Pepperdine University
Graduate School of Education and Psychology

Asian American Parents’ Subjective Experiences with the Utilization of Floortime Method for Children with Autism: A Preliminary Investigation

A clinical dissertation submitted in partial satisfaction of the requirements for the degree of Doctor of Psychology

by

Thao Trinh

October, 2008

Joy Asamen, Ph.D. – Dissertation Chair
UMI Number: 3325476

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Doctor of Psychology

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DEDICATION

I dedicate this dissertation to all families who have children with special needs.

Your courage to take on this challenge every day should be acknowledged. Your daily dedication to your children, constant search for ways to help improve their lives, and your commitment to never give up is tremendously inspiring. It is my hope that the information obtained in this dissertation will help professionals better understand you and the struggles you experience so they can better serve you.
ACKNOWLEDGEMENTS

I would not have been able to complete this dissertation without the help and support of many individuals. First and foremost, I would like to thank my family for their continuous support throughout these past 4 years. Additionally, I am thankful for my parents’ teachings about perseverance and giving my personal best to everything that I do throughout my 32 years. I am who I am today because what they taught me. Secondly, I would like to thank my husband-to-be for his endless words of encouragement when I felt it was all too much to handle. He constantly reinforced me with kind words and reminders of how far I have come and consistently reassured me of his confidence in me. Without his encouragement, this process would have been even more difficult.

I would like to express my gratitude and appreciation to my dissertation chairperson, Dr. Joy K. Asamen, for the amount of time and commitment she has dedicated to this work in addition to the tremendous amount of patience she has had with me when I encountered some rough patches during this project. Thank you, Dr. Asamen, for your expertise and excellent feedback throughout this dissertation process. Your dedication to helping me gather important information that will inform clinicians about Asian/Asian Americans families’ needs is much appreciated. This project would not have been completed without your in-depth understanding of the clinical issues and your constant encouragement and guidance. Thank you to my committee members, Drs. Amy Tuttle and Deryl Goldenberg for their time and dedication to this project. Their feedback was very helpful. Their care and interest in the topic made the process that much more pleasant. Finally, I would like to thank the parents who volunteered their time to speak to me about their experiences. I appreciate their willingness to open up to me and share
personal information about their lives. Their genuine interest in the project, the important information that was derived from their disclosures, and their willingness to inform clinicians about Asian/Asian American families’ needs should be commended. Without their help, this project would not have been possible.
VITA

Thao Trinh, M.A.

Education

2004-Present  Pepperdine University  
               Doctoral Candidate  
               Psy.D. (APA-accredited program in Clinical psychology)

1998-1999  Pepperdine University  
           M.A. in Psychology

1994-1998  University of California, Riverside  
           B.A. in Psychology

Clinical Training Experience

Pre-doctoral Clinical Internship at Pacific Clinics (APA-accredited)  
2000 hour clinical internship providing short- and long-term individual  
and group therapy, using cognitive behavioral therapy and other  
theoretical orientations, to recent immigrants from Asia and Pacific  
Islands, specifically Vietnamese-speaking, who have been experiencing  
severe mental disorders and to those at risk for developing serious  
emotional difficulties in a community mental health setting. Clients  
presented with a wide spectrum of diagnostic categories including  
schizophrenia, delusional disorders, severe mood disorders, anxiety  
disorders, adjustment disorders, and/or posttraumatic stress disorder.  
Facilitated psychosocial rehabilitation groups for individuals using  
client-centered and strengths-based approaches in an adult day treatment  
program to help re-integrate clients back into society. Clients included  
individuals who, at the time of their arrest for a misdemeanor crime,  
were deemed as incompetent to stand trial due to their mental illness.  
These clients had been diagnosed with schizophrenia and/or substance  
abuse. Clients had been ruled as not guilty by reason of insanity and had  
served jail time. Conducted psychodiagnostic and neuropsychological  
assessments in Vietnamese as well as English to aide with treatment  
planning and diagnostic clarification. Attended and participated in bi-  
weekly case conferences. Created and maintained collaborative working  
relationships with an interdisciplinary treatment team including  
psychiatrists, social workers, and case managers. Maintained appropriate  
DMH paperwork.  
Supervisors: Monica Ng, Psy.D., Tamar Bourian, Psy.D.
Doctoral Practicum at Metropolitan State Hospital
Provided short- and long-term therapy for individuals within several penal code systems, including those deemed Incompetent to Stand Trial and Not Guilty By Reason of Insanity. Co-facilitated psychosocial rehabilitation groups (including substance abuse and psychoeducation on client’s symptoms) in order to help these individuals prepare to return to court and participate in the trial for their crime. Documented individuals progress in their charts. Followed individuals’ progress through their admission to their transfer to the next placement. Conducted individual therapy using Cognitive Behavioral Therapy and Motivational Interviewing techniques. Assessed clients using psychodiagnostic, neuropsychological, and forensic assessments when necessary. Implemented crisis assessment and interventions. Conducted a literature review project on domestic violence prevalence in the Asian/Asian American community. Assisted an interdisciplinary treatment team in communicating treatment plans and goals to monolingual Vietnamese-speaking clients. Conducted wellness and recovery team interviews. Attended weekly Wellness and Recovery Plan (WRP) conferences. Provided feedback about individual clients' progress to the treatment team and assisted with the decision-making process regarding clients' goals.
Supervisors: Gordon Rose, Ph.D., Michelle Vorwerk, Psy.D.

Doctoral Practicum at LAC+USC Medical Center
Conducted cognitive, psychodiagnostic, and neuropsychological assessments of adults afflicted with a variety of disorders ranging from schizophrenia to bipolar disorders. Conducted clinical interviews in addition to cognitive and personality assessments with Vietnamese patients who do not speak English. Wrote assessment reports which included interpreting test battery results to aide the mental health team treatment planning. Attended weekly didactic training on various topics ranging from assessment of psychological trauma in children to forensic interviewing and assessment.
Supervisors: Elaine Eaton, Ph.D., Robert Sitzman, Ph.D

Doctoral Practicum at Verdugo Hills Autism Project
Trained novice therapists in behavior modification, Floortime Training, Developmental Individual Relationship-based techniques, discreet trial training, and behavior analysis in order to work with children diagnosed with an Autism Spectrum Disorder. Duties included creating behavioral and educational programs for clients diagnosed with this disorder, monitor clients' progress throughout the intervention program, conducted functional behavioral analysis of behavior excesses, and provided support to clients’ parents via parent training, which taught parenting techniques and ways to handle difficult behaviors such as aggression towards self or
others and self-stimulating behaviors. Conducted peer supervision with other staff who directly worked with the clients to ensure there was consistency in the program. Completed quarterly progress reports to California regional centers as well as school districts to address clients' progress that was essential to clients' program funding.

Supervisor: Deryl Goldenberg, Ph.D.

Psychological Assistantship at Pepperdine Community Counseling Center
Conducted intake interviews with adult clients afflicted with a wide range of disorders which may include anxiety, OCD, depressive disorders, personality disorders, and relational issues. Formulated client’s diagnosis using an integrative theoretical orientation in order to adequately plan clients' treatment course. Conducted individual therapy using various theoretical orientations as it best fitted clients' needs.

Supervisor: Anat Cohen, Ph.D.

Research Experience

2006  Research Assistant
UCLA Neuropsychiatric Institute
Acted as coach for adolescents with developmental delays during social skills training. Used behavior intervention to redirect participants from engaging in inappropriate behaviors. Conducted fidelity checks to ensure group facilitator followed training protocol.

2002  Clinical Research Coordinator
UCLA Neuropsychiatric Institute
Coordinated details of clinical trials that examined the efficacy of medications used to treat children diagnosed with Attention Deficit Hyperactivity Disorder. Coordinated patient visits and patient data collection. Acted as liaison to psychiatrists, psychologists, and project managers of pharmaceutical companies to ensure the study is run smoothly. Created recruitment strategies to advertise the study to the general community. Submitted study application to the UCLA Institutional Review Board to obtain study approval. In charge of developing each study’s budget and submitted all paperwork required to UCLA Office of Grants. Conducted ADHD, neuropsychological, and psychophysiological assessments to adults and children afflicted with Attention Deficit Hyperactivity Disorder for research purposes.

2001  Research Assistant
Matrix Institute
Aided with data gathering during a clinical trial of a medication treating side effects as a result of Methadone treatment for heroine addiction. Assisted with submissions of appropriate documents to Institutional Review Board, Federal Drug Administration, and pharmaceutical
sponsors. Assisted with data collection, recruitment, and intake interviewing of participants in a psychosocial research study examining the efficacy of the Matrix Model on recovery from substance abuse/dependence. Assisted in the operations of clinical trials from initiation to study close, assuring adherence to FDA requirements and Matrix policies and procedures. Maintained regulatory documentation and Case Report Forms. Completed data collection and entry. Administered quarterly assessment of patient’s drug-use history via the Additions Severity Index.

1998 University of California, Los Angeles Psychology Conference
Presentation session: *Negative Effects of Self-Focused Rumination on Negative Thinking and Concentration in Dysphoric and Nondysphoric Participants*

1998 University of California, Riverside Psychology Conference
Poster session: *Negative Effects of Self-Focused Rumination on Negative Thinking and Concentration in Dysphoric and Nondysphoric Participants*

Continuing Education and Clinical Training

May 2008 *Eleventh Annual Latino Conference*
Steven Lopez, Ph.D.
Pacific Clinics Sponsored Conference

Mar. 2008 *Co-occurring Disorders*
*Henry van Oudheusden, MSW*
Pacific Clinics Sponsored Training

Feb. 2008 *Major Mental Illness*
Michael DiPaolo, Ph.D.
Pacific Clinics Sponsored Training

Jan. 2008 *Elder Abuse Reporting*
Carol Tryon, Ph.D.
Pacific Clinics Sponsored Training

Jan. 2008 *Legal and Ethical Issues*
Pam Harmell, Ph.D.
Pacific Clinics Sponsored Training

Jan. 2008 *Aging 101*
Jaye Ashby, MSW  
Pacific Clinics Sponsored Training

Oct. 2007  Behavioral Emergencies  
Scott Fairhurst, Ph.D.  
Pacific Clinics Sponsored Training

Oct. 2007  Cultural Competency  
Glenn Masuda, Ph.D.  
Pacific Clinics Sponsored Training

Sept. 2007  How to Recognize Domestic Violence  
Chris Mohandie, Ph.D.  
M.I.L.E.S. Conference  
Conference sponsored by Pacific Clinics

Employment

Behavior Program Supervisor  
California PsychCare  
Conducted supervision and training with staff who provide direct Discreet Trial Training service to children with autism. Created behavioral and educational plans for clients. Monitored clients’ progress throughout the program. Attended Individual Education Plan meetings to discuss client’s yearly progress. Completed progress reports for the Regional center and/or school districts that were essential for funding.

Mental Health Rehabilitation Specialist  
Hathaway Children and Family Services  
Facilitated and co-facilitated group counseling sessions during a day-treatment program for emotionally disturbed children. Groups focused on issues related to bereavement, self-esteem, daily living skills, and positive reinforcement with relation to attachment disorders, post-traumatic stress disorders, sexual/physical abuse, and issues of abandonment.

Introductory Psychology Instructor  
Institute for the Academic Advancement of Youth (IAAY)  
The Johns Hopkins University  
Taught first-year college level introduction to Psychology to 15 gifted students. Created lesson plans and activities to facilitate learning. Held teacher-parent conferences to encourage parent involvement in the student's learning process. Supervised teaching assistants.
Behavior Specialist  
The H.E.L.P. Group  
Acted as classroom aide for a child diagnosed with autism. Worked with client to help integrate him into the classroom environment. Created lesson plans that maximized his daily learning. Used reinforcement schedules, Picture Exchange Communication System to facilitate learning of receptive skills. Performed behavioral interventions to prevent client from hurting himself and others.
ABSTRACT

There has been research on Asian/Asian Americans’ view of mental illness and the role of culture on treatment and treatment adherence. However, there has been little to no research that explores Asian/Asian American families’ experience with an Autism Spectrum Disorder (ASD) and their views on which treatment interventions they prefer. This study explored Asian/Asian American parents’ experience with having a child diagnosed with an ASD and receiving Floortime training as an intervention for their child’s ASD symptoms. More specifically, the purpose of the study was to examine if Asian/Asian American families are a good fit with the unstructured and play-focused nature of this intervention in light of their view of their child’s disability, their parenting style, and cultural beliefs and values. Interviews were conducted with 3 parents whose families met study eligibility. The parents were interviewed regarding their experiences with their child’s condition and the use of Floortime. The data were analyzed using Spradley’s (1979) method of content analysis. All 3 parents experienced difficulty coping with their child’s diagnosis and adjusting to the many changes that followed. Two of the 3 parents supported the use of Floortime Training while the third parent expressed having had a negative experience with its use. Several additional themes emerged from the study, including changes in the parents’ outlook on life and their priorities as well as suggestions for improving the use of Floortime. Finally, general recommendations for clinicians working with Asian/Asian American parents are offered.
Chapter I

Introduction

*Autism Spectrum Disorders: An Overview*

Autism Spectrum Disorders (ASDs) are a group of disorders that share in common some clinical features; although individuals diagnosed with an ASD may exhibit different symptoms and variability in the degree of symptom severity (National Institutes of Health [NIH], 2007). ASDs are often collectively referred to as “autism”. Autistic Disorder, the most common of the ASDs (NIH, 2007), is a neurological disorder that is first evidenced prior to the age of 3 years, as described in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revised* (*DSM-IV-TR*; American Psychiatric Association, 2000). Parents often report noting their child’s lack of interest in social interactions since birth or shortly thereafter. Some children deteriorate behaviorally during adolescence while others improve significantly (*DSM-IV-TR*). The manifestation and severity of the disorder may vary greatly depending on the developmental level and chronological age of the child (*DSM-IV-TR*). Other disorders categorized as ASDs include Asperger’s Disorder and Pervasive Developmental Disorder Not Otherwise Specified (NIH, 2007). The former ASD is distinguished from Autistic Disorder in that “there are no clinically significant delays or deviance in language acquisition” (*DSM-IV-TR*, p. 80), while the latter ASD is used when the symptom presentation is either atypical or below threshold to meet the criteria for Autistic Disorder or other specific Pervasive Developmental Disorder as well as Schizophrenia, Schizotypical Personality Disorder, or Avoidant Personality Disorder (*DSM-IV-TR*).
A child affected with autism may show significant deficits in three areas: communication, social interaction, and bonding and play activities (R. L. Atkinson, R. C. Atkinson, Smith, Bem, & Nolen-Hoeksema, 1996). Impairment in communication may be marked by the inability to communicate either verbally or nonverbally. Those children who have expressive language may lack the ability to initiate or sustain a conversation with others, or may engage in stereotyped and repetitive language that may be scripted from the child’s favorite television show. For example, a child may engage in a conversation with his friend during lunch time. While he and his friend are discussing the items they are having for lunch, the child with an ASD may interject with an inappropriate line from his favorite television show that may not be relevant to the current conversation topic. Furthermore, while there is expressive language, he/she may lack spontaneous make-believe or imitative play that is appropriate for that child’s developmental age (DSM-IV-TR, 2000).

The second major impairment is the child with an ASD may lack the ability to engage in reciprocal social interactions as demonstrated by the lack of acknowledgement of nonverbal cues such as eye contact, facial expressions, and body gestures (DSM-IV-TR, 2000). A study by Wimpory, Hobson, Williams, and Nash (2000) found that infants with autism have marked limitation in both person-to-person and person-person-object social engagement. This evidence further substantiates that these children have difficulties developing peer relationships that are appropriate for the developmental level. For the most part, they rather play alone than with children their own age. Younger and more severely affected children may not even notice other children playing around their proximity. Additionally, these children may lack the desire to spontaneously seek to share
enjoyment or interests. It is rare that a child with an ASD will point to an object of interest and show excitement to others around him/her.

Finally, children with an ASD have restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (DSM-IV-TR, 2000). These behaviors are often excessive and behaviorally unusual. Thus, these self-stimulatory and stereotyped behaviors can be socially stigmatizing, thereby precluding significant inclusion in natural social, occupational, and educational environments (Newsom & Lovaas, 1987). Some examples of these behaviors may include spinning the wheels of a truck because it is visually appealing, flapping his or her hands, turning in circles, vocalizing portions of video or television scripts, eating non-edibles, ripping or shredding items, or making vocal noises (Taylor, 2005). Other behaviors may include rocking, dipping, swaying, finger flicking, and walking on tiptoe (DSM-IV-TR). Ringdahl et al. (2002) identified that these behaviors occurred mostly in the absence of social consequences, and when the child was alone. Results from this study revealed that verbal reminders may not be sufficient to keep stereotypic behavior at low rates when adults are not present.

Self-stimulatory and stereotyped behaviors may also be self-injurious. A child who engages in self injurious behaviors (SIBs) may head-bang, hand-bite, and self-rub excessively and scratch. Some clinicians may argue that these behaviors are functioning as intentional acts to communicate needs (Durand, 1986); while others hypothesize that it is due to frontal lobe dysfunction (Gedye, 1989). In either case, it is suggested that there is not one particular treatment procedure that is universally effective (Repp, Felce, & Barton, 1988). It has also been suggested that self-injurious behaviors are difficult to curtail without the proper analysis of the reinforcement contingencies that may play an
important role in the development and maintenance of SIB (Weis, 2002). More importantly, a functional analysis of the behavior would help the clinician to understand problem behaviors and identify the relations between environmental events and behavior, in order to accurately describe the nature of the self-injury (Mace, Lalli & Shea, 1994), which would aid in treatment planning.

In addition to the above-mentioned impairments, in most cases, children with an ASD also have a comorbid Mental Retardation diagnosis that range from mild to severe (DSM-IV-TR, 2000). Cognitive skills development may be abnormal and uneven, with verbal skills being weaker than nonverbal skills. Furthermore, these children may either have unusual responses to sensory stimuli, as demonstrated in their ability to withstand a high level of pain or be hypersensitive to sounds. Examples may be a child who picks at the skin around her nails to the point of bleeding but does not display any affect of pain, or a child who screams when he hears his baby brother cry and requires immediate removal from the proximity of the crying child. These children also have sensitivities to different textures, which limits their diet to a few foods. Their sleep patterns are often abnormal. They also display abnormalities of mood or affect, as displayed by inappropriate giggling or weeping, or lacking any affective reactions when it is appropriate to do so.

A number of different theories for explaining the emergence of an ASD have been proposed over the years. Many researchers have generally accepted autism to have an organic cause (Kaminska, Czaja, Kozielska, Mazur, & Korzon, 2002). By that, many theorists attribute the cause of autism to biological sources, although the exact nature of the relationship is still unknown (Dykens & Volkmar, 1997; Minshew, Sweeney, &
Bauman, 1997; Rutter, Bailey, Simonoff, & Pickles, 1997). Recent genetic and
behavioral genetic data support the notion of a strong heritable basis for autism (Cook,
1998; Folstein & Rosen-Sheidley, 2001; Piven, 1997; Rutter, 2000; Smalley, Asarnow, &
Spence, 1988; Spence, 2001; State, Lombroso, Pauls, & Leckman, 2000; Szatmari,
1999). Other theories that have been investigated include medical conditions due to what
children ingest, mercury exposure, and the immunization for mumps, measles, and
rubella (Dales, Hammer, & Smith, 2001; D. Geier & M. Geier, 2004; Kaye, Melero-
Montes, & Jick, 2001; Wakefield et al., 1998), although support for these theories has not
been strong.

ASD is one of the fastest growing developmental disorder in the United States,
occurring in as many as 1 in every 166 births (Gibbons, 2005). A study by Newschaffer,
Falb, and Gurney (2005), comparing the prevalence of autism and other disabilities,
found that autism prevalence has been rising with time, as evidenced by higher
prevalence among younger birth cohorts. Furthermore, data collected from the Office of
Special Education Programs emphasized increases in autism prevalence with successive
(younger) birth cohorts born between 1987 and 1992. For those born after 1992, the rate
of increase in prevalence for successive birth years was not as great as for the previous
cohorts.

Similarly, increasing prevalence rates have also been found with international
populations. For example, studies conducted in Asian countries such as China (Tao,
1982; 1987), Hong Kong (Chung, Luk, & Lee, 1990), and Japan (Tanoue, Oda, Osano, &
Kawashima, 1988; Kobayashi et al., 1992) estimate that there are 4 to 10 persons
diagnosed with autism per every 10,000. More recent research has suggested the prevalence has increased to 20 to 48 per 10,000 (Wing, 1997).

Given the increasing number of children meeting this diagnosis, there is also an increased need to provide services to help families more effectively cope with the difficult behaviors exhibited by these children. Often, the treatment entails teaching the parents how to manage their child’s behavior through home visits in which a behavior therapist models the behavior management strategies that the parents can use when alone with the child. Despite these in-home sessions, though, some parents do not appear to conform to the behavioral program established for their child between the behavior therapist’s visits. Thus, it is important to take into consideration the factors that are crucial in helping parents be more successful in implementing the recommended intervention strategies.

One particularly important factor that was considered in this study is how one’s culture may influence treatment adherence. Recent legislation, such as the Individuals with Disabilities Education Act of 1990, P. L. 101-475, has enhanced family participation in making educational decisions for their special needs children (Parette, VanBiervliet, & Hourcade, 2000). But despite the ability to become more involved in the treatment of their children, some families encounter challenges with implementing the interventions their children require. For example, Bruns and Corso (2001) noted the following characteristics as having potential relevance to a family’s adherence to treatment: (a) cultural background, (b) economic and social status, (c) educational background, and (d) family structure. Van-Biervliet and Parette (1999) concur that a family’s cultural
background has substantial influence on the success of their child’s intervention. Of specific interest in this proposed dissertation are families from Asian cultures.

*Asian/Asian American Parents: Views of Their Children’s Mental Disability*

There have been a number of studies that have investigated the importance of culture in the outlook of Asian/Asian American parents toward their children with disabilities (Huer, Saenz, & Doan, 2001; Parette, 1998; Parette & Huer, 2002). For example, in a study comparing the perspectives of Asian American families to those of European American families, it was found that these groups held different views about the disability (Parette). It was reported that Asian American families often attributed their child’s disability to supernatural influences or sins committed by the child’s ancestors (Chan, 1997). Due in part to these beliefs, the family experiences a great deal of shame because of their child’s condition (Hanson, Lynch, & Wayman, 1990; Sotnik, 1995), while at the same time, feeling a strong sense of obligation to care for the child (Chan).

Although the description of “Asian/Asian American” encompasses a diverse collection of unique cultural groups, beliefs such as the one proposed here appear commonplace in many of these ethnic groups, including Pacific Islanders (i.e., Hawaiians, Samoans, and Guamanians), Southeast Asians (i.e., Vietnamese, Thai, Cambodians, Laotian, Burmese, and Filipinos), and East Asians (i.e., Chinese, Japanese, Korean, and Taiwanese); (Huang, 1993; Schwartz, 1995).

