

# AUTISM EVALUATION: WHAT TO EXPECT

Autism Evaluation: A What to Expect Educational Brochure

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### **Abstract**

The purpose of this quality improvement project was to examine the usefulness of a “*What to Expect*” educational brochure for parents of children awaiting an autism evaluation. Parents of children who need an autism evaluation require pertinent information, guidance, and resources on what to expect and how to prepare. Studies have shown that patient educational materials increase knowledge, promote good health outcomes, and positively alter behavior. The components of the project were as follows: preliminary brochure development; stakeholder engagement session with parents who have firsthand experience with the autism evaluation to review the brochure and provide feedback; brochure refinement to reflect the data collected from the engagement session; and brochure evaluation via the Patient Education Materials Assessment Tool (PEMAT) completed by nurse practitioners to assess the usefulness of the brochure. Eight parents participated in the engagement session and four nurse practitioners completed the PEMAT. 75% of the participants agreed that the brochure helped to know what to expect and 62.5% agreed that the brochure helped to understand how to prepare. The mean score from the PEMAT, 91.66%, was indicative of a high level of understandability/actionability and therefore usefulness of the brochure. This quality improvement project can generate a practice change whereby practitioners offer this evidence-based brochure as an educational tool to increase parents’ knowledge and prepare them for the autism evaluation.

*Keywords:* educational materials, diagnostic services, parental anxiety, diagnostic procedures

## **Introduction**

Patient education is imperative in improving healthcare. It provides necessary information to ensure that patients are well-informed about their condition. Patients should be knowledgeable about their condition, know what to expect, understand the diagnostic processes and treatment plans, and aware of the signs and symptoms that require immediate attention. Patient education materials are important and effective tools that may be utilized to convey such healthcare information (Bester et al., 2016). These materials may also help increase the patient's knowledge, increase retention of the information, and reduce anxiety related to the condition (Blanck & Marshall, 2011).

When the patient is a child, both the parent and child need to be educated. Parents of children who are ill experience a great level of anxiety and stress. As a result, they look to healthcare providers for guidance and support (Bonis, 2016). Parents of children diagnosed with Autism Spectrum Disorder (ASD), a neurodevelopmental disability, experience greater levels of stress than those with typical developing children or children with other disabilities (Wong, Yu, Keyes, & McGrew, 2017).

ASD is characterized by impaired social, communication, and behavioral skills. To date, the specific cause for ASD has not been identified. However, research has shown that genetic, neurobiological, and environmental factors play a significant role in the development ASD (American Speech-Language-Hearing Association, 2018). Persons diagnosed with ASD may have mild to severe symptoms including but not limited to avoiding eye contact, limited or no pretend play, echolalia, repetitive behaviors, learning disabilities, hypo or hyper sensitivity to sensory input, and speech delays ("Facts about ASD," 2018).

Studies have shown that parents of children with ASD are the first to notice development delays in their child (Estes et al., 2013) . An estimated 50% of children with ASD show delays within the first year of life and 80% show signs by the second year of life (Frye, 2016). While ASD may be reliably diagnosed as early as 18 months of age, the average age of diagnosis is approximately 4 years old (“Data and Statistics,” 2018). Upon scheduling an appointment for an ASD evaluation, parents are left feeling ill-informed about what to expect. Delays in diagnosis and a lack of information before, during, and after the diagnostic process have been cited as reasons for increased parental stress (Wong et al., 2017).

To help alleviate some of these negative feelings, healthcare providers should supply parents with the much-needed information they are seeking. Physicians and Nurse Practitioners play a key role in evaluating, diagnosing, treating, and educating the patient and family. Parents of children undergoing an ASD evaluation should be educated about the diagnostic process. Supplying an educational brochure informing parents about what to expect and how to prepare for an ASD evaluation is imperative.

### **Background and Significance**

Child Psychologist, Child Neurologist, Developmental and Behavioral Nurse Practitioner, and Physician are all equipped to evaluate and diagnosis ASD (“Screening and Diagnosis,” 2018). The diagnostic methods and tools that are utilized vary depending on the facility where the assessment is being performed and the practitioner conducting the evaluation. A systematic review by Penner, Anagnostou, Andoni, and Ungar (2017), identified several inconsistencies in the recommendations for an ASD evaluation. Per Penner et al. (2017), while there are several recommendations promoting the use of a multidisciplinary team to assess and diagnose ASD, no empirical evidence has shown that a multidisciplinary team is more equipped

or more effective at establishing a correct diagnosis than a single provider. Additionally, the number and type of psychometric tools utilized during an assessment varies (Penner et al., 2017). With the multitude of methods used in diagnosing patients with ASD, finding information about the evaluation process can lead to increased frustration in an already stressful time for families. The diagnosis process for ASD can be lengthy and taxing for many parents. In a study conducted by Braiden, Bothwell, and Duffy (2010), parents described the diagnosis process as unsettling and extremely stressful.

Per Wong et al. (2017), parents seek out information about ASD and the diagnostic evaluation through immediate sources such as the internet. There are educational materials on what to expect and how to prepare for an ASD diagnostic evaluation available on several websites including the Autism Support Network.com, Autism Awareness Speaks.org, and Children's Hospital of Philadelphia.edu, however, the information contained varies from source to source. Some organizations are very detailed and provide a list several diagnostic tools that may be used during an evaluation. Others are more vague noting that the child will be assessed through observation and cognitive testing. A common thread however, is that parents should be prepared to answer questions about the child's medical history and developmental milestone accomplishments (Amato, 2016; Autism Speaks, 2018; Children's Hospital of Philadelphia, 2018). Per Braiden et al. (2010), parents stated they would have preferred to be advised of the kinds of questions asked during the interview as they had trouble remembering certain aspects of their child's early development. An educational brochure providing information on what to expect and how to prepare for an autism evaluation including what possible questions you will likely be asked would address some of these issues and concerns.

### **Needs Assessment**

Statistical data indicate one percent of the population worldwide is diagnosed with ASD (Autism Society, 2016). According to the 2014 Autism and Developmental Disabilities Monitoring Network Surveillance, 1 in 59 (8-year old) children have been diagnosed with ASD in the United States (Autism New Jersey, 2018). In New Jersey, 1 in 34 children have been diagnosed with ASD, representing 3% of the 8-year old child population in this state. Compared to other states, New Jersey continues to see the highest prevalence of Autism Spectrum Disorder with the most current data indicating a 19% rise. (Autism New Jersey, 2018).

Parents of children with ASD experience daily challenges affecting their ability to parent well, manage their home, and maintain employment (Bonis, 2016). Additionally, their mental and physical health may be negatively affected as a result of increased stress, lack of sleep, and fatigue (Vasilopoulou & Nisbet, 2016). Furthermore, the increased demands, responsibilities, financial burden, and decreased opportunities for parents to socialize can lead to deficits in the parents' quality of life (Vasilopoulou & Nisbet, 2016). With these constant hurdles and rising rates, it is imperative that healthcare providers find ways to support parents throughout the diagnosis process and beyond.

As a New Jersey Leadership Education in Neurodevelopmental and Related Disabilities (NJLEND) fellow, there have been several opportunities to discuss concerns and issues regarding ASD during didactic lectures. Participants in these lectures include practitioners, specialty directors, policy advocates, fellows, and others. In a lecture conducted by members of the New Jersey Birth Defects and Autism Registry, one participant stated that while the diagnostic tools used among providers vary, the most common tool utilized for the diagnosis of ASD is clinical judgement. This is consistent with the systematic review by Penner et al. (2017),

which discussed variations in the recommended methods and psychometric tools used to diagnose ASD.

During an informal discussion with parents from the NJLEND program, the parents revealed that they did not know what their child's autism evaluation entailed. One mother stated she anticipated an electroencephalography and genetic testing. She also indicated that she was not prepared for her child's evaluation and expressed how anxious she became when she had no information to help guide her thoughts. Additionally, she had no set time frame for the diagnostic assessment and upon completion of the evaluation, she stated she expected more.

In a separate informal discussion with a Neurodevelopmental and Behavioral Nurse Practitioner (NP), similar thoughts about the preparedness of the parents were expressed. According to the NP, parents are at times ill prepared to answer questions with respect to family history, their child's past medical history, or developmental milestones. Furthermore, the parents' perception of what is involved in the diagnostic evaluation far exceeds what takes place. As a result, she noted that parents are often frustrated when their expectations for the evaluation are not met.

At [REDACTED], a child may be evaluated for ASD through a comprehensive autism team evaluation (ATE) or by a neurodevelopmental and behavioral nurse practitioner. Should a parent have a prescription and opt for an ATE, a brief description of the assessment and medical history questionnaire is mailed to the parent. In the description letter, parents are told which specialists are involved in the evaluation (i.e. psychologist, speech therapist, occupational therapist, and others), how many appointments will be required, and how long each appointment will be. While this information is pertinent, it is also limited. For parents to understand the role of each specialist, understand the meaning of cognitive testing, or identify

the steps and objectives of an Autism Observation Diagnostic Schedule (ADOS), they would need to conduct further research. Alternatively, should a parent have their child evaluated by the neurodevelopmental and behavioral nurse practitioner, no description letter is offered leaving the parent with no guidance on what to expect.

An educational brochure designed with detailed and relevant information about the diagnostic process may help parents modify their expectations, minimize any concerns related to the evaluation, and facilitate preparedness.

### **Problem Statement**

The nation-wide prevalence rate of ASD continues to rise. Within a 14-year period (2000-2014), autism rates have increased approximately 150% (“Data and Statistics,” 2018). Parents of children who need an ASD evaluation require pertinent information, guidance, and resources as early as possible. The lack of information regarding the diagnostic process and the inconsistencies in the method and types of psychometric tools used in the diagnostic process can make it difficult to obtain accurate information on what to expect and how to prepare. Barriers to pertinent information at a time when parents report feeling confused, uncertain, unadvised, and uninformed further magnifies the level of parental stress (Wong et al., 2017). Providers may help reduce parental stress, increase preparedness, and increase the parents’ knowledge regarding the ASD evaluation by providing relevant information on what to expect. Knowledge is an essential tool and with it, providers and families can make informed decision, provide the best care, and promote better outcomes.

This quality improvement project will examine the usefulness of a “*What to Expect*” educational brochure for parents of children awaiting an ASD evaluation.

### **Clinical Question**

Is a what to expect educational brochure effective in providing understandable and actionable information to prepare parents for their child's autism evaluation?

### **Aims and Objectives**

Aims:

- To increase parents' knowledge of the formal ASD evaluation process
- To prepare parents for the formal ASD evaluation by providing information of what to expect

Objectives:

- To develop an evidence-based "*What to Expect*" educational brochure for parents of children awaiting a formal ASD evaluation
- To conduct a stakeholder engagement session with parents who have previous experience of the ASD evaluation process for the purposes of reviewing the "*What to Expect*" educational brochure and providing feedback
- To refine the educational brochure using data collected from the stakeholder engagement session
- To evaluate the usefulness of the educational brochure with the use of a Patient Education Material Assessment Tool to be completed by Developmental Behavioral Nurse Practitioners

### **Review of Literature**

A thorough review of literature was conducted. CINAHL and PUBMED were the databases used. The keywords used in the inquiry were *parents, anxiety, patient education, patient educational materials, diagnostic services, and diagnostic procedures*. The results were

limited to articles that were published in the last 5 years. A total of 428 articles were found. After screening the articles, eight were chosen for the literature review. These articles were appraised and incorporated into an evidence table found in Appendix A.

### **Patient Education**

Patient educational materials increase knowledge, promote good health outcomes, and positively alter behavior. They provide information about diagnostic tests, medical procedures, illnesses and other health-related topics. They are used as instructional material to help prepare patients for diagnostic evaluations or surgical procedures and they help in the decision-making process by presenting risks, benefits, or side effects (Elsevier Clinical Solutions, 2015). In children undergoing an Autism evaluation, patient education should be developed to provide pertinent information to the caregiver. When patient education materials are generated, they must be directed towards the “key learners” (Elsevier Clinical Solutions, 2015). Key learners are not only the patient, but they are the people responsible for the care of said-patient (Elsevier Clinical Solutions, 2015).

Pidgeon, Blore, Webb, Horton and Evans (2017) recognized the parent’s need for information prior to diagnostic evaluation. In this study, the parents were asked to participate in a survey to identify any concerns or desire for information prior to their child’s first craniofacial multidisciplinary outpatient appointment. The survey revealed that 86.6% of the parents communicated the desire for more information related to the different aspects of the appointment and 65.4% were concerned about what the appointment entailed. Lastly, 50% preferred the information in the form of an educational leaflet (Pidgeon, Blore, Webb, Horton, & Evans, 2017).

Krishan, Lawler, and Hyfte (2017) reviewed the appropriateness of parent educational materials regarding the newborn hearing screening (NHS) process by state. The research showed that parents wanted more information about what to expect during their child's diagnostic evaluation. When the information was adequate, mothers were well-informed and behaved positively regarding the NHS. Additionally, the benefits of both verbal and written information were noted (Krishnan, Lawler, & Van Hyfte, 2017). Landier et al. (2017) found that written information as a supplement to verbal information significantly improved the parent's understanding and memorization. In this research study, 164 parents were randomly selected and placed into two groups. Each group received educational information prior to their child's procedure. Group 1 (intervention) was given verbal information with written educational material and group 2 (control) was given verbal information only. On the day of the surgical procedure, both groups were given a multiple-choice questionnaire. The results of the questionnaire indicated that the intervention group had significantly higher memorization scores when compared to the control group ( $p=0.0002$ ) (Landier et al., 2017). This study also addressed the effects of a written educational material on parental anxiety. Upon completion of the verbal consultation and the delivery of the written educational material, parents from group 1 and 2 were asked to complete the Visual Analog Scale (VAS) and Amsterdam Preoperative Anxiety and Information Scale (APAIS). While the anxiety level of the intervention was lower compared to the control group, the difference was not significant ( $p=0.11$ ). However, when parental anxiety levels were measured on the day of surgery, significant lower anxiety levels were noted within the intervention group ( $P=0.0001$ ) (Landier et al., 2017).

**Parental Anxiety**

Anxiety embodies an individual's cognitive, physiological, and behavioral response to a situation (Fernandes, Arriaga, & Esteves, 2014). Research has shown that a common reason for parental anxiety is the absence of information and not knowing what to expect (Munn & Jordan, 2014). Providing a what to expect educational brochure for children undergoing an ASD evaluation may not only help prepare the parent for the visit but may also be useful in alleviating any concerns regarding the evaluation.

