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Ready, set, go! Parents of children with autism spectrum disorder: decisions of readiness to visit a museum

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Thesis

READY, SET, GO!
PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER:
DECISIONS OF READINESS TO VISIT A MUSEUM

by

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READY, SET, GO!

PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER:
DECISIONS OF READINESS TO VISIT A MUSEUM

KAYLA MARIE PIRRI

ABSTRACT

Little is known about the factors involved in parents’ with a child with autism spectrum disorders (ASD) decisions to visit a community outing with their family. The purpose of this research is to describe the factors that families consider when making a decision to visit a museum of science with their child with ASD. Data were analyzed based on data from a previous study in which observations and interviews were completed in order to describe the experiences of nine children and their families visiting a science museum. The findings indicated that families considered their child and his/her age and abilities, the community environment, and the features of the activities in the community space as a family when deciding whether their child was ready to visit the museum. Additionally, parents appeared to consider their available strategies for use while in the community when making readiness decisions. The information learned in this study may aid families who are trying to appraise whether their child is ready for a family community outing. Additionally, findings from this research may benefit museums interested in creating inclusive experiences for families with a child with ASD. Recommendations are provided for future research in the area of readiness for community outings for families with a child with ASD.
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Introduction

For all children, participation in community activities promotes learning and development and provides structure to their life (Dunst, Bruder, Trivette, Raab, & Mclean, 2001). For children with autism spectrum disorder (ASD) and their families, participation in community activities can be challenging, due to the child’s functional limitations in verbal and nonverbal communication and social relationships (American Psychiatric Association, 2013). Consequently, families of children with ASD learn to modify their daily routines to support their child’s successful participation in community activities (Maul & Singer, 2009). Although researchers are beginning to understand how parents modify activities to support their child’s participation, little is known about how parents of children with ASD determine their child’s readiness to participate in a community activity. Understanding parents’ perspectives is important, as their perspective affects insights that may help to support families trying to decide if their child and their family is ready to participate in a community activity. Understanding parents’ experiences may also help to identify strategies to prepare children to develop “readiness” behaviors or skills for successful participation in community activities.

Participation

The examination of readiness for community activities is informed by the definition of ‘participation’ as it relates to engagement in an activity. The World Health Organization’s International Classification of Functioning (ICF) defines participation as “involvement in a life situation” (WHO, 2001, p. 10). Higher levels of participation in recreational, out-of school activities are associated with a better quality of life and
emotional well-being, more social competence, health benefits, and overall educational success in both typically developing children and children with disabilities (Law, Petrenchik, King, & Hurley, 2007; King, Law, King, Rosenbaum, Kertoy, & Young 2003). Conversely, participation is considered restricted when individuals experience any problems with their involvement in life activities (Bedell, Khetani, Cousins, Coster, & Law, 2011). Although participation is broadly defined, high rates of participation in all types of activities are correlated with positive outcomes in multiple facets of life.

Factors associated with participation. The ICF outlines many interrelated factors that may contribute to an individual’s ability and willingness to participate in an activity (WHO, 2001). The characteristics and demands of the activity itself act as either supports or barriers to participation (Bedell et al., 2013). Participation may include features of the environment or personal factors (WHO, 2001). The environment involves the physical space, social situation, the existence of supportive relationships between the child and parent(s), and the attitudes of the people within the settings in which the activity occurs (Bedell et al., 2011; Bedell et al., 2013; King et al., 2003). In addition to the environment, a child’s activity preferences, sense of competence, and other personal factors (i.e. physical, cognitive, emotional, communicative, behavioral, and social functioning) may also be associated with the degree of participation in an activity (King et al., 2003). Additionally, family factors such as a supportive home environment, the family preference for recreation, and family income and socioeconomic status are also related to participation, as these factors may provide more opportunities for community engagement (King, et al., 2003; Anaby et al., 2014). The ICF also includes health
condition and body structures and functions as factors potentially influencing activities and participation (WHO, 2001). Research has suggested that presence of a disability may impact the frequency and involvement of participation, but does not appear to be associated with activity preferences in children (Bedell et al., 2012; Anaby et al., 2014). Therefore, one’s participation in an activity encompasses several variables that may be associated with the quality, frequency, and degree of participation in activities.

**Community participation among children with and without disabilities.**

Children with disabilities have different activity participation patterns, participate in activities less frequency, and report fewer environmental supports when compared to typically developing children (Anaby et al., 2014; Bedell et al., 2013). Specifically, for children with ASD, participation is less frequent during structured community based activities, such as school activities, clubs, and organizations when compared to the participation of students without disabilities in these same community settings (Coster et al., 2012).

Current research reports that the environment plays a more prominent role in the participation of children with disabilities than it does for typically developing children (Anaby et al, 2014). For children with disabilities, community participation is influenced by the physical, attitudinal, and social environments; thus, these children are often observed to have lower levels of involvement and less frequent participation (Bedell et al., 2013). Additionally, child factors, such as the child’s perceptions of competence; physical, cognitive, emotional, behavioral, and social functioning; and activity preferences are all directly related to participation for children with disabilities (King et
al., 2003). For example, an individual’s participation may be influenced by whether the activity is formal and is organized, structured, and involves rules and goals, or whether the activity is informal and spontaneous, such as engaging in hobbies, crafts, or social activities (King et al., 2006).

Research indicates that parents and grandparents of children with developmental disabilities make accommodations, as needed, to facilitate participation for their child (Maul & Singer, 2009). To increase community participation and decrease problem behaviors, these families integrate positive behavioral supports within their family routines (Maul & Singer, 2009). Parents often describe a “tag team” approach, in which all members of the family contribute to and modify the routine in order to ensure success (Maul & Singer, 2009). Although we know that families with a child with ASD may utilize a range of strategies to support a successful community outing, we know little about the way in which these families appraise their child’s readiness to participate in a community-based activity.