In contrast, some research contradicts that Asian/Asian American parents hold these negative perceptions of their children’s disabilities. For example, Parette, Chuang, and Huer (2004) found that Chinese American families tended to have a more positive outlook toward their children’s disabilities rather than viewing their children as a source
of shame. The authors offered two explanations for these findings. First, at least one parent in these families was more highly educated (although “highly educated” was not operationally defined) as well as educated in the United States, which broadened their understanding of their children’s disabilities. Furthermore, these parents were better informed about the resources available to their children as well as the legislation that protected their children’s rights. Second, these Chinese parents were professionals who had lived in the United States more than 10 years, which gave them time to acculturate and be more experienced with the American culture. These findings speak to the need for educating families both in terms of their child’s disability and available treatments, but to help families come to a better understanding of the American culture and what resources and legislation exist to support them in meeting their child’s needs.

Regardless of how families view their child’s disability, a related issue is how Asian/Asian American families make decisions about seeking appropriate treatment for their children. It was noted by Chan (1997) that Asian American families place a great deal of trust in the knowledge of teachers and others professionals such as medical doctors or counselors. Because of their faith in the expertise of these professionals, Asian families are more likely to defer to these individuals to help them make decisions about what is best for their children. Building on these observations, one might, on one hand, speculate that Asian families may follow the suggestions of psychologists or other mental health professionals without fully understanding what the treatment entails so may not understand the importance of a consistent regimen. While on the other hand, these families may question the value of instituting interventions that they, themselves, dispense rather than the experts to which they defer.
Research Objective

Floortime is a popular early intervention program used in the treatment of children diagnosed with an ASD. In the investigator’s anecdotal observations of Asian/Asian American parents that participate in this treatment approach as well as through informal conversations with other therapists who work with these families, it appears Asian/Asian American families may not be deriving as much benefit from the experience as the parents appear to have difficulty maintaining adherence to the treatment protocol and the children appear to make less progress than their White/Caucasian counterparts. For example, during her work with a Korean family, the investigator noted the child’s parents’ hesitance to carry out recommended interventions using Floortime when the focus was on the child’s socialization deficits. However, they were more compliant when more structured techniques were proposed to help the child improve upon his academic functioning.

The standard Floortime protocol is less structured and the primary technique of this approach is free play, with the therapist allowing the interactions to unfold naturally. With this approach, there are no specific steps one can follow to guide his/her work with the child, rather the therapist must take advantage of opportunities that arise during the interaction with the child. This approach may not be a good match for some families, particularly families that do not have a full appreciation for how this method is helpful to their child. Given this observation, it raises the question—How might the cultural beliefs of Asian/Asian American parents about making treatment decisions and their understanding of the Floortime approach influence adherence to their child’s treatment? More specifically, the aims of this study were as follows:
1. Explore how Asian/Asian American parents view, understand, and cope with their child’s diagnosis of an ASD.

2. Explore the treatments, if any, Asian/Asian American parents tried prior to engaging in Floortime and their experience with these treatments.

3. Explore how Asian/Asian American parents made the decision to engage in Floortime and their experience with using the technique.

4. Identify how Asian/Asian American parents feel they have benefited from Floortime.

5. Identify how Asian/Asian American parents feel their Floortime experience could be improved.

From an analysis of their perceptions, the intent of the study was to generate hypotheses as to how Asian/Asian American parents made the decision to try the Floortime approach, what they understood about the Floortime approach, and how they viewed their role in their child’s treatment.

Summary

Families with children with an ASD are provided with Floortime Training to improve their child’s symptoms, and although many children benefit from this treatment modality, others experience less progress. Of specific interest in this study was to examine if Asian/Asian American families are a good fit with the unstructured and play-focused nature of this intervention in light of their view of their child’s disability, their parenting style, and cultural values.
Chapter II

Review of the Literature

Overview

This chapter provides a review of the following bodies of literature: (a) early interventions programs for children with autism, (b) parental stressors and needs when raising a child with autism, (c) parental adherence to treatment, and (d) Asian/Asian American parenting styles and values.

Early Intervention Programs for the Treatment of Autism

Numerous treatment modalities have been established to help children with autism and their families cope with their disorder. Unfortunately, many of these interventions have neither undergone controlled investigations nor do data exist to substantiate the effectiveness of these treatments (Herbert, Sharp, & Gaudiano, 2002). Examples of such interventions include sensory-motor therapies (Smith, 1996), facilitated communication (Green, 1994), Auditory Integration Training (Stehli, 1991), and Sensory Integration Therapy (Ayres, 1979).

In addition, various forms of psychotherapy have been used in the treatment of children with autism. These psychotherapies include psychoanalysis (Beratis, 1994; Bromfield, 2000); holding therapy (Welch, 1988), which attributes autism to a lack of appropriate attachment between child and mother; and options therapy (Kaufman, 1976), which encouraged parents to mirror the actions of their child as a way to enter their child’s world in an attempt to draw him/her out. Finally, despite the absence of supportive data, some medically based interventions have also been utilized in the treatment of autism such as injections of Secretin, a hormone that stimulates the secretion
of pancreatic juices that aid in digestion (Horvath et al., 1998), and the use of Gluten- and Casein-free diets that eliminate the ingestion of proteins found in wheat bread and dairy products (Kvinsberg, Reichelt, Nodland, & Hoien, 1996; Whiteley, Rodgers, Savery, & Shattock, 1999).

However, there are some interventions that are theoretically-based and for which data do exist (Herbert et al., 2002). Among the most popular and more widely accepted of these interventions and for which supportive data exist is Discrete Trial Training (DTT; Newsom, 1998). DTT was established by Dr. Ivar Lovaas at the University of California, Los Angeles in the early 1970s. His original research cited a 47% recovery rate with the implementation of DTT for 40 hours a week in the child’s home. However, its use has met with controversy in the treatment of young children with autism due to the rigorous schedule that may be unrealistic to maintain for this age group (Lovaas, 1987; Smith, 1993, 1999).

It is said that typically developing children continuously learn from their environment through exploration, creative play, modeling, and conversation (Bredekamp & Copple, 1997). Since children with autism tend to have limited ability to use these methods of learning, it is likely they may encounter frustration when asked to learn in this manner since it is not a comfortable style for them (Spradlin & Brady, 1999). Lovaas’ (1987) more structured DDT approach, which utilizes the principles of operant conditioning, may be a more natural fit for these children. A discrete trial is a small unit of instruction, which usually lasts 5-20 seconds, that is implemented by a teacher who works one to one with the child (Smith, 2001). This technique follows a stimulus-response-consequence sequence. For example, a child might be presented with three
pictures of different items and given the verbal stimulus “touch apple.” If the child touches the apple (response), a reward (consequence), such as a small snack or verbal praise, is provided (Lovaas, 1981). DTT is a method that individualizes treatment to meet the client’s needs. This technique is especially useful for teaching new forms of behaviors, such as speech sounds or motor movements, as well as training the children how to respond correctly to requests made by others (Smith, 2001).

While DTT has been effective in teaching new behaviors such as imitation, discrimination, increasing receptive and expressive language as well as managing disruptive behaviors, it also has limitations (Smith, 2001). Its main critics contend that DTT lacks the ability to generalize skills across more global social situations. For example, children are taught to respond to cues from the therapist; consequently, without these clear cues, they may not learn to initiate behaviors, thus, may become dependent on them. Secondly, they may use learned play skills only when prompted by the therapist; therefore, they may not engage in self-directed toy play when they are not engaged by an adult or the therapist. Lastly, the child’s learning environment is tightly controlled, making it much more difficult for him/her to transfer his/her acquired skills to other environments, such as classrooms and other social situations. For example, a child who is taught to maintain eye contact during conversations may use this skill only if there are no outside distractions, if he/she is interacting individually with a specific adult, or if he/she is given a particular cue to use the skill by an adult.

Another popular early intervention program, Floortime technique, was developed by Stanley Greenspan. This model is child-centered and relies heavily on the natural interactions and support from adults in the child’s environment to facilitate the learning
of skills (Hilton, 2005). Although children with an ASD are grouped together based on similar clinical features, Greenspan and Weider (1998) see each child as having differences, such as how the child’s nervous system functions and the development of his/her mind, which they consider to be more important than the similarities. Thus, Greenspan’s Floortime model, “relies on the ability of parents and professionals to work with the features of each child’s nervous system, to construct the therapeutic approach based on the child’s uniqueness rather than follow a standard program designed for all children with the same diagnosis” (Greenspan & Wieder, p. 2).

Furthermore, the Floortime method of teaching is referred to as a relationship-based model in which a systematic way of working with a child is implemented to help him/her climb the developmental ladder (Greenspan & Wieder, 1998). The model emphasizes the interactive relationship between the child and his/her environment in order to promote development, and such growth is nurtured by providing the child an emotionally supportive environment. Additionally, this model of intervention respects individuality and acknowledges the unique creative potential of each child. For example, in helping a child develop fine motor skills through a coloring activity, traditional DTT therapist may prompt the child to pick up a crayon while giving the directive, “Color.” In contrast, the Floortime therapist may show the child a box of crayons and ask, “What color do you want to use?” As the child reaches for a red crayon, the therapist may narrate with, “Oh, you want to use red.” If the child were to reach for a different color, the Floortime therapist would not stop the child. Instead, the therapist would continue to narrate the child’s behavior and reinforce the child’s ability to attend to the task. It is
typically recommended that six to ten 20- to 30-minute sessions of Floortime intervention be implemented per day.

The Floortime model hypothesizes that there are six developmental skills that form the basis of intelligence and social development: (a) the ability to take interest in the sights, sounds, and sensations of the outside environment while being able to self-soothe or self-regulate; (b) the ability to engage in relationships with others; (c) the ability to engage in two-way communication; (d) the ability to create complex gestures, while stringing them together in a purposeful manner to problem-solve; (e) the ability to create ideas; and (f) the ability to build bridges between ideas and organize them into logical and comprehensive thoughts (Greenspan & Wieder, 1998). During typical development, these skills are mastered relatively easily, but children with developmental challenges have difficulty mastering these skills. Thus, the Floortime approach, takes a child back to the very first milestone he may have missed and begins the developmental process anew. By working intensively with parents and therapist, the child can climb the ladder of milestones, one rung at a time, to begin to acquire the skills he is missing. (Greenspan, & Wiedner, p. 121)

This functional emotional development model emphasizes affect and cognition and relies on the use of symbolic elaboration (Greenspan, 1979, 1989, 1992; Greenspan & Shanker, 2003). Through the use of Floortime, feelings and impulses are elevated to the level of thoughts and ideas that are expressed through words and gestures (Wieder & Greenspan, 2003). Thus, instead of impulsively acting out aggressively to cope with one’s frustrations, a child is taught to associate the therapist’s narration of the behavior with the affect the child experienced. For example, a child may resort to throwing books
across the room to display his/her anger toward his/her father who did not come home as
the child expected. Instead of stopping the child from throwing the books, the Floortime
therapist may repeatedly verbalize, “I’m so mad that daddy is not home” as the child
throws each book, until the child is able to connect the statement with his/her feelings,
express his/her feelings with words, and, thus, end his/her book-throwing behavior.

As an illustration of how the Floortime technique is distinctive from DTT,
consider a child with severe apraxia who is unable to verbalize the word “no”. The DTT
therapist would sit the child before him/her and would give the child a verbal stimulus
(e.g., “Say ‘no’.”), wait for a response (the child may or may not give a response), and
offer a consequence that is congruent with the quality of the response (i.e., praise if the
child says “no” and looking away if the child offers no response or gives one that is
incorrect); (Smith, 2001). In contrast, the therapist using the Floortime technique will
attempt to get the child to say, “No” within the context of his normal daily activities by
creating opportunities in the child’s environment where such a response would be a likely
reaction. For example, as a child lines up his/her LEGO bricks by color, the therapist may
insert a red LEGO into the child’s line of blue LEGO bricks, which meets with the
child’s disapproval and result in him/her crying out in protest. The therapist would react
by shaking his/her head vigorously from side to side and emphatically saying, “No, no,
no,” to narrate and model for the child the gesture and words that are connected to the
feeling he/she is experiencing. During the first few occurrences, the child may ignore the
therapist or attempt to deal with the intrusion by pushing the therapist’s hand away.
However, the therapist persists in modeling the gesture and words associated with the
child’s feelings with the expectation that the child will eventually say “no.”
In selecting an early-intervention program for a child with autism, there are some features that parents should consider. Dawson and Osterling (1997) suggest six features that are found in comprehensive early-intervention programs: (a) a curriculum that emphasizes selective attention, imitation, language, toy play, and social skills development; (b) a highly supportive instructional environment that explicitly attends to the generalization of skills gained; (c) an emphasis on predictability and routine; (d) a functional approach to problem behaviors; (e) a concern for developmental transitions required of children as they move through grade levels, or the need for other appropriate placements; and (f) parental involvement in treatment.

In reviewing literature regarding treatment for autism in Asian countries, it was noted that there has been little research in this area. However, one study by Bernard-Opitz, Kwook, and Sapuan (2001) found that of the 176 study participants from the nations of China, Malaysia, India, and those of Eurasian descent, 32% were in a one-to-one structured teaching program; 36% were in private kindergartens or private program; 16% were in public kindergartens, public schools, or special education classes; and only 5% were enrolled in a public school. In the same study, data suggested these children received treatment from a number of different specialists (84% psychologists, 67% speech therapists, 53% medical doctors, 21% occupational therapists, 10% sensory motor therapists). In addition to the above-mentioned specialists, it was also noted that some Singaporean parents turned to religious healers (2% of the study participants). During follow-up interviews, it was found that some Chinese parents living in Singapore reported consulting temple spirit mediums. Malay parents were noted to have sought help...
through ritual specialists, while a few Christian respondents consulted “faith healers” or participated in healing sessions.

*Parental/Caregiver Needs and Stressors When Raising a Child Diagnosed with Autism*

With the recognition that children and adolescents with a developmental disability are at increased risk for the manifestation of behavioral and emotional problems (Bregman, 1991; Dykens, 2000; Rutter, Graham, & Yule, 1970), it may be safe to assume that the parents of these children may have a number of challenges with which to cope. In fact, an ASD has a direct influence on day-to-day family existence (Koegel et al., 1992). For example, a child diagnosed with an ASD may start to cry as he/she takes his/her mother’s hand and raises it toward a kitchen cabinet, communicating to the mother that he/she wants something from there. Because of his/her deficits in verbal communication, the child is unable to tell his/her mother what he/she wants from the cabinet. Instead, the child communicates his/her need by physically engaging the mother. His mother opens the cabinet but does not know what her child specifically wants from the cabinet. She gets down a box of cookies, her child continues to cry. She takes down another item. The child cries louder. After several attempts at unsuccessfully guessing her child’s need, the child is now in a full tantrum. Coping with such challenges require a substantial commitment of time on a pragmatic level, and may have an emotional toll on the parent in that she/he may feel inadequate as a parent for not being able to effectively meet her/his child’s needs. In addition to having a direct effect on the lives of the other family members, a child with an ASD may also have an indirect influence on family life (Koegel et al.). For example, the financial resources needed to meet the professional services required to meet the needs of their child may indirectly influence the competing demands
of his/her unaffected siblings, resulting in family conflict over having to do without. Adding to the intensity of these stressors is the inability to engage in activities from which one might typically derive support or that offer relief from one’s stressful life (Gray, 1997).

In addition to having direct effects on families, researchers have also considered the indirect consequences of parental stress. Recent studies have shown that while parents of children with intellectual disabilities are likely to report high levels of stress, they also engage in different parenting behaviors, due to their anxiety about their child’s condition, which may affect child outcomes (Hastings, 2002). For example, stressed parents respond differently to their children’s conduct problems (Conger, Patterson, & Ge, 1995; Deater-Deckard & Scarr, 1996), or when parents are suffering from depression, they may interact very differently with their children (Downey & Coyne, 1990). In a study where parent behaviors were observed, Floyd and Phillippe (1993) found that parents who self-rated being depressed were less likely to actively manage their child’s behavior and more likely to engage in coercive parenting behaviors. A number of other researchers have shown that high parental stress predicts less beneficial outcomes for children in early intervention programs (Brinker, Seifer, & Sameroff, 1994; Robbins, Dunlap, & Plenis, 1991). Furthermore, parents who are in behavioral training interventions and are experiencing high stress show fewer gains in parenting skills (Baker, Landen, & Kashima, 1991).

While parental stress levels may increase as one has to take on the numerous responsibilities that are required for the care of a developmentally delayed child, studies have also noted the relationship of successful treatment to parents’ well-being (Hastings
Successful interventions, which result in an improvement of skills or a reduction of problematic behaviors in children with intellectual disabilities, have been found beneficial to parents’ overall health. Specifically, there exists a relationship between the severity of behavior problems exhibited by children with intellectual disabilities and the degree of parental stress, including symptoms of depression and anxiety (Baker, Blacher, Crnic, & Edelbrock, 2002; Baxter, Cummins, & Yiolitis, 2000; Blacher, Shapiro, Lopez, Diaz, & Fusco, 1997; Orr, Cameron, Dobson, & Day, 1993; Quine & Pahl, 1985, 1991; Sloper, Knussen, Turner, & Cunningham, 1991; G. Stores, R. Stores, Fellows, & Buckley, 1998). Based on these data, it appears treatment success may be an important consideration in regards to the psychological well being of parents of ASD children.

A study by Bristol, Gallagher, and Holt (1993) showed that parents, who enrolled their children with autism or severe communication impairment in TEACCH programs, reported a reduction of depressive symptoms over an 18-month period when compared with those parents who elected not to enter the program. Similarly, Baker et al. (1991) observed a significant improvement in parental teaching skills after a 16-week intervention as well as a significant reduction in parental stress and depression. Furthermore, several correlational studies have established that receiving services for their child’s disability is associated with reduced parental stress (G. King, S. King, & Rosenbaum, 1999), while other investigations suggest that parents who disagree with the services offered their children experience increased stress (Baxter, 1987; Sloper & Turner, 1992).
Given the chronic course of autism, Batshaw (1991) believes this diagnosis could contribute towards an emotional crisis for all family members. This is particularly the case since most families have not faced challenges of this nature, hence, have not developed the coping strategies with which to manage their child’s special needs, while attempting to balance the needs of the other family members (Aguilera & Messick, 1990).

Byrne and Cunningham (1985) state that children with an intellectual disability induce more parental stress than children without such a disability. In fact, research studies of families of children with autism have found that parents of children with autism experience more stress than parents of children with other disabilities (Bouma & Schweitzer, 1990; Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001). It is noted, however, that the stressors experienced may not primarily be due to the child’s disability. Rather, the reported stress may be related to these children continuing to reside with their parents and siblings rather than being institutionalized as was more common in the past (Baxter et al., 2000). The availability of and greater accessibility to government and state-funded services has made this possible for these families (Baxter, Cummins, da Costa, & Volard, 1991). Despite the availability of funds and services to families, Rodrigue, Morgan, and Geoffken (1990) state that parents of children with autism or Down’s syndrome experience stress because they are not able to find respite from the numerous responsibilities connected with having a developmentally delayed child. Holroyd and McArthur (1976) have gone so far as to report that the stress of those parents with children diagnosed with an ASD is greater than the stress of those parents with children diagnosed with mental retardation and Down’s syndrome.
As parents play a pivotal role in maintaining the physical and emotional health of their children (Hentinen & Kyngas, 1998), it is important to consider how well they adjust to living with a chronically ill child and how their own adjustment affects their child’s health (Johnston & Marder, 1994). Lazarus and Folkman (1984) discussed two forms of coping strategies in which parents of a child with a developmental disability may engage: (a) problem-focused and (b) emotion-focused. Problem-focused coping refers to planning or taking action to change the stressful situation, e.g., seeking information to become better informed about their child’s condition and more familiar with treatment options. In contrast, emotion-focused coping, e.g., avoidance and denial, refers to the parent’s efforts to contain or regulate his/her feelings about the stressor (Lazarus, 1993). Moreover, in a critical review of relevant studies (Fisher, 2001), three major themes emerge in regards to parental adjustment: (a) the need for normality and certainty, (b) the need for information, and (c) the need for partnership.

After the initial diagnosis, parents are thrown into a way of life that requires a number of adjustments, including managing their child’s time-consuming therapy needs in addition to normal parenting responsibilities (Hodges & Parker, 1987; Jerrett, 1994). Gravelle (1997) observed that some parents were able to successfully make substantial lifestyle changes and learned to accept these changes as a normal way of existence. While other parents were more limited as to the degree of adjustments they could make in their lives (Jerrett & Costello, 1996). Although parents of children with chronic disorders worked toward achieving some degree of normalcy in their lives, Butler and Smith (1992) found the lack of certainty about the course of the disorder was a major stressor for them. As a way to manage the uncertainty, these parents tried to control things they
felt were within their power to control, such as the management of time (Cohen 1993; Jerrett 1994), care for their own illnesses (Cohen; Jerrett; Gravelle; Jerrett & Costello), and seeking information on their child’s disorder (Cohen).

Unfortunately, such attempts at gaining control over one’s life do not address the uncertainty these families face. Cohen (1995) identified seven triggers that have the potential to heighten feelings of uncertainty in the family’s daily routine. These include: (a) routine medical appointments, (b) symptoms that are variations from the child’s norm, (c) specific medical words or phrases, (d) changes in therapeutic regime, (e) evidence of negative outcomes for other children, (f) changes in developmental stages, and (g) nighttime absence of distractions for parents from their child’s illness, which play a role in increasing their anxiety. Although these triggers were based on populations of children with chronic medical conditions such as cancer, these items do have relevance for the parents of children with an ASD as they experience many of these same triggers. For example, these children have numerous medical appointments, their symptoms may vary in response to environmental stimuli, and any changes to their therapeutic regime may result in mood disruptions or behavioral problems. Cohen (1995) asserts that the repetition of such uncertainties may have a negative impact on restoring normalcy to the lives of the families.

Upon being told their child’s diagnosis, parents have an overwhelming desire for information regarding their child's condition and treatment (Butler & Smith, 1992; Diehl, Mofitt, & Wade 1991; Gravelle, 1997; Hodges & Parker, 1987; Jerrett & Costello, 1996; Scharer & Dixon, 1989). The amassing of information is a way to reduce uncertainty.
(Cohen, 1993). Noteworthy is that once parents collected the information, they tended to discount, transform, or modify information that they considered negative.

To minimize uncertainty and feel in control over their situation, parents often desire to be regarded as partners in the care of their child. By developing alliances and choosing those health care professionals whom they perceived as helpful (Jerrett & Costello 1996), parents were able to build partnerships so that they could be more intimately involved in informing the direction of their child’s treatment.

