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Experiences of families of children with autism spectrum disorder visiting a science museum

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EXPERIENCES OF FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER VISITING A SCIENCE MUSEUM

by

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Dedication

I dedicate my thesis project to my family and the families I have encountered through working in Early Intervention, and as a researcher when completing my MSOT degree at Boston University. I am grateful for the support I received from my family and friends throughout my graduate studies. You gave me the confidence to pursue my vocation, allowing me to discover a fulfilling and meaningful career. I continue to learn from each family I have had the privilege to work with as a clinician and as a researcher. You inspire me, and I appreciate each opportunity I have to share in your family moments.
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I would also like to acknowledge and thank our colleagues at the Museum of Science, Boston. Christine Reich, Catherine Lussenhop, Leigh Ann Mesiti, and Liz Kunz Kollmann, thank you for your support and assistance, and for sharing in our mission to promote inclusion in the community for all families.
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ABSTRACT

Little is known about the experience of families of children with autism spectrum disorder (ASD) in community settings. The purpose of this research is to learn about the family experience when visiting a science museum, focusing on the motivations of the family, environmental features of the museum, strategies used by family members, and definitions of a successful visit to the museum. Data were collected through semi-structured interviews and observations of four families that included a child with ASD. The families in this study appear to want the same community experiences for their children as families with typically developing children. Both the motivations for the visit and features of the environment appeared to influence the family’s approach and strategies they employed for a successful visit. Strategies included those completed before the visit (visitor planning strategies), as well as during the visit (strategies at the museum). The strategies enabled families to enjoy and experience success within the museum environment. The information learned in this study may help families with a child with ASD prepare for and use features of the museum to enjoy successful museum visits. Recommendations are provided for museums seeking to create inclusive opportunities for all families.
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Visits to museums, as natural settings outside the home, provide community-based opportunities for all families to feel welcome, to be included, and to enjoy leisure time together (Reich, Rubin & Steiner, 2010). While researchers have some understanding of the benefits and barriers to participation in community activities for children with physical disabilities, we are just beginning to learn about the experiences of families with a child with autism spectrum disorder (ASD) (Law, Petrenchik, King, & Hurley, 2007; Rudy, 2010; Langa et al., 2013; Little, Sideris, Ausderau, & Baranek, 2014). The aim of this research is to better understand the experience of children with ASD and their families while visiting a science museum. Specifically, this examination focuses on family motivations, environmental features at the museum, strategies used to have a successful visit, and family definitions of a successful museum experience. A more thorough understanding of the entire family experience and family members’ interactions with the museum environment will be useful in developing recommendations for families and museum personnel. The information shared by parents and children in this study may be useful to families with a child with ASD as they prepare for and use features of the museum to enjoy successful museum visits. The findings may also offer recommendations for museums seeking to create inclusive opportunities for all visiting families.

Children with Disabilities and Community Participation

Participation in community activities has been found to contribute to the development, health, well-being, and quality of life of children with disabilities (Bedell, Coster, Law, Liljenquist, Kao, Teplicky & Khetani, 2013). Community activities provide
children with opportunities to learn societal expectations and social interaction skills; these experiences have a positive influence on peer relations, school engagement, academic outcomes, and life satisfaction (Law et al., 2007). Despite the benefits to community participation, studies demonstrate that children with physical disabilities are less involved in community activities than children without disabilities (Law et al., 2007; Bedell et al., 2013; Houtrow, Jones, Ghandour, Strickland & Newacheck, 2012). Bedell et al. (2013) report that a lack of information, programs, and services, problems with government policies, inadequate social supports, negative attitudes, and inaccessible physical environments are frequently reported barriers to participation. Additionally, when exploring the frequency and involvement of children with and without disabilities at home, at school, and in the community, researchers have determined that the influence of the environment on participation differs across settings (Anaby et al., 2014). In a study with 282 parents of children with disabilities and 294 parents of typically developing children, Anaby and colleagues reported that the effect of environment on participation was most pronounced in community settings. Environmental supports included the availability of information and services, while barriers were related to the cognitive, physical, and social demands of the activity. Although barriers to participation have been identified in the literature, less attention has been directed to the features of the environment that support successful community experiences for families. Moreover, the majority of this research has focused on children with disabilities in general, or children with physical disabilities.
Children with ASD and Community Participation

An understanding of the community participation needs of families with a child with ASD is emerging. When compared to families with children with other types of disabilities, these families may experience unique challenges when engaging in community activities. Common characteristics of ASD include impairments in social interaction and communication, as well as restricted, repetitive, and stereotypical patterns of behavior, interests, and activities (American Psychiatric Association, 2013). This range of potential characteristics may interfere with a child’s ability to participate in community activities, and these characteristics may not be visible for others to recognize or understand when briefly interacting in a public setting. Researchers have documented that children with ASD participate less frequently and with less variety in community activities than do typically developing peers (LeVesser & Berg, 2011; Rodger & Umaibala, 2011). For instance, Brewster and Coleyshaw (2010), when describing community activities as leisure outside of the home, found that children with ASD ranging in age from 2 to 19 years old participated in fewer community activities compared to typically developing peers. Children with ASD also spent more time with family when in the community. In another study of parents of preschool aged children with ASD, parents reported that community activities were challenging areas of participation for their children (Lam, Wong, Leung, Ho & Au-Yeung, 2010). Barriers to participation in the community have been identified by children with ASD and their parents and include difficulties with relationships and social interaction, safety concerns, and a need for consistency and predictability (Brewster, 2011).
Because of limited community experiences, children with ASD may have fewer opportunities to practice skills that typically developing peers are practicing (Little et al., 2014). Many community activities lack structure and have high social demands. Children with ASD may have difficulty interacting with others in new settings and handling unexpected events that occur in unfamiliar environments (Ross, 2011). While barriers have been described for families with a child with ASD, we are just beginning to understand how to address potential barriers to community participation (Law et al., 2007; Langa et al., 2013; LeVesser & Berg, 2011; Little, Sideris, Ausderau, & Baranek, 2014 Reich, Rubin & Steiner, 2010; Rodger & Umaibala, 2011; Rudy, 2010). Moreover, little attention has been paid to how the environment might impact community participation for these families. Features of the environment may make a meaningful difference in participation and accessibility for families with a child with ASD.

**Community Participation in Museums**

Museums are unique institutions of learning where people of all ages and backgrounds can expand their understanding of culture and science (Haden, 2010). Visitor experiences may range from exploring intellectually challenging material to having meaningful social experiences within a new community (Falk, 2009). Yet, individuals with a range of disabilities have reported that they do not always feel welcome or accepted in museums (Linton, 2006; Verdonscot, de Witte, Reichrath, Buntix & Curfs, 2009; Poria, Reichel, & Brandt, 2009). Therefore, efforts have been made to make museums more inclusive community settings. Science museum professionals define inclusion as looking beyond physical access, and incorporating
cognitive and social accessibility (Reich et al., 2010). Inclusion means that all people, regardless of their abilities, are able to participate as a part of the social group and community (Reich, Rubin & Steiner, 2010). Science museum professionals strive to design the space so that all visitors can move around comfortably and safely. Science museum professionals also encourage cognitive and social accessibility by creating environments that facilitate engagement with exhibits and provide meaningful experiences (Reich et al., 2010).

