IMPROVING FAMILY-PROVIDER RELATIONSHIPS THROUGH CULTURAL TRAINING AND OPEN-ENDED CLIENT INTERVIEWS

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Behavior analysts form parent-professional relationships with families of many different backgrounds. The study evaluated the effectiveness of a training program to teach behavior analysts to utilize an open family interview format. The study was conducted at an autism treatment program. A pre-post treatment design with in vivo simulation probes before and after training was used to assess the effects of the workshop on the participants and parents’ verbal behavior. Results showed that rate of questions per minute and number of closed-ended questions decreased after training, the duration of interviews decreased after training, the number of closed-ended questions significantly decreased after training, and frequency of the discussion topic of child goals increased after training. In general, interviewer responses varied. Preliminary data and parent questionnaire responses suggested parents were comfortable with the new interview format and felt the behavior analyst understood cultural and family needs.
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INTRODUCTION

Every family has its own unique social, cultural, and behavioral ecology. One goal of early-childhood intervention is to become acquainted with each family’s unique ecology and to develop a participatory relationship to best serve the child of that family (Lutzker & Campbell, 1994; Lynch & Hanson, 2004). This paper describes an evaluation of two interview tools utilized at an early autism intervention center. One tool was the existing agency interview format and the other was specifically developed to initiate a more participatory relationship between the staff and family.

The autism intervention center in this study strives to involve the family in stating concerns and expectations, participating in goal setting, as well as becoming involved in the implementation of the treatment plan (Easter Seals North Texas, n.d.). The mission of this center is “to provide a comprehensive program utilizing evidence-based practices that is culturally responsive and collaborative in nature, regardless of ability to pay” (Easter Seals North Texas, n.d.). Family involvement with the staff at the autism intervention center occurs at many levels such as assessments, individualized education programs (IEPs), and parent training. The first step in creating a participatory parent-professional relationship is the family intake assessment.

Traditionally, in early childhood intervention in autism, a parent meeting and a series of assessment procedures initiate the parent-professional relationship and services to the child. Assessments utilized in the autism spectrum disorder (ASD) population typically assess stress levels and symptoms of depression of family members as well as
family support resources but glean little information regarding quality of life for families, family resources, and the effects of the child on the family (Ozonoff, Goodlin-Jones, & Solomon, 2005). Family assessment domains and questions differ according to format and areas of family functioning considered to be useful (Barney, 2005; Beach Center on Disabilities, 2003; Boyle, Cunningham, Georgiades, Cullen, Racine, & Pettingil, 2009; Eggenberger & Nelms, 2006; Ellenwood & Jenkins, 2007; Johnson, Stone, Lou, Vu, Ling, Mizrahi, & Austin, 2006; Whiteside-Mansell, Johnson, Aitken, Bokony, Conners-Burrow, & McKelvey, 2010). The autism intervention center where this study took place assessed families in keeping with practices described in the literature. For example, the initial parent meeting began between the family and professional with a 5-page, 72 question packet. In this packet, the professional focused on four domains of information: pregnancy and birth history, medical and childhood history, rapport and communication, and play and preferences of the child. The interview format was designed to obtain information from domains considered beneficial in creating an effective treatment plan.

Types of questions and format of the interview further determine how the interviewer conducts the meeting and how families answer questions about child and family. Format determines the type of questions used, and the diagnosis and its effects on the patient and family determine what is important. Johnson et al. (2006) categorized family assessment formats as client self-report, observation, or interviews. Self-reports generally require the client or primary caretaker to complete a questionnaire, with most questions answered according to a Likert scale. Structured interviews usually have a rating system or open-ended questions (Johnson et al., 2006). The agency interview used
at the autism intervention center is a combination of a self-report and structured interview. The interview format utilized with families is important to determine how to obtain information.

Cultural and familial experiences also influence how an individual behaves and communicates with healthcare providers to implement treatment plans for child and family. Family behavior towards healthcare providers and treatment was of importance in the present study. The study took place in a large, urban, metropolitan area at an autism intervention center. As part of the agency mission, one goal is to improve the initial family assessment between staff and families. An interview format thought to be culturally responsive was developed. The autism intervention center deemed the development of a new interview format necessary based on several factors. One factor is the continual growth of minority populations in the United States. The U.S. Census Bureau (2009) estimates by 2050 the percentage of persons classified as Asian, Hispanic, or a member of two or more races will nearly double. Other factors include cultural, societal, and communication barriers. For example, medicinal and treatment beliefs and living in a low socioeconomic status may hinder access to healthcare services. In addition, an individual speaking a language not familiar to the service provider may prevent effective communication of the clients’ needs and expectations (Chan, Lam, Wong, Fong, & Leung, 1998; Leung, 1993; Leung & Sakata, 1988; Lynch & Hanson, 2004; Mandell, Wiggins, Carpenter, Daniels, DiGuisepppe, Durkin, Giarelli, Morrier, Nicholas, Pinto-Martin, Shattuck, Thomas, Yeargin-Allsopp, & Kirby, 2009; Mandell & Novak, 2005; NACHC Community Health Corps, 2008; Palmer, 2010; Shattuck, Durkin,

The open-ended interview format was developed to conduct initial meetings between the families and staff of different backgrounds. The staff participated in a workshop on how to conduct this new interview format. As with other cultural training packages, the workshop focused on defining culture, the importance of learning and understanding culture, the unique cultural factors of a family, and how to interact with individuals in a community different from the dominant culture (Curt, 1984; Department of Developmental Services, 1997; Department of Health and Human Services, 2001; Kassebaum, 1992; Lynch & Hanson, 2009; Saldana, 2001; Washington State Department of Health, 2010). The training manual given to all participants specified how to interact with individuals in a different community and the types of open-ended questions and examples for each topic area during the interview process. The types of questions utilized came from the ethnographic interview process, a qualitative method of obtaining information utilized by anthropologists (Spradley, 1979). Ethnographic interviews use descriptive questions, open-ended questions that ask about a particular setting and allow the individual to respond in a variety of ways (Spradley, 1979). It is also suggested that a limited number of questions during the interview allows more time for the families to elaborate (Creswell, 2007). Ethnography, primarily an anthropological tool, is used in other fields as a family assessment tool to learn about the family and build rapport for a better parent-professional relationship. For example, use of ethnography for speech language pathology allows therapists to understand the cultural context in which the child
learns a language, to determine language skills, and to identify possible punishers and reinforcers of the child’s and family’s language use (Centeno, Anderson, Restrepo, Jacobson, Guendouzi, Muller, Ansaldo, & Marcotte, 2007; Dominique & Siegel, 1998; Scheffner Hammer, 2011).

In addition to directly identifying child and family needs and goals through an ethnographic interview, it can also benefit individuals by expanding their cultural knowledge and understanding. For example, Allen (2000) received feedback from participants interviewing international students for a class assignment. Participant reports indicated they increased their knowledge of other cultures and of their own, facilitated more understanding for a second culture, and increased awareness of their own beliefs, attitudes and values (Allen, 2000). In another study, Bateman (2002) had undergraduate English speakers interview foreigners about American culture. Results indicated an increased positive attitude toward individuals of the targeted community (Bateman, 2002). The benefits of cultural understanding are also reflected in training materials. For example, Terry Cross (as cited in Centre for Addition and Mental Health, 2004) recommends clinicians to acquire awareness of their own values and biases as well as the clients’ viewpoints, knowledge of other cultures, and skills to be successful with interactions between individuals of different backgrounds. Cultural understanding and competency increases with this process to meet the unique needs of a diverse population (Cross, 2008). These resources suggest the benefits for everyone understanding different cultural perspectives.
The shifting demographics in the U.S. and Texas display the ever-changing clientele for families seeking treatment. These changes prompted the intervention center to set guidelines and expectations in place to create a culturally responsive program. In an earlier study, Pritchett (2010) evaluated this autism intervention center’s progress on meeting the program mission. Data showed clients spoke a total of 12 different languages at home and a majority of families lived below poverty levels. Half of the clients were Caucasian, one-fourth were African American, and the remaining clients were Asian or Hispanic (Pritchett, 2010). However, the majority of staff was upper middle class Caucasian, spoke English and did not speak a second language. Data showed a discrepancy between client and staff demographics. This discrepancy makes cultural destructiveness and incapacity more likely (Centre for Addition and Mental Health, 2004; Cross, 2008). At the same time, training programs that address cultural understanding are likely to increase cultural competence (Cross, 2008).

This is a case study designed to evaluate an alternative family interview and a cultural training package on the behavior of service providers and families in an autism intervention program.
METHOD

Setting

The staff received training and conducted family interviews with new clients at a non-profit autism intervention center in North Texas. The autism treatment program obtains government grant funding through the Texas Department of Assistive and Rehabilitative Services (DARS) to support families. DARS funds and oversees services, education to parents and staff, and research through the collaboration with the Department of Behavior Analysis at the University of North Texas (UNT). The mission and goals of the autism intervention center are to serve the underserved, to uphold client dignity, and maintain a positive, family centered, and culturally responsive atmosphere, to provide evidence-based, effective services and service learning opportunities, and to create a lasting change (Easter Seals North Texas, n.d.). As part of that mission, DARS allocates funding to develop interview tools to increase cultural understanding and competency when interacting with parents (Easter Seals North Texas, n.d.).

Trainer and participants utilized the conference room to conduct pre- and post-training assessment probes and the training workshop. Case managers utilized the Director’s office for new family interviews, with staff and family sitting at a round table.

Participants

Case managers. Three case managers from the Easter Seals Autism Treatment Program (ESATP) participated in this study. Case Manager 1 was a 27-year-old female, self-identified as Caucasian and English speaking. She received an undergraduate degree
in psychology and a master of science degree in behavior analysis. Trainee 1 had 6 years and 9 months of experience as an applied behavior analyst. At the time of the study, the participant was a board certified behavior analyst (BCBA) for 1 year. Her experience consisted of working both in-home and center-based services, providing direct therapy on a 1:1 basis, and supervising and training staff on clients’ treatment teams. Case Manager 1 aimed to open her own center-based program for children on the autism spectrum and typically developing children within a classroom structure. Case Manager 1 recently received a promotion from case manager to lead BCBA, overseeing all case managers.

Case Manager 2 was a 30-year-old female, self-identified as Caucasian/Hispanic, fluent in English and semi-fluent in Spanish. She received an undergraduate degree in psychology and a master of science degree in psychology with a concentration in applied behavior analysis. Case Manager 2 had 9 years and 8 months of experience as an applied behavior analyst. At the time of the study, the participant was a BCBA for 7 years. Her experience consisted of developing and implementing treatment programs for children with developmental disabilities, including on the autism spectrum, children and adults with traumatic brain injury, and children transitioning from a group home to a less restrictive environment. Case Manager 2 aimed to become involved in a management position and to be a self-employed consultant. She was a case manager at the autism intervention center.

Case Manager 3 was a 26-year-old female, self-identified as Caucasian and English speaking. She received an undergraduate degree in psychology and a master of science degree in Behavior Analysis. Case Manager 3 had 4 years of experience as an
applied behavior analyst. At the time of the study, the participant had not completed the examination to receive her certification as a BCBA. Her experience consisted of direct 1:1 therapy with children with autism, sibling and parent training, and staff supervision and training goals. Case Manager 3 aimed to manage a team of ABA therapists in an intervention center setting. She was a case manager at the autism intervention center.

Trainer. The primary trainer was a female, senior graduate student in the Department of Behavior Analysis at UNT. She was 25 years old and self-identified as Caucasian/Hispanic, English-speaking, and understood and spoke some Spanish. The trainer was a junior applied behavior analysis coach at the autism intervention center for 1 year and 8 months.

The graduate advisor oversaw program development and was present during the workshop. She was an associate professor in the Department of Behavior Analysis at UNT. She had 30 years of experience working as an applied behavior analyst, working directly with children, families, and staff. She self-identified as Asian/Caucasian and speaks English, Spanish, and understands a limited amount of Farsi. The director of the autism intervention program assisted in overseeing the development process of the new interview format and training and was present during the workshop. The director is a Caucasian female with a master of science degree in behavior analysis from UNT.

Participants contributed to the study to improve the interview tool used with families.

Families. New family members entering the autism treatment program participated in the pre- and post-training interviews with consent. All families received the opportunity to participate regardless of cultural background, education,
socioeconomic status, and English language proficiency. Participating families ranged from ages 25 to 45 years old. Families consisted of different races and ethnicities: African American, Asian, White, Filipino, Indian, and Hispanic. All families had one child receiving treatment for 1 to 2 weeks prior to the interview.

Materials

A Flip© camera recorded all pre- and post-training interviews and scenario probes and stayed at the autism intervention center. A password-protected computer in a locked laboratory room in the Department of Behavior Analysis at UNT held all interview recordings and data. A password protected USB drive saved all recorded interviews for transference from the autism intervention center to the password-protected computer. The trainer and observers received a datasheet and writing utensils for each interview recording. Participants during the training workshop received and kept a training manual for personal use (see Appendix A).

The pre-training performance assessment, the workshop, and the post-training performance assessment utilized family simulation scenarios for assessment and practice (see Appendix B). The family simulation scenarios contained families from a mix of ethnicities, education, and socioeconomic backgrounds. Family simulation scenarios included background information, such as place of birth and upbringing, and communication style of a family member. Each phase of the study had a similar mix of family simulation scenarios for assessment and practice.
Measures

The measurement system assessed types of verbal behaviors of the case managers and family during the interview process. The trainer adapted types of questions posed to participants by Spradley (1979). The trainer adapted interviewer responses by Blell’s supportive communication training workshop (Blell, 2010).

*Verbal behaviors.* Observers scored three major areas of verbal behavior: interviewer questions, interviewer responses, and family topics. Interview questions included the grand tour, mini tour and example, experience and strict inclusion, native language, means-end, rationale, and other questions (see Table 1). Interviewer responses included acknowledgement, supportive response, non-supportive response, other comments and introductions, and program information (see Table 2). Family topics included family life, family values, family support and challenges, child strengths, program expectations, family and child goals, and other (see Table 3).

*Recording procedures.* Participants used a Flip® camera to record the interview. Participants explained to families the rationale for recording and changing the initial interview format. Participants received verbal permission from the family before recording.

*Interobserver agreement (IOA).* Two independent observers scored the interviews. The trainer scored all interviews for each case manager. Another observer scored one interview in every condition for each case manager. Both observers practiced reviewing the code and watched videos together. The code defined types of interviewer questions, interviewer responses, and family responses. The code provided an example
conversation and blank datasheet (see Appendix C). The trainer calculated IOA scores by dividing the smaller frequency count by the larger frequency count then multiplying the answer by 100. Average IOA for type of interviewer questions was 83%, for interviewer responses was 82%, and for family responses was 65%.

Procedure

*Baseline.* Participants conducted initial family interviews with parents new to the autism intervention program. Participants recorded the initial interview and conducted it utilizing the standard agency interview format. Participants explained to families about the project to improve initial parent-professional meetings. Each participant conducted a pre-training performance assessment. It was a role-play interview with the trainer 1 to 2 days before the training workshop (see Appendix D). All trainees conducted the interview utilizing the standard agency interview format. The trainer role-played as the new parent and the participant as the interviewer. The pre-training performance assessment probe determined types of questions asked and amount of family and child information obtained.

The existing interview format was a 5-page, 72-item document of questions for staff to utilize during the interview. Participants questioned families regarding four domains: pregnancy/birth history, medical/childhood history, rapport and communication, and play and preferences. The first domain, pregnancy and birth history, required information such as the obstetrician’s name, complications with the child before and after pregnancy, and the overall health of the child after birth. The second domain, medical and childhood history, required information such as childhood milestones and
possible medical treatments and diagnoses. The third domain, rapport and communication, required information such as if the child can communicate to family members in certain situations, the emotional response to certain situations, and what kinds of things make the child upset or happy. The fourth domain, play and preferences, required information such as preferences on toys and games, things that the child does not enjoy, and the duration of play with individuals. The interview format consisted of closed-ended questions sufficiently answered with a yes or no, dates, based on a likert scale, and open-ended questions (see Appendix E).

*Training workshop.* Case managers participated in a group training session during a four-hour period with a lunch break in a single day. The presentation provided a description of the roles in a family context, the intervention context with autism and culture, and how to create a responsive relationship and meaningful conversation with the family. The trainer reviewed the manual with the participants, answering all questions. The trainer concentrated on types of interview questions, provided with a description and examples. All participants received an opportunity to role-play with the trainer utilizing the new interview techniques. All role-plays utilized family simulation scenarios different from the pre-training performance assessment (see Appendix F). To begin the initial interview, the staff also received a one-page document with a general guideline on how the interview may progress and the types of topics to be discussed (see Appendix G). The trainer informed the participants during the workshop that more than one interview might be needed to discuss all topics on the general guideline. Participants observing the role-play received a checklist and the group gave feedback to the participant conducting
the role-play interview (see Appendix H). Licensed BCBA participants received three Ethics CEU credits at the completion of training.

Post-training assessment and interviews. Post-training performance assessment probes and interviews determined whether there was a change in type and amount of information obtained using the new interview techniques. Post-training interviews utilized family simulation scenarios different from the pre-training performance assessment and training workshop. (see Appendix I). The trainer reviewed the feedback checklist results with the participants, discussing areas of strength and areas for improvement. Participants conducted initial family interviews with parents new to the autism intervention program utilizing the modified agency interview. At end of the interview session, participants asked new families to complete a questionnaire regarding the interview process (see Appendix J). Participants who completed the questionnaire were anonymous and returned it to the intervention center at a later date (see Table 4).

