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**RECONSTRUCTING FAITH:
A PSYCHOLOGICAL AND SPIRITUAL JOURNEY
FOR PARENTS OF CHILDREN WITH AUTISM**

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**Thesis Submitted in Partial Fulfillment of
Requirements for Doctor of Ministry Degree**

**Hebrew Union College-Jewish Institute of Religion
Graduate Studies Program
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SUMMARY STATEMENT

Number of Chapters: 5

Contribution of this Thesis:

The author finds that for parents struggling with or living with the diagnosis of a child with autism, the experience presents challenges to their faith system and belief in God. This informal, or embedded, theology, based on the theological assumptions they make both consciously and unconsciously about the way and the why the world works as it does collapses in light of their changed reality.

Goal of the Thesis:

The support group enables parents in such a predicament to explore their faith assumptions and their relationship with God in order to reframe their life's experiences into a theologically, emotionally and mentally meaningful understanding, into a deliberative theology consciously articulated. Creating such a deliberative theology offers the participants hope and courage as they face the trials and tribulations that life inevitably throws their way.

Division of the Thesis:

Chapter 1: The State of Need.

Chapter 2: Religious and Clinical Principles.

Chapter 3: Method.

Chapter 4: Results

Chapter 5: Discussion of Outcomes.

Materials Used:

The author conducts a support group for 20 parents (ten couples) of children diagnosed with autism who are Jewish and affiliated with the Conservative Movement. Each participant receives a HOPE spiritual assessment tool to complete prior to attending the group sessions. The group then meets for eight weeks. Each session begins with a centering meditation followed by a listening exercise to quickly bond the members of the group and begin the session's discussion. Twenty minutes before the conclusion of the group discussion the facilitator distributes a Biblical or Rabbinic text related to the day's topic for the participants to read and respond. The sessions close with a prayer of healing. Following the eight group sessions, the participants receive another copy of the HOPE spiritual assessment tool for their completion. The baseline and final assessments are then compared.

ABSTRACT

The author conducts a support group for 20 parents (ten couples) of children diagnosed with autism who are Jewish and affiliated with the Conservative Movement. Each participant receives a HOPE spiritual assessment tool to complete prior to attending the group sessions. The group then meets for eight weeks. Each session begins with a centering meditation followed by a listening exercise to quickly bond the members of the group and begin the session's discussion. Twenty minutes before the conclusion of the group discussion the facilitator distributes a Biblical or Rabbinic text related to the day's topic for the participants to read and respond. The sessions close with a prayer of healing. Following the eight group sessions, the participants receive another copy of the HOPE spiritual assessment tool for their completion. The baseline and final assessments are then compared. The author finds that for parents struggling with or living with the diagnosis of a child with autism, the experience presents challenges to their faith system and belief in God. This informal, or embedded, theology, based on the theological assumptions they make both consciously and unconsciously about the way and the why the world works as it does collapses in light of their changed reality. The support group enables parents in such a predicament to explore their faith assumptions and their relationship with God in order to reframe their life's experiences into a theologically, emotionally and mentally meaningful understanding, into a deliberative theology consciously articulated. Creating such a deliberative theology—based on carefully reflected theological convictions—offers the participants hope and courage as they face the trials and tribulations that life inevitably throws their way.

For Noam

His ways are ways of pleasantness and all his paths are peace.

Proverbs 3:17, adapted

I sought *Adonai* who answered me, freeing me from my fears.

Psalm 34:5

Members are inspired and expectations are raised by contact with those who have trod the same path and found the way back.

Yalom, *The Theory and Practice of Group Psychotherapy*

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PREFACE

Monday, April 5, 1993 is a day that will live in infamy for me. On that day, part of me died. On that day my wife and I entered Alberta Children's Hospital with what we thought was a healthy, almost three-year-old little boy, with blond hair and blue eyes, named Noam. Hours later, we left with the same almost three-year-old little boy, with blond hair and blue eyes, named Noam, only he was not as healthy as we thought. He had what the Early Childhood Development Assessment team called pervasive developmental delays. It was not until two months later, on June 15, that we were told his official diagnosis: mild-to-moderate autism.

Funny thing, though, it wasn't Noam who was the problem; it was me. Noam is a blessing to us. His disability brought our family closer together in many ways we hadn't considered before and we have seen him grow and mature. He is a beautiful boy, who is very affectionate and has a strong relationship to his immediate family members and some of his teachers. Noam has many strengths that give us the hope, the desire and the drive to pursue appropriate treatment so that he can maximize his potential.

No, the problem was with me. Those words, "pervasive developmental delays" and "mild-to-moderate autism" stabbed me in the heart like a knife. In one instant, gone were all my hopes and dreams and expectations. Gone was seeing him go to college, marry and raise a family. Gone was seeing him as the "All-American" Rhodes Scholar. Gone were all my preconceived ideas of Noam's life, and my assumptions about my role as parent and father. Gone was my sense of self in relationship to him. I was adrift in a flimsy rubber dingy in the midst of a raging storm and I was drowning in my confusion, my self-pity and my mourning. I shut down and I turned inward, away from those I love. I was

bitter and grieving; I couldn't see all the joy and happiness that Noam brought us, I couldn't see his successes and I couldn't appreciate his love and affection. I was consumed with myself, my frailties and the unfairness of life; I was so absorbed with my sadness and mourning that I was dying more than I was living.

When, at age three, we were looking to buy him a tricycle, my wife suggested getting a bicycle with training wheels. I thought it would be a waste of money and that he would never learn how to balance himself and to use a chain driven cycle. Why bother trying, I thought. It was just one more stab in the gut of my lost images and assumptions of Noam. My wife, bless her soul, ignored my pessimism and bought the bicycle. Within a week or ten days Noam was riding it independently. We would run along side to direct his steering, but he pedaled and rode. Had my wife listened to my preconceived notions about what Noam could or could not do, it would have interfered with his development, he would not have learned. But because I listened to my wife (I think there's probably a lesson in that too!—at least she would like to think so!) and did not limit his potential, he excelled beyond my expectations.

When Noam was almost seven, I took him out on his sister's bicycle—one without training wheels. Within ten minutes, he was riding on his own, and I was running after him with tears of joy in my eyes. When we returned home and I put the bike in the garage, I had a good, long cry. Maybe something within me was reborn at that moment, or perhaps merely rekindled. For the book of Proverbs teaches (Proverbs 20:27): "The candle of the Lord is the soul of humankind" and through his life and deeds, Noam gives expression to this sentiment and to God's command to be holy in our lives—to strive for holiness in our lives and to see holiness in the lives of others. Instead of mourning what I thought I lost

(but never really had to begin with), I learned to celebrate what I had; and what I had was a beautiful, affectionate, healthy, happy son who looked at life through wondrous eyes, a loving heart and a gentle soul. That's enough to make any father burst with pride and joy.

So now one of the things I try to teach others is to let go of the things that torment them because if they don't they their souls may die while they are yet alive. It reminds me of one of my favorite short stories, James Joyce's *The Dead*. All the characters at a party have a good time but, in the end, we discover that they are all ghosts, mere shadows of themselves. The main character learns that his wife mourns the love of her youth and never felt the same affections for her husband. Part of her died with that young man. The protagonist sees a connection between those who are dead while living and those who are dead and buried. It is the same for Miss Havisham, in Charles Dickens' *Great Expectations*, who was jilted at the altar and never got over it. She sits in the dark in her wedding dress waiting for her original great expectations to be fulfilled. So many of us, like Miss Havisham, cannot get past the disappointments of our lives and we just stop living. For many years after Noam's diagnosis that is how I felt. I kept hoping one day I would wake up and it would all be just a bad dream and that Noam would be neurologically typical. But my great expectations were never fulfilled and I mourned my loss for years before I realized how futile it was and how much more there was to my life and my relationship with my son.

When the Israelites left Egypt, they left a land consumed by death. For most of their lifetimes the people of Egypt toiled to make great mausoleums for their kings—the pyramids. All those lives went into building tombs for the dead. The Egyptians lived for death, but the Israelites had the opposite view; they lived for life. They were in Egypt for

400 years, but the Egyptians did not convince them to focus on death. The Exodus from Egypt was a departure from a culture obsessed with death to one emphasizing life. Judaism believes in life; so much so that the Torah teaches (Deuteronomy 30:19): "Behold this day I place before blessing and cursing, living and dying. Therefore, choose life." I used to think that was a trite statement; after all, who would not choose life over death? But then, as I learned more about people and life, and as I wrestled with my own circumstances, I realized that it was a very profound declaration.

Choosing life means doing what we really want to do no matter the gamble. It means seeing life as an adventure and grabbing hold of it with glee. It means being grateful for what we have and not mourning for what we don't have. It means not being so scared of death that we never live. It means not being like the woman in Joyce's story, who never gets over a lost flame and never gives her love to anyone else. It means not being like Miss Havisham, who never gets over her disappointments. It took time and hard work, but I learned what it means to really be alive. And the next time you are driving along a road and you see a bicycle built for two with a tall handsome teenager and his dad wearing matching yellow helmets and bright shiny smiles, slow down and wave; Noam and I will wave back. May all of us who are dead while yet alive learn to live again, and may we find the courage to risk, to hope, to try, to persevere and to experience so that we can truly live.

Thanksgiving, November 24, 2005.

22 *Heshvan* 5766.

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Many thanks as well to those members of Temple Emanu-El of Closter, NJ and its President, Mark Hirschberg, who believed in the value of this project and in my doctoral studies. They understood the worth of this endeavor for enhancing my skills as a pastoral counselor and the benefit to the congregation that would result. My gratitude to my colleagues and staff with whom I work everyday in bringing Torah, sacred service and loving kindness to the congregation and with whom I serve God: Cantor Israel Singer, Executive Director Ilene Anesini, Education Director Diana Yacobi, Youth and Family Programs Director Yonina Creditor and Early Learning Center Director Susan Rosembaum, as well as Administrator Phyllis Cunningham, Secretaries Carol Gaughan, Shayron Saunders and Randy Unsell.

This project would not have been possible without the encouragement, support and expertise of Dr. Georgia Hooper-Peck and Rabbi Dr. Bennett Miller, my advisors and colleagues. They inspired me to further study and personal reflection in order to understand the psychological and spiritual impact of disabilities and their effect on others. In addition, special thanks to Dr. Carol Ochs and Rev. Ann Akers, Dr. Gary Alshkog, Dr. Mark Banchick, Rev. Doug Clark, Sister Vivian Joyce and Rabbi Dr. Hesh Sommers for their contributions to my personal development as a Pastoral Counselor, as well as my classmates in the D. Min. program who were a constant source

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On a personal note, I want to thank my eldest daughter, Ariella, who taught me that gifted intelligence and a compassionate heart can go hand in hand. She is a devoted big sister to her brother with autism and her endless love for him inspires me daily.

Special thanks are also due to my youngest daughter, Leora, for reminding me that there is a world of wonder and joy to be experienced and for refreshing my spirit each day. She also heightens my awareness that everyone is special, whether they are "special need" or not.

To both Ariella and Leora: thank you for showing me the very special love you have for your brother and for showing me joyous and positive effects that a child with autism can have on his siblings. You are the ones who motivated me and gave me the courage to explore the field of Pastoral Counseling and this project.

And to my son, Noam: I would like to say thank you for teaching me to be sensitive to the needs of others and to appreciate the blessings I have in my life, some of which were not always so obvious to me. You challenged me to find the presence of God in the midst of personal anguish and taught me to see the precious child beyond the disability, not just the disability.

Aharon, aharon haviv, "the last is the dearest:" I want to thank my wife, Gilah, for her patience, understanding and support throughout my rabbinical career and particularly throughout these past three years of my doctoral studies. She sacrificed much to allow me the personal and professional success I've enjoyed and I can never thank her

enough or put into words the love and respect I have for her and the debt of gratitude I owe her. As a wise person once said, "Behind every great man there is an even greater woman!" I thank her for her constant love and continuous devotion to our relationship and our family.

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ABBREVIATONS

AA	Alcoholics Anonymous
ABA	Applied Behavioral Analysis
AD	Asperger's Disorder
ASA	Autism Society of America
ASD	Autistic Spectrum Disorder
CAN	Cure Autism Now
CBT	Cognitive-Behavioral Therapy
CDD	Childhood Disintegrative Disorder
DAN	Defeat Autism Now
IBI	Intensive Behavioral Intervention
JCC	Jewish Community Center
NA	Narcotics Anonymous
NAAR	National Alliance for Autism Research
NWHIC	National Women's Health Information Center
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
RD	Rett's Disorder

CHAPTER ONE:

DO NOT PLACE A STUMBLING BLOCK BEFORE THE BLIND.

(Leviticus 19:14)

CHAPTER 1

DO NOT PLACE A STUMBLING BLOCK BEFORE THE BLIND

Parents of children with autism frequently face challenges to their belief system as they confront the tribulations of raising a child with a disability. Ochs (2004) claims: "Our God-images are formed in childhood, when we think of God as parent, teacher, and police officer all rolled into one. Too often, people carry this primitive conception right into adulthood and old age, instead of modifying it constantly or even replacing it entirely as they mature and gain life experiences" (172). Thus, the diagnosis of a child with autism can engender a crisis of faith that causes parents to withdraw from participation in the Jewish community and particularly the synagogue, which is a symbol of religious expression and of God's presence in their lives. These parents need to give and receive support from one another, explore their faith-based assumptions, and find a place of acceptance within the Jewish community in order to better cope with their life situation and retain their connection to the organized Jewish community.

Disability is Different

Death is a finite event. A loved one dies, is buried and the family and friends grieve. A myriad of books exist that explain the stages of grief and offer advice for coping with one's loss. With time and distance from the event itself, individuals learn to turn their mourning into memory, to overcome their grief and compensate for their loss. Disability is different. It is like a death that occurs over and over again. For parents struggling with the diagnosis of autism and the disability of their child, each day brings a

recurring grief experience. Each time a child with autism confronts a life situation or challenge that accentuates his or her disability it is another loss. It is like experiencing death yet again: the death of hopes and dreams for one's child, the death of perceived "normalcy," the death of high academic achievement, the death of "typical" social interaction, the death of independence, of progeny, of family, of future. Even within the families of those who overcome the initial shock, denial and sense of loss, who come to a point of acceptance of, coping with and advocacy for their disabled child, there are always moments of despair, of hopelessness and of helplessness.

What is Autism?

Lovaas (1981) calls autism "one of the severest of all disabilities." He refers to it as such because of the complete dependence individuals with autism have on the care and guardianship of others, be it family or state stewardship. Autism does not only affect the child, but the whole family. A child with autism means having a constant awareness of his or her disability and a constant responsibility for his or her care. The needs surrounding a child with autism continuously affect the life of the family and the family must shape itself and its schedule around those needs.

Hart (1980) defines autism as "a neurological disorder that affects an individual's ability to process information from the senses and different areas of the brain" (16). He points out that

The basis for this neurological problem probably begins before birth but often can't be recognized until several years later when the child shows problems developing skills common to others of the same age. Since the rate and pattern of development is the primary concern with autism, we call it a "developmental disability."

The primary challenges for people with autism include language development and other forms of human interaction, including subtle gestures of facial expression, tone of voice and body language—features of what we call the total communication. For this reason, we often call autism a “communication disorder” and look to communication therapy as an important aid for the individual. (Hart 1980, 16)

Other developmental milestones falter with autistic individuals such as appropriate socialization with peers and adults, and interactive, creative and imaginary play skills. Other symptoms include maladaptive behavior such as tantrums, self-stimulation (like twirling or hand-flapping) and problems with sleeping, eating and toileting.

The diagnosis of a child with autism leaves the parents and family devastated. Unlike Down's syndrome, for example, autism is not apparent at birth. Autism does not become noticeable until one's child is between 18 months and three years old. Initially, then, parents celebrate the birth of what all believe to be a healthy baby. Only later, when the peculiar symptoms of autism begin to appear and professionals evaluate, is the diagnosis made. Only then do parents start reeling in shock and denial, only then are they overcome with grief and desperately try whatever therapy or treatment might be available to reverse the overwhelming reality of a child disabled with autism. When all this fails, the parents are left alone to cope with their loss, their unending grief, their self-consciousness at being different from other “typical” families, their shame, their guilt, their suspicions, their accusations and their hurt.

Initially, families of children with autism seek medical and therapeutic attention for their child with autism. Although experts and researchers have not yet identified the cause or causes of autism with complete confidence, many theories abound. Bettelheim (1967), a psychoanalyst and pioneer of the psychogenic theory of autism, thought that

poor parenting caused autism and advocated removing children from their parents as a form of treatment. However, the overwhelming evidence gathered since the 1960s now discredits Bettelheim's theory and supports, instead, a biological theory for the cause of autism. Schreibman (1988) discusses the origins of autism by describing non-empirical conjectured relations between children with autism and their social environments as well as empirical, data-based, hypotheses focusing on organic, biological and neurological factors. Baron-Cohen and Bolton (1993) assert that "in autism there are one or several abnormalities in the brain, and that these are caused by one or several biological factors (such as genes, complications during pregnancy or birth, or viral infections)" (26).

Powers (2000) identifies and describes the conditions collectively referred to as autism or Pervasive Developmental Disorder (PDD), including Autistic Spectrum Disorder (ASD), Asperger's Disorder (AD), Rett's Disorder (RD), Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). McCandless, Binstock and Zimmerman (2002) understand that autism spectrum disorders (ASD) are complex biomedical illnesses resulting in significant brain malnutrition. They believe that genetic vulnerability in many children, activated by "triggers," such as pesticides and heavy metals in vaccines, lead to damage of the immune system, gut dysfunction, and invasion by pathogens such as yeast and viruses. McCandless, Binstock and Zimmerman clarify major therapies available and identify options to improve the health of children with autism.

DeFelice (2002) holds that digestive enzymes are one of the causes of autism and advocates for Enzyme Therapy as a successful treatment for children diagnosed with autism. She reports significant improvements in health, pain reduction, language, food

tolerance, socializing and other benefits. Likewise, Seroussi (2002) traces her autistic child's problems to an immune system breakdown that coincided with his vaccinations. As a result, his digestive system was unable to break down certain proteins. This led to abnormal brain development which she believes is the cause of her child's autism. On the other hand, Hallaway and Strauts (1995) suspect that one cause of autism is heavy metal poisoning. Toxic levels of lead, arsenic, aluminum and cadmium in the bodies of these young children affects them with severe autistic tendencies. They recommend Chelation Therapy to draw these heavy metals out of the body as a means to rehabilitation.

Many other early interventions abound. Lewis (1998) draws upon her own success with removing gluten and casein from her son's diet to advocate for a dietary intervention. Harris and Weiss (1988) insist on the efficacy of a teaching method known as Intensive Behavioral Intervention (IBI), particularly for children aged five and under. Similarly, Hamilton (2000) advocates for Applied Behavior Analysis (ABA) as the parents' treatment of choice for their children with autism. She also explores other interventions and treatments such as secretin and immunotherapy, as well as dietary interventions and sensory and auditory integration.

Siegel (2003) claims that the difficulty with autism is that it is a spectrum disorder, a combination of a number of symptoms and causes. To varying degrees, and each case is different, autism robs a child of social bonds, language, and intimacy. Therefore, she asserts, the key to understanding autism is to view each case as a distinct set of learning disabilities, each of which must be treated individually. Siegel believes that before treatment can begin, an inventory of a child's particular disabilities must be made and reviewed. Once parents and professionals make these assessments, they can

examine existing and suitable treatment strategies and select them for treating their child appropriately. Siegel underscores that there is no simple cure for this multifaceted disorder, and therefore, an individual program with a unique assortment of specific treatments must be constructed for each child.

A Crisis in Thinking and Feeling

Once the parents of a child with autism find the medical and therapeutic attention that they seek, they must cope with the feelings they have as well as their embedded theology. Stone and Duke (1996) describe embedded theology as "the theology that is deeply in place and at work as we live...in our homes, churches, and the world" (13) and distinguish it from deliberative theology:

Deliberative theology is the understanding of faith that emerges from a process of carefully reflecting upon embedded theological convictions. This sort of reflection is sometimes called *second-order theology*, in that it follows upon and looks back over the implicit understandings embedded in the life of faith. By its very nature, second-order reflection is marked by a certain critical distance. (Stone and Duke 1996, 16)

Embedded theology is the way in which individuals learn about their faith from countless daily encounters, formal and informal, planned and unplanned. It is the theological assumptions they make, both consciously and unconsciously, about the way and the why the world works as it does. It is "*first-order theology* or *the language of witness*, being made up of the most immediate and direct testimonies to the meaning of faith" (Stone and Duke 1996, 13). It stems from one's immediate interpretations of the world in which he or she lives filtered through the teachings of one's faith tradition as taught or preached

or practiced. In other words, it is the implicit theology with which one lives out his or her daily life.

Whether one is aware of it or not, each person functions in this world with some sort of theology. He or she may not articulate it in theological language, but he or she operates with certain faith assumptions, one's embedded theology. When faced with catastrophe or trauma, such as the diagnosis of a child with autism, these faith assumptions are often challenged by the reality that parents face. Their embedded theologies no longer explain their reality in a meaningful and significant way and they begin to question, challenge and even abandon these assumptions, if not their ideas of God, spirituality and religion altogether. It, therefore, behooves parents of children with autism to explore their faith, their theology and their relationship to God in order to reframe the meaning of their life's experience into a theologically, emotionally and mentally healthy understanding. Not to do so may lead such parents into despair, loneliness or hopelessness. This could lead to psychological harm in the form of depression, suicidal thoughts or other detrimental and self-destructive conditions or behaviors. Often, however, Jewish parents of children with autism do not take this second step because the Jewish community does not provide the necessary resources and services. The synagogue, the one place that should provide sanctuary for the troubled soul, often disregards families struggling to come to grips with the reality of living with a disabled child.

A History of Jewish Communal and Synagogue Disregard

When parents learn that their child is diagnosed with autism, they often feel helpless and bewildered. Their child appears to live in an isolated, almost impenetrable world that seems impossible to bridge. To understand autism and overcome their fears, parents need both information and hope. Information about the nature of autism, possible treatments, theories of its origin, and how to advocate for one's child with autism is readily available. But where do parents find hope, the strength and will to persevere, the alleviation of their suffering and the renewed will to live?

For those stricken with alcoholism or substance abuse, there is Alcoholics Anonymous (AA) or Narcotics Anonymous (NA). For those coping with chronic illness or cancer there are organizations like Gilda's Club. For those recovering from the death of a loved one, there are grief support groups sponsored by hospitals, funeral homes, community centers, churches and synagogues. For parents and siblings of disabled children, such as Down's syndrome, Cystic Fibrosis, or Cerebral Palsy, there are advocacy and support groups as well. Even for parents and siblings of children with autism there are such organizations as the Autism Society of America (ASA), Cure Autism Now (CAN), Defeat Autism Now (DAN) and the National Alliance for Autism Research (NAAR). These groups focus on advocacy, awareness, education and research fundraising, as well as offering support groups. However, these support groups are not the main thrust of these organizations and often support is in the form of practical responses to issues in the home, school or public setting rather than on exploring the emotional, psychological, spiritual or internal state of being for the parents. Where then is one to turn?

Obstacles Facing Jewish Parents

Where such support is available, there are often additional obstacles for Jewish parents of children with autism. Many times these groups meet in churches and have a Christian theological bent, if led by church members, which make Jewish parents feel uncomfortable, peripheral or unwelcome. Often such groups meet at the convenience of its members, which may be on Friday night or Saturday, the Jewish Sabbath, and make it inappropriate or prohibitive for Jewish parents to attend. And sad to say, synagogues and Jewish community centers (JCCs) do not offer such support groups to Jewish parents of children with autism. Indeed, for many Jewish institutions, children with disabilities are not welcome at all:

Some parents are too worried about upsetting others even to try to attend services. And some still run up against religious and lay leaders and fellow congregants who are unnerved by a child wandering through the pews, muttering or crying during devotions or compulsively rocking in his seat. Parents have told...about being asked to leave the service or to leave the church [or synagogue] entirely. (Hyman 2005, 5)

According to Hyman (2005), when the Jewish parent of a child with autism inquired about support groups and special classes from her local Jewish organizations, "they told her they weren't aware of any Jews with disabilities" (5). The parent replied: "I was really angry because what they were saying to me is that my son was not disabled, he was invisible in the Jewish community and that is an unacceptable thing to say" (Hyman 2005, 5). She started a Jewish special education class for her son and within a month three others joined and a year later, 11 children attended the class. Now there are more than 100 enrolled. Synagogues and Jewish community centers (JCCs) need to learn from

this anecdote and begin to offer such support groups to Jewish parents of children with autism.

In Bergen County, NJ, for example, Janoff (2005) records that there are 74 synagogues (27 Conservative, 8 Hassidic, 24 Orthodox, 1 Reconstructionist, 12 Reform, and 2 unaffiliated) and three JCCs. Of these, only 14 (5 Conservative, 3 Hassidic, 1 Orthodox, 0 Reconstructionist, 5 Reform, 0 unaffiliated) provide special needs programming and 14 provide support groups of any kind (6 Conservative, 0 Hassidic, 1 Orthodox, 1 Reconstructionist, 4 Reform, 2 unaffiliated), none of which are specifically geared toward parents of children with autism (or any disability for that matter). The three JCCs do offer programming for special needs children, including therapeutic nurseries for children with autism, and support groups, but not specifically for parents of children with autism. Thus, in total, only 19% of the synagogue community (and only 22% if the JCCs are included) provide any programming for special needs children. And although 14% (and only 22% if the JCCs are included) provide some type of support group environment, not a single Jewish institution in Bergen County offers any type of spiritual or psychological support for Jewish parents of children with autism (or any other disability for that matter).

Table 1. Special Needs and Support Groups in Synagogues and JCCs

Affiliation	Number of Institutions	Special Needs	Special Needs (%)	Support Groups	Support (%)
Conservative	27	5	18.5	6	22
Hassidic	8	3	37.5	0	0
Orthodox	24	1	4	1	4
Reconstructionist	1	1	100	1	100

Reform	12	4	33	4	33
Unaffiliated	2	0	0	2	100
Totals	74	14	19	14	19
JCC	3	3	100	3	100
Inclusive Totals	77	17	22	17	22

Thus far, then, the Jewish community in general, and the synagogue as a caring institution in particular—with rare exceptions—fails to adequately address the psychological and spiritual needs of parents coping with their children's disabilities. Indeed, in one congregation the rabbi stood up at his pulpit, glared at a young mother who was trying desperately to keep her fussing child quiet, and said: "Noisy children are like the Ten Commandments – they should be carried out." Embarrassed and red in the face, she rose to leave with her child as the eyes of the entire congregation silently watched her walk up the aisle. One can hardly imagine a more humiliating and unwelcoming sight.

In another episode, in a different congregation, a young couple had a child disabled with autism sitting between them. Earlier, when they first arrived, they brought him into the empty daily chapel and took him to the Ark. They opened the doors, pointed to the Torah and prompted him by saying the word "Torah." He just looked at the Torah, but did not respond. Now, as they rose in the synagogue for the Torah service and the Ark was opened, the little boy pointed towards it and blurted out, "Torah, Torah." Clearly, his parents were exhilarated. Here was this little boy, struggling to express

himself, who used appropriate words in the appropriate context at the appropriate time. It was a moment of triumph in their battle to overcome his disability.

But their exhilaration was short-lived. The Cantor stopped *davvening* (praying) and looked at them with the sternest of scowls. He motioned for them to take the little boy out of the service. After the service, the Cantor, Executive Director and President of the congregation told this couple, in front of their child, how he disrupted the service with his outburst and that they would appreciate it if the boy did not come to services with them anymore. Angrily, they stormed out of the building. No doubt they refused to come back again. How could they stay in a congregation that treated people with disabilities in such a manner?

The Torah teaches (Leviticus 19:14, trans. Orlinsky 1962, 217): "Do not set a stumbling block before the blind." This verse clearly asks one not to take unfair advantage of those with disabilities. It beckons one to help smooth the way for them to live as normal a life as possible by removing obstacles from their path. It asks one to show a little sensitivity, a little understanding and caring; to help one's fellow human beings; to live by the Biblical dictum, "Love your neighbor as yourself" (Leviticus 19:17, trans. Orlinsky 1962, 217) and the Rabbinic maxim, "All people are responsible for one another" (Shavuot 39a, trans. Epstein, 1935, 347).

While this attitude may seem obvious now, there was a time not long ago when people would spurn those with special needs. Either out of ignorance or fear or because of stigma or awkwardness, people would avoid the issue of disabilities and disabled individuals. It was an issue that was "shushed," especially in the Jewish community. Indeed, one congregant tried to comfort another after getting his son's diagnosis of

autism by saying, "He can't be autistic because there are no autistic Jews." In a sense, his perception was right; that is, the Jewish community was unaware of the disabled because it wasn't a priority; it wasn't on the communal agenda. The Jewish community was too busy struggling for the physical survival of threatened Jewish peoples around the world to focus on "quality of life" issues. With Soviet Jewry, Ethiopian Jewry and all sorts of resettlement issues, with fighting anti-Semitism and confronting the challenges of intermarriage and assimilation, it just wasn't a priority. But now, when attention has turned to spiritual survival, when Jewish communal leaders constantly talk of Jewish continuity, and are concerned with political correctness, new attention focuses on those with disabilities, and their quality of life now has a place on the Jewish communal agenda. For those with disabilities are, indeed, a part of the continuity of the Jewish People.

