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Asperger Syndrome: A Case Study on One Family's Understanding

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Asperger Syndrome: A Case Study on One Family's Understanding

by

Ben Graffam

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy,
Department of Special Education
College of Education
University of South Florida

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Understanding Asperger Syndrome: A Case Study

Ben Graffam

ABSTRACT

This study explored the way members of one family understand the presence of developmental delays, especially Asperger Syndrome, in the children of that family. Specifically the study sought to glean how each parent constructed individual understanding of the presence of Asperger Syndrome in their twin, 13 year-old boys. It also sought to explore how each twin experienced the phenomenon of being labeled a child with Asperger Syndrome, and how their experiences affected their growing understanding of the syndrome. A third son, 10 years old, with PDD-NOS, was also a central focus in this study in that he also created and shared experiences that affected his, his brothers', and his parents' understanding of Asperger Syndrome.

Findings indicate that each member of the family constructs an individual understanding of the syndrome, based on personal experiences and attitudes. While this is not surprising, it is interesting to note how these divergent constructed understandings mesh and mingle with each other in the family's experiences. Both parents approached the onset of their boys' Asperger Syndrome by sorting through very different world views and backgrounds. Yet both essentially define the syndrome in the same terms. They deal with their children differently, especially when juxtaposing similar tasks, i.e., helping with the child's homework, yet they often describe the basic deficits each child has as if speaking from one voice.

Within the range of understanding how a learning difference affects a child, it is natural that there would be some denial and/or rejection of the effects on that child. This study found that to be quite true in this family. The study also found that the boys' understanding was not that well developed, perhaps a function of some denial and/or rejection by the parents.

But perhaps not. The study asserts that this family, because of a strong support base and clear family bonds, may be approaching the time when family understanding blossoms. As no child will be able to understand some particular mental challenges prior to moving into the proper developmental stage of intellect, so too a family must move into the proper developmental stage of family understanding.

CHAPTER ONE: INTRODUCTION

Some Background

This ethnographic case study explored, described, and analyzed parent-child interactions in a family that has three children identified with disorders on the Autism Spectrum of Disorders with a goal of gleaning the way each family member understands the presence of Asperger Syndrome and developmental delays in the family. The case for this study is a family of five: Thomas (49), Elizabeth, (41), twin sons, Ringo and Bob (13), and one other son, Cosmo (10), residing in a small community in New England. The twins have diagnoses of Asperger Syndrome and the youngest son has a diagnosis of PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified). The ethnographic methods that were used in this study are: participant observation, active-member research (Angrosino & de Perez, 2000), phenomenological interview (Seidman, 1998), and document review (Angrosino, 2002; Cresswell, 1998). Extensive field notes (Bernard, 1988; Hammersley & Atkinson, 1983; Patton, 1990) were generated for all of these strategies.

As the principal researcher for this study, I lived with the case family for six weeks. This shared living experience availed me to many types of interactions within that group, aside from those central to my study. While it was the interactions that hope to engender general and particular social skills in the child(ren) that framed this study, those other interactions were helpful and informative in juxtaposition. Families are systems of dynamic interactions (Seligman & Darling, 1997; Lambie, 2000) and so many different kinds of interactions had implications on the goals of this study.

The Problem

Families of children with Asperger Syndrome face the difficult challenge of teaching social skills to children who, for the most part, are not able to assimilate these skills through naturally occurring reciprocal social interactions (Attwood, 1998; Bashe & Kirby, 2001; Holiday-Willey, 1999; Powers & Poland, 2003; Szatmari, Bremner, & Nagy, 1989; Shaked & Yirmiya, 2003). This challenge is often exacerbated by the fact that most children with Asperger Syndrome have normal to above normal intelligence (Henderson, 2001; Little, 2002; Neihart, 2000) and so, intuitively, many parents and other caregivers feel that social skill learning ought to occur naturally, as in neurotypical children. Yet this kind of intuitive social learning rarely happens for these kids.

The literature on Asperger Syndrome also supports the idea that no child with Asperger Syndrome is like any other child with Asperger Syndrome (Attwood, 1998; Bashe & Kirby, 2001; Holiday-Willey, 1999; Powers & Poland, 2003). Diane Wilson, former director of Asperger Training and Parent Support Groups for the Center for Autism and Related Disorders at Florida Mental Health Institute, states in her sessions, “when you’ve seen one child with Asperger Syndrome, you’ve seen one child with Asperger Syndrome” (personal communication). Social skills training, then, will take on a very individual tone in the kinds of interactions that occur between parent and child. Children with Asperger Syndrome face different degrees of impairments in the characteristic hallmarks of the syndrome (see literature review, below) and so where one family may need to spend a good deal of time and energy on the understanding of gaining entrance into a social conversation, another might have to spend time on learning the

skills of turn-taking, while another may need to focus on the reasons the child should even consider becoming more social.

Since I began reading about Asperger Syndrome and the need for social skills training, this spectrum of possibilities faced by the family has consistently reminded me of the opening line in *Anna Karenina*: “Happy families are all alike; every unhappy family is unhappy in its own way” (Tolstoy, 1978). That is not to say I feel families with children who have Asperger Syndrome are unhappy—that is far from the truth. Rather it is to say that each family with any kind of disability will be affected by and deal with that disability differently. Those differences, I think, are important, for they represent a range of possibilities in human experience. And because it is probably safe to assume that few families hoped to have a disabling condition, the presence of that condition has the potential to engender a certain amount of unhappiness.

Stake (1995) tells us that observing struggles and conflicts brings a clearer understanding and familiarity to the nature of human systems. He argues that research is effective to the degree it recognizes “the pervasive problems in human interaction” (p. 17). Families are surely interacting systems. Seligman and Darling (1997) point out if one member of a family has a disability, it is wise to think of the whole family as having the disability. This shift in perspective has the potential to change the thinking about family interactions and dynamics. Interactions between the members of the family are seen to be more significant than the individual deficits that are present.

It will be the interactions, then, in families of children with Asperger Syndrome that tell us a good deal about the dynamics of understanding within the family. Observing the nature of these interactions, in their natural setting, will have the potential

to reveal: 1) the contextual nature of those parent-child interactions; 2) certain family beliefs about how such interactions should occur; 3) general and specific frustrations and celebrations in being a family with Asperger Syndrome; 4) differences in family roles and the understanding of those roles; and 5) different manifestations of the effects of Asperger Syndrome. Such are the goals of my study.

My study framed its observation and interview data-gathering strategies on several parental behaviors (Crowley & Spiker, 1983; Grolnick, 2003; Marfo, 1990) that occur in parent-child interactions:

- Directiveness: how much the interactions are based on parental command and child compliance
- Elaborativeness: how much the parent elaborates and acts on the child's behaviors
- Sensitivity: how much the parent notices the child's cues and signals
- Stimulation: how much the interactions supply sufficient cognitive stimulation.
- Intrusiveness: how often the parent disrupts and interrupts the behavior of the child
- Responsiveness: how much the parent responds to the child's cues and signals

The model I used to frame my observations is Bromwich's (1976; 1997) interactional model, generally referred to as the Mutual Enjoyment Model (Marfo, Dedrick, & Barbour, 1998), where the idea is that a strong emotional attachment between the parent and child provides the proper context for healthy parent-child relationships.

Bromwich (1976) posits six levels of interaction behaviors and skills, with the first three levels revolving around primarily affective issues. Those are:

- Parental capacity to enjoy the child
- Parental sensitivity to read the child's communication and attachment skills
- Parental ability to engage in the kind of interactions that promote mutual satisfaction, develop attachment, and engender a system of communication

The second three levels have more to do with cognitive and social growth and include:

- Parental awareness for those materials and activities that are suitable for the child's developmental level
- Parental skill in initiating new and stimulating play based on their own experiences with similar activities
- Parental skill in generating a wide range of activities and play from a brainstorming frame of reference

As the researcher, I sought understanding as to how each of these play a role within the parent-child interactions, and whether one or more appeared to dominate the parental style for each parent. Furthermore, part of the analysis included the degree to which the parents believed these behaviors ought to function in primary roles during the interactions they have with their child(ren).

Why Ethnography

According to Bashe & Kirby (2001), to think properly about Asperger Syndrome, it is important to do two things: 1) attempt to experience the life of a child with Asperger Syndrome from the inside out, and 2) abandon all assumptions about what life is for these children. Both of these will ultimately be impossible, just as the child with Asperger

Syndrome will be unable to apprehend how the neurotypical person experiences the world. But attempting to understand their world from the outside looking in will not get us very close to what it is like.

This is why an ethnographic case study was proposed here: Living with the family, even for such a short time as six weeks, allowed more of an insider's look at Asperger Syndrome. Though in many ways I was still an outsider, actually being in the house where so many significant activities and interactions occurred—planned and inadvertent—gave me a chance to see the hidden dilemmas of daily life these children with Asperger Syndrome and their family experience.

As mentioned, the family of my study has three boys on the Autism Spectrum, a rare occurrence (Szatmari, 2004; Wing and Burgoine, 1983). The two older boys, Ringo and Bob, are 13-year-old twins and were diagnosed with Asperger Syndrome at age 8; their younger brother, Cosmo, was diagnosed with PDD-NOS at 6 and is now 10 years old. I have known the family for all of their time as a family, and I have shared a great friendship with the father, Thomas, for much longer than that. Though I have lived away from them for the past ten years, they have always been a part of my return trips to visit family, a happening that occurs almost annually, and we share letters and phone calls on a regular basis. In short, I have a good knowledge of the family, and they were instrumental in the design of this study. (See Appendix A for the introductory letter and other letters I wrote to them about the study, as well as their first signed consent to agree to take part in the study.)

The parents reported they embraced the kind of interactions this study sought to understand more deeply. Both parents work and play with all three children, helping with

schoolwork and with social understanding. They implemented a self-designed summer homework program for the youngest boy two summers ago (2003), and did the same for all three boys in the summer of 2004. Teaching in these ways, however, in both social and academic contexts, has not been an easy task for them (father, personal communication). A difficult part of the process, as they see it, is that this teaching is very different from what they assumed parental teaching would be like. Skills and understandings they help develop are often those they see occurring naturally in their boys' age mates. Another difficulty is that the parents have different ways of teaching the boys. This is manifest more often when they are helping with different kinds of homework, but it does play a part in their social skills teaching as well.

Parents and other caregivers who attempt to teach social skills will have to be quite savvy of not only the nature of Asperger Syndrome and its affect on learning, but also on the potential interpretations that will occur later in time, both by the child with Asperger Syndrome and those with whom she interacts. Caregivers will need to manifest a kind of self-advocacy in their children so they can have an affect on the context in which they are interacting. In order to do this, the caregivers will need to be able to speak Asperger's (Goldfarb & Devine, 2001). This means they will have to be able to see through the language and situations their child encounters in order to decipher and then assist in that situation. Yet they will need to be careful not to see everything through Asperger's eyes (Bashe & Kriby, 2001), meaning that some things that happen to their child is a factor of the child's age and not a factor of Asperger Syndrome. In other words, a fairly comprehensive understanding of Asperger Syndrome and normal child and adolescent development is needed.

The Questions

As my study was firmly grounded in the qualitative camp of research, it was predominantly seeking to understand a particular phenomenon more than it was seeking to explain it (Greene, 1997; Kelly, 2000; Locke, Spirduso, & Silverman, 2000).

Questions in such a study can be more tentative and often develop through periods of alteration and evolution during the study itself. In fact, it is argued by Locke, Spirduso, and Silverman that quite often “experienced [qualitative] researchers. . . elect not to package their curiosity, interests, concerns, and foreshadowings into the form of explicit research questions” (p. 14). In truth, prior to beginning this study, my experiences as a researcher were probably not up to the level where such a decision was prudent.

However, in defense of those limited experiences, I had conducted an eight-week ethnographic case study with the Polk County Citizens for Peace and Justice during the peace vigils of 2003; I had used the proposed interview protocol (Seidman, 1998) for this study during my study of teachers of gifted learners in Polk County (Graffam, in press); and I am presently involved in a qualitative study of families who have children identified as a gifted learner with Asperger Syndrome, a study that began before this dissertation. As these experiences did not warrant the label of ‘seasoned ethnographic researcher,’ it was important for me to frame and explicate the questions that directed this study, not only to better prepare me for the prefigured focus (Eisner, 1998) I took into the family’s home with me, but also to help clarify particular research methods to be explained later.

The core questions for this study were these: 1) *What does it mean to these parents to have children with Asperger Syndrome?* And 2) *How do these children*

understand the label of Asperger Syndrome as it has been applied to them? Specifically, by focusing on those interactions that intend to facilitate the learning and use of social skills, I felt I should be able to observe the parents' intent with some clarity. They would be engaging their children for a purpose, and, hopefully, the outcome of that engagement would be manifest in both better understanding and better use of social skills. Following the interactions, then, I would interview the parents to get their sense of purpose within the interaction, allowing me to explore Walcott's (1999) idea that with ethnographic methods we get to see not only what people do, but also to hear what they say about what they do. I did the same with the children, both observing their behavior during the interaction and also questioning them about the nature of that interaction afterward.

Of course, since this was an ethnographic study, many other kinds of interactions were observed, many of which did not include both parent and child. In fact, many observed interactions involved the children with peers, classmates, playmates, etc., often without their parents immediately present. In this way I sought some insights into the effectiveness of the teaching of social skills, providing me with a sense of how those interactions made an impression on the child.

It is important to note that along with those two questions, an overlapping question was: *What are the salient parent-child experiences that help the child's learning about his own experience with Asperger Syndrome?* I say overlapping as I had pictured each of the first two as a circle in a Venn diagram, with the meeting place of the two circles representing the third question. The first two led me to more descriptive and narrative data, recording the interactions between parent and child and then probing through interview what these interactions meant to them. The third question, however,

required a more analytical process, melding my understanding of meaning-making systems of the parents and children with the specifics of the behaviors and statements observed, and weaving those with the literature on Asperger Syndrome. As the reader will see, for several reasons this third question was nearly impossible to answer.

Saliency means different things to different people, but certainly those experiences and interactions that help the child develop new social skills he can use on his own in a particular and proper way could be deemed salient. My task in answering this third question was to discern the how the conflation of the parent interaction, the Asperger Syndrome, the observed situation, and the child all work to manifest the new behavior. Intuitively we all might be able to spot some of these interactions, but since understanding has to do with the transformation of intuitive beliefs (Stone-Wiske, 1998), my task—as with all qualitative research—was to understand how these phenomena occurred.

One way this occurred was through observing the children in social interactions at their school and then querying their teachers and other supervisors about changes in their behavior in particular social settings. The principal of the boys' school allowed me to visit the school on several days while I lived with the family. I interviewed the boys' teachers at the school. I interviewed the community's recreational director. These allowed a broader scope of the parent-child interactions in question.

But whereas I had thought the parents would engage the boys in some very particular social skills lessons, focused on understanding the effects Asperger Syndrome had upon them, these were not forthcoming. Consequently obtaining significant data on the saliency of particular interactions question three sought was not possible.

However, each of my questions gave a structure to the way I observed and pondered all of the interactions that occurred during my stay with the family. Each required the development of a deep understanding of the context of the interactions (i.e., the place, the time, and the situation that motivates them). Each required the engagement of all participants in order to understand how they perceived their role within the interactions. In this sense, each worked to build the argument for this ethnographic case study.

Possible Benefits from the Study

This study pushed me toward greater understandings of Asperger Syndrome, parent-child interactions, and qualitative research. It also made me reflect upon the significance of friendship, a reflection that continues as I rewrite this opening chapter. I believe this study can benefit the field of Asperger Syndrome and Autism Spectrum Disorders in many ways. A first way will be a clearer understanding of how this family of children with Asperger Syndrome constructs their understanding of the syndrome. Another is the understanding of how these boys manifest the many possibilities of the syndrome. But mostly this study will reveal some of the living situations this family experienced in dealing with the affects of Asperger Syndrome.

To me this is highly important as the newness of the diagnosis of Asperger Syndrome makes it a relative unknown to educators and to parents. Descriptive, narrative research can bring insightful understandings to both of those groups. The present paradigm within research on Autism Spectrum Disorders is the bio-medical model, and I think this is surely not the only way to be investigating a spectrum of disorders that affects an individual's experience in the social milieu. This study allowed

me to observe not only the moments when either one or both parents helped their children through problems beyond their ken, but also those moments when the parents may have acted as and become the problems their children faced.

The next two chapters present a review of the two literatures that inform my work and the methods I used during my stay with the family in New England.

CHAPTER TWO: LITERATURE REVIEW

Two Literatures

Two significant literatures inform this study. The first, of course, is the literature on Asperger Syndrome, a pervasive developmental disorder (Bashe & Kirby, 2000) found at the higher functioning end of Autism Spectrum of Disorders. Asperger Syndrome was first identified in a paper published in 1944 by Hans Asperger, though at that time he referred to the disorder as a kind of “autistic psychopathy” (Asperger, 1999). The naming of the disorder did not come until 1981, in a paper by Lorna Wing, “Asperger Syndrome: A Clinical Account” (Wing, 1999). Perhaps more interesting, it was not until 1989 that there were diagnostic criteria for the disorder, the first being developed by Gillberg’s of Sweden and the second by Szatmari, Bremner, and Nagy of Canada (Attwood, 1998). In 1994, the DSM-IV offered its criteria for the disorder for the first time (Attwood). And in 1995, Attwood (Bashe & Kirby) offered his own scale on identification, not so much as a diagnostic criteria, but more of an aid to parents who were spotting interesting behaviors in their children.

The prevalence of the disorder seems to be on the rise. In 2000 it was estimated that 1 in every 250 children have disorders on the Autism Spectrum, a number higher than childhood cancer, Down’s syndrome, muscular dystrophy, or cerebral palsy (Bashe & Kirby, 2000). And Asperger Syndrome appears much more often in males than females, at a rate of nearly 9 to 2.

Asperger Syndrome, like other pervasive developmental disorders offers many issues for families, which brings about the second significant literature of this study, parent-child interactions. It is interesting that this field of study has a long history, but one that was initially focused on only parent-child interactions with non-handicapped children (Marfo, 1988). And mostly it was the mothers of those children who received the attention. According to Marfo, full investigations into the interactions between parents and children with developmental disabilities is fairly new. Connecting the newness of this field to the other literature of this study, a computer search of peer-reviewed journals revealed that only five articles were available that dealt with parent-child interactions on the autism spectrum, and none of those focused on families with Asperger Syndrome. And yet, as I hope this literature review and full study demonstrate, it will be the parent-child interactions in families that deal with childhood disabling conditions that reveal the greatest degree of possibilities that exist in all such interactions.

The following literature review will be presented in two sections: the first will deal with Asperger Syndrome, and the second will deal with parent-child interactions.

Asperger Syndrome Literature

Introduction

People with Asperger Syndrome quite often have: marked difficulties in social interactions (Asperger, 1999; Burgoine & Wing, 1983; Gilchrist et al, 2001; Szatmari et al, 2000; Tager-Flushberg, 2003; Wing, 1999;); one-sided and inappropriate social interaction (Burgoine & Wing; Wing); misinterpretations of social cues (Asperger; Tager-Flushberg); social isolation (Asperger; Wing); little ability to form friendships (Asperger; Burgoine & Wing); difficulty negotiating the social world (Tager-Flushberg);

poor nonverbal communication skills (Asperger; Burgoine & Wing); improper turn taking in conversation (Tager-Flushberg); repetitive and pedantic speech (Burgoine & Wing; Tager-Flushberg; Wing); literal speech and thought (Andron, 2001; Holiday-Willey, 1999; Pyles, 2002); fluent but pragmatically impaired speech (Asperger; Szatmari et al; Wing); unusual tones of voice and flat, monotonous speech (Attwood, 1998;Tager-Flushberg); bizarre obsessions and preoccupations (Asperger; Burgoine & Wing; Szatmari et al); circumscribed interests (Attwood, 2003); desire to be rule and routine followers (Andron; Burgoine & Wing; Holiday-Willey; Pyles); impulsivity (Asperger; Pyles); usual disturbances of active attention (Asperger; Pyles; Tantum, 2003); abnormalities in patterns of behavior and interests (Asperger; Gilchrist et al); lack of empathy (Burgoine & Wing); poorly developed theory of mind (Attwood, 1998; Burgoine & Wing; Frith, 1999; Pyles); physical clumsiness (Burgoine & Wing; Holiday-Willey); hypersensitivity to sensory stimuli (Holiday-Willey; Pyles); rich and varied vocabularies (Asperger; Attwood, 1998; Tager-Flushberg; Wing); normal to above normal intelligence (Asperger; Neihart, 2001);difficulty to assimilate ideas from other sources (Asperger); large collections of unlikely objects (Asperger; Attwood, 2003); thinking that is not goal directed (Asperger).

Yet such a list really can't put images or empathetic connections into the reader's mind as to what AS has the potential to do to (and for) an individual. For that I think it is important to take the time to place yourself in the world of the child with Asperger Syndrome, by attempting to do what it is considered nearly impossible for them to do (Burgoine & Wing, 1983; Frith, 1999; Pyles, 2002; Wing, 1999): think about how another person experiences the world. The following list has been developed from

Holiday-Willey (1999), set up so that the reader can get a sense of the personal experience of having Asperger Syndrome:

- Imagine loving words so much that you could escape into them and leave nearly all of your stressful experiences behind. But also imagine such a strong connection to those words that the sound of some would hurt your ears or that their sight would be so ugly on the page that you could be driven to anger.
- Imagine finding a kind of joy in the sense of touch, that could only be fulfilled by grinding the striking strip of a book of matches between your back teeth.
- Imagine the oral needs—and the love of the taste—to consume mothballs and toilet bowl sanitizing bars.
- Imagine some noises and lights being absolutely unbearable. The mid-day sun sears your eyes, and all whistles, trumpets, flutes and high frequencies would disarm you.
- Imagine being so interested in other people that you observed them extensively, mimicked their behaviors, borrowed their accents, and copied their tiniest little gestures. Every spot on their face intrigued you. But also imagine that you'd rather not associate with any of them, afraid of the social interaction they represent and so you choose to be home in the small nook under your bed, behind your bed board rather than be in even the smallest group.

- Imagine all of these things occurring while you grew to the age of 12, a time when you were labeled as a gifted learner.
- Imagine being unable to differentiate between what should and should not be said in company, because your sense of communication was that it was based on one person telling another what was felt and known to be truthful regardless of the situation.
- Imagine your belief in rules makes you unable to accept as right any behavior that goes against those rules. Imagine when those rules come into conflict, as when the classroom rule is ‘no speaking’ and someone whispers to you across the aisle.
- Imagine being unable to coordinate your body so that you could swim an identifiable stroke, yet loving to be on the swim team. Imagine knowing that your coach didn’t work with you as a swimmer because your skills, to her, made you invisible.
- Imagine that your love of words and of seeking solitude made you seek competitive public speaking, not for the joy of speaking but because it was a chance to speak uninterruptedly and not have to converse.
- Imagine these occurring while you’re a teen, a time when your test scores and GPA are such that all of the greatest colleges in the country write to you with academic offers.
- Imagine going off to college and finding that nothing about it accommodated you: not the place, not the people, not the practice.

Imagine finding out you were all alone in the world, with behaviors, attitudes, and proclivities that were unlike all of those people around you.

- Imagine that what made you different made it nearly impossible to assimilate the give and take of social interactions and meetings of large (even small) numbers of people, so seeking friends in this society was beyond difficult.
- Imagine the irony in discovering that the best place for you to work is probably a university where everything is linked by a common tie to solitude. And so you earn a doctoral degree and are considered to be among the top in your field, yet in “simple” communication you cannot understand the conversation unless it is filled with well-spoken descriptions and rich visual images.
- And imagine having to tell your spouse that your fingers felt like they were being torn apart when he held hands with you; that you felt bugs crawling under your skin upon the slightest touch; that certain colognes made your mouth water and your nose burn; or that being too near to another person made you want to push that person away.

Finally, though that word is desperately out of place here, for there is no finality to all that we could imagine happening to the individual with Asperger Syndrome, imagine being intellectually savvy enough to know that the condition affecting you

makes it necessary to plan for even the simplest of things. For example, when traveling, a very elaborate map will need to be made for you, with both written and visual cues, and the directions will need to be rehearsed time and again, well before you venture out on the road. And then think of the fact that even this preparation must include giving you a cell phone and reminding you to call a particular number the minute you get lost.

Because you are going to get lost. And when you do, you will feel out of place, you will panic, and all of your Asperger Syndrome traits will take over, rendering you totally uncomfortable, completely socially inept, and unable to formulate any kind of logical decision.

The amazing thing about all of this is that what often saves individuals with Asperger Syndrome is something all of us without the syndrome all take for granted: knowledge of self. Yet for people with Asperger Syndrome, this is a knowledge that is hard won, and slowly developed, through training and accommodations and lots of social and personal practice. Without it the individual with Asperger Syndrome will accomplish very little in social circles, probably never finding more than one or two good friends in life; and maybe never finding a life-mate. With it, many things can happen, although there will still be the constant knowledge—self-knowledge is always this way—that the limitations of your condition will turn up whenever they want to. The life you lead, then, is as a bewildered stranger in the social world. You are, in the words of Temple Grandin, an anthropologist on Mars (Sacks, 1995).

Need for Social Skills Training

Families of children with Asperger Syndrome face the difficult challenge of teaching social skills to children who, for the most part, are not able to assimilate these

skills through naturally occurring reciprocal social interactions (Attwood, 1998; Bashe & Kirby, 2001; Holiday-Willey, 1999; Powers & Poland, 2003; Szatmari, Bremner, & Nagy, 1989; Shaked & Yirmiya, 2003). This challenge is often exacerbated by the fact that most children with Asperger Syndrome have normal to above normal intelligence (Henderson, 2001; Little, 2002; Neihart, 2000) and so, intuitively, many parents and other caregivers feel that social skill learning ought to occur naturally, as in neural typical children. Yet this kind of intuitive social learning rarely happens for these kids.

Individuals with Asperger Syndrome, especially children, have a great deal of difficulty reading social cues in all contexts (Asperger, 1999; Tager-Flushberg, 2003). Many cannot read the facial expressions or other body language that accompanies conversation (Szatmari et al, 2000). Many cannot decipher idiomatic language (Andron, 2001; Holiday-Willey, 1999; Wing, 1999) or are too literal minded to appreciate and apprehend the nuance of expressive language (Andron; Holiday-Willey; Pyles, 2002). Many do not understand the turn-taking behavior that forms most conversational interchange (Burgoine & Wing, 1983; Wing). And many have difficulty understanding the very need for social interactions (Bock et al, 2001).

The literature also supports the idea that no child with Asperger Syndrome is like any other child with the syndrome (Attwood, 1998; Bashe & Kirby, 2001; Holiday-Willey, 1999; Powers & Poland, 2003). Diane Wilson, former director of Asperger Training and Parent Support Groups for the Center for Autism and Related Disorders at Florida Mental Health Institute, states in her sessions, “when you’ve seen one child with Asperger Syndrome, you’ve seen one child with Asperger Syndrome” (personal communication). Social skills training, then, will take on a very individual tone in the

kinds of interactions that occur between parent and child. Perhaps more significantly, the kind of teaching needed for developing these social skills is not the kind most parents felt they would be using while engaging their children (father, personal communication). All parents expect to teach their children to tie their shoes and learn table manners; none seem to anticipate teaching their children how to differentiate between angry and happy eyes. And of course, children with Asperger Syndrome face different degrees of impairments in the characteristic hallmarks of the syndrome and so where one family may need to spend a good deal of time and energy on the understanding of gaining entrance into a social conversation, another might have to spend time on learning the skills of turn-taking, while another may need to focus on the reasons the child should even consider becoming more social.

Parents, or caregivers, then, need to step in and help develop these skills in their children. In many ways, this is a natural process: families have always been the places where children learn social rules. Families are rule-centered places (Powers and Poland, 2002; Seligman & Darling, 1997), though for sure, some of those rules are explicit and some are implicit. Children with Asperger Syndrome are pretty adept at following explicit rules; implicit ones, however, are not so easy for them. But, all things considered, the home and the family are optimal places for engaging the child with Asperger Syndrome in social skills learning.

But what are the processes for such learning? How do parents go about this task? The family I will be studying (father, personal communication) finds the teaching somewhat difficult partially due to their lack of training in things teacherly. They recognize that the teaching profession develops skills in differentiation, in addressing

different subject matter, and in approaching the learning styles of different learners. However, they have not had this training, and the father mentioned that the teaching they're doing with their children is not at all what they had expected to be doing. Parents, he said, have a kind of framework for what parenting will be, always knowing that unpredictable moments will arise, but mostly feeling that their own experience of being a child will assist in the learning interactions. However, this has not always been the case with their children, nor with children with Asperger Syndrome generally.

Teaching social skills to children with Asperger Syndrome requires some things that more 'normal' parental teaching might not require. The approach to this learning will need to be more explicit. Because anticipation skills are not well developed, due to that missing understanding of social cues, children with Asperger Syndrome will need to be told quite specifically what the learning is about. They'll not assimilate learning the way neural typical children do (Powers & Poland, 2002). This kind of teaching requires a well-set plan. It is not the teaching of an assortment of skills simultaneously, but rather it is a development of an understanding of the particular skills and contexts in which the child will find himself functioning.

There seems to be, though, certain skills that all children with Asperger Syndrome need to learn: knowing when to be quiet and when to talk, knowing how to share, knowing how to be polite, and knowing how to wait are a few. But there is also a hidden social agenda (Powers & Poland, 2002) that neural typical children pick up on easily. For example, rules of politeness change as venues change; sharing is a different behavior at home than it is at a friend's home. Teaching social skills to children with Asperger Syndrome is fraught with challenges that often pop up when the teacher isn't looking.

Historically, there have been prepackaged programs for this training, but these have proved to be ineffective (Ozonoff & Miller, 1995). Part of the problem is that many of the social skills packages begin with a ‘given’ that won’t work for most children with Asperger Syndrome. For example, a social challenge might read, ‘if you and another person disagree, how will you rectify the situation?’ Well, this immediately puts the child with Asperger Syndrome at a disadvantage because she will be unable to mentally access the thinking of the other person. The father (personal communication) in my family of study explained how the twins had difficulty in a state writing test, when they were asked to think about what a young girl who had been molested might think about in certain social situations. Though this prompt was designed to help kids understand the nature of social interactions and the sensitivity they might need with different participants in those interactions, there was no good way the twins could access the knowledge to enable them to write the essay.

Researchers report that it is much better (Ozonoff & Miller, 1995; Powers & Poland, 2002; Pyles, 2002) to teach the social skills in the context where the skill will be used. Powers & Poland point out that studies have shown how children with Pervasive Developmental Disorders enjoy learning about shopping more if that learning takes place in a store and not in a classroom. And this makes good sense. Children with Asperger Syndrome are often visual learners (Grandin, 1995; Holliday-Willey, 1999; 2002) so putting them in the places where they can see exactly the surrounding in which they’ll be acting is a good method. And there are some other significant rules of thumb for teaching these skills to children with Asperger Syndrome.

Theory of Mind

It seems that the major issue both prompting and affecting the teaching of social skills to children with Asperger Syndrome is the concept of theory of mind. Essentially Theory of Mind is that capacity that empowers the individual to be empathetic, to identify another person's point of view, and to recognize that there are some bits of knowledge the individual knows that others do not know (Powers & Poland, 2002). Neural typical children develop this capacity with little difficulty, through their natural experience in the world. Children with Asperger Syndrome (and autism) do not.

It is this lack of Theory of Mind that presents the child with Asperger Syndrome with so many of his social impairments. Not knowing that another sees and thinks of the world differently changes the manner of engagement. It even changes the purpose and understanding of engagement. One adult with Asperger Syndrome spoke of the real puzzlement friendship and social interactions had for him when he was a child: "I didn't know why people cared about making friends. I'd ask my classmates, 'what is all the interest in dating?'" (Strangers, 2001; and see Bock, 2001) If the meaning or purpose of social interactions is not comprehended, then the manner of undertaking them will be affected. Children with Asperger Syndrome do not approach social interactions in the same ways that neural typical children do. Nor, when engaged, do they participate in similar ways.

Children with Asperger Syndrome 'take over' conversations, inserting their interests and rules to the point where others are not even participating (Marks, et al, 1999). In these conversations, they use odd voices, pedantic and adult-like speech, often with little understanding of the turn taking that goes on in regular conversations

(Attwood, 1998; Burgoing & Wing, 1983; Tager-Flushberg, 2003). Consequently, they are seen by peers and age mates as unusual and, more often, avoidable. Children with Asperger Syndrome need a good deal of help to overcome these obstacles to social interaction, but fortunately, this help is obtainable.

Learning these skills, though, is not easy. Part of the problem is that children with Asperger Syndrome do not transfer information well: what they learn in one context stays there (Attwood, 1998). Since so much of social interaction seems ubiquitous to the neural typical person—dinner at home is similar to dinner at a restaurant and both are similar to dinner at the church—she needs only a small cue to see that she should bring other behaviors with her when she changes venues. A child with Asperger Syndrome, however, will see each of those dinner contexts as very different and while he may know that staying quiet and politely waiting for food at grandma's house is necessary, he will not necessarily know that the same behavior is needed at church.

A difficulty in the teaching of social skills is the fact that children with Asperger Syndrome love rules and routines but will not know how or when to turn them off, even in extreme context changes. For example, a child who learns that it is polite to say hello when someone enters a room may do that each time a person enters the room, even if that person has been greeted already and has merely left for a moment. Or the child might say hello to everyone individually when a group enters the room, an occurrence a neural typical person will see to be accommodated with a group hello (Andron, 2001; Pyles, 2002).

Much of this ties to Theory of Mind. Since children with Asperger Syndrome cannot think about the nature of another person's thoughts, they are living in a world that

needs nearly constant translation for them. People make sense of their world in terms of mental states (Happé & Frith, 1995). Without a properly developed Theory of Mind, individuals would face an unpredictable and almost unknowable world. Powers & Poland (2002) write:

The ability to make the distinction between our own thoughts and knowledge and the thoughts and knowledge of others is crucial [to social learning]. It allows us to lie and deceive, to be sure—but it also allow us to care about other people, to engage in irony, to appreciate humor, and to create imaginary images in art and drama. When it is impaired, we are less able to sympathize with others, or to anticipate the effect of our behavior or words on others (p. 28).

And so parents, or other caregivers, need to spend a good deal of time and focus teaching social skills and Theory of Mind concepts to their children with Asperger Syndrome.

Theory of Mind doesn't improve just through aging and maturity; interventions are needed, especially for the child with Asperger Syndrome (Ozonoff & Miller, 1995). Sadly, there is a 'catch 22' involved with the social and Theory of Mind impairments faced by children with Asperger Syndrome (Ziadas, Durkin, & Pratt, 1998). Which begets which? Because most neural typical children seek out personal interactions and relations with age mates, they naturally develop the skills and inclinations to enrich their social skills and theory of mind. However, most children with Asperger Syndrome do not have the friends or opportunities to socialize in ways that will grow these skills. Teasing and rejection has occurred enough so they are not welcomed into groups and

they don't seek them. Then, of course, their own awkwardness in social approach adds fodder to the teasers and rejecters (Ozonoff & Miller).

Uniting Social Skills and Theory of Mind

Powers & Poland (2002) write of three Golden Rules when helping children with Asperger Syndrome learn to negotiate their world:

- I. Predictability: This is the lifeline for a child with Asperger Syndrome. Prepare for as many changes as possible. Set schedules in advance. Use calendars. Use timers. Block out the time of the week. Experiment occasionally with 'what-ifs' as a setback training.
- II. Structure: Children with Asperger Syndrome have a great deal of difficulty structuring their own time, and they benefit a great deal when their time is structured for them. Even schedules that outline free time, though sounding contradictory, are good ideas.
- III. Routine: These provide children with Asperger Syndrome with the predictability and structure they need.

They also mention two Silver Rules:

- I. Responsibility: Contributions to the well being of the family are important for every family member, and no less so for children with Asperger Syndrome. But it is very important to structure those responsibilities so that the children can obtain success with them. Start small and grow. Take complex tasks and break them down into simpler step-by-step processes. Develop tasks that promote independence: shopping for a particular product at the grocery store, for example.

II. Flexibility: All tasks offer the opportunity for flexibility. Rolling with the punches is important in life, but it is very difficult for children with Asperger Syndrome to develop that skill. It can be taught. Play what if games around situations that commonly happen in the larger scheme of things. What if you got home and no one was here? What if the sandwich meat you like is not available at the deli?

The combination of these rules can help the child begin to form a better sense of Theory of Mind. By emphasizing routine and structure, the child will see others behave in ways that will demonstrate certain predictability. Responsibility to a task will help the child see that some people will do what they're supposed to do—and some people won't. That kind of understanding will begin to frame some of the thinking that allows an appreciation of other people's minds and how different they can be. As the child's Theory of Mind develops, potential for social understanding increases.

Another very important part of the social skills training is an on-going conversation about emotions, both what they are and what they are called. Children with Asperger Syndrome have a great deal of difficulty understanding not only their own emotional expressions, but also those of others (Asperger, 1999; Attwood, 1998; Bashe & Kirby, 2001). The more often they get a chance to engage in conversations about their emotions; the more often they get a chance to practice interpreting other's emotions; the more adept they'll be in understanding those emotions when they are encountered (Powers & Poland, 2002; Pyles, 2002).

What's especially nice about this kind of learning for children with Asperger Syndrome is that research has shown a link between verbal ability and Theory of Mind

(Ziatas, Durkin, & Pratt, 1998). As children with Asperger Syndrome speak about their emotional and social expressions, they can begin to discern differences in belief concepts like thinking, guessing, and knowing. Ziatas, Durkin, and Pratt have shown how those words basically mean the same thing to 3 and 4 year olds, but that differentiation—in neural typical children—comes about in the fourth and fifth year. Their research shows that children with impaired Theory of Mind also have impaired developments of the belief terms, think, know, and guess. While they do not go as far to say that there is a clear causal link between the belief terms and Theory of Mind, they do speculate that each probably helps engender the other. And because children with Asperger Syndrome generally possess strong vocabularies and a solid ability to learn new words, it is possible that rich conversations focused on how they might know if someone was sad, or how they might guess if someone had heard good news, or how they might tell what someone was thinking might engender stronger Theory of Mind capacities.

This, though, begs one of the major questions in teaching social skills to children with Asperger Syndrome: Do we teach through the cognitive realm, through the emotional realm, or through both? There is some disagreement on this in the literature.

One thing to consider here is the evidence that children with Asperger Syndrome have difficulties when they are asked to combine cognitive and social tasks. Because these children have such a difficult time with social interactions, combining them with cognitive tasks creates a potential for frustration in the learning process. Happe and Frith (1995) see “cognition and emotion as inextricably intertwined” (p. 161) and thereby posit that the child on the autism spectrum has social deficits because of problems in both the emotional and cognitive realms. They feel that learning ought to combine the cognitive

and affective domains, but they do note that in certain projects with high functioning children with autism, the children used cognitive skills even in social challenges that included empathetic responses. It was “as if they were solving math problems” (p. 168) and not apprehending personal interactions.

This debate troubled me for a while as I wondered why we might separate the learning here. There seems to be enough information available on the need for emotions to be included in nearly all learning situations (DaMasio, 1994; Goleman, 1995), so why did some of these researchers feel it wise to stay only in the cognitive realm while working with children with AS? (And how could learning be arranged so to stay in that realm?) Thinking it through, now, however, I see that the issue might be connected to the lack of interest in things social that children with Asperger Syndrome manifest. Neural typical children grow and develop an interest in others’ frames of mind and affective states. Hence they automatically connect and are probably motivated in part by that interest. Children with Asperger Syndrome, though, do not develop this interest, and even shown a disdain for it. As Bock (2001) has pointed out, many children and adolescents with Asperger Syndrome ponder the reasons people have friends or seek dating companions. Nothing about those interactions makes sense to them.

Consequently, individuals with Asperger Syndrome might disengage when those social and affective moments present themselves. Moving the learning through a more cognitive domain keeps the engagement potential higher. This is not something I can verify in the literature, though Happe & Frith (1995) allude to it. It may, though, be something I might observe in the parent child interactions of this study.

Family Patterns of Denial and Acceptance

Although the individual with Asperger Syndrome will find family life to be more easily negotiated than the real world, quite often families are slow to recognize Asperger traits. Part of this difficulty is probably based on the delayed onset of apparent deficits. For example, children with Asperger Syndrome usually learn to speak in the same time frame as neural typical children (Bowman, 1988), and often they speak with exceptional vocabularies (Asperger, 1999; Attwood, 1998; Tager-Flushberg, 2003; Wing, 1999). While it is true that their speech is often noticeably abnormal (Bowman), parents are more likely to be acceptant of that, just happy that their children are interacting with them in the normal range of time. Because of this lack of delay, Asperger Syndrome in most children is not recognized until after 30 months.

In fact, one study (Gilchrist et. al., 2001) discovered that while 62% of parents of children with High Functioning Autism had sought professional help before the child was three years old, only 20% of parents of children with Asperger Syndrome sought help that early. Asperger Syndrome's disabling effects, then, can go unnoticed, masked by the fact that most of the children with the syndrome do not have the language delay. Worse is the fact that most kids with Asperger Syndrome are not diagnosed until they're five years old, and as many as 40% are not diagnosed until they are ten (Gilchrist et al).

There is also the possibility that parents deny or avoid recognizing the syndrome because it shares similarities with other, perhaps, more desirable identifications. According to Little (2002), children with Asperger Syndrome and those who are gifted share some similar characteristics.

- Both groups can be highly verbal

- Both groups can be intensely interested in particular objects or concepts.
- Both groups can have great memories.
- Both groups can experience social isolation.
- Both groups can be hypersensitive to certain sensory stimuli.

Certainly if those five characteristics were to be discovered in an infant, the first three would be interpreted in positive and empowering ways, placing in the parents' mind an image of their child as verbally precocious, highly focused, and possessing a great mind. The last two might be seen less positively, but surely not as deficits. More likely they would be seen as idiosyncratically linked to the positive aspects of the first three.

In a similar light, Henderson (2001) maintains:

- Of all the children with Asperger Syndrome, 11.9% are probably gifted
- It is possible that of every 1000 gifted children, 72 have Asperger Syndrome

While there are not many studies juxtaposing giftedness and Asperger Syndrome, the two conditions do seem to mask one another, making identification of either more difficult, particularly when professionals are generally trained in either giftedness or Autism Spectrum Disorders, but rarely in both. Parents may be prone to deny one diagnosis—Asperger Syndrome—in hopes that another—giftedness—is obtained.

Neihart (2000) finds that the closeness of the characteristics in the very young gifted children and children with Asperger Syndrome will have great affects on education services. Since:

- Both can be verbally fluent and precocious
- Both can have excellent memories

- Both can evidence a fascination with letters or numbers and enjoy memorizing factual information at an early age
- Both can demonstrate an absorbing interest in a specialized topic
- Both can annoy peers with limitless talk about personal interests
- Both experience uneven development, particularly when cognitive development is compared to social and affective development at a young age

there can be problems there, too, as gifted children with Asperger Syndrome may not be diagnosed because their unusual behaviors and characteristics are attributed to either their giftedness or to a learning disability. Such identifications contribute not only to misunderstandings about the nature of the child's difficulties, but also to the formulations of an inappropriate educational plan. It behooves parents, then, not only to seek understanding, but also to seek a diagnosis that will best serve their child.