Experimental design. A pre-post treatment design with in vivo simulation probes before and after training was used to assess the effects of the workshop on the verbal behavior of the participants and parents.
RESULTS

Data were tabulated and analyzed in order to evaluate the effects of training on the rate and frequency of responses (Figure 1), interview duration (Figure 2), interviewer questions (Figure 3), family responses (Figure 4), and interviewer responses (Figure 5). Data analysis for one phase of the study was unavailable for Case Managers 1 and 2. Technology issues prevented the video retrieval for Case Manager 1 during baseline interview phase. Case Manager 3 accepted another job opportunity prior to completing the post-training interview phase. Case Manager 2 completed all interview phases of this study.

Figure 1 displays rate of interviewer questions and frequency of family responses for each interview conducted in all phases. In general, the data illustrated a decrease in rate of questions per minute after training for all participants. During baseline interviews, however, questions occurred at a variable rate. Case Managers 2 and 3 each conducted one interview with a low rate of interviewer questions. Case Manager 2 delivered a rate of 1.06 questions per minute. Case Manager 3 delivered a rate of 1.07 questions per minute for the first baseline interview. However, Case Manager 3 delivered 4.17 questions per minute for the second baseline interview. Baseline scenario probe across participants showed high rates of questions per minute. During baseline scenario probe, rate of questions ranged from 3.52 to 5.41 questions per minute. Data illustrated a decreased rate of questions per minute for the post-training scenario probe across case managers. Case Manager 1 decreased the rate of questions from 4.82 during baseline
scenario probe to 0.64 during post-training scenario probe. Case Manager 2 decreased the rate of questions from 3.52 during baseline scenario probe to 0.9 during post-training scenario probe. Case Manager 3 the decreased rate of questions from 5.41 during baseline scenario probe to 1.81 during post-training scenario probe. The rate of questions remained low during post-training interview, ranging from 0.65 to 0.87 questions per minute.

The frequency of family responses varied across all phases. During baseline interview and scenario probe, frequency of family responses ranged from 110 to 587. During post-training interview and scenario probe, frequency of family responses ranged from 79 to 225. However, since rate of interviewer questions decreased after training, the interview contained mostly family responses.

Figure 2 displays the interview duration in minutes for each participant and interview conducted in all phases. Overall, interview duration decreased after training for all participants. Baseline interview duration ranged from 25.2 to 74.65 minutes. Case Manager 3 conducted two interviews with a significant difference in duration. Duration of interview one was 64.35 minutes and interview two was 25.2 minutes. After training, interview duration ranged from 27.23 to 49.58 minutes. Baseline interview for Case Manager 2 lasted 74.65 minutes and decreased to 32.33, 33.83, and 49.58 minutes in post-training phase, respectively.

Scenario probes showed a difference in duration for Case Managers 2 and 3. Case Manager 2 decreased interview duration from 33 minutes to 16.75 minutes. Case
Manager 3 decreased interview duration from 23.83 minutes to 13.25 minutes. However, Case Manager 1 had similar interview duration for baseline and post-training interview.

Figure 3 displays the number and type of questions posed by each participant in all interviews and phases. The number of closed-ended questions significantly decreased after training for all participants. During baseline interview, the number of closed-ended questions ranged from 65 to 100. During baseline scenario probe, the number of closed-ended questions ranged from 64 to 122. During post-training scenario probe, the number of closed-ended questions ranged from 4 to 17. During post-training interview, the number of closed-ended questions ranged from 11 to 29. The number of open-ended questions remained in a small range of 3 to 9 questions in an interview before and after training. Participants did not ask other questions in all phases.

Figure 4 displays the number and type of family responses for each participant in all phases. Overall, family members responded to the majority of questions with family functioning information, before and after training. During baseline interview, the number of family responses for family functioning ranged from 148 to 579. During baseline scenario probe, the number of family responses for family functioning ranged from 106 to 235. During post-training probe, the number of family responses for family functioning ranged from 68 to 102. During post-training interview, the number of family responses for family functioning ranged from 40 to 210.

Child goals responses increased after training for Case Managers 1 and 2. During baseline interview, child goals responses ranged from 0 to 22. During baseline scenario probe, child goals responses ranged from 4 to 11. During post-training scenario probe,
child goals responses ranged from 6 to 18. During post-training interview, child goals responses ranged from 10 to 97. Other information was minimal or zero, with the exception of baseline interview for Case Manager 2. During baseline interview, other ranged from 0 to 69.

During baseline and post-training scenario probe, all case managers received 0 other from the family. During post-training interview, other ranged from 0 to 3. The third post-training interview with Case Manager 2 illustrated more than double the number of child goals responses than family functioning. Case Manager 2 received a significant amount of other responses not related to the child and family in the baseline interview. This interview also received the most amount of family functioning information than all of the other interviews, before and after training.

Figure 5 displays the number and type of interviewer responses for all participants. The number of acknowledgements decreased after training across all participants. During baseline interview and scenario probe, number of acknowledgements ranged from 71 to 180. During post-training interview and scenario probe, number of acknowledgements ranged from 15 to 60. Number of supportive responses remained in a similar range for the participant in all phases, with the exception of Case Manager 2. Case Manager 2 gave 157 supportive responses in baseline interview, in comparison to 29 to 58 supportive responses for scenario probes and post-training interviews. One participant emitted a single non-supportive response.

Other comments and introductions showed variable results. Case Manager 1 increased number of other comments and introductions after training. For Case Manager
1, post-training other comments and introductions ranged from 12 to 15, in comparison to 0 during baseline scenario probe. Case Manager 2 varied across all phases. During baseline interview, there were 42 other comments and introductions. During baseline scenario probe, there were 0 other comments and introductions. During post-training scenario probe, there were 28 other comments and introductions. During post-training interviews, other comments and introductions ranged from 1 to 38. Case Manager 3 slightly increased other comments and introductions. During baseline interview probe, other comments and introductions ranged from 0 to 8. During post-training scenario probe, participant gave 16 other comments and introductions.

Program information increased for Case Managers 1 and 2. Case Manager 1 gave 15 program information during baseline scenario probe. During post-training scenario probe and interview, program information given was 40 and 53. For Case Manager 2 during baseline interview and scenario probe, program information was 17 and 29. During post-training scenario probe and interviews, program information ranged from 29 to 119. However, Case Manager 3 decreased program information during post-training scenario probe. During baseline interview and scenario probe, program information ranged from 13 to 28. During post-training scenario probe was 8.

Table 4 displays parent interview evaluation responses that parents received after the post-training interview from the participant. The questionnaire contained questions pertaining the interviewer, interview format, and interview questions. The family rated the questions in a scale from 0 to 7 for not satisfied to very satisfied. The questionnaire also contained open-ended questions about the best and most difficult about the
interview, as well as any additional comments from the family. All families rated questions between 5 and 7, with the exception of one question. The fourth family gave a rating of 0 to the question, “Do you feel comfortable with this number of people in the first interview?” Family 4 consistently gave a lower rating for all questions compared to Family 1, 2, and 3.

Two families reported the best thing about the interview was the participant’s understanding of the family’s needs and asking the parent what he wants achieved for his child. Two families gave differing opinions regarding what is difficult about the interview. One family felt the interview was not difficult. The second family reported it was difficult reviewing information written on the application. The second family even suggested the participant review the application before the interview. Two families also reported different comments. One family reported the participant was nice, knowledgeable, and professional. Another family believed the interview should be one-on-one, the interview should review issues and behavioral plan for child before staff background, and the meeting should not be videotaped. The family felt the interview seemed like research.
DISCUSSION

The cultural training package to teach staff at an autism intervention center was developed to support the goals and mission of this center. The new interview format and training program were an effort to create a holistic and culturally responsive experience that encompasses the goals of the autism treatment program (Easter Seals North Texas, n.d.). The autism intervention center is a rehabilitation center for children with disabilities that strives to be family centered, culturally responsive, and use evidence-based practices (Easter Seals North Texas, n.d.). The developers of the cultural training package took into consideration cultural differences and the various aspects of everyday life crucial to identify during the interview process (Beach Center on Disabilities, 2009; Ferguson & Candib, 2002; Kassebaum, 1992; Leung & Sakata, 1988; Mandell & Novak, 2005; Mandell et al., 2009; Matuszny, Banda, & Coleman, 2007; Palmer et al., 2010; Shattuck & Grosse, 2009). The training utilized in the study is both culturally responsive and open-ended. Overall, the training produced a change in social climate between the staff, between the staff and families, and the development of a participatory relationship with incoming families to the autism treatment program. More specifically, the data suggest that the new format produced better staff to parent question ratios, more open-ended questions and more elaborate family responses.

The two interview formats utilized by the autism treatment program showed consistencies in the behavior of the staff and the families. The baseline interview format showed that staff rarely, if at all, shared their background and experiences. The interview
commenced with a short introduction about the questions on the interview packet and the staff generally focused on the packet and the next question instead of the family. During questioning, the staff generally expected yes or no answers to questions. In addition, the families more than likely did not elaborate on answers or give child and family information not required by the prepared questions in the packet. With the amount of quick, yes or no questions, the staff spoke more than the parents did during the interview and for an extended amount of time.

The open interview format, however, showed more staff and families sharing background and personal experiences during the interview. With the initial open-ended introduction question, families elaborated more on their family life compared to the baseline interview format. In addition, they generally spoke more about other family topics like their goals and expectations for their child in the program. During the interview, the staff focused on the family’s responses. Based on the family’s responses, the staff asked additional questions for further elaboration. The open interview format showed the family spoke significantly more during the interview than the staff.

The cultural training workshop to teach case managers the new family interview format and techniques was successful in decreasing the rate of questions per minute and the number of closed-ended questions during initial family interviews. The training workshop reviewed the importance of cultural understanding, the family and intervention context, and the approach and skills required to develop a meaningful conversation with the family. There were also opportunities for practice of the new interview skills with participants. All attendees of the workshop had the opportunity to ask questions and
make comments throughout the workshop. The purpose of the training and new interview format was to increase understanding of family life as well as creating and maintaining a positive attitude in the parent-professional relationship (Allen, 2000; Bateman, 2000; Spradley, 1979).

Data obtained from the study revealed changes in rate and frequency of questions, duration of the interview, types of interview questions, the types of family responses, and the types of interview responses. Families had a lower ratio of responses per minute after training. Other findings showed decreased interview duration after training, with the exception of Case Manager 1 during scenario probes. Discussion of child goals increased somewhat after training and the number of acknowledgements from participants decreased after training with an increase of program information. Family functioning remained the main area of conversation for families pre- and post-training, with the exception of the third interview for Case Manager 2. The number of open-ended questions asked remained the same before and after training. The number of open-ended questions is close to the suggested number proposed by Creswell (2007) for an open conversation with families during assessment. The findings are to be considered preliminary due to the small number of participants and the lack of pre-/post-data for all participants in the actual family situations.

By using the open interview format, current and future staff members and families of the autism intervention center will more than likely maintain a short duration for the family interview. Another positive outcome of using this tool is the significant decrease of the staff member speaking throughout the entire interview. The family had additional
time throughout the interview process to elaborate on family topics without too many responses or initiations to different topic areas from the interviewer. With the use of the open-ended interview format, family increased the amount of time speaking about child goals. Obtaining more child goals information is beneficial for the case manager and family to begin a participatory relationship and create a treatment plan valuable for the child and family. The current study revealed helpful information for the use of the open-ended interview format.

Other anecdotal changes were noted. For example, with the new interview format, one mother described her own father’s behavior and a possible diagnosis of autism based on current symptoms of ASD. She elaborated by stating she thought his behavior was normal for him and was not a concern. She stated she currently understands the behavior and traits of autism her father emitted. She also spoke of her older children and described their current goals and future plans. The previous interview format would have gleaned little information in this important area. The previous interview format inquired how the child in the program interacts with siblings, compared to creating an open conversation where the family can describe the siblings, the interactions and what is important to them. In another example, staff reported changes they felt had occurred as a result of the cultural training. Case Manager 1 stated she liked the new format and felt she can better learn to understand families. She also reported using the techniques from the workshop with a personal acquaintance and said that her acquaintance thanked her for a great conversation by the end of the evening. Both of
these examples illustrate the possibility of shifting from cultural incapacity to cultural competency (Cross, 1988).

As a case study in the process of researching and discovering what is beneficial for families and professionals to create a participatory relationship, it is helpful to review aspects of the study design. For example, all participants were familiar with the trainer before training. Two of the three participants were coworkers and school companions in the Department of Behavior Analysis program at UNT. The trainer associated with the two participants during classes and outside social events. Further investigation may prove to be of assistance to modify aspects of the study and clarify concerns. For example, data showed areas of discussion by the family slightly shifted after training. However, it would be beneficial to break down the topic of family life. Family life is a broad category and would be useful to determine what areas of family life the type of interview format gleans from the family.

Another consideration are the scenario simulations. The scenario simulations involved only one person from the family unit. Participants practiced the new interview format on a one-on-one basis with the trainer. One-on-one interviews are not representative of all family interactions at intake. In the future, scenario simulations may include more than one family member of different cultures, family dynamics, and other influential factors. Several scenario simulations contained personal background information on the trainer’s friends and family. It is possible the trainer performed the role of the family member and friend with closer accuracy than other simulations. Other scenario simulations involved family members the participants knew from a previous
parent-professional relationship. It is a possibility the participants changed their behavior to better accommodate the family role based on prior knowledge. Continued study would be useful because of the lack of pre- and post-data for all participants.

A longer workshop might prove to be beneficial for all participants than the 4-hour workshop in this study. Interestingly, during the open-ended introduction, individuals spent the majority of time speaking about their own family background and dynamics. All staff shared unknown cultural background information, despite the years of supposed familiarity between all individuals attending. This was a result of beginning the workshop with open-ended questions. Extending the workshop duration would leave the participants ample time to freely speak more about their backgrounds and understand each other better. More workshop time would also provide the participants the opportunity to practice the interview techniques with more than one family simulation card. Participants had sufficient time to practice the new interview techniques one time during the workshop in the current study.

Data collection is also important to understand the effects of training. A concern during the study was filming and technology issues when retrieving data. The trainer’s work schedule prevented her from setting up the camera and overseeing possible complications at the autism intervention center. Unfortunately, some recorded interviews are incomplete. Lack of sufficient memory space on the camera hindered complete recording. The trainer coded all interviews despite incomplete interviews. Another technology concern was the corruption of an interview file. The corrupted file prevented Case Manager 1 from having a full data set. Other concerns are the limited number of
families available to film for all phases and lack of permission from family to film the interview. More interview recordings and families available would more than likely permit a more complete understanding of what is important to families and how to strengthen further research.

Several other issues may have impacted representativeness and analysis of the data. For example, staff received new caseloads based on availability at the center. This created an uneven number of interviews in each phase for all participants. Another concern was staff meeting with the family prior to the interview. The family may have previously provided information to the staff during the filmed interview for this study. Families received an opportunity to stay at the intervention center to observe their child and ask further questions during their stay. At times, the recorded interviews were not representative of a true first meeting interview between the family and service provider.

Modifications to the training program may also improve the development of the interview process with parent interactions. One suggestion is to include video models of interviewers utilizing the new interview format and techniques. Future training packages may use multiple exemplars of interviewers from various backgrounds to show how different communication styles are effective.

Finally, it would be beneficial to include measures of outside evaluators of the staff’s cultural competency and open nature of the interactions (Quinn, Sherman, Sheldon, Quinn, & Harchik, 1992). One suggestion is to include independent judges to observe interviews before and after training. Judges may rate on the appearance of a negative or positive affect for the staff and families. Observers may rate based on the
types of questions used, the interaction atmosphere between the staff and families, and the overall conversation. Another suggestion for improved analysis is to increase confidence in IOA through revising verbal behavior definitions. Accuracy of frequency of verbal information may improve through this method.