The Specific Need

There is a need in the Jewish community, and specifically in the synagogue environment, for a safe and nurturing place where parents of children with autism can explore and discuss their feelings, fears, hopes and aspirations in the context of Jewish life, tradition and sacred text. Parents of children with autism need a place where they can explore the meaning of their lives in light of their child's disability, confront their existential questions, challenge their beliefs, struggle with their understanding of God and of human purpose, and come to a greater spiritual understanding of their place in their world and in their relationship with God. Where else can they find such a place if not in

the synagogue, which serves as the spiritual and religious center of the Jewish community?

Parents need a place to make conscious their embedded theology, reflect on their personal experiences of the emotional and spiritual challenges that having a child with autism raises and create a deliberative theology that incorporates the results of their efforts and struggles to make life meaningful for them once again. Where else can they go, if not to the synagogue, which serves as a *beit tefillah*, a house of prayer, a *beit midrash*, a house of study and a *beit kneset*, a house of assembly for the Jewish community? These are theological, spiritual and religious struggles, as well as psychological and social ones. The synagogue must be the place where parents can find theological meaning and spiritual relevance for themselves if they are to live their lives in hope and joy, despite their child's diagnosis.

The Torah tells of God's command to make a sanctuary (*mishkan*) in the midst of the Israelite camp that will be the symbolic dwelling place of God during their desert wanderings and encampments: "Let them make Me a sanctuary that I may dwell among them" (Exodus 25:8, trans. Orlinsky 1962, 143). God does not dwell "in it," that is to say, in the sanctuary, but rather "among them," or as the Hebrew *betokham* may be translated, "in them," meaning in the hearts, minds and spirits of the Israelites. Likewise, the synagogue must be a sanctuary for parents of children with autism so that God's presence may dwell "in" and "among" them. Thus, the synagogue is the ideal place for Jewish parents of children with autism to get together in a supportive group environment to explore their spirituality and theology in the face of the challenges brought about by having to cope with the reality of a child disabled with autism.

The Efficacy of Group Therapy

Yalom (1990) makes a strong case for the importance and efficacy of group therapy. Along these lines, Vinogradov and Yalom (1991) assert that participant-participant and leader-participant interactions in a group setting can effect changes in behavior. Similarly, Jacobs, Harvill and Masson (2001) show how groups can be useful in conducting intense personal therapy and how members' roles can aid in bringing about decisions, promote sharing, and facilitate therapeutic change. Yalom (1994) further demonstrates that therapeutic things occur in an atmosphere of safety and honest, self-disclosing communication. The synagogue as a house of God and a place of caring can and must create that atmosphere.

Velasquez, DiClemente, Crouch, and Maurer (2001) show that therapeutic groups engage, motivate and stimulate processes of change in clients. Thus, such a group in a synagogue setting can help Jewish parents of children with autism find healing and spiritual growth by engaging in group work with others facing similar challenges. Northen and Kurland (2001) emphasize establishing a common core of values, knowledge, purposes in group work that enable clients to effect change. The synagogue, as a center for the transmission of Jewish tradition and values can thus be an effective venue for a group of Jewish parents of children with autism exploring the meaning of their experiences in a religious and spiritual context.

Relevance in a Wider Context

For more than 2000 years, the synagogue was the instrument of Jewish survival, the place where Jews came to sing praises to God, to learn God's word and to share in

each other's lives and concerns. When the Temple in Jerusalem was destroyed long ago, it was the synagogue that enabled Judaism to survive and prosper. While living in the lands of the Diaspora, it was the synagogue that provided a place to gather in social context as a *beit kneset*, for study and education as a *beit midrash*, and for prayer as a *beit tefillah*. A Jew could travel anywhere in the world and feel comfortable, welcome, and at home in the synagogue. When Jews came to America, it was in the shelter of the *landsmanschaften* – the brotherhood of the synagogue – that made transition to life in this country possible and easier. When one looks back upon the Jewish American experience, one relishes the fond memories of and creates great nostalgia for what one thinks the synagogue used to be: a close-knit neighborhood center.

The synagogue once was the center of Jewish lives, the place not only to pray and learn, but also to be with friends, to exchange news, to band together for a common cause and to watch children grow, but, as Dosick (1988) claims, in recent times that changed. Now, the synagogue is a building to which the majority of Jews come at a specific time for a specific purpose and then leaves for the next appointment, the next event in their busy lives. They become consumer Jews, purchasing their Jewish needs when they need them, most notably life cycle events, and ignoring their Judaism the rest of the time. Yet, they still yearn to feel a sense of belonging, a sense of community in the synagogue; but that can only come about if each member of the community helps create it. To do this involves transforming the congregation into a sacred community. Schwarz (2000) defines a sacred community as one that provides its members with a sense of acceptance and love, warmth and belonging. To create a sacred community people cannot be strangers – cold and indifferent – to one another. They must make the effort to reach out and get to

know the wonderful families and individuals who make up their special synagogue community.

Indeed, no two people are alike, even if they dress similarly, work in similar fields, and enjoy similar lifestyles and incomes. Those similarities mask the profound depths of human individuality. All people are unique, and that difference in each person makes sense not only psychologically but theologically as well. The Torah states that all human beings are made *b'tzelem Elohim*, "in the image of God" (Genesis 1:27, trans. Orlinsky 1962, 4). If God is infinite, then every creature made in God's image will reflect a different, finite, aspect of that infinite Source of life. The fact that each new person presents a new aspect of God's image is a consequence of God's creative energy. Aware of this reality, the synagogue—as a religious and spiritual institution—and its members must respect each individual for his or her special qualities and are, therefore, commanded to imitate God's attributes of love and kindness. After all what else can it mean to "walk in God's ways?" Just as God responds differently to each person based on that particular mixture of desire, need, perception, and ability, so to should everyone. Creating an atmosphere where parents of children with autism can gather in safety and honesty will enable the synagogue to successfully put into practice its noble calling and, as a result, present an opportunity to add value and meaning to the lives of its congregants well beyond the group.

The Synagogue as Sacred Community

The message of caring transmitted by the synagogue as a sacred community must provide member-to-member support in times of illness, death or other life crisis,

including the diagnosis of a disability like autism. The congregation is only as strong as the relationships between its members. Community comes from members spending time with one another, getting to know each other personally and forging bonds of friendship. Community comes from giving each other a sense of belonging and being in a caring network of relationships. A synagogue providing the kind of supportive atmosphere needed for Jewish parents of children with autism to explore their connections to God, Torah and tradition would help it transform itself into this caring and sacred community. Indeed, it may spawn other support groups focusing on different needs and thus create a warm and welcoming place for all Jews. After all, part of being a warm and welcoming sacred community is reaching out to those often feeling disenfranchised from the Jewish community.

The synagogue as a sacred community should be an inclusive community and welcome into their midst, among others, those in need of spiritual guidance, sincere compassion and true understanding. Currently, rare is the synagogue that makes it possible for deaf, blind, developmentally disabled or the mentally challenged to participate in services and programs. Yet, they should feel at home in the synagogue. If the synagogue truly is a sanctuary, it should be a sanctuary to all. Instituting such a project would have wider relevance for the synagogue and Jewish community because it would bring the synagogue community closer together, it would provide programming and services to a wider population base, and make Judaism more meaningful and relevant in the lives of all its members.

Furthermore, everyone can help to bring healing to others by their words, their deeds, their presence, and their caring. One can accomplish this on one's own or through

organized community-based efforts. Any synagogue or JCC that creates a group for parents of children with autism to meet and explore their theology and spirituality helps bring healing and comfort. If the synagogue is willing to listen to what others feel, need and yearn for, and what they wish they could express in words, and if the synagogue would listen to the resources of the Jewish tradition, which deal with pain and has tried to heal for so many centuries, then the synagogue would make its member-families, itself as a religious and spiritual institution, and the Jewish community what they are really supposed to be: places of healing for the soul. In such an environment, members and participants would be able to feel more readily the presence of God in their midst through the good works of the congregation and experience the real impact and relevance of their Jewish heritage, mores and traditions, which are often ignored as antiquated, irrelevant and not meaningful to their contemporary lives. If the synagogue can do this, then it would, as the *Aleinu* prayer asks, "fix the world so it reflects the glory and caring of God;" and that would be a very special place in which to live.

A Place of Welcome for All

A member of a synagogue decided to strengthen her commitment by attending worship services more regularly. She was deaf and showed up with her hearing-ear dog, which alerted her to sounds of warning, protected her from harm and allowed her to function normally in a sound-oriented society. She was stopped at the door by an usher, a member of the synagogue board. "You cannot bring that filthy animal into the Sanctuary," he said. In tears, she explained to him that this dog was not a pet, was not filthy, but a working dog, that it was illegal to prevent her from entering, immoral and

very un-Jewish. He literally turned his back on her so she could not read his lips and respond. Tears rolling down her cheeks, she started to leave just as the rabbi was arriving for services. She recounted her story and he begged her to stay and welcomed her into the worship service. The rabbi put aside his prepared remarks for the day and addressed the issue of welcoming those with special needs. She stayed for services, thanked the rabbi for his sensitivity and his words on her behalf. She left and never came back to services there again. She is, to this day, a very active member of another temple instead.

A synagogue must be a place of welcome to all people, and that must include those with special needs and their families. When Moses comes before Pharaoh demanding that he let the people of Israel go free, Pharaoh asks: "Who are the ones to go?" (Exodus 10:8, trans. Orlinsky 1962, 115) and Moses responds: "With our young and with our old we will go forth. With our sons and with our daughters, with our herds and with our flocks we will go" (Exodus 10:9, trans. Orlinsky 1962, 115). Stridently, Moses tells Pharaoh that the whole Jewish community will go forth into the light of freedom. The phrase, "with our young and with our old," is all inclusive. When Moses tells Pharaoh "everyone," will go and worship God, he means "everyone."

Similarly, the Hebrew word for Temple, *Beit Miqdash*, literally means "House of Holiness," or more commonly, "Sanctuary." The Hebrew word for synagogue, *beit kneset*, literally means "House of Gathering." The synagogue must be a sanctuary to all who wish to gather in assembly under its roof. It must be a place of gathering for all, including those with special needs and their families. In this way, the modern synagogue too can claim: "With our young and with our old we will go forth. With our sons and with our daughters," with everyone in the community, it will go forth into the light of

accessible worship and freedom of religious practice for all who wish to pray, study Torah and perform acts of loving kindness. If a group for parents of children with autism, by their very presence within the synagogue can be, in a wider context, a source of education about disabilities, advocacy on behalf of those who cannot speak for themselves but deserve a place and a presence in the synagogue and create a culture of caring and compassion, then they will remove the biggest stumbling blocks of all: ignorance and insensitivity. And that, alone, gives the group importance and relevance in a wider context.

CHAPTER TWO:

FOR I HAVE BEEN GUIDED ON MY ERRAND BY *ADONAI*.

(Genesis 24:27)

CHAPTER 2

FOR I HAVE BEEN GUIDED ON MY ERRAND BY *ADONAI*

Religious Principles that Guide and Inform

Kushner (1986) observes: "it is a devastating thing to have God fail you" (119). However one conceives of God and whatever name one gives to God, it is a shattering experience to base one's life on certain assumptions, one's embedded theology, and then to have them collapse on him or her as a result of a devastating, life altering experience, such as the diagnosis of a child with a disability like autism. It leaves one with the feeling that his or her theology is wrong and that, indeed, nothing in the world is right: "Take God out of the picture, let events force a person to admit that the fundamental assumptions of his life are false, and the whole world seems meaningless" (Kushner 1986, 119). For parents anticipating the joy of raising their child there are assumptions, preconceived notions, about how the world works, the beneficence of God and the beauty of life. They have plans for the future and look forward with excitement to their child's growth and development, his or her years in elementary and high school, college, graduation, career, marriage and children. All these ideas, which form the framework of their existence, die with the diagnosis of a child's disability. How then can these parents continue to live? How can they cope with their new reality and have trust in a world and in a God that failed them? Where can they find meaning?

Losing Faith in God

Many people believe God is a supernatural being that is omnipotent, omniscient and omnipresent. While God's power and grandeur give God control of the universe, they, nevertheless, believe that God can intervene in the particulars of human suffering on an individual basis. Thus, when tragedy strikes, like the diagnosis of autism, they believe that God is somehow responsible for bringing this disability upon their child, perhaps as punishment for some real or imagined sin. And just as God is responsible for giving their child autism, so too God should be responsible for removing it! In the words of the silent devotional (the *Amidah*): "You support the falling, heal the ailing [and] free the fettered" (Cahan 1998, 3b).

Thus, many believe that God could, should and would intervene in the particulars of human suffering on an individual basis, but when this does not occur they lose faith in God. They believe that God is somehow responsible for bringing this disability upon their child—and by extension upon them and their family—and God let them down. They can no longer trust such a God; they can no longer believe in such a God. What they are really saying is that the image of God that they had died and they have not found another concept to replace it. They feel abandoned and alone, and therefore, angry at the God-concept in which they no longer believe. Yet, they have nothing to replace it, so in their yearning for God, they turn their back on God because they see no alternative.

In this thinking, such parents, in the midst of their struggle and theological crisis, articulate an embedded theology based on a common misinterpretation and transformation of a liturgical metaphor for God's acting into a literal understanding of God's being. This image of God as Divine Overseer and Shepherd comes from the High

Holy Day liturgy in the *Unitaneh Toqef* prayer attributed to Rabbi Amnon of Mayence (ca. 1100), who died a martyr's death at the hands of Crusaders. In the first of these images, God takes on the attributes of a wise old man with a long white beard sitting at a Scribner's table pouring over a huge, worn ledger book determining "who shall live and who shall die," who will or will not be "written into the Book of Life:" "we envision You on the throne of judgment, judging us in truth, but with compassion ... You record and see, count and measure; You remember even what we have forgotten" (Greenberg and Levine 1978, 283). The second image, from the same prayer, portrays God as a Divine Shepherd: "On this day we all pass before You, one by one, like a flock of sheep. As a shepherd counts his sheep, making each of them pass under his staff, so You review every living being, measuring the years and decreeing the destiny of every creature" (Greenberg and Levine 1978, 283).

However, this view of God as ethical and beneficent Sovereign now collides with the reality of these parents' predicament and their anger at God for doing something bad to their child peppers them with feelings of guilt. Thus, they are torn by conflict. On the one hand they hold God responsible, yet on the other, they feel responsible. After all, did they not do something to bring upon this Divine wrath and punishment? Therefore, they feel a strong sense of responsibility and with it, a tremendous amount of guilt and anger. The words of the Bible echo with profound personal meaning and immediacy: "The Lord! The Lord! a God, compassionate and gracious, slow to anger, abounding in kindness and faithfulness, extending kindness to the thousandth generation, forgiving iniquity, transgression and sin; yet He does not remit all punishment, but visits the iniquity of the parents upon the children, and children's children, upon the third and to

the fourth generations" (Exodus 34:6f, trans. Orlinsky 1962, 161f). Parents of a child diagnosed with autism may well be thinking that their sins as the parents are being undeservedly visited upon their child diagnosed with autism.

An Alternative to Abandoning God

Rather than abandon God completely these parents need to examine their embedded theology of God's image and abandon their previous understanding of God in favor of one that reflects both their desire to find comfort in their faith and make sense of their different understanding of God's presence in light of their child's diagnosis. Where was God when they felt overwhelmed by the burdens of life? Where was God when they felt vulnerable and alone? During their times of trial and suffering, no doubt it was hard for them to see God's love carrying and sustaining them, but it is important for them—in order to keep their sanity and their hope alive—for God's love to be there. One can choose to bring God close to him- or herself, to feel God's presence in the "still small voice" (I Kings 19:12, Potok 1985, 556) of human kindness; God is with those who let God into their lives.

Kingsley (2000) describes the experience of raising a child with a disability by comparing it with planning a trip to Italy:

When you're going to have a baby, it's like planning a fabulous trip to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum; Michelangelo's David; the gondolas in Venice! You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands and the flight attendant comes and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in flight plans. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there awhile and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is so busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that is where I was supposed to go. That's what I planned."

And the pain of that will never, ever, go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland. (1)

The key to rebuilding one's life after such emotional devastation, to maintaining faith in God—even if that means redefining how one understands his or her conception of God—is not to give up. Kushner (1986) says, "Take God out of the picture...and the whole world seems meaningless" (119). Therefore, to find meaning, to maintain faith, one must not remove God from his or her life. Rather, one must step back from his or her embedded theology, reflect upon it and create a new deliberative theology that takes into account the meaningfulness of the new experiences of coping with a disability and living with and raising a child with autism. To do this successfully, Kingsley (2000) claims that, "you must go out and buy new guidebooks. And you must learn a whole new language"

(1). One must reinterpret his or her experience, learn to appreciate and redefine one's image and understanding of God in light of his or her new reality, because if one does not, he or she will never get beyond mourning his or her loss and appreciate, even enjoy, the life he or she has. Through theological reflection, one can reveal elasticity in his or her world-view that can incorporate this new reality in a meaningful way that preserves faith and sustains hope, thus giving renewed meaning to an otherwise shattered life.

Cannon (1929) asserts that fundamental to human nature is the "fight or flight" response. When faced with fear or anxiety, some people will naturally respond by fleeing the perceived or real danger. Others will stand and fight. So too with one's experience of God; some people flee by losing faith and abandoning God when their fundamental life assumptions come crashing down and devastate them. Others stand and fight; they find strength, perseverance and hope through their attachment to God and the comfort, support and presence they feel in their faith.

Kushner ([ca. 1985]) observes that people long to come face to face with God; to banish all doubts that God is real. Indeed, the Torah itself portrays this human longing in the story of the golden calf and its aftermath. Four months after the Israelites leave Egypt, they feel a desperate need to see God; to have tangible proof that God is still with them and has not abandoned them after leading them into the desert. As long as Moses is around, they look at him as an embodiment, an incarnation of God. For the Israelites, Moses is God in human form. He tells them what God expects of them. He works miracles; brings the ten plagues, splits the sea. But Moses is now on Mount Sinai getting the details of the Torah beyond the Ten Commandments. During this time the Israelites fashion a golden calf to represent the power and glory of God: "They have turned aside

quickly from the way which I commanded them; they have made them a molten calf, and have worshipped it, and have sacrificed to it, and said, 'This is your god, O Israel, who brought you out of the land of Egypt'" (Exodus 32:8, trans. Orlinsky 1962, 157). God is no longer an intellectual abstraction. Now they can see the God to whom they pray. They can see that God is present in their midst.

But, God gets angry at them for turning God into a thing; an idol. Moses is so upset that he breaks the tablets of the law. These people don't deserve the revelation; one of whose commandments is not to fashion an image of God, and Moses has to plead with God to give them a second chance, reminding God that they were raised in Egypt where representations of gods were all around them. Right after the incident of the golden calf, Moses confronts God with that problem claiming that the people of Israel have trouble believing in a God they can't see. To avoid further transgressions of the magnitude of the golden calf Moses asks God to see what God looks like.

God answers, "You can not see My face; for no man shall see Me and live" (Exodus 33:20, trans. Orlinsky 1962, 161). In other words, God says to Moses: "The reason you can't see Me is because I have no form or shape. I'm not a thing." But then rather than send Moses away empty-handed, God utters what may be the strangest, most puzzling verse in the entire Torah: "See, there is a place near Me. Station yourself on the rock and as My Presence passes by, I will put you in a cleft of the rock and will shield you with My hand until I have passed by. Then I will take away my hand, and you will see My back; but My face must not be seen" (Exodus 33:21-23, trans. Orlinsky 1962, 161). But how can that be? God just insisted that God has no form or shape! God just severely punished the Israelites for portraying God in physical form and now God tells

Moses, "You can see My back!" Kushner ([ca. 1985]) suggests what it means: "We can't see God, but we can see God's after effects. That's what this reference to seeing His back implies. All we can see of God is the difference that God makes as He passes through our lives just as we can't see the wind, we can only see things being blown around by the wind."

Advances made in sub-atomic particle physics help clarify this theological conception. No scientist has ever seen an electron. No physicist has ever actually seen a quark, but they are absolutely convinced that quarks and electrons exist, because when they look through their microscopes they see things happening that could only happen if quarks and electrons were real. That is what the Torah says about God. One cannot see God, but one can see things happening that could only be happening because God is at work. In much the same way, no one ever sees fear or anger or love. They see people acting out of fear, out of anger, out of love. They see feelings of fear, anger and love make people do things and have no doubts that those feelings are real.

The existence of God, then, is not a "fact" that can be checked against the evidence, but a presence that serves as the starting point for a world view and the understanding of one's place in it. This is the God of Doing, YHWH, in the Torah. YHWH (*Yahweh* or euphemistically, *Adonai*, "the Lord") comes from the verb "to be" in its causative form, meaning "the One who causes to be." God, then, is not a noun, but a verb; not a presence, but an action in one's life. Such a God is not a being to whom one can point. Instead, "He is present when we look for meaning in the world, when we work for morality, for justice, and for future redemption. For such believers, a description of God's nature emerges out of our shared traditions and stories as a community. God is a

presence and a power that transcends us, but His nature is not completely independent of our beliefs and experiences" (Gordis 1988, 18).

Raskas (1986) retells an anonymous story that illustrates the challenges faced by someone struggling with faith who turns to God, rather than away from the Divine Presence:

One night a man had a dream. He dreamed that he was walking along the beach with God. Across the sky flashed scenes from his life. For each scene he noticed two sets of footprints in the sand – one belonging to him and the other to God. When the last scene finished flashing before him, the man looked closely at the footprints and noticed that many times along the path there was only one set of footprints in the sand. He also noticed that this happened during the lowest and saddest times in his life.

This really bothered him and he questioned God: "Lord, You said that once I decided to follow You, You would walk all the way, but I noticed that during the most troublesome times of my life, there was only one set of footprints. I don't understand why, when I needed you most, You departed me."

God replied: "My precious, precious child, I love you and would never leave you. During your times of trial and suffering when you see only one set of footprints, it is because then I am carrying you." (23)

Often in one's loss and pain, he or she does not notice that he or she is carried, not only by the love of family and friends, but by the love of God as well. The Torah teaches: "I will be ever present in your midst: I will be your God and you shall be My people" (Leviticus 26:12, trans. Orlinsky 1962, 232). It is a caring God who seeks to be in a caring relationship with each person that can sustain and strengthen him or her until he or she can once more walk on his or her feet, safely and securely. For indeed, God will always appear where people of good will, of good faith and good hope let the Divine Presence in. The challenge for those facing the devastation of lost assumptions about God

and life after the diagnosis of their child's disability is to welcome God into their midst and walk together with God so that "He will be our God and we shall be His people" (Exodus 6:7 adapted, trans. Orlinsky 1962, 107).

Midrash Tehillim, an early Rabbinic commentary on the Book of Psalms, interprets the verse from Isaiah, "You are My witnesses that I am God" (Isaiah 43:12, trans. Potok 1978, 451), to mean "When you are My witnesses, I am God; when you are not My witnesses, I am—as it were—not God" (Buber 1977, 123:2). In other words, God needs each individual just as each individual needs God. When one acknowledges the presence of God in his or her life, he or she finds strength, hope and perseverance that give him or her a connection to the Divine. When one turns his or her back on the perception of God in his or her life, he or she lives in despair and anxiety, detached and distanced from God and from appreciating God's Creation, including the pleasures of life that can be found even when living and coping with a child with disabilities. Hence Kingsley's (2000) conclusion: "But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland" (1). Rather than turn away from God, Kushner (1981) advocates turning to God: "I don't believe that God causes mental retardation in children or chooses who should suffer from muscular dystrophy. The God I believe in does not send us the problem. He gives us the strength to cope with the problem" (127).

Sacred Stories

Ochs (2001) writes, "We develop a theology not by studying God, which we cannot do, but by deriving insights from our own experiences" (188). God's nature

emerges out of one's stories and one's ability to frame them in a spiritual context that gives added meaning to his or her life. Thus, while God is a presence and a power that transcends each person, God's nature is not completely independent of one's beliefs and experiences: "We encounter God through all aspects of our lives. God is the context of our story" (Ochs 2001, 192).

White and Epston (1990) describe story or self-narrative as the ordering of one's life experiences or events in sequences across time, thus giving a sense of continuity and coherence to one's life (10). White and Epston (1990), along with Borden (1992) and Howard (1991) explore both oral and written narration as a means of externalizing problems in ways that invite the writer or speaker to both reflect upon the problem and accept ownership of his or her experiences and relationships. In retelling one's life experiences, narratives shape lives and relationships. Perry (1991) adds that "shared stories are intrinsically binding and bonding" (17) and the act of sharing stories shapes both the writer's (or speaker's) life as well as the lives of others.

God's nature also emerges out of one's shared traditions and stories as a community. Torah is, for the Jewish people, that shared story and tradition. The Torah is the human response to the mysteries of Creation and being. It is the human writing down, a national-spiritual diary, of Jewish self-discovery as an "evolving religious civilization" (Kaplan 1934/1994). It is the national-cultural-religious myth that Jews tell themselves to explain who they are, how they developed, what is their cultural uniqueness, what gives their lives and their society meaning and purpose. It is the "expression of ancient Israel's attempt to base its life on a declaration of dependence upon God, and on a constitution which embodies the laws according to which God expected ancient Israel to live. The

declaration is spelled out in the narrative part of the Torah, and the constitution is spelled out in the law code of the Torah" (Kaplan 1966, 120).

But Torah does not stop with the Pentateuch. The Prophets and the Writings—what is called *Tanakh*—is also Torah, for it contains additional chapters in the story of the Jewish people's encounter with God through the individual experiences of the narrators as well as the national experience portrayed in its books. Each adds its own layer of understanding and experience of God whether taken as separate books or looked at in units such as the Early Prophets, the Later Prophets, the Five *Megillot*, the pre-exilic authors, the post-exilic authors and so forth.

Nor is the individual Jew separate from these books. As members of the Jewish People, these books are his or her inheritance and legacy. They inform the Jews' worldview, shape their values and serve as the lens through which they make moral judgments. They shape and inform one's identities as a Jew and as a human being. Thus, these books are part of each individual Jew's story—in addition to the national legacy of the Jewish People—and they connect the individual Jew with his or her community through time and across the globe; and it is through the eternity of that community that one can come to feel a sense of eternal relationship with God.

While the books of the Written Torah form the first rings in the concentric circles of Jewish communal storytelling, the Oral Torah—the *Mishnah*, Talmud and *Midrash*—are also part of what Judaism considers Torah. Jewish literature, philosophy, history, grammar and the codes form the next rings. Indeed, ultimately, all learning that leads to a greater understanding of Creation, the radical amazement and wonder of the ineffable and that forms part of the story of the Jewish people and of oneself as an individual is Torah.

Thus, nuclear physics and economics can be as much Torah as a commentary on the book of Psalms. And certainly, the stories of one's life and the way in which one interprets them to enhance and embrace one's relationship with God can also be understood as Torah.

The ongoing experience of self-discovery, both personal and communal, includes one's own experiences and encounters with God in his or her everyday life. Certainly a mountain vista, a beautiful sunset, the power of the raging seas and the poetry that one uses to describe them are an experience of God in one's life when they leave him or her with a sense of awe, wonder and mystery, when they leave him or her in awe of his or her ability to be in awe. But God is present for each person at other times too. The joy of a wedding day, the births of one's children and the support one receives in coping with the diagnosis of a child with disabilities, such as autism, are all manifestations of God's Presence in one's life. One's sense of being loved and needed, one's ability to show compassion and caring—even his or her passion and anger—are all manifestations of God's presence in one's life when he or she sees them as such. The Kotzker Rebbe (1787-1859) once said that God is present wherever we choose to let God in; it is each individual's thoughts and actions that determine whether or not one sees God's presence in his or her life.

When the Israelites gather at the base of Mt. Sinai to experience the theophany, the Torah states: "Now Mount Sinai was all in smoke, for the Lord had come down upon it in fire; the smoke rose like the smoke of a kiln, and the whole mountain trembled violently. The blare of the horn grew louder and louder" (Exodus 19:18-19, trans. Orlinsky 1962, 133). The people respond in fear:

All the people witnessed the thunder and lightening, the blare of the horn and the mountain smoking; and when the people saw it, they fell back and stood at a distance. "You speak to us" they said to Moses, "and we will obey; but do not let God speak to us lest we die." (Exodus 20:15-16, trans. Orlinsky 1962, 135)

Moses beckons them not to be afraid, but they remain at a distance while Moses approaches the cloud in which God is.

In contrast to this the Prophet Elijah climbs Mt. Sinai yearning to experience the presence of God. After a clash with King Ahab, Elijah flees for his life and hides in a cave on the mountain. There, tired and discouraged, he waits for word from God. Suddenly there is a roaring windstorm, whose fury bends and breaks the trees. But the Torah teaches: "The Lord is not in the wind" (I Kings 19:11, trans. Potok 1978, 272). An earthquake follows the storm and shatters the surrounding landscape, but the Torah again teaches: "The Lord is not in the earthquake" (I Kings 19:11, trans. Potok 1978, 272). A raging fire follows the earthquake and still the Torah insists: "The Lord is not in the fire" (I Kings 19:12, trans. Potok 1978, 272). Then all grows quiet and there is "a still small voice" which speaks the word of God to Elijah (I Kings 19:13, trans. Potok 1978, 273).