Of course, many parents do not have the confidence to speak with their doctors about the behaviors they see in their children, some times for fear that a diagnosis may come they do not want, other times because they suspect the behaviors will go away. Many parents look at Asperger Syndrome as something that can be grown out of, leading to thinking like 'this year will be different' when considering schools and new beginnings (Pyles, 2002). Pyles also suggests that the language parents and teachers of children with AS use is revealing. Phrases like, "He's just having a bad day," or "He may have some problems, but he just needs more discipline and he'll straighten out" might mean there are perspective issues. These could be a form of denial, especially if they're said by adults in the family—but surely they do not recognize the reality of Asperger Syndrome as a way of life.

None of this is to blame parents for wanting a certain kind of diagnosis or for behaving in certain ways upon seeing the characteristics that might be Asperger Syndrome. It is rather to establish that many parents and caregivers don't always see the need for facilitating the special needs Asperger Syndrome creates for their children, because they have some good reasons not to think Asperger Syndrome is affecting their child.

Home Life

In order for a child with Asperger Syndrome to work toward her potential, there needs to be a sense of order, focus, and calm in the living environment. There needs to be a way for the development of self-confidence to occur (Holliday-Willey, 2002). Often this is little more than being sure the child knows home as a safe place: safe to engage in all of the characteristic traits that are Asperger Syndrome. Still, this safety needs to be mixed with a regiment of action on the part of the parents and/or caregivers so that the qualities of Asperger Syndrome can rise in the behavioral repertoire while the deficits can subside.

Before that regiment can occur, however, the parents and/or caregivers who will be conducting the regiment of action need to be able to "speak Asperger's" (Goldfarb & Devine, 2001). This skill for the parents and caregivers is just as important as the learning of social skills for children with Asperger Syndrome, and quite often the latter is contingent upon the former. Speaking Asperger means understanding the way information is passed and processed by individuals with the syndrome. Many parents report (Andron, 2001; Pyles, 2002) that their children have been punished for extreme behavioral reactions when, in fact, the child was just reacting to what had been explicitly

promised to her. For example, some children with Asperger Syndrome will experience a ‘melt down’ if a song that was only to be sung once is suddenly sung twice, or if they are asked to put work away they had been told they could finish. The teacher or leader of the group of singers or students may not understand how a simple statement can cause the undesirable behavior. But someone who speaks Asperger would be able to discern the problem in a second.

Communication is a very complex human behavior, entailing many aspects, most of which the child with Asperger Syndrome finds difficult to negotiate. Tones of voice and body language that convey meaning to people with normal neural functioning are generally not considered as significant communicative elements by children with Asperger Syndrome. Common phrases which do not mean what their words indicate, but are understood by people with normal neural functioning are quite often taken literally by children with Asperger Syndrome. If the parent or caregiver cannot appreciate these differences and differentiate conversational patterns and messages accordingly, little in the regiment of action alluded to will be successful.

“The primary challenge these children face is social interaction, [and] all those who love and work with them” need to find ways to teach them how to function ‘normally’ (Andron, 2001, p. 67). Often this teaching is best done in a naturalistic, home setting, where various situations and interactions can and do occur. Before this happens, however, those who will do the teaching need to be aware that children with Asperger Syndrome will make meaning of their experiences in very different ways from neural typical children (Andron, 2001; Pyles, 2002; Shaked & Yirmiya, 2003; Wing, 1999). Frith (in Andron) uses the theory of central coherence to explain meaning making

differences in children with and without Asperger Syndrome. The theory describes meaning making as the drawing together of various and differentiated bits of information in order to construct contextual webs of understanding. Individuals with normal neural functioning do this fairly automatically; children with Asperger Syndrome (and autism) do not.

Following the theory of central coherence, we see how the child with Asperger Syndrome sees the part without seeing the whole. This is where the importance of teaching these skills in a safe, naturalistic environment, where those involved not only allow the child to make mistakes, but also endeavor to assist the child in managing her anxieties, which can paralyze her in many social situations. Home should be a place where mistakes are not followed by the laughter of age mates and peers as can happen at school (Holliday-Willey, 2001; Pyles).

In their home, Pyles (2002) finds time to engage her son in activities that address the social impairments that affect him. They spend time in role-playing activities that promote the use and interpretation of nonverbal communication cues. Such interactions allow for immediate feedback and videotaping (Andron, 2001), which can then be watched and contextualized. She has created a long list of idiomatic phrases and terms, something many people with Asperger Syndrome find difficult to decipher (see also Tager-Flusberg, 2003), and engages her son in their use; then she quizzes him on his use of language in multiple contexts. Such engagements, when conducted by a trusted family member approach what Attwood (1998) calls the teaching of friendship skills rather than social skills. This places the teaching into a narrower context, increasing the possibility that a holistic view might replace the more typical parts-only view.

Another skill that can be practiced at home is the naming and talking about emotions. Children with Asperger Syndrome need to be able to recognize not only their emotions but those emotional expressions of others (Andron, 2001; Shaked & Yirmiya, 2003). Of course, this is another area where an understanding of theory of mind and central coherence comes into play. If the child cannot deal with or understand her own emotions, she will not be able to understand or empathize with the emotional expressions of others (Andron). Often the emotional situations that are most difficult are those that are doubly presented, and parents need to be careful how they teach the understanding of visual and verbal emotional expressions. Andron speaks of a study where children with Asperger Syndrome were shown video clips from soap operas. When the sound was turned down, these children were right on target at reporting the feelings of the actors. When the sound was included, however, they could not process so accurately.

As has been mentioned, a basic understanding of theory of mind is very important in the teaching of social skills to children with Asperger Syndrome, because their inability to understand that another person is thinking and feeling differently about the same thing creates a great deal of the social impairments they face. Without that understanding, this teaching might be reduced to a simple, rule-based instruction whereby different social interactions are taught through methods like social scripting or behavioral programs (Andron, 2001). But both of these have significant drawbacks, as they tend to treat social behaviors non-contextually. According to Andron:

What happens is that they develop a routine that requires them to say hello and good-bye to each individual in the room, without getting the contextual cue that a 'good-bye everyone' would be more appropriate. Many

children who have come from structured behavioral programs learn to greet and introduce themselves in a rote manner. Every time they enter a room they walk up to each child and say, 'Hello, my name is', even if they have played with the same child week after week. (p. 69)

Dignifying the syndrome at home is important as it will allow open communication between the family members. For Holliday-Willey (2002), this meant she had to be open and honest with her family about her own Asperger conditions. She had to let them know when her Asperger traits made it impossible for her to follow a conversation, even in those moments when she knew someone was revealing significant information to her, and the information to which she could not pay attention would be painful. She had to tell them when she was unable to put herself in their mind and feel their pain, their joy. And she had to tell them that certain textures, touches, sounds, and brightness made her world a constant aggravation. All of this had to be done not only to be fair to them and inform them about her dealings with Asperger Syndrome, but also to help her daughter, also with Asperger Syndrome, whom she felt would learn from her. Helping Asperger kids develop certain skills makes sense as their brain, though developmentally delayed, still processes the world as a neurotypical brain does (Holliday-Willey).

One significant area where assistance can occur at home deals with the circumscribed interests (Attwood, 1998; 2003) that nearly 90% of all people with Asperger Syndrome report. The essential components of the circumscribed interests are the accumulation of desired objects and the learning of the processes of the physical world. Such attention to these details often gives these children (and adults) an

encyclopedic knowledge. In turn, this knowledge can make them more prone to converse with adults or to take on a very pedantic mode of discourse with peers. Consequently, this behavior can result in a stigma (Goffman, 1961) being placed on the child.

Parents are wont to reduce the occurrence of circumscribed interests, as they can be detrimental to the child's social and cognitive development. On the other hand, a child will seek to increase the time spent with the interest, as it has a tendency to reduce stress gives them enjoyment, and allows them to avoid the difficult social interactions that plague their lives. In short, it reduces their anxiety. Consequently, a balance needs to be found, and it is in the home where this balance is best sought. Pyles (2002; but also see Shaked & Yirmiya, 2003) suggests setting times for allowing an uninterrupted engagement with circumscribed interests, and adhering to that time strictly. It is very important, she notes, to have something immediately available for the child to turn to, especially something the child has shown to be enjoyable in the recent past. She even allows her son's circumscribed interests—which can change often and nearly immediately (Attwood, 2003)—to be used as a reward or goal for other social and introspective goals.

This process of retraining circumscribed interests, though, can be a difficult process, for there are both positive and negative aspects of the circumscribed interests. Children with Asperger Syndrome ought to be taught—this is a need, since they generally cannot learn this on their own—how to recognize the relevant cues and responses to ensure that conversations are reciprocal and inclusive (Attwood, 2003). Consequently they need to be able to consider the possibility that their interest needs a context, a time and a place for engagement. There is probably no better place than the home to begin

this process of retraining, especially if it is a place where surprises are kept to a minimum. There are not many good surprises in the life of a child with Asperger Syndrome, and that child should be able to know home as a place where she can feel centered and safe (Pyles, 2002). That feeling of safety comes from the interactions she has with her parents or other caregivers as much as it might come from anything else.

Parent-Child Interaction Literature

Introduction

Children's psychological development is entwined and enhanced through the involvement they have with the important caregiving relationships in their lives. Through the complex patterns of reciprocal interactions with parents, siblings, relatives, and other close caregivers, children learn about the social world and the human relationships that will be important for their social development (Bronfenbrenner, in Marfo, Dedrick, & Barbour, 1998). Children with disabilities offer a particular challenge to parents and caregivers, as their disability, coupled with other characteristics, has an effect on parental interaction patterns and behavior (Marfo, Dedrick, & Barbour). This matches with Seligman and Darling (1997) who point out that if one member of a family has a disability, it is wise to think of the whole family as having the disability. In this way, the interactions just mentioned are seen in a very different light. Common misconceptions about families posit family interactions as linear, but a better view presents them as a system of interactions (Lambie, 2000).

As has already been stated, this study proposes an investigation of a family in which three boys have been diagnosed with both Asperger Syndrome and PDD-NOS. The major focus will be on the parent-child interactions that attempt to teach the children

significant social skills. Parent-child relationships in which the children are encouraged and assisted in the learning of social interaction and communication have been studied before (Crawley & Spiker, 1983; Grolnick, 2003; MacDonald & Gillette, 1988; Marfo, 1992), but not in families with Asperger Syndrome. However, because these studies—and others cited within these—looked almost exclusively at parent-child interactions where the child was developmentally delayed, a connection to families with Asperger Syndrome makes good sense as that is also a pervasive developmental disorder (Bashe & Kirby, 2000).

According to MacDonald and Gillette (1988) three guidelines frame interactions between parents and their children with developmental delays. The parents must:

- Deal with the skills children need for communication development
- Discover the problems that interfere with the children's interactions
- Develop strategies that allow the teaching of naturally occurring communication skills in order to resolve interaction problems.

Significant in these guidelines are the ideas: 1) communication and interaction are contingent upon expectations, activities, and motivations that are jointly made; and 2) the child's development is seen as a function of the interactions and not something separate from them (MacDonald & Gillette).

In other words, these interactions don't make the child function in a particular way in a causal sense, but rather the child's function is a part of the interactions in a constructive sense. The parents and the child build the social competencies through naturally occurring interactions. Both have a say in the nature and direction of those interactions.

Directiveness, Control, and other Parental Behaviors

Spread across the literature on parent-child interactions is the concept of directiveness or control, operationalized in a number of ways (Marfo, Dedrick, & Barbour, 1998), but generally presented as falling within four classes of behaviors:

- Response control, where the parents issue commands and makes demands on the child
- Topic control, where the parents drive the selection of topics within the interaction
- Turn-taking control, where the parents tend to dominate the interaction so there is a turn imbalance
- Inhibitize control, where the parents restrict, terminate, or interrupt the interaction regularly.

Almost without exception, directiveness is seen as a negative influence on a child's development (Dunst & Trivette, 1988; Grolnick, 2003; MacDonald & Gillette, 1988; Mahoney, 1988; Marfo, 1990 & 1992). Yet it is important to note that too often this characterization of directiveness and control as negative is quite simplistic (see Marfo, 1990, for a full discussion).

One of the issues in discerning the positive/negative effects of control concerns the adaptive abilities of parents during the parent-child interactions. Grolnick (2003), for example, maintains that as long as parents are sensitive and responsive to the child's cues and signals during the interaction, and adapt to those accordingly, control is just another way of being an authoritative parent. She juxtaposes the negative authoritarian parent: one who attempts to share, control, and evaluate the child based on set standards, with the

positive authoritative parent: one who attempts to direct the child in a rational, issue-oriented manner. She maintains that only the latter is concerned with independence and individuality, and thereby is the only one to create a positive interaction.

According to Marfo (1992), a problem in the literature is that most researchers seem to have posited that the child with the disability is enough to bring variance into the interactions, and that the parents of children with disabilities are basically a homogenous group. Marfo, Dedrick, and Barbour (1998) liken this to “another myth of behavioral science: the view that one of the attributes that mothers of children with [disabilities] share in common is a pervasive tendency to be overdirective” (p. 646). Researchers interpret findings of directiveness, intrusiveness, and insensitivity as evidence of the parent’s inability to respond correctly to their child’s cues. Rather than viewing the interaction as that which occurs between two people with their own variations of behaviors, researchers have seen the parent as constant and the child with disability as the variation. In other words, they have not allowed themselves to see how the parents have been able to adapt to the child’s cues during interactions. Without this adaptive nature, the child’s role within the interactions—or the family—will not be cultivated and there will be potential long term developmental ramifications for the child (Marfo, Dedrick, & Barbour).

Grolnick (2003) argues that in order to think about control or directiveness properly, researchers must think about it as that which does or does not adapt to the child’s perspective. It does both. Mahoney (1988) agrees, noting that parents who are directive while also being sensitive and responsive to their children’s behavior help to

develop the child's sense of control. This can occur through aspects of shared control, such as through turn-taking strategies or an interactional match (Mahoney).

An interactional match occurs when the style of interaction adopted by the adult is compatible with the child's interactional style, and when the focus or topic of interactions are compatible with the child's current interests. In interactions geared to help the child learn new competencies, the parent's behavior must take the child to a new level of thought and activity without exceeding the child's capacity to process information. Mahoney (1988) argues that parents who are sensitive and responsive during the interactions—and who have developed this repertoire over time by adapting to their child's particular interaction behaviors—find that parental control can be delivered in an autonomous supportive way. The child is still under the authoritative control of the parents, still held to particular responsibilities and duties, but is also developing skills that will make her the autonomous director of much of her own life (Grolnick, 2003).

Directiveness and control are important issues in this study because it has been shown that parents of children with disabilities show a greater amount of directive behaviors than do parents of neural typically developing children (Crawley & Spiker, 1983; Dunst & Trivette, 1988; MacDonald, 1988; Mahoney, 1988; Marfo, 1990 & 1992; Marfo, Dedrick, & Barbour, 1998). Equally significant is that these studies included disabilities like Down Syndrome, mental retardation, and cerebral palsy, which share characteristics with Asperger Syndrome. Particular characteristics of the children in the studies (Mahoney; Marfo, Dedrick, & Barbour) included limited understanding of turn-taking, poor eye contact during interactions, repetitive vocalizations, and inappropriate

social behaviors. All of these are found in a significant number of individuals with Asperger Syndrome (Attwood, 1998; Bashe & Kirby, 2000; Powers & Poland, 2002).

Other interaction behaviors are also important, especially as they form relationships with parental directiveness and control. Marfo (1992), in a study that looked at 1) turn-taking, 2) response control, 3) topic control, and 4) inhibitive control, found several other interactive behaviors that warrant further understanding:

- Sensitivity: an awareness of the child's cues and signals
- Stimulation: an orientation of actions to provide cognitive, social, and linguistic stimulation
- Responsiveness: an appropriate response to the child's cues and signals
- Elaborativeness: a following and/or expanding of the child's responses and behaviors
- Intrusiveness: the intervening, interrupting, and disruption of the child's ongoing behavior

This study found that intrusiveness, and not directiveness, was probably more detrimental in facilitating children's development, and that when directiveness and intrusiveness worked in concert, the most dysfunctional interactions tended to occur.

Crawley and Spiker (1983) listed similar parental behaviors that occur during interactions with children with disabilities. Key in their findings was the fact that directiveness and sensitivity were not mutually exclusive of each other, nor were directive parents always intrusive. Either/or characterizations don't seem to work when understanding parent-child interactions.

Studies as have been cited here work from the assumption that observing the parent child interactions for a short period of time, say 20 minutes, in an activity that begins with a prescribed parent-child task—stacking rings on some sticks—and concludes with a ‘free-play’ session, allows us to see significant parent-child interactions at work. This, to me, is doubtful.

An important point coming from the literature for my study is the overriding theme that parent-child interactions combine a broad range of behaviors, adaptations, and modifications. While an extreme occurrence of two of those behaviors (directiveness or intrusiveness) will prove to be developmentally negative, the general trend is that all of the behaviors appear in the parental repertoire in different degrees, based upon the context of the interaction. Hence it must be a more contextual research that is needed for understanding these interactions. Hect, Levine, and Mastergeorge (in Marfo, Dedrick, & Barfour, 1998) point out that “even within a single setting, such as the home, different activities may exert unique influences on interaction because of the particular goals and interpretations imposed on each activity by the participants” (p. 661). Marfo (1990) asks us to seek “a more multivariate . . . understanding of the complex ways in which directiveness, in combination with various other parental interactional behaviors, influences the development of competence in children” (p. 546).

This is why a research plan that includes the ethnographic practice of living with a family engaged in the kind of interactions that hope to engender social competencies in their children can be so valuable here. In any family, parent-child interactions will occur in such a wide variety of contexts, for an equally broad number of reasons, that it is impractical to think that we might understand those interactions by separating one or two

out for laboratory studies. The complex and dynamic nature of families precludes the possibility that a simple understanding of parent-child interactions could be obtained without seeing these interactions in their proper context (Lambie, 2000; Seligman & Darling, 1997).

Dealing with context, Grolnick (2003) argues that a child needs to have a safe environment in which these parent-child interactions will allow the exploration and discovery of the person she is. That safe and nurturing environment is made up of:

- Autonomy support (versus control)
- Involvement
- Structure

Individuals with Asperger Syndrome also require an environment where they can explore social situations and dilemmas in safety (Andron,2001; Holiday-Willey, 2001; Powers & Poland, 2002; Pyles, 2002). These individuals sometimes seek involvement in social activities, but cannot always obtain it due to a lack of social skills. Ultimately, they need structure and routine in their lives, like so many other adolescents, need places and opportunities to develop autonomous actions in their world. Grolnick maintains that the most salient aspects of the environment are the interpersonal ones—again this links to the difficulties that families with Asperger Syndrome will have since interpersonal and other social skills are generally quite impaired in these individuals.

This is also why research with families of children with Asperger Syndrome can be so important. As is demonstrated by the literature on Asperger Syndrome, parents of these children need to play an active role in the teaching of social skills to their children.

Without that engagement, it is fair to say the child won't learn the necessary skills to cope well in our social world.

It is important, here, to think back to a point made earlier: Parent-child relationships in which the children are encouraged and assisted in the learning of social interaction and communication have been studied before (Crawley & Spiker, 1983; Grolnick, 2003; MacDonald & Gillette, 1988; Marfo, 1992), but not in families with Asperger Syndrome. Research with these families, then, that focused on parent-child interactions in the natural settings where they occur has the potential to reveal: 1) the contextual nature of those parent-child interactions; 2) certain family beliefs about how such interactions should occur; 3) general and specific frustrations and celebrations in being a family with Asperger Syndrome; 4) differences in family roles and the understanding of those roles; and 5) different manifestations of the effects of Asperger Syndrome. Such are the goals of my study.

To describe how that study will be undertaken is the purpose of this proposal, and much of that will be found in the next chapter on methods. Here, though, one more significant aspect from the parent-child literature will be presented as central to this study.

The Observational Model

Several models for intervening in parent-child interactions have been developed over the years (Marfo, Dedrick, & Barbour, 1998). Mostly they were developed to aid in the stimulation of developmental competence in both the parents and the children. For the parents the idea was to enhance interactive skills so to develop higher levels of responsiveness in them. For the children the hope was to stimulate optimal psychological

and social development. The model my study will use to frame the kinds of observations I'll be making while with the family is Bromwich's (1976; 1997) interactional model, generally referred to as the Mutual Enjoyment Model, where the idea is that a strong emotional attachment between the parent and child provides the proper context for healthy parent-child relationships. In this model, bonding and attachment are the core elements of a pleasurable and satisfying set of interactions (Bromwich, 1997).

There are two chief goals in the framework that seek the development of strong emotional attachment between the parent and the child. One is a short-term goal: promote mutually pleasurable parent-child interactions. The other is long term: foster optimal development in the child. Of course, because my study won't be an intervention study, I won't be applying goal development strategies (Bromwich, 1976) with the family. Rather I'll be observing to see if such goals are manifest in the interactions. Hopefully, since the boys are older than most of the studies used to explore and establish this model, the first goal will have been met, and my focus will be on the fostering of optimal development in the child. It must be seen as true, though, that all parent-child interactions have the potential to be or not to be mutually pleasurable, so part of my observations will be informed by this thought.

Bromwich (1976, 1997) posits six levels of interaction behaviors and skills, with the first three levels revolving around primarily affective issues. Those are:

- Parental capacity to enjoy the child: the goal here is to find as many kinds of interactions as possible and to develop enjoyment in all of them
- Parental sensitivity to read the child's communication and attachment skills: the goal here is to see that the interaction has as much to do with the child's terms

(see also, Golnick, 2003) as with the parents'. If the first skill has been internalized, then this skill can be learned

- Parental ability to engage in the kind of interactions that promote mutual satisfaction, develop attachment, and engender a system of communication: here the goal is to develop a reciprocal and positive feedback system so the parents can not only spend more enjoyable time with the child, they can read the child's alertness signals and develop interactions around those (Browwich).

The reader will note how each of these link nicely with the issues of parental sensitivity and responsiveness mentioned earlier by Grolnick (2003), MadDonald & Gillette (1988), and Mahoney (1988).

The second level has more to do with cognitive growth and includes:

- Parental awareness for those materials and activities that are suitable for the child's developmental level: here we see that the parents not only know what stimulates their child, but also plan activities and experiences that fit the child's development and hence are more enjoyable for all involved
- Parental skill in initiating new and stimulating play based on their own experiences with similar activities: here we see that knowledge of the child's interests allow the parents to take stimuli from other sources and bring them to the child. This expands the interest potential of the child while also expanding the parents' knowledge
- Parental skill in generating a wide range of activities and play from a brainstorming frame of reference: here we see that the parents are knowledgeable

enough of their child to be creatively engaging and providing a variety of experiences and activities in all developmental areas (Bromwich, 1976).

These link to Mahoney's (1988) idea that the parent's behavior must take the child to a new level of thought and activity without exceeding the child's capacity to process information. And the whole six level theoretical frame aligns itself with Grolnick (2003) who defines

involvement as the provision of resources by the parent to the child. Resources can be in the form of time devoted to the child; more tangible resources, such as the provision of books necessary for school; or more emotional resources, such as warmth and availability. Furthermore, involvement includes taking an interest in the child's activities and world and knowing what is going on in them. When parents and children have a shared understanding about what happens on a day-to-day basis, their sense of connection and relatedness are enhanced (p.16).

Bromwich (1997) takes the view that as parents experience and adapt to their children's responses within the interactions, a growth occurs which allows the parents to become more comfortable as their children's primary agent of change. This posits a directiveness within the parental frame, but one that is clearly honed on behaviors of sensitivity, responsiveness, stimulation, and elaborativeness.

In closing, MacDonald and Gillette (1998) write:

In the field of developmental disabilities, helping a delayed person communicate more effectively may be one of the major tasks that requires interdisciplinary and home-based attention. Both theory and research into early

communication development have led to the conclusion that children learn language and communication from natural play relations with their significant people (Bronfenbrenner, 1979; Bruner, 1983). The dual view that language and communication develop within reciprocal turntaking relationships and that such relationships are central to improving the communication of handicapped persons is supported by investigations into several areas: parent-child interactions (Brazelton, Koslowski, & Main, 1974; Greenspan, 1985; Moerk, 1976; Stern, 1977); preverbal communication (Dunst, 1978; Mayo, 1979); communicative pragmatics (Bates, 1976; Watzlawick, Beavin, & Jackson, 1967); semantic development (Bloom, 1973; Brown, 1973); maternal speech to children (Cross, 1978; Girolametto, [1988]; Mahoney, [1988]; Snow, 1972); and language intervention in classrooms (Hart & Risley, 1977; Warren & Rogers-Warren, 1984) and with parents (Horstmeier & MacDonald, 1978; Howlin, 1984; MacDonald & Gillette, 1984, 1985b).

(p. 220)

It is here, I think, that many of the issues and difficulties presented in both literatures come together. Parents of children with Asperger Syndrome not only will have to engage their children in opportunities to learn social skills, they will have to create these engagements with children who, for the most part, are not developmentally ready to participate in reciprocal social interactions. Since these social and communication skills are so important for the children's development, the parents will have to discern ways to teach and to develop them without being overly directive or controlling, behaviors the literature points out are more prevalent in parents of children with disabling conditions.

If the parents of my study are successful in developing the necessary social skills in their children, I may be able to observe how they have been able to balance the behaviors Marfo (1992) says are so important. I may also be able to see how the six stages of Bromwich's (1976, 1997) model are manifest in those behaviors. And I will certainly have the opportunity to see how each of the boys individually deals with both Asperger Syndrome and the teaching of social skills, regardless of the parents' success.

Linking the two literatures, then, makes good sense in many ways. By definition, children with Asperger Syndrome are developmentally delayed (Bashe & Kirby, 2000), and they will need help in social and communication skill development. However, children with Asperger Syndrome will not have the social savvy to allow them to learn their language and other social skills behaviors through natural, reciprocal social interaction. The reciprocal turn-taking that can help many children develop language and communication skills is problematic for children with Asperger Syndrome, as many do not understand the concept that communication is a collection of shared 'turns' between speakers. Consequently, there is a need for helping the child with Asperger Syndrome develop communication skills, but due to a lack of social understandings, the avenues that seem to be working for other children with handicaps may not work for children with Asperger Syndrome.

It is for these reasons I feel this study will be valuable. The next chapter outlines the methods it will use.

CHAPTER THREE: METHODS

The Ethnographic Case Study

Ethnographic data collection techniques are a proven means for exploring and describing how individuals in a group interpret their world (LeCompte & Schensul, 1999a). The case study methodology seeks meaning from context by observing specific encounters and interactions in ordinary settings (Cresswell, 1998; Denzin & Lincoln, 1998; Merriman, 1988; Stake, 1995). In this study, ethnographic data collection techniques were applied to a case study methodology. According to Lecompte and Schensul, “ethnographies are culturally informed case studies” (p. 82) which focus on an individual or a group. My study focused on a family of two parents and three boys; each boy had been diagnosed with a disorder that falls on the autism spectrum. As it explored the characteristics and generalities of the interactions this particular family had concerning Asperger Syndrome, my study was a case study that employed ethnographic data collection techniques, in order to discern the cultural interpretations the family constructed about both their interactions and Asperger Syndrome. Atkinson & Hammersley (1998) write that ethnographies share particular features, including:

- Exploration of social phenomena rather than hypothesis testing
- Working with and collecting unstructured data that is not pre-coded
- Investigation of small numbers of cases—sometimes just one
- Seeking interpretation and meaning of human actions

Each of those will be shown to be a part of this study as this methodological chapter continues.

Equally important is the history of ethnographic methods' contribution to the deeper understanding of human life (Eisenhart, 2001; Stake, 1995). Wolcott (1999) tells us: "Social behavior and interaction are amenable to observation—an ethnographer can record what people do and say and what they say they do" (p. 119). Understanding, then, and a sense of the worldview constructed by those people, come from what the ethnographer makes of those observations. Such observations by an ethnographer for a prolonged period of interactions and shared life with her participants engenders an ability to think like the observed culture (Tedlock, 2000). It is this ability, developed through the prolonged stay, that transforms the ethnographer's thinking about the culture and their way of life, providing her with a sensibility to construct and describe critical and informed interpretations, rather than relying on intuitive ones. As Eisner (1998) says: "Sensibility alerts us to nuanced qualities and the schema relevant to a domain, the significance of what to seek and see. Without sensibility the subtleties of the social world go unexperienced" (p. 34).

Geertz (1973) refers to this as 'thick description,' a phrase he borrows from Ryle to acknowledge that there is a great difference between a twitch and a wink, and a greater difference between those two and the purposeful mimicking of a twitch. And yet, they all might appear to be the exact same behavior to the uninformed observer. A similar thought is presented by Pirsig (1974) in his philosophical discussion of the difference between ego-climbers and selfless climbers. "Both kinds of climbers place one foot in front of the other. Both breathe in and out at the same rate. Both stop when tired. Both go forward when rested" (p. 189). An untrained observer of hikers might never spot the difference. The ethnographer's task, then, is to pursue the "multiplicity of complex

conceptual structures, many of them superimposed upon or knotted into one another, which are at once strange, irregular, and inexplicit” (Geertz, p. 10).

After a while, during the prolonged experience with the group (LeCompte & Schensul, 1999a; Tedlock, 2000), some aspects of the very particularistic thinking of one group have the potential to become assimilated by the ethnographer (Merriam, 1988; Stake, 1995). This assimilation helps enrich the nature of critical thinking that simultaneously informs on-going observation while it also frames the thinking that future analysis will use (Eisenhart, 2001). Pirsig (1974) argues that critical thinking is the combination and interweaving of both inductive and deductive reasoning, somewhat akin to Strauss & Corbin’s (1998) idea that data substantiate earlier concepts while simultaneously generating new ones.

The ethnographer, then, is engaged in an iterative and constructive process (Stake, 1995), that ultimately circles back to the original plan, constantly reframing and re-asking significant questions so to interpret those data being collected. It is a flexible process, able to take advantage of new observations not necessarily anticipated in the original design, but it is not a haphazard process (Lecompte & Schensul, 1999a). Through this methodological engagement, especially when well planned, the ethnographer has an opportunity to see things others have not seen in ways, perhaps, others have not even thought possible (Eisenhart, 2001; Stake, 1995). Adler and Adler (in Angrosino & de Perez, 2000) call ethnographic observation the most powerful aspect of the methodological spectrum, noting that such observation discovers that which is constant in life.

Another reason for selecting ethnography for this study is that the family to be observed resides in what some would call a marginalized space (Sleeter, 1999). Children with Asperger Syndrome, and by default their families, are seen as behaving outside the norms of social interaction, something that often makes them the brunt of many jokes and negative comments, in schools or in their neighborhoods. The space where they live is seen as different and, sometimes, less worthy. Understanding the nature of that space and those who live there, as well as understanding how marginalized populations interact with the mainstream world, requires an immersion into that space (LeCompte & Schensul, 1999a; Tedlock, 2000) so that both particular and general interactions can be observed. Ethnographic observation provides the possibility for the ethnographer to define herself, at least partially and temporarily, as a member of the marginalized group (Angrosino & de Perez, 2000) and then to observe and engage in the interactions alluded to. A major goal of ethnographic research is to develop the ability to think like the group being studied, to grasp their point of view (Malinowski, in Tedlock, 2000).

The family I studied is made up of five members: Elizabeth, the mother; Thomas, the father; Ringo and Bob, twin 13-year-olds; and Cosmo, 10-years-old. They live in a very small New England community, the same community where the mother was raised. As I have mentioned, I selected this family because I knew them well, and they agreed to let me live at their home for a period of time to undertake this study.

Within the context of this study, I framed this family—the case—as one that has a direct lived experience, perhaps similar to but also with its own unique qualities that differs it from other families—the class—with Asperger Syndrome. Families—cases—are conglomerates of many ideas, systems bounded in space and time, continually

defining themselves (Merriam, 1988). The family of my study was no different, and, as mentioned, had particular characteristics that set them apart from other families. The ideas they brought together to construct the way they understand Asperger Syndrome were affected by the specifics of their life: the community, the school, the medical profession, and the personal and familial interactions they had with each other (among other specifics). In this sense, one aspect of this ethnographic case study was about discovering the meaning-making processes of the case family (Merriam).

In turn, case studies are definable (Stake, 1995) as either that which explore an intrinsic case, i.e., centralized around an interest in the specific case itself; or as that which explore an instrumental case, i.e. representing a broader attempt at understanding issues larger than the case, though still focusing on the case. This study was of the latter sort. I explored my participants in order to glean information about them, but as part of my study hoped to understand the unique aspects of Asperger Syndrome as it was experienced by individuals and a family, a larger issue of the possible range of manifestations of the disorder was explored simultaneously.

Qualitative researchers, and so ethnographers and case study researchers, study social settings in order to understand the meaning of participants' lives on their own terms (Janesick, 2000). Ethnography is defined as studies of groups of people embedded in communities, generally of their own making (LeCompte & Schensul, 1999a). A case study is an investigation of a bounded system over time within a particular setting (Cresswell, 1998; Merriam, 1988; Stake, 1995). The ultimate goals of ethnographic research is the weaving of a multi-voiced text that combines the participants' story with the ethnographer's analysis, without framing one of those as more significant than the

other (Kelly, 2000). Designing my study under the banner of ethnographic case study made good sense.

Ethnographic Understanding

Qualitative researchers search for the meanings of behaviors and symbols as understood by the people under study rather than for generalized explanatory principles (Greene, 1997; Kelly, 2000). They endeavor to make sense of what they see, exploring the meaning that undergirds the action. Within the realm of qualitative research, ethnographers know that the purpose of their work will be to present the worldview of the participants studied “*as understood and related by the ethnographer*” (Wolcott, 1999, p. 138, italics original). Understanding is an ongoing process, never achieving fullness (Stone-Wiske, 1998), but always—it is hoped—becoming more refined so that clearer, more concise presentations of what actually happened arise. Gadamer (in Schwandt, 2000) says this of understanding:

[W]here it is successful, understanding means a growth in inner awareness, which [occurs] as a new experience enters into the texture of our own mental experience. Understanding is an adventure and, like any other adventure is dangerous. . . but. . . it is capable of contributing in a special way to the broadening of our human experiences, our self-knowledge, and our horizon, for everything understanding mediates is mediated along with ourselves (p. 196).

Ethnographers often enter their research space as an outsider, hoping to be accepted at least enough so that they might observe more closely those interactions that evoke and engender meaning; in short, so they can develop understanding. When they get that

acceptance, they can become participant observers (Cresswell, 1998; LeCompte & Schensul, 1999a; Merriman, 1988; Stake, 1995; Tedlock, 2000) and even active-members (Angrosino & de Perez, 2000) of the group. Such roles make the search for connections, parallels, and contrasts (Eisenhart, 2001) that is the lifeblood of the ethnographic researcher—that is necessary for understanding—easier.

My advantage here is that I have maintained a long-standing friendship with this family for all of their time as a family. Indeed, my relationship with the father predates his marriage to the mother. This gave me the confidence that I could begin this study in both roles mentioned.

Equally I was confident that my relationship with the family would be central to the success of this study. Indeed, it was our friendship that was helpful in negotiating the “contested terrain” (Eisenhart, 2001) and the “cultural meanings” (Kelly, 2000) that take place between researchers and participants. It was never my intention nor would it have been correct for me to think of the interpretations I would build as more accurate than theirs due to my position as the researcher (Denzin & Lincoln, 1998). Rather it was the relationship the family and I shared that realized significant and valuable understandings about families with Asperger Syndrome.

Data Gathering Strategies

Participant Observer/Active Member Researcher

During this study I assumed the role of participant observer (Angrosino & de Perez, 2000; Atkinson & Hammersley, 1998; Cresswell, 1998; LeCompte & Schensul, 1999a; Tedlock, 2000) and active member researcher (Angrosino & de Perez, 2000). The former role was important “because we cannot study the social world without being a part

of it” (Atkinson & Hammersley, p. 111). Indeed, participant observation is better defined as a being-in-the-world characteristic rather than a research technique.

The latter role, active-member research, gave a more significant meaning to the idea of participant observation. While occasionally I was the proverbial fly on the wall, the majority of my time was spent trying to become fully involved with the day-to-day activities of this family. I wanted not just to be an observer-bystander. In fact, part of my data collection strategies included some direct active-member engagements with the boys in order to observe how Asperger Syndrome was manifest differently in each of them, as well as to get a direct interactive experience of their nonverbal communication deficits. Active-members sometimes take on roles and responsibilities that are good for the group being studied (Angrosino & de Perez, 2000). They help out and engage in far more significant participation with the group. My background as a teacher and a student of special education made this role fitting and proper for this research project.

Many of the active-member engagements I had with the boys were designed to explore those particular and idiosyncratic aspects of Asperger Syndrome so common in the literature: poorly developed theories of mind (Shaked & Yirmiya, 2003; Tager-Flusberg, 2003), circumscribed interests (Asperger, 1999; Attwood, 2003), communication impairments and the prosodic quality of voice (Asperger, 1999; Tager-Flusberg, 2003), and lack of eye contact in social interactions (Asperger, 1999; Attwood, 2003; Pyles, 2002; Wing, 1999), among others. I say designed, but generally these activities occurred within the scope of regular daily life. For example, one of my first active-member engagements was a bike ride to the schoolyard, where the boys and I shared off-road riding experiences. Basically, I engaged and interacted with the boys

directly, during play, during homework, during mealtimes, and during leisure time activities on a daily basis.

The parents were very acceptant of this part of the design of this study, encouraging me to observe and interact the twins while they watched a favorite video or TV show, did their homework, and played at computer games. In many ways, they helped me design my role as an active-member researcher.

Focus of Observations

Observations and interactions were ongoing for the six weeks I spent with the family (see Appendix B for a general schedule of data collection strategies). I participated in nearly all day-to-day family activities while at their home, and was involved with many activities—athletics, shopping, socializing, entertainment, etc.—that occurred outside the home. As far as observational targets were concerned, I entered the family site with a prefigured focus (Eisner, 1998), informing my early observations. Essentially, as my research questions indicated earlier, my focus was the interactions between parent(s) and child(ren) that facilitated an understanding of not only the child's experience with Asperger Syndrome but also the nature of social skills needed to function in their world. I concentrated much of my attention on how, when, where, and why these interactions occurred, as well as what happened during the interactions.

The parents had informed me (personal communication) that a difficult part of the process of living with children with Asperger Syndrome was that these children need training and teaching that is very different from what parents were probably ready to give. Though all parents teach their children thousands of 'things,' most parents are not trained teachers, capable of delivering learning opportunities to a broad array of learning

differences. Asperger Syndrome tends to force parents to change their strategies from what they had thought would be their normal interaction patterns, and those interactions were the core of my pre-figured focus.

Informing the prefigured focus was both the theoretical model developed by Bromwich (1976, 1997) and the behavior characteristics described by Marfo (1992) detailed in the literature review. Bromwich (1976) theorized that strong emotional attachments help engender and develop mutually pleasurable parent-child interactions along with optimal development in the child. Her six levels of interaction and behavior skills will allow me to be on the look out for specifics in those areas. And since Marfo's characteristics fit so well within Bromwich's model, they too allowed me to begin my study with a sense of the kinds of things I watched for.

However, I also operated with an emergent focus paradigm (Eisner, 1998) and let the many and various situations and interactions speak for themselves. My research on Asperger Syndrome prepared me to watch for reciprocal social impairments (Asperger 1999; Gray, 1998; Shaked & Yirmiya, 2003), circumscribed interests (Attwood, 2003; Wing, 1999), stims and tics (Pyles, 2002; Willey, 2002), literal thinking and speech (Holliday-Willey, personal communication) among other hallmark characteristics of the syndrome, and there were a broad set of experiences to observe that helped me better understand the fuller context in which the facilitating interactions of my prefigured focus took place. Ethnographic research design needs to be flexible (LeCompte & Schensul, 1999a) and these two foci allowed me to approach data with both a plan and a practical acceptance that while living with a family day to day, life happens.

Note-Taking Processes

The nature of my observations put a great deal of emphasis on the field notes I took during this study, and in that regard I followed guidelines developed by Bernard (1988), Hammersley & Atkinson (1983), Patton (1990), and Richardson (2000). Basically my notes were taken and recorded in four different places: on-going, in the field ‘jottings’; daily field note transcriptions of those jottings; a research log; and a personal research diary. Each performed a different function in the research process as each allowed a different entry point for the data being collected. And each ‘communicated’ to the other as the process of analysis occurred.

However, there was a time in my study when I engaged in a different kind of inscription of information. During the first week of my study, when I reviewed the documents and records the family had collected regarding the boys, I followed Sanjek’s (1990) idea of head notes and organized the observations and interactions I had with the family in my mind as they occurred. Rather than constantly jotting notes on what I saw, I spent some time acclimating myself to the environment where I would be living for the next six to eight weeks. This allowed me to sensitize myself to particulars that my prefigured focus might not allow. Sanjek suggests a few days of this will suffice, and I found this to be true. Save for the first two days where we attended a folk festival, the routine-driven life of the family was fairly well acclimated in a short period of time. Indeed, by the time I was finished with the document review, I stopped formal engagement of head notes. However, as a process, keeping head notes remained a part of my methodology.

A detailed description of the other note-taking processes I used follows.

Field Jottings

The ongoing, in the field ‘jottings’ were collected as the events being observed occurred. These notes were kept by hand in a small notebook I had in my possession all the time I was in the field. Essentially, this kind of note taking assured data would be there when memory failed (Bernard, 1988; Patton, 1990). Bernard also stresses that the field-jottings notebook protects the researcher from the possibility of ‘going native’ and becoming too inconspicuous to the research process. It is much better to be known as “what you really are: an observer who wants to participate as much as possible” (p. 182). Several pocket sized notebooks made up this aspect of my note taking. I would pull them out and write whenever the urge hit me, and everyone was witness to this process.

Within these small notebooks I scribed the notes of daily interactions as they occurred. I detailed conversations as best I could. In short, I tried to make a record of each event throughout my day of observation. I didn’t write in great detail in this notebook. Mostly it worked as a trigger for recalling details later in the day, when I transcribed those notes into my second type of field note.

Daily Field Notes

These notes are the lifeblood of the ethnographic research process (Hammersley & Atkinson, 1983) as they record, in detail, the interactions and activities that inform the analysis of the project. Field notes are generally made up of three kinds of notes: methodological, descriptive, and analytical (Bernard, 1988). Mine followed that plan. The first type, methodological, records the way data was collected. A notebook recorded the things I hoped to encounter and the manner by which that information might come.

For example, one entry spoke of getting Bob to speak about his math homework in order to discern to what level he understands the process.

As I proceeded through this research project I became more adept in the manner of my observations as well as in my note taking skills. It may seem a small part of the study, but with each bit of growth I achieved as a researcher, subsequent days at the site found me more effective in that role. Comments and interactions made and observed late in the study seemed to be more significant, especially as they could be laid across a deepening backdrop of understanding. As the study moved forward, I sought particular interactions with the boys and their parents, made appointments for interviews, and followed up on planned interactions. And I observed regular day-to-day occurrences with a more refined eye. Recording these methods allowed me later to be able to see how my manner of collecting data changed over the course of the study. It helped in the analysis as it offered a more substantial way to seek crystallization (Richardson, 1994).

Most of my daily field notes were descriptive notes, and there were a great deal of them. Each day, and sometimes more than once a day, I would record my observations onto my computer, using a voice interactive program. Essentially a mini narrative was created about what I had observed. These were the notes I made available to the family for member checks (Jansick, 2000; LeCompte & Schensul, 1999b) during the study. These checks were done on a regular basis, generally as soon as these notes were typed and printed. I left them on the table in the living room—and informed Thomas and Elizabeth about them—so that each family member might read them and comment on the accuracy of my descriptions (Ellis & Bochner, 2000). Within my descriptive notes most of the developing coding emerged (Bernard, 1988; Hammersley & Atkinson, 1983).

