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**THE PROCESS OF DIAGNOSIS DELIVERY  
OF AUTISM SPECTRUM DISORDERS**

By

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## **ABSTRACT**

The process of diagnosis delivery of Autism Spectrum Disorders (ASD) is a topic area that has not been given ample attention by academic researchers. Some researchers have focused on delivering bad news (i.e. Buckman, 1992; Gordon, 2008; & Myers, 1983). Yet, no communication researcher has utilized communication theory and/or method to focus on diagnosis delivery of ASD. This study expands this area of focus in academic research using a communication perspective that provides an understanding of the process of diagnosis delivery of ASD at the Center for Developmental Disabilities' (CDD) Early Childhood Evaluation Program (ECEP)—New Mexico's number one center for providing a diagnosis of Autism Spectrum Disorders (ASD).

There are two goals that guide the study. The general goal is to investigate how professionals that are a part of the ECEP at the CDD at New Mexico's UCEDD at the UNM can co-construct an effective and efficient process of delivering diagnosis of ASD to parent(s), caregiver(s), and/or family member(s). Another goal is to modify and utilize the existing theory of the CMM for an academic research setting and provide another possible methodological approach for other research studies.

To attain the goals, this research utilizes the Coordinated Management of Meaning (CMM) as a theory and a method. The theoretical framework provides the communication perspective and understanding that the researcher is a part of the process that facilitates the process of understanding. Several concepts of the theory assist in making sense of the process, including: logical force, a communication perspective, stories, resources and practices, cosmopolitan communication, co-construction, reflexivity, and coordination, coherence, and meaning. The method provides several heuristics to collect and analyze data. The SEAVA model (Storyboarding, Enriching, Analyzing, Visioning, and Acting) is the main CMM model used in this research. Other CMM heuristics include: the daisy model, the hierarchy model, the Serpentine model, and the LUUUTT model. The researcher's data collection methods included: observations, individual interviews, and a group interview.

Through a reflexive process, the study explains how the diagnostic team creates meaning by identifying their communication patterns, rules of symbol use, rules of meaning and action, strengths and weakness of the process, and individual and team goals.

## Table of Contents

Table of Figures .....	xvi
CHAPTER 1 .....	1
INTRODUCTION .....	1
Site of Study.....	3
Social Constructionist Research .....	6
Rationale/Problem Statement.....	11
Key Concepts and Definitions .....	14
Chapter Preview .....	17
CHAPTER 2 .....	19
LITERATURE REVIEW .....	19
Related Themes.....	21
Interventions with Families.....	21
Non-Communication Interventions. ....	22
Communication Interventions.....	23
Family Interaction .....	24
Attachment Style.....	25
Family Stress.....	27
Communication with Persons with ASD .....	30
Health Communication .....	32
Professional-Patient Communication.....	34
Health Care Teams.....	35
Diagnosis Delivery.....	36
Studies on Autism .....	37



Studies on Family .....	39
Studies on Professional Training .....	40
The PACE Model for Diagnosis Delivery .....	41
Other Models of Diagnosis Delivery .....	42
CMM Research .....	43
CMM and ASD .....	44
CMM and Practice .....	44
Health Studies. ....	44
Intellectual Disability.....	46
Theoretical Background.....	48
Garfinkel and Ethnomethodology .....	48
Wittgenstein and Ordinary Language Philosophy .....	50
J.L. Austin and Performatives.....	51
Searle and Speech Acts .....	51
Shimanoff and Rules Theory .....	53
Conversation Analysis .....	54
Pragmatics of Communication.....	54
E. Rogers and Relational Communication.....	55
Pearce and the Coordinated Management of Meaning .....	55
Summary and Conclusions .....	57
CHAPTER 3 .....	60
METHODS .....	60
CMM as a Research Method.....	61

Method of Participant Observation .....	63
Method of Interviews .....	68
Selection of Participants .....	70
Avoidance of Risk.....	73
Research Stages .....	74
Stage 1—Orientation, Consent, and Initial Observations .....	74
Stage 2—Use of Storyboarding in Individual Interviews .....	77
Stage 3—Use of Storyboarding in the Group Interview.....	80
The Daisy Model.....	82
The Serpentine Model.....	83
The LUUUTT Model.....	84
Analysis.....	86
Chapter Summary .....	87
CHAPTER 4 .....	89
STAGE 1 RESULTS: ORIENTATION, CONSENT, AND INITIAL OBSERVATIONS .....	89
Procedures .....	89
Episodes of Observations.....	93
Episode 1: First Clinic Observation .....	93
Phase 1: Staff Meeting.....	94
Phase 2: Family Meeting. ....	94
Episode 2: Second Clinic Observation .....	95
Phase 1: Staff Meeting.....	95
Phase 2: Family Meeting. ....	95

Phase 1: Staff Meeting.....	96
Phase 2: Family Meeting. ....	96
Episode 3: Third Clinic Observation .....	96
Phase 1: Staff Meeting.....	96
Phase 2: Family Meeting. ....	97
Episode 4: Fourth Clinic Observation.....	99
Phase 1: Staff Meeting .....	99
Phase 2: Family Meeting. ....	100
Episode 5: Fifth Clinic Observation .....	103
Phase 1: Staff Meeting.....	103
Phase 2: Family Meeting. ....	104
Phase 3: Debrief.....	106
Episode 6: Sixth Clinic Observation.....	107
Phase 1: Staff Meeting.....	107
Phase 2: Family Meetin .....	107
Episode 7: Seventh Clinic Observation .....	109
Phase 1: Staff Meeting .....	109
Phase 2: Family Meeting. ....	110
Episode 8: Eighth Clinic Observation.....	111
Phase 1: Staff Meeting .....	111
Phase 2: Family Meeting .....	112
Episode 9: Ninth Clinic Observation .....	113
Phase 1: Staff Meeting.....	113

Phase 2: Family Meeting. ....	114
Episode 10: Tenth Clinic Observation .....	115
Phase 1: Staff Meeting. ....	115
Phase 2: Family Meeting. ....	116
Episode 11: Eleventh Clinic Observation .....	118
Phase 1: Staff Meeting. ....	118
Phase 2: Family Meeting. ....	119
Episode 12: Twelfth Clinic Observation.....	121
Phase 1: Staff Meeting. ....	121
Phase 2: Family Meeting. ....	122
Conclusions .....	123
CHAPTER 5 .....	127
STAGE 2 RESULTS: INDIVIDUAL INTERVIEWS .....	127
Interview Procedures .....	127
Interview Data.....	130
Question 1. ....	130
Question 2. ....	134
Question 3. ....	137
Question 4 .....	139
Question 5. ....	142
Question 6. ....	143
Question 7. ....	146
Question 8. ....	148

Question 9.....	149
Question 10.....	152
Question 11.....	154
Question 12.....	157
Question 13.....	159
Serpentine Model Questions.....	161
Conclusions.....	162
CHAPTER 6.....	164
STAGE 3 RESULTS: GROUP INTERVIEW.....	164
Interview Procedures.....	164
Facilitation Using Serpentine Model.....	168
Data from Serpentine Model Facilitation.....	171
Concern 1.....	171
Concern 2.....	172
Concern 3.....	172
Concern 4.....	173
Concern 5.....	173
Concern 6.....	174
Concern 7.....	174
Concern 8.....	174
Facilitation Using the LUUUTT Model.....	176
Data from LUUUTT Model Facilitation.....	177
Team Functioning.....	177

Involvement with Early Intervention Teams .....	179
Family Experience. ....	180
CHAPTER 7 .....	183
DISCUSSION AND CONCLUSIONS .....	183
Findings.....	183
RQ1: What communication patterns do ECEP professionals commonly use in episodes of diagnosis delivery at the ECEP?.....	183
RQ2: What rules of symbol use, meaning and action guide the patterns of communication used by professionals during diagnosis delivery? .....	186
Family .....	186
Process .....	187
Team .....	188
Communication.....	188
Rules of Symbol Use. ....	189
Rules for Meaning Making. ....	189
Rules for Action .....	191
RQ3: What strengths and weaknesses do ECEP professionals identify about their own communication practices?.....	193
RQ4: What goals would the professionals like to accomplish with their communication patterns? .....	195
The Communication Patterns.....	196
The Rules of Meaning and Action. ....	197
Norms about the Communication Practices.....	199

Reflections on Method .....	201
Reflections on Theory .....	203
Limitations .....	205
Future Research .....	206
Follow-up .....	207
Appendix A .....	208
Appendix B .....	210
Appendix C .....	212
References .....	213

## List of Figures

Figure 1: Proposed Theoretical Framework .....	40
Figure 2: The Hierarchy Model .....	79
Figure 3: Strange Loop .....	79
Figure 4: The Daisy Model .....	82
Figure 5: The Serpentine Model .....	83
Figure 6: The LUUUTT Model .....	84
Figure 7: Serpentine Model .....	162
Figure 8: ECEP Serpentine .....	166
Figure 9: Vertically Extended ECEP Daisy .....	167
Figure 10: ECEP Daisy .....	168
Figure 11: Concern .....	169
Figure 12: Complex Element .....	170
Figure 13: LUUUTT Model.....	176
Figure 14: Hierarchy Model of Contexts .....	199



## List of Tables

Table 1: SEAVA .....	63
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# CHAPTER 1

## INTRODUCTION

In a recent National Health Statistics Report, Blumberg et al. (2013) discussed the increase in parent-reported prevalence of Autism Spectrum Disorders (ASD) amongst school-aged children. The results indicated 1 in 50 school-aged children have ASD, a considerable increase since the 2007 survey (Blumberg et al. 2013). ASD are complex neurological disorders; “these disorders are characterized in varying degrees, by difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviors” (Autism Speaks, 2013). Many studies have sought to develop a better understanding of ASD. As researchers seek to know more about ASD, it becomes clear that very little is actually known. Many have stated, “If you have met one person with ASD, then you have met one person with ASD.” This statement explains that ASD span a large breadth of difference. As scholars continue to study ASD, the definition of ASD is altered; even the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), which came out in 2013, changed the spectrum and the criteria for diagnosis.

Much research continues to focus on intervention, family interaction and communication with persons with ASD. Pharmaceuticals are one feature of intervention by researchers that focus on non-communicative intervention (Benvenuto, Battan, Porfirio, & Curatolo, 2013). Others also stress non-communicative intervention through the use of technology (Dickstein-Fischer et al. 2011; Mazzei et al. 2011). Other scholars take a communicative approach to intervention. For example, Wright et al. (2012) utilized workshops to strengthen relationships; and Boutot and Dukes (2011) stressed Discrete Trial Trainings (DTT) about interactions between a trainer and a person with

ASD. Extending the focus from interactions with a trainer to family interactions, Sigman and Ungerer (1984) emphasized attachment styles of children with ASD. Other researchers elaborated on the idea of family interaction patterns of children with ASD (e.g. Bowlby, 1969; Capps, Sigman, & Mundy, 1994; Collins & Freeney, 2004; Crowell & Feldman, 1989; Dissanayake & Crossley, 1996; Domingue & Mollen, 2009; Donaldson, Elder, Self, & Christie, 2011; Farinelli & Guerrero, 2011; Rutgers, Bakermans-Kranenburg, Van IJzendoorn, & Van Berckelaer-Onnes, 2004; Schieve et al. 2007; Sigman & Mundy, 1989). Continuing with the lens on families, several other researchers examined a variety of elements related to family stress (e.g. Benson, 2006; Boutot & Walberg, 2011; Hall & Graff, 2011; Karst & Van Hecke, 2012; Lecavalier, Leone, & Wiltz, 2006; Plant & Sanders, 2007; Rao & Beidel, 2009; Read & Schofield, 2010; Strauss et al. 2012; Zaidman-Zait et al. 2011). Communication was a key element in many of the aforementioned research studies stressing communication with persons with ASD (e.g. Lee, Walter, & Cleary, 2012; Miller, 2008; Sigafoos, Schlosser, O'Reilly, & Lancioni, 2011). These studies comprise the foundation for this research study, but I move this study in a new direction by emphasizing how the diagnosis of ASD is communicated to family members and caregivers by a team of clinicians.

The prevalence of ASD increases the exigency for better understanding the many elements of ASD (i.e. communication, family interaction, health care, etc.). Although much research has been done in the area, there is still much more unknown than is known. The general goal of my study is to investigate how professionals that are a part of the Early Childhood Evaluation Program (ECEP) at the Center for Development and Disability (CDD) at New Mexico's University Center for Excellence in Developmental

Disabilities Education, Research and Service (UCEDD) at the University of New Mexico (UNM) can co-construct an effective and efficient process of delivering diagnosis of ASD to parent(s), caregiver(s), and/or family member(s). Another goal is to modify and utilize the existing theory of the Coordinated Management of Meaning (CMM) for an academic research setting and provide another possible methodological approach for other research studies. One objective of the research is to assist the professionals at the ECEP in developing and understanding an effective way of delivering the diagnosis of ASD. A second objective of my study is to introduce a new research methodology for academic research. This introduction outlines the process for achieving these goals through 1) describing the site of the study; 2) explicating the social constructionist research; 3) stating the rationale with a preview of the research questions; 4) providing key concepts and definitions; and 5) previewing the following chapters.

### **Site of Study**

I chose the CDD as my site of study for the following reasons. First, the CDD is a research center that is affiliated with the campus where I am completing my dissertation. Second, this location is a state of the art research center that is the leading location for the diagnosis of ASD in the state. Third, the CDD has an existing program specific to early childhood diagnosis that involves communicating with the family members about the diagnosis.

As a family member of persons with ASD, I want to understand interactions with them as well as help to improve the lives of individuals with ASD. After meeting several professionals that work with individuals with ASD, I began to understand the importance of early childhood diagnosis. After taking courses on ASD at the University of New

Mexico (UNM), I was able to establish communication networks with individuals who work with children and family members of children with ASD.

Through these experiences, I learned about a local center that focuses on early childhood diagnosis CDD, which was the site for my dissertation study. The CDD is “New Mexico’s University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD)” (UNM Center, 2014). The CDD, established in 1990, consists of “centers that are authorized by the Developmental Disabilities Assistance and Bill of Rights Act to build the capacities of states and communities to respond to the needs of individuals with developmental disabilities and their families.” It is also an “organization in the Association of University Centers on Disabilities Research, Education and Service (AUCD)” (UNM Center, 2014). Funding for this center is provided by the Administration of Intellectual and Developmental Disabilities (AIDD), state contracts, federal grants and private funding. There is one CDD in the state of New Mexico; however, there are 67 centers across the nation that create a national network of programs for those with ASD, and at least one center exists in each US state and territory. The national network of programs has a mission of “full inclusion of people with disabilities and their families in their community by engaging individuals in making life choices, partnering with communities to build resources, and improving systems of care” (UNM Center, 2014, [www.cdd.unm.edu](http://www.cdd.unm.edu)).

The CDD in New Mexico currently has 47 programs. One program at the CDD aligns well with my interest of early childhood diagnosis and treatment; the program is the Early Childhood Evaluation Program (ECEP). The ECEP is a program that “provides evaluations for children ages birth to 3 living in New Mexico. ECEP addresses concerns

regarding developmental delay, complex medical conditions, Autism Spectrum Disorders, cerebral palsy, behavioral/regulatory issues, and other specialized evaluation questions for young children” (UNM Early, 2014, [www.cdd.unm.edu/ecep/index.html](http://www.cdd.unm.edu/ecep/index.html)). Early diagnosis is key to the goals of this program.

Funding for the program is provided by “the New Mexico Department of Health, Family Infant Toddler Program (NM FIT) and the New Mexico Public Education Department. ECEP’s administration is provided through UNM, Health Sciences Center, Department of Pediatrics, Center for Development and Disability” (UNM Early, 2014, [www.cdd.unm.edu/ecep/index.html](http://www.cdd.unm.edu/ecep/index.html)). The ECEP has evaluated children with complex medical and developmental issues for more than 20 years. The program utilizes a team approach that includes family members, service providers and ECEP staff. Members of this team constitute participants of my study. The ECEP staff includes a combination of pediatricians, psychologists, speech-language pathologists, physical therapists and occupational therapists. The staff evaluates children in all parts of the state. Some concerns that are evaluated relate to “developmental delay, complex medical conditions, [A]utism [S]pectrum [D]isorders, cerebral palsy, behavioral/regulatory issues, and other specialized evaluation questions” (UNM Early, 2014, [www.cdd.unm.edu/ecep/index.html](http://www.cdd.unm.edu/ecep/index.html)). The ECEP as a part of the UNM Health Services Center serves as “a training site for a variety of students, trainees, and professionals who often observe and/or participate during ECEP evaluations” (UNM Early, 2014, [www.cdd.unm.edu/ecep/index.html](http://www.cdd.unm.edu/ecep/index.html)). This location is an ideal site for the Ph.D. research I conducted.

Based off of the 2012 ECEP Annual Report, there were 285 children seen by the professionals of the ECEP. In each evaluation, a team of professionals conducts the evaluations. The team consists of four professionals: 1) a physician or nurse practitioner, 2) a developmental/clinical psychologist, 3) a speech-language pathologist, and 4) a physical or occupational therapist. From the evaluations in 2012, 30% of the children were diagnosed with ASD (2012 Annual Report), which shows the ECEP is a prominent site for ASD diagnosis and for this study.

### **Social Constructionist Research**

The site of the ECEP is an ideal location for me to use the interpretive research perspective because this site permits me to study interactions, the symbols that constitute them, the significant others involved in the interactions, and the strategies used in these interactions. Focusing on these elements assisted me in developing an emic perspective of the interactions during the diagnosis delivery at the ECEP. An emic perspective means developing an understanding of the culture through the community members that (re)create the culture. By focusing on an emic perspective, the study lends itself to the use of ethnomethodology. I explore the history of ethnomethodology and other twentieth century methodologies that influence and shape CMM and propose CMM as my research method in more detail in Chapter 3. I briefly mention my social construction worldview here because CMM is part of this interpretive paradigm.

A constructionist viewpoint identifies the relationship between the persons, symbols, and the objects in their social reality; the signs and symbols connect persons one another in social reality (Littlejohn & Foss, 2010). As a social constructionist, I assume that “meanings are developed in coordination with others rather than separately

within each individual or in the world of things, making social interaction the loom upon which the social fabric is woven” (Leeds-Hurwitz, 2009, p. 892). In my study, the coordination element of this research is demonstrated by the focus on the collaboration professionals engage in when delivering the diagnosis. By first observing the delivery of diagnosis, I can locate elements of the symbolic constructions of the communicators as they take place in a clinical setting. Then, during the interviews with the professionals, I can identify narratives and language patterns that participants use. By sharing narratives and constructing their stories, the professionals “make sense of [their] experience and give it shape” (Leeds-Hurwitz, 2009, p. 894). Thus, as an interviewer, I can learn how to study how participants make meaning when delivering the ASD diagnosis.

Making sense and giving meaning demonstrates elements of my research assumptions. I identify with Anderson and Baym’s (2004) discussion of language and communication as neither referential nor post priori, but as ontologically constitutive. Growing out of Wittgenstein’s concept of language games, I understand individuals as primarily linguistic beings who exist within and through dialogue and interaction. The fundamental objects of explanation are communicative action and localized patterns of shared meaning, so I give special attention to the discourses that I observe and those that emerge from interviews. Similarly, I understand truth to be created in conversation; knowledge is not found in an individual’s mind; knowledge is part of the communicative process that is constructed in the mind. Knowledge is constructed in part by the justifications that people use within communities that accept the content of shared information as truth. For example, as part of the ECEP evaluations, providers try to convey a diagnosis they believe is true and give justifications for their diagnosis.



Therefore, knowledge differs across groups, communities, cultures, boundaries, etc.

Since developing an understanding from a research perspective is constructed within the group, then developing an understanding of what is true for a specific group without interacting with the group is not possible.

Understanding the importance of systems theory is embedded in this perspective. The ECEP is part of a communication system in general and a clinical communication system in particular. Littlejohn (2009b) explains, “A human system such as an organization achieves its unique character through the interaction patterns among persons and groups. This quality of systems makes the parts interdependent: they affect one another and create something together that no one part could construct alone” (951). A system also has permeable boundaries. Observers can set the boundary wherever; “[h]owever, once an observer looks at a system, he or she becomes part of that system because looking itself influences what is happening. This view, known as second-order cybernetics, takes system theory into a new and exciting direction” (953). The ECEP has a system for delivering the diagnosis of ASD; from the outside it is possible to look at the website and see the parts of the system and how they are interdependent on one another. Team members have specific roles in the system; there is an evaluation process; there are discussions among team members; community members play a role in the system, etc. Although gathering an idea of the clinical system from the website is possible, by physically looking at the system, I further understand that my participation affects and influences the system. Through observing and interacting with the clinical system and its participants, I developed a better understanding of the system and the elements/processes of the system.

The reflexive relationship between myself as the observer and the clinical system of the ECEP forms a cybernetic loop. “Because everything is systemic, knowledge itself is always constructed in this cybernetic loop between the knower and the known. The categories and methods used to observe shape what is seen, and once viewed, the observed phenomenon shapes the categories and methods of observation. As a result, theorists and researchers are never separate and outside of the systems they purport to explain” (p. 953). As a researcher, I reflected on my observations and interactions to understand this clinical system and its participants without separating myself from the system. There are several parts and participants involved in the clinical system of the ECEP. Although I do not fully understand the system, I am aware of some of the parts and participants. Participants involved at the ECEP include pediatricians, psychologists, speech-language pathologists, physical therapists, occupational therapists, the child’s family, and service providers; elements of the evaluation process of the clinical system include a two hour assessment, one hour break, and a one hour meeting where results and recommendations are shared with the family and providers; parts of the clinical system outside of evaluation include weekly meetings, emails, work office conversations and discussions, as well as reading and research.

Taking a systems approach reveals that the mere act of observing a system changes the system. Cronen (In Anderson & Baym, 2004) looked at theory as a way to improve human systems through empirical research that was fixed in observations rather than ideas, which is a perspective I hope to employ in my research. Although I do not try to impose my methodological practice or theoretical framework on others, I closely identify with qualitative methodologies and social construction theories that also

demonstrate my value-based assumptions. I understand research to be subjective rather than objective, and value-intended rather than value-free. Separating my values from research is impossible; I do not conduct research with a completely clear slate. However, I identify my values and reflect on my experiences when appropriate to distinguish my understanding from that of the community I am researching.

Reflecting or more specifically the element of reflexivity recognizes that people create, contribute, and reshape knowledge; individuals create and use and knowledge as part of a loop: individuals affect knowledge and knowledge affects individuals. Individuals create meaning by having resources to impact their understanding, Gadamer's inter-determinancy allows the creation of individual meaning. For example, the resources offered by the clinical system and members of the ECEP had an impact/(re)constructed my meaning of delivery diagnosis of ASD. Understanding that people socially construct understandings of episodes of communication originates from Watzlawick, Beavin, and Jackson's (1967) axiom of the punctuation of the sequence of events. When new information is provided, an individual is able to reconstruct his/her understanding of an interaction. During each interaction at the site when new information is gathered regarding the delivering of diagnosis of ASD, my understanding was reconstructed or modified by my reflections on that interaction. When I discussed and interacted with members of the ECEP, all of our understandings were reconstructed through the discussion about the process.

Construction and reconstruction of understanding and meaning is fundamental to the Coordinated Management of Meaning (CMM), the specific social constructionist worldview that I take as a researcher and adopt in my daily life. Utilizing this

interpretive, systemic perspective is key to understanding how I make sense and construct meaning with a goal of understanding human communication in a clinical system. Some tools that are relevant to this focus include: observations, interactions, and the process of reflexivity.

This study extends theory about how people in health care teams communicate with one another and how these communication practices influence the delivery of diagnosis especially of ASD diagnosis by providing a communication perspective and gaining an understanding of the process by observing and working closely with the professionals on the health care team. The outcome provides insight on the communication interactions of health care team members in the specific setting of professionals that deliver the diagnosis.

### **Rationale/Problem Statement**

Social construction research is important in any context that seeks understanding of the inception, maturation, and exemplification of a social group, organization, community, etc. A variety of scholarly research utilizes a constructionist perspective. Yet, constructionism is not a typical approach in diagnosis delivery. Research studies in diagnosis delivery demonstrate a variety of conditions that range from cancer to Down syndrome. This section provides an introduction to the research done in the area and uses it to establish a rationale for my research project.

Research exists on diagnosis delivery for medical, pediatric, Autism, behavioral medicine, medical genetics, childcare, oncology, and physician-patient studies. Relatively little research has been done on delivery diagnosis of ASD. Rather, the focus of current research on Autism includes: intervention, family interactions including stress

and attachment styles, communicating with persons with ASD, and professional-patient communication. My dissertation research builds upon theories of the delivery of diagnosis, which means it introduces new concepts regarding the process of sharing information related to the medical diagnosis of an ailment, disease, disorder, etc. For example, Gordon (2008) gave the following advice about delivering diagnosis to those with cancer. He mentioned that professionals should provide hope and reassurance; be sensitive of cultural differences; and have self-awareness. The diagnosis of cancer differs from that of ASD in several ways. My study took into account these differences and explains how the delivery of diagnosis needs to be done differently.

Another study by Dent and Carey (2006) concluded that the generally accepted guidelines for delivery have not been supported with evidence or research. They provided a basic framework for delivery in a newborn setting as well as two recommendations: 1) professionals should be trained with a specific focus on delivering difficult news; and 2) each health organization should develop an individualized system for assuring updated and relevant information as well as referral information. The results are relevant to the study of diagnosis delivery of ASD, and I expand upon the conclusions by further research in the area. I also take into account how and why these recommendations can be included. As my literature review indicates, existing theories need to be expanded in order to study delivery of diagnosis of ASD.

Research in health communication is connected to my study because a body of that research emphasizes patient-provider interaction. Several researchers investigated patient-provider interactions—the communication and interactions between the health professionals and the individuals they see and help. Roter and Hall (2011) provided

information on patient-provider communication in general. They stated, “Interaction is the fundamental instrument by which the doctor-patient relationship is shaped and through which medical care is directed” (p. 55). They went on to discuss national reports that “have focused attention on the centrality of patient-centered communication to the safe delivery of quality medical care and the practice of ethical medicine” (Roter & Hall, 2011, p. 56). Having a patient-centered approach to communication has many benefits that range from trust and comfort to medical safety. My study takes a quasi-patient-centered approach to communication in a clinical context by stressing the delivery of the diagnosis of ASD; it also helps to fill in the gap in health communication research related to provider communication by including how teams of clinicians deliver the diagnosis to families of patients with ASD, a neurological disorder.

The field of communication has much to contribute to the literature. Providers are typically not aware of the intricacies of the communication process; my study fills this gap by providing concepts and units of analysis that go far beyond the existing literature about information and interaction in clinical settings and introduces and explains the content and relationships embedded in information and the complexities of different types of interactions.

This project adds communication theory and methodology to the literature on diagnosis delivery. As a preview, the research questions that shape the research method follow:

RQ1: What communication patterns do ECEP professionals commonly use in episodes of diagnosis delivery at the ECEP?

RQ2: What rules of symbol use, meaning and action guide the patterns of communication used by professionals during diagnosis delivery?

RQ3: What strengths and weaknesses do ECEP professionals identify about their own communication practices?

RQ4: What goals would the professionals like to accomplish with their communication patterns?

### **Key Concepts and Definitions**

In order to address the aforementioned research questions, certain key concepts and definitions are needed. The underlying element for this research is meaning making; there are several elements involved in the process of *making meaning*. The three main concepts are *coordination*, *coherence* and *mystery*; Pearce (1999 & 2007) mentions that the events of our social worlds can be evaluated through these three concepts.

*Coordination* refers to the joint activity in social interactions that instills a flow of conversation through managed turn taking among the individuals involved in an interaction. Coordination occurs if communicators organize meanings and action into some kind of pattern that makes sense to them. Through coordination, one is able to focus attention on patterns produced by the interconnectivity of participants' actions. By looking at all interactions as interrelated, one views interactions as a part of a system. One who exploits coordination assumes that nothing can ever be exactly articulated for understanding since there are an infinite number of contexts and relationships that play into the meaning. Through coordination, persons collaborate in an attempt to bring into being their vision of what messages and interactions are necessary, noble, and good and to preclude the enactment of what they fear, hate, or despise.

Through *coherence*, people create meaning through the stories that they tell or are told. By utilizing CMM, one realizes that the stories that are ‘told’ do not always align perfectly with the stories that are ‘lived’ (Pearce, 2007). Lived stories are the co-constructed actions individuals perform with others. The told stories are the narratives that individuals use to make sense of their stories lived. Meaning making includes the management of meaning (coherence) which involves the adjustment of our stories told to fit the reality of stories lived or vice versa. Individuals make choices about which story to tell and how to share each story. Utilizing a CMM framework requires researchers to understand that context plays a significant role in each story that is told and the meaning that is attributed during interactions about ASD diagnosis. When there is consistency and clarity in an interaction, there is coherence. *Mystery* accounts for the inability to consider the infinite relationships and contexts that play into each conversation; the universe contains far more stories than the stories that one knows and uses to make sense of it (Pearce, 2007). Mystery also accounts for the change that occurs in the stories people share, live, and perceive. Mystery is part of the interaction of participants in the clinical system of the ECEP, but I was not able to consider the infinite relationships and contexts that contributed to each professional’s viewpoint.

Looking at meaning making through coordination, coherence, and mystery, indicates the importance of *communication messages*. Communication messages are sequences of interactions that construct meaning among communicators. The primary focus on communication messages in this study is the process professionals use for sharing messages with family members about ASD in order to make meaning. Focusing on the process of coordination between the professionals of the ECEP allows everyone



involved to see how the diagnosis delivery is constructed. Then, messages can be shared about the existing process to enhance the communication process and achieve a better outcome for the diagnosis delivery. By better outcome, I mean a feeling of satisfaction felt by all professionals a part of the ECEP that they did the best possible job at delivering the diagnosis of ASD; the outcome is better than previous situations where professionals may not have felt the diagnosis was delivered in the best possible way. All professionals involved use communication practices that contribute to the process. Some of the practices may enhance and others may impede this process.

Through communication, professionals demonstrate relationships and content. One axiom of communication defined by Watzlawick, Beavin, and Jackson (1967) states that all communication has a content and relationship aspect. There are two levels that are referred to by this axiom: the report and command level. Report refers to the content, and command defines the relationship and explains how to understand the content. A second axiom that relates to CMM is the punctuation of the sequence of events. This axiom demonstrates that we socially construct our understandings of *episodes* of conversation. Episodes of communication are compilations of acts that can be seen as a part of a larger conversation; each episode is different from a previous or future episode. For example, the messages and reactions to these messages are acts that occur during the evaluation stage of the ECEP can be considered an episode. One evaluation episode was not the exact same as the previous evaluation or the next evaluation. When new information is provided and new messages are constructed (i.e. a different way of punctuating an episode of conversation), an individual is able to reconstruct his/her understanding of the interaction. The ideas of episodes, punctuation, social construction

and reconstruction found in these axioms established concepts and parameters for my use of CMM in analyzing data I gather from my observations and interviews at the ECEP.

Episodes, punctuation, social construction and reconstruction are terms that are useful for explaining elements of communication practices that occur during the data collection stage of this dissertation. An episode, in short, refers to a communicative interaction. Several episodes of communication play a role in the (re)construction of meaning. Since identifying the actual beginning of any episode is not possible, punctuation helps to put a beginning and end to an episode. Punctuation, as briefly mentioned above in the axioms of communication, refers to how an episode is defined; a certain point is identified as the beginning and a certain spot is marked as the end. The application of the punctuation stems from the understanding how our meanings are socially constructed and reconstructed in communication. I further develop these concepts Chapter 3 as part of my observations, individual interviews and group interviews that I use to collect data.

## **Chapter Preview**

This dissertation is organized strategically to provide the clearest rationale, explanation, and summation of the actions during planning, executing, finalizing, and summarizing this study. In the subsequent chapter, I review the literature to explore the (re)construction of delivering the diagnosis. After reviewing the literature, I provide a rationale for utilizing ethnomethodology through a CMM framework. Chapter 3 demonstrates the importance of utilizing an innovative qualitative method for exploring the process of delivering the diagnosis of ASD. Chapter 4 explains procedures and data gathered from observations. Similarly, chapter 5 explains the procedures and data

gathered from individual interviews. Chapter 6 then explains the procedures and data gathered from the group interview. Chapter 7 provides answers to the research questions and reflects on the theory and method and offers other implications of this study.

***Keywords: Autism, ASD, CMM, bad news, informing patient of diagnosis, informing interview, diagnosis delivery***

## **CHAPTER 2**

### **LITERATURE REVIEW**

The Communication discipline offers beneficial methods and theory for research on ASD; specifically, I examine a key moment in the lives of individuals with ASD, the diagnosis. Existing research has not looked at the interaction between professionals and parent(s), caregiver(s) and/or family member(s) of individuals with ASD. The aim of this chapter is to review current research on interactions with individuals with ASD by looking at intervention techniques, health communication studies, and relevant literature that discusses delivery of diagnosis. Additionally, this chapter reviews literature on the Coordinated Management as one way to interpret the communication that takes place by professionals with families of those being diagnosed with ASD.

My strategy utilized in this review process identifies research in key areas. The first phase surveyed relational communication books (DeVito, 2009; Duck, Starch, & Starch, 2010; McCornack, 2013; Mottet, Vogl-Bauer, & Houser, 2012) for theory and research affiliated with mental illness, intellectual disability, or health conditions and interactions or relationships. There is not a focus in the interpersonal communication literature that discusses relationships with individuals with a mental illness, intellectual disability, or health condition. The second step involved looking at current research on ASD; many studies that are mentioned later include elements of communication in intervention strategies without including concepts, theory or methods from the communication discipline. A third element focused on health communication research and determined significant implications from research projects.

I understand that one study cannot encompass all of the relevant literature for such a broad category. Instead, this chapter explores a new area of focus by combining three key areas of research interest: the Coordinated Management of Meaning (CMM) of interpersonal communication; provider-patient interactions in health communication; and diagnosis delivery of ASD. Reviewing the current practices in each area revealed fruitful research that focuses on interaction, communication, and intervention. The research presented here demonstrates some of the relationships between communication theories and interactions between professionals and family members of individuals with ASD.

