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# Caregiver Perceptions of Healthcare Providers and Environments Related to Children with Autism Spectrum Disorder

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Caregiver Perceptions of Healthcare Providers and Environments Related to Children with  
Autism Spectrum Disorder

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Akron Honors College.

### Abstract

The healthcare setting can be intimidating for any child. For children with autism spectrum disorder (ASD), in particular, this setting can cause anxiety and elicit disruptive behavior. The reactions of children with ASD to healthcare settings have not been widely studied. This study explores the lived experience of caregivers of children with ASD related to healthcare providers and environments. A qualitative phenomenological approach and methods guide the study.

Purposive sampling was utilized at a resource center to identify and recruit participants fulfilling inclusion criteria. Sample size consisted of four female and two male adults. Semi-structured interviews were performed and voice recorded. The interviews were then analyzed and revealed themes like sensory considerations, acknowledgement that every child is different, caregiver responsibilities, needed preparation and organization, and the need for more compassion, understanding, and knowledge within the healthcare setting. In conclusion, it was found that there is a strong need for more education and compassion in healthcare providers when working with children with ASD.

## Caregiver Perceptions of Healthcare Providers and Environments Related to Children with Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a generalized term for a group of developmental disabilities that affect communication and social interactions (CDC, 2012). This group of disabilities includes a spectrum of symptoms and differing levels of severity (National Institute of Mental Health, 2012). Primary symptoms of ASD include trouble with social interaction, communication, both verbal and nonverbal, as well as continual behaviors (Autism Speaks, 2014). ASD has been associated with intellectual problems, health issues, and motor coordination issues, but it has also been linked to proficiency in subjects such as art, math, music, and visualization (Autism Speaks, 2014). Early brain development is thought to be where ASD begins, but key symptoms typically present around ages two and three (Autism Speaks, 2014).

In 2009, nearly 560,000 children between birth and twenty-one years of age in the United States had been diagnosed with ASD (Scarpinato et al., 2010). In 2014, over two million people in the United States had been diagnosed with ASD (Autism Speaks, 2014). Approximately one in every 42 boys and every one in 189 girls in the United States is diagnosed with ASD (Autism Speaks, 2014). In recent years the occurrence of ASD has been increasing ten to seventeen percent every year (Autism Speaks, 2014). As prevalence increases, so does the need for understanding and managing this disorder (Scarpinato et al., 2010). This is particularly true for healthcare providers who may be seeing more of these children on a daily basis (Scarpinato et al., 2010).

Going into any healthcare setting can be a challenge for children with ASD, their caregivers, and the healthcare providers. In order for healthcare providers to provide an

environment that would be conducive to these children's needs, knowing caregivers' perspectives of problems and their suggestions for improvement can be vital (Johnson & Rodriguez, 2013). These perspectives may help to determine how to provide an appropriate environment and experience in healthcare settings for children with ASD (Johnson & Rodriguez, 2013). This study explores the lived experience of caregivers of children with ASD related to healthcare providers and environments. The following research questions are answered: What are the experiences of caregivers of children with ASD in relation to healthcare providers and environments? From the caregiver's perspective, what changes in the healthcare environments and providers' care techniques would support a positive experience for children with ASD?

### **Review of Literature**

While many studies about ASD exist, study objectives vary. Researchers have identified and examined the behaviors of children with ASD (Brookman-Fraze, Drahot, Stadnick, & Palinkas, 2012b; Brookman-Fraze, Taylor, & Garland, 2010; Drake, Johnson, Stoneck, Martinez, & Massey, 2012; Hallett et al., 2013), interventions to affect the behaviors (Brookman-Fraze et al., 2010; Drake et al., 2012; Rosenblatt et al., 2011; Virues-Ortega & Rodríguez, 2013), and perceptions of how these children react in healthcare settings from the standpoint of therapists and caregivers (Brookman-Fraze, Baker-Ericzén, Stadnick, & Taylor, 2012a; Brookman-Fraze et al., 2012b; Green, 2007; Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013; Minnes & Steiner, 2008). Researchers have found that children with ASD exhibit signs of disruptive behavior problems and anxiety (Brookman-Fraze et al., 2012b; Brookman-Fraze et al., 2010; Drake et al., 2012; Hallett et al., 2013). At 84.6% predominance, these disruptive behaviors are some of the most common challenges faced in the healthcare setting during care of children with ASD (Brookman-Fraze et al., 2012 b; Brookman-Fraze et al., 2010). Different