This study presents an initial evaluation of a training package that addressed cultural understanding and communication with families. The training package was paired with an ethnographic interview format (Creswell, 2007; Spradley, 1979). This was compared with a more typical approach to initial family assessments used in autism (Ozonoff et al., 2005). The agency participating in the study has a stated mission that is important for service providers to understand the family’s background to provide quality service for their child and family (Easter Seals North Texas, n.d.). Family understanding begins with the first family interview. The family can determine and set expectations and goals for the child and family environment. All families are unique and the development of an open, connected interview format may be only the beginning of a healthy parent-professional relationship. Hopefully, this data contributes toward that end.
Table 1

*Types of Interviewer Questions*

<table>
<thead>
<tr>
<th>Type of Question</th>
<th>Brief definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grand tour</td>
<td>Open-ended question about what usually occurs with people, events, activities, objects, space and time</td>
</tr>
<tr>
<td>Mini tour &amp; Example</td>
<td>Open-ended question asking about a smaller unit of experience discussed from the grand tour or an example about a single act that has occurred or family wants to occur</td>
</tr>
<tr>
<td>Experience &amp; Strict Inclusion</td>
<td>Open-ended question asking about the family’s interpretations, feelings, and observations in a particular setting or what kinds of activities the family wants to see regarding the child or family</td>
</tr>
<tr>
<td>Native language</td>
<td>A question that asks about words or phrases the family uses to describe people, single acts, objects, and events</td>
</tr>
<tr>
<td>Means-end</td>
<td>A question that asks how the family behaves or behaviors they want see in others to accomplish a goal</td>
</tr>
<tr>
<td>Rationale</td>
<td>A question that asks the individual’s and/or family’s reasons for doing something or for someone else to do something</td>
</tr>
<tr>
<td>Closed</td>
<td>A question that can be sufficiently answered with a yes or a no or provides the family with a forced choice</td>
</tr>
<tr>
<td>Other questions</td>
<td>A question not directly related or related at all to the child and family</td>
</tr>
</tbody>
</table>
### Table 2

**Types of Interviewer Responses**

<table>
<thead>
<tr>
<th>Type of Interviewer Response</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgement</td>
<td>A general, non-specific statement or comment that denotes understanding and/or acknowledgement of family’s responses</td>
</tr>
<tr>
<td>Supportive response</td>
<td>Speaker correctly describes the family’s feelings/perspective, empathizing with their feelings/perspective, confirms/indicates what family is thinking and feeling, and/or relating their feelings/perspective to a broader context that includes a possible beneficial outcome</td>
</tr>
<tr>
<td>Non-supportive response</td>
<td>Speaker places responsibility of situation on family, by verbalizing skepticism of family’s feelings/perspective, incorrectly confirms/indicates what the family thinks or feels, or by telling the family how/what to think, feel or do</td>
</tr>
<tr>
<td>Other comments &amp; introductions</td>
<td>Comments not related to the child and family, and interviewer introductions about the interview process, program, and personal background</td>
</tr>
<tr>
<td>Program information</td>
<td>Comments about the entire treatment program or comments about family’s child in the program</td>
</tr>
</tbody>
</table>
Table 3

*Types of Family Topics*

<table>
<thead>
<tr>
<th>Type of family topic</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family life</td>
<td>What has occurred with the family and child from pregnancy to current time, family background of parents and child, stories related to family, and family members who contribute to the wellbeing/life of the child and family</td>
</tr>
<tr>
<td>Family values</td>
<td>Family beliefs and values, what the family holds true or is important, and the interactions and observations on how people treat the child and family</td>
</tr>
<tr>
<td>Family support &amp; challenges</td>
<td>What or whom assists or does not assists the family currently with their needs and any challenges the family faces that needs extra attention</td>
</tr>
<tr>
<td>Child strengths</td>
<td>What the child can do at anytime of their life that is beneficial for the individual</td>
</tr>
<tr>
<td>Family &amp; child goals</td>
<td>Goals the family wants to accomplish for their child and family either with or outside of the program. Responses may include what the family wants to see for the child and family</td>
</tr>
<tr>
<td>Program expectations</td>
<td>Expected or unwanted progress and changes for the child and family through the program and expected communication style with staff; can include questions from the family to the professional staff</td>
</tr>
<tr>
<td>Other</td>
<td>Discussion topics that do not involve the child and/or family members</td>
</tr>
</tbody>
</table>
Table 4

*Parent Interview Evaluation Responses*

<table>
<thead>
<tr>
<th>Interview features</th>
<th>Rating</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not satisfied</td>
<td>Very satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>6</td>
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<td>6</td>
<td>7</td>
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<td>7</td>
<td>7</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>6</td>
</tr>
</tbody>
</table>

| Interview format                                                                 |        |        |        |        |
|                                                                                   | F1     | F2     | F3     | F4     |
|                                                                                   | 7      | 7      | 7      | 6      |
|                                                                                   | 7      | N/A    | 6      | 5      |
|                                                                                   | 3      | 2      | 1      | 2      |
|                                                                                   | 7      | 7      | 7      | 0      |

| Interview questions                                                               |        |        |        |        |
|                                                                                   | 7      | 7      | 6      | 5      |

*(table continues)*
Table 4 (continued)

<table>
<thead>
<tr>
<th>Interview features</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not satisfied</td>
</tr>
<tr>
<td>Rating</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interview questions</th>
<th>7</th>
<th>7</th>
<th>7</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel the questions will help staff your child?</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Were all important topics covered by these interview</td>
<td>5</td>
<td>7</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>questions?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Best thing about the interview was: CM 3 was very understanding of our families needs. That I was asked specific questions about what I would like achieved for my child.

Most difficult thing about the interview was: Nothing was difficult about the interview process. Having to review information that was already provided in the application. The interviewer should have read my child’s application first.

Comments: She was really nice, and knows, has knowledge on the autism spectrum. Very professional. I believe the first interview should have been one on one. I believe the program overview, behavioral plan for my child addressed/introduced…and appropriate staff background then given. The meeting seemed like more like research. I don’t think it should have been videotaped.
Figure 1. Rate of interviewer questions and frequency of family responses for each interview conducted by participants in all phases.
Figure 2. Duration in minutes for each interview conducted by participants in all phases.
Figure 3. Frequency of interviewer questions by type for each interview conducted by participants in all phases.
Figure 4. Frequency of family responses by type for each interview conducted by participants in all phases.
Figure 5. Frequency of interviewer responses by type for each interview conducted by participants in all phases.
2011
ESATP Family-Case Manager Conversation Guide

Megan Thompson, Shhla Ala’i-Rosales,
Nicole Zeug, Jennifer Fressen
Easter Seals of North Texas & University
of North Texas
6/29/2011
Special thanks is extended to
Dr. Jesus Rosales-Ruiz, Dr. Alicia Re Cruz, Dr. Paul Leung,
Ms. Kellyn Johnson, Ms. Laura Bierck, and Ms. Mona Al Haddad
for invaluable effort, feedback and guidance.
ESATP Family-Case Manager Conversation Guide
Overview of Initial Meeting Protocol

East Seals Autism Treatment Program Mission
To provide a comprehensive program utilizing evidence-based practices
that is culturally responsive and collaborative in nature,
for families from all income levels.

The first meeting is designed to begin a collaborative and responsive relationship between the family and the ESATP case manager. Our purpose is to get to know one another: to hear the family’s stories, understand their dreams, concerns and values and to also share our experiences and background.

It is important that the interviewer enter the meeting with compassion, kindness, a sincere desire to get to know the family and a willingness to work towards identifying and meeting the child’s individualized goals. This is a sensitive period in the family’s life and response to the involvement of the case manager will vary. Each family’s experiences with intervention, their response to the diagnosis, their beliefs about disability and their action-orientation will affect how families behave. Your job is to converse with the families and form a starting point to understand needs and options for the child you are serving.

There are three important points to take into consideration before every meeting:

- **Knowledge and awareness of family and cultural differences is a strength.**

  Understanding of families will assist you in better serving the family and child. Family lifestyles change and adapt to what is going on around them. The ability to understand and communicate with families builds creativity in interacting with families.

- **Understanding families is a continual process that takes practice over time.**

  Unfortunately, one-time training will not create a completely culturally competent and sensitive individual. However, with practice and an awareness of one’s understandings and biases, an individual can better understand families’ wants and needs and grow into a cultural competent service provider.

- **Obtaining important family information may take more than one meeting.**

  Every family is different in how and what they communicate. Families’ needs also change. It is okay not to get everything at one time. The goal is to start a relationship with the family in order to help the child. The family members should feel comfortable without feeling obligated and forced to divulge information.
Starting

Remember the key to getting to know the family is to ask about stories of the family and child. It is important to create an environment where the family is comfortable sharing both the joys and tribulations of life. Telling stories may illustrate the families’ responses to particular pleasant or traumatic events. Stories describe how the child is unique and can help focus on the more positive aspects of the child’s behavior, not the negative impact of the disability.

All three components are interconnected for each family. One area may determine how the family raises their children or the expectations for each family member. Be sensitive to each family’s unique traits. Focusing on one component area will create biases and stereotypical expectations.

3 major components to consider for each family
- Gender
- Ethnic and cultural background
- Socioeconomic status

The Conversation

Greet family with respect, warmth, and friendliness. Introduce yourself by first and last name, as well as your position in Easter Seals. Formally (Mr., Mrs.) address the family unless they ask you to address the differently. The interview room should be comfortable and conducive to conversation (e.g., a small table with 4 or 5 chairs). Invite the family to interview room, making small talk if you are comfortable ("The weather is beautiful", "This is our new gym", etc.). Invite the family to take a chair and offer them refreshments (coffee, water, tea, juice). After getting refreshments, choose a seat to begin a comfortable conversation.

The form to the right is the parent orientation packet and is meant to provide information for this first meeting.
Meeting the family. Amongst different cultures and families, direct eye contact, physical contact, and even expressing happiness at a sensitive time may or may not be acceptable. It is understandable that you may not have extensive information on every family's cultural background. A good tip is to follow the family's lead and be responsive. It is helpful to look at the high/low context communication guide and see where the family might fit. Respond in kind and then adjust your responses based on your observations of the family's comfort. Below are examples of different families behaving in a particular fashion, possible reasons for their behavior, and a suggested way for the interviewer to respond.

### Family uncomfortable and quiet at greeting

<table>
<thead>
<tr>
<th></th>
<th>Family 1</th>
<th>Family 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family not yet</td>
<td>Family not yet comfortable with new people</td>
<td>Family wants a more friendly and talkative</td>
</tr>
<tr>
<td>comfortable with</td>
<td>and/or environment</td>
<td>environment</td>
</tr>
<tr>
<td>new people and/or</td>
<td>Low amount of small talk until family</td>
<td>Average/high amount of small talk</td>
</tr>
<tr>
<td>environment</td>
<td>responds differently</td>
<td></td>
</tr>
</tbody>
</table>

### Minimal eye contact

<table>
<thead>
<tr>
<th></th>
<th>Family 1</th>
<th>Family 2</th>
<th>Family 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sign of respect</td>
<td>Sign of respect</td>
<td>Gender roles</td>
<td>Uncomfortable with topic</td>
</tr>
<tr>
<td>Continue with</td>
<td>Continue with conversation</td>
<td>Speak with dominant family member</td>
<td>Change to a different, more comfortable topic</td>
</tr>
<tr>
<td>conversation</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### One family member speaking for entire group

<table>
<thead>
<tr>
<th></th>
<th>Family 1</th>
<th>Family 2</th>
<th>Family 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender/Cultural Roles</td>
<td>Gender/Cultural Roles</td>
<td>Family member has more information on child</td>
<td>Others uncomfortable speaking with professional</td>
</tr>
<tr>
<td>Converse with main</td>
<td>Converse with main speaking family member</td>
<td>Continue speaking and posing questions to all</td>
<td>Continue speaking and posing questions to all</td>
</tr>
<tr>
<td>speaking family</td>
<td></td>
<td>members</td>
<td>members</td>
</tr>
<tr>
<td>member</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Explaining Interview Purpose**

"The main reason for this meeting is so that we can get to know you and your family better and so that you can learn more about ESATP. By doing so, we can all work together to help Kayon. We would like to understand what you experience day to day and what you would like your child to experience in our program."

Thank the family for coming to Easter Seals to meet and let them know that you look forward to working with their child. After that you will want to explain the purpose of the meeting. Inform the family member(s) Easter Seals wants to get to know the family better and what they experience day to day. Easter Seals also wants to understand what goals the parents have for their child and what issues need to be addressed to better serve the family.

**Explain to the family member(s) Easter Seals wants to create interactions that build rapport and increase responsiveness to the unique background and experience of each family.**

 arabian women in the middle east

"We would like to create an open conversation so that you are comfortable sharing your family's goals and values. It is important to us to build a relationship so we can work together to help your child. We will use the information from the Family Conversation to inform the intervention program for your child and family."

**Recording Explanation**

"We also like to take notes during the interview and video record the meeting. The video recording will help and allow us to go over any information that we missed and we can share the information with the staff working with your child. Are you comfortable with us video recording the interview?"

Tell the family member(s) that you, the interviewer, will be taking notes and recording. Be sure to let them know that the video and notes are confidential and only staff related to your child’s case would have access to the information. Be sure the family is comfortable with the interview process before beginning. The family should fill out the video release form before or after the conversation meeting.
Introduction

Begin with introductions, starting with you and going around the table so everyone has an opportunity to introduce themselves. Describe your background in education and work experience in the field of autism intervention services. You may also describe your family background (where you grew up, languages spoken, your family heritage). The family may cover discussion areas from the agenda during the family introductions. It will be important to listen and work with what they brought up as a starting point. Try not to ask questions that have them repeat what they have already shared. Be sure to encourage sharing of pictures as this might increase comfort initially and help you have a fuller understanding of the family.

Topic Elaboration

Any discussion area that was not covered or needs elaboration may then be addressed. What follows in the next few pages are strategies for increasing the chance that you will have an open and informative conversation. In general, you will want to ask general questions and be a responsive listener to their replies. Be careful of giving family specific examples of each topic. Reiterate to the family if they have any concerns to feel free to state them. Attempt to stay with the natural flow of conversation. Encourage the family member(s) to speak freely and expand on what they say. Pay attention to what discussion areas have been covered so the family does not repeat themselves. The conversation does not have to go in order of the ESATP Family Conversation Guide but according to what the family talk about and how you follow up the responses.

"We can start by all introducing ourselves. I can start and then we can go around the table. I am Meglan Rojas. I have work with children with autism for the last nine years. I was trained at the University of North Texas and am a Board Certified Behavior Analyst. At Easter Seals I am case manager for seven children and their families. I am very happy to be working with Kavon. Here is a picture of me with our intervention team.

I will share a little bit about my family. My dad's family is from Pittsburgh. His grandfather was a coal miner and emigrated from Scotland. My mom is from El Salvador and moved to the United States when she was 24 years old. English is her second language and I think that has affected how I learned English. It is also why I am interested in understanding how we can have our interventions work in harmony with each family. Here is a picture of our family El Salvador and our family in Dallas."

We have stories to tell, stories that provide wisdom about the journey of life. What more have we to give one another than our 'truth' about our human adventure as honestly and as openly as we know how?

Rabbi Saul Rubin
There are ways to gather information from the family that are non-judgmental and leave the responses open for elaboration. There are also ways to avoid overwhelming the family and stopping the flow of information. The goal is for the family to provide thoughtful and relevant responses and not one-word answers. Below are definitions and examples of open-ended and structural questions for each topic from the ESATP Family Conversation Guide.

**Open-ended questions**

- **Grand tour**
  - A description of how things usually are.
- **Mini-tour**
  - Identical to grand tour question but asks a more specific unit of experience.
- **Example**
  - An example of a specific act or event.
- **Experience**
  - Ask for experiences of a particular event. It is best to ask after numerous grand-tour and mini-tour questions.
- **Native-language**
  - Asks about commonly used terms and phrases. Used to minimize influence of interviewer's translation competence.

**Descriptive questions are broad and general. They do not allow for one-word answers. There are different types of descriptive questions that will allow the family to elaborate.**

**Structural questions**

- **Strict-inclusion**
  - How a person organizes information.
- **Means-end**
  - Gathers information on behaviors.
- **Rationale**
  - Gathers information on causes of or reasons for behavior.

**Structural questions are used to explore descriptive questions. Listen to any reoccurring issues and words to follow up on.**
"You don't choose your family. They are God's gift to you, as you are to them."
— Desmond Tutu

"All our dreams can come true, if we have the courage to pursue them."
— Walt Disney

"The purpose of life is a life of purpose."
— Robert Byrne

"Tell me and I'll forget, show me and I may remember, involve me and I'll understand."
— Chinese proverb

"Other things may change us, but we start and end with family."
— Anthony Brandt

"Happiness is not in our circumstance but in ourselves. It is not something we see, like a rainbow, or feel, like the heat of a fire. Happiness is something we are."
— John B. Sheerin
Increasing understanding and comfort

- Restate what client says
- Summarize parent's statements and give them an opportunity to correct you
- Ask for use instead of meaning
- Nonverbal

What to avoid when asking questions

- Allow time to respond
- Avoid using why questions
- Avoid using yes or no questions
- Avoid multiple questions
- Avoid leading questions

Meeting summary and closing comments

Wrap up the conversation meeting by thanking the family for taking the time to come to the clinic and telling us about their family life and trusting us with the information. Ask the family if they have additional questions or comments.

Parent Suggestions and Feedback

We are continually striving to enhance the way we work with families and it is important to get feedback from the parents on the process and outcomes. Offer the feedback form with instructions and encourage them to provide any additional thoughts on the back of the paper or at anytime with staff.