This teaches that God is not always in the roar of Mt. Sinai; sometimes God's presence is in the "still small voice" that touches one deeply. All one needs do is be open to the experience of God in his or her life and to interpret his or her life through the awareness and possibility of God's presence. For parents of children with disabilities, such as autism, searching for understanding and for God's imminence in the wake of a devastating diagnosis, finding God in their stories and connecting them to the stories of their heritage, such as Biblical and Rabbinic tales, can restore to them the strength of

faith and the optimism of hope. It can give them new meaning and insight and the strength to cope—and even thrive—in spite of the adversity they face.

Searching for God

Gordis (1988) articulates a statement of the principles of Conservative Judaism wherein he describes Conservative Judaism's perspective in three areas of thought: God in the world, the Jewish people and living a life of Torah. The section on God in the world discusses the nature of God, revelation, Jewish law, the problem of evil and eschatology. The Jewish people component articulates theological positions on God's covenant and the election of Israel, the State of Israel and the role of religion, Israel and the Diaspora, relations between Jew and fellow Jew, relations with other faiths and social justice. The final part, living a life of Torah, delves into issues pertaining to women in religious life, the Jewish home, prayer, Jewish study and a vision of the ideal Conservative Jew.

Dorff (1977) explains the theology of the Conservative movement by way of comparison with Orthodoxy and Reform. He distinguishes between the verbal revelation held by the Orthodox, in which God spoke to Moses, giving him the entire Tradition, both Oral and Written from the progressive revelation of the Reform, in which later ages replaced earlier ones, such as the prophetic tradition replacing the Torah-legal tradition. In between is the concept of continuous revelation of the Conservative movement with its understanding of word, message and essence, depending on one's stance in the movement.

Himmelfarb (1966) edited a symposium on the condition of Jewish belief, where luminaries from various fields of Jewish scholarship responded to five questions. These include: (1) In what sense do you believe the Torah to be divine revelation? Are all 613 commandments equally binding on the believing Jew? If not, how is he to decide which to observe? What status would you accord to ritual commandments lacking in ethical or doctrinal content? (2) In what sense do you believe that the Jews are the chosen people of God? How do you answer the charge that this doctrine is the model from which various theories of national and racial superiority have been derived? (3) Is Judaism the one true religion or is it one of several true religions? Does Judaism still have something distinctive—as it once had monotheism—to contribute to the world? In the ethical sphere, the sphere of *ben adam lahavero*, what distinguishes the believing Jew from the believing Christian, Moslem, Buddhist—or for that matter, from the unbelieving Jew and the secular humanist? (4) Does Judaism as a religion entail any particular political viewpoint? Can an individual be a good Jew and yet, say, support racial segregation? Can a person be a good Jew and be a Communist? A Fascist? (5) Does the so-called “God is dead” question which has been agitating Christian theologians have any relevance to Judaism? What aspects of modern thought pose the most serious challenge to Jewish belief (Himmelfarb, 1966, 7).

Kaplan's *magnum opus*, *Judaism as a Civilization* (1934), as well as his *Questions Jews Ask: Reconstructionist Answers* (1956) and *The Meaning of God in Modern Jewish Religion* (1962) describe Judaism as an evolving religious civilization and reinterpret the nature of God from supernatural to trans-natural. He argues that Judaism changes as the Jewish people encounter new social, political and cultural

conditions. Therefore, in order for Judaism to survive and grow in this scientific era, Jews must continue the process of reconstructing their heritage in response to today's reality, producing new literature and liturgy, adding and eliminating customs and traditions.

Finally, Gillman (2000) explores who is God, what is God's nature, what the sacred texts tell about God and why one should seek to define God. Is God the creator, a friend or a force in nature? Is God caring and loving or abandoning and abusive? Gillman explores these questions by examining traditional and modern sources to reveal the way one's views about God change through time. He helps one understand what the search itself says about one's own spirituality.

For parents of children diagnosed with autism, exploring the various classical and contemporary ideas of God will provide comfort and insight as they come to recognize and reassess their embedded theologies and wrestle with new God ideas. This exploration will help them articulate a deliberative theology that incorporates the pain and wisdom resulting from their particular life experience in light of their child's diagnosis. Such emotional and theological engagement can help these parents find a meaningful place within Jewish belief and a new place of acceptance and inclusion within the Jewish community that validates them and their family situation.

Grief, Suffering and Hope: A Theological Perspective

With regard to the question of suffering and why bad things happen to good people, Kubler-Ross' (1969) landmark study on death and dying must be considered. In it she outlines five stages of grief: shock, denial, anger, bargaining and acceptance. Similarly, Kushner (1981) offers a moving and humane approach to understanding life's

maelstroms. He addresses the struggle faced by those who are hurt by life and who know in their hearts that if there is justice in the world, then they deserve better. Blech (2003), an Orthodox rabbi and child of Holocaust survivors, offers a counterpoint to Kushner. He gleans insight from traditional Rabbinic literature to respond to the question of evil and posits that human beings will never be able to fully explain why the righteous suffer and the wicked prosper. Yet, he sees evil as necessary to enable one to change and gain understanding. Similarly, Levine (1996) shows how everyone can find an eternal friend in God, even in the face of one's gravest doubts.

Kraus (1988) explores how to survive life's tragedies and use pain as a new way to understand God. Kraus believes that even in one's bleakest hours, there is room for hope. It is during these times of crisis that one actually has the greatest opportunity for growth and to transcend sorrow, anger, guilt and fear. He believes that one can emerge from his or her crisis with a greater capacity for life and a deeper appreciation of his or her own uniqueness. Keiner (2002) claims that the Jewish experience of suffering is ever present: "it is a mathematical constant embedded in the entire history of the Jewish people" (1). In addition to the experience of suffering common to the human condition—loss of a loved one, setbacks in making a better life for family and friends, personal tragedies and ironic *dénouements*—there is the undeniable fact that wherever Jews lived throughout their long history, they received "the longest hatred" of what today is called anti-Semitism. It is not that Jews want to suffer; it is rather that Jews are constantly made to suffer.

Kraemer (2000) examines medieval Jewish philosophical traditions on suffering and evil by the leading thinkers of the day. Joseph Saadia el Fayoumi (Saadia Gaon, 882-

942), insists that humans have free will and offers that suffering is either punishment for the sins a person commits or a test from God. Judah Halevi (1086-1145) likewise writes that a person's troubles serve to cleanse sins, and therefore he recommends a pious attitude of acceptance and joy. Maimonides (1135-1204) argues that God does not create evil in any of its forms. Instead, evil is privation, the absence of some thing or quality. Maimonides enumerates three species of evil: those that befall people because they possess a body that degenerates, those that people cause one another because of their absence of wisdom, and evils that people cause themselves because of their ignorance. God creates none of these evils or their associated sufferings; they are, instead, caused by natural forces, by essential human failings, or by human ignorance. However, in addition to these understandings, many medieval liturgical compositions exhibit a considerable degree of horror and even anger, some complaining against the God who is "mute" or who "hides his face." Braiterman (1998) rejects traditional theodicy attempting to justify and vindicate the relationship between God and catastrophic suffering.

Kraemer (2000) further examines suffering in medieval Jewish mysticism and claims that early Qabbalistic texts record the belief that evil is a product of the unchecked growth of Divine judgment; judgment without mercy is wicked. The domain of judgment gone awry is called the *sitra ahra*, "the other side." According the Lurianic Qabbalah, God—the *ein-sof* ("the limitless one")—contracts in order to create space for Creation. In this space special vessels preserve sparks of Divine light. This light contains concentrated "shells" of stern Divine judgment that, when shattered, scattered throughout Creation. This is the root of all evil. Redemption requires repairing the vessels by performing the *mitzvot* (commandments) of the Torah. Likewise, Tishby (2001) seeks to understand evil

within the context of Lurianic mysticism, claiming that the source of evil is the result of a catastrophe that takes place deep within the Godhead itself.

Steinberg (1947/1975) demonstrates that attempts to justify God's ways and the presence of evil and suffering in the world group themselves into four logical classes. First there are the theories that seek a moral understanding. These claim that evil and suffering result from a prior individual sin, or the expiation of sin not of an individual but from his or her community. Other theories in this class include the idea that evil is necessary to appreciate the good, or that it is necessary to develop a moral conscience or "attachments to justice, compassion and love" (54). Second are the metaphysical theories: evil is merely the absence of good, evil only appears that way because humans have only a partial view of the Divine plan, evil is simply nature's law affecting humans adversely. Third, evil is something temporary and compensation will be received in the afterlife or that it is part of human development on the way to human perfection. Finally, is the theory that evil is beyond human understanding. Similarly, Pinnock (2002) presents existential and political considerations to the problem of evil.

Blech (2003), Soloveitchik, Wolowelsky, Shatz and Ziegler (2002), Carmy and Hirt (1999), Bulka (1998) and Boteach (1994) explore the reason for suffering from a Jewish perspective. Each explores such questions as: Why does God allow sickness, torture and evil to exist? If I suffer, does that mean I deserve it? Why do innocent people, especially children, die tragically? Does God ever intervene during times of trouble? Who really runs the world—God or man? Do my prayers do any good? Gibbs and Wolfson (2002) analyze the complex relationship between religion and suffering. Olitzky and Friedman (2000) seek answers and comfort from Judaism and Jewish sources. Their

book chronicles their journey of faith while providing sources of inspiration, healing and insight culled from Jewish tradition.

Since there is no literature that directly addresses the emotional or religious suffering of parents coping with their child's diagnosis of autism (or any other disability for that matter) or issues unique to them, they must look to other literature for answers. Thus, exploring the various classical and contemporary ideas of grief, suffering and hope within the Jewish context and in light of Jewish history can provide solace and understanding. The literature demonstrates that they do not suffer alone, even if they feel that their suffering is unique; it shows that they are not alone in grappling with the issue of evil and suffering and that answers that satisfy some do not satisfy others. The literature also enables them to contribute to this understanding by articulating their feelings and coming to grips with the reality of their pain and expressing it so that others like them can find meaning, compassion and solace. Such interaction can help these parents find a meaningful place within Jewish belief that validates their experience.

Although theologians continue to struggle with the meaning of wickedness and suffering in the world, Jewish tradition, nevertheless, maintains a theology of hope and optimism. Judaism is a life-affirming religion. At every lifecycle event Jews recite the *SheHeHiyanu*, the "Prayer of Thanksgiving," which expresses their gratitude to God for "keeping us in life, sustaining us and enabling us to reach this day." One of the most famous statements in the Torah proclaims: "I have set before you life and death, blessing and cursing; therefore choose life that both you and your seed may live" (Deuteronomy 30:19, trans. Potok 1985, 323). The national anthem of Israel is *HaTiqvah*, meaning "The Hope." Throughout history, Jews never lost hope. Hope in a better tomorrow has always

been a pillar of the Jewish faith. In the face of incredible horrors, in the face of persecution, expulsion and even genocide, the Jewish people always held onto their hope for a better tomorrow. Indeed, Leo Tolstoy once observed that Jewish hope, Jewish faith in the future, "is the true force of life" (Baron 1985, 186). For the Jew it always has been so.

Clinical Psychology Principles that Guide and Inform

Sharing their stories and reading their tradition through the lens of their personal experiences can engender healing and restored faith to the parents of children with autism. Indeed, Boje (1999) observes that "narrative therapy assumes that people's lives are strongly influenced by their story sense-making" (1). Deconstructing their stories allows them to identify, name and externalize dominant stories and examine their effects on their lives. Narrative therapy then reframes those stories into "preferred stories of being" allowing clients to re-interpret their life-stories in new and healthier ways. (Boje 1999, 1). This also enables individuals to realize that "the person is not the problem, the problem is the problem," thus empowering them to break away from previous assumptions about themselves and restructure their lives accordingly (Boje 1999, 2).

Psychology and Narrative

Vaknin (2005) notes that storytelling is an early form of communication and "serves a number of important functions: amelioration of fears, communication of vital information, ...the satisfaction of a sense of order (justice), the development of the ability to hypothesize, predict and introduce theories and so on" (1f). Yet, he notes, "while we

have been successful at imposing the structures of our mind on the outside world, we are less successful when we try to cope with our internal universe" (Vaknin 2005, 2). Framing one's experience as "a unique narrative...invented for every patient (client) in which s/he is the protagonist (hero or anti-hero)" helps provide that structure and gives the individual a means to understand and cope with his or her internal universe (Vaknin 2005, 3).

Bruner (1990) says this is possible because there are two ways of knowing: paradigmatic and narrative. Paradigmatic knowing is logical and scientific; it attempts to be mathematical and use formal systems to describe and explain one's world. Ruiz (1997) and Botella (2005) note that the way a computer works serves as a good metaphor for paradigmatic knowing. Ruiz (1997) further remarks, "It allows us to solve the majority of practical problems in everyday life" (1). In this, Botella (2005) also notes that "the basic psychological act in the construction of meaning is the creation of a metaphor" and that this is true not only of self-theories but also "so-called scientific theories in general," including psychoanalytic theory (Botella 2005, 2).

The second way of knowing described by Bruner (1990) is through narrative. As Ruiz describes it, "Narrative thought consists of telling stories of oneself to oneself and to others. By telling these stories, we start to construct a meaning with which our experiences gain sense" (Ruiz 1997, 1). It is this continual self-narrative that allows one to create a personal identity by individuating and differentiating from the world around him or her; thus, it is a continual process. It is, therefore, not only a way of perceiving the world, but most importantly, a way of feeling in it. As such, "the way in which the construction of a vision of the world is perceived is not something purely intellectual,

each sequencing of events and scenes also comprises an activation of the emotional events world and the reverberating of prototypical events corresponds to the reverberating of specific emotional modulations" (Ruiz 1997, 2). Thus, Botella (2005) points out that "it is often useful to deconstruct the client's discourse so as to identify his or her root metaphor in order to refine it or help him or her to revise the metaphor" (Botella 2005, 2). In the case of parents coping with the reality of living with a child diagnosed with autism, narrative psychology can be very helpful in reframing their experiences because it adopts a view of "human beings as proactive and future-oriented," thus instilling hope and enabling resilience (Botella 2005, 1).

According to Bruner (2004) narrative psychology is interested in the "storied nature of human conduct," which examines how one deals with experience by constructing stories and listening to the stories of others (1). He believes that the stories of human activity and experience are filled with meaning and are the vehicle by which meaning is communicated, more so than logical arguments or legal formulations. Crossley (2000) and Plummer (2001) see narrative psychology as a means to understanding the nature and function of the self with a depth and breadth not found in traditional sources of social science data. Rosenwald and Ochsberg (1992) focus on the "relationships between personal stories, cultural and political forces influencing these stories and the processes of coming to a self-identity" (Bruner 2004, 6). The common denominator of these approaches to narrative psychology is an awareness of subjectivity and reflective thinking as a means of knowing (Josselson, Lieblich and McAdams 1993, 7).

Elkins (2001) views narrative understanding as a basic form of human reasoning. Dividing reasoning into four "mental modules," Elkins (2001) identifies four stages of mental module development (that parallel basic human development), which places narrative reasoning into a continuum that shows why it is essential to examine people's self-narratives as a form of therapy. The first of these is spatial reasoning, which is closely associated with visual processing and is "both ontogenetically and phylogenetically the earliest of [one's] mental modules," paralleling an infant's first interactions with the universe (Elkins 2001, 1). Social reasoning is the second of these modules, enabling one to handle radial relationships, those between an individual and others, as well as circumferential relationships, those involving three or more parties "in which the individual calculates likely behaviors between two [or more] others with respect to that individual" (Elkins 2001, 2). This parallels an infant's individuation and differentiation from its mother and then others.

The third module in the sequence is verbal reasoning, which provides two important expansions: temporality and action. Temporality provides the ability to think in tenses—past, present and future—which, according to Elkins is something only humans can do; animals think only in the present. The final stage is narrative reasoning, which builds on verbal reasoning by enabling causal reasoning to take place: "narrative reasoning is the mental module that was originally developed to handle causality" (Elkins 2001, 3). It is narrative reasoning that allows one to understand how and why things happen. Thus, reflecting on one's personal narratives enables him or her to re-evaluate causes and effects and to reframe one's experiences in a more positive and healthful way. This is particularly important for parents of children with autism who often feel guilty

and wonder about the cause of their child's disability and whether or not they somehow are responsible and could have, therefore, prevented it.

McLeod (2000) discerns several consistent themes among clients when using narrative processes in experiential therapy: building a story-world in which personal stories are embedded in a narrative framework, the cycle of storytelling, the story as an invitation to empathic engagement, and the significance of meta-narratives. He deduces from these recurrent themes that "vivid stories function as *openings* into the experiential world of a person" (McLeod 2000, 1). Thus, appreciating one's personal narrative or story enhances the effectiveness of a psychoanalytic or psychodynamic approach to psychotherapy by recognizing that the underlying cognitive construct through which the person makes sense of his or her world is expressed and structured as a story.

Since "narrative and storytelling are ways of using language to convey experience and organize interaction," therapy becomes the process of "re-authoring" one's story to give it new and more healthful meaning (McLeod 2000, 2). As well, this re-examination of the "macro-narrative," or overarching life-narrative of the person "offers the client a way of understanding his/her difficulties, and a means of re-telling his/her life-story, that emphasizes the core assumptions of person-centered theory and philosophy: the importance of affirming the inner self and an inner private world, and the value of authentic expression of feeling" (McLeod 2000, 13). In so doing, counseling and psychotherapy enable a process of personal integration and of social inclusion, which, in the case of parents coping with a child with autism, is an important goal.

McLeod (2000) defines three stages in the qualitative analysis of narrative. First is a succession of "readings and re-readings of the text" at which time identification of

themes and discursive phenomena takes place (4). The second stage involves selecting portions of one's story for more in-depth analysis, which he calls "micro-analysis" (McLeod 2000, 4). Finally, the analytic insights are integrated into a coherent and interpretive account of the material presented.

Grief, Suffering and Hope: A Psychological Perspective

For parents of children with autism, personal narratives include stories about and feelings of loss and grief. Indeed, Rawson (2005) observes that grief touches everyone during the course of a lifetime. For some it is earlier in the lifespan than for others, but everyone struggles to find ways of going through a loss of any kind, be it the death of a loved one, the loss of a job, the loss of an unborn baby or the loss of ability. She provides information on the "symptoms" of people faced with loss and her view on the different cycles of grief. In this she builds on the landmark work of Kubler-Ross (1969/1997) regarding death and dying, in which Kubler-Ross defines five stages of grief: shock and isolation, denial, anger, bargaining and acceptance. While those grieving—and those offering support to the grieving—often see these as progressive stages, Rawson (2005) points out that these stages often work in cycles or in a non-linear fashion with those in grief moving forward and backward through these stages at varying times depending on many variables. Likewise, Brammer (1992) states: "The process does not proceed in nicely calibrated phases and people often recycle through the process" (2).

Blatner (2005) observes that unresolved grief is an all too common problem in life and that the psychological process of coping with a significant loss is called grief work. He claims that just as one can heal a bodily wound if he or she cleans out the foreign

material, brings the edges of the wound back together and gives the body the proper nutrients, so too will the wound of psychological loss also heal if one can clean out—that is, work through—unnecessary contaminants such as unreasonable guilt and resentments, connect the individual to others and prevent him or her from feeling isolated, and help the person tap into the psychological nutrients that come from some kind of positive outlook on life. He further presents three general categories of grief work: ventilation, empathy and re-integration.

Ventilation involves “simply being genuinely present with those who are grieving” by being willing to tolerate and empathize with the pain they feel, and giving them a chance to “talk openly to someone who will give them appropriate support and make sure they go through the whole process” (2). Time is an important factor because “people tend to avoid their feelings using a wide range of defensive maneuvers” (Blatner 2005, 2). Empathic support means becoming aware of the person’s real feelings—which can include both the need to avoid thinking and talking of the loss as well as the need to talk in detail—and imagining what it would feel like to be in the same situation. Re-integration involves “integrating the various parts of the self, reconciling with the lost person and the loss itself, and rediscovering one’s personal meaning and direction” by renewing his or her commitment to life (Blatner 2005, 5f). For parents of children with autism, this would involve reconciling oneself to the loss of the person-image one had of what his or her child would have been like had he or she been neurologically “typical,” acknowledging the loss of ability and rediscovering the child that lives beyond the autism.

Roehl (2003) offers practical advice to parents coping with grief including respecting one's own needs and discerning what advice from others may or may not be helpful, having realistic expectations for grieving and not to expect the process to follow a particular time frame. Thus, for example, just because Jewish tradition marks the first phase of mourning with "sitting *shiva*" for seven days, that does not mean that after the seven days the most intense part of grieving will be over. It may take much longer. *Shiva* is a symbolic period of time reflecting a spiritual desire to come to grips with the finite nature of death and the feelings it engenders. For parents grieving over the diagnosis of autism for their child, it can take years before healing begins. Roehl (2003) advises such parents to let their grief flow and honor their feelings while maintaining faith that eventually they will feel better: "Instead of imagining grief as a bottomless pit, imagine a tunnel. When you are in the middle of it, you may not see any light. But as you work through your feelings of yearning, anger, guilt, failure, sadness and hurt, you will come out the other side" (2). She also advises accepting the support of others; pursuing things that help one cope with his or her feelings; and making a conscious choice to get through one's grief without letting it destroy his or her life:

This can be a significant key to survival. You can decide whether to face or to hide from your feelings; you can choose whether to triumph over your loss or be defeated by it. Many parents mention that eventually they reach a point where they just decide to stop wishing it didn't happen and start learning to live with it. When you're ready, you can do that too. (Roehl 2003, 2)

Her approach allows one to hold onto some hope for the future and lets parents know that they are not alone.

Coping with Stress

Part of coping with one's grief and with the reality of having a child with autism is understanding the stresses involved. Naughton (1997) analyzes stress and coping and concludes that there are three components: biological/physiological, cognitive and learned. In the biological/physiological component, the body responds to a threat or challenge that an individual perceives in the environment. The brain triggers a chain of neuroendocrine events consisting of two separate responses: a sympathetic/adrenal response with the secretion of catecholamines (epinephrine, norepinephrine) and a pituitary/adrenal response with the secretion of corticosteroids.

The cognitive approach to coping emphasizes how an individual appraises a situation. The level of appraisal then determines the level of stress and the unique coping strategies that the person applies. There are two types of appraisals: primary and secondary. A primary appraisal takes place when a person makes a conscious evaluation of a matter at hand and determines whether or not it is harmful—a loss, a threat or a challenge. Secondary appraisal takes place when the individual asks him- or herself how to respond by evaluating the coping resources around him or her. The learned component assumes that much of human motivation and behavior is the result of learning through experiential reinforcement, learned helplessness phenomena and through cultural and societal norms.

The interplay of these three components is the subject of much debate. The reductionist model of stress emphasizes a purely physiological perspective in which the brain alone determines the presence of stress. In the interactionist model, both the brain (biological/physiological) and the mind (cognition and learning) affect stress, but the

brain operates in a unidirectional path leading the mind to stress. The transactionist model operates on a bidirectional path in which stress influences both the brain and the mind and through the stress the brain and the mind mutually affect one another. Thus, Naughton (1997) concludes that coping is a complex process influenced by personality characteristics, situational demands, as well as the social and physical characteristics of the setting.

Kauser and Powell (1992) point out that "relatives play a major role as caregivers of their ill and dependent family members," far more than outside service agencies or the government. As such, these caregivers, most often parents in the case of caring for a child with autism, face multiple stressors in the course of caring for their child, often at the same time. Schmall and Stiehl (1998) list some of these stressors as demands on time, energy or money, conflicts in responsibilities, differences in expectations between family members, work and oneself, a lack of understanding about nature of the disability—in this case: autism, difficulties meeting the child's physical or emotional needs, the pressure of financial decisions and lack of resources, a loss of freedom, disagreements among family members, unrealistic demands and expectations, and a lack of open communication. This list is by no means exhaustive, although it is almost always overwhelming to parents trying to cope.

Kauser and Powell (1992) demonstrate that cognitive processes influence the outcome of stress. They define cognitive appraisal as:

A process in which one evaluates a particular encounter with the environment, estimates whether the situation is relevant or important to him or her (known as primary appraisal) and if so, whether it requires the mobilization of coping strategies, and whether the necessary strategies are

within the means of coping resources (referred to as secondary appraisal). (Kausser and Powell 1992, 1)

They find that caregivers perceive personality and behavior changes in their charges to be more stressful and more threatening than physical changes. As well, the caregiver's well-being and self-esteem seem at risk and they express more financial worries. Caregivers express a need to accept and to get information, although they may have difficulty with both. Personality and behavior problems in patients, such as sudden mood changes, irritability, emotional coldness, social avoidance, meanness, unreasonableness and immaturity, may also lead to anger and distress in caregivers and make them realize that they need to restrain themselves and not lose their temper.

The National Women's Health Information Center (NWHIC, 2001) reports that care-giving often takes a great deal of time, effort and work resulting in the caregiver's struggle to balance care-giving with other responsibilities including full-time jobs and caring for other children. The NWHIC records that constant stress can lead to burnout and health problems for the caregiver, including increased risk for depression and illness. Among the many practical suggestions the report makes is finding a support group for other caregivers who are in the same situation, in this case, caring for a child with autism.

Antonovsky (1987), Wong (1993) and Halama (2000) demonstrate that a sense of meaningful life is important for positive coping and stress management. They find that "personal meaning [is a] major resource contributing to resistance to stress" (Halama, 2000, 1). Halama (2000), in particular, examines the breadth of meaning (number of sources of meaning) and depth of meaning (intensity of self-transcendence of values) and concludes that breadth of meaning is a weak predictor of coping, while depth of meaning is a strong one: "individuals with deep values, beliefs and goals can use these as sources

of active and constructive coping" (9). Conversely, Zika and Chamberlain (1987) find that the level of life meaningfulness correlates negatively with the level of daily stress one experiences. As daily stress increases, life meaningfulness decreases.

Similarly, Zeidner and Endler (1995) note that, "how a person adjusts to life stresses is a major component of his or her ability to lead a fulfilling life" (1). They trace the history of coping from its origins in the psychoanalytic theories of unconscious defense mechanisms and review the latest conceptualizations, models, and constructs. Likewise, Conte and Plutchik (1994) explore the nature and manifestations of defense mechanisms and trace ego defense theory and research from Freud's initial conceptualization through recent work in object-relations theory and other psychoanalytically oriented approaches. They also provide clinical guidelines for diagnosing, assessing, and dealing with defenses. Brammer (1992) identifies the defense mechanisms most often utilized as rationalization, denial and fantasy.

In particular regard to stress and coping with a disability, Murphy (2005) claims:

From a psychological point of view, a person's response to disability is related to his or her level of psychological functioning prior to the [onset of disability]. In other words, if they had difficulty coping with life problems and if they had low self-esteem prior to disability, they are likely to have more difficulty adjusting than previously well-adjusted people. (1)

He further notes that social factors can often have the most profound impact on one's adjustment to disability. Jinks (2005), Pinter (2005) and Tipton (2005) agree and suggest ways to cope positively with disability including making time for oneself and time to be with friends (respite care), putting words of love on paper and reminding the disabled individual how much the family caregiver loves him or her, overtaking the disability by

keeping a journal and not letting the disability frustrate the caregiver, focusing on what one can do instead of what one cannot do, emphasizing who the disabled individual is rather than what (i.e. "handicapped") he or she is, turning to "the One who made you" (Tipton 2005, 11) to give one peace of mind and the strength to face each hurdle as it comes, and putting guilt into perspective.

Shame

Panos (2003) claims that after experiencing a traumatic event, whether recent or in the distant past, shame can haunt victims in a powerful and often unrecognized manner. For parents of children with autism, this shame may take the form of feeling different from other families who do not have children with autism, feeling somehow responsible for bringing this disability on one's child, feeling ostracized by communal institutions or its members because of their inflexibility in accommodating one's child with special needs. The shame can run deep and be accompanied by guilt, humiliation, demoralization, degradation and remorse; it can be debilitating emotionally. "Shame impairs the healing and recovery process causing victims of trauma to stay frozen, unable to forgive themselves [and] leaves victims with feelings of sadness and pain at the core of their being. They are unable to feel the fullness of joy in their lives" (Panos 2003, 1). In so doing, shame can dissolve positive self-esteem and leave individuals no longer feeling worthy of being loved, accepted, and having good things happen to them in their life. Thus, claims Panos (2003), "shame complicates the healing and recovery process from trauma on many levels including psychologically (victims blame themselves for being vulnerable) and spiritually (changes relationship with higher power)" (2).

Bradshaw (1988) distinguishes between good shame (the kind that keeps pride in check and makes one modest) and toxic shame. He claims that toxic shame is the core problem in the compulsions, co-dependencies, addictions and the drive to super-achieve in many people. In the case of parents coping with children disabled by autism, the drive to super-achieve or the self-consciousness of having a child that does not measure up to others' or one's own expectations can be a source of shame. Bradshaw advocates using affirmations, visualizations, "inner voice" and "feeling" work plus guided meditations and other healing techniques to free oneself from toxic shame.