interventions to affect behaviors include psychotherapy (Brookman-Fraze et al., 2010), coping kits (Drake et al., 2012), yoga (Rosenblatt et al., 2011), and intensive behavioral interventions (Virues-Ortega & Rodríguez, 2013). Because the focus of this study is on caregiver perceptions, the following paragraph will describe studies about caregivers of children with ASD, experiences in healthcare settings, children's behaviors, and children's care.

Although few researchers have studied healthcare providers' perceptions of children with ASD (Brookman-Fraze et al., 2012b), more have studied caregivers' perceptions of their children's reactions, needs, and care in healthcare settings (Brookman-Fraze et al., 2012a; Green, 2007; Kopecky et al., 2013; Minnes & Steiner, 2008). Caregivers have had both positive and negative experiences when taking their children with ASD to healthcare settings (Brookman-Fraze et al., 2012a; Minnes & Steiner, 2008). Outcomes of these experiences were dependent on the abilities of practitioners to provide care to children with ASD, and more significantly children's behavior during healthcare visits (Brookman-Fraze et al., 2012b; Brookman-Fraze et al., 2010; Drake et al., 2012; Hallett et al., 2013). For example, in a quantitative study, Kopecky et al. (2013) collected data with a 21-question survey filled out by 80 caregivers of children with ASD. The survey focused on children's needs and how their behaviors were addressed in healthcare settings. The researchers found that 29% of caregivers reported that specific words or actions may be triggers of anxiety in children with ASD (Kopecky et al., 2013). In addition, 59% of caregivers suggested that distance and space were the best strategies when trying to help their anxious children, while 23% indicated that trying to engage with the children may be most helpful (Kopecky et al., 2013). Being aware of the needs and challenges for these children is essential to providing better care and could possibly lead to improved

treatment results and an overall greater understanding of children with ASD (Kopecky et al., 2013).

Many of the researchers used a sample size smaller than 25 (Brookman-Fraze et al., 2012a; Brookman-Fraze et al., 2010; Drake et al., 2012; Green, 2007; Minnes & Steiner, 2008; Rosenblatt et al., 2011; Virues-Ortega & Rodríguez, 2013), limiting generalizability of findings. Future studies using larger samples of children may verify the results of earlier studies.

Additionally, some researchers only studied children on the higher functioning end of autism (Brookman-Fraze et al., 2010; Hallett et al., 2013). Future studies should also study children with ASD who are lower functioning. There is also limited research on caregivers' views of the reactions of children with ASD in the healthcare setting. More research is needed to find out triggers and obstacles for children with ASD and ways to manage these issues in healthcare, which is the gap in knowledge addressed by this study.

### **Theoretical Framework**

Phenomenology guided this study. This perspective involves describing the lived experience with the aim of finding the meaning in experiences and making sense of it (Schmidt & Brown, 2012). Meaning is found by examining the viewpoints of persons who have been through the experience (Schmidt & Brown, 2012). The current study focuses on describing and understanding caregivers' perceptions of reactions their children with ASD have had in the healthcare setting. Caregivers' observations were analyzed to identify and describe themes and trends, as well as to find ways to help their children have more comfortable experiences. As is common with many phenomenological studies, data were obtained through semi-structured interviews of caregivers who were chosen using purposive sampling techniques (Schmidt &

Brown, 2012). Through these interviews, data were collected and analyzed, resulting in theme descriptions.

## **Methods**

### **Design**

This study used a qualitative design based in phenomenology to describe the lived experience of caregivers of children with ASD related to healthcare providers and environments. Recruitment and data collection began after the study was approved by The Institutional Review Board of the University of Akron.