Museum professionals often apply principles of Universal Design for Learning when selecting subject matter, designing exhibits, and coordinating staff trainings (Reich, 2005). Universal Design for Learning is an evidence-based approach to the design of products and environments to be usable by all people, with widely diverse backgrounds and learning styles (Center for Universal Design, 2002). Applying principles of Universal Design for Learning provides an optimal way for museums to fulfill their mission of education, leisure, and public service for all (Reich, 2005). Science museum professionals also promote Informal Science Education (ISE); defined as learner-motivated, voluntary, and ongoing. ISE encourages an appreciation for learning within the context of the science museum. All visitors, no matter their ability or disability, are provided with meaningful opportunities to engage with science learning alongside other community members. By being included in the learning experience within a community setting, access to ISE may lead individuals with disabilities to feel empowered and included (Reich, Rubin & Steiner, 2010).

Although families with a child with ASD may face barriers when visiting a
science museum, this environment may be particularly well suited to support their needs. Some individuals with ASD have focused interests related to a specific subject (Wei, Yu, Shattuck, McCracken, & Blackorby, 2013); when a child with ASD visits a science museum, they may have access to information about their focused area of interest (American Psychiatric Association, 2013). These children may find that relationships with family members and peers are strengthened in the science museum environment, as there are enriched opportunities to learn about focused interests. Experiencing a museum visit together and sharing interests may offset daily stressors and provide moments of enjoyment together for families with a child with ASD (Lerner-Barron, 2007).

Moreover, in many museums, the layout of a museum tends to stay the same over time, and some exhibits are permanent. Permanent exhibits provide predictability and consistency. Most museums provide access to maps online, as well as photographs of exhibits. Families with a child with ASD may review these resources before visiting a museum so that their child is prepared for any new or unfamiliar situations (Rudy, 2010; Langa et al., 2013).

Recently, Langa et al. (2013) conducted a study of the museum experiences of families with a child with ASD. These researchers explored the factors that promoted successful experiences in the museum environment, including the families’ motivations and preparatory strategies that families used. Langa and colleagues collected data from children, parents, and teachers of children with ASD who visited the Smithsonian Institute. Parents perceived that a meaningful experience would, “foster the child’s curiosity or to allow the child to be independent in exploring and experiencing” (Langa et
Families expressed the need to possibly leave early if their child had unpredictable behaviors, to be in a less crowded and manageable space, to engage in interactive exhibits, and to have access to a quiet space. Langa et al. (2013) also evaluated the usefulness of pre-visit materials, including web-based documents that contained museum hours, directions, content, and possible activities to prepare for the visit. Following their visits, families suggested ways to improve visitor planning. They recommended preparing the night before or morning of the visit and identified a need for better directions for use of public transportation, more detailed floor maps to indicate where bathrooms and exits were located, and an online resource dedicated to inclusive efforts at the institution (Langa et al., 2013). We extend this research by further exploring the museum experience for families with a child with ASD, focusing on how families consider the environment in preparation for their visit, and how they use the environment during their visit to facilitate a successful experience.

Family Involvement in Community Participation

While all children depend on family members to facilitate opportunities to engage in community activities, individuals with disabilities may have greater reliance on family involvement to participate. Consequently, supportive family members are important for integration into community settings for individuals with disabilities (Verdonschot et al., 2009). Because children with disabilities receive additional supports from family members when participating in the community, parents and siblings may be intimately involved in these experiences (Rosenberg, Ratzon, Jarus & Bart, 2012). Thus, it is important to understand the entire family’s perspective regarding community activities.
When researchers explored the everyday experiences of family members of children with developmental disabilities, family members described adaptations used in daily activities in order to accommodate child needs (Maul & Singer, 2009). Maul and Singer interviewed 11 families that included a child with a developmental disability, 8 of which included a child with ASD. Family outings were mentioned as a source of difficulty for some families, as it was not always possible to do everything or to stay in the community for a long time, but there were still moments of enjoyment; this alternative was described as a “different kind of fun” (Maul & Singer, 2009, p.160).

While parents may be wary of introducing their child with ASD to new community activities because they feel their child may be overwhelmed, may display atypical behaviors, or may need unusual accommodations, it is valuable to learn from the adaptations families use to make participation in the community possible (Lerner-Baron, 2007; Maul & Singer, 2009; Langa et al., 2013). Families described the value of planning ahead, slowing the pace of the activity, communicating effectively with one another, and appreciating moments of normalcy for their families (Maul & Singer, 2009).

Effective strategies used by families may be helpful to other families; thus, the goal of this research is to understand the experience of families with a child with ASD within a science museum environment. Specifically, we focus on understanding the motivations that influence family participation in this setting, environmental features of the museum, strategies used by families, and their definitions of a successful visit. Through collecting information from families, it may be possible to share
recommendations with other families planning a museum visit, as well as with museum personnel so that institutions may offer an inclusive experience to all visitors.

This study addressed the following questions:

1. What is the motivation of parents who have a child with ASD when visiting the Museum of Science?
   a. What is the motivation of a child with ASD when visiting the Museum of Science?
   b. What is the motivation of siblings who have a brother or sister with ASD when visiting the Museum of Science?

2. What features of the environment do parents of a child with ASD use when visiting the Museum of Science?
   a. What features of the environment appear to support participation for a child with ASD when visiting the Museum of Science?
   b. What features of the environment do siblings who have a brother or sister with ASD use when visiting the Museum of Science?

3. What strategies do parents of a child with ASD use when visiting the Museum of Science?
   a. What strategies does a child with ASD use when visiting the Museum of Science?
   b. What strategies do siblings of a child with ASD use when visiting the Museum of Science?
4. How do parents of a child with ASD define a successful visit to the Museum of Science?
   a. How does a child with ASD define a successful visit to the Museum of Science?
   b. How does a sibling of a child with ASD define a successful visit to the Museum of Science?

Method

Participants

The four families participating in this study had a child with ASD, were interested in visiting the Museum of Science, Boston (MOS), and lived within 75 miles of the museum. Recruitment flyers with a general description of the study and contact information were distributed by email through a MOS database to families with a child with ASD. These families had previously shared their contact information with the MOS because they were interested in participating in research. Recruitment flyers were also distributed following a presentation for parents of children with ASD at a public school district within the Greater Boston Area. The institutional review boards at Boston University and the MOS approved this research. Table 1 presents the characteristics of study participants. The children with ASD ranged in age from 7 to 10 years old. Based on parent-report, three of the four children had a diagnosis of pervasive developmental disorder not otherwise specified (PDD-NOS), and one child had a diagnosis of Asperger’s disorder. In two of the four families, two parents attended the museum visit, while in the other two families only one parent attended. Siblings also visited the
museum, except in one family who had an only child with ASD. Siblings ranged in age from 4 to 12 years old.

**Data Collection**

Parents of potential participants who received recruitment flyers contacted the primary investigator, who then completed a telephone interview with the parent. This interview screened families to confirm the child was between 7-11 years old, and had a diagnosis of ASD from a professional. The first author then contacted families who met the inclusion criteria to schedule a home visit. During the home visit, the study was described to the family, then written consent was obtained from at least one parent, and verbal assent was obtained from the child with ASD. Following the consent and assent process, a semi-structured interview was conducted with the parent. The child with ASD and/or siblings could be present during the interview, but they were not asked direct questions. The interview posed questions to parents about previous experiences at the MOS, and hopes and preparations for the upcoming visit (see Appendix A). At the end of the home visit, a museum visit was scheduled with the family. Holidays were not provided as options when scheduling the museum visit, which was a decision made by museum staff since holidays are crowded at the MOS. All other weekday and weekend days were offered to families as they made plans to visit the museum. Following the home visit, the first author completed a field note describing the family’s neighborhood and home environment, a brief account of the interactions with the child with ASD, observations related to family interactions, and observations about strategies family members used to support the child with ASD within their home.
On the day of the scheduled museum visit, the MOS provided family members with vouchers for admission and parking. The first author explained to the family that they could explore the museum for as long as they preferred and she observed the family during their entire museum visit. Using a structured observation protocol (see Appendix B), the researcher recorded the amount of time spent in each exhibit, interactions among family members, behaviors of all family members, and strategies the family used during their visit to communicate with their child, interact with the museum exhibits, and to manage challenging situations. When the family finished their visit, a semi-structured interview about their experience at the museum was completed in a conference room at the museum (see Appendix C).