**Parental Adherence to Treatment**

It has been noted that the treatment of children and adolescents has made a shift toward increasing the utilization of intervention approaches which rely heavily on parents’ involvement in the process (Fauber & Long, 1991; Rodrique, 1994). Studies have shown that parental involvement in child and adolescent treatment play a positive role on the effectiveness of the interventions for externalizing (Erhardt & Baker, 1990; Page, Poertner, & Lindbloom, 1995) and internalizing disorders (Clarke et al., 1992). The involvement of parents as well as other caregivers has been observed to be a crucial part of achieving therapeutic success and has been recommended for both the planning and treatment phases of therapy (Henggeler, 1994).

Unfortunately, many studies have found that among families who initiate treatment, adherence rates tend to be less than 50% for psychological treatment recommendations (Kazdin, 1996; King, Hovey, Brand, Wilson, & Ghaziuddin, 1997; Sirles, 1990; Wierzbicki & Pekarik, 1993). Nonadherence to behavior therapy was defined as either missing or arriving late to sessions, forgetting or refusing to do homework, or terminating treatment prematurely. Individuals who fail to adhere to
pharmacological interventions may miss doses, take more medication than was
prescribed, or discontinue medication without informing their physician. Another study
of families seeking evaluations for ADHD at a hospital-based clinic found that only 55%
followed a recommendation to pursue counseling or behavior therapy (Bennett, Power,

These low rates of adherence raise concern for clinicians and researchers for
several reasons (Stine, 1994). First, assuming there is a positive relationship between
adherence and treatment success, poor adherence may possibly result in a prolongation or
exacerbation of symptoms. As a result of the nonadherence, little improvement has been
made, increasing a family’s frustration level, which could result in further nonadherence.
Thus, this may have significance in regards to their potential for future treatment-seeking
behavior. Second, considering the limited number of qualified therapists and long waiting
lists, patients who are inconsistent in their attendance to therapy sessions and fail to
demonstrate a commitment to therapy may be keeping other families from receiving
therapy. Furthermore, when participating in treatment outcome research, nonadherence to
the protocol may confound the results of the investigation.

Another critical issue for research and practice has been premature termination
from treatment. A study by Bennett et al. (1996) looked at parents’ adherence to
professional recommendations for psychological counseling and medication evaluation
for their children who have been diagnosed with Attention Deficit Hyperactivity
Disorder. The authors found that of the 72% of the parents who pursued the medication
evaluation, only 54% of these parents abided by the psychological intervention
recommendations. These statistics have substantial clinical implications as well as the
ability to conduct valid treatment outcome studies (Stine, 1994). A study by Prinz and Miller (1994) demonstrated that individuals who prematurely terminate treatment are less likely to exhibit the benefits of treatment, as compared to those who remain in treatment.

Clearly, the success of an intervention is not only dependent upon its effectiveness as a form of treatment, but consideration must also be given to the clinician’s ability to competently deliver the treatment as well as the parents’ adherence to the suggested interventions (Albin, Lucyshyn, Horner, & Flannery, 1996; Detrich, 1999). Several studies have examined the relationship of adherence to demographic variables such as gender, race, intelligence, and age (Armbruster & Fallon, 1994; Ogrodniczuk, Piper, & Joyce, 2006). Additionally, psychological variables such as pretreatment illness severity and perceptions of behavior change have also been hypothesized to impact treatment adherence (Firestone, 1982; Kazdin, Mazurick, & Siegel, 1994). A specific psychological variable that has been linked to adherence is Prochaska’s (1984) transtheoretical model of readiness for change. Finally, the social validity of a treatment may play a role in a patient’s treatment adherence (Phelps, Brown, & Power, 2002) as might culture (VanBiervliet & Parette, 1999).

Demographic Characteristics

The relationship of demographic characteristics to treatment adherence has been studied by a number of investigators. The most commonly studied characteristics include ethnicity, social class, education, gender, and age. Ogle (2001) looked into the issue of social class, gender, and age in relation to compliance in psychotherapy. This study defined adherence as whether or not a patient attended therapy. It was noted that age was a significant predictor of compliance. Older patients tended to remain in therapy for more
sessions. The author hypothesized that older patients were more likely to participate longer in treatment due to the greater stability of their life circumstances (e.g., stable housing and employment situations), which made it possible to regularly attend therapy. Furthermore, Ogle posited that older patients may be more tolerant of maintaining a longer therapeutic relationship since they have more life experience with long-term relationships. These results were further substantiated by another study by Ogrodniczuk et al. (2006). These authors also found significant associations between age, session attendance, and termination status for patients who were receiving supportive group therapy. In this study, age was directly related to attendance and completion of therapy. Results showed that younger patients are more likely to be at risk for poor treatment compliance than older patients. Extrapolating from these findings, one might hypothesize that parents who are more mature may more likely adhere to the recommended Floortime intervention strategies than those parents who are younger.

Other variables such as gender and education did not yield statistical significance in Ogle’s (2001) study. However, results suggested that ethnicity may play a part in treatment compliance as it was found that African Americans had greater risk of terminating treatment prematurely. The findings for African Americans were consistent with previous results reported in a study by Sue, Fujino, Hu, Takeuchi, and Zane (1991) in which groups of different ethnicities were studied on their utilization of mental health services and their compliance with treatment. This study found that Mexican Americans, Whites, and Asian Americans exhibited greater improvement after treatment than did African Americans. Furthermore, despite utilizing mental health services, African Americans tend to exhibit little positive change, which may be related to terminating their
services prematurely. The authors did not elaborate on the reasons for early termination or the lack of improvement, although these investigators underscored the importance of ethnic matching between therapist and client. Although there have been inconsistent findings, it was proposed that therapist-client matches in ethnicity and language should be associated with better outcomes. Additionally, it was also found that matching the gender of the therapist and client was associated with lower dropout rates for Asian Americans and Whites, but it was unclear why this same observation was not found for all ethnic groups. Thus, it will also be important to take note of the effects of ethnic matching between Floortime professionals and parents on their ability to follow through with the recommended interventions.

Finally, occupation, blue-collar workers in particular, were at greater risk of terminating therapy prematurely (Ogle, 2001). This may be explained by the fact that social class, for which occupation is often used as a gauge, was found to be correlated negatively with acceptance for therapy, ease of establishing rapport, and duration of therapy and that one’s social class impacted their treatment compliance (Lorion, 1974; Schubert & Miller, 1980). It has been suggested by some researchers that lower socioeconomic status (SES) clients leave treatment prematurely because they are less psychologically minded (Garfield, 1994; Ogle, 2001). Furthermore, numerous studies have found, for the most part, that lower SES has been shown to be a significant contributor to decreased adherence (Daniels, Renee, & Daniels, 1994; Kissinger et al., 1995; Wallsten et al., 1995). Components of lower SES that were specifically associated with decreased adherence include unstable or substandard housing, low income, and being less educated (Coons et al., 1994; Draine & Solomon, 1994) as well as the lack of
medical insurance (Broers, Morabia, & Hirschel, 1994). ASD affects those from all socioeconomic levels. Hence, it will be important to note whether a family’s SES affects their psychological mindedness that may play a role in their ability to comprehend and follow through with Floortime’s intervention strategies.

Psychological Considerations

In the treatment of children, it would be logical to assume the emotional state of the parents may influence compliance with treatment as the parents make decisions on their children’s behalf (Pekarik & Stephenson, 1988). It has been found that caretaker depression may play a role in the child’s psychotherapy non-compliance (Dover, Leahy, & Foreman, 1994; Fisher, Winne, & Ley, 1993). It can be hypothesized that the caretaker’s symptoms of depression, which may include loss of interest in activities, low mood, and feelings of hopelessness, may interfere with the caretaker’s ability to follow through on his/her child’s psychological treatment regimen. With the negative impact depression has on parents’ ability to utilize prescribed intervention strategies, the more indirect influence of parents’ depression may be seen in premature termination from treatment (Kazdin, Mazurick, & Bass, 1993). A study by Kazdin (1990) found that mothers in families who withdrew prematurely from treatment for their child’s antisocial behavior endorsed more items on the Beck Depression Inventory than did mothers who continued with treatment.

Corkum, Rimer, and Schacher (1999) studied adherence in 81 families who participated in a 12-month study. These families either received medication or placebo combined with parents training group therapy or supportive group therapy. The relationship between parental knowledge of ADHD and its treatment, and adherence with
treatment were examined. Results supported the idea that families were more likely to enroll in parent training group if they had greater knowledge of ADHD.

Another factor that affected adherence to treatment was described by Armbruster and Fallon (1994). This study found that family environment variables such as low family cohesion, harsh child rearing practices, and single parenting are more prevalent in nonadherent families than those who complete treatment (Kazdin, Holland, & Crowley, 1997; Kendall & Sugarman, 1997). Furthermore, in considering caretaker personality variables, it was found that parents who were viewed as uncooperative, who themselves had problems, or who were less willing to accept change in themselves were more likely to have influence over their children’s early termination of treatment (Venable, 1997).

Readiness for Change

Studies on psychotherapy outcome demonstrate people can successfully change with the help of professional intervention (Lambert, Shapiro, & Bergin, 1986; Da Silva Cardoso, Chan, Berven, & Thomas, 2003). In contrast, investigations have also revealed that people can change behavior without the benefit of formal psychotherapy (Marlatt, Baer, Donovan, & Divlahan, 1988). So what might explain the change that is observed? Prochaska, DiClemente, and Norcross (1992) discuss how change may be related to one’s stage of readiness. Although each theory of psychotherapy may differ in its language and model, the process by which people change appears to remain the same. Thus, Prochaska (1984) proposes that similar change processes occur when one prepares to enter treatment or change his or her behavior. For example, Geller, Zaitsoff, and Srikameswaran (2005) examined the readiness for change and its effects on their treatment of patients with eating disorders. Overall, it was found that patients demonstrated they were ready to
make changes in their behaviors before they were prepared to make modifications to the
cognitions that contributed to the disorder.

Prochaska et al. (1992) delineates five stages of change that are relevant to
treatment adherence. The first stage is *Precontemplation* (Prochaska et al.) during which
there is no intention to change the target behavior in the foreseeable future. Individuals in
this stage are unaware, under-aware, or are in denial of their problems while others in
his/her social network, such as one’s spouse/partner, family members, friends, and
employer, are well aware of the issues involved. Additionally, the individual may
underestimate the benefits of treatment and overestimating the cost of change. Thus,
when an individual in this stage of change presents for treatment, it is generally due to the
pressures of others, which will often prove make therapy especially difficult and place
them at the greatest risk of terminating prematurely.

The second stage of change is *Contemplation* (Prochaska et al., 1992). Individuals
in this stage are aware that a problem exists and are seriously considering ways of
overcoming the problem, but have yet to commit to take action. The individual may
weigh out the pros and cons, both of the problem itself and the potential solutions to the
problem. The individual may seek additional information regarding the problem, its
treatment options, and possibly enter into therapy. However, he/she may not be ready to
change his/her behavior immediately. At this point in his/her process, it may be
advantageous to start moving the individual towards the next stage through an evaluation
of his/her self-image as being free of problems as well as help him/her accept that he/she
is capable of change.
The third stage is the Preparation stage (Prochaska et al., 1992). Individuals in this stage are intending to take action in the immediate future, such as next month, but have been unsuccessful in doing so in the last year. Individuals who are preparing for action may report behavioral changes, such as engaging in less of the behavior, when compared to those individuals in the precontemplation or contemplation stages (DiClemente et al., 1991). Although some reduction in the problematic behavior has occurred, individuals in this stage have not reached the criterion that would imply effective action has been taken, such as complete abstinence from a target addictive behavior.

Once the individual has begun to change his/her behavior, he/she has entered into the Action stage. This is the fourth stage where modifications have been made to the individual’s lifestyle over the past 6 months. Furthermore, it is during this stage that problematic behaviors, experiences, or environments are modified so as to remove obstacles that may impede behavior change (Prochaska et al., 1992). This stage requires a substantial commitment of time and energy since it includes both the preparation for change and taking steps toward change itself.

Lastly is the Maintenance stage (Prochaska et al., 1992). During this stage, individuals work to prevent relapse and consolidate the gains attained during the action stage. Traditionally, maintenance was viewed as a static stage in which the individual engages in behaviors that are in opposition to those that he/she was trying to cease that may last for the rest of his/her life. However, there are those who return to the precontemplative or contemplative stages and need to begin the entire process over again.
It has also been noted that maintenance is a continuation, rather than an absence, of change.

Those who have children understand the substantial commitment required of them to provide quality care to their children. Parents of a child with an ASD have additional challenges with which to contend that require an even higher degree of dedication on their part. Parents must be willing to accommodate and adjust their lives to meet the needs of a child with an ASD, be it daily living or treatment needs. Therefore, having an understanding of how prepared the parents are to commit to such changes is relevant to understanding treatment adherence.

**Social Validity**

Originally, the concept of "social validity" was rooted in applied behavior analysis, a field which utilizes principles from Skinner to study methods for producing changes in observable behavior (Baer, Wolf, & Risley, 1968). Classic researchers such as Kazdin (1977) and Wolf (1978) defined treatment social validity as having the perception that the treatment goals, procedures, and outcomes are appropriate for one’s needs. Social validity also encompasses the idea of acceptability, which was defined by Kazdin (1981) as "judgments by lay persons, clients, and others of whether treatment procedures are appropriate, fair, and reasonable for the problem or client" (p. 493). Most current researchers such as Gresham and Lopez (1996) have followed Wolf's and Kazdin's lead and defined three different yet highly linked elements of any type of intervention that can be used to assess for its social validity: (a) whether or not the goals of treatment are viewed as important and worthy of acceptance by the client, (b) are the treatment
procedures perceived as important and worthy of acceptance by the client, and (c) are the outcomes produced by the treatment procedures viewed as beneficial to the client.

Research has tested the hypothesis that treatments that are more highly accepted by parents are more likely to be implemented with their children (Watson & Gresham, 1998). Analogue studies have shown that investigators who can clearly describe how to implement the treatment to parents (Cross-Calvert & McMahon, 1987; Kazdin, 1980) and the treatments are determined collaboratively rather than unilaterally (Kusick, Gutkin, & Witt, 1991) influence how acceptable treatments for children are rated by the parents. Despite the limited empirical evidence that links reports of treatment acceptability with actual treatment adherence (Allen, & Warzak, 2000), investigators have nonetheless suggested the existence of a positive relationship between acceptability and treatment adherence, which would, in turn, have an effect on the treatment’s effectiveness (Reimers & Wacker, 1988; Von Brock & Elliott, 1987). These results raise the question of whether positive parent ratings of treatment acceptability will influence not only immediate treatment adherence, but sustain treatment for the long-term (Reimers, Wacker, & Cooper, 1992).

In a study examining the acceptability of behavioral treatments for children, Reimers et al. (1992) measured the relationship between parents' treatment acceptability ratings and their reported use of treatment and treatment effectiveness ratings at three separate intervals. Results from this study revealed that parents who rated the recommended treatments as most acceptable also reported higher levels of compliance at each of the follow-up contacts. A positive relationship was also found for treatment
acceptability and treatment effectiveness ratings. Lastly, parents who rated treatments as being least acceptable reported negative changes in their children's behavior.

From the research, it appears the social validity of treatment is likely to have an influence on the parents’ willingness to engage in the use of treatments recommended for their children. Of direct interest to the proposed dissertation are issues of social validity raised by the use of traditional modes of therapy in treating ethnically diverse clients, particularly Asian/Asian American families, who may not perceive the Floortime intervention as potentially beneficial for their child.

**Issues Relevant to Treatment Adherence among Asian/Asian American Families**

Given that the proposed dissertation is interested in better understanding treatment adherence to Floortime intervention among Asian/Asian American families, the remainder of this chapter is devoted to the literature on these families. Specifically, the following areas are reviewed: (a) attitudes and assumptions about psychological treatment, (b) family structure and parenting style, and (c) therapeutic styles and Asian cultures.

**Attitudes and Assumptions about Psychological Treatment**

Much research has yielded similar results in that Asian Americans are more likely to underutilize mainstream mental health services than other ethnic minorities such as African Americans, American Indians, Latino Americans, and White Americans (Matsuoka, 1990b; D. W. Sue, 1993; Sue, Nakamura, Chung, & Yee-Bradbury, 1994). It can also be said that the underutilization rate of mental health treatment by Asian Americans is due to a reluctance to seek services and not lower levels of psychopathology (Uba, 1994). It was asserted by D. W. Sue that Asian Americans
usually would avoid seeking mental health treatment since there is a shame factor and stigma attached to a person who needs to utilize these types of services. Furthermore, Asian Americans may have views of mental health care as being Western-based forms of treatments that are absent of cultural and linguistic considerations that may make the experience more relevant and understandable to members of this group. A consequence of these views is that Asian Americans tend to avoid or delay utilizing services until the symptoms have exacerbated to the point that support no longer exists from family or other social support systems.

Other researchers have discussed the lack of willingness to seek mental health services in terms of culturally-based psychological barriers and the incompatibility of mental health services with Asian Americans’ needs (Zhang, Snowden, & Sue, 1998). In these studies, psychological barriers were defined as specific cultural values and attitudes about mental illness. It has been argued that there is strong stigma and shame associated with the recognition of mental illness in Asian cultures (S. Sue, 1993). Considering that mental illness carries such negative connotations, disclosing or having public awareness of such issues about a family member might bring shame to one’s family. Additionally, since the Asian culture puts a strong emphasis on restraining and managing strong emotions and willpower to overcome emotional difficulties, thus, leading to delaying help-seeking for mental illness would be less shameful than showing that one is unable to control her or his mental illness. Therefore, it has been suggested that Asian Americans tend to value solving personal difficulties through personal efforts (Tamura & Lau, 1992) instead of using formal mental health services, which may bring shame upon their family (Sue & Morishima, 1982). Because of these values and attitudes, psychological distress
may manifest as somatic complaints, thus, masking the actual mental health issues that may be troubling the individual. Even when there is the recognition of a potential psychological cause for the somatic complaints, Asian Americans may still choose not to discuss their discomfort due to the negative social stigma attached to such a disclosure and consequent feelings of shame and self-denigration.

Furthermore, Asian Americans are more likely to rely on themselves to initially manage their distress (Narikiyo & Kameoka, 1992). If unsuccessful, they may turn to family members and friends for support (Akutsu, Snowden, & Organista, 1996). After attempts to seek assistance from their immediate supports systems fail, community members, such as elders or spiritual healers, may be consulted (Sue & Morishima, 1982). By cultural standards, to contain one’s mental illness by handling its symptoms on one’s own may be more honorable than to seek formal services with someone who is outside the family. This, in turn, may be considered an embarrassment or disgrace (Uba, 1994).

In a study by Tata and Leong (1994), Chinese American students’ attitudes toward seeking professional psychological help were investigated by examining the values of “collectivism” and “individualism.” Since individualism has been found to be more congruent with seeking formal mental health services than collectivism (Kim, & Omizo, 2003), it was hypothesized in this study that individualistic students would have more positive attitudes toward seeking formal mental health services. It was found that those Chinese American students who were more individualistic reported more positive attitudes toward seeking formal psychological services than did collectivistic individuals (Tata & Leong).
Collectivistic groups, such as Asian Americans, often emphasize the importance of interdependence, loyalty, harmonious interpersonal relationships, and peaceful coexistence (F. Lee, 1997). These collectivistic views also include feeling concerned that the consequences of one’s behaviors will also be placed onto members of their group. Tata and Leong’s (1994) study also hypothesized that those who were collectivistic may be more likely to avoid help-seeking because of his or her fear that seeking psychological help would have negative consequences on members of their group. Conversely, it was hypothesized that participants who had individualistic views would have less concern about affecting those in their group, thus, would engage in more help-seeking behaviors. It was found that individualism was a significant predictor of attitudes toward seeking professional mental health help. Those with a more individualistic viewpoint tended to do more help-seeking than those who had a less individualistic viewpoint.

A study by Zhang et al. (1998) investigated the commonly accepted belief that Asian Americans prefer family and friends to mental health professionals for assistance with psychological difficulties. Results from their study supported this assumption; 12% of Asian Americans talked with their friends or relatives while only 4% of Asian Americans talked with psychiatrists or specialists. Though, despite these data, fewer Asian Americans confided in their relatives and friends when compared to White Americans. Thus, Asians or Asian Americans are more likely to express their emotional complaints through the disclosure of somatic discomfort, allowing one to seek care. In fact, this way of addressing one’s emotional needs can be considered an adaptable coping strategy (Chun, Ecomoto, & Sue, 1996).
As previously mentioned, the second obstacle Asian/Asian Americans face is mental health services that are incompatible with their needs (Zhang et al., 1998). Incompatibility of mental health services is defined as a lack of match between mental health professionals and Asian American clients in terms of language, ethnicity, and cultural understanding. Research has noted that mental health services are better utilized by Asian Americans if the therapist and client share the same language and ethnicity (Flaskerud & Liu, 1991; Takeuchi, Sue, & Yeh, 1995). In addition, a study by D. W. Sue and Sue (1999) found the effectiveness of the counseling process was determined by whether or not the client’s and the counselor’s cultural values, and the values inherent in the counseling interventions were matched. Another study using clients seeking career counseling illustrated that Asian American clients who had high adherence to Asian cultural values appraised Asian American counselors to be more empathic and credible than did those clients with low adherence to Asian values. Clients who had low adherence to Asian values deemed European American counselors to be more empathic than did their counterparts with high adherence to Asian values (Kim & Atkinson, 2002).

With the potential cultural factors that may influence an Asian American client’s treatment seeking behavior, this investigator postulates that Asian/Asian American parents who have children with a developmental disability, such as an ASD, may be less likely to seek professional support until the problem becomes unbearable. Even when these families do obtain services for their child, the social stigma associated with the child’s disability may hinder their full participation in and compliance with recommended intervention strategies.
Family Structure and Parenting Style

There are a number of important differences between Asian and American cultures that can potentially influence daily functioning. For the most part, the values, beliefs, and customs of the American culture are guided heavily by Judeo-Christian religious beliefs (Jung, 1998). American cultural beliefs also include an emphasis on equal rights as well as equal opportunity for individuals within its economic system. Furthermore, the culture supports a less hierarchical approach to family and places more emphasis on individual advancement within its economic system over the good of the community (Wang, 2004). However, Asian values, beliefs, and customs are highly connected with Confucianism, Taoism, and Buddhism (E. Lee, 1997). Thus, more weight has been placed on sustaining harmonious interpersonal relationships and valuing interdependence among individuals. To facilitate relational harmony, a hierarchical system exists in which each person has his or her role in maintaining the structure of the home and the community. As an example, in traditional Chinese culture, wives are subordinate to husbands, younger children submit to older children, girls to boys, and wives to their mother-in-laws (Jung). Within the context of a family, the father acts as the stern enforcer, while the mother provides affection and care. Furthermore, the mother’s role in the traditional Chinese family is to make sacrifices for her husband and children, suffer in place of her family, induce guilt in her children to maintain the family structure, and be exceedingly involved with her children. The eldest son is expected to continue the family legacy and, in exchange, is offered special privileges such as having the final decision-making power on allocating the family’s expenditures. The most valued relationship within the family hierarchy is that which is between the father and son (E.
Lee, 1997) since the family lineage, legacy, birthright, and patrimony will be passed on to the eldest son.