### **Sample and Setting**

Data collection took place at the service organization's camp for children with special needs. The sample included four female and two male participants who are between the ages of thirty to sixty, English-speaking, and provide care for a child with ASD, ages four to twelve years. No participants were excluded based on gender or ethnicity. The sample size was six participants.

### **Sampling and Data Collection Procedures**

Purposive sampling was used to recruit participants who met the inclusion criteria. The service organization supported the co-investigators (Co-I) by initiating contact between potential participants and Co-I. The Co-I met with potential participants at specified locations including the resource center, a personal residence, and a place of work. At these locations, informed consent was obtained (see Appendix A). During the meeting, the Co-I described the study and addressed any questions. Once informed consent was obtained, demographic information about participants and children was collected, followed by the voice recorded, semi-structured interview. The meetings and interviews were conducted in private rooms, and participants were

reminded that involvement and responses were voluntary. Following interviews, recordings were analyzed, and the original recordings were destroyed after the research project was complete. Until recordings were destroyed, they were stored on password protected computers. Only study Co-I and sponsor had access to recordings. Co-I also wrote field notes during interviewing and recruitment, which were shared and used during data analysis. Recruitment and data collection continued until data saturation was reached. The interviews lasted 20-30 minutes.

### **Data Collection Tools**

The data collection tool consisted of semi-structured interviews with nine initial interview questions that focused on perceptions of how the participants' children react to healthcare settings and providers. The interview schedule is in Appendix B. The questions aimed to focus participants' recollections and ideas, but when additional questions were identified as data collection progressed, they were included as well. Additionally, if participants suggested that a question should be used for future interviews, this question was considered by Co-I and the project sponsor and then added to the interview schedule before the next interview with a participant.

### **Data Analysis Plan**

Descriptive statistics were used to describe the sample. Interview questions and answers were analyzed by the Co-I. Field notes from Co-I were also shared and used during analysis. Meetings with Co-I and the sponsor were held to discuss and analyze findings to come to a consensus about common themes and trends in the interviews. Conclusions were drawn from this analysis.

## **Findings**

Many common themes were discovered during analysis of the interviews and included: Sensory Considerations, Every Child Is Different, Caregiver: It Is All Our Responsibility, Prepare and Organize, and A Trio of Needs: Compassion, Understanding, and Knowledge.

### **Sensory Considerations**

During the course of the interviews, all six participants talked about sensory issues that children with ASD face in the healthcare setting. These issues included both the presence and the absence of certain environmental aspects that could calm or agitate their children. Most of the caregivers expressed complaints about the current environment of healthcare settings, explaining that there are aspects that disturb their children and could disturb other children with ASD. One mother said: “When you go to some places that deal with autistic children ..., you would think that they have no idea because there is no sensory corner. There are all of these things that trigger kids to have meltdowns.”

Frequently overlooked aspects of the environment can be over-stimulating for a child with ASD. Fluorescent lights, for example, can be overwhelmingly bright and emit an agitating high-pitched noise. The walls are often stark white in color, and the strong scent of perfume or cologne can aggravate a child with ASD. Loud noises, like the flush of a toilet, the bathroom fan, and the paper that crinkles on the exam room table, can cause further stress to the child during a visit.

Further, most participants talked about the lack of color and absence of distractions available for their children during appointments. Some addressed the fact that there were books to read, but then stated that those books were not helpful in diverting a child’s attention. Therefore, in addition to the suggestions about having dimmer lights and quieter rooms,

participants suggested ways of adding to a room to make it suitable for a child with ASD. One participant described what has worked for his son and what he would like to see, saying:

When he goes through [the hospital and] the wall is puffed out and you've got, you know, different murals and little mirrors or whatever and stuff like that. And I mean he even walks by it and just looks at it all the time.

This participant then explained the purpose of such designs and distractions by describing how he thinks that his child would react to this new environment. He said:

If he walked into a place like that he would be like, "Oh my gosh, where am I? ... This isn't a doctor's office." [The distractions would help to] take their blinders off that "I am going to have a horrible time right now."

