase problematic behaviors related to autism. The results disclosed that problematic behaviors occur on a daily basis for more than half of the families who had a child diagnosed with ASD and participated in this survey. It is evident that problematic behaviors peak during un-routine events, however the research also confirmed that these behaviors occur during routine events such as mealtime and bedtime. This directly correlates to the former study mentioned earlier which also concerned behaviors during mealtime and bedtime. Whenever these mealtime routine activities were disrupted, 82% of mothers reported behavioral challenges that affected the family as a whole (Marquenie, Rodger, Mangohig, & Cronin, 2011). This study assessed particular social situations in which autistic behaviors are increased. The results found that other than non-routine events, the child not getting their way was another instance where problematic behaviors associated with autism peaked. Attending doctor appointments and shopping also resulted in these behaviors being displayed. Parents deserve to know what type of activities routine or not, may impact the behavior of their child with ASD. That way they could be prepared as possible for these situations, and construct a positive coping mechanism to help all of the members of the family.

Identifiable Behavioral Characteristics of Autism

Autism is defined as being a developmental disorder that interferes with communication and social aspects (American Speech-Language-Hearing Association, n.d.). Early intervention is important in the diagnoses of autism so appropriate actions can take place as soon as possible. Since there is a window in language development for a child, the faster a delay is noticed, the

more manageable the situation is. Distinguishable traits are ones that cause concerns to the parent to the point where they contact a pediatrician or other child developmental specialist. For this study the researcher asked the 27 parents who took the online survey what the first autistic characteristics they identified in their child. The most common behavior was language delay at 67%, followed by meltdowns at 63%, and minimal social interaction at 59%. This compares to the previous research that concluded the top three identifying features of autism that led parents to be concerned about the development of their child were: language delay/regression, problems with eye contact, and repetitive behaviors (Kishore, & Basu, 2014). Other behaviors that concerned parents were resistance to be touched, sensory issues, and stimming of objects. The age at which these delayed behaviors are noticed is important to identify, so parents can be educated on what to be looking for during developmental milestones that might be linked to a disorder like ASD. The former study mentioned above found the average age that the mothers identified these autistic characteristics was 2.2 years (Kishore, & Basu, 2014). The online survey confirmed that most parents noticed autistic behaviors between seven months and two years. 33% noticed behaviors between 7 months and one year and another 33% picked up on behaviors from age one to two years. This totaled as 66% who observed autistic traits by two years of age.

Sibling Relationships

Siblings tend to be raised with similar values and rules that guide them throughout their lifetime. As mentioned earlier the sibling relationship is one of the most personally rewarding relationships a person experiences during their life (Brody, 2004.) Research shows that typically developing children are impacted by having a sibling with ASD. These typically developing children often experience more anxiety, as well as have more negative interactions with the child diagnosed with ASD (Pollard, Barry, Freedman, & Kotchick, 2013). The majority of parents who

completed the sibling portion of the survey expressed that their typically developing child has learned coping strategies in dealing with their sibling's autistic behaviors. Former research stated in the literature review found that parents of children diagnosed with autism are resilient in adapting to the challenges of caring and raising their child with autism (Tway, Connolly, & Novak, 2007). This can explain why typically developing siblings must also figure out adaptive strategies to help cope with the autistic behaviors. Parents get to see interactions between their children firsthand and can construct a reliable judgment of the relationship between the siblings. In this study the researcher examined the relationship between the child with ASD and the typically developing sibling(s). The study found that according to the parents' perception the relationship between the child with autism and their sibling(s) is comparable to that of a normal sibling relationship. The study also asked parents about the disciplinary actions toward their child with autism. The research was similar to previous studies resulting in 37% of parents having different disciplinary actions for their child with ASD. Earlier research viewing mealtime found that parents consider this task stressful which often resulted in the child with autism being exempt from standard rules set for the rest of the family (Marquenie, Rodger, Mangohig, & Cronin, 2011).

Limitations

A possible limitation of this study includes the inability to collect data from a larger demographic group. The survey link was shared through social media, more specifically on Facebook in various Autism related groups. It was also promoted by the primary researcher through a status that was shared with multiple friends who have a child diagnosed with autism. This could account for many of the responses of the survey to be people located in Arkansas. Also no socioeconomic factors were taken into account, so parents taking the survey could all

have been educated and known the developmental signs associated with autism, which would skew the age of identification. Another limitation is the study did not account for which parent; mom or dad completed the survey. It also did not have the parents specify if their child diagnosed with autism was male or female.

Future Directions

The ability to identify behaviors that indicate a developmental delay is vital to implement the idea associated with early intervention. If parents were aware of the warning signs of autism they would be able to recognize when a certain behavior is abnormal.

It is evident that more nationally based research should be done to confirm behaviors associated with autism. A more detailed survey should be sent out to a larger demographic area. The information regarding the sibling relationship could be categorized based on which parent, mother or father, completed the survey, and compare the different views of the mothers versus the fathers.

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