The research team collecting data for this study recognizes how prior experiences working with children with ASD and families may influence personal views, observations of the participants, and interpretations of data. The first author is a graduate student studying occupational therapy and an Early Intervention clinician with experience completing home visits with children with ASD under age three. She has had many conversations with parents related to the significance of and desire to participate in community settings. These experiences provided the first author with an awareness of the challenges families face when participating in leisure activities in community settings. This research is shaped by a family-centered philosophy that values learning from parents about their beliefs, concerns and the strategies they use to support inclusion and participation (Rosenbaum, King, Law, King, & Evans, 1998). Additionally, this study was informed by an ecological systems perspective, which states that human
development is influenced by the different types of environmental systems that individuals interact with throughout their lives (Bronfenbrenner, 1979). This perspective reinforces the dynamic and reciprocal influences between an individual, his or her immediate environment, and the broader social and cultural context. Accordingly, our observation protocol attended to the interaction between all family members and the museum physical and social environment.

**Data Analysis**

The first author and a second research assistant (also a graduate occupational therapy student) each transcribed the data for two participating families, including the field notes, interviews, and observations from the museum visits. NVivo software was used to organize the data. The first author and research assistant then reviewed the transcripts and considered the research questions to develop initial codes, which focused on the families’ motivations, environmental features, strategies, and definitions of success. Two researchers with expertise in family accommodation to disability joined the research team to develop consensus on definitions for the initial codes (see Table 2). Following this step, the first author and research assistant used these definitions to complete line-by-line coding of all data (Strauss & Corbin, 1990).

In the axial stage of coding, the researchers developed subcategories that described the strategies families used to facilitate a successful museum visit. The subcategories included the perspective of individual family members, as well as observations made by the researcher related to the environment. Strategies were defined as actions or thoughts directed at solving an immediate or ongoing problem or achieving
an immediate or future goal (Merriam-Webster, 1993). We categorized strategies into those used in preparation for a visit to the MOS, as well as strategies used during the museum visit. Visitor planning strategies were defined as intentional, preparatory actions completed by parents or family members before the day of the museum visit with the purpose of supporting the museum experience for all family members. Strategies used at the museum were defined as intentional actions completed by parents or family members and explicitly communicated to the first author during the museum visit, as well as observed by the first author, with the purpose to support the museum experience for all family members. Families capitalized on the features of the environment when using visitor planning strategies and strategies at the museum. The strategies implemented required interactions between family members and environmental features, and supported families to create a successful visit. The four members of the research team agreed upon definitions for the axial codes, which were added to the coding book, and served as an organizing framework for coding the data (see Appendix D for all initial and axial code definitions).

Following this analysis, Figure 1 was created to illustrate the factors that we observed to influence successful museum visits. In this conceptualization, family motivations influence the strategies families use, both prior to and at the museum, as well as how they use the museum environment. A successful visit depends upon congruence between family strategies and environmental features and resources at the museum.

**Findings & Interpretations**

A summary of each family’s description of motivations, environmental features
the parent identified as helpful, use of strategies, and definitions of success is provided in Table 3. This table also includes details about the length of time, day and time, and number of exhibits visited for each participating family. The four families in this study visited the museum between 1 and 6 hours, and the number of exhibits visited ranged from 6 to 29. The findings and interpretations related to the factors presented in Figure 1 are described below using examples from all four families.

**Motivations**

The range of motivations expressed by families during the home interview before the museum visit were to experience hands-on learning, to have fun, to see new exhibits and old favorites, and to have a social outing. All participating families expressed the desire to engage in hands-on, interactive learning. When asked what she hoped her children would get out of the MOS visit, Jacob’s mother stated she looked forward to:

> Just them running around wanting to touch everything and learn about everything and asking about what this and that is.

In addition to prioritizing learning, all families discussed a desire to enjoy the day at the MOS. Nancy’s father stated, "I think I'll get to see my family enjoy a nice day in Boston.” Jacob’s mother expressed that her family looked forward to “a fun day all together.” Furthermore, all four families hoped to see new exhibits, as well as old favorites. Each family had previously visited the museum, so they had specific exhibits that family members remembered and wanted to re-visit. The families also shared an interest in seeing new exhibits that may be at the MOS temporarily. Arnold’s mother described her family’s interest in visiting a variety of exhibits, both old and new. She stated:
There's always one headlining exhibit, like one or two, so usually we look forward to seeing that. That's always nice, whatever it is. And then, also the kids, because we have gone in the past, they always look forward to same old favorites, you know what I mean? The playground is always a hit. You know, they like seeing the live animals. Sitting in the monkey place, seeing the chickens… They'll want to see different things.

Having an opportunity for a social outing with family members was articulated by three of the four families as a motivation for the visit to the MOS. Beyond interacting with one another, Jacob’s family made plans to meet with two additional families during their visit to the MOS. Jacob’s parents looked forward to spending time with these families in the community, where they could explore the museum together while socializing with one another. Although this family’s desire to socialize with others families at the museum was different from that of the other three families in the study, all four families had motivations for social interactions as they anticipated their museum visit.

**Environmental Features**

Environmental features that influenced the family’s museum visit, as reported by families and observed by the first author, included limited crowds, interactive exhibits, clear signage, information related to sensory stimuli, spacious exhibit halls, and knowledgeable museum staff. Limited crowds were observed by the first author during all four museum visits, as families were able to easily and comfortably move throughout the exhibit halls. The MOS is a spacious environment, which allowed all family members to maintain personal space even if other children and families were nearby. Families were observed using interactive exhibits, which provided hands-on materials to touch, as opposed to available exhibits that did not allow visitors to manipulate objects or press
buttons. Clear signage was present throughout the museum; colors are associated with each wing of the museum, and colored arrows are placed above doorways. As visitors left an exhibit space they were able to easily view the arrows when deciding where to go next. All families used the signs to navigate through museum. Information related to sensory stimuli is posted on signs in some parts of the museum, such as outside of the Theater of Electricity. The show about electricity ends with loud cracking and popping sounds, and this information is explicitly stated outside the door of the theater so that families are aware of the auditory stimuli before entering the show. Additionally, the museum staff served as supports in the environment throughout family visits, sharing information related to museum programming and answering questions for parents and children. When Arnold’s family visited the Hall of Human Life, a museum staff member explained the bone structure of a primate to the family. They sat with the staff member at a low lab table, and each of the family members touched the bones as they learned about the differences between primate bone structure and human bone structure. The staff member answered questions posed by the children and Arnold’s mother, and Arnold’s mother later mentioned she was impressed with the knowledge the staff member shared during this interaction.

**Family Strategies**

Strategies used by families that appeared to facilitate a successful visit at the MOS included planning prior to the visit, as well as strategies used at the museum during the visit.