Other suggestions included making the rooms more visually stimulating by painting them different colors and putting well-known animated characters on the walls. Participants also liked the idea of having stuffed animals, puzzles, and plants in the waiting and appointment rooms to entertain and calm their children. Finally, there were multiple suggestions about adding technology to the room. Many of the caregivers described how technology is often a good way to engage their children and to make them feel at ease during healthcare visits. As a result, they would like to have music and a television or computer available that offers video games or other child-friendly entertainment in the room.

### **Every Child Is Different**

All six participants described the temperament of their children, which varied depending on the child. A common theme among the participants was the need of the healthcare providers to work with a child's individual needs. In occurrences when their child's individual needs were not met, it resulted in a lot of issues for caregivers, children, and healthcare providers. One

participant said: “You’re in a children’s hospital. You should understand that all these kids are different, but they don’t. It’s frustrating.”

All of the participants’ children have the diagnosis of ASD and portray behaviors from this diagnosis. However, all of the children have at least one other accompanying diagnosis that contributed to their day-to-day temperament and interaction. The participants described the disposition of their children in various ways. The words used to describe them ranged from funny, sweet, and calm, to anger and aggression, all depending on the child and the situation. One mother described the variance in her daughter by saying:

She is generally very happy, very loving, but she is loving on her terms. So she is going to give you a hug...but when she’s done she will push you away or slap you. It’s all on her terms....Because she is completely nonverbal, she doesn’t really have a way to effectively communicate with us. She can get frustrated easily, and that frustration can lead to a major meltdown. It doesn’t happen all the time, and it doesn’t happen hourly, or even daily, but she can get very frustrated easily and it can be hard to get her under control. She will try to hurt herself or lash out at other people.

There are many different severities of ASD and accompanying diagnoses. Caregivers know their children best, so listening to caregivers’ advice on how to interact with their children is what the participants described as being the best approach. At least four out of the six participants described situations in which they felt no one was listening when they were talking about their child. One caregiver said:

When we went to give blood, I even called them, and said, “Look my kid is going to be a handful,” ...I’m just trying to bear hug him and the nurse said, “Well, you need to get

ahold of him or we aren't going to be able to get this," and giving us attitude...when they act like that it doesn't help the situation because he can feel them and the way they are.

One mother explained that healthcare providers need to talk to the caregivers of children with ASD about how to approach the child. She also stated that providers should include the child in the conversation so the child does not feel left out. Many of the participants found that providers approached their children too suddenly or were too loud when speaking. The best results came from when the providers listened to the caregivers and were careful about the way they worked with the child, being mindful of the child's individual needs.

### **Caregiver: It Is All Our Responsibility**

Another theme was that of the participants having a great deal of responsibility when having healthcare interactions that involved their children. While all talked about being responsible for their children and the different tasks associated with appointments, managing these appointments was very challenging for participants, as well as for the children with ASD.

Before the day of an appointment, the same participants expressed that it is their responsibility to call the healthcare providers' office staff in advance to inform them that they may need special accommodations during the appointment. On the day of the appointment, then, participants talked about needing to remember what medications their child is taking, what concerns they may have for the doctor, and even remembering to bring toys to entertain their child during the visit. Upon arriving at the appointment, many talked about being faced with the stress of accurately filling out paperwork while trying to handle the variable moods and actions of their child. One participant shared his advice for this specific situation, saying: "Some of those forms they could actually have online where they can be partly or mostly filled out before people ever get into the office." Another caregiver elaborated on this topic, saying that she is

more focused at home and has more time to sit down and accurately complete paperwork that could either be available online or mailed to her home before the appointment. If this were to be done, the stress of the responsibilities placed on these caregivers can be lessened for the better.

In addition to the challenges before and during the appointment, at least three of the participants mentioned their concerns about recalling the information they had obtained during healthcare visits. A testament from one mother went as follows:

[I would like them] to have written down what we're supposed to do because, you know, with all of the commotion and everything the doctor ... gives all these instructions and you get home and you're like, "Well was it before that, or after that? I can't remember exactly what he said." So if it was written down I could go back and look at that paper and go, "Oh, okay. This is what needs to be done." And I could have something to refer back to ... your mind is already all over the place, trying to keep the kid out of this, fill out these papers, and gotta do this and this and this ... [with written instructions] there is no misunderstanding.