The third kind of daily field note, the analytic, began to appear in my notes as minor points. According to Bernard these notes take “a lot of time and effort,” and even more thought (1988, p. 194). They are the product of a great deal of understanding, and so they seem to increase in magnitude as the study progresses. And they are born of the other two kinds of field notes, which need to have ample time in developing their own frames of representation. As my study grew, this part of the note taking became more significant.

In keeping with the idea that analysis in an ethnographic study begins as soon as the topic is selected (Patton, 1990), these field notes underwent a brief daily analysis when they were transferred from the handwritten form to a computer file, narrated and more fully detailed. This format allowed my notes to have the immediacy of the on-the-spot notation as well as to provide me with the opportunity to reflect on them in juxtaposition with other events of the day or even with events of other days. This method also helped develop the idea that data both substantiate and generate concepts (Struass & Corbin, 1998) in the process of understanding the family interactions. It also kept me framed in the thinking that no one observation had meaning and substance alone. This was important as it engendered in me the constant search for the patterns and structures (Lecompte & Schensul, 1999a) that informed my final report.

Personal Research Journal

The third note taking form, the personal research journal, also occurred daily and allowed me to process the actual experience of being an ethnographer. Self-reflection, according to Habermas “is at once intuition and emancipation, comprehension, and liberation from dogmatic dependence” (in Greene, 1997, p. 190). Processing the journal

allowed a focus on many things, including my own biases about my observation, something I will address in the last chapter. In this way, the personal journal had a direct influence on the field notes as well as on the rest of the data gathering strategies. Such a reflective frame also helped me continually question my position with the data and the family, allowing me to accept more readily their input into the document, as well as the input from other outside readers. I feel this has allowed me to present here a text full of negotiated meanings, not privileged ones (Kelly, 2000).

Janesick (2000) maintains that the whole process of qualitative research is imbued with ongoing analysis and interpretation. Consequently my journal and field notes were visited every day, and even more often when the data demanded it. But equally important in this ongoing process is the ordering of data collection strategies, as they introduced me to the information I was processing (See appendix B). Certainly the role of participant observer began as soon as I enter the home (Bernard, 1988; Patton, 1990). However, some of the strategies were better served by entering the study early on, while others could wait.

Researcher's Log

The last type of field note I recorded is the research log (Bernard, 1988). This helped plan and document the events and activities I hoped to observe and record. Initially I followed Bernard's lead on this and made it a two-page log, where the left hand page recorded the things I wanted to observe and the right hand page recorded the things I did observe. During the study, this log and the methodological notes became a single set of notes.

Record and Document Review

One of the first parts of my data collection was to review the records and documents (Cresswell, 1998; Janesick, 2000; LeCompte & Schensul, 1999a) the family had collected over time concerning the boys. These data familiarized me with not only the degree to which ‘outsiders’ had identified the boys with Asperger Syndrome, but also, by juxtaposition, with how the family saw that outside influence. As a major aspect of this study focused on how a family constructs an understanding of Asperger Syndrome, those data and that interpretive frame were significant early on. They informed many of my daily observations; they framed initial questions in the interviews; and they directed some of the active-member engagements with the family.

As with all the note-taking systems in this study, I used a voice activated program to record these data. Working through the many documents I would read specific passages of text; collect pertinent comments from teachers, therapists, and parents; and record various grades and assessments for each boy.

Interviews

Formal interviews entered the research design in the second week. Because people symbolize their experiences in words and stories, interviewing offers a way to get at people’s personal meaning systems (Seidman, 1998). Indeed, a root reason for interviewing is to understand another person’s experiences as well as to see how that person makes meaning of those experiences. In this regard, interviewing offers access to people’s sense of what is in their world. Whereas observing an actor allows us to see behavior, interviewing that same actor allows us to have access to the meaning behind that behavior (Seidman).

In my study, informal interviews occurred on a daily basis as a function of the give and take of participant observation. The family and I were already good friends, and since we have always, we continued to share question and answer quite comfortably. As Eisner (1998) points out, we know that interviews can occur in the strangest (or most familiar) of places and are often most successful in those places where people are more willing to talk.

The central focus of the interviewing part of the study, though, were three long interviews (Seidman, 1998), conducted with each parent, interspersed through the duration of the study. Seidman's technique is phenomenological, combining life history with other phenomenological strategies. Mostly his is an open-ended interviewing structure, using three different foci of interviews—life history, present experience, and meaning making—to build on previously gained information. It seeks a reconstruction of the process and meaning of an experience. Each was approximately 60 minutes long, recorded onto audiotape, and transcribed. There is much debate on the nature and necessity of transcribing interviews, and I attempted to assimilate these ideas into my research plan.

For example, Fontana and Fey (2000) note that field workers often have to “make do; their ‘tales’ of their methods range from holding a miniature tape recorder as inconspicuously as possible to taking mental notes and then rushing to the privacy of a bathroom to jot notes down, on toilet paper at times” (p. 656). I see in this a need for some transcription, but not nearly a call for a verbatim text. Krueger and Casey (2000) champion the abridged transcript concept, noting that some conversation during the interview is irrelevant and/or redundant and that good analysis can come often just by

frequent listening to the taped interview. McCracken (1988) continually stresses the importance of verbatim transcriptions, as does Patton (1990); Seidman (1998), however, leans in that direction but doesn't seem to think verbatim transcriptions are absolutely necessary. Merriam (1988) feels that the verbatim transcription is the ideal, though she also supports a system she developed for her graduate students, the "interview log" (p. 82), which resembles the aforementioned abridged transcript. Her point was that graduate students could rarely afford—the time or the money—for full scale, verbatim transcriptions. Finally, Stake (1995) even warns against being too committed to tape recording an interview, writing "a good interviewer can reconstruct the account and submit it to the respondent for accuracy and stylistic improvement" (p. 66).

Taking the advice of those authors, my transcription process proceeded in the following manner: as soon as possible after the interview occurred I transcribed it by listening to several seconds of tape and then repeating the words into the voice activated program on my computer. This process was allowed me to get the actual words of the speakers, when pertinent, but also to move through sections of tape that did not deliver significant meaning. I have found in the transcription of interviews during a study with teachers of gifted learners (Graffam, in press) that some of the text is not pertinent to the issues at hand. By transcribing only the essential information, and presenting much of that in whole, verbatim phrases, I expedited the process and still remained in good contact with the data. In this way, the text became better known so that if very particular data points from the interview needed to be re-explored later in the study they could be found more easily. This process also made the transcriptions more quickly available to the respondent to be read and commented upon (Ellis and Bochner, 2000).

By taking us into the mental world of the participant, a long interview can be very revealing as well as “one of the most powerful methods in the qualitative armory” (McCracken, 1988: 9). It offers a way to access pertinent information without violating the privacy of the participant. It is one of the better ways “to gain access to the cultural categories and assumptions according to which one” makes meaning of her world (McCracken, 1988: 17). In my study, the long interview allowed the participants to tell their own story in their own words in essentially unconstrained contexts. This also availed me to the common vernacular used by the participants.

For the parents, I interviewed each separately, following a schedule we established between us in the first week. As previously noted, some of the questions were framed by the document review I conducted in the first week, while others came from the literature review conducted on Asperger Syndrome. And, of course, some came from the relationship already forged between the family and me. Most questions, though, were geared to allow the parents an open opportunity to respond freely about topics of their choosing. I wanted their stories, not their short answers.

The schedule was set so that the parents might share information back and forth about the questions and their answers if they chose to, but I asked that they would not do that. I sought data that differentiated the way each of them understood and made meaning of their world. However, even if they had shared, I don’t believe it hurt the process. As part of the instrumental focus of my case explored the nature of understanding and how it was constructed within a family setting, any interaction about the issues of my exploration really just epitomized that construction.

Following the Seidman (1998) protocol, the first interview was a life history interview, focusing on the background of the parents and their connection to and understanding of parenting, Asperger Syndrome, and disabilities in general. Attention was drawn toward how the parents saw development in their understanding of the world of parenting as well as how their views of disabilities have evolved throughout life. Interview two focused on the present engagement of being a parent of three children on the Autism Spectrum of Disorders, their current dilemmas and goals, and some thoughts about the next few years. The final interview sought to glean the kind of meaning each parent has constructed by being a parent of children with Asperger Syndrome. In this interview I sought some definitions of the syndrome as well as some ‘what ifs.’

For the boys, the interviews took on a different set of parameters. There were only two interviews, and they were much shorter, only 15 to 20 minutes each. I also only focused on the present experience of life with Asperger Syndrome. Because the boy’s lack of reciprocal conversation skills made the interview to conduct, I began each by allowing them to tell me a joke. Since they loved humor and jokes, this helped them have a little more positive attitude toward the interviews. I also allowed them to tell another at the interview’s end. Though the boys were never long winded during the interviews, the joke telling provided me with some extended sections of their recorded voice. Most of my significant interviews with them occurred informally.

Checking the Process

Perhaps the most significant checking that occurred in this study was the reading of the document by Liane Holiday-Willey, Ph.D. Dr. Holiday-Willey is an adult with Asperger Syndrome raising a daughter with Asperger Syndrome, and she agreed

(Appendix C) not only to read and comment on my literature review and formal proposal for research, but also to read and comment on the distillation my analysis engendered.

Dr. Holiday-Willey has written two books on Asperger Syndrome, made many presentations at national and international conferences on Autism Spectrum Disorders, and is seen by many as a leader in the field. Her help was greatly appreciated.

I also had the help of three teachers who read the text to discern if the descriptive narrative technique I employed obtained the level of verisimilitude I sought. As teachers and families are the significant audiences for this study, I felt it was important to hear from those groups about the quality and clarity of the work. Their help, too, was greatly appreciated.

Within the context of the study itself, certainly a major component of checking the process came through member checks (Ellis & Bochner, 2000; Janesick, 2000). These helped me discover if my analysis reflected the meaning of the parents. Of course, their meaning alone was not what I was after: ethnographic study is a revealing of the meaning of the participant and the researcher seen through the eyes of the researcher (Wolcott, 1999). But as it is the voice of the participants that should ring clear, getting such feedback from them was highly significant.

All data gathering strategies mentioned gave the potential to perceive information from many different angles. In this way they represented a type of triangulation (Cresswell, 1998; LeCompte & Schensul, 1999a; Stake, 1995), offering different lenses through which to see and consider the data. But as far as triangulation itself is concerned, I like Janesick's idea—borrowed from Richardson (1994)—of crystallization. This concept builds on the original idea of triangulation, in a sense, by jumping to a new

mental dimension. Where as a triangle is a two-dimensional shape, a crystal occupies three dimensions, moving us “from plane geometry to the new physics” (Janesick, p. 392). Thinking about the combination of my data, whether they came from the daily observations, the document and record analysis, the interviews, the engaged-member activities, the reflective researcher’s journal, or the member checks, crystallization allowed a more complex approach and understanding of the story they tell. And as stories evolve, so do crystals, which grow and change over time.

Since triangulation ought not be seen as “a tool or a strategy of validation, but [as] an alternative to validation” (Denzin & Lincoln, 1998, p. 4) we need to reframe it as a different and better way to think about data. Allowing the opportunity to see such a process as a growing and changing process—as a crystal and not a triangle—keeps the researcher in a flexible mindset. Triangulation, it seemed to me, made some data generative and some supportive. By thinking in triangulation terms, I might have looked for ways to substantiate what was found by seeking out other sources of data. Crystallizing, on the other hand, allowed the context of my data to be both generative and supportive *simultaneously* (Strauss & Corbin, 1998), and so I looked deeper into them and allowed them to be speculative on concepts further down the road.

Crystallization also reflects an idea about that moment when a concept becomes understood (Freeman, 1999). Crystallizing moments are those that solidify a significant bit of learning, by creating a memorable connection between the learner and the materials. In other words, to crystallize is to understand. Gardner (in Freeman) says that “In speaking about crystallizing experiences I have in mind moments when an individual feels they have discovered their calling, something sufficiently sustaining so that they

make a long term commitment to it” (p. 80). This made sense as a data-collecting concept because I surely needed to be committed to my data for a prolonged period of time both while and after it was collected. In this way, the crystallizing, rather than the triangulation of data, was the mental frame for bringing together my data collecting strategies.

Analysis of Data

Analysis within an ethnographic case study is best seen as an ongoing process that begins as soon as the researcher knows the general area of investigation (Merriam, 1988; Patton, 1990; Stake, 1995). For me, this began with an extensive reading in the literatures of Asperger Syndrome and parent-child interactions. That, and a fairly constant long-distance conversation with the parents of the family I’ll be studying framed my thinking. Questions were formed, revised, jettisoned, and otherwise dealt with. The study was underway since just after Christmas, 2003.

This initial preparation readied me for the sensitizing concepts (Patton, 1990) I took into the study. These concepts, as presented in the literature review, framed initial observations, interviews, and active-member engagements. Seeing is a learned skill, honed in the field (Patton; Wolcott, 1997); however, much of my background preparations were a determining factor of where that honing began. I took with me a good deal of information about the need for parents of children with Asperger Syndrome to teach necessary social skills; this was one sensitizing concept I worked with; so too was my growing understanding of the nature of parent-child interactions.

Of course, what became most significant for the value of this study was my growing ability to balance the sensitizing concepts with the emerging findings and to let

them direct me to observe and question well while also allowing me to let my participants relate the experience they have within those events. It was key that human behavior I observed be explained through the inside view—the participant’s description—and not just through mine (Patton, 1990; Wolcott, 1997).

And so I needed a plan—structurally informed by my sensitizing concepts, but also flexibly empowered by the interactions of the family—to lead me into and through the analysis phase of this study.

Logistics

As has been noted, the analysis of this study was ongoing. As a matter of course, each time I turned my daily field jottings into my more formal field notes, some analysis occurred. This helped me see the direction and the nature of my questions, both of which changed to some degree as the study went forward. Such change is a good thing, provided it is controlled. Indeed, an “overlapping of data collection and analysis improves both the quality of data collected and the quality of the analysis so long as the evaluator is careful not to allow these initial interpretations to distort additional data collection” (Patton, 1990, p. 378).

After leaving the site, after all data have been collected, transcribed, and copied, I created a ‘contents’ of the information, labeling each audio tape, and each written document (Patton, 1990). LeCompte and Schensul (1999b) refer to this process as tidying-up, and they extol its necessity. It put me in touch with my data; it established a resource to which I could return when questions arose during the analysis, and it allowed me, once again, to juxtapose gathered data with questions asked, as essential part of the analytical process.

Coding and Framing the Data

As with nearly all qualitative data, mine was coded. Essentially, I began building my coding scheme based on the Bromwich (1976, 1997) model addressed in the literature review. Her six levels of parent-child interaction, based on her theoretical frame of mutual enjoyment allowed me to distinguish and categorize the behaviors within the interactions I observed. The common sense nature of her model facilitated the process by which I discerned the levels of item, pattern, and structure in the data (LeCompte & Schensul, 1999b). Another aspect of my coding came from Marfo's behaviors (1992), also listed in the literature review.

My coding was somewhat preexisting (LeCompte & Schensul, 1999b; Patton, 1990) in that I knew going in just what general areas of interaction and what behaviors I'd be using to sort my data. In other words, I conducted a kind of top-down analysis with and through my coding. However, like all other ethnographers, I relied more on words than on anything else to reveal the nature of my case, and so some of my coding was built during the study. In this way, my analysis also worked from the bottom up.

Looking for patterns and categories meant sensitizing myself (Patton, 1990) to the kinds of experiences that might reveal them. Such a sensitizing, at least in part, came from a somewhat extensive review of the literature, a review that allowed the framing of experiences and activities that informed observation, interview, and category spotting. For example, I observed parent-child interactions that informed me of the family's understanding of:

- Experiencing Asperger Syndrome
- Learning about Asperger Syndrome

- Acceptance and Denial
- Appreciating Asperger Syndrome
- Developing interaction and other social skills

Central to this task was discerning the language the participants used to describe both the feelings and the meanings behind the activities that revealed these categories.

Such categories were revealed in open declarative statements during the interviews and during more informal interactions that I shared with the family. They were noticeable through particular omissions: one parent interacted in ways that the other did not. And they were revealed in the combination of intentional and inadvertent interactions that I observed (LeCompte & Schensul, 1999b). But these meanings also were instrumental in building the more significant emergent coding (Patton, 1990).

As has been noted here, some of that analysis occurred on a daily basis when the field jottings were turned into the more formal field notes. Though I did look for the preexisting codes of my study, I also searched for the unfamiliar, the unexpected, and the absences of data (LeCompte & Schensul, 1999b; Patton, 1990; Wolcott, 1999). This process was a more difficult one, as it is somewhat counter intuitive to basic observation. We are not 'trained' to look for those things that are not there. However it is central to the understanding gleaned here. This emergent coding began to appear in the third week of the study.

I organized the data as systematically as possible, to make for better analysis and interpretation. Frames of mind helped construct the routes by which my analytical and interpretive thoughts traveled. Loftland and Loftland's (in LeCompte & Schensul, 1999b) posit that human interactions include a narrow range of elements, and that by

focusing on those elements in particular interactions, inferences into the larger groups from which the interactions are observed can be made. The six elements of their hierarchy include:

- Acts and actors
- Activities
- Settings
- Ways of participating
- Relationships
- Meanings (p. 78)

This made sense for my study as it allowed me to begin to look at my data in a systematic and manageable way (Patton, 1990). I began with the members of the family, identifying their roles and basic behaviors within the family structure. Then I can described the sets of the activities I spent my time observing. I described places of importance where the family interacts, and I included how each of the family members—and I—participated in the activities and settings mentioned. I outlined the relationships the family developed, attempting to see the many facets of the interrelationships. And ultimately I outlined the meanings I observed in the family—how they define family, learning, teaching, Asperger Syndrome, etc.

This kind of organizing strategy helped me discern the essential items that began the analysis of my data. In concert with the coding strategy I used, this put me in close contact with my data, a necessary step toward the process of understanding the patterns and structures that emerged.

Ultimately, this organization of the data prepared me for an analysis that led to a higher quality interpretation, one that acknowledged the fine line between description and interpretation. According to Patton (1990),

Interpretation, by definition, involves going beyond the descriptive data.

Interpretation means attaching significance to what was found, offering explanations, drawing conclusions, extrapolating lessons, making inferences, building linkages, attaching meanings, imposing order, and dealing with rival explanations, disconfirming cases, and data irregularities as part of testing the viability of an interpretation. All of this is expected—and appropriate—as long as the researcher owns the interpretation and makes clear the difference between description and interpretation (p. 423).

Part of that acknowledgement came through the establishment of case records and studies for each family member, building a descriptive data base from the information gathered through observations, interviews, active engagements, and document review. These, in time, became the cases that are presented here, detailing narratively each member of the family.

Building these cases allowed me to understand them as unique entities unto themselves (Patton, 1990). When that occurred, when the cases were appreciated through their individual description, then the process of cross-case analysis (Patton) and of constant comparison (Strauss & Corbin, 1998) occurred. It is through those processes that interpretation began to separate itself from description.

At that point, the full final cases that appear here were written. Such cases bring together what is central to qualitative research: a blending of the participants' and

researcher's voice and meaning making paradigms; a descriptive picture of the conditions within the study's setting; a unique set of circumstances addressing the study's questions; and verisimilitude.

CHAPTER FOUR: THE ROLE OF THE RESEARCHER

It seems to me that the roles of the ethnographic researcher fall into two basic categories: the first is a collector of data, and the second is a disseminator of data. Functioning within both of these roles is the task of interpretation, though from my perspective it is not a role unto itself: one interprets while both collecting and disseminating; it is not a separate act. However, this simple dualistic description does little justice to the actual tasks of the ethnographic researcher, who, while carrying out these two roles, discovers there are roles within roles in all parts of the research process. For me, one of the first things I discovered while plying that first role was the fact that doing ethnographic research is as much about understanding me, as it is about understanding the family I'm studying. This quickly let me see how the questions I was asking were not exactly headed in the most proper direction. Though I was wondering how the parents understood Asperger Syndrome, in truth, I was discovering what I understood about Asperger Syndrome and what can be understood about Asperger Syndrome living with the family with children who were identified as having it. This is not the simple difference it seems.

Recognizing this change of perspective changed other things as well. For many days early in the study I needed to reflect on the kind of me that would be doing this research. In many of those ruminations, I discovered that who I was as a researcher was not always the right person for the job at hand. For example, I have always found it difficult—even when I was teaching—to interrupt someone who is comfortably in her own space in order to ask a question. Yet, certainly, that was one of the tasks I would

need to undertake in order to function well as an ethnographic researcher. The first time I interrupted in this way, asking Ringo about cross-country practice and meets, showed me that I could step outside of my character to develop the researcher's persona. Gaining insight into myself, then, added a dimension to the process and clearly affected the roles I would be filling.

And, of course, when there are roles within roles, one new turn leads to another. As I reflected on the difficulty just mentioned, I realized that in my role of researcher, I had to include the roles I have filled in many other parts of my life. I was—*I am* a teacher. As a teacher, when a young boy is doing homework, and seems to be engrossed in the activity, I don't want to stop that process merely to query the boy on his conceptualization of how he gets that work done. As an ethnographic researcher, however, it is important that I engage in many such activities. But how do you watch someone doing homework who seems not to want to be watched? Early on in my stay with the family, I attempted to watch Bob do his homework, and twice he moved to another site in the house. He wasn't being malicious. I'm not even sure that he was trying to avoid me by moving. Kids with Asperger Syndrome are notorious for reacting to the most obscure stimuli (Attwood, 1998; Holiday-Willey, 2001). But he moved, and after the second move I decided not to pursue him that day. Would an ethnographic researcher who had not been a teacher make the same decision?

Another role I played in this research is friend. I have already mentioned that I have known Thomas for many years—since 1977. I have known his wife since just before they were married, in 1986. I was still living close to them the summer the twins were born. Of course, I knew this as I entered their house, but I was unaware to the

degree it would play a role in my data collection. At times, my friendships within the family made me question if what I had just observed was, in fact, data at all. For example, Thomas related a tale about Melissa's cat and how it had bitten Ringo on the face—not badly. Elizabeth and I were the only two listeners, and she had heard the story before. When it got to the part where Thomas described how he got down on his hands and knees, looked the cat in the eyes, and growled at it (he said he was trying to make sure the cat never attacked one of his boys again), Elizabeth and I started to laugh and I made a joke about not knowing Tom could speak feline. Elizabeth picked up on that and asked if he had had any serious chats with their two adorable cats, Hermoine or Sylvester, recently.

Tom looked at her and then at me and said, “Sometimes she thinks I'm really stupid.”

“No I don't.”

“Yes, you do.” And he left the room.

Is that data? It certainly reveals something about Tom and Elizabeth's relationship, which, in turn, might be helpful in developing an understanding of how each of them understands and deals with Asperger Syndrome and developmental delays. But there I was in the middle of a conversation where one of them had one-upped the other, and I felt a little uncomfortable. That time I chose to stay where I was, and Elizabeth and I began talking about the boys. Other times brought other outcomes.

So this research showed me, in ways that no prior reading could properly inform me, that ethnographic research is about the self, about the self-as-researcher, as much as it is about those being studied. No information I would gain in this study would come

without being filtered through my own sensibilities, my own processes of constructing understanding. With that in mind, and before the reader gets to the data I have collected, let me say a few things about myself.

I am a 47 year-old white male and spent the first 35 years of my life living in the general area of the family I was studying. I had a fortunate background. I was raised by two wonderful parents, in a home where my mother did not need a paying job. I have a bright, older sister, who has three daughters and two grandchildren of her own. Our family was and is very close. My father moved up the ladder of success at a local oil-distributing firm, retiring 12 years ago from his position as an executive vice-president. Our family is well known in the community where I grew up. It was a great childhood.

My first career was teaching high school English in a small, rural town in New England. After ten years I left that job to pursue an advanced degree in anthropology. One thing led to another, and I moved to Florida, where I worked with the primates at the Lowry Park Zoo in Tampa. I married there—actually *there* on the Siamang (*Hylobates syndactylus*) exhibit. My wife and I are still married, and we are childless, by choice. After two years at the zoo, I returned to teaching at an International Baccalaureate (IB) School in Bartow, Florida.

Up to that point, I had little experience in my life with exceptional learners. In my first teaching position, all students with disabilities were kept in a separate classroom in a special wing. At the IB school, however, I came in contact with many learners of exceptional abilities. Because of that, I sought resources at the local university, the University of South Florida, to give me skills and materials to deal with these bright minds. In a short while, I earned a Master's Degree in Gifted Education, under the

mentorship of Dr. Hilda Rosselli, who instilled in me a strong belief that exceptionalities were not as rare as many believe, that many people had them, and that often gifts and disabilities found themselves functioning in the same mind.

Now I am finishing a degree in Special Education, with a special interest in Asperger Syndrome, a condition that is beginning to be seen in greater frequency in populations of gifted learners, though a condition that is still ‘under the radar’ for most people in our society. All of this, and I’m sure much more, informed my role as a researcher. As I think back on these aspects of my life, I can imagine those that influenced this research:

- A childless-by-choice individual studying a home of three children
- A child from a home without disability studying one of three sons on the autism spectrum
- An adult returning home to conduct a study
- A teacher having access to the academic situation—at home and school—of this family of three boys: a home of non-teachers
- A fairly well-read student of Asperger Syndrome living with a family with that condition
- A close friend

These roles surely prepared my mind in certain ways to undertake this study. An early entry in my researcher’s journal acknowledges this fact:

I would think a family who wants to understand Asperger Syndrome would look first to the behaviors of their children, noting those idiosyncratic occurrences that make them different from other

children. Then, it makes sense to me, they would consult some of the literature on Asperger Syndrome. This, I think, would include literature for the adults and the children in the family.

As my stay with the family lengthened, my roles continued to evolve. One clear change was the fact that with each stay at the house—I stayed there four times, for at least seven days each time, with three and four day breaks between stays—I had gained deeper understandings about how this particular household functioned, and I was becoming more comfortable there. It seems safe to say that I was beginning to take on and function in a new role: a budding (though still quite green) ethnographic researcher. My journal also recorded some of those thoughts:

Coming back to the house to restart my research has been interesting. I came in with a plan a little more specific than my first week.

I'm also finding that I'm seeing things differently right now. It's probably not a big thing, but a simple statement made by Thomas on the way to soccer Saturday morning, said a whole lot to me. Thomas's words to Bob were, "What part of riding together don't you understand?"

I'm not sure I would have heard them in the same way last week.

And a later entry:

As a researcher becomes more comfortable with the setting, espying evidence of what is sought becomes easier. Of course, this also creates the dilemma: do I see what I believe, or do I believe what I see? I came back this week hoping to find out if indeed Thomas did see

Asperger Syndrome differently from Elizabeth, especially in the way he thinks a concentrated effort by his boys was all that was needed sometimes to overcome this syndrome.

I feel I am finding several things to make that clear. I know I received corroboration from at least five people. I feel I received corroboration from a sixth, Elizabeth.

My study certainly is not just about Thomas, but it seems as though his behaviors with the boys is an obstacle to a richer understanding of this syndrome for the family.

So many factors play in that aforementioned single role, collector of data. I still think of it that way, singularly, though now I know that myriad textures and contexts reside there. These many nuances showed me that my study would reveal a very different kind of information than I had initially planned for, while still allowing me to frame my study under the same basic parameters of my proposal. I am still exploring what it means to these parents to have children with Asperger Syndrome—how they understand that phenomenon—and I am still exploring how these children understand the label that has been placed upon them. That, I don't think, will stop for some time.

But more clearly than before, I know now that it is my understanding, not theirs, that I have collected here. I have spoken and lived with them, while they have spoken and lived with me. Knowledge and understanding are the interaction between mind and stimuli. I can only report faithfully the interactions that stimulated my mind into a state of processing. This certainly does not include all interactions that occurred. And so I have

collected data in that context, filling the first role of the ethnographic researcher, as only I as an individual could have done.

The second role concerns the dissemination of the data: the researcher must organize and materialize the data in a way so that others can glean significant information from it. Research serves little function if it is not shared with others, especially others who stand to benefit from its findings. While some might say the mere conducting of research is, in the very least, instructive to the researcher, the truth of the matter seems to be—now that the data collection part of my project has been completed—without ample concentration on how the data will be presented in text (or in some other form) no real understanding of that data will emerge. Hence, any valuable instruction that might come from the data is only half-given. And I would say, from a learning perspective, half-given instruction is worthless.

In this sense, one might argue that this second role is more important than the first, though I will withhold my decision on that matter for now. Suffice it to say, in this role, the researcher arranges and then rearranges the data, revisits the questions that prompted the study, establishes the codes (if needed) that will help organize the analysis, and begins to probe the depths of understanding the data will reveal. It is, as has been discussed in the methodology section, an iterative process that might be, for all intent and purposes, never-ending. Yet in this role, one of the tasks that befalls the researcher is bringing to an end this particular process of research. This is done by digging deeply into the data to discern not only what is significant about it, but also how it might best be presented to a cadre of specific readers. Once the significance and presentation form are

decided, once the audience is appreciated, the full responsibility of the second role comes into play: the researcher writes the document.

I determined that certain steps toward this process would best lead me toward completion. It seemed fitting that I should first select my audience for this document, as that would help me determine which data were pertinent and which would be better left for another day. My selection here was fairly easy: as a teacher I wanted my work to be beneficial to those who worked in classrooms that had students with Asperger Syndrome. But since the predominant part of my study involved life at home, I also wanted families to benefit from this work. So my audience became a collective of teachers and families, two groups that surely overlap to some degree.

In my second step I considered just what information would be pertinent—in a general sense—to these audiences. As a teacher, I am aware how the relationships I build with my students are important toward their success. I also know how their success is affected by the relationships they have at home. Since many teachers are not privy to the home life of their students, at least not to any descriptive depth, I felt the value in my data would be found in showing that life through the words and actions of my study family. If teachers had a better sense of how a family of children with Asperger Syndrome came to understand and then deal with that particular deficit, lines of communication might be enhanced, instructive practices might improve, and relationships with families and students might become more meaningful. Much of my observation focused on the school/home interface, especially through the homework the boys did and did not do. Because of my teacher audience, those data became quite significant to the cases I built.

Equally, families of children with Asperger Syndrome would benefit, I felt, from the same kinds of descriptions that would help the teachers, at least inasmuch as those descriptions might be similar to experiences they have with their children. As an ethnographic researcher I hesitate to generalize my data and say that the Berkley family represents all, or even many, families affected by Asperger Syndrome. However, some elements of my observations probably would have been present in a vast majority of homes in our contemporary American society. Certainly families of children with Asperger Syndrome who are in elementary and middle school deal with homework issues, with extracurricular activity issues, with leisure time issues, with friendship issues, etc. While the particular way the Berkleys dealt with these situations might be very different from how another family deals with the same thing, a juxtaposition of behaviors still could be valuable for that family.

Understanding a condition like Asperger Syndrome is a constantly changing process. Both groups I have designated as my target audience might benefit from more information of contexts similar to their own experiences. This choice and understanding led me to process my data in a particular way, to reject some and emphasize other elements for this document, and, as step number three, to establish the voice and style from which to write the work.

Acknowledging that I am a teacher helps me to see that this document needs to be written as a teacher to teachers. My teacher voice can work well here. But because I am childless, I also need to write this from the perspective of the family I studied, using their voice as often as possible. Consequently, your reading experience will be predominantly a first person narrative, mixed with occasional third person renderings from the family

members. This changing perspective, I think, will capture the changing nature that is the process of understanding Asperger Syndrome. No one mind grasps it alone. Rather it is a shared, constructive system of understanding.

In determining the style of the presentation, I discovered that there is a third audience of importance in this process: me. I am the chief reader of this document, and it is my ear and eye that will determine what and how things are said. It must, first and foremost, be pleasing and informative to me, else the writing will be arduous and dysfunctional. And, echoing the argument made earlier, it will no longer be instructive, but only perfunctory. Research should never be that.

It was my decision, then, to write of the family in five distinct cases, each member being the major character of one case. The cases would present as clearly as possible the thoughts and behaviors of the family member while also including insights I gleaned about the individual during my stay with the family. But I also felt that some aspects of the family should not be revealed except by reading all the cases. For example, there might be some parts of the first case, Cosmo, that leave the reader wondering, what are the fuller implications of this activity or attitude on the child and family? Hopefully, the reader will find, in subsequent cases, a weaving and overlapping of description, sometimes from a changed perspective, that will answer those queries.

Consequently, I have written these cases so the reader is exposed to a growing degree of analysis throughout the five cases, coming, I hope, to a clearer and fuller picture of the family by the end of the last case, Thomas. In no way will it be a complete picture: no research study could accomplish that. But it should be one that allows the reader to think, to feel, and to see into this family in a way that reveals their combined

constructed understanding of Asperger Syndrome. In other words, it endeavors to be that which allows the reader to empathize with the Berkleys to some degree.

I have chosen to present the family chronologically, from the youngest to the oldest. There were two reasons for this decision. One is the ease that it allowed, no other thoughts needed to be debated except age. But the other is that both parents talk about not suspecting anything in the twins until Cosmo came along. It was his set of behaviors and subsequent diagnosis that lead Tom and Elizabeth to see Ringo and Bob differently. It makes sense, then, to let the reader begin where the family began.

Saving Thomas for last also made sense in many ways. First, he is the oldest, so he fit into my chronological design. Second, of the two parents, his understanding of Asperger Syndrome sometimes borders denial, though he would not admit that. He works, at times, as a foil in the narrative, and leaving him to last seemed to work well there, too.

But he is also an old, dear friend, and I found writing about him to be a most difficult task. As I said earlier in this chapter, I did not want this study to be about Thomas, but oftentimes it was just that. How could it not be? Here was a person I knew well many years ago when we shared myriad conversations over politics, sports, literature, history, music, and all sorts of legal and illegal activities. I may be overstating my influence a bit, but I believe we both had an impact on each other's worldview—then and now. To observe him in this family situation, day in and day out, was to see a different person than the one I knew. Or better, it was to see the same person behaving differently than I had seen him behave before.

I hope I have done him and his family justice here, for I admire them greatly. He and his family are doing everything they can do to be sure their children have the most opportunities to flourish in their world. He and his family are not always successful in their task. And he and his family know that.

Let those thoughts, then, be the preface to the cases that follow.

CHAPTER FIVE: COSMO

An Introduction

Cosmo is the third son of Elizabeth and Thomas, born in November 1993. At ten years old (the time of this study) he is a delightful young boy, who wants to be a part of nearly every conversation that takes place in the Berkley home. He was the first of the three boys to engage me in social interaction, and he continued and initiated that interaction throughout my stay. Of all three boys, Cosmo is the most affected by his developmental delay, but unlike the twins, his is Pervasive Developmental Disorder—Not Otherwise Specified (PDDNOS). He received this diagnosis in January 1999.

Essentially he is unaware that he is affected by a developmental disorder, though he can, at times, call himself “stupid” and wonder why other kids are “getting it when I’m not.” However, when I reminded him that I was at his home to observe how a family lives with Asperger Syndrome and developmental disorders, and that I was interviewing him to gain some insight into his understanding of being a child with a developmental disorder, he responded by asking, “is that bad?” I assured him it was not, and that it just showed that he was different.

“Oh,” he said “That’s okay. Everybody’s different.”

Cosmo is a large child for his age: 153 pounds in the fifth grade, the tallest in his class. He keeps his brown hair cut short, wears glasses, and for much of the time of this study wore an eye patch over his left eye to help improve a ‘lazy eye’ condition. Most of the time he managed this patch on his own, though occasionally he needed reminders from his parents. And though he received some bullying about the patch at school—

some of the kids called him ‘one eye’—he seemed to wear it willingly. On the first day of school, he asked his mother about having to wear it to school.

“Do I have to wear my patch to school everyday?”

“Well, your doctor says you have to wear it about 7 to 8 hours a day.”

“Is that a long time?”

“It’s long enough so that if you don’t wear it at school, you’d have to wear it right from the moment you got home until you went to bed.” Elizabeth reminded Cosmo that he’d be seeing his doctor on Friday, and that maybe he would be able to stop wearing it after that.

“What would Dr. Lavin tell me about wearing my patch to school?”

“I think he’d tell you to wear it, guy.” Cosmo went to the counter and put a patch on his eye.

Cosmo has a pretty serious asthma condition, requiring daily treatments. Most days he takes care of his own treatments as soon as he gets home from school. Sometimes he needs a reminder to do this. Once during my stay this condition got so bad—five nebulizer treatments in a three-hour period—Thomas had to take Cosmo to the emergency room. Often it caused Elizabeth to be up at night to administer a treatment.

When asked to describe his family, Cosmo said: “My dad is pretty tall, really likes reading, and he actually ran cross country when he was a kid. For a job he works at [the] medical center and gets supplies around. My mom, mom is shorter than my dad. She’s the short one, and, well, she has, she doesn’t have long hair, she has hair like ah, like I do. Same length, but not the same color. She also works at the medical center and she works, ah, works, she works in infection patrol.

And there's Bob, who, sometimes he has, well, ah, actually not, but, ah, he's a lot like me. He's taller. Ringo looks a lot like Bob, only shorter. They have a tendency of joking around some, like, ah, Bob will say 'I'm Ringo,' and Ringo will say, 'I'm Bob.' And, ah, things like that."

When I asked him what the best thing about his family was, Cosmo said: "Best thing? There are a lot of good things about them. Ah, I wouldn't really say there's one thing, ah, over the other. They're very nice. They don't ground us. You could do something really bad, like, ah, push a kid, and they won't ground us. We'll just be in big trouble."

Cosmo's interests are varied and have been constantly changing in his life, from Thomas the Tank to Theodore Tugboat. Presently he loves *Pokemon* and *Yu-Gi-Oh!*, and he can sit and watch those cartoons constantly. He enjoys reading, though he likes it better when his mother reads to him, and he loves engaging in jokes and story telling—almost always from some comedy show or movie—with his brothers. Where there's an audience, Cosmo will be in front of it. If he had the chance to do something that he and his family have not done yet, it would be to go to Leggo Land in California.

One thing noticeable about Cosmo's connection with people is that he will sensitize to their issues quite quickly. Tom and Elizabeth point out that Cosmo is very sensitive to others' feelings, and to how people perceive him. During my study, when my wife was back in Florida fending off the hurricanes of 2004, Cosmo was constantly asking me about Frances, Ivan, and Jeanne and how much damage my home had received. He wondered about my wife, and whenever I got off the phone, he asked if I had been talking to her. I also noticed that after taping him for his first interview, and

then allowing him to hear himself on tape, that Cosmo was immediately concerned about how he sounded.

“Do I really sound like that?” he asked me.

“Sure,” I said. “Why do you ask?”

“It’s just that, um, ah, just tha, that I need to work on that.” He emphasized the word, work.

I told him I thought he sounded fine, and that people often find their voices to be strange when heard on tape. “Had you ever heard your voice on tape before?”

“Yeah, and I hate it.”

“Well, most people dislike their voice on tape. I wouldn’t worry about it too much. I think you communicate quite well.”

A Closer Look

Looking back over Cosmo’s short life, his speech has been a nearly constant issue for his parents, his teachers, and for those who give him special services. At about the time he received his diagnosis for PDDNOS, a Special Education Specialist noticed the prosody of Cosmo’s speech, noting that it is quite atypical. Her suggestion was to approach it by choosing a dozen or so routine phrases, sentences, and sentence forms to try to get him to imitate these uses. Two years later, this same specialist wrote that Cosmo’s speech was markedly unusual, appearing stilted and mechanical. And in his developmental assessment of 1999, Cosmo’s greatest challenge was his difficulty with the use of spoken language.

Speech issues abound in his Individualized Education Plans (IEP), and he saw a speech and language therapist for a couple of years. These issues certainly combine with

social issues, and for Cosmo they have gone hand-in-hand. His IEP set goals to improve social communication skills; share communicative turns; and to initiate, maintain, and terminate a conversation. A goal set to be reached by September 2001, read that Cosmo would improve his social language skills so he could use conversation rather than actions to interact with others. His IEP of October 2001 notes that Cosmo continues to have difficulty getting eye contact, though he had made progress on turn-taking skills during games. And Cosmo has difficulty interpreting other people's facial features and body language.

Yet, amid all these difficulties, an undated note sent home from his speech and language therapist reports that Cosmo had been coming to speech with "another student and that those two get along great. Cosmo had been working on initiating topics and maintaining them through asking questions. He is doing well in participating in conversation that includes more than just himself and one partner. He is working hard on turn taking skills as well." Elizabeth thought this might have been written in the fall of 2001.

It is interesting to note that, despite the social deficits alluded to in those few paragraphs, nearly all of Cosmo's teachers report they enjoy working with him in their class. His sense of humor is always pointed out as one of his endearing traits, and his second grade teacher wrote, in her end-of-the-year-letter-home, that she'd miss their "daily chats." I know from my experience that Cosmo was the easiest of the boys to communicate with, in that he welcomed questions and conversation. Cosmo often extended conversations far beyond the point where his brothers might stop.

It is true that his conversations were sometimes hard to follow, and on more than one occasion, his literal mindedness evoked a frustration in his father. For example, while watching America's Funniest Home Videos, Thomas told a story about Blockbuster closing down in the future because of video streaming capabilities on home computers.

Cosmo asked, "You mean the Blockbuster where we get our movies and games is going to close?"

"No, bub, I'm talking about Blockbusters everywhere."

"But if they all close, then ours will too. Right? Where will we get our games?"

"Cosmo. Cosmo. Wait. I'm only speaking of the theory. Not about reality."

Cosmo appeared to be okay with that and turned his attention back to the television.

Regardless, I'm sure that most people would find social interactions with him to be friendly and positive.

But Cosmo does have his quirks. As with so many on the autism spectrum, he has some idiosyncratic eating preferences. He basically refuses to eat meat, though he will eat chicken nuggets. And during the time of my study he began to eat spaghetti and meatballs and even cheeseburgers. That latter feat, very surprising to both parents, was described to his father by the soccer coach: "Cosmo stood with arms folded in front of the cashier at Wendy's, and said, 'I want a cheeseburger with no mustard, no ketchup, no onions, and no pickles. Just cheese.'"

Every morning at breakfast he'll eat a banana, though he first inspects it closely to remove all of the spots, bruises, and other abnormalities as he sees them. He peels the

banana, then, with an intent gaze onto the fruit, he twists it somewhat deftly in his hands and slices out the ‘badness’ with a butter knife. Watching this work, one would never guess he had fine motor skill problems. One morning he removed so much badness that there were hardly more than two small bites. His mother got him another one from the bowl of fruit that is ever present in the kitchen.

His favorite food is pizza, though not the pizza served at school. And Cosmo loves bread, any kind of bread. His whole diet would be bread, I think, if he had his choice. He’ll eat his bread buttered, toasted, or plain. He could eat his grandmother’s Texas toast every morning, smothered with maple syrup, of course. Then, every night for supper—Cosmo doesn’t really like lunch—he could eat so much Italian bread that he wouldn’t be able to eat his Cream of Wheat, something he has when the rest of the family is eating more traditional, but unpalatable to him, dinner time fare.