Ji et al. (2016) noted a significant reduction in anxiety levels and increased satisfaction when parents received anesthesia education prior to their child's surgical procedure. In this study, the drawMD APP, a visual preoperative educational tool was developed to identify its effects on child and parental anxiety and parental satisfaction. 102 children ages 4-12 and 102 parents were randomly assigned to the intervention and control group. Parents were asked to complete the Amsterdam Preoperative Anxiety and Information Scale (APAIS) before and after the administration of the drawMD APP-aided preoperative anesthesia education followed by the Spielberger State-Trait Anxiety Inventory (STAI) 6 to 24 hours post-surgery. Children's anxiety was evaluated using the modified Yale Preoperative Anxiety Scale. Results of the study showed a significant difference in parental anxiety between the two groups post education ( $p < 0.05$ ). As it pertains to the child's anxiety, no significant difference was noted between the two groups before or after the distribution of the educational tool (Ji et al., 2016).

Sadegh Tabrizi et al. (2015) examined the effects of preoperative education when it comes to reducing anxiety in children and their mothers. In this randomized study, 36 children ages 8-10 years and 30 parents were assigned to either the intervention group or control group. The intervention group was given verbal information and educational material in the form of a

booklet the night before the procedure. A questionnaire to measure mother and child anxiety was completed before the intervention and again before entering the operating room. A significant reduction in parental anxiety within the intervention group was noted ( $p < 0.05$ ) (Sadegh Tabrizi et al., 2015)

Simeone et al. (2017) evaluated the impact of a preoperative educational intervention in reducing anxiety in parents whose children have a congenital heart disease (CHD). Like Autism, CHD is a chronic condition noted to cause increased levels of parental stress. Additionally, it may be associated with less cognitive, emotional, and social functioning as compared to parents of children without a chronic illness (Simeone et al., 2017). In this research, 60 parents were randomly assigned to the experimental group or control group. A preoperative nurse-led educational intervention was implemented and parental anxiety was measured using the Spielberger State-Trait Anxiety Inventory (STAI) survey. The data analyzed concluded that the parental anxiety of the experimental group was significantly lower than the control group post-intervention ( $t=2.78$ ,  $p=0.00$ ) (Simeone et al., 2017).

Regardless of the type of educational material provided, the consensus is that education may have a positive effect on parental anxiety when information is given before an evaluation or procedure. Per Fernandes, Arriaga, and Esteves (2015), 90 children and 90 parents were randomly assigned to the experimental group (i.e., an educational multimedia application), the comparison group (i.e., an educational video game), or the control group (i.e., no intervention). Parental anxiety was assessed using the STAI-Form Y. Results indicated a significant reduction in parental anxiety in the experimental and comparison group compared to the control group ( $p < 0.05$ ). However, no significant difference was noted between the groups who received an

educational tool ( $p>0.05$ ) (S. Fernandes, Arriaga, & Esteves, 2015). These findings indicate that the educational modality was not relevant.

### **Summary**

Whether a parent is preparing for a child's outpatient appointment, surgical procedure, or screening test, an increased level of parental anxiety is noted and the need for information exists. Overall, the review of literature recognizes the importance of educational materials. While the type of educational materials discussed in the review of literature varied, the outcomes were similar.

### **Theoretical Framework**

The theoretical framework utilized in this DNP project is the Plan-Do-Study-Act (PDSA) Model. The PDSA is an improvement model that examines the effects of change and identifies if said change leads to improvements (Gillam & Siriwardena, 2013). The model is comprised of three key questions and a four-phase PDSA cycle. The essential questions (i.e., what are we trying to accomplish, how will we know that a change is an improvement, and what changes can we make that will result in an improvement) must be addressed prior to utilizing the PDSA cycle (Institute for Healthcare Improvement, 2018). In the first phase of the cycle, the problem is identified, the objective is stated, and a plan is developed. The second phase involves the implementation of said plan and the collection of data. Data is analyzed and reviewed to identify what was learned in the third phase of the cycle. Lastly, modifications are made in the fourth phase and the cycle repeats if additional change is warranted (Gillam & Siriwardena, 2013). The purpose of this quality improvement DNP project is to provide parents whose children are awaiting an ASD evaluation a better understanding of the diagnostic process. This was done by:

- a) developing an evidence-based educational brochure to provide parents with information

regarding an ASD evaluation; b) conducting a stakeholder session so that parents who have firsthand experience of the ASD diagnostic process could review the brochure and provide feedback via the brochure refinement survey; c) improving the brochure to incorporate the main ideas generated from the stakeholder session; and d) assessing the usefulness of the brochure via Patient Education Materials Assessment Tool (PEMAT) which was completed by Nurse Practitioners. A graphic representation of the PDSA model may be found in Appendix B.

### **Methodology**

This is a quality improvement project to develop an evidence-based “*What to Expect*” educational brochure for parents awaiting their child’s formal evaluation for Autism Spectrum Disorder (ASD). The components of the project are: preliminary brochure development, stakeholder engagement session to refine brochure, brochure refinement, and brochure evaluation by certified nurse practitioners with a subspecialty in developmental behavioral pediatrics. The tools that were used in this project are the brochure refinement survey, the demographic data form, and the Patient Education Materials Assessment Tool (PEMAT). The preliminary “What to Expect” educational brochure, the brochure refinement survey, the demographic data form and the PEMAT may be found in Appendices (C, D, E, and F respectively).

The brochure refinement survey was obtained from a research study conducted by Messner, Reck, and Curci (2005) to assess the usefulness of a patient education brochure in an emergency department. This brochure was modified by the Principal Investigator to reflect the current project. It consists of six questions (5 Likert scale questions and 1 open ended question) and it may be found in Appendix D of this paper. The PEMAT was developed by Shoemaker, Wolf, and Brach (2014) and was acquired from the Agency for Healthcare Research and Quality

website where it is made accessible to the public. It has been shown to be a reliable and valid tool that may be used by healthcare professionals to measure the understandability and actionability of educational materials. According to Shoemaker et al. (2014), “patient education materials are understandable when consumers of diverse backgrounds and varying levels of health literacy can process and explain key messages” (p.3) and are actionable when these same characteristic consumers are able to recognize what steps to take based on the information provided in the educational material. The PEMAT completed four rounds of reliability testing and revisions with the use of raters who were inexperienced with the tool. Internal consistency was measured using Cronbach’s alpha coefficient  $>0.7$  and correlations  $>0.2$ . Internal consistency was strong and revealed alpha coefficient 0.71 and correlation 0.62 (Shoemaker, Wolf, & Brach, 2014). The PEMAT is included in Appendix F.

### Setting

The stakeholder engagement session was conducted in coordination with the director of [REDACTED]. [REDACTED] is a non-profit independent 501(c) organization that serves as [REDACTED] and is a chapter of the [REDACTED]. Its vision and mission which are to empower and support families by providing resources and information, align well with this project. After procuring the adequate number of participants for the engagement session, the director synchronized a time and location that limited any costs or burdens for the parents. This session was held on October 9, 2018 in the 2<sup>nd</sup> floor conference room of the [REDACTED] located [REDACTED] in Newark NJ.

The review of the refined brochure (Appendix L) and completion of Patient Education Material Assessment Tool (PEMAT) was conducted online. Eligible certified nurse practitioners

were contacted via email to review the refined brochure then directed to Qualtrics.com to fill out the PEMAT.

### **Study Population**

**Parents.** A convenience sample of parents whose children have been diagnosed with ASD and who are participants of [REDACTED] Network were selected for the stakeholder engagement session of this quality improvement project. The projected sampling size was approved for up to 12. Demographic information including age, sex, ethnicity, education level, and primary language was collected from all participants. The inclusion criteria for participation in this project consisted of English-speaking parents who were 18 years of age or older and have children previously diagnosed with ASD. The exclusion criteria included parents under 18 years of age, those who were non-English speaking, and those who did not have children diagnosed with ASD. A total of 8 parents (12.5 % male and 87.5 % female) participated in the engagement session. One hundred percent of the participants were between the ages of 40-49 years old, 50% identified themselves as Latino/Hispanic ethnicity, 50% reported having some college education, and 62.5% spoke English as their sole primary language. Appendix M depicts a more detailed demographic data.

**Nurse Practitioners.** To examine the refined educational brochure and complete the Patient Education Material Assessment Tool (PEMAT), a convenience sample of certified nurse practitioners with a subspecialty in developmental behavioral pediatrics was selected. The projected sampling size of nurse practitioners was approved for up to 12. The inclusion criteria for participation consisted of certified nurse practitioners with a subspecialty in developmental behavioral pediatrics who have experience with the ASD evaluation. The exclusion criteria consisted of certified nurse practitioners who did not specialize in developmental behavioral

pediatrics and have no experience with the ASD evaluation. A total of 16 nurse practitioners were emailed, however, only 4 responded to the survey.

### **Subject Recruitment**

**Parent Population.** For the parent stakeholder engagement session, a flyer advertising the quality improvement project was designed (Appendix G). To elicit voluntary participation and ensure a sufficient sample size, the flyer was posted in the office of [REDACTED] [REDACTED] Newark, New Jersey. Additionally, a staff member within the organization distributed the flyer via email to eligible participants. The flyer identified the purpose of the project and the inclusion criteria for participation. Moreover, the incentives for participation which included a gift card, food, and beverages were indicated in the flyer. Furthermore, the Principal Investigator's contact information was made available for questions and concerns.

**Nurse Practitioner Population.** For the evaluation of the refined brochure, an email was addressed to certified nurse practitioners with a subspecialty in developmental behavioral pediatrics who have experience with the ASD evaluation process. Recruitment of these nurse practitioners occurred via snowball sampling. The Principal Investigator utilized a convenience sample of known nurse practitioner colleagues to participate in this study. The PI later obtained a list of other eligible nurse practitioners from these existing colleagues to ensure a sufficient sample size of participants to review the educational material and complete the accompanying assessment tool.

### **Consent Procedure**

**Parent Population.** At the onset of the stakeholder engagement session, the Principal Investigator was introduced and the purpose of the study was discussed. From there, each

participant was given a paper consent letter for review. Parents were informed that participation was entirely voluntary and that they could choose to withdraw from the study at any time. After reading the terms of consent the participants were given the opportunity to pose questions relevant to the project. No questions or concerns were expressed. The parents proceeded to sign and date the consent form.

**Nurse Practitioner Population.** To obtain consent from the eligible participants, an email was sent to each certified nurse practitioner. In this email was an introduction of the Principal Investigator, a description of the project, an attached copy of the refined educational brochure (Appendix L), and an attached online consent form which can be found in Appendix I. Participants were instructed to read and review the educational brochure and consent form. After thoroughly reviewing the terms of the consent, the nurse practitioner had the option to give consent by proceeding to the PEMAT survey. This was done by clicking on the embedded hyperlink located at the bottom of the consent form directing the nurse practitioners to the assessment tool. Participation in this study was completely voluntary and participants had the option to withdraw at any time.

### **Risks/Harms**

This quality improvement project was reviewed, approved, and determined to be a minimal risk project by the Rutgers University Internal Review Board (IRB) prior to its implementation. As previously mentioned, participation in this project was completely voluntary and a signed consent was obtained. No identifying information was collected at any time. The foreseeable minimal risks for the parents participating in the stakeholder engagement session was the potential for some emotion discomfort. During this session, parents were asked to review the preliminary educational brochure and provide feedback via survey. Doing so may have caused

them to remember their own personal experience with the ASD evaluation process therefore leading to some emotional discomfort. However, it must be noted that no parent expressed any concern or emotional discomfort during or after the session. Throughout the engagement session, parents contributed by completing the survey and sharing their personal experiences.

As for the nurse practitioners, there were no anticipated risks of harm for those who chose to take part in this study by completing the Patient Education Material Assessment Tool (PEMAT).

### **Subject Costs and Compensation**

Parents who chose to participate in the stakeholder engagement session may have incurred several costs. These costs include travel expenses such as mileage, gas, parking fees, and public transportation fees or child care services. Parents and nurse practitioners were also likely to incur opportunity cost which is the time taken away from a different activity to participate in the project.

To offset some of these expenses, parents were compensated with a \$25 Amazon gift card for their participation in this quality improvement project. Additionally, food and beverages were served during the stakeholder meeting. The costs for these items were incurred by the Principal Investigator. The gift cards were distributed at the end of the engagement session. No incentives or compensations were offered to the nurse practitioners for their participation.

### **Study Interventions**

**Parent Population.** For this project, parents of children with ASD were solicited to partake in a stakeholder engagement session to review the preliminary “*What to Expect*” educational brochure (Appendix C) and provide feedback by completing the brochure refinement survey (Appendix D). During the session, parents were introduced to the Principal Investigator,

the intent of the project was communicated, and a consent letter (Appendix H) was given to each participant. The parents were given an opportunity to pose any questions or express any concerns regarding the project. No questions or concerns were voiced, and each participant signed and dated the consent. A demographic data form (Appendix E) was then distributed to each participant. After the forms had been filled-out, the Principal Investigator collected each form and placed them in a combination lock utility box. The preliminary “*What to Expect*” educational brochure was then given to each participant for review followed by the brochure refinement survey. No identifying information was requested on the brochure refinement survey. The participants took approximately 20 minutes to review and complete the brochure refinement survey. The Principal Investigator retrieved the brochures and the completed brochure refinement surveys and placed all documents in the combination lock utility box. This was followed by an open discussion whereby the participants had the opportunity to make comments and express any thoughts regarding the preliminary “*What to Expect*” brochure. Commentaries were recorded in real-time by the Principal Investigator with the use of a flipchart. The participants were engaged and informative. The session which was projected to last one hour, began at 10:00 am and concluded at 1pm.

Upon completion of the stakeholder engagement session, all documents (consent forms, brochure refinement surveys, demographic data forms) were scanned and saved in a password protected flash drive. Additionally, the information gathered from the flipchart, brochure refinement surveys, and demographic data forms was transcribed on a password protected excel spreadsheet. Furthermore, hard copies of all documents including the flipchart were stored in a locked filing cabinet located at the [REDACTED].

**Nurse Practitioner Population.** The information gathered from the engagement session was utilized to enhance the educational brochure. This refined brochure (Appendix L) was then emailed to a list of eligible certified nurse practitioners for review and assessment. Within the email was an overview of the proposed quality improvement project and a request for voluntary participation. All emails included an attached refined educational brochure and consent form. The nurse practitioners were instructed to review the attached brochure and complete the Patient Education Material Assessment Tool (PEMAT) by clicking on the embedded hyperlink located in the consent form. The link directed the nurse practitioner to Qualtrics.com where they were able to view and complete the PEMAT (Appendix F). No identifying information was requested for this assessment tool. Participation was completely voluntary and the completion of the PEMAT by the certified nurse practitioners was used as the consent.