Psychological Resilience

The capacity for a person to avoid psychopathology despite difficult circumstances is, according to Neill (2005), the definition of psychological resilience. Thus, "the central process involved in building resilience is the training and development of adaptive coping skills" which will either be focused outwardly on problem-solving, inwardly on emotions or socially through support groups (2). However, he cautions that resilience is a dynamic quality and that "resilient individuals demonstrate dynamic self-renewal, whereas less resilient individuals find themselves worn down and negatively impacted by life stressors" (2). Neill (2005) characterizes resilient people as those who have one or more of the following qualities: the ability to "bounce back" and "recover from almost anything," have a "where there's a will, there's a way" attitude, have the tendency to see problems as opportunities as well as the ability to "hang tough" when things are difficult, are able to recover from experiences in the panic zone or of a traumatic nature, have deep-rooted faith in a system of meaning and have a healthy social

support network (3). The common element to all these characteristics is hope and an optimistic outlook. These elements seem critical to the success of coping with disabilities, in particular, for parents coping with the reality of a child with autism.

Falcon (2002) observes that many stressful events in one's life can lead to depression and rob one of hope. What distinguishes those who continue to maintain a happy and hopeful disposition from those who succumb to depression is, in part, "a courageous choice of loving life in the face of suffering, a chosen position or view of things" (2). Pessimism, then, destroys one's will to persevere and overcome one's difficulties: "Expecting dissatisfaction and failure, depressed people often give up easily and thereby bring on failure" (Falcon 2002, 3). He notes that happy people experience failure, disappointment, rejection, negative emotions, pain and great sorrows too, but "happy people keep a positive attitude by gracefully accepting sadness and suffering as normal parts of life while doing what they can about their problems" (Falcon 2002, 2). He advocates reframing one's experiences by reexamining one's expectations or priorities in life and adjusting them to better suit reality, as well as by finding a good network of support.

In light of this, Dunavold (1997) examines the nature of happiness, hope and optimism to determine if they involve biological, learned or cognitive processes. These factors would have an impact on the ability of parents of children with autism to acquire or maintain a positive, hopeful outlook that would enable them to lead a happy life and successfully cope with the stress of raising a child with a disability. It would also impact the way they view their self-narrative and their ability to reframe negative experiences into positive ones. Spiritually speaking, it would have an impact on the parents' ability to

find personal meaning in relationship to God based on reconfiguring their theology in light of their experiences and the interpretation of them.

Dunavold (1997) concludes that happiness, hope and optimism differ in the means by which individuals acquire them. Happiness, as an emotion, is a biological state brought about by the release and blocked re-absorption of certain neurotransmitters triggered by physical and cognitive activities. Learned differences account for the disparity in levels of happiness by individuals after experiencing similar activities. Hope, on the other hand, is primarily a learned condition. People learn to be hopeful at an early age through the socialization process. It requires little cognitive thought and, in fact, actively thinking about the pros and cons of some situations could lead one to lose hope. Optimism, by comparison, is primarily a cognitive activity. Certain people do have an optimistic attitude about life while others do not, but their optimism, unlike hope, is based on logical, rational facts that are processed cognitively. Finally, hope and optimism differ in that "hope is situation particular (specific condition) and contingent upon one's own abilities (internal condition), [while] optimism is an overall explanatory style (global condition) that positive things will occur independently of one's ability (external condition)" (Dunavold 1997, 5).

Psychodynamics

It is clear, then, that being the parent of a child with autism is complex and fraught with many obstacles, both physically and mentally, as well as externally and internally. Looking at the psychodynamic of such parents from Freud's (1923/1977) structural theory, the id (source and repository of sexual and aggressive impulses) is the

seat of all desire, seeks pleasure and wants to avoid pain. The id, "not directly influenced by reality, morality logic, or social convention" (Schamess 2002a, 54) and not represented by the conscious mind, seeks to escape the emotional pain and entrapment of the overwhelming grief and associated emotions that accompany and follow after receiving news of the diagnosis. Counterbalancing this is the superego, "the enduring organization of moral beliefs and prohibitions within the mind," which is only partially conscious in that it also "represents developmentally early, punitive, and persecutory tendencies" that are preconscious, if not unconscious (Schamess 2002a, 56).

As the seat of civilized moral behavior, the superego can be as demanding and unreasonable as the id and thus diminish one's self-esteem. The guilt, shame, humiliation, demoralization, degradation and remorse that parents of children with autism often feel comes from the oppressive nature with which the over-stimulated superego can make itself manifest. It is then the task of the ego to mediate between the two. The purpose of the ego is to "maintain psychological cohesion and stability in the face of powerful, conflictual forces that arise when id, superego and/or external reality clash, that is, when people experience a combination of wishes, moral demands, social expectations and fears that are inherently incompatible" (Schamess 2002a, 59). It is the ego, when functioning in a healthful way, that perceives the physical and psychological needs of the self, evaluates and integrates perceptions of the self and external reality as well as ensures that the internal demands adjust to better correspond with that perceived reality. It is also the ego that preserves "a reasonable level of self-esteem by maintaining good relations with the superego" (Schamess 2002a, 59). Whenever the ego feels itself under attack by anxiety, different defense mechanisms unconsciously come into play and try to help the ego

resolve its mental conflicts. With parents of children with autism, some of these defense mechanisms may include rationalization, intellectualization, denial, avoidance, magical undoing, projection, dissociation, conversion or regression.

Ego psychology expands Freud's theories by focusing on the human developmental processes across the lifespan and how they respond to environmental influences and internal potential. These include:

- (1) perceiving, filtering and selectively remembering the enormous amounts of information that originate both inside and outside the mind; (2) organizing (editing) the filtered information in ways that allow individuals to think, feel, and act coherently; (3) finding socially acceptable ways of satisfying the conflicting demands of the id and the superego; (4) facilitating all of the routine mental activities (loving, learning, playing, acquiring new skills and capacities, etc.) that characterize human experience; (5) mastering the developmental and social challenges that arise normatively over the course of the life cycle; (6) developing capacities that make it possible to deal adaptively with the ordinary stresses of everyday life; and (7) finding ways of minimizing the disruptive effects that trauma has on overall functioning. (Schamess, 2002b, 69f).

The ego uses various ego functions to organize and synthesize these activities such as reality testing, judgment, impulse control, modulation of affect, object relations, self-esteem regulation, mastery and the use of defense mechanisms.

For parents of children with autism these ego functions serve to help them negotiate life and point to areas in need of help when these functions break down. With regard to reality testing, parents of children with autism work to understand and accept the physical and social reality of their lives as defined by the inclusion of a disabled child in light of their internal wishes and fears. Judgment helps them determine what is and is not appropriate behavior in light of their wishes, feelings and memories, particularly as

they compare and contrast their lives before and after diagnosis. Impulse control keeps sexual and aggressive feelings in check. This is important for parents coping with their child's disability because there is a high probability of aggression directed toward their child or toward themselves that could lead to terrible consequences, particularly when frustrated, anxious or tired.

Object relations are the "ability to form and maintain coherent, loving and/or friendly ties with significant others" (Schamess 2002b, 76) and refers not only to current relationships, but past ones as well. It plays an obvious role in parents' ability to love the child despite the autism that may block his or her reciprocal demonstration of affection. This will have an impact on another ego function: self-esteem regulation. It is difficult for parents coping with the daily issues of a child with autism to maintain a positive self-regard in the face of overwhelming external challenges and inner emotional turmoil. Mastery reflects "the epigenetic view that individuals achieve more advanced levels of ego functioning by mastering successive developmental challenges" (Schamess 2002b, 77).

Flanagan (2002a) notes that "Object relations theory is based on the belief that all people have within them an internal, often unconscious world of relationships that is different and in many ways more powerful and compelling than what is going on in their external world of interactions with 'real' and present people" (127f). Thus, object relations theory considers not only the real and tangible relationships one has, but also the internal self and object representations as well, including those stemming from past relationships. Object relations theory differs from ego psychology in that it concentrates on how needs are or are not met in relationships, rather than on satisfying impulses.

Consequently, the relationship is the center of the experience rather than just the self. Thus, for parents of children with autism, their internal representations of object experiences from the past can take over the present inner world to such an extent that it renders life painful and confusing by distorting present relationships with their child, spouse and others.

For example, immediately after diagnosis and for some time afterwards, parents mourn the loss of their "neurologically typical" child. Sorrow fills them and they find no interest in the present or future. Thoughts of how their child was before the diagnosis haunt and comfort them at the same time. Familiar places of past joy mingle with sadness, remorse and anger. Parent's struggle to hold onto what was in the face of what is. In time, however, reality ultimately requires letting go of the "neurologically typical" child-object in order to face the challenges of today. They must return to the present and to the new object relationship: the one with their autistic child. But not everyone progresses through this stage and melancholia settles in:

There is the same dejection, the loss of energy and interest, but in melancholia these things do not pass. There is no sense of anything being worked through. The [grieving parents] remains in mourning, unable to move forward and, strikingly, in addition to being sad about the loss, seems full of complaints about the self. The [parents] seem to be suffering from a disturbance in self-regard that often reaches the level of self-hatred. (Flanagan 2002a, 132)

Rather than letting the "neurologically typical" child-object go and creating inner space for the new "autistic" child-object and experiences, the melancholic parents turn their energies inward toward the self with self-loathing and low self-esteem.

Self psychology, in contrast to ego psychology and object relations theory, concentrates on the kind of life experiences that mold someone into a cohesive self and

how the self further develops in relationships with others. In other words, whereas ego psychology and object relations theory look at the component parts of the self, self psychology looks at the self as a whole. Self psychology is essentially hopeful because "there are almost no dark forces in self psychology since the self is viewed as having a tremendous desire and capacity to grow if its needs are met" (Flanagan, 2002b, 175). However, if needs are not met, "secondary narcissism occurs later in life when the libido that has been directed toward others is withdrawn from objects back into the self due to illness, trauma or old age" (Flanagan, 2002b, 177). Clearly, parents facing the trauma of a diagnosis of autism, which is a debilitating developmental disability, akin to chronic illness, are susceptible to secondary narcissism. The key to warding off this secondary narcissism is empathy, "to *understand* from within the experience of another, no matter what the experience. Much more than a feeling, empathy is a way of knowing" (Flanagan, 2002b, 179). However, empathy is morally neutral; it can be good or bad depending on the empathic experience. Thus the need for mirroring other self-objects in one's life. Emulating others enables one to feel whole, cohesive. However, this too has its drawbacks: if others are idealized too much, the self can feel devalued, worthless and ashamed. Thus the need for twinning, the idea that there are others in the world who are similar to the self.

When faced with the uncertainties of a future with a disabled child, self psychology calls upon the idealized parent imago to provide a sense of security. This aspect of the self reflects the self-object need "to have someone strong and calm to idealize and merge with in order to feel safe and complete within the self" (Flanagan, 2002b, 185). This is especially important for parents who feel like their whole world is

crashing down around them. It can give them mental stability to act and advocate on behalf of their needs and the needs of their child. In a similar vein, twinning, the idea that there are others in the world who are similar to the self, can result from attending and participating in a support group where others experience life through the lens of autism just as these parents do.

Flanagan (2002b) points out that there is a concern about psychopathology in which there is an understimulated self, an overstimulated self, a fragmenting self or an overburdened self. An understimulated self means one's self-object did not have the opportunity to mirror his or her grandiosity sufficiently and thus he or she feels flat, bored, listless or apathetic. The overstimulated self suffers from the opposite experience: intense, excessive and inappropriate mirroring that leaves the self-object overwhelmed and too full of feeling. For parents of children with autism, fragmenting could be a concern, for if the parents had little sense of cohesion earlier in life, the stresses of coping with the disability externally as well as internally could lead to a crumbling or fragmenting of their sense of cohesion. Likewise, the overburdened self, feeling too alone and unsupported can break the spirit and hope of parents trying to cope: "the overburdened self feels he or she must 'go it alone' in what is experienced as an unnerving, demanding, even hostile world (Flanagan 2002b, 193). Too often, when facing governmental and medical bureaucracy in seeking services for one's child or one's self, the overburdened self can become exposed and vulnerable.

While many services are available to cope with and attend to the practical functions of day-to-day living with a child disabled by autism, not many resources—particularly in the Jewish community—address the internal core beliefs of the parents,

especially when those beliefs come under assault by the reality of living with a child with autism. Parents need to grapple with their embedded theology in order to find renewed hope and purpose in their lives, they need a deliberative theology that is flexible, incorporates and makes sense of their self-narrative and enables them to find the coping skills to live a hopeful and meaningful life. They need to explore their psychological selves in order to transition from a less adaptive to a more adaptive state of thinking, feeling and behaving that will enable them to live their lives fully, purposefully and happily.

Types of Psychotherapy

There are many types of psychotherapy that can help bring about this outcome. This is because "any human being at any time is in the process of change and development" (Lunn 2002, 1). While this is most obvious in children and adolescents, it is also true of adults and thus can help parents of children with autism find new meaning and adaptation to the reality they face. Among the most popularly practiced forms are: psychoanalysis, psychodynamic psychotherapy, behavioral, cognitive, existential, humanist, transpersonal/psycho-spiritual and eclectic.

Psychoanalysis is the personality theory and psychotherapeutic approach pioneered by Freud (1923/1977), which emphasizes making the unconscious conscious and thereby giving the individual choices in life rather than being at the whim of unknown forces within him- or herself. Psychoanalysis frequently uses dreams and free associations (spontaneous uncensored communications) as the subject matter for treatment. The therapist (analyst) says little, but guides the patient in interpreting the

meaning of the intrusion of unconscious material into everyday life. Richmond (1997) points out that, in its pure and classical form, psychoanalysis requires daily visits to the psychoanalyst where one lies on a couch with the analyst sitting out of sight and therapy takes several years.

An alternative to this is psychodynamic psychotherapy, which is based on psychoanalytic principles, but is conducted less frequently, over a shorter duration and allows a small amount of eclecticism. Richmond (1997) points out that sessions are usually just once a week, client and psychotherapist sit face-to-face and the psychotherapist is more active (communicative) compared to the relative silence of the psychoanalyst. Treatment is an interactive process between the client and the psychotherapist.

Compton, March, Brent, Albano, Weersing and Curry (2004) note that behavior therapy "evolved within the theoretical framework of classical and operant conditioning" (931) championed by Skinner (1976), while Selig (1999) explains that it "employs learning theory to effect changes in behavior" (4). Essentially, behavior therapy works on unlearning unwanted behaviors (even thoughts and feelings can be viewed as behaviors) and learning desired ones in their place. As such, behavior therapy primarily focuses on symptoms rather than working on unconscious material.

Cognitive therapy works to change thoughts and feelings which then result in positive changes in behavior. Richmond (1997) observes: "the way we perceive situations influences how we feel emotionally, and so, by changing thoughts, then behaviors will also change" (7). Selig (1999) explains that "unrealistic expectations, wishful thinking, living in the past (or future) and over generalizing can all lead to disappointment and

frustration" (4). By working to eliminate these inappropriate thoughts and feelings, cognitive therapy emphasizes a rational and positive world view.

Some practitioners combine behavioral and cognitive therapy (CBT) to achieve the desired results. In contrast to the psychodynamic emphasis on insight into unconscious motivation, Richmond (1999) explains, "the cognitive-behavioral therapies emphasize the ability of people to make changes in their lives without having to understand why the change occurs. As such, these therapeutic techniques usually take much less time and are therefore less costly than psychodynamic psychotherapy" (7).

Existential therapy examines some of the major issues in one's existence, such as the meaning of life, loneliness, mortality, and free will, to find constructive ways of coming to terms with the challenges of everyday living. It focuses on taking responsibility for one's choices and creating one's own meaning and purpose. Though it emphasizes the needs of the individual it usually helps people find new meaning in their relationships. Somewhat related to existential therapy and sometimes used together with it, humanistic therapy looks at the whole person including mind, body and spirit. Strisik and Strisik (2005) mention that humanistic therapy uses a broad range of therapeutic methods to realize the self-healing capacities of the individual seeking treatment.

Jackson (2000) and Strisik and Strisik (2005) also describe transpersonal/psycho-spiritual psychotherapy, which focuses on the spiritual dimension rather than on the content of therapy. It views the human psyche as having a central core Self or Soul as the heart of identity as well as a personal ego. Psychotherapists uncover past psychological material based on spiritual insight and experience. Therapy deals with ego-transcendence and includes both repair and individuation, recognizing spiritual crises and taking a

holistic approach. The final type of psychotherapy, mentioned by Selig (1999), is eclectic therapy and not a formal school of thought. It uses a combination of approaches or theoretical orientations and recognizes that individuals may benefit from a variety of techniques.

Group Psychotherapy

When it comes to applying psychological theory in a group setting, Earley (2005) claims that there are three types: psychodynamic, interpersonal and action-oriented. The psychodynamic uses Freudian principles and emphasizes making the unconscious conscious, thereby giving the individuals in the group the ability to choose the direction of their lives. Interpersonal approaches focus essentially on personal interactions and relationships among members of the group. Action-oriented groups (e.g. cognitive-behavioral) make a commitment to action as well as to self-exploration. While psychodynamic and interpersonal groups tend to be client-oriented, action-oriented groups tend to be leader-centered. In each of these types, someone is left out: the leader in the first two and relationships among group members in the third. As a result, Earley (2005) proposes an interactive approach which is both action-oriented and group-centered.

In his conception, the primary focus of the group work is on the relationships among the members and on what happens in the group. The group becomes a microcosm for members' lives and any interpersonal problems they have most likely occurs at some time in the group. Rather than just talking about the problems, members act them out in the group and get feedback about the way they impact others, about their feelings and

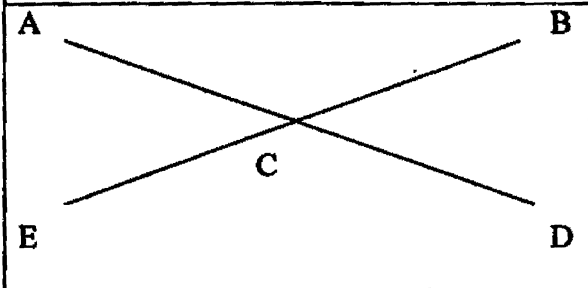
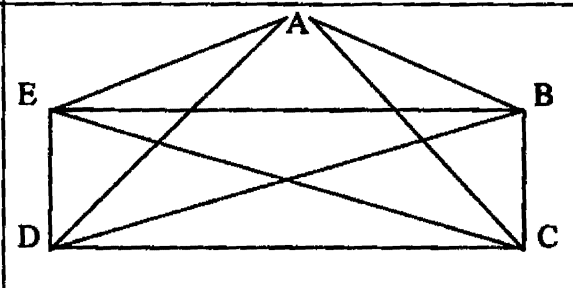
motivations, and about experimenting with healthier behavior. During this process, the leader facilitates them with awareness and communication skills empowering them to work on healing the pain and experimenting with healthier behavior in the group. Other common types of group work involve clients exploring their feelings about being in the group or the group-as-a-whole exploring an issue that affects everyone. In Earley's approach, the interpersonal work for each client changes over time.

Kraut (2002) points out that there are two basic mechanisms by which groups do better than individuals: aggregation and synergy. Aggregation refers to the fact that individuals who make up a group bring unique resources, energy, knowledge and skills and attitudes to it. Synergy refers to the increased effectiveness that comes through joint action and cooperation that builds on the combined resources of the group. In other words: the whole is greater than the sum of its parts. Hackman (1987) further notes that groups also need to have the capacity of working together as they move into the future (group maintenance) as well as supporting the needs of individuals within the group (member support) to be successful. Kraut (2002) also cautions that working in a group influences the motivations of the members. Sometimes being in a group enhances individual motivation and at other times it undercuts it.

Another important component to the success of a group, according to Kraut (2002), is communication among its members: "A basic finding from both laboratory experiments and field studies in organizations is that the right combination of volume, structure, content and interactivity in group communication depends upon the task" (13). For example, having all messages flow through a "communication coordinator" increases efficiency in a simple problem solving task group, as demonstrated through a hub-and-

spoke communication structure (Table 2A). Person C receives all messages and then passes them on to their destination. This form of communication is more efficient than the fully connected graph (Table 2B), where each group member can connect directly with every other one. However, in a moderately complex or difficult task, the fully connected graph is superior to the wheel. This also reveals that groups are different than individuals because they need to coordinate their efforts to achieve success.

Table 2. Group Communication Structures

A: Hub-and-spoke Communication Structure	B: Fully-connected Communication Structure
	

Yalom (1995), in discussing the benefits of group psychotherapy, divides the therapeutic experience into 11 factors: instillation of hope, universality, imparting information, altruism, corrective recapitulation of the primary family group, development of socializing techniques, imitative behavior, interpersonal learning, group cohesiveness, catharsis and existential factors. He points to the importance of instilling and maintaining hope. Not only does faith in the treatment mode instill hope, but "therapy groups invariably contain individuals who are at different points along the coping-collapse continuum. Each member thus has considerable contact with others—often individuals with similar problems—who have improved as a result of therapy" (5). By gathering together in support of one another, members find inspiration from those who preceded

them and raise their expectation of finding their way comforted by the knowledge that others have been down this path and found the way back to living their lives in wholeness. Indeed, Boje (1999) points out that one of the most important aspects of group work is the ability to share one's stories and hear other people's stories in return and thus draw strength and inspiration from one another.

Many individuals enter therapy thinking that they are the only ones suffering in their situation. Yalom (1995) sees the relief when new members turn to a group and find that others share their predicament and concerns. That knowledge alone is comforting and supportive and this is the universality of which he speaks. Similarly, altruism is a uniting factor since members of the group "receive through giving, not only as part of the reciprocal giving-receiving sequence but also from the intrinsic act of giving" (12). In the course of sharing, members also experience didactic instruction and direct advice thus learning a great deal about psychic functioning and about themselves.

Since the therapeutic group resembles a family in many respects, it has authority figures, peer siblings, and strong feelings. Thus, "working out problems with therapists and other members is also working through unfinished business from long ago" (Yalom 1995, 14f). From these interactions also comes the development of basic social skills and the ability to learn from each other and the leader through imitative behavior. Related to this is the interpersonal learning that takes place and which cultivates relationships, corrects emotional experiences and transforms the group into a social microcosm. Part of this is the group cohesiveness that emerges and which exerts a therapeutic influence, similar to the relationship an individual has with his or her therapist and individual counseling. Yalom (1995) points out that catharsis is an important part of the therapeutic

process, but it alone is not enough. Studies indicate that "catharsis *plus some form of cognitive learning*" is necessary (80).

CHAPTER THREE:
DO AS YOU HAVE SAID.

(II Samuel 7:25)

CHAPTER 3

DO AS YOU HAVE SAID

Objective

The objective of this project is to establish a therapy support group for parents coping with the diagnosis of their children with autism using an eclectic approach that incorporates both psychological and spiritual mechanisms to explore their feelings and their thinking. This objective will be reached by utilizing narrative and storytelling to elicit, retell and relive the moments of crisis in the faith of the parents. Psychodynamic concepts and ideas will then inform the underlying nature of the crisis in faith and examine how such parents can restore or maintain their faith in spite of the shattering experience through which their basic life assumptions (embedded theology) became meaningless. A cognitive psychotherapeutic approach, through the use of sacred texts, will help parents reframe their experiences to incorporate their new understanding and begin their restoration of faith (deliberative theology). Finally, spiritual practices will help center the group for its task, help guide the direction of discussion and create a sacred dimension to this endeavor, thus distinguishing it from secular forms of psychotherapy.

Terms of Engagement

When the Early Intervention Team assessing one's child concludes that the atypical behavior and development he or she displays is the result of autism, parents face the struggle of not only coping with the practical realities of providing services, care and

advocacy for their child, but also with issues of depression, anxiety or other concerns which present stubborn obstacles to satisfying relationships, connected emotional lives and a multitude of other psychological wants and needs. Robbins (2005) emphasizes that "therapy is, first and foremost, an effective way to better understand human emotions and, consequently, to significantly enrich interpersonal relationships" (7). Thus, a therapeutic approach enables parents coping with the diagnosis of autism to explore their relationship with God, themselves, each other and their child. By learning to identify and resolve detrimental patterns of thinking, feeling and behaving, these parents can learn to develop deeper, more fulfilling relationships with family and friends, as well as with God and the spiritual dimensions of their lives. The cooperative process of psychotherapy can also resolve persistent problems that keep parents from successfully coping with the emotional and theological repercussions of autism and from enjoying certain aspects of life.

Group psychotherapy consists of a gathering of parents coping with life after their child's diagnosis of autism. They meet on a regular basis to discuss both private and group issues. The main advantage of group psychotherapy is its emphasis on multiple relationships with particular attention to how each person's character dynamics express themselves in a wide variety of situations. Robbins (2005) emphasizes that "whereas in individual therapy, the therapist is the primary object of transference, a diversity of transference issues and situations are likely to arise in a group setting in reaction to different individuals" (7). Not only does this allow the parents to get multiple perspectives about the way others perceive them, but also gives them the opportunity to see how others react to similar situations and to incorporate more successful coping

strategies into their lives as well as possibly the insight to heal their relationship with God.

Using stories and personal narratives as way of sharing with others the feelings and theological crises engendered by the diagnosis of autism is a natural and non-threatening way for parents to reveal their underlying issues of concern. White and Epston (1990) see such stories as a healthy way for parents to provide order, meaning and coherence to their life experiences. Telling their stories gives parents the opportunity to externalize their problems and concerns in ways that invite the speaker—and listener in a group setting—to reflect upon the problem experiences and relationships. In retelling their life experiences, narratives can help reframe their lives and relationships, particularly their relationship with God.

The basis of psychodynamic psychotherapy (Kahn, 2002) is that the way a person solves relationship issues at many early life developmental stages impacts the formation of the person's adult personality. At any stage, a person may become stuck in a way of reacting or problem solving that is not effective. As an adult and parent of a child with autism, these patterns may interfere with one's ability to have intimate relationships with others, bounce back from rejection, or fully and spontaneously experience their true feelings. This, in turn, can have negative effects on their understanding of and relationship with God. Thus, psychodynamic psychotherapy enables the parents of children with autism to become aware of unconscious feelings, desires and thoughts that are not usually available to the conscious mind. Consequently, this approach helps parents understand how these unconscious aspects affect the way they think, react, feel and relate. In exploring the deepest layers of personality formed in early childhood, this

psychodynamic psychotherapy also addresses deeper existential issues relating to death, disability, grief and loss as well as hope, optimism and happiness.

Cognitive therapy assumes that a person's feelings result from learned thinking patterns. It also assumes that behavior, thoughts and feelings affect one another so that changes one area affect the other areas: "The treatment works by changing negative patterns of thinking and by solving concrete problems through brief sessions in which a therapist helps a client challenge negative thoughts, consider alternative perspectives, and take effective actions" (Dictionary Page CO.UK 2005, 1). Thus, when it comes to the parents of children with autism, identifying faulty thinking patterns and reevaluating core beliefs and cognitive patterns allows for a more informed decision as to whether these beliefs are, in fact, accurate or desirable. This would then enable parents to reassess their ideas of God, faith and hope in a restorative manner that enables them to reconstruct their belief system to incorporate their life situation while maintaining a spiritual connection with God.

The sacred art of listening, according to Lindahl (2002), requires three qualities: silence, reflection and presence. Silence creates the space for listening to God, exploring one's "relationship to Source" (16). Reflection allows one to listen to the inner voice, find internal calm and patience and then the ability to speak with wisdom and assurance. Presence "is the awareness of listening to another, of connecting at the heart level" (Lindahl, 2002, 16). She further explains that "a circle is one of the key elements for facilitating listening in a group" because it removes boundaries, creates community and equality and a shared sense of vulnerability because there is no place to hide (Lindahl 2003, 79f). A centering exercise or prayer enables the members of the group to transition

from the busy schedule of daily living to a more reflective state of listening. It is a way to become present in the moment, focused, open to new ideas and ready to engage in the group activity.

Materials

The materials are the tools or apparatus necessary for the performance of the project and are concerned with the physical, as distinct from the intellectual or spiritual, aspects of the study.

Participants

The participants in this project are Jewish parents of children with autism who come from Conservative congregations in Bergen County, NJ. Although their income levels vary, they are all from middle and upper-middle class homes. To minimize variables, all are Jewish, affiliated with synagogues within the Conservative movement, are married and have several children in their nuclear family unit. In order to have a reasonable sample from which to draw, ten couples (20 individual participants) make up the group, thus enabling there to be a large enough group should members be absent for some of the sessions.

Setting

To create an environment conducive to group discussion in a non-threatening atmosphere, where silence, reflection and presence can manifest themselves, a comfortable room with ample space, but not so large as to create distance or too small to be cramped, is ideal. It should be warm and inviting like a living room, family room or

den. The Rabbi's Study, with book lined shelves and comfortable chairs and sofa, is such a space, and the one utilized for this study in order to provide easy access for parents when carpooling their children to religious school. (The proposed meeting time is Sunday mornings when the children are accounted for and the parents have free time to meet.) It also maintains confidentiality and anonymity because the Rabbi's Study has sound-proofed walls and the ease of coming-and-going is typical of the traffic flow in the office area. None would seem out of place knocking on the Rabbi's office door and entering his study for a meeting.