Cosmo gets along with his brothers fairly well, though he is probably closer to Bob than to Ringo. According to Elizabeth and Thomas, “Ringo and Cosmo can push each other’s buttons.” I never saw that in my stay with the family, though I did see, on two occasions, Bob show concern for Cosmo that exceeded Ringo’s. Both were brief, and neither would be called heartfelt from a more common understanding of that term within sibling scenarios, but concern was present. Cosmo, however, denied Bob’s concern and told me that, “secretly, Bob wants to kill me.” He laughed, “Not really.”

Cosmo’s closeness with Bob may have to do with their love of video games. Several times during the last two weeks of my stay, Bob helped Cosmo through some of the stages of his GameBoy games. In many of these exchanges, Cosmo willfully sought Bob’s help and generally was patient if Bob did not help him right away. Cosmo would

ask, and Bob might tell him, “in a few minutes,” or “wait until I get to a point where I can save this game,” and Cosmo would sit nearby, holding his GameBoy, and would wait.

One of the fascinating aspects of this study was to observe the intent concentration youth have on their computer and/or video games. When he is playing a game, Cosmo is nearly oblivious to the world around him. Thomas, Cosmo’s grandmother, Cosmo, and I went to watch the twin’s cross-country meet at a school nearly an hour away. During the whole trip there, and during most of the meet, Cosmo played his GameBoy. A question or two might go his way, but he’d not answer. At the meet, when his father needed to talk to him about something that had happened at school, Cosmo was asked to stop playing for a while. It took several minutes for him to make that stop, as he had to slowly remove himself from the game.

Cosmo gets along well with his parents, and he shares affectionate moments with his mother quite often. Elizabeth will make physical contact with Cosmo on many occasions, walking with him hand-in-hand and placing her hand on his lap when sitting beside him. At the folk festival, I observed him kiss his mother on the cheek while sitting beside her, and another time, when he was sitting a couple of seats away from her, he blew her a kiss. He does not seem to be bothered by hugs from his father, who occasionally will kiss Cosmo on the top of the head and then give him a noogie.

His father also kids with Cosmo a good deal. At the festival, Cosmo asked his father about the music being played on the stage. Tom kidded by saying, “Yes, that’s the band,” though it was only the music being played between sets, and the people on the stage were the roadies.

Then Bob said, “Cosmo, does it look like a band is playing?”

Cosmo looked at the stage, apparently confused at Bob's question. Thomas stepped into the conversation to say that "Cosmo probably saw the people on the stage and heard the background music and made the connection. So just leave it alone."

Much of the parent-child interaction that goes on at the Berkley house revolves around homework, as that is an area where all the boys have difficulty. Most of the time, Cosmo completes his homework with his mother, who has a strategy of sharing and encouraging while assisting her son.

"Let's do this example, guy," she says to him at the kitchen table one evening while doing some math homework. "You've figured out that 1 goes into 18, and that 2 goes into 18, what about 3?"

Cosmo thinks about this, but he doesn't answer. His head looks at the ceiling and he holds his pencil in both hands.

"How many times does 3 go into 9?"

Cosmo thinks. "3 times," he says.

"And how many times does 3 go into 12?"

"4?" but he seems to be asking, not telling.

Elizabeth looks at him with very little change in her demeanor, though it is clear she is encouraging him to think, to take his time, and to work toward an answer. "You're right," she says. "And how many times does 3 go into 15?"

"3 times 5 is 15," Cosmo says.

"Right. And 3 times 6?"

Cosmo answers, "18."

"And isn't 18 the number we're trying to get, guy?"

Cosmo smiles. He seems to like the interactions with his mother during homework. She never rushes him. She never seems to make him uncomfortable. She shares the moments and moves the work toward him without assaulting him with it.

Tonight's task, though, is more than multiplication. Cosmo also has to build geometric arrays to show the mathematical formulae he has been computing.

"So three times six is 18. What's 6 times 3?"

Cosmo has to think a bit, as the immediate reversal of the multipliers is not obvious to him. But he does get it and says, "18."

"So, how do you do a 3 by 6 array, guy?"

Cosmo looks at his mother, confused.

"How will it look?" Pause. "Look at your paper." Pause. "See those examples?" Pause. "How will you do it?" Pause. "Where will it start?" The pauses here take many seconds, and with each Elizabeth uses her hands to direct Cosmo's attention to his paper and the set of examples presented there. She leaves the table for a second and comes back with a handful of pennies, placing them in front of her son.

"Look, here you've got 1, 2, 3; and here you've got 1, 2, 3, 4, 5, and 6. Since we know we've got 18 pennies, guy, we don't have to count everyone, do we?" Her voice remains calm and encouraging. She catches Cosmo's attention as much as possible. They look at each other, then to the work. Somehow she seems to sense that he has started to understand the problem.

"So how will you start your array?"

Cosmo asks, "Can I start here?"

"Yup. You've got to put 6 in a row. How many rows will there be, guy?"

Cosmo uses his pencil and struggles to scribble in dots for the three rows. A small part of his difficulty in doing math is the very small spaces provided in the worksheets he needed to complete.

“Good job. Perfect. So now you’ve done a 3 by 6. Can you do a 6 by 3?”

Cosmo looks up at his mother, who reminds him, “you had 3 rows and 6 columns, but now you need 6 rows and 3 columns. Can you do that?”

“Yut.”

“Where will you start?”

“The 3 over here.”

“Okay.”

“Do I need to go down here?” Cosmo shows her where the rows will go.

Elizabeth nods her head and smiles.

Thomas also works with Cosmo on math occasionally, though it is mostly Elizabeth’s domain. One evening while preparing supper, Thomas helped Cosmo work on some math problems that were due in a couple of days. This was a set of problems given to the rising fifth graders at the beginning of summer in order to keep them sharp while they were away from school for the summer months. Cosmo has many to do before Friday, though he is not sure if they’re even due on Friday. “You can ask your teacher tomorrow, bub,” his father tells him, “but remember, you’re not going to be at school Friday morning. You have an eye doctor’s appointment.

“It’s not a problem, Cosmo,” his father tells him. “You can find out tomorrow when the problems are due. You can tell your teacher that you won’t be at school Friday

morning. And if she needs the problems on Friday, you can tell her that you'll bring them to her when you get back to school."

"But I don't know if they're due on Friday." Cosmo's voice is frustrated to the point where his thoughts and sentences are hard to decipher.

"That's what you've got to find out." His dad tries to calm the frustration. "Just do as many as you can now, bub, and we'll worry about passing them in later."

Bob has been watching this and offers, "I can pass them in for him on Friday."

"No," Thomas says. "This is Cosmo's work. He has to find out how to pass it in." He returns to preparing supper.

After a while, Thomas looks at Cosmo and says, "Cosmo, you've been working on this same problem for 24 minutes. That's too long, bub." He sits down at the table and takes the worksheet from his son. He sees that Cosmo is having difficulty writing the numbers underneath the problems. The space is too small for Cosmo's writing skills. Thomas says, "What you need to do Cosmo is get a piece of paper."

Cosmo grabs for his binder, just to the right of him at the table. Getting a sheet of paper, though, is difficult for him: another aspect of his minor motor skills deficits. He struggles with the sheet, sighs aloud, and tears the paper while trying to remove it.

Thomas is still looking at the worksheet. "There are 200 problems here. That's way too many for you to get done." Cosmo slaps the table hard. "But think about this for a second, bub. Let's be realistic." Cosmo's face and eyes are getting red. "It's okay if you can't get them all done. I couldn't do 200 problems before Friday."

Cosmo begins to cry here. Thomas continues to engage him in conversation, and his voice approaches a calm and encouraging level. "Let's do a problem, bub. We'll get

started that way.” Cosmo grabs a tissue from the counter behind him. He wipes his eyes and blows his nose.

“What’s 7 times 5?”

Cosmos thinks for a second and says, “35.”

“So, put a 5 here.” Thomas points to a spot on the worksheet. “And carry the 3.”

Cosmo scribbles on the sheet.

“Okay, what’s 7 times 7?”

Cosmo again thinks for a second and says, “49.” They work through a couple more problems. Thomas seems intent on preventing frustration. Cosmo’s discomfort is apparent. At one point he says to his father, “I’m confused.” And a bit later: “I don’t know this.”

Thomas responds, “Cosmo, stop. You’ve done this. You know 3 times 6.” He is looking down at his son whose head is bent over his work. “Carry the 1.” Thomas points to the worksheet. “Now, 3 times 3.” He sits down with his son once more. “Look at the next problem, bub.” He gets Cosmo’s attention by tapping lightly on his arm. “What’s 7 times 7?”

Cosmo ponders this for a while, or maybe not: the look on his face does not reveal he is thinking about it.

Thomas says, “7 times 7 is 49.”

“I was just going to say that,” Cosmo whines and brings his hands up in front of him. He is about ready to cry again.

“It’s okay, sweetie,” Thomas comforts him. “We’ll work on this a little later.”

Thomas and Elizabeth have a different way of dealing with their boy's homework needs and abilities.

One morning at the Berkley home, while Thomas was in the kitchen preparing breakfast, and Elizabeth was upstairs getting ready for work, an agonizing scream came simultaneously with the sound of a body tumbling down a flight of stairs. Cosmo was crying and obviously very shook up. All three of us arrived at the staircase at the same time. With Elizabeth up stairs and Thomas down stairs, they talked him out of his frustration and fear, assured him he was alright by checking his body parts, and they both walked him into the living room. Each held and caressed Cosmo, spoke in quieting tones, and brought him to a calm state. It was a time, Elizabeth told me later, that might have escalated into a meltdown phase. "Those moments," she said, "are important to spot. If you do, you can prevent the meltdown. If not, Cosmo can be uncontrollable for a while."

Of course, a fall down the stairs is easy to spot. But another moment occurred with Cosmo, and Elizabeth reacted quickly and no meltdown occurred. We were at the folk festival, and we had just gotten our lunch. All six of us were sitting in an area that overlooks the river. Cosmo was eating some fried dough and French fries, when one of the chicken nuggets fell out of his container onto the ground. He went to grab it and some French fries also fell. Then, with a small whine and sigh, he set his bottle down on the ground, but it fell and spilled. He started to rage, and a tear dropped from his unpatched eye. I had watched all of this, and then saw, in what seemed an immediate approach, Elizabeth kneel in front of Cosmo, place one hand on his knee, and tell him that there was plenty of food, and that she'd be glad to share her fries with him, and that

he needn't worry about the nugget. "Everything's okay, guy. We can take care of this easy." And Cosmo calmed.

When Cosmo's rages escalate to a point of meltdown, his frustration often turns to a physical reaction. During the last week of my stay, he kicked a classmate during a game of 4-square. His brothers told me about it while we were waiting for his soccer practice to finish. When practice was over, and Cosmo came to the bleachers where I was, we talked about it.

"How did you know about that?" he asked me.

"Your brothers told me."

"Why would they do that?"

"I think they knew you might be in trouble, and they wanted to help. I think it shows they care about you."

"My brothers?" He paused. "Bob secretly wants to kill me." He laughed. "Not really. I'm just kidding."

"How did it happen?" I asked him.

"There's always trouble on the playground. They're going to have to do something about the 4-square, because of the trouble. Maybe they'll have to take it away from everyone."

"But what happened that made you kick someone?"

Cosmo was silent for a while. "We were just playing. And some kids were adding rules. And Kevin was standing behind me and said, 'I guess it's an idiot's rule.' And I got mad and kicked him."

It surprised me that the boy was Kevin as both of them are on the soccer team, and Kevin is one of the few kids Cosmo might call friend.

“Do you think Kevin might have been kidding?” I asked.

“Maybe.” I think he meant it.

This incident reminded me of a day when the whole family and I went to the schoolyard to play Frisbee and 4-square. In the 4-square game, as the competition heated up, the boys began to pick sides, and some unfair play occurred. Most of the time, Elizabeth and Thomas would encourage the boys not to do that, and Thomas might mildly chide them about their behavior. One time he spoke to Cosmo.

“Do you behave this way in the playground with your friends?”

Cosmo had just accused Ringo of cheating. “I was just kidding,” he said.

“But if you joke like that on the playground,” Thomas said, “I can see why some of the kids might not like playing with you.” Thomas then reminded Cosmo that there were times when he had difficulty getting along with his friends and maybe he needed to be careful how he played with them. It was an significant moment of sharing, a father looking out for his son.

At School

Because of the nature of his learning difference, Cosmo began school in a class of two other students. By the time he progressed to the second grade, he was moved to a regular education classroom of 20 students. Beginnings and transitions are tough for Cosmo, as they include learning new procedures, changing schedules, and great flexibility. In third grade, he had ten meltdowns by the fourth day of school, and one of them was extreme enough for the staff to intervene to keep Cosmo safe. They note that

Cosmo cannot process language when he's upset or in a meltdown phase, and that he reverts to physical expression. He had no meltdowns during the beginning of this school year.

Cosmo needs a lot of prompting to produce work in the classroom. According to several who have worked with him, perfectionism interferes with Cosmo's productivity in many areas, especially math and writing. Once, while writing a timed prompt, where Cosmo was assisted by his educational technician, the rest of the class not only worked independently, but also produced two to three pages of work whereas Cosmo had only completed four sentences.

His teachers mention one of Cosmo's strengths as his willingness to accept help and to give help to his peers. They say he enjoys reading independently, and they report that Cosmo likes to talk to others and that he seems to enjoy science and social studies classes.

He has difficulties with fine motor skills, and he hates writing. He is also not too fond of math. When asked what he liked best about school, he said, "My three favorite classes are gym, art, and library." And then he added, "What I like least about school are my three least favorite classes: music, guidance, and social studies." Part of this must come from the difficulty he has in completing his work, both at school and at home.

Cosmo energetically welcomed my presence at his school, telling me he really liked his class, especially his teacher, who had become his friend last year. Cosmo's class, a fifth grade of 20 students, begins each day with a mad minute math exercise: 30 math problems on a work sheet, and one minute to do as many as possible. Cosmo, apparently uninterested in this work, tapping his pencil much more than writing with it,

completed 11 of the problems; all of the other students completed more than 20, and most finished all 30.

A wonderful lesson on DNA followed this activity, taught by a visiting student from the local university. Students used red and black twizzlers, tooth picks, and mini-marshmallows to build DNA molecules. Cosmo had an energetic interest in this activity, and he occasionally interacted with the girl who sat in front of him. When the class got to the part where they could eat their molecule, Cosmo ate his first piece quite loudly.

After this, when the teacher instructed everyone to clean their desks, Cosmo moved about the room for the first few minutes, though he did not interact with anyone. Once redirected, he took everything out of his desk, placing most of that on top. But whereas all the other students wiped their desk with a dry paper towel, Cosmo did not. Many of the students then began to share the reorganization of their desks: “Shelly, look at my desk.” “Kevin, see how I’ve put my books in here?” Cosmo is not asked to look, nor does he request that others look at his.

When all the students have finished cleaning their desks, the teacher returns some papers. Cosmo still has a bunch of stuff on the top of his desk. As papers come back, he seems to have difficulty knowing what to do with each piece.

“What do I do with this?” he asks his educational technician.

“That goes in your science folder.”

“Oh.” He looks around. “I don’t have that with me.”

“Yes you do. You used it during the DNA activity.”

“Oh yeah.” She gets the folder for him.

Cosmo's teacher announces that today, after break, the class will begin a new social studies state assessment, and she passes out a packet of information to each student. While she talks about their task, Cosmo plays with his pencil, bouncing it on his desktop.

The students go outside and play in the schoolyard during break. Cosmo plays 4-square with eight or nine classmates. All of them, save Cosmo, engage in animated conversation. Cosmo, though physically animated, shares few words with any of them. However, it is a friendly game, and everyone there seems to enjoy the time outside.

After break, Cosmo talks with three classmates, especially Belinda, the girl who sits directly in front of him. When the teacher asks that they get ready, Cosmo is surprisingly quick to do this. The students build little fortresses on their desk to prevent any group mates from looking onto their papers. Cosmo puts a roof on his. Directions are given—again—but Cosmo is looking out the window, or at least in that direction. The assessment lasts until lunch—one hour. Most students are finished before lunch, but Cosmo and a few others will need time afterward to finish. Ultimately, he is the last one to finish, and near the end he fidgets in his seat, continually rests his head on his left hand, and sighs aloud several times. His educational technician encourages him to focus. It doesn't seem to work.

At lunch Cosmo sits with Kevin, Jack, and two girls. He and the two boys are on the soccer team. Cosmo has brought his own lunch today, though on some days—especially when the lunch is bread sticks—he eats school lunch. There is some conversation at their round table by the window, though the two girls do most of the talking, and mostly to each other. Cosmo has a tug-of-war with one of the girls over a

Twix bar that was in his lunch. It seems neither a friendly nor an antagonistic tug; he has the bar at the end. When excused, all four go out to the schoolyard for lunchtime recess.

After lunch, and after Cosmo finished the assessment he had begun before lunch, the class went to music class. Cosmo hates music, both the class and the art form. He especially hates to sing, though if you push him, he'll tell you he likes "Who Let the Dogs Out," a popular song of a few years ago. This class is highly interactive, and the teacher encourages the students to take part in all aspects. Cosmo has difficulty with the rhythmic clapping when it becomes round clapping, and he doesn't seem too interested. When it becomes Simon Says clapping, his interest picks up and he studies the rhythm, but he still has difficulty and has to sit down soon into the game.

When the recorders come out, for the accompaniment to "Mama don' 'low," Cosmo looks around for the proper fingering. After a few tries at that, he asks to go to the bathroom, and the teacher lets him. Cosmo never returns to class. On the way back to his regular classroom, when we walk by the boys' bathroom, he is looking out the door.

"Did I stay away too long?" he asks me as I walk past.

"Yes, you did."

When the class begins its study of math, Cosmo goes to the resource room. He likes his teacher there, and she interacts with him in a friendly manner. On this day Cosmo had to take a math test, and another student, Shelly, joined him at the testing table. He has a good deal of trouble with many of the examples, and his teacher needs to encourage him often, and even show him alternative ways to demonstrate his knowledge.

“Can you use pictures instead of names to show me you know that?” she asks him. “Do you remember the rhyme for division operations?”

Cosmo shakes his head and sighs.

“Dead Mice Smell Bad. Remember?”

Cosmo nods, but it is clear he doesn’t remember what they stand for.

“Divide, multiply, subtract, and bring down, Cosmo. Now do the ones you can.”

This lack of remembering is an interesting aspect of Cosmo’s make up. Both his parents and nearly all of his teachers remarked about his great memory. It’s true that for things which interest him—movies, *Pokemon*, *Yu-Gi-Oh!*—he has a fabulous memory and can recall and relate details in great number. But when the task at hand has no interest for him, no details seem to stick.

The work in the resource room ends his day in school. At school, Cosmo receives special services in the following manner:

- direct instruction from the special education teacher every day in the resource room
- speech language pathology for 60 minutes per week
- extended school year for 30 minutes per week for six weeks in the summer
- occupational therapy 60 minutes per week
- behavioral consultation once per quarter

Cosmo is also to be out of the regular classroom 20% of the time, and he gets modifications on his IEP. For example his tests should be described and dictated by a staff person in the essay sections. He should get extended time to take test, and the teacher may rephrase questions to insure Cosmo understands them.

School/Home

School life for Cosmo, as with nearly every 10 year old in America, also includes work at home. Cosmo needs constant supervision while doing his homework, or it will not get done. Mostly, his mother is the overseer of all the boys' homework, but sometimes it is his father. Cosmo prefers it to be his mother. A constant battle is getting Cosmo to recall exactly what is to be done each night at home. There are some standard assignments, like his spelling words, that are nightly, but regularly the teacher will assign something specific to go along with the day's task that, if it is not written down, Cosmo will not remember. And then there are the long-range assignments, like reading projects, where the assignment sheets can be misplaced or the due dates put out of mind.

Add to this the fact that Cosmo, certainly like all other 10 year olds, would rather be doing something else, and the problem is exacerbated. But there's more to this issue. Cosmo's developmental delay makes it extremely difficult for him to work smoothly on his homework. His attention is drawn elsewhere easily; he has difficulty remembering a math formula from one problem to the next; his perfectionism makes him restart many projects over and over—sometimes it prevents him from starting at all; and his poor fine motor skills make the actual writing of the homework so difficult as to be painful. This adds an amazing amount of time to the process of actually doing homework.

Cosmo, a fifth grader, regularly spends more than three hours a night on homework. He often has to do some of his homework on Fridays and weekend days. The moment he arrives home from school, he hears his father say, "What do you have for homework, bub? Let's get at it." It may be about four o'clock when this happens, and

Cosmo may not be done until well after supper. Several hours on most weekends were also spent doing homework.

Other things at home are not so difficult. Cosmo, like the twins, has a few chores, some of a regular nature, some on an occasional basis. He is asked to help take the trash out to the street each week, and he must strip his bed and put the sheets in the cellar every other week. Both of these need constant reminders, although one time during my stay all three boys were up early one Sunday, stripped their beds, and put the sheets in the cellar before anyone else was awake. Elizabeth said it was the first time that had happened. She was very pleased. It was also the only time it happened during my stay.

He is not an unclean child, though he doesn't care too much for the cleanliness routines, and he always looks discouraged when he's asked to take a shower. He dresses himself, but he needs his clothes to be laid out for him the night before or he will have difficulty making decisions about what he will wear. And as the weather became colder with the onset of fall, he needed to be reminded to wear (or to take) a coat to school with him in the morning. He also needs to be reminded to bring these extra articles of clothing home from school, but since there's not always someone there to do that, he forgets. Last year he lost a new jacket at school, and one morning his father reminded him of that in rather stern tones. Cosmo cannot tie his shoes. He loves to sleep, and of all the boys, Cosmo will sleep the longest, often staying in bed until 8:30 or later.

The two family cats, Hermoine and Sylvester, draw his positive attention often, though he admitted he would like to have another dog. He energetically watches some TV shows: America's Favorite Home Videos, *Seinfeld*, *The Simpsons*, and, of course, *Pokemon*. And he tells highly animated stories about all of those interests, often weaving

some of them together into a humorous holistic tale. He can talk for many minutes and with full choreographed displays about Monty Python, reliving the “Saga of the Black Knight,” or *The Pink Panther*, and about how Kato is always there waiting for Inspector Clouseau. And, like the twins, he loves to tell jokes.

Cosmo carries things with him almost all of the time, perhaps as some young people carry a ‘security blanket.’ When he is outside in the yard, he likes having his gray plastic baseball bat. He’ll walk around the yard and toss that bat from hand to hand and occasionally tap it on the ground. This can go on for an hour or so, but it clearly gives him pleasure, and it is rare to see him outside without it. Inside he has another piece of plastic, a different shade of gray, smaller, with a flat surface and a sharp curve. It seems to have come from a computer frame or some such device. As with the baseball bat, he moves this from hand to hand and often holds it in his right hand and strikes his left hand with it. Rarely is it far from his location in the house. And when he goes to his uncle’s, on the coast, Cosmo may be found carrying a rock with him, though this was not as constant as with the pieces of plastic. At school his teachers report that he always has a pencil with him.

His favorite place to be is in his room, playing his GameBoy, while laying in his bunk bed. He uses both bunks on the bed, having no favorite, but claims “if I don’t sleep on both, ah, both, my parents will take it down.” He also likes to play his Leggo games there. He wants to be an inventor when he grows up and already has some ideas for a home-made pinball set and a “boat alarm, like, ah, if you were in trouble, you could warn other people that were around.”

CHAPTER SIX: RINGO

An Introduction

Born one minute after his brother, in August 1991, Ringo is the second son of Elizabeth and Thomas Berkley. Now, at 13, Ringo offers us a chance to look at and engage with a child with Asperger Syndrome. Much of the syndrome presents itself in Ringo's actions and demeanor, though for the most part, Ringo has little understanding of both the syndrome and how it affects him. He knows it is a neurological disorder, but he does not feel it affects him at home, at school, or with his friends. He sees himself as similar to, not different from, his family and his friends. And while it may be true that Ringo is similar to his family, general observations reveal that he does have some differences from his peers at school.

Ringo loves to tell jokes and hopes to be a comedian one day. It is not uncommon to observe him relating a story or segment from a favorite movie—*Monty Python and the Holy Grail*, *Clue*, or any of the three *Austin Powers*—and see him move from sitting to standing to rolling on the floor to give the full experience to his audience. When such an excited tale ensues, Ringo's voice will show the unusual prosody common in children with Asperger Syndrome. Elizabeth tells me that when the twins were younger, people thought they came from Prince Edward Island and not New England. And I must agree that he doesn't have his mother's strong New England accent. When excited, his tone gets high, audible gasps pop up, and frequent "yut's," as with both his brothers are inserted. None of these obscure the story he is relating, and without some of the other aspects of Asperger Syndrome, one would not hear them as particularly different from

another excited storyteller. Animation like Ringo's is hard to come by, and it can be quite contagious.

Television would be Ringo's preferred activity if he had his choice. He loves many shows: *Seinfeld*, *The Simpson's*, *The Family Guy*, *America's Favorite Home Videos*, to name a few. And when Cosmo is outside with his baseball bat, and Bob is playing a video game, Ringo can quite often be found in his parent's bedroom, watching TV. Often it isn't a TV show but a DVD of a movie he really likes. He loves adventure, like James Bond, Indiana Jones, and the *Matrix*. But he also loves Abbott and Costello, *The Pink Panther*, and Victor Borge.

It's important to note, however, that it is not just the liking and/or interest that a 13 year old boy might have for certain films. Ringo can generally tell you the actors' names and what other movies they are in. He knew right away that a character in the new TV series, *Lost*, was one of the hobbits in *Lord of the Rings*. He knows the directors. Given enough time with a particular film, maybe three or four viewings, and Ringo can recite many parts of the dialogue right along with the character, or, as was just mentioned, in a personal retelling to an audience. Ringo, like Cosmo and Bob, likes an audience.

Early on in my stay with the family, Ringo was the one who said "Hi" to me nearly every time we crossed paths. This literally meant being said hi to six or seven times within a twenty-minute time frame, and this happened for several days. It never really stopped, though there were greater durations between 'hi's' as my stay got longer. For example, because I had to walk through the two bedrooms used by the three boys to get to my room, I often walked through while Ringo was in the twins' bedroom. In that

first week, whether I was going in or coming out of my bedroom, and no matter if I had just gone in and was now coming out, perhaps five minutes later, Ringo would say hi. Nothing else, just hi.

Ringo is an incredibly polite young man with a contagious energy about him, provided you are around him when he is engaged in something that interests him personally. In most situations Ringo is friendly, though I would say it is friendliness that one has to become accustomed to. He is well liked by his teachers and the other staff people at his school, by his coaches and the leaders of the local recreational programs, though he is not commonly seen to be social with his peers. He seems to get along well with his siblings, although Elizabeth and Thomas mentioned that Ringo and Cosmo can push each others' buttons, something I did not see an example of that during my stay.

However, the first thing Ringo mentioned when I asked him to talk about his family was that "Cosmo is kind of annoying sometimes. He can be really annoying, and sometimes he thinks that's funny. Now Bob, Bob is funny, but he can also be annoying sometimes. But not as annoying as Cosmo." Later in the interview, though, Ringo said, "Cosmo, I like him. I was just saying that before."

Continuing on about his family, Ringo revealed his penchant to be short winded about most things: "Dad has got a good sense of humor." And Ringo clearly engages and is engaged by his father humorously often.

At the folk festival, Ringo asked, "How will we know if Aunt Melissa and Uncle Patrick are staying at our house?"

Thomas, starting to kid, tells him, "Well, we'd know if there was anybody staying who wasn't normally at the house."

Ringo looked at him and squinted his eyes a bit.

“Like a couple of weeks ago we had that person at the house. You remember. It was, ah, Bill. Yeah. You remember. Bill stayed at our house.”

Ringo shook his head.

“Well, ask Ben if you don’t believe me. He’ll tell you I almost always tell the truth.”

Ringo looked at me with a grin on his face, and I told him I never trusted a thing his father said. He chuckled at that.

In speaking about his father, though, Ringo added, “He can be a bit crabby, sometimes.” During the time in our interview that asked him to describe his family, Ringo didn’t offer anything about his mother, but at a later time he did say that “Mom is a really good cook. She makes really good desserts.” It was his mother, though, who made the one rule in the house that Ringo did not like. “I don’t like the rule that our mom, she made this rule that we can’t watch TV or play video games until we’ve made our beds in the morning.”

A Closer Look

Ringo was diagnosed with Asperger Syndrome in March 2000. This diagnosis followed an assessment in October 1999, where the same psychiatrist who was asked to see Ringo after a pupil evaluation team meeting at the school, recommended a formal evaluation to determine whether Asperger Syndrome may be impacting Ringo. It was noted in the report that accompanied the diagnosis that Ringo has social difficulties relating with peers and that Ringo recognizes he is not a close friend with anyone. At

that time, Ringo had not been on a sleepover to any peer's or age mate's home, though that now has changed.

The one clear example I observed of Ringo dealing with a friend concerned the time Roger came by to watch a Pink Panther movie, *A Shot in the Dark*. Roger had been a classmate of the twins' the year before, but was now at a new school. I was outside when Roger arrived, but Ringo came and invited me to watch with them. Very little conversation went on between Ringo, Bob, and Roger, but several times during the film, both Ringo and Bob spoke along with the characters, especially Clouseau. There was some laughter during the film, but mostly there was just quiet observation.

When the movie was over, I left the television room and returned to the main part of the house. Ringo came along a few minutes later and saw that Cosmo was having a snack at the kitchen table.

“Can I have a snack too?” he asked his father.

“Don't you want to see if Roger wants some snacks?” Thomas asked.

“He's leaving in about five minutes,” Ringo said.

Thomas chuckled. “Well, shouldn't you go back and wait until he leaves?”

Ringo grinned and walked back toward the TV room. In about two minutes, Roger left the house, saying “Good-bye, Mr. Berkley” as he left. The twins then came to the kitchen for a snack.

Of course, many children with Asperger Syndrome have difficulty understanding the complexity that is friendship. Ringo and his brothers are no different. Both he and Bob had difficulty finding the words to explain to me how they knew Roger and Larry—

the only two friends both mentioned in their interviews—were their friends. And both parents are aware that none of their three boys have good social interaction skills.

The psychiatrist's report also mentioned that Ringo showed some obsessive behaviors, for example, knowing all the exits on the interstate for a 120 mile stretch from his home to a major city to the south, something his dad can do for a greater expanse of highway. It is also mentioned in the report that early on in Ringo's development, his parents felt that he and Bob communicated with each other in their own personal language.

Other language issues arise with Ringo from time to time. The following incident might also be deemed an attention issue.

One breakfast, Elizabeth was speaking to Cosmo about his inhaler. Cosmo was at the kitchen table with Ringo.

“Should I put your inhaler in your fanny pack or your book pack, guy? Which one will be easier for you to take to practice?”

Cosmo isn't sure. He hasn't been to a soccer practice yet, so he doesn't know the drill. Cosmo looks at Ringo. “Can I take my back pack to practice? Will I have time to do that?”

But Ringo has only a vague idea of what they were talking about. “Your meets will be at different schools. And the bus will leave at different times.”

Cosmo attempted to clarify, but was confused by Ringo's response. He asked the same question: “Can I take my backpack to practice?”

Ringo spoke, sarcastically, “Yeah.”

Cosmo was still unsure. “So is it yes or no?”

Ringo did not reply.

Another time, Thomas asked Ringo, “Can you tell me about the spaghetti dinner? When is it? Who’s going?”

“It’s October 1. And it’s for the parent-teacher organization.

“Is the whole school going?

“No.”

“Oh, it’s just for the middle school students and their families.”

“No. The elementary school families can come too.”

“So anyone can come if they want to?”

“Yut.”

Literal mindedness, which can be another language issue especially as it is mingled with an inability to understand metaphors, brought this observation from his assessor in 1999: “Ringo was asked . . . what it meant if someone had broken their heart, to which he stated they would be in trouble because their heart wasn’t working.” Ringo was also unable to explain what raining cats and dogs meant.

At breakfast one morning, Ringo and Cosmo were telling me stories from the movies, *Home Alone* and *Home Alone II*. As has been mentioned, Ringo can get quite animated, and he did so here, explaining how ammunition was fired over the heads of some of the characters in the movie. His voice speeds up, his energy is high, and he is clearly enjoying the telling of this tale. He moved from sitting to standing to crawling on the kitchen floor, back to standing, and back to sitting. It all happened quite quickly.

When he finished, Elizabeth asked me if I had ever seen the movie, *Hook*. She told me that when the twins were four or five, the two of them could act out the full battle

between Hook and the crocodile. She said they had all the moves and dialogue down to a near-perfect representation of what was on the screen.

As she ended her story, Ringo interrupted her. “Mom, why did you tell him that story about *Hook*? Nobody in that movie was in either *Home Alone* movies.”

In another context, one night at dinner I joked aloud that, “Ringo said he didn’t want a peanut butter chocolate square for desert.” The look he gave me clearly indicated he had no idea I was kidding, slowly spinning his head in my direction, but saying nothing. I immediately told him I was just kidding.

In regards to joking and kidding, as has been mentioned, Ringo hopes to be a comedian one day, and presently he loves telling jokes: it is his favorite hobby/pastime. And, as with both his brothers, people acknowledge that Ringo has a good sense of humor. The district ESE specialist, in an observation of October, 2002, writes: “Ringo enjoys telling jokes, as do many students with Asperger's disorder. Laughing seems to relax him, as it does most of us, and I expect he likes having a predictable social script, such as jokes provide. However, I’m not sure he fully understands the content of some of his jokes, as some of them bordered on inappropriate to share with teachers, and he didn't know the meaning of ‘second opinion,’ which was pivotal in one of his jokes.”

This lack of understanding became clearer when Ringo and I watched an episode of *The Family Guy* in his parents’ bedroom. The show dealt with death, with the character death making an appearance in full black robe, bony fingers, and scythe. Several times during the show—a show he had seen many times—Ringo asked me about the situation being shown. For example, at one point in the show, Peter puts on death’s

robe and touches a plant, which immediately dies. Peter then says, “note to self, don’t go to the bathroom.”

Ringo looked at me and asked, “What does that mean?”

I said, “Well, it means that anything he touches. . .”

And Ringo jumped in, “Oh, so his (thoughtful pause and brief silence) would fall off?”

“Yes. And you don’t want that to fall off.”

Ringo laughed.

In another scene, death was giving Stewy a brief history of his life. In his telling, we are shown a car parked under a moon, overlooking a city. The car is rocking, there is moaning coming from the car, and we clearly hear two voices: death’s and a woman’s. All of a sudden the woman’s voice is silent.

“Oh, no,” death agonizes, “I guess I’m going to die a virgin after all.” There is a long pause. “Well, maybe I don’t have to.” And the car starts rocking again.

Ringo looks at me again and asks, “What does he mean by that?”

We talked a bit about the portrayal of death in this show, and how everything it touches dies, and so his girlfriend would be dead in the car. But Ringo was unsure about what was happening between death and his girlfriend in the car, so much of this scene—which to me isn’t funny nearly as much as it is shocking—was missed by him.

Ringo’s resource room teacher told me that Ringo tells many jokes that he should not, and when she questioned him about the jokes, he generally did not know what the punch line meant. He did know, however, that jokes got people laughing, and that many

of the jokes he told tickled the fancy of adults, and it gave him a chance to interact with them in ways some, but not all, found appealing.

The first long conversation I had with any of the boys was with Ringo, a 25-minute exchange in the yard by the picnic table. His voice was clear and soft, and he articulated his words with care, though one might detect a bit of singsong in its phrasing. That unusual tone is not difficult to hear. Most of the time he looked directly at me. Indeed, at times he seemed to be looking into me. Often he took some seconds to think through a response before giving it.

He told me that he was not looking forward to going back to school on Wednesday. There was a math teacher there that many of the kids thought was evil. “He has a jar on his desk. Guess what’s written on it,” he asked with a grin.

I had no idea.

“Ashes of problem students.”

Ringo was looking forward to running cross-country track, something he’s done for two years. He mentioned a meet at the Greyhound School, a meet “with the best snack shack in the world.” He said that several of his friends also ran cross-country.

“In the spring I’m going to be on the track team again. Last year I ran the 400. This year I’m also going to run the 1600. My dad made me a deal that if I improve my time by three seconds at every meet, he’ll give me \$100.00.” Ringo, like his brothers, seems to respond well to positive carrots.

Then Ringo told me a story about his cats, about the time he “saved a squirrel from sure death. I saw Sylvester running across the yard and he had something in his mouth. I thought it was a squirrel, so I chased Sylvester until he dropped it. But

Sylvester only looked at me, and then he picked up the squirrel again, so I chased him back into the woods. When Sylvester dropped the squirrel this time, I grabbed Sylvester so the squirrel could run free. Then I brought Sylvester back into the house.” This story was followed by a tale about Hermoine catching a mouse; about Sylvester catching a bird; and about a dead squirrel that they all decided was killed by Sylvester.

Ringo is not always very talkative. At a soccer game, I could barely get him to speak. He told me he was not really interested in soccer, and that he only came because “we all have to come.” We talked about the players on the field.

“Do you know those players?” I asked him.

“Yes. I know most of them.”

“Which ones playing now are the best players?”

He sized up the group of kids, thought for a moment, and told me “they were all good. They’ve all played soccer for a while.” A few moments later he left our conversation to get a drink of water.

Comments from many who have interacted with Ringo—parents, teachers, relatives—indicate that Ringo wants to 1) please people; 2) be liked by his peers; and 3) be successful in the classroom. His telling of jokes surely is a part of that desire. Yet, and especially in the third point, Ringo’s organizational skills seem to preclude him being adept at always pleasing others. Nearly all of his Individualized Education Plans (IEP) have set as a goal something about structuring his time and/or organizational skills. It may be as simple as bringing a pencil and some paper to class with him, but without any doubt, those who have close contact with Ringo recognize that he is not always on task, and not always aware of the task to which he should be attending.

Historically, Ringo has had attention problems in many things, but these usually arise in school. An observation in October 2002, noted that “Ringo was still unpacking his bag when the rest of the class had begun their reports. Ringo missed the first two presentations due to this. When given a break in the middle of the two classes for snack and bathroom needs, Ringo uses the time to socialize with friends and discuss computers. He told jokes to staff members, who repeatedly asked him if he needed to take a break between sessions. When it was time to reconvene, Ringo looked at one of the teachers and asked for permission to go to his locker and to the bathroom.”

Ringo is a bright young man, despite—or because of?—his learning differences. His IQ was measured at 108, with a verbal IQ of 115 and a performance of 99. The report that accompanied that test, though, mentioned Ringo’s organizational skills and that he would need plenty of 1:1 assistance in the classroom to be successful. His parents note that he is a solid reader, and his teachers, for the most part agree. His reading teacher says he tends to have some difficulty drawing inferences from a text, but he is quite able to read for literal meaning. Mathematics gives him some difficulty, and his math teacher is not able to say that Ringo will successfully complete the high school requirements in order to graduate in four years.

An issue that popped up time and again, both in the records and the documents his parents kept, and in the conversations we had concerning all of their boys, was the amount of homework they do. Quite often, Ringo does more than three hours of homework a night, beginning at the time of his arrival home, after cross-country practice, and continuing, after supper, until bed time. On most weekends he also needs to work on his homework for a few hours. In January 2002, at a pupil evaluation team meeting,

Thomas expressed his concern that Ringo should do the same work as his peers, and by this I know him to mean both in the classroom and for homework. The teachers, however, noted that Ringo should be able to get frequent reduction of work, though it was unclear if they meant for the classroom activities, for homework, or for both.

At School

Almost regardless of the class, Ringo is non attentive to most activities. Whether the work is individualized or group designed, Ringo is generally late to be ready, slow to interact, and behind in the quantity of work produced by classmates. For example, in his social studies class, 9 of the 12 students present had pencils in hand and were writing the ideas of their group mates. Ringo had neither paper nor a pencil during this activity. There wasn't even a pencil behind his ear, something that nearly always was the case the rest of the day.

In groups, Ringo is uninvolved. In that same social studies class, his group was pivoted away from him, in a conversation of their own. I did not sense they had shut him out: more likely he was not aware of how they were working, so he did not shift positions with them. He did, though, on more than a few occasions, joke and converse with Jamie, a student in another group. But when that interaction stopped, either through a word from the teacher, or a question to Jamie from his group, Jamie was fairly quick to get reengaged with his work and his group, whereas Ringo was not.

Elizabeth feels Ringo doesn't like school but only puts up with it—tolerates it. It's a place he has to go, but he hasn't found a reason for it yet. She's not sure when that reason will show itself.

Something Ringo must deal with at school is the autonomy being engendered by the teachers and the curriculum. Apparently, he is not dealing with that well. His attention is drawn elsewhere—to other students, to an opening door, to the window, and to the basic décor of the classroom. To his credit, Ringo recognizes he has some attention problems, as that was one area he felt his Asperger Syndrome affected him. He did not know what to do about those problems, and clearly, when he is involved in something in which he is greatly interested, these problems are not an issue.

Only twice during the day of my shadowing was Ringo called on directly by his teacher—and both of those occurred in the same class, reading. In neither situation could Ringo correctly answer. One of the situations had to do with a simile from the book: “it was like a death.” They were reading Steinbeck’s *The Pearl*, and Ringo was unable to explain what that figurative language might mean in the context of the chapter. A little later, Ringo was asked if he had his ‘stickies’ for the chapter. Each student was to gather some questions or thoughts they had while reading chapter five, and write these onto PostIts. Ringo said that his were in his book and that he couldn’t find his book. When asked if he could remember any that he might have written down, he could not. Later in the day, during his resource room study hall, he was reading the chapter in question.

In fact, during this time, I got an insight into Ringo’s problems with attention. In some ways Ringo may not be aware of how much his attention problems affect him. While catching up on the chapter that had been due in his reading class, his resource room teacher caught him looking into the adjoining room—and clearly he was doing this, as I was observing him directly at this time. But he claimed not to be doing that, but to be reading his book. While it is true that 13 year olds will lie to get out of trouble, this

did not seem like that to me. It seemed as though he really did feel he was reading his book.

The rest of the day was similar to this. Ringo would enter class, generally one of the last to do so, slowly gather his work, and sit silently in his seat. He did engage his brother, Bob, in both math and science class, and occasionally this seemed to be focused on the work. In math, for example, Ringo looked at Bob's in-class worksheet quite often, though it did not seem that he copied that work onto his own sheet. On the contrary, Ringo seemed unable to get started on this worksheet, and when the teacher asked if everyone was doing okay, "Does anyone need any help?" Ringo did not raise his hand or seek her out. He did eventually get some of the problems finished, but as I browsed the work of other students in class, I noticed that each of the math problems they had completed had seven or eight steps to them. On Ringo's paper—and on Bob's—only an answer was given.

In science class, Ringo was working with Rachael on an experiment involving speed measurement. But whereas all of the other groups in class, save Bob's, were actively talking about their experiment, Ringo and Rachael barely conversed. The work required the team to follow the directions of an experiment designed by another group in a previous class. Ringo and Rachael had to make a ramp, measure the ramp, and then time a Hot Wheels car as it descended the ramp. Ringo grabbed the car right away and played with it on his desktop. Rachael was left to do the rest of the work: she stacked four dictionaries to create the angle of the ramp, got some cardboard to build the ramp, grabbed a meter stick to measure the ramp, and borrowed a stop watch from the teacher

to time the car. When it came time to begin the actual experiment, Ringo was glad to be the one who let the car go down the ramp to be timed.