**Museums and community participation.** Museums, along with other community sites such as libraries, schools, and churches, are community settings that emphasize learning (Ellenbogen, 2002). While schools exist as formal learning environments that are curriculum-based and teacher-facilitated, museums can be considered informal learning environments due to their voluntary and open-ended nature (Ellenbogen, 2002). Furthermore, museums are places where families can learn together, exchange information, and interact with exhibits both within their own family and with other visitors (Ellenbogen, 2002). A museum is a place where families can engage in
conversations about abstract or general ideas or concepts (Crowley & Jacobs, 2002). This learning can be planned, but it can also be unintentional (Crowley & Jacobs, 2002). For example, in research completed by Ellenbogen (2002) with typically developing children, one family described visiting museums as an educational activity where they could “leave the books behind,” “bump into information,” or “hang out with stuff” (p. 91). Crowley and Jacobs (2002) explained that typically developing children can build “islands of expertise” at museums, where they develop rich knowledge about a topic of interest and are given the opportunity to apply learned facts to museum exhibits. Current research reflects the idea that museums are informal community settings where families can develop knowledge while interacting with each other and other community members.

**Museums and ASD.** Families with a child with ASD have described two main motivations for visiting museums: (a) accommodating their child’s interests and (b) having “family time” (Langa et al., 2013). Langa et al. (2013) interviewed 10 families with a child aged 7–11 with ASD and found that a primary motivation for visiting a museum was to visit exhibits that were consistent with their child’s interests. This motivation is congruent with the theory of building “islands of expertise,” as parents supported their child’s interest in a particular area by enabling learning through interaction with a museum exhibit (Crowley & Jacobs, 2002). For families with children with ASD, goals for a museum visit were “to be pleasantly occupied together as a group, to enjoy ourselves, to be mentally stimulated and to be better informed” (Langa et al., 2013, p. 326). Additionally, museums were viewed as a leisure activity that allowed for relaxation and interaction with others (Langa et al., 2013). Although families that
include a child with ASD described motivations similar to families with typically
developing children, they also described challenges such as long lines, crowds, new
stimuli, and their child’s unpredictable behavior (Langa et al., 2013). Consequently,
deciding to visit a museum may require consideration of a range of factors for families
with a child with ASD.

**Readiness**

The term ‘readiness’ does not have an explicit definition in either the education or
disability literature, although the term is most commonly used when discussing readiness
for school transitions from grade to grade. The National Association for the Education of
Young Children (2009) identifies the need for the readiness term to be “flexibly and
broadly defined” and include all of the domains that reside within the child (p. 1). This is
likely because readiness has been described as an entity residing within the child that
gradually evolves as the child develops (Wesley & Buysse, 2003; Powell, 2010).
Although age is not directly related to readiness, a child’s readiness does increase as he or
she participates in a wider range of experiences (Wesley & Buysse, 2003; Docket &
Perry, 2009). Readiness is also measurable and observable, and influenced by factors
such as families, environments, schools, and communities (Maxwell, 2004; Docket &
Perry, 2009).

**Readiness to visit a museum for children with ASD.** Little is known about how
families with a child with ASD determine their child’s readiness for a community outing,
such as a visit to the museum. Only one research study was identified, in which
McNamee (1987) discussed how parents of typically developing children, ages 3 to 8,
determined their child’s readiness to visit an art museum. McNamee (1987) identified three factors that help support museum readiness: creating a home environment that facilitates excitement for museum exhibits, facilitating sensory development, and facilitating a sense of story related to the museum visit. McNamee (1987) emphasized the importance of beginning with (a) ‘participation museums’ before progressing to ‘observation museums,’ (b) a short stay before a long stay, (c) a smaller group before a large group, and (d) a focused or purposeful visit before a visit that spans a wider range of areas. In order to facilitate a child’s readiness, McNamee (1987) recommended that, a few days prior to the museum, the child should be told what to expect and shown what to expect using pictures. Although this research does address children’s readiness to visit a museum, it is limited in that it only addresses readiness for an art museum for typically developing children. Furthermore, this research was conducted over 25 years ago, before resources and information could be accessed through the Internet.

Despite the growing appreciation of the museum as an appropriate and enjoyable community setting for families that include a child with ASD, there is limited research addressing a child and family’s readiness to visit museums. Furthermore, the research has not addressed the needs of children with ASD and their families. An examination of the ways in which families decide whether their child is ready for a science museum outing will augment the existing literature and highlight factors to consider for families who are trying to determine if their child is ready for a museum visit or a similar community outing in the future.
**Research Question**

The goal of this research is to understand how families decide that they are ready to visit a community venue, such as a science museum, with their child with ASD. By increasing our understanding of “readiness,” we may be able to make recommendations to families hoping to participate in a community activity with their child with ASD in the future.

The study will address the following questions:

1. How do parents with a child with ASD determine their child’s readiness to participate in a museum visit? And
2. According to parents, what factors indicate their child’s readiness to visit the Museum of Science, Boston (MOS)?

**Method**

**Participants**

Data were obtained from a sample of 9 families with a child with ASD aged 7 to 11 years. The families all lived within 20 miles of the MOS, and all children had a parent-reported diagnosis of Asperger syndrome (n=1), autism spectrum disorder (n=2), or pervasive developmental disorder-not otherwise specified (n=8). Eight males and three females with ASD ranging in age from 7–11 years (Mean age = 9 years) participated in the study; one family who participated had triplets, two of whom had ASD. Six families visited the museum with two parents, while two families visited with just a mother, and one family visited with a mother and grandmother. Additionally, four families visited with one sibling, two families visited with two siblings, and one family visited with two cousins. The duration of the visit ranged from one hour to six hours,
with the number of exhibits visited ranging from 6 to 29. Written consent from parents and verbal assent from children with ASD and siblings was obtained before collecting data. See Table 1 for participant demographic information.

Recruitment of families was completed through personal and professional contacts, as well as from an existing database at the MOS. A research team member conducted an initial phone screening to ensure that the child had a diagnosis of ASD from a professional.