My assumptions about communication are located in a worldview that focuses on the interactions between and among people, CMM (Pearce, 1987; 2007). CMM grows out of the social constructionist perspective and utilizes the communication perspective, which looks at communication rather than through communication. Through description, explanation, and intervention, researchers look at unique processes of creating better patterns of interaction. Briefly, CMM's assumptions and principles provide a way to study a) "the frames we [human beings] employ to process and perceive our experience, b) the language we use and the stories we tell to name our experience, and c) the actions we take, which affect what we make together" (Pearce, Sostrin, & Pearce, 2011 p 5). Coordination, coherence, and mystery are key concepts in making sense of the social worlds that *we* create collectively (Pearce, 2007).

This review of literature is organized into six overall categories, including: related themes, research in health communication, diagnosis delivery, related CMM research, a theoretical context and summary and conclusions. Within each category are subcategories that are more specific, including intervention, family relationships,

communicating with persons with ASD, professional-patient communication, Autism studies, parental delivery issues, the PACE Model, diagnosis delivery of other conditions, CMM and ASD, other related CMM research, Garfinkel and Ethnomethodology, Wittgenstein and Ordinary Language Philosophy., J.L. Austin and Performatives, Searle and Speech Acts, Shimanoff and Rules Theory, Conversation Analysis, Watzlawick and Pragmatics, E. Rogers and Relational Communication, and Pearce and the Coordinated Management of Meaning. Some subcategories have a third layer including: non-communication interventions, communication interventions, attachment style, family stress, health care settings, and intellectual disability. The conclusion of this review summarizes what is known, what gaps exist in research, and what research questions I suggest.

### **Related Themes**

Throughout the process of reading literature on ASD, a few key themes emerged from the information. The themes listed include intervention, family interaction, and communication with persons with ASD. Each theme is discussed below.

#### **Interventions with Families**

The focus of much research on ASD is intervention. Intervention-oriented communication research is ‘first-person-perspective research’ and ‘engaged scholarship’ (Frey & Sunwolf, 2009). The styles of intervention utilized in research with individuals with ASD range from a pharmacological approach to technological approaches. Although communication intervention strategies are most relevant, I briefly introduce other areas of focus for intervention to increase the breadth of intervention as a process and practice.

**Non-Communication Interventions.** One area of intervention involves pharmaceuticals. Benvenuto, Battan, Porfirio, and Curatolo (2013) reviewed the main concerns of pharmacologists for individuals with ASD. They use drugs to manage comorbid symptoms (i.e. aggression, irritability, and self-injurious behaviors; hyperactivity/inattention symptoms; and stereotypy/repetitive behaviors). This resembles a typical medical model. The authors demonstrated the promising results of certain antiepileptic drugs and selective serotonin reuptake inhibitors and explained the mere potential benefit rather than guaranteeing the effectiveness for all individuals with ASD. The pharmacological approach is the dominant intervention for individuals with ASD even though there is a lack of evidence about the success of these medications. One contributing factor, but an underdeveloped idea of this research, is the role of parental stress and family needs of family members of a person with ASD.

A second area is technological intervention, a relatively new area that is growing quickly with the rapidly evolving technological knowledge. Dickstein-Fischer et al. (2011) presented their proposal of a pilot research project that utilizes a compact humanoid robot for ASD interventions. The authors assumed that the robot would provide simple emotional responses and interaction, which could benefit peer relationships for children with ASD. Mazzei et al. (2011) also discussed the idea of using a social robot. These researchers utilized FACE Theory (FACET) with a humanoid platform. FACET is an application designed for Human Robot Interaction (HRI) studies for individuals with ASD; the application involves a Facial Automation for Conveying Emotions (FACE) android, a multi-sensory room, and a psychologist to operate a stepwise protocol with the android and person with Autism. FACE, an artificial

humanoid head, focuses on facial expressions. Although the researchers claim the therapy demonstrated positive effects, there were only 6 participants in the study, 4 participants with ASD and 2 control participants. The authors concluded that the children with ASD accepted the humanoid and that the FACET can be used as therapy for social skills. In contrast, my study emphasizes face to face interaction between professionals and families of those diagnosed with ASD.

**Communication Interventions.** One other study focused on grandparents of grandchildren with ASD and strengthening relationships through technology. Wright et al. (2012) utilized workshops for young children with ASD. During the workshops, the children used computer programming that focused on social interactions. The researchers then conducted focus groups with the grandparents after six weeks of the therapy. The grandparents revealed that their grandchildren increased the social interactions with peers, parents, siblings, and grandparents. As technology continues to advance, more studies emerge that look at the benefits of using technology for individuals with ASD. Those studies that combine technology with human interaction show promise, because they focus on communicative practices, but they are not yet available in the clinical site where I conducted my research.

Lastly, the most relevant area of intervention involves communication strategies. Goldstein (2002) emphasized communication interventions for children with Autism. He reviewed 60 studies over a 20-year period that were primarily from the descriptions of psychology, special education, and communication sciences and disorders. This review identified intervention strategies ranging from parent training group meetings to discrete trial trainings [interventions that utilize the Applied Behavior Analysis (ABA) theoretical



framework; discrete trial trainings utilize a three-term contingency of antecedent provided by the trainer, response from child, and a consequence that rewards or marks the response (Boutot & Dukes, 2011)]. Of the studies, he concluded six primary areas of focus including: communication interventions incorporating sign language; intervention incorporating discrete trial training formats; interventions designed for implementation in the natural milieu; communication interventions to replace challenging behavior; interventions to promote social and scripted interactions; and classroom and parent interventions applied to groups. Several interventions involved training the parents and family support members: training parent groups; teaching parents behavioral techniques; presenting lectures and conducting consultations for daycare staff, parents, and family support; introducing modeling, rehearsal, and token reinforcement to help parent/adult interventions; social-interactive training with parent/adult partner; teaching parents Natural Language Paradigm (reinforce attempts, turn taking, vary task, and share control); instructing parents in time-delay procedures; and informing parents about the way to use signs.

### **Family Interaction**

Throughout the aforementioned interventions, researchers stressed the importance of social interactions and relationships. In the studies mentioned, parents, grandparents, and siblings served as the primary interveners with individuals with ASD. The importance of informed and caring relationships with family members represents another area of emphasis, family interaction. Research on family interaction falls into the categories of attachment style and family stress.

**Attachment Style.** Although the importance of relationships appears in the literature of several disciplines, such as psychology, psychopathology, psychiatry, pediatrics, child development, at this point in time communication scholarship has not contributed to this area of research. When seeking studies on relationships with individuals with ASD, the majority of the results focused on attachment styles in parent-child relationships. In 1984, for example, Sigman and Ungerer discussed attachment behaviors in children with ASD. Attachment behavior relates to attachment theory, which identifies styles of attachment of the caregiver's behavior that has positive or negative effects on health (Farinelli & Guerrero, 2011). Sigman and Mundy expanded on this research in 1989 and identified the social attachments of children with ASD. In the same year, Crowell and Feldman (1989) assessed working models of relationships of mothers and children with a specific focus on children with mental health needs. They characterized parent-child relationships through parents' childhood histories and laboratory play sessions. After providing case study examples, the authors supported the approach of characterizing relationships through parents' childhood histories through demonstrating that parents' behaviors were associated with their childhood histories. After focusing on the mother-child relationship, Capps, Sigman, and Mundy (1994) shifted the focus to levels of secure attachment in children with ASD. They determined that children with ASD that displayed underlying secure attachments demonstrated more requests, responded more often to bids for attention, and exemplified receptive language more so than children with ASD that demonstrated insecure attachment styles. Dissanayake and Crossley (1996) also focused on attachment when looking at sociable behaviors in individuals with ASD.

In 1997, Dissanayake and Crossley redirected the concentration of attachment styles to separation and reunion of children with ASD with their mothers. In 2004, a meta-analysis of research focusing on attachment styles and Autism was conducted (Rutgers, Bakermans-Kranenburg, Van IJzendoorn, & Van Berckelaer-Onnes). Rutgers, Bakermans-Kranenburg, Van IJzendoorn, and Van Berckelaer-Onnes (2004) concluded that children with Autism were less securely attached to their parents than children without Autism. Yet, the authors concluded that children with ASD showed signs of attachment security. For example, although lower than control group members, when choosing between a stranger and the mother, children with ASD clearly preferred their mothers. Also, after a period of separation, children with ASD increased the proximity seeking with their mothers. Mothers were preferred, because they provided security. The analysis demonstrated that promoting secure attachment relationships may be a protective factor that provides a positive prognosis for social development for children with ASD (Rutgers, Bakermans-Kranenburg, Van IJzendoorn, & Van Berckelaer-Onnes, 2004; Capps, Sigman, & Mundy, 1994). The review of parent-child relationships in the literature implicitly identified communication between parents and children as an important element that should be further examined as part of the delivery of ASD diagnosis.

The majority of research stresses the parent-child relationship with mothers, and the majority of research on attachment styles has been conducted with mothers (e.g. Bowlby, 1969; Collins & Freeney, 2004; Domingue & Mollen, 2009). Donaldson, Elder, Self, and Christie (2011) focused on interactions with fathers after providing in home training for fathers to enhance the parent-child interactions. Another study looked at

parent-child relationships (Schieve et al. 2007) and introduced the element of parenting stress as it related to children with ASD. Schieve et al. supported a need to consider the effects on the family of planning services for family members of children with ASD. The authors called for future studies to expand on research regarding stress that has impact on family members. Communication research has focused on communication patterns that increase stress levels and family conflict from negative communication practices of family members (Wilmot & Hocker, 2011). More specifically, studying ways to relieve stress in families of children with ASD through communication practices is needed.

**Family Stress.** Families with a member(s) with an ASD face many obstacles and burdens that increase the stress levels of members. Boutot and Walberg (2011) discussed obstacles related to caring for the child, emotional burdens, expenses, time requirements, to name a few elements that lead to family stress. Hall and Graff (2011) utilized the PSI-SF to measure parental stress. The PSI-SF utilizes three subscales to measure stress, including difficult child; parent-child dysfunctional interaction; and parental distress. Lecavalier, Leone, & Wiltz (2006) addressed the impact of behavior problems of children with ASD on caregivers. The parent and teacher ratings specified the primary indicator of stress as behavior problems. Benson (2006) considered the role of stress proliferation on parents with children with ASD. He concluded that significant psychological distress is often the result for parents raising children with ASD. Of the participating parents, almost half were classified as “likely cases of clinical depression” (p. 692).

Plant and Sanders (2007) then looked at the predictors of caregiver stress in families of children with developmental disabilities. The identified predictors of stress included: difficulty of care-giving tasks; time involved in care-giving tasks; difficult child

behavior during care-giving tasks; and level of child disability. There were four areas of developmental disabilities that were included. The primary two disabilities represented by the participants were ASD (23.8%) and Down syndrome (23.8%). The other two disabilities were chromosomal abnormality other than Down syndrome (8.6%) and cerebral palsy (6.7%). However, the remaining percentage (37.1%) was not explained. Despite the unclear representation of the population, the authors provide a unique model of factors contributing to parents stress associated with care-giving tasks (Plant & Sanders, 2007, p.111). Overall, the difficulty of care-giving tasks was the best predictor of parental stress level.

Family function has also been studied in relation to family stress. Rao and Beidel (2009) elaborated on family stress by including sibling adjustment and its influence on family functioning. They concluded that siblings had increased levels of stress and restricted family functioning, more psychological problems and poorer mental and physical health than control families (p. 447). The data also revealed that parents experienced significantly more parenting stress than parents of children with no psychological disorder. Also, families of children with High Functioning Autism (HFA) reported participating in fewer social and recreational activities and less independence among family members in the following terms: assertiveness, self-reliance, and decision making (p. 449). The most intriguing element of the research was that when “families feel significant stress, they often believe that they do not have the time to comply with ... the necessary components of treatment” (p. 448). Rao and Beidel recommended assessing level of parental stress and family functioning prior to implementing an

intervention in order to address the relevant factors in a treatment plan. The level of stress of families should also be considered in the delivery of ASD diagnosis.

A specific element of family function that has been a focus of research is the health outcomes of family members. In 2010, Smith and Elder reviewed twelve research studies on parental and sibling characteristics, relationships, and adaptation support intervention measures for siblings and family members of persons with Autism. The articles contained into four categories: parental characteristics, sibling behavior, sibling relationships, and sibling adaptation. Overall, the review supported the finding that siblings of individuals with ASD are at risk for producing negative health outcomes and are at risk for less positive environments for those with ASD.

Hall and Graff (2011) also looked at family support and parenting stress in relationships with children with Autism. The authors first discussed the exigency of helping families and children with Autism, because families experience high levels of stress and thus have a dire need for family support. The caregivers of children with ASD included relatives and grandparents as important members of their support system. The researchers note that understanding family experiences is necessary in order for professionals to “make more informed decisions and appropriate referrals for intervention and support” (p. 6). Lastly, Hall and Graff recognized the importance of knowledgeable nurses for families with members with ASD, and suggest that knowledgeable nurses should be involved in the diagnosis and treatment process.

Several other studies focus on the stress of family members and parents of children with ASD (e.g. Karst & Van Hecke, 2012; Read & Schofield, 2010; Strauss et al. 2012; Zaidman-Zait et al. 2011). Yet, the current studies provide some information

regarding the importance of considering the family stress and learning how to reduce stress by focusing on communication among the family members. Looking at stress through these studies demonstrates approaches that do not take into account many elements of the communicative interaction. In communication studies, the focus is on episodes of interaction, punctuation of events, stories, resources and practices (e.g. Bruss et al. 2005; Cronen & Pearce, 1981; Forbat & Service, 2005; Montgomery, 2004; Pearce & Cronen, 1980; Pearce & Pearce, 2000, 2001; Raboin, 2010; Salmon & Faris, 2006).

The research on family stress provides several examples that have demonstrated the significant importance of understanding the stress of family members of children with ASD. The potential stress that is affiliated with having a family member with ASD should be considered by professionals when interacting with parents during the diagnosis.

### **Communication with Persons with ASD**

When considering the importance of communicating with family members, the methods for communicating with persons with ASD must also be considered. Miller (2008) emphasized the need for sensitivity when communicating with children with Autism. He stated, “Children on the [A]utism spectrum are often intimidating to both the parents who live with them and the professionals who are trying to help them” (p. 16). A child with ASD “needs for parents and professionals to be emotionally available to reach out and make emotional contact with them” (p. 18). Miller recommended a ‘high support, high demand’ stance for parents and professionals. For example, this high support, high demand stance is very supportive and active, but carefully intrusive toward the child with ASD.

Another important consideration is for caregivers to acknowledge and address speech disorders. Sigafos, Schlosser, O'Reilly, and Lancioni (2011) discussed the speech and language problems of individuals with ASD. "Communication problems are a defining characteristic of ASD" (p. 98). Some of the communication problems mentioned include: absence of effective verbal language; absences of nonverbal communication skills; presence of inappropriate ways of communicating; and communicating through tantrums, aggression, or self-injurious behavior. Also, "because the communication problems associated with ASD can vary widely from one individual to the next, it is important to assess each individual to identify his or her particular communication strengths and limitations" (p. 98). The authors briefly discussed the importance of communication partners. They said, "Effective communication intervention often requires teaching new behaviors or communicative interaction patterns to both the speaker and his or her communicative partners, such as parents, teachers, and peers" (p. 99). They continued, "While children with ASD may also need help with difficult tasks, they may be unable to request help when needed unless they have learned good communication skills" (p. 99). Since individuals with ASD may not be able to request help or communicate in unfamiliar situations (i.e. with physicians), those individuals who are normal communication partners –typically parents or caregivers— hold an important role of communicating for the child with ASD. There is a need to develop strategies for caregivers to help children with ASD to communicate verbally and nonverbally.

Lee, Walter, and Cleary (2012) elaborated on the challenges of caregivers communicating with persons with ASD. The authors identified many difficulties that



children with ASD experience in interacting with others, specifically physicians. Some of the difficulties included: nonverbal children, attachment to security items (i.e. toys or blankets), distress with change in routine, and sensitive sensory processing (i.e. lights that are too bright, loud noises, or touch). The article provided an introduction about how to improve the interactions of health professionals with young individuals with ASD. Advice provided involved: respecting cultural differences, using observation skills, creating a safe haven, seeing the child first, showing the child rather than telling the information, using shorter sentences to break up the information, reducing sensory overload, and involving parents. The authors also discussed the impact of the last decade of research as well as the exigency of much more research. “While there have been considerable advances during the past decade in understanding the manifestations of [A]utism and ongoing study of potential interventions, ASD remains baffling condition for parents” (p. 41). The authors briefly discussed communication and the challenges of communication for individuals with ASD. “Children with ASD tend to not understand what people are saying and fail to tell others what they need or feel” (p. 41). Social interactions can be frightening for children with ASD. The authors provided vignettes of children and elements of effective communication for health care professionals. The authors suggested that physicians having “knowledge, skills, patience understanding, empathy, tolerance, and commitment” (p. 42). The authors also warned physicians not to make assumptions, but to be sensitive and inquiring instead.

### **Health Communication**

Health Communication is a growing area of study for researchers. Many scholars from a variety of disciplines have studied patient and provider contexts (e.g. Bundesmann

& Kaplowitz, 2011; Galassi & Ware, 1992; Helitzer et al. 2011; Matthias et al. 2010; Simon et al. 2010; Song, Hamilton, & Moore, 2011; Wagner et al. 2010). Others have looked at the communication and relationships between patients and providers (e.g. Baker ,Gallois, Driedger, & Santesso, 2011; Bohnert, Zivin, Welsh, & Kilbourne, 2011; Carpenter et al. 2011; Ciampa, Osborn, Peterson, & Rothman, 2010; Davis, 2010; Hou & Shim, 2010; Robinson, Turner, Levine, & Tian, 2010; Siminoff & Step, 2011; Smith, Wolf, & Wagner, 2010; Weissmann et al. 2010; Wen-Ying et al. 2011). More specifically, there are only a few studies that have emphasized interactions with individuals with ASD (e.g. Hample, 2008; Holton et al. 2012).

One of the articles that considers communication and ASD relates to the media and mass communication (Holton et al. 2012). Holton et al. (2012) evaluate the legitimacy of blaming the cause of ASD on the MMR vaccination. Much media coverage has been given to the Autism-vaccine controversy in the United States and the United Kingdom. The authors discuss the parents' interpretations of the interactions of the child prior to and after the vaccination. Although the authors conclude that there is not enough evidence to say that the vaccination caused ASD, the key finding of the research was how the parents explained the interaction patterns of the child.

Hample (2008) focused on the pattern of interaction in relation to support, which refers to "using communication theory to provide structure for peer support interventions [to] help capitalize on potential benefits and minimize potential risks [of peer support]" (p. 324). Hample (2008) looked at how support "can improve the quality of supportive interactions and help us discern when and why an intervention may be counter-productive in a particular context or for some subgroup of participants" (p. 327). In the essay,

Hample discussed the opportunities for multidisciplinary collaboration to improve quality of life by focusing on “what people say, how they say it, and why that matters” (p. 327).

These qualities are communication practices relevant to diagnosis delivery of ASD.

### **Professional-Patient Communication**

The importance of health care professionals in the lives of patients with ASD is implicitly acknowledged in the aforementioned articles. Yet, a specific area for the health care professional relationship with patients with ASD is needed. Mahoney and Perales (2005) provided one study that included children with ASD and family members. They suggested one approach that emphasized a relationship-focused intervention. The authors stressed the importance of creating a relationship with the child with ASD and family members. Weil and Inglehart (2010) also addressed the necessity for dentists to prepare for interacting with patients with ASD.

Although other studies exist that discuss patients with ASD, developing a skill-based approach is not the focus of this paper. Rather, Roter and Hall (2011) provided information on patient-provider communication in general. They stated, “Interaction is the fundamental instrument by which the doctor-patient relationship is shaped and through which medical care is directed” (p. 55). They went on to discuss national reports that “have focused attention on the centrality of patient-centered communication to the safe delivery of quality medical care and the practice of ethical medicine” (Roter & Hall, 2011, p. 56). Having a patient-centered approach to communication has many benefits that range from trust and comfort to medical safety. This kind of patient-centered approach is also needed for diagnosis delivery of ASD.

**Health Care Teams.** Effective communication amongst teams of health care professionals has been the focus of current health care research (e.g. Grumbach & Bodenheimer, 2004; Haynes et al. 2009; Lemieux-Charles & McGuire, 2006; Lingard et al. 2008; Real & Poole, 2011; Williams et al. 2007). Real and Poole (2011) demarcated teams from groups since teams consist of high levels of “interaction, interdependence, boundedness, commonality, and motivation” (101). They discussed the interdisciplinary nature of research on health care teams; yet, communication research has contributed to the literature (e.g. Anderson, 2001; Apker, Proop, & Ford, 2005; Apker, Proop, Ford, & Hofmeister, 2006; Coopman, 2001; Davis, 2008; Ellingson, 2003; Grice et al. 2006; Hewett et al. 2009; Martin, O’Brien, Heyworth, & Meyer, 2008; Paulsel, McCroskey, & Richmond, 2006). Real and Poole (2011) identified two main perspectives for considering communication within the research. One perspective was communication as meaning construction, which focuses on social construction. They also discussed the importance of communication to ensure effectiveness of the health care team.

One approach to ensure effectiveness was introduced by Haynes et al. (2009). They discussed the implications for a health care team after creating a communication checklist; the rate of negative outcomes that occurred prior to the checklist decreased after the checklist was implemented. I understand the exact checklist created for that specific team will not be the best for every team, but the idea of co-creating meaning amongst team members is an effective strategy that could be helpful in other health care teams. Real and Poole (2011) utilized McGrath’s input-process-output (IPO) model as a framework for communication and effectiveness in health care teams. The goal in providing the framework was to generate thinking about how to understand

communication and the influence on effectiveness in different health care teams. Real and Poole (2011) stated, “Theories are needed which account for the complexity of health care team interaction in order to better understand communication and effectiveness in health care teams” (114). They concluded with a call for future research to examine team processes and communication practices episodically and temporally to understand the critical components for effective outcomes. This call to action should also apply to patient-professional(s) communication research that focuses on patients with disabilities, specifically ASD.

This research will extend the study of health care teams to focus on micro-level communication practices associated with CMM concepts that occur within health teams during the delivery of diagnosis.

### **Diagnosis Delivery**

The role of communication in the process of diagnosis delivery is crucial. When referring to diagnosis delivery, I emphasize the process after diagnosis is determined when the practitioner or team of physicians informs a child with an ASD and his/her caregivers of the diagnosis. The delivery of the information is a complicated communication transaction that should occur in several phases. There has been limited research on diagnosis delivery in the field of ASD. There are other areas of focus that offer valuable information including research on delivering the diagnosis of chronic conditions, Down syndrome, and cancer. Below the information is categorized into sections on Autism studies, parental concerns for delivery, the PACE Model, and diagnosis delivery of other conditions.

## **Studies on Autism**

Four studies related to Autism and ASD when discussing diagnosis. The first two studies were not directly related to the delivery of diagnosis that I am referring to. Rather, the focus on diagnosis was on other medical conditions. The first study extended the focus of parents' experience of diagnosis to include obstacles to the diagnosis and treatments when misdiagnosis occurred. Smith, Graveline, and Smith (2012) provided two case studies of adults that had ASD and acquired life-threatening illnesses that the diagnosis was delayed due to the focus on the individuals having ASD. The focus on diagnosis in this study was not on delivery of the initial diagnosis of ASD, but on a diagnosis as an adult of a life-threatening illness, specifically Lou Gehrig's disease and Multiple Sclerosis. The second study was a review of literature on "how general physicians may approach the management of the adult and pediatric patients with an ASD and the common disease processes that can result in their need for acute care" (Venkat et al. 2012, p. 472). The authors described the importance of general physicians in understanding the requirement of preparation and sensitivity for patients—pediatric or adult—with ASD. The focus of diagnosis was on other medical conditions or illnesses for individuals that have already been diagnosed with ASD.

The third study was the only study that directly addressed the delivery of diagnosis of ASD. Braiden, Bothwell, and Duffy (2010) evaluated the experience of 11 parents in Northern Ireland with the process of diagnosis of ASD; in-home interviews were conducted and transcribed. The authors performed a thematic analysis of the transcription data and found key points that contributed to the parents' experience with diagnosis. The points included: perceiving acknowledgement of initial concerns,

receiving the diagnosis in a face-to-face setting, receiving informational materials, and being assisted in understanding the information. The four points provide information for other studies such as my project to consider what elements are important to parents.

The fourth study, published in 1984, emphasized helping parents understand the diagnosis of Autism. Morgan (1984) addressed the informing session rather than focusing specifically on the process of delivering diagnosis. The idea of the informing session or information interview occurs in several other areas of health care diagnosis, including: diagnosis of cancer, Down syndrome, dementia, and other chronic conditions.

The manner in which the bad news is presented has an effect on the outcome of the message reception; this idea is behind the use of the informing interview.

Myers (1983) provided some guidelines for physicians who have to deliver difficult messages to parents of children with chronic or terminal illnesses that prevent a 'normal' life. She reviewed psychological stress and coping strategies and discussed the importance of professionals to understand elements of the grieving process that parents experience. Myers also described key characteristics that professionals should demonstrate when informing the parents; the characteristics included: competence, self-confidence, warmth and interest, ability to listen, patience and acceptance, tolerance of expression of emotion, sensitivity to feeling states, tolerance of parents' non-acceptance, ability to be direct and honest, good clinical judgment, and use of language that parents can understand. The setting and elements of the informing interview were also discussed as critical for a successful informing session. The aspects included: place (privacy), participants (both parents if possible, child, and limited professionals to avoid intimidating the parents), process (the professional should be aware of the process of the

informing interview), comfort (professional should establish rapport with parents), presentation (repeating and summarizing information when necessary), understanding (inquire about clarity and comprehension), management (provide information for guidance, support, expertise, etc.), closure (answer questions), and facilitate memory (letter, phone call, or written information). Lastly, Myers revealed two common problems that professionals should be aware of: disturbed parents and unclear diagnosis. These situational factors for informing parents of an ASD diagnosis should be observed.

### **Studies on Family**

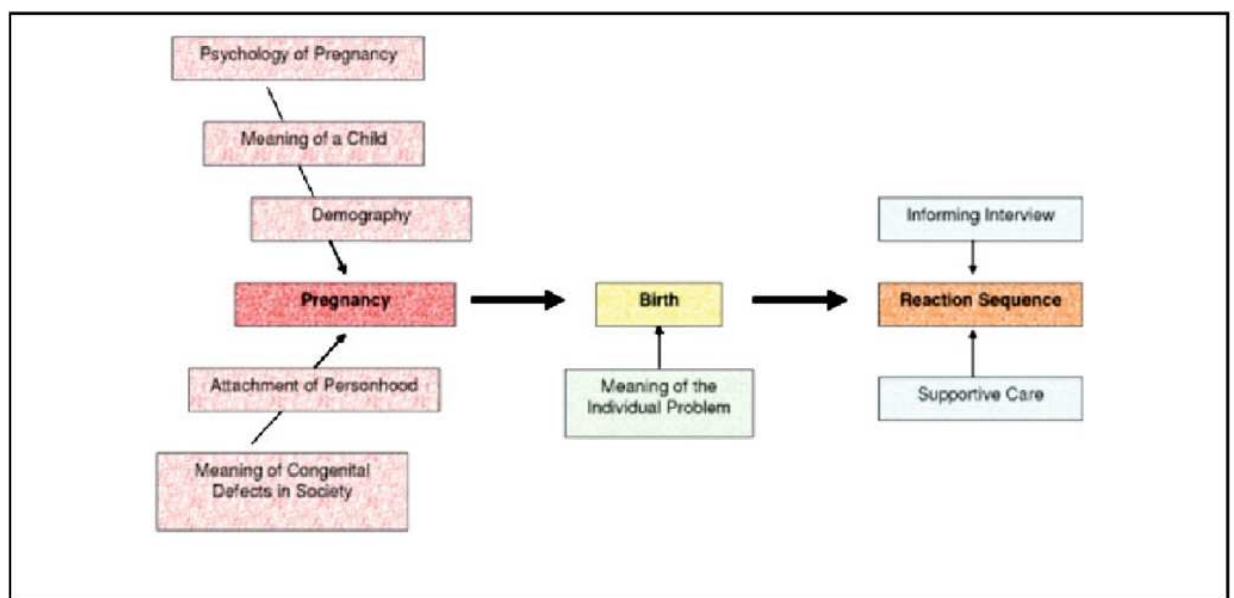
Although Myers did not specifically mention informing parents of children with ASD, the information provided is relevant in any situation where the parents may experience grieving. Similarly, Gayton and Walker (1974) looked at parents' preferences when receiving diagnosis. The authors utilized an interview questionnaire over the telephone with 85 sets of parents of children with Down syndrome. The results of the questionnaire indicated the following preferences: parents desired to know diagnosis as soon as possible; parents desired to be told by the physician; parents indicated the importance of both parents being present at diagnosis; and parents revealed the importance of receiving written information at the time of diagnosis. These preferences are similar to the essential elements discussed by Myers (1983) and are relevant to the delivery of ASD diagnosis delivery.

Preferences of parents for delivery of difficult news has been another focus of research. Dent and Carey (2006) review literature that has addressed the issue of breaking bad news. Buckman (in Dent & Carey, 2006) defined bad news as "any news that drastically and negatively alters the patient's view of his or her future" (p. 174). The



authors began the article with a recollection by the senior author of her first task of delivering a clinical diagnosis of Down syndrome to a set of parents. She stated, “I had been given no instruction or guidelines as to how to rise to this occasion” (p. 174). The authors later mentioned, “The details of this event [of informing parents of a difficult diagnosis in a newborn setting] are recalled vividly by the family” (p. 174). After identifying the need for some guidance and importance of the situation, the authors discussed that the few generally accepted guidelines for delivery have not been supported with evidence or scientific research. Rather, the guidelines were based on expert opinions. The authors provided a framework; however, the theoretical model was very basic (see Figure 1; Dent & Carey, 2006) and not particularly useful for my study.

### Studies on Professional Training



**Figure 1: Proposed Theoretical Framework**

Aside from providing a basic framework, Dent and Carey (2006) provided two recommendations: 1) to “train healthcare professionals, including medical genetic residents and genetic counselors in clinician-patient communication, in general, with a

specific focus on breaking difficult news” and 2) to “develop and establish an infrastructure within each hospital system that makes it routine for the provision of current and accurate information and current referral to parent support groups and experienced parents” (p. 178). Lastly, the authors endorsed providing families with a positive, confident, and informative discussion with appropriate referrals to support groups and experienced families. This piece of advice does apply to diagnosis delivery of ASD.

### **The PACE Model for Diagnosis Delivery**

Garwick, Patterson, Bennett, and Blum (1995) conducted interviews with family caregivers in the homes of 43 children with Down syndrome or congenital heart disease; each interview consisted of a set of caregivers. “The goal of the study was to identify the major factors that the families identified as influencing their reactions to the news that their child had CHD and/or DS” (p. 996). Similar to the parental preferences discussed by Myers (1983), family caregivers “preferred to be informed in person, in a private place, and along with their spouse or another family support person” (p. 996). The final recommendation by the authors was for professionals to “PACE the news that they provide at the time of diagnosis by Planning the setting, Assessing family caregivers’ previous knowledge and experience about chronic conditions, Choosing strategies that best fit the family and their particular situation, and Evaluating the family’s understanding of the news” (p. 997). Elements of the PACE method have been mentioned in other research studies; the identified method could be an easier way to remember the elements in future studies, research, and clinical practice.

## **Other Models of Diagnosis Delivery**

Similar to the elements of the PACE method are the suggested techniques for delivering the diagnosis of cancer. Gordon (2008) discussed the needs of patients and relatives for “privacy; for a clear, concise, and unambiguous message; for a caring and concerned manner; for attention to the patient's emotional state; and for the opportunity to ask questions.” Gordon also noted options specific for patients with cancer; however, some suggestions were similar to those mentioned in other studies regarding delivery of diagnosis: professionals should provide hope and reassurance; be sensitive of cultural differences; and have self-awareness. Having self-awareness was a new element that had not previously been discussed; other studies mentioned the importance of being self-confident and competent while having tolerance for emotional expression (Myers, 1983). Gordon mentioned “recognizing and acknowledging our emotional ‘blind spots’ and ‘hot buttons’ can reduce feelings of guilt and sadness, promote compassion and connection, and restore objectivity.” Gordon provided competency-based learning and certification for students, residents, and practitioners, such as clinical evaluation exercises (CEX) and objective structured clinical examinations (OCSE) on delivering difficult news; yet, limited studies provide evidence of change in practice after the examinations. An oncologist specific intensive 3-day course was also briefly mentioned; however, improvement was demonstrated after the course, which allowed time for “didactics, skills practice, and personal reflection.” Not enough details were provided about the oncologist course to utilize elements for general delivery of diagnosis. Nonetheless, the idea of an intensive course could be significant for my study of ASD diagnosis delivery.

Other studies provided relevant calls for future research in the concluding remarks. Kallergis (2009) focused on informing families of a diagnosis of cancer. Kallergis stated, “Usually, doctors and nurses approach patient and family using their experience. Therefore, we need a training that will equip health professionals with the necessary knowledge to approach the family” (p. 109). Lalor, Devane, and Begley (2007) studied women’s encounters with caregivers during an unexpected diagnosis of a fetal abnormality. The authors concluded the study by stating, “The way in which adverse diagnoses are communicated to parents leaves room for improvement. Health professionals should receive specific education on how to break bad news sensitively to a vulnerable population. A specialist midwifery or nursing role to provide support for parents after diagnosis is recommended” (p. 86). Although many researchers have identified elements of importance when considering diagnosis, much research still needs to be done to demonstrate how this research can be used in the diagnosis of ASD.

### **CMM Research**

CMM has been applied to many settings, including: childhood obesity, organizational collaboration, families, community dialogue, identity, interpersonal interactions, citizenship, and school climate, etc. (e.g. Bruss et al. 2005; Cronen & Pearce, 1981; Montgomery, 2004; Pearce & Cronen, 1980; Pearce & Pearce, 2000, 2001; Salmon & Faris, 2006). The common goal of these studies is to provide research that suggests improvements for well-being. Only one study is explored that focused on CMM and ASD; several other studies are explored that demonstrate related focuses on health settings and intellectual disabilities.

## **CMM and ASD**

Only one source related to CMM and ASD. Fishwick (2009) created a literature review that looked at the experience of parents raising a child with a disability such as ASD for her doctoral dissertation in Clinical Psychology. She conducted a met-analysis of six qualitative papers related to a raising a child with a physical or intellectual disability. Of the six papers, one involved a parent of a child with ASD. One conclusion that emerged from the thematic study was “the importance of formal support systems” (Fishwick, 2009, p. 27). The systems included professionals and family members who have aided the parents through coping with the challenges they face as a parent of a child with a disability. Fishwick (2009) includes a call for future qualitative research “to explore the positive experiences and more protective factors” affiliated with the parent (p. 33).