### **Outcomes Measured**

To measure the outcomes of this quality improvement project, participants were asked to review the educational brochure and complete a survey. All questions were used to determine the effectiveness of the brochure.

**Parent Population.** Parents participating in the stakeholder engagement session were asked to complete the brochure refinement survey and demographic data form. The brochure refinement survey consists of 5 questions in which responses were made via an ordinal 5-point Likert scale (strongly agree, agree, neutral, disagree, and strongly disagree) followed by 1 open ended question. Questions 1-3 appraised the overall usefulness of the preliminary “*What to Expect*” educational brochure. Questions 4 and 5 asked about the presentation of the information and question 6 gave parents an opportunity to identify any pertinent additional information that they believed would be beneficial to the brochure. The demographic data form consisted of 5

questions: sex, age, ethnicity, educational status and primary language. This information was used to illustrate the sample of participants in the study.

**Nurse Practitioner Population.** The certified developmental behavioral pediatric nurse practitioners were asked to complete the Patient Education Material Assessment Tool (PEMAT). The PEMAT consisted of 17 questions to examine understandability followed by 7 questions to examine actionability. All responses to these questions had an option for disagree or agree and some had an option for not applicable. No identifying information was requested for the brochure evaluation, demographic data form or PEMAT.

### **Timeline**

The projected timeline for this quality improvement project was 12 months. The written proposal was constructed from January 2018 to July 2018. The formal proposal presentation to the DNP chair and team member was conducted on July 10, 2018. The project was approved by the DNP team members and the final version was submitted to the Rutgers University Institutional Review Board (IRB) on July 24, 2018. The project was approved by the Rutgers IRB on September 20, 2018. The recruitment process for the stakeholder engagement session began immediately after IRB approval and the session was held on October 9, 2018. The data collected from the engagement session was analyzed and used to enhance the brochure. The first round of recruitment for nurse practitioner participation began on October 23, 2018. Data retrieved from the PEMAT survey was scored and analyzed by the Principal Investigator during the months of October 2018 and November 2018. The final project paper was completed and submitted to the DNP team members for review in November 2018. The project timeline is illustrated in (Appendix J).

**Projected Budget and Resources Needed**

The Principal Investigator incurred the cost of all printed documents which include flyers, educational brochures, and brochure evaluation survey. Moreover, the compensation and incentives that were made to the parents for participation in stakeholder engagement session was also incurred by the Principal Investigator. The estimated cost for this quality improvement project was \$550 (i.e., \$150 for materials, \$400 for the compensation and incentives). See Appendix K for the itemized budget.

**Evaluation Plan****Data Maintenance and Security**

There was no identifying information obtained from the parent or the certified developmental behavioral pediatric nurse practitioner. All documents received throughout the project timeframe was placed in a combination lock utility box and locked in a filing cabinet accessible only by the Principal Investigator. The secured filing cabinet was located at the office of the [REDACTED]. All analyzed data and back-up information was stored on password protected flash drive. Upon completion of data analysis and final acceptance of the quality improvement project, the Principal Investigator will provide Dr. Sallie Porter with a password protected flash drive containing the scanned written informed consents and aggregate data. The flash drive will be hand delivered to Dr. Porter in a sealed heavy-duty envelope labeled with the Principal Investigator's name, the full title of DNP project, and the date of final project acceptance. The sealed envelope will be stored and maintained at the Rutgers University School of Nursing, 65 Bergen Street, Newark, New Jersey 07107 within the office of Dr. Sallie Porter and held in accordance of the Rutgers University Office of Information Technology guidelines.

## **Data Analysis**

A descriptive analysis of the brochure refinement survey was conducted. All responses made using the ordinal 5-point Likert scale (i.e., strongly agree, agree, neutral, disagree, and strongly disagree) was examined and presented in terms of means and percentages. The information obtained from the open-ended question was analyzed and the main ideas identified were incorporated in the final version of the brochure.

Demographic information was examined using univariate descriptive analysis. All descriptive statistics was performed using the IBM Statistical Package for the Social Sciences (SPSS) version 23 software to determine the mean, median, standard deviation, frequency, and percentage.

The Patient Education Material Assessment Tool (PEMAT) was scored and analyzed as follows: 1) All questions that are given a response of disagree received a score of 0; 2) Questions with a response of agree received a score of 1; and 3) Questions with a response of not applicable were not scored and were excluded from the calculations. All scores were added and divided by the total possible points then multiplied by 100 to get the final score in terms of percentages. Higher final scores equate to a greater understandability and actionability of the educational brochure.

## **Findings**

### **Parent Population**

All information obtained from the brochure refinement survey was inserted into the SPSS software. As anticipated, the results from that data analysis showed that parents awaiting a formal ASD evaluation would find the brochure effective in providing information on what to expect and how to prepare. Frequency data with respect to the five Likert scale questions are as

follows: 75% of the participants agreed that the brochure helped to know what to expect at an Autism evaluation; 62.5% agreed that the brochure helped to understand how to prepare for an Autism evaluation; 62.5% agreed that they would recommend the brochure to other parents; 50% agreed that the brochure layout made it easy to read; and 75% disagreed that the words used in the brochure were too difficult. Included in Appendix N is the comprehensive frequency data.

Although it was apparent that the brochure was effective in communicating what to expect and how to prepare for an Autism evaluation, the participants used question #6 (What additional information would you have liked to see in the brochure?) and the open discussion to give recommendations on how to enhance the brochure. Some of the key themes expressed were: 1) The title “Autism Spectrum Disorder Evaluation: A “What to Expect” Brochure” may cause parental anxiety. At first glance, the participants were concerned that the title suggested a diagnosis had already been made prior to an evaluation. Parents believed that the title was a bit disconcerting and would therefore cause an increase to parental anxiety as opposed to a decrease. 2) Suggestions were made to include examples of developmental milestones to increase the readers’ understanding of the different skills and behaviors a child exhibits during varying stages of growth. 3) Recommendations were made to define communication skills, fine motor skills, sensory issues, and behavior so that the reader could fully comprehend what was being assessed at an evaluation. 4) Additionally, it was advised to include information regarding how long it would take to get an appointment and what to do while waiting for an appointment. 5) Furthermore, it was proposed that certain words be bold or highlighted to draw the readers’ attention. Participants felt it was important for the readers to know that ASD was

characterized by a *range* of deficits, that only *some* of the symptoms were included in the brochure, and the children *may* or may not exhibit the symptoms mentioned in the brochure.

After completing a thorough analysis of the data collected during the engagement session, the brochure was modified to include the main ideas communicated by the participants. The enhanced brochure was then emailed to a list of Nurse Practitioners for review and assessment.

### **Nurse Practitioner Population**

As previously mentioned, a group of Nurse Practitioners (NP) were solicited to complete the Patient Education Material Assessment Tool (PEMAT) to determine the effectiveness of the educational brochure. Each completed tool was scored to establish the level of understandability and actionability of the educational brochure. Although several requests were made for NP participation, only 4 eligible participants chose to complete the PEMAT. The scores for each survey are as follows: 100%, 100%, 87.5%, and 80.95 %. These scores are indicative of a high level of understandability and actionability.

### **Discussion**

The purpose of this quality improvement study was to assess the effectiveness of a “*What to Expect*” educational brochure for parents of children awaiting an Autism Spectrum Disorder (ASD) evaluation. The brochure was created with the intention of increasing parents’ knowledge of the formal ASD evaluation process and increasing preparedness by providing understandable and actionable items within the brochure. The main goal of this study however is to provide a readily available educational material that can help decrease parental anxiety during this stressful time. As revealed in the literature review, studies have shown that parental anxiety can be significantly reduced when parents are properly educated about their child’s impending

procedure or test. Research has also demonstrated that parents seek out information and prefer the data be communicated as early as possible.

The results for this quality improvement study were no different. After meeting with parents of children who have already experienced the autism evaluation process, it was evident that the educational brochure would be a vital resource. Parents were eager to know who would be delivering this information and at what juncture the brochure be made available. One of the common threads during the engagement session was “I wish I had something like this when I was going through it”. This same concept was reiterated in the data analysis with 62.5% agreeing and 25% strongly agreeing with the question “I would recommend this brochure to other parents”. In the engagement session, one participant who was going through the ASD evaluation process for the second time stated that although she had one child evaluated and diagnosed years ago, she felt that there are still many things about the formal ASD evaluation that she does not know.

The educational brochure which was developed to provide this pertinent information was examined via the Patient Education Material Assessment Tool. While the results of the assessment tool showed that the refined brochure displayed a great level of understandable and actionable material, the findings were limited in that only 25% of the Nurse Practitioners that were petitioned chose to take part in the study. Nurse Practitioners were recruited through snowball sampling whereby the Principal Investigator solicited participation from known colleagues, then sought out additional participants via an email notification. These additional participants were acquired from the contacts generated by the known colleagues. Although several email notifications and follow-up phone calls were made, response was low. An in-person recruitment method may have led to an upturn of participants.

## **Implications/Recommendations**

### **Clinical Practice**

To improve patient education and good health outcomes, a transformation in clinical practice is needed. This quality improvement project can generate a practice change whereby practitioners offer this evidence-based brochure as an educational tool to prepare parents for the autism evaluation. Practitioners should provide parents with the necessary resources and educational materials as soon as a referral is made for an autism evaluation. For parents with self-referral or referrals from school, resources should be mailed to the parents while they are awaiting their scheduled appointment. This will not only increase the parent's knowledge about autism and the evaluation process, but it will also enable them to become proactive in their child's care by finding ways to begin the screening process prior to the formal autism evaluation.

### **Healthcare Policy**

In discussing the qualified practitioners able to perform the autism evaluation, it was surprising to see that parents preferred that the evaluation be conducted by a physician rather than a nurse practitioner. One specific recommendation was for the nurse practitioner to perform follow-up examination after a child has been officially diagnosed by a physician. The three concerns that were broached were a) a lack of understanding regarding the nurse practitioners' scope of practice; b) resistance from schools to accept an autism diagnosis from the nurse practitioner thereby delaying the initiation of the Individualized Education Program (IEP); and c) a notion that some insurance companies will not cover an autism diagnosis from a nurse practitioner.

To combat some of these issues, autism policy changes, specifically state laws regarding insurance coverage for children with autism need to be advocated. According to the National Conference of States Legislatures (2018), forty-six states including the District of Columbia have been mandated to provide insurance coverage for autism services per legislation passed on June 8, 2017 (National Conference of States Legislatures, 2018). New Jersey was one of the first group of states to pass this law in 2009. However, amendments which were made in 2015 state that only a select group of insurance companies are required to abide by this law. These include “all insurance companies regulated by the State of NJ; the NJ State Health Benefits and the School Employees’ Health Benefits Programs; and all fully-insured plans purchased in the New Jersey Marketplace and offered by small employers or purchased by individual consumers.... Health plans that are self-funded are not required to provide this coverage” (Conner, Strong, & Buckelew, 2015, p.1).

After reviewing the New Jersey Autism Coverage Act of 2009, it was noted that there were limits to the number of visits per year, eligibility for renewal of ongoing services, and annual caps for autism services. Additionally, subsection d of each section within the New Jersey Autism Coverage Act of 2009 implies that a diagnosis, treatment plan, request for ongoing services, etc... needs to be accompanied with a physician’s signature (New Jersey Autism Coverage Act, 2009). With that said, healthcare policy changes promoting full practice authority for nurse practitioners should also be advocated to help overcome some of these barriers.

### **Quality and Safety**

As it pertains to quality and safety, this brochure may help ease the fears of parents and reduced any anxiety related to the evaluation. Patients are often fearful of the unknown and these feelings can impede care. A delay in an autism diagnosis may lead to a gap in services. Due to

their deficits in communication skills, developmental delays, and behavioral issues, children with Autism Spectrum Disorder are at an increased risk for safety concerns (Sicile-Kira, 2012).

Initiating autism services as early as possible may help to reduces some of these safety risks.

### **Education**

Patient education is essential to providing quality care and promoting good health outcomes. Practitioners have a responsibility to ensure that their patients are well informed and proactive. For parents of children awaiting an autism evaluation, an educational brochure such as this can provide the fundamental information they are seeking and access to available resources. When referring a patient for an autism evaluation, education must be given in a manner that will provide answers without eliciting fear. In the same token, the Nurse Practitioner (NP) should be educated on the kind of information the parent is seeking. Just as this educational brochure was enhanced with feedback from parents, the delivery of information regarding autism should be modified with the parent in mind. In clinical practice NPs should not only provide information on the fundamental aspects of autism and the evaluation. The NP should seek guidance from the parent about what information and resources they need so that the conversation about autism can be tailored. The brochure created can help the Nurse Practitioner begin the conversation about autism, what to expect at an evaluation, and how to prepare.

On the collegiate level, nurse practitioner students should not only be educated on the signs and symptoms of autism. The student should be knowledgeable about the diagnostic process and the overall effects of this disorder on the patient and the family members. With the autism prevalence rate that continues to rise, it is essential that NP student be prepared to provide education and the necessary resources that help guide parents throughout the diagnostic process.

### **Economic Implications**

As previously mentioned, there is an increased monetary burden for families of children with Autism Spectrum Disorder (ASD). Results from a study conducted by Lavelle et al. (2014) to assess the expenditures associated with the care of a child diagnosed with ASD showed that there was an increased financial burden of over \$17,000 annually (Lavelle et al., 2014). Horlin, M. Falkmer, Parsons, Albrecht, & T. Falkmer, (2014) suggested that there is even greater indirect financial burden for parents whose child's diagnosis had been delayed (Horlin, Falkmer, M., Parsons, Albrecht, & Falkmer, T., 2014). Providing resources such as the educational brochure as early as possible can help to decrease a delay in care and promote early intervention.

### **Professional Reporting/Dissemination**

The preliminary goals, objectives, and expected outcomes for this project were displayed in a poster presentation during the NJLEND Maternal and Child Health symposium on May 11, 2018 (Appendix O). Since then, this quality improvement project has been amended and the final outcomes will be presented to the Rutgers School of Nursing faculty, staff, and students via a power point presentation (Appendix P) in December 2018. Additionally, these results will be publicized in poster presentation during Rutgers University- Newark's research week in the year 2019 (Appendix Q). Likewise, a poster presentation at a conference organized by the National Association of Pediatric Nurse Practitioners (NAPNAP) is desired. Furthermore, a power point version of the poster presentation (Appendix Q) and the refined educational brochure (Appendix L) will be emailed to the director of the [REDACTED]. Moreover, scholarly publications in the Journal of Autism and Developmental Disorders and the Journal of Educational Research will be sought.