Data Collection

The data used in the current analysis were originally collected during a collaborative study between Boston University and the Museum of Science, Boston (MOS). The purpose of the original study was to understand the experiences of families with children with ASD visiting the MOS. Research team members from either Boston University or the MOS completed semi-structured interviews and observations of nine families visiting the museum. An initial home-visit interview was first completed with all participants, in which each family member, including the child with ASD (age 7 to 11), parent(s), and siblings (age 7 to 11) were interviewed prior to their visit to the MOS. Parents, siblings, and the child, if s/he could communicate verbally, were asked questions about the upcoming museum visit including questions about past experiences, expectations for the visit, what they have done to prepare for the visit, and hopes for the visit (see Appendix). The same research team member then observed the family during their museum visit, and recorded qualitative field notes at every exhibit visited using a semi-structured observation protocol that was provided by the MOS. A second interview
with all members of the family was completed at the museum immediately following the visit regarding their feelings about the visit, preparatory actions or strategies used before or during the visit, strategies that were and were not successful, and plans to return. With permission, all interviews were audio recorded. Two occupational therapy graduate students and MOS research staff transcribed and analyzed responses to interview questions and observation notes using NVivo software. The researchers developed initial codes and definitions for each code based on the initial research questions. Based on frequent comments from parents reflecting on their child’s readiness to participate in this community outing, the researchers identified the open code of “readiness.” We then conducted a focused analysis of transcript data initially coded as readiness.

The Person-Environment-Occupation Model (PEO) provides a broad framework for data analysis. In this model, the environment is viewed as a resource, an enabler or facilitator of performance, as well as a feature that can present barriers or demands that can hinder performance. Human behavior is the outcome of the transaction of the person’s abilities, the environment and the demands of the activity or occupation (Law et al., 1996). Consequently, I considered the child’s intrinsic characteristics that supported his or her “readiness” and the transaction among the environmental context and activity demands of visiting a museum. My past experiences working with children and adolescents with ASD diagnoses in both daycare and middle school settings influenced the analysis. Expectations for children in formal education settings often provide a benchmark for determining a child’s readiness for grade transitions and other school activities. These experiences have undoubtedly shaped interpretations of readiness to
participate in a community setting.

**Data Analysis**

Using principles informed by grounded theory, seven researchers, including two Boston University professors, two Boston University graduate students, and three members of the research team at MOS reviewed transcripts to develop consensus regarding initial open codes related to the initial research questions (Charmaz, 2006). Initial codes included the following broad categories: strategies, facilitators, barriers, definition of success, motivations for visit, and “ASD moments.” The readiness code was identified in this initial coding process. In coding the data, it was noted that parents frequently reflected on their child’s readiness to participate in the community outing at the museum. See Table 2 for list of initial codes.

First, all instances of readiness were identified within the data. The research team defined readiness as including at least one of the following elements: (a) a description of the parents’ feelings related to the child with ASD’s ability to be ready to visit the museum, and the family’s ability to be able/ready to visit the museum together; (b) the evaluation of risks noted by parents when deciding when the child with ASD and the family are ready; or (c) the description of actions taken by family members to initiate readiness.

Next, all instances of readiness were analyzed and new codes were created based on the recurring ideas expressed in the data such as the child’s age and developing skills; the parent’s evaluation of the facilitators, barriers, and perceived inclusiveness of the environment; the family’s past experiences and awareness of the child’s limits; the
strategies employed; and an overall decision of readiness (See Table 3). The new codes were reviewed with the research team to consider how the codes may relate to one another. The codes were grouped together into a conceptual framework to explain the process parents use to determine their child’s readiness for a museum visit (See Figure 1).

**Findings and Interpretations**

Several factors appeared to influence a parent’s decision to visit the Boston Museum of Science. Figure 1 illustrates the factors in these data that appear to be associated with parents’ assessment of their child’s readiness to visit the MOS. In this conceptualization, the child’s age and abilities, the environment and associated facilitators and barriers, and past experiences transact, demonstrating that parents consider the transaction among the activity, environment, and their child’s skills and abilities when making a readiness decision. Parents appeared to reflect on potential strategies and available resources to support a successful community outing as they considered whether or not their child and family was ready for a community outing, such as a visit to the Museum of Science, Boston.

**Parent Evaluation of the Child**

**Child’s age.** When speaking about their child’s readiness to visit the MOS, many parents referenced their child’s age at the time of the visit, stating that they felt their child was finally old enough for a community outing. Some families described experiences when they took their child places when they were younger and found that their child was not able to participate in the outing in a positive way. The Smith family reflected that they “never took a vacation until [their sons with ASD] were nine …nine was the first
year and it was an unmitigated disaster.” In the case of the Smith family, their children’s young age acted as a barrier in the past. Ms. Smith later reported that, now that her children are older, she believes her sons can be successful in community spaces. She stated, “I never thought that [Sam] would be able to handle it up to this point, and I think he can now.” Other families also described feeling confident that their child would do well at the museum as compared to the past because their child was now older. Kenny’s mother stated that she “wouldn’t be as worried about [her children] now that they’re older, but especially when [Kenny] was a lot younger, we always had to worry about him going off, you know, running away.” For most families, their child’s older age and abilities appeared to be a reassuring factor that their child would be successful in the museum.

Although many families voiced an opinion that the older their child was, the better they would do, other families described positive experiences when their children were younger. The Clark family described their successful visit to the museum when their child was still using a stroller:

“It was a success I would say because we were able to do it…He wasn’t really out of the stroller at that point, the last time we went, so it was easy to maneuver the stroller around, for him to get up close and see things. It made it a lot easier.”

