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Through My Eyes: The Effect on Family Life of Having Siblings with Autism Spectrum Disorder as Experienced by a Typically Developing Adolescent

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Through My Eyes: The Effect on Family Life of Having Siblings with
Autism Spectrum Disorder as Experienced by a Typically Developing Adolescent

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Abstract

As the prevalence of Autism Spectrum Disorder (ASD) continues to increase, research efforts have begun to focus on the effects a person with ASD has on family life. The dominant voice in the extant literature is that of parents and caregivers, but only a small body of research explores the experiences of siblings. Using a phenomenological approach, a qualitative study was conducted to understand how a typically developing (TD) adolescent experiences the effects of having siblings with ASD on family routines and activities. Findings indicate that the family's performance context—including routines, relationships, and activities—acts as the mediator of the bidirectional relationship between the siblings with ASD's person factors and the TD adolescent's identity. These findings support the use of a family-centered approach in occupational therapy when working with individuals with ASD and tailoring interventions to support the needs of all.

Background

Autism Spectrum Disorder (ASD) is a developmental disability characterized by difficulties in social-emotional reciprocity, nonverbal communication, and the formation and sustainment relationships. Individuals with ASD may also display limited but immersive interests and a preference for repetition and routine, including behaviors and actions (American Psychiatric Association, 2013). The most recent estimates, based on data collected in 2010, report that 1 in 68 children have autism (Center for Disease Control and Prevention, 2014). As the prevalence increases, more research is required to understand the effect of having a family member with autism on family routines and activities from the perspective of each member, including siblings.

Family occupations consist of the routines and rituals family members collectively participate in. Segal (2004) noted that routines organize and coordinate behaviors to achieve instrumental goals. When these routines evolve into symbolic and meaningful experiences, they become rituals. The meaning associated with rituals contributes to a family's identity. When a family is unable to construct routines, meaning is lost and a family's identity is negatively affected. Families with a child with ASD and families with typically developing (TD) children maintain common routines, but differ in how their routines are carried out (Bagatell, Cram, Alvarez, & Loehle, 2014). DeGrace (2004) found four major themes regarding the ways families with a child with ASD experience everyday life. They were 1) family life revolves around

autism, 2) families felt robbed of the experiences families with TD children have, 3) means of occupying and pacifying the child with ASD were often used to keep them in a “manageable” state, and 4) moments that captured the identity of the family were fleeting. While family routines have been found to increase health and well-being for family members, stress associated with having a family member with ASD can have the opposite effect. For example, mealtimes, which are normally routines but can become rituals when meaning is ascribed, are engaged in and rated as more important by families with TD children than families with a child with ASD. Challenges faced by families with a child with ASD include accommodating for a variety of palates and eating together as a family. These require more organization and effort to overcome, and thus may occur less often and hold less meaning than families with TD children. Family routines tend to be centered on the child with ASD, which can prevent them from holding meaning for the family as a unit (Rodger & Umaibalan, 2011).

The life of a family is created by the dynamic interaction of each member’s needs and their fulfillment (Seligman & Darling, 2009). These dynamic interactions develop into routines, which are centered on the roles of the family members (Larson, 2006). Some typical family roles include a parent also identifying as a worker, or a child also identifying as a student. When a family member has multiple needs and cannot meet them independently, such as a child with ASD, other family members will prioritize their own needs to ensure the needs of the child with ASD are met. Routines then become organized around this child, leading to more structure, less

spontaneity, and often the inability to fully meet the needs of every member (Boyd, McCarty, & Sethi, 2014).

Shared family routines are important for stabilizing, creating a collective identity, promoting health, and ensuring well-being (DeGrace, 2004). Families with a child with ASD make accommodations to activities to ensure the whole family can participate. By increasing flexibility, modifying participation, manipulating the environment, choosing activities based on the child's preferences, and having alternate plans, families are able to "occupy and pacify their children with ASD to allow them to engage without behavioral disruptions" (Boyd et al., 2014, p. 329). However, the rigidity of family routines often negatively affects health and well-being, instead contributing to feelings of stress and disappointment (DeGrace, 2004). DeGrace (2004) demonstrated, sometimes occupations that usually bring families together require too many accommodations to still hold meaning for the rest of the family.