Despite these traditional beliefs and values that have been upheld by the older generation of caregivers, E. Lee (1997) summarized several distinct shifts in the contemporary Chinese American family since the rise and acceptance of more Western political ideas such as democracy. Of most importance is the shift from a patriarchal family system to one that is diarchal in which both mother and father share the decision making process. Other changes also include the reduction in the traditional extended family and the increase in the nuclear family. The earlier described father-son or parent-child relationship weighs less in the family versus the husband-wife relationship. Daughters’ value is equal to that of sons as they are able to obtain the same education as sons and are counted on to take care of aging parents.

Despite the fact that decision making might be done more often by both parents in some Asian American households, the task of parenting remains primarily the responsibility of the mothers (Jung, 1998). Studies of ethnic groups reveal that parenting styles vary based on the parent’s country of origin, the reason for leaving their country and immigrating to the United States, their religious affiliation, and the number of years they have resided in the United States (Quah, 2004).

Although dated, research by Baumrind (1971) has shown that the primary style of parenting for Asian parents is an authoritarian approach. Although this style of parenting may be perceived as controlling, restrictive, and hostile from a Western worldview (Lin & Fu, 1990; Steinberg, Dornbusch, & Brown, 1992), parents from many Asian cultures
view this authoritarian style not only acceptable but a way to show concern, care, and involvement in the lives of their children (Chao, 1994).

In a study by Lin and Fu (1990) comparing childrearing practices among Chinese who still live in China, immigrant Chinese who live in the United States, and European American parents, it was found that immigrant Chinese mothers were more controlling, placed a greater emphasis on achievement, and promoted interdependence more than their European American counterparts. Furthermore, a study conducted by Julian, McKenry, and McKelvey (1994) found that minority parents, including Asian American parents, placed more importance on children exercising self-control and achieving academic success than did the European American parents.

In a study examining parental attitudes toward childrearing, Jambunathan, Burts, and Pierce (2000) found that Asian Americans, African Americans, Latinos, and Asian Indians possessed unrealistically high expectations of their children when compared to Europe Americans. Furthermore, it was also found that Asian American, Asian Indian, and African American mothers had lower empathic awareness of their children’s needs. Other researchers have found that these mothers lived in multigenerational families in one household (Roopnarine & Hussain, 1992; Stevenson, Chen, & Lee, 1992) where aging parents also need their attention and care. In turn, mothers also expect their children to do the same for them as they do for their aging parents.

When it comes to disciplining their children, Asian/Asian American parents have been described strict as and more restrictive than their European American counterparts (Chao, 1994; Kelly & Tseng, 1992; Wang & Phinney, 1998). Results from Jambunathan et al.’s (2000) study also presented data that indicated that Asian American and African
American mothers are more likely to use corporal punishment than European American and Latina mothers. The groups that endorsed the use of corporal punishment (e.g., spanking, hitting, slapping) did so as a means of developing their child’s character and a way to teach their child what is right from wrong. Deater-Deckard, Dodge, Bates, and Pettit (1996) suggested that minority parents, which include Asian parents, may believe they have not adequately fulfilled their role as parents if they do not use strict physical discipline with their children.

In addition to differences in parenting style, Jambunathan et al. (2000) noted that Asian Americans, African Americans, and Latinos tend to live in multigenerational households. Because of this living arrangement, children may receive support from their grandparents in addition to or in lieu of their mothers. Fathers, on the other hand, are perceived to be dominant, stern, and to be feared (Jambunathan et al.). Thus, it may be possible that mothers have less of an opportunity to be aware of all their children’s needs since there are other adults occupying the same living space who are involved in raising their children.

Therapeutic Styles and Asian Cultures

As Asians/Asian-Americans cope with family cross-generational differences, gender-role conflict, and an unfamiliar bicultural way of life, more members of this population will enter the mental health system (Yu, 1998). Although there is a substantial amount of evidence suggesting that psychotherapeutic treatments are effective in treating Caucasians or individuals of European descent, there is little to no empirical support that the current psychotherapies are effective in treating Asian clients. In fact, research has demonstrated that ethnic minorities are less likely to receive quality health services and
may experience worse treatment outcomes when compared with Caucasians and other European groups (Institute of Medicine, 1999; U.S. Department of Health and Human Services, 2001).

Research studies conducted in university counseling centers reveal that there is less attention focused on the psychological needs of ethnic minority populations and there still exists a heavy reliance on Western-oriented counseling approaches. Furthermore, with the emphasis placed on intrapsychic functioning, members of ethnic minority groups may feel that the counseling services offered are not relevant to them (Austin, Carter, & Vaux, 1990; Thorn & Sarata, 1998). This may be particularly true for Asians in that they may emphasize the integration of body and mind placing more emphasis on the body over the mind (vs. mind over body). As a result, Asians often equate seeing a therapist with seeing a physician (Uba, 1994), and clients anticipate that the therapist will be able to alleviate their symptoms similarly to how physicians alleviate medical conditions. Drawing parallels between therapy and medical interventions provide Asian clients who are unfamiliar with the U.S. mental health system a way of understanding the psychotherapeutic process (Yu, 1998). Additionally, studies have suggested that Asian American clients favor ethnically similar counselors over ethnically dissimilar counselors (Atkinson & Matsushita, 1991; Atkinson, Wampold, Lowe, Matthews, & Ahn, 1998).

Others would suggest that behavioral therapy, with its instructional approach, is consistent with the parenting style that is inherent in the Asian parent-child relationship (Ford, 1981; Ho, 1984; Wang, 1994). Other researchers have suggested that cognitive therapy and rational-emotive therapy are particularly beneficial in helping Asian clients generate alternative conceptualization of their problems since the emphasis on one’s
cognitions may be more compatible with the intellectualization that has been observed in members of Asian cultures (Chen, 1995; Matsuoka, 1990a).

It has also been found that Asian students viewed counseling as a process that is directive, paternalistic, and authoritarian (Arkoff, Thaver, & Elkin 1966). This outlook on counseling is consistent with Asians’ social structures and beliefs about mental health. With these views, how will Asian parents experience Floortime Training, a method that is neither directive nor authoritarian? In a study by Atkinson, Maruyama, and Matsui (1978), Asian American students were reported to prefer counselors who provide empathy, nurturance, structure, and guidance. Consistent with the findings of Atkinson et al., Yuen and Tinsley (1981) found that in comparison to Caucasian students, Chinese students wanted their counselors to be directive, empathic, and nurturing. These students also felt that clients do not have to be as responsible, open, and motivated as the counselor.

Results from another study found that Chinese students in Hong Kong preferred their therapist to have a directive approach rather than one that is nondirective (Exum, & Lau, 1988). This finding was corroborated by Waxer (1989) with Cantonese students who reported preferring the style of Ellis to that of Rogers. Another study showed that Asian American clients also favor a logical, rational, and directive counseling style to a reflective, affective, and nondirective one, especially if the counselor is an Asian American (Atkinson & Matsushita, 1991; Li & Kim, 2004). A study of counseling strategies found that clients in a single session of counseling favored immediate resolution to their problems over exploration of theses problems to gain insight (Kim, Li, & Liang, 2002). These findings, collectively, may suggest that Asian clients prefer more
structure in their therapeutic experiences, expect more direction on how their problems can be resolved, and prefer to steer clear of therapeutic approaches that are more self-exploratory in nature (Atkinson & Matsushita; Kim, 2004). Finally, Asian-American clients reported preferring therapists who were trained to be culturally sensitive and view them as more credible and culturally competent than less sensitive counselors (Gim, Atkinson, & Kim, 1991).

There are some researchers who posit that traditional psychodynamic therapy has been successful with Asian clients. With the use of this approach, including dream interpretation and analyzing transference, the Asian clients were able to achieve insight into the origin of their unresolved conflicts, understand their own defense style, and work through old, undesirable patterns of behavior (Tung, 1991). Furthermore, some researchers argue that the psychoanalytic approach of exploring the underlying, unconscious, and unresolved issues with the client’s family members may be helpful in alleviating one’s symptoms. However, for traditional Asians, this technique may be threatening and leave the client feeling disloyal to his/her family (Kim, 2004).

Although there may not be agreement on the preferred theoretical orientation in working therapeutically with Asian/Asian American clients, other authors have offered helpful suggestions for working with these clients and their families. For example, Paniagua (1994, as cited in E. Lee, 1996) suggested effective treatment strategies, including but not limited to (a) exhibiting expertise and authority, (b) maintaining formality and conversational distance, (c) offering concrete and tangible advice, and (d) providing assurance that stress will alleviate as quickly as possible. Ho (1987) suggests incorporating unique Asian cultural values and family characteristics in the therapeutic
process. He posits that there are three distinct phases in which it is important to consider these values in treating Asian/Asian American families: (a) the beginning phase, (b) problem-solving phase, and (c) terminations phase. By taking into account these culturally important considerations from the first contact with the family, premature termination from therapy may be avoided.

The beginning phase of therapy involves establishing rapport with the family, assessing the family’s readiness for therapy, getting family members involved in therapy, and establishing mutual goals for treatment (Ho, 1987). During this phase, what is particularly important is the clinician’s attention to the power structure of the family. Thus, in a traditional Asian family, the first appointment should be made with its decision maker, which is generally the father. In addition, the appointment should be set at a time that does not conflict with the parents’ work schedule as their value of work exceeds the value placed on therapy. Furthermore, the clinician should offer the family a brief explanation of his/her role and an overview of his/her training so as to avoid being confused with a physician. During the first session, the clinician should address the family in a polite, formal manner while showing “warm expressions of acceptance” (E. Lee, 1996, p. 240) and genuine concern for the family members. Examples of appropriate gestures include greeting the family with a smile and offering the comfortable chairs to the older family members. Examples of appropriate gestures if the session is held in the family’s home are the clinician hanging up his/her coat or accepting an offered cup of tea (Ho).

It is believed that many Asians are more comfortable receiving help from friends or elders, so to become more familiar with the clinician, it is not unusual for the family to
ask the clinician personal questions, e.g., country of origin, marital status, and number of children (Ho, 1987). It is important for the clinician to feel comfortable answering these questions since appropriate self-disclosure can help facilitate a positive cultural alliance as well as a level of trust and confidence. Aside from disclosing personal information about oneself, is it suggested the clinician attempt to form a cultural connection with the family during the initial sessions. For example, if the clinician is from the same Asian country as the family, it would help establish a connection if he/she discloses his/her familiarity with the culture. For clinicians who are unfamiliar with the client’s culture, it would be important to show his/her interest and appreciation of the client’s cultural background.

Asian family members are generally not accustomed to verbally communicating their personal issues in therapeutic context (Ho, 1987). Thus, it is important to initially ask non-threatening questions, engage in small talk, and avoid direct confrontation, in order to put the family at ease. Additionally, there is often an intense feeling of shame and humiliation associated with publicly admitting that family members have mental health problems. To counter these negative emotions, it is suggested the clinician empathize and encourage the expression of these feelings, reassure the family that their confidentiality and anonymity will be maintained, and reframe the family’s courage in seeking help as love and concern for the affected family member(s).

As stated earlier, Asian clients often come to therapy believing that the clinician is an authority who can tell them what the problems are and provide resolutions to their problems. Thus, it is helpful for the clinician to establish credibility immediately in order to ensure that the client will return. Ho (1987) suggests that the clinician display
confidence, empathic understanding, maturity, and professionalism when meeting with the client. For example, it is suggested the clinician use professional titles when making introductions, display one’s credentials, obtain ample information about the client and family prior to the first visit, offer plausible explanations for the origin of the problem, show some knowledge of the family’s cultural background, and provide immediate intervention in the event of an existing crisis. Not only will these strategies present the clinician as competent but may instill a sense of hope. It may also be necessary for the clinician to be flexible in the roles he/she is willing to assume in order to enhance the therapeutic relationship. For example, the clinician may at times serve as teacher, advocate, or intermediary.

After rapport has been established, it is important to assess the family’s readiness for therapy (Ho, 1987). Although the family may have entered into therapy voluntarily, they may still be reluctant about the experience due to their lack of familiarity with the concept of therapy. In the event of family conflict, Asian Americans may not understand the problems of individual family members are affected by the family system. Because Asian American families are less inclined to exhibit free verbal expression of emotions, they may be less willing to communicate their feelings openly in a family session. Furthermore, if parents discuss their problems or express their sadness in front of their children, it could be considered as culturally inappropriate and viewed as losing control over one’s family. More often, Asian husbands/fathers resist attending family sessions. For these men to admit that they may require support from an authority outside of the family may be construed as a sign of weakness, i.e., “losing face”. When events occur that require their children receive treatment, husbands usually send their wives to serve as
the family spokesperson as well as participate in the treatment of their children. Thus, Ho posits that it may be difficult to conduct family therapy without the cooperation and participation of the primary adult male figure so encourages clinicians to educate the family about the importance of full family participation in an attempt to enlist their cooperation.

The last step in the first phase is to discuss setting mutual goals for treatment (Ho, 1987). It is often difficult for Asian Americans to admit having family problems or psychological difficulties, which make establishing mutually, agreed upon treatment goals a challenge. What is suggested as helpful during the initial phase of therapy is establishing short-term goals in which the clinician treats the client’s presenting problem using a problem-focused, goal-oriented, and symptom-relieving approach. Furthermore, long-term goals should be divided into a series of comprehensible, achievable, and measurable short-term goals. Once the family has achieved some success with meeting their treatment goals, the clinician can introduce more insight-oriented goals to the family treatment plan.

The second phase, problem-solving, describes several techniques that a clinician can utilize to help the Asian American family gain some immediate results (Ho, 1987). The first technique that may be helpful for the family is to focus on the problem as it was presented by the family. In order to engage the family in therapy, it may be helpful for the clinician to acknowledge the family’s feelings about the identified patient having a problem, verbalize the family’s pain, help the family focus on the problem instead of the identified patient to avoid placing blame on one particular person for the current difficulties the family is experiencing, focus on how the problem has affected each family
member, and emphasize the importance of working together as a family to solve the problem (Lee, 1990). This technique may help family members feel more comfortable expressing their feelings openly, given the modesty of many Asian families when discussing family or personal matters (Parette, Chuang, & Huer, 2004).

Considering that the Asian culture highly values education and may view the clinician as an authority figure, a psychoeducation approach may be a useful strategy (Ho, 1987). It may also be advantageous to provide communication training to facilitate more direct exchanges among family members (Ho), since research has shown that people from collectivist cultures, such as Asians, tend to use a more indirect style of communication than people from individualistic cultures, such as Americans (Ambady Koo, Lee, & Rosenthal, 1996; Holtgraves, 1997). Furthermore, Asian families may view asking questions as a challenge to authority (Huer, & Parette, 1999) so such training may give them permission to communicate their needs. Behavior management strategies along with conflict resolution techniques may also be perceived as valuable by Asian American families, given the importance placed on the efficient resolution to their problems or symptom relief (McGill & Lee, 1986).

Given the tendency to engage in a more indirect style of communication and viewing confrontation as disrespectful, the clinician, at least initially, may also wish to take an indirect approach in addressing the family’s problems (Ho, 1987). Many Asian families may hear constructive criticism as a personal attack or even rejection. Ho suggests that the clinician may need to read between the lines in order to grasp the major issues. Otherwise, the family may perceive the clinician as too blunt, pushy, or even insensitive. Hong (1989) states that Asian clients often speak of emotional difficulties in
an understated manner and with little observable emotion, which may give the impression that the problem is minor. It is also stated that negative emotions such as anger, grief, and depression are often expressed in an indirect way. Thus, it may be important for the clinician to recognize this style of communication as culturally linked instead of mistakenly perceive it as denial, lack of awareness of his/her own feelings, deceptiveness, or resistance (Sue, 1990).

Reframing is another technique encouraged by Ho (1987) as it allows Asian families to redefine behaviors in a more positive light as well as emphasize their strengths as members of a proud cultural community. Examples of these strengths include the availability of supportive extended family members as well as their religious and ethnic communities, family loyalty to its members, and the self-sacrificing nature of parents to meet their children’s needs.

During the last phase of therapy, termination, it is important for the therapist to understand that since it is generally difficult for Asian Americans to express their feelings openly, they may also be uncomfortable verbalizing anger over termination or expressing anxiety over the impending separation (Ho, 1987). Furthermore, the client may not be able to verbally acknowledge the progress that has been made in therapy. However, the client’s appreciation may be expressed by inviting the therapist to dinner or offering a gift. In this case, it is recommended that, if clinically appropriate, the clinician should accept such gestures with genuine appreciation. It may also be common for the client to expect the therapist to continue as a friend after termination and include him/her in family celebrations. These gestures are culturally sanctioned and should not be considered as signs of pathology.
A key consideration in providing therapy to Asian/Asian American families that transcends all phases of treatment is the family’s communication needs and style. Ho (1987) offers a number of suggestions to negotiate any potential communication issues for non-English speaking families. Even in the case where the clinician shares the culture and is fluent in the family’s particular dialect, an issue that can emerge is determining a common language among family members. This issue often emerges when the children are more westernized so are no longer fluent in their parents’ and/or grandparents’ native dialects. Ho suggests the therapist and family decide together on the dialect they are most comfortable speaking. In the case where the clinician is not fluent in the language of the family but the child and family share a common dialect, Ho suggests avoiding the use of the bilingual child as an interpreter for his/her parents. Not only would the use of the child as interpreter disregard the traditional Asian family structure but may reinforce a sense of helplessness in the monolingual parents. If interpreters are utilized, they should share the same cultural background as the family as well as speak in the same dialect.

Although Floortime Training is a type of intervention that requires the involvement of caretakers and other family members, the majority of its tenets are nondirective in nature, which may be in conflict with the more directive approach that has been observed as preferred among Asian/Asian American clients. Furthermore, the focus of Floortime Training is on the child. Although, a considerable portion of the work is psychoeducational in nature so as to explain and teach the caretakers strategies which will facilitate their interactions with the child, it may be difficult to work directly with all members of the child’s family due to scheduling conflicts that may occur with having working parents. Floortime Training may also be perceived as relying heavily on the
Western assumptions of individuation, independence, and verbal expression of feelings. Thus, this therapeutic approach may be incongruent with the Asian American values of collectivism, interdependence, and restraint of emotional expression. Because of these potential incompatibilities between Floortime and the values and beliefs of Asian/Asian American families, this study examined how these families relate to the use of this particular intervention.

Summary

With the steady rise in the number children receiving an ASD diagnosis, there are many parents faced with selecting an appropriate treatment for their child. Additionally, treatment providers must also consider factors that will influence how families will respond to these various treatments. Although there have been many treatment modalities developed to help children with an ASD and their families cope with the disorder, only a few have empirical data to support its efficacy (Newsom, 1998). Two of the early intervention evidence-based treatments include DTT and Floortime Training.

Although parental involvement has been noted as one of the major contributors to successful treatment planning and therapeutic progress in working clinically with children (Henggeler, 1994), the literature reports parental adherence to treatment is generally low (Kazdin, 1996; King et al., 1997; Sirles, 1990; Wierzbicki & Pekarik, 1993). Among the factors that may potentially influence therapeutic adherence include gender, race, intelligence, and age (Armbruster & Fallon, 1994; Ogrodniczuk, Piper, & Joyce, 2006) as well as social class (Garfield, 1994; Lorion, 1974; Ogle, 2001; Schubert & Miller, 1980). When working specifically with Asian/Asian Americans families, cultural factors, such as their views, attitudes, and assumptions about mental illness (F.
Lee, 1997; S. Sue, 1993; parenting style (Chao, 1994; Julian, McKenry, & McKelvey, 1994; Kelly & Tseng, 1992; Wang & Phinney, 1998); and the compatibility of therapeutic style with client needs (Arkoff, Thaver, & Elkin, 1966; Atkinson & Matsushita, 1991; Exum, & Lau, 1988; Li & Kim, 2004; Ford, 1981; Ho, 1984; Wang, 1994; Flaskearud & Liu, 1991; D. W. Sue, & Sue, 1999; Takeuchi, Sue, & Yeh, 1995; Zhang et al., 1998) may also influence compliance. In general, research has shown that Asian Americans are less likely to utilize mainstream mental health services than other ethnic minority groups (Matsuoka, 1990b; D. W. Sue, 1993; Sue et al., 1994) due to their fear that the illness may have negative consequences on them and members of their group (Tata & Leong, 1994). Instead, these individuals may attempt to resolve difficulties by themselves (Tamura & Lau, 1992; Narikiyo & Kameoka, 1992) or seek the support of family members and friends if unsuccessful going it alone (Akutsu et al., 1996). These ways of coping, thus, may lead to somatic manifestations of the psychological distress, which further masks the individual’s mental health issues.
Chapter III
Method

Overview

This chapter will describe the methodology and procedures of the study. The following content areas are discussed: (a) research approach, (b) participants, (c) instrumentation, (d) procedures (recruitment and screening, consent, research, data management), (e) data analysis, and (f) methodological limitations.

Research Approach and Design

In order to generate clinically relevant hypotheses regarding how Asian/Asian American parents decided to try the Floortime approach, what they knew about the approach, and how they viewed their role in their child’s treatment as well as gain a descriptive understanding of family life when living with a child with an ASD and their attitudes and beliefs about ASD, this qualitative investigation operated from a transformative paradigm and utilized a phenomenological inquiry approach. Despite the potential conflict between the values often observed among Asian/Asian Americans and the tenets of Floortime treatment, these families still sought this intervention for their children. Hence, this research paradigm and approach were chosen because of the interest in providing a voice for the subjective experiences of Asian American parents in regards to the Floortime treatment they received for their child with an ASD (Mertens, 2005).

Through the use of a multiple case study methodology with an instrumental purpose, the intent of the study was to gain an understanding of and insight into the phenomenon of the Floortime treatment modality from the perspective of Asian American parents (Stake, 1995). Families identified as Asian American who sought
Floortime intervention at the recruitment site of this study were from diverse ethnic cultures with no one culture in the majority, therefore, this study proposed hypotheses that were pan-ethnically descriptive, although this methodology allowed for identifying hypotheses that may are unique to particular Asian cultures as well (Mertens, 1998). Furthermore, the use of multiple cases allowed for triangulation of data source across individuals, which improved the credibility of the findings (Mertens, 2005).