Yet, here, Ringo showed some minor motor skill difficulty in holding the car properly for an accurate timing. He was either pushing it along, which the teacher informed him caused the timing to be inaccurate, or he could not release the car when Rachael said, “go.” As much as she tried to be clear on her, “ready, set, go,” Ringo could not release on time. Other motor skill problems came when he and Rachael had to build a data chart for their experiments. At one point it was clear they needed to increase the length of their ramp as the shortness they had was making too many discrepancies in their times. Ringo’s attempts to erase earlier data showed this skill to be poorly developed, and it slowed their progress in the experiment.

When the teacher called the class back to order, and the groups put their materials away, Ringo returned almost immediately to his seat while Rachael put their equipment back in its proper places. As the teacher debriefed the exercise, getting many students to speak about the issues of following other people’s directions and of creating good experiments, Ringo sat at his desk but was neither focused on the teacher nor on anybody else in the class. I couldn’t tell what he was looking at, though it seemed to be the stack of shelves in the corner of the room where the board games are.

At lunch, Ringo sat with Bob, Jamie, and Mike, though it seemed that only Mike and Jamie talked. He brought his own lunch this day, but he does eat school lunch regularly. Ringo’s eating issues are mild, and his parents tell me—and I observed—that he will eat most things. After lunch, when the three boys go outside for recess, Ringo returned to the resource room to make up some work from other classes. If he gets

caught up, which means getting a note from each teacher saying he is caught up, he can participate in an ice cream party this afternoon. He did get caught up, and he did get the notes, and he did get his ice cream.

Like both of his brothers, Ringo has difficulty putting thoughts on paper. His writing process is hindered both by an inability to move his hands as quickly as his mind works, and by a deficit in linking certain cause/effect ideas together. This problem, manifest in many ways at home during homework time, was made all the clearer in his language arts class on this day. This was a 'time as needed' class, as the teacher called it. A state assessment of writing was ongoing, and students would be given this class period, as they needed it, to work on that assessment. She handed back the work that had been done in a previous class.

Whereas all other students had progressed to the second page, and some were on a third page, Ringo's work showed less than five lines of writing on it. Yet this was a kind of work, the teacher affirmed to me, that Ringo really liked. He had to write a script, directed to a particular audience that would 'sell' a product. Within the writing he had to demonstrate that he had an awareness of certain propaganda techniques. I knew from Elizabeth that Ringo had attempted to write a script in the summer, so I did know he liked this kind of activity. And she had mentioned this to his teacher. I also knew that Ringo had not finished his summer script, but I was not sure if the teacher knew this.

As I watched Ringo work, I caught the same physical demeanor that had appeared in other classes that day: unattentiveness, a looking away, a lack of engagement. Ringo did occasionally write on his paper, but whereas other students had that familiar look of leaning forward with one arm on the table while the other arm and hand put words onto

the paper, Ringo often sat up straight with arms crossed in his lap, swaying a bit from side to side. His hands held up his head more than they handled the paper. By the time the teacher called, “time’s up,” Ringo had nearly filled one page. The other students, though, either were finished, or were very close, and all were onto or beyond three pages.

School/Home

Ringo is often very frustrated with his homework, finding a great deal of difficulty in mathematics. Elizabeth helps him a good deal here, though she does so in a way that it is he who does the work. She has noticed over time, as I was able to during my stay, that Ringo has the most trouble when problems reciprocate themselves, changing the order of functions without changing the nature of the problem. One night, after returning from one of Cosmo’s soccer games, this dilemma was shown clearly.

The work this evening was of the algebraic type: $M + 5 > -7$ and $2 + P \geq -4$ and $3.3 \geq 4 + P$. As she did with Cosmo, Elizabeth focuses her work on getting Ringo to understand the problems, especially the kind of thinking required to solve several similar problems at one sitting. She rarely does a problem for him, but she always asks questions and gets him to think about the mathematical procedures.

Looking at the first problem, she asks, “How do you get the M to stand alone?” Ringo is not sure. “Somehow, guy, you’ve got to get this problem arranged so that the M is on one side of the equation sign, and everything else is on the other.” She pauses.

“Did you do anything like this in class?”

Ringo doesn’t remember, so Elizabeth works on the problem at hand. “What happens if I subtract five from this side of the equation?”

Ringo looks at where she is pointing and says, “that five would become zero.”

“Good. Now everything you do to one side of the equation, you must also do to the other side. Right, guy?”

A little more explanation, and Ringo seems to get this concept. He is able to work the next problem on his sheet, $M - 6 \leq 13$, by adding 6 to each side. However, when he gets to $2 + P \geq -4$, he is unable to complete the challenge.

“Okay, this is the same kind of problem. Do you remember how you got the M to stand alone?” Ringo nods. “So in this problem, what do you have to get to stand alone?”

Ringo sees it is the P, but its new placement in the problem baffles him. Elizabeth gets him to see the similarity of the problems, and he does subtract 2 from each side and eventually solve the equation. But when he moves on to the problem with the letter coming after the equation sign, the same kind of difficulty arises. He can come to understand, at least enough to finish a few examples, an equation like $4X + 7 = 27$. However, when that type of equation is turned around and becomes $36 = 9 + 7P$, Ringo has difficulty.

Elizabeth presses onward, sometimes working with Ringo—and Bob and Cosmo—for hours at a time. Thomas rarely helps the twins in their math, though he does query them on their reading and vocabulary work. His concern with the twins is their organizational skills, as he sees those as the biggest barrier to their success on the high school level.

Of course, there are times when Ringo is fairly content with his homework. One such example was a poster he had to create early in the school year. This poster had to take an important character trait—Ringo chose “Responsibility”—and link that trait to a movie in a creative poster. The movie he chose was *Jaws*, and his poster was colorful,

complete, and allowed him to be able to talk about a movie he loved. It took him nearly three hours to complete that poster, but he enjoyed nearly every minute of it.

An interesting aspect of this assignment was that Ringo had not remembered to bring home the poster paper the teacher had provided to each student. While Bob was making his poster on his paper, Ringo was not sure what to do.

“Can you make your own poster paper?” I asked.

“I don’t know.”

Then Thomas remembered that Ringo had an easel with a large pad of paper, so he used that. The paper was just as wide as that which the teacher had supplied, so it worked fine.

Part of Ringo’s problems with homework is the actual remembering of what was assigned. Elizabeth and Thomas both assert that none of their boys are dishonest and that quite often they just forget all of the pertinent details of a particular assignment. This came to a head during my stay when Elizabeth and Thomas found out that Ringo and Bob were both receiving zeros for math at nearly the mid point of the first quarter. According to their teacher, they had not submitted any work up to that point.

This was quite confusing to all three of us—the parents and me—because we had seen Ringo and Bob do lots of math homework, nearly every night. Elizabeth often assisted them in this work. Papers were dutifully put into their binders and the binders then put into the book bags, which were taken to school each morning. Somehow this work was not being turned into the teacher at the proper time.

“They just forget,” Thomas told me. “It is amazing how much they can forget, when I think of how good their memories are and how much they know.” Nearly all of

Ringo's teachers agree that he not only has a great stock of knowledge available to him, but that he also has a good memory. So how does this happen?

To conquer this forgetfulness, Tom has encouraged the use of a homework chart that has cells for recording not only what needs to be done for each class, but also a place for the teacher to indicate if and when the homework was assigned and passed in. But this chart is only effective if Ringo (Bob has one too) remembers to show it to the teachers and then bring it home with him. When he doesn't, which was fairly often while I was there, he can't recall the assignment to any degree of accuracy, and so he doesn't get all of his homework done. The teachers don't seem to be eager to remind him of the chart, either.

Yet there was a Monday morning when Ringo grabbed a sheet of paper off the dining room table—the family's catchall area for documents, mail, etc.—and asked his mother, "Will you please sign this so we can go to the spaghetti dinner this Friday night?"

No one had spoken about the spaghetti dinner since Friday, three days previous, when the slip came home. At that time only a small conversation ensued, and there had been no real decision as to whether they would go.

Part of the concern was that Cosmo was only now just liking to eat spaghetti, and Thomas thought taking him could be unfair, since he might not eat. And Thomas generally only supported family events that included the whole family. But Ringo remembered the dinner—spaghetti is one of his favorite foods—even after nearly 60 hours of no conversation about it. So, clearly, his memory does work for the things he's interested in.

CHAPTER SEVEN: BOB

An Introduction

At the end of his fifth grade year, in the note his teacher wrote to accompany his last report card, Bob's teacher commented: "Bob had a great quarter! Writing is still sometimes hard for him—hard time staying focused. He has become very independent!"

Independence may be the mark that sets Bob apart from his twin brother, Ringo. According to his mother, Bob already has a dose of pubescent adolescence in him, much more than Ringo does, even though he is only one minute older. At times there even seems to be angst about him, in the way he reacts to his parents and his brothers. Though both other boys express great frustration at times in their lives, in Bob this kind of expression seems to be a part of his developing identity. I'm not saying he is a frustrated young man; rather, it seems to me that his expressions of frustration are fully in character.

For example, there are times when Bob deals with what might seem to be frustrating moments extremely well. He is an avid video game player, and he is quite good at many games, but whereas his brothers can be given to loud verbal expressiveness when the games do not go their way, Bob is rather stoic in his playing. In fact, he teaches himself the games he plays by working through many of the levels in order to master their nuances. I watched him learning a new game that involved a car that morphed into other vehicles, and many times he faltered and the game stopped. "Doesn't it bother you when that happens?" I asked him.

“No. I’m just practicing now. Maybe later, when I actually start playing, it might bother me. But not usually.”

Bob applies his own learning curve to the games he plays, and because of that he showed me two important things: 1) he is a good learner who understands much about his own processes of gaining knowledge; and 2) he can understand the difference between the process of learning something and the time when he is actually *doing* that thing. Would that all learners had this skill.

Many mornings, especially Saturday and Sunday, Bob is up with the sun—and earlier—and plugged into the PlayStation. He has some favorite games, like SIMS, but by my observation he is a more global game player. During my stay with the family, I saw him play five different games in a random rotation. Bob is the one his brothers go to when they are having difficulty with a game.

Those interactions that position Bob as the information giver to his brothers show a type of interaction the boys have with each other. One evening Cosmo was having a very difficult time moving “to the next level” on his GameBoy, and he approached Bob, who was playing SIMS.

“Bob?” Cosmo asked, “can you show me what I’m supposed to do here?”

“What level are you on?” Bob asked, while still working his thumbs speedily on the controls.

“Ah, it’s level three, where I have to jump the barrels and the blocks.”

“Okay. Can you wait a couple of minutes?”

“Yeah.”

Cosmo sat with both hands on his GameBoy while Bob continued to build his SIMS house. It was more than a couple of minutes, but at no time did Cosmo interrupt Bob's game, not even with a comment on the action that was appearing on the screen. When Bob got to a stopping point, he put down the controls and asked Cosmo for his GameBoy, not verbally, but just by reaching out his right hand.

"You just need to move the guy over here," Bob showed the small screen to his brother. "And then you make him go through that spot there." He said "there" with an emphasized body movement.

"Okay," Cosmo said, and he slid back into the swivel chair and pushed the buttons with his thumbs. Bob went back to the SIMS game on the TV screen. No 'thank-you,' no nods of approval, no eye contact in the exchange. But it was a sibling interaction, and the boys knew the roles they'd be playing before it began.

Of the three boys, Bob was the hardest for me to engage conversationally. Part of that may be his earlier entry into adolescence: as an outsider, I was unfamiliar and perhaps not to be trusted. But as my time with the family lengthened, it was Bob who offered some of the more telling bits of information, stuff that must have come through a developing trust of sorts.

For example, Bob informed me that for the mock election at school, he was going to vote for Kerry. When I asked him why, he told me "Because that's who my father's voting for, and it's just easier to go along right now with that. When I'm older, I suspect that I'll think differently politically."

And two other times Bob made remarks that showed a tension that can exist between him and his father. Once it was at the dinner table, and Bob told Cosmo not to

continue to argue with his father because, “It’s not worth it. You won’t win.” Another time, while playing miniature golf, Bob told me he was glad he was playing with me and not with his father: “Sometimes he can take the fun out of it, always telling me what I’m doing wrong.”

Of course, both of his brothers mentioned that it is their father more than their mother that they worry about when they’re in trouble. Ringo, in his chapter, noted that his father “can be crabby sometimes.” But their comments were hidden almost, whereas Bob’s were out in the open. It may have even been possible that his father heard the comment at the miniature golf course. So in this regard, Bob is very different from his brothers, more independent in his thinking.

Bob obviously likes his father and seems to cherish some of the moments they share together. Occasionally Bob and Tom compete in video games against each other, something Thomas doesn’t do with the other brothers. The few times I observed this, it came as a friendly challenge from father to son. Bob generally wins these matches, and he seems to like the bragging rights that come along with those wins. He isn’t highly verbal about it, and I never caught him gloating or even bringing it up away from the context of the duel competition, but he did show a sense of approval when he’d beat his father, which, I might add was all the time.

Bob was the only one of the boys who, when asked to describe his family, said they “spend a lot of time together. Actually,” he continued, “there was one time when at least once a week we would all get together and play a board game.” Neither Ringo nor Cosmo mentioned the family’s togetherness during our interviews. A little later into our

conversation, Bob admitted to me that he'd like the playing of board games to occur again, and regularly.

Like his brothers, Bob mentioned that "Everyone in our family has a good sense of humor. My mom and dad both know how to cook really well." But at that point he stopped, saying "I can't really, ah, I'm having a hard time with this one." It was our second question.

I was also intrigued at Bob's choice of hobbies and interests: "I like to go biking, I like to tell jokes, and I like to play video games." When I asked him what his favorite of those three were, he told me biking. Yet while I was with the family, I only saw him go biking three different times. On the other hand, as I have already mentioned, he played video games daily, often for many hours a day.

Like his twin brother, Ringo, Bob is short worded in conversation, unless he is relating a tale from a favorite movie or television show. He also has an interesting vocal quality, though not one unpleasing to hear. His phrasing is clear; his consonants, his vowels, and his words are all wholly sounded out. He rarely slurs any words together. His speech therapist described it as mechanical, though I would not go that far. There is an unusual quality in his intonation, but it is easy to become accustomed to.

As with all three boys, he is well liked by his teachers and, seemingly, his peers. Bob is the only one of the boys whom I saw enter a group of peers who were already playing together, but I'll say more on that a bit later.

Standing beside Ringo, Bob is taller, leaner, and harder in his physical appearance, though these differences are more difficult to discern when the boys are far apart. I got an initial impression that Bob was more athletic than Ringo, but that didn't

pan out when I went to the cross-country meets, where Ringo always finished ahead of his brother.

Still, Bob was the only one of the three boys who I saw respond to a direct challenge from a stranger: at the end of one cross-country meet, a boy from another school was gaining on Bob near the finish line. As the opposing runner approached, Bob worked harder and harder, making sure he did not get passed. This is another part of Bob's independence, I think, as it shows him asserting his identity upon his world. I don't believe either Ringo or Cosmo would have the fortitude to work as Bob did here. Nothing in my observations showed me that kind of strength in them.

A Closer Look

Though all of the boys have this tendency, Bob is affected more by his literal mindedness. Early in my stay, Tom was checking on the boy's progress with their evening's homework. When he got to Bob, who was apparently finishing his math, he asked, "Did you have any other homework tonight, bub?"

"What?"

"What other homework do you have to do?"

"It's already done."

"Where is your other homework?"

"I did it in school."

Tom, now a little agitated, says, "Bob. I don't care when it was done. I don't even care if it was done. I just want to know what other homework you were assigned for tonight."

"I had to read a chapter in my science book."

“Okay. And you got that done at school?”

“Yut.”

“Great. That’s what I wanted to know.”

Another time, Bob and Ringo had ridden their bikes up to the schoolyard, while Tom, Elizabeth, Cosmo, and I walked up later. Upon arriving there, Tom’s first words to Bob were, “What part of riding together don’t you understand?”

Bob was riding alone at one end of the athletic field, and Ringo was not in sight. Bob did not answer the question.

Thomas then asked, “Where’s your brother?”

“He’s riding over by the school somewhere.”

Tom asked again, “Is this what riding together is?”

Again Bob didn’t answer. At home, before leaving for the athletic field, Bob had asked his father if he and Ringo could ride up to the field on their bikes.

“As long as you ride up together,” Tom told him. The boys then got out their bikes, their helmets, and headed off for the field. In some ways, Bob had done exactly what his father had told him to do: he had ridden to the field on his bike with his brother. Once at the field, though, he was in a new situation. Riding with his brother was no longer mandatory by his father’s edict. Perhaps there was no reason to answer the question, as Bob understood everything he needed to understand about riding together.

That day at the field I observed Bob approach a group of six age-mates who were playing soccer on an adjacent field to the recreational games Cosmo was involved in. As soon as Bob arrived at that field, the group put him in the goal, and they played three on three soccer.

“Hey, Bob.” A couple of them said. And one pointed at the goal cage, saying, “Bob, play goalie for us.”

Bob trotted awkwardly to the net and stood firm in the goal, his right hand across his body holding onto his left arm, hanging straight to his side. The ball started toward him, but then a player intercepted a pass and began dribbling the ball downfield. Bob’s posture did not change. As play continued, and the ball came back toward him, this time getting within shooting distance, his right hand did drop to his right side, but his feet stayed still. There was no shot on goal while Bob was the tender.

After about four trips up and back the field, the boy who had directed Bob into the goal took his place. But rather than joining the five other players in their three on three match, Bob stood near the side of the field and watched.

“Bob, Bob. Come on in. Get up here. Take the wing.” Several different voices shouted to Bob from the playing area. Bob stayed on the side. At one point he sat down and played with the grass in front of him. Play on the field broke down, either from fatigue or just the way playground ball can breakdown at odd times.

One of the players grabbed an extra ball and brought it onto the field. Another kid joined the boy in the goal. The kids started taking shots on goal, and their conversation picked up quite a bit. I’m standing a good ways away, so I can’t make out the exact topics of conversation, but I can see face-to-face engagements, hand gesturing, and general good fun going on with the six kids kicking the ball toward goal.

At one point a ball goes over by Bob, but none of the kids chase it. Bob gets up and walks to the ball, then dribbles it to where the kids are. After a couple more dribbles, he takes a shot on goal, but the ball goes wide. He doesn’t chase the ball. Many similar

situations follow, and I notice that Bob kicks the ball with his right foot sometimes, and with his left sometimes. Neither foot gives a stiff kick. I also notice that Bob does not engage the others in conversation—I see no gestures and no face-to-face exchanges, though the other six continue to talk and kick continually.

Bob did chase one ball that went wide of the goal, though it was not one he kicked. As he dribbled that ball back to the playing area, from behind the end line, he attempted a quick turn and kick for a goal, but he missed. Both the turn and the kick were awkward, especially in comparison to the six other players on the field. Bob chased this ball, and then he kicked it through the back of the goal, raising his hands as if he scored. No one seemed to notice this action.

None of Bob's social interactions are energetic. It is rare for him to begin a conversation, though he will say an opening "hello" or "hi" most of the time. And he seems to try to avoid some kinds of interactions, though the particular types are random by my observation. I've already mentioned that when he was describing his family, he stopped and told me he was having difficulty with that question. Another time I asked him if he had gotten anything in Baltimore, the time when Cosmo had gotten his poster on Mars. Bob stopped for a second—we were right outside Cosmo's bedroom—brought his hand to his chin, and said, "I don't remember."

Now certainly it is possible that he did not remember, but I also heard him use that line to respond to his father and mother on several occasions. Never were the occasions pressing; often they had to do with simple daily experiences at school. But it struck me that Bob had learned a way to avoid the conversations that might have given him anxiety.

Bob has nearly always had interesting situations interacting with others. Even in the interview during the assessment that brought on his diagnosis of Asperger Syndrome, in January 2000, he admitted that, at times, he does not get along with his peers. Sometimes they are interested in playing with him, but generally he is not interested in playing with them.

Later that year, in a school observation by the ESE specialist, Bob was involved in a paper plate lion activity. He was supposed to pass materials to the next person in his group, but he did not do that. When that person grabbed the necessary materials and then mildly chastised Bob, he did not seem bothered by her words. He rarely spoke during the activity, nor did he smile or seem to be enjoying himself when his peers interacted with him about their creations. As the activity came to an end, and the students were preparing to go home, Bob took much longer than the others to get ready. He was distracted during this process, but his distraction was not caused by others, but from his own wandering attention.

Distractibility is an area where Bob has a great deal of problems, and an area noted in his diagnosis for Asperger Syndrome. Bob often needed multiple redirections in order to complete many of his school tasks over the years. His kindergarten teacher saw this as a fascination with school, but other teachers have seen it as a deficit. It causes him to seem to be motivated on some days, while on other days he has a hard time getting focused on any work at all.

A classroom observation from April 2003 reads this way: “Bob came into the classroom at the same time as his peers. He stood up in his chair until the teacher began lecturing. At this point, he sat down and watched the teacher. But he really didn’t seem

to be paying attention to her. As he saw other students taking notes, Bob began to look through his book bag to find his materials. Bob spent the next five minutes of class looking for a pencil, looking through his folders in his binder, and watching other students work. He did not respond to any of the questions the teacher asked the class as a group, but he did respond quietly to the questions she asked him specifically at his desk. Bob was prompted twice by the teacher to get back on task.”

Certainly these behaviors can be seen as characteristics of Asperger Syndrome. But as far as that condition goes, Bob feels he is basically unaffected by it. He admits to knowing very little about it, and doesn't even mention the neurological aspects that Ringo mentioned. Bob does feel that Asperger Syndrome affects his organizational skills, but that's as far as he goes. It is, to him, not affecting him at school, at home, or with his friends.

At School

Bob told me he was looking forward to school this year, a response that was different from his brother, Ringo's. Yet, when Ringo heard Bob's comment, he changed his to one of a more positive anticipation. And whereas both Ringo and Bob dislike math, it is only Ringo who would like the school day a “whole lot better” if there were no math at all. Bob told me quite stoically that it was important to take math, no matter how much he didn't like it. He felt he would need it later in life.

On the day I shadowed Bob at school, he gave the morning announcements. He did not tell me he was going to do this, so I did not go with him when he left his homeroom at 8:05. I thought he was probably going to his locker, so when his voice came over the intercom, I was quite surprised. It is something he has done regularly, and

for the most part he did it very well. It was certainly Bob's style of announcement: no wasted words and clear phrasing. He ended with a monotonal, "have a good day."

He returned to his homeroom and sat beside John, who leaned over and said something quietly to Bob. Bob laughed, but he did not seem to return comment. He noodled with his binder on his desk and got up to leave when the bell rang.

Throughout the day, this kind of interaction was the most common from Bob: listen, laugh, nod, and acknowledge, but he rarely talked with his classmates. Considering he worked in groups or pairs in three of his classes, social studies, science, and math, this lack of interaction was quite apparent. It also, at times, made it difficult to say whether or not Bob was paying attention to any of the activities or information being shared in the class. He almost never engaged the teacher, and rarely was his gaze directed in her direction while class was conducted.

There were times contrary to that brief description. In social studies, he, Larry, and John splintered off from their group—the class was forming political parties—to form their own group. Once the three of them circled their desks together, Bob did engage them in conversation, and he seemed to make eye contact with them as they spoke. However, this initial engagement brought about a good deal of laughter, and after the teacher mildly admonished them to focus on forming their party, the conversation shifted to one between John and Larry, and not so much Bob. He was still paying attention to them, but it was clear that he was not offering any words or ideas to their discussion.

When the teacher attempted to get the attention of all the groups, to remind them of the specific elements their political parties would need, Bob's attention diminished

greatly. He swiveled in his desk and seemed to focus on the ‘talking wall,’ the place where he and his classmates could write captions to their school pictures. This was a class that demanded a good deal of student autonomy, and most of them enjoyed that style. It seemed as though all of the groups worked well toward a goal, and even Bob’s group had some intent, though often Bob did not seem to be a part of that.

In the next class, language arts, learning began with a pop quiz over materials covered in yesterday’s class and for homework. Students were given about five minutes to write the eight basic human emotions/desires to which advertisers appeal. Bob was slow to be ready, and by the time all the other students were making their lists, he was still without paper or pencil. He fumbled in his binder, slowly, to get these items. When time was called, though, Bob had finished his work and did have eight items on his list.

The teacher then takes the class through the list by soliciting responses from her students. Bob raises his hand and offers two items—appeal to the opposite gender and issues of superiority. This class is quite different from the last one in that the teacher seems to have her hand in everything. Students work individually and are called on by her when they raise their hand. Though there is some talking going on among students—this is a middle school, after all—the class is more ‘orderly’ than the social studies was.

Bob seems to be more involved in this class. After offering two ideas from the list of quizzed concepts, he added “humor is another area advertisers appeal to.” And when the teacher asked if there are others anyone could think of, Bob’s hand was up again: “Some advertisers like to use children and animals to get our attention.” His teacher thanked him for the extra ideas.

But when this class shifts to another activity, Bob has difficulty making that transition. Everyone is supposed to have a handout that was distributed on the previous day, but Bob does not have his.

“I think it’s in my locker,” he tells the teacher who lets him go and check. He returns empty handed.

“I must have left it at home.”

“You will need that everyday,” she tells Bob. “This is the new state assessment, and we’ll be working on it for a while now.” She gives him another copy.

For the next several minutes the teacher explained the assessment they would be engaged in for the next few weeks. It was a new assessment, and they would be collecting materials, writing drafts, organizing their time, and, finally, writing a script for a commercial that hoped to sell a particular product to a particular group of people. Many in the class were taking notes, and the teacher encouraged them to write on their handout: due dates, quick ideas, planning and organization information, etc. Bob did not write on his sheet. The teacher informed the students that much of the work would be done in groups, and in this class, the teacher would make the groups. However, in doing this, she put Bob, Larry, and John in the same group, adding Mark to that mix.

Once in this group, Bob’s engagement with the class diminished noticeably. He did engage the others when they first come together, but it was short lived, and apparently not to the point of the work at hand. The teacher approached this group first and encouraged them to “Take some time and come up with a product you’ll all want to work on together. You’ll be able to do this at each other’s homes if you want, so take

some time and be sure it's something you really want to do." While she was speaking Bob was paying attention to another group.

As the class came to an end, assignments for tomorrow were given. Students were to brainstorm ideas for their product; they were to divide some of the group responsibilities; and they were to be ready for this week's spelling test. Bob wrote none of this down, and that night, when he was home, he only remembered to study for his spelling test.

Bob and Ringo share some classes, and when they do, they sit together. Math, Bob's next class, is one of these, and both of them arrive after nearly all other students have arrived, Bob coming in behind Ringo. Their teacher is at the door for nearly all the arriving students, but she has stepped inside before Bob and Ringo get there, so they do not hear her, "How ya doin'?" when they enter. I wondered if they ever had.

This class encourages pair sharing, so Bob and Ringo sit at the same table and do just that. As the class goes over the homework—both boys have theirs out in front of them—students are encouraged to offer answers to particular problems. Neither of them offers a response, though when unison responses are asked for, Ringo echoes with the class and Bob remains silent. This homework is collected and the teacher introduces a new kind of formula.

The class then turns to table work from the textbook.

"You'll need your own paper for this," the teacher tells them, and Bob grabs his binder from under his seat. He is meticulous at getting his piece of paper from his binder, folding it carefully along the perforated edge and then tearing it slowly. He needs to pick off the extra paper that makes the tear uneven, and this takes him a good deal of time,

mainly due to the deficit he has in his fine motor skills. But it is interesting to watch the contrast of his action with his paper set against most of his classmates, who merely rip their paper out of their binders. Ringo, on the other hand, has some single sheets in his binder, and he grabs one of those.

The class is given about 15 minutes to do the work from the text, and Bob has taken nearly five of his to prepare his sheet. When the teacher calls time, Ringo has completed only two of the examples—there were four—and Bob has not completed any. Bob takes a long stretch here, arms over his head and then out to the side, as the teacher goes over the work on the overhead projector. She then walks around the classroom to collect the work. By then, both Ringo and Bob have completed theirs, having written the necessary information as it was presented by the teacher.

During most of the day I observed Bob, I found him to be basically a good student who has a good deal of difficulty staying organized. He has some interactions with peers, finds time to laugh with friends, though it is not a great number of students with which he does this. He is generally slow to be ready for class, and he seems to be unable to look ahead to the common things that happen in the classroom. Clearly he has some attention problems that I'm sure exacerbate his organizational issues.

Because of his Asperger Syndrome, Bob, like both of his brothers, receives special services from the Special Educator in the resource room. Each day the twins spend two study hall periods in the resource room, with a teacher they seem to tolerate more than they like. Occasionally they are in there together, though it is more likely that they spend this period without their twin but with their other brother, Cosmo.

Today's study hall has Bob by himself for a while, with the emphasis on catching up on missed assignments. Initially Bob is unaware if he is caught up or not in his subjects. His teacher speaks to him about why that is.

"Let's get your binder out, Bob. Okay?" Bob grabs his binder from under his seat.

"Can you show me your math folder?" He can't.

"Can you show me your social studies folder?" He can't.

"How is it you're ending up with so much loose stuff here?" She sorts through the many sheets of paper that are floating freely in his binder. "What are all these papers for, Bob?"

"I don't need most of them," he says. "I just stuffed them in here."

"Are you sure you don't need them? Don't you think your mom and dad would want to see some of your finished work?"

Bob shakes his head, "I don't know."

"Well," she tells him. "Why don't you go through each of these sheets, and if you're sure about them, you can recycle them in the yellow basket. Then, when you have only the ones that are important, we'll arrange your binder so you can get to the work you need, when you need it. Okay?"

Bob nods and goes about the task. He works at a small cubby—the same one that Ringo works at when he's in here—but I'm not so sure I'd call what he's doing work. He played with his pen a lot of the time, and seems to collect whole bunches of pages without looking at them too closely. When he throws them into the recycle bin, his teacher encourages him to make some new separators for his binder by using the three-

hole punch and some file folders. Bob has difficulty working the three-hole punch and takes longer than his teacher would have liked. But she is patient with him, and she encourages him all the way through the task.

Early the next week I met with her to conduct a more formal interview, and she told me that Bob came back to her study hall the next morning looking for some of the papers he had recycled. It seems that at least three of them were assignments he should have passed in to his language arts teacher. Fortunately, she still had them, and he dug through the recycle bin and retrieved them.

In science class, taught by the same woman who teaches math, groups of three were formed, and each group was asked to assign roles to the group members: recorder/reader, task master, and time keeper. Bob's group, again with John and Mark, could not make a decision, so the teacher stepped in and assigned them: Bob was to be the recorder/reader. He would have preferred to be the taskmaster.

Much of this activity had to do with following directions well, and so Bob's role played an important part, as he was the one who would not only read the directions to the group, but he also was the one who would record the data as it was collected. He had some difficulty in both parts. First, the teacher caught him reading carelessly, and had him reread a section that dealt with drawing lines and creating spaces. Then, while the data was being collected, Bob's deficits in motor skills made it difficult for him to get the data neatly into the proper place.

Lunch followed science class, and Bob sat with Ringo and John at a round table in the middle of the lunchroom. Occasionally John would talk toward Ringo and Bob, but generally they did not respond in kind. They ate their lunch and then went out to the

playground for the remainder of the lunch period. In the schoolyard, Bob basically hung out with a few kids, John and Mark included. Ringo went back to the resource room to do some work. The boys in Bob's group walked around the yard, stopped occasionally, but didn't get involved in any games that were going on.

Mark and John, I came to find out, were outcasts at the school. Mark was an especially likeable kid, in my mind, interested in many things that could bring a spark to a classroom. I liked him as soon as I heard him talking to his reading teacher about a great blue heron he saw once by a river. It seems as though Mark is looking to make friends, but he's finding it difficult at this school.

One day, after school, Mark stopped by the Berkley house to get the twin's phone number. He called later that night, and Cosmo answered. He brought the phone to Bob, who was still at the dinner table, eating supper. I could hear Mark's voice on the other end of the phone—he just wanted to talk.

“We're eating supper,” Bob told him.

“Oh, I'm sorry. I'll call back later.”

“Okay,” and Bob nearly hung up.

“Wait, Bob,” his father and mother both told him, almost immediately. “Get his phone number, and then you can call him back.” They relish the idea that a potential friend is on the other end of the line.

“What's your phone number?” Bob asked, and Mark started to tell him. “Wait a minute. I need to get a piece of paper.” Bob left the kitchen.

Later that evening, Mark called again, and Bob told him he was doing his homework, which ended the phone call. Mark didn't call again during my stay.

The rest of Bob's school day followed the same pattern as the beginning: he was generally late to his classes, he is slow to be ready to work, and he has difficulty when the work changes from one activity to another. I was able to look at a test Bob took over the book, *The Wave*, which was being read in his reading class. The teacher also let me see other students' tests. With only two exceptions, Bob's work was the best in the class. His responses were in complete sentences; several were two or three sentences; and he even answered an inferential question fairly well. His teacher told me he did need much more time than his peers in finishing this work. Whereas they were done in one class period, Bob took a major part of three class periods to do his. But the quality was there in a way that showed him to be a good worker and thinker.

Bob, like his brother, Ringo, runs cross-country for the school team. Neither of them are great runners, though they go to practice everyday, they compete in the meets, and they get very excited about their performances, especially when they surpass previous finishes. For a while it was doubtful if Bob was going to run this year, finding little joy in the actual running, but he did decide to participate, as there were other runners on the team he called friend. At the first meet this year, Ringo came in 30th and Bob came in 31st, which meant they both got a ribbon for their participation.

Bob was especially excited when he got home. "It was great. Ringo was 30th, and I was 31st, and the whole team got ribbons," he told his dad eagerly.

"So are you glad you stuck it out this year?"

"Oh, yeah!"

And both boys work as ball boys at the soccer games. This is an interesting experience, as neither of the boys really cares for soccer. And if truth be told, I'm pretty

sure that Bob would say he doesn't like being a ball boy either. Neither runs the sidelines very energetically, and at one game, Bob solicited the help of a younger schoolmate, who really took the task to heart, running up and down the field with the action. At another game, the twins arrived late, and two players were running the sidelines.

When he sat down beside me, I asked him if he were going to be the ball boy for the game. "No," he told me. "Today I'm going to watch."

Then his father, sitting a couple of seats away from us said, "Bob, go and take Mike's place [as ball boy]."

"I thought I'd just watch today."

"Brian's depending on you, bub," his father told him. Brian is the soccer coach.

Bob looked at his father and then at the ground. He got up and walked to Mike, who returned to the team bench. At the next game, Bob not only came late, he stayed quite far away from his father.

Another example of Bob's literal mindedness was apparent at the soccer game where he replaced Mike on the sidelines. At one point, a soda can blew near the field and it was looking like it might blow onto the field. Tom yelled to Bob, "Bob, pick up that can."

Bob did, but then he held it for nearly 15 minutes, walking the sidelines with a soccer ball in one hand, and an empty can of soda in the other. He never seemed to recognize that what his father wanted him to do was pick up the can and throw it away so it wouldn't blow onto the field. Bob could have very easily walked the 10 to 15 feet to the trashcan or to his father and gotten rid of the can. But he merely followed the directions of his father and picked up the can.

School/Home

Like his brothers, Bob does an inordinate amount of homework. All of the middle school teachers who work with the twins say they do too much homework. The problem, they tell me, is that Tom absolutely stresses that the boys do just as much work, and the same work, as their classmates. Trouble is, this can take the boys a lot longer than their peers, and as has been mentioned, each can have nights where he does more than three hours of homework. Almost regardless of the kind of work it is, that amount of homework is never pleasing to Bob. Ringo can tolerate some of the work, if it plays with his interest of drawing and creating. Not Bob.

Most of the time, Bob does his homework in solitude, either at the couch or love seat in the living room, or at the kitchen table. Ringo, too, has a spot to do his work: at the desk in the TV room. But on occasion the twins work together, and sometimes, all three can be found at the kitchen table doing schoolwork. That arrangement, however, can become problematic quite quickly.

One evening Elizabeth was at the kitchen table, helping the boys with their math homework, and especially giving attention to Bob as he was computing the formulae to calculate slope. I was watching from behind Bob, trying hard to recall that work from my limited mathematical past. It was not coming back. So I asked Bob to explain his processes to me, and he did so, but very slowly.

“Each of the lines,” he told me, “cross the point somewhere. Some go to the right and some go above the two lines, the X and Y coordinates.” He rarely looked at me when he spoke, but he was nearly constantly looking across the table to his mother.

“You pick two spots on the line,” he continued, “and you label their intersections.” He traced his pencil awkwardly along one of the lines on his worksheet. “Then, after you, ah, pick those two points, you figure out the slope by using the formula in the book.” He looked at his mother. “Mom, maybe you can explain this part more clearly than me.”

But I then asked him, “so are you just counting on this point here and this point here?” I pointed at the points I was referencing.

He thought for a second. “Yes,” he said. “Those two points cross, and so they gave me these numbers.”

Bob is actually pretty good at math, and according to his mother and his math teacher, he is more proficient at it than Ringo. But Bob lacks the confidence in the subject that might let him get over the obstacles he sees therein. Ironically, Bob is not as skilled in writing as Ringo is, but the work he did on the test over *The Wave* belies that fact. Again, it seems as if it is his self-confidence that hinders his skill development.

His greatest academic skill comes in reading, something his teachers and parents have noted throughout his life. He enjoys books, and voluntarily began *The Wave* early in the school year, even before it was officially assigned. On the bookshelf he and Ringo share in their bedroom, are paper back and hard bound copies of the whole set of *The Chronicles of Narnia*, *Harry Potter*, *Goosebumps*, *A Series of Unfortunate Events*, and *The Lord of the Rings*. Bob was also reading the parody, *Chicken Poop for the Soul: Stories to Harden the Heart and Dampen the Spirit*, and getting great delight out of that.

Bob is very good at taking care of himself in nearly all situations. One morning he arrived to the breakfast table to find that his plum was badly bruised and, to him,

inedible. (Thomas sets out the boy's breakfasts each morning before he goes to work, making sure they each get a piece of fruit they like.) He attempted to work with the piece of fruit for a few moments, but finally decided that it was not worth the effort. He tossed it away and scavenged through the fruit bowl for a better choice. He eats his breakfast quickly, especially on days that he takes the first shower, so that he can have more time to play video games. Neither Ringo nor Cosmo have mastered the breakfast routine as well as Bob.

When Bob was ill, he also took good care of himself. Even with his father at work, his mother at the dentist, and his brothers at school, Bob does what is needed to help himself get better. He administered a nebulizer treatment. He took care of his coughs, a process that involved going back and forth to the bathroom several times. And he is aware that when he is sick, he needs to stay away from food to some degree. He has, according to his mother, "a very sensitive gag reflex that often forces him to cough up phlegm. When he has food in his stomach, that comes right along with it." Bob knows how to tend to that sensitive gag reflex.

A final aspect of Bob that is important is his concern for his brother, Cosmo. He is concerned about Ringo, but not in the same way. I've mentioned, in Cosmo's chapter, that Cosmo doubts his brothers' concern, but I saw it come one evening from Bob quite clearly. Ringo, Bob, and I were in Tom and Elizabeth's bedroom watching television and sharing our favorite *Seinfeld* episodes. The door between the parents' and Cosmo's bedroom was open. Cosmo suddenly appeared, and it was clear he had been crying. He looked at us and closed the door. But as soon as the door was closed, Bob, who had been telling a story about Putty and Elaine, stopped and spoke through the door to Cosmo,

“Cosmo. Are you okay?” He walked toward the door to listen. “Cosmo. Cosmo,” he repeated.

Cosmo never answered, and Bob never opened the door. However, his concern was clear to me.

CHAPTER EIGHT: ELIZABETH

An Introduction

Elizabeth Berkley, in November 2004, was 42 years old. She is an infection control nurse, working in a prominent medical center in New England. She has been at the job for 2 ½ years, and she has been a nurse for 20 years. She lives with her husband and three sons, in the same small town where she grew up. Her mother lives close by, as does one of her sisters, and Elizabeth sees both of these women often.

Elizabeth has a second cousin with Down syndrome, but that family moved to Indiana when Elizabeth was very young. Before her children were diagnosed with Asperger Syndrome and PDD-NOS, she had little contact with any children or adults on the autism spectrum or with disabilities in general. Her initial information about autism came through her studies at nursing school, focusing mostly on classic autism, and she read about children with helmets and repetitive head banging action. Autism, to Elizabeth, meant cold children who shunned physical contact. It meant mental retardation.

When Cosmo needed to be assessed for the possibility of having autism in 1999, it was very scary to her. And when she heard the term, especially in regards to Cosmo, she thought of the state mental health hospital. These days her fears are quite different as she knows her boys are not bound for the mental health ward. Now her concerns are about transitional elements in their lives: moving from middle school to high school,

from a small neighborhood school to a larger community school, and ultimately from school and home life to independent living.

When Elizabeth recalls the first signs of Asperger Syndrome in her family, now that she is fully aware of the diagnosis, she goes “all the way back to the beginning when I was pregnant. Ringo was twin B; he was on the right side. You know, in mid-afternoon, he was just this rambunctious little thing. I’d have legs, and feet, and butt, everything just sticking out, you know. In one of his ultrasounds, it looked like he was riding a bicycle, his legs were just going.” She remembers Ringo being a crawler and, later, a walker, when he had some anxiety. More in hindsight, she remembers him being a hand flapper, though not to the extent that he was a pacer. “When he was a toddler,” she adds, “we had a small trampoline and, well, they both jumped on it so much that they actually broke some of the S hooks on it. And Ringo was primarily the one that used that.” So Elizabeth remembers the incredible, nearly hyperactivity of the twins, but especially Ringo.

She also recalls some transitional issues with all the boys, but these weren’t issues that really became apparent until after the initial diagnosis, Cosmo’s. Some of this recognition came from the reading material the psychiatrist gave Elizabeth and Thomas after that diagnosis, and they noticed almost immediately that Bob “had a transition problem with things like shirtsleeves length, from short to a long or a long to a short. Ringo had the issue that we didn’t realize at the time, as far as grass on his feet. We didn’t know it then, but he didn’t like the feel of grass on his bare feet. He’d be kind of curling his feet up, you know, and trying to lift them off the ground. Let’s see, that was a Labor Day weekend, so [looking back] he was a little more than 12 months old.” She

showed me a picture of Ringo that day with his tiny feet in the air above the grass. But clearly, her understanding began to be developed after the first diagnosis, when she was able to rethink many idiosyncratic behaviors in a more informed way, based on some literature the doctor had given her.

Cosmo, for example, wasn't a talker early on. But according to Elizabeth, "We were never really aware that he wasn't speaking. Say if I was standing at the sink, and he wanted water, he would come up and point and I would know what he wanted. Or he would look at me and look at the sink and whether he wanted a drink or if he wanted the light on, you know, he got his point across." Cosmo got excited easily, but he always calmed well. And he was so unlike the stereotypical kid with autism in that "he loved hugs and was the snuggliest baby. He always loved being hugged and cuddled." Looking back, she doesn't think she was in any kind of denial, but rather was reacting differently to the very different kinds of stimuli presented to her from across the spectrum.

Ideas of real problems weren't raised until the ESE specialist came to Cosmo's class to observe another child, but saw Cosmo playing at the rice table. She noticed some tendencies for perseveration, and she suggested that he be evaluated, as she also spotted major transition issues when Cosmo went from one activity to the other, not settling into the next activity until it was almost done. But thinking back on this, Elizabeth recalls: "We had nothing like that at home. I think, you know, we can give them fair warnings, we had our own little routine. You know, it's kind of like, you get up, you have breakfast, you get dressed, there is some playtime, and by then it's lunchtime, and you eat. And, you know, if he wanted to play a little bit longer, we let him play a little bit longer. It was never like you know, OK there's 10 minutes for this activity, 20 minutes

for the next activity, and now everybody's got to go do whatever. And it was in those kinds of things that the transition issues showed up. It was never an issue at home.”