**Visitor planning strategies.** Visitor planning strategies described by families and
observed included the use of Social Stories™ and/or pre-teaching of social skills and rules, packing and bringing snacks, preparing siblings, reviewing the MOS website, making a plan of exhibits to visit, planning a time frame for the visit, and knowing where to find quiet space at the museum.

Social Stories™ and pre-teaching social skills and rules were strategies used by three of the four families in this study to prepare their child with ASD to visit the MOS. Social Stories™ are short stories with realistic pictures designed to prepare individuals of all abilities for what they will see and do in an unfamiliar environment; the stories often portray how people manage behaviors during a social situation. Social Stories™ enable people to engage in anticipatory planning as the stories describe the details and expectations about an event or situation (Gray, 2004; Kokina & Kern, 2010). Nancy’s mother shared:

A couple days before we’re going to go [we will] probably do Social Stories™ about like when someone else is there, that we share. You know, kind of go over some social skills and rules. You know don’t push people out of the way, wait your turn.

Kenny’s mother added an example of pre-teaching about the gift shop as a particularly challenging location that may require preparation. She stated:

Because my youngest son on the spectrum, he always perseverates wherever we go on the gift shop, especially because this will be our fourth time going to the museum that might be the first place he wants to stop and I might not be able to get him out. So that might be a pre-teaching that I might do for him.

All of the families packed and brought snacks. Children with ASD and their siblings requested snacks at different points throughout visits, and parents were easily able to find a bench to stop and take a snack break. Additionally, two of the three families
with siblings expressed that it was important to preparing siblings to be flexible and to help. During the initial interview, Arnold’s mother described how she prepares Arnold’s siblings:

I just remind them, I'll try my best to accommodate everything, but of course if their brother has major issues the focus has to be on keeping him somewhat calm. So we can finish the visit, and/or get to the car.

All four families considered the environment by visiting the MOS website, which they used to familiarize themselves with the space, and to plan what to see and where to go during their visit. Nancy’s mother talked about using the website to review all of the exhibits beforehand. She stated:

Well before we came, I looked online and picked out a few things that we would want to see. So we had at least a couple things that were a primary.

Using the MOS website allowed families to develop a plan for the visit that considered the interests of all family members visiting the museum. Parents discussed and agreed upon a plan with family members, some families with more detailed plans, and others with a flexible plan for the visit. For instance, Jacob’s mother did not mention the visit until the day before the family was scheduled to visit the MOS. She shared, “I did not want to say too much until I was sure it was happening or it was going to be a big disappointment.” Arnold’s mother made sure that all three of her children could agree on where to go before visiting the museum. Kenny’s mother expressed that their plan was to have each family member (mother and two sons) take turns choosing what part of the museum to go to next during their visit. Arnold’s mother articulated the value of having a plan, sharing the following advice:

It works to have a game plan, and you know you have to know your family. If
your family is the type who can go and have a wide open day, then it's even easier for you. But if your family is the type, like similar to our family that it works to have a little bit of structure, then planning it and not being overly ambitious helps.

In addition to planning which exhibits to visit, families planned a day and time frame for their MOS visit. Kenny’s family preferred to visit on a weekday that was not a school holiday, since their previous experiences visiting on weekend days and school holidays had been busy and crowded. Kenny’s mother shared:

> When we have time off it’s in the same time that everybody else has time off so we know it’s going to be crowded so we tend to try not to go when it’s overly crowded. So it’s a rare occasion that we can get there on a day that the rest of the state is not there.

Arnold’s mother explained that visiting in the morning on a weekend day worked best for her family, since she experienced that earlier in the day on weekends is less crowded than the afternoon time. The other two families visited during the afternoon time on weekend days and did not express concerns about crowds. Each family approached the duration of their visit differently. For example, Arnold’s family scheduled a one-hour visit, and they fulfilled this plan by staying for that set, short time frame. Nancy’s family intended on staying for as long as they could to “see everything,” and their visit lasted seven hours.

Parents from two families also described that a visitor planning strategy was to know where quiet spaces were at the MOS in case their child with ASD experienced challenges. This included avoiding sensory-stimulating environments, such as the loud cafeteria and the Theater of Electricity at the MOS.

**Strategies used at the museum.** Strategies used at the museum, as described by families and observed, also were related to the environmental features of the MOS. These
strategies included modeling expected behavior for the child with ASD, redirecting, prompting with reminders about time, following a previously agreed upon plan, providing one-on-one support to the child with ASD, using spacious exhibit halls, engaging in “science talk,” using interactive exhibits, following clear signage, using information related to sensory stimuli, taking breaks in quiet spaces, and interacting with knowledgeable museum staff.

Based on parent and sibling report following the museum visit, in addition to observations made during the museum visit, both parents and siblings shared strategies used at the MOS. For the one family who visited with their only child with ASD, parents served as models for the child, occasionally using an exhibit to demonstrate what to do before the child with ASD participated. Siblings frequently served as models for children with ASD, helped the child with ASD with transitions, and provided reminders when waiting in line with other museum visitors. Additionally, all parents provided warnings to their children about the time before transitioning from exhibit spaces, and before ending the visit.

Providing one-on-one supervision to the child with ASD was a strategy used by all four families at the museum during visits. In families with two parents visiting the museum, parents took turns providing one-on-one support to the child with ASD. For instance, Jacob’s mother would walk through the exhibits with him. If his younger brother needed supervision, then Jacob’s father would step in to continue to support Jacob. In families with one parent and siblings, siblings helped to provide one-on-one support to the child with ASD when the parent was assisting others or engaging with the
exhibit. Arnold’s siblings described how they helped their brother at the MOS. Arnold’s brother shared that sometimes Arnold became distracted, so he was “making sure he kept going and kept walking.” Arnold’s sister added another example, stating:

Sometimes he wanted to go to one place and he would go to the front of the line. But other people would be waiting in line and they don't want people to go in front of them. So we had to bring him back to the end of the line.

Parents and children stayed close together and transitioned to new exhibit spaces together. By being together in the exhibit halls, all family members were in view of each other at all times. Each family mentioned that the spacious environment allowed their family to have personal space even if other children and families were nearby. In three of the four families parents needed to redirect their child’s attention and behaviors to keep their children nearby and safe.

Using “science talk,” defined as the back-and-forth conversation about science information presented in museum exhibits (Haden, 2010), served as a strategy to engage family members. By asking questions and reading aloud information from the exhibits to one another, family members stayed near each other and experienced learning opportunities together. In each family, parents asked questions to their children throughout the museum visit about memories of previous visits to the MOS. Arnold’s mother supported all of her children by pointing out exhibits they had visited before, and asking them what they remembered about the exhibits. Jacob’s father consistently read material in the exhibits aloud to Jacob, and then related the science concept to everyday scenarios that Jacob could relate to. For example, when learning about air pressure at an exhibit, Jacob’s father compared the exhibit to how an air hockey table works; air comes
up from the table and helps move the hockey puck along the surface. When asked what would make the visit to the MOS a success, Kenny’s mother mentioned she looked forward to the conversations she could have with her sons at the museum, and that they could have with one another, as she shared:

When we come away with things that we can talk about as a family when, [or] what they learned and something new that they didn’t know before and things like that.

In addition to promoting science talk during the museum visit, Nancy’s family discussed continuing science learning following their visit. When interviewing the family after their visit, Nancy’s mother asked Nancy:

So what would you want to, if you were to go home and learn something, what would you want to go home and learn more about?...Well pick one, then we'll go to the library and get a book on that this week.