When a family member has autism, family dynamics can change and affect relationships. This is true for sibling relationships. Smith and Elder (2010) pointed out the disparities in the literature on the effect of having a sibling with a disability. Some studies reveal that siblings of individuals with disabilities have high stress levels, low self-competence scores, and poor psychosocial adjustment. Other studies have found high levels of empathy and patience, high self-concept and social competence, and few behavioral problems. All of these findings are valid, as individual experiences vary. Sibling relationships depend on what disability the individual

has, how it manifests itself, and how the family chooses to react to it. Bachraz and Grace (2009) found that family dynamics play an important role in shaping sibling relationships, where sibling relationships were rated stronger when the diagnosis was less severe. Regardless of birth order, TD siblings often take on the “big brother” or “big sister” role to a child with autism, assisting them with self-care tasks and teaching them life skills. While it would seem that this added responsibility would increase the stress of the TD sibling, it was not perceived as burdensome, but merely “ordinary and intrinsic to their life and the role they played in their family” (Bachraz & Grace, 2009, p. 322).

Although research concerning the effects of a child with ASD on sibling relationships exists, the dominant voice is that of the parent and their understanding of their children’s relationships (Smith & Elder, 2010; Petalas, Hastings, Nash, Reilly, & Dowey, 2012; Orsmond, Kuo, & Seltzer, 2009). Since these studies have relied on parents’ reports of the quality of sibling relationships, they have therefore only been able to make inferences about the TD sibling’s quality of life. Moyson and Roeyers (2011) stated “sibling research should focus on hearing the voices of siblings by asking them directly for their perspectives, by attempting to understand their adjustment, and by having them identify areas of needed support” (p. 42). I agree with this statement, as the sibling’s perspective is underrepresented in the present literature.

The conclusion that having a sibling with ASD or another disability is a negative experience is at odds with the few studies that have directly explored TD siblings’ perspectives.

Findings have showed that TD siblings expressed positive effects of having a sibling with ASD, such as empathy, acceptance, and an understanding of disability and diversity (Bacharaz & Grace, 2009; Petalas et. al., 2012). There is a need to be more cognizant of family routines and activities from the perspective of TD adolescents with a sibling with ASD. By gaining a more complete understanding of the influence a child with ASD can have on all family members, professionals will be able to better support the family as they face and overcome the challenges of autism.

Research Aims

The purpose of this study is to understand how a typically developing (TD) adolescent with siblings with Autism Spectrum Disorder (ASD) experiences the effects of their siblings on family routines and activities. Therefore, this study will address the following questions:

- How do TD adolescents with a sibling with ASD describe family routines and activities?
- How do they describe the actions and behaviors of their siblings with ASD in the context of family routines and activities?
- How do they describe the effects of the actions and behaviors of the sibling with ASD on family routines and activities?
- What does it mean to these TD adolescents to have a sibling with ASD in the context of family life?

Methods

This study utilizes a phenomenological approach. Phenomenology is “the study of people’s conscious experience of their lived-world” (Merriam & Tisdall, 2016, p. 26). It was initially developed by Edmund Husserl and was expanded upon by Martin Heidegger, a pupil of Husserl. Heidegger focused on the Being, or essence, of the human experience, and held that meaning comes from the context in which they live (Wilding & Whiteford, 2005). This study, like other phenomenological research, assumes there is an essence to experiences such as being a TD adolescent and having brothers with autism, and seeks to depict the structure of one experience.