The parents would sit in a circle because it is egalitarian—no one is at the head—and because the circle prevents people from hiding. In this way, the circle also becomes a symbol of common ground for the participants. The circle also becomes a sacred place for sharing and everything said stays in the circle, i.e. confidential: "The circle draws the boundary between social time and circle time. We connect. We see each other" (Lindahll 2003, 68). The circle opens up a space for listening to others and is conducive for heart-to-heart communication.

Resources

The resources are the additional tools used for support or help in executing the project. The first of these is the HOPE spiritual assessment tool which will be administered twice, once at the beginning of the project and once at the end, and used to determine any change in deliberative theology (Appendix A). The next tool is a "listening stick" which can be made out of anything, but for the purpose of this study is a *yad* (a pointer used for reading the Torah) will be used, thus connecting the sacred texts of

Judaism with the sacred stories of the participants' lives. It also creates a focus for deep listening and generates the awareness of listening to others as they speak as well as of others listening to the individual holding the listening stick while speaking. It also further enhances the sense of community engendered by participating in the group process. The third resource consists of the sacred texts used in the cognitive portion of the session (Appendix B). Fourth is the text of the "ABCs of Coping" (Appendix C). Finally, with the permission of the participants, the sessions will be taped for review and analysis of the discussions. Thus, a tape recorder and tapes are also necessary.

Administration Time

The first step of the project requires participants to complete the HOPE spiritual assessment tool, which takes about an hour to complete. Participants then take part in eight one-hour group sessions followed by completing the HOPE spiritual assessment tool once more. The first HOPE assessment would be completed at least one week in advance of the start of the group sessions. The group sessions would take place once a week on consecutive Sunday mornings from 10:00 a.m. to 11:00 a.m. for a period of eight weeks. The final HOPE assessment would take place shortly thereafter, seeking to complete them within two weeks of the conclusion of the group sessions.

Procedure

The use of the word "procedure" to indicate the body of practices, the set of working methods, the series of steps taken to accomplish the necessary tasks and the rules used in this project replaces the words "method" or "methodology" because of

usage concerns with regard to the latter terms. Picket (2000) asserts that "methodology" properly refers to the "theoretical analysis of the methods appropriate to a field of study or to the body of methods and principles particular to a branch of knowledge" (894). Recently, however, researchers began using the term "methodology" inappropriately as a substitute for the term "method" in scientific and technical contexts. But the misuse of the term "methodology" obscures an important conceptual distinction between the tools of investigation (properly "methods") and the principles that determine how one deploys and interprets those tools. Thus, for the purpose of clarity, the term "procedure" here indicates the method by which the project is conducted.

Recruiting Participants

Potential participants will initially come through contact with the known members of Temple Emanu-El of Closter who have children with autism. However, since the temple's population does not contain ten families fitting the necessary criteria for participation, other candidates from Conservative synagogues in Bergen County, NJ will be contacted through their rabbis and referred to this study. Initial contact will come by way of a telephone call asking for the parents' participation and then followed by a cover letter outlining the nature of the project and the time commitment involved (Appendix D) and a letter soliciting their informed consent to participate (Appendix E).

After obtaining informed consent from the parents, the HOPE spiritual assessment tool will be administered to get a baseline appraisal of the parents' spiritual lives and the schedule of the group sessions will be distributed to them. At the time of administering the HOPE assessment, a brief oral introduction explaining, once again, the nature of this

study and reiterating the contents of the informed consent letter will be given. Each participant will also know that he or she will not receive the results of the spiritual assessments (the initial or the concluding) unless he or she specifically requests it and that they will not be returned until after the completion, submission and acceptance of the final draft of the project.

The Initial (Baseline) Assessment

Sherwood (1998) writes about spiritual and religious assessment and interventions claiming renewed acceptance of and attention to them, reflecting the current interest in the life of the spirit in society at large. In spite of this renewed interest, there is a lack of well-developed resources. Romer (2002) identifies three spiritual assessment tools that have universal application and do not represent the bias of any religious group or tradition; however, all three contain an "end-of-life issues" component because physicians and chaplains use them most often in palliative care situations. Nevertheless, these assessments provide important insights into the spiritual life of the clients involved and can be adapted to the needs of parents coping with their child's diagnosis of autism.

The three spiritual assessment tools are FICA (Appendix F), HOPE (Appendix A) and SPIRIT (Appendix G). The FICA spiritual assessment tool, developed by Puchalski (1999), uses this acronym to remember what to ask in a spiritual history: faith, importance (influence), community support and address (issues of immediate concern). Anandarajah and Hight (2001) developed the HOPE spiritual assessment to respond to the growing interest and association of connecting spirituality with medical practice. The HOPE assessment tool looks at sources of hope, involvement in organized religion,

personal spirituality and practices, and the effect these have on medical care and end-of-life issues. Weismann (2000) developed the SPIRIT assessment tool which investigates one's spiritual belief system, personal spirituality, integration in a spiritual community, ritualized practices, implications for medical care and terminal events planning. Each of these spiritual assessment tools distinguishes between spirituality, referring to the human search for transcendence, meaning, and connectedness beyond the self, and religion, defined as a more formal embodiment of spirituality into relatively specific belief systems, organizations, and structures:

Spirituality has many definitions, but in general refers to those aspects of a person's views and beliefs that are concerned with meaning, hope, transcendence (that is, a sense that there is a power or reality beyond the human experience), purpose, and connection. ... *Spirituality is different than religion.* Religion is the organized, often institutionalized beliefs and practices that express a person's spirituality. There are many people, however, who have a strong sense of spirituality without belonging to a specific religion. Spirituality is broader than religion, and includes the relationships or connections with the self, others, nature, and God or other power. (Bonnema 2003, 1)

The SPIRIT assessment tool was eliminated from possible use with parents of a child with autism because 33% (2/6) of its focus is on medical care and end-of-life issues. The FICA assessment was also eliminated because most of its contents are also found in the HOPE assessment, but the latter also includes more precisely targeted questions whereas the FICA assessment is more open ended. More directed questions will help the participants focus their thinking and help with the final evaluation.

Each participant will be asked to complete the HOPE assessment tool individually even though they are members of a couple-unit. Just because one is married to another, it

does not mean that each member of the couple interprets his or her life story in the same way or that they are at the same place on their spiritual journey. Indeed, these differences in perspective may be part of conflicts in the marriage and obstacles in effective coping as a family unit. Each participant will complete the assessment prior to the first group session and the completed assessments will be sealed until the conclusion of the eight sessions and the completion of the final assessment. Only then will they be unsealed and examined for the purpose of comparison with the final assessment and a determination if a change in theology and behavior occurred.

The final section of the HOPE assessment tool was adapted to address the parents of children with autism. The original HOPE assessment includes a fourth section (E: Effects on medical care and end-of-life issues) which does not apply to the case of parents struggling with their faith while coping with a child with autism. Therefore, the author of this project adapted the questions in the final section to address parental concerns regarding their child with autism. Focus changed from effects on medical care and end-of-life issues to effects on general care and coping. In addition, the final (fifth) question of the "Effects" section of the original HOPE assessment tool was eliminated to balance this section (giving it four questions) and because it did not apply to the parents' circumstances. The eliminated question is "Are there any specific practices or restrictions I should know about in providing your medical care?" Similarly, a fourth question was added to the "Personal Spirituality" section (from the SPIRIT assessment tool) to balance this section with the others (giving it four questions) and to gain more understanding of the individual's motivations. The added question is: "How are your personal spiritual beliefs meaningful to you?" No other changes were made to the format or to the

questions addressed in the original HOPE assessment tool. The original HOPE assessment tool appears in Appendix A, the adapted version appears here:

Table 3. HOPE Spiritual Assessment Tool (Adapted)

H:	Hope (Sources of meaning, comfort, strength, peace love, and connection)	<ol style="list-style-type: none"> 1. What is there in your life that gives you internal support? 2. What are your sources of hope, strength, comfort and peace? 3. What do you hold on to during difficult times? What sustains you and keeps you going? 4. For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; is this true for you? <ol style="list-style-type: none"> a. If the answer is "Yes," go on to O and P questions. b. If the answer is "No," consider asking: Was it ever? If the answer is "Yes," ask: What changed?
O:	Organized Religion	<ol style="list-style-type: none"> 1. Do you consider yourself part of an organized religion? 2. How important is this to you? 3. What aspects of your religion are helpful and not so helpful to you? 4. Are you part of a religious or spiritual community? Does it help you? How?
P:	Personal Spirituality and Practices	<ol style="list-style-type: none"> 1. Do you have personal spiritual beliefs that are independent of organized religion? If "yes", what are they? 2. How are your personal spiritual beliefs meaningful to you? 3. Do you believe in God? What kind of relationship do you have with God? 4. What aspects of your spirituality or spiritual practices do you find most helpful to you personally? (e.g., prayer, meditation, reading scripture, attending religious services, listening to music, hiking, communing with nature)
E:	Effects on Care	<ol style="list-style-type: none"> 1. Has your current situation affected your ability to do the things that usually help you spiritually? (Or affected your relationship with God?) 2. Is there anything that I can do to help you access the resources that usually help you? 3. Are you worried about any conflicts between your beliefs and your situation, care or decisions? 4. Would it be helpful for you to speak to a clinical chaplain or community spiritual leader?

The Support Group Sessions

Once the participants are recruited and the initial HOPE assessment is completed by each participant, the group will meet for an hour each over the period of eight consecutive weeks (eight hours total). Since the identified parents of children with autism who are members of Temple Emanu-El form the bulk of the participant group and since they all drive carpool to the Religious School of the Temple on Sunday mornings to deliver their other children to class, it seems that Sunday mornings from 10:00 a.m. to 11:00 a.m. is optimal for the group meeting. The group will meet and discuss their experiences of coping with their child's disability and look at their personal stories through the prism of Biblical and Rabbinic stories, poems and perspectives to find faith and healing.

Once the participants arrive and take their seats in a circle in the Rabbi's Study, a centering exercise to focus the group's attention to the task at hand will be conducted. This centering exercise invites all the participants to sit in silence with the intention of being present in the moment and to, perhaps, sense the presence of the Divine in the activity as well. Lindahl (2003) recommends the best posture for this exercise: "seated comfortably with both feet on the floor, hands resting on the lap and eyes gently closed" (125). The aim is to let the body rest deeply during the centering exercise, to be wholly relaxed and supported.

The group facilitator calls upon the participants to quiet down and let the presence of the moment and/or the love of God's Presence to be at the center of their being. The facilitator asks the participants to choose a word as a symbol of their intention to be part of the group and to be with God. The participants are asked to gently introduce their word

by saying it quietly to themselves. The word chosen can be a love word, a prayer word or a sacred word; something special and meaningful to the participant. The participants are asked to clear their minds of thoughts and whenever they become aware of thoughts, feelings, sounds or sensations, they should simply return to the use of the word they chose and focus on it to regain the presence of the moment and/or of God. After a few moments (one-three minutes initially, no longer than five minutes later on in the series), the facilitator will ask the participants to let peace flow up to the conscious levels of the participants' being and to gradually return to the present moment and then slowly open their eyes. The participants will then be asked to sit for a minute or two before moving into the session itself.

To initially get participants comfortable with each other and talking with each other, the listening stick exercise will be used. The exercise gives participants an opportunity to experience deep listening and to create awareness of listening and of being listened to. It helps develop a sense of respect for others and a sense of community and trust. After two or three sessions, when the leader feels the participants are comfortable with each other, the use of the listening stick can be eliminated.

The facilitator invites the participants to select a volunteer to be first in beginning this exercise. The facilitator then gives the first volunteer the listening stick. For the purpose of the project, a *yad* (a pointer used for reading the Torah) will be used, thus connecting the sacred stories of the participants' lives with the sacred texts of Judaism. The facilitator explains the exercise and then models it.

The person holding the listening stick states a question to which another participant will respond. For the initial meeting, it would be best to move in a clockwise

or counter-clockwise direction until everyone has a turn. The respondent closes his or her eyes and reflects on the question for 20-30 seconds looking for his or her response rather than for the answer. The participants will be instructed to go deeper than their immediate response before speaking. After reflecting, the participant opens his or her eyes and says whatever comes to mind in response to the question and is given as much time as needed to respond. Once the respondent finishes speaking, he or she then closes his or her eyes, returns inside him- or herself to ask: "What is the next question that wants to be asked?" Since this is not a linear exercise, the question need not be related to the one previously asked or what was said in response. The person opens his or her eyes, states the question that comes to mind and passes the listening stick to the participant next to him or her. He or she will then respond to the new question and repeat the process. The last person to respond also generates a question even though the exercise stops at that point.

The participants not holding the stick also listen to what is said. Lindahl (2003) suggests what listeners should be looking for: "Listen for each other's souls. You may find yourself doing your own reflection during the times of silence. Notice that your response may be very different. Notice how your mind may wander when someone else is speaking. Train yourself to be present. Practice undivided attention" (128). When the exercise finishes, the participants reflect on the experience and then further enter into discussion giving consideration to questions such as: What was it like for you? What did you hear? What did you notice about the process? What opened up for you? The discussion may also turn to other topics of discussion prompted by the participants themselves.

About twenty minutes before the end of the session, the facilitator introduces a Biblical or Rabbinic text that reflects the nature of the discussion and the issues brought out by the participants. The purpose of the sacred text is to give a sacred context to the discussion, to demonstrate to the participants that their struggles are not wholly unique to them and to gain insight that might help reframe their experience on the basis of the meaning the text presents to them. Since there are eight sessions, eight texts will be presented. Table four presents the texts and the themes they address:

Table 4. Texts and Contexts

Text	Context	Theme
Genesis 18:16-33	Abraham challenges God	Confronting injustice
Genesis 22:1-20	The Binding of Isaac	Is faith blind?
Genesis 32:23-33	Jacobs wrestles with a being	Struggling with faith
Genesis 44:14-33	Judah pleads before Joseph	Ties that bind
Exodus 3:1-4:17	Moses' call to service	Serving against our will
Midrash Mishei	The death of Rabbi Meir's sons	Consolation
Psalms 23	God as Source of Protection	Light at the end of the tunnel
Psalms 121	God as Source of Help	Support

Each of these texts also reflects one of the stages outlined by Kubler-Ross' (1969) landmark study on death and dying. In it she outlines five stages of grief: shock, denial, anger, bargaining and acceptance. Although presented in linear fashion, as though one proceeds through each stage sequentially, reality demonstrates that those experiencing a loss oscillate between these stages. This is particularly true of parents with children

diagnosed with autism in that a setback in their child's academic, social or other type of development may trigger recurrences of prior stages. Table 5 presents each stage of grief and the classical texts associated with it for the purposes of this project.

Table 5. Stages of Grief and Associated Texts

Stage	Text	Context
Shock	Midrash Mishei	The death of Rabbi Meir's sons
Denial	Exodus 3:1-4:17	Moses' call to service
Anger & Bargaining	Genesis 18:16-33	Abraham challenges God
Bargaining	Genesis 32:23-33	Jacobs wrestles with a being
Bargaining	Genesis 44:14-33	Judah pleads before Joseph
Bargaining & Acceptance	Genesis 22:1-20	The Binding of Isaac
Acceptance	Psalms 23	God as Source of Protection
Acceptance	Psalms 121	God as Source of Help

The session concludes with the facilitator summarizing the session's thrust. The group then convenes the following week. This procedure follows for the eight group sessions.

The Final Assessment

Romer (2002) reminds one that during times of illness and crisis people may find that their spiritual needs increase. Often parents of a child with autism find strength and hope from their religious and spiritual beliefs; however, this is not always so. Others lose faith and feel abandoned by God at their time of woe. Spirituality, then, is an ongoing issue; part of a parent's journey, not something addressed at the last minute. Thus, it is

something that can and should be addressed by the Jewish community. Romer (2002) asserts: "Attention to spiritual needs can contribute to an increased quality of life for some patients" (2). By partaking in an initial assessment, participating in the group sessions and then engaging in a final assessment that repeats the initial one, but allows the participant to respond with newly found insight and newly formulated conceptions of his or her spiritual life, it is possible to measure any changes that occur and also to make conscious one's embedded theology, challenge it and formulate a deliberative one that may help restore faith and give added meaning to one's life story.

Saunders (2001) distinguishes between spiritual and physical pain. Spiritual pain implies a loss of meaning, a loss of hope, a loss of identity due to lost roles, lost activity and lost independence. This, she observes, can lead to anger at God, a sense of betrayal and abandonment by God and, consequently, a disruption in one's faith system. Furthermore, classical texts of Western religious traditions (Judaism, Christianity and Islam) define suffering in many different ways including redemptive—earning one "points" in heaven (*mitzvah* points)—and as punishment for disobedience to God's law, willful separation from God's commands, sin and alienation from the will of God. Thus, religion can further contribute to spiritual pain by fostering guilt or a sense of condemnation and rejection from God. With such guilt and shame, many people feel discouraged in their individualized search for meaning including the expression of painful feelings and difficult questions.

However, by participating in the group sessions, exploring one's feelings and presumptions as well as by wrestling with traditional sources to find new meaning and relevance for their lives, parents of children with autism can work to discover new

meaning and restored faith and wholeness in their lives. Thus, spiritual healing is an important part of rebuilding one's faith and finding a place in one's spiritual community. Romer (2002) observes that "spiritual healing, as well as psychological and emotional healing, can happen even when physical cure is not possible"(5). This healing comes about by parents being open to spiritual healing and by reshaping one's image of or experience of God. Using the HOPE assessment tool after the parents complete the eight group sessions can determine if these parents have indeed begun to reconstruct their faith. Thus, Romer (2002) distinguishes spiritual healing from physical cure by pointing out that spiritual healing can bring about "restoration of meaning by finding meaning in the present situation, reviewing meaning that has sustained the patient throughout life, re-evaluating/re-working one's faith system in light of crisis" (6).

Conducting a final assessment using the HOPE assessment tool will take place following the conclusion of the last session group session and should be completed within two weeks. It will then be reviewed and compared with the initial baseline assessment of each participant to determine if there is any renewed hope, closure to spiritual wounds, reconciliation between the participant and God, or a reframing of their God-idea that brings them peace of mind and alleviates their spiritual suffering.

CHAPTER FOUR:

JUST AS *ADONAI* COMMANDED HIM, SO HE DID.

(Exodus 40:16)

CHAPTER FOUR

JUST AS *ADONAI* COMMANDED HIM, SO HE DID

The Support Group

Composition of the Group

As expected, the participants in this project were Jewish parents of children with autism who came from Conservative congregations in Bergen County, NJ. Originally plans called for contacting other Conservative synagogues in the area to help secure the requisite number of families to run the support group. However, once word spread of the formation of this support group, families in the host congregation came forward to volunteer. This meant that participants from other congregations were not necessary to reach the minimum number required to form the group. This was unanticipated because it was thought that there were not enough identified families in the congregation to make up the total number of participants.

While the rabbi and administration of the synagogue were able to identify the bulk of the families targeted for participation, word of mouth from these already-identified families spread to other member-families that included children with autism not previously known to the leadership. Thus, not only was the quota for the group reached easily within the congregation, it also served as a gateway for families to come forward and make themselves known to the rabbi and synagogue leadership. In this regard, the announcement of the support group and the search for volunteers also served to articulate a principle of inclusion and welcome to families heretofore unknown to or on the periphery of congregational life. Establishing a support group for parents of children

with autism clearly filled a void in synagogue offerings and provided an entrée into the synagogue for members who might otherwise remain marginal to the congregation, and perhaps, to the greater community as well.

In keeping with the proposed composition of the group, all the participants were Jewish, affiliated with a synagogue within the Conservative movement, married and had several children in their nuclear family unit. Of the 10 families participating, three consisted of a nuclear family unit in which the child with autism was the eldest; five consisted of family units in which the child with autism was in the middle; one family had a child with autism who was the youngest sibling and one family had triplets of which the firstborn of the three was the child with autism. All the children with autism in the participant families ranged in age from 11 to 16. It is interesting to note that only one family of an adult child with autism (age 19) solicited to participate in the group declined.

Setting: the Rabbi's Study

For the rabbi (who served as the facilitator of the group) and those familiar with the synagogue through regular participation, conducting the group in the Rabbi's Study was not threatening. To them it was a comfortable environment conducive to group discussion where silence, reflection and conscious presence could manifest themselves. However, when these newly-identified families also became part of the support group, the facilitator was concerned about their comfort level, thinking that perhaps they would feel intimidated by the Rabbi's Study with its book lined shelves and sense of being in the private inner *sanctum* of the rabbi's office. Yet, upon inquiry, these families "felt

honored" to be invited into the Rabbi's Study for this "special group." They "felt privileged" to participate and "excited" about the opportunity to be involved.

As anticipated, seating the participants in a circle equalized the members of the group. Each participant felt included because it was egalitarian, with no one formally at the head, and because the circle prevented the participants from hiding. As participants shared their stories and comments, the circle became a sacred and confidential place conducive for heart-to-heart communication.

Completing the Baseline Assessment

As mentioned earlier (Chapter 3), Anandarajah and Hight (2001) developed the HOPE spiritual assessment to respond to the growing interest and association of connecting spirituality with medical practice. The HOPE assessment tool looked at sources of hope, involvement in organized religion, personal spirituality and practices, and the effect these had on medical care and end-of-life issues. The HOPE spiritual assessment tool was adapted for this study to reflect the concerns of parents of children with autism by redirecting the final element, the "effects" component, to issues of caring for their child with autism.

The HOPE spiritual assessment tool was used to establish a baseline of thinking and feeling for the participants. Families were contacted by telephone and then sent a packet of material including a letter of explanation, consent forms and the HOPE assessment (see Appendixes). Each adult (husband and wife) was asked to complete an assessment individually and independently of his or her spouse out of the awareness that just because one was married to the other, it did not mean that each member of the couple

interpreted his or her life story in the same way or that they were at the same place on their spiritual journeys.

The participants were given two weeks to complete the baseline HOPE spiritual assessment prior to the first group session and could either mail it back together with the consent forms or bring the completed packet with them to the first session. Three couples sent the material prior to the first session and the rest brought the completed forms with them to the opening session. The group sessions took place once a week on consecutive Sunday mornings from 10:00 a.m. to 11:00 a.m. for a period of eight weeks.

Results of the Baseline Assessment

Section I: Sources of Hope

Section I of the HOPE assessment focused on sources of hope, meaning, comfort, strength, peace, love and connection. The first question asked participants to identify the things that gave them internal support in their lives. Most wrote that their family, friends or their own self-reliance and self-confidence were sources of support. However, Shira* wrote, "I am a deeply spiritual person. I am a Reiki master. I spend a substantial amount of time meditating/praying every day. It is a huge part of my life." Reiki is a form of spiritual healing thought to have origins in Tibet but made its way to the West in the 1970s by way of Japan. "Reiki practitioners channel energy in a particular pattern to heal and harmonize" by fostering deep relaxation, destroying energy blockages, detoxifying the system and increasing the vibration frequency of the body (ICBS, 2006, 1).

* Pseudonyms are used throughout to protect the identities of the participants.

John also looked to Eastern traditions for sources of hope, meaning and comfort. He wrote: "My practice of Taekwondo has been a great source of comfort and meaning. It is more than a martial art. It teaches focus, concentration, self-discipline, respect and self-control. It is a philosophy of life that speaks deeply to me." Fran wrote that "being able to pray—speaking quietly with God—mostly in the car on the way to the next meeting" was a source of internal support. Only Jill directly related her prayer experiences to Jewish practice in the home or synagogue:

Lighting candles on Friday night is a deeply comforting moment for me. I feel embraced by God and blessed by what I have, especially my family. Sometimes I feel that way when I am sitting in *shul* [synagogue]. It doesn't always happen, but there are moments of transcendence where I feel loved by God.

The second question of the Hope section asked participants to directly identify their sources of hope, strength comfort and peace. For many, these included very tangible things such as good medical care, education for their children, relationships with family and friends, "good food, good wine, good company" as Fran put it. But for others, intangible things also provided comfort, strength, hope and peace. Shira, the Reiki master, felt that "my connection to God/Source is a profound source of peace and comfort. I choose to think and live a positive life." Barb, who feels a strong ethnic connection to the Jewish people but is uncertain about a belief in God, also felt positive about life: "I feel I have an internal source for these things. I try to keep things in perspective and try to enjoy life." Jerry listed "optimism" as one of his sources as well while Henry, Shira's husband, felt comforted by the notion that "everything happens for a reason." Gary, Fran's husband, agreed with Henry: "Knowing that I am not alone; that

things happen for a reason and that things could always be worse. Sometimes it's OK to decide that whatever is happening is not important, that 'this too shall pass.'" In identifying sources of comfort, Diane and Jill agreed that "the cycles of life, Jewish life, family and time for myself" were important sources of comfort and stability.

When asked what the participants hold on to during difficult times, the participants were unanimous in pointing out that they "had weathered bad times in the past and survived, so I feel like this will pass too." The couples pointed to the strength and faith they had in their partners and the knowledge that they faced tough times before and would again. Barb seemed to declare for all of them: "I try to keep things in perspective and enjoy the good times while I can, knowing that the bad times are in the past, and that there will be other bad times ahead. It is just part of living my life. Without perspective, I'd be lost. With it, I keep my buoyancy and my sanity."

The final question of the hope section asked if their particular religious or spiritual beliefs acted as a source of comfort and strength in dealing with life's ups and downs. The responses brought out interesting perspectives in which couples tended to be together in their thinking. Thus, for example, Shira and Henry felt very strongly that their spiritual beliefs helped them through difficult times, while Barb—who is an avowed agnostic—and Billy, who has "walked away from God," felt strongly that they did not affect them in the slightest. Jerry and Marcia, who only recently began attending synagogue regularly on Friday nights, felt that prior to this, spiritual beliefs played very little role, but now they felt things were changing and that somehow Friday night services helped them put the hustle and bustle of the week behind them and gave them an opportunity to connect with each other as a couple and with their children as a family—

something they felt was missing prior to coming to temple. Jill and John, who are ritually observant, felt that their spiritual beliefs did help them, but that sometimes it was hard to see. They maintained, however, that they continued even when they didn't feel moved spiritually because they were rewarded often enough with feelings of spiritual comfort and "God's protecting presence." Fran and Gary, Jack and Lily, Lynn and Stuart, Susan and Scott, Jeff and Rachel, Ari and Diane simply said "yes" without further elaboration.

Section II: Connections with Organized Religion

Section II of the HOPE spiritual assessment explored the participants' connections with organized religion. All the participants identified themselves as being part of an organized religion (Conservative Judaism), which makes sense since they are all members of a Conservative synagogue, but affiliation alone is not a determinant of meaningful involvement or importance in one's life. Indeed, Shira expressed her "disappointment when attending services, which I admit is not very often." Thus, in response to the second question, "How important is this to you?" she wrote: "I wish I felt more inspired and uplifted during prayers, but unfortunately I do not. My connection to God is personal and profound. I start every day connecting to God and my days are blissful as a result." Thus, her spirituality exists outside of affiliation with organized religion, and indeed, she felt that organized religion hampered her spiritual self-expression. Her husband felt much the same way, claiming "strong spiritual beliefs" but "minimal importance" with regard to organized religion.

Most of the other participants felt that organized religion was extremely important to them when it came to home celebrations, such as Passover, and instilling values of

honesty, integrity and goodness in their children, which they felt was at the core of Judaism. Marcia put it succinctly: "It is important as a part of a bigger picture; it is very important that we are part of something so big, so strong and so traditional." Likewise, the majority of respondents felt that it was important because it made them feel like "part of a community and culture that defines ways to live and ways to understand the world." Even Barb and Billy, who struggle with "God" felt the importance of their Jewish identity, as Barb explained, "I'm trying to make it more important, but I'm having trouble figuring it out."

The third question of Section II asked about ways in which aspects of the participants' religion were helpful or not. All the respondents replied that the values, *mitzvot*, integrity and world view of Judaism were helpful to them. Indeed, Lynn wrote, "I love that the ideas of Judaism fit what my experience teaches me is true." But while some found the rituals warm and meaningful to them, others found them alien. Stuart commented: "I like belonging to a synagogue, listening to Jewish music, and giving my kids a Jewish education, but I don't really understand or enjoy services in the synagogue."

The final question of Section II asked if being part of a religious community was helpful. Those who attended synagogue services regularly replied that they felt a certain comfort in the rhythms of the week and in Shabbat service attendance, particularly on Friday nights when attendance was less than Saturday morning. They felt the service was more intimate. Those who did not attend temple regularly felt more comfortable with the values of Judaism, as they understood them, than with the rituals of Jewish practice. Although, Ari commented that he found "the home rituals, like Friday night dinner with

the family, immensely enriching and comforting." On the other hand, Shira's discomfort with synagogue services and rituals was replaced by her involvement in a spiritual healing group in which "we do healings on the earth and try to raise the vibration of people we meet. We take our role and our time on earth very seriously."

Section III: Spirituality and Practices

The third section of the HOPE spiritual assessment dealt with personal spirituality and practices. The first question asked respondents if they had spiritual beliefs that were independent of organized religion and the second question asked in what way were they meaningful. Of the 20 participants, 14 stated that they had no spiritual practices outside their involvement in organized religion. Of the six who answered affirmatively, Marcia identified her strong commitment to goal setting as a spiritual practice. She claimed, "We are very serious about designing our future and living that way. These goals become almost spiritual in that we practice what we preach daily. It sets the frame for our lifestyle."