## **CMM and Practice**

CMM research has been applied to a variety of related areas. Salmon and Faris (2006) evaluated multi-agency collaboration with a CMM framework, focusing on the importance of collaboration between multiple organizations. The authors described CMM as an important theory of human communication. Two processes were discussed: social practice through interaction and practical application. When discussing situations where CMM has been applied, Salmon and Faris (2006) included family communication practices and the construction of a family identity. The study discusses social reality, coordination of meaning, constitutive rules, and regulative rules.

**Health Studies.** In communication studies, some researchers utilized CMM for applied health projects. Forbat and Service (2005) used the hierarchy model of CMM to

look at end-of-life specifically for persons with ID and dementia. The hierarchy model is a “method of directing attention to the context of an utterance or action” (Pearce, Sostrin, & Pearce, 2011, p. 128); there can be multiple layers of context as well. The model is helpful for determining underlying value, influence, perception, and understanding certain health conditions, situations, etc., and how communication occurs in the context. Forbat and Service (2005) provided an example of how to utilize the hierarchy model in a health care environment. Forbat and Service (2005) described CMM as “a language- and relationship-based approach to therapy and communication” (p. 416). The hierarchy heuristic showed how multiple contexts affected action. Through the identification of contexts, Forbat and Service identified the system of relatives as an important for understanding the context. They suggested extending existing research on caregiving relationships with people with ID and dementia to individuals in other service settings.

Raboin (2010) utilized heuristics from CMM for her research in hospital setting. She specifically focused on the reflexive process of text and context. For discourse analysis, “CMM captures both elements of discourse analysis by offering heuristics that spiral between the immediate situation and the influences of a discourse or contextual forces” (Raboin, 2010, p.56). Raboin looked at the relational process through Pearce’s suggested four phase approach: description, interpretation, critical, and practical.

In the first phase, Raboin utilized the Serpentine model and triplets to focus on the punctuation of episodes of interaction. The Serpentine model is a model of CMM that “shows successive action in an episode as coming ‘out of’ the embedded contexts of meaning of one participant and ‘into’ the embedded contexts of another, and so on” (Pearce, Sostrin, & Pearce, 2011, p. 131); the focus is on the ‘back and forth-ness’ of

interactions. An episode can be thought of as what is being discussed, when it began and ceased, what parameters are placed to understand it as an experience independent from other experiences (Pearce, Sostrin, & Pearce, 2011, p. 100). Raboin used two steps for the phase. First, the author listened to the audiotapes and read transcriptions of conversations when available while listening. She looked at tone, patterns, and word choices. Second, she used punctuation and coding were as sequences of turns in triplets. In the interpretation phase, she identified logical forces and the hierarchy model. There were four parts to the second phase. The first step was coding the four forces: prefigurative, contextual, practical, and implicative. Briefly, “prefigurative force is that which we feel based on what other people have just done; contextual force is that which we feel based on the situations in which we are in; practical force is that which we feel based on what we want the other person to do next in response to our acts; and implicative or reflexive force refers to the effects our current actions are intended to have on the contexts in which they occur” (Pearce, Sostrin, & Pearce, 2011, p. 129). The second step was coding contextual resources. The third step was constructing hierarchies of meaning. The last step was a final review of the coding and punctuation. The critical phase consisted of one step: reflection. In the final practical phase, an invitation for co-creating the future was presented in two steps. First, the transcripts were reviewed. Then, the review is aligned with my research since the method utilized could be beneficial for looking at children with ASD in similar health context.

**Intellectual Disability.** The next relative area of research involved CMM and intellectual disabilities (i.e. disabilities with mental processes, abstract thinking, reasoning, etc.). Farinelli and Guerrero (2011) also studied parents’ interaction with

children with mental illnesses. The focus of the study was on the physical health consequences experienced by parents/caregivers. Although CMM was not the framework, the authors concluded that parents face several health issues affiliated with being the caretaker of a child with mental illness. Some of the specified issues included: frustration, hopelessness, distress, depression, anxiety, fatigue, dizziness, headaches, nausea, and sorrow. CMM allows me to take physiological effects into consideration by understanding communication has systemic effects and discussing all elements of the clinical system of the ECEP.

Although the focus was on the social-relational model, Haydon-Laurel (2009) utilized aspects of CMM. For example, the author used episode work, reflexivity, and the hierarchy model of CMM to “illustrate the process of conversation” (p. 9). Haydon-Laurel (2009) addressed the issue of a tension between the social model of disability and psychological therapy. Haydon-Laurel (2009) introduced the idea of significant persons in the lives of individuals with intellectual disabilities coming together to work with the practitioner. Haydon-Laurel (2009) described systemic psychotherapy as “a modality that creates the possibility for the therapist, the person and significant others in her or his life to come together and hear, create, elaborate and celebrate the stories that people bring” (p. 7). The study included a variety of individuals with different intellectual struggles (i.e. ASD, behavioral issues, intermittent explosive disorder, etc.). The author emphasized reflexivity throughout the paper, referring to how individuals reflect on their experiences. In the future research section, Haydon-Laurel (2009) calls for research on those in the position of care-taker of the person with an intellectual disability. ASD is a neurological disorder that also needs to be studied. By focusing on



the process of communication, reflexivity, the hierarchy model, and episode work, the author also indicates the importance of CMM for future research with situations such as the delivery of ASD diagnosis.

### **Theoretical Background**

Twentieth century theories and methodologies have shaped CMM as a research method. I explore some of the influences and provide a basis for utilizing CMM as a methodology. Viewing CMM as a methodology contributes to communication research by expanding the current boundary between theory and method.

Pearce began a discussion of an applied practical theory that focused on coordination and meaning in the 1970s. In 1976, Pearce labeled this theory as the Coordinated Management of Meaning (CMM). Since its inception, the theory has expanded and adopted new applications. Although commonly thought of as a theory, CMM can also be utilized as a method for empirical research. To better understand the implications of CMM as a research method, I review other methodological traditions that influenced CMM. I organize this section of the chapter into several key sections including: Garfinkel and ethnomethodology; Wittgenstein and Ordinary Language Philosophy; J.L. Austin and Performatives; Searle and Speech Acts; Shimanoff and Rules Theory; Conversation Analysis; Watzlawick and Pragmatics; E. Rogers and Relational Communication; and lastly, Pearce and CMM. I then provide another section that identifies the procedures I use as part of this CMM methodology.

#### **Garfinkel and Ethnomethodology**

In the 1950s and 1960s, Garfinkel founded ethnomethodology, which places emphasis on the importance of language use, interpretation, and communication as well

as on culture, linguistics, and practice. Interaction is a focal point for the ethnomethodology which analyzes practical actions and reasoning. Typically, ethnomethodology examines action or talk-in-interaction within specific contexts. Paying significant and close attention to detail is very important, which provides more depth than most quantitative analyses.

Focusing on practical understanding and action in local contexts requires researchers to pay attention to shared, inter-subjective methods for understanding and action. To develop an understanding of local contexts, meaning and language are key areas of interest. Specific elements of meaning and language include indexicality, talk as practical action, accountability, a documentary method of interpretation, and reflexivity. Indexicality is the contextual or embedded nature of meaning. The meaning of talk and text is indexical in that both always rely on people's situated knowledge of a relevant context to ensure understanding. Talk as practical action refers to the emphasis on the practical nature of language use. Berard (2009) discusses the practical nature of language use, claiming language is understood in terms of language use, which is a medium of social interaction and action. Accountability occurs because speech and actions are produced collectively, and these shared meanings produce social interactions that promote understanding. CMM also embraces this approach to practical action.

My study makes use of Garfinkel's approach to the documentary method of interpretation as incorporated in CMM. Garfinkel (1976) describes the documentary method of interpretation as a type of reasoning used by researchers to explain social patterns adhering in communication interactions. Moreover, he emphasizes the reflexivity of the researcher that forces the research to shift from descriptions that are

independent from the content to descriptions that depend on how interactants uses symbols in a context. This method makes a significant shift in how researchers use causal explanation in ethnomethodology because they try to discover the reasoning of those they observe and the meaning those they observe attribute to social phenomena, context, and practice. My study uses this method of documentary interpretation as modified by CMM to discover the reasoning ECEP professionals use when they deliver an Autism spectrum diagnosis.

### **Wittgenstein and Ordinary Language Philosophy**

Ludwig Wittgenstein is concerned not as much with the method of the researcher's interpretation as Garfinkel is, but he is concerned with how the people in an interaction use language. Wittgenstein (1965) claimed that meaning in language derived from its actual use in real situations, a tenet of ordinary language philosophy. He understood that people follow rules in order to accomplish a particular goal, and that communication is a set of language games (Fleming, 2004). Wittgenstein viewed language as an instrument, a tool for getting things done (Berger & Palomares, 2011) and emphasized a variety of ways in which language is used aside from the traditional understanding of solely transferring information (McGlone, & Giles, 2011). As part of his innovative idea of language use, Wittgenstein claimed an utterance is an action aimed at getting things accomplished (Fleming, 2004). Both Wittgenstein's approach and CMM emphasize language use in real contexts that serve the purpose of the communicators. This study focuses on the language of the ECEP professionals.

## **J.L. Austin and Performatives**

Extending Wittgenstien's focus on utterances, J.L. Austin introduced the theory of performatives (Littlejohn, 2009a) as a type of speech act. Austin included illocutionary and perlocutionary acts in the theory of performatives. An illocutionary act is an utterance that a person uses to perform an intention and thus it has illocutionary force. A perlocutionary act is an utterance a person uses to elicit a certain kind of response from others (i.e. persuade). If the person understands the intention of the speech act, then it is perlocutionary and illocutionary force (Littlejohn, 2009a). The difference between the content of an utterance and illocutionary force is that content is the claim (i.e. I am tired), and the force is the intention (i.e. I want sleep). During observations, I take fieldnotes that include specific utterances that may demonstrate illocutionary or perlocutionary force. During the interviews, I ask communicators about the specific statements and seek understanding about the force behind the statements.

## **Searle and Speech Acts**

Austin's work on performatives informed Searle's work on Speech Acts Theory (SAT) that explained illocutionary acts and force by focusing on the speech acts called propositions and declaratives (Littlejohn, 2009a). Through messages, communicators express intentions, and the intentions behind their utterances are the focus for SAT. A well-performed speech act produces meaning, because the intention is conveyed by a communicator and understood by another communicator. Searle claimed misunderstanding resulted from the failure of a listener to distinguish the speaker's intention. Searle also noted that not all misunderstandings occur due to missed intentions; yet, the act is a common source for misunderstanding. Another element of

SAT is that speech acts are understood because they conform to certain rules. Two classes of rules govern the practice and understanding of speech acts: constitutive and regulative rules.

Constitutive rules are connected to the intended message of the person initiating the speech act, and regulative rules are linked to the proper response of a communicator to the speech act. Four constitutive rules apply to illocutionary acts: 1) an act must conform to a proportional content rule; 2) an act must meet a preparatory rule; 3) an act must incorporate some sort of sincerity rule; and 4) an act must be understood by both speaker and listener in the same way. Regulative rules provide the steps or processes necessary for the speaker to perform the act and tell listeners how to respond (Littlejohn, 2009a). CMM focuses on the ways in which communicators rely on constitutive and regulative rules to coordinate their actions by constructing meaning at several levels. In my study, the flow of interaction that is achieved through professional coordination provides the outline for how the understand speech acts and the regulative rules that guide the responses. The rules demonstrated by the professionals of the ECEP help professionals to better understand the actions of each other during the process of diagnosis delivery of ASD.

SAT has had a major impact on communication theory and research in a variety of ways. Two prominent examples include Conversation Analysis (CA) and the Coordinated Management of Meaning (CMM). Although there are several forms of CA, SAT is basic to most CA within the discourse analysis tradition. CA focuses on the back-and-forth talk used for collaboration during communicative interactions that includes turn-taking, requests, and arguments.

Grice's four maxims provide a framework for doing a conversational analysis. The four maxims include: quantity, quality, relevancy, and manner. Conversation analysts look at how coordination and cooperation is attained between communicators, if violations occur, and how they are handled (Littlejohn, 2009a). By utilizing CMM, I look at coordination between communicators that are a part of the ECEP, which assists me in understanding the process of diagnosis delivery.

### **Shimanoff and Rules Theory**

Grice, Wittgenstein, and Austin influenced Searle and rules theory in communication. Rules theorists identify and describe the rules of a speech community, and they use those rules to explain and predict behavior within the community (Shimanoff, 2009). Several assumptions are present in rules theories of communication. First, rules are prescriptive (they tell people what to do). Second, rules are changeable and contextual. Third, communication is rule governed. Fourth, rule violations are common in communication (Shimanoff, 2009).

Rules theory has had a significant influence on other communication theories including CMM. Pearce and associates demonstrated that sometimes communicators get caught in unwanted repetitive patterns when they feel compelled to act according to unproductive rules (Pearce, 1989, 2007; Pearce, Sostrin, & Pearce, 2011). In order to break these destructive communication loops, people need to create rules (Shimanoff, 2009). During interviews, I ask professionals about the effectiveness of existing rules and about the necessity for other rules. I use CMM heuristics (described later in this chapter) to assist in the discussion about the effective and ineffective rules, as deemed so

by professionals, that occurred during the group interview to discuss agreement on effective rules and encourage a discussion about establishing new, more effective rules.

### **Conversation Analysis**

Another approach for looking at the collaborative creation of meaning in CMM is borrowed from Conversation Analysis (CA). CA describes conversations and how they take place in naturally occurring interactions. Several basic assumptions focus on the conversational competencies displayed by communicators. First, CA describes patterns of interaction that allow communicators to successfully manage and express understanding or misunderstanding of one another. Second, CA tries to predict individual successes and failures of those interacting in the conversation. Researchers recognize joint interaction in conversation requires coordination to manage the conversation. Third, CA examines the elements of the interaction patterns that enable or impede comprehension of the interaction during talk, using the categories of: membership, turn design, turn taking, and sequential organization (Swieringa, 2009). I utilize the Serpentine Model of CMM to focus on stories embedded in conversations.

### **Pragmatics of Communication**

Watzlawick, Beaven, and Jackson (1967) also focused on actual situations rather than successful interactions but emphasized problems as pragmatics. A simplistic definition of pragmatics is the study of signs and symbols actual situations. Watzlawick, Beaven, and Jackson (1967) presented axioms explaining how interpersonal relationships lead to self-maintaining systems that are dysfunctional and difficult to change—demonstrating unwanted repetitive patterns (Pearce, 2007). Edna Rogers (2004) extended the study to include discourse pragmatics, the study of language in use.

Similarly to performatives theory and SAT, the aforementioned theorists also considered intention for discourse pragmatics because they understood that interaction has both intended meaning and unintended meanings (Craig & Robles, 2009). Identifying functional and dysfunctional patterns of communication occurs during individual and group interviews. The LUUUTT model assists in uncovering the stories that explain how patterns are dysfunctional or functional. Explaining and understanding patterns helps the communicators to make sense of the practice and reconstruct better functioning patterns.

### **E. Rogers and Relational Communication**

Relational communication theories focus on how individuals interrelate with others through the process of communication and how different patterns of behavior and meaning characterize and impact relationships (Rogers, 2009). The connection between communication and relationship formation is called relational communication, and this body of theory concentrates on understanding relationships as communication-focused, relationship-dependent, and collaboratively constructed. CMM focuses on relationship development among communicators; relationships are deciphered through the stories told by the communicators and by their responses to questions during interviews.

### **Pearce and the Coordinated Management of Meaning**

Influences from others on CMM inform my explanation of CMM as a method. CMM includes the elements in a unique way to provide a different way of focusing on understanding through an emic and etic perspective. I modified the traditional ethnomethodology to gather data both from an etic and an emic perspective. I use an emic perspective in the sense that I try to discover how the ECEP professionals understand their own communication practices in the delivery of ASD diagnosis, but I am



also using an etic perspective since I impose outside categories from CMM to construct questions and interpret data.

Utilizing CMM allowed me to start as an observer and gather an etic perspective then switch to an emic perspective as I focus on gaining an understanding from the professionals' perspective. The major tenets of CMM include: meaning and action, coordination, and storytelling. The central claim of CMM is that in all social situations, communicators must manage their own meanings and actions while responding to the meanings and actions of others. Communicators do two things in every encounter: interpret and act. Interpretation and action create a reflexive loop during interactions. After an act, interpretation of the act provides meaning and understanding; then performing an act helps to produce meaning and understanding, which is then interpreted; the production is interpreted as an act and so on. In this example of the reflexive nature of interpretation and action, meaning leads to an act and acts form meaning. Communicators must coordinate meanings and actions throughout interactions for clarity and coherence.

Meaning, action, and coordination are also influenced by rules and CMM acknowledges that rules help people to assign meaning and take action. In CMM, rules of meaning are constitutive rules that tell communicators how to understand the meaning of something. Rules of action are regulative rules that tell a person how to act in a situation. Rules are influenced by logical force, that is the cognitive connections people make among meanings and actions. There are four types of logical force: prefigurative, contextual, implicative, and practical. Prefigurative force is based on past experiences that influence how a person interacts. Contextual force is based on specific contextual

experiences that influence how a person acts in that context. Implicative and practical forces help communicators focus on future actions. Logical force is based on deontic logic; that is, one condition creates an expectation or obligation that takes an if-then form (i.e. if I act this way, then that will happen).

When people experience consistency and clarity in an interaction, they have coherence. When people are unable to make sense of an act from their own resources and rules, there is mystery. Coordination occurs to the extent that communicators organize meanings and action into some kind of pattern that makes sense to them. When interaction feels appropriate and logical to communicators, then their coordination occurs without mystery.

Storytelling allows communicators to establish meaning and to define actions in relation to their goals and contexts. Through stories, people can explore their own and others' social worlds that are created through meaning and action that are resources shared during storytelling.

### **Summary and Conclusions**

Research from a variety of disciplines provides a basis for understanding potential methods and theory for research on delivering the diagnosis of ASD. Research on intervention provides the current focal point for researchers studying ASD. The non-communication interventions reveal the importance of communication and interaction. Communication interventions provide focus on communicative practices that reveal the importance of parent(s) and family member(s) in the lives of individuals with ASD. The research on attachment styles demonstrates the importance of parent-child relationships in a variety of research contexts; research on attachment style also introduces the element

of family stress in relationships with individuals with ASD. The vast amount of information provided on family stress reveals a need to focus on ways to help families of children with ASD that experience high stress. Much research is dedicated to stress of families with individuals with ASD. The discussion reveals the importance of communicating with the caregiver(s) to help to manage the levels of stress.

Research on communication with persons with ASD includes information on the importance of communication with the person with ASD through a caregiver, parent, or family member, since that person understands the communicative practices of the person with ASD. Also, the literature reveals the necessity of professionals to create a welcoming non-threatening environment for the individuals; a very important part is that the requirements of the environment vary depending on the person. Health communication research provides countless studies that have looked at health care teams and patient-provider relationships. The studies demonstrate the importance of relationships, communication, and constructing meaning together for effective interactions. Lastly, information on diagnosis delivery provides examples from other contexts that are elements to consider when creating an effective diagnosis delivery. Based on parental concern, the aforementioned health researchers recommended professionals' characteristics, obstacles, setting, and elements are aspects that should be considered when delivering diagnosis. Also, planning, assessing, choosing, and evaluating are elements of the PACE method that provide a method for diagnosis delivery in general.

Yet, there is a gap within the research areas because research has not stressed communication practices of professionals within diagnostic teams that deliver diagnoses

to parent(s), caregiver(s), or family member(s) of individuals with ASD. Research is needed to fill the gap by bridging the bodies of research. The current literature review provides a strong rationale for pursuing research that further investigates delivery of the diagnosis of ASD through a CMM framework. CMM provides a way to address the calls for future research in a way that accounts for the important aspects revealed through research. Applying methods of CMM utilizes a social construction approach to understanding how to effectively communicate between health care teams and parent(s), caregiver(s), and/or family member(s) to deliver the diagnosis of ASD while focusing on the parental/familial concerns.

## **CHAPTER 3**

### **METHODS**

This study utilizes a qualitative approach to investigate an internal perspective of professionals of the Early Childhood Evaluation Program (ECEP) at the Center for Development and Disability (CDD) at the University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) at the University of New Mexico (UNM) who deliver the diagnosis of disabilities to parent(s), caregiver(s), and/or family members after evaluation of each child. Although the professionals deliver a variety of diagnoses, this study focuses on the delivery of diagnosis of ASD specifically. Within the CDD, the ECEP performs evaluations and delivers diagnosis in one room.

The primary goal of the research is to assist the professionals at the ECEP in developing and understanding an effective way of delivering the diagnosis of ASD. One secondary goal of my study is to introduce a new research methodology for academic research based on the Coordinated Management of Meaning (CMM), what I call a CMM enriched ethnomethodology. This chapter provides the objectives and research questions that guide the study; describes CMM as a research method for gathering and interpreting data for this study; explicates the specific procedures in stages 1, 2, and 3 of the method; and provides a timeline for completion of the dissertation. A second secondary goal is to extend theory about CMM and to develop theory about health care team communication interactions.

There are several objectives to this study that develop these goals:

- 1) To describe/depict the communication process used in episodes of communication to deliver ASD diagnosis to parent(s), caregiver(s), and/or family member(s).
- 2) To engage professionals in a process of evaluating their communication patterns.
- 3) To elicit professionals' ideas about what they wish to accomplish and how to improve the communication patterns.
- 4) To provide an example of a methodological approach for other research studies.

My research questions are as follows:

RQ1: What communication patterns do ECEP professionals commonly use in episodes of diagnosis delivery at the ECEP?

RQ2: What rules of symbol use, meaning and action guide the patterns of communication used by professionals during diagnosis delivery?

RQ3: What strengths and weaknesses do ECEP professionals identify about their own communication practices?

RQ4: What goals would the professionals like to accomplish with their communication patterns?

### **CMM as a Research Method**

The theoretical history of CMM is summarized in chapter 2; here I demonstrate CMM as a research method. CMM is used as a method of practice by professionals (i.e. consultants, mediators, etc.) and has research applications as well (e.g. Bruss et al. 2005;

Cronen & Pearce, 1981; Fishwick, 2009; Forbat & Service, 2005; Montgomery, 2004; Pearce & Cronen, 1980; Pearce & Pearce, 2000, 2001; Raboin, 2010; Salmon & Faris, 2006). I along with Noblet and Littlejohn (Noblet, Barnett, & Littlejohn, in press) created a research guide that provides a variety of ways to implement CMM as a method for academic research. The guide utilizes several of the aforementioned concepts as well as a variety of strategies unique to CMM.

CMM is an appropriate method for this dissertation for several reasons. The main reason is that CMM provides a framework for looking at the social construction of specific social worlds and actions of social life while providing unique tools that look at the communication process, rather than through it, and accesses what participants understand from the process. Second, CMM can take an emic and etic perspective that allows me to develop an outsider perspective of the ECEP professionals and switch to focus on developing an understanding of the way they deliver diagnosis of ASD through the community members that (re)create the culture.

Rather than telling professionals what they should do and about how they are communicating, I argue that it is more useful to get the participants in my study to figure out this for themselves. Third, CMM allows me to focus on logical force, that is, how ECEP professionals at the CDD co-create, prefigure, contextualize, use implicative structures and gain practical force during their interactions related to communication of ASD diagnosis. In doing so, I am able to show how these professionals use patterns of interaction that coordinate their meaning with others in the ECEP, the site of this study. Fourth, CMM as a method has consequences for other health professionals in other settings. For example, when an unwanted repetitive pattern of interaction occurs,

professionals can brainstorm the possibility of creating new rules of interaction. Fifth, by focusing on the concepts of coordination, coherence and mystery, I can illuminate how professionals understand meaning and action at a deeper level than just using words to accomplish their goals. In this way, my CMM-enriched ethnomethodology can demonstrate the intricacies and importance of communication in ways that are restricted by other methodologies.

The main framework that I have selected from CMM for this study is SEAVA, a series of stages utilized by practitioners to explore interactive situations (i.e. Pearce, Sostrin, & Pearce, 2011). SEAVA stands for Storyboarding, Enriching, Analyzing, Visioning, and Acting (see Table 1).

Storyboarding	Identifying episodes, constructing the series of events, and punctuating the episodes
Enriching	Naming the patterns and describing the social world
Analyzing	Looking at logical force and checking for other special features
Visioning	Constructing an ideal pattern for the process and checking the reality of utilizing the process
Acting	Determining next steps

**Table 1: SEAVA**

### **Method of Participant Observation**

CMM is demonstrated as a research method in chapter 3. Here, I summarize what scholars say about how participant observation can and should be used and demonstrate how participant observation is appropriate when using the SEAVA model of CMM.

CMM is used as a method of practice by professionals (i.e. consultants, mediators, etc.) as well as researchers (e.g. Bruss et al. 2005; Cronen & Pearce, 1981; Fishwick, 2009; Forbat & Service, 2005; Montgomery, 2004; Pearce & Cronen, 1980; Pearce & Pearce,



2000, 2001; Raboin, 2010; Salmon & Faris, 2006). In collaboration with Noblet and Littlejohn (Noblet, Barnett, & Littlejohn, in press), we created a research guide that provides a variety of ways to implement CMM as a method for academic research. The main framework is SEAVA—a series of stages utilized by practitioners to explore interactive situations (i.e. Pearce, Sostrin, & Pearce, 2011). SEAVA stands for Storyboarding, Enriching, Analyzing, Visioning, and Acting (revisit Table 3.1). The SEAVA model and the phases of the research take place in two stages, orientation and managing meaning. The orientation stage involves participant observation. Participant observation usually produces thick description, but I interpret this participant observation data using categories from CMM and also allow other categories to emerge.

In the several models and heuristics of CMM, the SEAVA model is the most appropriate for organization of the data in this study. Utilizing observations and interviews fits well with this model. During the process, I approached the observations through my systemic perspective. I understand any system has permeable boundaries; “[O]nce an observer looks at a system, he or she becomes part of that system because looking itself influences what is happening. This view, known as second-order cybernetics, takes system theory into a new and exciting direction” (Littlejohn, 2009b, p. 953). The ECEP has a system for delivering the diagnosis of ASD; from the outside it is possible to look at the website and see the parts of the system and how they are interdependent on one another. Team members have specific roles in the system; there is an evaluation process; there are discussions among team members; community members play a role in the system, etc. Although gathering an idea of the clinical system from the website is possible, by physically looking at the system, I understand that my

participation affects and influences the system. Through observations, I interacted with clinical system and its participants to develop a better understanding of the system and the elements/processes of the system.

Understanding my system approach and considering the many other researchers perspectives on the practice of participant observation is also relevant. In the abundant supply of research that utilized a participant observation approach, there are several ideas about the correct or best way of exploiting the method. Danziger (1979) provided an illuminating example of using participant observation in doctor watching. Danziger (1979) stated it best when she said, “[The] problems of the field strategy and how they are resolved...are shaped to some extent by the specific context of the field situation” (p. 513). As a social constructionist, Danziger’s statement aligns well; the specific context of this field situation creates a unique situation that the participant observation shifts to accommodate. Since Danziger’s context was similar—a health care setting—I was able to anticipate problems with the method and compensate for some problems in execution that could have—and did—arise during my research.

In the article, Danziger identified three problems of participant observation: 1) obtaining access to medical setting, 2) establishing rapport with highly stratified classes of participants, and 3) avoiding ‘going-going-gone native.’ For the first problem, she recommended attaining an insider advocate as well as framing the purpose as that of seeking understanding of the staff’s perspective. After gaining access, establishing rapport was the second difficulty of participant observation research. Danziger described her choice of conduct as a “serviceable manner, to be not just untroublesome but even a little useful, handy for the staff to have around” (p. 518). She elaborated, “I never

minded claiming ignorance and encouraged them to lecture about this or that aspect of medicine whenever they so desired” (p. 519). During this rapport building, she added, “At the expense of writing up good fieldnotes, I immersed myself in their world of work, so as to be in a more comfortable, familiar status when I would alter shorten my observation time and focus my attention on specific aspects of the work setting” (p. 520). For the third problem, Danziger (1979) commented, “In general, I overcame the pressures to go native by capitalizing on and maintaining cognizance of the role expectations that all others in the setting had for me. This enabled me to distance myself from all participant perspectives and not overidentify with any one group of participants” (p. 524).

Danziger’s (1979) article provided useful advice for my approach to participant observation. In order to obtain access, I developed a relationship with a team member, so I had an “insider advocate” for my research as well. When establishing rapport, my actions were similar to those of Danziger. First, I focused on learning the process of the clinic days and did not take good field notes. Paying attention to the interactions and asking questions rather than taking extensive notes on the first couple of days of observing allowed me to establish rapport with the team members. I also attempted to be “untroublesome” and “even a little useful.” My usefulness was different from her actions to help the staff; however, I tried to provide comments and questions that may have generated ideas for the conversations and discussions. My attempt to be untroublesome took place in my choice of seating and learning the clinic process so I knew where to go and could transition without needing help. Lastly, avoiding going native was fairly easy for me since I did not have a motor therapy, psychology, medical, or speech and language

pathology background. Similarly to Danziger's approach, I avoided over-identifying with any group by distancing myself from a specific group's perspective.

Danzinger's example of participant observation provided a great example for me to imitate and make adjustments based on her experience. In the execution of my participant observations, I attempted to be as unobtrusive as possible. During staffing meetings, I sat and observed. During the evaluation process, I observed behind a one-way mirror. Professionals talked to me throughout the process about information specific to their discipline that was not relevant to my study (i.e. describing the elements of the ADOS testing and reasons for specific toys in the evaluation room). I also observed the family meeting behind a one-way mirror as well. I was a participant to the extent that I encouraged and commented to the team about their communication. I did not directly participate in the diagnosis process.

My participation in the study did not allow for objectivity. Yet, the goal of my study was not to be completely objective since my philosophical position is that complete objectivity is not possible. Rather, I provide an intersubjective approach. I attempt to identify the professionals' perspectives through my understanding of their descriptions, dialogue, and interactions, a difficult task. Throughout the process, I wrote detailed notes of my specific interpretations and feelings about the process to attempt to separate my interpretations from those of the team members. I also acknowledge that the specific findings for this project are relevant to the participants of the study. The process for developing the understanding and the findings is the objective element that can be replicated in future research.

Throughout the collection stage, I kept my field notes in a one subject notebook. After handwriting the notes of my observations, I typed my notes into a word documents. The document was organized by date and episode of observations. The notes consisted of 53 single-spaced pages. All 15 team members were included in the 74 hours of observation. Other details of the data collection appear later in the chapter.

### **Method of Interviews**

Conducting interviews is a unique and common process for studying communication from the point of view of those participating in the process. Specifically related to the delivering the diagnosis of Autism, Morgan (1984) utilized an information interview. Similarly, Gayton and Walker (1974) utilized an interview questionnaire over the telephone to look at parents' preferences when receiving the diagnosis. Garwick, Patterson, Bennett, and Blum (1995) conducted in-home interviews with a set of family caregivers when looking at major factors that influenced reactions to a diagnosis of Down syndrome or congenital heart disease. These studies provided examples of possible approaches to interviewing; however, because of my goals and research questions, I modified the suggested interview methods.

Others have provided specific contexts that call for an interview as the best form of data collection. Keats (2000) suggested interviewing as an efficient method for data collection in eight specific situations. Of the eight situations, at least three are applicable for this research project. The first is, "If you want to know what people are thinking" (p. 72). This study focused on understanding, which aligns with comprehending what people are thinking. The second is, "If you want to explore the reasons and motivations for the attitudes and opinions of people" (p. 72). Looking at the reasons that influence the

opinions of the team members provides insight into the actions and communication practices that are exercised by the team. The third is, “If ideas are likely to be difficult to express” (p. 72). Utilizing an interview format allowed me to follow up main questions with probing questions to most accurately address the question; many times the questions were difficult to answer succinctly and required providing examples for understanding. Elaborating on some questions or rewording also helped me to help the team members know how to answer the question and best explain their thoughts and opinions. A fourth possible situation is, “If the topic is threatening” (p. 72). The topic of understanding the process of delivering the diagnosis of ASD may not seem threatening at first. However, when considering the population that the health care team works with and the sensitive issue of receiving a diagnosis, the topic is threatening.

Keats (2000) also discussed three main research designs for utilizing interviews. The first design was relevant when the interview data would be the sole source or information. The third design mentioned utilized interviews with some performance on a separate measure. The second design was most relevant; it included the interview as supplementary to another form of data collection. She stated, “There are many techniques used in ... work with children which take this approach” (p. 75). She continued, “Responses and reasons can be treated separately or combine to form total score” (p. 75). Although I did not develop an overall score for the data as Keats (2000) suggested, I did interpret and critique the data individually as well as overall. Keats discussed individual or collective evaluation of data; rather than separating, the data called for evaluation throughout the process as well as overall. Modifying the “or” to an “and” was appropriate for the specific theoretical perspective utilized in this study. Keats

also stated, “Criteria for scoring [or analyzing] need to be set up according to whatever theoretical basis is being used” (p. 75).

In general, I followed several steps that are typically included in interview guidelines. DeVito (2008) suggested seven steps including: selecting a person; securing an appointment; preparing questions; establishing rapport; taping the interview; asking open-ended questions; and closing and following up the interview. I executed six of the seven steps. During the one-on-one face-to-face interviews, I focused on establishing rapport. I had a baseline of knowledge from the many hours of observations, so I felt comfortable taking notes to capture the responses during the interview rather than recording the interviews. To ensure reliability, I was the only interviewer. I followed the same interview guide for all participants. I did follow up questions with probing questions; however, the probes were included to provide a more rigorous answer to the main questions. In considering validity, the questions were designed to adequately provide the information needed to address the research questions. Also, when considering the construct validity, one must make sure the underlying theoretical basis is exemplified in the questioning (Keats, 2000). The word choice of each question was strategically chosen to make sure the CMM theoretical framework—which exploits a communication perspective—was clearly demonstrated.

### **Selection of Participants**

This study utilized a qualitative approach to understand patterns of communication used by the professionals of the Early Childhood Evaluation Program (ECEP) at the Center for Development and Disability (CDD) at the University of New Mexico (UNM) who delivery the diagnosis of ASD. Within

the CDD, the ECEP performs evaluations and delivers diagnosis in one room. There are other conference and meeting rooms on the same floor that serve as interview rooms.