And, of course, this is a key area for dealing with Asperger Syndrome and developmental delays in the Berkley household. Elizabeth compares herself with other families she knows who have children with Asperger Syndrome. She sees a great difference in their view of school and of family cohesiveness. “I hear a lot of parents and coworkers who just hate the summer, because they have to deal with day care, because they have the kids around all the time. But for us that's the most fun. Because in those times you can be with them, and *just* be with them. You don't have to be checking if they've got their homework done, or if they're doing this or doing that. It's just kind of being a family. Whereas during the school year there's always something getting in the way, always something that has to be done.”

Elizabeth describes Asperger Syndrome as a wiring issue. “As far as we are all wired differently, and as far as some people have kind of a straight wiring, where all the messages go where they are supposed to go. Some of us have little circuits off to the side, and messages sometimes take a long way around to get where they're going to. And other times they get lost and don't ever get there. And the information is still somewhere in that circuit, but they can't tap into it. So just trying to figure out their wiring, how to help them accomplish what they want to accomplish, and to be healthy, happy, productive adults. We need to figure out what they want to be and to do. Which is difficult for anyone, anyways. I mean, how does anyone know what they want to be when they grow up?”

She adds to this a foundational philosophy of a sort: “Every child is different in many ways, no matter if you’re neurotypical or not. I guess this kind of reinforces the thinking that, you know, everybody needs to be treated as an individual, and we should try to work with their strengths, and try to figure out other ways around, and not to have their weaknesses be as much of a weakness.”

For Elizabeth, the boys’ strengths are their sense of humor, their honesty, their memories, their adherence to rules, and their politeness. She also finds each of them completely charming.

Building Her Understanding

Again, thinking back on the early years, she recalls that “there were things like, like getting them ready for school—you couldn’t just say to them ‘finish your breakfast or get your coat on, brush your teeth, wash your face’—you actually had to kind of check with each step. And we just thought that’s the way that all kids are. You know, they don’t automatically do what you ask them to do in two or three steps. So we just kind of went with the flow and dealt with it.” This going with the flow early on, even before diagnosis, allowed Elizabeth to be quite flexible with her boys later in their lives, after she and Thomas knew there was something specific creating difficulties for their children.

At home, Elizabeth reads to the boys regularly, either in a one-on-one situation, usually with Cosmo, or with all three on Friday or Saturday nights, sometimes both nights. And it is with Elizabeth that the boys have ‘discussions’ about the frustrations their world offers. She, much more than Thomas, will engage the boys on *why* they must do what they do, reminding and encouraging them often, that “when you demonstrate that

you can remember to bring your lesson plan sheets home and get your homework done without our reminders, those reminders will stop.” And Elizabeth seems tolerant of the obstacles the boys face in organizing their world. Some of these obstacles—arriving to class with a pencil and notebook, arriving on time so not to miss initial comments from the teacher, remembering to pass in a completed homework assignment—seem to have simple fixes for one not familiar with Asperger Syndrome, but Elizabeth knows, I’d say more than Thomas does, that no such label as ‘simple’ works for the obstacles faced by a child with Asperger Syndrome.

She thinks both she and Thomas have characteristics of Asperger Syndrome in their behavioral repertoire. She is, though, quick to come to Thomas’s defense, saying that he has dealt with his kind of Asperger Syndrome very well. “He’s competent socially. He’s what many would call a successful person. He’s highly intelligent with a magnificent memory. And he’s doing a good job raising three boys who are not the easiest to raise.”

Recognizing that just as every child with Asperger Syndrome is different, so too are the parents who deal with them. “Every person, no matter if they're on the spectrum or not, is different. We all learn differently, we all have different coping mechanisms, and sometimes I don't think it's just saying it again, or saying it louder. Sometimes, for whatever reason, things just aren't making sense. And I think that sometimes you just have to step back, and maybe try a different way. Yes, they need to be doing the work, but if it is just leading to frustration, and they aren't getting anything out of it, we need to try to find a way that they will actually get to that end, and not end up with them being a ball of jelly.”

According to Elizabeth, “Tom and I have differences in the way we approach things anyways, and I don't know that was any different [early in the boys' lives]. You know, we really weren't aware there were any issues. So we were just going about our, you know, own way of dealing with things. We just kind of went with the flow and dealt with it.”

In retrospect, both parents do wish that one thing was different: they wish they had waited one year before putting the boys in school. Not only are the boys the youngest kids in their grade level, their lack of social skills make them more noticeably immature. But their health reports were fine; they had spoken, crawled, and walked on time; and the boys had a couple of friends in the neighborhood who would be starting school that year, so they were enrolled. But when Elizabeth thinks back on those friends, she's convinced that one of them is on the spectrum himself, so maybe that had something to do with the bond that was there.

Elizabeth read a good deal about Asperger Syndrome and Developmental Delays, an activity enhanced by her work at the medical center. She had access to the research library there, and she had colleagues who also had children with the diagnosis. “So we kind of just shared with them, and if I found an article that I thought they'd like, or if they found one they thought I'd like we'd just shared them. One of their children, the first time he was diagnosed, was in his teens. You know, it was one of those things. He always had issues in school, and they thought he was ADHD. And he's in his twenties now. So we kind of keep an ear out for each other.” She enjoyed Atwood's (1998) text, saying it was real to life. And she liked Holliday-Willey's (1999) because of “how it helped me, and

I'd think, hmmm, I used to do that. But it wasn't really as helpful for the children at that point in time.”

This is an important detail in determining just how Elizabeth understands Asperger Syndrome. She spoke often of how “the diagnosis was kind of like a light bulb going off. That kind of thing. There were many things that I could see in my family, you know. The way I was as a child, or my father, or my sister. You know it kind of helped explain life in general. We have always been a little odd. You know we've always been going to our own drummer. One of my sisters has always been very eccentric. Kind of an artist, an individual, very intelligent, but leading a kind of round peg in a square hole life. The other one fit in with everyone more than any of the three of us. She was the bubbly outgoing one but, well, the diagnosis did kind of help explain. Not just with the kids, but some things about myself. It kind of helped explain why I felt I was out in left field for, what was 35 years then.”

Several times she related experiences and thoughts of her own past with Asperger Syndrome. And while it is important to note that she does not have an official diagnosis, it is significant that her understanding of the syndrome and her ability to observe and juxtapose different characteristics for hers and her family's past show her to be a fairly good judge of the syndrome's effects upon people. “As far as my case is concerned, I always met people pretty well, but with the second and third meetings there was never much depth to it. So in those second or third meetings, when you're supposed to get more friendly, it just wasn't happening. I just never really caught on to that then. You know, I never expected to have children, and I didn't really date. So I never really considered the possibility of having children. I had one boyfriend in middle school. And then I went

out once in high school . . . [Later when] I went to nursing school . . . I didn't have any real long-term ideas of what adulthood would be. I really thought I would probably stay at nursing school and work there for my entire life. And you found a lot of nurses there doing just that. It became their life.”

Elizabeth also related tales of her lack of organizational skills and how they impaired her curiosity during her studies. She was a great procrastinator, right up until finishing her academic nursing degree, two years ago. Part of that, she speculates was her tendency toward perfectionism. That, she thinks, had a great deal to do with her lack of ability in starting any kind of long-range project. She would know what it ought to look like, but she'd have no idea of how to go from step one to the final step, so she could not begin.

This helps her, she thinks, to understand what the boys are going through, as each of them has procrastination issues and perfectionist tendencies. But the way to help them is difficult for Elizabeth: “How do you, when you're in your late thirties, try to get someone who is, you know 12 or 13, to do the same things? There is such a big difference between us.” And because she sees some of the same tendencies in Thomas, she adds, “some times I know we're not the best people to be addressing this issue, but I also know the guys are going to have a big problem with it. And they'll suffer from it.” So she does what she can.

There was a situation concerning missing math homework that I was able to observe Elizabeth and Ringo deal with how to rectify the situation. Elizabeth told me afterward that because the next school day was going to be a half-day, she knew that the

boys would have difficulty doing what was needed to be done at school to get on top of things.

“Ringo,” she called him to the dining room table. “You need to check with your teachers, especially Mrs. Gilmore, about your homework situation.”

“Tomorrow’s a half-day,” he told her. “I won’t have class with her.”

“That’s fine. But you know, guy, you don’t have to have a class with her to ask her a question. You might go and see her before class or even after school ends at noon.”

“Okay,” he said. But it was clear the okay wasn’t a strong one.

“And remember, guy, you need to ask her directly what you’re missing.”

“Okay.” But when he got home, he had not seen his teacher.

It was a short exchange, but it can show how the interactions occur. Elizabeth encouraged and reminded Ringo, who agreed to do what he was asked, but ultimately he did not do it at that time suggested. Both were fully aware of the nature of the conversation; both spoke directly to each other about the situation, but when Ringo got to school, on an atypical day, he could not reorganize himself to take care of a necessary task.

Situations like this are creating a good deal of frustration in the boys, because they are barraged with reminders about their lesson plan sheets, their homework, and their long range projects. Sometimes Elizabeth’s comments follow the same ones given by Thomas, and vice versa, so that just adds to the frustration. Her goal, though, is to move them to a point where they don’t need constant reminders to be on task. “But how we get that balance, without going over to either extreme, is a part of this goal. Do we want to be right on top of them? Have them right under our thumb? And not give them

any responsibility? And all they get from that is frustration. Or should we step back, and not be on them so much? But then they're not being reminded, and they might not be trying to internalize.

“You don't want them to make the same mistakes. But how do you provide them with those skills, so they don't have to make those mistakes? And I don't know how to do it.

“Of course there's no perfect way, but even what's the best way, I don't know.”

For many individuals with Asperger Syndrome, it is the social realm that offers the most challenge. Elizabeth recognizes the social weaknesses in her boys, but as with their lack of organizational skill, she is not always aware of what to do to help them. Relating her own social impairments, she tells a story of her ‘courtship’ with Thomas. She begins by talking of her decision to become a traveler, one who goes to different hospitals to do her nursing work. “I had made arrangements to go on this assignment, to Ruskin and Sun City, Florida. And while I was in Florida for the three-month assignment, I found out that Tom was back. And he had been like my big brother when we worked at the restaurant. You know, whenever someone would be mean to me, he came to my defense. If I put too much ice cream or too much sauce on a Sundae, he'd bail me out.

“Like I said, he was a big brother to me, so I drove home from Florida, because my sister was graduating from high school, and we went up to the restaurant, and he came up and gave me this big hug. And we started going out. And six-months later we were married. But what's kind of funny about it is, I was here for about a month, and then my sister and I left for a month to go to Expo '86 in Vancouver. We took the train

across Canada, and then we came back, and I was here for a couple weeks. And then I had to go to Texas and work for three months in San Antonio. And Tom came down and visited like two times during the three months. And when I came home we got married. So we were going out for six months before we get married, but I wasn't here for four of those months. You know? Kind of strange now that you look back on it. I really hadn't thought about getting married, and I hadn't thought about having kids.”

But Elizabeth’s concerns for her boys are heart felt and constant. She is very worried about the twin’s transition into high school at the end of this school year, especially because she knows that in high school they’ll not have the same friendly supportive environment they have enjoyed over their first nine years of school. When she spoke of her immediate goals for the boys this year, she said, “For Ringo and Bob, a major goal is trying to get the organization down, to try and get them to be responsible for their own organization. Because I don't know what next year, what resources are going to be available for them, as far as what they’ll need at the beginning of the day, to get to their locker and know what books they are going to have to have with them, and then get from point A to point B. I see that being overwhelming for them.”

Like most mothers, Elizabeth will speak of her children at length and with great joy. Though it would be impossible to include all the pertinent comments she made about her boys, some of her thoughts on each boy follow:

Bob: “There’s a part of him that really wants to be social, though there are aspects of that desire he cannot overcome. He’s not always sure just what to do in social settings, though unlike Ringo, he will put himself into those. When I think ahead several

years, I think Bob is going to be okay. He's pretty self-sufficient on most matters, and he's maturing at a little quicker rate than Ringo.

“As far as remembering to bring things home, if he's got a particular assignment, sometimes bringing home the correct book and remembering the actual assignment is where he needs reminders. He can get kind of off-track, but sometimes I wonder, is it that he doesn't remember it, or does he just want to play with his PlayStation-II?

“Bob loves his video games, and he'd probably be playing those if he had a totally free time period given to him. But he'd also be just as likely to choose a book, if it was one he was reading and was particularly interested in at the time.

“Unlike Ringo, Bob will come to Cosmo's defense quite often. There's a sensitive side to him that is quite endearing. He knows his brother gets picked on, and he tries to help him through those times.”

Ringo: “In kindergarten and first grade, he loved to write lists. If you told him to do something, whatever it was, he'd write a list. I don't know if you've noticed, but when he's watching *Last Comic Standing*, he keeps a little notebook and lists the people who are voted out. He's got a list for the first season, and for the second season. And sometimes when he watched *Wheel of Fortune*, he'd write down the three contestants' names, how much they won, and what the answer was. That sort of stuff. So again, when it interests him, he likes to make lists. But I don't think he likes school, *per se*. I mean, he puts up with that. He tolerates it. It's a place he has to go.

“For a while, he was really into oceanography and the search for the Titanic. But that stopped. Recently, he really enjoyed reading *The Wave*. He told me a couple of times, he really was interested in the book. He does have an interest in poetry. Not so

much prose, but he does enjoy reading. He doesn't really like challenging reading. Like at April break, he had read *City Boy*. And Bob had read, *Man Child in the Promised Land*, at the same time. And in the summer, they were going to alternate books. Bob very quickly read *City Boy*, but Ringo never really got into *Man Child*. You know, it just didn't interest him.

“In fact, with Ringo, interests come and go and don't quite ever settle in. He's expressed an interest in fencing recently, and I'd like to find him something at the university so he could explore it, but I'm not sure how long he'll pursue it.”

Cosmo: “There's a kind of frustration with him, that once he gets off track, and the circuit or cycle isn't completed initially, there can be another little barrier thrown in there, another little on/off switch that kind of diverts him. And he can easily escalate from that point. So someone has to be there, to keep him from escalating, because once he does, getting him back on track is much more difficult.

“He's really just a very sensitive guy. He's like one of those big bears, you know he's going to be a . . . handful . . . it's one of those things, again; it has to do with his size. It's a detriment. People get a look at him, and they immediately think he's older than he is. And then they expect him to behave more like a 12-year-old, and not like a 10-year-old. And of course, they don't realize he has a learning disorder, and sensory issues, and at times he has the behavior of a five or seven-year-old.

“His sense of self-esteem is sometimes so fragile. I mean, just take him not understanding a math assignment, or not being able to get through his spelling. It's just so easy for him to get down on himself. Then he gets frustrated and starts calling himself

stupid. You know, that gets so self-defeating. And the more he repeats that, the worst things are or will be.”

Elizabeth says that all three boys are affectionate, sensitive, and polite in nearly every situation you find them in. And she sees in them a growing maturity and responsibility. This pleases her, and it causes some of her greatest worry. “The boys have good hearts, and I hate the idea of them becoming jaded because people don't have the ability to see them as the individuals they are.” She loves their sense of humor and often tells a story about one teacher at the boys school who told her, “my daughter always likes being in group with the boys because they are so polite and they don't swear. And they never cheat, and some of the other boys at the school will.” She hopes her boys grow up knowing how to cook, to clean, and to do other household chores. She wants them to understand many parts of life.

Elizabeth and the Boys' Learning

As has been shown in each of the boys' chapters, Elizabeth is often working with them, either one-on-one or in a group. Quite often these interactions involve homework, and in that task Elizabeth is always sharing and encouraging. There is always a “what if” quality about her questioning with the boys: “What if you tried to do this with this problem?” or “What if you thought about this in a different way?” She rarely tells them what to do, though she will remind them about a step or process they had used correctly previously.

Elizabeth is the one who organizes the boys for school mornings. Thomas makes the lunches and lays out the breakfasts; Elizabeth makes sure the book packs are ready. This process is one she tries to share with them, asking, “Did you get your pencils? Do

you have your homework in the right folders?” rather than just putting the bags together without their help. Much of this work had been done the night before, when, at the end of the homework sessions, Elizabeth would ask the boys where their work would be going, and to whom it would be submitted.

One Tuesday morning the boys had to take their picture money to school, in order for their pictures to be taken that day. The forms had been filled out, the checks had been written, and now Elizabeth was ready to put the checks and forms where they needed to be in order for the boys to remember them at school.

“Cosmo,” she called into the kitchen. “I’m putting the check for your pictures in your binder with the form. Is that okay with you?”

“All right,” he said.

“Bob? Where do you want me to put this?”

He came from the kitchen, toward his mother. “Just leave it on the table. I’ll get it when I go to school.”

“Are you sure? Will you remember it?”

“Yes,” Bob’s head nodded once, and his voice nearly squeaked.

“You know, guy, that if you don’t remember this today, they won’t let you get your picture taken.”

“I know. I’ll remember.”

Elizabeth looked concerned, but she placed the check and form on the table, in fairly plain sight. Looking at it a couple of times, she finally walked away, back into the kitchen to clean up the breakfasts.

“Mom,” Bob spoke from the entry way as he was walking to the TV room to play a video game, “leave that on my science book so I’ll see it.”

She returned to the table and did that. While there, Ringo asked her if she’d “put mine in my lunch box for me?”

She’s often on top of the things that just might matter most to a young boy in middle school. On the first day of school, she noticed that Bob had put on black socks, which just would not go well with his shorts and sneakers. “Bob,” she said. “Why don’t you wear your white socks this morning, guy.” She told me later she thought some of the kids might have made fun of him with those socks on. Elizabeth is always looking for moments that can change the nature of the day for her boys.

A long-range success with the boys revolves around the swimming lessons they have taken for many years. Since about the time Cosmo was 18 months old, Elizabeth or Tom—mostly Elizabeth—took the boys to swimming lessons at the YMCA. Elizabeth recalls “with Cosmo, at the beginning, I had to be in the pool with him because he was so young. But he participated in the swim classes. Oftentimes I’d have to be right there beside him and make him pay attention, because he wouldn’t want to be listening to the instructor. And I’d have to tell him, if he wanted to stay in the water you have to pay attention.”

All the boys respond well to “positive carrots,” and generally they were willing to put up with some things in order to get to something else they preferred more. With the swimming lessons that meant waiting for the free time in the pool. “All three of them enjoyed the free time much more than the structured time. They loved being able to be in

the water, to do cannonball's and all that sort of stuff. It was when they were asked to use, you know, the flutter boards and kick out—they didn't like that all.”

The swimming lessons stopped a little more than two years ago, but Elizabeth still remembers them positively in many ways. Not only were the kids working on physical skills they could use in their real world lives, they were also socially engaged with age mates on a regular basis. “They got along with the other kids. I mean, they didn't interact a lot with them, but we didn't know if it was just because they were shy, you know. Whenever there was frustration, there weren't fisticuffs, and it wasn't that they weren't getting along with kids.”

The frustration may have been caused by the fact that the kids they started taking lessons with always advanced a little more quickly than they did, getting to the next skill level before Ringo and Bob. But for the most part, Elizabeth doubts that. “It was always like they were there more for the free time than to learn to swim.” When her job situation changed about 2 ½ years ago, she was unable to take them to the lessons on a regular basis, so they stopped.

Though both parents are aware of how Asperger Syndrome and developmental delays affect their boys, Elizabeth is unsure how aware the boys are of the conditions that affect them. She admits to having had only superficial conversations about Asperger Syndrome with the twins and almost no such conversations with Cosmo. “Ringo and Bob are aware that they have the diagnosis of Asperger Syndrome,” she tells me, “and we've talked about how, because of it, some things will be easier and some things are going to take more work. And that's kind of the way we've approached their difficulties in many areas.”

She does say that it might be better if the twins were more cognizant and more aware that they have Asperger Syndrome, and she thinks Bob may be ready for trying that. “He just might, you know, take the ball and run with it. Maybe he’s at the point now where it could make sense to him, and he might realize that we truly aren’t just bugging him about things, but are trying to help, because we are aware of some of these issues that we think he needs to address.”

But up until now, none of the boys have been asked to read any articles, and there have been no serious conversations about what truly affects them. There was some work with Social Stories, but that was just working with the stories, it wasn't explaining to the boys that the reason they were reading and writing the social stories is because they might have issues with developmental disorders.

At Home

At the dinner table Elizabeth sits to Thomas’s left, across from Cosmo, and beside Ringo. Bob sits across from Ringo, diagonally from Elizabeth. My bet is that dinnertime conversation occurs more often between Thomas and Elizabeth, as during my stay, when I also sat at that dinner table, the conversation generally occurred between adults. The boys were included, but more often when direct questions were posed to them by either their mother or father. At breakfast, however, only the boys sit at the table, and the conversation, though minimal, is theirs. Elizabeth is more often the one to share breakfast with the boys, as Thomas is off to work very early on Monday, Tuesday, and Wednesday. He is the one to set out the breakfast, but he is rarely there during the week for it.

Each of the boys wake differently, and Elizabeth does whatever is necessary to bring each to their necessary alertness for the morning chores. She has arranged it so that Cosmo, who hates to shower, takes his in the evening, and the twins take their showers in the morning, trading days for going first. On days that Bob has the first shower, the breakfast table often only has Ringo and Cosmo present, because Bob has showered and eaten his small breakfast and exited to the TV room to play video games. Elizabeth is okay with that, especially as she sees that Bob has started to be a bit more conscious of his morning, get-ready-for-school duties. She stays in the kitchen and shares morning chatter with the other boys. This generally begins slowly, but, at least while I was there, it very often turned into the boys trying to one-up each other in funny stories taken from TV or the movies. Elizabeth is always the best audience for this, and I got the impression that the boys were not telling these tales for me, but for them and for her.

According to Thomas, Elizabeth is a bit more permissive with the boys in some matters. For example, he says he wishes the boys would play outdoors more often, especially in the summer and early fall months. He says he tries to “throw the kids outdoors, so they can enjoy the fresh air and be playing in the yard. Elizabeth,” he continues, “will let them stay inside and play the games and do the things they want. I respect that in her, and at times it works for them, because they are happy when they’re doing those things, but I would like to see them a little more active outdoors.”

It was a rare occasion to see Elizabeth force an activity upon any of the boys, save for their homework. But then, in the way she worked that with them, the forced aspect of homework surely came from school. She was sharing in the work they had to do.

There were several times when differences between the two parents became apparent. One occurred after the boys had received zeros for not submitting any math homework. This was a baffling situation because they had done their homework. I had seen Elizabeth work with them on several nights, and I had seen the homework get placed in their binders to be taken to school. However, that homework was never passed in. Both Thomas and Elizabeth were upset at this, and Thomas told me that the boys would be working all weekend to make up the missing work in order to be able to submit it on Monday. Elizabeth had told the boys that there would be no video games or television for a week until their homework was caught up.

Two mornings later, a Friday, during breakfast I walked past the television room on my way to the kitchen. Thomas was in there with Bob, who was playing video games. A few minutes later, Thomas came to the kitchen. "I thought there was to be no video games until the homework was caught up," I asked him.

"That's what I thought, too."

I decided I'd ask Elizabeth if she had changed that policy, though I felt a bit like a snitch asking about this. "Didn't you say the boys were not to be playing video games until their math homework was finished?"

"Yeah. Why?"

"Well, I just saw Bob playing SIMS, so I wondered."

She walked immediately to the TV room. When she came back, she asked Thomas, "Did the boys' math teacher say they didn't need to make up the homework?"

"Yeah. I talked to her at the soccer game yesterday. She said it wouldn't be worth their time as it might cause them to get behind on what they should be doing now."

Elizabeth hadn't known Thomas had spoken with the math teacher. She walked back to the TV room, telling Bob, "Okay, guy. If that's what your teacher said, I guess you can play the game."

Another time, Elizabeth and Tom were talking about Cosmo's homework for the week. They were concerned about a book report due on October 4. Elizabeth knew the book had been read, as she had read most of it to Cosmo, who finds that process better for his understanding of the whole text. And Thomas knew that Cosmo wanted to make a poster for the book, but he felt there was more to the assignment than just that. Elizabeth and Tom talked about the other possible work, and they looked for the description sheet somewhere on the dining room table, the Berkley's catchall place. They found it, and it did contain the description they needed.

Their concern now was on the amount of time Cosmo would need to complete all the work; today was September 26. Thomas spoke to Cosmo first: "Cos. There's more than a poster for you to do on your book report." His voice was demanding.

"I didn't know anything about it." Cosmo is quickly agitated at this bit of news, and, I think at the tone it was delivered in.

"It's okay, Cosmo. Calm down." He places a hand on Cosmo's shoulder. "We just want to see the work you have to do." He shows Cosmo the sheet of paper. "See, bub, there's a written component, and there's an oral component to the project."

"Okay." There is defeat in his voice. "What do you want me to do?"

Elizabeth says, "I think we need to find some time for you to be able to work on this, so that we can get it done before it's too late, guy."

Thomas adds, “You’ve got three soccer games this week, bub. And your school work has to come before those.”

Cosmo looked at his parents, one at a time. Thomas suggested that “it’s about 12:20 now, bub. Let’s say that at about one o’clock you’ll stop playing video games, and we’ll get started on this.”

At about 1:15, when I looked in the kitchen, Elizabeth was there with Cosmo. Thomas was watching a football game on TV.

The teachers at the school have also noted differences in Elizabeth and Thomas. While the teachers admit they love how involved both the Berkleys are, and that they wish other parents were so encouraging and accepting of what went on at the school, they say that Elizabeth is a bit more understanding of the idea of deficits that Asperger Syndrome can cause for a person. Thomas, to the teachers, occasionally seems to be in a small amount of denial, acting as if only an extended effort on the part of the boys would get them through some of the obstacles they face.

If It Were My World

Elizabeth is frustrated because in her present world, available research on the syndrome affecting her children is at the “concrete stage, at best.” She would love to have some knowledge that would allow her to affect some serious changes in her boys. “You know, in order to do one thing, you do this thing. But of course, you can’t do that with kids in general, anyway. Every kid is going to respond differently, whether they have a disorder or are typical.

“And it would be kind of nice to know, is there anything to this nutrition thing? Should we be avoiding yeast? Should we be avoiding fructose? Should we be doing the

omega-3? Should we be keeping them back, and having them start school later? Should we be doing speech therapy? Occupational therapy? Is there a benefit to the, you know, brushing? Yes, you know, these things work for a majority of kids. This might work for a small amount. So it would be kind of nice to have that sort of information. But that stuff isn't going to be known for 20 or 30 years.”

And she'd like some clarification on what early intervention means in regards to her children and children with Asperger Syndrome in general. “Is it preschool age? Is it 18 months to 24 months? Some kids are being diagnosed in grade school or even middle school, so they are in this window of opportunity. Whatever therapy might have worked, it may be too late.”

She'd like to think that a greater understanding of Asperger Syndrome was growing in the schools and medical professions. “I remember, when I went for one of my checkups, I was reading *Diagnosing Jefferson*. My physician, who was very knowledgeable about many things, and I respect him completely, asked me what the book was about. So I told him. And he asked me if I just had an interest in it, or what ever. And so I told them I had two children with Asperger Syndrome and another one on the spectrum.

“He wasn't familiar with the terminology. Then he said, ‘that's amazing. Isn't autism syndrome so rare? Isn't it like 1 in 10,000 or something?’

“And so I did a little in-service for him. I told him about how prevalent it really was and about some of the effects it has on people. And this was totally new to him. Of course, he has adult patients. He's not a pediatrician. But I'm sure even some of his

patients, if they haven't been diagnosed, are probably on the spectrum. So it would be nice to have some of this information more available to more people.”

One of Elizabeth’s fears is that people without proper understanding will play havoc on individuals on the spectrum. She has seen this in action, and it has spurred her to become more knowledgeable and somewhat active in her advocacy. Her discovery that her physician had no idea about spectrum disorders made her wonder just how few in the general public have any knowledge whatsoever. And how much do teachers know?

“It would be nice for teachers, not just special education teachers, to have an awareness, and along with that, an ability or acceptance of the overall affects the syndrome can have. I've heard some horror stories from people I work with. One boy, a good friend’s son, was in second grade, and the teacher demanded that he be placed on Ritalin. There was no diagnosis, but as things were, because of the teacher’s evaluation, he ended up on Ritalin. Several months later he was losing weight, and his personality was flat, and he wasn’t laughing. So my friend took him off it, and she got her son back.

“Later in the year, talking to other parents, she found out that this was a teacher who expected all her kids to be facing forward, sitting up straight with their hands folded on their desks. And in second grade, these kids only got two bathroom breaks a day. Well, my friend was really kicking herself that she let this one woman dictate what her child would do.

“She realizes now, after spending some time looking into it, and getting professional help, that her son has Fragile X Syndrome. And to imagine that a teacher, a non-medical individual, could demand that a child be placed on Ritalin. It's probably our society. We want just to be able to take a pill. We want that simple fix; we don't want

any round pegs in square holes. We want everybody to be the same. And when that square peg comes along, or someone with a different frame of mind, or a different learning style, say he's more visual, or perhaps he has some fine motor issues, it doesn't matter if he has a diagnosis or not. These kids aren't getting services, and they're falling behind.

“So I'd really like to see a greater understanding in the general population, the teachers, the parents, the physicians. That Asperger's is something you can have and still grow up and live a normal life if you are given the opportunity.” This thought leads Elizabeth to say that given a chance, she would not take the Asperger Syndrome or developmental disorder away from her boys. “It's part of their being. It's their sense of humor, the way they look at the world, the way they interact.”

But more than that, Elizabeth sees a worth in the interactions between herself and her children that the syndrome has created. She and Thomas help the boys understand the world, and, in turn, the boys show them a different way to view their existence. Life blends good and bad, bad and good, and for the most part it may be disingenuous to attempt to say just which is which.

Elizabeth sees that a great problem people have dealing with children with Asperger Syndrome or other developmental disorders is that our society wants everybody to fit in the same mold and wants things to be easy, from A to Z. Predictability is considered a strength, and so is the quick fix. But she has found a different way to look at the differences her boys have presented her, rejecting the quick fix and sameness her world craves and accepting the uniqueness and excitement such differences can bring.

“It would be pretty boring if everybody was exactly the same. And you know, we wouldn't be where we are, if everybody was the same. If everybody thought the same, you know, we'd still be making a fire around this little hole in the ground. You've got to have some eccentric people out there, or life would be pretty boring. If you can just find a school system, and you could find some people who had some way to see them as individuals, rather than just as different, and then you accept them as individuals and actually cherish that difference, well. . . but for anyone, neural typical or not, teens to about 24 or 25 are horrid years, and if they can get to 24 or 25, and not been totally beaten down by society, well . . . For us, it's just getting that next 10 to 15 years. You know, 10 to 12 years for Ringo and Bob, and 10 to 15 years for Cosmo. And having them still have that fire in their eye. And still enjoying life.”

CHAPTER NINE: THOMAS

An Introduction

Right at the beginning of our second interview, when I asked Tom to comment on how he sees his boys reflected in the definition of Asperger Syndrome he gave at the end of the first interview, Tom draws a bell curve on a sheet of paper. He taps his pencil around it as we talk, drawing my attention to it quite often when he speaks about his boys. “Bob,” he tells me, “just looking at him with an untrained eye, I’m saying he is the closest to the middle, in terms of the spectrum.” He puts a spot near the peak of his curve. “I put Ringo here,” and Tom puts a mark about one standard deviation to the right, “and I put Cosmo over here,” another mark is put way out on the tail of the curve. “So I don’t quite worry about Bob as much as I do Cosmo.” Yet, by the time we get to the third interview, about one week later, Tom expresses his concerns a little differently about Bob: “You know, I had always thought that Bob was going to have a little easier time in high school than Ringo. But I don’t think that’s true anymore. I think Ringo has enough of that, ‘I don’t really care what you think of me,’ to get him through.” Perhaps this is just an aspect of the ever-changing world of raising a child with Asperger Syndrome; perhaps it is the changed understanding of the syndrome as seen by Tom; perhaps it is something else.

Thomas Berkley is 50 years old, and I have known him for 27 of those years. He is an inventory specialist at a prominent medical center and has held that position for 15 ½ years. Thomas has received no college degree, though he has enough credit hours for one, and could probably earn a degree in two fields with a couple of courses in either one.

Thomas had a very limited connection with people who have disabilities prior to having his own children. His cousin, John, has dyslexia. Years ago, Tom used to help John with his reading, but he never really knew how much success he was having. Thomas says he had no knowledge or understanding of autism, or any connection with a person with autism, prior to having his own children. Over time, through his experience with his children and his wife, and now knowing something about autism and Asperger Syndrome Thomas admits some people in his life, including himself to some degree, clearly had some of the characteristics of the disorder. He is not generally willing to speak of his own characteristics.

One of the first things Thomas will talk about when discussing his boys and Asperger Syndrome is that he finds the use of the word 'disorder' to be completely out of place. Disorder and disability seem to indicate a level of ability that is lacking in a person. For Thomas, that diminishes the skills that are present in the individual affected with Asperger Syndrome, and it forces people only to see the negative traits. This leads him also to consider the general use of the word 'normal' to be improper. "There is no normal," he says. "I mean, we think we're a country that is so fond of independent thinkers, but we really don't want that. People get wary if they're branded not normal. You know, I've come to a point in my life where I don't want to be around people that worry about things like that. That's just stupid."

The next thing he'll talk about, and clearly his most significant issue during my stay, was how a person helps a child with Asperger Syndrome learn to organize his life. This is Thomas's greatest source of frustration and fascination. He is impeccably organized at his work, and he is fairly meticulous about his activities at home. It is Tom,

everyday, who prepares the boy's lunches for the next school day, knowing the schedule of school lunches so he doesn't make a lunch on days that one of the boys will eat what they serve. It was Tom organized the trip to the office supply store to get the necessary items for the boys to begin school: binders, paper, pencils, and book bags. He was adamant about the binders being the kind with folders so that work for individual classes could be placed in the proper space in order to be delivered on time to the right class.

It is arguable that Tom is too much the manager of his boy's world. Even in the simple task of preparing their lunches, a task the twins could readily learn and do, he never solicits their help. And he more than occasionally interrupts conversations they have—with me, with their mother, with each other—to insert information or directions. In short, Tom is almost trying to micromanage the boys' organization skills.

Yet something comes of this overbearing management. Last year, for example, because there was such a fiasco with schoolwork, Thomas went to school every day for two months and spoke to each of the twins' teachers. During that time the boys showed great improvement in their performance in every class. The teachers saw a difference, and they commented to Tom and Elizabeth about it. But he discontinued the practice after the two months, because "it was not a good way to develop organizational skills. They've got to be able to do that on their own. It's not somebody else's job." He did mention that if things got as bad again this year, he would repeat the visitations, though first he would use a homework chart to monitor the assignments and their submissions.

Thomas sees himself as a family guy, and when talking about his boys, he is constantly reflecting on the many things the boys and the family do together. It is clear that he sees their family unit as one cohesive whole. He relates activities, adventures, and

numerous joys he and Elizabeth have had with the boys. “I love having the guys with us when we do anything. When we go to Portland, we take them with us. We’ve been to Philadelphia, Baltimore, and we go to Acadia all the time. I just don’t see us doing things without them.” And, pretty much, it has always been that way.

Early on, especially with Ringo and Bob, Tom didn’t notice any differentiating or indicating behaviors that would lead him to think there was a disorder. It wasn’t until the boys were about four—and reading—that Tom began to see differences, as each boy interpreted and reacted to stories differently. “We could ask them questions about their stories,” he told me, “and it became clear that Bob’s interest in reading was much different from Ringo’s, and, when his skills developed later, that Cosmo could create entire worlds with his mind.”

Thomas also mentions that when the boys got to school, things started to happen that gave him and Elizabeth some indications, but even then, “we didn’t noticed some of these things in kindergarten, because the amount of responsibility that's put upon them there is minimal. So it probably wasn't until the second grade that people started realizing these guys are having problems.”

Tom likes the fact that his boys express their emotions, and that they have always been very emotional kids. These emotions can express the range from great joy to sadness. Every once in a while, Tom initiated what I came to call a ‘tickle attack.’ He finds the nearest boy, hugs him close, and tickles him either on the belly or feet. Generally the boy falls to the floor in total laughter. Then Tom moves on to the next victim, trying to be sure to get all the boys in one attack. The boys surely enjoy it, and at least twice I saw one of them come running from another room when they heard the

attack begin. This, of course, made him vulnerable for the attack, but that was just part of the joy.

Of course, this expression of emotions allows the observation of the boys' sensitivity when people get mad at them, as well as when people are mad at other kids around them. The boys can easily be distracted at such situations, and Tom has to watch his own demeanor, especially when he is punishing one of his sons when the others are around. However, that doesn't stop Tom from occasionally being sarcastic in his conversations with them.

When asked to comment on their present situation, Tom says, "My feeling is right now the twins know they're being watched. So they're trying hard. And it will be interesting to see. They know that there are some expectations. Whether or not they realize what those expectations are, I don't know. So everyday I've tried to remind myself to remind them to get pencils and paper. Those were the biggest things that drove their teachers crazy last year, walking into the classroom with nothing." It is an experience he and Elizabeth live daily.

Looking Ahead

Thomas's goals for Ringo and Bob this year are the learning of how to organize themselves, because, as Tom sees it, they'll be on their own next year. Neither he nor Elizabeth are aware of what kind of services they'll be getting in high school, but they expect it will be a lot less. So Tom has decided that he'll need "to be a pain in their ass for a while," in order to get them ready for the personal responsibility they'll need in high school. This doesn't always work as well as he would hope. "I do get mad at them, and I bark at them, and the guys know that. And it doesn't help me, and it doesn't help them.

And it doesn't help anything when they know you are visibly upset with them. So, I have to step back and visibly watch what I am doing with them from time to time. And the thing I can't do is try to force them to do anything.”

Thomas is learning this message in a number of ways, but perhaps the clearest example came the night he attempted to teach Cosmo how to tie his shoes. Tom had told me he'd be doing this, as he knew it would be something I'd be interested in. As has been mentioned, Cosmo is ten years old and cannot tie his own shoes. This situation would play a role in whether or not Cosmo could play soccer this year, as getting his own uniform on in less than fifteen minutes would be a requirement. Tom had planned to do it after dinner, but Cosmo had a good deal of homework to do, so Tom put it off for a while and watched some television. He did not tell Cosmo it would be happening.

At around 9:00, on his way to bed, Tom remembered his goal of teaching Cosmo to tie his shoes. So, he grabbed a pair of Cosmo's sneakers and brought Cosmo into the kitchen. Cosmo looked exhausted, having only finished his homework about 20 minutes before. Thomas untied both of Cosmo's sneakers and told him they would be learning to tie them.

“Put on your right sneaker for me, bub.”

Cosmo had trouble from the get-go. His gross and fine motor skills are not well refined, and it took him a few minutes just to slip his right foot into the sneaker. The laces were very long, and as his father barked out directions, Cosmo had a great deal of difficulty manipulating them.

“Okay, Cosmo. What you've got to do is cross the laces, and then loop one under the other. Right?”

Cosmo pulled the laces up tight—they came to above his knees. Keeping his hands on the tips of the laces, he could not successfully make the looping move his father described.

“Come on, bub. Don’t you want to do this?”

Cosmo sighed aloud, dropped and then re-grabbed the laces, and began the process again, with no success.

“Cosmo. Work with the left lace. Move it around the right one.” Thomas was touching Cosmo’s hands to show him what he meant. “This isn’t that hard, bub.” Then, a few minutes later, “Come on. You’re not trying.”

Cosmo’s frustration became tears. He never said a word to his father during the episode. Ultimately, Tom saw that it was not working, and he sent Cosmo away. “We’ll try this again another time, bub. Okay?”

The next morning, I asked Tom about this incident, and he said, “Well, the shoe tying was a mistake last night, for a lot of reasons. He was exhausted. And I tried for five minutes, and I said to myself, ‘no, no, no, no, this isn’t going to work.’ He was really getting upset. And so we back up and try again later at a different time. Now, four years ago, I would have kept trying, and he and I both would have become more and more frustrated. And now I just tell them, don’t worry about it, we will work on it. But he had hit a wall then. You know, last night he was exhausted. And you can tell he doesn’t know how to do this. He has no idea. But you get to a point, somehow, we’ve got to try to do this.”

I asked Thomas if he felt he had failed with Cosmo in this situation, wondering if he met with his own understanding and expectations of the patience he needed in his interactions with his boys.

“I would have failed, if I had kept forcing him. Not teaching him in one night is not a failure, you know. Realizing that this isn't going to work tonight, you know, you pat him on the head, and he was so exhausted that when he went to bed, a minute later, he was asleep. I'm not really sure what happened. It would have been worse to continue, and he would've thought less of himself, the longer he spent time, and he didn't do it.”

Thomas, like Elizabeth, can talk about his boys extensively, and like her, it is one of his favorite things to do. However, he sees them differently than she does, and so, I'm sure he understands their Asperger Syndrome differently.

Tom sees Ringo as being able to say, 'I don't care' to a lot of things, and that, for Thomas, is one of Ringo's strengths. It keeps Ringo comfortable with his lack of social skills, though Tom would like it if Ringo “learned how to be able to walk into a group of people, listen, get a feel for wherever the conversation is going, and then enter it. Ringo, he's his own man sometimes. He doesn't care sometimes.” But Tom would like to see him a little more social.

Ringo is less organized than Bob, though he has an occasional surprising moment now and then. This lack of organization affects his success at school greatly. Tom says that Ringo's academic interest is poetry, especially writing it. And Ringo is learning to draw fairly well, and Tom thinks he would benefit from some art classes, though “I don't even know if he has art this year. I don't know if it's actually offered to them at the school.”

And Ringo is a better athlete than Bob, according to Tom. He's a better runner and a better bike rider. Ringo works a little harder at his running and finishes before Bob in cross-country meets. He'll generally seek to go for a bike ride more often than Bob.

Bob, according to Tom, is a reader, which has to be pleasing considering how much Thomas reads. "If given an amount of free time to do whatever he wanted, Bob would probably pick video games," his father says, "but he might pick reading." Tom would put Bob's reading abilities up against kids three grade levels above him.

However, a problem Tom sees in Bob is that he has to learn things the hard way. "You can't just tell Bob what to do, or how to do things more effectively. And I've found out," Tom says, "that by criticizing him, I can take the joy away from his activities. Inadvertently, of course. But I try not to do that so much now."

Thomas does think Bob is a good problem solver and a good learner. He uses Bob's skills on video games to support that claim. "If you watch Bob playing a video game, you'll see a monster at work. His whole focus is on the game, and no matter what it throws at him, he figures it out." Tom even takes time to practice on some of the games Bob likes to play, in order to compete with him head to head. He never wins any of those competitions, but he truly enjoyed the three I observed.

However, even as Tom expresses his concerns about the twins, he allows them a degree of freedom in much of their world. He does demand that they get to their homework as soon as they get home, but Tom rarely hovers over them or even monitors their progress. He will occasionally check their work and see that they put it in the proper folder in their binders, but even with as much emphasis on organization that he

has for the twins, he generally lets them be in charge of how that organization occurs, at least on the personal level.

In this regard, Thomas worries about Cosmo more than he does the twins. He monitors his homework, and regularly gets Cosmo to complete his work in the kitchen where Tom is preparing dinner. “Cosmo gets frustrated when he doesn’t do well in his homework, and especially in video games. He was very hyper as a kid, and he still is, and he’ll lose control, and shake, and exaggerate things. And he has a tendency to not be able to focus on things for very long.”