**Participants**

Asian/Asian American families were recruited from a program that used play-based therapy and Floortime Training to treat children diagnosed with an ASD and their families. Asian/Asian American families of all ethnic descents whose children participated in the program for at least 6 months were eligible for study participation. In two-parent households in which both parents were Asian/Asian American, the interview was conducted with the parent who was most involved with the child’s treatment and use of Floortime Training. In the event both parents were closely involved in their child’s treatment, the parents were welcome to participate in the interview together. In the case of families with one Asian/Asian American parent and one non-Asian parent, the family was recruited only if the Asian/Asian American parent was the parent most involved in treatment decisions and the use of Floortime Training with the child. Furthermore, intact, blended, and adoptive families were eligible candidates for the study. At the time of recruitment, the agency served approximately 146 families using a multitude of interventions, including Floortime and behavior-focused treatment. Of these families, approximately 55 were currently receiving Floortime services funded by the California Department of Developmental Services Regional Centers. Although some families may
be private-pay clients, the majority of families that are receiving services are referred to
the agency by the Regional Centers. Of these 55 families receiving Floortime Training, 5
families (9%) were Asian/Asian American. Three of these 5 families volunteered to
participate in the interview. The parent interviewed was fluent in the English language.
Children with a history of a seizure disorder or serious head trauma that required
hospitalization and/or ongoing treatment were excluded from the study as these medical
conditions may have affected the child’s overall functioning in ways that would confound
the intent of the study. That is to say, this study was designed to explore how families of
children diagnosed with an ASD related to the use of the Floortime technique and the use
of this technique with children who have additional medical conditions superimposed on
the ASD diagnosis is its own unique phenomenon.

Instrumentation

The primary data collection instrument was an interview developed by the
investigator (see Appendix A). Five domains of information were obtained in addition to
personal history data. Personal history data, which were collected during the interview,
included items related to age, ethnicity, gender, marital status, education, and occupation
of heads of household, and nation of birth. Other information, including their child’s age,
gender, and psychiatric status (e.g., when the ASD diagnosis was established, how long
the child had been receiving treatment in the program, prior treatment history), were also
obtained during the interview. The five content domains of the interview and the
literature that prompted inquiring in these areas are as follows:

1. How Asian/Asian American parents view, understand, and cope with
   their child’s diagnosis of an ASD. Some research has reported family
beliefs that the child’s disability may have supernatural influences or is caused by sins committed by the child’s ancestors, hence, the family may experience shame while at the same time feel obligated to care for him/her (Chan, 1997; Hanson et al., 1990; Sotnik, 1995). There are other researchers who posit, at least for some Asian cultures, e.g., Chinese Americans, that these families may possess a more positive outlook toward their children’s disabilities if at least one of the parents is more highly educated, if the parent was educated in the U.S., and/or resided in the U.S. for 10 years or more and held a professional occupation (Parette et al., 2004). Furthermore, families may experience numerous stressors related to having a child with autism. These feelings may range from frustration due to the child’s inability to communicate with others and the concomitant behavioral problems, the need to make numerous trips to physicians and other specialists, financial burdens, and the demands from the unaffected siblings (Bregman, 1991; Dykens, 2000; Koegel et al., 1992; Rutter et al., 1970), which raised questions about how these families coped.

2. The treatments, if any, Asian/Asian American parents tried prior to engaging in Floortime and their experience with these treatments. A number of interventions are available to families of children diagnosed with autism. Some of the interventions have more empirical evidence to support its effectiveness while others lack support for its veracity (Herbert et al., 2002). These interventions include DTT, medically
based treatments such as the use of Secretin, sensory-motor therapies, facilitated communication, Auditory Integration Training and Sensory Integration Therapy, and Floortime Training (Ayres, 1979; Green, 1994; Greenspan, & Weider, 1998; Horvath et al., 1998; Lovaas, 1987; Newsom, 1998; Smith, 1996; Stehli, 1991). To understand a family’s decision to engage in Floortime Training, it was useful to have an understanding of what they had previously experienced in seeking assistance for their child.

3. How Asian/Asian American parents made the decision to engage in Floortime and their experience with using the technique. Although the father in Asian American families is typically viewed as the family decision maker while the mother provides affection and cares for the children (E. Lee, 1997), Asian American families often defer decisions for meeting the needs of their special needs children to those in whom they trust and view as authority figures, e.g., teachers, medical doctors, and counselors. Thus, a family may commit to an intervention without fully understanding the nature and scope of the treatment (Chan, 1997). The questions in this domain provided a context for understanding why these parents elected to engage in Floortime Training.

4. How Asian/Asian American parents feel they had benefited from Floortime. Floortime is a popular early intervention program for children diagnosed with autism that was developed by Stanley Greenspan. Although this intervention may appear incongruent with the
parenting style found in Asian/Asian American families, these families do, nonetheless, enroll their child in the program and continue to participate in the intervention. The model is child-centered and relies heavily on the adults in the child’s environment to facilitate the learning of skills (Hilton, 2005). This intervention focuses on the child’s uniqueness rather than assuming a standard program is equally effectively with all children in this clinical population (Greenspan & Weider, 1998). The questions in this domain were used to uncover how this select sample of Asian/Asian American parents who are using Floortime Training viewed their experience with this intervention.

5. How Asian/Asian American parents feel their Floortime experience can be improved. Although Asian/Asian Americans may generally underutilize mental health services, when they do participate in these services, research indicates that they may prefer interventions that are more directive, paternalistic, authoritarian, and utilizes an instructional approach, which has been observed as being more consistent with the parenting style of Asian/Asian American parents (Arkoff et al., 1966; Ford, 1981; Ho, 1984; Wang, 1994). Furthermore, research indicates that Asian/Asian American parents value academic achievement, favor interdependence, and engage in more strict and restrictive disciplinary styles (Chao, 1994; Kelly & Tseng, 1992; Lin & Fu, 1990; McKenry & McKelvey, 1994; Wang & Phinney, 1998). Despite its popularity, given the less structured nature of Floortime, it would appear that what might
be more natural to Asian/Asian American parents may be incongruent with the intervention in which they were participating, therefore, this study was interested in investigating whether what is reported in the literature is congruent with the expressed experiences of these families.

Procedures

Recruitment and Screening Procedures

After obtaining the approval of the Pepperdine Graduate and Professional Schools Institutional Review Board and the director of Verdugo Hills Autism Project (see Appendix B), a recruitment brochure was disseminated by case supervisors to families on their caseloads who were Asian or Asian American (see Appendix C). Parents who were interested in participating in the study were asked to contact the investigator directly by phone. The investigator contacted the parent via phone and used a script to explain the purpose of the study as well as gathered information to ensure inclusion/exclusion criteria were met by the family (Appendix D). If the parent met the inclusion/exclusion criteria and voiced interest in participating in the study, the investigator arranged a time to meet and completed the interview protocol. Parents were sent the informed consent form prior to the appointment so they could have an opportunity to review it prior to meeting with the investigator, although they were informed not to sign it until the appointment time, during which the investigator reviewed the form with them. The consent form included an explanation of the purpose of the research, the procedures of the research, the risk and benefits of the research, the voluntary nature of research participation, the subject’s right to stop the research at any time, and the procedures used to protect the participants’ confidentiality.
Consent Procedures

Prior to commencing data collection, the consent form (Appendix E) was reviewed with the parent using a consent script (see Appendix F). In the case of two Asian/Asian American parents who were both closely involved in their child’s treatment and both wanted to participate in the interview, the parents signed her/his own consent form. After all questions were answered to the parent’s satisfaction, the parent was invited to sign the consent form. Participants were also provided with a list of referrals to mental health services in the event they wished to seek support or the researcher believed such a recommendation was warranted (see Appendix G).

Research Procedures

Upon obtaining consent from the parent, the investigator conducted the interview. The parents were offered the option to either meet in their home or a private study room at a public library near their home, but all parents elected to meet in their home. If both parents were Asian/Asian American, closely involved in their child’s treatment, and interested in participating in the interview, the parents were interviewed together. The audiotaped interview took 1-2 hours to complete. After the completion of the interview, a $30 gift card to Barnes and Noble was given to each parent as a token of gratitude for participating in the study. The parents were also able to request an abstract of the study findings by completing a form with their contact information (see Appendix H).

Data Management Procedures

The interviews were digitally recorded. Following each interview, each CD was identified by a random number that corresponded to the family. All interviews were transcribed by the researcher. The CDs and the interview transcriptions are securely
stored in the investigator’s office separate from the consent forms and the list of names and identification numbers to prevent linking identities of families to their data. The investigator is the only person who had access to these data. Back-up copies of the recordings are on the same computer on which the content analysis was performed. This computer is password protected and only the investigator has access to the password. The data will be maintained in a secure manner in the investigator’s office for at least 3 years and destroyed when no longer required for research purposes.

Data Analysis

The data were analyzed using Spradley’s (1979) content analysis model. The analysis consisted of four stages: (a) domain analysis, (b) taxonomic analysis, (c) componential analysis, and (d) theme analysis. Before engaging in the domain analysis of data, the investigator first reviewed the transcripts of the interview and identified key terms, descriptors, or concepts that were relayed by the interviewee. The investigator searched for elements that were deemed unusual, appeared frequently, or otherwise caught one’s attention. After these bits of data were identified, the investigator organized the bits of data (included terms) into categories or domains which are referred to as cover terms (the first step of domain analysis). As an example, “Facing Reality” is a cover term while “stunned” and “devastated” are the included terms. Once the included terms were assigned to cover terms, the investigator further refined the organization by linking each included term to the cover term using semantic relationships of which there are nine (strict inclusion, spatial, cause-effect, rationale, location-for-action, function, means-end, sequence, and attribution). For example, feeling stunned, is a result of facing reality, i.e., feeling stunned is connected to facing reality by the use of a cause-effect semantic
relationship. The investigator’s included term-cover term links were reviewed and questioned by her dissertation chairperson to improve the quality of the linkages (i.e., setting boundaries). Once a defensible set of cover terms and related included terms were established, the investigator engaged in the taxonomic analysis of the data. The taxonomic analysis of data provides an opportunity to more fully refine how the data are organized (Spradley, 1979). The investigator systematically reviewed each domain in an attempt to determine if subsets of covered terms could be collapsed together with a new semantic relationship linking these data to a new and more inclusive cover term. In other words, the original set of cover terms now became the included terms for a new set of cover terms. So assuming there were two domains, one called “Facing Reality” and the other called “Denial”, these two domains were combined under a new, more inclusive cover term, “Cope with child’s ASD”. Following the construction of the taxonomy, a componential analysis was completed (Spradley, 1979). The componential analysis, unlike the prior levels of analysis, focused on the contrasts that existed among the data within each case, not what the data shared in common. In making these comparisons for contrasts, the data were further refined. The basic idea in the componential analysis is that all items in a domain can be broken down into combinations of semantic features which combined to give the item meaning. The process of componential analysis included searching for contrasts, sorting them, and grouping them together into dimensions of meaning.

The final stage of analysis was theme analysis (Spradley, 1979). It was during this analysis that complex patterns or themes identified from the information gathered from the interviews. These themes were obtained from comparing and contrasting domains
across cases rather than focusing on individuals cases, as has been the case up to this point.

Methodological Limitations

The use of a semi-structured interview may raise reliability concerns. However, given that the qualitative method emphasizes the subjective experience of each case, no one interview was identical to other interviews. In other words, the uniqueness of each interview was valued. Grand tour questions established some general parameters for the interview. However, it was expected that unique mini tour questions would emerge during the interview process to allow the investigator to follow up on issues that required more information to fully understand the subjective view of each family. To reduce variability in the manner in which the interview questions were administered, the investigator was the only individual who conducted the interview.

Two sampling related issues may have raised concerns about the quality of the data. The first of these two concerns was not using a random sampling procedure to recruit study participants. Unlike quantitative research, using a probability sampling procedure for recruiting participants for a qualitative study is less of a concern since case study research is not designed to study a case to understand other cases (Stake, 1995). The second sampling related concern was the small sample size of the study. According to Mertens (2005), the sample size for case study research can be 1 or more, and for phenomenological studies, the recruitment of 6 participants is considered reasonable. Given that the total pool of potential participants was only 5 cases, the recruitment of 3 of these 5 cases seemed appropriate.
Finally, there are few Asian/Asian American families receiving services at the recruitment site. Therefore, it was impractical to set more rigorous criteria for inclusion and exclusion such as controlling for ethnicity and the type of family. In order to better understand the potential relevance of these attributes and obtain a richer contextual basis for each case, a more detailed description of the family’s background was obtained during the interview, although care was taken to protect the identities of the families.

Summary

This qualitative study utilized the phenomenological approach in order to obtain information regarding the unique experiences of Asian/Asian American parents who have a child diagnosed with an ASD. In addition to having a child diagnosed with ASD and being of Asian/Asian American descent, families in this study were required to meet additional criteria for inclusion and exclusion to participate in the study. These criteria included being fluent in the English language, the child being free of a seizure disorder or serious brain trauma, and the family participating in Floortime for at least 6 months. Three families volunteered to complete the interview. The data were analyzed using Spradley’s content analysis method.
Chapter IV
Results

Overview

This chapter presents the findings from using the Spradley (1979) model of content analysis. The following steps were involved in the analysis.

1. The first step of the analysis involved the review of the interview transcripts and highlighting major descriptors of the families’ experiences.

2. The second step was the domain analysis. During this stage of analysis, the data were categorized into cover terms (domains) that contained included terms (major descriptors that support the existence of the cover terms). As an example, Facing Reality was a cover term while “stunned” and “devastated” were the included terms. These included terms were linked to the cover term through the use of a cause-effect semantic relationship, i.e., being stunned or devastated were the result of facing reality.

3. The next step was the taxonomic analysis of the data. During this process, each domain was reviewed and it was determined if subsets of established cover terms could be grouped together and semantically linked to a more inclusive cover term (master domain). For example, there were three cover terms related to changes that occurred for families after their child was diagnosed with an ASD (i.e., Change in disposition, Priority shifts, and Exclusively attending to child’s needs). This set of cover terms was placed under the master domain of “Life adjustments.” The four master
domains that emerged from this step were: (a) cope with child’s ASD, (b) life adjustments, (c) using Floortime Training, and (d) improve Floortime experience.

4. The fourth step was the componential analysis of the data. This step focused on examining the contrasts that exist among the data within each case. Based on these first four steps of analysis, an individual case summary was written that incorporates both the similarities and differences found within each case (see Case Summaries section below).

5. The final step of the analysis was theme analysis. During this step, themes were identified by comparing and contrasting the data across the three cases (see Results of Cross-Case Analysis section).

Case Summaries

In presenting the case summaries, every attempt was made to mask the identity of the parents and their child. Furthermore, rather than identifying the gender of the parent or child, both the masculine and feminine pronouns (he/she, him/her, his/her) were used to refer to family members.

Parent 1

Parent 1 was born in Asia and immigrated to the United States with his/her parents as a preschool age child. He/she was educated in the United States, including an undergraduate degree in the sciences. His/her spouse is an American-born Asian and they have two children. Results from the domain and taxonomic analyses are presented in Appendix I.
**Cope with child’s ASD.** One of Parent 1’s two children was diagnosed with an ASD as a toddler. His/her child’s ASD symptoms were first brought to his/her attention by a friend whose child was experiencing similar symptoms. Parent 1’s initial reaction was to deny the potential existence of the condition (e.g., “I didn’t get [i.e., I didn’t want to get] what she was telling me” or “[child] can’t be autistic because [child] was affectionate”) and then he/she engaged in minimizing its seriousness (i.e., “[My child]’ll be ok because [my friend’s child] is ok” or “maybe [child]’ll be a savant”).

After another friend helped him/her face the reality of his/her child’s condition, Parent 1 sought help for his/her child and the child was formally diagnosed with an ASD. He/she reported feeling “stunned” and “devastated” upon hearing the news of his/her child’s diagnosis. However, through individual and couple’s therapy, Parent 1 and his/her spouse were able to face the situation, which, in turn, helped them cope with their child’s condition.

After facing reality, Parent 1 sought information to become better informed about his/her child’s condition. He/she researched the disorder on the Internet and read everything he/she could find on the condition. He/she also found “other parents” were a valuable resource. He/she reported asking “a lot of questions” in his/her search for improving his/her knowledge of ASDs.

Parent 1 reported having a positive outlook helped him/her cope with his/her child’s diagnosis. He/she referred to the support that his/her family derived from their “Christian faith” and “friends in the church”. Parent 1 also talked about humor as a way to cope with the various challenges the family encountered.
*Life adjustments.* Parent 1 reported he/she underwent a number of changes following his/her child’s ASD diagnosis. For example, Parent 1 experienced a change in his/her outlook on life. He/she found herself being more patient, compassionate, and empathetic toward others as well as being able to “let things go” and reconsider what is important in life.

Parent 1 also reported how his/her priorities shifted as a consequence of his/her child’s condition. For example, he/she learned the importance of “friendships” and “people skills” over placing a strict emphasis on academic achievement. He/she attributed the latter observation to the cultural messages that were transmitted to him/her.

Finally, due to the extensive needs of his/her child (“It was really busy” and “I drove [child] everywhere”), Parent 1 reported changes in their day-to-day existence. The most substantial of these changes was “not work[ing] since [child] was 1”. In general, Parent 1 reported that life changed drastically and nothing remained the same since his/her child’s diagnosis.

*Using Floortime.* Parent 1 enumerated a number of ASD symptoms that led him/her to seek treatment for his/her child (“Wasn’t talking” and “Avoid[ed] eye contact”). He/she also reported negative reactions to the use of DTT (“Painful to watch”, “[Child] does not get it [DTT]”, “It [DTT] was just awful”), which was the original form of treatment sought for his/her child. Most importantly, Parent 1 felt that the DTT techniques “didn’t feel natural” to him/her and his/her child, so he/she discontinued treatment. In seeking alternative treatments, Parent 1 reported that he/she encountered a number of advocates of Floortime, including the preschool his/her child was attending, someone at the Regional Center, and a Floortime therapist who is considered one of the
foremost experts in the use of the intervention. The encouragement of these advocates as well as his/her negative feelings about DTT prompted him/her to choose Floortime.

When his/her child first received Floortime Training, Parent 1 admitted he/she had some difficulty replicating the intervention strategies as was demonstrated by the Floortime therapist. To increase his/her skill with the use of Floortime, Parent 1 attended a conference and “training with the Regional Center.” At the conference, he/she viewed videos of how Stanley Greenspan coached families. He/she also invited the Floortime trainer/expert to work with his/her family. It was through these various methods that Parent 1 was able to fully appreciate the use of Floortime.

Parent 1 described Floortime as a “better fit” for his/her child and family and it “made sense.” Parent 1 also stated that as he/she learned and understood more about ASDs, the more he/she “understood that relationships were important.” Furthermore, he/she cited a number of advantages to the use of Floortime. For example, Parent 1 felt focusing on the individual needs of the child and family while taking into account “strengths and weaknesses,” and using the strengths to compensate for the weaknesses, made the intervention “more effective.” Lastly, Parent 1 felt it was important to “Expect [parents] to be involved” as it allowed parents “more opportunities to have input in the program.”

While using Floortime Training, Parent 1 noted positive behavioral changes in his/her child. For example, his/her child can now initiate playing games, talks more, can express a wider range of emotions as well as be more appropriate in the expression of emotions, and can follow directions. Others have also observed improvements in his/her child’s behavior. An illustration of his/her child’s improvement is at Sunday school.
classes. Others have noted that his/her child “complies” and is able to “sit and listen” during the Sunday school class. Furthermore, the child participates in “craft activities”, “sings songs”, and “follows the routine” of the class.

*Improve Floortime experience.* Beside the benefits, Parent 1 also discussed his/her criticisms of Floortime, made suggestions as to how one could better help a parent to feel competent with its use, and what from other forms of treatment might enhance the Floortime experience. One of the major criticisms had to do with the use of “novice therapists” to provide the training. Particular concerns that were expressed with the less experienced therapists are they did not fully understand Floortime Training themselves or the importance of an agenda with a set of established goals to work toward. Furthermore, they did not appear to understand that there is more to Floortime Training than simply following his/her child around. Parent 1 suggested all Floortime therapists watch the Greenspan video as well as get more supervision, themselves, by Floortime trainers.

Another major area of concern was the quantity and quality of supervision offered the parents—the “training was not as good as I would have liked”. In part, the concern raised above is related to this particular issue, i.e., the use of inexperienced therapists. Furthermore, Parent 1 suggested parents would benefit from “more supervision” themselves and it would be helpful for the trainer or a well trained therapist to give “hints and tips” while parents are trying to work with their child.

Although Parent 1 had a negative experience with other treatments such as DTT, there were several aspects of another similar behavior treatment intervention, Applied Behavior Analysis (ABA), which he/she felt might be helpful to incorporate with Floortime. What he/she appreciated about ABA was its reliance on an “agenda” that
delineated the “goals” the child was to work toward in therapy and the use of “semi-structured activities” to help guide the child toward meeting these goals.

**Parent 2**

Although Parent 2 was the primary informant, his/her spouse also joined the interview session. Parent 2 was born and raised in an Asian country, although he/she attended a private Catholic school run by an American nun. Parent 2 came to the United States in his/her late teens to complete his/her university studies. His/her spouse was born and raised in the United States by Asian immigrant parents. The couple has four children, one of which was diagnosed with an ASD as a toddler. Results from the domain and taxonomic analyses are presented in Appendix I.

*Cope with child’s ASD.* Parent 2 reported knowing something was wrong with their child during infancy, although his/her spouse felt their child “seemed ok.” Although it is interesting to note that his/her spouse felt their child’s eye contact was poor while Parent 2 felt it was “good.” Despite his/her feelings that something might be wrong, Parent 2 dismissed his/her initial perception since their child did not consistently display behaviors that raised concern.

After seeking services from physicians, such as a neurologist, who were unable to diagnose Parent 2’s child’s problems, the parent eventually went to the Regional Center, upon the recommendation of another parent, and his/her child received the diagnosis of an ASD. Parent 2 reported feeling relieved that the problem had been identified so “we can get all the services we want.” His/her spouse, on the other hand, was skeptical about the diagnosis and initially questioned its validity. Parent 2 and his/her spouse faced the reality of their child’s condition by telling “everyone [child] has autism.” Additionally,
his/her spouse reported that the more he/she learned about ASDs, he/she was more able to recognize that his/her child’s behaviors “fit the diagnosis.” Both parents were invested in learning as much as they could about the disorder by “talking to people who already know about it,” speaking to “other parents,” doing research online, including a Yahoo group that discussed ASDs, and speaking to advocates. Parent 2 also added that he/she appreciated the support of the Parent Center at the California Department of Developmental Services Regional Center in providing him/her with resources for treatment. Both parents reported being “determined to do the best we could” to help their child and not allowing this situation to “stop us.”

Finally, another way Parent 2 and his/her spouse coped with their child’s condition was to maintain a positive outlook. They were able to gain positivity through the support of friends who understood autism. They also took their child everywhere with the rest of the family, despite some behavioral challenges, to meet their other children’s “need [for] normal social interactions.” In other words, they did not allow their child’s disorder to prevent a relatively normal family life.