Prior to the study, I met with the Program Evaluator and the Director of Clinical operations at the CDD to explain the purpose of my study and gain permission to complete the study. After several emails and a one hour face-to-face meeting, the Program Evaluator and Director of Clinical Operations gave their support of my project. To recruit participants, I made arrangements to attend an ECEP weekly team meeting to announce my study.

Purposive sampling is necessary for this study, since there are specific criteria that participants must meet to be selected for the study based on the research questions. Lewis and Sheppard (2006) describe purposive sampling as, “based on the notion that in order to gain the most insight into a particular problem, one needs to select a sample that can provide the most appropriate information” (p. 298). Bernard (2002) also describes purposive sampling as a choice of participants based on the characteristics of the participants. Other research projects that require a specific population have used this method. One example of a research study is Bonner et al.’s, (2014) study on communicating cardiovascular disease risk. They utilized purposive sampling to obtain a sample with a range of characteristics known to influence CVD risk management (Bonner et al. 2014). In another health context, Valiee et al. (2014) used purposive sampling “to recruit nurses working at the ICU, CCU, and Dialysis unit; who had at least one year of work experience in critical care units of hospitals affiliated to



Tehran and Kurdistan Universities of Medical Sciences” (p.207). These research projects provide good resources for academic projects that exploit purposive sampling in a health care context.

Individuals for this study were screened based on two criteria. First, participants are screened for eligibility based on their actual involvement in the process of evaluation and delivery of the diagnosis of ASD to parent(s), caregiver(s), and/or family member(s) as a part of the ECEP in Albuquerque, NM. Second, individuals are screened for eligibility based on availability and willingness to participate. No individual is included that is not part of the ECEP. Those individuals who are in the room during observations that do not meet the first criterion are not included in the study. This study excludes any adult that is unable to consent, such as individuals who are not yet adults, pregnant women, and prisoners.

Collecting demographic information about the ECEP professionals was not an extensive process. All of the professionals were adults; the program manager informed me that some of the staff was on maternity leave, but those professionals did not participate in the study; and any other demographic information was not a relevant aspect of the study.

Currently, seventeen professionals are part of the ECEP, including four Speech and Language Pathologists, three physical therapists, one physical therapist intern, one occupational therapist, three psychologists, one psychologist intern, three pediatricians, one nurse practitioner. I did not write specifically about individual participants in the study. I removed all names and titles from

this dissertation to maintain anonymity and confidentiality for participants. Rather than names and titles, I used the generalized *participant* so my description of events and interactions did not allow for participants to be identified. To distinguish different participants' responses, I number the responses to each question numerically and arrange the responses randomly. For example, participant one, participant two, and participant three in the responses to question one are not the same as one participant, a second participant, and a third participant in the responses to question 2. The numbers are included to clarify the separate responses.

A variety of steps were taken to secure and backup the data. Authorization of access was only given to me. The written analysis of the data was kept on a USB that is password protected and was kept with me. The back-up files were stored in OneNote on my laptop; the notebook in OneNote is password protected and the laptop is password protected, so there were two passwords protecting the material.

### **Avoidance of Risk**

A few procedures were performed to lessen the probability or magnitude of risks. First, the observations occurred without the participants being distracted or affected by the researcher since the observations occur behind a one-way mirror. Second, all real names were removed from all transcriptions of interviews and fieldnotes. Third, the individuals that were a part of the study participated voluntarily and were informed that they were able to leave the interview at any time. No drugs or devices were used in the research. No source records were

used to collect data about subjects. No long-term follow-up was planned for the current study.

### **Research Stages**

This study took place in a series of stages:

1. Orientation, consent, and initial observations
2. Individual interviews with team professionals to create session storyboards
3. Facilitated group meetings to interpret the patterns of interaction observed in sessions

#### **Stage 1—Orientation, Consent, and Initial Observations**

Having already received permission to do so, I attended an ECEP weekly team meeting to explain the study and distribute consent forms. I supplied all members with a written consent form for their review (see Appendix A).

Providing the consent for the participants allowed time for the participants to read and understand the consent form.

After distribution of the consent forms, I observed diagnosis delivery sessions, which take place on Wednesdays and Thursdays. Prior to observation, I read the same consent form to the participants to gather a verbal agreement to participate. Verbal consent was attained rather than written consent to protect the identity of the participants. Participants in this setting were told to let me know if they did not want to be in the research study by verbally stating that they do not want to be a part of the project.

After gaining consent, observations were conducted. Through a one-way mirror, I observed the process of delivering the diagnosis of ASD to a parent(s),

caregiver(s) and/or family member(s). During observations, I took extensive fieldnotes on the ECEP members' process of delivering the diagnosis of ASD. There is no prestructured guide that was used during observations. I utilized thick description for note taking and describe the process holistically. I looked at what was going on to learn more about the process and to prepare to facilitate stages two and three. Utilizing a holistic, open-ended, grounded approach allowed me to see what emerged and educate myself as a facilitator.

After observations, I set up individual interviews with the ECEP team members that were a part of the observed diagnosis delivery. From the fieldnotes, I developed an interview guide based on my understanding about delivering the diagnosis of ASD determined during observations. The interview guide was moderately scheduled (see Appendix B). Some questions included:

- 1) I understand the process of delivering the diagnosis of Autism Spectrum Disorders (ASDs) to parent(s), caregiver(s), and/or family member(s) is difficult. Will you please discuss the process with me?
- 2) In your experience, is there a standard process that is utilized in the delivery of the diagnosis parent(s), caregiver(s), and/or family member(s)?
- 3) Are there any elements of the process of delivering the diagnosis that must be included?
- 4) What are some things you consider when planning for delivering the diagnosis?
- 5) What else would you like to share about delivering the diagnosis of ASDs to parent(s), caregiver(s), and/or family member(s)?

The guide was organized to create a storyboard of the process of diagnosis delivery. Questions were structured to allow for as much detail as possible.

I observed 16 professionals, including: four speech therapists, three psychologists, one psychologist intern, four motor therapists, one motor therapist intern, and three medical providers. Over the 74 hours of observation, I handwrote my fieldnotes on approximately 200 pages of notebook paper. I typed the fieldnotes for coding purposes. I combined opened and closed coding. For the closed coding, I used CMM concepts and elements of my research questions, which follow: communication patterns, rules of meaning and action, strengths and weaknesses, and goals. Then, I used open coding to see what emerged outside of these categories.

After compiling extensive fieldnotes and developing an initial understanding of the communication patterns, rules of meaning and action, strengths and weaknesses, and goals, I used the information to re-construct my interview guide. I had to address my research questions, but I wanted to present my questions in a way that indicated my initial understanding of the process. Here are a few of my questions:

- What are some things you consider when planning for delivering the diagnosis of ASD (for example when you are walking from the staffing meeting to the family meeting when it is individualized time)?
- Are there other ideas you have about delivering the diagnosis differently?

- In your experience, are there alternative ways of delivering the diagnosis to parent(s), caregiver(s), and/or family member(s)?

## **Stage 2—Use of Storyboarding in Individual Interviews**

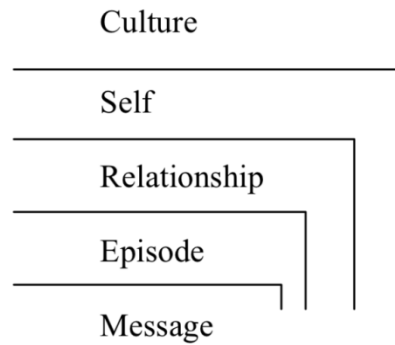
After observations, individual interviews were scheduled. To ensure ongoing consent, as the researcher, I reminded individuals at the start of each interview meeting that anonymity is guaranteed, confidentiality is guaranteed and participation is voluntary. I took extensive notes during the interactions. To avoid discomfort or vagueness in responses, I chose not to record the interviews. The interviews had a moderately scheduled interview guide, an example is provided (see Appendix B). The professionals' offices, conference rooms and meeting rooms served as the interview rooms.

I started off each of the 14 interviews with an explanation that although I had developed an understanding of the process from my observations, I wanted to get individual perspectives on specifics of the process. Then, I used specific examples for each team member to probe for further explanation. The data was helpful in organizing a few examples of each professional prior to the interview to use during the interview. For example, when I asked one professional, "How do you gauge the family?" The professional did not provide any specific answer or context. I then reminded the professional about one of my observations during the diagnosis delivery when there was a father that did not say anything during the entire meeting and did not have any other family member or EI team members to support him at the meeting. The professional then explained the process of

gauging that parent, which revealed some of the professional's ways of gauging family members and caregivers.

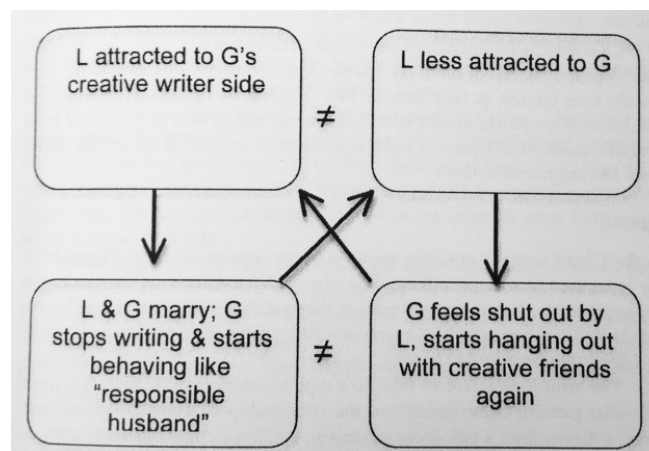
Stage 2 was designed to address the first Research Question: *What communication patterns are commonly used in episodes of diagnosis delivery at the ECEP?* In these interactions stage, I identified the patterns of communication through Storyboarding. Each professional constructed his/her storyboard—the sequence of events that compose the narrative shared by all participants—of diagnosis delivering of ASD to parent(s), caregiver(s), and family member(s). I facilitated the process by writing down and organizing the information provided by the professionals, who created the storyboard. This information was saved for stage 3 of the study. As the interviews continued, I asked questions that allowed the professionals to enrich the existing storyboard to create an enhanced storyboard, the Enriching stage of SEAVA. Two concepts of CMM that helped me gain understanding and clarity on participants' responses were the hierarchy model and charmed or strange loops. The hierarchy model is a tool that allows me to distinguish the importance of elements meaning in a situation since each communicative message has multiple layers of meaning wrapped up in the meaning. Pearce (1999) states, “the hierarchy model is designed as a tool to help identify the interpretive wrappings with which communicators surround the messages that they exchange....The key idea in CMM is that the meaning at one level of the hierarchy is not necessarily the same as at others” (p. 35). For instance, if professionals discuss a situation of diagnosis delivery with another ECEP professional, several layers of meaning are involved; the professional may

discuss the relationship between the professionals, the culture of the family of the child in the evaluation, the episode, the message of diagnosis, etc. Arranging these layers by relevance may look like Figure 2 (Pearce, 1999, p.35).



**Figure 2: The Hierarchy Model**

Charmed or strange loops allow me to check for special features in the storyboard. Loops demonstrate patterns of behavior that may be useful and work well— charmed loops—or may be contradictory—strange loops. Loops may help to explain a feature of the storyboard that may not make sense without understanding the strange loop. Figure 3 provides an example of a strange loop (Crede, Fisher-Yoshida, & Gallegos, 2012, p. 35).



**Figure 3: Strange Loop**



These first steps of the research study assisted me in developing an etic perspective and enhance that with an emic perspective of the process of delivering the diagnosis of ASD. After observing and interviewing study participants about the process, I clarified my foundation and understanding that was utilized during the next stage. Information attained from the individual interviews allowed me to prepare for the stage 3 of the project, managing meaning.

### **Stage 3—Use of Storyboarding in the Group Interview**

Stage 3 is designed to address the following research questions:

RQ2: What rules of symbol use, meaning and action guide the patterns of communication used by professionals during diagnosis delivery?

RQ3: What strengths and weaknesses do ECEP professionals identify about their own communication practices?

RQ4: What goals would the professionals like to accomplish with their communication patterns?

During this stage, the Enriching, Visioning, and Acting (EVA) steps were explored. I worked with the professionals in a forum similar to a group interview, in which there is a group of professionals of a team and one researcher that asks questions. I had a moderately scheduled interview guide (see Appendix B). However, I did not drill the professionals with questions. Rather, I facilitated a discussion amongst team members through the EVA stages of SEAVA. The group interview was held on a Monday during the weekly meeting—from noon to 1pm—to allow for the most professionals at the center to participate.

Arrangements were made with the Program Manager at the time to manage the meeting information for that week. The interview lasted around two hours.

The group interview followed several steps. Here, I include the steps:

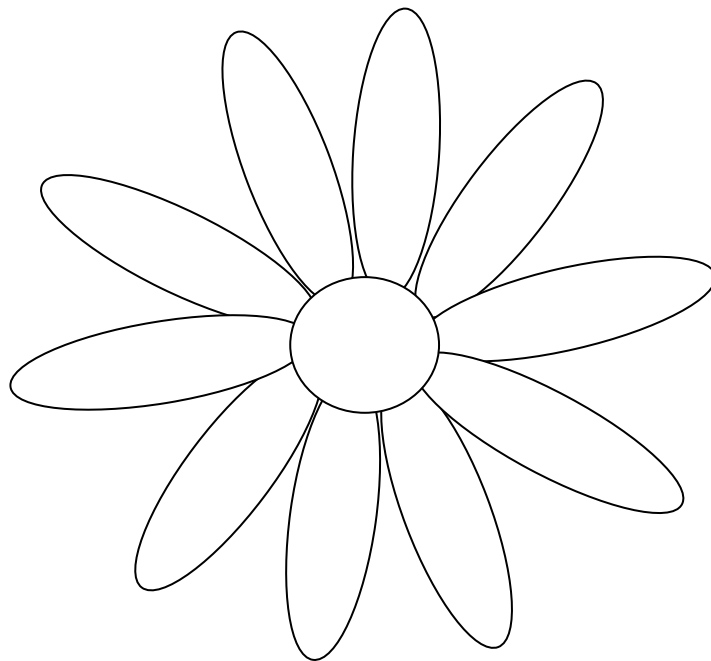
- I prepared a cohesive storyboard based on the observations and interviews
- I presented this storyboard to the group and invited them into a discussion about it
- I next highlighted certain areas of concern that were voiced by the professionals and asked team members questions that created a discussion about the concerns
- Then, I added other relevant features that emerged in the conversation to the process by asking the team if they agreed that the element should be added
- During the discussion of concerns, some issues were clarified
- Finally, the team collectively created a list of concerns and areas for clarification for them to further explore after the group interview and at their retreat

Understanding that SEAVA is not a linear model is very important.

During any stage of the model, I was able to return to a previous stage to fill in gaps and clarify meaning. During the group interviews, the discussion began in the Analyzing phase. However, it moved back to the enriching stage when the participants felt some additional information needed to be included. The group discussed existing patterns of communication and other possible patterns that may

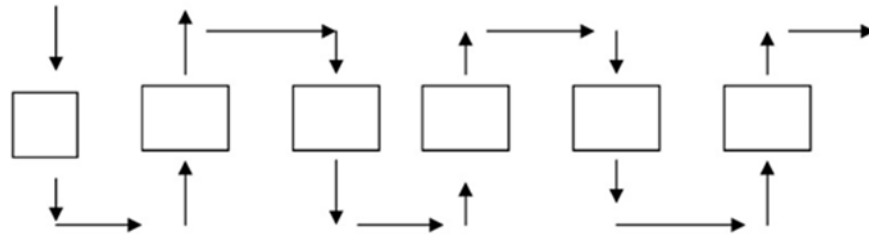
enhance the current patterns. I examined the logical forces and identified special features or key elements to the participants' patterns of communication. My understanding of the existing patterns of communication were strengthened through identifying logical forces that create and maintain patterns of communication and by noting key episodes of communication. This procedure relied on the three main heuristics of CMM.

**The Daisy Model.** The Daisy Model takes into consideration communication ecosystems—the notion that each person is a part of several conversations created from personal, relational, and communal realms. The Daisy Model (see Figure 4; Pearce, 1999, p.55) places an event at the center of the daisy and uses the petals to explore all of the possible conversations that constitute the event.



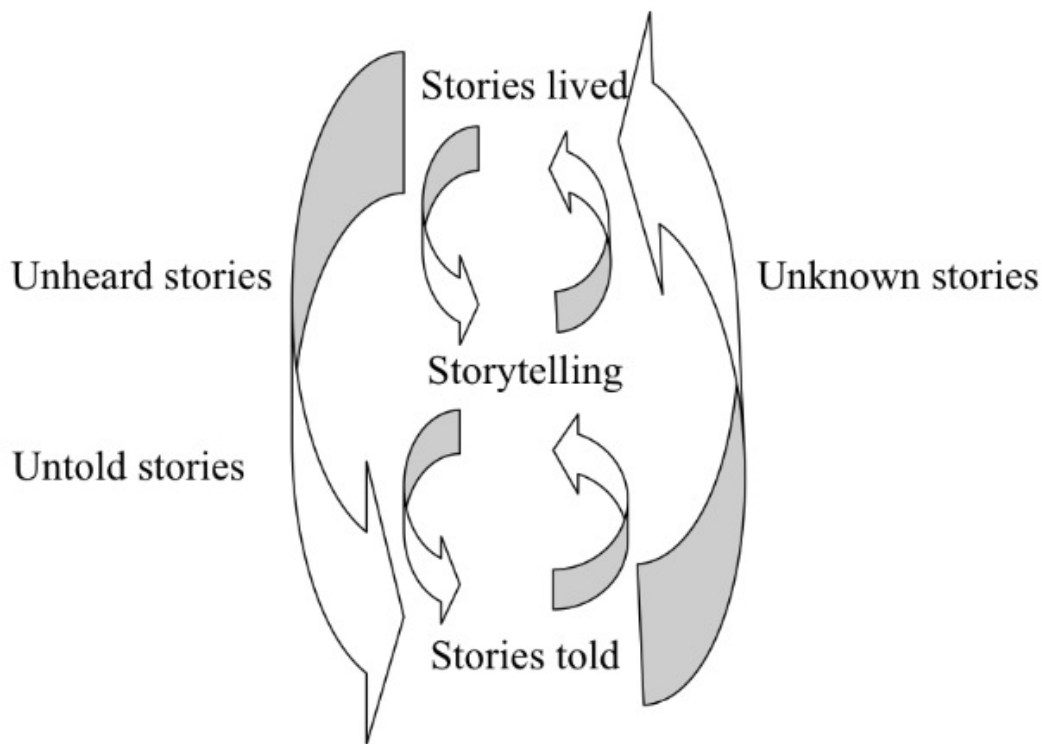
**Figure 4: The Daisy Model**

After the daisy is filled, the heuristic is used to discuss the privileged conversations and the patterns around the event as well as the vocabularies and grammar around the events (Pearce, 1999). The Daisy Model helped me create an enriched description of the event. This heuristic also helped professionals to enrich the storyboard content created during the individual interviews.



**Figure 5: The Serpentine Model**

**The Serpentine Model.** This model elaborates on the conversations between participants. The model presents the social worlds of individuals in an interaction. The arrows in the model (see Figure 5; Pearce, 1999, p.56) demonstrate “a constitutive (this counts as that) or regulative (if s/he does then, then I must/should/must not do that so that s/he will do that) rule” (Pearce, 1999, p. 56). When given the opportunity to explain the rules, a person follows during an interaction, the forces are revealed providing new understanding to individuals and providing an opportunity to explore other forces and change/shift future interactions. This heuristic helped professionals to understand specific interactions and adjust to best suit future interactions.



**Figure 6: The LUUUTT Model**

**The LUUUTT Model.** LUUUTT is a storytelling analysis tool that stands for the Lived stories, Unknown stories, Untold stories, Unheard stories, storyTelling and Told stories (see Figure 6; Pearce, 1999, p. 58). The focus of this heuristic is on storytelling—how the story is told. Individuals who take a systems’ perspective are accustomed to the concept of tension between the stories lived and the stories told. This model explores the principle that stories lived cannot be the exact same as stories told since the stories lived are co-constructed between communicators and the stories told are the narratives that one person explains (Pearce, 1999). Focusing only on the difference between stories lived and stories told is not enough to explore the richness of the specific situation. Rather, the stories untold, unknown, and unheard help to enrich the storytelling.

Pearce (1999) described stories untold, unknown, and unheard; “[T]here are unknown stories which the participants are not (currently) capable of telling; untold stories which participants are perfectly capable of telling but have chosen not to (at least, not to some of the others in the situation); and unheard stories which, although they have been told, have not been heard by some important participants in the situation” (p. 59). The LUUUTT Model helped me to analyze events and also enrich the stories of participants in order to enhance comprehension of events. This model allowed participants to gain an enhanced understanding of their own interaction as well as hear and discuss differing narratives.

After utilizing heuristics to enrich and analyze the process of diagnosis delivery of ASD, Visioning was the next step during the group interview process. During this stage, I continued to facilitate the discussion. The discussion was guided by the topic of creating an alternative pattern of communication for delivering the diagnosis of ASD that was based upon the experiences of all professionals present during the interviews.

The final step of the process was Acting intentionally. The interview continued to be mostly controlled by the professionals. They discussed the preferred pattern of communication and the possibility of the new pattern being effective. I utilized the tools of CMM throughout the final stage to facilitate the process. At the conclusion of the interview, I congratulated the individuals on successfully co-constructing some alternative patterns and ideas to further explore

that may enhance their effectiveness of delivering the diagnosis of ASD to parents, caregivers, and family members.

### **Analysis**

At the conclusion of stage 3 of the method—the group interviews—all data was collected (notes from observations, notes and videos from individual interviews, notes and videos from group interview). The procedure for this phase of the research was careful recording at each stage of the process. I reached the point of saturation when the participants decided that no more time was needed to enrich or analyze their story and when the visioning was agreed upon by all participants that have created steps for acting intentionally. When they reach a point of agreement, then I had enough data to report.

For the analysis, a global analysis was performed. Throughout the analysis, the CMM heuristics assisted in addressing the research questions. I used concepts of CMM to write up the responses based on three sources of data—observations, individual interviews, and the group interview.

RQ1: What communication patterns do ECEP professionals commonly use in episodes of diagnosis delivery at the ECEP?

RQ2: What rules of symbol use, meaning and action guide the patterns of communication used by professionals during diagnosis delivery?

RQ3: What strengths and weaknesses do ECEP professionals identify about their own communication practices?

RQ4: What goals would the professionals like to accomplish with their communication patterns?

Research questions 1 (What communication patterns do ECEP professionals commonly use in episodes of diagnosis delivery at the ECEP?) and 2 (What rules of symbol use, meaning and action guide the patterns of communication used by professionals during diagnosis delivery?) address the first objective to describe/depict the communication process used in episodes of communication to deliver ASD diagnosis to parent(s), caregiver(s), and/or family member(s). The second objective to engage professionals in a process of evaluating their communication patterns is addressed by research question 3 (What strengths and weaknesses do ECEP professionals identify about their own communication practices?) Research question 4 (What goals would the professionals like to accomplish with their communication patterns?) addresses the third objective to elicit professionals' ideas about what they wish to accomplish and how to improve the communication patterns. The write-up of the study addresses the last objective to provide an example of a methodological approach for other research studies.

### **Chapter Summary**

This chapter explored the qualitative approach that this study utilizes. The goals and objectives of the study were described and the research questions were listed that guide the research. The chapter validated the application of CMM as a research method and the site, sampling techniques and participants for the study. The SEAVA model and the phases of the research were explained through two stages, orientation and managing meaning. To complete the orientation stage, observations and individual interviews were described. The group interviews were explored for managing meaning. Several models



of CMM were provided as a preview of the research process including: the Daisy Model, the LUUUTT Model, the Serpentine Model, and the hierarchy model.

## **CHAPTER 4**

### **STAGE 1 RESULTS: ORIENTATION, CONSENT, AND INITIAL OBSERVATIONS**

Three methods of data collection were utilized to collect the data for this research—participant observation, individual interviews, and group interviews. My goal for the participant observation method was to view how the ECEP team delivered the diagnosis, that is, to observe what they said and how they said it. The data from the participant observation emphasized the actual practices whereas the data from individual and group interviews yielded information about how the diagnosis team conceptualized and explained what they did.

In this chapter, I (1) identify the episodes and phases of diagnosis delivery and (2) present my participation observation findings. As I follow the structure outline here, I also link in a general way my findings to the research questions stated in previous chapters.

#### **Procedures**

Several specific procedures emerged as the study progressed. In this section, I name the phases of emergence as episodes, a term commonly used in CMM. I made my entry after 16 months of preparation and execution. I felt nervous and excited about meeting and working with the ECEP team, but I became very comfortable around my new friends. As I retraced my steps, there were several conversations that played a role in the research. The introduction to the topic occurred after getting to know a colleague in a graduate course at UNM, where we were furthering our knowledge on Autism. We began discussing our lives and interests in class activities. I was intrigued by the work

that she spoke about, and she was curious about my research interests. We set up a meeting outside of class to chat more. We met at Starbucks on February 8, 2013, where the initial discussion of looking at diagnosis delivery occurred. After that discussion, we exchanged several emails. I also began working on a review of the literature regarding diagnosis delivery. In the fall, I put together my Institutional Review Board (IRB) application packet.

In September, I set up a meeting to see the clinic space on the following Friday. After getting an idea of the location, room sizes, observation room, etc., I added specifics to my research protocol and IRB application. In October, the program evaluator at the CDD, contacted me via email and asked for additional information. We exchanged some emails, and I sent her a copy of my IRB application prior to submitting it. When I sent the application, the program evaluator and the Director of Clinical Operations at CDD reviewed my proposal. In the follow up meeting on December 10, 2013, the CDD contacts provided copies of the application with feedback, suggestions, and questions that I followed and received approval of my IRB proposal later that month. In March, I coordinated with the program manager on a time to introduce myself and observe the ECEP team.

The first time I met the team was at the weekly team meeting on March 17, 2014. The team met as if it were a normal weekly meeting; however, I joined the meeting for the last 15 minutes. When I entered the room, the team was finishing some discussion. I sat down next to the program manager, who was the only person in the room with which I previously had conversations about the project. After the program manager introduced me, I thanked the team for allowing me to join their meeting, and then briefly introduced

myself and my intentions for research. During this first observation of the team's nonverbal communication, I briefly introduced myself, my research focus, and my methods of research. I provided hard copies of the consent forms, read the forms, and explained that they should read over the forms prior to giving consent for the research project. I also informed them that anyone could decide to withdraw from the project at any point in the research.

After my explanation, I allowed some time for questions. Some questions were about the specific research questions and others sought clarification that I would not involve the families in the research project. The team also suggested observing the entire clinic day a couple of times and attending the staffing meeting as well as the family meeting. The invitation to observe the staffing meeting was a significant change from my research plan. Originally, I was not sure what parts of the process that I would be allowed to attend and observe. Accepting the suggestion and invitation to attend the staff meeting along with observing the family meeting was a benefit to me. At the end of the meeting, I provided my email address, left consent forms with the program manager to pass out to other team members that were not able to attend the meeting, and provided an electronic copy to be sent to team members.

The observation phase occurred during March and April of 2014. During my observations, there were twelve episodes. An episode consists of two phases: phase 1 is the staff meeting and phase 2 is the family meeting; sometimes there was a third phase, the debrief meeting. One clinic involved one child and his/her family member(s) or caregiver(s). Each clinic lasted approximately 2-2.5 hours and occurred on a clinic day—Wednesday or Thursday—of each week. The episodes and phases are separated below.

The first two episodes served as orientation and included two full clinics—4.5-5.5 hours per clinic—that included the two phases as well as three additional phases, including: a brief team meeting, an introduction to the family meeting, and the evaluation testing. Team members verbally consented to the process and were reminded at the beginning of each episode that their participation was voluntary and they could decline participation at any moment.

I was present for every observation along with at least four team members; I observed all members at least once when delivering the diagnosis of ASD. The observation stage of the process addressed the Storyboarding and Enriching stages of the process. During storyboarding, I took notes of my observations to identify episodes, construct the series of events, and punctuate the episodes. Enriching occurred when I named the patterns and described the social world of diagnostic delivery. To continue orienting to ECEP and building a storyboard, I agreed with the team's suggestion to observe a couple days of full clinic prior to taking extensive fieldnotes.

Prior to the last episode, I had observed all team members that participated in clinic full time at the CDD. I planned to stop observing and begin interviews after episode 11, and I began the interview phase; however, I discovered that two other team members would be in clinic at the CDD a couple weeks later. So, I chose to observe two other team members. One team member had participated in outreach clinics and the other had recently retired and only participates in 25% of the clinics. Since they were both going to be in clinic, I decided to observe one more day for episode 12.

## **Episodes of Observations**

To clarify the acronyms that were commonly used during observations, I provide a table with the acronyms and explanations related to the participant observation (See Appendix C).

### **Episode 1: First Clinic Observation**

The first day provided much context for me about how a clinic day functions. I arrived around 8 a.m. and met team members in the West building. One team member helped me to test out the sound in the observation room and showed me how to adjust the camera in the room to see a different view on the monitor. I learned that the light has to stay off during observations. The team gathered in the evaluation room and participated in small talk for approximately 15 minutes. After the team gathered, the team walked together to the family room for the initial family meeting and then walked back to the evaluation room with the family for the evaluation process. In both rooms I sat behind a one-way mirror and observed the interactions. I was cautious not to interrupt the process and not to make contact with the family. When I transitioned, I either left right before or after the team left the room.

During the evaluation process, I was never bored. There was so much going on that it was amazing to just observe without taking notes. Professionals entered and vacated the evaluation room and the observation room with ease while assisting other professionals with specific testing, talking with the family member(s), and taking their own notes, not to mention avoiding objects that are thrown, tossed, or spilled in their direction. The two hours of testing passed quickly. I was so curious about the process and what each step meant; I found myself wanting to ask questions but refraining because

the questions were not relevant to the research or to the process. Yet, the team encouraged me to ask questions even if I thought the question was irrelevant. The team members answered my questions no matter how relevant they were.

**Phase 1: Staff Meeting.** After the evaluation, the team dismissed the family for a break while ECEP members held the staffing meeting. All members transitioned to the East building after the evaluation and for the meeting. The team met in a room that was arranged to seat twelve people. When I entered, I sat at the furthest seat in hopes of not taking someone's unofficially identified seat, and I waited for all team members to arrive. During this observation, there were four team members and one intern. Staffing involved scoring the tests that were done during the evaluation, discussing observations, filling out staffing sheets, discussing family concerns, and identifying the diagnosis/es. After about 50 minutes, the team discussed how they wanted to conduct the family meeting to discuss the diagnosis. After a short discussion, the team decided that two members would go into the family room and one member would observe. At some point during the discussion, the team was informed that the family had returned from break. The team members took a few minutes to use the restroom, get a drink, grab papers from their offices, and then headed back to the West building.

**Phase 2: Family Meeting.** When entering the West building, the diagnosis team and I walked to the family room. The team member who was to observe and I went into the observation room prior to the team members opening the door to enter the family room for the final family meeting. At this point in the day, the team members delivered the diagnosis. Although I did not take specific notes about the team members, I recall that during the conversation the team properly communicated with the family in a way

that met the family's needs, identified the diagnosis, and answered any questions. The family meeting lasted approximately thirty-five minutes. At the end of the meeting, the family members left the room. The team members waited in the room for a minute or so to allow the family time to leave. I then spoke with the team members for a couple minutes in the hallway. They explained that not all of the family meetings go so smoothly and quickly. Yet, some do. The team members then went back to the East building to their offices for a short break.

The second evaluation process started around 1 p.m. The same team members from the morning clinic were participating in the afternoon clinic. The process was very similar. I became more aware of how to transition between rooms and of the process.

### **Episode 2: Second Clinic Observation**

On day two of orienting through observation, only one team member from day one was in morning clinic. There were three different members, two students and a translator, so seven people involved excluding me. The process was the same as episode 1; however, I noticed a couple different parts of the process.

**Phase 1: Staff Meeting.** First, there is a coordinator. At this point, I was not quite sure of the role of the coordinator; yet, I noticed the term used to describe the person. During the discussion of who would go to the family meeting, the team agreed that two members would go.

**Phase 2: Family Meeting.** During the final family meeting, the team members went over information in a pamphlet provided for the family. During the first day, I did not notice the pamphlet since the team did not spend any time on it. Rather, the team gave the pamphlet to the family to go over at their preferred time.



**Phase 1: Staff Meeting.** The team changed for the afternoon session. There was a different graduate student that attended and one different team member. At this point, I felt familiar with the process while noticing unique elements about each clinic.

**Phase 2: Family Meeting.** During the final family meeting, three team members went, but the fourth member was not able to attend due to an appointment. After orienting to the process for two days, I was ready to start reflecting about the process in fieldnotes.

### **Episode 3: Third Clinic Observation**

Moving forward from the initial basic observations, the ECEP team and I decided that I should observe the staffing meeting and the final family meeting. I started on Wednesday, March 26.

**Phase 1: Staff Meeting.** In the staffing meeting, there were seven people present: one speech therapist (SLP), one psychologist (PSY), one medical provider (MED), one motor therapist (MT), one motor therapist intern (MTI), an early interventionist (EI) and me.

After 45 minutes of the staffing meeting, the psychologist on the team stated, “We have to consider the parents.” At this point the discussion switched to the delivery of diagnosis. One team member brought up the parents’ concern that the interactions of the child were not typical and did not represent the normal actions of the child. The PSY noted she was concerned about the parents’ reactions since they had a very positive assessment of the child’s cognitive abilities. The psychologist discussed providing recommendations for where the parents could go from that point. She also mentioned focusing on feedback from the evaluation, such as the child’s “strong visual learning

skills.” The motor therapist spoke to the medical provider and the psychologist telling them that they could decide who would start; the two then spoke to each other. The psychologist decided to start and for the medical provider to transition into the discussion. The MT then asked the SLP if she wanted to “skip” the family meeting. The SLP said “I can.” The MT explained that the SLP did not have to skip the family meeting, and talked about “limiting the number of people in the room.” She went on to say, “When the family hears this, their brains kinda (she used her hands and arms to show a gesture of explode) with info.” The MED then asked the MT, “Do you need to go?” Her response was, “I am the evaluation coordinator.” After pausing for a moment, the MT looked to the MTI and said, “You could go.” She then discussed observing behind the glass with me.