Thomas mentions that Cosmo is more affected by the spectrum than Ringo and Bob, but he adds that Cosmo is also more honest than they are, more direct. And while he admits that all three are less mature than their age mates, Tom seems to like it that they still get away with kid stuff at times. They are, after all, kids.

For Cosmo, right now, Thomas’s goal is to find two or three things that he can get really good at, which is also his thinking for Ringo and Bob. He feels that being able to spend time with an interest is a good survival skill.

The next few years of school bring a worrisome concern to Thomas about Cosmo. He knows that people do, and will, treat Cosmo poorly as he moves through those years. “Up to now he’s had his brothers at the same school with him. But that is going to change next year. And when he gets to high school, he’ll only have them for one year. I worry a lot about Cosmo in high school, and I don’t think I have as much hope for him there.”

One of Thomas’s greatest joys is having been able to learn from Elizabeth the skill of patience. “Elizabeth’s a lot more patient than I am. And there were times I knew

I had to draw back, because I was getting impatient, and they knew I was mad at them, but I was mad at them for the wrong reasons. And so lots of times I know I want to go with her reasons. I mean, I try to use the same kind of reasoning, or explanation, instead of just saying ‘God damn it, don't do that,’ you know?”

Thomas tries to be sure he is not blaming the boys for something the Asperger Syndrome causes, as that would be the wrong reasons for getting impatient. He often juxtaposes what he sees to be the causes of the twins’ behavior: Asperger Syndrome and adolescence. He knows that he is not always successful understanding the difference.

These differences come out in many ways. At the folk festival, for example, when we were all gathered to discuss lunch options, Bob expressed some concern over the choices to which Tom replied quickly and sharply, “Don’t get pissy, now.” And at home, Thomas answered a question I had asked of Bob at the dinner table.

“Where is the next cross-country meet being run?”

“At the Christian school,” Tom said.

“I was going to say that, but I had milk in my mouth,” said Bob.

“I didn’t know I wasn’t supposed to answer.” Thomas’s tone was a bit condescending.

“You answer sometimes when we wait too long. And I thought you were doing that.”

Much that Thomas has learned about Asperger Syndrome comes through conversations with Elizabeth, who started reading quite intensely just after Cosmo’s initial diagnosis. Thomas, however, who reads more than anyone I have ever known, has read very little about the disorder affecting his children. During my stay he brought six

or seven books home from the library each week. He was also in the process of reading from his own collection. His uncle is a professor of American History at Brown University, and they have shared books for many years. As far as reading on Asperger Syndrome, though, Thomas has read only Temple Grandin's (1995) work in its entirety. When he began another source about the syndrome and its affects on teenagers, he was troubled that it did not differentiate clearly enough whether it is Asperger or Syndrome of adolescence that is most affective, and he discontinued the read about half way through. He is glad, though, that Elizabeth continues to read about the disorder.

Ever since being introduced to the field, Elizabeth has always suspected she and her sisters have Asperger Syndrome, something Elizabeth's mother and one sister agree with. Elizabeth readily speaks of her social deficits, her lack of organizational skills, and her literal mindedness. And Elizabeth, as was mentioned in her chapter, feels she is pretty good at spotting individuals who might be on the spectrum.

Thomas doesn't see things quite in the same light, and he occasionally takes issue with Elizabeth's perceptions. "Elizabeth sees disorders in everybody now, and sometimes I think she's right, and at other times, I don't know. Sometimes, to me, it's just a tendency, and I'm not always sure what the difference is. But you'd like to think that they've missed a lot of people." He admits that her understanding of Asperger Syndrome is different from his, to some degree.

And the effects the syndrome has upon them are different too. Elizabeth admits to being literal minded, but Thomas, less willing to say so, is quite literal minded in his own right. One weekend we were going to go to camp to bring in the dock for the winter. I asked, "What time are we going to the lake tomorrow?"

“Probably pretty soon after breakfast. But keep in mind that breakfast for us on Sunday is a little later,” Thomas told me.

“Yeah,” Elizabeth chirped in. “It’s more like a brunch.”

“No, it’s not a brunch.”

“Well, it’s like. . .”

“No,” he interrupted her. “For most people a brunch is like 11 o’clock, and we’ll probably have breakfast around nine or so.”

Another time, when Tom was checking Bob’s science homework, he commented on a couple of sentences Bob had written: “Sound needs air to travel through. Without air, there can be no sound.”

“Bob,” he called into the other room. “Come here, bub. You’ve got to think about the way you word your sentences.”

Bob looked at what he’d written. “What’s wrong with that?”

“It’s not a big deal,” Tom said. “It’s just not the way you ought to word it. You should have placed the word ‘air’ after ‘through.’ And you should have added ‘to travel through’ after ‘air’ in the second sentence.

Thomas and the Boys

One of the ways Thomas shows his different approach to Asperger Syndrome occurs while the boys are doing their homework. Mostly, like Elizabeth, he tries to encourage their thoughtfulness and energies toward the work. He is also a question asker, but he has a much shorter wait time for the responses he’d like to get to those questions. Consequently, Tom can get frustrated with their difficulties much more easily than Elizabeth.

One evening Thomas was working with Cosmo on a set of vocabulary words that included grammar terms: preposition, conjunction, adjective, adverb, and pronoun. Tom worked with these terms for a while, asking Cosmo numerous questions about them in order for Cosmo to be able to place the words properly on his worksheet. The next set of words were dance terms: polka, waltz, jazz, ballroom, and square dance. Cosmo claimed not to know any of these. Tom tried for a few seconds to get Cosmo to ponder the words. When that seemed futile, he just read, in order, the terms as they would be written on the worksheet. This is something Elizabeth would not do.

And Thomas's work with the boys, especially as he is quicker to demand responses to some of his queries, gets more than an occasional "I don't understand what you mean" from each of them. This can raise his frustration a bit. But it was interesting to see that nearly each time that frustration rose, Thomas would either completely change the tone of his voice, bringing it down and softening it, or he would put an easy stop to the activity. There was always a sense of him pursuing his goal of more patience in nearly every interaction.

Certainly Thomas recognizes the difference between his and Elizabeth's work styles, and while he doesn't juxtapose their methods, he does willingly talk about how he sees and works with the boys' deficits. "Their real problem is in their writing. Bob will give the bare minimum, you know. His teacher will say, give me three sentences on this, and that will be it. So, what I try to do here, in that case, is write down who, what, when, where, how, and why. And I tell them to answer each one of those questions in relation to the problem that's been set up. So then you know the name of the person, you know what the problem is, etc. And the hardest of those is the 'how.' How does it affect them?"

“Sometimes you have to try to make it as personal as you can. You know, how does that make you feel? And you try to get them to answer those questions. And so each one of those questions they answer is a sentence. So if you can do that, the bare minimum you’re going to get is six sentences. Which is a lot better than three. So that’s how you have to look at that for them.”

Interestingly, this is the kind of thinking with which Thomas knows the boys have difficulty, and he has related this to me on several occasions. Lacking a strong theory of mind, they find it difficult to express what the feelings of others might be. The questions, who, what, when, where, why, and how may well engender more sentences, but at times they seemed to also create some frustration at the boys’ inability to make it personal.

With Thomas it seems as though amounts matter a good deal. How much work do you have? How many words do you need to know? But Tom also talks about the problem being one of recognition—or a lack thereof—of the boys’ own worlds. “The problem is that most people are thinking in their own world. And they’re not trying to see into the world of different thinkers. In some ways, these boys are pure stream of consciousness. They’re jazz musicians. Especially Cosmo. They come out with things that you’re just going, wait a minute, you know, why are you doing this? And he’ll say, because of this, and you’ll go, I see.”

Tom knows a lot of people don’t see his boy’s world—sometimes he doesn’t—and so he works with them in order to help them make their worlds more knowable.

Tom’s Growing Understanding

Like so many parents who get their child’s diagnosis for Asperger Syndrome, Tom admits it made him rethink a lot about his own background and behaviors. But

unlike Elizabeth, who comfortably speaks about deficits she connects with having the syndrome herself, Tom only rarely acknowledges a characteristic or two that might place him on the spectrum. While both of them have goals of helping their kids, Thomas doesn't mix his own needs with theirs so readily. "Your first concern is you've got to protect them. Then you go, 'no, no, no, no, no' you don't protect them. You help them." Helping begins, he says, with convincing "yourself that this is not a one-way street. This is a chance to think about things in a way you've not thought before. But if you think this is the end of the world, you're in trouble. You're not going to go anywhere. And the kid is gonna have a harder time."

Part of that thinking, for Tom, was learning to be more patient, something he says he has done, though not to the degree he would like to have obtained, and not without some struggle. "You have to back off lots of things and force yourself to realize the way you see the world is not the only way it can be seen. And those things you think can just be done easily, well, they have to be rethought of too. Think of it as an opportunity to rethink how you learn and teach." And if you're successful, Thomas says, "You see that they're still kids before they are somebody with a disorder of any kind. I'm not sure that all of us aren't walking around with a disorder of some kind. If you're successful, you don't look at it as a hindrance anymore."

An important moment in the development of Thomas's understanding came when he was able to accept that Asperger Syndrome had not left his children deprived of their cognitive functions. Their problem, as Thomas saw it, was how they access certain cognitive abilities. "Once you learn that, you realize you're going to have to find

strategies to help teach them, and then to help them find out some strategies on their own. You just can't worry about whether or not they are different.

“As a parent, your anxiety level goes way up—mine did—because as a parent, you don’t want anything to go wrong for your kid.” What touched Tom first was a story he read from college sports. Gene Stalling was a football coach from the University of Alabama, and he had a child with Down syndrome. Stalling’s story convinced Tom that it is incorrect to think that you’ll have to teach your kids everything. In fact, they’ll give back to you in ways you cannot always explain. “It was the first time that I stopped to think about what was going on,” Tom told me. He was very impressed that “Stalling quit coaching soon after he won the national championship, to spend more time with his family.”

That has been a battle for Tom, wanting to spend more time with his family, but also being sure that his kids have their freedom, and that as they get older, they learn to do their own things. He talks often about the dilemma of learning not only what to teach them, but how. And it’s the how, he feels, where the real difficulty comes in. He’s considered hundreds of strategies, but it always seems to come back to patience: “The first thing that I have to learn, and that I continue to have to learn, is that you have to be infinitely more patient. I do. Not Elizabeth. But I do. So as a parent, that’s my major strategy, where do I need to be patient? And I don’t know what it’s brought to me yet. Because we’re not through it yet. Maybe 20 years from now. You can ask me that then.” It is a process, he sees, that is never-ending.

Thomas recognizes that his own social habits are probably not going to be good models for the boys, especially as he sees how their social deficits are affecting them in

myriad ways. He claims that he and Elizabeth are not very social and don't have a lot of friends. It is one of the areas where he accepts that Asperger Syndrome probably plays a role in his own life.

His social deficits make it difficult to spot the affection Tom has for his wife on a regular basis. They are rarely together in their own home, save for meal and bedtime. He is often off with a book or watching television, while she is just as often helping the boys with their homework, or reading to them, or straightening up some part of the house. Tom has always been very comfortable by himself, and in his own words doesn't "need many people to live." Prior to being married, he lived for a couple of years without a telephone, by himself, far away from town. But he said he never thought too much about it when he lived that way—it was just the way he liked it.

As for other characteristics that might put him on the spectrum, Tom is more routine-driven than he would like to admit. Each day he prepares the lunches and the supper at almost exactly the same time. He has a remarkable memory and can stop folks dead in their tracks by recalling sports records and scores. And, as has been shown, he can be quite literal minded at times.

As far as the boys' understanding of Asperger Syndrome, Thomas knows the twins don't think too much about it, though he says they know they are on the spectrum. All three boys, he says, think of themselves as not being very smart, with Cosmo the most vocal on that part. "Cosmo thinks he's dumb. Whenever he meets with any kind of difficulty, he just thinks he's dumb." Tom knows that he and Elizabeth have talked only a very little with the boys about their situation, and he thinks they would benefit with more information and discussion. But Tom also fights a battle between the effects of

Asperger Syndrome and adolescence, often trying to tease out the difference. “Once they get into junior high, you run smack dab into adolescence. And adolescence, sometimes, is a more powerful force than Asperger Syndrome or anything you can think of.”

Sometimes this played out like a denial of Asperger Syndrome, and Thomas did occasionally push the kids just to concentrate more and assert themselves more directly in their endeavors. But at other times, it seems quite clear that an attitude or behavior displayed by Bob or Ringo is far more connected with the identity building that comes with adolescence than it is with Asperger Syndrome. “I’m pretty sure that they’re aware they have something that prevents them from grasping things, but not as much as realizing where they are in the spectrum.” It may be that the boys’ lack of understanding and awareness is partially a result of Cosmo’s highly visible affectedness. Thomas does think that both Ringo and Bob think they are supposed to look out for Cosmo.

When asked if knowing more about the syndrome would be beneficial for the boys, Tom responded: “I think it would be a benefit if the kids were aware of how the syndrome affects them. I mean you’ve got to be as honest with somebody as you can be. You’ve got to say, ‘look Ringo, you’ve got a developmental. . .’ But Thomas stops here and ponders the terms he is using. He doesn’t like ‘developmental,’ as a descriptor, preferring ‘different,’ as in, “Ringo, you’ve got a different way of looking at things.” And he certainly doesn’t want his boys to think they have a disease. Rather, Tom would speak metaphorically to his kids about this: “You know, for me it’s still just a roadblock. You’ve got 15 highways, and the shortest one is I-95, and that’s the one most people use. But for some reason there’s a tractor-trailer there, blocking the way. So what you do, do

you try to ram your way through it? Or, ah look, there's another road right there. It takes longer, it's a little more complicated, but there's your goal.”

But such a conversation with his boys has not taken place, not by Thomas or Elizabeth. Yet both parents feel that such a conversation, in order to impart a deeper understanding of the syndrome to their children, would be valuable to the boys.

It would also, I think, be valuable for Thomas. There are times when his rapport with his kids, as has been mentioned, is one of a just-buckle-down-and-do-the-work approach, or a do-as-I-say approach. For example, Tom doesn't want his kids taught any differently from other students at the school. He tells the teachers he expects the twins to have their work done the same as anyone else in class. He admits this means that his boys will spend much more time on their homework than their peers, often working three hours a night and even extensively on the weekends, but he doesn't want them to have the privilege of doing less or doing different. He's afraid their friends might hate his boys if they found out. So Thomas is on his boys as soon as they get home: “What's your homework tonight, bub? Well, get it out and get going on it.” It is rarely a conversation; rather it is a set of demands laid out in clear, non-negotiable terms.

In fact, this approach even becomes clear in conversations with Elizabeth. Another example sheds some light on this. Tom and Elizabeth were discussing with Cosmo the chances of his attending a karate class in Newton, a city about 30 miles away. He had been there once before for an introductory lesson.

Tom said, “Cosmo, I know you really want to go, but it's far away. Unless your mother wants to drive, bub, I don't think you can take that class there. There are other classes around here we can check out.”

“But it’s the class I want to take,” Cosmo whined.

“But Cosmo, this place isn’t here in town. It’s 30 miles away. It’s not in the next town. It’s not even in the town after that, bub. It’s too far.”

Cosmo was quite shaken, and his eyes became red.

Elizabeth runs her hand across Cosmo’s head, “We’ll talk about it later, okay guy?”

Cosmo sniffs, nods, and leaves the room.

“We’ll talk about it later?” Tom asks. “Newton is way too far. Didn’t we just say?”

“Well, you said if I wanted to drive, and he really did enjoy himself at that class.”

Thomas left the room abruptly, apparently irritated that another approach might be considered.

Yet more than once Thomas engaged in a conversation with his boys (and Elizabeth) where he sought out their opinions and used those to build a decision. These conversations not only helped to reveal the twins’ nature, but also increased Thomas’s understanding and appreciation of it. And Thomas does appreciate the different world his boys experience. However, these seemed more the exception than the rule of interaction.

For example, Tom had a conversation with Cosmo about playing soccer—it was just the two of them. During the talk, Tom told Cosmo he would not be able to play, because it would cause too much frustration for Cosmo: he couldn’t tie his own shoes, he’d never be able to be ready to ride the bus on time, and his frustration at those things would hinder his chances to interact with his teammates. Cosmo left this talk in tears and went to his room.

Only a few minutes later, Thomas called everyone to dinner. Bob, Ringo, and I were the first ones to the kitchen. (Bob and Ringo nearly ran as they knew supper was going to be cheeseburger pie.) Once the boys sat down, Tom discussed Cosmo's issue with them.

"Do you guys think Cosmo could get his uniform on in time enough to be on the bus for his soccer games?"

Bob, who has shown some sensitivity for Cosmo's situation, spoke first, "I don't know. I think he could. It might not be easy for him, but I think he could do it."

"What will he have to do to get ready?"

"He'll have to get his uniform on in the locker room. And he'll have to take his cleats with him to the bus. They won't let him walk through the school with his cleats on." Bob had played one year of soccer for the school, so his information here was based on personal experience.

"Ringo? What do you think?" Tom wanted to be sure that both twins had some input.

Typically short worded, he replied, "Yeah, I think he can." Both boys looked directly at their father during this exchange. They seemed to know their words would be valued.

When Elizabeth and Cosmo arrived at the table, Cosmo still looked quite shaken.

"Cosmo," Tom asked him. "Do you think you can be ready in time for the bus on days the soccer teams has away games?"

Cosmo was still too shaken to speak.

Tom told Elizabeth that the twins thought Cosmo would be able to get ready, though it would be hard for him. Elizabeth asked them what getting ready entails, to which they repeated basically what they had told Tom a few moments earlier.

Tom asked Cosmo again, “Do you think you can get yourself ready in time, bub?”

Cosmo nodded slowly, his red eyes looking right into his father’s face.

“I think it’s going to be okay, Cosmo,” Thomas said. “We’ll give it a try. I’ll talk to your coach about it. You can play soccer this year.”

It struck me that Thomas went into the initial situation with Cosmo as the information giver, the sole arbiter, and in that role he decided Cosmo would not be able to play. But then he became the information seeker, a part of the collective, and with the insights of those who actually are beset by the sometimes disabling condition, the decision Tom made changed. He engaged a conversation about what affects his children with his children, and his understanding grew. I thought it was a telling event.

Elizabeth affirmed to me later that, “yes, working through the twins is something we do, especially as the twins probably spend more time with Cosmo than we do” now that school had begun. She did, though, wish the situation had been handled differently, and she had spoken with Cosmo prior to the big conversation, knowing that Thomas was leaning against letting him play. “I told him to be ready, and not to get all emotional about it. I said to him, ‘make a case for playing, and then be ready to answer some questions about it.’” Like so many parents, Tom and Elizabeth go about certain significant conversations separately, often, it seems, without the other knowing about it.

But very often, Tom does seek out the necessary information from others who have engaged with his boys. He is quick to speak with the boys’ teachers and coaches to

find out how their work is going with them. At times the information he gets from these sources is different from what he had initially thought, but Tom is generally quick to incorporate that information into new thinking on his part. For example, he went immediately to the math teacher after the situation with the missing homework, and he entirely rethought his idea of what the boys should have to do after talking with her. Of course, he didn't tell Elizabeth of meeting with the math teacher or what she had told him.

Thomas defines Asperger Syndrome in similar terms as his wife: "The way I understand it is that you just have a synapse that's firing differently. Okay? So you find this synapse, which is basically a highway, it's blocked, you back up to try and find a different way to the goal. You back up, and find a different way. You try to find something that he can relate to."

Like his wife, Tom would not take Asperger Syndrome away from his boys. However, he speaks about this issue a bit differently: "Well the first answer you're going to get is yes, take it away, make it easier for him. But you stop and think because you don't know if you're going to make it easier. So you'd be taking away some life experiences and you don't have any idea how it's going to affect this person 20 years from now.

"As a parent, if you think you could make it easier for them through high school, you'd probably say yes. But, I really don't know what combination of factors a parent can possibly give to their kids and say, well, here you go, this is going to make your life easier. As a parent, if I can make anything easier, sure. But you tell me, is this going to make it easier for them? What you just ask me, is that going to make it easier for them?"

And, you don't know. So that's my answer. I have no idea. If I could make it easier for them, I will. But I don't know that that will make it easier for them. It probably would with Cosmo in some ways. But I don't know. Does that make how I've become a parent, different? I don't know.”

If It Were My World

In Thomas's perfect world, his children would be respected because of the differences they have. They wouldn't be seen as having a disorder, and for the most part that word would disappear from use as applied to people. Being different would be cherished, dignified, and not held out as a stigma.

Yet in Thomas's world there would also be that which joined his children with peers and age mates in similar activities and appreciation. They would do much of what other children were doing. They wouldn't be given an easier route to travel, but would be asked to complete and compete in equal proportions.

Thomas's world would be filled with people who would understand and appreciate that children of all ability levels see things from very different perspectives. Students with learning differences should be expected to do all the work that other students complete. Yet it should be expected that the students with learning differences will have unique difficulties that sometimes preclude them from completing the work assigned to them. This would be the way Thomas's world would come together.

And in Thomas's perfect world, his whole family would just be left alone to be the five people they want to become. They would be able to discover and then to pursue their own interests. Those interests, especially in the schools, would be cherished and dignified.

Nobody would have to know that some ‘disorder, disability, or difference’ affected his children. And nobody would be trying to mold them into something they neither wanted to be nor could become. Life would be family based and shared in continual interactions between family members. All would be done for the benefit of the individuals within the family unit. It’s a pretty good world when you think about it. And it was through the experience of being the parent of three children on the autism spectrum that brought this vision to him.

CHAPTER TEN: LOOKING BACK AT THE QUESTIONS

As seen through the lens of this family, understanding Asperger Syndrome, like understanding the role of the researcher, is all about understanding the self. As shown in the cases of the parents, each has taken a different path in order to apprehend the condition that afflicts their boys. Though it is true that the personal parent-child interactions each has with each boy is central to this understanding, other avenues into the make up of the self have been taken by both parents. Thomas's path has focused on aspects of his and their educational experiences and his love of athletic competition. His concentration is on the work the boys must do and on the possibilities that they will 'win' or 'lose' in the 'games' they are forced to play. Elizabeth's path has taken her through a rediscovery of her family and their idiosyncrasies. She spends much time trying to discern the many different ways she can view behaviors of her father, her sisters, and even more distant relatives and how those behaviors open windows into the world those people have experienced.

In the process of developing this understanding, both parents have built reflective and predictive skills into their repertoire of interactive behaviors. In this sense, understanding Asperger Syndrome is truly a constructive process as the parents must take experiences from the past, blend these with experiences of the present, and then project possibilities of the future, knowing that each situation will be different. Realizing that the experiences the parents call on to build this understanding are their own, their spouse's, and their boys' lets us see that such an understanding must be hard built and surely difficult to maintain. This may account for the changing views in Thomas's

understanding over the duration of my stay. Such inconsistencies may then be seen as a natural occurrence of developing an on-going understanding of Asperger Syndrome . . . or any learning difference for that matter.

And because these parents see the assimilation of this understanding into their boys as one of their prime tasks, certain skills of reflection and prediction are part and parcel of their interactions, in hopes they will be engendered in their boys. Here is where being a parent of a child with Asperger Syndrome comes to a central conflict. Regardless of how successful the parents have been in understanding their own relationship with the disorder—and I'd say that Elizabeth has been more successful here than Thomas—much about the nature of the child with Asperger Syndrome is going to work as an obstacle to the smooth transferal of those skills. Time and again, each parent met moments where the perceived objective of their interaction with any of the three boys met with difficulty and failure. Sometimes it is where that failure is placed that makes the biggest difference.

It makes me wonder what this syndrome of developmental disorders can do to parents' expectations about their role and about their children's role in the family. Surely all parents have a sense of a picture of the family, and of course that picture must be an ever-changing scene. Both Thomas and Elizabeth spoke about the moment they became parents and how their whole world changed. "You think you know what being a parent is going to be like," Thomas told me, "but you have no idea." And then when diagnoses came, "You get a feeling that everything has gone wrong, but you can't dwell on that. I mean, sure there are going to be things you had hoped for that won't happen. But you can't think about that. You've got to move forward."

But there must be times when each parent returns to an original thought or an original plan about how that family would be and would function. Developmental delays and Asperger Syndrome have the potential to change those plans greatly. When expectations are not met, it is probable that patience can be tested. Such tests can affect the developing understanding in many ways.

Building an understanding of Asperger Syndrome requires the development of an understanding about the way communication paths and patterns change, often within the occurrence of a single conversation. Assumptions made about how the other people in the conversation are interpreting the information can change everything. An example that appeared often was the statement-as-question: a statement by the parent takes the place of a grammatically structured question to the boy. More times than not, these statements did not receive answers, and the silence more than occasionally aggravated the parent. Elizabeth and Thomas noted that those moments changed the way they understand both interactions and language.

Intent becomes a key to a parent of children with Asperger Syndrome. Because of the literal mindedness of their boys, both Elizabeth and Thomas found they had to be more careful in their examination of the words they and their boys used in conversation. Admittedly, and as the cases show, this is not an area where they met with constant success, either with the boys or with themselves.

This is more than a connotation/denotation issue. Communication always must include the intent of the speaker, and that, probably, can never become perfectly clear. Words, tones, phrasings, and gestures play a role, but their use can be misunderstood even by the most astute and familiar observer. In the most common of interactions, it is

important that the speaker and listener have interacted enough to be familiar with each other's speech and body patterns. And yet it is not just time that is the factor for familiarizing oneself with speech and body patterns. If it were so, Thomas would not have missed so much in the communication here. For example, when Elizabeth said 'brunch' one morning, Thomas immediately corrected her and gave her the proper time for brunch, when, clearly she was referring to just a combination of breakfast and lunch. Time was not her concern.

So a full understanding of this phenomenon must include the question: Is it the person with Asperger Syndrome who misses the communication or is it the person who is neurotypical who fails to comprehend the audience? This dilemma is a central part of being a parent of a child with Asperger Syndrome.

Another area of meaning making for the parents concerns what I call the Acceptance, Denial, Cooperation triad. It seems to me that the degree to which Acceptance and Cooperation are increased improves the understanding of the syndrome. This improved understanding generally made for better parent-child interactions (and parent-parent) and normal, day-to-day activities seemed to function more smoothly. Elizabeth was more often in the Acceptance camp, and her interactions generally became more cooperative, resulting in greater success and good feeling from the boys. Thomas, on the other hand, would occasionally seem to Deny the condition and that would lead him to a more directive, i.e. less cooperative, interaction with his boys. As has been noted, all three boys saw their father as the disciplinarian and the one who could get quite upset with them.

This Acceptance, Denial, Cooperation triad also played a role in the way Thomas and Elizabeth encouraged me, or not, to seek information outside the family/school setting. Whereas Elizabeth was comfortable with my meeting the director of recreation for the community, Thomas wondered why I'd be seeking information there. And Thomas essentially forbid me from querying one of the twins' friends about his interactions with them, saying that he did not want that friend's mother knowing anything about the boys.

This difference did not change their belief that their boys would be better off if they knew more about how Asperger Syndrome played a role in their adolescent lives. But it also did not change the fact that neither parent had begun any kind of process with the boys to give them that knowledge. It is this conflict, I think, that gets to the heart of what it means to be a parent of a child with Asperger Syndrome, and it epitomizes Stake's (1995) earlier point about conflict revealing the most about human interactions.

How does a parent tell a child that a condition affects him in a way that will make parts of life more difficult? How does a parent tell a child that he is not quite normal? Is this a duty of a parent? Or is it more significant that the parent, despite knowledge of the child's disability, endeavor to make every part of the child's life normal to the nth degree? Does this include the failure to fully inform a child of the condition that affects him?

I cannot answer these questions, and neither could the parents in my study. They did, at different times, and through different interactions with their boys, offer answers. However, in each case the answer was particular to the context of the ongoing event. There was no consistency in their responses, at least not enough for me to discern

patterns that might help delineate their central beliefs on the topic. Yet it does tell me that being a parent of a child with Asperger Syndrome requires incredibly flexibility, high tolerance, and infinite compassion. It means being reflective and predictive simultaneously, while at the same time being protective and empowering. It means knowing oneself, to the point where such knowledge communicates a constantly changed self. And it means trying to engender a balance and stability into a child who, by his very nature, is unable to discern that balance and stability from outside cues or even from reciprocal conversation. It has sent both parents in this family on an inward search of self that may be never ending.

Yet at this point it is not clear whether the same kind of self-search is beginning in the three boys, as none of them are really cognizant of the effects their condition manifests in them. Even when the boys show extreme frustration at not being able to complete certain tasks, no connection to the possibility that their difficulties might reside in their Asperger Syndrome or developmental delay is raised. They were not asked to consider any aspect of Asperger Syndrome while I was staying with the family. Any talk of the condition while I was at the home was raised by me. So it is hard to say that the boys have any sense of how the label or the condition affects them.

The twins spoke to me of friends but were generally unable to describe how someone might know that a particular person was their friend. They surely saw extensive personal interactions at school and in extra-curricular activities, like cross-country, though they rarely shared in these interactions. An example of this was shown at one meet when, after the race, the team gathered with the coach, while the twins stood with

their father. Yet both of the twins would say that they were running cross-country in order to spend more time with friends.

As the questions above intimate, it is surely hard to step into the arena that addresses the presence of a disability to your child. Yet there must be some part of the parenting process that reveals that fact when it is manifest in the child. Certainly if a child had a condition that required her to be very careful about her diet, or to take a particular medication at specific times, a parent would need to be quite clear as to the many possibilities that could occur if certain actions were not taken. The child in this situation must know her status.

Is the same true for a child with Asperger Syndrome? I would say yes, but then I'd hesitate, and perhaps retract, knowing that many people have lived highly successful lives with no knowledge whatsoever of their Asperger Syndrome. Would their world have been better had they known what made them a bit different from their peers? I doubt it.

I went into this study feeling that a family who wants to understand Asperger Syndrome would look first to the behaviors of their children, noting those idiosyncratic occurrences that make them different from other children. Then, it made sense to me that a consulting of some literature base on Asperger Syndrome would be key. This, I thought, would include literature for the adults and the children in the family. This exploration of literature would engender a self-search, and then the family could share with each other their thoughts about what they had discovered. To me, family understanding would be built this way. I may have been somewhat naïve.

In the Berkley family, only Elizabeth has read any significant amount in the field of disorders that affects her children, while Thomas has read almost nothing. Elizabeth admits that, as a family, they have had only superficial conversations with their children about Asperger Syndrome and developmental delays. Both she and Thomas admit that the more their children know about Asperger Syndrome, the better they would be able to deal with it. Yet something is preventing them from engaging their children with a formal and open understanding of the syndrome.

Their boys deserve an opportunity to know what it is placing obstacles in front of them. These interactions, informing and sharing about experiences that fall within the characteristics of Asperger Syndrome would become the salient interactions of my initial questions. As the family stands right now, neither Elizabeth's nurturing, nor Thomas's directiveness is doing that for their boys. Both parents must come together, with their boys, to give their boys the necessary information to begin the process of understanding who they are. Normally developing children would have begun this process much earlier through naturally occurring reciprocal interactions with their parents and peers. But because these boys have a special disorder, a special set of deficits, it is only fair that they be engaged in a process that reveals how that disorder affects them. For a child to grow and be able to build an independent and happy life, that child must have a growing understanding of his abilities and deficits.

This is not meant to place blame on Elizabeth and Thomas for not taking on this task. I sense it is in their future, as both did admit that their boys should know more about what affects them. Indeed, the interactions I saw both of them share with their children demonstrated a love and affection that was exemplary. Looking back, it was a

very good thing I spent some days at their home prior to the beginning of school. As Elizabeth told me, that is a time when they can all just be together and be a family. A note in my researcher's journal captures my thoughts at that time:

The world had clearly changed by the time the boys began school. What had been a time of day—when they returned that first day—that was clearly their own, now became a time when they had to do work for other people. Time that had allowed them to do things they wanted to do became time when they had to do tasks they did not want to do. At the same time, whereas before Thomas had been free to read or play or make the supper, it is now a time when he, too, has to focus on a task that he might rather not do: their homework. So the changing nature of the time of year, the context of the activities during those times, can evoke frustration levels of different kinds in different times of the year.

School, and especially homework, did change the nature of the interactions in the family. Not only that, it changed the flow of time. As has been shown, these boys spend an inordinate amount of time on homework, seven days a week, in part due to their Asperger Syndrome. More significantly, expectations for the boys come from a broader base during the school year. These expectations, woven into the patterns of understanding and interactions being constructed by the parents, bring about a context that, perhaps, magnifies the differences in Thomas and Elizabeth.

The Berkleys want their understanding of Asperger Syndrome to be, first and foremost, an understanding of family, formed within the family. Without that, no dealing with Asperger Syndrome can occur. Unfortunately, they live in a world where labels

create boundaries that might just place their children outside of where they want them to be. Of course they'd be reluctant to jump into conversations that might bring those labels into full light within the family realm. I think I understand that now.

The irony may be that the lack of in depth conversations with the boys—and with themselves, recently—have developed in the Berkleys a nearly perfect place to begin a family wide understanding of Asperger Syndrome. As things stand right now, all five members have a great deal to contribute to the process that will bring about that understanding. The boys, for sure, have their experiences, many of which epitomize the characteristics of a child with Asperger Syndrome. On top of that, they do, at times, ponder the difficulties they have in areas their peers seem to negotiate with ease. Consequently, a space has been created in their minds, ready for input and expression.

Both parents, too, are primed for the discussions, though, as the data have shown, probably for different reasons. Thomas's measured denial will bring a necessary skepticism into the conversation, probably the perfect match to Elizabeth's penchant of seeing Asperger Syndrome in many others. Her nurturing nature of working with the boys is a fine enough example of love and caring to bring his more controlling approach of directing and demanding toward a more giving center. Each also has seen and interpreted enough of the boys' experiences through their own lens to make for rich fields of interaction.

And clearly they have established a cohesive family pattern so that no one will be surprised when the family is together for one of its many encounters, that speaking of Asperger Syndrome is the topic of the day.

Thomas once likened his family to musical types, calling his wife a classical musician, while labeling himself and Cosmo as improvisational jazz musicians. Thinking of that now, I am drawn to an apocryphal story about the great jazz trumpet player, Louis Armstrong. Before I relate that, though, let me look once more at this idea of building family understanding, and just how the Berkleys have shown me something significant about it.

Children, when they grow, move across thresholds of understanding, allowing themselves to apprehend something today that, essentially, they did not understand yesterday. In the world of Asperger Syndrome the idea of theory of mind is a function of this concept, as it is also a part of every developing child's growing mental competence. A three year old child, for example, tends to believe every one thinks what she thinks, and if she sees a pencil get placed in a box, while another child was prevented from seeing that, she'll still say that the other child would look for the pencil in the box. Yet a four-year-old child generally knows that if the other child were out of the room when the exchange took place, she would not look in the box upon her return.

In other words, understanding is temporally and developmentally dependent. As individuals, we do not understand something before we are ready to. Indeed, when we look at something before our capacity has been allowed to develop to the proper level, we will miss the significant point. We need to experience a richer world, full of many opportunities to juxtapose similar engagements, before we can grasp the information at hand. We need to be ready. And that readiness is a part of our metacognitive abilities. In other words, we can know that we are ready, because we can think about being ready to understand the phenomenon at hand.

I think families of children with Asperger Syndrome—and probably all families—work the same way: they do not understand something before they are ready. A difference, though, resides in the kind of things each family must need to understand. Families of children with Asperger Syndrome must go outside of themselves and their experience to gain the necessary information to construct that understanding, whereas families of neurotypical children can generally assimilate the experiences they need to understand. Let the parents in the Asperger family also have characteristics of Asperger Syndrome, and the understanding they seek will be even more difficult.

The Berkleys, despite many of the issues raised here that might indicate otherwise are, I think, right on the cusp of that understanding, almost ready to take the step into rich, deep conversations about the syndrome that affects not only their boys, but all of them as a family. Their experiences have been vast enough; their concern is clearly shown; and the time is right, especially as the twins are nearly ready to enter high school, a time of change in most American boys' lives. And I believe the parents know they are ready: Elizabeth's comments about Bob probably being ready for "this kind of information," and both of their comments about how the boys would benefit with a firmer personal understanding of the syndrome, show a space nearly made for the beginning.

How then might we know if a family was ready—for to start such a conversation before readiness would doom it to misunderstanding—for such a conversation? That takes me back to the Louis Armstrong story just mentioned.

It seems that after a concert he was approached by a fan who had been mesmerized by his playing. She had been brought to the concert in order to experience something outside of her culture, she of the highbrow elite world, and jazz music, to be

sure, of the more common, baser world. When these two worlds met in her that night, though, she was captivated and wanted to know more. Her position in her world allowed her to speak to Mr. Armstrong, by requesting that he come to her. Once together, she spoke:

“Mr. Armstrong, can you tell me what jazz is?”

“Lady,” Louis responded, “if you’ve got to ask what it is, you’ll never know.”

Some people will never know what jazz is, just as some people will never understand how Asperger Syndrome affects a human being or a family. Families of children with Asperger Syndrome, though, will have an understanding, relative unto themselves, that is deep and informative, not only about the syndrome’s affects on an individual, but also on that family.

However, gleaning that particular understanding through the asking, ‘what is Asperger Syndrome to you,’ may not be possible. Watching, living with, and sharing with the family—just as practicing, playing with, and improvising with the jazz musician—may be the only way. My questions still feel right to me, though it was not possible to glean a significant response to my third one as the parents have not yet undertaken the interactions that will lead their children toward the understanding they will need. When that move occurs, certain salient interactions will occur. Would that I could be there. Perhaps my continued connection to this family that was and remains a close friend will reveal some of that in time.

I do know this: It might not be the luckiest thing to have three children on the autism spectrum, but it might be the luckiest thing for these three boys to have these two parents.

CHAPTER ELEVEN: REFLECTIONS AND FINAL THOUGHTS

In this study I sought to glean particular and general insights on how a family comes to understand the affects of Asperger Syndrome. I sought to explore how each parent constructed individual and shared understanding of the syndrome, as well as how that individualized understanding affected the relationships each had with their boys. In turn, I endeavored to discover how the boys were affected by and understood the label placed upon them by having been diagnosed with Asperger Syndrome. All things considered, I feel that the family cases and the chapter reconnecting those cases to the questions have presented these aspects of my research process successfully.

Thinking back over this study makes me realize that one doesn't conclude a study like this nearly as much as one reflects on it. Certainly such reflection helps to organize the experiences and their analyses by combining the many levels of interpretation and understanding that have occurred, but it does not bring the study any closer to what might be called a final statement or interpretation. Rather, such reflection blends my understanding of the Berkley's experiences with my own transformed understandings about Asperger Syndrome and creates a spiraling interpretation, one that turns back upon itself even as it moves upward and outward into new areas on understanding. As I have alluded to several times, one of my chief discoveries was that research of this nature is as much about the researcher as it is about the participants. That simple reflection presents the never-ending nature of this work: for as long as my understanding of Asperger Syndrome adapts and is transformed by various information I encounter, I will revisit my

time with the Berkleys, both vicariously, by reviewing the notes I have taken, and directly, through my continued connection to them as friends.

Thinking back also reveals a set of significant new questions: How did our friendship affect the data and conclusions of my study? How will the study affect our friendship? How do I now understand Asperger Syndrome? How have the interpretations I have made about the family fit into my schema of fairness, of friendship, of research? And, what does it mean to understand something?

What follows in this concluding chapter are some thoughts about the process after the project has been completed. I hope it allows the reader a chance to see the place where the researcher and the research met.

The Friendship Factor

An interesting aspect of this study was the way it allowed, and at times, forced me to look at the friendship I had with the Berkleys. Generally this was a pleasant reflection, as they are people whom I've admired and enjoyed for many years. Theirs was one of the first great marriages I knew within my peer group, and their attitude and perceptions about the world at large was critical without being cynical, something to which I felt a kinship. As I have mentioned before, a good deal of my world view was developed in cooperative spirit with Thomas, so much of my time in their home was positive in many ways.

I was included in nearly everything the family did while I stayed there: dinnertimes, family visits, school visits, weekend recreation activities, and at-home family activities. Elizabeth and Thomas encouraged me to interact with the boys, stating that I'd surely see things differently from the way they did, and that the boys, in turn,

would probably benefit from the different kinds of interactions they had with me. All of this, when I would reflect in my researcher's journal, would meet with pleasing tones and descriptions. I was with friends, and they were treating me as such: welcoming me into their world, and opening it up in ways that engendered opportunities for deep insights into my exploration, revealed, I believe, in the cases that make up the five family chapters.

There were times, though, that life in the Berkley house did not have the air of friendship and welcome. I mentioned at one point I did not want the study to be just about Thomas, though, at times it was exactly that. I reflect again: How could it not be? The reader should be aware that Thomas and I have always been able to 'begin where we left off,' even if we 'left off' more than a year previous. When I arrived at the Berkley home that first Friday, Thomas yelled from the door as I parked my car, "Smig!" to which I replied, "Berr!" our nicknames for each other for 25 years. We had not seen each other for 18 months. But within 15 minutes we were sharing stories of music, sports, politics, old friends, and new worlds of experience, just as if we were roommates again. The same assumptions were in place, with, perhaps, a few different nuances. After all, we are not in our early 20's anymore. But Thomas was Thomas in those opening moments, same as he ever was, like water on the bottom of the ocean, always predictably Thomas.

Or was he? The astute reader might, from time to time, detect a tone of disappointment in my treatment of Thomas here. Indeed, I did become disappointed at some of the behaviors I saw, the thoughts I heard. During my study, Thomas was not always the understanding person I had come to know over the years, and consequently,

an occasional tension grew. Such tensions were not unheard of in our past. Thomas and I have disagreed on many things in our lives together, and we have argued vehemently about them, often agreeing to disagree in order to close the debate. Yet those never really gave birth to disappointment.

Wolcott (1999) tells us that ethnography's power is in the way it lets us see what people do and hear what people say about what they do. Times of my most interesting personal reflections occurred when Elizabeth and Thomas had explained their beliefs in fairly clear terms but had behaved in ways contrary to those statements. As a researcher I was left to wonder which side of that coin revealed the truth. Ultimately, I discovered both sides, together, were needed for that.

Hearing Elizabeth speak of the great relief it was to have a diagnosis for her boys, as that helped her explain so many things of her own family and childhood, didn't always mesh with the fact that I never heard her use the term Asperger Syndrome with her boys or with Thomas, unless she was speaking with me. She often spoke of the way Asperger Syndrome explained much about the world she and one of her sister's inhabited in their teens and early twenties. She said that, if she had known then what she knew now, things would have been quite different. She might not have thought of herself and her family then as quite so 'weird.' I could get Elizabeth to relate stories about her father, her sister, and herself, showing me she had a powerful sense of Asperger Syndrome and the obstacles it might place in a person's life. I could get her to talk about how the same kind of information would be helpful to her boys, but, at least while I was there, she did not have that conversation with them.

Thomas, too, with his often passionate wish that people would just accept the differences they saw in his boys, presented a strange juxtaposition when he would demand they do exactly the same work their classmates did and that no ‘special privileges’ be given to them. I had a difficult time placing these seemingly opposite thoughts and actions side by side. I felt they showed a contradiction in the parents that didn’t speak toward either understanding or dealing with Asperger Syndrome in any kind of positive way.