Farewell

Thank family for taking the time to speak with you and helping Easter Seals improve the parent interview process. Inform family Easter Seals staff is available to answer additional questions and address concerns. Walk with family to entrance of center to bid farewell.
### Family Life and Values

<table>
<thead>
<tr>
<th>Structural Questions</th>
<th>Example</th>
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<tbody>
<tr>
<td><strong>Grand tour</strong></td>
<td>~ &quot;Tell me about your family life.&quot;</td>
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<tr>
<td></td>
<td>~ &quot;What is a typical daily routine for you?&quot;</td>
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<td></td>
<td>~ &quot;What was your experience with the autism diagnosis?&quot;</td>
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<tr>
<td><strong>Mini-tour</strong></td>
<td>~ &quot;Could you describe what usually happens during family time outside of the home?&quot;</td>
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<tr>
<td></td>
<td>~ &quot;What was your mother's reaction to the doctor's report?&quot;</td>
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<tr>
<td></td>
<td>~ &quot;What usually happens during dinner time?&quot;</td>
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<tr>
<td><strong>Example</strong></td>
<td>~ &quot;Can you give me an example of when your child becomes aggressive while in public with the family?&quot;</td>
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<td></td>
<td>~ &quot;Can you give me an example of his tantrums that happen at church?&quot;</td>
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<td></td>
<td>~ &quot;What kinds of things does your child do that bring a smile to your face?&quot;</td>
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<tr>
<td><strong>Experience</strong></td>
<td>~ &quot;What was Ramadan like for your family?&quot;</td>
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<td></td>
<td>~ &quot;You say that you had to modify your name when you moved here. What does your name mean and did you change it for a particular reason?&quot;</td>
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<tr>
<td><strong>Native-language</strong></td>
<td>~ &quot;What are special names you call one another?&quot;</td>
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<td></td>
<td>~ &quot;What are the names of your religious days and gatherings?&quot;</td>
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<tr>
<td><strong>Strict-inclusion</strong></td>
<td>~ &quot;What kinds of family gatherings would you like your child to participate in?&quot;</td>
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<tr>
<td></td>
<td>~ &quot;What kinds of community activities would like to participate in as a family?&quot;</td>
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<tr>
<td></td>
<td>~ &quot;Would you like her to go through the Bar Mitzvah?&quot;</td>
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<tr>
<td><strong>Means-end</strong></td>
<td>~ &quot;How do your other children deal with is screams and tantrums?&quot;</td>
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<td></td>
<td>~ &quot;What do you do to make it easier to spend time as a family?&quot;</td>
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<tr>
<td><strong>Rationale</strong></td>
<td>~ &quot;What are the reasons you do not go out as much as a family?&quot;</td>
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<td></td>
<td>~ &quot;What are the reasons you feel autism is hereditary?&quot;</td>
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<td>~ &quot;Can you talk a little bit more about your feelings of conflict about staying in the states?&quot;</td>
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# Family Supports and Challenges

<table>
<thead>
<tr>
<th>Open-ended and structural questions</th>
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<tbody>
<tr>
<td><strong>Grand Tour</strong></td>
<td></td>
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<tr>
<td>~ &quot;Can you tell me about your family supports?&quot;</td>
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<tr>
<td>~ &quot;What do you usually do as a member at an autism organization?&quot;</td>
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<tr>
<td><strong>Mini-tour</strong></td>
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<tr>
<td>~ &quot;Can you tell me what you usually do during your organization's meetings?&quot;</td>
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<tr>
<td>~ &quot;What do your family's members do for you on a typical day?&quot;</td>
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<tr>
<td><strong>Example</strong></td>
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<tr>
<td>~ &quot;Can you give me an example of one of your financial concerns?&quot;</td>
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<tr>
<td>~ &quot;What is an example of a friend helping you out in a difficult situation?&quot;</td>
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<tr>
<td><strong>Experience</strong></td>
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<tr>
<td>~ &quot;Would you describe an experience you've had with transportation issues?&quot;</td>
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<tr>
<td>~ &quot;What are some experiences you have had at autism organization meetings for parents?&quot;</td>
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<tr>
<td><strong>Native-language</strong></td>
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<tr>
<td>~ &quot;What is another way you would describe being financially burdened?&quot;</td>
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<td>~ &quot;You mentioned that your family does not help. What kinds of things do they do and what would you like them to do?&quot;</td>
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<tr>
<td><strong>Strict-inclusion</strong></td>
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<tr>
<td>~ &quot;What kinds of memberships and responsibilities do you have with the autism organizations?&quot;</td>
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<tr>
<td>~ &quot;What kinds of things has your family members said about your child?&quot;</td>
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<tr>
<td><strong>Means-end</strong></td>
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<tr>
<td>~ &quot;In what ways do family members help out?&quot;</td>
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<tr>
<td>~ &quot;How does your husband deal with the lack of transportation because of volunteering with autism organizations and going to therapy?&quot;</td>
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<tr>
<td><strong>Rationale</strong></td>
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<tr>
<td>~ &quot;What are the reasons you volunteer with so many organizations?&quot;</td>
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<tr>
<td>~ &quot;What does it mean to you that your family is not helping?&quot;</td>
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## Child Strengths and Needs

<table>
<thead>
<tr>
<th>Open-ended and structural questions</th>
<th>Example</th>
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<tbody>
<tr>
<td><strong>Grand tour</strong></td>
<td>~ &quot;What are your child's strengths and needs?&quot;</td>
</tr>
<tr>
<td></td>
<td>~ &quot;Tell us about your child's relationships with everyone in the family.&quot;</td>
</tr>
<tr>
<td><strong>Mini-tour</strong></td>
<td>~ &quot;What is a typical activity like with your child and his sisters?&quot;</td>
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<td></td>
<td>~ &quot;How much does your child take care of himself during a typical day?&quot;</td>
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<tr>
<td><strong>Example</strong></td>
<td>~ &quot;What is an example of your child talking too much to people in public?&quot;</td>
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<td>~ &quot;What is an example of your child not being able to get dressed?&quot;</td>
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<tr>
<td><strong>Experience</strong></td>
<td>~ &quot;Can you describe one of the times he talked too much?&quot;</td>
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<td>~ &quot;Tell me about your experience with getting your child to go potty.&quot;</td>
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<td></td>
<td>~ &quot;Does your child respond in a way that makes you believe he understands your native language?&quot;</td>
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<tr>
<td><strong>Native-language</strong></td>
<td>~ &quot;What do you call toileting, urination, and bowel movements?&quot;</td>
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<td></td>
<td>~ &quot;What's another word you would use to describe his isolation?&quot;</td>
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<tr>
<td><strong>Strict-inclusion</strong></td>
<td>~ &quot;What kinds of advice have you gotten about what to do for your child's communication problems?&quot;</td>
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<td></td>
<td>~ &quot;What kinds of sensory difficulties does your child have?&quot;</td>
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<tr>
<td><strong>Means-end</strong></td>
<td>~ &quot;In what ways do you think your child would benefit from other therapies?&quot;</td>
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<td></td>
<td>~ &quot;What ways do you try to improve your child's communication?&quot;</td>
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<tr>
<td><strong>Rationale</strong></td>
<td>~ &quot;What are your reasons for seeking additional therapy?&quot;</td>
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<tr>
<td></td>
<td>~ &quot;What are your reasons for focusing on toilet training?&quot;</td>
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</table>
## Overall Goals for Child and Family

<table>
<thead>
<tr>
<th>Open-ended and structural questions</th>
<th>Example</th>
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</thead>
</table>
| **Grand tour**                     | ~ "What goals do you have for your family life?"  
~ "What communication goals do you have right now and for the future?" |
| **Mini-tour**                      | ~ "What do you want to see during dinner time?"  
~ "What would you like a typical day to look like if your child reached your communication goals?" |
| **Example**                        | ~ "Could you give me an example of a goal for your child when dressing himself?"  
~ "What is an example of your child spending quality time with the family?" |
| **Experience**                     | ~ "Tell me about your experience with searching for additional therapy."  
~ "Tell me about your experience with getting your son dressed in the morning." |
| **Native-language**                | ~ "What would we see/hear when your child is affectionate?"  
~ "What's another way you would describe being fulfilled?" |
| **Strict-inclusion**               | ~ "What kinds of school homework would you like your child to do on his own?"  
~ "What kinds of family activities would you like to do?" |
| **Means-end**                      | ~ "What do you want your child to do in school?"  
~ "What do you want your child to do with the family?" |
| **Rationale**                      | ~ "Why do you feel it is important to follow teacher instructions?"  
~ "Can you talk about the importance of him being able to get help if lost in a crowd?" |
### Expectations of our ESATP Program & Questions

<table>
<thead>
<tr>
<th>Open-ended and structural questions</th>
<th>Example</th>
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</table>
| **Grand tour**                     | ~ "What kinds of expectations do you have from the Easter Seals Autism Treatment program?"  
~ "What areas in your child's life do you want to improve or change?" |
| **Mini-tour**                      | ~ "What do you want to see change in your family's community activities?"  
~ "What would you like to see in a typical interaction between you and staff?" |
| **Example**                        | ~ "What is an example of how Easter Seals should interact with you in regards to your child's problem behavior?"  
~ "What is an example of not changing your child's eating habits?" |
| **Experience**                     | ~ "Tell me about your experience interacting with teachers and other interventionists for your child."  
~ "Tell me about your experience with staff changing how your child eats." |
| **Native-language**               | ~ "Can you describe what we would see if he had more community activities?"  
~ "What's another way you would describe being overwhelmed with change?" |
| **Strict-inclusion**              | ~ "How would you like us to help with dressing?"  
~ "How would you like the staff to interact with you?" |
| **Means-end**                     | ~ "In what ways would you like Easter Seals to contact you about progress?"  
~ "In what ways do you want Easter Seals to help increase family support?" |
| **Rationale**                     | ~ "In what ways will frequent food updates be helpful?"  
~ "Why would you like to concentrate on Spanish?" |
ESATP Family Conversation Guide

- Purpose of the meeting and process
- Introductions and picture sharing

Discussion Areas – Family Life

- Family life and values
- Experience regarding the diagnosis of autism
- Family supports and challenges
- Overall goals for child and family
- Specific child strengths and needs

Discussion Areas – Program

- Overview of ESATP
- Expectations of the program and questions
- Short and long term goals (child and family)
- Additional questions
- Family feedback
## ESATP Family Conversation Guide

### Introductions
- Education
- Work experience
- Family life

### Family life and values
- Members
- Daily Routines
- Special events
- Community activities
- Religious, cultural practices
- Beliefs and feelings about autism

### Family supports
- Family members or friends
- Financial
- Memberships to organizations
- Transportation

### Child strengths and needs
- Self-help routines
- Social
- Communication
- Additional therapy

### Overall goals for child and family
- Self-help routines
- Social
- Communication
- School

### Expectations of our ESATP program & questions
- Areas not to change
- Community Activities
- Communication
- Daily Routines
- Availability of ABA Case Managers and Senior Coaches

### Possible Elaboration Topics
- Undergraduate and Graduate experience, years working with targeted population, cultural background from both sides of family, languages spoken
- Who lives in household, caretakers, siblings, dressing, potty, bedtime, grocery shopping, holidays, weddings, birthday parties, going to the fair, going to the park, holidays, food, religious rituals, holiday rituals, external or internal causes of autism
- Caretakers, supportive friend(s), income, government assistance, financial assistance from family, memberships to groups for autism and/or research, transportation, available vehicles
- Performs self-help routines independently or not: potty eating, dressing, etc., easily makes friends or stays away from peers, school, conversational skills, repetitive speech, no speech, additional therapy, speech, occupational, or physical therapy
- Improve self-help routines such as dressing, eating and potty; plays with other children, approaches peers/adults; increases use of words or sentences; improve ability to do homework and follow teacher instruction
- Eating habits, food, language, going out to public events, family night out, talking with peers and adults, increase vocalizations, dinnertime, dressing, ability to email, call, or set up a meeting with ABA case manager and/or Senior Coach
Sources


APPENDIX B

FAMILY SIMULATION SCENARIOS
Family Simulation Card #1

Name: Maria Sandoval  
Age: 45  
Race: Hispanic  
Country of Origin: El Salvador  
Spoken language(s): Spanish, English

Background:

Maria is an older Hispanic woman, born and raised in El Salvador. She was raised in a financially secure family. Her father worked in an office and her mother stayed at home. Maria worked for a year in a store before going to university. She was unable to finish her education because of university closings from the civil war in the country.

She immigrated to the United States at the age of 24 and at first lived with her uncle in Houston, TX. Two of her sisters moved to the United States afterwards, while her eldest sister stayed in El Salvador and her brother moved to Canada. She learned English by taking classes and cleaned houses to pay bills. She is currently married to an Anglo-European man with three children. She moved from Houston to the DFW area three years ago. She speaks English and Spanish in the home and is a stay-at-home mom to take care of her youngest son. Her youngest son, Rory, was diagnosed with autism at 2 years of age and is currently 5 years old. Maria had Rory when she was 40 years old. Maria thought she was finished having more children, having two already. Her two older, female children are 15 and 13 years old.

It has been difficult for Maria since learning of her son’s diagnosis. She does not have any family members, that she is aware of, that have a child with a disability. Her husband tries to spend time with Rory but his job does not permit him to take extended time-off. He feels incompetent when dealing with their child and leaves much of the parenting to Maria. Her parents passed away years ago and her husband usually works 6 out of 7 days of the week. The move from Houston drastically changed the family dynamic. Before the move, her two sisters lived with her family and shared parenting responsibilities. She is now living with only her husband and children for the first time since the beginning of her marriage.

Family is very important and wishes she could be closer to them. Maria wishes she can move back to Houston to be with her family but the job opportunity her husband received gives the family more financial security and benefits. However, she struggles to understand what her child needs and how to help him. Maria drives to Houston with her children as much as possible to visit her sisters. She holds a more traditional mother role. Maria tries to clean, cook dinner, and take care of all the children to the best of her ability. She does not have anyone she feels comfortable relying on in the DFW area to watch her children or to have an in-depth conversation about what she is going through.

Maria wants her son to be able to communicate effectively his needs. She wants him to speak English so he can better communicate with other people outside of the family. Toileting is another important issue for Maria. She feels that this is a big step towards independence for her child and an issue that will help decrease her stress. Lastly, she is concerned with his eating. She wants him to be able to try new foods without a tantrum.

Her son enjoys video games, music, and playing with his family. He is very affectionate but needs extra attention on communication. Rory’s older siblings give extra attention to their little brother and attempt to give him whatever he needs, especially in cases when he throws a tantrum. His siblings enjoy playing games with him and tossing him up in the air. They also spend their afternoon time babysitting him when both parents go to the store.

Communication style:

Maria enjoys talking about her children and telling stories about their childhood. She has no problem talking about what she wants for her children. Most of the time she describes what she expects by using examples and stories to clarify her point. She respects authority figures and will listen and nod to what the therapist says. She does not ask many questions and will wait until an issue comes up to ask an authority figure about it. She does not know how to use a computer so her best form of communication is the phone.
Family Simulation Card #2

Name: Aliya Mirza
Age: 25
Race: Asian
Country of Origin: Tanzania, East Africa
Spoken language(s): Kuchi, English

Background:
Aliya was born and raised in Tanzania, East Africa in a traditional home life. Her father worked to provide for the family financially and the mother took care of the children and household. Unlike her sisters, Aliya took on the “male” role in the family when her brother moved from the country. She worked as a secretary for the Yugoslavian embassy to help her father with the bills and learned how to drive. Aliya describes her family as strict. She and her siblings were unable to date and their style of dress was conservative, with a restriction from low cut tops and no dresses above the knee.

Aliya had an arranged marriage at the age of 20 with another Muslim man and immigrated to the United States. She had her first child, Bilal, at the age of 21 and her second child, Maryam, at the age of 23. She describes her marriage as difficult because she does receive emotional support from her husband. He provides for the family by taking care of the finances but she feels he neglects his wife, children, and household chores. Aliya’s in-laws live with her and her family. Her mother in-law helps her with the children’s feeding and morning routine while Aliya takes care of everything else.

Religion is very important to Aliya. She is passionate about the Koran and the values stated in this holy book. She attempts to stay true to values of nondiscrimination of others different from herself, the protection of women and every human being, prayer for others, and charity.

Her child, Bilal, was diagnosed with autism at 3 years of age. Since discovering the diagnosis, she has devoted her life to making sure her child is comfortable, safe, and receiving all the education necessary for him to succeed. Her husband and in-laws accept the diagnosis and they support her efforts. Communication is important for Aliya. She is not concerned about particular self-help skills such as toileting as long as he can communicate his needs. She wants her child to learn her first language, Kuchi, and then English. Eating habits is another area that Aliya finds critical. She is concerned about her child receiving all the nutrients and energy needed. She will change her eating habits for her child, as longs as it is healthy and the meat is halal. Aliya wants to know more about parent training so she can implement the necessary skills at home.

Bilal enjoys watching movies and looking at pictures in books. His grandmother makes sure he is not upset and always happy. If he begins to cry, his grandmother will try to do anything to stop the crying and make him happy.

Communication style:

Aliya will speak her mind with other women and will talk about her personal life if it will help her child. She believes in not hiding information when she is receiving assistance. Any questions she asks will be about communication and increased independence. She refers to God throughout her conversation. She claims God makes things happen for a reason and it is a test of faith. She states that she puts herself in God’s arms and trusts Him in whatever happens. If Aliya feels comfortable with another woman, she may hug her or touch her hand.

Aliya is very shy with men. She may speak about her child but keep private information, such as her marriage, from a male interviewer. She will keep her eye contact to a minimum and attempt to sit as far as possible from a male interviewer.
Family Simulation Card #3

**Name:** Galina Ivanov  
**Age:** 26  
**Race:** White  
**Country of Origin:** Russia  
**Spoken Language(s):** Russian, English

**Background:**
Galina emigrated from Russia at the age of 20 to move forward in her education. She came from a family of four children and lived in a small town. She decided to move to the United States to improve her way of life. During her time in the United States receiving her education, she was unable to visit her family because of the restrictions on her student visa. She married three years later to an American born man and did not complete her education. She received her permanent residency and then her citizenship after a couple of years of marriage. Once she became a permanent resident, she made a trip to home to visit her family she had not seen in years.