**Phase 2: Family Meeting.** The staff meeting ended with some ambiguity. I was not sure what the team had agreed upon. When we walked to the family meeting, I went into the observation room and was joined by the SLP and the MT. The PED and PSY walked into the room with the family, the translator, and the EI. The conversation began with small talk about the break. The PSY then explained that the time was the family’s “time to make sure all questions are answered.” She discussed the long report that the family would receive and expressed the option for parents to get in touch with the team if needed. She then told the family that the team members were going to “talk about what we did today.” She then mentioned with the parents’ concerns and the question of Autism. Then, she stated, “We are giving a diagnosis of Autism today.” She discussed the DSM V categories for an Autism diagnosis. When she discussed speech, social

interaction and repetitive behavior, she described what each meant and provided examples of communicating that the child used during the evaluation.

After providing a baseline for the family, they began to ask questions. In response to a question about how the child got Autism, the PSY discussed the inability to do a blood test and noted the differences between children with ASD. She also discussed the one thing all children on the spectrum share, “problems in the three core areas: communicating, interacting, and following routines.” The family continued to ask questions, and the PSY responded and provided answers that focused on the positive elements of the child’s abilities. The MED also added comments and discussed therapies. The PSY stated, “The more therapies when kids are young, the better,” and then mentioned that the diagnosis helps therapists know “how to teach a child better and more effectively.” The PSY also introduced the standard packet of information, but was interrupted with a question about school. After addressing the question, the PSY said, “It’s a lot of information.” The parents decided to review the information at home. The PSY discussed parents reaching out (PRO) as being helpful with school stuff. She then offered to have someone call parents about parent home training (PHT) and discussed those involved as good resources.

At this point in the meeting, emotional reactions were evident. The MED switched the topic. She shared that no one knows all of the information to answer the “why” question. She then explained, “What I can tell you is that nothing during your pregnancy caused this nor [did] the family history.” She went on to discuss genetic testing and a couple other recommendations. The parent asked another question. The MED described the many behaviors that are part of the spectrum and the areas of the

DSM V. One parent asked another question, and the MED described positive actions and areas of the child and stated, “She will continue to make progress.” She also discussed the good interactions with the family members. The PSY then added that the child “will develop skills” and then discussed the packet of information. The next question was about insurance. The MED discussed qualifying for Supplemental Security Income (SSI) that will help pay for therapies. The PSY reassured the parents that at this time, “You are doing what you need to.” The MED reiterated that they family could call if they have any questions and added more positive examples of the child’s interactions. She asked if there was anything else then said the child “was fun to work with” and shook the parents’ hands. After shaking hands, the family left. After waiting a few minutes, the team members left as well; when I saw the team members exit the room, I followed and exited the building.

#### **Episode 4: Fourth Clinic Observation**

On Thursday, March 27, I arrived at the CDD, checked in at the West building as a visitor, and headed to the East building for staffing. After entering the room, the team members and guests arrived at different times.

**Phase 1: Staff Meeting** After everyone arrived, there were eight people in the room for staffing: four team members, one new SLP, two EIs, and me. The SLP first introduced the topic of parents; she mentioned the parents’ positive perspective about the child. The MT commented, “I don’t think they will be surprised.” Followed by, “But it will be hard,” from the MED. The team used head nods and nonverbal gestures to agree with the MED. One of the EI discussed a statement from the parents that indicated that the parents did not think the child had ASD. The MT brought up that the EI team had

discussed the possibility of ASD with the parents and asked the EIs for suggestions on how to discuss the diagnosis with the family. The EIs suggested leading with positive attributes of the child. The SLP added, “They [the parents] were very positive about him, which is probably related to how happy he is.” The team nodded in agreement. The team members then discussed their recommendations, which were followed by the MT stating, “Who’s going?”

The PSY first responded with, “I’ll go.” Then the MT asked, “Do we all need to go?” The PSY added, “She [parent] was concerned about language.” The SLP said, “I can go.” The SLP then added, “It’s really important in our diagnosis, (pause) she’s done her research, so she just wants to know.” She discussed talking about research both good and bad sources. At this point the staffing meeting ended and team members dispersed and walked to the family meeting. Since team members acted differently at this point—go to the restroom, grab something off his/her desk, get a drink, etc.—I walked over to the West building and went into the observation room.

**Phase 2: Family Meeting.** When the team arrived, there were only two team members, the PSY and the SLP. They began with small talk about the break. The PSY then transitioned with thanking the family for coming. She also discussed the helpfulness of their support and explained that the meeting is a time to say what the team members saw and to discuss next steps. She then stated, “One thing was the question of Autism, and it sounds like you’ve looked up things. We will walk through what we were doing. We can’t take a blood test; we look at behaviors: social interaction, communication, and repetitive behavior.” She then went on to discuss each of the three areas by starting with positive actions then transitioned into tasks that are more difficult for the child. During

the discussion, she also mentioned some of the actions that the parents had described as concerning. She mentioned that the team, “See[s] it as a style of learning,” and continued, “When we put everything together, it does match Autism, so we are going to give that diagnosis.” She then told the parent that it was okay to question the diagnosis and wonder and that “all of those things are normal” and to continue to follow her gut and intuition.

After a short pause, a question about if the child will ever talk came up. The SLP responded, “The answer is I have no idea; it’s hard to tell.” She then discussed the benefits of continuing with therapy and related it to the child’s actions. She also added, “Getting therapy for him as young as he is makes a really big difference.” She also mentioned the importance of support. She stated, “The diagnosis helps people to focus in on therapies he needs, so you’re already doing the right thing, the thing that will help him most, so that’s really good. He already has these really nice pockets of things and ways of beginning to communicate some of the time.”

Then the parent asked a question regarding the type of Autism. The PSY assured the parent that was a good question then discussed the recent change in diagnosis and the spectrum and how the child is just on the spectrum. The question of moderate or severe also came up. The PSY addressed the question by stating, “We don’t have a crystal ball to see the future, so it’s hard to tell.” She also discussed continuing the therapies and adding Autism specific services and added information about the re-evaluation process that should take place in two years. She then pulled out the pamphlet and discussed other options (i.e. PRO and PHT). Throughout the discussion of the pamphlet, the PSY referred to research and to good and bad sources.

When discussing sources, the parent asked a question about diet. The PSY discussed different research regarding diets specifically related to Autism; she stated, “research doesn’t support that a specific diet helps Autism.” She then switched the conversation to focus on “what we know is going to help.” She went on to discuss the library. When talking about books, the team member stated that the child had a teacher that had a child with Autism that was supportive. The PSY acknowledged the information and transitioned to statements about other resources. She stated, “Like your teacher, there are other parents that volunteer their time; it's called parents reaching out.” She then explained PRO and discussed possibilities for funding. After some discussion, she stated, “There's all different information in here [the pamphlet] for you to read. One more thing, you'll get a copy of huge report and then if you want you can take it to an IEP [Individualized Education Plan] meeting to get help with school.”

When discussing school, a parent expressed concern about bullying. The PSY addressed the concern, she stated, “Right now he enjoys going to school and other kids. It’s good that you want the best for your son.” At that moment, the SLP grabbed tissues in the room and gave them to the parent who was crying, and the SLP also touched the parent’s shoulder. After a moment in silence, the PSY stated, “It’s nothing that parents do.” Then, she stated, “There is an option in the report for genetic testing to check genes, etc, and just give more information. When there is a prevalence in one, then there is some a possibility of having more children with Autism. You need to do what is best for your family. We do see families with multiple kids that only have one child with Autism.” The SLP added, “There is more of a chance of having another child that doesn't have Autism than having a child with Autism.” The PSY then discussed support for

families and added, “Again, all feelings are okay.” After the parent stated that she felt like she did something wrong, the SLP stated, “We can see the things you did; he has a loving and supporting family; he has happiness in his smile, that's what you did.” The PSY continued, “This diagnosis does not change your child; it just helps us to understand him and open doors to more help.” The SLP stated, “It’s true; he’s really lucky that you started early.”

After discussing support, the conversation came to a close. Gratitude was expressed and the SLP reminded the family that her contact number was in the packet and to call if they needed anything. The PSY added that the family members that were not present could also call. The family then exited the room; the team stayed in the room briefly before exiting as well. I followed the team out of the building and left.

### **Episode 5: Fifth Clinic Observation**

On the following Wednesday, April 2, I arrived at the CDD, checked in at the West building as a visitor, and headed to the East building for staffing. As I waited for staffing to start, more people kept entering the room.

**Phase 1: Staff Meeting.** This was a unique staffing meeting for several reasons. First, eleven people were present; this was the largest group that I had seen as part of staffing. Second, this was also the first meeting that any males were present. The group included: four team members, a PTS, a MED resident, and four EIs. Third, the EIs provided some background information regarding the reason for coming to ECEP. They stated that the child had received an ASD diagnosis, but a parent questioned the diagnosis when one EI—who was not present and was a part of a different organization that did not have representatives in the staffing—questioned the diagnosis. The EI then explained



that the parent became upset about the diagnosis. This conversation started the staffing meeting.

After the unique beginning, the team went through the scoring procedures of the testing. During the last few minutes of the staffing, the team began to focus on the delivery of the diagnosis. One team member discussed, “Us[ing] the DSM criteria to structure how we talk to [the family].” They discussed recommendations and who would go to the family meeting. One team member also suggested mentioning that the ECEP team could talk to the team of EI who was not present and the other family members on the phone. Then, the MED talked to the MED resident and the MT talked to the MTI. Then the MT—who was the evaluation coordinator—talked to the PSY, who asked the MED if the MT should go to the meeting since there were no motor concerns. They discussed a small group being better for the family meeting. Then the MED asked the PSY, “Do you want me to talk to them?” The PSY responded, “Yeah I didn’t talk to her a lot.” The MED stated, “I did talk to mom.” The PSY added, “I can talk about the ADOS. You can start, and I will jump in.” The MED stated, “I will start with diagnosis.” The group then transitioned to the next part; some left or went to their offices, and others headed to the West building for the family meeting. I walked over to the observation room for the family meeting.

**Phase 2: Family Meeting.** When the team entered the room, there were two team members and two EIs. The PSY and the MED were the team members who engaged in small talk when entering the room. The MED began with positive examples of the child’s actions and informed the family that, “This is your time to get feedback.” She also added, “It seems like there was the question of Autism. It is important to be on

the same page about what Autism is. There is a lot of information out there. You've read and read a lot, but let's get on the same page. There are three areas of struggle for children with [A]utism." She then went on to explain areas of struggle where there is concern.

After some discussion, the MED stated, "The really nice thing is we have seen a lot of gain. (pause) Autism tells us how to teach him." One family member then starts to make comments which the MED and PSY respond to. One example is the discussion of the child's eye contact. The family member discussed the good eye contact the child has with the family. Then, the MED responded, "And that really speaks to your relationship. The windows are really nice." The PSY discussed stereotypes and people's thoughts. Then she stated, "[The child] has difficulty communicating. He has learned a lot of strategies from [EI organization] but it's not something that comes naturally for him." The family member continued to inquire and the team addressed the questions and comments. One comment centered on over-diagnosis. The MED responded, "The reason for diagnosis is not a label but to direct adults how to help [children with ASD] learn better," and she continued to provide a further explanation. In response to one comment, the PSY answered, "It is too early to tell if there is a learning disability. We do know kids his age that get the therapies he is getting show significant improvements." She continued, "Autism is a style of learning."

As the comments continued, the team provided responses that highlight positive characteristics of the child's actions as well as other areas that are difficult for the child. Then the family member commented about the whole picture of the child. The team members then discussed seeing the child again at a different location. After some

conversation about what the team saw, what the family reported, and what was discussed by the EI teams, the PSY asked, “Is there something else you want us to see? I’m curious about what you think we didn’t see.” After the family member’s explanation, the team members looked at each other and agreed that the two of them would see the child at a separate location. Prior to discussing the specifics of the meeting, the MED stated that she would go over recommendations first and then the team could talk with the family to establish specifics.

After discussing recommendations, the team and family finalized the dates and times for following up with other family members that were not present and the follow-up observation. Then the PSY stated, “We’ll be in touch with you and we will include notes from our observation at head start in our report.” She also stated, “We really enjoyed our time with him.” When the EIs left, the PSY thanked them for coming. Then, when the family and team members were still in the room preparing to leave, one family member spoke with the MED. The MED stated, “You have a fabulous grandson.” Then the family walked out together.

**Phase 3: Debrief.** After a few moments, the team walked out of the room; I joined them in the hallway. We chatted for a few minutes about the family meeting. Both team members discussed the difficulty of the meeting. The PSY referred to the difficulty of the family feedback and said it was the hardest family meeting ever. The MED also emphasized the difficulty. She also stated, “That type of feedback happens about 10% of the time.” After a short debrief, I went back to the East building to type up notes from the meeting.

## **Episode 6: Sixth Clinic Observation**

Later that afternoon, I joined the team for the second staff meeting of the day.

**Phase 1: Staff Meeting.** There were nine people in the afternoon staffing, including: four team members, one MTI, two EIs, and me. The MT was the evaluation coordinator, and she started the meeting with the staffing sheet. The parents' concerns included Autism. The team went through the scoring procedures and the recommendations. Toward the end of the meeting, the Med asked the EIs for thoughts on the family meeting. EIs said communication was a big concern. The MED asked the PSY, "How do you wanna do it?" PSY responded, "You can do it." The MED then asked the SLP, "Can you stay?" The SLP responded, "Yes." The MED then stated, "It might be nice to have the whole team." Then, the team members left the staffing room for a brief break and headed to the West building for the family meeting. I waited in the observation room and waited for the team to arrive.

**Phase 2: Family Meeting** When the team arrived, they entered the room and began small talk and got seated. All four team members were present, both EIs and the family. The MT began by explaining the process; she said, "So this is where you guys get to ask questions and clarify." The MED mentioned the question of Autism and explained the three areas of focus. She then added, "When we make a diagnosis we base it off of observation and what you have told us. So based off of observations and report, we are going to give a diagnosis of [A]utism today. (pause) I can let it sit in or answer questions for you." A family member mentioned a follow up. The PSY responded, "Before we go there, do you want me to discuss what we saw and provide an explanation of what we saw?" The family agreed, and the PSY went on to explain specific behaviors.

After discussing areas of concern, the PSY gave positive examples of eye contact. She then said, “He has fabulous windows [of opportunity]; he has the smarts. Through EI, already he has increased skills. By making the diagnosis, it allows us to intensify services. (pause) You are doing what you should be.” One family member then asked why the child had ASD. The MED responded. She stated, “To address the ‘could’ve,’ ‘should’ve,’ ‘would’ve’ question, there is nothing about your pregnancy or medical problems or vaccines.” A family member then asked about age. Then the other family member made a comment, and everyone in the room laughed at the comment. After one family member began to cry, the MED got up, got tissues, and handed them to the family member. After a short pause, the MED highlighted the child’s intelligence and focused on the re-evaluation in two years, “to make sure it’s the best diagnosis for him.” She said, “Children grow and change, and they look different. And keep in mind he’s only been in EI for two months.” The MT added, “The diagnosis does not change him; it provides opportunity for more services.”

After the family asked another question, the PSY discussed the packet of information. After some discussion, the MED stated, “It takes a while to sink in; it’s a lot. You have my number, so feel free to call. After the MED listed some myths about vaccinations, she reassured the family that, “He’s still the same kid. We just have a way of understanding what’s going on.” Then each member went through a few recommendations. The MED ended the recommendations, and added, “I can call you guys next week. We can talk next week and see what questions you have. Does that sound alright?” The conversation ended with small talk before the parents left. Shortly after, the team and I also left.

## **Episode 7: Seventh Clinic Observation**

The next day I returned to the CDD, checked in at the West building and walked to the East building for staffing in the afternoon.

**Phase 1: Staff Meeting** During staffing, there were eight people in the room, including: four team members, one new observing SLP, two EIs, and me. After discussing and determining the diagnosis, the SLP stated, “I don’t know how the family meeting will go today.” The other team members agreed verbally and nonverbally. One EI mentioned giving recommendations for home and school. The SLP asked the PSY for an opinion. The PSY responded, “Be respectful, lay the framework, and say what we have; we can’t bring him up to speed.” The MED referred to the family member when she stated, “I wish he had support by his wife or someone.” The MT, also the evaluation coordinator, asked if everyone needed to go. The PSY suggested a small group. The SLP asked the EIs for their opinion on size; they suggested a small group and encouraged strong recommendations. The SLP said, “That is good to know.” The MT/EC told the SLP, “You’re gonna have to help me.” She went on, “So it seems like no matter what we say, they will do what we want.” The SLP responded, “Well, it is our job.” The EIs then added a comment about word choice, and the team discussed changing some words in the report.

When the discussing ceased, the team members all looked at the PSY on the team. The MT/EC told the PSY, “You had a good rapport with him.” The PSY responded, “I think pretty direct and to the point, and talked about the packet.” The MED added, “The packet is crucial.” Then she asked the MT, “Are you going with [the PSY]?” The PSY

stated, “The question was speech.” The SLP commented, “I can go.” Then the staffing ended and everyone left the room. I walked to the West building to observe.

**Phase 2: Family Meeting.** When I got to the other building, I went to the normal observation room. Shortly after, the SLP entered the room and told me they switched rooms since the child had fallen asleep in the other room. So, I moved to a different observation room; the room connected to the evaluation room. This room was a lot smaller than the normal room for the family meeting.

The PSY was already in the room and the SLP joined after I was settled there. There were only two team members, one EI, a family member, and a sleeping child. The PSY began, “To start off, the primary concern [about the child] was not talking. Any other questions that came up that you would like us to answer this afternoon?” The family member indicated no, so the PSY continued, “This is your time to ask questions, but you do have the number, so feel free to give us a call. So today, our team looked at all areas of his development. One thing we look at is Autism. I’m gonna talk about it a tiny bit.” The PSY then explained the three areas, the ADOS, and concerns. The PSY then stated, “What we saw today was difficulty in all three areas. A diagnosis of Autism most accurately explains the difficulties he is having. I know you don’t know a lot about Autism, but your team does, and we will work with you to make sure you do. Do you have questions before I continue?” The family member again shook his head to indicate no. The PSY proceeded with recommendations and reviewed the packet, scooting closer to family member to discuss the packet. The PSY then stated, “We went through a lot of information. Any questions?” The family member again shakes his head to indicate no.

The PSY commented about the child's communication and behaviors and on focusing on progress. The PSY stated, "He's a great little guy and he knows [you]... And you do a great job of providing security. (pause) Anything else we should talk about?" No response from the family member. The SLP then added, "You guys are doing a lot of the right stuff. You have him in therapy. You have a head start, which will make a huge difference in his future. It would be nice to have some therapy at the house, not all, but some. Otherwise you guys are doing what you need to do." The PSY reiterated the SLP's statement to the family member, "You've done a really nice job." The SLP then added, "It was really nice meeting you guys." The family member exited the room and said, "Thank you." The PSY ended the conversation with, "Absolutely." After the family member left, the team waited a few moments and left as well. I followed the team out and left.

### **Episode 8: Eighth Clinic Observation**

On Wednesday, April 9, I checked in at the West building and walked over to the East building for the next observation.

**Phase 1: Staff Meeting** There were six people involved in staffing, including: four team members, one new SLP, and me. During the last few minutes of the meeting, the PSY—also the evaluation coordinator—asked, "How should we go about this?" The MED stated, "The mother doesn't know a lot." The SLP stated, "If I could bug off, you guys could explain language delays." The PSY/EC asked the MT, "Do you wanna come?" The MT responded, "I don't have to, just talk about PT/OT, and it sounds like she'll need a lot of educating about Autism." PSY stated, "I'm gonna keep it simple."



The MED stated, “I think that’s a good plan.” The meeting ended, and everyone transitioned.

**Phase 2: Family Meeting** I walked over to the West building and went to the observation room. When the team entered the room, there were two members. They engaged the family with small talk about break. The PSY then stated, “Don’t be nervous this time is for you. We’re going to talk about all the things we saw. He’s such a sweet boy; we had fun playing with him today. He’s attached to you. On the phone, you had a question about Autism. We are the team that looks at that. Tests help us look at Autism, and our conversations with you [help]. To be all on the same page, I will explain Autism. We can’t do a blood test. We do look at a few things: social communication and restricted/repetitive behaviors. We saw today that he is really bonded to you, and you know what he’s saying to you. He does really nice stuff. When we were playing with him, he really liked the truck, so much that it was so hard to get him to stop. So because of these things and what you told us, we are going to give the diagnosis of Autism.”

After giving the family a moment, the MED discussed the re-evaluation process. She also explained the importance of early intervention and improvement from it. The PSY then added, “It doesn’t change who he is. He’s still the same little guy.” The MED added, “It isn’t caused by parenting; you’ve done nothing wrong. We know he has difficulty, but we know he can make progress.” She went on to state, “He’s now going to qualify for intensive therapy. He’s a smart little guy. He’s the same little boy. Diagnosis doesn’t change that, but the diagnosis allows for intensive therapy. He has really good characteristics.” She then provided examples then stated, “I know you want what’s best for him and with that he will get better.” The team went on to discuss the spectrum. The

MED then provided the packet for the family and explained some of the resources. She also mentioned the report which includes recommendations. After answering a few other questions from the family and some small talk, the meeting ended with everyone saying thank you. The family exited and a few moments after the team left. I followed the team out.

### **Episode 9: Ninth Clinic Observation**

The following day, I checked in at the West building and went to the East building for staffing.

**Phase 1: Staff Meeting.** There were seven individuals present during the meeting, including: four team members, one new SLP, one EI, and me. At the beginning of the meeting, when the evaluation coordinator was covering the staffing sheet, the team discussed the parents' concerns. The PSY mentioned, "Mom has a good idea of where he's at." The SLP added, "This will be affirming for mom, because she couldn't figure out what was wrong." The MED/EC asks the EI about her opinion for the family meeting regarding a small or large group. The MED went on to say, "[Autism] seems like the main question." The SLP stated, "It seems like that's the thing for mom to know." Everyone nodded in agreement. The MT stated, "Talk about windows [of opportunity]." The SLP then discussed examples of positive characteristics, which were followed by more positives described by the MED. The MED then asked the PSY, "Do you wanna talk about it?" The PSY responded, "Yeah, I can." The MED stated, "I think just going right there." Then the PSY said, "Yeah, she's done her research." Then the staff meeting ended and everyone transitioned. I walked over to the observation room with the team.

**Phase 2: Family Meeting.** I entered the observation room, and the team walked into the family meeting and started with small talk. When the team was seated, the MED started by thanking the family member for coming. She went on, “We enjoyed him; he’s a sweet guy; he’s getting a ton of services, which is great. We’re going to review his development and address the question of Autism. Anything else you want us to talk about?” The PSY continued, “I know you’ve looked things up, but I want to spend time clarifying.” She then discussed the DSM and the changes from the version 4 to version 5. The PSY described some areas of concern for him as well as some skills. She then stated, “When we put all these characteristics together, it does seem like Autism, so we are giving that diagnosis, and with this diagnosis, It opens up the door for more therapies for him.” The MED added, “You started him so early, which is tremendous.” The PSY stated, “I kinda wanna stop there and see what your thoughts are.”

After the family member struggled through explaining how she was feeling, the MED and PSY briefly addressed her response. Then the PSY asked if the family member wanted the team to go through some of the services available with the diagnosis. The PSY then stated, “I just kinda wanna know how much you can take. It’s a lot.” The family member responded; then, the PSY continued by talking about the packet of information. The family member interrupted with questions, and the team addressed them. One question was about the severity of the child’s ASD. The PSY explained the spectrum. The MED added, “He’s too young right now. We don’t want to make predictions or label him to limit him, so right now, it’s just Autism.” The PSY then stated, “With the diagnosis, there are ways to learn more.” She then continued explaining some other resources in the packet.

The PSY then stated, “So that’s a lot of information. And this is yours.” She handed her the packet, and continued, “So, I think one of the biggest things is you don’t have to start tomorrow. It’s up to you how you want to do it.” The MED went on, “Again, it’s a ton of information, and I have some medical recommendations, so I kinda wanna talk to you about that. Is that okay or I can call you?” After the parent agreed for the MED to talk about recommendations, she continued to discuss specific medical concerns for the child. Throughout her discussion, she provided examples of things that he did well and complemented the family member for doing what she did to help him. The PSY then added, “So he’s still, it’s the same little kiddo; it’s just a better way of understanding him and matching him with the therapies he needs.” The family member asked about re-evaluation. The MED responded, “Yes, thank you for asking. [We recommend a re-evaluation] in two years, to re-evaluate where he is.” After addressing a couple other comments, the MED thanked the family member for coming and engaged in small talk. The family member left and the team waited a few moments before leaving as well. I left when the team left.

### **Episode 10: Tenth Clinic Observation**

The following week, I arrived at the CDD on Wednesday morning, went to the West building, signed in, and walked to the East building. I got situated in the meeting room and everyone started coming in.

**Phase 1: Staff Meeting.** After everyone arrived, there were twelve people in the room, including: four team members, one new SLP, one PSY intern, one MTI, two EIs, two MED residents, and me. After scoring and deducing the diagnosis, the PSY/EC asks the team, “How do we want to do this?” The SLP asked the EIs, “What does your team

think is the best way?" One EI discussed the parent's readiness to hear the diagnosis. The PSY followed up with a question, "Do you think more or less people?" One EI mentioned less would probably be better. The MT then stated, "Motor doesn't need to go. You can talk about what I would say." The PSY mentioned, "[PSYI] and I will definitely go." The SLP added, "[The SLPI and I] can go or not go." The MED said, "I can go; I spent a lot of time with mom." The PSYI stated, "She did have a concern for speech." So the SLP said, "Okay, we'll go." The MED asked the PSY, "How do you want to do it?" The PSY responded, "[The PSYI] and I talked, and I said I would." The MT added, "Probably you Mareth, because you spent a lot of time with her." The PSY responded, "Well, I talked to her on the phone." The MT said, "That's true." Then the MED said, "Okay, so you can do it." The new SLP added that she could observe instead of going into the room to decrease the amount of people in the room. Then, the staff meeting ended and everyone transitioned. I walked over to the observation room.

**Phase 2: Family Meeting.** The team entered the room and began the small talk. There were three team members, one intern, and one EI with the family. The PSY transitioned from the small talk by saying, "We are meeting to answer any questions you have and to make sure it makes sense. So we started out; asked your primary concerns... Are there other questions that came up?" After the family member indicated no, the PSY continued, "Well if it does, let us know. I'm not the smartest guy in the world, but I do know how to get ahold of the team. Really, the main question is of Autism. So we'll address that too. If I give too much detail, let me know. There are three areas of difficulty to have Autism. First, communication." The PSY then provided examples from the evaluation. The PSY continued with the second and third areas and provided

examples and then finished with, “We do have concerns in these 3 areas, which when we put these together, it is a diagnosis of Autism, and at this time, we are giving her that diagnosis.” The family member then asked a question. The PSY responded, “First of all early intervention is crucial,” and went on about the opportunities that the diagnosis provides.

The next question was about the spectrum. The PSY addressed the question, “Fair question and asked every time. There really isn’t a classification especially when a child is young, more so for an adult. It’s the behavioral characteristics, but no way of predicting what will happen when she’s older.” The PSY then referred to and discussed the packet. The MED jumped in with, “I don’t mean to interrupt, when we’ve had families getting ready to move, [the library employees] can help you get resources.” The PSY then continued to discuss the resources in the packet. After covering some of the resources, the PSY asked, “What kind of questions do you have now?” The family member asked about the cause.

The PSY responded, “Fair question, I’ll have the doctor talk about that.” The MED stated, “That’s why I’m on the team... It’s not associated with anything during your pregnancy. The best explanation right now is possibly genetics. We do see often if one child has [A]utism then there is probably a family member, even distant, that has [A]utism, and you’ve probably read that siblings have a higher chance. So it’s really good to make sure other children stay on track. We don’t know causes. We know it isn’t the vaccines or parenting styles. We really want to commend you for being an advocate for her. Also, just think of the improvement she’s made in the last 4 months.” The MED continued with a few other questions and thoughts.

Then, the family member asked about re-evaluation. The PSY responded, “We recommend re-evaluation in two years.” The team then discussed scoring on the standardized test. The PSYI added some positive examples of the child’s actions from the evaluation. The family member then asked about a regular classroom. The PSY and the PSYI explained the options and things to consider. The MED added the focus of safety to the discussion. Then the PSY asked, “What other things would be appropriate for us to talk about? (Pause) It’s a lot of information.” After the family member discussed a book that she had heard about, the PSY briefly discussed the book. After a brief discussion, the PSY stated, “Well, if you have any other questions, feel free to contact us. You’ll receive the report. Any questions, give us a call.” The MED quickly added a couple recommendations as the team stood up and thanked the family member for coming. The family member also thanked the team. The ECEP team exited first, and I followed at the same time.

During the afternoon session, no ASD diagnosis was given. I returned to the CDD the next day, Thursday, April 17, but no diagnosis was given during the afternoon session either.

### **Episode 11: Eleventh Clinic Observation**

On April 24, I signed in at the CDD and walked over to the East building for ECEP staffing meeting.

**Phase 1: Staff Meeting.** There were seven people present for staffing, including four team members, one new SLP, one EI, and me. During the meeting, the MT discussed the phone call with the family member and explained that the family member is very knowledgeable. The EI also added that the family member is aware of the

possibility of ASD. The MT stated, “I don’t think she’ll be surprised.” She also discussed that another family member is in the military, so she pulled some special books to give to the family. The MED/EC asked the PSY, “Do you need a break?” The PSY shook her head to indicate no. The MT added, “I would like to go to address the sensory.” The MED asked the SLP, “Do you want us to talk about hyperlexia?” The SLP said, “Yeah.” The MED then said, “Or do you wanna go?” The SLP stated, “I can.” The MED responded, “I feel comfortable explaining it.” The MED then turned to the PSY, “Do you wanna talk about it? Do you want me to since you talked this morning? I liked how you did ... this morning. Do you think we should just start with the diagnosis since [the family member] has done her research?” The PSY said, “I don’t know.” The MED also discussed commending the parents for getting started early. Then the staff meeting ended and everyone transitioned.

**Phase 2: Family Meeting.** I walked to the observation room and watched the team members enter the room and begin small talk. Three team members attended the family meeting, including: the MT, the MED/EC, and the PSY. The MED started, “First, we commend you guys for doing this.” Then she discussed the research that the family member had done. She discussed the primary concerns of the family then invited the PSY to start with the question of Autism. The PSY went on, “You guys have done a lot of research, but just so we are on the same page, we are looking at three things. When we look at those three areas, what we saw today and what you guys told us, a diagnosis of Autism does fit, so we are giving that diagnosis today.” The family member began to cry, so the MT grabbed the tissues and handed them to her.



After a few moments, the PSY continued, “It is a spectrum. If you see five kids with Autism, they can all look different. He does have words, so that’s good for him. Also at his age, he’s in intervention, so he has foundation and support so he is in a great position to make great progress.” The PSY continued to answer some questions of one family member. All team members added examples from the evaluation when answering the questions. Then one of the family members make a statement that demonstrates blaming himself. The MED responded, “He is a combination of both parents. People try to place blame on themselves. We don’t know what causes Autism. We looked at your family history and nothing caused his Autism. So there’s no one to blame.” The other family member then asked about other children. The MED addressed the question, “So chances are higher [of having another child with Autism], but your chances of having a typically developing child is higher than that.”

The next question related to sensory issues. The MT stated, “I’ll jump in about sensory... we can use sensory to help him...I recommend reading the book and getting ideas to get him calm and focused. I hauled all these books here.” The MT also provided examples from the evaluation and activities for sensory regulation while she spoke. One family member then asked about the future of the child. The PSY responded, “He’s just going to get better.” Then, the MED added, “We’ve identified a learning style, so he would qualify for specialized preschool, but he should be re-evaluated in two years to check diagnosis, because children look different.” The group went on to discuss school, therapies, and activities to practice at home. Then the PSY added, “Also, you don’t have to start doing things tomorrow. We do have a lot of information for you to take with you. We recommend in a couple years to see if an Autism diagnosis still fits, and they can list

his cognitive processing.” The MED added, “We are not saying he has a disability; he has a learning style.” A family member asked if ASD is curable. The PSY responded, “With early intervention, we see a lot of improvement.”

After a couple other comments, the PSY asked, “So, any other questions?” After no response, the MED stated, “We’re glad you came,” and engaged in small talk. The team also mentioned the report, and the MED reminded the family, “Well, you have my number; call me if you have any questions.” Everyone stated “thank you,” and the family exited. After a few moments, the team left as well. I followed the team.

### **Episode 12: Twelfth Clinic Observation**

On May 22, I signed in and learned the team was still conducting evaluations. I stayed in the West building and observed some of the interactions of the team with the child during testing. After a few minutes of observing, I went to the staff meeting room.

**Phase 1: Staff Meeting.** Since there was some remodeling in the original staffing room, we met in a different room for staffing. There were nine people present during the meeting, including; four team members, one intern, three EIs, and me. At the beginning of the meeting, one team member mentioned scoring the ADOS quickly. After scoring, the team discussed the Vineland questionnaire and how the family member’s ratings aligned with the scoring results. The EIs were very vocal with a lot of questions. When the question regarding how the parent would take the diagnosis emerged, one team member stated, “I don’t think she will be surprised,” and the other team members agreed. The team also discussed the family’s position and the changes they were going through. The SLP asked the PSY/EC, “How do you want to handle the meeting? Mom’s kinda focused; I say get it done quick.” The MT added, “it probably needs to be said, it is a

spectrum, so he won't look exactly like [his sibling who received an ASD diagnosis]."

After a few other comments, the SLP asked, "If it's okay with you, I'd rather not sit in."

Then the PSY asked the EIs, "Do you guys have any input on how the mom will take it?"

After a few comments from the EIs, the meeting wrapped up with some small talk between the MED, PSY, MT, and MTI. Then everyone transitioned, and I walked to the observation room.

**Phase 2: Family Meeting.** Two team members, one intern, and two of the EIs entered the family meeting room. One member mentioned that they were waiting on one other team member. There is one family member in the room, and the child is not present. After a couple minutes of small talk, the third team member entered the room. The PSY started off stating the concerns of the family member. Then, she stated, "I wanted to start with Autism. I know I don't need to educate you on Autism since [older child] has received that diagnosis." She went on to discuss the strengths of the child and difficulties and provided examples from what the team saw that day and the family member's report. She went on, "When we look at all of these together, his particular learning style does fit with Autism. So we are giving him the diagnosis today. With this diagnosis, it really opens doors for him. We also will recommend a re-evaluation in 2 years." The MT added, "All of the recommendations will be in the report too." After a couple comments, the PSY stated, "Before we jump to all of the recommendations, how does that sit? Or what kind of reaction?"