*Life adjustments.* Parent 2 and his/her spouse reported aspects of their life clearly changed following their child’s ASD diagnosis. In regards to their outlook, they no longer need to have their child reach “a certain level of achievement” as they previously expected. Furthermore, they have accepted that they will have to take care of their child “for the rest of [child’s] life.”

Not only has their outlook changed, but so have their priorities. For example, Parent 2 expressed that he/she and his/her spouse no longer had expectations that their child will achieve “a certain education level.” In fact, they emphasized that it is one’s
“people skills” rather than grades that are most important in life, which is more the emphasis of Floortime. Parent 2 recalled his/her mother emphasizing grades as he/she grew up, but when he/she entered the workforce, he/she found the ability to relate or “interact with others” and “communicate” were more important than the grades he/she earned for having “the skills” required to do the job.

Parent 2 reported he/she did not work to accommodate the increase in doctor’s appointments and visits to treatment facilities—“I was driving [child] around [a lot].” Consequently, the family did not have the financial security they had when he/she did work.

Using Floortime. Parent 2 and his/her spouse identified a number of symptoms that describe a child with an ASD, e.g., excessive crying, poor eye contact, not interacting with people, and clinging. The parents reported that they had always favored Floortime Training, but they also tried the Gluten- and Casein-free diet but did not have a favorable view of the experience and discontinued its use. In fact, Parent 2 referred to the diet as “voodoo stuff.”

From early on, Parent 2 reported hearing a considerable amount of support for the use of Floortime by other individuals, such as his/her child’s teacher. When he/she met a local expert of Floortime, Parent 2 reported the expert “convinced me Floortime is the right thing for [my child].” So he/she and his/her spouse attended Floortime training offered by the Regional Center and sought training from the Floortime trainer/expert so as to fully appreciate and understand the intervention.

Parent 2 provided a number of advantages of Floortime use. He/she believes Floortime “cures the core of the issue” by teaching the child “how to learn and how to
play.” In doing so, the child learns to “expand” the interaction to other interactions, i.e.,
 generalize the behavior and experience to other situations.

Parent 2 reported seeing numerous changes in his/her child’s behavior since the
use of Floortime. For example, their child talks more, is “sociable,” is “more recovered”
when compared to other children in the classroom, and appears to “enjoy and understand
what [child’s] supposed to do and why” rather than robotically complying with the
instructions given. The parents have also received positive feedback from others who
describe their child as “fine,” having “blossomed,” and having grown “out of it.” Some of
these people even believe it was a “misdiagnosis.”

_Improve Floortime experience_. Although there were benefits to Floortime, Parent
2 openly shared some criticisms of the intervention. Parent 2 confessed that some of the
drawbacks of Floortime are that it is “not as quantifiable” and may require some time
before observable improvements are noticeable. Another criticism of Parent 2’s
experience with Floortime is that there are often new, inexperienced therapists who may
not implement the intervention correctly. Parent 2 asserted that “Floortime has a bad
name because it’s not properly implemented” since the therapists “don’t have enough
training.” To remedy this issue, Parent 2 suggested the therapists receive “more
supervision” and “more training” with someone who has greater expertise in the use of
Floortime, and this expert should “spend more time shadowing” the therapists to ensure
their competence with the intervention. Parent 2 also feels the same intensity of training
should be offered to parents as they work with their children at home. Furthermore,
he/she suggested that “more trainers” need to be available to train both therapists and
parents to competence so more families can benefit from Floortime.
Finally, Parent 2 made a noteworthy recommendation for improving Floortime by incorporating elements of DTT into the Floortime protocol. For example, he/she felt the identification of “more solid goals” would improve Floortime outcome. Moreover, Parent 2 reported feeling more comfortable with interventions like ABA that are able to quantify outcome, and he/she views this intervention as having the capacity to “teach a child to do many things…quickly.”

**Parent 3**

Parent 3 was born and educated in an Asian country and immigrated to the United States as a young adult. This parent completed his/her education in his/her country of origin and works in a trade since residing in the United States that required a year of trade school training. Parent 3’s spouse is also an immigrant from the same Asian country. They have two children. Results from the domain and taxonomic analyses are presented in Appendix I.

*Cope with child’s ASD.* Parent 3’s child was diagnosed with an ASD as a toddler. Initially, Parent 3 “did not think there was anything wrong” with his/her child. He/she reported not having “heard of ASD” and actually not believing that such a disorder exists since no one in his/her family had such problems. Parent 3 recalled thinking that his/her child was “a late starter” and he/she assumed his/her child would be fine since his/her other child was fine. Although Parent 3 appeared to understand his/her child was experiencing challenges, he/she minimized the seriousness of his/her child’s situation as simply “having a hard time learning to talk” and he/she and his/her spouse discussed getting their child “help to learn to talk.” They consulted their child’s pediatrician who
not only educated them about autism but also helped them face the reality of the seriousness of their child’s condition.

According to Parent 3, “I was surprised” by what the pediatrician said and he/she talked about it feeling “strange” and a “very new” experience for him/her. However, their friends advised them to “listen to the doctors,” so they accepted the seriousness of their child’s condition. To learn more about autism, Parent 3 read the “big book of resources” provided by their local Regional Center.

To maintain hope and a more positive outlook about their child’s situation, Parent 3 reported he/she kept thinking since “our [other child] was fine,” perhaps his/her child with an ASD would also be fine at some point. In addition, Parent 3 reported doing “what the doctors told us to do” in order to maintain a sense of hopefulness about the situation.

Life adjustments. Parent 3 described their family life as having “changed a lot” and “very disruptive” since their child was diagnosed with an ASD. Though, he/she did not report undergoing any changes in regards to his/her outlook on life as a result of this experience, Parent 3 did dwell on how the family’s priorities changed (“Everything was done for [child’s] treatment”), particularly in regards to the extensive attention their child required to meet the child’s needs (“We had to take [child] here and there all the time” and “Our schedule was so busy all the time”). Parent 3 also reported the need to place a higher priority on working more in order to provide for the family and its newfound needs.

Using Floortime. This particular master domain focused on the positive elements of Floortime Training for which Parent 3 had little to report. The paucity of evidence for this master domain is useful data, in and of itself. Although Parent 3 could identify
symptoms associated with an ASD such as “not speaking” and “couldn’t tell us what [child] wanted,” he/she had no positive things to report about Floortime but could report positive things about alternative forms of interventions (i.e., ABA and speech therapy). He/she reported trying Floortime since it was suggested by the Agency at which his/her child was receiving services.

Interestingly, Parent 3 did note that his/her child appeared to “play better” and could “talk more,” and he/she also observed that his/her child could “talk to teachers and other kids at school” as well “play with his/her [sibling] a little better.” But he/she also added that he/she was uncertain if the improvements in his/her child’s ability to converse were attributable to Floortime or to the speech therapy that his/her child received.

*Improve Floortime experience.* Although Parent 3 had little positive to report about his/her family’s experience with Floortime, he/she had a number of criticisms of the intervention. He/she acknowledged that the Agency’s description of “Floortime seemed good at the time,” but “it didn’t work for [his/her child] like they said it was going to work.” For example, although his/her child learned to play, Parent 3 reported the child’s play behavior was limited to a particular toy, i.e., the child “only knew to play with cars.” Additional criticisms included the use of weekends for the sessions that took time away from the family spending time together and the intervention “took too much time” in general. It was clear Parent 3 favored other interventions and felt these alternative interventions benefited his/her child. He/she spoke particularly highly of ABA and speech therapy. Parent 3 felt the intervention was “good” and his/her child “learned a lot” from ABA, e.g., sit quietly, pay attention, and follow directions. From speech
therapy, Parent 3 reported his/her child was taught to “talk normal” as well as learned “more words.”
Results of Cross-Case Analysis

The results of the cross-case analysis revealed major themes in the four categories that emerged from the taxonomic analysis of the interview data: (a) cope with child’s ASD, (b) life adjustments, (c) using Floortime Training, and (d) improve Floortime experience.

Cope with Child’s ASD

Based on the data, it was evident that the denial and then the minimization of the condition were how the three parents dealt with their child’s problems during the initial stages of the coping process. These parents reported initially experiencing disbelief that their child may be experiencing the symptoms of an ASD, or even denied the existence of such disorders. But as the parents began to acknowledge that their child may be experiencing difficulties, the parents considered alternative conditions that they perceived as less serious (e.g., speech problems) or began to play down the existence of symptoms commonly associated with ASDs (e.g., poor eye contact). Projecting that their child would be “ok” was a concept that was shared in common by the three parents.

All three parents seemed to vary in the methods they used to help them face the reality of their child’s diagnosis. Parent 1 utilized individual and couple’s therapy while Parent 2 was able to face this reality after seeing other children with an ASD who exhibited similar behaviors as his/her child. Parent 3 was only able to face the reality of his/her child’s diagnosis once his/her friends encouraged him/her to “listen to the doctor”. When the reality of their child’s condition could no longer be denied or minimized, it was not uncommon for the parents to report feeling “stunned” or “surprised” by the news. Interestingly, one parent reported relief when the condition was identified as it helped
direct them to services that were appropriate for meeting their child’s needs. Both during the process of coming to terms with their child’s condition and after accepting the reality that their child was diagnosed with an ASD, these parents sought information from a number of sources that included the physician who identified the problem, other parents who had children with similar conditions, books, and the Internet. The one consistent information source reported by the three parents was the Regional Center.

Although the three parents found ways to maintain a positive outlook despite their child’s condition, they differed in the way they achieved this end. Both Parents 1 and 2 reported the support of “friends” helped them remain optimistic, although for Parent 1 these friends were members of their church, while for Parent 2, these friends were individuals who had an understanding of autism. Parent 3, however, depended on their child’s physicians for support and did everything they suggested to maintain a sense of hope.

Life Adjustments

All three parents appeared to experience substantial changes to their daily life as a result of having to attend to their child’s numerous needs. “Driving” or “taking” their child to appointments, etc. was referred to by all three parents. Parents 1 and 2 did not work in order to provide full-time support to their child, which impacted the family’s financial well being. Parents 3 continued to work, and, in fact, found the need to work more hours in order to support the family and meet his/her child’s needs.

In regards to changes in one’s outlook on life and priorities and the emotions tied to these changes, Parents 1 and 2 were more similar than dissimilar. Both these parents referenced similar changes in regards to reframing what is important in life for both
themselves and their child (i.e., less emphasis on academic achievement and more emphasis on relational skills). Furthermore, these shifts in how these parents perceived life were clearly made in support of their child, and despite the challenges, their outlook remained positive. In contrast, Parent 3 emphasized the negative aspects of having a child with an ASD. Although he/she acknowledged their life had changed, the changes reported were all negative. Furthermore, this parent, unlike Parents 1 and 2, did not report undergoing any personal-transformation as a consequence of this experience.

Using Floortime

In the area of using Floortime, Parents 1 and 2 are more similar than dissimilar. Both these parents had unfavorable reactions to treatments other than Floortime (i.e., DTT, special diets) and found Floortime as most congruent with their child’s needs and believe it is the most effective of the treatments available for ASDs as it takes into account where each individual child is developmentally and uses the child’s strengths to overcome his/her weaknesses. These are the same two parents who placed an emphasis on the development of relational skills over academic achievement. Both these parents also sought training from one of the known experts in the use of Floortime in order to gain a full appreciation of its use. In other words, Parents 1 and 2 were fully committed to adhering to this particular intervention. The reward for their treatment adherence was that their children exhibited positive changes that were observed by both the parents and other individuals in their child’s life, such as the ability to speak more, experience a fuller range of emotions, being sociable, the ability to initiate play, and being capable of following directions more effectively.
In contrast, Parent 3, despite reporting his/her child could “play better” and could “talk more” after engaging in Floortime Training, did not offer any positive reactions to the use of Floortime and had no negative reactions to the use of other interventions. In fact, Parent 3 highly praised the use of ABA since his/her child “can sit quietly” and “pay attention” more effectively. He/she also reported that the speech therapy helped his/her child learn “more words.”

**Improve Floortime Experience**

In regards to improving the Floortime experience, Parents 1 and 2 provided criticisms and recommendations that were more similar than dissimilar. One issue that arose was the quality of training that the Floortime therapists receive, which, in turn, affect the quality of training the parents receive from them. In fact, one parent went so far as to say that the less favorable reputation of Floortime may be attributed to the use of inexperienced therapists for training families in the use of this intervention. The parents reported the need for more “hints and tips while you are doing FT” and “shadowing” by experienced Floortime trainers. Finally, Parents 1 and 2 suggested that integrating some of the elements of other interventions (DTT and ABA) may strengthen the Floortime experience, although both parents had different ideas as to which of the elements might be the most helpful. The one element on which both these parents agreed was the use of more specific goals that the child can work towards achieving.

As was consistent with the sentiments expressed for the prior master domain, Parent 3 offered a number of criticisms of Floortime (e.g., “took too much time”, “[child] only knew to play with cars”) and provided no suggestions for improving the Floortime experience as it was clear he/she had no intent of re-engaging in the experience. He/she
unquestionably supported the use of other interventions, specifically ABA and speech therapy.

**Summary**

The following is a summary of the major themes and subthemes that emerged from the interview data:

1. The denial and the minimization of their child’s ASD diagnosis appear common during the initial stages of the coping process.

2. After the initial feelings of disbelief and surprise, parents reported relying on various methods (e.g., therapy, observing other children with an ASD) to help them face the reality of their child’s condition.

3. During the process of coming to terms with their child’s condition and after accepting the reality that their child was diagnosed with an ASD, the parents actively sought information from diverse sources to better understand the condition; the Regional Center was the only resource consistently reported by the 3 parents.

4. The parents sought support from others in the process of coping with the knowledge of their child’s ASD diagnosis, although the individuals from whom support was sought varied in their relationship to the parent.

5. The parents reported undergoing substantial changes to their family’s lifestyle in order to meet the needs of their child; money and time were specific issues that arose.
6. One’s outlook on life and priorities changed as a consequence of their child being diagnosed with an ASD; 2 of the 3 parents deemphasized academic achieved but stressed the importance of developing relational skills.

7. Two of the 3 parents reported Floortime to be the most effective treatment available for ASDs since it met the child where he/she is developmentally and uses the child’s strengths to overcome his/her weaknesses; in contrast, 1 parent expressed high praise for ABA and speech therapy and did not find Floortime a good experience for his/her family.

8. The 2 parents who favored the use of Floortime raised concerns about the adequacy of training offered to the therapists who work with families as some of these therapists do not appear to fully understand how to implement intervention.

9. These same 2 parents suggested integrating elements of other interventions, DTT and ABA specifically, to strengthen the Floortime experience; both parents agreed on the importance of establishing specific goals the child can work towards achieving.
Chapter V

Overview

The purpose of the study was to gain an understanding of Asian/Asian American parents’ subjective experience with their child’s ASD diagnosis and the use of Floortime training as a treatment intervention for autism. This qualitative study utilized a phenomenological method of inquiry in order to understand the unique experiences of each family. Three of the 5 Asian American families who participate in Floortime Training and met the criteria for study inclusion volunteered to complete the audiotaped interview.

The transcribed interviews were analyzed using Spradley’s (1979) method of content analysis, which yielded four master domains: (a) cope with child’s ASD, (b) life adjustments, (c) using Floortime Training, and (d) improving Floortime experience. From these master domains, nine themes emerged. Of these nine themes, five themes were corroborated by the 3 parents: (a) the use of denial and minimization during the initial stages of coping with their child’s ASD diagnosis; (b) the reliance on various methods for facing the reality of their child’s diagnosis, such as individual therapy or observing other children who also displayed ASD symptoms; (c) seeking additional information from various sources about the condition and obtaining help through the Regional Center; (d) reaching out to various support systems to help them cope; and (e) experiencing a significant number of changes to their family’s lifestyle in an effort to meet their child’s needs.

The remaining four themes were either split between the 2 parents who supported the use of Floortime Training and the 1 parent who provided a dissenting voice or were
only reported by the 2 parents who supported the use of Floortime: (a) 2 parents expressed changes in their outlook on life and priorities as a consequence of their child ASD diagnosis, i.e., they now deemphasize the importance of academic achievement and stress the importance of developing relational skills, while the third parent did not express any changes in his/her outlook; (b) 2 of the parents consider Floortime the most effective treatment for ASDs because it meets the child where he/she is developmentally and can use his/her strengths to overcome weaknesses while the third parent highly praised the success of ABA and speech therapy in treating his/her child; (c) the 2 parents who supported the use of Floortime reported their concern about the adequacy of training provided Floortime therapists, which, in turn, influenced the quality of the training they received; and (d) the 2 parents who supported the use of Floortime suggested establishing specific goals for the child to work towards to strengthen the Floortime experience.

Clinical Implications

The results of this study indicate there were some commons themes shared by the 3 parents who were interviewed, particularly in regards to their own process with coming to terms with their child’s condition, actions taken to cope with the situation, and the experiences of the families as a consequence of their child’s disorder. Although this investigation was not designed to compare and contrast the data of these 3 families to other groups of families, based on the investigator’s personal clinical observations of other families from diverse ethnic backgrounds, these parents’ initial reactions and attempt to cope with the news of their child’s ASD diagnosis were not unique from other families. In fact, these observations have been corroborated by Lazarus and Folkman (1984) in their discussion of problem- and emotion-focused coping strategies, in which
parents raising a child with a developmental disability may engage, as well as the
discussion of other researchers on how families cope with and gain control over their
feelings of uncertainty that disrupt the normalcy of family life (Butler & Smith, 1992;
Cohen, 1993; Diehl et al., 1991; Gravelle, 1997; Hodges & Parker, 1987; Jerrett &
Costello, 1996; Scharer & Dixon, 1989). Hence, facilitating the acceptance of and coping
with their child’s condition is likely a universal treatment goal.

What may be unique for Asian/Asian American families, which has been
addressed in the literature, is the degree to which they perceive a social stigma associated
with a mental condition may influence the process of acceptance and coping with the
disorder (S. Sue, 1993; Sue & Morishima, 1982). In these cases, the process of coming to
terms with their child’s condition may be more protracted; an issue with which clinicians
should be aware as it has implications for the psychological health of the family-at-large
as well as treatment adherence.

Another key consideration in the acceptance and coping process is the role of
acculturation, which was not directly assessed in this study. Yet, there were data that
could argue that acculturation may be an issue worthy of consideration. For example,
although all 3 parents sought information to improve their knowledge of a child with an
ASD and used different ways to cope with the knowledge of their child’s condition, the 1
parent who was more likely the least acculturated to an American lifestyle (immigrated to
the U.S. as an adult, had no prior formal experience with the American culture, and was
married to a spouse who is also an immigrant) relied only on physicians for information,
(beside the Regional Center), which is a common observation cited in the literature of
Asian Americans (Chan, 1997). In contrast, the parents who appeared more acculturated
by virtue of their life experiences (e.g., exposed to the American culture from childhood, attended American universities, married spouses who were American-born) pursued other avenues for information and support, including online research, speaking with other parents who had children with an ASD, and personal therapy. One also cannot ignore the interaction of education with the acculturation process, i.e., both the exposure to American ideals early in one’s life and engaging in higher education are likely to enhance the acculturation experience. It would appear the work of Parette, Chuang, and Huer (2004) with Chinese American families corroborates this observation in that they found parents had a more positive outlook toward their children’s disabilities when at least one of the parents had a higher level of education and was educated in the United States. Hence, acculturation and education are factors that require consideration in understanding the coping process for Asian/Asian American families with a child diagnosed with an ASD; perhaps the less acculturated and less educated parents experiencing a more prolonged adjustment period, which, in turn, influences their readiness for change. Furthermore, the parents who were seemingly more acculturated appeared to have a more extensive support system, which facilitated them coming to terms with their child’s condition. Therefore, it would be important for clinicians to encourage parents who appear more isolated in their experience to create a system of support to facilitate coping with this life changing situation.

There were also two treatment related themes that distinguished the parents from one another. Generally, Parents 1 and 2 were thematically in agreement, in contrast to Parent 3. Parents 1 and 2 were proponents of Floortime Training because of its emergent approach, while the third parent devalued the use of Floortime and supported more
structured and targeted forms of intervention, such as ABA. The parents who supported
the use of Floortime shared about their personal transformation in which they placed less
emphasis on academic achievement and more highly valued the development relational
skills, which is a view that is more in congruence with the purpose of Floortime.
Although Parent 3 did not directly state the importance of academic achievement over
relational skills, he/she assessed progress by considering behaviors that are relevant to an
academic context, such as sitting quietly and following directions. In fact, there were no
data that implied Parent 3 had undergone any sort of shift in his/her outlook that
facilitated his/her adjustment to having a child with an ASD. Of course, consideration
must be given to the prospect that sharing in one’s personal journey with the investigator
may not have been considered culturally appropriate by this parent, particularly given
what appeared to be his/her less acculturated status (Sue & Morishima, 1982; Tamura &
Lau, 1992).

As has been previously acknowledged, this study was neither designed to contrast
these 3 families to other families nor was acculturation directly assessed. Therefore, it
cannot be claimed that the thematic differences relevant to the use of Floortime observed
with these 3 families may not also be observed with other families, regardless of ethnicity
or acculturation level. Yet, there appears to be literature in the area of treatment
adherence, and treatment adherence specifically among Asian/Asian American families
and therapeutic styles, which allows for hypothesizing about the clinical implications of
the themes that emerged in regards to the social validity of Floortime for these families.

As was previously mentioned, acculturation differences might be argued to exist
for the 3 families who participated in the study, although not formally assessed, based on
exposure to American ideals early in one’s life and engagement in higher education in the U.S. that provided opportunities to become more acculturated. When taking these two factors into account, the division of families between those who may be viewed as more acculturated versus those who are not are aligned perfectly with the 2 parents who supported Floortime (the more acculturated) versus the parent who expressed a clear preference for the more structured ABA approach (the less acculturated). There is a body of literature that observes Asian clients prefer a more instructional, structured, and directive style of intervening (Arkoff et al., 1996; Atkinson et al., 1978; Atkinson & Matsushita, 1991; Chen, 1995; Exum & Lau, 1988; Ford, 1981; Ho, 1984; Kim et al., 2002; Li & Kim, 2004; Matsuoka, 1990a; Wang, 1994; Wexer, 1989; Yuen & Tinsley, 1981). Moreover, some argue that Asian clients may view their psychological state tied to the physical (mind-body), therefore, seek and expect relieve from their psychological symptoms as they would for medical conditions (Uba, 1994; Yu, 1998). Therefore, interventions that are less targeted and do not exhibit more immediate outcomes may be less attractive to Asian/Asian American parents, particularly those who are less acculturated. These generalizations, may, in fact, provide a context for understanding Parent 3’s preference for ABA over Floortime. It is important to note, though, that both parents who were strong Floortime Training advocates and who may be characterized as more acculturated recommended that they felt the intervention could be strengthened by developing specific goals toward which their child could work rather than relying strictly on the learning opportunities emerging from the experience itself. Hence, issues of acculturation, and factors such as education that may influence the acculturation process, may need to be taken into consideration in making decisions about appropriate
interventions. For example, if a parent immigrated to the U.S. as an adult and had little experience with the American culture prior to his/her arrival, one can likely assume that this parent may hold more traditional values and views than someone who has lived in the U.S. his/her entire life. In this case, an intervention that is considered more structured and academically oriented might be more congruent with the parents’ needs, particularly at the initial stages of their child’s treatment. Interventions such as Floortime can be introduced as the clinician observes the parents are developing a better understanding of the relational needs of their child. In the broader treatment adherence literature, this observation is rooted in the concept of social validity, i.e., the perception that the treatment goals, procedures, and outcomes are congruent with one’s needs (Kazdin, 1977; Wolf, 1978).