Participant

Approval from the Internal Review Board at the University of New Hampshire was obtained. Participants were recruited through personal contacts, groups, agencies, and service providers that work with individuals with disabilities and their families. Research flyers were shared via email and featured in several newsletters. Purposive sampling (Robinson, 2014) was used with the following inclusion criteria:

- typically developing adolescent
- between the ages of 13 and 18
- in grades 7 - 12
- residing full time with their sibling with ASD

One participant was recruited for this study. A sample size of one allows for in-depth study and analysis of the phenomenon (Robinson, 2014). Pseudonyms have been used to maintain confidentiality. Ellen is a 16-year-old girl. She has two brothers, Ben and Kevin, both

of whom have Autism Spectrum Disorder. Ellen, Ben, and Kevin are triplets. Their parents are divorced and they live with their mother, but visit weekly with their father.

Data Collection

Data was collected using three semi-structured interviews and participatory observation (Creswell, 2012). Consent and assent was obtained from Ellen and her family before data collection began. An introductory interview was conducted in a public area chosen by Ellen to collect preliminary background information, including information about her life, her siblings Ben and Kevin, their relationship, and her family's routines and activities. The researcher, Ellen, and her family took part in a participant observation of a meaningful family routine or activity, which Ellen identified as bowling. A follow-up interview was conducted in the same public area to collect further data using observations from the bowling activity, questions about Ben and Kevin's influence on family routines and activities, and the meaning Ellen ascribed to being the sibling of two individuals with autism. Five months later during data analysis, a third interview was conducted via video call to clarify responses and check emerging themes. Interviews were audio recorded for later transcription and analysis, and field notes were recorded of observations (Merriam, 2014). Each interview took approximately thirty to forty minutes, and the observation lasted approximately two hours. See Appendix A for a full list of interview questions and field note prompts. Data collection spanned three weeks. This time period allowed the researcher and participant to build a rapport, as well as gave Ellen time to reflect on her experiences throughout the interview process.

Data Analysis

Analysis began with the transcription of data, when the researcher began to fully engage with it (Nayar & Stanley, 2014). HyperRESEARCH software (Version 3.7.3, ResearchWare,

2014) was utilized to transcribe the audio recorded interviews. A modification of the Van Kaam Method of Phenomenological Data as discussed by Moustakas (1994) was utilized to analyze the data. First, the researcher reviewed all transcripts and highlighted constituents related to the experience in a process of horizontalization. Each constituent was checked to ensure it contained a relevant piece of the experience and if it was able to be abstracted and labeled. Second, the researcher used HyperRESEARCH software (Version 3.7.3, ResearchWare, 2014) to code the data and develop clusters of meaning, which are themes that make up the core of the experience. Examples of themes are displayed in Table 1.

Table 1: <i>Examples of themes</i>	
Advocacy Behaviors of siblings with ASD Behavior of sibling without ASD Effect of sibling with ASD Environment Fairness Different treatment of sibling with ASD Family routine/activity Major differences Mild differences Similarities Meaning	Chaos Characteristics of siblings with ASD Coping Strategies Mom Relationships Services Standing up for siblings with ASD Understanding Weekday routines Weekend routines Activities Activity Drivers