But then I remembered Whitman, who wrote that people are large and may contain contradictions, and we should revel in such truths as are shown through contradictions. Indeed, it may be the contradiction in a person’s spirit that really opens the window to their meaning-making systems. How, then, will the apparent contradictions in what Elizabeth and Thomas say and do reveal their understanding of Asperger Syndrome? And how would I deal with the disappointment those contradictions brought to me?

Disappointment in friends is not an easy thing to deal with in any context. That bond which unites also endeavors to assist. When friends behave in ways that seem detrimental to character, a friend helps turn that toward positive, where possible.

But can a researcher do that? I asked myself time and again if my disappointment was properly construed. I knew it was apropos as a friend, but how might it affect my research? There was certainly the possibility that my disappointment would change the way I observed interactions. Would I believe what I saw, or would I see what I believed? A good deal of my time, especially after those moments when I did become disappointed, was spent reflecting on the veracity of my interpretation of data.

Moreover, I was present in the Berkley home to discover how they understood Asperger Syndrome, something they lived with every day, and would live with everyday for the rest of their lives. If I was becoming disappointed at the way Thomas dealt with homework assignments, or how Elizabeth avoided the conversations she knew were needed, wasn't I disallowing the possibility of accommodating their experiences into my schema? Didn't my disappointment indicate a preconceived notion on my part as to what anyone's understanding must be?

This connects to the naiveté I mentioned earlier. Some behaviors I had hoped to observe were not always present, and because of their absence I became disappointed. Disappointment brought a feeling into the research process I had not thought about beforehand. For a short while it brought some confusing reflections on my part. I mean, I went to Thomas and Elizabeth because I knew them to be thoughtful, intelligent, caring people who, from all correspondences we had shared, were dealing with a disabling condition in ways that might be exemplary, and might be valuable for others dealing with the same situation. I was hoping to share in their world in order to take the next step and to share their world with others. And they agreed to my request. Disappointment in this light almost seemed dismissive of what they were offering me. And I thought, wasn't I being a shit for a burgeoning disappointment at what I saw?

Perhaps. But perhaps not.

Ultimately, I came away with an acceptance of my disappointment, that it was well placed and important in this study. Research into human behavior and understanding is interesting and valuable so long as it makes the researcher look inside. My understanding of Asperger Syndrome was challenged through my disappointment in

Thomas. I had to look differently at the ways I contextualized the syndrome. I also had to look differently at my relationship with Thomas.

Our relationship is not at the same place it was before this study. The next time I see Thomas, we may not begin just where we left off. One of the reasons for that—and a major dilemma for me as a researcher—is that Thomas and his family have not only revealed their home life to me, but I have also revealed my observations and analysis of that life to them in these pages. At no time previous in our relationship have we shared to that degree. Whereas disappointment and disagreement in earlier times in our relationship could have been swallowed and not talked about, that could not be the case now. In times past, Thomas would have had no reason to share with me his belief, albeit a small one, that he probably had a touch of Asperger Syndrome. Nor would he have any reason to believe that Elizabeth had shared with me the fact that she thought the both of them we affected by it. Heretofore, we never played the roles of observer and observed. Now, however, for the first time in 27 years, we saw and interacted with each other in a different context, and that changed things.

Reflecting on the disappointment, the changed nature of the relationship, and the close study of interactions, I accept the role of friendship as a positive force in this study, but I wonder if our friendship was the best one to test it upon. Living 1,800 miles apart makes personal contact difficult, and I think it would be good if I could just ‘drop in’ on occasion to talk with the boys, or see one of their cross-country meets, or have a beer with Elizabeth and Thomas. Personal contact, after spending such an intimate time at their home, would be helpful. It would continue the growth of understanding, but

moreover, it would bring the relationship back to its original plane in gradual steps. A plane we may not find again.

Reconnection: Asperger Syndrome

Without question, living with the Berkleys showed me a great deal about Asperger Syndrome. I have attempted to describe several of those characteristics and the insights I gained in the cases here, including moments that demonstrate the boys' literal mindedness, lack of conversational skills, inability to read social cues, undeveloped understanding of reciprocal interactions, as well as their unusual vocal quality and occasional repetitive behaviors. Rarely did a day go by that I did not observe something that showed me how different their world was from mine.

Yet, in many ways, each boy is as 'normal' and 'naturally behaving' as any of his peers, something akin to the contradictions mentioned above. On the one hand I saw two 13 year old boys having difficulty with their homework, often taking as much as three hours to complete what the teacher thought to be a 20 minute task. Clearly this had much to do with their inability to focus on the task, their inability to carry with them—even from one problem to the next—formulae and newly learned information, as well as their inability to regard the significance of the task at hand. These are the manifestation of Asperger Syndrome's affects upon them. On the other hand, I saw 13 year old boys who would clearly rather be doing something other than their homework, who found more pleasure playing a video game or watching *The Family Guy*, and who could laugh and tell an animated story to their mother or father, or me, in ways that only a 13 year old could. These epitomize the typical early teen.

And so I saw behavior that manifest both Asperger Syndrome and adolescence, and I had to sort them out. Or so I thought I did, thinking that I might discern a ‘place’ where adolescence ended and Asperger Syndrome began. But that, of course, was futile. No such place exists, and as with the contradiction just mentioned, it became important for me to see both the adolescence and the Asperger Syndrome as integral to understanding each of the boys.

In that light, I began to see them as fairly competent students while they were at school, though not equally competent when they were at home. I also noticed that they were much better students when they had a one-on-one situation with their mother, or with their teacher, but were not that good in a group situation. I knew from my literature review on Asperger Syndrome that this was typical of students affected by it. But I also knew from my teaching experience that this was a fair description of nearly all students I had taught in my 17 years in the classroom. Again, a combination of contradictions was in order.

Now, however, rather than contradictions I was seeing idiosyncratic dissimilarities. This, too, reflected the literature on kids with Asperger Syndrome. I was discovering that understanding Asperger Syndrome required me to observe a world of possibilities through multiple lenses, knowing that each lens would reveal and distort basic views of that world. Like so many adolescents, Ringo and Bob liked it when a friend came over on a weekend to watch a video with them. Like so many kids with Asperger Syndrome, neither Ringo nor Bob had much to say to Roger when he came over and watched *The Pink Panther*. If I had only used the Asperger lens to view this interaction, I might not have seen that the twins were glad that Roger came by. If I had

only used the adolescent lens, I might have misconstrued the silence that accompanied the movie as rapt interest.

Discerning the affects Asperger Syndrome has upon an individual requires a fuller appreciation of the individual than one might imagine. I now find myself having to be very careful when someone tells me their child has Asperger Syndrome, as that term says so much and so little simultaneously, something I'll deal with later in this chapter.

Reconnection: Parent-Child Interactions

Looking back at the several interactions related in the cases here, the reader can see how both Elizabeth and Thomas have developed a rich capacity to enjoy their children, the first stage of the Bromwich (1976, 1997) model. Indeed, in many ways, they have revolved their lives around the three boys, attempting to make sure that the connections that exist in the family engender an enjoyment that builds a family cohesiveness.

It is equally obvious that the next two stages of Bromwich's (1976, 1997) model are also met: Elizabeth and Thomas are able to read their boy's communication and attachment skills—in fact, so well that with Cosmo they were unaware that he was not speaking on time—and they regularly engage in interactions that promote mutual satisfaction. Elizabeth, perhaps, said it best when she spoke of loving the summer months because the family was together, all together, and just being a family. I have shared summer moments with them at their camp on the lake. Would I have understood that point as well if such a sharing had not been a part of our friendship?

Marfo's (1990, 1992) work, too, is seen in the family, as there clearly are moments of sensitivity, stimulation, responsiveness, and elaborativeness throughout the

interactive descriptions presented in the cases. These positive characteristics drive a myriad of parent-child interactions within this family. Yet there are also moments Marfo would call intrusiveness—mostly on the part of Thomas—that enter the interaction repertoire and affect the outcomes therein. I believe Thomas's friendship for me allowed my direct observation of his occasional intrusions.

Moving up Bromwich's (1976, 1997) model, each parent has more difficulty consistently meeting the descriptors of the stages. Though there is awareness for materials and activities for each boy's developmental level, there is also often a denial of that level, especially as it applies to activities such as homework. And while there are some examples of initiating new play from their own experiences—family outings and activities revolved around those things the parents found pleasurable—there does not seem to be a wide range of activities and no exploration into that which might be referred to as brainstorming new and diverse possibilities.

Because of the friendship between us, Thomas and Elizabeth didn't seem to hide their behaviors from me. Their different natures showed them to be an intriguing mix of the authoritarian and the authoritative parent (Grolnick, 2003). Interestingly, both parents would fit both descriptions, depending on the specific interaction encountered. While it is true that Thomas might more easily be called authoritarian, and Elizabeth authoritative, it would be unfair to levy just that one descriptor onto either of them.

Here is a place where I must temper my disappointment in Thomas, especially as I reflect back on both the study and the literature. Parent-child relationships have been explored through experiments and observations involving the interactions of parents (usually mothers) and their children in very short segments of time, often not more than

30 minutes. I think my research points to the probability that a much broader understanding of parent-child relationships will come from working in the environment of the most natural set of interactions available: the home. Only in this way will the contradictions become fully apparent. Only through those contradictions will there come a fuller understanding of parent-child interactions. The more I reflect on my disappointment, the more I see its necessary place in this study. Ironically, it allows me a fuller appreciation of those behaviors worthy of admiration in both Thomas and Elizabeth.

Time and again I had to ask myself how it can be that such negative and positives exist in the same behavioral pattern. Why would the sensitivity, responsiveness, and elaborativeness of Thomas, that which allows him to find an alternative way to understand Cosmo's difficulties with dressing for soccer, morph into the intrusiveness, directedness, and authoritative control that would engage Cosmo in a very difficult and unsuccessful episode in learning to tie his shoes? Why would Elizabeth's ability to read her children's needs, allow her to stand by as Thomas occasionally turns a moment of sensitive cooperativeness into one of intrusive directedness?

And why does Elizabeth, whose inquisitive nature has spawned an exploration into her own family and their possible characteristics of Asperger Syndrome, not engender interactions with her children on the nature of the disorder, especially when both she and Thomas speak of how that knowledge would surely help their children? And why does Thomas, who speaks of not caring about how others perceive him in regards to what is normal in the social world, demand that his children do all that is asked

of their classmates at school, especially when he sees not only how difficult that is but also how much potential free and/or family time it takes away from his boys?

I'm thinking there's a possibility that friendship might enhance a fuller understanding of the bevy of behaviors and attitudes displayed in parent-child interactions. The closeness that allows strong personal interactions between the researcher and participants might reveal more of the parent-child relationships than will the more formal and detached researcher role. Mahoney's (1988) idea of an interactional match speaks of knowing when the parent's behavior takes the child to new levels of thought and activity without exceeding the child's capacity to process information. In some ways it is akin to Vygotsky's zone of proximal development (Vygotsky, 1978). Mahoney argues that the match develops in relationship to the parent's sensitivity and responsiveness. However, how well can a researcher know this without having the experience of many years of close knowledge of the parents? Powerful descriptions of parent-child relationships cannot be given by a researcher who has only spent disconnected segments of time with the participants. Mahoney's concept may be on target, but what it is shooting for is of limited value without the close knowledge of the family.

My present observations—and many recollections of times past—show that Thomas and Elizabeth have moments when their interactions with their boys mesh nearly perfectly and one sees a sensitivity and responsiveness manifest in the adaptations the parents make. An interactional match is made. Thomas's handling of Cosmo's kicking incident shows this quite well. Yet both parents also break that match at times—and have in times past—replacing autonomy goals with directiveness, and in that way move away

from authoritative toward authoritarian parenting. How might Mahoney (1988) deal with these discrepancies without seeing the often seamless transition from one to the other? I don't believe he could.

I am more convinced that friendship is a fulcrum for good research in explorations that hope to uncover familial understanding. After all, it was the time spent in the natural environment that was the most revealing of pertinent information that matters here. Without that time in the home in direct contact with the participants, no understanding of the mental frame behind the interactions would have occurred. Without that time in, I might never have been able to become disappointed in Thomas or Elizabeth. Had I not been disappointed at some of the behaviors I observed, I don't think I could say I fairly saw the interactions that inform this study.

Disappointment for a friend demonstrates concern for that friend's well being. That I am able to mix that reaction with one of admiration for how Thomas and Elizabeth continually endeavor to make their boys' world a better place to be, tells me that I have not been one sided in my pursuits. It reveals my understanding of how someone ought to interact (or ought not to) with a child with Asperger Syndrome, thereby reconnecting me to views in the literature; it reveals my concern for the well-being of the children, thereby eliciting the attitude that my research will seek to do no harm; and it reveals the bond I have with Thomas and Elizabeth, thereby showing that my research hopes to help make changes.

Understanding Asperger Syndrome

For me, the term Asperger Syndrome represents a cadre of variable characteristics, mostly affecting the individual's ability to understand and interact within

the social milieu. But such a term is not without a range of differing interpretations. For example, several diagnostic tools are available, but each posits a different sense of what Asperger Syndrome is. According to Atwood (1998), the Gilberg's scale places significance on the narrow interest shown by the individual, whereas the scale by Szatmari, Bremner, and Nagy does not. And while both of those tools emphasize odd and peculiar language, the DSM-IV emphasizes that no significant language problems be present.

Furthermore, whereas Szatmari et al (Attwood, 1998) address the idea of a solitary nature in the individual with Asperger Syndrome, neither the DSM-IV or the Gilberg's specify that aspect of the impairments affecting social interactions within the disorder. And only the Gilberg's mention motor clumsiness in their instrument.

Of course, I was aware of this spectrum of understanding going into my study, and I was comfortable that many 'experts' in the field had differing views. My experiences in all things with a label of disability have been filtered through a strong believe in the social construction of reality (Berger & Luckmann, 1966; but also see Hacking, 1999). There may be collections of characteristics within the behavioral repertoire of an individual that make her stand out in comparison to behaviors of others around her, but gathering those characteristics into one coherent whole set of descriptors falling under one heading, i.e., Asperger Syndrome, seems reductive and potentially demeaning.

And yet I accept the logic in exploring the nature of those characteristics and that label as fully as possible. Certainly that is one of the major reasons for my study: to glean a deeper understanding of Asperger Syndrome by examining the meaning making

system—and label-regarding attitudes—of one family. Elizabeth and Thomas spent several years observing and interacting with their children prior to any label being applied. They knew how their boys were different from their age mates, as well as how they were different from each other. It was my belief that their expertise was just as valid, if not more so, than any of the aforementioned researchers.

They surely had constructed some kind of understanding, and perhaps many kinds, beginning with their early observations, moving up to and beyond the time of diagnosis. They might, I thought, fall into either the Gilberg's camp, the Szatmari camp, or even the DSM-IV camp. More likely, though, I thought they would be building their own camp, their own base of understanding.

Equally, I knew that my time with the Berkleys would alter and challenge my understanding of Asperger Syndrome. How could it not? As one who believed in the social construction of reality (Berger & Luckmann, 1966), I knew my thoughts and understandings could not help but be affected by my time with this family and their experiences with Asperger Syndrome.

Consequently, one central dilemma for me during this study was the nature of Asperger Syndrome, itself. Initially, I wondered in what way the syndrome was 'real' for the Berkleys. Had they built their understanding based on the possibility of many different ways to view the syndrome? Did they see all views as being necessary for their understanding, or did they sense that one way might be superior to all others? What kinds of definitions and characteristics did they reject? Certainly the way a person understands something has as much to do with those ideas rejected as those accepted. After all, every choice is an exclusion.

But I also came to see that the same kind of exploration into my own acceptance of the reality of Asperger Syndrome was a necessary part of this study. My spiraling reflection made me question my own understanding of the syndrome, in ways that I had not predicted the study would. What was I rejecting and accepting in the construction of my definitions? How was I bringing the many views together? Of course I had known that my understanding would be transformed, but I thought of that as only a changed and more informed view of the syndrome itself. I did not expect to engender a new understanding of reality itself. But such was the result of my reflection and this study.

I entered this study as a constructivist. I saw life as a collection of multiple realities formed by individuals constructing understandings from both personal beliefs and social experiences. I did not believe there was a reality ‘out there.’ Even if there might be, I was sure we could never know it.

Lincoln (1985) asserts that reality may exist on four different levels, which I will simplify here: 1) Objective reality: tangible reality exists and is knowable fully through experience with it; 2) Perceived reality: tangible reality exists but cannot be known fully but only through particular vantage points; 3) Constructed reality: there may or may not be a tangible reality; regardless, it cannot be known. Rather it is constructed by multiple and divergent interpretations that do not have a one-to-one relationship with the tangible world; and 4) Created reality: there is no reality. Reality is *realized* (italics in original, p. 85) when something is observed by an observer.

Applying Lincoln (1985) to the literature on Asperger Syndrome, I’d say we discern a perceived reality. The literature speaks of the highly individualized nature of a child with Asperger Syndrome: “if you’ve seen one kid with Asperger Syndrome, you’ve

seen one kid with Asperger Syndrome” (Wilson, personal communication). Even the spectrum nature of the disorder speaks of differing realities depending upon where one sits on that spectrum. The literature does not speak of knowing Asperger Syndrome fully, and even the different scales used to diagnose the syndrome (Attwood, 1998) argue for the different perceptions that play a role. Yet clearly, for those researchers in the field, Asperger Syndrome is ‘out there,’ affecting real people in real ways, and apparently in ever growing numbers. It is a tangible reality.

Though I was of the constructivist school, connecting the literature on Asperger Syndrome with Lincoln’s (1985) perceived reality did not concern me. I had accepted Thomson (1997) and Marks (1999), who argue that disability operates in cultural contexts, and needs to be seen via the cultural discourses that shape it. Certainly researchers of disabling conditions would have a culture of their own. If that research culture was one of perceived reality, I did not have to change my own belief to glean information from them. Asperger Syndrome, I believed as this study began, was not ‘out there’ as a discernable, tangible reality. Rather it existed as a collection of divergent observations, characteristics, and interpretations, brought together by a cadre of people and their experiences living with those who had been so labeled with the condition. It was not, for sure, something we could ever know fully.

There were characteristics that seemed to help a person identify the disorder. But such characteristic lists did not speak to a ‘science’ of identification, but rather toward a narrative of possibilities. My research was seeking another set of voices to be added to the perceptions already in the literature. I thought it had merit insofar as it offered a lens into the disorder that had not been used heretofore: an outsider living inside the family.

Filtered through my own sensibilities, the family's use of common and particular terminology, reflecting their own idiosyncratic understanding, would build on the gleanings of the larger group of people working in the field of Asperger Syndrome.

I felt my constructivist approach to knowledge, understanding, and research was on solid ground as this study began. Asperger Syndrome was being constructed in the contemporary world, by the many players observing and thinking about it. One can even see those simple changes occurring in the literature. For example, the name has evolved from its original, 'Asperger's Syndrome' to 'Asperger Syndrome' and now several researchers are using 'Asperger Disorder' with some regularity. A changing label seems to represent an on-going construction.

It should not have been surprising, then, to find that I, too, was going through changes of understanding as the study moved forward. But it was, especially when I found myself speaking of Asperger Syndrome as if it were quite real. "Asperger Syndrome is a neurological disorder affecting the social and emotional components of an individual," I told my parents when I stayed with them for those days between stays with the Berkleys. "But Bob has Asperger Syndrome, so he couldn't understand what he was supposed to do when he joined that group of soccer players," I told my father after he had read through some of my notes. "Thomas probably has Asperger Syndrome, himself," I told my sister. "You know, it kind of explains some things from years ago." (She was the first to notice my disappointment in Thomas.)

These were not the thoughts and words I was accustomed to saying. I found that my language portended a move from my belief in a constructed reality to a perceived reality. In a few ways, this would be a short move: both views allude to a set of vantage

points from which a person either constructs or perceives reality. But at least in the way that one posits a tangible reality and the other sees reality as dubious, it was a pretty large move. So, because of this study, I had to look closely at the epistemological underpinnings I thought were mine.

In some ways this was more of a mental exercise of pleasure than it was of a validation process of research. As I have said, I am comfortable that my descriptions are accurately presented, and throughout this whole process I have used a crystallizing system of corroborating the data I have collected. The time spent with the family let me see into their world in significant ways. But I continued to wonder: was I beginning to see Asperger Syndrome as 'real' in the way Lincoln (1985) proposes as a perceived reality? Or was I still a constructivist, accepting the syndrome as an ever-changing idea being constructed by myriad participants affected by it in some way?

Ultimately, it was the spectrum nature of Asperger Syndrome that let me see more clearly into my newly found understanding of reality. This nature posits that no one individual with the syndrome will be affected like any other individual with the syndrome. The more I thought about this, the more I realized that the same kind of thinking must be applied to Lincoln's (1985) four ways of understanding reality. A juxtaposition of the two categorical systems revealed that levels like hers are arbitrary constructs meant only to facilitate a deeper discussion on the issue. A diagnosis of Asperger Syndrome provides the individuals affected—as it did for the Berkleys—a way to talk about, in clear and concise terms, the nearly unexplainable behaviors and quirks that have happened up to that point. However, it does not categorize the understanding of Asperger Syndrome into one concrete frame. Rather it opens up a possibility of building

an understanding that will be able to grow and flex with all new coming information over time.

Lincoln's (1985) levels are just that. By positing that there are four ways to understand reality, her work allows others to speak more clearly—and argumentatively—about it. Her levels help organize certain experiences, putting them in a place where they can be seen and spoken about more clearly. A sharing of understanding can ensue.

But categorizing on a spectrum is not really possible. There are literally infinite places along that continuum where a category might rest, and there are infinite opportunities for categorical definitions to overlap. Ringo's Asperger Syndrome is not Bob's. That they share some behaviors and characteristics is obvious, though the sharing differs in kind, and in degree, hence the manifestations of the characteristics are different. As has been shown, Bob will join a group of age mates, though he will not engage with them verbally to any degree. Ringo will not join a group, and thereby will not engage with one verbally. This would motivate many in the field to say that both boys have social deficits, a category often used in describing a condition of Asperger Syndrome. But clearly such a description is limited.

So, too, are Lincoln's (1985) levels. Reality seems best understood as a continuum beginning somewhere around objective reality and continuing beyond created reality. I am not, then, a *member* of the constructed reality group, but rather I find myself best able to discuss my current level of understanding of reality with the terms that level uses. I will, though, as happened in this study, be presented with times when those terms and concepts do not work as well to define my place along the continuum.

This, I am coming to understand, should be expected *especially* from a constructivist position. Reality is ever changing, because the perspective from which we view it is ever changing. I understand Asperger Syndrome differently now; I understand the Berkleys differently; and I understand myself differently. Those differences weave together to construct a worldview that is at once grounded on evidence but also situated in a spiral. It cannot help but be defined by theories, practices, and human understanding. But it should not be limited by those either.

What we have come to call Asperger Syndrome affects this family to a great degree. Their interpersonal interactions both within and outside the family, as well as the potential success the boys face are all interwoven into the multiple perceptions that define Asperger Syndrome in our world. The way the Berkleys have chosen to wrap themselves around the syndrome is telling of the syndrome itself, and understanding how they are affected by it will hopefully help foster greater understanding about Asperger Syndrome.

Final Thoughts

“A better understanding for your child will lead to your child feeling better understood. And your child will be a much happier child for that. After all, we all want to be understood” (Bashe & Kirby, 2001, 125).

I believe the findings of my study suggest that children with Asperger Syndrome should develop an awareness and understanding of how the syndrome affects them. This awareness may come from many places, but predominantly, in families like the Berkleys, it ought to come first and foremost from the parents. The children need information that

will clarify the syndrome to them, explaining how certain deficits they knowingly experience (or do not) are characteristic of their Asperger nature. Parents offer the potential for this to occur in a safe place between loving partners.

Both parents in this study recognized and spoke of this need, yet neither made it happen. Consequently, all three boys had little to no understanding of their condition. How this lack of understanding will affect them is hard to say. On the one hand, as the boys grow and move into a broader world of experiences, they may be unable to understand certain social contexts and nuances, thereby unable to obtain the goals they seek. On the other hand, a good argument has been made that Thomas Jefferson (Ledgin, 2000) had Asperger Syndrome, and since he clearly had no understanding of the syndrome, it is possible these boys will be just fine.

As for the intended audience of this research, observations here of Thomas and Elizabeth working with the three boys on homework could be instrumental in helping teachers understand how a family deals with that school/home interface. Only one of the teachers I interviewed at the boys' school had read anything at all on Asperger Syndrome, and so these descriptions might be quite valuable to that particular audience. In turn, observations of the boys at school will help parents see into the world of their children as they spend their seven to eight hours away from home each day.

As a practicing teacher, I know that too often that twain does not meet, and that neither side has much knowledge of what goes on in the other venue. Such a set of cases as these, accompanied by the analysis and reviews of literature, has the potential to help those who serve children with Asperger Syndrome, from two sides of that service. The more we know about the special world of children with Asperger Syndrome, the more we

will understand ways to make that world more enjoyable, more successful, and more accessible to outsiders.

That has to be seen as a good thing.

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APPENDICES

Appendix A:

First Letter to the Family:

January, 2004

Several things come to mind as I tell you that I'm hoping to do during my research project on Asperger's Syndrome. Much of it is still in the formation stage, as I am not nearly well enough read on the pertinent research. That, though, will be rectified throughout this semester, and as that occurs, much of what I'm hoping to explore will be refined and transformed. So, as you look at this, don't hold it as a final, here's-what-my-project-is-about explanation.

To give you an idea of how some of this has evolved, you can see a 'mock' proposal for a class I took this past fall, by going to <http://home.tampabay.rr.com/bgraffam/aspres.html>. It was a class on the sociology of disability, and we had to focus on a 'disability' that had pertinence to some area of study or interest. I selected Asperger's as it is becoming more prevalent in Gifted circles. As you'll see, it was more about studying teachers of gifted learners who have been identified with AS. But I'm thinking there's more to learn outside of the classroom right now, as too many people inside education have yet to hear the term!

Method

The Method and form of my research will be an ethnographic case study, where the _____ family will be the case. As it will be ethnographic, I would be living with you for a period of time—I'm saying six weeks, now—though not entirely at your house for all of that time. In my mind I see a need for spending a few days in a row away from there in four different sessions, probably two weekends and two in the mid week. In that way I have a full schedule of observations, which will include numerous weekly and weekend events, but I can also see mom and dad and be away to think. I suspect two of those days away might turn into a three day run. But you can figure that I'll be at your house most of the time from when I begin until about six weeks later.

During the stays I would like the chance to interview all of you several times, sometimes as individuals, sometimes in groups. Those would be taped, if possible: audio not video. Mostly they'd be 60 minute interviews and we could schedule those as we went along. And of course, all of our conversations would be a type of interview, insofar as we were talking about living in a family with Asperger Syndrome.

As much as possible, I'd like to be a fly on the wall rather than as an invited guest—though I am aware that will be quite difficult, given mine and _____ need to converse whenever we're around each other. However, I also want to incorporate a type of research known as 'active-member research,' and through that be a major part of many things that occur at your home daily: meals, gatherings, shopping trips, movie nights, walks, etc.

As this is an ethnographic case study, I'll also want to visit the schools the boys attend, talk to their teachers, coaches, doctors, diagnosticians, etc., and basically observe them in their world outside of the home. This is a more touchy area as my presence will have the potential to draw attention to them, and certainly I don't want any of this to be negative for them. If something like a classroom visit was thought to be too invasive, we could remove that from the study. Though I'm thinking I might be able to spend a day at the school, staying with their teacher all day, so others in the school would think I was observing that class and not the boys. Still, please know that almost everything about the study is negotiable to a degree: this is just a set of suggestions, not a set in stone proposal.

Purpose

Since Asperger's is still a new 'disability' (I'm not comfortable with that word, hence the quotations) as far as recognized conditions go, it makes sense to me that families who live with Asperger's have much to tell us about its nature. With what little I know of the syndrome, I am of the mind that if you know one child with Asperger's Syndrome, you know one child with Asperger's Syndrome. Therefore, the more we discover about the range of possibilities the Syndrome presents, in its actual lived experience, the more effective we can be in establishing better learning and living environments for Aspies.

I am very interested in how the world of an Asperger's family interfaces with the non-Asperger's world. I think that the way you have constructed an understanding of the syndrome will be very different from the way the boys' teachers have constructed that understanding, and again different from those who have offered clinical and/or diagnostic services. My thought right now is that my study will be looking at the way these different sets of constructs build a larger understanding of AS.

Liane Willey uses the term neurotypical, which she shortens to NT, to describe those people without Asperger's. As a great deal of my link will be back to education, and more specifically special education, I'll be hoping to discern where the educational interface between those who understand AS and those stuck in a NT frame of mind occurs. Clearly, as with all social interactions, this occurs in place and time, but is not locked in a place and time. So what happens at school between the boys and their teachers, the boys and their age mates, the boys and their friends, and between you and all of those players, also happens at home, even when none of the players are present.

It is my belief that your family knows things about living with Asperger's that will reveal the nature of those interfaces in ways no other kind of research can reveal. To discern lived experience, we must live with those having the experience.

I must add that part of my purpose also links back to Gifted Education, a major focus of my Special Education degree. Demographic information indicates that 72 of every 1000 children in America might be Gifted with Aspergers. In the past (Liane Willey, for example) many young gifted learners who had Aspergers were never identified with the syndrome, but were often called bright but spoiled. Many others had their gifts missed because of the idiosyncrasies of the syndrome. I'm hoping to develop an understanding of the condition that will help create a more effective identification system that dignifies children with Asperger's in ways that heretofore has not occurred.

Curiosities

In some ways this will be an epistemological study, focusing on the construction of meaning in one's world. But it will have a meeting place of at least three areas where those constructions come together. I am very curious at the conflicts that arise there, how they are worked out, and what kind of knowledge comes out at the other end of the meeting place.

I am intrigued with the sensory integration disorders that often accompany Asperger's, as I think it must have an affect on how Aspies interact with NT's. Consequently, I am intrigued with the way children with Asperger's Syndrome socialize with age mates, parents, and friends. I am intrigued at the sometimes obsessive behaviors that occur around objects or ideas. And I'm intrigued at the possibility of observing how a family who is dedicated to loving and nurturing each other lives with a syndrome that, according to the literature, makes the emotional part of life very difficult, sometimes impossible.

My belief in education is that, at its best, it is about building positive relationships between learners. Such relationships are always more than merely intellectual exchanges, but explore the reaches of emotional response to the world at large. Knowing that Aspie kids are often weak socializers and have difficulty with interpersonal relationships makes understanding those issues vastly important for improving educational opportunities for them.

Knowing that Aspies are often rule followers and very routine oriented, hits at the heart of education because good education often works around rules so that what is good for the child becomes paramount to the process. Again, knowing how your family lives with these situations will inform me about the syndrome in ways other research cannot.

Cautions

One has already been mentioned: my presence in classrooms etc might draw attention to the boys in ways we would not want.

Another is the possibility that my living in your space will put an unpredictable strain on household activities and behaviors for the whole family. We can't know what its like to have another body in the house until that actually occurs. I will surely hear and see things that you would wish I had not. I will probably want to know about things, and I may probe into things that you would rather leave unseen. We will have to find ways to know when I have stepped into an area you wish to leave yours. But we will also have to find ways to reveal some things that will be hard to reveal.

Still another is that a friendship, built over years, will be 'tested' in a way that most are never tested. This won't be a visit of friendly conversations over beer and ballgames—though that may surely be a part of the case—but rather might be a time when all six of us feel that someone is always watching us do something. That kind of watching could surely be problematic and stressful.

I'm sure there are many more that will come to light.

But I believe there are more benefits than cautions, and I believe that the idea of understanding Asperger's in the way a particular family lives with it is very significant information for our world of special education.

I'll be calling in a couple of weeks to talk some more about this, so if you can, take some time and talk about all that's here. I'm excited about the possibility. I hope this leaves you that way as well.

Thanks,

Graff

Second Letter to the Family

February 3, 2004

_____,

Enclosed you'll find a few sheets of paper and an envelope.

One clarifies, at this point in time, the "problem" of my study as well as listing the several questions I'll probably be investigating while at your home. If you see issues or concerns with any of these, please let me know. More will be developed, I'm sure, and I'll pass them by you too.

Another is a table of how some of those questions will be explored.

And a third is a permission form of sorts. Please read and sign this one and return it in the envelope. If you find any part of it problematic, clarify and send and I'll fix it. Every study undertaken by research institutes these days has to pass an Institutional Review Board (IRB). One thing they'll want to know is how I planned this study without having a particular family in mind. Or they'll wonder how I knew this particular family would agree to the study. Either way, this form will let them know that you acknowledged to me that it was okay to plan an ethnographic study with your family. It will help when I make the formal proposal in June or July.

Thanks.

By the way: on the phone the other night you mentioned that there were some books _____ found especially useful, aside from the obvious ones by Temple Grandin. If you could add a couple of those to a sheet of paper, and include them with this return letter, that would be great.

Till I hear again,

Graff

Proposed research project:

Constructing Asperger Syndrome: An Ethnographic Study of How One Family Constructs an Understanding of Asperger Syndrome

Site Permission Form:

This document acknowledges that _____, of _____, agree to allow Ben Graffam of the Special Education Department of the University of South Florida, conduct an ethnographic study at their home. The study is planned to be approximately six weeks in duration. They also agree that their children, three boys, will be a part of that study.

The research involves Asperger Syndrome, and the Vassar's have been selected because their three boys have been identified as having the syndrome.

In no way should this document be mistaken for an informed consent to the research planned. Once a more complete research plan has been assembled, the _____ will be availed of that plan, and at that time they can make a firm decision as to whether the research can proceed and sign the formal consent form. Rather this document is a statement to Ben Graffam that he can begin the planning stages of this study will reasonable assurance that the study will proceed.

Signature: _____

Signature: _____

Date: _____

Principal Investigator: Ben Graffam, 1717 East Elm Road, Lakeland, FL. 33801
863-688-0976
At USF: Office of Special Education, EDU 162, Tampa Campus
813-974-9767
bgraffam@tempest.coedu.usf.edu

Third Letter

April, 2004

_____,

Not sure what I left you with last time I sent anything concerning the study in the fall. So I'm including here a clip from the opening "chapter" of my research proposal, that speaks to the kinds of issues my observations and interviews will chiefly cover. Obviously, as I'll be there all the time for so many days, many other aspects of Asperger will be seen, talked about, and included in the study. But my committee is—as are all dissertation committees—set on being sure I have a clear focal point to conduct the data gathering and on-going analysis. And that makes sense.

I'm also including a 'schedule' of my stay so that you can start thinking about what it will mean for you to have an extra body in the house for such a time. As with a lot of what's going on, this is tentative, and if there are dates in here that conflict with stuff you, _____, and the boys need to do, just let me know and we can make adjustments.

Don't know if I told you, but I've gotten acceptance from Dr. Liane Holiday-Willey, an adult with Asperger and a parent of a daughter with Asperger to read my proposal and my dissertation as it comes together. That will be a great help, as she will give an outside-inside kind of view to what comes of this. Certainly you, _____, and the boys will also be reading what I'm writing when I'm at your house, and I'll be sending you stuff to 'proof' after I get back here in the fall, but getting Liane's viewpoint will really help in framing the study as significant for the field. She has written two pretty good books on being a person and a parent within the AS world.

Not much is new here as so much of my life now is getting focused on writing up the proposal and completing my qualifying exams. I have started, with the director of gifted studies at USF, a research project with two families here who have sons who are gifted with Asperger. That should be a neat study. And Cheryl is trying to find her way into

the environmental policy and advocacy world. She's networking well right now, but we're finding that maybe this isn't the place to be looking for work like that. She's seen a bunch of stuff in North Carolina and some things in Connecticut that look good. But she's gonna keep searching here for a while.

We've had a fairly cool April, and consequently haven't had to turn on the AC too much. That's always nice: sleeping with the windows open. But that won't last long, as you know.

Drop me a line if any of the added information is confusing. And tell _____ I do plan on calling some Monday—maybe this one—but the last two have been taken up with the project with the families I just mentioned.

Take care,

Graff

Fourth Letter

May 2004

_____,

As we get closer to the time of this study, I'd like to just touch base again on both its nature and the research activities that will occur. I've included a stamped envelope and a 'form letter' so you can reply that things are or are not where they should be to create a comfortable situation for you and the boys during the study. This will help both my committee and the Institutional Review Board as they decide to approve my study.

I think I told you that my committee is pleased with the nature and direction of this study, but the IRB has not yet seen it. I won't submit to them until mid/late June as that was the time they suggested in order to meet my late August deadline. The submission to them must include the full proposal that I'll present to my committee, and as of this written that proposal is only about 90% complete. Your response here helps them to see that all is and has been in line during these past few months of planning. It is an important response for me and this study.

Since I sent you a tentative schedule for my stay in my last letter, I'll not go into specific day-to-day details here. I'll just briefly describe the nature of my activities for the study, and you can respond on the other sheet:

Nature: In this study I hope to glean significant information about the parent-child interactions that occur in your family. Since an accepted understanding of Asperger Syndrome and PDD-NOS is that 'if you've seen one child with an Autism Spectrum Disorder, you've seen one child with an Autism Spectrum Disorder,' observing and sharing in your family's interactions will be very significant, as will hearing you speak of

the nature of your interactions and how Asperger Syndrome and PDD-NOS has affected your life. This is a research project where I'll be using ethnographic methods—living with your family in your home (and see below) for an extended period of time—and conducting a case study, where your family is the case.

Observations: I will be observing nearly all family activities and interactions while at your home. These will include many activities away from the home as well: shopping, recreation, meetings, etc. My focus is on the interactions the two of you have with Stu, Bill, and Jim, especially those interactions geared to help the boys engender and develop better social and cognitive skills as well as a better understanding of life with their particular disorder.

I will also be engaging in activities with the family. I say this only to make sure that you have not interpreted my stay as being a 'fly on the wall,' but rather that you know as much as possible I want to be an active member of the things that go on. This may include times when I interact with _____, _____, and _____ as a group, in pairs, or individually.

Interviews: I will be interviewing the two of you both formally and informally during the stay. Three formal interviews will be conducted with each of you individually, and one will be conducted with the two of you together. Those interviews will be approximately 60 minutes and will be audio taped. They will have three different foci: 1) background, 2) present experience, and 3) meaning-making. Informal interviews will occur often, as the events of any particular day might create.

I will also be interviewing _____, though for much shorter times, approximately 20 minutes.

Document and Record Review: During the first week of my stay at your home I will spend a good deal of time reviewing the documents and records you have saved concerning ___ and _____ Asperger Syndrome, and _____ PDD-NOS. These records will include diagnostic tests and measures as well as school records you have kept. As the study continues, I would also like to see the documents that are collected by the boys while at school. These may include comments on papers and projects they submit for class, and/or even grade report cards.

Please share this information with the boys and, on the separate sheet, make any comments necessary. I remain excited about the time we will spend together.

Thanks,

Graff

(The following would begin on a new page and have different spacing in Original Document)

Under the following headings, please write any comments or questions you have about the study. Then return this sheet to me in the supplied envelope.

Nature of Study:

Observations:

Interviews:

Document and Record Reviews:

Signed: XXXXX

Signed:

XXXXX

Appendix B

Observation/Interaction Schedule

August 27 to September 2 ~~

participant observation of family at home and in general family settings;
review records and documents as available;

September 3 to September 7 ~~

continued participant observation of family;
conducted first set of formal interviews with parents;
engaged in first active-member observation with boys (bike ride);
joined play day at school yard on weekend;

September 8 to September 10 ~~

Time away for analysis, reflection, and rejuvenation

September 11 to September 18 ~~

continued participant observation of family;
conducted second set of formal interviews with parents and first set with boys;
visited school for one day—parent/teacher night one night;
engaged in second active-member observation with boys (movie);
joined recreational soccer activities on Saturday;
cross-country track meet, away;

September 19 to September 21 ~~

Time away for analysis, reflection, and rejuvenation

September 22 to September 29 ~~

continued participant observation of family;
visit school for second day; cross-country track meet, home and away;
engaged in third active-member observation with boys (board game);
joined recreational soccer activities on Saturday;

September 30 to October 3 ~~

Time away for analysis, reflection, and rejuvenation

October 4 to October 10

continued participant observation of family;
conducted third set of formal interviews with parents and second round with boys;
visited school for one day; cross-country track meet, away;
engage in fourth active-member observation with boys;

Appendix C

Hi,

I miss interacting with students and their work, very much. Therefore, I consider it an honor to work with you on your dissertation. I will, of course, read it, provide critical analysis, and personal reflections on it. Thanks for thinking I've the smarts to do so!

As it happens, I'm having a colon resection thanks to my nasty diverticular disease. FWIW, people with ASDs often (if not always) have weak 'guts' and it is not uncommon for us to present with IBS, Chrons, etc. My lucky straw is diverticular disease. Thrills. I'll be in the hospital for six days beginning the eve of my surgery on 4/20, so do let me know the if that interferes with your dissertation work. I'm thinking you're just beginning to start the work...

I'll pet all 4 of my dogs heads for you! Alas, my big guy can barely get up. So damn sad! I can't think of his future.

Speaking of dogs, my little Bichon, Chami, is barking to get in! Better go get him. He gets so nervous. I've no idea how he'll do with me in the hospital for so long. My dogs are more attached to me than my teenage girls. LOL!

Have a blast with your parents. Oh- send me your snail mail again. My computer is down and out and I'm on my kids- my publisher will send you the books direct, and I want to get your address to her before my computer gets home from the shop. Sorry I didn't do so earlier.

Off to NJ this weekend for another conference.

Take care,

Liane

Ben Graffam wrote:

Hi Liane,

Hope all things are well at your end. Life is great here: my parents are visiting from Maine, and we're having a great time. They arrived two days early, though, and that surprise prevented us from cleaning the house like we wanted to. Oh, well, my mother is used to my messy room from my boyhood, so she can live with it now, too. They'll be here a couple of weeks and then head home.

I am going to ask a big favor from you, and one that I probably don't have the right to ask at this time, since our friendship is still forming. But I'll ask anyway: would you be willing to read parts of my dissertation--sections of the proposal and the distillation of data--as I put it together, and then offer comments to me about its nature? My committee is wondering how I'll decide if my interpretations of the interactions between the parents and their children are accurate. I'm thinking that you would be a great source to tell me how well my thoughts fit into the world of the Aspie family, since you've been a child with AS, a parent of a child with AS, and are an adult with AS. What better lens to perceive if my study is on target?

This is probably way too much to ask, and I will understand if you say you cannot. And I trust you will tell me exactly how you feel about this request. I don't want to jeopardize the opportunity of continuing to exchange correspondence with you, but when the point came up in a meeting today, I thought immediately that you would be just right for this part of my study.

I feel funny asking, but at the same time, I feel it is right.

I look forward to hearing from you on this.

Ben

PS: give your dog a nice pet on the head for me.

ABOUT THE AUTHOR

Ben Graffam is an educator with a broad range of experiences: he has taught high school English for 17 years, in Maine and in Florida, working with learners needing remedial help in reading as well as those searching for the existential conflicts in Shakespeare's characters. He has also designed classes in epistemology, writing the Theory of Knowledge class for an International Baccalaureate School in Florida. In 2000 he earned his Master's Degree in Gifted Education, using the understanding gleaned there to create better curriculum at that International School.

His doctoral work has attempted to blur the lines differentiating exceptionalities, focusing as much on disabilities, like Asperger Syndrome, as on giftedness. A major research project he has been involved in explores families of children identified as Gifted and having Asperger Syndrome.

He hopes to have a wine cellar of renown one day.