Similarly, the Taylor family described a time where they “thought [Jacob] would be too young and it actually was great.” For these two families, visiting the museum when their child was younger was successful, as they were able to utilize strategies such as handholding or a stroller to navigate the space. Conversely, the Johnson family described their challenges with having an older, pre-adolescent child when they stated, “I think he’s getting to the age where he kind of likes to be on his own and we want to get him more
social, you know?" In this account, the Johnson family associated their child’s age with his increased desire to be alone, therefore presenting a barrier to engaging him in family time.

For some families, the child’s younger age was used as a reference point to define success. Ms. Newman described a change in her definition of what a successful visit was when she stated, “if it was two years ago, it’d be a way different story of what is successful.” For the Newmans, the child’s age influenced their expectations for the family outing, as Ms. Newman had higher expectations for her daughter as she got older and she developed more skills over time. Similarly, when describing their child’s visit to the MOS, the Williams and Clark families both explicitly stated that the conversation and preparation about the visit would have been much different if it was happening two to four years prior, again due to their children’s older ages and more advanced skills.

**Child’s developing skills.** Closely related to their child’s age are the child’s developmental skills and behavioral changes that evolve over time. Families described their child’s gains in communication, flexibility, calmness, and curiosity that they attributed to age. The Newman family recalled that community outings were difficult because their daughter used to have “meltdowns” when they were in a public place if there was a loud or unpredictable noise. The Williams family described that their daughter, Kelsey, used to have difficulty when a lot of children were around, but is now able to “tolerate a bunch of little kids knocking into her and running around.” They attributed Kelsey’s ability to remain in a space to her recently developed ability to “center herself, and then go calm down and then go back to the activity [they] were doing.” The
Davis family commented that their son’s attention span and motivation to explore environments has increased as their son has gotten older. Because these families ultimately decided to bring their child to the MOS, it appears that the child’s evolving skills influenced their decision.

Parents also described community outings with their child as a learning process that evolved and in which parents learned more about their child and his/her limits over time. The Newman family recalled that when their child had difficulty in a community space in the past they wondered, “What do we do, do we leave or what?” Similarly, the Smith family stated that now they “recognize when the breaking points are so we know…it’s four o’clock so let’s get going.” Likewise, Ms. Clark also described that her family has learned to adapt to Cory’s needs, including his need for routine and his short attention span. She also stated that Cory’s limits have changed over time and explained how his worst days are not as difficult as they used to be when he was younger.

Therefore, parents not only became better able to understand their child’s cues and limits, but their children were also able to remain in community spaces for longer amounts of time as they become older and developed behavioral skills.

**Parent Evaluation of the Environment**

**Evaluating facilitators and barriers.** When speaking about readiness for a community outing, parents also described the supports and barriers of the environment, and compared these environmental factors to their current trip to the MOS. The Taylor family mentioned that a strong motivating factor for visiting the MOS in the past was to visit the dinosaur exhibit, as their child was “a serious, serious dinosaur fan,” and they
found the outing to be positive. Similarly, the Clark family reflected that they believed their child would have a positive experience visiting the MOS because their child “loves the city. He loves sitting on the trains and loves the ride in [to the city]. He loves seeing the buildings.” Therefore, the degree to which the environment is consistent with the child’s interests appear to be a factor in parent’s decision to visit a particular community space with their child.

Conversely, the Williams family described an experience in which they took their daughter with ASD to the zoo because she loves animals, but she was unable to safely remain in the space, due to “the people around…the noises…the smells, the brightness, anything.” The Smith family also stated that crowding and heat during their visit to the zoo interfered with their community participation for their family. Several families mentioned that they developed strategies over time to address environmental barriers, such as visiting a space when it was less crowded. Thus, we see that the environment can play a role in a parent’s decision of whether or not the child will be ready to be successful in the space.

Perceived inclusion. In addition to the physical environment, two families considered whether or not the environment was inclusive and accepting of their child. The Williams family described past experiences in places similar to the MOS in which they were given the “evil eye” when their child showed challenging behaviors while in public. Mr. Williams reported that others would scold him for not spanking his child when she would have “meltdowns” and shared that he believed others thought he could just “spank the autism out of [his daughter].” Mr. Williams later described that, overall,
he was impressed that people appeared accepting of his daughter and family when visiting the MOS. Ms. Davis described negative experiences that she had when her son began screeching in public and “people look[ed] at him and his hands.” However, Ms. Davis later reflected that she thinks, “a lot of people know about autism these days.” It appears that, for these two families, over time, they have felt increasingly more included in community spaces due to increased awareness about ASD and when choosing to visit environments that they felt were more inclusive, such as the MOS. In considering the accounts of the Williams and Davis families, it would appear that inclusivity may influence parents’ assessments of whether or not their family should visit a space and/or their appraisal of how successful the outing was.

**Parent Evaluation of the Activity**

**Remembering past community outings.** In evaluating readiness to participate in a family community outing with their child, parents frequently referenced past community outings with their child. Some parents reflected that they had been to similar venues prior to visiting the museum. Ms. Clark remembered,

“We went to the Museum of Science and History two months ago and it’s a much smaller scale in comparison, but he’s been to those environments before. He’s been to the aquarium, he’s been to other places, we’ve been to an alligator farm too. We just haven’t made it to the Museum of Science, we just haven’t done it yet.”

The Taylor family also reflected on a past experience that they had at the MOS in which they believed their child would be too young to visit, but he was successful. The Taylors voiced feelings of readiness for this visit to the MOS because visiting this museum was a familiar outing that they had been successful in in the past. This family stated that they
had been hoping to visit the museum again for a while but stated that they have not made it back because of budget and time constraints.

Some parents remembered negative experiences that they had had in similar settings. Ms. Smith described a difficult trip to an aquarium stating that, “it was well over 100 dollars and my son lasted 15 minutes…we just turned around and went home in defeat basically!” Ms. Smith mentioned that her cautiousness for visiting a community outing stems from being “afraid to spend all that money and having to turn around and leave the moment [they] got there and it’s also frustrating for the other two [the siblings]. Like, if we’re there and they want to see stuff and we have to turn around and go home because their brother can’t handle it. It’s always…it spoils it for them, you know?”