Before her son was born, she was a homemaker and took care of all the household chores. Galina and her husband experienced trouble in their marriage. Galina describes her relationship with her husband during that time as rough and filled with miscommunication. Galina and her husband had financial troubles and their different communication styles only added to the stress. Three years into her marriage, her son Dmitri was born. Her marriage temporarily improved after Dmitri was born but their son’s diagnosis, at age two, created a strain on their relationship. Recently, her husband was diagnosed with bipolar disorder.

Currently, Galina and her husband are in the process of finalizing their divorce. Their communication is minimal, only discussing Dmitri’s needs, such as transportation and treatment. They communicate with Dmitri’s doctors and therapists separately. Since the separation from her husband, Galina had to find a job and is currently living in a hotel. She is now working and paying for a room weekly. She feels stressed because of the divorce, her living arrangements, and the need for treatment for her son.

Galina does not have any family in the United States to help her financially or emotionally. She tries to call her family as much as possible but does not want to burden them with all her problems. Although her estranged husband helps with Dmitri, she feels alone in the United States but does not want to leave because of the opportunities and treatment available in the country.

Galina and her husband agree increased communication skills and potty training are necessities for Dmitri and the family. They are also interested in biomedical treatments. He is on a medical intervention, chelation, and is on the Gluten Free/ Casein Free diet. Dmitri’s challenging behavior consists of lying on the ground and kicking around to escape from demands. He has moments where he appears to be extremely hyperactive, jumping around, tearing items off the wall and banging on counters. Hysterical laughing precedes these moments.

**Communication style:**
Galina appears to be exhausted and quiet mouthed about her relationship with her estranged husband. She keeps her answers short and to the point and does not expand on sensitive issues. She will give the basics about her failed marriage but feels it is not necessary for her child’s progress, unless it becomes important for his therapy. She is actively informed with current treatment for her child and will speak about other kinds of treatment.
Family Simulation Card #4

Name: Lucinda Smith
Age: 35
Race: African American
Country of Origin: United States
Spoken language(s): English

Background:
Lucinda was born and raised in Denton, TX and has lived there all her life. Her family has lived in the Denton community for three generations and is active in the community. Lucinda left the Denton area to pursue a degree in civil engineering in Austin. She met her husband in the same degree track and married after both graduated with a PhD in civil engineering. Lucinda and her husband moved back to the Denton area to be close to family. She enjoyed her experience away from North Texas but feels there is no place like Denton.

Lucinda and her family live in a predominantly white neighborhood and are financially secure. They are deeply involved in the Baptist church, attending sermons and charity fundraisers organized by church residents. Most of their social interactions involve church activities and the people who attend their church. Her son, Jackson, was born two years after completing her degree and is an only child. Jackson was diagnosed with Asperger’s at 3 years of age and was a surprise to the family. Lucinda and her husband were proactive in researching the diagnosis and the kinds of help they can provide for their son. Jackson is currently 6 years old and received in-home treatment and some therapy in the clinic for three years.

Lucinda and her husband’s mothers are involved with Jackson’s life, providing childcare and additional help. They do not live with Lucinda and her family but are near for frequent visitations and emergencies. Her husband, Charlie, works most of the time and is not as involved in Jackson’s life as Lucinda. He remains informed with Jackson’s progress but leaves most of the treatment responsibilities to Lucinda. He exhibits some behaviors of Asperger’s, such as resistance to change and difficulty in social situations.

Lucinda oversees the bulk of Jackson’s treatment program and actively searches for new programs. She is beginning to feel tired most of her day from working and helping Jackson achieve his goals. She wants more help in providing treatment and ideas to make home life easier.

Jackson has trouble with social and comprehension skills. He is unaware of what is appropriate and inappropriate to say in front of others and in what contexts. He watches peers of his age from afar but does not know how to approach them. His comprehension skills stem from lacking the ability to understand humor, such as sarcasm, and metaphors to describe something else.

Communication style:
Lucinda is guarded with her life experiences and is not comfortable speaking with unfamiliar people. She is attentive to what the service provider is explaining and will consider the provider’s explanations and comments. She will ask questions regarding her child’s progress and how the program improved skills for children on the autism spectrum. Lucinda will not contradict with the service provider openly. If she does not feel the service provider and the company will help her son and optimize his results, she will look somewhere else for better treatment.
Family Simulation Card #5

Name: Tamika Jones
Age: 19
Race: African American
Country of Origin: United States
Spoken language(s): English

Background:
Tamika was born and raised in the downtown Dallas area with her mother, grandmother and two older brothers. Her birth father rarely visits and does not financially support his family. Her mother works full-time to support her, her brothers, and grandmother. However, her mother’s job cannot support the whole family and receives government assistance. Tamika lives in a low socioeconomic area and does not associate much with other residents for safety reasons. Her family has always valued education but safety and food takes precedence.

Tamika became pregnant with her daughter, Jasmine, at 16 years old. The arrival of Jasmine was unexpected but the family successfully coped with the surprise and supported Tamika and her child. The strain on supporting an infant and the family finances forced Tamika to drop out of school and search for a job. The father of her child sporadically comes to see Tamika and Jasmine but is usually away for long periods of time and cannot be reached. Currently, she is taking night classes to complete her GED but it leaves very little time to spend with her child. She is exhausted at the end of the day.

Tamika recently discovered the doctor diagnosed Jasmine with autism. Jasmine is currently 3 years old and Tamika’s grandmother is the primary caretaker. She is the primary caretaker while Tamika and her mother are working. The family is not comfortable with others taking care of Jasmine. This leaves with the trio constantly changing schedules to accommodate everyone and Jasmine’s extra needs. Tamika has found it difficult retrieving information on what to do for her child and Tamika is grateful to have found Easter Seals. However, transportation is a major concern. Her grandmother is available to bring and pick up Jasmine for treatment sessions but the family car is old and unreliable.

Tamika wants to take advantage of this opportunity but feels like she does not have all the resources needed to help her child. She also feels hesitant to speak with service providers because she does not have enough experience speaking with clinicians and opening up on personal issues. She is worried that her age and socioeconomic status will affect how service providers will speak with her and the quality of treatment her daughter may receive.

Jasmine is very affectionate and approaches her grandmother for most of her needs. Her grandmother and mother try to attend to all her needs and attempt to make her as comfortable as possible. She loves music and dancing with her family and is always smiling. Her biggest strength is her ability to socialize with others. However, her family is concerned about her understanding of stranger danger and who not to speak to, as well as what are appropriate conversations with other people.

Communication style:
Tamika is hesitant to open up on personal issues because she feels she will be judged by the interviewer. She is very respectful to elders and will listen to any suggestions they may have. Once she is comfortable with someone, she may joke around and will talk with her hands. The service provider needs to be aware that she may be guarded about her situation. Some signs are arms folded across her chest, eye rolling, and looking upward.
Background:
Hassan was born and raised in southern Iran as the eldest son in the family. Hassan’s father was an educated man and stressed the importance of receiving a good education and career. He learned to speak Farsi, English, and sufficient Arabic to read the Koran. Hassan entered the military after completing high school. As part of his military duty, he taught children in a small village school subjects they would not have had the opportunity to learn. He describes his experience in the village as a life altering experience. He realized his love of children and a need to help children in any way possible. Available universities in Iran are difficult to enter. Acceptance from a university in Iran requires a competition of the best scores and political connections. Hassan was advised to apply for higher education in the United States.
He completed his Bachelor’s degree in mechanical engineering at Louisiana State University (LSU). During his stay at LSU, he was engaged to his wife but the long distance relationship proved to be difficult and he wanted to be married as soon as possible. His wife, Azdeh, studied in Germany for a year before receiving her visa to move to the United States. Hassan and Azdeh married after a year and half of being apart in different countries. He was unable to obtain a job prospect in mechanical engineering. Currently, he and his wife opened a successful restaurant in Denton, TX. Hassan was 25 years old when he had his first child, Sabah. It was not until nine years later their son, Mohammad, was born.
Mohammad is a 5-year-old child with a diagnosis of autism and has previously been in another treatment program. Hassan and Azdeh feel he can benefit greatly from a different environment and program. Hassan actively researching the best possible treatments for his son and spends as much time as he can with both children. Hassan is primarily in charge of the financial aspects for the family and Azdeh stays at home more frequently to take of Mohammad. The family is waiting for several family members from abroad to move in with them in Texas. Family is very important to Hassan and Azdeh but feel staying in the DFW area is the best option for their child. In the meantime, they have close family friends that help with babysitting and emotional support.
Hassan’s main concern for Mohammad is general independence. He wants his son to be able to go to the toilet, dress himself, and eat a healthy meal without too much dependence from family members to complete these tasks. Hassan would like Mohammad to communicate well enough for the family to understand his needs, but wants independence to be established. They do have an older daughter, Sabah, who is 14 years old. She helps her mother as much as possible with responsibilities taking care of her brother. Sabah is involved with Mohammad’s treatment programs and school.
Communication style:
Hassan will sit and absorb information given from the service provider. He will ask questions to be certain he is doing or saying something correctly but generally waits to see if progress occurs before speaking with the provider. He prides himself as being trustworthy. He will correct an individual if they misunderstood what he said about his opinion or ideology. He is a man who will give the service provider space and keeps his hands in his lap and to himself.
Family Simulation Card #7

Name: Phoebe Reynolds
Age: 25
Race: Anglo-European
Country of Origin: United States
Spoken Language(s): English

Background:
Phoebe Reynolds was born in a conservative family who has lived in Texas for four generations. As a child, her parents did not socialize much with others except for their children’s after school programs. She describes her childhood upbringing as accepting of others but not open-minded. She says that her parents accept differences in individuals and families but it is not right for them. She graduated from high school early and her point of view in life changed drastically. Phoebe met her husband at her first full-time job after high school. Phoebe’s husband is 15 years older and was her previous manager at work. She moved out of her parents’ house to be closer to him without parental disapproval.

Soon after Phoebe graduated from university with her Bachelor’s, she and her husband, Fred, were pregnant and married. Their son Jimmy was born early into their marriage and with welcome arms. The family discovered Jimmy’s diagnosis of autism four months ago and it dumbfounded the family. Autism does not run on either side of the family and Phoebe wondered if she did something wrong or could have done something to prevent it. She is frustrated with the situation. She does not understand the diagnosis or what she can do to help her child. Her mother is willing to help with whatever she needs but the rest of the family is detached because of a lack of understanding.

Phoebe and Fred have financial difficulties that affect their family life and available treatments. Fred lost his job and unable to obtain another managerial position for two years. Phoebe works at the Fort Worth zoo and already stretches her budget to pay the bills. Phoebe and Fred do not know how they can afford to stay above poverty and pay treatment for their child. Fred is available at home to care for Jimmy but cannot fully provide the care he needs without outside help and more financial assistance. If their situation does not improve and receive assistance for treatment, they have considered giving up Jimmy for adoption. They feel another family will be able to better provide for him. Their primary concern for treatment is communication. They feel if they know what their child needs they can deal with current and upcoming issues and concerns.

Jimmy is an affectionate 3 year old who is unable to vocalize his needs. He relies much on leading an adult by hand and various grunting noises. He loves music and beating any flat surface to create a sound.

Communication style:
Phoebe will walk into the meeting open-minded but will be quick to judge. She will listen to the service provider and will interject if she disagrees with a comment or is unsure about an explanation. If she feels the service provider makes an offensive comment, Phoebe will furrow her brow and ask her to repeat or explain what they said in a condescending or judgmental tone of voice. If the provider comes across as open and interested, she will answer all questions and elaborate. If the provider appears aloof and uninterested, she will answer all questions but will refrain from elaborating.
Name: Suong  
Age: 27  
Race: Asian  
Country of Origin: Vietnam  
Spoken language(s): Vietnamese, English

Background:
Suong was born and raised in South Vietnam in a middle class family in the city. Suong is small in stature and has had medical issues starting at a very young age that impacts her mobility to this day. Her parents encouraged her to be independent because of her size and to pursue her education. Suong states her parents helped develop her critical thinking, reading, and creative writing. Suong received her Master’s degree in foreign languages. She is a translator for Vietnamese and English speaking individuals.

Suong and her husband, Hien, moved to the United States because her husband received a promotion working in the IT field. Suong easily obtained a job in the United States working with Wycliffe Bible Translators Group. Suong and Hien waited a couple of years to begin a family to settle into a new country and careers. The family rejoiced having a son come into the family. Bao is the only boy in her husband’s family and is expected to take on the family role to worship the ancestors once his parents pass away. Upon discovering Bao’s diagnosis, Hien was completely frustrated. He had high hopes for his son to uphold the family name and continue to fulfill the family role of worshipping his ancestors. Hien feels guilty not having a child for his parents to uphold the family line. Suong and Hien experienced marriage troubles, blaming each other for actions during the pregnancy that may have contributed to the disability. Upon reading more about the diagnosis and available treatments, they both have come to terms with the situation to the best of their ability and work together. Although the diagnosis is a disappointment for her husband, both he and Suong are willing to cooperate with therapists.

Unfortunately, Bao’s grandparents were unable to move to the United States with Suong and Hien and visit only once a year. They accept Bao’s diagnosis and financially support the family. Hien’s parents believe their financial assistance is more beneficial for Bao than frequent visits. They also fully support Suong’s decision to have another child once Bao shows substantial progress.

Independence is very important to Suong and self-help skills are a priority. She does not want to leave her child helpless in this area because of individuals who may take advantage of her child. After self-help, communication skills are a must. Suong believes that if her child has improved communication skills, it will be easier for her child to develop play and social skills. Mom wants a weekly report on her child’s programs and any skills mastered. She wants to be updated frequently to understand where her child is at in terms of skills and what to do at home.

Bao is a rambunctious little 3-year old boy who loves music and rough play. He is the only child and not used to sharing or being around too many children.

Communication Style:
Suong is hesitant sharing personal information with a therapist. If she feels the therapist is honest, sincere, and really wants to help her child, she will try to give as much information as possible about her child. Suong will wait to hear everything the therapist says before asking any questions. It is easier for her to communicate with the therapist by listening to the therapist in big chunks and then ask any questions afterwards.
Family Simulation Card #9

Name: Ashley Pond
Age: 35
Race: Anglo-European
Country of Origin: United States
Spoken language(s): English

Background:
Ashley was raised in Dallas, TX in an upper middle class family. She briefly lived away from the city during her university years. Her family was fortunate to be successful in business and their standard of living has always been comfortable with advantages in education and material goods. Her family always stressed education to their children as a means to improve their mind and body. They emphasized the need to appreciate all that they received and to help those less fortunate. Ashley states her family taught her to live life with a positive attitude towards everything. She describes this type of thinking as taking life issues as they come and deal with them in a positive outlook.

Ashley met her husband at university and was friends for two years before beginning a relationship senior year. Ashley and Mitch married a month after they graduated and moved back to Dallas. They are both working individuals and strive to share all the chores around the house. One of their goals for their marriage is equality. Their goal is to share the responsibilities and not rely solely on one person. They have two children, ages 10 and 7, and little 4 year old David. Ashley and Mitch were alarmed upon hearing David’s diagnosis because of the lack of positive feedback they have read and heard about autism. Neither Ashley nor Mitch is aware of any family member with a developmental disability. Before the diagnosis, Ashley was upset because her child did not look at or play with her. Ashley’s family was shocked when they heard about David. However, little time passed before they began researching treatments and the changes needed in their lives to improve David’s quality of life. David’s family, however, are distant and not involved with David’s affairs. They only see David’s family once a year, if they are available and not traveling. Mitch has a strained relationship with his parents but it is rarely an issue. Ashley and Mitch claim to be blessed with supportive friends who are willing to listen to their troubles and even help research more on the diagnosis.

Ashley wants David to reach his potential, whatever it may be. Ashley would like David’s communication and self-help skills to improve during his stay with the program. Her future for David is to be able to live independently or at least able to function independently.

David is quiet and loves to look at books and play with electronic toys. He loves being around other children but not sure how to interact with them. He dislikes entering the bathroom because of the echo from other people’s voices and the flushing sound. He loves playing with his older siblings but they have a hard time understanding his different needs. His older siblings avoid David at times because they are unsure how to interact with him.

Communication style:
Ashley is very respectful towards professionals. She listens to all the information the professional provides before asking questions. Ashley feels she can learn more from them by listening because of their extensive knowledge. She has certain goals for her child but is open to other ideas that will help improve David’s skills and future independence.
Family Simulation Card #10

Name: Lalita Kapoor
Age: 30
Race: Asian
Country of Origin: India
Spoken language(s): Hindi, English

Background:
Lalita was raised in Delhi, India with a traditional Indian family dedicated to education for all their children. Her father supported the family financially and her mother maintained the household and caregiver responsibilities. She is the youngest of four children and had more freedom from chores and expectations to start a family. She met her husband, Mahinder, at university while taking classes for a teaching degree. Lalita married Mahinder at the age of 19. Mahinder graduated with a degree in computer science. Soon after Mahinder graduated, he received an opportunity to move the United States for his career. Lalita was unable to complete her education before moving with her husband.

Lalita and Mahinder first moved to California and had their child, Chandra. Chandra was their first exposure to the world of autism. They were devastated with the news and prayed for a cure. The family moved to Dallas for a better job opportunity. Lalita and Mahinder found and received services for Chandra. The couple postponed extending their family for several years until the arrival of Kiran. Lalita and Mahinder discovered Kiran’s diagnosis of autism at the age of 3 years old. They experienced further disappointment because they had high hopes of Kiran supporting them and Chandra later in life. Mahinder supports his wife’s efforts to maintain the family home and children.