### **Conclusion**

The findings from this quality improvement project indicate that the objectives have been met. The participants involved in the engagement session were enthusiastic about having an educational tool to help increase parents' knowledge about ASD, prepare them for the autism evaluation, and gauge their expectations. The results for the Patient Education Material Assessment Tool showed that the education brochure had understandable and actionable material. Additionally, it was projected that parents would experience a reduction in anxiety due to the increased knowledge acquired about the ASD evaluation process. While a decrease in anxiety was anticipated, no tools were used in this project to measure anxiety levels.

Parents of children with Autism Spectrum Disorder have a great deal of stress and experience many challenges. They have prolonged wait times for scheduling an autism evaluation, barriers with insurance coverage for services, increased financial burdened, and daily challenges with managing their home. Ultimately, practitioners play a key role in helping to reduce some of these obstacles by proving parents with education and available resources.

### References

- Amato, J. (2016). Preparing for your child's evaluation. Retrieved from <http://www.autismsupportnetwork.com/news/preparing-your-childs-autism-evaluation-998623>
- America Speech-Language-Hearing Association. (2018). Autism. Retrieved from <https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935303&section=Overview>
- Autism New Jersey. (2018). New Jersey Autism prevalence rate rises to in 1 in 34. Retrieved from <https://www.autismnj.org/prevalence-rates>
- Autism Speaks. (2018). 5 thing to do while waiting for an autism evaluation. Retrieved from <https://www.autismspeaks.org/blog/2013/05/24/five-things-do-while-waiting-autism-evaluation>
- Autism Society. (2016). Facts and statistics. Retrieved from <http://www.autism-society.org/what-is/facts-and-statistics/>
- Bester, N., Di Vito-Smith, M., McGarry, T., Riffkin, M., Kaehler, S., Pilot, R., & Bwire, R. (2016). The Effectiveness of an educational brochure as a risk minimization activity to communicate important rare adverse events to health-care professionals. *Advances in Therapy*, 33(2), 167-177. doi:10.1007/s12325-016-0284-y
- Blanck, A. W., & Marshall, C. (2011). Patient education materials from the layperson's perspective: the importance of readability. *Journal for Nurses in Staff Development*, 27(2), E8-10; quiz E11-12. doi:10.1097/NND.0b013e31820eeff6
- Bonis, S. (2016). Stress and Parents of Children with Autism: A review of literature. *Issues in Mental Health Nursing*, 37(3), 153-163. doi:10.3109/01612840.2015.1116030

Braiden, H., Bothwell, J., & Duffy, J. (2010). Parents' Experiene of the diagnostic process for Austim Spectrum Disorder. *Child Care in Practice*, 16(4), 377-389. doi:

10.1080/13575279.2010.498415

Center for Disease Control and Prevention. (2017). Data and statistics. Retrieved from

<https://www.cdc.gov/ncbddd/autism/data.html>

Center for Disease Control and Prevention. (2017). Facts about ASD. Retrieved from

<https://www.cdc.gov/ncbddd/autism/facts.html>

Center for Disease Control and Prevention. (2017). Screening and diagnosis. Retrieved from

<https://www.cdc.gov/ncbddd/autism/screening.html>

Childrens' Hospital of Philadelphia. (2018). Your child's intial autism evaluation. Retrieved from

<https://www.chop.edu/centers-programs/autism-integrated-care-program/your-childs-experience>

Connor, Strong, & Buckelew. (2015). Legislative update: New Jersey autism mandate-recent

amendments . Retrieved from [https://www.connerstrong.com/wp-](https://www.connerstrong.com/wp-content/uploads/2018/03/New-Jersey-Autism-Mandate-Recent-Amendments.pdf)

[content/uploads/2018/03/New-Jersey-Autism-Mandate-Recent-Amendments.pdf](https://www.connerstrong.com/wp-content/uploads/2018/03/New-Jersey-Autism-Mandate-Recent-Amendments.pdf)

Elsevier Clinical Solutions. (2015). *White paper: How to develop and use effective*

*patient/consumer education*. Retrieved from

[https://www.elsevier.com/\\_\\_data/assets/pdf\\_file/0006/139902/Elsevier\\_WP\\_PatientEduc](https://www.elsevier.com/__data/assets/pdf_file/0006/139902/Elsevier_WP_PatientEducationWhitepaper5_29_15WEB.pdf)  
[ationWhitepaper5\\_29\\_15WEB.pdf](https://www.elsevier.com/__data/assets/pdf_file/0006/139902/Elsevier_WP_PatientEducationWhitepaper5_29_15WEB.pdf).

Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., & Munson, J. (2013).

Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain & Development*, 35(2), 133-138.

doi:10.1016/j.braindev.2012.10.004

- Fernandes, S., Arriaga, P., & Esteves, F. (2015). Using an educational multimedia application to prepare children for outpatient surgeries. *Health Communication, 30*(12), 1190-1200. doi:10.1080/10410236.2014.896446
- Fernandes, S. C., Arriaga, P., & Esteves, F. (2014). Providing preoperative information for children undergoing surgery: a randomized study testing different types of educational material to reduce children's preoperative worries. *Health Education Research, 29*(6), 1058-1076. doi:10.1093/her/cyu066
- Frye, L. (2016). Fathers' experience with Autism Spectrum Disorder: Nursing implications. *Journal of Pediatric Health Care, 30*(5), 453-463. doi:10.1016/j.pedhc.2015.10.012
- Gillam, S., & Siriwardena, A. N. (2013). Frameworks for improvement: clinical audit, the plan-do-study-act cycle and significant event audit. *Quality in Primary Care, 21*(2), 123-130.
- Horlin, C., Falkmer, M., Parsons, R., Albrecht, M. A., & Falkmer, T. (2014). The cost of autism spectrum disorders. *PloS one, 9*(9), e106552. doi:10.1371/journal.pone.0106552.
- Institute for Healthcare Improvement. (2018). *How to improve*. Retrieved from <http://www.ihl.org/resources/Pages/HowtoImprove/default.aspx>
- Ji, L., Zhang, X., Fan, H., Han, M., Yang, H., Tang, L., . . . Li, D. (2016). DrawMD APP-aided preoperative anesthesia education reduce parents anxiety and improve satisfaction. *Patient Education and Counseling, 99*(2), 265-270. doi:10.1016/j.pec.2015.08.027
- Krishnan, L. A., Lawler, B., & Van Hyfte, S. (2017). Parent educational materials regarding the newborn hearing screening process. *International Journal of Pediatric Otorhinolaryngol, 95*, 34-38. doi:10.1016/j.ijporl.2017.01.025
- Landier, M., Villemagne, T., Le Touze, A., Braik, K., Meignan, P., Cook, A. R., . . . Binet, A. (2017). The position of a written document in preoperative information for pediatric

- surgery: A randomized controlled trial on parental anxiety, knowledge and satisfaction. *Journal of Pediatric Surgery*. doi:10.1016/j.jpedsurg.2017.04.009
- Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., Prosser, L. A. (2014). Economic Burden of Childhood Autism Spectrum Disorders. *Pediatrics*, 133(3), e520-e529. doi: 10.1542/peds.2013-0763
- Munn, Z., & Jordan, Z. (2014). The effectiveness of nonpharmacologic interventions to reduce anxiety and increase patient satisfaction and comfort during nuclear medicine imaging. *Journal of Medical Imaging & Radiation Sciences*, 45(1), 47-54. doi:10.1016/j.jmir.2013.10.006
- National Conference of State Legislatures (2018). Autism and insurance coverage state laws. Retrieved from <http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx>
- New Jersey Autism Coverage Act, c.115, A2238 ACS 1R (2009). Chapter 15. Retrieved from [ftp://www.njleg.state.nj.us/20082009/PL09/115\\_.PDF](ftp://www.njleg.state.nj.us/20082009/PL09/115_.PDF)
- Penner, M., Anagnostou, E., Andoni, L. Y., & Ungar, W. J. (2017). Systematic review of clinical guidance documents for autism spectrum disorder diagnostic assessment in select regions. *Autism*, 1362361316685879. doi:10.1177/1362361316685879
- Pidgeon, T. E., Blore, C. D., Webb, Y., Horton, J., & Evans, M. (2017). A patient information leaflet reduces parental anxiety before their child's first craniofacial multidisciplinary outpatient appointment. *Journal of Craniofacial Surgery*, 28(7), 1772-1776. doi:10.1097/scs.0000000000003955
- Sadegh Tabrizi, J., Seyedhejazi, M., Fakhari, A., Ghadimi, F., Hamidi, M., & Taghizadieh, N. (2015). Preoperative education and decreasing preoperative anxiety among children aged

8 - 10 years old and their mothers. *Anesthesiology and Pain Medicine*, 5(4), e25036.

doi:10.5812/aapm.25036

Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): a new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, 96(3), 395-403. doi:10.1016/j.pec.2014.05.027

Sicile-Kira, C. (2012). What are the safety concerns for people on the Autism Spectrum? *Psychology Today*, Retrieved from <https://www.psychologytoday.com/us/blog/the-autism-advocate/201202/what-are-the-safety-concerns-people-the-autism-spectrum>

Simeone, S., Pucciarelli, G., Perrone, M., Rea, T., Gargiulo, G., Dell'Angelo, G., . . . Vosa, C. (2017). Comparative analysis: Implementation of a pre-operative educational Intervention to decrease anxiety among parents of children with congenital heart disease. *Journal of Pediatric Nursing*, 35, 144-148. doi:10.1016/j.pedn.2017.01.008

Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 23, 36.

Wong, V., Yu, Y., Keyes, M. L., & McGrew, J. H. (2017). Pre-Diagnostic and diagnostic stages of Autism Spectrum Disorder: A parent perspective. *Child Care in Practice*, 23(2), 195-217.