Fran, Jill and John anchored their personal spiritual practices in their Judaism. Jill found spiritual fulfillment in the practice of *kashrut*, the Jewish dietary laws. She felt that "they are a constant reminder of God's presence in my life and of my need to be sensitive to the living things in the world around me." John liked to spend time sitting in the synagogue chapel "just thinking" and practiced daily prayer both in the synagogue and privately. He also found that music "speaks to me" and that listening, composing and playing Jewish or "spiritual" music "brings me closer to God." Fran summed up her personal practice by saying that "Anything I need, spiritually speaking, can be found in

Judaism." She found meaning in the fact that although she was a unique creation, she nevertheless felt a strong connection to others and this "is what lets me know myself."

Shira, the Reiki master, and her husband Henry, felt that their spirituality affected their daily life. Shira, in particular, felt that she had a "unique mission or purpose" in life and "was placed on this earth for a reason." She felt that respecting and helping others, striving to be her best and encouraging others to fulfill their own potential, smiling and being cheerful, and "healing them is contributing to the overall well-being of everyone on the planet and that the good work I do spreads to others."

The third question of Section III asked if the participants believed in God and about the nature of their relationship with God. Most of the respondents said that they believed in God and felt they had a "close" relationship with God. However, Jerry, Stuart and Lynn pointed out that they "don't often think of God outside of temple." Barb claimed to have difficulty in her belief, she said "I don't believe in God, but in case I'm wrong I like to live my life like I believe in God." Susan and Jeff also expressed feelings of uncertainty. They both felt that they wanted to believe in God, but given the crises they sometimes faced, they had trouble believing and oscillated between belief and questioning. Fran framed her relationship with God and the questions it raised for her with more onus on her role: "God has a personal story to share with me. Pieces of this story are revealed when I need to know something. When I am ready to see, understand and accept. The 'Aha' moment comes around. God and I share many funny moments and the occasional temper tantrum."

Henry said that he believed in a "higher spirit" and claimed that "it can be called whatever one wants." Shira claimed a belief in a "God-force" which was "not a man or a

woman but so much more than we understand in our earth bodies: infinitely compassionate and loving." To her God was not angry but loving; "God does not judge, we judge ourselves!"

The final question of Section III asked about the helpfulness of the participants' personal spiritual practices. For those who responded that they had no spiritual practices outside organized religion, attendance at synagogue services, they claimed, fulfilled their spiritual needs. Jeff and Gary said, in particular, they liked attending Friday night services which were "more intimate and included some innovative things like guided meditation and instrumental music now and then." Jerry, Lynn, Lily, Marcia and Shira identified "walking in the woods, sitting in peace and meditating" as helpful to them. In addition, Marcia, Diane, Ari and Jack felt that spending time with family and doing what they set out to do was spiritually meaningful to them. Gary, Scott, Henry and Marcia also claimed that their spirituality was "all encompassing" in that the activities they chose to do were "fulfilling my life's desires." Both Shira and Fran found "teachable moments" in their lives to be meaningful. Shira "read a tremendous amount of spiritual books" and was emphatic in stating, "I do not watch TV!!!!" Fran found these teachable moments "in periods of extreme emotions and in quiet silences. Most of the time we are too noisy to hear what's going on. Going to a weekly Sabbath service has made a big impact on my life—and my life with my family."

Section IV: Effects on Care

The final section of the HOPE spiritual assessment focused on effects on care. Questions one and three targeted conflicts between their current situation and their beliefs

while questions two and four asked them if they were in need of help. Half the participants felt that their current situation did not affect their ability to do the things that usually helped them spiritually. Some simply responded "no," while others elaborated. Thus, for example, Jill said that "this is the hand God dealt me and so I will play it the best way that I can." Fran and Susan made similar comments to Jill's: "What will be, will be. I can only plan and look for the best for my child and our family." Likewise, Barb said, "I am determined to live my life as 'normally' as possible." Shira claimed that "my spirituality keeps growing and as it grows I encounter more and more like-minded people. My connection with God is profound."

Others wrestled with their situation. Jerry, Gary, Bill, Lily and Marcia all felt that it took time away from their couple relationship with their spouses and that peace and quiet in the house was missing. Rachel said, "Boy was I pissed off at first! God and I were not on speaking terms for a while. But he brought people into my life that helped me and comforted me. He let love remain in my heart while the bitterness faded." Lynn and Stuart both feel anger and grief: "Sometimes I like to ask 'why me' but then I say, 'enough!'"

When it came to asking for help, all the couples replied that they were alright "right now." Although two asked if the synagogue would consider helping provide a babysitting network for parents of children with autism. Shira wanted help integrating Judaism into her Reiki spiritual practice. What was unanticipated was the level of acceptance and comfort these families possessed. Although they clearly articulated conflicts, these were mostly in the past and they were functioning reasonably well at the time the group took place. Given that the youngest child with autism in the group was ten

years old, these families had quite a number of years to learn how to cope with their predicaments. Perhaps a group with younger children would react differently.

Attending the Support Group Sessions

The group met for an hour each over the period of eight consecutive weeks (eight hours total). Since the participants were all members of Temple Emanu-El and since they all drove carpool to the Religious School of the Temple on Sunday mornings to deliver their other children to class, the group met on Sunday mornings from 10:00 a.m. to 11:00 a.m. while their children were studying.

When the participants arrived and took their seats in a circle in the Rabbi's Study, the facilitator engaged the group in a centering exercise to focus the group's attention to the task at hand. This centering exercise invited all the participants to sit in silence with eyes closed for one to two minutes with the intention of being present in the moment and to, perhaps, sense the presence of the Divine in the activity as well. Once the facilitator asked the participants to partake in a *niggun*, a wordless melody stemming from the Hassidic tradition in Judaism and used by members of that sect to focus their intentions, thus giving the centering exercise a clearly Jewish tone. Another time, the facilitator asked the members of the group to focus on an attribute of God, such as patience, kindness, forbearance, etc., thus connecting the centering exercise to the Jewish understanding of Exodus 34:6: "The Lord! The Lord! A God compassionate and gracious, slow to anger, abounding in kindness and faithfulness, extending kindness to the thousandth generation, forgiving iniquity, transgression and sin" (Orlinsky 1962,

161f). After the allotted time, the facilitator asked the participants to open their eyes and engage in a listening exercise.

The listening exercise consisted of a person holding a listening stick asking a question to which another participant responded. After reflecting, the participant said whatever came to mind in response to the question and was given as much time as needed to respond. Once the respondent finished speaking, he or she then asked the next question and passed the listening stick to the participant next to him or her to respond to the new question and repeat the process. The participants not holding the stick also listened to what was said. When the exercise finished, the participants reflected on the experience. The focus of the listening exercise was to get participants comfortable with each other and talking with each other. It helped develop a sense of respect for the others in the group and helped build a sense of community and trust in a short period of time. After three sessions, the participants felt comfortable with each other, and went from the centering exercise right into discussion without the need for a listening exercise.

The group discussed their experiences of coping with their child's disability in various contexts including social and religious settings as well as in the home environment. They shared their hopes and fears, their triumphs and tribulations with each other. About twenty minutes before the end of the session, the facilitator introduced a Biblical or Rabbinic text that reflected the nature of the discussion and the issues brought out by the participants. Selection of the text was made by the facilitator after listening to the discussion and then choosing an appropriate text that contained the same broad theme as the general thrust of the discussion. The purpose of presenting the holy text for further discussion was to give a sacred context to the conversation, to demonstrate to the

participants that their struggles were not wholly unique to them and to gain insight that might help them reframe their experience on the basis of the meaning the text presented to them. It was an opportunity for the participants to look at their personal stories through the prism of Biblical and Rabbinic narratives, poems and perspectives.

In presenting the Jewish sacred texts, the extent of Jewish illiteracy of the participants was unanticipated. None of the texts presented were familiar to the vast majority of the participants even though some of the texts were popularly known stories such as the binding of Isaac and Jacob's wrestling with the divine being. These narratives were chosen by the facilitator precisely because they were popularly well-known, yet with the exception of Jill, John, Fran and Henry, no one ever heard these stories before. As a result, each time the group looked at a text, the facilitator had to put it into a context for the participants and often had to read through the text with them just to provide a simple meaning of the text for them to then discuss.

Although the sessions were supposed to conclude with the facilitator summarizing the session's thrust, at the end of the second session Fran asked for a closing prayer just as the group began with a centering exercise at the beginning of the session. She exclaimed: "You can't just send us back into the real world now that we've bared our souls in here. It's just too raw. We need prayerful closure to our session." As a result, the facilitator offered a closing prayer based on the topic of discussion each week. Thus, for example, the first prayer offered, at the end of the second session together, focused on the demonstration of compassion by the participants of the group towards those willing to open themselves emotionally and willingly so early in the tenure of the group. Everyone stood together in a circle holding hands while the facilitator offered the prayer:

אבינו שבשמים, Heavenly Father, we are aware—so soon after the High Holy Days—of Your מידת הדין, Your measure of justice, and Your מידת הרחמים, Your measure of compassion, in our lives. We are grateful to those among us who so willingly shared themselves with our group and to all those in our session who modeled those same qualities of compassion and fair judgment.

We are thankful to You for bringing us together to share, to learn and to grow from each others' experiences. May Your nearness give us strength and hope in the days ahead as we go out and face the world fresh with the experiences we shared today. May we return next week enriched by the intervening moments and by the strength we find each day. ה' עז לעמו יתן ה' יברך את עמו בשלום. "Adonai gives His people strength, Adonai blesses His people with peace." Amen.

The intention of the prayer was to give thanks for the openness of the group, to encourage trust among the participants, to bring closure to the session and to give the participants strength to face the world outside the group once more. It also utilized traditional metaphors and elements of traditional Jewish prayer in Hebrew to connect the group to its heritage and sacred language.

A second example comes from the third group session in which discussion focused on the struggle to accept the reality of autism and its impact on the child's behavior as well as its ramifications for the dynamics of the family. The Biblical text reflected upon by the group spoke of Jacob's connection to Benjamin through the poignant phrase, "his life is bound up in the lad's life" (Genesis 44:30, trans. Orlinsky 1962, 84). Thus, the closing prayer took this concern into account:

אב הרחמים, Compassionate Father, we ask Your blessing for those in our group who struggle with the daily issues of raising their children, each one created בצלם א-להים, "in Your image." We ask for comfort to those who are restless, we ask for understanding to those who struggle, we ask for insight to those who question. Grant us all peace of mind, wisdom and understanding so we may do Your will and

realize our greatest human potential. וכל העולם כולו ואמרו אמן. עושה שלום במרומו הוא יעשה שלום עלינו ועל כל ישראל "May He who grants peace in the heavens grant peace to us, to all Israel and the entire world!" May the peace that God grants us be peace of mind, blessing of spirit and strength of will. Amen.

The purpose of this prayer was to validate the various feelings shared in the group, give strength and courage to those wrestling with their demons and to let them know that Judaism welcomed their questions, to bring closure to the session and to give the participants strength to face their inner world as well as the world outside the group. Again, traditional elements of Jewish prayer were incorporated as a way of subtly demonstrating the relevance of these ancient words to their very modern predicament.

Instituting these closing prayers was unanticipated, but filled a perceived void on the part of the participants in the group sessions (Appendix H). It also brought the participants closer together as a group by gathering them collectively in a close-knit circle and holding hands while reciting the prayers. This created group cohesiveness and strengthened their trust in each other. In addition, gathering together for group prayer presented a gateway to traditional Jewish prayer, especially for those not used to this mode of Jewish spiritual practice. It also taught and encouraged the participants to create their own prayers incorporating their own feelings and words as well as using traditional prayer phrases in creative ways that spoke to them spiritually.

A final comment about the group sessions: each session began by allowing the participants to set the agenda. Sacred texts were utilized in response to the topics raised by the participants. In classical group therapy sessions, this format enables the client to set the agenda and gives the therapist a passive role, allowing the issues of concern to

emerge through client self-assessment and self-articulation. This process was used in the group sessions of this study, with sacred texts responding to the participants' concerns rather than selected by the facilitator in advance to set the agenda for discussion. While this process worked, it may be noted that since the facilitator was also the participants' rabbi and as such, there was an expectation that the rabbi would teach text, fruitful discussion could also have taken place had the rabbi set the tone of the session by beginning with the study of a sacred text. In this way inductive learning, rather than deductive learning would take place. However, this would give the rabbi a more active role than usually assumed by group therapy leaders.

Results of the Final Assessment

Conducting a final assessment using the HOPE spiritual assessment tool took place following the conclusion of the last group session and was completed within two weeks. Each adult (husband and wife) was again asked to complete an assessment individually and independently of his or her spouse. Seven couples delivered their completed assessments within the two week allotment. The remaining three couples required contact by telephone and reminders to return their assessments. All final assessments were returned within the week after the requested due date.

The Final HOPE assessment administered to the participants was the same as the one given at the outset of the group sessions. This was done in order to determine if there were any changes in thought or feeling among the group session participants. The initial assessment was used as a baseline while the second was compared to it to see if the group sessions made an impression upon the participants and were an agent for change. Thus

the candidates were familiar with Section I of the HOPE assessment which focused on sources of hope, meaning, comfort, strength, peace, love and connection.

Section I: Internal Support

The first question asked participants to identify the things that gave them internal support in their lives. All wrote that their family, friends or their own self-reliance and self-confidence were sources of support. This was no different than the baseline; however, unlike the baseline assessment, the participants expressed greater spiritual awareness. Now their answers often included references to feeling watched over by God or being comforted by Jewish traditions. Thus, for example, Fran, Shira, Henry Stuart and Jeff spoke of being guided on a path through life. Fran said that "sometimes the answer is not clear at the moment, but will be at a later point." Stuart claimed internal support from "a belief that all will work out in a way that makes logical sense, as being consistent with my world view that good is rewarded and evil is punished." Both Marcia and Jerry expressed confidence in their "being a good, decent human being" and their feelings of "hope" for the future. Jill expressed a "sense of comfort from knowing that I am not alone in the world. Even if I feel abandoned by those I care about, I feel a sense of support from my Jewish beliefs." John claimed that "I feel that my Taekwondo is a way of harnessing my energy for good; a sort of checks-and-balances system that keeps me from falling apart. It helps me be the kind of person God meant me to be."

The second question of the Hope section asked participants to directly identify their sources of hope, strength comfort and peace. Whereas the baseline assessment revealed that for many these included both very tangible things as well as some intangible

ideas, the final assessment revealed a shift in focus to greater emphasis on the intangible. Fran and Gary identified "remembering accomplishments" as being an important source of comfort and strength, as did Marcia, John, Jack, Lily, Susan and Jerry. Indeed, Jerry expressed this well when he said: "Looking at the progress we have made despite all the challenges we face." Barb, Shira, Henry, Lynn and Stuart found it in the notion that, in Barb's words, "life is precious and we have to enjoy it and learn all that we can while we are here." Shira, Henry and Stuart also felt a keen sense of "trust" that all things happen for a reason and that, quoting Henry, "making the logical decisions on your path gives you the inner strength to move on." Stuart put in the proviso that "if that principal were incorrect, life would be unbearable." In identifying sources of comfort, Diane and Jill agreed that "the cycles of life, Jewish life, family and time for myself" were important sources of comfort and stability in the initial assessment and again in the final one, but this time Fran also identified the "cycles of the Jewish year" as an anchor in her life.

When asked what the participants hold on to during difficult times, the participants were unanimous, as they were in the initial baseline spiritual assessment, in pointing out that they "had weathered bad times in the past and survived, so I feel like this will pass too." Fran seemed to declare for all of them: "Understanding that things come and go in cycles and usually from difficult times come greater understanding and insight; knowing that even in difficult times there are choices we can make to help us overcome the obstacles we're facing." The participants expressed this spiritually by noting that "faith in the future, faith in God gave me the strength to persevere." For these participants, greater spiritual awareness came from feeling a sense of connection to God through God's protecting care, as Lily exclaimed: "I just guess that God wouldn't give

me something I couldn't handle." They sensed God's presence and protection through the strength, hope and ability to endure they felt inside themselves.

The final question of the hope section asked if their particular religious or spiritual beliefs acted as a source of comfort and strength in dealing with life's ups and downs. The responses were similar to the ones expressed in the baseline assessment in which Shira and Henry, Jill and John, Fran and Gary, Jack and Lily, Lynn and Stuart, Susan and Scott, Rachel and Jeff, and Ari and Diane all stated "yes" without further elaboration, while Barb and Billy, who came to the sessions questioning God's existence said "no" and Marcia and Jerry—for whom synagogue attendance was new—claimed "not really, but we're trying."

Section II: Organized Religion

Section II of the HOPE spiritual assessment explored the participants' connections with organized religion. While all the participants identified themselves as being part of an organized religion (Conservative Judaism) because they were members of Conservative synagogue in the baseline assessment, they explored the meaning of this question with greater depth in the final spiritual assessment. Thus, while all of them again answered "yes," except for Shari, they looked at the idea of organized religion with more complexity than they did initially. At first, the vast majority of the participants did not directly connect their religious tradition with their struggles over autism. They compartmentalized their religious identity distinctly from their parenting identity, their psychological or emotional identity. They did not see Judaism speaking to them through its sacred texts. After participating in the group sessions, they began to see the relevance

of Judaism in their lives. They felt welcomed by a Jewish community willing to reach out and include them despite the travails of dealing with a child with special needs. They looked at sacred texts differently; instead of seeing them as tales of people who lived long ago, they began to see these texts speaking to them out of the universal concern for the human condition. This gave the participants a sense of comfort, belonging and spiritual nourishment. No longer did they feel alone in their world of autism and alienated from Judaism. Now they felt more concretely part of a community—the Jewish community.

Thus, Fran and Gary, Marcia and Jerry, Barb and Billy, Jack and Lily, Ari and Diane, Scott and Susan identified themselves as part of the “Jewish People,” “Jewish community” or “Jewish family,” placing emphasis on their ethnic identification with a people. Jill and John, Rachel and Jeff, Lynn and Stuart and Henry associated organized religion with ritual observance and ethical practice in addition to ethnic identity. Thus, Jill and John as well as Rachel and Jeff claimed that “the destiny of my people and its religious traditions connect me to Judaism” and “the traditions we keep in our home strengthen our connection to the Jewish people here and in Israel.” Lynn and Stuart felt a “strong connection to Judaism and the Jewish people, but not as observant as we’d like to be.” While Henry expressed a connection with the religion and people of Israel, Shira claimed that “even though I was born Jewish, I never really felt that connected to Judaism.”

Most of the other participants felt that organized religion was extremely important to them. The baseline spiritual assessment pointed to the importance of home celebrations and instilling values in their children. This carried over to the final assessment as well,

particularly among the female participants. Barb, Jill, Lynn, Rachel and Diane felt organized religion, i.e., Judaism, was important in order to "create an environment for my kids to learn about Judaism and their heritage." Fran, Marcia, Susan, Lily and Shira felt that, in Fran's words, "it is important to me to have people around me that understand and share my way of looking at the world and who support me in ways that make spiritual sense to me; likewise, I can do that for them." Lily added that it made her feel part of "something bigger" and Shira felt that organized religion was important for her understanding of "how being born into a Jewish family is part of my learning path."

Among the male participants, the idea of "chosenness" was central to their sense of religious importance. Henry claimed that "knowing my ancestry and the history of my people gives me a sense of identity and direction." John and Gary said that "being part of the Jewish people means having a special mission in life; to live honorably and be an ambassador of good will to others." Jerry, Jack and Scott simply said that it was "very important," while Stuart added that "I have a sense of belonging to a special group that has suffered a great deal but survived nonetheless." Jeff and Ari, the fervent Zionists in the group, felt that Judaism, as an organized religion was the inescapable destiny of the Jewish people: "We are different than other nations, with a unique destiny and a unique mission, as evidenced by the rebuilding of Israel in our life times." Bill, like his wife Barb, saw Judaism as an important identity builder for their children: "it gives them a sense of meaning and purpose in life."

The third question of Section II asked about ways in which aspects of the participants' religion were helpful or not. As with the baseline spiritual assessment, all the respondents replied that the values, integrity and world view of Judaism were helpful

to them. They felt grounded in a religious tradition that was eternal, and therefore, had wisdom to share with them during their temporal moments of crisis and calm. As well, now they looked at sacred texts differently, through eyes of spiritual seekers struggling to cope with the diagnosis of a child with autism. Now, in the final HOPE assessment, they indicated that Jewish texts offered them "hope," "strength" and the "ability to hang in there until the crisis passes." The texts provided comfort and knowledge that their struggles with faith and destiny were struggles throughout Jewish history and among Judaism's forefathers. Thus, they no longer felt out of place or estranged from their Judaism. Indeed, Lily and Fran expressed similar ideas when Fran said:

The continuous cycle of holidays helps me understand that things come and go and give structure to the year. The tradition of study and asking questions helps when going through tough times. I enjoy the laws of the Jewish religion; when I don't think of them as restrictions I find freedom and peace in them.

Marcia saw the universal aspects of Judaism as helpful and comforting "in knowing I am part of something bigger." Shira expressed this same idea about the "cosmic nature of my spirituality" while Jerry felt the bigness in the sense of community he experienced.

Half of respondents said that they felt a strong sense of connection through synagogue membership and attendance although they found the services boring and alienating because they didn't understand the Hebrew or what was going on. Lynn said she enjoyed attending services and singing the prayers, but doing this "did not give me a strong sense of connection to God." All agreed that the social aspects of synagogue attendance motivated them more than participation in worship, as Stuart summarized: "The social aspects of the synagogue and the sermons are helpful. The prayers and

Hebrew service are incredibly boring and a turnoff." This was unchanged in comparing the two (before and after) assessments.

The final question of Section II, asking about the helpfulness of being part of a religious community, brought responses of spiritual depth from Fran, Marcia, Jerry, Shira, Henry, Lynn, Rachel, Jill, John and Jeff. They all felt that *Shabbat* in particular made them feel "at peace." Shira and Marcia felt that their meditation and yoga, respectfully, also gave them a sense of spiritual wholeness and calm. For Ari, Diane, Scott, Susan and Lynn, being part of a community gave them a sense of belonging and took away their feelings of loneliness.

Section III: Spiritual Beliefs

The third section of the HOPE spiritual assessment dealt with personal spirituality and practices. The first question asked respondents if they had spiritual beliefs that were independent of organized religion and the second question asked in what way were they meaningful. Initially, 14 of the 20 participants stated that they had no spiritual practices outside their involvement in organized religion. After the group sessions all the respondents felt they had some sort of spiritual practice whether it was meditation, prayer, goal setting or consciously seeking to "do unto others," as Stuart put it. When it came to assessing the meaningfulness of their spiritual beliefs, all the respondents answered "yes." All felt that these beliefs reflected the core values of who they were as human beings. Even the participants who questioned God's presence in their lives, or God's very existence felt that their value systems were, in essence, a belief system and as such held great importance for them.

The third question of Section III asked about the participants' relationship with God. Fran, Gary, Shira, Henry, Jill and John, Rachel and Jeff expressed a belief in God as "a force within all of us" and that "we are pieces of a larger force." As such, Fran concluded: "God is the conversation within me." While most of the respondents held some sort of belief in God or a "Source of all things," Barb and Bill maintained their agnostic stance, but insisted that they "live life as though God exists, just in case I'm wrong!" Lynn and Stuart struggled with their belief in God; they wanted to believe but felt that life's experiences challenged that belief. Nevertheless, Stuart said, "Even though I have my doubts, I still pray to God in times of extreme stress." Whereas in the initial spiritual assessment, the respondents reflected on their relationship with God only in terms of synagogue attendance or ritual behavior, after the group sessions they began to explore their very individual and personal relationships with their images of God. Thus, the comments in the final spiritual assessments focused on what "I believe" rather than on what "Judaism teaches."

The final question of Section III asked about the helpfulness of the participants' personal spiritual practices. Initially, most of the participants identified spiritual practices with Jewish ritual and synagogue attendance or communing with nature, meditation or yoga. However, after the group sessions, respondents to this question included other activities such as reading, knitting, canoeing, cooking, study and discussion, listening to music, fitness pursuits and other leisure activities that "bring me peace" or "calm me down" as personal spiritual practices.

Section IV: Impact

Section IV focused on the impact of disability on participants' spirituality in that questions one and three targeted conflicts between the participants' current situation and their beliefs. As with the initial spiritual assessment half the participants felt that their current situation did not affect their ability to do the things that usually helped them spiritually. However, three respondents (Fran, Jack and Lily) felt that "having a child with a disability took a big toll on me in the beginning, but has ultimately made me richer. I've had to really learn to respect life and be tolerant." Fran, in particular, spoke of "shock and awe." Shock at the diagnosis and the struggles she faced as well as awe in her ability to persevere and overcome the obstacles placed in her path. She also found awe "in the small and large triumphs that my son made as he learned new skills and I learned new respect for the miracle of life and of human development." Shira, Henry Scott and Susan expressed closeness to God because of their children. In Shira's words, "[My son's] honesty, purity and love have changed me for the better."

Lynn, Jill, John, Rachel and Jeff felt that coming to synagogue and sending their children to either the synagogue's Religious School or to a local community program for children with disabilities helped them spiritually: "Seeing him sing the prayers and feeling comfortable at Shabbat services is a huge accomplishment. It makes me feel like someone is watching over us and wants us to be part of the Jewish community." Diane said: "I don't blame God for the fact that I have an autistic child, but I do question the justice of it. I can live with the conflict because I find comfort in his and my small victories."

Others continued to wrestle with their situation. Jerry, Gary, Bill and Marcia expressed anger at first, then sadness, bargaining and finally acceptance. Ari felt that he still oscillated among these stages of grief and coping: "At times I plead with or pray to God and at other times, I curse at or don't even talk to God. But when I see how my wife interacts with him or I have a good day with him, then it all melts away and I realize how much I love him, and in his own way he loves me."

When responding to the question of help, the participants focused on their experience in the group sessions. Scott, Ari and Stuart felt that the support group wasn't really helpful or beneficial to them. Stuart concluded: "To be honest, I did not get much out of the group. I did enjoy the sessions while I was there and I assume that it had some kind of impact on me but I can't articulate what it might be. Perhaps in time I will realize the way it affected me." For these participants, opening up to the group and sharing their emotions was very difficult. Often they sat and listened, absorbing what others were saying, but not contributing readily to the conversation. Often, as well, their body language—arms crossed over their chests, rigid sitting posture, tucked in a corner of the sofa—conveyed resistance to participation. Clearly, each of these participants was still struggling with issues of grief and acceptance, but was not prepared to talk about it in front of others. They were still coming to emotionally know themselves internally and were not prepared to share themselves externally at this time.

All the other participants felt that the group sessions were meaningful and helpful to them. They expressed surprise at their interest and in the openness and honesty in themselves and in others as they shared their stories. Marcia felt that the sessions "were interesting and reached a part of me I didn't realize existed. It reaffirmed my beliefs and

my appreciation of everyone's differences and assured me that my path in life is right for me." Henry declared: "This is the first time I publicly voiced my spiritual beliefs. It cemented my beliefs even more when I actually voiced them." Fran said that it was sometimes hard to come to the sessions and open up so deeply and then return to the world outside the group: "It made me realize how far down we have to push our feelings to make life work in the world that has trouble including our kids." Likewise, Lynn confessed:

The first session I cried most of the session because I had so much pent up emotion. I found that since Ben was 2½ (He's now 10) I have forged ahead trying so many therapies, drugs, diets, doctors, programs, etc. that I was on a mission. I never took the time to think about the emotional impact it had on me, my marriage, my mental and physical health and my family. I felt that the weights I was holding on my shoulders for tackling this battle came crumbling down during the group sessions. It was comforting for me to speak and listen to other families dealing with similar issues.

Susan reflected on her experience and "felt very hopeful at times and a bit sad at times to see so many people struggling with these issues." Lily expressed that same feeling when she said: "First, I did not know that there were so many other families in a similar situation." Jill and John agreed:

At first I did not know what to expect. I didn't realize that there were so many families like ours and that we were not alone. I didn't realize that others had the same questions as I had or found comfort in the same things I did. It made me feel closer to my temple community and this group in particular.

Gary concurred when he wrote in his assessment: "It also reminded me of how important it is not to isolate oneself from community, but to let others know how things are going

and to hear the stories of others." Jerry simply declared: "Good to share information and help support one another."

For Susan, Rachel and Jeff, the group sessions were helpful because they were "a safe place to confront my feelings." Rachel, in particular, expressed her "sense of comfort seeing all these people and getting to know them intimately as they got to know me. In a short time, special bonds were created because of the special stories we shared." Likewise, Shira felt safe to share her ideas with the group, admitting that it was a bold move for her to do so:

I shared my "other worldly" experiences with a group of "regular earthlings," which was very risky for me to do. I usually would not allow myself to possibility of being ridiculed by others. I gained strength and realized that I have tremendous courage to put myself into a position like that.