Lalita’s parents attempt to support the extra needs of the children but do not understand fully what autism entails and the difficulties the children have now and later in life. Both Lalita’s and Mahinder’s parents are unable to visit them for financial reasons. They feel supporting they grandchildren financially from afar is more effective than using their finances to visit.

Lalita is foremost concerned with communication. Kiran can tact items but has difficulty speaking in full sentences. Her second concern is expanding his food interests. She wants her child to have a vegetarian lifestyle and foods that are available in their culture. Kiran’s current eating habits are offensive to Lalita but she knows that for the time being it is necessary.

Kiran loves singing to himself, playing with musical toys and videos. He can sing full sentences but speaks few words at a time. He can navigate the internet searching for YouTube videos of his favorite movies and songs. His other interests are playing with figurines. He enjoys lining up figurines into a certain order and watches them for minutes at a time. Kiran rarely approaches his older brother for play interactions.

Communication style:
Lalita is very respectful with professionals. She will listen to everything the professional has to say before making a commitment. She will not disagree with the professional but state what she and the family do. Lalita is more comfortable with the professional taking the lead and will take some time to speak more about her family issues. She will answer a direct question but other concerns are addressed in an indirect manner. Any mention of difficulties the child has is more likely a concern she has and something the professional should focus on. When Lalita is with her husband, she will let Mahinder answer most of the questions.
Coding System for Types of Interview Questions and Responses, and Family Topics

Megan J. Thompson & Shahla Ala’i-Rosales, Ph.D., BCBA-D
University of North Texas

Code revised on 10/16/11
Instructions

Scoring:

Write the name of the parents, initials of child, name of interviewer, date, and the start/end times of the scoring session. During the scoring session, observers will tally the frequency for the following:

- Types of questions the interviewer asks
- Types of responses from the interviewer
- Family topic responses from the family

The scoring will be done in 10-minute intervals until the end of the interview. Observers will tally each question and response under the correct column and row. Each piece of information is to be scored. For example,

"Our brothers do not live close enough for much family time and they are unable to help us out with babysitting."

The first half of the statement, "our brothers do not live close enough for much family time," can be recorded under the topic area, family life. The second half of the statement, "they are unable to help us out with babysitting," can be recorded under family support and challenges. There are two pieces of information in the above sentence the family provides.

Begin scoring video when interviewer discusses interview purpose and describes his cultural background and work experience. Stop scoring when interviewer explains to family the interview is finished. Pause after each response or question or slow down the video, if necessary, for accurate scoring. Pay attention to each piece of information and how to score it. For example,

"The diagnosis was difficult for us, especially with my husband thinking it was my fault."

The first piece of information, "the diagnosis was difficult for us" will be scored under family life. The second piece of information, "especially with my husband thinking it was my fault" will be scored under family values.

Use different colored writing utensils to differentiate between multiple interviewers and the questions asked, if needed. Score family information from all family members present. Any questions or comments not related to the interview towards a child or family speaking amongst themselves will not be scored.

During or at the end of the scoring session, the observers can write additional notes on the side of the data sheet.
Types of Interview Questions
# Open-ended Questions

<table>
<thead>
<tr>
<th>Type</th>
<th>Definition</th>
<th>Examples</th>
<th>Non-Examples</th>
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</thead>
<tbody>
<tr>
<td>Grand tour</td>
<td>An open-ended question about what usually occurs with people, events, activities, objects, space and time</td>
<td>What is your family like? What is a typical daily routine for you? Could you describe what expectations you have from our program?</td>
<td>What does your normally do when he is upset?</td>
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<tr>
<td>Mini tour &amp; example</td>
<td>Are open-ended questions – <em>mini tour</em> is identical to grand tour question but asks about a smaller unit of experience that was discussed from the grand tour question; <em>example</em> asks an example of a single act or event that has occurred or the family wants to occur that is representative of what usually can be seen or heard by the family member</td>
<td>Could you describe to me the kinds of food you usually make for dinner? What do you usually do when all the children are at their grandparents? What is an example of your child spending time with your family? What is an example of your financial situation?</td>
<td>What do you usually do as a member or an autism awareness organization? What is an example of a friend helping you out in a difficult situation? Why would you like to concentrate on your child speaking Spanish? Tell me about your experience about staff changing how your child eats.</td>
</tr>
<tr>
<td>Experience &amp; strict inclusion</td>
<td>Are open-ended questions – <em>experience</em> asks about family/child experiences regarding the family's interpretations, feelings, and observations in a particular setting; <em>strict inclusion</em> asks the family the kinds of behaviors or activities they see or want to see regarding a family/child issue. The question gives the provider an insight to what is important to the family. X is a kind of Y X is a way to do Y</td>
<td>What are experiences with autism support groups? What are your experiences with additional therapy? What kinds of family gatherings you would like your child to participate? How would you like staff to interact with you?</td>
<td>What kinds of schoolwork you want your child to do on his own? What is an example of your child not being able to get dressed? What is a typical activity like with your child and his sisters? What are your reasons for seeking additional therapy?</td>
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</table>
### Structural Questions

<table>
<thead>
<tr>
<th>Type</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Native language</td>
<td>A question that asks about words or phrases the family uses to describe</td>
<td>What is another way you would describe being fulfilled?</td>
<td>Why do you feel it is important for your child to listen to teacher</td>
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<tr>
<td></td>
<td>people, single acts, objects, and events</td>
<td>How does your family refer to each other?</td>
<td>instructions?</td>
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<td>What do you and your family do to make sure your child sits nicely at the</td>
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<td>dinner table and eat all of their dinner?</td>
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<td>Means-end</td>
<td>A question that asks how the family behaves or behaviors they want see in</td>
<td>What do you do to make it easier to spend time as a family?</td>
<td>What kinds of family activities would you like to do?</td>
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<td>others to accomplish a goal</td>
<td>How do you try to improve your child’s communication?</td>
<td>What are special names you call each other?</td>
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<td>X is a way to do Y</td>
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<tr>
<td>Rationale</td>
<td>A question that asks the individual’s and/or family’s reasons for doing</td>
<td>What are the reasons you do not go out as much as a family?</td>
<td>What is another way you would describe financially burdened?</td>
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<td>something or for someone else to do something</td>
<td>Why do you feel it is important to follow teacher instruction?</td>
<td>What are your child’s strengths?</td>
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<td>X is a reason for doing Y</td>
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</table>
### Other Types of Questions

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<thead>
<tr>
<th>Type</th>
<th>Definition</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Closed</td>
<td>A question that can be sufficiently answered with a yes or a no, or provides the family with a forced choice/answer</td>
<td>Do you have daily routines?</td>
<td>What does your child do to get your attention when he can’t communicate his needs?</td>
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<td>Did you take any prenatal vitamins while pregnant with your child?</td>
<td>What kinds of sensory difficulties does your child have?</td>
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<td>Please answer the question with happy, neutral, or agitated.</td>
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<td>How does your child feel when eating?</td>
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<td>How old is your youngest child?</td>
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<tr>
<td>Other questions</td>
<td>Questions that are not directly related or related at all to the child and family</td>
<td>How do you spell asthma?</td>
<td>In what ways does your child talk too much in public to strangers?</td>
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<td></td>
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<td>Did you get a chance to watch that T.V. show we talked about earlier?</td>
<td>Did your child like going to the store after he calmed down?</td>
</tr>
</tbody>
</table>

- **Closed:** A question that can be sufficiently answered with a yes or a no, or provides the family with a forced choice/answer.
- **Other questions:** Questions that are not directly related or related at all to the child and family.
Types of
Interviewer Responses
<table>
<thead>
<tr>
<th>Type</th>
<th>Definition</th>
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<th>Non-Examples</th>
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<tbody>
<tr>
<td>Acknowledgement</td>
<td>A general, non-specific statement or comment that denotes understanding and/or acknowledgement of family’s responses</td>
<td>That is fun!</td>
<td>So it was very hard to hear from your family that they were unable to support you and your efforts to help your child.</td>
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<td></td>
<td></td>
<td>Okay.</td>
<td>That issue could have been prevented if you and your husband did not follow through with your plan.</td>
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<td></td>
<td>Yes, I understand.</td>
<td>Don’t forget to read that new romance novel that came out.</td>
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<td></td>
<td>That is so cute.</td>
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<td></td>
<td></td>
<td>Repeating family’s responses</td>
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<tr>
<td>Supportive response</td>
<td>Speaker correctly describes the family’s feelings/perspective, empathizing with their feelings/perspective, confirms/indicates what family is thinking and feeling, and/or relating their feelings/perspective to a broader context that includes a possible beneficial outcome</td>
<td>Your family was shocked by the diagnosis.</td>
<td>I got it.</td>
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<td>I have a family member with autism and understand what you are going through. It is hard for you and the family to adjust to something you are not familiar with and search for solutions to help your child.</td>
<td>Sure, no problem.</td>
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<td>Okay.</td>
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<td>I loved seeing the elephants at the zoo.</td>
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<td></td>
<td>Make sure you do not do that again.</td>
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<td></td>
<td>Interviewer finishes family’s sentence that incorrectly confirms/indicates family’s feelings and perspective.</td>
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<tr>
<td></td>
<td></td>
<td>interviewer finishes family’s response and correctly indicates family’s feelings and perspective.</td>
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<tr>
<td>Non-supportive response</td>
<td>Speaker places responsibility of situation on family, by verbalizing skepticism of family’s feelings/perspective, incorrectly confirms/indicates what family thinks or feels, or by telling the family how/what to think, feel or do</td>
<td>That was probably not a good idea.</td>
<td>Great, that is helpful.</td>
</tr>
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<td>Are you sure that’s what you want to do?</td>
<td>My sister had almost the same dinner routine and sometimes it could be very trying for the family.</td>
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<td>I saw her yesterday at the store.</td>
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<tr>
<td></td>
<td></td>
<td>Interviewer finishes family’s sentence that incorrectly confirms/indicates family’s feelings and perspective.</td>
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<tr>
<td>Type</td>
<td>Definition</td>
<td>Examples</td>
<td>Non-Examples</td>
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</tr>
<tr>
<td>Other comments &amp; introductions</td>
<td>Comments not related to the child and family, and interviewer background information, including childhood, likes/dislikes, education, and career</td>
<td>It is really hot in this room.</td>
<td>That is understandable.</td>
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<tr>
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<td>I love that show too.</td>
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<td>I am a big football fan.</td>
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<td>I've worked for the company for 2 years.</td>
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<td>I was born in Texas to a White father and a Hispanic mother.</td>
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<tr>
<td>Program information</td>
<td>Comments about the entire treatment program or comments about family’s child in the program</td>
<td>I was with her yesterday and she talked to the other kids and joined game time.</td>
<td>Yes, excellent.</td>
</tr>
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<td>The senior coaches develop programs for your child and supervise the junior coaches to make sure they are implementing the programs correctly.</td>
<td>That must be hard to go through that all alone.</td>
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<td>She kept her shoes on for most of the time and listened to the coach.</td>
<td>I received my BCBA on 2002 and have been working here for 10 months.</td>
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<td></td>
<td></td>
<td></td>
<td>That is so cute.</td>
</tr>
</tbody>
</table>
Family Topics
<table>
<thead>
<tr>
<th>Type</th>
<th>Definition</th>
<th>Examples</th>
<th>Non-Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family life</td>
<td>A family topic about what has occurred with the family and child from pregnancy to current time, family background of parents and child, stories related to family, and family members who contribute to the wellbeing/life of the child and family</td>
<td>Family background, Family members, Daily routines, Pregnancy complications, Stories about sister's child</td>
<td>Increase interaction with peers, Loves talking with people, Stranger Danger, Weekly updates from professional staff, Stories about neighbor's child</td>
</tr>
<tr>
<td>Family values</td>
<td>A family topic about beliefs and values, what the family holds true or is important, and the interactions and observations on how people treat the child and family</td>
<td>Internal causes of autism, Extended family involved in rearing of child, GF/CF diet will help child, The nurses at the hospital were rude</td>
<td>Family lives below poverty line, Government assistance, Child grunts and leads adult, Family wants to be at session at all times</td>
</tr>
<tr>
<td>Family support &amp; challenges</td>
<td>A family topic about what or whom assists or does not assist the family currently with their needs and any challenges the family faces that needs extra attention</td>
<td>Caretakers outside of immediate family, Financial assistance, Memberships to groups, One-car family</td>
<td>Living with extended family, Increase imitation skills, Toilet training at center, Keep to strict food ciet</td>
</tr>
<tr>
<td>Child strengths</td>
<td>A family topic about what the child can do at anytime of their life that is beneficial for the individual</td>
<td>Great conversational skills, Good play imitation, Potty trained</td>
<td>Family wants entire family involved, Need for better fine motor skills, Family friend helps family, Want child to be completely independent and with a career</td>
</tr>
<tr>
<td>Type</td>
<td>Definition</td>
<td>Examples</td>
<td>Non-Examples</td>
</tr>
<tr>
<td>------</td>
<td>------------</td>
<td>----------</td>
<td>--------------</td>
</tr>
<tr>
<td>Family &amp; child goals</td>
<td>A family topic about goals the family wants to accomplish for their child and family either with or outside of the program. Responses may include what the family wants to see for the child and family</td>
<td>Self-help routines. Increase communication skills. Academics. Pretend play with sister.</td>
<td>Typical dinner routine. Ne close family members available. Child is very affectionate. Discussion about another autism treatment center.</td>
</tr>
<tr>
<td>Program expectations</td>
<td>A family topic about expected or unwanted progress and changes for the child and family through the program and expected communication style with staff; can include questions from the family to the professional staff.</td>
<td>Areas not to change in ATP. Appropriate communication with ATP. Change in daily routines because of ATP.</td>
<td>Family emigrated from England. Discussion about toys from parents' youth. Child pinches and hits when upset. Child very good with puzzles.</td>
</tr>
<tr>
<td>Other</td>
<td>Discussion topics that do not involve the child and/or family members.</td>
<td>TV shows parents enjoy watching. Vacations parents and professional staff had as children. Comparison between clothing from past and present. The medicine tasted awful.</td>
<td>Child and family bilingual. Family takes month long vacation to see family every year. Child plays and speaks with siblings. Family wants to focus on articulation and increase child interests.</td>
</tr>
</tbody>
</table>
Data Sheet and Interview Example

"This is the nicest conversation we've had in weeks. Let's not spoil it by talking."
Below is an example of the data sheet for scoring question type, type of interviewer response, and information on family topics. There is also an example of an interview between a case manager and parent. The numbers represent questions and comments and correspond on the data sheet where the information is to be scored. The dark purple conversation is the case manager and the dark blue is the parent.

<table>
<thead>
<tr>
<th>Time (min)</th>
<th>Child</th>
<th>Mental health &amp; social behavior</th>
<th>Adaptive &amp; social</th>
<th>Native language</th>
<th>Maternal</th>
<th>Paternal</th>
<th>Other</th>
<th>Acknowledgment</th>
<th>Acknowledgment &amp; response</th>
<th>Non-verbal response</th>
<th>Non-verbal responses</th>
<th>Program information</th>
<th>Child welfare</th>
<th>Family</th>
<th>Family support &amp; challenges</th>
<th>Child strengths</th>
<th>Program expectations</th>
<th>Parent &amp; child goals</th>
<th>Other</th>
</tr>
</thead>
</table>
1: Thank you for coming in to see us. We like to talk with you about your family so we can get to know you better and what you are looking for in the program.

2: So, could you tell me a little bit about your family?

My family is very close. We spend all our holidays together, even my husband is closer to my family than his.

3: Do you visit your husband's family a lot?

No, not really. They are not very close.

4: I know you mentioned that you are close to your family, but what kinds of challenges do you face as a family?

Well, when we found out about the diagnosis, my husband and I went through a rough patch. We blamed each other for it happening or not seeing it sooner. It's much better and we're there for each other but I think it's something we still need to work on. Part of the fighting nowadays has to do with our finances. We both have respectable jobs but with therapy, we are struggling. I think Dylan knows when we're fighting.

5: What does Dylan do to make you think he knows you're fighting?

He would watch us and cry and lock himself in his room. We are not sure what he does because he doesn't let us in at the beginning. I've noticed he finally lets us see him when we've both calmed down.

Yes, I understand. I never liked it either when my parents fought.

6: Does this happen often?

No, not anymore. I do think he is afraid of it happening. He is so good at coping with the bad things in life, even things he doesn't like to do. For example, he refuses to go potty in public but he will go at home.

7: What is a typical potty routine at home for you?

Since I stay home with him, I try to take him every hour to 2 hours. He tries to runaway and tell me no but I pick him up to go if I have to. Once we're there he will go but he doesn't tell me if needs to go and it's always a fight to get there. That is something we want to work on here. I would like for him to be independent in the bathroom, especially for when he is older.
That is great! That is something we can work on and also work with you so you can continue with it at home.

8: What do you call the potty or are there any special names we need to know about that you use at home and we also use here?

Just the normal stuff. Potty, pee-pee for his privates.

Okay, great.

9: What kinds of other self-help skills you want Dylan to work on?

Hmm... getting dressed independently and knowing what clothes to wear for the occasion. He has some trouble with his fine motor skills so he always needs help tying his shoes and buttoning his pants. And he tries to wear swim trunks when we have to visit family. He doesn’t understand that swim trunks are for swimming and not all occasions.