The team members exchanged some comments with the family member. Then, the PSY discussed resources available for the child's "learning style." After some discussion, she explained, "He is the same kiddo, we just have a better way of

understanding him.” The PSY and the MED responded to some questions and concerns of the family member while providing recommendations of resources. After discussing genetic testing and causes, the MED stated, “We do know it’s not related to parenting style or vaccinations and that children who are evaluated early and get therapies, do better. The reason we have the nerve to diagnose at two and a half is that we know it offers so much help.” The MTI then stated, “[the MT and I] were looking at gross and fine motor skills. First, he was great to be around. He brought smiles to all of us.” She then elaborated on examples and provided a recommendation, which was followed by a question from the family member. The MT addressed the question and the PSY and MED jumped in to assist. The PSY then provided the SLP’s comments and recommendations.

After some recommendations, the PSY asked, “What other questions do you have?” After a pause, the MED added, “There are a lot of strengths.” The group then discussed school and summer programs. Then, the MED stated, “The key is to have parents as advocates for children, and it’s very clear that you are an advocate.” The report was briefly discussed and the PSY said, “You have my contact information, so we are still available.” Then all said thank you and the family member exited. The team left shortly after and I followed.

### **Conclusions**

I observed twelve episodes of delivering the diagnosis of ASD. In each episode, there were two phases, the staffing meeting and the family meeting. In one episode that I observed, there was a third phase, the debriefing among team members. Throughout the orientation and consent process, emails were exchanged and face to face conversation

took place. All of the communication for the observations were in person; the staff meetings were face-to-face and the family meetings were conducted behind a one-way mirror.

I initially interpret the data collected from the observations by addressing the first research question: What communication patterns do ECEP professionals commonly use in episodes of diagnosis delivery at the ECEP? The data revealed that the main communication patterns in the staffing meeting, included: discussing the staffing sheet; reviewing concerns of family; reviewing concerns of EI teams; scoring the tests of the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2); Bayley Scales of Infant Development, Third Edition (BSID-III); Vineland Adaptive Behavior Scales, Second Edition; Preschool Language Scale, Fifth Edition (PLS-5); Peabody Developmental Motor Scales, Second Edition (PDMS-2); Infant/Toddler Sensory Profile; and the Rossetti Infant-Toddler Language Scale (RITLS)]; determining the diagnosis; discussing the family's perspective on the child; discussing the family's knowledge of ASD; discussing the EI teams' perspectives on the child; discussing the EI teams' perspectives on the child; reviewing rapport established amongst team members and family members/caregivers; deciding on the appropriate size of group to attend the family meeting; deciding on what team members should attend the family meeting; deciding which team member that will attend the family meeting should start the interaction and which should transition in; and discussing specific approach (i.e. start with the question of Autism; start with an explanation of Autism, etc.).

The data also demonstrated that the main communication patterns in the family meeting, included: beginning the interaction with small talk; addressing the level of

knowledge about ASD and providing the relevant amount of information; addressing specific concerns of the family; discussing the categories of diagnosis (i.e. social interaction, communication, and restricted repetitive and stereotyped patterns of behavior); providing examples of the child's performance from that day; reviewing family report of behavior at home; giving the diagnosis of ASD clearly; explaining the meeting is a time for the family member(s)/caregiver(s) to answer any questions; answering any questions of the family member(s)/caregiver(s); demonstrating empathy; gauging the family member(s)/caregiver(s)' feedback and responding accordingly; reviewing resources and information in the pamphlet; encouraging the family to continue EI therapies and discussing new options with the diagnosis; providing a few recommendations; stating the child is still the same child; maintaining a strength-based approach by discussing some of the windows of opportunities and strengths of the child; offering contact information for follow-up or discussion with other family members; expressing gratitude for coming in for the evaluation; and finalizing the conversation with appropriate well wishes (i.e. take care, have a safe drive, etc.).

There was only one example of the follow-up/debrief stage of an episode. The two main communication patterns that occurred were (1) debriefing from the family meeting about the effectiveness of the meeting, and (2) supporting the other team member's actions that occurred during the family meeting. A summary of my observations follows:

- During the staffing meeting, the team spent very little time discussing the execution of the diagnosis delivery in the staffing meeting.
- I did not observe much preparation specifically for the diagnosis delivery.

- There was some discussion about what team members would attend the meeting, but there was not a clear decision.
- Some word choices used by the team members during the family meeting were not precise and did not seem to be chosen to convey clear meanings to the family members.
- The team discussed size of the team for the meeting, but never mentioned anything about the rest of the team members observing the diagnosis delivery.
- The nonverbal practices seemed routine and normative for situations where the participants in an interaction become emotional and shed tears.
- In some of the episodes the severity of the diagnosis was a factor in creating this empathy between the diagnostic team and the family.
- At the end of the staffing meeting the team members came to consensus quite quickly and seemed to be rushed to decide that they could just depend on the routine scripts they used to present the diagnosis.
- The diagnostic team used a routine and script to deliver diagnosis.

In this chapter, I identified the episodes and phases of diagnosis delivery presented my conclusions using concepts from CMM. My participant observation data provides thick description of twelve different episodes in the diagnosis of delivery. I also linked my findings to the research questions stated in previous chapters.

## **CHAPTER 5**

### **STAGE 2 RESULTS: INDIVIDUAL INTERVIEWS**

The participant observation data presented in the previous chapter provides information about how the diagnostic teams communicate verbally and nonverbally in the clinical setting both in staff and family meetings. The interview data provides information about how they think they communicate and the how they approach the goals of communication. I divide chapter 5 into two parts. In part 1, I describe my procedures for the interviews in my research and provide responses from interviewees. In part 2, I supply conclusions from the interview data.

#### **Interview Procedures**

After developing an understanding of the process of diagnosis delivery at ECEP through observations, I met with as many team members as possible in a one-on-one setting to clarify my understanding through continued Storyboarding, Enriching, Analyzing and Visioning (Pearce, Sostrin, & Pearce, 2011). Storyboarding in this phase included continuing to identify episodes, construct the series of events, and punctuate the episodes. Enriching involved (re)naming the patterns and extending the description of the social world. Analysis and Visioning were new tools for this phase. Analyzing included looking at logical force and checking for other special features. Visioning consisted of constructing an ideal pattern for the process and checking the reality of utilizing the process. I interviewed fourteen team members. One of the interviews was fairly short due to availability, but the other interviews lasted around one hour. There were only two team members that I did not interview; one of them was on maternity



leave during the observations and interviews. The other team member was recently retired and her time in clinic cut down to 25% of the time.

Storyboarding was a useful heuristic that encouraged team members to build their stories and enrich them through elaborating with details; when the team members saw a visual representation of their description, they added to the storyboard and discussed concerns or difficulties with the process. The hierarchy model was also useful during the interviews; although I did not state that I was using the hierarchy model nor did I draw a representation of the hierarchy, I was able to discuss levels and rank by asking open-ended questions. I also referred to the LUUUTT model to build the story and find out the untold or unknown stories of the process. Similarly to the hierarchy model, my word choice—influenced by the communication perspective—aided in discovering these untold and unknown stories. These heuristics were used throughout the interview process. I present samples and interpretation of these responses.

For my first attempt to utilize the heuristics and interview guide, I met with the program manager to make sure the questions made sense, to get feedback, and to make sure I was comfortable using the heuristics. We met on April 21 in her office on the second floor of the East building at the CDD. We sat at a square desk; I sat on the east side and she sat on the north side of the table; the door to the office was closed. I utilized the wall behind me to put up sticky notes. The second interview was conducted with one of the MEDs on Wednesday in the MED's office on the same floor and building of the CDD. She was the only MED present, so we stayed in the office and closed the door. She sat at her desk, and I borrowed a chair from one of the other MED's desks. The third interview was with a team PSY on May 7. We met on the third floor of the East building

of the CDD in a small office near her office since there was one other person working in her office. The fourth interview was with a PSY on May 13. We met in his office since no one else was there. The rest of the interviews continued in the same format; uninterrupted one-on-one face-to-face interviews that lasted approximately an hour in an environment that allowed the professionals to be comfortable.

To maintain anonymity, I provide the responses of the ECEP team members by question and random order. The interview questions are listed first. Then, I provide the randomized responses beneath the question. Originally, I wanted to include labels for each of the responses (i.e. participant A, participant B, etc.) and label each participant with his/her respected discipline (i.e. motor, speech, medical, or psychology). However, since the participants were very open with me and were informed that I would not share who provided what information, I wanted to avoid the possibility of recognition of any participant's responses. Providing the responses randomly is a way to ensure the participants' confidentiality. Not providing the responses in this fashion could have revealed a participant's identity. For example, some team members made comments such as, "I've brought this to the team's attention before, so they will probably know it's me." Another commented, "Which I suggested and we tried, but it didn't work." If I were to identify either statement as participant A or B, then label the rest of that participant's responses, the team members would be able to clearly identify all of that person's responses.

The responses are written in paraphrased summations. There is not always the same amount of responses since the process was voluntary and I did not require

participants to answer every question. I removed any content that would have directly revealed the participants' identity.

### **Interview Data**

The responses of the interview questions initiated a process in which the team members began to reflect on their own communication.

**Question 1.** Twelve interviewees responded to *question 1: I understand the process of delivering the diagnosis of Autism Spectrum Disorders (ASDs) to parent(s), caregiver(s), and/or family member(s) is difficult. Will you please discuss the process with me?* In this and in the subsequent section, I provide quotations from the participants and indicate what kinds of categories of communication from these quotations refer to CMM principles and concepts.

There were eight professionals that discussed the preparedness and understanding of the family as important to the process of diagnosis delivery. The other four professionals that responded did not specifically mention the words 'prepared' or 'understanding'; however, they did discuss understanding and adjusting for each family. One participant emphasized that the success of the process of diagnosis delivery depends on preparedness. The participant noted:

The level of preparedness of the parents plays a huge role. The more prepared the family is, the higher the number of professionals. If a family is not as prepared, typically a smaller number will go. Preparedness refers to the awareness of Autism as a possible diagnosis for the child, the concern of the child having Autism, an introduction to Autism and/or the demonstration of any previous research.

This participant also showed her concern with the family as an audience to a message about Autism when she said that the way you deliver the message depends on the knowledge of the audience. The participant noted that, “If the family has a good deal of knowledge and understanding, then they want to know answers from professionals. They tend to have more questions.” This participant emphasized consideration of the families and what they currently know and want to know as key factors for the diagnosis team in planning their interactions and the content of their messages. The focus was on knowledge and preparedness of the family, an important element for managing of meaning.

Sticking with the theme of preparation and knowledge, a second participant discussed the notion of team consensus. The participant noted:

We come to a consensus on the family, which is always difficult. Some families are prepared; other families have not heard of Autism. Then, we prepare for the family type. We take into account the family understanding of Autism and how well we feel the family can process the information and how much they can process. We consider the family’s ability to take in the information.

The participant also mentioned considering the appropriate size for the group and determining who should do the majority of the talking. The participant stated, “Having fewer people for the family meeting is better,” and added “[deciding] who is best to give the diagnosis.” She also discussed the team members that normally attend the family meeting; she included the psychologist and the medical. The focus was on team consensus, knowledge and preparedness of the family demonstrating the many elements

that play a role in the process and demonstrating the importance of the daisy model to consider all relevant information.

A third participant provided more information about two elements of the clinic day, the staff meeting and the family meeting. She stated:

We discuss what we saw during the evaluation; we start with the question of Autism; then, use the child's interactions with us for discussion and making a decision. Then, there is the family meeting. Depending on the questions and concerns, we decide who goes to the meeting. Definitely the psychologist and the pediatrician go.

The participant also mentioned, "If the team feels the family would be better with a smaller group or if [the family] will have more questions and need a larger group." The focus was on the steps of process, an important element for understanding the communication practices.

A fourth participant elaborated on the steps of the process. The professional stated:

The process includes the coordinator; chart review; internal perspective and adjustments to that perspective; team discussion, which includes respecting team members' opinions; a family meeting; independent decisions occur during the evaluation; try to have light hearted humorous relation to family like positioning; have a running dialogue throughout the evaluation to set the state is important.

The participant also included, "We are preparing the family during the whole process." This participant's focus was also on revealing the elements of the process.

A fifth participant added the following to the response:

We collect data and talk about it. There are mainly two individuals who give the diagnosis, the doctor or the speech therapist, or the psychologist, so I guess three. Deciding who will deliver the diagnosis is based on three things: (1) who has established the best rapport with the family, (2) the concerns of the family (i.e. speech), and (3) who did the most talking. Based on the family, we decide how much information to share; we take into account the family on evaluation day. It is not a set out process, but it is what is done.

This participant discussed who is involved in one part of the process, the actual delivery of the diagnosis. Providing the components of deciding provides more understanding about managing the meaning of diagnosis delivery.

A sixth participant also dealt with preparedness in relation to the preparation of the diagnosis team and the need to learn about the family. In addition to the first participant example, the third participant identified specific actions with the family and with the diagnosis team that should take part prior to delivering the diagnosis. She said:

The start of diagnosis delivery is getting a feel for the family; as a coordinator, one first reviews the record of the child. Then, the coordinator calls the family and gets a feel for how much they can take in and understand during the initial phone call after the evaluation is scheduled. The coordinator also calls any EI that has worked with the child. The coordinator writes up everything and puts the information in the chart and emails it to the team.

The participant provided information regarding the coordinator's role and actions in the process. She then explained how she gauges the family on the evaluation day. In a similar way to the first participant, this participant emphasizes getting to know the family

and their preparedness as crucial to the process of diagnosis delivery. She stated, “It is all about audience awareness.” She also mentioned the importance of “the preparation work of the EI team.” In this way, the participant puts into practice the CMM concept of co-creating the social world by considering the perspectives of the family, the EI team, and the ECEP team.

Several elements of the process appeared in these responses. The professionals supplied many of the same elements; however, no team member provided all of the elements individually, and no two professionals provided all of the same elements of the process. The team collectively provided the following elements: processing the referral and paperwork; scheduling; creating the chart; contacting the EI team and family prior to the scheduled evaluation; making a progress note; reviewing the chart; meeting with the team on the day of the evaluation; having an initial family meeting on the day of the evaluation; conducting the evaluation; having a staffing meeting; having the family meeting where the diagnosis is delivered; providing the option for follow-up and following-up if desired; and writing the report.

**Question 2.** Twelve interviewees responded to *question 2: In your experience, is there a standard process that is utilized in the delivery of the diagnosis parent(s), caregiver(s), and/or family member(s)?* The responses from this question and their connection to CMM follow.

Seven professionals responded that there is no standard process. Five professionals responded that there is a standard process or there are standard elements of the process. Of the respondents that said there is a standard process, some of the responses are listed. One participant noted:

Yes, a family may need to hear a diagnosis first and then a description, or a family may need to be educated first, then hear what we saw and finish the diagnosis....The team tries to make sure the family knows this is what Autism is, knows this is what we saw today, and knows this is the diagnosis we are giving.

The participant provided some possible ways to deliver the diagnosis based on the family that she may considered standard to the process. However, she also focused on the process being family-specific without a standard process that applies to all, which demonstrates the importance of considering the other involved in the communication.

Similarly to the first participant, a second participant explained her understanding of the standard process. She stated:

It is standard to explain the three primary components and help the family make sense of them. We utilize the DSM V as a standard for the diagnosis. Being as specific as possible with the child's behaviors in those categories assists the families in coming to a conclusion. There are child specific recommendations. In general, we try to teach and make the family familiar with Autism and [with] ways to teach the child effectively.

This professional's focus was also on relating to the child and assisting the family as a way of making sense of the process; CMM describes this process of co-creating meaning of the social world.

A third participant provided a response that indicated how a standard process provided a great deal of information. The professional mentioned:

A discussion of recommendations is standard....Some fairly standard recommendations are the PRO (parents reaching out), PHT (parent home



training), DD waiver, SSI, Resources (library and online), and genetics testing....

One also must know and understand the parents. Explaining Autism is essential; there is a sheet in the packet that provides an explanation, but typically the psychologist explains at least the three elements that the team looks at during the evaluation and relates to what was seen during the evaluation. The higher the level of preparation of the family for an ASD diagnosis the more likely the team members will start off with the diagnosis. The lower the preparation level of the parents for an ASD diagnosis, the more likely the team is to explain Autism first prior to giving the diagnosis.

Here, the professional reiterates the point that several team members made in their responses to question 1. She states the importance of managing meaning through taking into consideration the families' levels of preparedness and understanding.

Others that disagreed with the notion of a standard process supported their answers. A fourth professional responded:

No, everyone has different styles....Sometimes we start the discussion with the EIs about more or fewer people in the room and what the family needs....Usually the psychologist goes over [the pamphlet]. The team members change and can make a night and day difference.

The participant indicates that the process looks differently depending on who is on the team. Focusing on this response allows us to see the significance of looking at communication, rather than through communication, to see the impact that changing the group of team members has on the process.

Similar to the fourth participant's focus on different styles, a fifth participant added:

No, but there are similarities in delivery. Delivery follows a personal style, so it depends on the person and the family itself. The family is always a consideration and the team member usually has a pattern.

Again, the team member emphasizes the consideration of team members and their unique styles of delivery. The focus on personal style demonstrates the importance of each individual in the overall process.

**Question 3.** Thirteen interviewees responded to *question 3: Are there any elements of the process of delivering the diagnosis that must be included?* Interviewee responses and my analysis follow.

Three participants indicated that there were not any elements of the process that must be included. One person stated, "I am not sure; it is unclear." That participant provided some elements that possibly 'must' be included, the professional noted:

I assume one thing is the diagnosis delivery should be clear (i.e. stating specifically, "We are giving the diagnosis of Autism today"), and a second thing is to address the strengths of the child. The report should be strength-based for the family. A third thing is giving the family time to ask questions.

This participant emphasizes the importance of word choice for diagnosis, for describing the child, and for allowing the family to ask questions. The focus on wording is a key element of taking a communication perspective and communicating in a cosmopolitan form of communication.

Nine participants, however, provided a statement of elements that must be included. Three participants included three specific areas or elements. A second participant noted:

We have to tell them it is Autism and be clear that Autism is the diagnosis—sometimes it is unclear. There are three elements that are included: the criteria, examples of what the team saw, and the diagnosis. There has to be some explanation of Autism. It is very important to say some recommendations and that it is not their fault. We state the strengths of the child and that the child is still the same child.

Along with the three criteria, the professional stressed the importance of discussion that the diagnosis is not anyone's fault and that the child is the same as when he/she walked into the building. The focus on removing blame and stressing the child is the same, and it demonstrates the importance of empathy for the team.

Similarly to the second professional, a third participant discussed three characteristics that must be included. The professional stated:

There are three characteristics we describe. We discuss how we arrived at the diagnosis. We kind of explain the process and explain the ADOS testing. We take in information from parents from home experiences. We explain taking in a breadth of the child through EI input, at home description, and the evaluation rather than just that day, in order to get the whole picture. Recommendations and where to go are involved. We give assurance that we understand the child better and this is a gateway to help in making progress. The packet is always given and a written follow-up, the report.

Although three criteria are provided, they differ from the first three elements. This participant focused on discussing how the team arrived at the diagnosis, explaining the process of the evaluation and gathering the ‘whole picture’ of the child to better understand him/her.

The other professional that mentioned three elements simply responded, “We must discuss all three areas.” When probed, the person discussed the three areas of social interaction, communication, and restricted repetitive and stereotyped patterns of behavior.

Other professionals discussed the packet of resources, recommendations, and input from all participants. A fifth participant provided a slightly different response. The professional indicated:

All groups cover the primary concerns of the family. We are family-centered.

We request if there is anything we missed. There is the diagnosis and explanation of behaviors that correlate with each question or concern and correlations and what it means for the family.

The participant demonstrated concern with the family and their concerns. The focus on the family-centered approach to delivering the diagnosis provided a core value for this professional.

**Question 4.** Thirteen interviewees responded to *question 4: What are some things you consider when planning for delivering the diagnosis?* The subsequent section provides the responses and connections to CMM principles and concepts.

The responses to this question were very specific to the individual team members. One team member even stated, “It is very personal.” Two members mentioned thinking about the family’s concerns and questions. One participant related the following:

I consider questions and concerns that the family may have for me specifically and what I can tell the family about the child's communication that may be informative to them and some things that may be supportive (i.e. actions specifically). I think about presentation and framing it positively; it's tricky to give a diagnosis and highlight positives.

Considering the original concerns of the family in order to frame the conversation with the family was of significant importance to this participant. The participant also notes other elements that are important to consider, which demonstrates a hierarchical relationship between family concerns, child's ability with communication, providing information, providing support, highlighting positives, and framing the message.

Similarly, a second participant also kept the family at the center of his/her focus. The professional stated:

For individual preparation, I consider the family's preparation and knowledge levels. In preparation for the family meeting, I consider the parents' and family members' original questions. If speech was a primary concern, the speech therapist may attend to discuss elements of speech. The team also depends on the recommendations that will be given and suggestions in order to provide appropriate feedback.

In addition to the concerns, the preparation and knowledge of the family is mentioned as an issue along with specific communication of team member, such as speech. This focus demonstrates the value that team members have for each other and their knowledge of their discipline; putting skills into practice is a significant part of coordinating meaning.

Creating empathy was also a relevant part of the process in many responses. A third participant indicated the focus on the family, she responded:

I think of families' levels of anxiety and comfort. Some families are open and others are resistant and still others are not cognizant of what it means. I consider culture, education level, and the family—keep a balance of graveness and hopefulness. Recommendations are very similar. I think about things that are different, strengths, and positives and think to tell the family that it is not their fault.

This participant re-emphasizes the previously mentioned consideration of the families. The focus on understanding the family demonstrates the significance of relationship building for team members with the families, another element is utilizing a cosmopolitan form of communication and valuing all parts of the process.

In relating to the families, fourth participant discussed experience. The professional claimed:

With experience, one develops a basket of ideas to pull from during the family meeting. I try to have encouraging words about Autism and avoiding information overload by reminding the family that all of the information covered and more will be in the report that the family will receive. Other team members have a specific routine.

Utilizing the resources from past experiences informs the practices that this professional uses to prepare for delivering the diagnosis of Autism. Understanding that resources shape practices is a relevant part of coordinating meaning.

Along the same lines as the fourth participant, a fifth participant focused on the individual contribution and avoiding information overload as well. The professional added specific actions and noted:

I consider the importance of my piece (i.e. if there's just a delay then I might not need to say anything). The main point should be about the diagnosis. I do not want to overload a parent. I keep what is important for that meeting. Sometimes I do not say anything; I just come for diagnosis and the rest is fill-in....Others may specifically state the ... problems.

The fifth participant also demonstrated her concern for the environment. She notes, "I consider the environment like where are the Kleenexes. If there is a child in room, I think of how I can occupy the child, so the parents can hear the meeting." This participant emphasizes the importance of creating an environment that allows for the families to hear the message and feel supported through the message. Her focus on hearing and supporting signifies the importance of coordination and coherence for the process.

**Question 5.** Two interviewees responded to *question 5: What else would you like to share about delivering the diagnosis of ASDs to parent(s), caregiver(s), and/or family member(s)?* Most of the team members addressed a response to this question at the end of the interview as the following data indicates.

One participant emphasized understanding the family members. The professional stated:

Be alert to parents' cues about when they are becoming overwhelmed. Watch for breakdowns, emotions and tears; give time to process what they are hearing; and be supportive.

The focus on support is another indication of the participants' use of coordination and co-creating a social world of support amongst team members and families.

A second participant elaborated on the coordinator roles of the team by stating: The evaluation coordinator is responsible for the report; he/she does the editing. There is a different evaluation coordinator for morning and afternoon clinics, almost always. There is also a clinic coordinator for the entire day of clinic. That person is assigned by [the program manager] and he/she calls the family prior to clinic. The evaluation coordinator is decided on the day of clinic.

This participant reports upon the practices of the team and clarifies elements of the process.

**Question 6.** Thirteen interviewees responded to *question 6: What elements of the process of delivering the diagnosis are most effective?* The responses and my analysis follow.

Six professionals indicated the importance of the team approach. Phrases such as “the team approach,” “the multi-disciplinary approach,” and “the trans-disciplinary discussion” were used. More specifically, one participant noted: The team is top notch at going in and talking with the families; we are good at reading families and keeping it low key. We keep fewer numbers and have very instantaneous thinking going on.



The focus on the team's ability to read and relate to the families demonstrates the importance of coherence and understanding the families as well as responding to that understanding through team practices.

A second participant elaborated on the benefits of the team. The professional mentioned:

The team collaborative and cooperative approach rather than just me and the family. I feel more confident in the diagnosis, especially when I trust my team. We see a variety of areas and it helps me to have a team. It is also nice for the family to have a team...If I were getting a diagnosis for my child, having four people would be better than one. In actually delivering the diagnosis, having another person present is helpful.

This participant highlights the families and professionals' mutual need of the team approach. The participant added, "And we have a strength-based approach to try to get child to be most successful and [for the families] to enjoy the child." The focus on creating a social world where the child is set up for the best possible outcome with the opportunity for success and a family that better understands him/her in order to enjoy the child signifies the importance of co-constructing meaning.

Along with the teams, one participant called attention to other significant factors such as testing. She stated:

First, standardized testing, because some people get a diagnosis without standardized testing; and it's harder to be objective without it. Second, the trans-disciplinary discussion in staff meeting; there is a variety of perspectives and each person brings different concerns to the table, which is really nice if someone is on

the fence, etc. Third, psychologists and pediatricians... their delivery and teamwork for talking with families are done really well; they are good at reading family response and adjusting.

Her focus on three elements of the team practices indicates that there are several aspects that make the team successful.

A fourth participant continued the discussion about the team. The professional claimed:

The multi-disciplinary approach, it takes the pressure off of us individually.

Others diagnose individually, but for us we see complex kids with other delays.

So it is important not to feel all alone, and we all see the children at the same time rather than on different occasions.

The participant reiterates the importance of the team approach and adds the significance of all the professionals seeing the children at the same time; coordination and coherence are highlighted again.

A fifth participant continued with the benefits of the team. She noted:

The personnel; we are very strength-based, very compassionate, and thoughtful in what we do. We put in a lot of thought and take our time. The staff meeting is very collaborative, and it is not just one person. We look at the big picture and take all things into account that is the beauty of the meeting. We think about what else could explain the behaviors and concerns. Everyone expresses their opinion.

Collaboration, coordination, and co-creating a social world of strength-based perspective are all part of her focus of the team according to this participant.

**Question 7.** Thirteen interviewees responded to *question 7: Are there any elements of the process of delivering the diagnosis that are not effective or could be enhanced?* In the subsequent section, I provide quotations from the participants and indicate what kinds of categories of communication that these quotations refer to CMM principles and concepts.

Six professionals acknowledged the time restraints of the current clinic schedule. Most team members were able to highlight benefits as well as weaknesses of the current time schedule. In discussing enhancing the restraint of time, one professional suggested, “It would be nice if we could build time into the schedule for follow-up or somehow get the EI involved.” A second participant noted, “The time frame; there is so much to do in such a little amount of time.” The professional also described a different time that could be improved. The participant added, “There needs to be time to train the interns... [and] EI therapists need to talk.” Fitting a lot of tasks into a short amount of time, needing more time to train, and involving EI therapists in dialogue amongst themselves were the focus of these two participants that highlight the importance of coordination among everyone that plays a role in the process of diagnosis delivery for the most successful outcome including managing the time.

A third participant added an area that may need to be enhanced. She noted, “It would also be nice to recap on what worked well and get feedback for my part of the family meeting and see how I can improve.” Encouraging discussion after the process is complete for constructive criticism and encouragement seemed to be a focus for this participant, an important process for any system to enhance resources and practices.

A fourth participant also mentioned time restraints; yet, the participant went on to discuss the environment. The professional noted, “Also the room; it is not warm and comfy. So the environment could be enhanced.” She also added:

Some professionals like to tell parents that they could outgrow the diagnosis, but that is controversial. Discussing the spectrum itself is tough like the severe versus not severe question. We have an ‘avoid it’ answer by discussing the change in the DSM IV to the DSM V. We are very positive, and we take the approach of saying that they are so young and it is hard to say.

The fourth participant adds the discussion of the spectrum, diagnosis change, and avoidant and positive responses to questions. The focus on the other and creating a positive space are elements of cosmopolitan communication.

Elaborating on the importance of discussion, a fifth participant discussed length of the delivery and personalizing the message to the individuals in the room during the diagnosis delivery. The professional noted:

Talking too much is least effective. It depends on the team. It is hard to know if short and sweet and then having the family ask questions is effective or not. We have to keep in mind who all is in the family meeting.

This interviewee, unlike some of the other participants, revealed her knowledge of specific communication practices. The importance of being flexible in the family meeting to adjust the length of the delivery and the responses based on the needs of those involved indicates a focus on utilizing the resources and practices of the team members.

Similarly, a sixth participant discussed the importance of creating relationships with the families to have effective conversations. The professional stated:

Relationships; the team is a bunch of strangers to the families that we are having conversations with. It is not effective when the family is not prepared [for instance] the person(s) who referred the child did not explain the reasons for the referral and/or did not discuss the notion that we test for ASD.

Extending the dialogue with the families to include those professionals that refer the children is an important factor. Changing the current practice to include a discussion about Autism prior to the clinic day demonstrates the need to re-create the social world with families.

**Question 8.** Thirteen interviewees responded to *question 8: Are there any elements of the process of delivering the diagnosis that should not be included?* In the subsequent section, I report responses and analyze the responses.

Six professionals did not identify elements that should not be included. Only a few participants added specific elements that should not be included. One participant specifically stated, “No one should give prognosis. Prognostications are not warranted. They should not be included.” This interview offers a specific rule for communicating in the diagnostic team. Avoiding predictions about the future relates to the notion that mystery exists in all communication. The participant also discussed the importance of mystery and stated that the future is unknown rather than providing false information that may or may not occur.

A second professional discussed the issue of time management and a possible adjustment to make more time during the staffing meeting. The participant claimed:

The explanation of the ADOS during testing may not be necessary; it is distracting for the parent, child, and maybe me. And who knows if that makes the

parents nervous. It is better if the process is explained before or after the evaluation. Maybe a debrief could help.

Suggesting an adjustment to the current practice of some professionals to explain the testing during the testing or before or after the testing places primary importance on coherence and demonstrates a way of managing meaning.

Similarly, a third professional focused on coherence by discussing the language of the written report. The professional said, “With Spanish speakers, we do not provide a translated copy [of the report]. All reports are in English.” The participant showed concern for the cultural differences of families. The lack of resources is an important element for this limitation of practice to not provide reports in the native language of the family.

**Question 9.** Thirteen interviewees responded to *question 9: Are there other ideas to share about delivering the diagnosis differently?* I report the responses and give preliminary analysis here.

One participant had a couple recommendations for delivering the diagnosis differently. The professional stated:

First, it is not fair to talk about Autism for the first time when delivering the diagnosis. Everyone should be prepared. If the child is in early intervention—which most that are referred are involved in EI—and there is a concern for Autism, the concern needs to be discussed. ECEP should be an EI supporter that provides education and helps them to talk about concerns with the parents....So there are a few things, including: EI teams having a strong education to discuss concerns; building relationships with EI teams; discussing Autism throughout the

evaluation; and having a more formal/specific evaluation when the concern is clear.

The interviewee said that talking about Autism when a concern exists with the family is important for the diagnostic process because it can help health care professionals show that they are concerned with the families and with the lives of children with Autism. The participant continued, “Second, it is a huge spectrum with vast diagnostic criteria and explaining how children on the spectrum are so different. The response is that it best identifies the child at that moment.”

A second participant provided two different elements. The professional said: First, the assessment difficulty; there should be an initial assessment before the initial family meeting if considering Autism. Second, a research project; we should look at families’ reactions to the diagnosis delivery to see what is effective and what is not. I am afraid families are going to remember and hate me forever for giving the diagnosis.

Focusing on possible adjustments to the current process that could enhance the overall experience was an important issue for this participant. The emphasis in this response was on improving the social world of diagnosis delivery.

Similarly, a third participant focused on enhancement. The participant suggested: We could change the time period that we have with the families; it seems to be cramped as is the staffing meeting. Two kids in one day is difficult; I feel under the gun. Rethinking the two evaluations in one day could happen. The two evaluations run together, especially if both focus on an Autism diagnosis.

To assist team member with time and with separating the evaluations (i.e. avoiding questions like, “was that the morning kiddo or this kiddo?” or “am I thinking of this kiddo or the morning kiddo?”). The focus of this participant was on adjusting the practices to increase coherence for the team members and to create a more comfortable understanding of the social world for the families.

Continuing with options for delivering the diagnosis differently, a fourth participant noted:

That is hard. First, we should have more consistent use of a smaller group of people during the diagnosis. The environment could be better. We should offer more support after the diagnosis is delivered through follow-up from people that gave the diagnosis. The follow-up would be for our own benefit too, seeing how the family is doing as well as learning the child’s progress through therapies.

Also, it would be nice to follow-up for the re-evaluation at the neuro [development] clinic.

This professional suggested a focus on group size, support, and follow-up to enhance the experience of families and the team members by decreasing some of the mystery in the process, enhance the coordination with the neuro-development clinic, and to change practices and enhance resources.

A fifth interviewee also mentioned continuing the process with follow-up and discussed the difficulty. The participant stated, “It would be nice in some ways to routinely touch-base with the families like having them come back or calling them just to see how the child is doing, but follow-up is really hard.”



**Question 10.** Twelve interviewees responded to *question 10: In your experience, are there alternative ways of delivering the diagnosis to parent(s), caregiver(s), and/or family member(s)?* Their responses and my analysis follow.

One participant emphasized the strengths of ECEP when providing past experiences. The professional noted:

Yes, I have experience working at a different university affiliated research center at other places, but Autism was not prevalent. I would give feedback in my area regarding child's development. There are strengths of ECEP in comparison to other programs; the interdisciplinary model is important when addressing these developmental diagnoses

This participant emphasized the importance of an interdisciplinary approach and the need to utilize the resources of all team members.