Finally, for the 2 parents who are proponents of Floortime Training, two themes emerged that have clinical implications for programs that offer this form of intervention. One issue had to do with the Floortime therapists who work with the families being trained to competence. In fact, the literature on treatment adherence does directly address this very issue (Albin et al., 1996; Detrich, 1999). Clinically, this observation has profound pragmatic implications for the families. Obviously, if those individuals working with the families are not themselves familiar with the theoretical basis of the intervention and its application, the families are being denied a potentially rich clinical opportunity. In fact, might Parent 3 have had a different experience if he/she worked with a therapist who could have knowledgeably educated the parent about the intervention and proficiently mentored him/her through the experience?
The second theme that emerged from both parents who supported the use of Floortime Training was the desire to integrate elements of the more structured interventions in the Floortime protocol. Specifically, they mentioned establishing specific, tangible goals the child can work toward rather than being an entirely emergent experience, so parents are clear about the direction of treatment and can more readily observe their child’s progress. In fact, it was this goal-oriented, structured approach of ABA that appealed to Parent 3. Again, since the data of these parents were not compared to the data of other families from diverse ethnic backgrounds, claims about the cultural basis for this recommendation cannot be made. On the other hand, although the literature on therapeutic style and Asian cultures is limited, what does exist may imply the importance of considering a cultural basis for the recommendation (Arkoff et al., 1966; Exum, & Lau, 1988; Ford, 1981; Ho, 1984; Wang, 1994).
Direction for Future Research

The clinically relevant hypotheses generated by this preliminary investigation imply the need to engage in a larger scale descriptive study of the cultural congruence of Floortime Training for Asian/Asian American families. In addition to providing much needed research on the use of interventions such as Floortime with Asian/Asian American families, a larger scale study would allow moving away from a pan-ethnic approach to one that is ethnic specific, which is clearly a limitation of the present study. Furthermore, acculturation should be directly assessed in such a study as it likely has considerable relevance when studying individuals who range from recent immigrants to generations in the United States.

Another issue that was not considered but potentially relevant to the study of the cultural relevance of Floortime Training, or any intervention for that matter, is the ethnic match between therapist and family as well as linguistic capabilities of the therapist. The literature indicates that ethnic minority clients faired better in treatment when the therapist and the client shared the same ethnicity and the therapist was capable of communicating with the client in his/her preferred language (Atkinson & Matsushita, 1991; Atkinson et al., 1998; Sue et al., 1991). This component of the therapist-client relationship may also play a role in sustaining the parents’ commitment to the use of Floortime.

In addition to the ethnic match between therapist and family, further research is necessary to examine the potential interaction of other therapist characteristics with the characteristics of families. For example, many of the therapists employed by the agency are women in their late 20s to early 30s who do not have children themselves. Might
these particular attributes influenced whether the parents viewed the therapist as credible, experienced, and adequately trained?

Lastly, more research must be conducted with the family system and its subsystems. For example, this study did not take into account the siblings of the child diagnosed with an ASD and how these siblings cope with the challenges their family faces. Moreover, how do the parents cope with the challenges they face on a day-to-day basis, how do they decide on the division of household responsibilities, and how are they relating to one another? These are important questions for which we need answers in order to provide optimal service to these families.

**Conclusion**

From the themes that emerged from this study, it is suggested that clinicians working with Asian/Asian American parents take into consideration the following recommendations:

1. Asian/Asian American parents, like all parents faced with a child diagnosed with an ASD, require time to come to terms with their child’s condition, elect to take actions to cope with the situation, and share similar experiences in the process of adjusting to their child’s needs.

2. Despite the universal need to help parents accept and cope with their child’s condition, clinicians should be mindful of culturally rooted beliefs, values, and attitudes that may contribute to a protracted adjustment period for Asian/Asian American families.
3. When assessing families’ adherence to treatment interventions, clinicians should be aware of the parents’ acculturation and education levels as these factors may potentially serve as cultural indicators for the appropriateness of particular interventions for the child and family.

4. Flexibility should be exercised in the implementation of Floortime Training so that adaptations that offer stronger social validity to culturally diverse populations are considered a welcomed practice rather than a breach of treatment fidelity.

Despite the preliminary nature of this study, the results raise some potentially useful clinical information about how Asian/Asian American parents might cope with the knowledge of having a child with an ASD and how they perceive the use of Floortime Training to treat their child. The literature on parental adherence to treatment considers a number of issues in trying to understand why families may or may not elect to remain on their treatment course, including the concepts of the client’s readiness for change and the social validity of the intervention. This study provides a culturally rooted illustration of both of these concepts. The finding related to acceptance of and coping with the knowledge of the child’s ASD may influence the development of the family towards preparing themselves for change. While it appears the social validity of the intervention might be among the more important factors when conceptualizing a family’s needs from a multicultural framework, as the perceived value of a proposed intervention appears mediated by one’s sociocultural context.
References


Appendix A

Interview Protocol
Interview Protocol

Introduction to interview:

Okay. Let’s begin our interview. I want to remind you now that I will be taping the interview. I also want to remind you that if I ask a question that you do not wish to answer, please let me know and we will move on.

Do you have any questions before we begin?

Demographic Information

I would like to begin by asking some questions so that I can obtain some background information about you and your family.

1. How old is your child?

2. What is your child’s gender?

3. Is (child’s name) your biological child?
   a. If “no,” ask: Is he/she your stepchild? An adopted child?

4. What is your marital status?

5. How old are you? (If two-parent household, ask: And how old is [insert other parent’s name]?)

6. Were you born in the U.S.? (If two-parent household, ask: And was [insert other parent’s name] born in the U.S.?)
   a. If “no,” ask: In what country were you born? (If relevant, ask: And [insert other parent’s name]?)

7. Was your child born in the U.S.?
   a. If “no,” ask: Where was your child born?

8. Do you have other children?
   a. If “yes,” ask: How many? What are their ages, gender, and do they live at home with you?

9. What is your ethnicity? (If two-parent household, ask: And the ethnicity of [insert other parent’s name]?)
10. What is the highest grade in school that you have completed? (If two-parent household, ask: And the highest grade completed by [insert other parent’s name]?)
   a. If not born in the U.S., ask: Did you complete school in the country in which you were born? (If relevant, ask: And [insert other parent’s name]?)

11. What is your occupation? (If two-parent household, ask: And [insert other parent’s name]?)

I. Parents’ Views, Understanding, and Coping Strategies

I want to now ask you some questions about your child and his/her diagnosis.

12. What prompted you to seek help for your child?
   a. Who did you see for help?
   b. What did the person tell you about your child’s problems?

13. When was your child diagnosed with an ASD?

14. Had you heard about ASD before your child was diagnosed with it?

15. If someone were to ask you to explain what was going on with your child, what would you tell the person?

16. How would you describe your first reaction to hearing of your child’s ASD diagnosis?

17. Has your life changed since your child was diagnosed with an ASD?
   If answers “Yes”, ask:
   a. In what ways has your life changed?
   b. Can you give me an example of how life was and how it is today?
   c. What stayed the same since the diagnosis?

II. Prior Treatments

I want to now ask you some questions about the sorts of help your child has received.

18. What other type of things did you try prior to Floortime Training?
If had prior treatment experiences, ask the following for each of type of treatment:

a. What was [insert type of treatment] like?

b. Why are you not using [insert type of treatment] any longer?

III. Utilization of Floortime and Experience with It

Okay. Now I want to ask you about your decision to get services from Verdugo.

19. Why did you decide to try Floortime Training?

20. How long have you participated in Floortime Training?

21. If someone were to ask you to describe what Floortime Training is, what would you tell the person?

22. How would you describe your experience with using Floortime Training?

IV. Floortime Benefits

Now, I’m going to ask you questions about how you and your family have benefited from receiving Floortime Training.

23. What changes, if any, have you seen in your child since he/she began Floortime Training?

24. What changes, if any, have others in the family seen in your child since he/she began Floortime Training?

25. What changes, if any, have others outside the family seen in your child since he/she began Floortime Training?

26. What do you like about using Floortime Training with your child?

27. Would you recommend Floortime Training to other parents of ASD children?

   If says would recommend, ask:

   a. Why would you recommend Floortime Training to other parents?

   If says would not recommend, ask:

   a. Why would you not recommend Floortime Training to other parents?
V. Floortime Improvements

Okay, now I’m going to ask you a question about how you would suggest Floortime Training might be improved.

28. If you could change some things about your Floortime Training experience, what would you change?

Ending interview:

I think that I have asked all the questions I need for my project. Do you have any questions for me, or do you have some additional information you feel I should know that I did not ask you about?

I want to thank you very much for helping me with my project. I am most grateful that you accepted my invitation to participate in this project. As a small token of my appreciation, I would like give your family a $30 gift card to Barnes and Noble. If you are interested in receiving a summary of the study findings, please complete this Summary Request Form and I will send you a copy after my study is completed. Please understand that it may take about 12 months or so before I can send you the summary.

If you think of any question after I leave, you may call me at the number on the consent form. Again, thank you very much for your time and support of my research project.
Appendix B

Verdugo Hills Autism Project Director’s Approval for Dissertation Project
To Whom It May Concern:

As the Clinical Director of Verdugo Hills Autism Project, I am authorizing Thao Trinh, M.A., to conduct her research project with the families to whom we offer services. I have been informed of the purpose of the study and I offer my approval.

Sincerely,

Deryl Goldenberg, Ph.D.
Clinical Director
Appendix C

Recruitment Brochure
WHAT IF I HAVE QUESTIONS?
If you are interested in finding out more about the study or have questions, please do not hesitate to contact me. The following is my contact information.

Thao P. Trinh, M.A.
Pepperdine University
Graduate School of Education and Psychology
6100 Center Drive
Los Angeles, CA 90045
(818) 602-1182
Thao.Trinh@pepperdine.edu

You may also contact Dr. Asamen who supervises my research project. Below is her contact information.

Joy Asamen, Ph.D.
Pepperdine University
Graduate School of Education and Psychology
6100 Center Drive
Los Angeles, CA 90045
(310) 568-5654
joy.asamen@pepperdine.edu

IMPORTANT INFORMATION

Participation is strictly voluntary. Your decision to participate in the study in NO way affects your relationship with Verdugo Hills Autism Project.

If you are interested in participating, please contact Thao Trinh for more information at
(818) 602-1182

Pepperdine University
Graduate School of Education and Psychology

ASIAN/ASIAN AMERICAN PARENTS AND THEIR EXPERIENCE WITH FLOORTIME TRAINING

Volunteers Are Needed to Participate in a Research Study
WHO IS CONDUCTING THE STUDY?

My name is Thao Trinh, and I am a doctoral student in clinical psychology at Pepperdine University, Graduate School of Education and Psychology.

I am completing a research project to help me understand the experience of Asian/Asian American parents whose children are receiving Floortime Training.

My research project is being supervised by Joy Asamen, Ph.D., Professor of Psychology.

WHAT IS THE STUDY?

In the field of psychology, we know very little about how different cultural groups benefit from the treatments typically offered to families with children diagnosed with Autism Spectrum Disorder. We do know that treatments for other diagnostic groups have required adaptations to more fully meet the needs of individuals from different cultural backgrounds. I am specifically interested in finding out more about how Asian/Asian American parents feel their child has benefited from using Floortime Training as well as hearing their suggestions for improving the experience.

WHO CAN PARTICIPATE?

To participate in the study, you must be:

- An Asian/Asian American parent who is closely involved in your child’s use of Floortime Training.
- The parent of a child who has been diagnosed with an Autism Spectrum Disorder.
- Receiving Floortime Training at Verdugo Hills Autism Project for at least 6 months.

Furthermore, your child should have no history of a seizure disorder or serious head trauma that required hospitalization and/or ongoing treatment.

WHAT IS INVOLVED?

If you decide to volunteer for the study, you will be asked to participate in an audiotaped interview that may take 1-2 hours to complete.

The interview will be scheduled at a time that works best for you and it can be conducted in your home to make it more convenient.

The interview will include questions about your experience with using Floortime Training. I will also ask questions about your child’s progress in the program and prior treatment experiences as well as how your family has coped with your child’s needs. I will also request some information that describes your family such as the gender and ages of family members.

To show my appreciation for your participation in the study, each family will receive a $30 gift card to Barnes and Nobles at the completion of the interview.
Appendix D

Telephone Screening Interview
Telephone Screening Interview

Hello. Thank you for calling me about the project. Let me tell you more about it so that you can decide whether you would like to participate. Will this be okay with you?

(If yes, continue, if no, say: Thank you for calling. If you change your mind, please feel free to call me again. Bye.)

In the field of psychology, we know very little about how different cultural groups benefit from the treatments typically offered to families with children diagnosed with an Autism Spectrum Disorder. We do know that treatments for other diagnostic groups have required adaptations to more fully meet the needs of individuals from different cultural backgrounds. I am specifically interested in finding out more about how Asian/Asian American families benefit from using Floortime Training as well as hearing their suggestions for improving their experience with using this treatment at Verdugo. Our talk will take about 1-2 hours.

Do you have any questions? Do you think this is something that you might be interested in doing?

(If yes, continue, if no, say: Thank you for calling and taking the time to hear more about my project. If you change your mind, please feel free to call me again. Bye.)

Okay, what I would like to do next is read you a list of statements. Please respond yes or no to each item. Do you have any questions?

1. I have at least one child who has been diagnosed with an Autism Spectrum Disorder.
2. I am currently receiving Floortime Training from Verdugo.
3. My child has been in the program for at least 6 months.
4. I am Asian/Asian American.
5. I am closely involved with my child’s use of Floortime Training.
6. My child has not been diagnosed with a seizure disorder or any serious head trauma that required hospitalization and/or ongoing treatment.

(If meets eligibility, continue, if does not meet eligibility, say: Thank you for taking the time to call and find out more about my project. Unfortunately, I can only include families in my project who meet all of the requirements that I just listed. Do you have any further questions? Again, thank you very much for your interest. Bye.)

It seems that you meet all of the requirements for participation. If it is okay with you, I would like to set up an appointment so we can meet and talk about the things that I mentioned earlier. Will this be okay?

(If yes, continue, if no, say: Thank you for calling and taking the time to hear more about my project. If you change your mind, please feel free to call me again. Bye.)
What would be a good day and time to meet?

I also need to confirm if it’s okay to conduct the interview in your home. As I already mentioned, it will take 1-2 hours to complete our talk. If we do meet in your home, it is important that we have a private place to talk. It is particularly important that your child/children do not overhear our conversation. Will meeting at your home work best for you?

(If yes, go ahead and schedule, if no, say the following: Another choice is to reserve a private study room at the public library that is closest to your home. Would this arrangement work better for you?)

Just to let you know, if your child’s father/mother is also Asian/Asian American and closely involved in your child’s use of Floortime Training, he/she may join us for the interview.

Okay, I would like your permission to send you a form that gives even more details about the project and your rights as a participant in my project before we meet. Please read the form before we meet, but do not sign it. When we meet, I am required to review the form with you in more detail. Is it possible for me to get your mailing address?

(If yes, continue, if no, say: Thank you for calling and taking the time to hear more about my project. If you change your mind, please feel free to call me again. Bye.)

________________________________   ________________________
Name of participant      Date of phone screen
______________________________________________________________________
Address

____________________________
Phone Number

______________________________________________________________________
Meeting Date/Time/Location

Thank you very much for agreeing to participate in my project. I look forward to seeing you on (insert date of interview). If you have any questions or concerns, just call me at the number on the consent form. If after reviewing the form you decide not to participate and wish to cancel our appointment, you can leave me a message at the same number. I want to thank you, again, for your interest in my project. Bye.
Appendix E

Informed Consent Form
Informed Consent for Participation in Research Activities

I, __________________________, authorize Thao Trinh, M.A., a doctoral student in clinical psychology at Pepperdine University, Graduate School of Education and Psychology, under the supervision of Joy K. Asamen, Ph.D., to include me in the research project entitled “Asian/Asian American Parents and Their Experience with Floortime Training.”

I understand my participation in this study is strictly voluntary. I understand that I have the right to refuse to participate in, or to withdraw from, the study at any time. My decision to participate or not will not affect the services that I already receive or will receive in the future at the Verdugo Hills Autism Project. I also have the right to refuse to answer any questions I choose not to answer.

I have been invited to participate in this study since I am an Asian/Asian American with a son/daughter who has been diagnosed with an Autism Spectrum Disorder (ASD). The research project in which I have been asked to participate is interested in exploring how Asian/Asian American parents experience Floortime Training as a treatment for their child’s ASD symptoms. The study is also interested in finding out more about how Asian/Asian American parents view and understand their child’s difficulties and ways they have coped with the challenges of raising a child diagnosed with an ASD. I will also be asked questions about the ways Floortime Training has been helpful to my son/daughter as well as ways the experience can be improved. The interview will take place in my home unless I prefer to be interviewed in a private study room at the public library nearest my home. I understand that the interview will be audiotaped and will take about 1-2 hours to complete. The audiotapes of the interviews will be written out word for word after the interview is over. I also understand that I may be contacted, again, by the researcher to answer additional questions that will help her clarify some of the things I said during our initial meeting.

While all attempts will be made to minimize any risks, by participating in this project, I may feel uncomfortable during portions of the interview that deal with personal issues related to my family’s experience. In the event I do experience any discomfort, the researcher will be available to discuss my feelings with me. I also have been provided with a list of referrals should I need further assistance after the interview. I am always welcome to request a break if I feel a need for one. As previously mentioned, I also have the right to discontinue my study participation. I also understand that there might be times that the researcher may find it necessary to end my study participation if she believes it is in my best interest.

I understand that there is no direct benefit from my participation in this project. However, the field of psychology may potentially benefit from hearing the experiences of Asian/Asian American parents who are raising a child diagnosed with an Autism Spectrum Disorder and who are seeking Floortime Training to help their child. Of particular value might be finding out more about how culture may influence the treatments used to help children diagnosed with an ASD.
I understand the Verdugo Hills Autism Project staff members who have worked with my family or will work with my family in the future, including therapists, case supervisors, and directors, will not be told about my participation in the project, unless I decide to tell them myself. I understand that no information from the interview will be released to others without my permission, unless such a disclosure is required by law. Under California law, confidentiality does not extend to information about the alleged or probable abuse of a child, the physical abuse of an elder or dependent adult, or if a person indicates she or he wishes to do serious harm to self, others, or property. If there is suspected abuse of a child, abuse of an elder or dependent adult, or if you communicate the desire to inflict serious harm to yourself, to someone else, or to someone’s property, I will be required to make a report to the proper authority.

I understand that the researcher will provide a summary of the study findings to the Verdugo Hills Autism Project clinical director. When the summary is provided to the clinical director, information that can identify me or my child will not be included and he will not be told that I participated in the study. If the findings of the study are published or presented to a professional audience, no personally identifying information, such as my name, will be released. The interview tapes and the written copies of the interviews will be stored for at least 3 years in a locked cabinet to which only the researcher will have access. When the data are no longer required for research purposes, these materials will be destroyed.

As a token of the researcher’s gratitude for helping her with the study, I understand that I will receive a $30 gift card to Barnes and Noble. I may also request a summary of the study findings by completing the Summary Request Form.

I understand that if I have any questions regarding the study procedures, I can contact Thao Trinh at 818-602-1182 or thao.trinh@pepperdine.edu to get answers to my questions. If I have further questions, I may contact Joy K. Asamen, Ph.D., at Pepperdine University, Graduate School of Education and Psychology, 6100 Center Drive, Los Angels, CA 90045, (310) 568-5654, joy.asamen@pepperdine.edu. If I have further questions about my rights as a research participant, I may contact Stephanie Woo, Ph.D., Chairperson of the Graduate and Professional Schools Institutional Review Board, Pepperdine University, Graduate School of Education and Psychology, 24255 Pacific Coast Highway, Malibu, CA 90263-4068, (310) 258-2845, stephanie.woo@pepperdine.edu.

I understand, to my satisfaction, the information in the consent form regarding my participation in the research project. All of my questions have been answered to my satisfaction. I have received a copy of this informed consent form, which I have read and understand. I hereby consent to participate in the research described above.

___________________________
Name of Participant (please print)
I have explained and defined in detail the research procedures in which the participant has consented to participate. Having explained this and answered any questions, I am co-signing this form and accepting this person’s consent.
Appendix F

Script for Obtaining Informed Consent
Hello. I want to thank you for your interest in participating in my dissertation project, which is called “Asian/Asian American Parents and Their Experience with Floortime Training.”

I would like to review the informed consent form with you at this time. I would like to review it and highlight some important things for you to consider before you decide on whether you want to continue with the interview or not. If at any time you decide not to participate, do not hesitate to let me know. Do you have any questions before we review the consent form?

The first paragraph lets you know that I am currently a doctoral student at Pepperdine University in the clinical psychology program. One of my professors, Dr. Joy Asamen, is supervising my research.

The second paragraph has some important information. It is important for you to know that your participation today is strictly voluntary. In other words, it is completely your choice as to whether you decide to participate in the interview. Your decision will not affect the services that you already receive or will receive in the future at the Verdugo Hills Autism Project. If you decide to continue with the interview, you do not have to answer any questions that you do not want to answer. You can also stop participating at any time, if you so choose. In other words, there are no consequences for choosing not to participate or not continuing to participate. Whatever you decide to do is your choice and your choice alone. Do you have any questions so far?

OK, so now I am going to talk about the third paragraph, which invites you to participate in an interview that will ask you about your child’s experience with an Autism Spectrum disorder as well as Floortime Training and that the interview will be audiotaped. The interview should take between 1-2 hours to complete. Do you have any questions about what kinds of questions you will be asked?

The fourth paragraph tells you more about any potential risks that may be experienced. Because I am asking you about your experience with your child and the treatments he/she has been receiving, some of the questions may cause you to feel uneasy. If this should happen, please feel free to speak with me during this session or contact either myself or Dr. Asamen if you wish to talk after I leave here. In addition, I have provided you with a list of referrals should you need further assistance after the interview. Do you have any questions about the possible risks that are involved or about the questions in the interview?