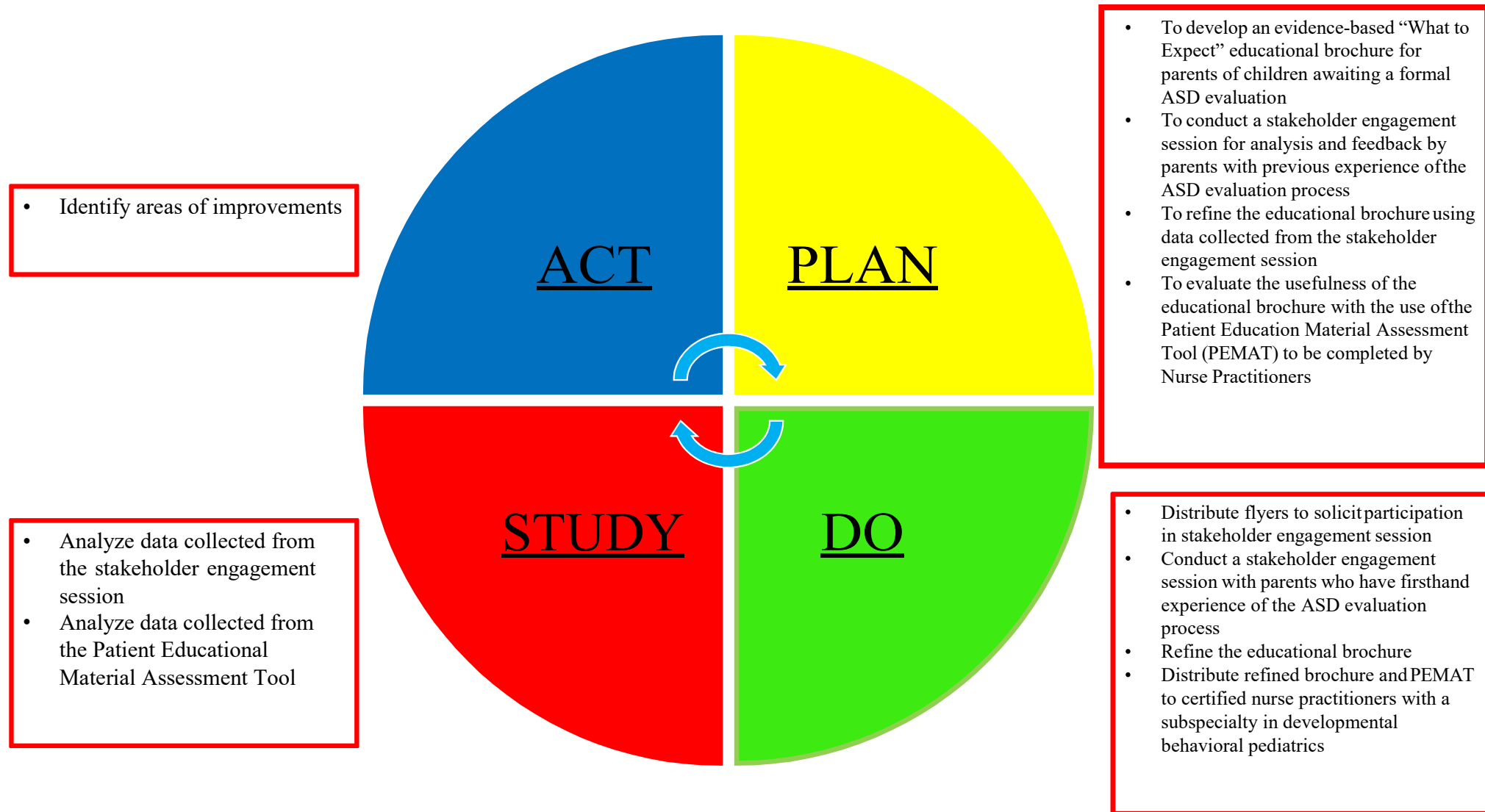
## Appendix A

## Table of Evidence

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study Findings that help answer the EBP Question	Limitations	Evidence Level & Quality
1	Pidgeon, Blore, Webb, Horton, & Evans, 2017	Prospective 2-part closed loop service evaluation	56 Parents, Birmingham Children's Hospital Outpatient in UK	Developed educational leaflet and assessed its effects in reducing parental anxiety related to a child's 1st craniofacial multidisciplinary outpatient appointment. Part 1: before distributing the educational leaflet, parents (n=26) were asked questions about their concerns and expectations. Results indicated that parents wanted information pertaining to what would happen during their child's appointment. Part 2: Parents (n=30) received an educational leaflet and were asked questions about their comprehension and level of anxiety. Results indicated that parents felt less worried about appointment after receiving educational leaflet.	Questions from the 1st group of participants were not repeated with the second group of participants. There were a limited number of participants in this study due to time limitation in the clinic where the study took place.	III/C
2	Munn & Jordan, 2014	Quantitative Systemic Review	8 Studies, Joanna Briggs Institute, Faculty of Health Sciences, University of Adelaide, South Australia	Systemic review to identify strategies effective in reducing anxiety related to nuclear medicine imagine. Pediatric preparation booklet was found to reduce anxiety in 75% of intervention group (n=30).	Of the 8 studies, only 2 related to pediatric population and parents.	II/B
3	Ji et al., 2016	Randomized Control	102 children (4-12 yrs); 102 parents, Second Hospital of Dalian Medical University in China	Developed a visual preoperative educational tool. Assessed parental and child anxiety level and parent satisfaction at different points of the procedure. Intervention and control groups were randomly selected. A significant reduction in parental anxiety and significant higher satisfaction scores were noted in intervention group post education and post operation.	Two different surgeries therefore anxiety levels may have been influenced by type of procedure.	I/A
4	Landier et al., 2017	Randomized Control Prospective Study	164 parents; Visceral, Urological 7 Plastic Surgery Dapartment, Gatién de Clocheville Hospital, France	Developed educational leaflet and assessed parental anxiety, satisfaction, and memorization. Participants were randomly assigned to group 1 (verbal consultation only) and group 2 (verbal consultation and written documentation). No significant difference in parental anxiety following intervention. However, on the day of the procedure memorization and satisfaction scores were significantly higher in the intervention group. Additionally, anxiety levels were significantly lower within the intervention group.	There were several different surgical procedures being performed and anxiety levels may have been influenced by the type of procedure.	I/B
5	S. Fernandes, Arriaga, & Esteves, 2015	Randomized control	90 children, 90 parents;	Developed an interactive educational tool and assessed the cognitive, emotional, and physiological responses of children and assessed parental anxiety. Participants were randomly assigned to the experimental, comparison, or control group. For children, significant lower levels of worry were identified in experimental group; no significant difference was noted in emotional response and physiological response. For parents, a significant reduction in parental anxiety was noted in the experimental group; anxiety level between the experimental and comparison group was not significant.	Sample of children were limited to two geographical regions. Children who were assigned the same preoperative room were given the same intervention and therefore not truly randomly selected.	I/B
6	Simeone et al., 2017	2 group randomized control	60 parents	Implemented preoperative nurse led educational intervention for parent's whose child was undergoing cardiac surgery for the 1st time. Parental anxiety of the experimental group was significantly lower than the control group post intervention.	Participants were all the same race and from the same region therefore generalization cannot be made.	I/B
Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study Findings that help answer the EBP Question	Limitations	Evidence Level & Quality

7	Sadegh Tabrizi et al., 2015	prospective 2-group randomized control	36 children (8-10yrs), 30 mothers, Tabriz Children Hospital, Iran	Developed a preoperative educational booklet and examined the anxiety level of the child and mother. Participants were randomly assigned to the control or intervention group. There was no significant difference in parental anxiety between groups. However, a significant reduction in parental anxiety was seen within the intervention group. No significant difference was noted in child anxiety levels.	The time between the delivery of the educational material and surgical procedure was limited. Participants may have shown a lower level of anxiety if the educational material was provided days before the procedure. Additionally, there was a lack of separation of parent and children as it relates to their educational level.	I/B
8	S. C. Fernandes, Arriaga, & Esteves, 2014	3-group Randomized control	125 children (8-12 years old), 125 parents, 3 hospitals in Lisbon Portugal	Developed 3 educational modes (booklet, video game, board game) and evaluated its effects on child and parental anxiety. Experimental group received educational material, comparison group received same material without education, control group received nothing. In children, there was a significant reduction in worries noted in experimental group compared to comparison & control. There was no significant difference noted between comparison group & control. Additionally, there was no significant difference noted between different modes of education within the experimental group. In parents, there was no significant reduction in anxiety noted between groups.	Children located in the same ward received the same material (booklet, video game, board game) regardless of the results of the random assignment tool. Educational material not designed for parents.	I/A
9	Krishnan, Lawler, & Van Hyfte, 2017	Literature Review	48 Brochures	Educational materials regarding the newborn hearing screening process were analyzed to identify if the information was current, pertinent, and consistent state- wide. Two of the 50 states had no available brochures. The analysis indicated that the educational materials were not consistent.	Some of the data was obtained through websites. There were no methods perform to identify if the information was current.	V/C
10	Elsevier Clinical Solutions, 2015	Expert Opinion	None	Information from Elsevier Clinical Solutions about how to develop and use educational material. Information about the importance of educational materials were also included.		V/A

## Appendix B- PDSA Model



Appendix C

Preliminary Educational Brochure

**How can I prepare for the ASD evaluation?**

An ASD evaluation will include an interview with the parent. The parent should be ready to discuss:

- **Child’s past and current medical history:**
  - Has your child been diagnosed with anything?
  - Does your child take any medications?
- **Family History:**
  - Do you have any family members with developmental delays?
- **Developmental Milestones:**
  - When did your child start to make sounds, point, wave, smile, talk and walk?
- **Behavioral Issues:**
  - What concerns do you have about your child?
- **Previous Tests:**
  - Has your child had any other tests done?
  - What were the results?

**For more information:**

**Autism Speaks:**  
<https://www.autismspeaks.org/>

**Autism NJ:**  
<https://www.autismnj.org/>

**Autism Society:**  
<https://www.autism-society.org/>

**Center for Disease Control and Prevention:**  
<https://www.cdc.gov/ncbddd/autism/index.html>

Autism Spectrum  
Disorder  
Evaluation

A “What to  
Expect” Brochure

## What is Autism Spectrum Disorder (ASD)?

ASD is a condition that is characterized by a range of impaired social, communication and behaviors skills.

## What are some signs and symptoms of ASD?

Children with ASD may:

- Avoid eye contact
- Have a speech delay
- Repeat words
- Have trouble adjusting to change
- Prefer to play alone



## Who can perform the ASD Evaluation?

Here is a list of providers who can perform an ASD evaluation:

- Child Neurologists
- Child Psychiatrist or Child Psychologist
- Developmental-Behavioral Nurse Practitioners or Pediatricians

## What Can I Expect at my child's ASD Evaluation?

Your child may have an autism team evaluation or a single provider evaluation.

### Autism Team Evaluation:

At a team evaluation, your child may be seen by:

- A speech therapist to assess communication skills
- An occupational therapist to assess fine motor and sensory issues
- A child psychiatrist or child psychologist to assess behavior

Your child will also be tested using the Autism Diagnostic Observation Schedule (ADOS)

- **ADOS** is a tool that uses different activities to assess:
  - Communication
  - Social Interaction
  - Imaginary Play

### Single Provider Evaluation:

The single provider may:

- Give some tests to see how your child works through problems and retains information.
- Use **screening tools** like the Modified Checklist for Autism in Toddlers (MCHAT) and the Screening Tool for Autism in Toddlers and Young Children (STAT) to assess development
  - **MCHAT** is a tool used in children 16-30 months to assess risk for ASD
  - **STAT** is a tool used to assess children 24-36 months who may be on the autism spectrum
- Complete the DSM-5 Diagnostic Criteria for Autism to **Diagnose** Autism Spectrum Disorder.



## Appendix D

### Brochure Refinement Survey

Your input on this “*What to Expect*” educational brochure is requested. This is an anonymous survey. Do not write down your name or any information that could identify you. You do not have to take part in this survey if you do not want to. Your answers to this survey will help us make sure this material meets the needs of families like yours. If you have any comments or think of questions you have not been asked, please tell us. If you have any questions about the brochure or about the survey, please ask.

Please read the brochure and fill out the following survey when you are finished. Select the response that best describes what you think.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. The brochure helped me to know what to expect at an Autism evaluation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. The brochure helped me to understand how to prepare for an Autism evaluation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I would recommend this brochure to other parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. The brochure layout made it easy for me to read	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. The words used in the brochure were too difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. What additional information would you have liked to see this brochure?

**Appendix E****Demographic Data Form**

Please do not write your name on this form. It will be stored separately from any other information that you complete during this study and will not be linked with your responses in any way. The information will allow us to provide an accurate description of the sample.

For the following items, please select the *one* response that is most descriptive of you or fill in the blank as appropriate.

Gender: Female ☐ Male ☐

**Age in years:**

- ☐ 18 – 29
- ☐ 30 – 39
- ☐ 40 – 49
- ☐ 50 – 59
- ☐ 60+

**Ethnicity:**

- ☐ Asian or Pacific Islander
- ☐ American Indian or Alaska Native
- ☐ Black/African American (*non-Hispanic*)
- ☐ Caucasian/White
- ☐ Latino/Hispanic
- ☐ More than one race (*please specify*): \_\_\_\_\_

**Educational Level:**

- ☐ Graduate Degree or Professional School (*for example: medical, dental or law school*)
- ☐ Undergraduate Degree
- ☐ Some College
- ☐ High School Graduate
- ☐ Some High School
- ☐ Middle School (*grades 6-8*)
- ☐ Elementary School

**Primary Language:**

- ☐ English
- ☐ Spanish
- ☐ Chinese
- ☐ Other (*please specify*): \_\_\_\_\_

## Patient Education Material Assessment Tool

## UNDERSTANDABILITY

Item #	Item	Response Options	Rating
<b>Topic: Content</b>			
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1	
<b>Topic: Word Choice &amp; Style</b>			
3	The material uses common, everyday language.	Disagree=0, Agree=1	
4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	
5	The material uses the active voice.	Disagree=0, Agree=1	
<b>Topic: Use of Numbers</b>			
6	Numbers appearing in the material are clear and easy to understand.	Disagree=0, Agree=1, No numbers=N/A	
7	The material does not expect the user to perform calculations.	Disagree=0, Agree=1	
<b>Topic: Organization</b>			
8	The material breaks or “chunks” information into short sections.	Disagree=0, Agree=1, Very short material*=N/A	
9	The material’s sections have informative headers.	Disagree=0, Agree=1, Very short material*=N/A	
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	
11	The material provides a summary.	Disagree=0, Agree=1, Very short material*=N/A	
<b>Topic: Layout &amp; Design</b>			
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1 Video=N/A	

Item #	Item	Response Options	Rating
<b>Topic: Use of Visual Aids</b>			
13	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	Disagree=0, Agree=1	
14	The material's visual aids reinforce rather than distract from the content.	Disagree=0, Agree=1, No visual aids=N/A	
15	The material's visual aids have clear titles or captions.	Disagree=0, Agree=1, No visual aids=N/A	
16	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	
17	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	

**ACTIONABILITY**

Item #	Item	Response Options	Rating
18	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	
19	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	
20	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	
21	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	
22	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=NA	
23	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	
24	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	



## Appendix G

### Recruitment Flyer

## Autism Evaluation: A “What to Expect” Brochure



### Your Feedback is Important!

Looking for parents who have experience with the Autism Spectrum Disorder evaluation process to participate in a quality improvement research study. The purpose of this study is to increase parents' knowledge of the formal Autism Spectrum Disorder evaluation process by providing a “*What to Expect*” educational brochure. Parents who choose to participate in the study will be asked to read the “*what to expect*” brochure and provide feedback by completing a survey during a 45 minutes stakeholder engagement session. The stakeholder engagement session will be held at the [REDACTED]

[REDACTED]. To be eligible for participation, parents must be 18 and older, English speaking and have a child diagnosed with Autism Spectrum Disorder. Participants will be given a \$25 Amazon gift card after completing the survey. Food and beverages will also be provided.

Your thoughts and opinions are important and by participating in this study, you will be contributing to knowledge about the Autism Spectrum Disorder evaluation process. Join by contacting the Principal Investigator, Manouchka Jean (Doctorate in Nursing student-Rutgers School of Nursing) at [REDACTED]

[REDACTED]. If you have any questions, please contact the Principal Investigator.



## **Appendix H**

### **Paper Survey-Informed Consent Form**

Study Title: Autism Evaluation: A What to Expect Educational Brochure

You are being asked to participate in a research study that is being conducted by School of Nursing at the Rutgers University. This is study that is being conducted by the Principal Investigator (PI), Manouchka Jean

#### **PURPOSE OF THE STUDY:**

The purpose of this study is to provide parents whose children are awaiting an Autism Spectrum Disorder evaluation a greater knowledge of the Autism Spectrum Disorder evaluation process and to help them prepare for the evaluation. This will be done by providing understandable information and actionable items via a “what to expect” educational brochure. You will be one of up to 12 subjects who will review the preliminary educational brochure and provide feedback.

#### **WHAT WILL BE DONE?:**

During this stakeholder engagement session, you will be asked to complete a demographic data form, review the preliminary “what to expect” educational brochure, and provide feedback by completing the brochure survey. The demographic data form will take approximately 5 minutes. Upon completion of the demographic data form, you will be given the educational brochure to review followed by the brochure survey. This should take approximately 20 minutes.

We expect the engagement session to last about one hour. This will include time to read all documents, asks questions, complete the survey and demographic form. Participation in this study is voluntary. The only alternative to this study is not to participate.

#### **RISKS OR DISCOMFORTS:**

There may be some foreseeable minimal emotional risks anticipated from taking part in this study. Participating in this quality improvement project may cause you to remember their own personal experience with the ASD evaluation process therefore leading to some emotional discomfort. If you feel uncomfortable at any time during this session, you may choose to withdraw from the study altogether. If you decide to quit at any time before you have finished the questionnaire, your answers will NOT be recorded.

#### **BENEFITS OF THIS STUDY:**

There is no direct benefit to you for participating in this study. You will be contributing to knowledge about ASD evaluation process.

#### **CONFIDENTIALITY:**

**Your responses will be kept strictly confidential.** No person identifying information such as name and address will be obtained. All documents received throughout the project timeframe will be placed in a utility box with a combination lock and locked in a filing cabinet accessible only by the Principal Investigator. All analyzed data and back-up information will be stored on password protected flash drive.

**COMPENSATION:**

For participating in this quality improvement project, you will be compensated with a \$25 Amazon card. Additionally, food and beverages will be offered during the stakeholder meeting. Gift cards will be distributed upon completion of the brochure survey.

**WITHDRAWAL:**

Your participation is voluntary; you are free to withdraw your participation from this study at any time. If you do not want to continue, you may turn in a blank survey.

**HOW THE FINDINGS WILL BE USED:**

The information gathered from the engagement session will be utilized to enhance the educational brochure. The refined brochure will then be evaluated by certified nurse practitioners to assess its usefulness in terms of understandability and actionability. The results of this quality improvement project will be publicized via a poster presentation during Rutgers University- Newark's research week in the year 2019.