A second participant also discussed the importance of utilizing all of the team members' resources. The professional stated:

Before, we used a medical approach, and scheduled evaluations at different times. The professionals would see really different things though. It is helpful when all clinicians see the same thing, because it is hard to reconcile when you see different things at different times....When we give the diagnosis, we also look at development and give that information. It gives a picture rather than just a diagnosis. When we use the ADOS, it is very helpful, that is not true in many places. We use a different approach too; we all score together—that is not supposed to happen. The psychologists here feel they miss too much if others were not observing.

This professional emphasized the unique practices of the ECEP team in comparison to other teams that he/she worked on. Her focus on creating a picture highlights the importance of managing the meaning within the diagnostic team.

A third professional discussed the uniqueness of the ECEP team's support for each other. The participant said:

I have worked at another place where diagnoses of other things were given; there, the psychologist always gave the diagnosis and lead the interaction. But here, [the psychologists] do not always lead or run the meeting; speech will jump in [for example]. There it was the same assessment information, but I felt less supported.

The focus on support within the team demonstrates the importance of a collective and coordinated approach to decision making and for delivering the diagnosis.

Continuing with the focus on support, a fourth participant discussed previous experience that involved preparing and supporting the family prior to going to a specialist to be tested for Autism. The professional noted:

I have worked with teams in many other places and at different stages; each followed a process up to the diagnosis then referred the individuals out. There, we would prepare the family with concerns and question about the possible diagnosis then we would refer them to a specialist... It was psychologist-based; the psychologist did all of the testing and the others watched. No diagnosis was given. It was a trans-disciplinary model, all were there but [the psychologist] facilitated. It was not always the psychologist, but psychologists liked to do it and

were comfortable giving all of the testing. The approach was tried by ECEP, but it was not successful.

The participant emphasized the strengths and credentials of each team member at ECEP and stressed how that plays a large role in the way the tests are performed. Her focus was on preparing families prior to an evaluation day, which demonstrates a concern for the audience of the diagnosis, the family, and for their concerns about what a diagnosis of Autism means for their families.

**Question 11.** Thirteen interviewees responded to *question 11: If you could improve the process of delivering the diagnosis of ASDs, what would you improve?* The responses of these interviewees indicate their concern for the process of diagnosis delivery.

A few professionals discussed the need for feedback. One stated, “It would be nice to recap on what worked well and get feedback for my part of the family meeting and see how I can improve.” Another participant added, “Discuss[ing] what works or does not work or meeting for feedback would be nice and [also] having constructive criticism.” A third participant discussed feedback during the family meeting. The professional stated:

When giving feedback after the family hears the diagnosis, they do not hear anything else after the diagnosis. To go into depth and explain my findings and recommendations is not relevant. The family is not in a position to discuss the issues. It would be better to separate time into a time to talk about the strengths of the child and where to go and a time to discuss some developmental issues that prohibit the child.

The focus for this participant was on separating the amount of time spent on different issues in order to be more effective when giving feedback, which demonstrates a need to adjust the practices during the family meeting and after.

Five professionals discussed the importance of preparation of the family prior to evaluation day. A fourth participant noted:

The process starts way ahead of time, before the clinic. During the phone calls by the coordinators, if there is any indication of Autism, I am talking to the family about ASD before the clinic and explaining what we look at it. There should be preparation of advanced warning on the phone call and during the pre-evaluation meeting on the day of clinic, so it should not be the first time the family hears the concern for Autism during the family meeting. EIs do not want to talk about ASD to their clients for fear of their client leaving the organization, but it is important to not spring it on a parent. Rather one should explain it might be a possibility for the child or might not and build a relationship even with the first phone call and expand on it during the evaluation.

Discussing the process of delivering the diagnosis of ASD begins prior to coming to the ECEP clinic; it reveals the importance of all individuals who are involved from the notice of a concern through the diagnosis, including all elements of the social world of the diagnosis. A fifth participant also discussed the importance of EI teams' preparation. The professional said, "EI would be direct, upfront, and educated. ECEP could be included in that process of educating. The family meetings would require more information and have certain expectations for what is required for a referral." Enhancing

the process through providing resources for the EI teams would be a significant help for these professionals.

A sixth participant continued the discussion about preparing the family for the diagnosis. The professional noted:

The element that is missing is the work of professionals to prepare the family.

ECEP is hoping to work with EI to bring up Autism in conversation prior to the evaluation. We are trying to implement the practice into EIs' trainings. Working with professionals to discuss with the family and with providers about why they are making the referral. The clinic coordinator during the phone call should mention Autism a few days before the clinic if the symptoms or questions pertain to Autism; it could be addressed in a question like have you heard about Autism. Autism should be mentioned a second time in the initial family meeting on clinic day. The evaluation coordinator should mention Autism and ask if that is a concern. The wording can be different; it depends on when the window of opportunity to discuss Autism is there. Yet, it can be difficult when the window is not there.

Discussing Autism at least three different times prior to the diagnosis is one suggestion for preparing the family for a better experience, and this could enhance the process of managing the meaning for the team and family members.

A seventh participant also discussed the process prior to and after the ECEP evaluation. The professional noted:

We try to involve primary caretakers as much as we can, but I do not know for sure how well we involve them. I would love to see these kids back in one year

with the same team, and I think we would learn a lot and see if our diagnosing is off-base. We could see which therapies are working and are not working.

Families could see us differently after they had time to process the information, see therapists, and view things in a good light, because when they leave it is a bad day.

The focus on the process as a whole signifies the importance of coordination of all parties on the diagnostic team and their concern with helping the families cope and in doing so creating coherence for those involved in the diagnosis interaction and trying to create a better social world for those with Autism.

An eighth professional mentioned the need for training as part of preparation.

The participant said:

[EI teams] should provide some information or concern of Autism to the family.

Some have skills and years of experience in doing so, others do not. There should be a piece of training for EIs where they are educated on proper ways of discussing concerns.

The concern for the family prior to and after the diagnosis is a clear focus for enhancing the process and one way to improve this process is with more training about communication within this process.

**Question 12.** Thirteen interviewees responded to *question 12: How do you gauge the family, parent(s), and/or caregiver(s)?* In the subsequent section, I report the data and provide preliminary analysis.

The team provided several ways of addressing the family of those diagnosed with Autism. Some ways include: seeking help from the EI teams, reading the body language,

listening to the information the family provides, and using test scores to gain perspective. One participant said, “The team seeks guidance from those who know the family like the EI team.” Another professional added, “You can gauge the family by the body language, the questions [they] asked and/or the lack of questions.” Similarly, a third participant noted, “Based on what they tell us, we get a feel for their understanding.” A fourth participant provided some context for when the information is gathered. The professional stated, “The phone interview beforehand, if Autism is a concern, allows me to gauge the parents’ knowledge.” Similarly a fifth participant noted: “Listen to comments. The Vineland test gives perspective of parents’ perspective. The scores are not necessarily great, but it is helpful for understanding the parents’ perspective. See if the parent is a talker or a listener.”

The focus on gaining perspective of the family continues to show the importance of understanding the other (the recipients of the diagnosis message) and using that process to coordinate the interaction with the family and to ensure the message content is coherent.

A sixth participant discussed the cultural relevance. The professional said: It is a case by case thing; cultural awareness is important....I wish for more follow-up with the family or at least with the team....Try to start whenever we start in the initial family room; I ask what have you heard about Autism. During the one on one time during the evaluation, I pick up on word choice and continue to throughout the evaluation. When I am the coordinator, I do the same on the phone. It is an unspoken rule to bring Autism up on the phone.

The focus on starting the process by taking into account the needs and feeling of the family as soon as possible indicates that several elements play a role in the overall process of diagnosis delivery.

Similarly, a seventh professional elaborated on the culture of the family. The participant added:

On a cursory level, there are family dynamics like is the parent alone, with partners, or other family members; language; culture; questioning diagnosis; relationship with EI team; ECEPs relationship with the EI team; and their intellectual capacity. I consider if they have heard about Autism and if they are on the same page. I try to build trust but that is tough. And you never know this information for sure; you just gauge it.

The professional places emphasis on the notion of mystery related to diagnosis and of using all of the resources available for the practice of relating to the family is the focus.

**Question 13.** Eight interviewees responded to *question 13: What other comments do you have?* Their responses and my analysis follows.

Three professionals mentioned the importance of preparing the families via a discussion with the EI teams. One participant stated:

Non-preparation is blindsiding, especially when the family has an EI team support. It is inappropriate to not mention the option or concern. EI teams needs to have rapport with the family, to be delicate, and to know where to go. They should know ways to have the conversation about concerns for Autism. There is



a need for EI teams to know how to start and develop this conversation with families.

Similarly, a second participant elaborated on specific communication practices: Some EI agencies avoid the “A” word. It depends on the agency. Some have supervisors who say discussing ASD is outside of their area. They want to avoid telling parents incorrect information; other agencies disagree. Overall, we have a good reputation. Some do not have training on discussing concerns of ASD with families. We used to do more consulting and training, but now the EI team members can only bill for an hour. Education would be huge; the neuro-[development] clinic has more manpower for training. When I worked at a different organization, we really had to educate the EI team. In certain areas, there are no resources available.

A third professional reiterated the issue of preparation by the EI teams: When there is classic behavior, the EI providers may have a discussion about Autism with the family. [Two team members] used to provide training with EI programs and on the website about how to talk to families when there is a concern for ASD. There should be a dialogue prior to the referral or at the time of referral. The EI teams do not give a diagnosis, but they would clarify a concern. Then, they could say, here is a team that can help us figure out our concern.

These three participants emphasized the importance of communication as a way of taking into account the families’ needs, preparation and knowledge as well as the importance of expressing concern for the child as key factors that affect the successfulness of the diagnosis delivery of ASD. The focus on enhancing the

communication process in order to improve the delivery of diagnosis shows the concern of the diagnostic team is for improving the experience of interactants and in doing so making a better social interaction for everyone involved.

A fourth participant mentioned the different dynamics amongst different team members. The professional stated, “There is a night and day difference between certain team members.” Understanding that each team member functions differently is important for coordination between team members.

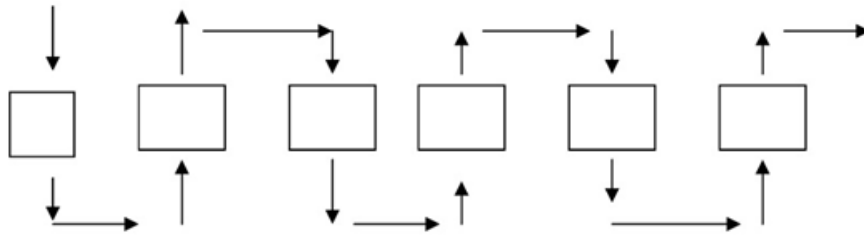
Lastly, a fifth participant discussed the importance of mentoring new team members. The professional noted:

Mentoring is different for each department; medical and psychologist mentor for delivering the diagnosis of ASD. Learning from the team is so important and great. It was one or two years before I started giving the diagnosis. I took what felt comfortable and what resonated with me to create my own toolkit for delivering the diagnosis. It depends on one’s background and experience, contracting work and comfort level.

The focus of this participant on mentorship demonstrates how team members understand principles of meaning creation found in CMM. They seem to recognize that their team co-creates and recreates the meaning making process with other team members. Understanding that the team relies on each team member to shape and manage the meaning of the team demonstrates the importance of team member communication with other team member.

**Serpentine Model Questions.** The second part of each interview involved utilizing the Serpentine model of CMM. For each person, I constructed a visual

representation— via a Serpentine model—that depicted the process of diagnosis delivery as they best could represent it. I began by using sticky notes and placing them in order and rearranging on the wall. However, the sticky notes did not stick to the wall very well, so I drew squares on a piece of paper. I left space in between the squares to allow me to be able to add or move information. An example of a process without the stages is in Figure 7 below.



**Figure 7: Serpentine Model**

No two representations were exactly the same. Many included similar parts, and each had something unique from the other representations. After all interviews were completed, I utilized the information from the individual interviews to organize a discussion-based group interview to discuss a cohesive picture of the process of diagnosis delivery.

## Conclusions

The answers to the interview questions helped supplement and give depth to the answers to the research questions. Above, I provided some initial thoughts for addressing RQ2: *What rules of symbol use, meaning and action guide the patterns of communication used by professionals during diagnosis delivery?* The family emerged as the focal point of the interview data. The issues related to preparing the family and assessing the family. The second focal point was the process and the sequence of the process. The third point was how the teams work together. The fourth point concerned communication and what

to do and not to do in the delivery of diagnosis. The details of these patterns and focal points appear in chapter 7.

These four focus areas of family, process, team, and communication provide an understanding—enhanced from the understanding after completing observations—of the significant elements of the process of diagnosis delivery at ECEP. These areas influence the stages of the process as an actual element of the process or as an area of concern. The concerns that were mentioned are elaborated further in the next section that discusses the group interview and are further explicated in chapter 7.

## **CHAPTER 6**

### **STAGE 3 RESULTS: GROUP INTERVIEW**

The final stage of the process utilized a group interview. The data from the group interview emphasized the team's conceptualization of the process and provided an explanation for their understanding of each element of the process. These facilitation procedures used in the group interview helped the team to reflect not just on individual concerns and rules but to reflect collectively about how they delivery diagnosis and to understand the teams communication practices and how they could be changed. In this chapter, I review my procedures and provide my interview findings and offer my conclusions of themes that emerged from facilitation of the interviews.

#### **Interview Procedures**

Rather than stick to a traditional group interview, I utilized a process that aligns with a CMM perspective. I used SEAVA—Storyboarding, Enriching, Analyzing, Visioning, and Acting. I previously mentioned the descriptions of each stage; here I elaborate to be more specific about each stage for the group interview. To begin the group interview, I provided the storyboard that was created from responses in the individual interviews. As we collectively discussed the storyboard, professionals were encouraged to enrich the storyboard if needed. Through discussing the storyboard, the participants noted areas of concern; the group analyzed these areas to determine actions going forward.

The storyboard that provided the foundation for the group interview emerged during the individual interviews. The data collected was combined to create a large picture of the process that could be analyzed during the group

interview. The storyboard also encouraged the team members to discuss elements of the process that they may have had a vision for how to improve or may have had an action to enhance the process.

The final phase of the research addressed the Enriching, Analysis, Visioning and Acting stages of the SEAVA process. This part of the process addressed RQ3: *What strengths and weaknesses do ECEP professionals identify about their own communication practices?*

On the original date of the scheduled group interview, we had to cancel due to availability since many professionals took some time for summer leave. On the second attempt for a group interview, we had to reschedule due to a retreat for the psychologists. On the third scheduled group interview, we almost rescheduled it due to a meeting for the medical providers. However, after speaking with the program manager, we were able to have one medical provider come to the meeting so at least one professional from each of the four disciplines was present.

Much work was done in preparation for the meeting. I organized all of the data for the individual interviews prior to the meeting. There was a lot of information to organize. I utilized the Serpentine model to organize the stages of the process first (see Figure 8). After all of the stages were included, I elaborated on each stage of the process and included the elements related to that stage. Whenever there was an area of concern, disagreement, or ambiguous element, I indicated that as an area in need of discussion.



**Figure 8: ECEP Serpentine**

After preparing for the interview, I met with the team on June 2, during the normal weekly meeting time in the normal meeting room, which is the same room where the staffing meetings were held. I arrived early in the morning on the day of the interview and set up the room. I brought large white flipboard paper and put three sheets across the smart board that was located at the head of the room. I kept each in place with scotch tape. Then, I took the sticky notes that described the process and placed them in a serpentine pattern on the paper in the order that the team had provided during the individual interviews.

The Serpentine Model was unique and new to the team since it was a means of combining all of the members' ideas of the process. There was one main stage pattern that ran across the middle of the pages. Then, there were daisy models strategically blended into the diagram linearly; throughout the discussion, the linear representation was explained cyclically to clearly represent the many elements that are a part of each stage. Figure 9 provides an example of one stage with the vertical elements. The next figure (Figure 10) shows the daisy model representation of the stage.



Figure 9: Vertically Extended ECEP Daisy



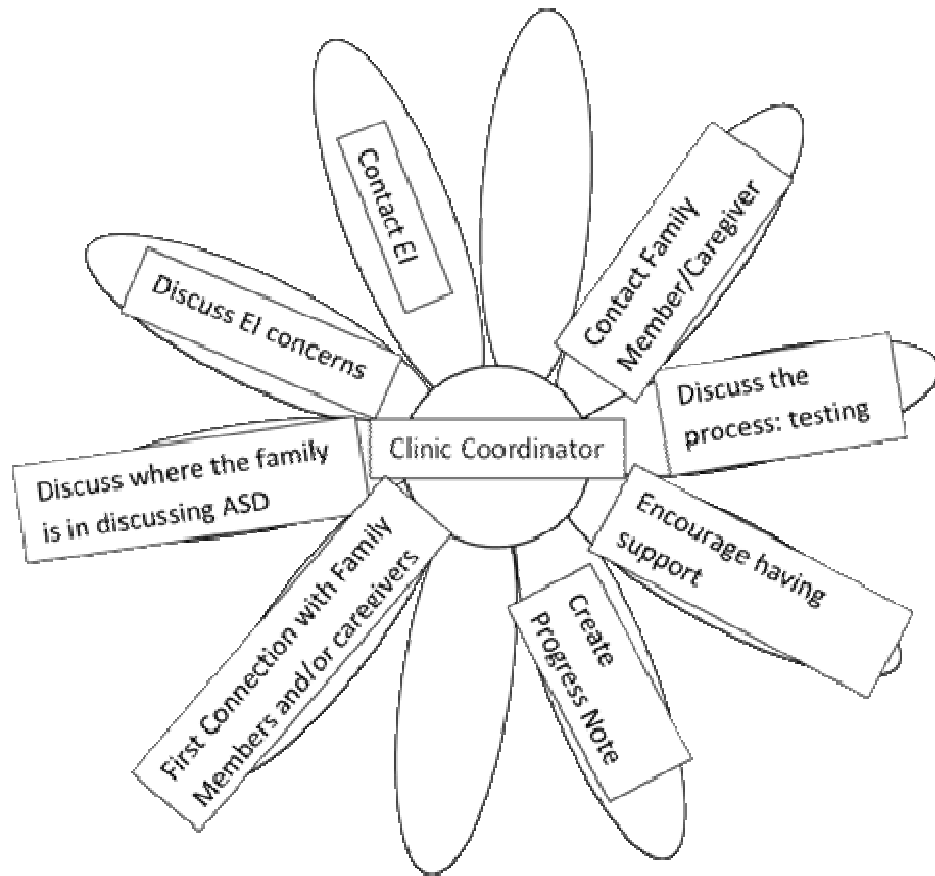


Figure 10: ECEP Daisy

### Facilitation Using Serpentine Model

In the example, the main stage of the Serpentine is the Clinic Coordinator's actions. The sticky notes that go vertically create the petals of the daisy. I utilized the data model in organizing the information from the individual interviews and chose the vertical representation for the team for clarity.

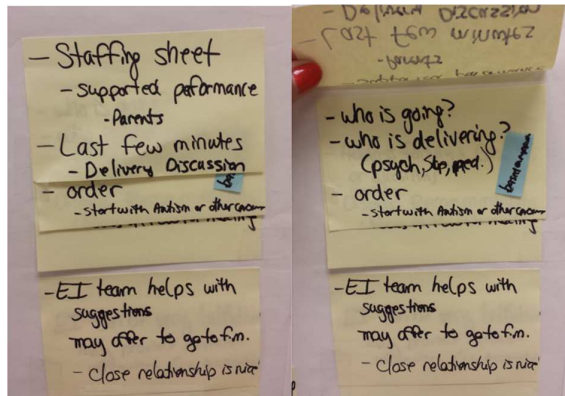
For clarity and a reminder, at the top of the board, I wrote "Organic-Depends on the family" on a sticky note. I referred back to the note whenever the team started becoming too specific (i.e. different examples of family experiences). The note reminded the team that although they were describing the process in steps, the steps were not all encompassing—every act of the process was not included—rather the steps were blocks

of areas that happen in an order. Focusing on the process as organic allowed for a general understanding while leaving space to be specific to each family.



**Figure 11: Concern**

The main sticky notes were a light yellow. I also used blue sticky notes—large and small—to indicate areas of concern or bifurcation points. In Figure 11 there is a large blue sticky note at the top of the row; this represented the concern for relationship development. The placement on the diagram was at a place where the relationship development could start or could not start depending on the clinic coordinator. The smaller blue sticky notes (see the small blue sticky note in Figure 12 on the last yellow sticky note) were also bifurcation points for the specific element that related to the main stage. For example, in Figure 9 the main stage is the clinic coordinator's actions; one element of the stage is the progress note; the blue sticky represents the bifurcation point of writing an email for the progress note or not writing the email. Although there were discussions about many elements of the process, the blue sticky notes highlighted areas in which the actions of the team members differed from one another.



**Figure 12: Complex Element**

There were a few places on the diagram where I placed yellow sticky notes under other sticky notes (see Figure 12). These represented complex elements of the stage; visually speaking, the petal on the daisy could have been separated into another daisy representation.

Team members began arriving around ten minutes before the hour. I placed a piece of notebook paper and a pen at each seat in the room for scratch paper and for team members to write down thoughts. When everyone had arrived, there were ten team members and all four disciplines were represented. I began the meeting with a brief “thank you” to the team, reflection of my experience, and then previewed the group interview/meeting. I explained that the group interview—similar to the individual interviews—would be different from normal interviews and would be a discussion with everyone’s participation; I told them to interrupt me and jump into the conversation at any time.

To start the discussion, I explained the diagram and the representation was their combined understanding of the process of diagnosis delivery of ASD at ECEP. After demonstrating the main row and the categories or stages of the process, I explained the vertical elements were part of the main stage and there was no specific order to their

alignment. I also explained the blue sticky notes as factors or ideas that were unclear or maybe there was concern expressed by a team member about the specific act in the overall process.

As I began describing the stages and the issues that play a role in the stage, team members nodded their heads and listened. I asked questions like, “Did I miss anything?” and “Does that seem to adequately represent that part of the process?” When I came to a blue sticky, I would mention the concern in a variety of ways. Although I cannot include every concern, here I include some of the concerns and the conversation regarding them.

### **Data from Serpentine Model Facilitation**

**Concern 1.** One concern was the proper and effective discussion of the concern of Autism. The team discussed the difficulties of discussing Autism during the family meeting. One team member said, “We all mention that we will look at Autism when we call the family as the clinic coordinator.” After the team member saw the nonverbal responses from other team members, the professional went on, “Or at least I thought we were.” The team then discussed making sure every member is at least mentioning the notion that the team will look at Autism on the clinic day to introduce the term at least once before coming into the clinic. The team discussed the benefit for the family members and caregivers of having time to do some research about Autism to increase their knowledge and preparedness prior to the clinic day.

The team also discussed the need to enhance relationships with EI teams to improve the discussion of concerns with families. The team brainstormed possibilities and noted the concern as a topic to explore further during their retreat.

**Concern 2.** A second concern was relationship development. For this concern, I highlighted several responses from team members that were shared during the individual interviews. For instance, during several interviews, team members mentioned ways they gauge the family members and caregivers or get an understanding of them. I explained that some members mentioned that some team members are very good at getting a feel for family members and caregivers. I also highlighted the practices that the team has in place for continuously communicating with them—the phone call prior to clinic, the initial family meeting, the interview during the evaluation, the vineland test, and the conversation during the final family meeting; highlighting these events demonstrated the parts of the process that assist the team members in establishing a relationship with families.

There was not a long discussion regarding this concern; the team members sat quietly, and some used nonverbal gestures to break eye contact and avoid responding. I know this is an area that team members want to enhance since many of them mentioned their desire to enhance relationship development with families in the individual interviews.

**Concern 3.** Another concern was in regard to the progress note written by the clinic coordinator. I told the group that, “Most team members reported that a progress note was written during this stage; however, some mentioned typing it in the form of an email and others mentioned writing a hard copy for the chart. What are your thoughts on an effective way to share the progress note?” The team then shared individual views. One such expression was, “Everyone writes an email.” Then other members’ nonverbal gestures indicated that they did not know what was expected. Then a reaction to the

nonverbal gesture was, “I thought everyone was writing the email, but maybe not.” The team then discussed making sure that the progress notes were sent via email to the team members.

**Concern 4.** A fourth concern was the little involvement of EIs on clinic day. One team member addressed the concern by sharing that, “Money is the reason.” The team then discussed the change in funding for EIs when attending the clinic day; the EIs are only allotted one hour of paid service. The team member discussed how some EIs stay all day despite not getting paid.

They also discussed the best time for the EIs to be present on clinic day, if they can only stay for one hour. The team decided that the staff meeting is most important to get their perspectives and experiences with the child. Then, they brainstormed ways of talking to the EIs before the clinic day, so that the hour could be used for supporting families during the diagnosis delivery in the family meeting.

The discussion regarding the concern ended when one team member addressed looking into how to have the discussions prior to the clinic day and communicating with EI teams to discuss times to attend clinic days that would enhance the overall process for the families and the team.

**Concern 5.** A fifth concern related to the lack of information about the program coordinator’s role. The team discussed not knowing what the program coordinator does before the initial family meeting on clinic day. Ideas that emerged included discussing the process, establishing rapport, helping the families to feel comfortable, etc. One team member made the assertion to ask the program coordinator about her interactions with the

family members and caregivers prior to the initial family meeting with the ECEP team members.

**Concern 6.** A sixth concern was the consistent discussion of the three areas of concern for an ASD diagnosis. At this point, one team member stated, “The two areas.” Then, I mentioned that all team members that mentioned the DSM criteria in the interview referred to the three areas of concern. The team then discussed making sure that everyone knew to describe the two areas of concern in the DSM V rather than the three areas of concern in the older DSM IV.

**Concern 7.** A seventh concern was the lack of follow-up. Team members expressed a desire to have a better system for contacting families or caregivers after the diagnosis is given. They also discussed making themselves more available to family members that could not be present on the clinic day. Others discussed following-up with EI teams after as well to see how the families were doing. After some discussion about options and time restraints, this topic was also written down for further discussion at the team retreat.

**Concern 8.** An eighth concern was the difficulty in providing hope while being realistic. One team member said, “We are too nice.” The team discussed the positive focus of all team members. After some discussion, another team member mentioned the strength-based approach as one reason for team members being so positive. Team members discussed the terms used in the family meeting as well as the report, and the issue of being very positive in the family meeting and not so positive in the report.

Another team member mentioned the team’s use of “learning style” when describing Autism. One team member shared, “I had never heard the term learning style

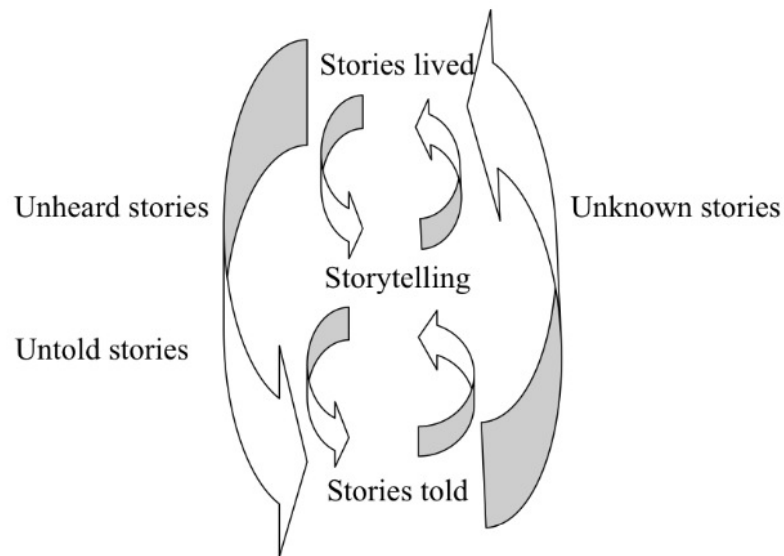
used when giving the diagnosis of Autism until I came here [to ECEP].” The professional went on, “But now I use it all the time.” The team then discussed learning phrases and statements from observing and working with other team members.

Another team member even mentioned that he/she sometimes uses more positive responses—such as learning style—as an “easy way out” for him/her as a professional. After receiving some support from other team members about being considerate of the families when providing the answers, the team member mentioned that some of the *easy way out* statements are not beneficial for the families. Other team then discussed some of their generic answers that they give to provide a somewhat relevant answer that avoids addressing the difficult questions. In the discussion of being too nice, the team described the difficulty as a fine line of being too nice and being too grave. They then noted the topic as needing more discussion.

During discussion of these and other concerns, the team introduced some organizations and affiliations that I had not heard of during my observations or interviews. The LUUUTT model best represents the stories that play a role in the process.



## Facilitation Using the LUUUTT Model



**Figure 13: LUUUTT Model**

After two hours of discussion, I wrapped up the meeting. I explained that although we could have spent a lot more time discussing the process that I was appreciative of their time and I hoped that the interview/meeting was helpful to the team. I also offered the team the opportunity to email me if anyone wanted to add some information, clarify or adjust, or ask questions. One team member took pictures of the diagram to share with the team.

After the team members exited, I utilized the LUUUTT model (see Figure 13) to make sense of the three stages of the process. I observed storytelling; and I heard stories lived and told. During the group interview, I discovered that there were some untold stories and became curious about unheard stories that team members chose to share with me but were not mentioned in the group interview. Some of the untold stories—for example, the actions of the program coordinator—seemed to be unknown stories until the

discussion. Since the team asked questions about the beginning of the process of diagnosis delivery, the story became an untold story that the team would seek to hear.

The LUUUTT model allowed me to think through stages of the process to see what stories were told and untold or heard and unheard or unknown. When considering the stories of the phases of the process, I considered the outlook from the group interview that the team members developed.

### **Data from LUUUTT Model Facilitation**

After the meeting, the program manager shared her notes from the meeting. She had written down all of the questions that were brought up during the meeting to share with the team members that were not present and for the team to review at their retreat. I related her notes to my reflections from the meeting. The questions and reflections relate to three patterns that emerged throughout the group interview: the patterns were team functioning, involvement with early Intervention Teams, and family experience.

**Team Functioning.** One pattern that emerged was team functioning. Several areas of concern related to functionality of the team. The items follow:

1. Are we all emailing our progress notes from the evaluation coordinator's calls prior to the evaluation?
2. Should we make this more consistent?
3. Should we discuss what is being addressed with the Program Coordinator at the initial meeting before signing evaluation papers?
4. What should we say in the evaluation papers?
5. When should we score the ADOS?
6. Who should score the ADOS?

7. Should we find a way to separate developmental assessments from diagnostic assessments for ASD?
8. Can we see one child/day?
9. Should we score the ADOS at time of clinic even though it can be time consuming?
10. Do we want to be consistent in what we say in the family feedback meeting?
11. How can we keep the family feedback meeting from going too long?
12. Should the program coordinator take photos of children at the initial meeting in metro?
13. Should SLPs complete some ADOSs?
14. Should we administer the Vineland differently?
15. Should the Vineland be done before the evaluation, or by the evaluation coordinator?
16. Should clinicians receive more specific ADOS trainings?

The issues of functionality surfaced in the observations and individual interviews as well. Some parts of the process were untold or unknown to some team members, but the same part of the process seemed very clear to other team members (i.e. writing the email for the progress note). Other functions and issues about the process were not clear, possibly told but unheard by some team members, and seemed like a repetitious story told to some members of the team (i.e. the team did not know what the program coordinator discussed with families prior to the team's introduction). Some features of the process according to the participants were not consistent and took up a lot of time (i.e.

scoring the ADOS and utilizing the Vineland differently). Other aspects were mentioned to improve the functionality of the process (i.e. seeing one child a day rather than two, or how much time to spend on what information in the family meeting). These functional issues covered a large majority of the concerns that I noticed during the observations and that participants mentioned during the individual and group interviews.

**Involvement with Early Intervention Teams.** A second issue that emerged was the involvement with the Early Intervention (EI) teams. Eleven areas of concern related EI involvement included:

1. How do we manage pre-evaluation relationship building when asking about ASD and with EI providers and families?
2. What do we do if there is no EI representation at the staffing?
3. Should team members make follow-up phone calls to the service coordinator to relay findings?
4. How do we keep EI providers comments during the staffing/ADOS relevant?
5. Is EI slowing down the ADOS scoring?
6. How do we provide meaningful TA to EI providers?
7. How do we provide TA as part of the evaluation?
8. How do we provide TA separate from evaluations?
9. How can we be encouraging and available to teams?
10. Can we find out more about families, needs at referral for scheduling?
11. How can we provide better continuity of care throughout the process: referral, scheduling, initial contact by clinician, initial family meeting, evaluation, staffing, family feedback, report, and follow up?

The notes from observations and the individual interviews support a second pattern in the data. Team members demonstrated a significant focus on involvement with the EI teams by connecting with EI teams and family members before evaluation day and after evaluation day, currently unknown stories. Effectively managing time to best score the tests was also clearly emphasized in comments, such as explaining to the EI teams that the scoring is only for the tests that were administered during the evaluation on that day not for the daily activities and encouraging the EI teams to bring up concerns at the appropriate time—possibly unheard stories that have been told to other members of the EI teams. Additionally, team members mentioned the need for establishing a closer relationship with EI teams to educate, provide help, and discuss families throughout the process (i.e. better continuity throughout the process).

**Family Experience.** A third theme focused on improving the overall experience of families. Here are the concerns that were noted:

1. How do we improve relationship building with families from the time of the referral to follow-up after the evaluation?
2. How are we providing feedback to families?
3. How are we being too positive?
4. How do we feel about the term “learning style” when explaining ASD?
5. How can we best set up the environment for the family meeting?
6. How do we accommodate families that need to drive home long distances after hearing difficult news?

These patterns and issues also surfaced in the previous responses from the observations and individual interviews. Relationship building was a primary focus, that is, improving relationships with families and not feeling like strangers—creating storytelling to have stories lived and told. Another was providing responses that are based off of trust and reveal the diagnosis encouragingly and practically, such as word choice and explanation—improving storytelling. Lastly, participants emphasized the importance of accommodating their processes and interactions for the family through expressing comfort at the clinic and showing concern about issues like the distance the family has to travel after the clinic.

Some of the concerns overlap with other patterns and issues as well. And although the answers and actions for every question were not reached, the team discussed some ideas that they will include in a later discussion with all team members at the retreat.

At the end of the data collection stage, I had spent more than 74 hours (74.25 not including the meetings and visits the semester prior) at the CDD, sent several emails, made a couple phone calls, and sent some text messages. Through the three phases of the collection process, I gained a better understanding of the communication process; I engaged professionals in an evaluation process; I elicited professionals' ideas about their communication patterns; and I also demonstrated the utility of my innovative methodological approach to data gathering. Through the process, the data provided much information for finding the communication patterns, the rules of meaning and action, the strengths and weaknesses of the communication practices, and goals for the process of

diagnosis delivery. The three phases describe the process of addressing these objectives and research questions.