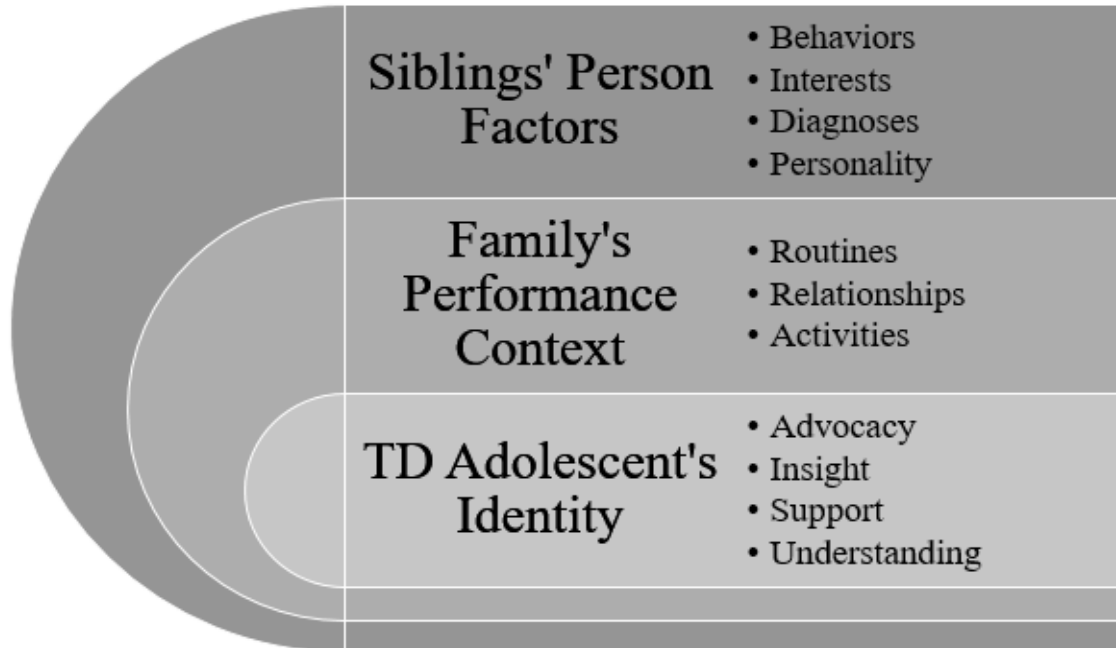
These clusters of meaning were checked against the original transcripts to ensure they were explicitly expressed. In order to validate themes developed and further refine them, the researcher met with her research advisor several times to discuss and analyze the data, ensuring that the interpretations were backed by the transcripts. Constituents and themes were used to develop a structural description of the experience, shown in Figure 1.

Trustworthiness was established through the use of multiple methods of data collection, including semi-structured interviews and participatory observation (Creswell, 2012). Multiple methods combined with discussions with a research advisor who was informed on the study and findings enhanced the validity of the findings through triangulation. The research advisor “asked the hard questions about methods, meanings and interpretations... and kept the researcher honest” (Creswell, 2012, p. 251). The third interview, which occurred during data analysis, was a source of clarification and member check, as the researcher asked questions to verify interpretations that had been drawn from earlier data.

Findings

A number of themes and subthemes emerged from data analysis. The first theme is the siblings’ person factors, including the behaviors, interests, diagnoses, and personalities of Ellen’s brothers. The second theme is the family’s performance context, made up of their routines, activities, and relationships. The third theme is the identity of the TD adolescent, Ellen, which included advocacy, insight, support, and understanding. See Figure 1 for a visual representation of all themes and subthemes.

Figure 1: *Structural representation of Ellen’s experience*



Siblings’ Person Factors

Diagnoses. Autism Spectrum Disorder often presents itself with comorbidities. For Ellen’s brothers, these include Attention-Deficit Hyperactivity Disorder (ADHD), Generalized Anxiety Disorder, Epilepsy, gastrointestinal disorders, and communication challenges. Ellen describes her brothers in the following quotes: “Ben is nonverbal, and he does struggle with communication,” and “Kevin's got autism, a little bit of ADHD, anxiety, and stuff like that.”

These comorbidities in combination with autism present a host of symptoms that have become a part of everyday life. During the participatory observation Kevin began having a seizure, but Ellen and her mother knew exactly what to do and handled the situation, and then continued bowling as if nothing had changed. Ellen summarized the situation perfectly when she said “Life kind of revolves around monitoring of side effects, seizures, um behavioral symptoms, meltdowns, and that's kind of how it works.”