She explained that she has been cautious after their experience at the aquarium, but later had a positive experience at a children’s museum, leading her to feel hopeful that her family might have a positive experience visiting the MOS. She stated, “I think at some point this year we probably would’ve gone [to the MOS] anyway because I just feel like he’s ready now.”

Alternatively, both the Taylor and Clark families made a direct connection between their families’ positive experiences in similar community outings in the past and their current decision to visit the MOS. Although Ms. Smith reflected on past experiences where her family was unsuccessful at the aquarium, she also remembered a positive experience at a children’s museum. She, too, voiced that, because her child was successful at a children’s museum, he would likely be successful at the MOS. For all three of these families, it appears that they reflected upon how successful they were during past experiences, and compared these venues to the MOS to determine whether
they believed their child would be successful in another community setting. Therefore, it appears that a family’s past experience helps frame their thinking regarding their child’s readiness for a visit to the MOS.

**Parent and Family Readiness**

**Evaluation of available strategies.** The families mentioned strategies that they utilized during community outings to ensure that the visit would be successful. Strategies that families mentioned included holding their child’s hand and/or using a stroller, having a very structured and “very in and out” visit, bringing a snack, and bringing items for positive reinforcement of desired behaviors. A frequent theme mentioned by multiple families was that they increased their child’s exposure to similar community settings. The Ryan family stated that Arnold has “evolved to be able to do this. It took us a lot of years to be able to see all that we saw.” The Smith family mentioned that they would “just keep trying to expose [Sam and Sally], go for a little bit longer every time. Push a little bit more each time.” Several families echoed this strategy of slowly increasing the length of each visit. The Williams family shared that they have a systematic method for testing their child’s limits in a space. They described a process in which they directed their daughter to “go calm down and then go back to the activity [they] were doing. And then [they] try to do that once or twice, if not three times. Three times is [their] limit” before they leave the space. By evaluating the strategies they have available to use during a particular family outing, parents were able to decide if their child was ready and if they were able to adequately support their child’s success during the visit.
Evaluation of parents’ own readiness. In addition to evaluating the strategies that families have available to them, parents considered their own readiness to visit a space in addition to considering their child’s needs. Ms. Clark stated, “you have to kind of mentally prepare more for the what-ifs of what if he acts out?” She elaborated that although she anticipated that her trip to the museum would be fun, “that is, of course, our expectation. We’ll see scientifically what happens, you know, when we actually go.” She acknowledged that, although she had expectations for her child, those plans might have changed and she must be ready to adjust to this change. Ms. Smith echoes the theme of having to manage her expectations when she stated,“I guess it’s kind of a nostalgia thing to me in a way. Just ‘cause I’ve always wanted to go and I’ve always wanted to take the kids and I’ve never been able to take them at all…It’s one of those things that you always anticipated that you would do these things with your kids and then when they have special needs sometimes you can and sometimes you can’t. So we’ve just had to adjust our expectations a lot.”

For Ms. Smith, her readiness related to her ability to manage her own emotions surrounding her hopes for a family outing. For both the Smith and Clark families, it appeared as though their own readiness for a family outing related to their ability to adapt their expectations of what might occur while in the community. When managing their own expectations, parents appeared to be open to a range of possibilities and were prepared to adapt their own expectations to meet reality.

Decision of Readiness

After a considering the activity, environment, the child’s age and abilities, and their own readiness as a family, parents in this study decided to visit the MOS. When describing their decision to visit the museum, the Smith family stated that they “just feel
like he’s ready now” while the Davis family stated, “now he seems like he’ll be okay.” Other families expressed their positive expectations for the trip. The Clark family stated, “I anticipate as a family our trip will be fun… I anticipate it to be a typical family trip in comparison to the average person with a child on the spectrum that may not have a typical trip. I expect our trip to be more typical than atypical.”

**Discussion**

Interviews with parents with a child with ASD revealed that, when visiting a community outing, families appear to complete an activity analysis prior to their visit, similar to the reasoning processes used by occupational therapists (Crepeau, Schell, Gillen & Scaffa, 2014). In this activity analysis, parents consider the child and his or her age, preferences and abilities, the aspects of the environment, the activity and activity demands as related to past experiences in similar outings, and available strategies in determining their family’s readiness for the visit. In a study examining factors that affect community participation of school-aged children with and without disabilities, families of children with disabilities approached family outings by essentially completing an activity analysis, considering their child’s impairments and challenges in addition to the environmental factors including the physical and social aspects of the environment (Bedell et al., 2011). The findings in the current study are similar to the findings of Bedell and colleagues’ (2011). In both studies, parents reported considering their child and the activity within an environmental context and appraised strategies prior to visiting a community outing. However, the current analysis is more specific, as it focuses on
families with a child with ASD’s readiness to visit an unstructured, interest-based community space, rather than examining participation of children with a wide range of abilities in various activities and settings.

In the current study, families reflected on their child and his or her age and abilities and appeared to vary in their opinion as to whether visiting a space with a younger or older child was best. Some families mentioned that visiting community spaces was best with older children, because the child had better developed skills in calmness, flexibility, and an ability to center himself or herself. Conversely, other families felt that visiting when their child was younger was easier, as they could utilize strategies such as strollers and hand-holding and one family felt that their pre-teen child was less inclined to desire family time. Although families varied in the opinion about age, many parents mentioned that, as time progressed, they were able to develop a better grasp on what their child could tolerate and how long they could encourage their child to stay in the space before deciding to go home. For many families, these were among the several strategies that were developed over time by parents.