Nancy responded she wanted to learn more about space, and her mother assured her they would learn more about space together.

Hands-on, interactive exhibits at the MOS allowed children and parents to touch and move objects, which appeared to support family engagement with the exhibit and each other. Families were observed to more frequently explore the exhibits that required manipulation of objects versus exhibits that did not provide opportunities to touch objects. Following the museum visit, Nancy’s mother expressed the value of hands-on learning, reflecting on the molecule exhibit as an example:

I really liked the molecule display because it made it that I could explain it to her. Like when we were showing the periodic table it had the little atoms with the electrons and you could count the electrons then find them on the chart, so it was all very hands-on.
Families navigated through the museum environment by using signs to find exhibits of interest, the restrooms, and the cafeteria. Nancy’s mother shared that she downloaded maps to her tablet to assist her during the visit, but did not need to use them because of the easily accessible signage.

Information about the sensory features of exhibits and spaces was posted in some areas of the MOS, such as nearby the Theater of Electricity where a lightening show takes place many times throughout a single day. All four families read the posted sign about the loud noises that occur in the theater. One of the four families attended the show for ten minutes before leaving due to the loud noises, as their child with ASD requested to exit the theater. The three families who did not attend the show chose not enter due to the signage, wanting to avoid loud noises to keep their child with ASD calm. Families were also able to find spaces in the museum that met their child’s sensory preferences. Nancy’s family reported that they found a restroom on the first floor without loud hand dryers, which they called a “sensory-friendly” restroom. Since the sound of hand dryers upsets Nancy, her family only used the first floor restroom during their visit. Nancy’s family also chose to eat in the small café area during lunch instead of in the larger, louder cafeteria.

Three of the four families took breaks on an unmarked bench in a quiet space for children to calm down, and to review rules for visitor safety. Kenny and his brother disagreed about where to go next while in the exhibit halls, and then started to push one another. Their mother separated them, corrected them for becoming physical with one another, and found a quiet bench for her children to sit and calm down before deciding
together where to go next. When Jacob and his family visited, he was excited when they saw signs for an exhibit of interest. He ran through the exhibit halls to reach the sign. His mother caught up with him and required that he take a short break on a bench in a quiet space. As they sat she explained he could not run in the MOS or move out of sight from their family.

Additionally, the museum staff served as supports in the environment throughout family visits. Three of the four families sought out opportunities to interact with museum staff within the exhibit halls, either during one-on-one demonstrations or small group presentations, When Arnold’s family entered the Hall of Human Life exhibit, they immediately approached a museum educator wearing a red lab coat who had a table set up with different sized bones on it. Similarly, Kenny’s family visited a computer exhibit and watched a demonstration conducted by a museum educator. Instead of walking through the exhibit hall independently learning from the posted information, it was possible to engage with a museum staff to ask specific questions.

Definitions of Success

Families described how they would define a successful visit at the museum during the home visit before visiting the MOS, as well as immediately following the family’s museum visit. The families’ definitions of success included having fun, having all members of the family engaged in the museum exhibits, learning something new, having enough time to see what family members wanted to see, and having a pleasant and calm experience.

All four families emphasized that they had fun during their visit to the MOS.
Jacob’s mother shared, "It was a fun day and so it was, it was a success." Families also shared that having all family members engaged in the museum exhibits made the visit successful. Nancy’s mother shared:

We thought all the exhibits held all of our interests, which is a hard thing to do (laughs). Usually if we're entertained she's bored and if she's entertained we're like okay that's enough of that after a certain amount of time. But the whole thing was engaging which was good.

Families viewed learning and sparking new interests as a positive outcome of the MOS experience. While Nancy told her parents she wanted to take out books about space from the library, Arnold’s brother worked on an engineering activity related to a school science project, which he planned to continue at home. Arnold was excited he was able to touch bones and put together a primate skeleton, and his mother was thrilled that he showed an interest in this topic for the first time. These examples illustrate the value of interactive learning, and parents described these instances as “aha” moments that made the visit to the MOS worthwhile.

All the families judged the success of their visit as ”having enough time to see what all family members wanted to see”. Two families viewed success as “seeing everything,” and two families defined success as having a pleasant experience (even if it was a short experience and not all exhibits were visited). Kenny and Nancy’s families were disappointed they did not see everything in one visit and wanted to return for a longer time frame the next time they visit the MOS. When asked what would make the visit to the MOS successful, Arnold’s mother shared her family’s perspective:

Not really about seeing everything, just everyone enjoying the afternoon or morning, whatever it is. That's success to us. Just everyone having a pleasant afternoon, a pleasant experience.
Other families talked about having a pleasant and calm experience when asked about the success of the MOS visit. Experiences were pleasant when families enjoyed their time together and got to see what they wanted to see. Arnold’s mother explained:

I feel good. You know, we kept it short, and did the things that we wanted. I look forward to coming again. I don't feel exhausted or disappointed or overwhelmed. And I'm not leaving dragging my kids out of the museum (laughs). So, I feel good.

Two of the four families also expressed the importance of calmness, with success being a visit where all family members are able to remain calm throughout the experience. Nancy’s father explained that for her “not to have a meltdown” was his definition of success. Before the visit, he shared:

I don't think she will have an episode now. She's gotten way better… if it was two years ago, it'd be a way different story of what is successful.

Arnold’s mother, who had thought about quiet spaces to use in case Arnold had difficulty during the visit, referenced his behaviors following their visit to the MOS. When asked if the visit was successful, she responded:

I did, I really did, it really, really was. He didn't have one meltdown.

**Discussion**

The interviews with parents and children and observations of family visits to the MOS revealed that family involvement and environmental features of the museum were important to how families approached their visit and their perceived outcome of the visit (See Figure 1). Both the motivations for the visit and features of the environment appeared to influence the family’s approach and strategies they employed for a successful visit. Strategies included those completed before the visit (visitor planning strategies), as well as during the visit (strategies at the museum). The strategies enabled families to
enjoy and experience success within the museum environment. While one prior study has identified motivations and visitor planning strategies used by families with a child with ASD (Langa et al., 2013), the ways in which motivations, the museum environment, and family strategies interact to lead to a successful visit have not been articulated. This conceptualization extends our understanding of how to best support inclusion and belonging for families with a child with ASD in the community.

The four families in this study have similar motivations, as they described wanting to have fun, to learn, and to socialize. Langa et al. (2013) also reported that families with children with ASD appreciated combining personal interests with something meaningful and enjoyable. Our findings are also consistent with the motivations expressed by families of children who do not have a disability. These families visit museums for social-related reasons, recreational/sight seeing reasons, learning/personal enrichment reasons, hobby/professional interest-related reasons, and reverential reasons (Borun, Gleichorn, & Garfield, 1995). Thus, we learned that families with a child with a disability, including ASD, appear to want the same experiences for their children as families with typically developing children.

Family motivations led parents and children to visit the museum, which has environmental features that influence the visitor experience. Environmental features that supported the family experience at the MOS included limited crowds, interactive exhibits, clear signage, information related to sensory stimuli, spacious exhibit halls, and knowledgeable museum staff. The MOS values inclusion, and museum professionals use principles of Universal Design for Learning when selecting subject matter, designing
exhibits, and educating staff (Reich, 2005). Because of their efforts, the families who visited the MOS used the environmental features to create successful experiences. When families with a child with ASD were interviewed following a visit to the Smithsonian Institute, families expressed a need for information related to the environment, including better directions for use of public transportation, and more detailed floor maps to indicate where bathrooms and exits were located (Langa et al., 2013). Environmental features such as online resources, signage in the museums, maps with sensory features of exhibits and spaces clearly identified, and accessible museum staff all contribute to inclusion.