This chapter presented some additional information about group reflections on communication that is developed in more detail as answers to my research questions in Chapter 7. The content of this chapter reports my data facilitation procedures as it took place in the group interview that was based on the individual interviews; and it provides reports about how the participants in this study responded to my process in ways that support the meaning making process recommended in the theory of the Coordinated Management of Meaning.

## CHAPTER 7

### DISCUSSION AND CONCLUSIONS

After spending over 74 hours with ECEP team members, I developed a clearer understanding of the process of diagnosis delivery of ASD. The three stages of the process—observations, individual interviews, and the group interview—created a unique way of developing, clarifying, and enriching my understanding. Collectively, the data provided answers to my research questions and implications for the ECEP team, other teams that deliver the diagnosis of ASD, and researchers that deal with health care teams.

I conclude with critique from the visioning stage and some ideas for action. I draw upon data mentioned in the chapters 4 and 5 to summarize the description and interpretation. In this chapter, I (1) summarize findings, (2) provide contributions to the method, (3) offer contributions to the theory, (4) provide the depth of involvement of the observer, and (5) list the limitations of the study and suggest directions for future research.

#### Findings

The data from participant observation, individual interviews, and the group interview helped to answer the research questions. I compiled and analyzed all of the data to provide responses to my research questions. The responses to each research question are below.

#### **RQ1: What communication patterns do ECEP professionals commonly use in episodes of diagnosis delivery at the ECEP?**

Several communication patterns that ECEP professionals commonly used were identified in chapter 4 through description and interpretation of the process. The twelve



episodes of observation provided many communication patterns. A summary of the observed patterns follows:

- Typically there are two phases during each episode of interaction that affect the communication patterns of the ECEP team; occasionally there is a third phase. The first phase is the staff meeting; the second phase is the family meeting; and the occasional third meeting is a follow-up/debrief meeting.
- During the staffing meeting, certain communication patterns were observed specifically related to the preparation of the diagnosis delivery. Some of the patterns in phase one included: reviewing the staffing sheet to discuss family members' or caregivers' concerns; asking EI teams (if available) their concerns; discussing interactions between the ECEP team members and the family members or caregivers to gauge preparedness and knowledge level as well as decide which team members established a closer connection with them; seeking input from EI teams about families' needs for a large or small group and the order of information to discuss; and deciding who will attend the family meeting.
- During the second phase, other communication patterns were observed. Some patterns that occurred in the family meeting included: having small talk with the family members or caregivers; explaining a succinct definition of Autism that includes three areas of diagnostic criteria; reviewing child's performance and behavior during the clinic

and reported by the family and or EI team; sharing child's strengths and areas of concerns; framing the diagnosis as a learning style; reviewing the packet of information and resources; answering questions; providing contact information for follow-up; discussing some recommendations; stating the positives effects of EI therapy and likelihood of improvement; encouraging re-evaluation in two years; reminding the family members or caregivers that the child is the same child; suggesting that the diagnosis will help everyone to better understand the child and help him/her get more therapies; and previewing the report.

- During phase three, possible communication patterns included: debriefing about the difficulties of the family meeting and supporting the other team member(s).

The observed communication patterns lead to seven initial critiques that can provide feedback for the team members to foster action that will aid them in enhancing the process of diagnosis delivery. Providing critique is an essential part of a CMM method, which focuses on creating better social worlds by looking at the communication rather than through it. The critiques of communication at this point of the project follow: instead of presenting the diagnosis in a similar scripted fashion, the delivery should be more carefully crafted with relevant and specific content; avoid ambiguity about who will attend the family meeting by spending more time discussion the specific needs for the diagnosis delivery; avoid ambiguous and confusing word choice and terminology; have team members that do not attend the family meeting observe the meeting to offer help if

needed and provide feedback after the meeting; pay attention and mirror the nonverbal communication that the family members or caregivers express including gestures and paralinguistics, such as tone, pitch, and speed; address and acknowledge emotions; allow more time during staffing to prepare for the diagnosis delivery and avoid using the same script. These critiques were adjusted after each phase of the process; the finalized critiques present possible areas to enhance the existing process of diagnosis delivery at ECEP.

**RQ2: What rules of symbol use, meaning and action guide the patterns of communication used by professionals during diagnosis delivery?**

The team members provided specific areas of focus that revealed rules of symbol use, meaning and action that guide the patterns of communication I observed in stage 1. The data revealed four areas of focus for the team. Within these areas of focus, the team also revealed rules specific for the area.

**Family**

In the responses, the professionals referenced the family in several questions. Some of the elements that relate to the rules of meaning follow: the knowledge and preparedness of the family; the family-specific process; the specifics of the child and assisting the family; families' levels of preparedness and understanding; the approach is family-centered; the family concerns; the ability to read and relate to the families; concern for the audience; the focus on the *other*; and the concern for the family prior to and after the diagnosis.

Other elements mentioned relate more specifically to rules of action for families. Those elements included: adjusting practices to create a more comfortable environment

for the families; adjusting the group size, support, and follow-up to enhance the experience of families; gaining perspective of the family; taking into account the needs and feeling of the family as soon as possible; using all of the resources available for the practice of relating to the family; supporting the family; creating a picture of the child; setting up the child for the best possible outcome with the opportunity for success and a family that better understands him/her in order to enjoy the child; and being flexible in the family meeting to adjust the length of the delivery and the responses based on the needs of those involved.

### **Process**

The process was mentioned just as often as the notion of family during the interview responses. Some of the elements regarding the meaning of the process follow: the steps of process; the process is family-specific; the practices and elements of the process; the professionals see each child at the same time; the collaboration and coordination; the group size and support; the process of delivering the diagnosis of ASD begins prior to coming to the ECEP clinic; and the process as a whole. Considering how many times the process was mentioned, the process must play a significant role in how the team decides to deliver the diagnosis.

Other elements referred to the action of the process. They include: having follow-up to enhance the experience of families; utilizing the resources from past experiences; fitting a lot of tasks into a short amount of time, needing more time to train, and involving EI therapists in dialogue amongst themselves; encouraging discussion after the process is complete for constructive criticism and encouragement; extending the dialogue with the families to include those professionals that refer the children; changing the

current practice to include a discussion about Autism prior to the clinic day; possibly adjusting the current process; adjusting the practices to increase coherence for the team members and to create a more comfortable environment for the families; separating the amount of time spent on different issues in order to be more effective when giving feedback; providing resources for the EI teams; and discussing Autism at least three different times prior to the diagnosis.

### **Team**

A third element that was also mentioned during the interviews was the team. This was not mentioned nearly as often as the family or the process. Yet, the theme of team was significant. Of the elements that related to team, here are some that were mentioned that related to meaning: team consensus; support within the team; mentorship and support; each team member has a personal style; each team member functions differently; team members value other team members and their knowledge of their discipline; the outcome depends on the team; the interdisciplinary approach and the need to utilize the resources of all team members.

Other phrases relating to team focused on action. Some included: utilizing the resources and practices of the team members and adjusting the practices to increase coherence for the team members.

### **Communication**

A fourth category that emerged was communication. Similar to the responses related to team, communication was not mentioned as often as family and process. Yet, it was mentioned often enough to demonstrate significant importance. Some of the wording referred to meaning; they included: child's ability with communication and the

need to provide reports in the native language of the family (i.e. Spanish). The majority of the responses relating to communication referred to action: removing blame, stressing the child is the same child, providing information, providing support, highlighting positives, framing the message, hearing and supporting, creating a positive space, avoiding predictions, adjusting the practices to increase coherence for the team members, creating a more comfortable environment for the families, and enhancing the communication process in order to improve the delivery of diagnosis.

I interpreted the description of these areas of focus by organizing the stated communication patterns into one overall process that included rules of symbol use, meaning and action that guide each step that team members provided. The rules of symbol use, action, and meaning may overlap into other categories, but I provide the observed rules here.

**Rules of Symbol Use.** Rules for symbol use differ from rules of meaning and action because the symbols here are simple physical signs that signal a part of the process that the diagnostic team routinely uses. A few rules of symbol use were revealed. They included: once every team member is in the staffing room, the last person closes the door to symbolize the start of the meeting; when difficult questions about the spectrum emerge, discuss the change in the DSM IV to the DSM V, during the family meeting; provide the packet of information and resources as a take home for families and caregivers; when a family member or caregiver cries, offer the person a tissue.

**Rules for Meaning Making.** There were several rules for meaning making. Some of the rules follow: use the scoring from the testing, the interactions with the child, and the reports of child's behaviors and actions to make the diagnosis; use the

information attained during interactions with the family members or caregivers to create an understanding for their perspective on the child, preparedness, and knowledge level; use their perspective, preparedness, and knowledge to prepare for the family meeting and shape the order of the discussion of information; and use the questions, comments, and nonverbal communication of the family meeting to make sense of the family members' or caregivers' understanding of the diagnosis.

There were more rules for action than meaning making or symbol use. There are a few reasons for more rules for action. One reason is the method for data collection; there was more data that supported rules for action than for the other rules since I observed actions and heard team members express actions during the interviews. Most of the rules for meaning making were only discussed in the interviews. The rules for symbol use mostly referred to the process of determining the diagnosis rather than delivering the diagnosis; those rules were not applicable to the purpose of this study.

After organizing the process, I added my critiques at that point of the process via blue sticky notes; my only critiques were the concerns of the team members. Here is a list of the critiques and concerns:

- The discussion about the possibility of ASD occurs at different points of the process; sometimes it occurs on evaluation day.
- The relationships with the EI teams are different which means preparation of family members and caregivers is different.
- The progress note is not always typed and sent via email to the team.
- Not all team members review the progress note.

- The interactions with the EI teams may only consist of one hour during the evaluation day.
- The discussion of the evaluation process occurs at different points of the process and in different levels of detail.
- During the evaluation some team members explain the testing; others do not explain the testing during the process.
- The process of deciding who goes to the family meeting is confusing.
- Not a lot of time is allowed for preparing for the family meeting.
- There is no time to gain feedback and constructive criticism from other team members about interactions and effectiveness during the diagnosis delivery in family meetings.
- One time, one team member mentioned two areas of concern for ASD; all other team members used three areas of concern for discussion ASD.
- The discussions with the family members or caregivers are very positive and instill a large amount of hope for change in the child and/or future predictions of the child.
- Some of the word choices and the amount of information provided are not the most effective for providing a clear understanding.
- The follow-up procedures are minimal.

**Rules for Action.** There were rules for action for the evaluation process, the staffing meeting, and the family meeting. The rules for action about the overall process included: after initial contact with the EI teams and family members or caregivers, the



clinic coordinator provides a progress note to the team via email; the team members choose to review each child's chart as in-depth as they choose; on the day of the evaluation, the team meets in the evaluation room of the West building prior to the initial introduction meeting; the team walks to the initial meeting together; after the introduction meeting, the team walks back to the evaluation room and conducts the evaluation; at the conclusion of the evaluation, the team informs the family members or caregivers that they have about a one hour break and to be back for the family meeting; the team walks to the East building for staffing; the team walks back to the West building for the final family meeting for delivering the diagnosis; and after the evaluation, the team members write their sections of the report.

Some of the rules for action during the staffing meeting included: the evaluation coordinator asks about the staffing sheet and the team provides family members' and caregivers' concerns; after the PSY reveals the scoring for the ADOS and says that there is a moderate to severe possibility that the child is on the spectrum, the team discusses individual thoughts on if the child has ASD; after scoring the tests, the team discusses the diagnosis of ASD and other possible diagnoses (i.e. language delay, developmental disabilities, etc.) and matches the diagnoses with the specific diagnostic code for the file; after agreeing on the diagnosis, the team decides on recommendations; near the end of the staffing meeting, someone asks who is going to the family meeting and the team decides who should go and who should do the majority of the talking; and after the team decides who will attend, the team transitions to a brief break.

During the family meeting, some of the rules included: starting the conversation with small talk; explaining the process of the family meeting; providing information

about Autism; asking the family members or caregivers if they have any questions; when the family members or caregivers ask questions, the team members answer them; when the team finishes providing information, one team member asks the family if there is any other questions or thoughts; at the end of the meeting, the team members have various actions that include thanking the family, providing well wishes, or simply standing and having small talk; and sometimes the family leaves first and other times the team leaves first to allow the family more time.

**RQ3: What strengths and weaknesses do ECEP professionals identify about their own communication practices?**

Team members provided new critiques when addressing the team's strengths and weaknesses. Many of the critiques reinforced, extended, or altered the aforementioned critiques. Team members reinforced and altered the following critiques:

- As the clinic coordinator, the team members should mention that the team will look at the possibility of ASD during the initial contact with the family to make sure the family has some knowledge of Autism prior to the evaluation day.
- The ECEP team should enhance the relationships with EI teams; provide some education about sharing concerns of ASD with their clients; and be available to assist EI teams' in their discussions.
- All team members should review the progress note since the clinic coordinator takes a significant amount of time to write the note and provide an initial impression of the family member or caregiver and concerns for the child.

- Some team members take up too much evaluation time by explaining the process; some team members do not take enough time to explain the process.
- The team is rushed to make decisions about the delivery of diagnosis due to time restraints.
- There should only be two areas of concern for ASD due to the change in the DSM V.
- Providing too much hope for the families is an issue and not providing a clear realistic picture.
- Team members should avoid prognosis.
- Some team members are wordy and long-winded; some also have ineffective phrases or statements.
- There is rarely follow-up with families after the clinic day.

Some of the extended critiques that the team members highlighted include:

- The process of establishing relationships with the families is not strong.
- The team members are too nice and focus too much on the positives of the child.
- The team members do not all have great communication skills; the team member that delivers the diagnosis should communicate in a manner that the family members or caregivers best understand.
- There should be follow-up with the family members and caregivers a couple weeks after the diagnosis is given to see how they are handling the diagnosis and see if they have other questions.

- The size of the group during the family meeting; some members think all team members should demonstrate support and provide feedback; others think a smaller group is more intimate.

**RQ4: What goals would the professionals like to accomplish with their communication patterns?**

The ECEP team is a unique team of health care professionals that deliver the diagnosis of ASD to family members and caregivers through an interdisciplinary team approach that incorporates the strengths of motor therapists, speech therapists, psychologists, and medical providers to gain a holistic image of each child in order to provide a better way of understanding the child and his/her needs for the family and caregivers in a coherent and coordinated fashion.

The team was faced with a goal that was difficult to accomplish because each family member and caregiver is different; effective ways of coordinating and coherently communicating with families change drastically from one family to the next.

Nevertheless the team was able to establish many unwritten rules—the rules for symbol use, meaning making, and action mentioned earlier in this chapter—that likely would assist them in developing communication patterns that would enhance their ability to coordinate and manage meaning.

Since providing interpretations of every action would not be an effective way of consolidating the data, I categorized my interpretations into a few key areas that were the focus of my research questions: the communication patterns, the rules of meaning and action, the strengths and weaknesses of the communication practices, and goals for the process of diagnosis delivery.

**The Communication Patterns.** The communication patterns overlapped with the rules of meaning and action. I differentiate communication patterns and rules based on my observations of the patterns. The communication patterns were observed actions; some of them were not listed as rules by the team members; however, their actions show consistency with the pattern. I listed some additional patterns that were mentioned as rules in the following section. Some of the communication patterns included:

1. One team member agrees to start and a second agrees to transition in.
2. The team briefly discusses families' perspectives about their children and helps the team discern whether the family expects or does not expect diagnosis.
3. The team discusses with EI team (if they are available) their understanding of how the family will respond to the diagnoses and what ways of framing the diagnosis message works best for the delivery.
4. The team identifies the level of preparedness/research and knowledge of the families before deciding how the diagnosis will be delivered.
5. The team begins the family meeting with small talk to re-establish the relationship/connection with family members prior to delivering the diagnosis.
6. The team explains the purpose of the meeting, which is that the meeting is the time families can ask questions and get answers.
7. The team also informs the family that they will receive a report.
8. At the meeting, the team discusses the three—which should be two—areas of the DSM V utilized in diagnosis.
9. The team provides examples of the child's behavior and relates that behavior to the criteria the team uses for diagnosis.

10. The team provides information about the benefits of early intervention.
11. A team member provides his/her contact information to family.
12. When one team member “puts his/her foot in his/her mouth” another team member will step in and reword it.
13. The team discusses benefits of a diagnosis for better assisting the child.
14. The team mentions that it is not the parents’ fault.
15. The team discusses the possibility of having other children with ASD.

**The Rules of Meaning and Action.** Similarly, there were several rules of meaning and action that apply both to the diagnostic team and to the meetings of the diagnostic team with the family. In relating to CMM, one way to interpret the rules is to categorize the rules according to the force that impacts the rule. As previously mentioned in Chapter 2, “prefigurative force is that which we feel based on what other people have just done; contextual force is that which we feel based on the situations in which we are in; practical force is that which we feel based on what we want the other person to do next in response to our acts; and implicative or reflexive force refers to the effects our current actions are intended to have on the contexts in which they occur” (Pearce , Sostrin, & Pearce, 2011, p. 129). I organized the rules into four forces, including: practical force, contextual force, implicative force, and prefigurative force.

Of the rules, most of them were influenced by *practical force* (i.e. if I do this, then someone else will respond accordingly). There were six practical rules, including:

1. The evaluation coordinator asks who is going to the family meeting at the end of the staffing meeting.

2. The team considers who will be present for the family meeting and decides how to approach the family meeting during the staffing meeting.
3. The team should explain the process of the clinic day to the family members or caregivers.
4. Team members should keep the family meeting positive to focus on the strength-based approach.
5. The team provides the packet of resources and information to the family members and caregivers.
6. The team recommends a follow-up reevaluation in two years.

The second greatest number of rules appeared to be influenced by *contextual force* (i.e. I must act this way due to the specific situation). There were four contextual rules, including:

1. The team discusses the families' concerns to determine who should go to the family meeting.
2. At least two team members attend the family meeting.
3. The team decides who attends the meeting based on who developed rapport and who spent a lot of the time talking with the family member(s).
4. The medical provider writes a letter to the doctor/pediatrician.

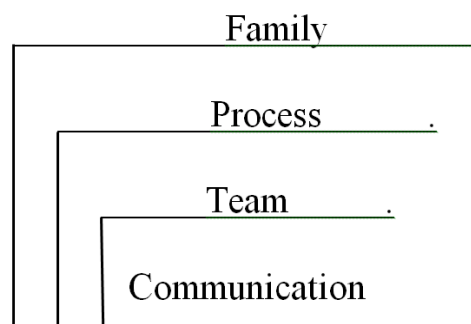
There was one rule that was influenced by *implicative force* (i.e. the actions will have a specific effect on the context I am in). The rule follows:

1. The team should word the diagnosis specifically and clearly.

Lastly, there also was one rule that was influenced by *prefigurative force* (i.e. based on what has happened, this is what is felt). The rule follows:

1. The person who has talked to the family member the most should talk the most in the family meeting and deliver the diagnosis.

These rules demonstrate the mind of the team; how it thinks about the team itself, the process, the family, and communication. Rules are influenced by logical force, that is the cognitive connections people make among meanings and actions. The team is driven by a way of doing things (practical force) and getting the job done (contextual force). Within the contextual force that drives the team, there is a hierarchy of contexts. My best interpretation of the hierarchy includes: the family, the process, the team, and the communication (see Figure 14).



**Figure 14: Hierarchy Model of Contexts**

In Figure 14, family is the most important context. The communication depends on the team, which depends on the process, which depends on the family.

### **Norms about the Communication Practices**

In addition to rules, the diagnostic team seemed to establish norms about what they consider to be strong and weak in their team communication practices. Collectively, the team provided several useful communication practices related to individual professionals and the team that contribute to the efficiency of the process and the quality



of interaction between the team and the family. Some of the self-reported strengths included: having a strength-based approach; keeping messages positive; paying attention to emotions and showing concern for emotional response of family; being available for follow up concerns; focusing specific discussion information during diagnosis to family needs; supporting family members/caregivers with positive actions that they have taken; delivering a clear diagnosis; offering positive encouraging words; and mentioning that the child is the same child. Others mentioned the same strengths as weaknesses indicating the difference of opinions and unique perspectives of some of the team members.

They viewed weaknesses of their communication practices in my three sources of data. Some that were also included as positives included: diagnosis should be clear; word choice should be more effective; and playing with/entertaining a child during a serious moment is distracting to team members and to family members. Other weaknesses that the team members mentioned follow: giving prognosis; using specific wording that is not effective; saying [we] “know” a child can make progress without providing a rationale (i.e. if it’s based on the progress the child has already made or research, etc.); and discussing the three criteria which should be two areas of the DSM V.

Team members provided some goals for the process of diagnosis delivery of ASD as well that demonstrate their understanding of communication. Some of the goals mentioned, included: deliver the diagnosis of ASD clearly and effectively; be available as support through the difficult processing (in meeting and after); answer questions of family members; provide information for families about resources and support via the packet; and provide detailed information for the family and care team via the report

## **Reflections on Method**

Applying CMM as a method for research on a health care team proved to be a useful and beneficial method. CMM provided several heuristics to use throughout the process, including: the hierarchical model, the LUUUTT model, the daisy model, and the Serpentine model. Utilizing SEAVA as a method for academic research worked well. SEAVA provided a great framework for gaining, clarifying, and enriching understanding.

I also utilized a unique application of the Serpentine model; typically, other CMM methodologists, such as W. Barnett Pearce, would appreciate the term because they have used the Serpentine model in a curved fashion to represent the back and forth nature of communication. However, I wanted to depict the many elements that are involved in each part of the process of the diagnostic team by incorporating information gathered from the daisy model. Rather than drawing a daisy for each box in the Serpentine model—which could be an alternative way of doing the same thing—I elongated the petals of the model to be boxes that were attached vertically to the center of the daisy, which was a box in the Serpentine model. I made sure to orally state that although the process was depicted linearly, the process occurs between the team members and the back and forth notion is embedded in the process.

Future researchers using CMM as a method should utilize the heuristics to best fit their research; re-organizing and combining models may be most effective in certain contexts whereas leaving them separated will be most effective in other contexts. For the purpose of this study, the combined visual representation was an efficient and effective option for portraying both models succinctly and coherently to a team that does not focus on models or heuristics of CMM.

Although experts on participant observation make clear that the observer participates in the process, I did not expect that while conducting this study I would become so emotionally involved with the diagnosis team that I observed. This was a difficult process for me as an observer because I could not remove myself entirely from the love and concern that took place in the interactions of parents, grandparents, uncles, caregivers, ECEP team members, EI team members, and others present for the diagnosis of Autism Spectrum Disorders. I became a participant observer since the entire system affected me as well as those I observed.

One way to understand my empathy with those I observed is by referring to the cybernetic loop as I described it in chapter 2. Even though I was only an observer of the process, I closely related to second-order cybernetics' perspective that even an observer is a part of the process, and I physically and emotionally felt that system's effect on me as a researcher. My experience as a participant observed showed me how observers' feelings and understanding converge with those that they observe. One example of this convergence occurred during the diagnosis of a young child that occurred early in my observations. In the family meeting, the mother and father were present. Although I did not take fieldnotes on the parents or the child, the sadness in the mother's eyes and tears combined with the blame that both parents wanted to put on themselves caused me to ache, physically and emotionally; these feelings were hard for me to handle. I was surprised that I could feel a physical reaction to the situation; then my emotions kicked in and tears came to my eyes. This situation caused me to conclude that delivering the diagnosis of ASD is such a difficult task not only for the content of the message but

emotionally and physically too. After several incidents like this situation, I gained an immense respect for the team's ability to support the family.

### **Reflections on Theory**

Along with extending the method of CMM, this study contributes to CMM as a theory by providing a contextualized example of the applied theory. Several CMM concepts are included in chapters 4 and 5: making social worlds; taking a communication perspective; using cosmopolitan communication; understanding coordination, coherence, and mystery; looking at resources and practices; co-creating and co-constructing, and managing meaning.

Applying a communication perspective can be done by using three terms that are offered by CMM. The events of a social world can be evaluated through coordination, coherence, and mystery (Pearce, 2002 & 2007). Through coordination, persons collaborate in an attempt to bring into being their vision of what is necessary, noble, and good and to preclude the enactment of what they fear, hate, or despise. Through coherence, one creates meaning through the stories that are told. By utilizing CMM, one realizes that the stories that are *told* do not always align perfectly with the stories that are *lived* (Pearce, 2002). Lived stories are the co-constructed actions individuals perform with others. The told stories are the narratives that individuals use to make sense of their stories lived. The management of meaning involves the adjustment of the stories *told* to fit the reality of stories *lived* or vice versa. Individuals make choices about which story to tell and how to share each story. Taking a CMM theoretical framework requires individuals to understand that context plays a significant role in each story that is told and the meaning that is made through the conversation. Mystery accounts for the inability to

consider the infinite relationships and contexts that play into each conversation; the universe contains far more stories than the stories that one knows and uses to make sense of it (Pearce, 2002). Mystery also accounts for the change that occurs in the stories we share, live, and perceive.

Utilizing a cosmopolitan form of communication requires communicators to accept and respect other cultures. Interactants coordinate together and consider all involved in the group as “we” rather than “us” versus “them” that occurs in an ethnocentric form of communication. As families and caregivers become involved in the group during the family meeting, collaboration occurs between the ECEP team members and the newcomers. Also, individuals share their perspectives with the group, which changes and recreates the social world. In a cosmopolitan form of communication, coordination is viewed as most important. The interdisciplinary team requires coordination among the different disciplines as well as with the families and caregivers to achieve the goal of delivering the diagnosis. Coordination occurs among team members to plan how to coherently communicate the diagnosis. The team members discuss how the family will “best hear” the message. Although there is coordination, there may not be coherence. In some episodes of communication, the team was able to leave phase two, the family meeting, and feel that there was coordination and coherence among everyone in the family meeting. After phase two of other episodes, team members indicated that there was coordination but coherence was not as easily identified. The mystery exists in the ample stories that are not shared.

Resources and practices were very important to the process. The team members often mentioned relying on their experiences to know how to act and what to say during

the diagnosis delivery in the family meeting. Members also mentioned observing the practices of other team members influenced their resources which impacted their actions. For instance, during the group meeting, one team member said she had never heard the terminology “learning style” until she came to ECEP; she continued by saying she picked up the phrase and uses it now.

This study also extends theory about how people in health care teams communicate with one another. The communication practices influence the delivery of diagnosis specifically in the context of ASD diagnoses. The process provides a theoretical and practical representation of the communication process that are involved in the diagnosis delivery process of this health care team.

### **Limitations**

There were some limitations to this study. Ideally, I would have been able to record interactions that were observed. However, to maintain confidentiality and privacy of the families and children that were involved in clinic at the ECEP, recording the interactions was not possible. I originally planned to record the individual and group interviews; however, to maintain rapport and build comfort and trust, I chose not to record the interviews. Having the audio and/or visual of the interviews would have allowed for revisiting the data for more clarification.

Another limitation was the group interview; ideally, all team members would have been present for the meeting. Due to the complex schedules of working professionals, I was not able to get all team members together during the time frame of this research project. Also, the ECEP team members were nice enough to delegate one of their weekly meetings to me for the group interview. They also went beyond that and

stayed with me for an extra hour to complete the interview; I was very grateful for their time. In future studies, having more than one group interview may be an interesting addition to the study.

The largest limitation to the study was not gaining the perspective of the family members and caregivers, which was not part of the objectives or goals of this research study. Gaining an understanding of the process as the professionals understand it was the first step; I hope to continue with research in the area that will effectively and respectfully address family members' and caregivers' perspective of the effectiveness of professionals' diagnosis delivery process.

This research provides an example of utilizing CMM as a research method and theoretical framework for an academic research project. The three stages of the process—observation and orientation, individual interviews, and a group interview—provide a framework for others who seek to use a similar approach for gathering ample information. Exploiting SEAVA throughout these three stages, or another framework, should also be explored more to provide examples of enriching understanding of communication patterns in any context.

### **Future Research**

Future research should continue to explore diagnosis delivery of ASD and other disorders to enhance current communication practices. Utilizing a CMM method and theory is beneficial for researchers that take a communication perspective and participants that are patient-centered and strength-based; this method aligns with the theory and the heuristics that are easily adaptable to different contexts. SEAVA is a useful method for any applied research project, and future academic research should

implement the method when enhancing the communication practices is an objective of the study.

Some suggestions for future research follow:

- Explore how communication among health care team members influences the diagnosis.
- Study the changes made based on the reflections that the diagnostic team concluded about the diagnosis and explore the effectiveness.
- Pay attention to how the gender of members of the diagnostic team influences the way the team members communicate with each other when on clinic together.
- Look at the effects of the professionals' disciplines on team member communication.
- Look at the pre-evaluation process and how it might impact the diagnosis delivery.
- Expand the study to include how the family responds to the diagnosis.

### **Follow-up**

Fortunately, the team members have continued to communicate with me after the conclusion of my data collection. I have the team listserv, on which I will provide this dissertation for the team members. I will also provide an executive summary of the project. I will continue my relationships with the ECEP team members. In the future, I plan to expand on the current study by collaborating with team members to look at parents' and caregivers' perspectives of the effectiveness of the diagnosis delivery at ECEP.



## **Appendix A**

### **The University of New Mexico Consent to Participate in Research Fall 2013-Spring 2014**

#### **PRINCIPAL INVESTIGATOR:**

Natasha Barnett, Student Investigator (812) 208-5395  
Dr. Julie Shields, Responsible Faculty Member (414) 378-9991  
Department of Communication and Journalism  
University of New Mexico

#### **Introduction**

Natasha Barnett, who is the Principal Investigator and PhD Candidate, from the Department of Communication and Journalism is conducting a research study in which she needs your consent. This research is studying the delivery of diagnosis of Autism Spectrum Disorders, which your child may or may not receive. You are being asked to consent to this study because you will be in the room at the Center for Development and Disability (CDD) at the University of New Mexico when Ms. Barnett observes the professionals.

This form will explain the research study. If you have any questions, please ask one of the study investigators.

#### **What will happen if I decide to participate?**

If you consent, the following things will happen: observations. There are three parts of the study. The first part is the only part that you will be included in. I will observe the interactions of professionals during Wednesday and/or Thursday sessions; during the observations, you will be in the room. You are expected to interact normally during the sessions, and your actions will not be a part of the notes the PI takes.

#### **How long will I be in this study?**

Being observed in this study will not require any additional time.

#### **What are the risks or side effects of being in this study?**

There are no risks.

#### **What are the benefits to being in this study?**

There are no potential benefits.

#### **What other choices do I have if I do not want to be in this study?**

You have the option to deny that I observe the participants of this study—the professionals of the ECEP—while you are in the room. There will be no penalties involved if you choose not allow me to observe the professionals.

#### **How will my information be kept confidential?**

Your name or any other identifiable information will not be collected for this study. Therefore, there will be no direct link to your name. Any information from this study that is published will not identify you by name. All data will be destroyed at the completion of the project.

We will take measures to protect the security of all your personal information, but we cannot guarantee confidentiality of all study data. Information contained in your study records is used by study staff and, in some cases it will be shared with the sponsor of the study. The University of New Mexico Institutional Review Board (IRB) that oversees human subject research and/or other entities may be permitted to access your records. There may be times when we are required by law to share your information. Your name will not be used in any published reports about this study.

**What are the costs of taking part in this study?**

There are no costs to you for this study.

**Will I be paid for taking part in this study?**

There will be no compensation.

**How will I know if you learn something new that may change my mind about participating?**

You will be informed of any significant new findings that become available during the course of the study, such as changes in the risks or benefits resulting from participating in the research or new alternatives to participation that might change your mind about participating.

**Can I stop being in the study once I begin?**

Your participation in this study is completely voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study.

**Whom can I call with questions or complaints about this study?**

If you have any questions, concerns or complaints at any time about the research study, contact the PI at (812) 208-5395.

If you would like to speak with someone other than the research team, you may call the UNM Office of the IRB at (505) 277-2644.

**Whom can I call with questions about my rights as a research participant?**

If you have questions regarding your rights as a research participant, you may call the UNM Office of the IRB (OIRB) at (505) 277-2644. The OIRB is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access the OIRB website at <http://research.unm.edu/irb/>.

## **Appendix B**

### **Individual Interview Guide**

This interview will last around one hour. Your participation is voluntary, and you do not have to participate in the process. I will ask you some questions, and feel free to ask me questions as well.

Note: The interview will be unique to the individual professional. The questions provided are broad structure questions; probing questions will come from the observations and information provided in the interviews.

- 1) I understand the process of delivering the diagnosis of Autism Spectrum Disorders (ASDs) to parent(s), caregiver(s), and/or family member(s) is difficult. Will you please discuss the process with me?
- 2) In your experience, is there a standard process that is utilized in the delivery of the diagnosis parent(s), caregiver(s), and/or family member(s)?
- 3) Are there any elements of the process of delivering the diagnosis of ASD that must be included?
- 4) What are some things you consider when planning for delivering the diagnosis of ASD (for example when you are walking from the staffing meeting to the family meeting when it is individualized time)?
- 5) What else would you like to share about delivering the diagnosis of ASDs to parent(s), caregiver(s), and/or family member(s)?
- 6) What elements of the process of delivering the diagnosis of ASD are most effective (or more effective than other parts of the process)?
- 7) What elements of the process of delivering the diagnosis of ASD are least effective (or less effective than other parts of the process)?
- 8) Are there any elements of the process of delivering the diagnosis that should not be included?
- 9) Are there other ideas you have about delivering the diagnosis differently?
- 10) In your experience, are there alternative ways of delivering the diagnosis to parent(s), caregiver(s), and/or family member(s)?

- 11) If you could improve the process of delivering the diagnosis of ASDs, what would you improve?
- 12) How do you gauge the family?
- 13) Is there anything else you would like to add?

## Appendix C

### Acronyms Glossary Related to Participant Observation Data

EI	Early Interventionist
SLP	Speech Therapist: Speech and language pathologist
MED	Medical Provider: Pediatrician or Nurse practitioner
MT	Motor Therapist: Physical Therapist or Occupational Therapist
PSY	Psychologist
EC	Evaluation Coordinator
CDD	Center for Development and Disability
ECEP	Early Childhood Evaluation Program
PTS	Physical Therapy Student
PRO	Parents Reaching Out
SSI	Supplemental Security Income
PHT	Parent Home Training

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