10: How do you get him to dress in appropriate clothing and out of the swim trunks?

It’s not easy! Sometimes I have to hide his swim trunks the night before so he has no choice but to wear something else. If I forget, I have to convince him to wear something else and we can get ice cream or something else he likes but not ridiculously expensive. He just wears me out.

11: What are your reasons for not letting him wear the swim trunks sometimes?

I just don’t want him to get into a habit that we will not be able to break. He needs to learn that he can’t always get what he wants and that people don’t appreciate someone wearing something at inappropriate times. As a mother, I want to make sure he does not stand out in a bad way.

My brother didn’t have clothes issues but we had to tell him that everything was chicken to make him eat any meat.

12: So, what are some of your long-term goals for Dylan?

Really, I want him to be as independent as possible with the option of going to college and living on his own. But I know right now we want to work on him reading, understanding more complex sentences, and some of the self-help skills we talked about.

Fantastic. These are definitely skills we can focus on.
13: What expectations do you have from our program?

I do expect to see great improvement that makes me want to stay in the program. I want to make sure that I know of any program changes and if there is anything that I can do at home that you are doing here. We have had exposure to different clinics and they are not always good.

14: What kinds of experiences did you have at these clinics?

Not good ones, that's for sure. They did not keep me up to date and did not take my advice. I felt like they just wanted to make money and not wanting to help my child.

Our program wants and welcomes our families to be fully involved in the process and make sure we do not implement or continue with something you disapprove.

15: Do you have any additional questions for us?

No, I'm great for now.
References


APPENDIX D

PRE-TRAINING PERFORMANCE ASSESSMENT

FAMILY SIMULATION SCENARIOS
Name: Maria Sandoval  
Age: 45  
Race: Hispanic  
Country of Origin: El Salvador  
Spoken language(s): Spanish, English

Background:  
Maria is an older Hispanic woman, born and raised in El Salvador. She was raised in a financially secure family. Her father worked in an office and her mother stayed at home. Maria worked for a year in a store before going to university. She was unable to finish her education because of university closings from the civil war in the country.

She immigrated to the United States at the age of 24 and at first lived with her uncle in Houston, TX. Two of her sisters moved to the United States afterwards, while her eldest sister stayed in El Salvador and her brother moved to Canada. She learned English by taking classes and cleaned houses to pay bills. She is currently married to an Anglo-European man with three children. She moved from Houston to the DFW area three years ago. She speaks English and Spanish in the home and is a stay-at-home mom to take care of her youngest son. Her youngest son, Rory, was diagnosed with autism at 2 years of age and is currently 5 years old. Maria had Rory when she was 40 years old. Maria thought she was finished having more children, having two already. Her two older, female children are 15 and 13 years old.

It has been difficult for Maria since learning of her son’s diagnosis. She does not have any family members, that she is aware of, that have a child with a disability. Her husband tries to spend time with Rory but his job does not permit him to take extended time-off. He feels incompetent when dealing with their child and leaves much of the parenting to Maria. Her parents passed away years ago and her husband usually works 6 out of 7 days of the week. The move from Houston drastically changed the family dynamic. Before the move, her two sisters lived with her family and shared parenting responsibilities. She is now living with only her husband and children for the first time since the beginning of her marriage.

Family is very important and wishes she could be closer to them. Maria wishes she can move back to Houston to be with her family but the job opportunity her husband received gives the family more financial security and benefits. However, she struggles to understand what her child needs and how to help him. Maria drives to Houston with her children as much as possible to visit her sisters. She holds a more traditional mother role. Maria tries to clean, cook dinner, and take care of all the children to the best of her ability. She does not have anyone she feels comfortable relying on in the DFW area to watch her children or to have an in-depth conversation about what she is going through.

Maria wants her son to be able to communicate effectively his needs. She wants him to speak English so he can better communicate with other people outside of the family. Toileting is another important issue for Maria. She feels that this is a big step towards independence for her child and an issue that will help decrease her stress. Lastly, she is concerned with his eating. She wants him to be able to try new foods without a tantrum.

Her son enjoys video games, music, and playing with his family. He is very affectionate but needs extra attention on communication. Rory’s older siblings give extra attention to their little brother and attempt to give him whatever he needs, especially in cases when he throws a tantrum. His siblings enjoy playing games with him and tossing him up in the air. They also spend their afternoon time babysitting him when both parents go to the store.

Communication style:

Maria enjoys talking about her children and telling stories about their childhood. She has no problem talking about what she wants for her children. Most of the time she describes what she expects by using examples and stories to clarify her point. She respects authority figures and will listen and nod to what the therapist says. She does not ask many questions and will wait until an issue comes up to ask an authority figure about it. She does not know how to use a computer so her best form of communication is the phone.
Family Simulation Card #5

Name: Tamika Jones
Age: 19
Race: African American
Country of Origin: United States
Spoken language(s): English

Background:
Tamika was born and raised in the downtown Dallas area with her mother, grandmother and two older brothers. Her birth father rarely visits and does not financially support his family. Her mother works full-time to support her, her brothers, and grandmother. However, her mother’s job cannot support the whole family and receives government assistance. Tamika lives in a low socioeconomic area and does not associate much with other residents for safety reasons. Her family has always valued education but safety and food takes precedence.

Tamika became pregnant with her daughter, Jasmine, at 16 years old. The arrival of Jasmine was unexpected but the family successfully coped with the surprise and supported Tamika and her child. The strain on supporting an infant and the family finances forced Tamika to drop out of school and search for a job. The father of her child sporadically comes to see Tamika and Jasmine but is usually away for long periods of time and cannot be reached. Currently, she is taking night classes to complete her GED but it leaves very little time to spend with her child. She is exhausted at the end of the day.

Tamika recently discovered the doctor diagnosed Jasmine with autism. Jasmine is currently 3 years old and Tamika’s grandmother is the primary caretaker. She is the primary caretaker while Tamika and her mother are working. The family is not comfortable with others taking care of Jasmine. This leaves with the trio constantly changing schedules to accommodate everyone and Jasmine’s extra needs. Tamika has found it difficult retrieving information on what to do for her child and Tamika is grateful to have found Easter Seals. However, transportation is a major concern. Her grandmother is available to bring and pick up Jasmine for treatment sessions but the family car is old and unreliable.

Tamika wants to take advantage of this opportunity but feels like she does not have all the resources needed to help her child. She also feels hesitant to speak with service providers because she does not have enough experience speaking with clinicians and opening up on personal issues. She is worried that her age and socioeconomic status will affect how service providers will speak with her and the quality of treatment her daughter may receive.

Jasmine is very affectionate and approaches her grandmother for most of her needs. Her grandmother and mother try to attend to all her needs and attempt to make her as comfortable as possible. She loves music and dancing with her family and is always smiling. Her biggest strength is her ability to socialize with others. However, her family is concerned about her understanding of stranger danger and who not to speak to, as well as what are appropriate conversations with other people.

Communication style:
Tamika is hesitant to open up on personal issues because she feels she will be judged by the interviewer. She is very respectful to elders and will listen to any suggestions they may have. Once she is comfortable with someone, she may joke around and will talk with her hands. The service provider needs to be aware that she may be guarded about her situation. Some signs are arms folded across her chest, eye rolling, and looking upward.
Family Simulation Card #8

Name: Suong
Age: 27
Race: Asian
Country of Origin: Vietnam
Spoken language(s): Vietnamese, English

Background:
Suong was born and raised in South Vietnam in a middle class family in the city. Suong is small in stature and has had medical issues starting at a very young age that impacts her mobility to this day. Her parents encouraged her to be independent because of her size and to pursue her education. Suong states her parents helped develop her critical thinking, reading, and creative writing. Suong received her Master’s degree in foreign languages. She is a translator for Vietnamese and English speaking individuals.

Suong and her husband, Hien, moved to the United States because her husband received a promotion working in the IT field. Suong easily obtained a job in the United States working with Wycliffe Bible Translators Group. Suong and Hien waited a couple of years to begin a family to settle into a new country and careers. The family rejoiced having a son come into the family. Bao is the only boy in her husband’s family and is expected to take on the family role to worship the ancestors once his parents pass away. Upon discovering Bao’s diagnosis, Hien was completely frustrated. He had high hopes for his son to uphold the family name and continue to fulfill the family role of worshiping his ancestors. Hien feels guilty not having a child for his parents to uphold the family line. Suong and Hien experienced marriage troubles, blaming each other for actions during the pregnancy that may have contributed to the disability. Upon reading more about the diagnosis and available treatments, they both have come to terms with the situation to the best of their ability and work together. Although the diagnosis is a disappointment for her husband, both he and Suong are willing to cooperate with therapists.

Unfortunately, Bao’s grandparents were unable to move to the United States with Suong and Hien and visit only once a year. They accept Bao’s diagnosis and financially support the family. Hien’s parents believe their financial assistance is more beneficial for Bao than frequent visits. They also fully support Suong’s decision to have another child once Bao shows substantial progress.

Independence is very important to Suong and self-help skills are a priority. She does not want to leave her child helpless in this area because of individuals who may take advantage of her child. After self-help, communication skills are a must. Suong believes that if her child has improved communication skills, it will be easier for her child to develop play and social skills. Mom wants a weekly report on her child’s programs and any skills mastered. She wants to be updated frequently to understand where her child is at in terms of skills and what to do at home.

Bao is a rambunctious little 3-year old boy who loves music and rough play. He is the only child and not used to sharing or being around too many children.

Communication Style:
Suong is hesitant sharing personal information with a therapist. If she feels the therapist is honest, sincere, and really wants to help her child, she will try to give as much information as possible about her child. Suong will wait to hear everything the therapist says before asking any questions. It is easier for her to communicate with the therapist by listening to the therapist in big chunks and then ask any questions afterwards.
APPENDIX E

ORIGINAL INTERVIEW FORMAT
NEW CLIENT INFORMATION

Name:__________________________ Date:________________
Parent:_________________________ Case Manager:_______________

1. Pregnancy/ Birth History

Prenatal care received from ________________ to _______________ (dates)

Obstetrician: _________________________________________________

Please circle Yes or No for the following:

a) Prenatal Vitamins: Yes No

b) IVF, other technology Yes No

c) Bleeding or spotting: Yes No

d) Mother’s infections: Yes No

e) Mother’s alcohol/drug use: Yes No

f) Mother’s cigarette smoking: Yes No

g) Mother’s illness (i.e. diabetes, high blood pressure): Yes No

h) Prescription drugs during pregnancy: Yes No

i) Accidents or Stress: Yes No

j) Decreased Fetal Movement: Yes No

If you answered Yes to (b) through (j), please explain:
________________________________________________________________________________________
________________________________________________________________________________________
_______________________________________________________
________________________________________________________________________________________

Other Problems:
________________________________________________________________________________________
________________________________________________________________________________________

Special Tests during Pregnancy (i.e. triple test, amniocentesis):
________________________________________________________________________________________

Duration of Pregnancy: _______ weeks

Birth weight: _____ lbs _____ oz Birth length: ____________

List any complications (i.e. breech, induced labor, meconium, caesarian, resuscitation):
________________________________________________________________________________________
________________________________________________________________________________________

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NEW CLIENT INFORMATION

Neonatal Intensive Care Stay:  Yes  No

If Yes, how many days:  _____  Problems:  _________________________

Regular Nursery Stay:  _____

Please circle if any of the following apply:

Bottle-fed  Breast-fed  Poor feeding  Jaundice
Low tone  Anemia  Fast breathing  Infections

Explanations:  _________________________________________________________________

2. Medical/ Childhood History

Milestones (please list approximate ages your child achieved milestone):

Held up head:  ____________  Rolled front to back:  ____________
Sat w/o support:  ____________  Crawled:  ____________
Pulled up to stand:  ____________  Walked:  ____________
Babbled:  ____________  First Word:  ____________  Combined words:  ____________
Finger-fed:  ____________  Fed self:  ____________  Toileting:  ____________

Please list any medical conditions your child has:  __________________________________

_______________________________________________________________________________

_______________________________________________________________________________

Please list past treatments (with dates of service):  __________________________________

_______________________________________________________________________________

_______________________________________________________________________________

Please list past and currents medications (with dates and dosage):  __________________

_______________________________________________________________________________

_______________________________________________________________________________

Please list any allergies (i.e. latex, food, seasonal):  __________________________________

_______________________________________________________________________________

_______________________________________________________________________________
NEW CLIENT INFORMATION

Please list any other important medical or physical information about your child:

________________________________________________________________________________________

________________________________________________________________________________________

3. Rapport and Communication

Does your child approach you to play?  
Yes  No

Are you able to play for extended periods of time with your child?  
Yes  No

Does your child take turns during play interactions?  
Yes  No

Do you usually understand what your child wants and does not want?  
Yes  No

Are there situations when it is more or less difficult to be patient with your child?  
Yes  No

What are the situations that you enjoy the most with your child?

________________________________________________________________________________________

________________________________________________________________________________________

How does your child respond when your or others approach him/her to:

<table>
<thead>
<tr>
<th>Activity</th>
<th>happy</th>
<th>neutral</th>
<th>agitated</th>
<th>fearful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Play:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eat:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watch tv/videos:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go outside:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go in the car:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go to school:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go to bed:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3. Rapport & Communication (cont):

How well does your child communicate with you? ____________________________________________________________

________________________________________________________________________________________________________

How well does your child communicate with other family members? ________________________________________________

________________________________________________________________________________________________________

How well does your child communicate with others outside your family? ____________________________________________

________________________________________________________________________________________________________

Describe the methods you use to help your child communicate. ____________________________________________________

________________________________________________________________________________________________________

What kinds of things make your child happy? ________________________________________________________________

________________________________________________________________________________________________________

How often does your child seem happy? ____________________________________________________________________

________________________________________________________________________________________________________

What kinds of things make your child upset? __________________________________________________________________

________________________________________________________________________________________________________

How often does your child seem upset? ____________________________________________________________________

________________________________________________________________________________________________________
4. Play and Preferences:

Please list your child’s preferences for the following:

Toys, Games, Books: ____________________________________________________________
________________________________________________________________________
________________________________________________________________________

Songs: _______________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Television/ Videos: ____________________________________________________________
________________________________________________________________________
________________________________________________________________________

Praise (such as hugs, tickling, etc.): ____________________________________________
________________________________________________________________________
________________________________________________________________________

Food Items: __________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Activities (such as peek-a-boo, soccer, coloring, etc.): ____________________________
________________________________________________________________________
________________________________________________________________________

Are there things he/she does NOT seem to enjoy? _________________________________
________________________________________________________________________
________________________________________________________________________

Approximately how long will he/she play on his/her own? _________________________
________________________________________________________________________
________________________________________________________________________

Approximately how long will he/she play with others (please list)?

Person: ___________________________  Length: ___________________________

Person: ___________________________  Length: ___________________________

Person: ___________________________  Length: ___________________________

Person: ___________________________  Length: ___________________________

Person: ___________________________  Length: ___________________________

Person: ___________________________  Length: ___________________________
APPENDIX F

WORKSHOP FAMILY SIMULATION SCENARIOS
Family Simulation Card #3

Name: Galina Ivanov
Age: 26
Race: White
Country of Origin: Russia
Spoken Language(s): Russian, English

Background:
Galina emigrated from Russia at the age of 20 to move forward in her education. She came from a family of four children and lived in a small town. She decided to move to the United States to improve her way of life. During her time in the United States receiving her education, she was unable to visit her family because of the restrictions on her student visa. She married three years later to an American born man and did not complete her education. She received her permanent residency and then her citizenship after a couple of years of marriage. Once she became a permanent resident, she made a trip to home to visit her family she had not seen in years.

Before her son was born, she was a homemaker and took care of all the household chores. Galina and her husband experienced trouble in their marriage. Galina describes her relationship with her husband during that time as rough and filled with miscommunication. Galina and her husband had financial troubles and their different communication styles only added to the stress. Three years into her marriage, her son Dmitri was born. Her marriage temporarily improved after Dmitri was born but their son’s diagnosis, at age two, created a strain on their relationship. Recently, her husband was diagnosed with bipolar disorder.

Currently, Galina and her husband are in the process of finalizing their divorce. Their communication is minimal, only discussing Dmitri’s needs, such as transportation and treatment. They communicate with Dmitri’s doctors and therapists separately. Since the separation from her husband, Galina had to find a job and is currently living in a hotel. She is now working and paying for a room weekly. She feels stressed because of the divorce, her living arrangements, and the need for treatment for her son.

Galina does not have any family in the United States to help her financially or emotionally. She tries to call her family as much as possible but does not want to burden them with all her problems. Although her estranged husband helps with Dmitri, she feels alone in the United States but does not want to leave because of the opportunities and treatment available in the country.

Galina and her husband agree increased communication skills and potty training are necessities for Dmitri and the family. They are also interested in biomedical treatments. He is on a medical intervention, chelation, and is on the Gluten Free/ Casein Free diet. Dmitri’s challenging behavior consists of lying on the ground and kicking around to escape from demands. He has moments where he appears to be extremely hyperactive, jumping around, tearing items off the wall and banging on counters. Hysterical laughing precedes these moments.