Another participant, a mother, suggested that the appointment could be recorded so that if there was any question as to what was discussed during the appointment, she could go back and listen to the recording.

Aside from these responsibilities, a different female caregiver also spoke about her concerns of handling her child's anxiety and behavior as the child grows. At the present time, the participants are caring for younger children who are more easily controlled during appointments because, physically, they are smaller in size. However, as they grow older and taller, caregivers talked about how the children may become less manageable if they have an outburst during appointments. This mother was concerned that she will have no help from

healthcare facilities in holding her child or keeping her child calm so that the necessary testing and treatment can be performed. A concern of this manner only adds to the plethora of responsibilities and challenges that caregivers of children with ASD face in healthcare settings.

### **Prepare and Organize**

A concern expressed by all participants during their interviews was how their appointments were organized. They talked about how the structure of the appointment, as well as the unfamiliar environment, can be challenging for a child with ASD. Participants identified struggles they have had in the past as well as recommendations to make appointments run more smoothly for all involved.

All spoke about how children with ASD often do not cope well with change. Unfortunately, many of the study's participants mentioned various changes associated with their healthcare interactions. Two main categories of change were mentioned: transitions and provider inconsistencies. One participant, a father, mentioned how constant adjustments during appointments were one of the most challenging aspects for his child. He said:

The hardest thing for autistics is the transitions between different things. So when you transition from the waiting room to the exam room it's a little harder on them....Then when you go back out that's another transition. That's when they get a little harder to control sometimes.

Other participants talked about changes in their children's temperaments during these types of transitions. Transitions could be as simple as moving from a hallway into an exam room, or more extensive, like moving from the parking lot into the waiting room. Either way, more transitions mean that there is a greater chance for an appointment to be disrupted. As a result, a

few participants agreed that decreasing transitions would help their child fare better in these settings.

Frequent switching of providers was a common theme addressed amongst participants. Whether it be for the inability to continue caring for a child, the lack of necessity to continue seeing a child, or a provider's decision to change job positions, all of these instances can force a child to learn how to readjust to a new provider. This is significant since familiarity and consistency are important to children with ASD. While not all instances lead to anxiety in a child with ASD, some may. Five of the participants, though, commented about how their children have become better at transitioning as they have grown older. Nonetheless, this is an aspect that can be addressed in organizing healthcare visits.

Aside from minimizing change, participants mentioned that the organization of healthcare appointments for children with ASD should include a plan. Since caregivers are the ones that prepare their children for these unfamiliar settings, healthcare providers need to work with caregivers to provide the structure they need in these appointments. One participant, a mother, expressed her enthusiasm about a positive experience when healthcare providers were prepared for her son's visit. She said: "They said they had this plan ready for him, which was awesome that they actually took the time when they saw him on the schedule and said, 'Okay what are we going to do to make this work.'" This example is one that healthcare providers can emulate in order to create a more positive experience for both a child with ASD and his or her caregivers.

### **A Trio of Needs: Compassion, Understanding, and Knowledge**

A strong theme that all of the participants voiced concern about during the interviews was a lack of compassion, understanding, and knowledge of ASD by the healthcare providers. The

participants not only expressed how they do not feel compassion from the providers, but they also said that they often receive judgement and dirty looks because of the way their child is acting. Participants felt like providers viewed them as bad caregivers or as caregivers who did not discipline their children. One mom voiced her frustration with healthcare providers' attitudes negatively affecting the appointment by saying:

You get one that says, "Well, can't you control your kid ... he can't be running around like that." That adds to my frustration because I'm trying to do the best I can and you're asking me to watch this kid and fill out papers and it's kind of like "my hands are full." I'm already frustrated when I get there because of what I probably had to go through to get there.