In addition to reflecting on their child’s age and abilities, parents also seemed to reflect on past community outings, comparing the environments to the MOS and past successes to decide whether or not their family was ready for the current outing. Even when families reflected on negative family outings that they had experienced in the past, they voiced that they expected a successful visit because their child was now older. Parents also appeared to evaluate the environment as it related their child’s interests and potential barriers. Parents identified barriers such as overcrowding and lines, noise, light,
heat and a lack of feelings of inclusivity. In Langa et al.’s (2013) research examining families visiting the Smithsonian Institution, parents identified similar challenges such as crowds, loud noises and unpredictable sensory stimuli, long lines, not feeling welcome, and their child’s behavior as negatively influencing their experiences. For the families in the current study, evaluation of the environmental barriers was closely related to the child’s age and skills, as many parents reflected that their child(ren) had developed the ability to tolerate aspects of the environment, such as noises and crowds that had previously been barriers for them. Thus, in the current study, we observed that parents’ considerations of these barriers appeared to influence their decision of their child’s readiness.

An analysis of families’ reflections on their MOS visit suggests that this activity analysis appears to be a continual process that occurs over time and is constantly considered before visiting a new space. As parents learned more about their child’s strengths, interests, and limits, they developed appropriate strategies, and were increasingly able to manage their own expectations for the visit over time. Likewise, parents reported that, as time progressed, their children were also able to participate meaningfully in a community space for increasingly longer periods of time, many times due to an increase in age, and oftentimes due to a development of skills. Therefore, as parents were accommodating their child and his/her needs, the child was able to accommodate to the family’s desire for an enjoyable family outing. A similar phenomenon is described by Bedell, Cohn, and Dumas (2005). They reported that families of school-aged children with acquired brain injuries (ABI) were able to appraise
the activity demands and their child’s skills in order to determine whether their child would likely be successful in a desired activity. These families also developed strategies to help ensure success for their children similar to the families in the current study, including, but not limited to, creating opportunities for participation, providing reinforcement, and providing structure and consistency. Parents in the current study also described an evolutionary process that occurred over time, as they provided their children with new experiences and tested and re-tested various strategies, such as bringing snacks, offering positive reinforcements, and planning shorter visits in order to ensure their family’s success. McNamee (1987) suggested that families with a typically developing child visiting an art museum should begin with short, purposeful visits before progressing to longer stays involving many exhibits. Parents in the current study describe their strategy development as a never-ending process that must be continually revised depending on the activity, environmental features, and the child’s abilities. As time progressed, these parents also became more accustomed to managing their own expectations and were better able to prepare for the range of possibilities that may arise. This concept is also echoed in Langa et al.’s (2013) research, documenting that parents of children with disabilities often monitor their own expectations when navigating a community space.

Limitations of this research study must also be considered. First, the families who participated in this study were not explicitly asked about their decision of readiness, as readiness was not the focus of the original study, but rather a concept that emerged from the data. Therefore, if families had been more explicitly asked about readiness, we may
have identified additional or different themes. Future research in which families are asked about their decision of readiness would be beneficial. Additionally, the nine families surveyed all had a child with ASD between the ages of 7–11. Because findings showed that their child’s age was a factor in some families’ decisions to visit a community space, future research would benefit from including participants with a wider range of ages to better describe the potential affect of a child’s age on his or her readiness. Finally, all families entered the study with the knowledge that they would be compensated for the price of their museum admission and that they would be observed by a museum staff member or Boston University occupational therapy student. These factors may have influenced these families’ decisions of whether or not to visit the museum, as there was little to no monetary risk, and there would be an additional person present who would be knowledgeable about ASD and the museum, should anything not go as planned. Despite these limitations, this study is the first to offer a description of the factors involved in families’ with a child with ASD’s decision to visit a community space.

**Conclusion**

Limited evidence currently exists that specifically describes how families with a child with ASD determine whether their family is ready for a community outing. In this study, we explored how nine families decided whether their family was ready to visit to the Museum of Science. These findings may be valuable to families who are also attempting to decide whether to visit a community space, as they delineate the components that contribute to other families’ readiness decision. As a result of this
research, an informational handout or flyer of readiness considerations could be
developed for families with a child with ASD who are hoping to visit a community space.
Furthermore, museums will likely benefit from the findings from the current study. Using
this research, museums could develop materials to post on their website for families with
a child with ASD seeking to visit their space. Additionally, museums can utilize aspects
of this research to help make their spaces more accessible for children with ASD and
their families, such as providing readiness checklists suggesting the skills and abilities
necessary to successfully visit the space. Future research examining the readiness of
children with ASD and their families visiting a community outing would be beneficial in
determining the extent to which families consider similar or different components when
visiting a community venue other than a science museum. Additional research examining
the readiness of families with children of varying ages might explain the way in which
readiness considerations or decisions may differ based on the child’s age and emerging
skillset. Extremely limited research currently exists that examines families with a child
with ASD’s readiness for community outings, and future research should aim to close this
gap in the literature in order to provide information for both parents and museum
personnel.
<table>
<thead>
<tr>
<th>Child with ASD &amp; family</th>
<th>Child age (years)</th>
<th>Parent-reported diagnosis</th>
<th>Length of visit (hours)</th>
<th>Number of exhibits visited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peters Family: Kenny, mother, brother (age 12)</td>
<td>10</td>
<td>PDD-NOS</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Newman Family: Nancy, 2 parents</td>
<td>9</td>
<td>PDD-NOS</td>
<td>6</td>
<td>29</td>
</tr>
<tr>
<td>Taylor Family: Jacob, 2 parents, brother (age 4)</td>
<td>7</td>
<td>Asperger syndrome</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>Ryan Family: Arnold, mother, brother (age 12), sister (age 10)</td>
<td>7</td>
<td>PDD-NOS</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Smith Family: Sally &amp; Sam, 2 parents, sister (age 11)</td>
<td>11, 11</td>
<td>ASD</td>
<td>2.5</td>
<td>14</td>
</tr>
<tr>
<td>Williams Family: Kelsey, 2 parents, sister (age 13), brother (age 6)</td>
<td>7</td>
<td>PDD-NOS</td>
<td>5.5</td>
<td>26</td>
</tr>
<tr>
<td>Johnson Family: Joseph &amp; Josh, 2 parents</td>
<td>12, 10</td>
<td>ASD, PDD-NOS</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Davis Family: Michael, mother, grandmother, two cousins (age 11)</td>
<td>7</td>
<td>PDD-NOS</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td>Clark Family: Cory, 2 parents, sister (age 6)</td>
<td>9</td>
<td>PDD-NOS</td>
<td>2</td>
<td>18</td>
</tr>
</tbody>
</table>