Family members considered the environment when using strategies before their visit (visitor planning strategies), and during their visit (strategies used at museum), illustrating an interaction between environmental features and family strategies. All strategies required family involvement, as parents and siblings (in 3 of the 4 families) provided support and often used the features of the environment when assisting the child with ASD. While most visitor planning strategies were employed by parents in preparation for the trip to the MOS, all family members were observed using strategies at the museum throughout the visit.

The visitor planning strategies used by the four families in this study are similar to strategies described by parents in other research with children with ASD. Comparable to findings shared by Langa et al. (2013), parents in this study used pre-teaching and Social Stories™ to prepare for experiences in the museum environment, familiarized themselves with the layout of the museum, and used web-based documents that contained museum hours, directions, and content of exhibits. Two parents in this study used the visitor
planning strategy of scheduling the MOS visit during a time frame when it would be least crowded (based on previous experiences). Another family planned to visit for only one hour and the parent was comfortable moving slowly and seeing only a few exhibits, as opposed to being focused on seeing everything. Maul and Singer (2009) highlight the value of planning ahead and slowing the pace of the activity. By planning ahead and considering the environment, family strategies support children to reach valued outcomes.

Following their museum visit, parents and children described aspects of the environment that served as supports, demonstrating how the interaction between individuals and the environment influenced how families experienced success. The experiences of families in this study align with the findings shared by Anaby et al. (2014), who reported that the environment plays an important role in how children with a disability experience community. The data reported here suggest that the environmental features of the MOS influenced the strategies families used, which in turn helped families enjoy a successful visit. These findings lead us to make recommendations to support inclusion for families with a child with an ASD. If family members are aware of features within the museum environment, it may be possible to support their participation in community outings. Additionally, insights gained from the families in this study have the potential to inform other families of strategies to prepare for and enjoy successful museum visits. Based on the findings from this study, recommendations for the ways families may use environmental features, and initiatives museums may employ to provide an inclusive environment are presented in Table 4.
It is important to recognize that some factors that facilitate successful visits are modifiable, and some are not. Museums may provide access to pre-teaching resources on their institution’s website, and it may be valuable to have different specialized Social Stories™ for first-time visitors and returning visitors (Rudy, 2010; Langa et al., 2013). If multiple versions of a story were available, families could select the story that best meets their needs and interests. Multiple versions of Social Stories™ may be useful for children of different ages, providing developmentally appropriate suggestions for exhibits to explore during the family visit to the museum.

In addition, photos of the exhibits would also be valuable. The images, along with information about exhibits, may help families decide which exhibit to see during their visit (Rudy, 2010). Some exhibits are temporary while others are permanent. If museums provide up-to-date information regarding current exhibits, families may have the opportunity to plan appropriately for their visits. Posting a description of suggested time frames when the space is least crowded may be useful to families who hope to avoid busy days. However, the timing of the museum experience may not be modifiable for all families, since some families are only available to visit a museum on holidays and weekends.

Table 4 suggests families follow their plan during the museum visit (Rudy, 2010, Maul & Singer, 2009). Using signage and asking museum personnel for assistance may support families as they follow their plans. Families may also plan for spontaneity at the museum so that their plans remain flexible. For instance, one of the families in this study had siblings take turns selecting exhibits to visit. A family visiting a museum may not
plan to see specific exhibits, but instead may plan to have family members take turns. This strategy allows for children with ASD to comfortably rely upon a plan, while also providing a modifiable plan so that new and interesting exhibits may be explored.

Taking breaks during the visit is a recommendation generated by the families in this study, as families found quiet spaces to sit and relax, and to have snacks. Families may plan a route that includes quiet spaces for breaks, and museums may support families by creating maps that mark quiet spaces, as well as labeling the sensory stimuli in exhibits and spaces. Families may help their child with ASD feel comfortable and remain calm by being aware of sensory stimuli within the museum. By knowing where the spaces with sensory stimuli are located, parents may avoid these areas with their families if necessary, or they may prepare their child with ASD before interacting with the sensory stimulating environment.

A useful strategy to support engagement is 1:1 support for the child with ASD, whether it be a parent or sibling. If a family visits with one parent, a child with ASD, and a sibling, it may be challenging for the parent to attend to both children’s needs. Museums may offer a professional development program to teach museum personnel and volunteers to recognize the needs of families with children with ASD and to engage the siblings so that the parent is able to support the child with ASD throughout the museum experience.

Implications

Since museum and rehabilitation professionals are both interested in promoting inclusion at museums for families with children with ASD, it is important to recognize
how families use features of the environment when visiting the MOS. It is also valuable to learn from families when making recommendations to promote inclusion. Seeking feedback from families is yet another mechanism to create a sense of belonging in a social, community setting (Hall, 2010). If families with a child with ASD recognize that environmental features may be used as strategies to facilitate successful experiences, it may be possible to not only create success at museums, but in other community settings. Families may be more aware of other community settings with environmental features that may be effectively used by families. Museum personnel may also ensure that environmental features that are present are maintained, and the importance of the environment may inform inclusion efforts at museums and other community settings.

**Limitations and Future Research**

Because data were collected from four families, each with unique perspectives and experiences, varying family structures, a child with ASD with expressive language, parents who spoke and understood English, lived within driving distance of the MOS and had visited previously, the recommendations may not match the needs of every family with a child with ASD visiting the MOS. While the family structure of the four families in this study varied, all four children with ASD were able to use expressive language to communicate. Thus, further research is indicated to explore the experiences of families with children with ASD who use argumentative communication systems or have a wider range of functioning than the 4 children in this study. Additionally, this study included families who could read and understand English. A study of the perceptions of a larger and more diverse sample of parents with children with ASD is needed. Finally, the
families also lived within 75 miles of the MOS, and were able to drive to complete a day trip. Many families visiting the MOS are from out of town, and may have other contextual factors to consider for their child with ASD (such as staying at a hotel, using public transportation, and being away from a typical, daily routine). The families in this study not only lived within driving distance to the MOS, but had also visited the MOS previously. First-time visitors, in contrast to repeat visitors, may have different motivations, use varying strategies (particularly environment-focused strategies if they are unfamiliar with the environment), and have their own definitions of success. We may learn that families’ experiences in a new space for the first time may generate additional strategies and recommendations.