Communication style:
Galina appears to be exhausted and quiet mouthed about her relationship with her estranged husband. She keeps her answers short and to the point and does not expand on sensitive issues. She will give the basics about her failed marriage but feels it is not necessary for her child’s progress, unless it becomes important for his therapy. She is actively informed with current treatment for her child and will speak about other kinds of treatment.
Family Simulation Card #6

Name: Hassan Sanna
Age: 40
Race: Asian
Country of Origin: Iran
Spoken language(s): Farsi, English, some Arabic

Background:
Hassan was born and raised in southern Iran as the eldest son in the family. Hassan’s father was an educated man and stressed the importance of receiving a good education and career. He learned to speak Farsi, English, and sufficient Arabic to read the Koran. Hassan entered the military after completing high school. As part of his military duty, he taught children in a small village school subjects they would not have had the opportunity to learn. He describes his experience in the village as a life altering experience. He realized his love of children and a need to help children in any way possible. Available universities in Iran are difficult to enter. Acceptance from a university in Iran requires a competition of the best scores and political connections. Hassan was advised to apply for higher education in the United States.

He completed his Bachelor’s degree in mechanical engineering at Louisiana State University (LSU). During his stay at LSU, he was engaged to his wife but the long distance relationship proved to be difficult and he wanted to be married as soon as possible. His wife, Azdeh, studied in Germany for a year before receiving her visa to move to the United States. Hassan and Azdeh married after a year and half of being apart in different countries. He was unable to obtain a job prospect in mechanical engineering. Currently, he and his wife opened a successful restaurant in Denton, TX. Hassan was 25 years old when he had his first child, Sabah. It was not until nine years later their son, Mohammad, was born.

Mohammad is a 5-year-old child with a diagnosis of autism and has previously been in another treatment program. Hassan and Azdeh feel he can benefit greatly from a different environment and program. Hassan actively researches the best possible treatments for his son and spends as much time as he can with both children. Hassan is primarily in charge of the financial aspects for the family and Azdeh stays at home more frequently to take of Mohammad. The family is waiting for several family members from abroad to move in with them in Texas. Family is very important to Hassan and Azdeh but feel staying in the DFW area is the best option for their child. In the meantime, they have close family friends that help with babysitting and emotional support.

Hassan’s main concern for Mohammad is general independence. He wants his son to be able to go to the toilet, dress himself, and eat a healthy meal without too much dependence from family members to complete these tasks. Hassan would like Mohammad to communicate well enough for the family to understand his needs, but wants independence to be established. They do have an older daughter, Sabah, who is 14 years old. She helps her mother as much as possible with responsibilities taking care of her brother. Sabah is involved with Mohammad’s treatment programs and school.

Communication style:
Hassan will sit and absorb information given from the service provider. He will ask questions to be certain he is doing or saying something correctly but generally waits to see if progress occurs before speaking with the provider. He prides himself as being trustworthy. He will correct an individual if they misunderstood what he said about his opinion or ideology. He is a man who will give the service provider space and keeps his hands in his lap and to himself.
Name: Phoebe Reynolds
Age: 25
Race: Anglo-European
Country of Origin: United States
Spoken Language(s): English

Background:
Phoebe Reynolds was born in a conservative family who has lived in Texas for four generations. As a child, her parents did not socialize much with others except for their children’s after school programs. She describes her childhood upbringing as accepting of others but not open-minded. She says that her parents accept differences in individuals and families but it is not right for them. She graduated from high school early and her point of view in life changed drastically. Phoebe met her husband at her first full-time job after high school. Phoebe’s husband is 15 years older and was her previous manager at work. She moved out of her parents’ house to be closer to him without parental disapproval.

Soon after Phoebe graduated from university with her Bachelor’s, she and her husband, Fred, were pregnant and married. Their son Jimmy was born early into their marriage and with welcome arms. The family discovered Jimmy’s diagnosis of autism four months ago and it dumbfounded the family. Autism does not run on either side of the family and Phoebe wondered if she did something wrong or could have done something to prevent it. She is frustrated with the situation. She does not understand the diagnosis or what she can do to help her child. Her mother is willing to help with whatever she needs but the rest of the family is detached because of a lack of understanding.

Phoebe and Fred have financial difficulties that affect their family life and available treatments. Fred lost his job and unable to obtain another managerial position for two years. Phoebe works at the Fort Worth zoo and already stretches her budget to pay the bills. Phoebe and Fred do not know how they can afford to stay above poverty and pay treatment for their child. Fred is available at home to care for Jimmy but cannot fully provide the care he needs without outside help and more financial assistance. If their situation does not improve and receive assistance for treatment, they have considered giving up Jimmy for adoption. They feel another family will be able to better provide for him. Their primary concern for treatment is communication. They feel if they know what their child needs they can deal with current and upcoming issues and concerns.

Jimmy is an affectionate 3 year old who is unable to vocalize his needs. He relies much on leading an adult by hand and various grunting noises. He loves music and beating any flat surface to create a sound.

Communication style:
Phoebe will walk into the meeting open-minded but will be quick to judge. She will listen to the service provider and will interject if she disagrees with a comment or is unsure about an explanation. If she feels the service provider makes an offensive comment, Phoebe will furrow her brow and ask her to repeat or explain what they said in a condescending or judgmental tone of voice. If the provider comes across as open and interested, she will answer all questions and elaborate. If the provider appears aloof and uninterested, she will answer all questions but will refrain from elaborating.
Family Simulation Card #9

Name: Ashley Pond  
Age: 35  
Race: Anglo-European  
Country of Origin: United States  
Spoken language(s): English

Background:
Ashley was raised in Dallas, TX in an upper middle class family. She briefly lived away from the city during her university years. Her family was fortunate to be successful in business and their standard of living has always been comfortable with advantages in education and material goods. Her family always stressed education to their children as a means to improve their mind and body. They emphasized the need to appreciate all that they received and to help those less fortunate. Ashley states her family taught her to live life with a positive attitude towards everything. She describes this type of thinking as taking life issues as they come and deal with them in a positive outlook.

Ashley met her husband at university and was friends for two years before beginning a relationship senior year. Ashley and Mitch married a month after they graduated and moved back to Dallas. They are both working individuals and strive to share all the chores around the house. One of their goals for their marriage is equality. Their goal is to share the responsibilities and not rely solely on one person. They have two children, ages 10 and 7, and little 4 year old David. Ashley and Mitch were alarmed upon hearing David’s diagnosis because of the lack of positive feedback they have read and heard about autism. Neither Ashley nor Mitch is aware of any family member with a developmental disability. Before the diagnosis, Ashley was upset because her child did not look at or play with her. Ashley’s family was shocked when they heard about David. However, little time passed before they began researching treatments and the changes needed in their lives to improve David’s quality of life. David’s family, however, are distant and not involved with David’s affairs. They only see David’s family once a year, if they are available and not traveling. Mitch has a strained relationship with his parents but it is rarely an issue. Ashley and Mitch claim to be blessed with supportive friends who are willing to listen to their troubles and even help research more on the diagnosis.

Ashley wants David to reach his potential, whatever it may be. Ashley would like David’s communication and self-help skills to improve during his stay with the program. Her future for David is to be able to live independently or at least able to function independently.

David is quiet and loves to look at books and play with electronic toys. He loves being around other children but not sure how to interact with them. He dislikes entering the bathroom because of the echo from other people’s voices and the flushing sound. He loves playing with his older siblings but they have a hard time understanding his different needs. His older siblings avoid David at times because they are unsure how to interact with him.

Communication style:
Ashley is very respectful towards professionals. She listens to all the information the professional provides before asking questions. Ashley feels she can learn more from them by listening because of their extensive knowledge. She has certain goals for her child but is open to other ideas that will help improve David’s skills and future independence.
APPENDIX G

ESATP FAMILY CONVERSATION GUIDE
ESATP Family Conversation Guide

- Purpose of the meeting and process
- Introductions and picture sharing

**Discussion Areas – Family Life**

- Family life and values
- Experience regarding the diagnosis of autism
- Family supports and challenges
- Overall goals for child and family
- Specific child strengths and needs

**Discussion Areas – Program**

- Overview of ESATP
- Expectations of the program and questions
- Short and long term goals (child and family)
- Additional questions

- Family feedback
APPENDIX H

INTERVIEW FEEDBACK FORM
Interview Feedback and Procedural Integrity Form

Date ____________________

Interviewer _________________________________________  Family _____________

Condition ______________________________________________________________

Strengths/Suggestions

☐  check if at criterion

General

☐  Kind voice tone throughout meeting
☐  Responses to family are sincere and understanding
☐  Greets family with respect and friendliness
☐  Addresses family formally until asked otherwise
☐  Offers refreshments
☐  ESATP Family Conversation Guide available

Rationale & Purpose

☐  Explains meeting purpose to family
☐  Recording Explanation
☐  Explains confidentiality of information
☐  Asks permission to video record meeting
☐  Provides family with video release form

Conversation

☐  Leads introductions
☐  Describes education, work, and cultural background
☐  Provides all family members and staff an introduction opportunity
☐  Opening question is an open-ended, grand tour question
☐  Does not repeat discussion topics
☐  Follows up responses with additional open-ended questions
☐  Follows up responses with structural questions
☐  Allows time to respond
☐  Restates what client says
☐  Summarizes family’s statements
☐  Asks for use instead of meaning
☐  Avoids using why questions
☐  Avoids using yes or no questions
☐  Avoids multiple questions
☐  Avoids leading questions

Closing

☐  Provides opportunity for additional questions
☐  Thanks family for time
☐  Walks with family to exit
APPENDIX I

POST-TRAINING FAMILY SIMULATION SCENARIOS
Family Simulation Card #2

Name: Aliya Mirza  
Age: 25  
Race: Asian  
Country of Origin: Tanzania, East Africa  
Spoken language(s): Kuchi, English

Background:
Aliya was born and raised in Tanzania, East Africa in a traditional home life. Her father worked to provide for the family financially and the mother took care of the children and household. Unlike her sisters, Aliya took on the “male” role in the family when her brother moved from the country. She worked as a secretary for the Yugoslavian embassy to help her father with the bills and learned how to drive. Aliya describes her family as strict. She and her siblings were unable to date and their style of dress was conservative, with a restriction from low cut tops and no dresses above the knee.

Aliya had an arranged marriage at the age of 20 with another Muslim man and immigrated to the United States. She had her first child, Bilal, at the age of 21 and her second child, Maryam, at the age of 23. She describes her marriage as difficult because she does receive emotional support from her husband. He provides for the family by taking care of the finances but she feels he neglects his wife, children, and household chores. Aliya’s in-laws live with her and her family. Her mother in-law helps her with the children’s feeding and morning routine while Aliya takes care of everything else.

Religion is very important to Aliya. She is passionate about the Koran and the values stated in this holy book. She attempts to stay true to values of nondiscrimination of others different from herself, the protection of women and every human being, prayer for others, and charity.

Her child, Bilal, was diagnosed with autism at 3 years of age. Since discovering the diagnosis, she has devoted her life to making sure her child is comfortable, safe, and receiving all the education necessary for him to succeed. Her husband and in-laws accept the diagnosis and they support her efforts. Communication is important for Aliya. She is not concerned about particular self-help skills such as toileting as long as he can communicate his needs. She wants her child to learn her first language, Kuchi, and then English. Eating habits is another area that Aliya finds critical. She is concerned about her child receiving all the nutrients and energy needed. She will change her eating habits for her child, as longs as it is healthy and the meat is halal. Aliya wants to know more about parent training so she can implement the necessary skills at home.

Bilal enjoys watching movies and looking at pictures in books. His grandmother makes sure he is not upset and always happy. If he begins to cry, his grandmother will try to do anything to stop the crying and make him happy.

Communication style:
Aliya will speak her mind with other women and will talk about her personal life if it will help her child. She believes in not hiding information when she is receiving assistance. Any questions she asks will be about communication and increased independence. She refers to God throughout her conversation. She claims God makes things happen for a reason and it is a test of faith. She states that she puts herself in God’s arms and trusts Him in whatever happens. If Aliya feels comfortable with another woman, she may hug her or touch her hand.

Aliya is very shy with men. She may speak about her child but keep private information, such as her marriage, from a male interviewer. She will keep her eye contact to a minimum and attempt to sit as far as possible from a male interviewer.
Family Simulation Card #4

Name: Lucinda Smith
Age: 35
Race: African American
Country of Origin: United States
Spoken language(s): English

Background:
Lucinda was born and raised in Denton, TX and has lived there all her life. Her family has lived in the Denton community for three generations and is active in the community. Lucinda left the Denton area to pursue a degree in civil engineering in Austin. She met her husband in the same degree track and married after both graduated with a PhD in civil engineering. Lucinda and her husband moved back to the Denton area to be close to family. She enjoyed her experience away from North Texas but feels there is no place like Denton.

Lucinda and her family live in a predominantly white neighborhood and are financially secure. They are deeply involved in the Baptist church, attending sermons and charity fundraisers organized by church residents. Most of their social interactions involve church activities and the people who attend their church. Her son, Jackson, was born two years after completing her degree and is an only child. Jackson was diagnosed with Asperger’s at 3 years of age and was a surprise to the family. Lucinda and her husband were proactive in researching the diagnosis and the kinds of help they can provide for their son. Jackson is currently 6 years old and received in-home treatment and some therapy in the clinic for three years.

Lucinda and her husband’s mothers are involved with Jackson’s life, providing childcare and additional help. They do not live with Lucinda and her family but are near for frequent visitations and emergencies. Her husband, Charlie, works most of the time and is not as involved in Jackson’s life as Lucinda. He remains informed with Jackson’s progress but leaves most of the treatment responsibilities to Lucinda. He exhibits some behaviors of Asperger’s, such as resistance to change and difficulty in social situations.

Lucinda oversees the bulk of Jackson’s treatment program and actively searches for new programs. She is beginning to feel tired most of her day from working and helping Jackson achieve his goals. She wants more help in providing treatment and ideas to make home life easier.

Jackson has trouble with social and comprehension skills. He is unaware of what is appropriate and inappropriate to say in front of others and in what contexts. He watches peers of his age from afar but does not know how to approach them. His comprehension skills stem from lacking the ability to understand humor, such as sarcasm, and metaphors to describe something else.

Communication style:
Lucinda is guarded with her life experiences and is not comfortable speaking with unfamiliar people. She is attentive to what the service provider is explaining and will consider the provider’s explanations and comments. She will ask questions regarding her child’s progress and how the program improved skills for children on the autism spectrum. Lucinda will not contradict with the service provider openly. If she does not feel the service provider and the company will help her son and optimize his results, she will look somewhere else for better treatment.
Family Simulation Card #10

Name: Lalita Kapoor
Age: 30
Race: Asian
Country of Origin: India
Spoken language(s): Hindi, English

Background:
Lalita was raised in Delhi, India with a traditional Indian family dedicated to education for all their children. Her father supported the family financially and her mother maintained the household and caregiver responsibilities. She is the youngest of four children and had more freedom from chores and expectations to start a family. She met her husband, Mahinder, at university while taking classes for a teaching degree. Lalita married Mahinder at the age of 19. Mahinder graduated with a degree in computer science. Soon after Mahinder graduated, he received an opportunity to move the United States for his career. Lalita was unable to complete her education before moving with her husband.

Lalita and Mahinder first moved to California and had their child, Chandra. Chandra was their first exposure to the world of autism. They were devastated with the news and prayed for a cure. The family moved to Dallas for a better job opportunity. Lalita and Mahinder found and received services for Chandra. The couple postponed extending their family for several years until the arrival of Kiran. Lalita and Mahinder discovered Kiran’s diagnosis of autism at the age of 3 years old. They experienced further disappointment because they had high hopes of Kiran supporting them and Chandra later in life. Mahinder supports his wife’s efforts to maintain the family home and children.

Lalita’s parents attempt to support the extra needs of the children but do not understand fully what autism entails and the difficulties the children have now and later in life. Both Lalita’s and Mahinder’s parents are unable to visit them for financial reasons. They feel supporting their grandchildren financially from afar is more effective than using their finances to visit.

Lalita is foremost concerned with communication. Kiran can tact items but has difficulty speaking in full sentences. Her second concern is expanding his food interests. She wants her child to have a vegetarian lifestyle and foods that are available in their culture. Kiran’s current eating habits are offensive to Lalita but she knows that for the time being it is necessary.

Kiran loves singing to himself, playing with musical toys and videos. He can sing full sentences but speaks few words at a time. He can navigate the internet searching for YouTube videos of his favorite movies and songs. His other interests are playing with figurines. He enjoys lining up figurines into a certain order and watches them for minutes at a time. Kiran rarely approaches his older brother for play interactions.

Communication style:
Lalita is very respectful with professionals. She will listen to everything the professional has to say before making a commitment. She will not disagree with the professional but state what she and the family do. Lalita is more comfortable with the professional taking the lead and will take some time to speak more about her family issues. She will answer a direct question but other concerns are addressed in an indirect manner. Any mention of difficulties the child has is more likely a concern she has and something the professional should focus on. When Lalita is with her husband, she will let Mahinder answer most of the questions.
APPENDIX J

ESATP PARENT INTERVIEW EVALUATION
# ESATP Parent Interview Evaluation

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<tr>
<th>Interview Features</th>
<th>Rating</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
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<td>Very Satisfied</td>
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<td>Were all important topics covered by these interview questions?</td>
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REFERENCES


Easter Seals North Texas. (n.d.). Texas Department of Assistive and Rehabilitative Services grant application: Services to children with autism. (RFA # 53802C10907). [Grant]


disparities in identification of children with Autism Spectrum Disorders.