*a pseudonym.*
<table>
<thead>
<tr>
<th>Initial Codes</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motivations</td>
<td>Description of feelings, experiences, or aspects of the museum (exhibits, shows, etc.) that family members anticipate and look forward to in preparation for museum visit</td>
</tr>
<tr>
<td>Environmental features</td>
<td>Characteristics of the museum setting that support family experience (time of day, exhibit design, signage, benches, interactions with museum personnel or other museum visitors)</td>
</tr>
<tr>
<td>Strategies</td>
<td>Actions or thoughts directed at solving an immediate or ongoing problem or achieving an immediate or future goal (Merriam-Webster, 1993)</td>
</tr>
<tr>
<td>Successful visit</td>
<td>Description of a positive outcome, achievement, or a fulfilled plan; overall perspective of visit; memories from the experience</td>
</tr>
<tr>
<td>Motivations for visit</td>
<td>Description of feelings, experiences, and aspects of the museum (exhibits, shows, etc.) that family members anticipate and look forward to in preparation for museum visit</td>
</tr>
<tr>
<td>“ASD Moments”</td>
<td>Researcher observations or parent report of instances when child with ASD experiences challenges within the museum setting; A positive or negative behavior that you might not observe from a typically developing child visiting the museum.</td>
</tr>
<tr>
<td>Readiness</td>
<td>Description of parents’ feelings related to child with ASD’s ability to be ready to visit the museum, and the family’s ability to be able/ready to visit the museum together; evaluation of risks noted by parents when deciding when the child with ASD and the family are ready (time has passed and child no longer has meltdowns, siblings are old enough to help, able to attend to activity in community due to increased attention span, potty trained, etc.); description of actions taken by family members to initiate readiness (potty training, visiting other community settings, adaptive equipment, therapy, medication, etc.)</td>
</tr>
</tbody>
</table>
Table 3. Initial readiness codes and their examples

<table>
<thead>
<tr>
<th>Initial Code</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passage of time/Age</td>
<td>“I wouldn’t be as worried about them now that they’re older, but especially when [Kenny] was a lot younger, we always had to worry about him going off, you know, running away.” —Peters family</td>
</tr>
<tr>
<td></td>
<td>“[The aquarium] was well over 100 dollars and my son lasted 15 minutes and it wasn’t the fish. The fish were fine, but it was very crowded and it was very hot. It was raining outside, the place was packed and so you know, we just turned around and went home in defeat basically!” —Smith family</td>
</tr>
<tr>
<td>Prior Experiences</td>
<td></td>
</tr>
<tr>
<td>Increased Exposure</td>
<td>“[Arnold has] evolved to be able to do this. It took us a lot of years to be able to see all that we saw.” —Ryan family</td>
</tr>
<tr>
<td>Developed Strategies</td>
<td>“He wasn’t really out of the stroller at that point, the last time we went, so it was easy to maneuver the stroller around, for him to get up close and see things. It made it a lot easier.” —Clark family</td>
</tr>
<tr>
<td>Parental Readiness</td>
<td>“I guess it’s kind of a nostalgia thing to me in a way. Just ‘cause I’ve always wanted to go and I’ve always wanted to take the kids and I’ve never been able to take them all. There’s certain things that I want them to see. A lot of it is nostalgia. I just think it brings back a lot of it just brings back good memories for me.” —Smith family</td>
</tr>
<tr>
<td>Child’s Personality and Skill set</td>
<td>“[Kelsey] found a place where she can center herself, and then go calm down and then go back to the activity we were doing.” —Williams family</td>
</tr>
<tr>
<td>Environmental (Contextual) Factors</td>
<td></td>
</tr>
<tr>
<td>Perceived Inclusion</td>
<td>Sometimes when he gets out of control he makes screeching noises and people look at him and his hands. We get by. I think a lot of people know about autism these days.” —Davis family</td>
</tr>
<tr>
<td>Understanding the Child’s abilities</td>
<td>“Back then it was like, what do we do, do we leave or what?” —Newman family</td>
</tr>
<tr>
<td>A feeling</td>
<td>“Now he seems like he’ll be okay.” —Davis family</td>
</tr>
</tbody>
</table>
Figure 1. Conceptualization of the interaction between the factors that may be related to parents’ readiness decisions.

**Parent Evaluation of the Child**
- Child's Age
- Child's Developing Skills
- Knowing the child's limits

**Parent Evaluation of the Environment**
- Facilitators & Barriers
- Perceived Inclusion

**Parent Evaluation of the Activity**
- Remembering past community outings

**Parent and Family Readiness**
- Parent’s evaluation of available strategies
- Parents’ evaluation of their own readiness

**Decision of Readiness**

**Time**
Appendix: Interview Questions

Parent(s) interview: Before museum visit

• What is your impression of the Museum of Science (M.O.S.)?
• Have you and your family visited the M.O.S. before?
  o If YES:
    ▪ How many times or how often have you visited the museum in the past?
    ▪ Please describe your previous visit(s) to the museum.
    ▪ Who in the family went on the museum visit(s)?
    ▪ Did you consider the visit to be a success?
      • If so, why?
      • What contributed to the successful experience?
      • If not, why not?
      • What contributed to the unsuccessful experience?
  o If NO: Why haven’t you visited the museum in the past?
• Did you have any interest in bringing your child to the museum before you heard about this study? YES or NO
  ▪ (If yes, what prevented you from acting on this interest?)
  ▪ Why did you decide to plan a visit with your child to the museum now?
• As you anticipate your visit to the M.O.S., what are you thinking about?
• Are you doing anything to prepare your child for your trip to the museum?
  o If so, what are you doing to prepare?
• What do you hope your child with autism will get out of your visit to the M.O.S.?
• What do you hope you and the rest of your family will get out of your visit to the museum?
• What would make you consider your visit to the M.O.S. a success for your family?