Diane was more timid, expressing the "hope that I was a comfort to our group and made others consider different possibilities. I hope my outlook helped contribute to the group in some way because I feel that others contributed to my development by sharing their stories." Barb and Bill expressed "enjoyment" and "honor" at hearing about other people's struggles with their "special needs children and with life" in general. Barb "found it interesting how different people have come to terms with having a special needs child—anger, extreme spirituality, learning, etc." while Bill "gathered strength and felt supported" by the others in the group. He said:

As a guy, it was hard for me to open up and share my emotions with others. Not because I was afraid, but because I had never explored them before. I just don't often think in those terms. It was refreshing for me and for me to see other guys doing the same thing.

Over the course of the sessions, as the participants discovered new meanings to the ancient texts they explored, and found that their religious tradition had something valuable to share with them. This gave the participants a sense of hope, inspiration and courage to face their daily trials and tribulations with new insight and energy. Furthermore, they came to appreciate Jewish wisdom and feel that there was a place for them within the Jewish community. This gave them comfort and a sense of safety as well as a place to explore their emotions and their lives in a Jewish context. As a result, one final note regarding the use of Biblical and Rabbinic texts to explore the participants' thoughts and feelings was expressed by Fran: "It was very interesting for me to compare and contrast the religious passages to our situation. I like having that context to work in to gain understanding." Shira, the Reiki master, came away from the group sessions concluding: "I want to thank you for asking us to be a part of the group. I am more interested in exploring my Jewish identity now, which is a tremendous gift. Thank you very, very much."

CHAPTER FIVE:

BLESSED BE YOUR COMINGS AND BLESSED BE YOUR GOINGS.

(Deuteronomy 28:6)

CHAPTER FIVE

BLESSED BE YOUR COMINGS AND BLESSED BE YOUR GOINGS

Outcomes

For parents struggling with or living with the diagnosis of a child with autism, the experience presents challenges to their faith system and belief in God. This informal, or embedded, theology is based on the theological assumptions they make, both consciously and unconsciously, about the way and the why the world works as it does. The crisis of diagnosis challenges those assumptions because it defies their understanding of how the world works, their assumptions about good and evil, right and wrong, God's attributes of justice and mercy, compassion and love. It, therefore, behooves parents in such a predicament to explore their faith assumptions and their relationship with God in order to reframe their life's experiences into a theologically, emotionally and mentally meaningful understanding, into a deliberative theology consciously articulated. Creating such a deliberative theology—based on carefully reflected theological convictions—can offer them hope and courage as they face the trials and tribulations that life inevitably throws their way.

The purpose of this study was to initiate and explore that process of reflection and to start the participants moving from their embedded theology toward a deliberative one that would give them peace of mind about the past and fortitude to face the challenges that lie ahead. The initial HOPE spiritual assessment created a baseline from which to measure and note changes in their thinking and feeling. The final HOPE spiritual assessment, given at the conclusion of the group sessions, was then reviewed and

compared with the initial baseline assessment of each participant to determine if there was any renewed hope, closure to spiritual wounds, reconciliation between the participant and God, or a reframing of their God-idea that brings them peace of mind and alleviates their spiritual suffering. Although the participants did not reach the endpoint of their spiritual journey (and one may argue that they cannot until till their lives are fully lived), the support group succeeded in starting them on their way.

Points of Congruence

As with every study, there were a number of working assumptions about the nature and dynamic of the individuals and group under discussion. The first of these was that disability—particularly that of autism—is different. A family coping with a disability is, by nature of the disability and the amount of attention needed to address it, different in its overall family dynamics than a family with neurologically typical children. Added to this mix are the individual personalities that make up the family unit, thus adding to the complexity of the family dynamic.

A second assumption, related to this first one, is the perpetual cycle of grieving and coping that individuals in the family unit experience. Unlike death, which is finite, coping with the realities of disability are on-going. Kubler-Ross (1969/1997), in her study of death and dying, identified five stages of grief: shock, denial and anger, depression, bargaining and acceptance. While her study focused on terminally ill patients, these stages also apply to families coping with children diagnosed with autism. Further complicating the matter is that any member of the family may be at a different stage than another member and the stages themselves do not necessarily progress linearly. Thus, a

mother could be accepting at one point, experience a crisis that slides her into depression or anger at another and then back to bargaining and acceptance once the crisis passes, while her husband experiences long periods of anger and denial or acceptance throughout this period of time, thus creating tension in their relationship as well as frustration with their predicament.

These two assumptions were verified through the group sessions. While Lynn, for example, accepted her son's diagnosis and worked to do whatever she could to realize his human potential, thus also experiencing the stage of bargaining, her husband, Stuart, sat stoically at the sessions, arms crossed and quiet most of the time. Not surprisingly, he commented that he felt he did not get much out of the sessions. He seemed to be angry about his son's diagnosis and not ready to cope with his emotions openly in a group setting. Jill and John are another example. Jill commented that she "tried to play the best hand with the cards that God dealt me" while John picked up on the metaphor and said, "I spend a lot of time wanting to trade cards or reshuffle the deck." Clearly, John was at a different stage in the grief process than was Jill.

A third working assumption in this study was that the participants possessed an embedded theology based on early religious school teachings and notions acquired by osmosis through their life's experience rather than a well thought out and articulated deliberative theology. They may not realize or articulate that embedded theology, but they operate with certain faith assumptions in their daily lives. When faced with catastrophe or trauma, such as the diagnosis of a child with autism, these faith assumptions are often challenged by the new reality that they face. Their embedded theologies are no longer meaningful or able to absorb their new experience. This creates

the faith crisis that can destroy faith unless steps are taken to consciously create a deliberative theology that enables the individual to reconstruct a meaningful faith.

Among the participants in this study, only Henry and Scott attended parochial Jewish day school in the form of an Orthodox yeshiva. Scott's experience was largely positive and when pressed to articulate his concept of God, spoke in the literary metaphors of God sitting on his throne dispensing justice and mercy. Scott said that this image of God "satisfied me because it was consistent with my view of the world." Henry, on the other hand, rejected the images of God with which he grew up. He said:

We were taught at yeshiva to fear God and not to ask 'dangerous' questions that might lead us astray and bring God's anger upon us. Well into my adult life, I lived in fear of that God and felt punished by Him every time something bad happened. But after a while I began to see things differently. I rejected that angry, vengeful God. I began to see life as an opportunity and I learned from Shira that each day is a blessing and that if we have a positive outlook, positive things will happen.

Henry learned from Shira to replace his "fear of heaven" with an "awe of heaven." He didn't express it this way, but conveyed this change in describing his experience.

Jeff and Rachel, Jill and John grew up in the Conservative movement, Jeff and Rachel attended Solomon Schechter Day School while Jill and John attended supplemental synagogue religious schools but then either majored or minored in Jewish Studies at college. Yet, of the three, only John wrestled with his understanding of God's revelation and his relationship with God as a result.

I do a lot of reading and thinking about this. When I look at myself I see that I've gone from a person who believed that God spoke to Moses in "discrete words and letters" on Mt. Sinai to a belief that God is the life force in all things and that the Torah is the written human response to the experience of that life force in the world. I know I've

changed because I see it in the way I live my life and the comments I make. As I encountered crisis after crisis, I needed an anchor to keep me sane. I found it in reading philosophy and trying to understand how I fit into this world. At one point I felt like abandoning religion altogether and even shouted out in anger one day, "There is no God." But I couldn't live with that thought. I guess I made an existential leap to believe in God in spite of my experiences, but the God I believe in now is not the God I grew up with.

Of all the participants, only John articulated a deliberative theology in response to his life experience prior to attending the group sessions.

The remaining participants either grew up with little or no formal Jewish education. Some, like Ari, Barb, Marcia and Jerry grew up in secular homes that were ethnically proud to be Jewish, but received little in the way of formal Jewish education or synagogue attendance. Others attended either Reform or Conservative supplemental synagogue schools but did not continue past their Bar/Bat Mitzvah years and possessed images of God based on these elementary years of education. As such, their ideas of God were often rudimentary or irrelevant to their sophisticated, adult lives. Indeed, Gary said:

I used to believe that God watched over me personally; that my family was somehow special and deserving of God's special love. This was reinforced by my father's behavior. He would talk about how special our family was, our last name, our ancestry, the famous people in the family. But when I hit stumbling blocks on my pathway in life, this image of God's protection rang empty and hollow. If God was watching over me, why did this bad stuff keep happening? I became resentful and God became irrelevant to me.

The only reason Gary remained connected with the Jewish community, he said, was because of his parents' and grandparents' connection to their temple. It was Fran who influenced him to become more Jewishly active and it was mostly out of social action

concerns that he engaged in Jewish communal activities. These experiences underscored the idea that the participants (except for John) were working with embedded, rather than deliberative, theologies.

The final assumption of the study that, unfortunately, proved correct was that parents of children with autism do not have the opportunity to explore their faith because the synagogue, the one place that should provide sanctuary for the troubled soul, often disregards families struggling to come to grips with the reality of living with a disabled child. Of 74 synagogues only 14 provided any kind of services for children with special needs and none of them provided support groups specifically tailored to parents of children with autism.

Points of Incongruence

There were two working assumptions in this study that proved be incongruent with the final outcomes. The first was assuming a basic level of Jewish literacy in which the participants would be familiar with some of the Biblical narratives used in the group sessions, such as the story of the binding of Isaac or the tale of Jacob wrestling with a divine being. The narratives selected for use in the group sessions were chosen precisely because they appeared in various forms in English literature, in art and painting, even in a Broadway show in the case of Judah's plea before Joseph, which was a part of Andrew Lloyd Webber's *Joseph and the Amazing Technicolor Dream Coat*. Similarly, the Psalms chosen (23 and 121) not only spoke to the concerns anticipated in the discussions of the group, but also precisely because they were commonly recited in religious settings, both

Jewish and non-Jewish, and specifically at funerals. Likewise, in the case of Psalm 23 in particular, it was quoted on many television shows and in a number of popular films.

Nevertheless, these stories and poems were foreign to almost all of the participants in the group. Indeed, with regard to Psalm 23, Bill commented: "I've heard it before but I didn't know it was Jewish. I've seen it in the *Gideon Bible* I find in hotel rooms when I travel. I thought the Book of Psalms was a Christian text." Only Jill, John, Rachel and Jeff recognized the selections. Henry and Scott, whose yeshiva education ended after middle school, vaguely remembered the stories. Indeed, Henry said: "My yeshiva education was such a horrible experience I've tried to forget everything about it." Scott, on the other hand, simply resigned himself to the fact that it was a long time ago that he studied this material and he forgot it all. For the others, even those who attended supplemental religious schools, these stories were totally unfamiliar to them.

The result of this incongruence was that the facilitator had to explain the plain meaning of the text before the participants could react and interpret them in light of their own experiences. The facilitator went through the texts with the participants asking them to read aloud and explain what was happening in the narrative or the poem. Once this was completed, the facilitator allowed a few minutes for personal thought and reflection on the text before discussion took place. The result of this experience was best summarized by Marcia, who exclaimed: "I never thought in my wildest dreams that these stories would have something meaningful to say to me!"

The second working assumption that proved false was the expectation that the participants were at some point in the grieving process, but not at the point of acceptance. Indeed, the texts selected to respond to the anticipated concerns raised in the group

discussions dealt with each aspect of the grieving process, but most of the texts contained an element of bargaining as well as some other aspect of the grieving process. One text emphasized shock, another denial and a third anger—but with an element of bargaining as well. Four texts, including the one on anger focused on bargaining and three emphasized acceptance; although one of the three also had an element of bargaining in it. Thus, of eight texts used, half dealt with—at least in part—the notion of bargaining. However, the majority of the participants seemed to be at a point of acceptance of their predicament. Lynn still ran around looking at all means of curative possibilities and thus manifested the qualities associated with bargaining while John wrestled with the meaning of his predicament in his thoughts, also bargaining, but just about everyone else had made peace with the diagnosis of their child and lived their lives accordingly. It must be said however, that Bill and Stuart, who had little to say in the group sessions and seemed resistant to participating conveyed the notion of being in the angry or depressed phase of grief.

The texts discussed were still of great value because they related to issues the participants talked about, even though some of the focus was on past events. Since all the participants were parents of children between the ages of ten and 15, with diagnosis typically occurring at approximately age three, these parents had many years to grapple with issues of grief and coping. Thus, it was not surprising that most of the participants were in the acceptance phase of the grief process at the time of the study. Perhaps results would be different if the families participating in the study were of newly or comparatively recently diagnosed children. Results might be different, as well, if the

families participating were in an active state of crisis, which was not the case among the participants in the group under discussion.

Finally, it should be noted, that the facilitator functioned in several roles simultaneously. These various roles helped give authenticity and authority to his role, but also made him susceptible to issues of transference and counter-transference. First, the facilitator of the group sessions was also a parent of a child with autism. This gave legitimacy to the content-worthiness of the group and trust by the participants in the facilitator. However, it also meant that the facilitator had to work diligently to prevent himself from over-identifying with the scenarios presented by the participants so that he would not facilitate the group inappropriately or monopolize the conversation.

Second, the facilitator was also the rabbi of the congregants participating in the group. This vested him with the trust of the participants who looked to him for guidance and answers, not just for passive facilitation of the group. They saw in him a teacher of sacred texts and conveyor of the tradition. They looked to him to tell them "what does Judaism teach about..." Thus, the facilitator had to continuously evaluate his role as facilitator versus that of pastor and rabbinic authority. Furthermore, for some the role of rabbi carried negative connotations and associations with rabbis of their past, parents or other authority figures from their past. This meant that the facilitator had to wield his authority with great care and recognize displaced feelings resulting from participants' transference issues. However, for many, validation for the group came precisely from the fact that the facilitator was one of them, that is, himself a parent of a child with autism and yet was also different from them because he was their rabbi and they looked to him for guidance, comfort and wisdom.

Last, it may be observed that the selection of texts for group discussion revealed something of the facilitator and his issues of counter-transference. Since the facilitator chose the texts and the facilitator had a child with special needs, the selection of texts may reflect where the facilitator was in his grief process rather than where the participants were. In addition to the four texts presenting issues of bargaining, three of the texts focused on issues of acceptance. Therefore, one may conclude that the facilitator was at the cusp of the bargaining and acceptance stages in his grief process.

Linking Outcomes to Needs

When King Saul fails to carry out God's command to destroy the Amalekites and everything belonging to them, the prophet Samuel chastises him saying: "Does the Lord delight in burnt offerings and sacrifices / As much as in obedience to the Lord's command? / Surely, obedience is better than sacrifice" (II Samuel 15:22, trans. Potok, 1978, 132). The point Samuel makes is that empty rituals without religious conviction are meaningless. For the participants in this study, the synagogue was a place of empty ritual and meaningless conviction. For the majority, the synagogue served as a place to come for life cycle events or High Holy Day worship (which was largely spent talking in the hallways with friends than in services focused on prayer). Only for Jill and John, Rachel and Jeff were the rhythms of traditional Jewish life a constant in their lives. For Fran and Gary as well as Marcia and Jerry, exploring their Judaism through synagogue involvement was relatively new; they were seekers on a Jewish journey, looking expectantly at the synagogue to provide them with meaning. For the others, until their participation in this support group and their exploration of the religious texts to which

they were exposed, the synagogue was not a place to which they could turn for help during spiritual crisis.

Indeed, Gary told the story that when he brought his son to services everyone gave him dirty looks and scowls when his son made odd sounds or vocal inflections. He felt uncomfortable in the sanctuary, even though his family membership there was three generations deep. When he got up to leave, the rabbi ran after him and asked him to stay explaining that his son's noises were "his way of praying to God." The rabbi then turned to the congregation and told a Hassidic story of a boy blowing a wooden flute in temple on the High Holy Days because he was filled with love for God and prayerful conviction. While the congregants were appalled, the rebbe told them that their prayers were stuck inside the temple until this boy blew his flute and sent them on their way to heaven. The rabbi told this story to comfort the congregants, make Gary feel welcome with his son and to educate the congregation about inclusiveness. After that, Gary began to bring his son to services and the congregation learned to accept him with love.

In spite of the appearance of reaction portrayed in Gary's recounting of his experience, the rabbi of the congregation took a proactive stance in educating the congregation about inclusion. Members of a local group home for developmentally disabled adults regularly attend services and the rabbi created a *tallit* (prayer shawl) presentation for the residents so they could have their own *tallitot*. He used the occasion to teach about inclusion to those assembled for this emotionally moving event. Furthermore, through sermons, classes, sensitivity training and social action programs, congregants learned about and interacted with disabled individuals. Advocacy by the rabbi enabled the synagogue to purchase large print prayer books for the visually

impaired, to install augmented hearing devices for the hearing impaired, to design the temple's new building with wheelchair accessibility and to enroll with the National Association for the Disabled as a welcoming and accessible congregation. These proactive contributions to creating an inclusive and welcoming environment helped give legitimacy to establishing a support group for parents of children with disabilities.

Although many of those participating in the group sessions arrived at the first meeting feeling disconnected from the synagogue, all the participants felt strongly Jewish in their identity. Often this resulted from support for the state of Israel, being children of Holocaust survivors, a nebulous feeling inside them that sparked Jewish pride, a desire to have their children educated in the way of their ancestors, and in the case of Jill and John, because they lived a Jewish lifestyle that included keeping the ritual *mitzvot*. However, with the exception of Jill and John, none of the families lived a traditional religiously oriented life. None, except Jill and John, Rachel and Jeff pursued Jewish studies beyond their *bar* or *bat mitzvah* and, therefore, they possessed a rather undeveloped Jewish religious or spiritual identity. Indeed, Shira was a Reiki master and Henry was more influenced in his spiritual identity by her than he was by his yeshiva upbringing. In other words, the participants felt that Judaism failed them as meaningful spiritual practice until they were exposed to the Biblical and Rabbinic texts used in the group sessions. As such, they would never have turned to Jewish texts as a source of comfort or meaning had they not been introduced to such meaning through the support group and its spiritual approach to Jewish sacred texts.

Clearly then, this points to a profound need in the Jewish community, and specifically in the synagogue environment, for a safe and nurturing place where parents

of children with autism can explore their feelings, fears, hopes and aspirations in the context of Jewish life, tradition and sacred text. There is a clear need for the synagogue to become a place where such parents can confront their challenges and struggle with their understanding of God and human purpose. Wiesel (2005) once said: "You may love God or you may hate God, but you cannot ignore God" (1). Until this support group, these participants largely ignored God because God and Judaism were not presented to them as relevant sources of personal meaning. The synagogue became a place to go for life cycle events, social gatherings, religious school for the children or the High Holy Days, but not a place to work out a deliberative theology that took an account of their individual experiences and gave them religious or spiritual meaning.

This study demonstrated that parents need a place to make conscious their embedded theology, reflect on their personal experiences of the emotional and spiritual challenges that having a child with autism raises and create a deliberative theology that incorporates the results of their efforts and struggles to make life meaningful for them once again. These are theological, spiritual and religious struggles, as well as psychological and social ones. This study demonstrated that the synagogue can and must be the place where parents find theological meaning and spiritual relevance for themselves if they are to live their lives in hope and joy as Jews, despite their child's diagnosis.

The study also demonstrated the efficacy of group therapy for these participants. The support group created a safe place where honest self-disclosing communication could take place and in which the members of the group aided in bringing about therapeutic change. The group, taking place in a synagogue, created an environment

where the participants could find healing and spiritual growth by engaging in group work with others facing similar challenges and from similar backgrounds and Jewish upbringing. Indeed, meeting in the synagogue and reflecting their experiences through the mirror of Jewish sacred texts helped establish a core set of shared values, knowledge and purpose in the group. Thus, for these participants, the synagogue became an effective place for exploring the meaning of their experiences in a religious and spiritual context; a concept that none considered prior to their participation in the group.

Finally, conducting this group in the synagogue demonstrated to the participants that the Jewish community, and particularly the religious community represented by the synagogue as a religious institution, really cares about them and that they are an important and meaningful part of the Jewish community. Hosting this group in the synagogue was seen as offering a hand of welcome to these parents and their families and impressed upon them that they and their children with special needs were welcome and precious to the Jewish community and to God.

Linking Outcomes to Religious and Clinical Principles

Connecting to Religious Principles

All the participants in this study reported that the diagnosis of their child with autism was a devastating experience that left them feeling helpless at first. For some the first response was, "Why me?" For others, it was: "How could this have happened?" For still others it was: "What do we do now?" For all it was a challenge, conscious or unconscious, to their embedded theologies; in Lily's words: "Nothing in my life experience prepared me for this."

For Jill and John, Rachel and Jeff, Fran and Gary and Jerry, the diagnosis of their child brought with it a crisis in faith. The God-image they had of an omniscient, omnipresent, omnipotent God who was beneficent, caring and personally connected to their lives was destroyed. Rachel commented: "I kept going back over my life and wondering, 'What did I do wrong that God is punishing me now?' and I couldn't find anything so horrific that would bring this about." Similarly, John reflected: "If I had done something wrong, let God punish me, but to strike an innocent little child with such a disability is so unjust!" Their images of a just and merciful God were challenged and found wanting.

Lynn and Stuart, Susan and Scott, Jack and Lily had similar experiences. Their images of God were based on their religious school upbringing and the Bible stories to which they were exposed as youngsters. Their images of a mighty God who intervenes with miracles like the Splitting of the Reed Sea or the Burning Bush proved empty when God did not intervene to restore their child's health. Shira and Henry walked away from traditional images of God and found comfort in Reiki philosophy, which provided them with a different God-image than the Jewish one. Barb and Bill, Ari and Diane and Marcia grew up in secular homes in which the Peoplehood of Israel, not the God of Israel were emphasized. Barb explained: "I never grew up believing in God so this was not a religious crisis for me per sé. It was still a crisis but I didn't blame God. I blamed pollution, I blamed biology, I blamed fate, but I didn't blame God because I didn't believe in God."

For John this became a theological struggle that pushed him to read, think and struggle with his ideas of God and the meaning of his life. For the others, the immediacy

of care overwhelmed them and the pursuit of treatment, coping with the day to day affairs of the family and the busy-ness of life precluded any serious thought about their God-images. God, for them, became irrelevant to the realities they faced. For some, like Henry, there was a conscious walking away from God and the traditions of Judaism about which he learned in yeshiva. For others, like Scott, it was an unconscious tucking away of God thoughts into the deep recesses of his mind while he coped with the day-to-day matters that sometimes overwhelmed his calendar; as Scott remarked: "Who had time to think about God, there was so much to do."

Rather than abandon God completely, this study helped guide these parents to examine their embedded theologies of God's image and to reframe their understanding in light of their experiences in the hope that such reframing would give them spiritual significance and new meaning to their predicaments. Creating such a deliberative theology would then give insight and hope to these families as they faced the future and the inevitable crises that arise from raising a family in general and raising a family with a disabled child in particular. In this way their images of God and their understanding of Judaism would become a source of comfort and strength to persevere, rather than a burden or irrelevancy to their lives.

While none of the participants completed their transition from an embedded theology to a deliberative one, they all made significant progress in that direction. Had the group continued beyond the eight sessions, no doubt more progression toward a deliberative theology would have occurred. Now that they experienced the group sessions, they may wish to pursue their theological deliberations individually or as couples. Indeed, some asked for the group to continue and that is under consideration.

One of the most significant developments to emerge from the group was the ability of the participants to reflect upon their experiences and create a coherent and meaningful narrative of their lives in light of their children's diagnosis of autism. Furthermore, by sharing their stories with the others in the group they created a bond with each other, found a sympathetic ear and a support group they had not had before. Indeed, Fran remarked that "coming to this group has made me feel accepted for who I am and what my family is. I don't feel alone anymore."

For many there was also a stronger connection made to Jewish tradition and to Jewish sacred texts. For almost all the participants, looking at the sacred stories of Judaism as a way to give meaning and contexts to their situations and their lives was a new experience. For the believers in the group, the texts were always of a distant past, the glories of an ancient people, but never a text that resonated with meaning for their lives. God was distant and revered, not immediate and loving. Relating the texts to their lives changed this. For the non-believers in the group, the texts were legends and myths that helped shape a ragtag group of people into a nation. They were nice stories to tell children, no different than Abe Lincoln and the chopping down of the cherry tree, but historically false and irrelevant to the concerns of the day. For these non-believers, too, there was a change of heart. They learned that a sacred text need not be historically true to be theologically or morally valid. They learned that these text conveyed values and emotional truths that made gave them eternal meaning and that, in part, is what made them sacred. Thus, Shira expressed a desire to find ways of making Judaism more meaningful to her Reiki perspective. Even Ari felt a "new curiosity about the Torah, beyond its significance as a claim to the Holy Land."

Finally, utilizing the sacred texts as tools to unlock the sacredness of their own life stories helped give meaning to the participants' experiences and helped give those experiences a sacred dimension. Indeed, Fran remarked: "I knew I was supposed to learn something from all this, but I didn't know what; now I have some ideas to explore further." Thus, for these parents of children with autism, searching for understanding and for God's imminence in the wake of their child's diagnosis, finding God in their stories and connecting them to the stories of their heritage through Biblical and Rabbinic tales, helped restore to them the strength of faith and the optimism of hope. It gave them new meaning and insight and the strength to cope—and even thrive—in spite of the adversity they faced.

Connecting to Clinical Principles

Creating the support group for parents of children with autism enabled them to share their stories and read Jewish tradition through the lens of their personal experiences. It engendered healing, restored faith and opened new venues of personal meaning and introspection for the participants. Thus, narrative psychology—the use of story telling in a therapeutic setting—was very helpful in reframing the participants' experiences, instilling hope and enabling resilience. It was helpful, as well, because it allowed the participants to articulate self-narratives as a form of therapy through reflective thinking, which brought about a deeper sense of self-knowledge. Fran's words: "God has a personal story to share with me. Pieces of this story are revealed when I need to know something." Narrative psychology also enabled the participants to re-evaluate causes and effects of their child's diagnosis and to reframe their experience in a more

positive and healthful way. Thus, for example, Lynn concluded: "I don't blame God for having an autistic child. I do question what caused it, though I can live with this conflict, which I believe is reasonable." Story-telling not only allowed the participants to create a meaningful understanding of their experiences, it helped them articulate and concretize their thinking. Story-telling also enabled the members of the group identify with each other, provide comfort and support as well as integrate their insights into a coherent and interpretive whole.

Common to all the participants was their coping with and working through the stages of grief identified by Kubler-Ross (1969/1997). However, none worked through their grief in progressive stages. Rather, as Rawson (2005) pointed out, the participants worked through these stages in a non-linear fashion in which they moved forward and backward through the stages of grief depending on the circumstances confronting them at the time. Fran and Gary, for example, said they "accepted things as they are until the next crisis occurs and we slip back to anger until we work it through." On the other hand, just because two individuals were married to each other and facing the same circumstances, it did not mean that they perceived and internalized the experience in the same way. Thus, while Lynn bargained with her grief by looking into any and all possible cures, her husband, Stuart, was still working through his anger and depression. While Jill moved onto acceptance, "playing the hand God dealt me," John was stuck in the bargaining phase "wanting to change cards or reshuffle the pack."

In response to these stages of grief, the support group enabled the necessary grief work identified by Blatner (2005) as ventilation, empathy and re-integration to occur. The members of the group were able to be a genuine presence in the lives of those

experiencing feelings of grief. This enabled the participants to talk openly knowing that the others were willing to tolerate and empathize with the pain they felt. Their unique ability to provide sincere empathy extended from their deep personal first-hand experiences of their own and their openness, as a result, to being emotionally vulnerable for others who were likewise wounded by their experience of having a child diagnosed with autism. Finally, the support and non-judgmental understanding of the participants in the group allowed those coping with grief to re-integrate the various parts of the self lost through the experience and aftermath of diagnosis, thus giving them a renewed commitment to the fullness of life.

The support group also helped the participants cope with the stress of raising a child with autism. The participants were able to talk with one another about stressful situations and seek advice. They were able to confide their feelings in each other and feel reassured that they were not the only ones experiencing these feelings or circumstances. Moreover, they could share painful and humorous stories with each other and, as Marcia said, "Laugh out loud because it's better than crying." The Book of Proverbs teaches, "A cheerful heart is good medicine" (Proverbs 17:22, trans. Potok, 1985, 230), which is probably the origin of the saying that, "Laughter is the best medicine," and indeed, the laughter shared among members of the group seemed to alleviate the stress some were feeling. Fran commented: "God and I share many funny moments and the occasional temper tantrum."

One common source of additional stress faced by parents of children with autism was shame. For the participants in the study, shame took the form of feeling different from other families who did not have children with autism, feeling somehow responsible

for bringing this disability on their child, and feeling ostracized by communal institutions or its members because of their inflexibility in accommodating their child with special needs. Many in the group session felt this shame acutely with regard to most Jewish communal institutions or their members. Even if the institution itself had a policy of inclusion, the members still made the parents feel unwanted. Thus, Marcia and Jerry told a story about being asked to leave a synagogue because their daughter was vocalizing loudly. The institution had a policy of inclusion, but the members did not have a sympathetic heart to the needs of their family. The support group, taking place in a Jewish communal institution, gave a clear message to all the participants not to feel ashamed of their situation and that they were welcome members of this congregation and of the Jewish community.