Behaviors. Repetitive behaviors and actions are characteristic of individuals with autism. Ellen identified multiple behaviors of her brothers that influenced her family’s participation in routines and activities. She said “Sometimes [Ben will] shake his hands more, or he'll just get louder, start crying, [or] he'll start doing his little hobble.” These behaviors were demonstrated during the participatory observation at the bowling alley. Of her other brother, Kevin, Ellen said “He's a lot louder, he'll say things that aren't always necessary.” Ellen noted that the behaviors of her brothers have disrupted activities in the past. Another time she and her family had gone bowling, they had to wait for a lane to open. Ben began walking back and forth, shaking his hands and having a tantrum. Kevin was persistent and loud in his asking about when the lane would be ready and why it was taking so long. The most common behaviors of Ellen’s brothers were repetitive movements, tantrums, trouble with volume regulation, and persisting on specific topics.

Interests. Ellen discussed interests of her family. She said “We can go to hockey games, we can go bowling, and we can go swimming in the summer.” She also identified ice skating, roller coasters, and trampoline parks as other interests of Ben and Kevin. Their interests were directly linked to the activities the family participated in, and they were identified as the activity drivers. When asked if any of her interests influenced the activities her family participated in,

Ellen said “We kind of share a lot of [interests], like we all share ice skating... Other activities are kind of hard to do.” Ellen identified interests unique to her, such as driving and martial arts, but she chose to participate in these activities on her own.

Personality. Ellen’s descriptions of her brothers came to life when she discussed the attributes of their personalities. She said Kevin “has the guts to go do and say whatever he wants. He doesn't hold back, which is something I'm jealous of,” and Ben “understands how other people feel, like whenever I’m sad [he] notices, and he’ll come and hug me.” These descriptions brought to light her brothers’ strengths, and demonstrated that they are more than their diagnoses. She shared a story about Kevin where he was playing in a three-on-three tournament, and when his teammates made a goal on the other team Kevin was so excited that he skated out of the goal to congratulate them. The story did not mention any of his diagnoses or idiosyncrasies, but described Kevin’s personality.

Family’s Performance Context

Routines. Individuals with autism tend to have a preference for routine. School plays an important part in establishing Kevin and Ben’s routines, as it is the primary location where they receive services. Ellen described their school days as structured with little changing from day to day. Once the school day ended, everyone would come home at different times, and “it’s chaos for dinner, especially since Kevin is so picky and Ben’s on a diet, there’s three different meals going.” Due to their mother’s erratic work schedule, there was rarely a set flow to the night’s events. The structure provided by the school day turned into the chaos of the family’s nighttime routine.

Relationships. Sibling relationships can take on a unique dimension when an individual has ASD. Ellen describes her relationships as follows: “I do relate to Kevin a bit more... and

then with Ben the relationship is more silly and laid back... Both of the relationships I have are good, just the way they are expressed is definitely different.” Ben was kept back a year in school, so Ellen and Kevin are a grade above him. Ellen and Kevin are also on the same hockey team. Kevin and Ellen share experiences that allow them to relate to each other. Being able to talk to Kevin also helps. Ellen explained that sometimes she and Ben have trouble communicating because he is nonverbal, but she said they were close and identified herself as a translator for him when others can’t understand. Despite the challenges, Ellen was still optimistic and positive about her relationships with her siblings.

Activities. The activities the family participated in directly correlated with Ben and Kevin’s interests. As previously discussed, one of these was hockey. Ellen said “[At] hockey games, Kevin and I play, [and] my dad coaches. Ben will stand on the bench and then Dad will [say] ‘Hey Ben, throw the puck.’ And then Ben will just throw it.” A majority of the activities Ellen discussed, including hockey, ice skating, and riding roller coasters all took place with her brothers and father. When asked if there were any activities that Ellen, her brothers, and mother all enjoyed doing together, she said “It’s kind of a little [too] chaotic for that... My mom, she’s busy being the single parent and stuff like she has to work a lot to support the family.” There were few opportunities during the week for Ellen, her brothers, and her mom to do an activity together outside of the usual nighttime routine.