Going to an appointment can be overwhelming for the child with ASD, which can lead to stress and frustration for the caregivers of these children, especially when providers are not treating them kindly. Participants recommended that healthcare providers should be working to help make the caregiver and child feel comfortable while at appointments, not causing more stress or making the caregiver feel judged. In general, they felt that healthcare providers need to work on being more aware and more understanding of how to interact with children with ASD and their caregivers. The study's participants explained that providers can make an appointment for a child with ASD more positive by being compassionate toward the child and his or her caregivers. The caregivers also explained that a provider needs to be understanding of that specific child's needs. As one father simply stated: "A little understanding goes a long way."

Another complaint of the participants was the lack of time they get to spend with the healthcare provider. Many participants voiced the desire to have more time with providers so that they can ensure the child has been thoroughly examined and that all problems have been

addressed. One participant said that she did not mind waiting longer for an appointment because it meant that the provider was spending an adequate amount of time with each patient. As a result, she knew that the provider would not rush and her child would receive the attention he needed. Another participant, a mother, emphasized the importance of the amount of time a provider spends with a child with ASD, by saying:

Sometimes they may not cooperate on your schedule. Giving enough time to observe, to listen to what a parent is saying. I would say observe the child because sometimes parents that have a special needs child and other children are either hypersensitive to certain things or maybe get so used to certain behaviors or certain activities that we may not be realizing that it is something that is an issue...pay attention and try to give the time.

Commonly seen throughout the healthcare system is a lack of knowledge about ASD. Participants spoke about providers needing to be more aware of how care for children with ASD may differ from that of a typical child. One caregiver, a mother, explained that the way providers talk to her child is inappropriate. She said: “You know he doesn’t like interaction but they are constantly in his face, trying to talk to him. You know what I mean, the tone of their voice. Just everything. They don’t get it. It’s just amazing.” They also talked about providers needing to know how to adapt when caring for these children. The participants in the study strongly suggested that providers should receive more education regarding ASD. With an increase in education, the providers can become more competent and knowledgeable while working with these children and their caregivers. One participant shared an example of a provider’s lack of knowledge. This participant said he went to a doctor that incorrectly stated that only males, not females, could be diagnosed with ASD. This example reinforces the plea of the participants for healthcare providers to be more educated and more informed about ASD. With

the increasing rate of diagnoses of ASD, providers need to understand ASD so they can provide the best care.

### **Discussion**

ASD is a complex disorder involving a wide variety of characteristics and symptoms. Nonetheless, caregivers of these children have similar experiences with healthcare providers and the healthcare setting. These experiences were brought to light by this study and can be used to improve healthcare interactions in the future. The caregivers addressed problems related to the current environment of healthcare facilities and the lack of planning involved with effectively responding to the special needs of their children. They also explained how much responsibility they alone have, a burden that they wish healthcare providers would help to ease through better methods of support. Finally, there was a strong emphasis on the need for more education and compassion on the part of healthcare providers when working with children with ASD, both as a group and as individuals. If all of these aspects were addressed, the quality of the current experiences that caregivers and children with ASD have within the healthcare setting can be greatly enhanced.

### **Limitations**

The limitations of this study included that it only took place in the Midwest, the use of a small sample size, and the use of only one site to recruit participants. Another limitation is that all of the children with ASD in this study also presented with additional diagnoses that may have had an impact on their behavior and interactions within the healthcare setting. In addition, the locations at which the interviews occurred could have limited the information obtained from the participants. Depending on the location, there was more or less distraction which could have affected the answers received from the participants.

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## Appendix A

**Informed Consent for Participation in a Research Study**

**Title:** Parent/Caregiver Perceptions of the Effects of the Healthcare Environment on Children with Autism Spectrum Disorder

**Researchers:** Lynn Wirfel, Deanna Klettlinger, and Brittany Bielak.

**Introduction:** The persons conducting this study are Lynn Wirfel, Deanna Klettlinger, and Brittany Bielak, students in the School of Nursing within the College of Health Professions at The University of Akron. You are invited to participate in a research study about your experience during healthcare visits for your child with Autism Spectrum Disorder (ASD).