Conclusion

By gaining a better understanding of parents and children’s perspectives, we may appreciate how environmental features may be used by families to promote inclusion and participation for families with a child with ASD in museums. Moreover, by recognizing the factors related to participation at the science museum, noting motivations, environmental features, and strategies, parents may be able to prepare for and engage in successful, meaningful experiences within the community. Additionally, researchers may use insights gained from families to inform large scale, population based research studies that examine how families with a child with ASD use environmental features as strategies to be successful in the community.
<table>
<thead>
<tr>
<th>Child with ASD*</th>
<th>Age of child (years)</th>
<th>Reported diagnosis**</th>
<th>Who attended the museum visit (age of siblings)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenny</td>
<td>10</td>
<td>PDD-NOS</td>
<td>1 parent, Kenny, and brother (age 12)</td>
</tr>
<tr>
<td>Nancy</td>
<td>9</td>
<td>PDD-NOS</td>
<td>2 parents and Nancy</td>
</tr>
<tr>
<td>Jacob</td>
<td>7</td>
<td>Asperger syndrome</td>
<td>2 parents, Jacob, and brother (age 4)</td>
</tr>
<tr>
<td>Arnold</td>
<td>7</td>
<td>PDD-NOS</td>
<td>1 parent, Arnold, brother (age 12) and sister (age 10)</td>
</tr>
</tbody>
</table>

*Names have been changed to honor confidentiality

**PDD-NOS and Asperger syndrome are included within the diagnosis of Autism Spectrum Disorder (ASD) in the DSM-5
<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>Child with ASD &amp; family</td>
<td>Length of visit (hours)</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Kenny, 1 parent, brother</td>
<td>2</td>
</tr>
<tr>
<td>Nancy, 2 parents</td>
<td>6</td>
</tr>
<tr>
<td>Jacob, 2 parents, brother (met family friends with 2 parents and 2 children at museum)</td>
<td>3</td>
</tr>
<tr>
<td>Arnold, 1 parent, 1 brother, 1 sister</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 4. Recommendations to promote inclusion for children with ASD

<table>
<thead>
<tr>
<th>For Families</th>
<th>For Museums</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use pre-teaching and Social Stories&lt;sup&gt;TM&lt;/sup&gt;</td>
<td>Provide specialized resources (Social Stories&lt;sup&gt;TM&lt;/sup&gt;) for first time visitors vs. experienced families</td>
</tr>
<tr>
<td>Develop plan (time frame, exhibits to visit)</td>
<td>Have access to photos of exhibits on website, information about current exhibits (permanent vs. temporary), and recommended quieter times</td>
</tr>
<tr>
<td>Follow plan during museum visit and plan for spontaneity</td>
<td>Provide signage and have museum personnel in the exhibit spaces to help families navigate</td>
</tr>
<tr>
<td>Take breaks during visit and be aware of sensory stimuli</td>
<td>Create a map for families to access online before visit with quiet spaces and sensory stimuli in each exhibit noted</td>
</tr>
<tr>
<td>Use 1:1 to provide modeling, redirecting, and to engage in science talk</td>
<td>Provide museum personnel with professional development to be comfortable communicating with children with ASD and develop program for museum volunteers to support sibling if needed</td>
</tr>
</tbody>
</table>
Fig. 1. Factors that influence successful visits to the Museum of Science, Boston

**Motivations**
- Hands on learning
- Have fun
- See new exhibits and old favorites
- Social activity

**Environmental Features**
- Limited crowds
- Interactive exhibits
- Clear signage
- Sensory-related information
- Spacious exhibit halls
- Knowledgeable museum staff

**Definition of Success**
- Have fun
- Engage in museum exhibits
- Learn
- Enough time to see what wanted to see
- A pleasant and calm experience

**Family Strategies**
**Visitor Planning**
- Social Stories/pre-teaching
- Pack snacks
- Prepare siblings
- Review website and photos
- Make plan of exhibits to visit
- Plan time frame for visit

**At Museum**
- Model, re-direct, prompt with time, provide 1:1 to child with ASD
- Stay together within spacious exhibit halls
- Engage in “Science talk”
- Use interactive exhibits, signs, and sensory-related information
- Find quiet spaces
- Interact with museum staff
Appendix A

Parent(s) interview: Before museum visit

- What is your impression of the Museum of Science (MOS)?
- Have you and your family visited the MOS before?
  - 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?
  - 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 MOS, what are you thinking about?
- Are you doing anything to prepare your child for your trip to the museum?
  - If so, what are you doing to prepare?
- What do you hope your child with autism will get out of your visit to the MOS?
- 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 MOS a success for your family?
Appendix B

Study Observation Protocol

Preparation

• Check your materials. You should have:
  o A clipboard
  o A museum map with open-ended observation sheets and debrief sheet
  o A stopwatch or clock
  o A pen or pencil

• Note the date, time of day, group number, and your initials on the observation sheet.

• Meet the family in the lobby, introduce yourself, and thank them for participating. Make sure they are comfortable and have gotten 'Visitor' stickers and validated parking.

• Remind them of the purpose of the study.
  o To understand the museum visitor experiences of families with children.

• Go over the schedule:
  o Explore the Museum as long as they want to.
  o When the family is ready to stop, the parent should tell the researcher.
  o Go to a quieter conference room for the interview.
  o After the interview, they're free to go.

• Before starting the observation, tell the family, "We are about to begin. As you know, I will be following along with you while you are in Museum, watching and taking notes. I will not interrupt you at all. You simply need to use the exhibits and the Museum as you normally would, in the way that works best for you. You can stay as long as you want and go to any public space in the Museum. Please don't feel that you are required to act in a certain way because I am observing you. Just as a reminder, I'll be interviewing you after your visit about the experience. The interview will take about 30 minutes, so when you think your family will be ready to leave the museum within that time frame, let me know and we will go to a quiet space to complete the interview. Do you have any questions before we start?"

• When they are ready, start the visit.

Tracking and Timing: This protocol uses a map of the museum to track where participants go in the Museum and how long they spend in specific areas. The Museum map is attached to this protocol.

• Mark the family’s starting point on the map with the word “Start.”

• Trace the family’s movements through the Museum using lines and arrows to mark the path and direction of travel. Try to make the arrows as continuous as possible so you can distinguish them if the family backtracks or goes through the same area more than once.

• If the family appears to stop in any exhibition or other area (cafeteria, stairwells, program spaces, benches, etc.), start a timer.
If they remain in the area for at least one minute, place a number in the area on the map. Then flip to the open-ended observation sheet and take notes there.

Each numbered stop will be considered areas that the family “visited.” Write the number 1 in the first area where they stop, the number 2 in the second, etc.

- Using a stopwatch, time the length of interaction in each of the visited exhibitions or areas. When the family leaves an area, turn back to the map and continue tracing their path.
- Follow the family until the parent indicates to you that their visit is finished.
- Mark the family’s finishing point on the map with the word “End” and note the time again.

Open-ended Observations

- In each area the group visits, record open-ended observations of what the visitors say or do while there.
  - These observations should be guided by the questions listed on the following page.
- At the end of the entire visit, quickly record your answers to the observation debrief questions listed at the end of the document.

Quiet Spaces

- In the event that the participant family needs a quiet space to calm down or regroup, the following areas can work:
  - The stairwells accessible from the Blue Wing in the Exhibit Halls usually have very few visitors in them.
  - The nursing room near the New England Habitats exhibit in the Green Wing has a door that you can shut. The key is kept at the Information Desk.
  - There is a family bathroom near the Hall of Human Life on the 2nd floor of the Green Wing.
  - The Mezzanine in the Red Wing is quiet and has accessible bathrooms. However, when Omni shows get out, a crowd will pass through this area.
  - The area outside the Planetarium is quiet if it's not a busy day, and the lighting in the space is lower. People will line up there for Planetarium shows on the half hour.

Miscellaneous Notes:

- You may appear too busy for visitors to approach you with questions, but if they do, feel free to use your discretion about answering them. For any questions that you do not have time to answer, politely direct visitors either to the information desk or to any other nearby staff member or volunteer.

Open-ended Observations:

For each visited area, record open-ended notes about the kinds of activities visitors engage in when visiting that particular area. These notes should be descriptive and depict what the visitors say or do. In these notes, you may want to be thinking about the following questions:
How would you characterize the overall nature of the activity in the area? What behaviors lead you to characterize their activities in this way?