Typically Developing Adolescent’s Identity

Insight. Ellen was very insightful into the thoughts and feelings of her brothers, and helped them to express themselves. She identified herself as Ben’s translator, especially when she helps others to understand him and point out things that people may be missing. With Kevin, Ellen said she is not so much of a translator, but said this: “I can tell how he feels, but he has a

hard time identifying them... So I have to explain to him that he's nervous and sometimes when people get nervous they bite their fingers or they shake a lot.” With each of her brothers, she has an insight into how they feel and think, and help themselves and other to understand.

Advocacy. Ellen’s mother is steadfast advocate for Ben and Kevin. This quality rubbed off Ellen, and she demonstrated this through her multiple stories of standing up for her brothers, and helping them to stand up for themselves. She recounted one instance when her brother Kevin wanted to speak with a guidance counselor at school in order to switch out of a class. The paraprofessional working with Kevin insisted going back to class instead, and Ellen stood up for him. She said “I had this argument... and then I brought it back to the point where Kevin was able to come back and jump in... and he [says] ‘I have the right to go into the next class and I have the right to go see the guidance counselor.’ ” Ellen was able to help Kevin be a self-advocate and express his needs. He was successful in going to see the guidance counselor and switching into a class he wanted to be in. Ellen was very passionate about being an advocate, and shared an idea she had for a law “that basically encourages everybody with disabilities of all kinds to advocate for themselves. And schools cannot discourage it because I notice that whenever my brothers try to speak up it's discouraged. And I don't think that's cool because it's really inconsistent.”

Support. Using her insight into Ben and Kevin’s thoughts and feelings and her passion for advocacy, Ellen supports her brothers. In the previous example with Kevin going to speak to the guidance counselor, Ellen supported her brother by helping him work out what she wanted to say to the paraprofessional when he got anxious, and giving him an opportunity to jump into the conversation and speak his piece. She also spoke about a time she supported Ben in art class. The art teacher set Ben up with a canvas and began leading the rest of the class in a new project

involving tiles. The art teacher assumed Ben was at a lower skill level and wouldn't want to do the new activity although he had prior experience with it and enjoyed it. Ellen said ““They just assumed because he was a nonverbal kid that he wouldn't want to do it, and I'm like ‘No, the kid knows how to paint. He can handle tools. You teach him anything, and he can do it.’” She helped Ben express this to the art teacher, and soon he was working on the tile activity with all of the other students. Ellen supports her brothers by creating opportunities and assisting them in expressing themselves.

Understanding. When asked what it means to have siblings with autism, Ellen responded “For the sibling it means to have pride in people around you and you just accept more people. You tend to understand more people, and you just have more pride in your family.” This understanding was exemplified in Ellen's descriptions of how she helps her brothers understand and process their emotions. She understands what coping strategies work best for them, and helps facilitate different emotion-focused coping strategies. For Kevin this means blasting music in the car, squishing boxes, or organizing the recycling. For Ben this means offering social support, “giv[ing] him a hug and... just let[ting] him work through it.” The meaning and understanding Ellen gains from having brothers with ASD influences the way she supports and advocates for her brothers.

Discussion

The purpose of this study is to understand how a TD adolescent with siblings with Autism Spectrum Disorder (ASD) experiences the effects of their siblings on family routines and activities. The findings describe a bidirectional relationship between the siblings' person factors, the family's performance context, and the TD adolescent's identity. Kevin and Ben's diagnoses, behaviors, interests, and personalities influenced the activities and routines the family

participated in and the sibling relationships that developed between Ellen, Ben, and Kevin. The interests of Ellen's brothers were directly linked to the activities the family participated in. Needs of individuals with autism, such as a preference for routine, were met at school for Ben and Kevin with highly structured days. Unfortunately, this structure turned to chaos at home, where routines were hard to form around their mother's erratic work schedule. Despite the challenges, the findings suggest that family activities and routines supported sibling relationships. Shared interests that developed also appeared to foster positive personality characteristics in Ellen, Kevin, and Ben. The family's performance context was an important mediator between the siblings' personal factors and the TD adolescent's identity. While the siblings' personal factors influenced the family's performance context, the family routines, activities, and relationships provided opportunities for Ellen's identity to develop. Her qualities of advocacy, insight, support, and understanding developed out of these interactions with her brothers, and were utilized during future opportunities to support them. One example of this can be found in Ellen's future plans. As a high school senior, she was applying to colleges and considering different majors. She said "I was thinking about special education, maybe with elementary school kids... encourage them to advocate for themselves at a young age and let them do it." Her lived experience of growing up with Kevin and Ben combined with her personal characteristic of advocacy got her interested in helping others and pursuing a degree in Special Education.