**CONTACT INFORMATION:**

If you have concerns or questions about this quality improvement project, please direct all inquiries to the PI, Manouchka Jean.

If you have questions about your rights as a research subject, please contact the IRB Director at (973)-972-3608 Newark/ (732)-235-9806 New Brunswick/Piscataway.

By beginning the survey, you acknowledge that you have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time without penalty.

Sign below if you agree to participate in this research study:

Participant Name:\_\_\_\_\_

Participant Signature:\_\_\_\_\_ Date:\_\_\_\_\_

Investigator Name:\_\_\_\_\_

Investigator Signature:\_\_\_\_\_ Date:\_\_\_\_\_

## **Appendix I**

### **Online Survey-Informed Consent Form**

Study Title: Autism Evaluation: A What to Expect Educational Brochure

You are being asked to participate in a research study that is being conducted by the School of Nursing at the Rutgers University. This is a study that is being conducted by the Principal Investigator (PI), Manouchka Jean

#### **Purpose of the study:**

The purpose of this study is to provide parents whose children are awaiting an Autism Spectrum Disorder evaluation a greater knowledge of the Autism Spectrum Disorder evaluation process and to help them prepare for the evaluation. This will be done by providing understandable information and actionable items via a “what to expect” educational brochure. You will be one of up to 12 subjects who will review the refined educational brochure and provide feedback.

#### **What will be done?**

You will be asked to review a what to expect educational brochure and complete the Patient Educational Material Assessment Tool. The survey includes questions about understandability and actionability of the educational brochure.

We expect the study to last about 20 minutes. Participation in this study is voluntary. The only alternative to this study is not to participate.

#### **Risks or discomforts:**

There are no anticipated risks from taking part in this study. If you feel uncomfortable at any time, you may choose to withdraw from the study altogether. If you decide to quit at any time before you have finished the questionnaire, your answers will NOT be recorded.

#### **Benefits of this study:**

There is no direct benefit to you for participating in this study. You will be contributing to knowledge about ASD evaluation process.

#### **Confidentiality:**

**Your responses will be kept strictly confidential.** No person identifying information such as name and address will be obtained. All analyzed data and back-up information will be stored on password protected flash drive. Once data collection is complete, your e-mail address will be shredded and no link between the survey data and identity will exist. There are no foreseeable risks to participation except for the remote possibility that your email address would be inadvertently disclosed. However, the principal investigator has put in place adequate protections for your privacy in that all information provided will be kept confidential by using a randomly generated number code in place of your email address. This code will be kept securely by the research team only until study completion which is anticipated in December 2018.

**Compensation:**

There will be no compensation for participating in this quality improvement project.

**Withdrawal:**

Your participation is voluntary; you are free to withdraw your participation from this study at any time. If you do not want to continue, you can simply leave this website. If you do not click on the "submit" button at the end of the survey, your answers and participation will not be recorded.

**How the findings will be used:**

The information gathered from the survey will be utilized to assess the usefulness of the educational brochure in terms of understandability and actionability. The results of this quality improvement project will be publicized via a poster presentation during Rutgers University- Newark's research week in the year 2019.

**Contact information:**

If you have concerns or questions about this quality improvement project, please contact the PI, Manouchka Jean, at [REDACTED]

If you have questions about your rights as a research subject, please contact the IRB Director at [REDACTED] Newark/ [REDACTED] New Brunswick/Piscataway.

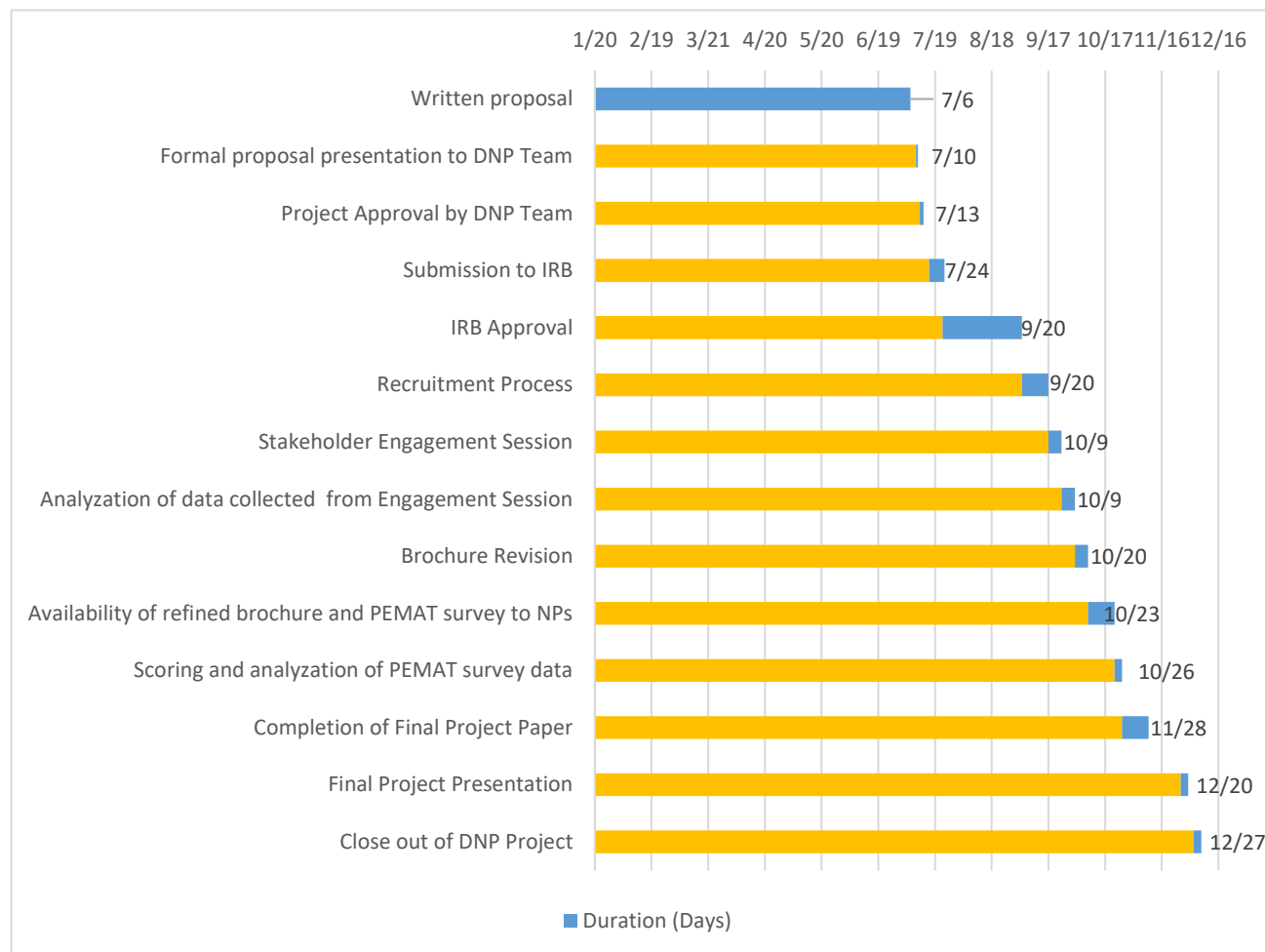
By beginning the survey, you acknowledge that you have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time without penalty.

Please click on the hyperlink below to begin the survey.

[Autism Evaluation: A What to Expect Educational Brochure-PEMAT Survey](#)

## Appendix J

### Projected Timeline



**Appendix K****Projected Budget**

Items	Cost
Materials (Brochures, Flyers, Consent Forms, Demographic Data Forms, Brochure Refinement Surveys, Flipchart, Markers, Combination Lock Utility Box)	\$150
\$25 Amazon Gift Cards	\$300
Food/Beverages/Plates/Cups/Napkins/Utensils	\$100

## Appendix L

### Refined Brochure

#### How can I prepare for the evaluation?

The ASD evaluation will include an interview with the parent. The parent should be ready to discuss:

#### Child's past and current medical history:

- Has your child had any other tests done? If so, what were the results?
- Has your child been diagnosed with anything?
- Does your child take any medications?

#### Family History:

- Do you have any family members with developmental delays?

#### Developmental Milestones:

- Did your child smile by 2 months?
- Did your child say "mama, dada, baba" by 9 months?
- Did your child point to show interest by 18 months?

#### Behavioral Issues:

- What concerns do you have?
- Does your child have any problems in daycare or school?
- Does your child struggle with eating or sleeping?

#### What should I do while I wait for an evaluation?

An appointment for an ASD evaluation may take several weeks to several months. While you wait for your scheduled appointment, you can:

Act Now and contact **some** of these resources for early developmental screenings:

- For children who are less than 3 years old contact **Early Intervention**:  
<https://www.nj.gov/health/fhs/eis/for-families/when/>
- For children who are 1-5 years old contact **Quick Peek Screening**:  
<https://www.childrens-specialized.org/programs-and-services/specialty-programs/early-developmental-screenings/?>

Expand your knowledge and visit **some** of these websites for more information:

- Autism NJ:  
<https://www.autismnj.org/>
- Center for Disease Control and Prevention:  
<https://www.cdc.gov/ncbddd/actearly/index.html>
- Center for Disease Control and Prevention:  
<https://www.cdc.gov/ncbddd/autism/index.html>



## Autism Spectrum Disorder?



## What to Expect at an Evaluation?

### What is Autism Spectrum Disorder (ASD)?

ASD is a neurodevelopmental condition characterized by a **range** of deficits in social, communication and behavioral skills.

### What are **some** of the signs and symptoms?

Children with ASD **may**:

- Have developmental milestone delays
- Have a speech delay
- Avoid eye contact
- Repeat words and behaviors
- Prefer to play alone or have social anxiety
- Have sensitivity to light and sound



### Who can perform an evaluation?

If your child has some of these signs and symptoms, the following *Pediatric Providers* can perform an ASD evaluation:

- Neurologists
- Psychiatrist or Psychologist
- Developmental Pediatrician or Nurse Practitioner

### What can I expect at my child's evaluation?

Your child may have an Autism Team Evaluation or a Single Provider Evaluation.

#### Autism Team Evaluation:

At the team evaluation, your child **may** be seen by:

- A **speech therapist** to assess:
  - **communication skills** – the ability to use words/actions to express feelings or ideas
- An **occupational therapist** to assess:
  - **fine motor** – the ability to use fingers and hands to complete an activity
  - **sensory issues**- difficulties responding to taste, sight, touch, smell, or sound
- A **pediatric psychiatrist or psychologist** to assess:
  - **behavior**-how a person acts in response to his surroundings

Your child will also be tested using the Autism **D**iagnostic **O**bservation Schedule (**ADOS**)

- **ADOS** is a tool that uses different activities to assess:
  - Communication
  - Social Interaction
  - Imaginary Play

### Single Provider Evaluation:

The single provider **may**:

- Give tests to see how your child works through problems and retains information.
- Use **screening tools** like the **Modif Checklist for Autism in Toddlers (MCHAT)** and the **Screening Tool for Autism in Toddlers and Young Children (STAT)** to assess development
  - **MCHAT** is a tool used in children 16-30 months to assess risk for ASD
  - **STAT** is a tool used to assess children 24-36 months who may be on the autism spectrum
  - Several other tools may also be used
- Complete the **DSM-5 Diagnostic Criteria for Autism** to diagnose Autism Spectrum Disorder.

## Appendix M

## Demographic Data

DEMOGRAPHIC DATA		
Gender	Frequency	Percent
Male	1	12.5
Female	7	87.5
Age		
40-49	8	100
Ethnicity		
Asian or Pacific Islander	2	25
Black/African American (non-Hispanic)	1	12.5
Latino/Hispanic	4	50
More than one race (please specify)	1	12.5
Primary Language Spoken		
English	5	62.5
Spanish	1	12.5
English and Spanish	1	12.5
English and Hindi	1	12.5
Total	8	100
Highest Level of Education		
Graduate Degree or Professional School (for example: medical, dental or law school)	1	12.5
Undergraduate Degree	3	37.5
Some College	4	50

## Appendix N

## Brochure Refinement Survey Frequency Data

<b>Q1. The brochure helped me to know what to expect at an Autism evaluation</b>		
	<b>Frequency</b>	<b>Percent</b>
Neutral	1	12.5
Agree	6	75
Strongly Agree	1	12.5
<b>Q2. The brochure helped me to understand how to prepare for an Autism evaluation</b>		
Disagree	2	25
Agree	5	62.5
Strongly Agree	1	12.5
<b>Q3. I would recommend this brochure to other parents</b>		
Neutral	1	12.5
Agree	5	62.5
Strongly Agree	2	25
Total	8	100
<b>Q4. The brochure layout made it easy for me to read</b>		
Neutral	1	12.5
Agree	4	50
Strongly Agree	3	37.5
<b>Q5. The words used in the brochure were too difficult</b>		
Strongly Disagree	1	12.5
Disagree	6	75
Agree	1	12.5

## Appendix O

## MCH Poster Presentation

# RUTGERS

Robert Wood Johnson  
Medical School

## THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

*New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service*

*New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program*

### AUTISM EVALUATION: A "WHAT TO EXPECT" EDUCATIONAL BROCHURE

Manouchka Jean, RN, BSN Rutgers School of Nursing Pediatric Doctor of Nursing Practice Student, NJLEND Fellow  
Sallie Porter, DNP PhD APN RN-BC CPNP FNAP, NJLEND Nursing Discipline Coordinator

#### INTRODUCTION

- Autism Spectrum Disorder (ASD) is a neurodevelopmental disability characterized by impaired social and communication skills
- Symptoms include but not limited to avoiding eye contact, limited or no pretend play, repetitive behaviors, and speech delays
- An estimated 50% of children with ASD show delays within the first year of life and 80% show delays by the second year of life
- Parents are often the first to notice development delays in their child but frequently feel unadvised, uninformed, and dissatisfied about the diagnostic process

#### BACKGROUND

- ASD can be diagnosed by a Child Psychologist, a Developmental and Behavioral Pediatrician/Nurse Practitioner, and a Child Neurologist
- Several inconsistencies regarding the recommendations for an autism diagnostic evaluation have been identified
- Variations in the number and type of psychometric tools utilized during an ASD assessment have been noted
- Parents seek out information about ASD and the diagnostic process via the internet
- Information via the internet varies from source to source and parents feel frustrated when their expectations of the evaluation are not met

#### SCREENING AND DIAGNOSTIC TOOLS

**M-CHAT:** Validated developmental screening tool used to identify toddlers between 16-30 months of age who may benefit from a developmental and autism evaluation