**Purpose:** We would like to know your perceptions of how your child with ASD reacts to healthcare settings, and what a usual healthcare visit is like. We want to know about your child's experiences in any healthcare setting (doctor's office, hospital, etc.). We are interviewing 10 parents and/or caregivers to explain the healthcare visits from their point of view.

**Procedures:** Individual interviews will be used to explore your experiences of healthcare treatment for your child with ASD. After giving informed consent for the audio-taped interview, the researcher(s) will ask you questions about your perceptions of healthcare experiences involving your child with ASD. The researcher will also ask you a few questions about demographic information (age, gender, ethnicity, etc.). The interview will take approximately 45-60 minutes.

**Exclusion:** Persons will be excluded from the study if they do not speak English or are not a parent/caregiver at least eighteen years of age to a child age four to twelve with ASD.

**Risks:** In this study, you will be discussing your feelings related to experiences your child has had in the healthcare setting. Interviews may trigger the recall of unpleasant events. This may lead to stress or anxiety.

**Benefits:** You will receive no direct benefit from your participation in this study, but your participation may provide healthcare professionals with a better understanding of what helps children with ASD have a pleasant healthcare visit.

**Right to Refuse or Withdraw:** Your participation in this study is voluntary. You can refuse to take part in this study or stop participation at any time during the study. The decision to not take part or withdraw will not influence the amount or quality of healthcare that you receive. Please let the interviewer know if you no longer wish to participate.

**Confidential Data Collection:** Information that you share in this study will be kept confidential. This data will not be reported in any way that identifies you. Aggregate data, supplemented by individual quotes, will be used. Your signed consent form and your responses will be separated so that your answers will not be linked to you.

**Confidentiality of Records:** Consent forms and a reference sheet that may connect your name to the research will be kept in a locked safe that is separate from the information gathered and will only be available to the research team. It will be kept until the study is finished. When the study is completed, the list matching your name to the study will be destroyed. The collective findings of this study may be published for scientific purposes, but no individual names will be included.

**Who to contact with questions:** If you have questions about your participation in this study at any time, you can contact Deanna Klettlinger by phone at (330)-203-8368 or by email at [dfk7@zip.s.uakron.edu](mailto:dfk7@zip.s.uakron.edu). The Institutional Review Board for the Protection of Human Subjects at The University of Akron has approved this study. If you have questions about your rights or the processes in place for your protection relating to this study, please contact Sharon McWhorter, Associate Director at The University of Akron Office of Research Services at 330-972-8311.

**Audiotape Recording:** As part of this project, an audiotape recording will be made of you during your participation during the interview. In any use of the audiotapes, your name will not be identified. If you happen to mention anyone's name during this interview, that identifying information will be deleted from the records of this interview. The tape will be destroyed after the research project is completed.

Your signature below means that you have read or been read the information regarding this study and have had an opportunity to ask questions and have them answered. Your signature also means that you have been told the requirements of the study and voluntarily consent to participate in it. Your consent is effective from this date to the end of the study unless you withdraw this consent earlier. If you want a signed copy of this consent, please ask and you will receive a copy.

Participant's name (printed): \_\_\_\_\_

Participant's signature: \_\_\_\_\_ Date: \_\_\_\_\_

Interviewer (s) signature(s): \_\_\_\_\_ Date: \_\_\_\_\_

\_\_\_\_\_ Date: \_\_\_\_\_

## Appendix B

## Interview Questions

1. Please describe your son/daughter's temperament.
2. Now, think about the different times you and your child have gone into healthcare setting and had interactions with healthcare providers. Think now about a positive experience you and your child had. Tell me about that experience.
3. What especially made that experience positive?
4. Now, think about a negative experience you and your child had when you went into a healthcare setting and had interactions with healthcare providers. Tell me about that experience.
5. What especially made that experience negative?
6. What do healthcare providers need to know about interacting with your child?
7. What recommendations can you give healthcare providers about interacting with children with ASD?
8. What recommendations can you give in terms of changes to the healthcare environment that would benefit children with ASD?
9. What question should I have asked you that I did not?