Limitations

This study presented several limitations. While a small sample size is in line with a phenomenological approach, the findings of this single case study cannot be extrapolated. This study brings to light the experience of one TD adolescent in one unique family situation. The data from this study cannot be generalized to the entire population of TD adolescents with

siblings with autism. However, the data can be taken into account to further inform practice when working with this population. Future research should aim to increase the sample size and explore the lived experiences of others involved, such as parents, friends, teachers, service providers, and the individuals with ASD themselves.

Implications

Occupational therapists can take the findings of this study into consideration when working with individuals with autism and their families. The data supports the family-centered approach occupational therapists already utilize. However, this study urges occupational therapists to continue utilizing a family-centered approach even as the individuals with ASD enter adolescence and young adulthood. The needs of the whole family should be taken into consideration, especially those of the siblings. In order to fully address the needs of all family members, occupational therapists should address activities, routines, and relationships within a family.

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Appendix A

Interview Questions and Field Notes

Interview #1: Before Observation

- Demographic questions (age, gender, family size, birth order etc.)
- Describe your sibling(s) to me. What makes he/she/they different as compared to you?
How are they the same as you?
- What is your relationship like?
- Tell me about a typical school day. What interactions do you have with your family members? What does a typical weekend look like and what interactions do you have with your family members?
- Give me an example of a family routine or activity that is meaningful.

Field Notes

- The physical setting: What is the physical environment like? What is the context? What kinds of behavior is the setting designed for? How is space allocated? What objects, resources, technologies are in the setting?
- The participants: Describe who is in the scene, how many people, and their roles. What brings these people together? Who is allowed here? Who is not here that you would expect to be here? What are the relevant characteristics of the participants? Further, what are the ways in which the people in this setting organize themselves?
- Activities and interactions: What is going on? Is there a definable sequence of activities? How do the people interact with the activity and with one another? How are people and activities connected? What norms or rules structure the activities and interactions? When did the activity begin? How long does it last? Is it a typical activity, or unusual?

- Conversation: What is the content of conversations in this setting? Who speaks to whom? Who listens? Quote directly, paraphrase, and summarize conversations.
- Subtle Factors: Was there any informal and unplanned activity? Symbolic and connotative meanings of words? Nonverbal communication such as dress and physical space? Unobtrusive measures such as physical clues?

Interview #2: Following Observation

- Questions regarding observations.
- Can you identify your sibling's behaviors and actions during this routine/activity for me?
- How do these differ from your behaviors and actions?
- What effect does your sibling's behaviors and actions have on this routine/activity?
- In your opinion, what does it mean to have a sibling with Autism Spectrum Disorder in relation to your family life?

Interview #3: Clarifications for Analysis

- Update on family and sibling relationship.
- Can you describe your relationship with your brothers?
- You seemed very intuitive about Ben's feelings and intentions, could you talk about that? Are you this way with Kevin as well? Do you think you need to be?
- You talked about how advocacy is very important to you. Can you elaborate on this? Can you talk about a time you have helped each of your brothers advocate for themselves?
- You talked about spending time with your dad and doing activities like playing hockey and going to theme parks. Could you tell me about some of the activities you and your brothers do with your mom, if there are any?

- A lot of the activities you mentioned participating in seemed to be driven by the interests of your brothers or seemed to be a shared interest. Are there any activities you all do together that are driven by your interests?
- Are there any activities that you and your brothers do together afterschool?
- Do you ever have any friends over to the house? Do your brothers?