**STAT:** Interactive screening tool for autism in toddlers between 24-36 months of age. Consists of 12 activities that assess play, communication, and imitation skills

**ADOS:** semi-structured assessment of communication, social interaction, and play for individuals suspected of having autism

**DSM-5 Diagnostic Criteria:** Provides standardized criteria to help diagnose ASD.

#### NEEDS ASSESSMENT

- According to the 2014 Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance, 1 in 59 (8 year-old) children were diagnosed with ASD
- New Jersey has the highest prevalence of ASD in the United States with 1 in 34 children diagnosed
- ASD prevalence in New Jersey did not vary by race or ethnicity in 2014
- Parents of children with ASD experience daily challenges affecting their ability to parent well and manage their home
- The lack of information pre/post diagnosis have been cited as reasons for increased parental stress
- With these constant hurdles and rising rates, healthcare providers must find ways to support parents throughout the diagnosis process and beyond

#### OBJECTIVES

- Develop an evidence-based "what to expect" educational brochure for parents/caregivers of children requiring a neurodevelopmental/autism team evaluation
- Prepare parents for the autism evaluation while helping gauge their expectations and minimize any concerns related to the evaluation

#### MODEL



#### EXPECTED OUTCOMES

- Parents are given the information they desire, they are able prepare for the evaluation and able to make informed decisions
- Long term goals: Brochures are made available at several facilities
  - Primary Care Providers' Offices
  - Children Specialized Hospital sites
  - New Jersey Department of Child Protection and Permanency



#### REFERENCES

- Bonin, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing*, 37(3), 153-163. doi:10.1109/01612840.2015.1116030
- Center for Disease Control and Prevention. (2017). Facts about ASD. Retrieved from <https://www.cdc.gov/ncbddd/autism/facts.html>
- Center for Disease Control and Prevention. (2018). Autism and developmental disabilities monitoring network: Community report of autism 2018. Retrieved from <https://www.cdc.gov/ncbddd/autism/adm-community-report/documents/adm-community-report-2018-4.pdf>
- Frye, L. (2016). Fathers' experience with autism spectrum disorder: Nursing implications. *Journal of Pediatric Health Care*, 30(5), 453-463. doi:10.1016/j.pedhc.2015.10.012
- Penner, M., Anagnostou, E., Andoni, L. Y., & Ungar, W. J. (2017). Systematic review of clinical guidance documents for autism spectrum disorder diagnostic assessment in select regions. *Autism*, 1562361316683879. doi:10.1177/1362361316683879

## Appendix P

## Power Point Presentation

**RUTGERS**  
School of Nursing

**Autism Evaluation: A “What to Expect” Educational Brochure**

Manouchka Jean, RN, BSN  
DNP Chair: Dr. Sallie Porter DNP, PhD, APN, RN-BC, CPNP  
DNP Team Member: Dr. Susan McColley, DNP, MSN, RNC, APNC, CPNP

1

**RUTGERS** School of Nursing

**Introduction**

- Patient education is imperative in improving healthcare.
  - Ensures that patients are well-informed about their condition
  - Know what to expect, understand the diagnostic processes, treatment plans, and are aware of the signs and symptoms requiring immediate attention (Bester et al., 2016)
- Patient education materials are effective tools that may be utilized to convey healthcare information (Bester et al., 2016)
  - Increase knowledge, increase retention, decrease anxiety (Blanck & Marshall, 2011)
- Parents of children who are ill experience increased levels of stress and look to healthcare providers for guidance
  - Parents of children with Autism Spectrum Disorder (ASD) experience a greater level of stress than those with typical development or those with other disabilities (Wong, Yu, Keyes, & McGrew, 2017)

2

2

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**Introduction**

- Autism Spectrum Disorder (ASD)
  - Characterized by impaired social, communication and behavioral skills (American Speech-Language-Hearing Association, 2018)
  - No specific cause
  - Mild to severe symptoms (“Facts about ASD”, 2018)
  - 50% of delays seen within 1<sup>st</sup> year of life (Frye, 2016)
  - Can be diagnosed as early as 18 months (“Data and Statistics”, 2017)
  - Delays in diagnosis and lack of information leads to increased parental stress (Wong et al., 2017)

3

3

**RUTGERS** School of Nursing

**Background and Significance**


- Who can evaluate and diagnose
  - Child Psychologist, Neurologist, Developmental Behavioral Pediatricians and Nurse Practitioners (“Screening & Diagnosis”, 2018)
- How is a diagnosis made
  - Multidisciplinary team or single provider
  - Psychometric tools
  - Clinical Judgement (Penner, Anagnostou, Andoni, & Ungar, 2017)
- What is the concern
  - Inconsistencies in the recommendation for diagnostic evaluation (Penner et al., 2017)
  - Online information varies depending on the source
- Common Thread
  - Medical History & developmental milestones

4

4

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**Needs Assessment**



- New Jersey Leadership in Neurodevelopment and Disabilities (NJLEND)
  - Parents perception of evaluation
  - NP’s perspective
  - Member of the Autism Registry
- Current Practice for Autism Evaluation
  - Multidisciplinary team evaluation
    - Letter and questionnaire
  - Developmental Behavioral Practitioner
    - Questionnaire


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**Needs Assessment**

- Statistics
  - 1 % of population worldwide (Autism Society, 2016)
  - 1 in 59 (8 years-old) children in the United States (Autism New Jersey, 2018)
  - 1 in 34 (8 years-old) children in New Jersey (Autism New Jersey, 2018)
  - Current data indicates 19% rise in New Jersey (Autism New Jersey, 2018)
- Parents report increased demands, responsibilities and financial burden (Vasileopoulos & Nisbet, 2016)



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### Problem Statement


- The nation-wide prevalence rate of ASD continues to rise.
- Within a 14-year period (2000-2014), autism rates have increased approximately 150% ("Data and Statistics," 2018)
- Inconsistencies and variations in the methods and types of psychometric tools used in the diagnostic process can make it difficult to obtain accurate information on what to expect and how to prepare (Penner et al., 2017)
- Barriers to pertinent information at a time when parents report feeling confused, uncertain, unadvised, and uninformed further magnifies the level of parental stress (Wong et al, 2017)
- Providers may help reduce parental stress, increase preparedness, and increase the parent's knowledge regarding an ASD evaluation by providing relevant information on what to expect

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### PICO Question



- Is a what to expect educational brochure effective in providing understandable and actionable information to prepare parents for their child's formal ASD evaluation?

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### Aims and Objectives

- Aims
  - To increase parents' knowledge of the formal ASD evaluation process
  - To prepare parents for the formal ASD evaluation by providing information of what to expect
- Objectives
  - To develop an evidence-based "What to Expect" educational brochure for parents of children awaiting a formal ASD evaluation
  - To conduct a stakeholder engagement session for analysis and feedback from parents with previous experience of the ASD evaluation process
  - To refine the educational brochure using data collected from the stakeholder engagement session
  - To evaluate the usefulness of the educational brochure with the use of the Patient Education Material Assessment Tool to be completed by Nurse Practitioners

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### Literature Review

- Databases
  - CINAHL & PubMed
  - Key words (educational materials, diagnostic services, parental anxiety, diagnostic procedures)
  - 5-year limitation
  - 428 Articles found
  - 10 articles used after screening

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### Literature Review

- Child's first craniofacial multidisciplinary outpatient appointment.
  - Parents completed survey to express concerns or desire for information
    - 86.6% of the parents desired for more information related to the different aspects of the appointment
    - 65.4% were concerned about what the appointment entailed.
    - 50% preferred the information in the form of an educational leaflet (Pidgeon, Blore, Webb, Horton, & Evans, 2017)

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### Literature Review

- Effects of preoperative education in reducing anxiety in children and their mothers
  - Randomized study, 36 children ages 8-10 years and 30 parents
  - Intervention group received verbal information and an educational booklet the night before the procedure
  - A questionnaire to measure mother and child anxiety was completed before the intervention and again before entering the operating room
  - A significant reduction in parental anxiety was noted within the intervention group ( $p < 0.05$ ) (Sadegh Tabrizi et al, 2015).

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### Theoretical Framework


- Plan-Do-Study-Act Model
  - Examines the effects of change and identifies if the change results in improvements
  - Three key questions
    - What are we trying to accomplish?
    - How will you know that a change is an improvement?
    - What changes can you make that will result in an improvement? (Institute for Healthcare Improvement, 2018)
  - Four-phases of the PDSA cycle.
    - 1<sup>st</sup> Phase: Identify the problem, state the objective, and develop a plan
    - 2<sup>nd</sup> Phase: Implement plan and collect data.
    - 3<sup>rd</sup> Phase: Analyze data and identify what was learned
    - 4<sup>th</sup> Phase: Make changes and repeat cycle if necessary (Gillam & Siriwardena, 2013)

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### Theoretical Framework



- Identify areas of improvement
- Analyze data collected from the stakeholder engagement session
- Analyze data collected from the Patient Educational Material Assessment Tool
- To develop an evidence-based "What to Expect" educational brochure for parents of children awaiting a formal ASD evaluation.
- To conduct a stakeholder engagement session for analysis and feedback by parents with previous experience of the ASD evaluation process.
- To refine the educational brochure using data collected from the stakeholder engagement session.
- To evaluate the usefulness of the educational brochure with the use of the Patient Educational Material Assessment Tool (PEMAT) to be completed by Nurse Practitioners.
- Distribute flyers to solicit participation in stakeholder engagement session.
- Conduct a stakeholder engagement session with parents who have firsthand experience of the ASD evaluation process.
- Refine the educational brochure.
- Distribute refined brochure and PEMAT to certified nurse practitioners with a subspecialty in developmental behavioral pediatrics.


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### Methodology

- Setting I-Parents
  - New Jersey
    - Non-profit organization that helps train parents and provide available resources/support
  - Sample Size
    - Approved for convenience sample of up to 12
  - Recruitment
    - Flyer
    - Inclusive Criteria
    - Compensation/Incentives



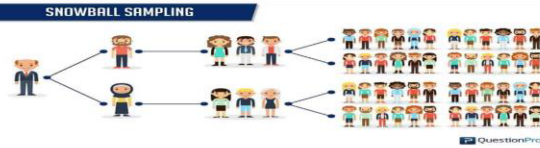
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### Methodology

- Setting II-Pediatric Developmental Behavioral Nurse Practitioners
  - Online
    - Approved for convenience sample of up to 12
    - Snowball sampling




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### Methodology

- Study Intervention
  - Parent Population: stakeholder engagement session with parents who have first-hand experience with the ASD evaluation process
    - Consent
    - Risks/Harms
    - Demographic Data Form
    - Brochure Refinement Survey
  - Nurse Practitioner: Refined brochure evaluation
    - Consent
    - Patient Education Material Assessment Tool (PEMAT)



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### Project Timeline

- Written Proposal: January 2018 – July 2018
- Formal Proposal Presentation: July 10
- Institutional Review Board Submission: July 24
- IRB Approval: September 20
- Engagement Session: October 9
- Recruitment for NP participation: October 23 – November 23
- Final Presentation: December 20, 2018
- Graduation: January 2019

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### Data Analysis

- Parent Stakeholder Engagement Session
  - Brochure Refinement Survey
    - Obtained from research study and modified by Principal Investigator
    - 5 question with responses made using ordinal 5-point Likert Scale
      - Descriptive analysis (means/percentages)
    - 1 question open ended
      - Identify main ideas to incorporate in refined brochure
- Certified Pediatric Developmental Behavioral Nurse Practitioners
  - Patient Education Material Assessment Tool
    - Obtained from the Agency for Healthcare Research and Quality website
  - 24 questions with responses in Disagree, Agree, Not applicable
    - Scores based on responses (Agree = 1, Disagree = 0, Not Applicable = not included)
    - Higher score = greater understandability and actionability (Shoemaker, Wolf, and Brach, 2014)

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### Demographic - Results

Gender	Frequency	Percent
Male	1	12.5
Female	7	87.5
Age		
40-49	8	100
Ethnicity		
Asian or Pacific Islander	2	25
Black/African American (non-Hispanic)	1	12.5
Latino/Hispanic	4	50
More than one race (please specify)	1	12.5
Primary Language Spoken		
English	5	62.5
Spanish	1	12.5
English and Spanish	1	12.5
English and Hindi	1	12.5
Highest Level of Education		
Graduate Degree or Professional School (for example: medical, dental or law school)	1	12.5
Undergraduate Degree	3	37.5
Some College	4	50

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### Preliminary Brochure

What can I prepare for the ASD evaluation?

ASD evaluation will include an interview with the parent. The parent should be ready to discuss:

- Child's past and current medical history:
  - Has your child been diagnosed with anything?
  - Does your child take any medications?
- Family History:
  - Do you have any family members with developmental delays?
- Developmental Milestones:
  - When did your child start to make sounds, point, wave, smile, talk and walk?
- Behavioral Issues:
  - What concerns do you have about your child?
- Previous Tests:
  - Has your child had any other tests done?
  - What were the results?

For more information:

- Autism Speaks: <https://www.autismspeaks.org/>
- Autism NLI: <https://www.autismlnli.org/>
- Autism Society: <https://www.autism-society.org/>
- Center for Disease Control and Prevention: <https://www.cdc.gov/ncbhd/autism/index.html>

**Autism Spectrum Disorder Evaluation**

A "What to Expect" Brochure

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### Preliminary Brochure

What is Autism Spectrum Disorder (ASD)?

ASD is a condition that is characterized by a range of impaired social, communication and behaviors skills.

What are some signs and symptoms of ASD?

Children with ASD may:

- Avoid eye contact
- Have a speech delay
- Repeat words
- Have trouble adjusting to change
- Prefer to play alone

Who can perform the ASD Evaluation?

Here is a list of providers who can perform an ASD evaluation:

- Child Neurologist
- Child Psychiatrist or Child Psychologist
- Developmental-Behavioral Nurse Practitioners or Pediatricians

What Can I Expect at my child's ASD Evaluation?

Your child may have an autism team evaluation or a single provider evaluation.