Next is some information about the potential benefit. Although you will not directly benefit from participating in this interview, my hope is that it will provide psychologists with information about how effective Floortime Training may be for Asian/Asian American families as well as find ways to improve the experience.
In the sixth paragraph, I am describing how the audiotapes and written documents of the interview will be treated in a confidential manner. In other words, your child’s therapy team will not be told that you are participating in this project and no information about you will be told to others without your permission. Although the information collected today is treated confidentially there are some exceptions. Under California law, I am required to make a report to the proper authority if there is the suspected abuse of a child, abuse of an elder or dependent adult, or if you wish to inflict serious harm to yourself, to someone else, or to someone’s property. Do you have any questions about how I will protect your privacy?

The next paragraph further describes how I will protect your privacy. I will not put your name on the audiotapes or transcriptions of the interview. Without your name appearing on these items, no one will ever know which belongs to you. The informed consent form and the interview transcript will be kept separately from each other for at least 3 years in a locked cabinet to which only the researcher will have access.

The eighth paragraph informs you that I will offer a $30 gift card as a small token of my appreciation for your participation in my project. And if you are interested, you can also request a summary of the study findings.

If you have any questions about the study, in paragraph 9, I have provided information on how I can be contacted. You can also contact Dr. Asamen about my study, if you prefer. If you have any questions concerning your rights as a participant in my survey, please contact Dr. Woo, who is the Chairperson of the Graduate and Professional Schools Institutional Review Board at Pepperdine.

Are there any questions or comments about the information that I just reviewed with you? If you have decided to go ahead and participate in the interview, please sign and date two copies of the consent form (point to where on form participant should sign/date). One of the copies is for you to keep and I will keep the second copy. However, if you have decided that you are no longer interested in participating in the interview, I want to thank you taking the time to meet with me and find out more about my project. I hope that I have not inconvenienced you.
Appendix G

List of Referrals
Referral List

As parents of a child with ASD, if you would like to seek additional support, below is a partial list of resources available in your community.

1. Foothill Autism Alliance
   Pasadena: (818) 662-8847

2. Pacific Clinics
   Rosemead: Asian Pacific Family Center (626) 287-2988
   El Monte: (626) 433-1316

3. Verdugo Mental Health Center (Glendale)
   818-244-7257
Appendix H

Summary Request Form
Summary Request Form

I would like to receive a summary of the study findings once it is completed.

Please send the summary to the following address.

____________________________________________________________________
Name

____________________________________________________________________
Address

____________________________________________________________________
City                  State                  Zip Code

Please note the summary may not be available for another 12 months.
Appendix I

Results of Domain and Taxonomic Analyses
### Case 1

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
<th>Semantic Relationship</th>
<th>Master Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>I didn’t think anything of it (referring to her child’s behaviors which resemble the behaviors of her friend’s child)</td>
<td>Is a kind of (Strict Inclusion)</td>
<td>Denial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I didn’t get [I didn’t want to get] what she was telling me (referring to friend hinting that there are possible behavioral concerns)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well, [child] can’t be autistic because [child] was affectionate.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[My child]’ll be ok because her [child] is ok (“her [child]” refers to friend’s child who has similar problems)</td>
<td>Is a kind of (Strict Inclusion)</td>
<td>Minimization</td>
<td>Is a way to (Means-end)</td>
<td>Cope with child’s ASD</td>
</tr>
<tr>
<td>It was probably some kind of weird speech/exotic speech problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We’ll work on it and [child]’ll be ok</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>{Friend’s child] spoke (so she assumed her child would speak)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maybe [child]’ll be a savant</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Read</strong> all this stuff</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Asked</strong> a lot of <strong>questions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I did <strong>meet other parents</strong> [who linked her to treatment resources]…that is invaluable</td>
<td></td>
<td></td>
<td>Improve knowledge of disorder</td>
<td></td>
</tr>
<tr>
<td>A <strong>friend</strong> of mine…told me about the Regional Center</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Get information from the <strong>Internet</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stunned</td>
<td>Is a result of (Cause-effect)</td>
<td>Facing reality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Was there a cure?”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Devastated</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>[Individual] Therapy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Couple’s therapy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

145
- Another **mutual friend** told my friend “You need to say something”

- We have a lot of **humor**
  - Perspective you know, **perspective** and **humor** are key
  - We have **jokes** with each other
  - **Friends** in the church
  - **My Christian faith**

- Much **more compassion** and **empathy** for parents
  - Learned a lot about **patience**…how much I have and how much I don’t have
  - **Re-prioritize** and **reframe** what’s important
  - Learn to **let things go**

- **Grades** and everything were **important**
  - Just **achievement** was **important**
  - I went to **college** [thinking that the children would also]
  - Classic Chinese **overachieving** student [not so now]
  - **Friendships** and **people skills** are much **more important** than academic achievement
  - **Achievement** was important [It’s **no longer important**]

- I **drove** [child] **everywhere**
  - It was **really busy**
  - **Life** has **changed**
  - I have **not worked** since [child] was 1

- Wasn’t talking
  - Wasn’t saying words
  - Avoid eye contact
  - Look at the lights in the hallway for 20 times

- [Child] **does not get it** [DTT]
  - [Child] **does not care** about it [DTT]
  - **Painful** to watch it [child being taught via DTT]
  - It [DTT] was just **bad**

---

<table>
<thead>
<tr>
<th>Another mutual friend told my friend “You need to say something”</th>
<th>Is a way to (Means-end)</th>
<th>(Have) a positive outlook</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have a lot of humor</td>
<td>Is a kind of (Strict Inclusion)</td>
<td>Change in outlook on life</td>
</tr>
<tr>
<td>My Christian faith</td>
<td>Is a kind of (Strict Inclusion)</td>
<td>Priority shifts</td>
</tr>
<tr>
<td>Much more compassion and empathy for parents</td>
<td>Is a kind of (Strict Inclusion)</td>
<td>Life adjustments</td>
</tr>
<tr>
<td>Re-prioritize and reframe what’s important</td>
<td>Is a result of (Cause-effect)</td>
<td>Exclusively attending to child’s needs</td>
</tr>
<tr>
<td>Achievement was important</td>
<td>Is a kind of (Strict inclusion)</td>
<td>ASD symptom</td>
</tr>
<tr>
<td>Did you work since child was 1</td>
<td>Is a kind of (Strict inclusion)</td>
<td>Using FT</td>
</tr>
<tr>
<td>Wasn’t talking</td>
<td>Is a reason for (Rationale)</td>
<td></td>
</tr>
<tr>
<td>It [DTT] was just <strong>awful</strong></td>
<td>Is a kind of (Strict inclusion)</td>
<td>Positive reaction(s) to FT</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>I was <strong>upset</strong>...really upset</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It [DTT] didn’t feel natural</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It was a <strong>better fit</strong> for us</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FT <strong>made sense</strong> to me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The more I understood developmental disability, the more I understood that relationships were important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It was much <strong>more effective</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It <strong>looks different</strong> with different kids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is <strong>very individual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relating</strong> to the child</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Figuring</strong> out their needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meeting them where they’re at and then expanding on it</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Look at</strong> your child’s <strong>strengths</strong> and weaknessess</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Building up</strong> the weaknesses by using the strengths</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Look at the</strong> needs of the family</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Expect [parents] to be involved</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afford more <strong>opportunities</strong> to have input in the program</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Pre-school</strong> he went to was <strong>developmentally based</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Diagnosed by</strong> a person at the Regional Center who was a big <strong>supporter</strong> of FT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We knew C.S. (Agency FT trainer/expert who provides training to parents and Agency therapists)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>I went to a conference</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. came and <strong>trained</strong> me and my husband at home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We did the <strong>FT training</strong> with the Regional Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stanley Greenspan showed videos of his coaching</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know what [child] likes [by [child] letting me know]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Child] tries to <strong>recreate</strong> all these pleasurable experiences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Child] <strong>initiates</strong>...games</td>
<td>Is a way to (Means-end)</td>
<td>Gain(ing) appreciation for FT</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Advantage(s) of FT</strong></th>
<th>Is a kind of (Strict inclusion)</th>
<th>FT advocacy</th>
</tr>
</thead>
</table>

| **Parent-reported positive behavioral change** | Is a kind of (Strict inclusion) | Parent-reported positive behavioral change |
- [Child] experiences a wider range of emotions, e.g., [child] used to [just] scream or laugh
- There’s more subtle differences in [child’s] emotions
- [Child] is remorseful…shows remorse
- [Child] talks more
- [Child’s] compliant
- [Child] follows directions

<table>
<thead>
<tr>
<th>[Child] complies</th>
<th>[Child] sits and listens</th>
<th>[Child] talks more</th>
<th>[Child’s] compliant</th>
<th>[Child] follows directions</th>
</tr>
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<td>[Child] talks more</td>
<td>[Child’s] compliant</td>
<td>[Child] follows directions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Less novice therapists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t follow the child’s lead without an agenda [like when parent used ABA]</td>
</tr>
<tr>
<td>Training was not as good as I would have liked</td>
</tr>
</tbody>
</table>

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<tbody>
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</tbody>
</table>

| \[ABA\] uses semi-structured activities |
|-----------------------------|-----------------------------|-----------------------------|
| \[ABA\] always have to have an agenda |
| \[ABA\] have goals [for the child to reach] |

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|-----------------------------|-----------------------------|-----------------------------|
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| \[ABA\] have goals [for the child to reach] |

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| \[ABA\] have goals [for the child to reach] |

| \[ABA\] uses semi-structured activities |
|-----------------------------|-----------------------------|-----------------------------|
| \[ABA\] always have to have an agenda |
| \[ABA\] have goals [for the child to reach] |
Case 2

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
<th>Semantic Relationship</th>
<th>Master Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Asking, “Are you sure?”</td>
<td>Is a kind of</td>
<td>Denial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• I didn’t think it was true</td>
<td>(Strict Inclusion)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• [Child] seemed ok</td>
<td>Is a kind of</td>
<td>Minimization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• I think [child] had good eye contact even though you [to husband] didn’t</td>
<td>(Strict Inclusion)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Talking to <strong>people who</strong> already <strong>know</strong> about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• <strong>Online</strong> research</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• From <strong>other parents</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• <strong>Parent Center</strong> at Regional Center</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Speak to an <strong>advocate</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• I was in a <strong>Mommy and Me group</strong></td>
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</tr>
<tr>
<td>• [We joined a] <strong>Yahoo group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Resources like <strong>books</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We <strong>told everyone</strong> [child] has autism</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Now we know the name, we can get all the services we want</td>
<td>Is a result of</td>
<td>Faceing reality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We were <strong>determined to do</strong> the <strong>best</strong> we could</td>
<td>(Cause-effect)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• It’s not gonna stop us</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Life didn’t stop</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Seeing other kids that had [child’s behaviors]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• The <strong>more I learned</strong> about autism the more I saw that [child] fit the</td>
<td>Is used for</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• I made a lot of <strong>friends</strong> [who understood autism and offered support]</td>
<td>(Function)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We still take [child] everywhere [just as we would if (child) did not have</td>
<td>Is a way to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We have other kids to worry about [we can’t let the</td>
<td>(Means-end)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: The terms and relationships are illustrative and may not reflect actual clinical or therapeutic practices.
<table>
<thead>
<tr>
<th>Diagnosis slow the family down</th>
<th>They [the other children] need to have normal social interactions [we can’t only focus on (child) with an ASD and ignore the other children]</th>
<th>Is a kind of (Strict Inclusion)</th>
<th>Change in outlook on life</th>
</tr>
</thead>
<tbody>
<tr>
<td>• I don’t need [child] to be at a certain level of accomplishment [like I expected before]</td>
<td>• We were ready [to accept] … that [child] would be with us [that we would have to take care of (child)] for the rest of [child’s] life</td>
<td>• Is a kind of (Strict Inclusion)</td>
<td>• Priority shifts</td>
</tr>
<tr>
<td>• I have no expectation for [child] to be a certain…education level [like I used to have]</td>
<td>• At the end of the day, it’s your <strong>people skills</strong> [rather than grades that are important]</td>
<td>• My mom said if you’re earning an A then you’re doing your job…but that’s not how life is</td>
<td>• Presentation and <strong>relationships</strong> you have with your peers [are important]</td>
</tr>
<tr>
<td>• I <strong>didn’t work</strong></td>
<td>• We <strong>didn’t have</strong> as much <strong>money</strong></td>
<td>• We just take [child] to a lot of <strong>therapy</strong></td>
<td>• I was driving [child] around [a lot]</td>
</tr>
<tr>
<td>• Scared of the world</td>
<td>• <strong>Cried</strong> a lot</td>
<td>• <strong>Didn’t look</strong> in the face</td>
<td>• Didn’t have good eye contact</td>
</tr>
<tr>
<td>• Clinged onto me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• That [Gluten-free casein-free diet] was like nothing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We <strong>didn’t think it</strong> [Gluten-free casein-free diet] really worked</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We knew it [Gluten-free casein-free diet] was voodoo stuff</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• FT cures the core of the issue</th>
</tr>
</thead>
<tbody>
<tr>
<td>• It’s <strong>better to teach a child how to learn</strong> than to cram the knowledge into the brain like discrete trials does</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• Play-based</th>
</tr>
</thead>
<tbody>
<tr>
<td>• <strong>Child-led stimulation</strong> method to entice the child to <strong>learn</strong> the circle of communication</td>
</tr>
<tr>
<td>• <strong>Follow</strong> what the child is interested in</td>
</tr>
<tr>
<td>• <strong>Expand</strong> it [play or interaction] out to what you want the child to learn</td>
</tr>
<tr>
<td>• <strong>Teach</strong> the child <strong>how to learn</strong> and <strong>how to play</strong> based on what child is learning and playing at the moment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• C.S. (Agency FT trainer/expert who provide trainings for parents and FT therapists) convinced me FT is the right thing for [child]</th>
</tr>
</thead>
<tbody>
<tr>
<td>• A <strong>teacher</strong> told me…FT is useless unless you have C.S. [to provide training]</td>
</tr>
<tr>
<td>• The preschool [older sibling] attended was a big advocate of child-led education</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• The Regional Center had trainings we went to</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Watching C. work with [child]</td>
</tr>
<tr>
<td>• C. trained me and (husband) to interact with [child]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• [Child] didn’t talk much before FT</th>
</tr>
</thead>
<tbody>
<tr>
<td>• [Child’s] <strong>sociable</strong></td>
</tr>
<tr>
<td>• [Child’s] <strong>mainstreamed</strong></td>
</tr>
<tr>
<td>• [Child’s] <strong>more recovered</strong></td>
</tr>
<tr>
<td>• [Child] really seems to <strong>enjoy and understands</strong> what</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• Is a kind of (Strict inclusion)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Negative reaction(s) to other treatments</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• Is a kind of (Strict inclusion)</th>
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</thead>
<tbody>
<tr>
<td>• Positive reaction(s) to FT</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• Is a kind of (Strict inclusion)</th>
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</thead>
<tbody>
<tr>
<td>• Advantage(s) of FT</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• Is a way to (Means-end)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Gain(ing) appreciation for FT</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>• Is a kind of (Strict inclusion)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Parent-reported positive behavioral change</td>
</tr>
<tr>
<td>[child’s] supposed to do [within the training context] and why</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>• Everyone thinks [child’s] fine</td>
</tr>
<tr>
<td>• They think it’s a misdiagnosis</td>
</tr>
<tr>
<td>• [Child] blossomed</td>
</tr>
<tr>
<td>• [Child] grew out of it</td>
</tr>
<tr>
<td>• It might not be as quantifiable</td>
</tr>
<tr>
<td>• Nor does it happen quickly</td>
</tr>
<tr>
<td>• There was this one [FT therapist], maybe [therapist’s] really good now (therapist was not good then), but [my child] was [therapist’s] first client</td>
</tr>
<tr>
<td>• I think FT has a bad name because it’s not properly implemented by a lot of people who don’t have enough training</td>
</tr>
<tr>
<td>• [Child] would have made improvements faster if C. was more available</td>
</tr>
<tr>
<td>• When [FT therapist] was sitting in our case meeting…it (therapist’s level of analysis of child’s current issues) was a whole different level (i.e., one that lacks C.’s expertise)</td>
</tr>
<tr>
<td>• More supervision [of therapists]</td>
</tr>
<tr>
<td>• More expertise in the home (referring to more intensive training of parents)</td>
</tr>
<tr>
<td>• C.…spend more time shadowing people (meaning therapists who are being trained)</td>
</tr>
<tr>
<td>• More training for those (meaning therapists) who don’t have enough</td>
</tr>
<tr>
<td>• Train more trainers [so more families can access FT]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Is a kind of (Strict inclusion)</th>
<th>Other-reported positive behavioral change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is a kind of (Strict inclusion)</td>
<td>Criticism(s) of FT training</td>
</tr>
<tr>
<td>Is a way to (Means-end)</td>
<td>Improve FT experience</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>[Presumed by parent although had no experience using DTT]</th>
</tr>
</thead>
<tbody>
<tr>
<td>• [DTT] has more solid goals</td>
</tr>
<tr>
<td>• [DTT can] teach a child to do many things and it can happen quickly</td>
</tr>
<tr>
<td>• It [DTT] is quantifiable</td>
</tr>
</tbody>
</table>

| Is a kind of (Strict inclusion) | (Knowing about) Positive reaction(s) to other treatments |
### Case 3

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
<th>Semantic Relationship</th>
<th>Master Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>• I did not think there was anything wrong with [child]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We never had this in our family (i.e., I don’t believe [child] really has it)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We had our [other child] too and [that child] was fine</td>
<td>Is a kind of (Strict Inclusion)</td>
<td>Denial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• thinking that child with an ASD would also be fine</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• My [other child] is fine so I don’t know this was happening with [child with an ASD]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• I had never heard of it [ASD] before (i.e., I don’t believe it exists since I’ve never heard of it)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• I thought [child] would be ok after a while</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• [Child] was [only] having a hard time learning to talk</td>
<td>Is a kind of (Strict Inclusion)</td>
<td>Minimization</td>
<td></td>
<td>Cope with child’s ASD</td>
</tr>
<tr>
<td>• rather than a more serious problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• We were going to get [child] help to learn to talk [but we didn’t think (child) needed more intensive interventions]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• [Child’s] a late starter</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• The doctor told us what autism was about</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• The Regional Center helped us with the big book of resources</td>
<td>Is a way to (Means-end)</td>
<td>Improve knowledge of disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• It was strange</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• It was very new</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• I was surprised</td>
<td>Is a result of (Cause-effect)</td>
<td>Facing reality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• [Pediatrician] told us something was going on with [child]</td>
<td>Is used for (Function)</td>
<td></td>
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<tr>
<td>• Our friends told us to listen to the doctors</td>
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<tr>
<td>• We did what they [doctors] told us we needed to do [to remain hopeful about the situation ]</td>
<td>Is a way to (Means-end)</td>
<td>(Have) a positive outlook</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Our [other child] was fine [so it gave me hope that child with an ASD may be fine at some point]</td>
<td>Is a way to (Means-end)</td>
<td></td>
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<tr>
<td>Is a kind of (Strict Inclusion)</td>
<td>Change in outlook on life</td>
<td>Life adjustments</td>
<td></td>
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<tr>
<td>--------------------------------</td>
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<tr>
<td>Everything was done for [child’s] treatment</td>
<td>Is a kind of (Strict Inclusion)</td>
<td>Priority shifts</td>
<td></td>
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</tr>
<tr>
<td>I had to work more [to provide for the family]</td>
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<tr>
<td>Our family life was <strong>very disruptive</strong></td>
<td>Is a result of (Cause-effect)</td>
<td>Exclusively attending to child’s needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We had to take [child] here and there all the time</td>
<td></td>
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<tr>
<td>Our schedule was <strong>so busy all the time</strong></td>
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<tr>
<td>It [life] <strong>changed a lot</strong></td>
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<tr>
<td>[Child] was <strong>not speaking</strong></td>
<td>Is a kind of (Strict inclusion)</td>
<td>ASD symptom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Child] <strong>couldn’t tell us what [child] wanted</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Would <strong>make noises</strong></td>
<td></td>
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<tr>
<td><strong>Cried more</strong> than talk</td>
<td></td>
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</tr>
<tr>
<td>[Child] was <strong>not speaking</strong></td>
<td>Is a kind of (Strict inclusion)</td>
<td>Negative Reaction(s) to other treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Child] <strong>couldn’t tell us what [child] wanted</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Would <strong>make noises</strong></td>
<td></td>
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</tr>
<tr>
<td><strong>Cried more</strong> than talk</td>
<td></td>
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</tr>
<tr>
<td>Maybe [child] can <strong>play better</strong></td>
<td>Is a kind of (Strict inclusion)</td>
<td>Advantage(s) of FT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Child] can <strong>talk more</strong> and [child’s sibling] can <strong>understand</strong> [child] [as a result of speech therapy and FT]</td>
<td></td>
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<tr>
<td>(But parent questioned which of the two interventions was</td>
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<tr>
<td></td>
<td></td>
<td>Using FT</td>
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<tr>
<td>Criticism(s) of FT training</td>
<td>Is a kind of (Strict inclusion)</td>
<td>Other-reported positive behavioral change</td>
<td>Improve FT experience</td>
<td></td>
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<td>-----------------------------</td>
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<tr>
<td>ABA was good [for child]</td>
<td>Is a way to (Means-end)</td>
<td>Become(Becoming) more competent with using FT</td>
<td></td>
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<tr>
<td>[Child] learned a lot [from ABA] …he can sit quietly, pay attention, and follow directions</td>
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<tr>
<td>It (speech therapy) was good</td>
<td></td>
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<tr>
<td>[Child] was learning more words [from speech therapy]</td>
<td></td>
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<tr>
<td>[Child] can talk normal [because of speech therapy]</td>
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<tr>
<td>It didn’t work for [child] like they [Agency] said it was going to work [since child was unable to interact/play more with others and could not use specific skills in different situations]</td>
<td>Is a kind of (Strict inclusion)</td>
<td>Criticism(s) of FT training</td>
<td></td>
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<tr>
<td>[Child] only knew to play with cars</td>
<td></td>
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<tr>
<td>The way [the Agency] described FT seemed good at the time [but it really wasn’t when we used it]</td>
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<tr>
<td>Our family did not like it</td>
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<tr>
<td>It made it hard to spend time with the family</td>
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<tr>
<td>Took away from our quality of life</td>
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<tr>
<td>Session had to be on weekends sometimes</td>
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<tr>
<td>It took too much time</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Positive reaction(s) to other treatments</th>
<th>Is a kind of (Means-end)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>more helpful with talking)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• [Child] can talk to teachers and other kids at school [as a result of speech therapy and FT]</td>
<td>Is a kind of (Strict inclusion)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• [Child] can play with [sibling] a little better</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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