- Exhibit or program related?
- Play? Resting? Planning?
- Non-museum related (such as being on a smartphone or reading a book)?

Who takes the lead in each area and who tends to follow?

- Is there one particular individual who always seems to be initiating what the group does and where they go, or does it change? How do you know?
- Is there one particular person that demonstrates any form of expertise related to the content, or who seems to take the lead in educating others about what is happening?

To what extent are the activities individual versus social?

- Does the group interact with each other at exhibits or programs, or do they work alone or in parallel?
- Do members of the group interact with museum professionals during their visit? If so, who interacts with whom and who initiates the interactions?

When the group interacts, what is the nature of their interactions, and what behaviors do you notice that leads you to characterize these interactions in this way?

- Behavior management?
- Interacting with each other at exhibits or programs?
- Learning activities (such as guiding someone through an activity or talking about the content or engaging in scientific thinking skills)?
- Play
- Visit planning
- Non-museum related tasks

Are there particular moments when the group members appear to be particularly happy, excited or engaged?

- What is happening during those moments? Who is happy, excited or engaged?

Are there particular moments when the group members appear to be particularly frustrated, annoyed, agitated, or upset?

- What is happening during those moments? Who is unhappy?

Initial Notes:

- On time? Who is in attendance? Other details?

<table>
<thead>
<tr>
<th>Stop 1:</th>
<th>Time spent:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stop 2:</td>
<td>Time spent:</td>
</tr>
<tr>
<td>Etc.</td>
<td></td>
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</tbody>
</table>
Appendix C

Parent(s) interview: After museum visit
- Please tell me about your experience visiting the Museum of Science (MOS) 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 MOS?
- How do you feel after your visit?
- Do you want to come to the MOS again?
  o Why/why not?
- What did your family get out of your visit to the MOS?
- 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 MOS?

Child with autism interview: After museum visit
- What was your favorite part of the MOS?
- 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 MOS?
- Please tell us about your experience exploring the museum with your [sister or brother].
Appendix D

Coding Book:

1. Motivations
   a. Initial: Description of reasons for and feelings about visiting the museum, goals for the visit, and/or hopes for the visit
   b. Axial:
      i. Family: Parent, child with ASD, sibling
      ii. Environment: Aspects of the museum (exhibits, shows, etc.) families reference when sharing feelings, experiences, and anticipations

2. Environmental features
   a. Initial: Description of characteristics of the museum that support family experience (time of day, exhibit features, signage, benches, interactions with museum personnel or other museum visitors)
   b. Axial:
      i. Family: Parent, child with ASD, sibling feedback related to environmental features
      ii. Researcher: Observations of environmental features/affordances of the museum that support the family experience and the researcher’s interpretation of family members’ responses to the environmental features (time of day, exhibit features, signage, benches, interactions with museum personnel or other museum visitors)

3. Strategies
   a. Initial: Actions or thoughts directed at solving an immediate or ongoing problem or achieving an immediate or future goal (Merriam-Webster, 1993)
   b. Axial:
      i. Family: Parent, child with ASD, sibling using strategies
      ii. Environment:
         1. Visitor planning: Intentional, preparatory actions completed family members before the day of the museum visit with the purpose to support the museum experience for all family members
         2. At museum: Intentional actions completed by parents or family members and explicitly communicated to researcher during the museum visit with the purpose to support the museum experience for all family members
3. At museum: Intentional actions completed by parents or family members and observed by the researcher during the museum visit with the purpose to support the museum experience for all family members

4. Definition of Success
   a. Initial: Description of a positive outcome, achievement, or a fulfilled plan; overall perspective of visit; memories from the experience
   b. Axial:
      i. Family: Parent, child with ASD, sibling description
      ii. Researcher’s observation of a positive outcome, achievement, or a fulfilled plan based on family descriptions
References


VITA

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EDUCATION

**Boston University, Sargent College**, Boston, MA 2012 – 2015
*Master of Science, Occupational Therapy*

**Boston College, Lynch School of Education**, Chestnut Hill, MA 2010 – 2011
*Master of Arts, Applied Developmental and Educational Psychology*

**Boston College, College of Arts and Sciences**, Chestnut Hill, MA 2007 – 2009
*Bachelor of Arts, Philosophy*

HONORS AND AWARDS

Pi Theta Epsilon, Occupational Therapy Honor Society, Boston University, 2013
Women Graduates' Club Scholarship, Boston University, 2013
Merit Scholarship Recipient, Boston University, 2012
Magna Cum Laude, Boston College, 2009 and 2011
Dean’s List, College of Arts and Sciences, Boston College, all semesters

RESEARCH EXPERIENCE

**Research Assistant**


*Department of Occupational Therapy, Boston University, Boston, MA*

Investigators: Gael Orsmond, Ph.D.
Ellen Cohn, ScD, OTR/L, FAOTA

*Title: The VIP Intervention: Using Video to Enhance Social Well-Being for Adolescents with an Autism Spectrum Disorder*

- Completed home visits to adolescents, negotiated assent and consent, reviewed research procedures
- Engaged adolescents in positive self-reflection via self-modeling, and collected data
- Collaborated with research team in organizing materials, managing data, and coding and interpreting data

**Research Assistant**

July – Aug. 2012

*Department of Occupational Therapy, Boston University, Boston, MA*

Investigator: Jessica Kramer, Ph.D., OTR/L

*Title: Evaluation of the Effectiveness of an Environmental Modification Training for Youth with Disabilities*
• Assisted in facilitation of intervention for 9 teenagers with disabilities for six-week summer program
• Led coaching sessions with individuals, chaperoned field trips, and collaborated with other facilitators
• Completed documentation following each session, and conducted final assessments for 2 trainees

CLINICAL AND COMMUNITY EXPERIENCE

Developmental Specialist Dec. 2011 – Present
Riverside Early Intervention, Needham, MA
• Complete home visits to children ages birth to three with a range of developmental delays and provide support
• Serve on an interdisciplinary assessment team, and lead an integrated toddler group at the EI center
• Help families transition children into the public school system, and communicate with school officials

Inclusion Consultant June 2012 – Nov. 2012
Museum of Science, Boston, MA
• Completed observations of summer camps and overnight programs to analyze environmental supports and barriers
• Led meetings, provided resources, and effectively communicated with museum administrators and staff

LEND Fellow Sept. 2011 – May 2012
Institute for Community Inclusion, Children’s Hospital Boston, Boston, MA
• Attend weekly seminars to improve knowledge of working with individuals with disabilities
• Complete clinical observations, develop service projects within the community, complete home visits
• Advocate at the Disability Rights Conference in Washington D.C. in April 2012

PRESENTATIONS


Boris, A. & Cohn, E. (2013, Nov.) Partnering with Museums: Creating Social Stories to Support Inclusion. Presentation at the Massachusetts Association for Occupational Therapy Annual Conference, Norwood, MA.


**PUBLICATIONS**

Boris, A. & Jacobs, K. *Three Bakers & a Loon*. Lightning Source Inc., La Vergne, TN.


**PROFESSIONAL MEMBERSHIPS**

American Occupational Therapy Association, Student Affiliate, 2012
Massachusetts Association of Occupational Therapy, Student Affiliate, 2012
Boston College Graduate Student Association, Member, 2010 – 2011
Boston College Alumni Association, Member, 2009 – Present