Autism Team Evaluation:

At a team evaluation, your child may be seen by:

- A speech therapist to assess communication skills
- An occupational therapist to assess fine motor and sensory issues
- A child psychiatrist or child psychologist to assess behavior

Your child will also be tested using the Autism Diagnostic Observation Schedule (ADOS)

- ADOS is a tool that uses different activities to assess:
  - Communication
  - Social Interaction
  - Imaginary Play

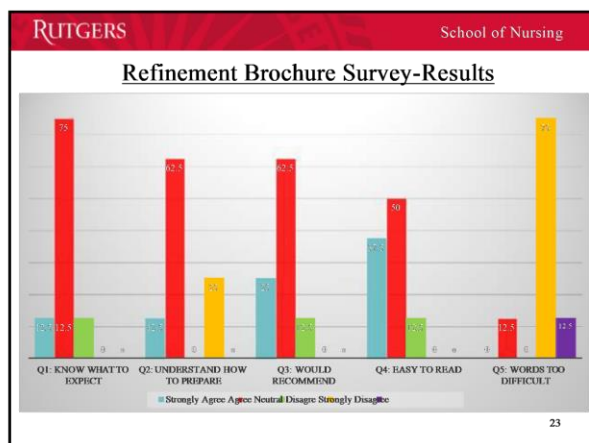
Single Provider Evaluation:

The single provider may:

- Give some tests to see how your child works through problems at various information.
- Use screening tools like the Modified Checklist for Autism in Toddlers (MCHAT) and the Screening Tool for Autism in Toddlers and Young Children (STAT) to assess development.
  - MCHAT is a tool used to assess risk for ASD in children 16-30 months to assess risk for ASD.
  - STAT is a tool used to assess children 24-36 months who may be on the autism spectrum.
- Complete the DSM-5 Diagnostic Criteria for Autism to Diagnose Autism Spectrum Disorder.

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### Key Themes

- Title may cause parental anxiety
- Include examples of developmental milestones
- Define communication skills, fine motor skills, sensory issues, and behavior skills
- Include information regarding timeline for appointment and what to do while waiting
- Bold or highlight certain words

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## Refined Brochure

**How can I prepare for the evaluation?**  
The ASD evaluation will include an interview with the parent. The parent should be ready to discuss:

**Child's past and current medical history:**

- Has your child had any other tests done? If so, what were the results?
- Has your child been diagnosed with anything?
- Does your child take any medications?

**Family History:**

- Do you have any family members with developmental delays?

**Developmental Milestones:**

- Did your child smile by 2 months?
- Did your child say "mama, dada, baba" by 6 months?
- Did your child point to show interest by 18 months?

**Behavioral Issues:**

- What concerns do you have?
- Does your child have any problems in daycare or school?
- Does your child struggle with eating or sleeping?

**What should I do while I wait for an evaluation?**  
An appointment for an ASD evaluation may take several weeks to several months. While you wait for your scheduled appointment, you can:

**Act Now and connect some of these resources for early developmental screenings:**

- For children who are less than 3 years old contact Early Intervention: <https://www.nj.gov/health/ncsl/csl-families.html>
- For children who are 1-5 years old contact Quick Pick Screening: <https://www.childrens-specialized.org/programs-and-services/specialty-programs/early-developmental-screening/>

**Expand your knowledge and visit some of these websites for more information:**

- Autism NJ: <https://www.autismnj.org/>
- Center for Disease Control and Prevention: <https://www.cdc.gov/ncbddd/actearly/index.html>
- Center for Disease Control and Prevention: <https://www.cdc.gov/ncbddd/autism/index.html>

**Autism Spectrum Disorder?**

**What to Expect at an Evaluation?**

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## Refined Brochure

**What is Autism Spectrum Disorder (ASD)?**  
ASD is a neurodevelopmental condition characterized by a range of deficits in social, communication and behavioral skills.

**What are some of the signs and symptoms?**

Children with ASD may:

- Have developmental milestone delays.
- Have a speech delay.
- Avoid eye contact.
- Repeat words and behaviors.
- Prefers to play alone or have social anxiety.
- Have sensitivity to light and sound.

**Who can perform an evaluation?**  
If your child has some of these signs and symptoms, the following *Professionals/Providers* can perform an ASD evaluation:

- Neurologist
- Psychiatrist or Psychologist
- Developmental Pediatrician or Nurse Practitioner

**What can I expect at my child's evaluation?**  
Your child may have an Autism Team Evaluation or a Single Provider Evaluation.

**Autism Team Evaluation:**  
At the team evaluation, your child may be seen by:

- A *speech therapist* to assess:
  - communication skills – the ability to use words/phrases to express feelings or ideas
- An *occupational therapist* to assess:
  - fine motor – the ability to use fingers and hands to complete an activity
  - sensory issues- difficulties responding to taste, sight, touch, smell, or sound
- A *pediatric psychiatrist or psychologist* to assess:
  - behavior how a person acts in response to his surroundings

**Your child will also be tested using the Autism Diagnostic Observation Schedule (ADOS).**

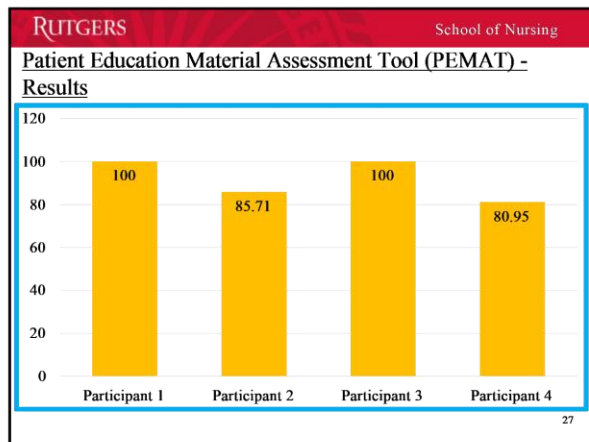
- ADOS is a test that uses different activities to assess:
  - Communication
  - Social Interaction
  - Imaginary Play

**Single Provider Evaluation:**  
The single provider may:

- Give tests to see how your child works through problems and retain information.
- Use screening tools like the Modified Checklist for Autism in Toddlers (MCHAT) and the Screening Tool for Autism in Toddlers and Young Children (STAY) to assess development.
- MCHAT is a tool used in children 18-30 months to assess risk for ASD.
- STAY is a tool used to assess children 24-36 months who may be on the autism spectrum.
- Several other tools may also be used.
- Complete the DSM-5 Diagnostic Criteria for Autism to diagnose Autism Spectrum Disorder.

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## Discussion

- Brochure proved be a vital resource for parents awaiting an autism evaluation
- Parents were eager to know who would be delivering this information and at what juncture the brochure be made available
  - 87.5% would recommend brochure to other parents
- Mean score of PEMAT (91.66%) indicating high level of understandability and actionability
- Goals of increasing knowledge and preparedness were met
- Limitations
  - 25% of the Nurse Practitioners that were petitioned chose to take part in the study

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## Implications

- Clinical Practice**
  - Practitioners have a responsibility to ensure that their patients are well informed and proactive
  - A practice change can be generated whereby practitioners offer this evidence-based brochure as an educational tool to prepare parents for the autism evaluation.
  - Practitioners should seek guidance from the parent about what information and resources they need so that the conversation about autism can be tailored
- Healthcare Policy**
  - Parental Concerns
    - NP Scope of Practice
    - Schools resistance to NP diagnosis
    - Insurance Coverage
  - Advocate
    - Autism policy changes-insurance
    - NP full practice authority

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## Implications

- Quality and Safety**
  - Delays in diagnosis can lead to gaps in services
  - Deficits lead to increased safety risk
- Education**
  - Increase students knowledge about autism and the many challenges parents face
- Economics**
  - Increased financial burden of over \$17,000 (Lavelle et al., 2014)
  - Greater indirect financial burden for parents with delayed diagnosis (Horlin, Falkmer, M., Parsons, Albrecht, Falkmer, T., 2014)

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### Dissemination/Professional Reporting

- Final presentation with findings to Rutgers School of Nursing faculty, staff, and students via a power point presentation
- Power point version of the poster presentation and the refined educational brochure to Span Parent Advocacy Network
- Poster presentation during Rutgers University- Newark's research week in the year 2019
- Scholarly publication in the Journal of Autism and Developmental Disorders and the Journal of Educational Research will be sought
- Distribution of brochure to primary care office

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### NJLEND Poster Presentation

**RUTGERS** THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES  
Robert Wood Johnson Medical School  
New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service  
New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program

#### AUTISM EVALUATION: A "WHAT TO EXPECT" EDUCATIONAL BROCHURE

Manuscript from: RN, MSN, Rutgers School of Nursing, Division of Nursing Practice, Rutgers, the State University of New Jersey, Newark, NJ 07102-1000

**BACKGROUND**

Autism Spectrum Disorder (ASD) is a developmental disability characterized by persistent deficits in social communication and restricted, repetitive patterns of behavior. Symptoms include but are not limited to: social interaction deficits, communication deficits, and restricted, repetitive patterns of behavior. Symptoms are present from early childhood and persist throughout life. An estimated 1% of children with ASD show delays within the first year of life and only show delays in the second year of life. The purpose of this study was to develop an educational brochure for parents of children with ASD. The brochure provides information on the diagnostic process, the current status from services to assess and provide the diagnosis, and the importance of the diagnosis for the child.

**NEEDS ASSESSMENT**

According to the 2014 Rutgers and Developmental Disabilities Research (DDR) Network Survey, 1 in 10 of parents of children with ASD reported that they were not satisfied with the current status of their child's diagnosis. The survey also found that parents were not satisfied with the current status of their child's diagnosis. The survey also found that parents were not satisfied with the current status of their child's diagnosis. The survey also found that parents were not satisfied with the current status of their child's diagnosis.

**OBJECTIVES**

Develop an evidence-based "What to Expect" educational brochure for parents of children with ASD. The brochure will provide information on the diagnostic process, the current status from services to assess and provide the diagnosis, and the importance of the diagnosis for the child.

**EXPECTED OUTCOMES**

Parents are given the information they desire, they are able to plan for the diagnosis and the current status of their child's diagnosis. The brochure will provide information on the diagnostic process, the current status from services to assess and provide the diagnosis, and the importance of the diagnosis for the child.

**REFERENCES**

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### DNP Poster Presentation

**RUTGERS** School of Nursing  
AUTISM EVALUATION: A "WHAT TO EXPECT" EDUCATIONAL BROCHURE  
Manuscript from: RN, MSN, Rutgers School of Nursing, Division of Nursing Practice, Rutgers, the State University of New Jersey, Newark, NJ 07102-1000

**INTRODUCTION**

Autism Spectrum Disorder (ASD) is a developmental disability characterized by persistent deficits in social communication and restricted, repetitive patterns of behavior. Symptoms include but are not limited to: social interaction deficits, communication deficits, and restricted, repetitive patterns of behavior. Symptoms are present from early childhood and persist throughout life. An estimated 1% of children with ASD show delays within the first year of life and only show delays in the second year of life. The purpose of this study was to develop an educational brochure for parents of children with ASD. The brochure provides information on the diagnostic process, the current status from services to assess and provide the diagnosis, and the importance of the diagnosis for the child.

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**EXPECTED OUTCOMES**

Parents are given the information they desire, they are able to plan for the diagnosis and the current status of their child's diagnosis. The brochure will provide information on the diagnostic process, the current status from services to assess and provide the diagnosis, and the importance of the diagnosis for the child.

**REFERENCES**

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### Conclusion

Parents of children with Autism Spectrum Disorder have a great deal of stress and experience many challenges. They have prolonged wait times for scheduling an autism evaluation, barriers with insurance coverage for services, increased financial burdened, and daily challenges with managing their home. Ultimately, practitioners play a key role in helping to reduce some of these obstacles by providing parents with education and available resources.

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### References

- Autism Society. (2016). Facts and Statistics. Retrieved from <http://www.autism-society.org/what-is/facts-and-statistics/>
- America Speech-Language-Hearing Association. (2018). Autism: Retrieved from <https://www.asha.org/Topics/Specific/Topic.aspx?topicid=8589935303&action=Overview>
- Autism New Jersey. (2018). New Jersey Autism Prevalence rate rises 1 in 34. Retrieved from <https://www.autismnj.org/prevalence-rates>
- Center for Disease Control and Prevention. (2017). Data and Statistics. Retrieved from <https://www.cdc.gov/ncbddd/autism/data.html>
- Center for Disease Control and Prevention. (2017). Facts about ASD. Retrieved from <https://www.cdc.gov/ncbddd/autism/facts.html>
- Center for Disease Control and Prevention. (2017). Screening and Diagnosis. Retrieved from <https://www.cdc.gov/ncbddd/autism/screening.html>
- Frye, L. (2016). Fathers' Experience With Autism Spectrum Disorder: Nursing Implications. J Pediatr Health Care, 30(5), 453-463. doi:10.1016/j.pedhc.2015.10.012
- Gillam, S., & Shriwardena, A. N. (2013). Frameworks for improvement: clinical audit, the plan-do-act cycle and significant event audit. Quality in Primary Care, 21(2), 122-130
- Horlin, C., Falkner, M., Parsons, R., Albrecht, M. A., & Falkner, T. (2014). The cost of autism spectrum disorders. PLoS one, 9(9), e106552. doi:10.1371/journal.pone.0106552
- Institute for Healthcare Improvement. (2018). How to improve. Retrieved from <http://www.ihp.org/resources/Pages/Howtoimprove/default.aspx>

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### References

- Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., Prosser, L. A. (2014). Economic Burden of Childhood Autism Spectrum Disorders. Pediatrics, 133(3), e520-e529. doi:10.1542/peds.2013-0763
- Penner, M., Anagnostou, E., Andoni, L. Y., & Ungar, W. J. (2017). Systematic review of clinical guidance documents for autism spectrum disorder diagnostic assessment in select regions. Autism, 13(2), 1316685879. doi:10.1177/1362361316685879
- Pidgeon, T. E., Blore, C. D., Webb, Y., Horton, J., & Evans, M. (2017). A Patient Information Leaflet Reduces Parental Anxiety Before Their Child's First Craniofacial Multidisciplinary Outpatient Appointment. J Craniofac Surg, 28(7), 1772-1776. doi:10.1097/ISS.0000000000000395
- Sadeh Taheri, J., Seydhejazi, M., Fakheri, A., Ghodini, F., Hamidi, M., & Taghizadeh, N. (2015). Preoperative Education and Decreasing Preoperative Anxiety Among Children Aged 8-10 Years Old and Their Mothers. Anesth Pain Med, 5(4), e2503
- Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): a new measure of understandability and actionability for print and audiovisual patient information. Patient Education and Counseling, 96(3), 395-403. doi:10.1016/j.pcc.2014.05.027
- Vasilopoulos, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. Research in Autism Spectrum Disorders, 23, 36
- Wong, V., Yu, Y., Keyes, M. L., & McGrew, J. H. (2017). Pre-Diagnostic and Diagnostic Stages of Autism Spectrum Disorder: A Parent Perspective. Child Care in Practice, 23(2), 195-217.

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## Appendix Q

## Poster Presentation