Parent(s) interview: After museum visit

• Please tell me about your experience visiting the Museum of Science (M.O.S.) today.
  o How long were you here?
  o What did you do at the museum?
  o Which exhibits did you see?
• What were the highlights of your trip to the M.O.S.?
• How do you feel after your visit?
• Do you want to come to the M.O.S. again?
  o Why/why not?
• What did your family get out of your visit to the M.O.S.?
• Was there any time during your visit when members of your family had a “aha” moment where they learned something new or experienced something new or novel?
  o (If yes, Can you describe to me what happened during that moment?)
• What aspects of the museum worked well for you and your family during your visit?
• What strategies did you use, if any, that influenced your family’s museum visit?
• What would you do differently during your next visit, if anything?
• Did you do anything to prepare your child for your museum visit? If so, what did you do?
• What recommendations would you make to other parents that want to bring their children with ASD to the M.O.S.?

Child with autism interview: After museum visit
  • What was your favorite part of the M.O.S.?
  • What was easy?
  • What was hard?
  • Would you like to come to the museum again?
    o If yes, why?
    o If no, why not?

Questions for siblings: After museum visit
  • Please tell us about your visit to the museum today.
    o Which exhibits did you go to?
  • What was your favorite part of the M.O.S.?
  • Please tell us about your experience exploring the museum with your [sister or brother].
References


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VITA

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Education

Candidate for Master of Occupational Therapy, Boston University, Boston, MA
Expected Graduation: May 2015
Bachelor of Arts, Stonehill College, Easton, MA
September 2009–May 2013
Double Major: Psychology & Sociology | GPA: 3.81, Magna Cum Laude
Honors & Awards: Dean’s List | Honor Societies: Lambda Epsilon Sigma; Alpha Kappa Delta (Sociology); Psi Chi (Psychology) | Scholarships: Stonehill College, Boston University; Bank of America: Dean Martin
Semester Abroad, John Cabot University, Rome, Italy
• Completed courses in psychology, public speaking and the sociology of Rome | GPA: 4.0

Fieldwork/Internship Experience

Boston Museum of Science, Boston, MA January 2015–April 2015
• Planned and led a social participation group for students ages 10–14 with ASD
Beth Israel Deaconess Medical Center, Boston, MA September 2014–December 2014
• Assisted in intensive care unit occupational therapy
Massachusetts Mental Health, Boston, MA January 2014–May 2014
• Participated in and helped to facilitate social skills training groups for adults with mental health diagnoses
Hale House, Boston, MA September 2013–December 2013
• Led small art therapy and social skills groups for older adults living in the facility
Intern, Southeast Alternative School, Middleboro, MA September 2012–December 2012
• Participated in clinical evaluations and attended classes for students with psychological, emotional, and learning disabilities
Intern, Rhode Island/Hasbro Children’s Hospital, Providence, RI July–August 2012
• Observed and assisted outpatient pediatric, outpatient adult, and inpatient adult and geriatric occupational therapy sessions
Shadow, West Warwick Middle/High School, West Warwick, RI June 2012
• Co-led innovative Social Thinking Groups with an OT for children with Autism in grades 5–8

Work Experience

Lead Toddler Teacher, The Children’s Workshop, East Greenwich, RI Summer 2014
• Led a classroom of fourteen toddlers consistent with a Bright Stars accredited curriculum
Assistant Teacher, **Learning Brooke**, Cranston, RI & **Creative Child, Co.**, Coventry, RI
Summers 2010–2013
• Acted as an assistant teacher to children ages 3–12, creating lesson plans and enriching activities for the students

**Office of Admissions, Stonehill College**  
**Student Ambassador** | September 2011–May 2013
• Provided campus tours to potential future students and aided in facilitating information sessions and open houses

**Office of Development, Stonehill College**  
**Phone-a-thon Caller** | September 2011–May 2013
• Briefed alumni on campus changes and facilitated in donating to the Stonehill College Fund

**Graduate & Undergraduate Research Experience**

**Thesis, Exploring Readiness of Families Visiting a Science Museum**  
Expected Completion: Spring 2015

**Research Assistant, Experience of Families Visiting a Science Museum**  
Spring, 2014

**Research Assistant, Exploring Negative Musical Response** (Craton, 2012)  
Fall, 2012

**Research Capstone, Alternative Schools and the Children Who Go There: An Exploratory Study**  
Fall, 2012

**Research Capstone, Autism Spectrum Disorder: Treatments**  
Fall, 2012

**Student Researcher, Is Chivalry Dead? Gender and Authority Effect on Helping Behavior**  
Fall, 2011

**Volunteer Experience**

**Service Trip, Cape Coast, Ghana**  
May–June 2014
• Participated in a two-week interdisciplinary service trip focusing on health education and health promotion

**Family Life Center, Brockton, MA**  
October–December 2011
• Provided supervision and positive play for children living in the building; offered homework help

**HOPE Alternative Spring Break, New Orleans**  
March 2010
• Collaborated with a group of students to provide housing and other services to those in need

**Massasoit Community College: Gateway to College, Brockton, MA**  
September–December 2010
• Implemented a class syllabus; facilitated weekly class discussions; designed a resource binder for future use

**VA Hospital, Brockton, MA**  
September–December 2010
• Provided company for patients with mental health issues; set up and oversaw arts and crafts activities

**Additional Skills**
Language: Proficient Spanish, Beginner Italian, ASL  
Computer: Microsoft Office, Excel; SPSS  
CPR and First-Aid Certified