As a group, however, the participants of this study showed great psychological resilience in that they demonstrated tremendous ability to bounce back and recover from the challenges they faced. Fran described this resilience when she wrote in her HOPE spiritual assessment: "I am sustained by the understanding that things come and go in cycles and usually from difficult times come wisdom and insight; knowing that even in difficult times there are choices." Likewise, Diane noted:

There have been times in the past that have been difficult to get through, but once they passed, I realized what strength they gave me to face the challenges ahead. It's hard to think of that when I'm going through a crisis, but once it passes, I can look back at it and see how much I've grown because of it.

The common elements in these testimonies, and that of the other group members, are a sense of hope and an optimistic outlook. These, claimed the participants, were critical to the success of coping with the challenges brought by having a child disabled with autism.

Indeed, this was the fundamental lesson that Shira claimed she learned: "I believe we are here on earth to learn and grow. I chose to think and live a positive life." Examining and reframing the experiences and expectations of the participants to better suit reality and providing them with support from the members of the group helped strengthen this resilience.

Ego functions used to organize and synthesize experiences also helped the participants in this study negotiate their lives. Reality testing helped these parents of children with autism understand and accept the physical and social reality of their lives as defined by the inclusion of a disabled child in light of their internal wishes and fears. Judgment helped them determine what was and was not appropriate behavior in light of their wishes, feelings and memories, particularly as they compared and contrasted their lives before and after diagnosis. Impulse control kept aggressive feelings in check. Object relations played an obvious role in the parents' ability to love their child despite the autism that blocked a reciprocal demonstration of affection by their child, which in turn, impacted self-esteem regulation.

Self psychology played a role in the support group because it allowed the participants to call upon the idealized parent imago to provide a sense of security when faced with the uncertainties of a future with a disabled child. This was especially important when the parents described times when they felt that their whole world was crashing down around them. It gave them mental stability to act and advocate on behalf of their needs. In a similar vein, twinning, the idea that there were others in the world who were similar to the self, resulted from attending and participating in the support group where everyone in the group experienced life through the lens of autism.

The discussions during the support group sessions made it apparent that while many services are available to cope with and attend to the practical functions of day-to-day living with a child disabled by autism, not many resources—particularly in the Jewish community—addressed the internal core beliefs of the parents, especially when those beliefs came under assault from realities that did not coincide with their embedded theologies. These parents needed to grapple with their embedded theologies to find renewed hope and purpose in their lives. They needed to construct deliberative theologies that were flexible, incorporated and made sense of their self-narrative and enabled them to find the coping skills to live a hopeful and meaningful life. They needed to explore their psychological selves in order to transition from a less adaptive to a more adaptive state of thinking, feeling and behaving that would enable them to live their lives fully, purposefully and happily. The support group created by this study did that and the bonds of friendship created by the members of the group and their desire to continue attests to its success.

APPENDIXES:

MAY THE LORD ADD ANOTHER.

(Genesis30:24)

APPENDIX A

HOPE Approach to Spiritual Assessment

H: Sources of hope, meaning, comfort, strength, peace, love and connection

We have been discussing your support systems. I was wondering, what is there in your life that gives you internal support?

What are your sources of hope, strength, comfort and peace?

What do you hold on to during difficult times?

What sustains you and keeps you going?

For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; is this true for you?

If the answer is "Yes," go on to O and P questions.

If the answer is "No," consider asking: Was it ever? If the answer is "Yes," ask: What changed?

O: Organized religion

Do you consider yourself part of an organized religion?

How important is this to you?

What aspects of your religion are helpful and not so helpful to you?

Are you part of a religious or spiritual community? Does it help you? How?

P: Personal spirituality/practices

Do you have personal spiritual beliefs that are independent of organized religion?

What are they?

Do you believe in God? What kind of relationship do you have with God?

What aspects of your spirituality or spiritual practices do you find most helpful to you personally? (e.g., prayer, meditation, reading scripture, attending religious services, listening to music, hiking, communing with nature)

E: Effects on medical care and end-of-life issues

Has being sick (or your current situation) affected your ability to do the things that usually help you spiritually? (Or affected your relationship with God?)

As a doctor, is there anything that I can do to help you access the resources that usually help you?

Are you worried about any conflicts between your beliefs and your medical situation/care/decisions?

Would it be helpful for you to speak to a clinical chaplain/community spiritual leader?

Are there any specific practices or restrictions I should know about in providing your medical care? (e.g., dietary restrictions, use of blood products)

If the patient is dying: How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

APPENDIX B

Sacred Texts

Genesis 18:16-33

16 Then the men set out from there, and they looked toward Sodom; and Abraham went with them to set them on their way. 17 The LORD said, "Shall I hide from Abraham what I am about to do, 18 seeing that Abraham shall become a great and mighty nation, and all the nations of the earth shall bless themselves by him? 19 No, for I have chosen him, that he may charge his children and his household after him to keep the way of the LORD by doing righteousness and justice; so that the LORD may bring to Abraham what he has promised him." 20 Then the LORD said, "Because the outcry against Sodom and Gomorrah is great and their sin is very grave, 21 I will go down to see whether they have done altogether according to the outcry which has come to me; and if not, I will know."

22 So the men turned from there, and went toward Sodom; but Abraham still stood before the LORD. 23 Then Abraham drew near, and said, "Will You indeed destroy the righteous with the wicked? 24 Suppose there are fifty righteous within the city; will You then destroy the place and not spare it for the fifty righteous who are in it? 25 Far be it from You to do such a thing, to slay the righteous with the wicked, so that the righteous fare as the wicked! Far be that from thee! Shall not the Judge of all the earth do right?"

26 And the LORD said, "If I find at Sodom fifty righteous in the city, I will spare the whole place for their sake."

27 Abraham answered, "Behold, I have taken upon myself to speak to the Lord, I who am but dust and ashes. 28 Suppose five of the fifty righteous are lacking? Will You destroy the whole city for lack of five?"

And He said, "I will not destroy it if I find forty-five there."

29 Again he spoke to Him, and said, "Suppose forty are found there?"

He answered, "For the sake of forty I will not do it."

30 Then he said, "Oh let not the Lord be angry, and I will speak. Suppose thirty are found there?"

He answered, "I will not do it, if I find thirty there."

31 He said, "Behold, I have taken upon myself to speak to the Lord. Suppose twenty are found there?"

He answered, "For the sake of twenty I will not destroy it."

32 Then he said, "Oh let not the Lord be angry, and I will speak again but this once. Suppose ten are found there?"

He answered, "For the sake of ten I will not destroy it." 33 And the LORD went his way, when he had finished speaking to Abraham; and Abraham returned to his place.

Genesis 22:1-20

1 After these things God tested Abraham, and said to him, "Abraham!" And he said, "Here am I." 2 He said, "Take your son, your only son Isaac, whom you love, and go to the land of Moriah, and offer him there as a burnt offering upon one of the mountains of which I shall tell you." 3 So Abraham rose early in the morning, saddled his ass, and took two of his young men with him, and his son Isaac; and he cut the wood for the burnt offering, and arose and went to the place of which God had told him. 4 On the third day Abraham lifted up his eyes and saw the place afar off. 5 Then Abraham said to his young men, "Stay here with the ass; I and the lad will go yonder and worship, and come again to you." 6 And Abraham took the wood of the burnt offering, and laid it on Isaac his son; and he took in his hand the fire and the knife. So they went both of them together. 7 And Isaac said to his father Abraham, "My father!" And he said, "Here am I, my son." He said, "Behold, the fire and the wood; but where is the lamb for a burnt offering?" 8 Abraham said, "God will provide himself the lamb for a burnt offering, my son." So they went both of them together.

9 When they came to the place of which God had told him, Abraham built an altar there, and laid the wood in order, and bound Isaac his son, and laid him on the altar, upon the wood. 10 Then Abraham put forth his hand, and took the knife to slay his son. 11 But the angel of the LORD called to him from heaven, and said, "Abraham, Abraham!" And he said, "Here am I." 12 He said, "Do not lay your hand on the lad or do anything to him; for now I know that you fear God, seeing you have not withheld your son, your only son, from me." 13 And Abraham lifted up his eyes and looked, and behold, behind him was a ram, caught in a thicket by his horns; and Abraham went and took the ram, and offered it up as a burnt offering instead of his son. 14 So Abraham called the name of that place The LORD will provide; as it is said to this day, "On the mount of the LORD it shall be provided."

15 And the angel of the LORD called to Abraham a second time from heaven, 16 and said, "By myself I have sworn, says the LORD, because you have done this, and have not withheld your son, your only son, 17 I will indeed bless you, and I will multiply your descendants as the stars of heaven and as the sand which is on the seashore. And your descendants shall possess the gate of their enemies, 18 and by your descendants shall all the nations of the earth bless themselves, because you have obeyed my voice." 19 So Abraham returned to his young men, and they arose and went together to Beer-Sheba; and Abraham dwelt at Beer-Sheba.

Genesis 32:23-33

23 The same night he arose and took his two wives, his two maids, and his eleven children, and crossed the ford of the Jabbok. 24 He took them and sent them across the stream, and likewise everything that he had. 25 And Jacob was left alone; and a man wrestled with him until the breaking of the day. 26 When the man saw that he did not prevail against Jacob, he touched the hollow of his thigh; and Jacob's thigh was put out of joint as he wrestled with him. 27 Then he said, "Let me go, for the day is breaking." But Jacob said, "I will not let you go, unless you bless me." 28 And he said to him,

"What is your name?" And he said, "Jacob." 29 Then he said, "Your name shall no more be called Jacob, but Israel, for you have striven with God and with men, and have prevailed." 30 Then Jacob asked him, "Tell me, I pray, your name." But he said, "Why is it that you ask my name?" And there he blessed him. 31 So Jacob called the name of the place Peni'el, saying, "For I have seen God face to face, and yet my life is preserved." 32 The sun rose upon him as he passed Peni'el, limping because of his thigh. 33 Therefore to this day the Israelites do not eat the sinew of the hip which is upon the hollow of the thigh, because he touched the hollow of Jacob's thigh on the sinew of the hip.

Genesis 44:14-33

14 When Judah and his brothers came to Joseph's house, he was still there; and they fell before him to the ground. 15 Joseph said to them, "What deed is this that you have done? Do you not know that such a man as I can indeed divine?"

16 And Judah said, "What shall we say to my lord? What shall we speak? Or how can we clear ourselves? God has found out the guilt of your servants; behold, we are my lord's slaves, both we and he also in whose hand the cup has been found."

17 But he said, "Far be it from me that I should do so! Only the man in whose hand the cup was found shall be my slave; but as for you, go up in peace to your father."

18 Then Judah went up to him and said, "O my lord, let your servant, I pray you, speak a word in my lord's ears, and let not your anger burn against your servant; for you are like Pharaoh himself. 19 My lord asked his servants, saying, 'Have you a father, or a brother?' 20 And we said to my lord, 'We have a father, an old man, and a young brother, the child of his old age; and his brother is dead, and he alone is left of his mother's children; and his father loves him.' 21 Then you said to your servants, 'Bring him down to me, that I may set my eyes upon him.' 22 We said to my lord, 'The lad cannot leave his father, for if he should leave his father, his father would die.' 23 Then you said to your servants, 'Unless your youngest brother comes down with you, you shall see my face no more.' 24 When we went back to your servant my father we told him the words of my lord. 25 And when our father said, 'Go again, buy us a little food,' 26 we said, 'We cannot go down. If our youngest brother goes with us, then we will go down; for we cannot see the man's face unless our youngest brother is with us.' 27 Then your servant my father said to us, 'You know that my wife bore me two sons; 28 one left me, and I said, Surely he has been torn to pieces; and I have never seen him since. 29 If you take this one also from me, and harm befalls him, you will bring down my gray hairs in sorrow to Sheol.' 30 Now therefore, when I come to your servant my father, and the lad is not with us, then, as his life is bound up in the lad's life, 31 when he sees that the lad is not with us, he will die; and your servants will bring down the gray hairs of your servant our father with sorrow to Sheol. 32 For your servant became surety for the lad to my father, saying, 'If I do not bring him back to you, then I shall bear the blame in the sight of my father all my life.' 33 Now therefore, let your servant, I pray you, remain instead of the lad as a slave to my lord; and let the lad go back with his brothers. 34 For how can I go back to my father if the lad is not with me? I fear to see the evil that would come upon my father."

Exodus 3:1-4:17

1 Now Moses was keeping the flock of his father-in-law, Jethro, the priest of Mid'ian; and he led his flock to the west side of the wilderness, and came to Horeb, the mountain of God. 2 And the angel of the LORD appeared to him in a flame of fire out of the midst of a bush; and he looked, and lo, the bush was burning, yet it was not consumed. 3 And Moses said, "I will turn aside and see this great sight, why the bush is not burnt." 4 When the LORD saw that he turned aside to see, God called to him out of the bush, "Moses, Moses!"

And he said, "Here am I."

5 Then He said, "Do not come near; put off your shoes from your feet, for the place on which you are standing is holy ground." 6 And He said, "I am the God of your father, the God of Abraham, the God of Isaac, and the God of Jacob." And Moses hid his face, for he was afraid to look at God.

7 Then the LORD said, "I have seen the affliction of my people who are in Egypt, and have heard their cry because of their taskmasters; I know their sufferings, 8 and I have come down to deliver them out of the hand of the Egyptians, and to bring them up out of that land to a good and broad land, a land flowing with milk and honey, to the place of the Canaanites, the Hittites, the Amorites, the Per'izzites, the Hivites, and the Jebusites. 9 And now, behold, the cry of the people of Israel has come to Me, and I have seen the oppression with which the Egyptians oppress them. 10 Come, I will send you to Pharaoh that you may bring forth my people, the sons of Israel, out of Egypt."

11 But Moses said to God, "Who am I that I should go to Pharaoh, and bring the sons of Israel out of Egypt?"

12 He said, "But I will be with you; and this shall be the sign for you, that I have sent you: when you have brought forth the people out of Egypt, you shall serve God upon this mountain."

13 Then Moses said to God, "If I come to the people of Israel and say to them, 'The God of your fathers has sent me to you,' and they ask me, 'What is his name?' what shall I say to them?"

14 God said to Moses, "I AM WHO I AM." And He said, "Say this to the people of Israel, 'I AM has sent me to you.'" 15 God also said to Moses, "Say this to the people of Israel, 'The LORD, the God of your fathers, the God of Abraham, the God of Isaac, and the God of Jacob, has sent me to you:' this is my name for ever, and thus I am to be remembered throughout all generations. 16 Go and gather the elders of Israel together, and say to them, 'The LORD, the God of your fathers, the God of Abraham, of Isaac, and of Jacob, has appeared to me, saying, 'I have observed you and what has been done to you in Egypt; 17 and I promise that I will bring you up out of the affliction of Egypt, to the land of the Canaanites, the Hittites, the Amorites, the Per'izzites, the Hivites, and the Jebusites, a land flowing with milk and honey.'" 18 And they will hearken to your voice; and you and the elders of Israel shall go to the king of Egypt and say to him, 'The LORD, the God of the Hebrews, has met with us; and now, we pray you, let us go a three days' journey into the wilderness, that we may sacrifice to the LORD our God.' 19 I know that the king of Egypt will not let you go unless compelled by a mighty hand. 20 So I will stretch out my hand and smite Egypt with all the wonders which I will do in it; after that he will let you go. 21 And I will give this people favor in the sight of the Egyptians; and

when you go, you shall not go empty, 22 but each woman shall ask of her neighbor, and of her who sojourns in her house, jewelry of silver and of gold, and clothing, and you shall put them on your sons and on your daughters; thus you shall despoil the Egyptians."

Chapter 4

1 Then Moses answered, "But behold, they will not believe me or listen to my voice, for they will say, 'The LORD did not appear to you.'"

2 The LORD said to him, "What is that in your hand?"

He said, "A rod."

3 And He said, "Cast it on the ground." So he cast it on the ground, and it became a serpent; and Moses fled from it. 4 But the LORD said to Moses, "Put out your hand, and take it by the tail"—so he put out his hand and caught it, and it became a rod in his hand—5 "that they may believe that the LORD, the God of their fathers, the God of Abraham, the God of Isaac, and the God of Jacob, has appeared to you." 6 Again, the LORD said to him, "Put your hand into your bosom." And he put his hand into his bosom; and when he took it out, behold, his hand was leprous, as white as snow. 7 Then God said, "Put your hand back into your bosom." So he put his hand back into his bosom; and when he took it out, behold, it was restored like the rest of his flesh. 8 "If they will not believe you," God said, "or heed the first sign, they may believe the latter sign. 9 If they will not believe even these two signs or heed your voice, you shall take some water from the Nile and pour it upon the dry ground; and the water which you shall take from the Nile will become blood upon the dry ground."

10 But Moses said to the LORD, "Oh, my Lord, I am not eloquent, either heretofore or since You have spoken to Your servant; but I am slow of speech and of tongue."

11 Then the LORD said to him, "Who has made man's mouth? Who makes him dumb, or deaf, or seeing, or blind? Is it not I, the LORD? 12 Now therefore go, and I will be with your mouth and teach you what you shall speak."

13 But he said, "Oh, my Lord, send, I pray, some other person." 14 Then the anger of the LORD was kindled against Moses and he said, "Is there not Aaron, your brother, the Levite? I know that he can speak well; and behold, he is coming out to meet you, and when he sees you he will be glad in his heart. 15 And you shall speak to him and put the words in his mouth; and I will be with your mouth and with his mouth, and will teach you what you shall do. 16 He shall speak for you to the people; and he shall be a mouth for you, and you shall be to him as God. 17 And you shall take in your hand this rod, with which you shall do the signs."

Midrash Mishei (Midrash to the Book of Proverbs)

Rabbi Meir sat learning Torah on a Shabbat afternoon in the House of Study. While he was there, his two sons died. What did their mother, Beruria do? She laid them upon the bed and spread a linen cloth over them. At the end of Shabbat, Rabbi Meir came home and asked her, "Where are my sons?"

She replied, "They went to the House of Study."

He said, "I did not see them there."

She gave him the havdalah cup and he said the blessing for havdalah. Then he asked again, "Where are my sons?"

She said, "They went to another place and they are coming." Then she gave him food to eat, and he ate and said the blessing. Then she said, "I have a question to ask you."

He said, "Ask it."

She said, "Early today a man came here and gave me something to keep for him, but now he has returned to ask for it back. Shall we return it to him or not?"

He replied, "He who has received something on deposit must surely return it to its owner."

She replied, "Without your knowledge, I would not return it."

Then she took him by the hand, brought him to the bed, and took away the cloth and he saw his sons lying dead upon the bed. Then he began to weep and said about each, "Oh my son, my son; oh my teacher, my teacher. They were my sons, as all would say, but they were my teachers because they gave light to their father's face through their knowledge of the Torah."

Then his wife said to him, "Did you not say to me that one must return a deposit to its owner? Does it not say, 'The Lord gave, the Lord took, blessed be the name of the Lord' (Job 1:21)?" Rabbi Hanina teaches that therefore, she comforted him and quieted his mind.

Psalm 23

1 A Psalm of David: The LORD is my shepherd; I shall not want. 2 He makes me lie down in green pastures: He leads me beside the still waters. 3 He restores my soul: He leads me in the paths of righteousness for his name's sake. 4 Yea, though I walk through the valley of the shadow of death, I will fear no harm for You are with me; Your rod and Your staff comfort me. 5 You prepare a table before me in the presence of my enemies: You anoint my head with oil; my cup runs over. 6 Surely goodness and mercy shall follow me all the days of my life: and I will dwell in the house of the LORD for ever.

Psalm 121

1 I will lift up my eyes unto the hills, whence comes my help. 2 My help comes from the LORD, who made heaven and earth. 3 He will not let your foot stumble: He who keeps you will not slumber. 4 Behold, He who protects Israel shall neither slumber nor sleep. 5 The LORD is your keeper; the LORD is your shade upon your right hand. 6 The sun shall not smite you by day or the moon by night. 7 The LORD shall preserve you from all evil; he shall preserve thy soul. 8 The LORD shall preserve your going out and your coming in from this time forth, and for evermore.

APPENDIX C

The ABC's of Coping with Disability

- A** Acknowledge/accept what has happened in self and others.
- B** Build support systems -- professional/other people with similar disabilities.
- C** Caregivers -- take care of yourself.
- D** Different is neither better nor worse -- it's just different.
- E** Emotional pains -- acknowledge losses, but don't get lost in them.
- F** Family and friends -- stay in touch. You contact them.
- G** Good grief -- expressing sadness or sorrow is important and healthy.
- H** Humor -- don't take things too seriously, especially yourself.
- I** Interest in others, interest in life -- keep learning.
- J** Joy in simple pleasures -- sunsets, birds, and children.
- K** Know when to give in -- know your limitations.
- L** Look at what you can do -- not at what you can't do.
- M** May not do same way, but still get the job done doing it differently.
- N** Nurture yourself -- give to yourself in healthy ways.
- O** One day at a time.
- P** Patience and perseverance.
- Q** Quit being a perfectionist, rigid.
- R** Resources -- metro, mobility, adult day care, congregate dining, senior programs.
- S** Self-image -- change who am I -- I'm still a woman, still a human being.
- T** Tolerance of others who are different.
- U** Use it or lose it.
- V** Visit others.
- W** Wheelchair -- it's liberation, not confinement.
- X** "Xercise" -- different ways.
- Y** YOU are special, unique, and important.
- Z** Zest -- keep it in your life. Don't zip yourself out of life!

APPENDIX D

Cover Letter

Rabbi Geoffrey J. Haber, MA
C/O Temple Emanu-El of Closter
180 Piermont Road
Closter, NJ 07624

Dear Parents:

My name is Rabbi Geoffrey Haber and I am a doctoral student in the Doctor of Ministry program at Hebrew Union College and the Postgraduate Center for Mental Health in New York City, NY. I am conducting a Pastoral Counseling project under the supervision of Dr. Georgia Hooper-Peek (Postgraduate Center) and Rabbi Dr. Bennett Miller (Hebrew Union College) in partial fulfillment of the requirements for the Doctor of Ministry Degree (D. Min.). I am writing to provide information regarding my project, *Reconstructing Faith: A Psychological and Spiritual Journey for Parents of Children with Autism*, so that you can make an informed decision about participating in this project.

The purpose of the study is to establish a therapy support group for parents coping with the diagnosis of their child with autism using an approach that incorporates both psychological and spiritual mechanisms to explore feelings and thinking. Utilizing narrative and storytelling to retell the moments of crisis in the faith of the parents, psychodynamic concepts and ideas will then inform the underlying nature of the crisis in faith and examine how to restore or maintain faith in spite of the shattering experience through which basic life assumptions (embedded theology) became meaningless. A cognitive psychotherapeutic approach, through the use of sacred texts, will help parents reframe experiences to incorporate a new understanding and begin restoration of faith (deliberative theology). Finally, spiritual practices will help center the group for its task, help guide the direction of discussion and create a sacred dimension to this endeavor.

Data will be gathered in such a way as to ensure anonymity (initials or code names will be used in analyses) and records or documents will be disposed of upon completion of the project. Once collected, responses will be kept in strictest confidence. The raw data will be kept in a locked filing cabinet in my home, only accessible to me. Information on responses of a specific participant will be released only to that participant and only if a written request is made to me within three months of the completion and submission of the project. All participants will be sent a brief summary of the findings at the conclusion of the project.

If you have any questions, please feel free to contact me at 201-750-9997 x204, my advisors Dr. Georgia Hooper-Peek at 914-949-8256, Rabbi Dr. Bennett Miller at 732-545-6484, or Dr. Carol Ochs, Director of Graduate Studies at Hebrew Union College, at 212-824-2267. Two copies of the consent form are provided with this letter. Please return one signed to me and retain the other copy for your records.

Thank you for your cooperation and participation.

Sincerely,

Rabbi Geoffrey J. Haber, MA

APPENDIX E

Letter of Informed Consent

We, the undersigned, hereby give our consent for _____ (wife) and _____ (husband) to participate in a pastoral counseling project entitled *Reconstructing Faith: A Psychological and Spiritual Journey for Parents of Children with Autism*. We understand that such consent means that we will participate in an initial baseline spiritual assessment, eight group sessions lasting one hour each (a total of eight hours) and a final spiritual assessment after the completion of the group sessions.

We understand that participation in this project may be terminated at any time by our request or the request of Rabbi Geoffrey Haber. Participation in this project and/or withdrawal will not affect our request for other services from the Postgraduate Center of Mental Health or the Hebrew Union College.

We understand that data will be gathered in such a way as to ensure anonymity (initials or code names will be used in analyses) and records or documents will be disposed of upon completion of the project. Once collected, responses will be kept in strictest confidence. Information on our responses will be released only to us and only if a written request is made to Rabbi Geoffrey Haber within three months of the completion and submission of the project. We further understand that only group results will be reported in any published studies unless full consent is obtained and that all participants will be sent a brief summary of the findings at the conclusion of the project.

We have received a copy of this consent form for our records. If we have any questions, we understand that we can contact Rabbi Geoffrey Haber at 201-750-9997 x204, his advisors Dr. Georgia Hooper-Peek at 914-949-8256, Rabbi Dr. Bennett Miller at 732-545-6484, or Dr. Carol Ochs, Director of Graduate Studies at Hebrew Union College, at 212-824-2267.

Signature of wife: _____ Date: _____

Signature of husband: _____ Date: _____

APPENDIX F

FICA Spiritual Assessment Tool

An acronym which can be used to remember what to ask in a spiritual history is:	
F:	Faith or Beliefs
I:	Importance and influence
C:	Community
A:	Address
Some specific questions you can use to discuss these issues are:	
F:	What is your faith or belief? Do you consider yourself spiritual or religious? What things do you believe in that give meaning to your life?
I:	Is it important in your life? What influence does it have on how you take care of yourself? How have your beliefs influenced your behavior during this illness? What role do your beliefs play in regaining your health?
C:	Are you part of a spiritual or religious community? Is this of support to you and how? Is there a person or group of people you really love or who are really important to you?
A:	How would you like me, your healthcare provider to address these issues in your healthcare?
General recommendations when taking a spiritual history:	
1.	Consider spirituality as a potentially important component of every patient's physical well being and mental health.
2.	Address spirituality at each complete physical exam and continue addressing it at follow-up visits if appropriate. In patient care, spirituality is an on-going issue.
3.	Respect a patient's privacy regarding spiritual beliefs; don't impose your beliefs on others.
4.	Make referrals to chaplains, spiritual directors or community resources as appropriate
5.	Be aware that your own spiritual beliefs will help you personally and will overflow in your encounters with those for whom you care to make the doctor-patient encounter a more humanistic one.

APPENDIX G

SPIRIT Assessment Tool

Spiritual Belief System
<ol style="list-style-type: none"> 1. Do you have a formal religious affiliation? 2. Do you have a spiritual life that is important to you? 3. What is your clearest sense of the meaning of your life at this time?
Personal Spirituality
<ol style="list-style-type: none"> 1. Describe the beliefs/practices of your religion/spiritual system that you personally accept. 2. Describe those beliefs and practices you do not accept or follow. 3. In what ways is your spirituality/religion meaningful to you? 4. How is it important to you in daily life?
Integration in Spiritual Community
<ol style="list-style-type: none"> 1. Do you belong to any spiritual or religious groups? 2. How do you participate in this group? 3. What importance does this group have for you? 4. In what ways is this group a source of support? 5. What types of help or support does this group or could this group give you in dealing with your illness?
Ritualized Practices
<ol style="list-style-type: none"> 1. What specific practices do you carry out as part of your spiritual/religious life, e.g. prayer, meditation? 2. What lifestyle activities/practices does your religion encourage, discourage, forbid? 3. What meaning do these restrictions and practices have for you? 4. Have you followed these guidelines?
Implications for Medical Care
<ol style="list-style-type: none"> 1. Does your religion forbid any specific parts of medical care? Do you follow them? 2. What aspects of your religion/spirituality would you like me to keep in mind as I plan your care? 3. What do I need to know about your religion/spirituality that would make our relationship stronger? 4. Are there any barriers to our relationship posed by your religion/spirituality? 5. Would you like to discuss spiritual or religious implications of health care?
Terminal Events Planning
<ol style="list-style-type: none"> 1. Are there particular aspects of medical care that you do not want or that you wish to have withheld based on your religion/spirituality? 2. Are there any spiritual or religious practices or rituals you would like to have available in the hospital or at home? 3. Are there spiritual or religious practices that you wish to plan for at the time of death, or following death? 4. From what sources do you draw strength in order to cope with this illness? 5. For what in your life do you still feel gratitude even though you are ill? 6. When you are afraid or in pain, how do you find comfort? 7. In what ways will your religion and spirituality influence your decisions as we plan for your care near the end of life?

APPENDIX H

Closing Prayers

A Prayer for Strength and Hope (From Session #4)

ממעמקים קראתיך ה' "O God, from the depths I cry to you:" help me to feel that the ways of Your providence are wise and good, though we understand them not. In this moment, my full soul feels but little strength to pray. Yet, You gave the miracle of life and now we ask for the miracle of hope.

Give us hope and strength that we may see the light at the end of this dark moment. Give us the love and the commitment to advocate on behalf of our children's needs and provide for them the best care, a loving home and the brightest future that we can.

May the light of love that our children kindled in our hearts continue to burn brightly so that we may bring cheer to all our dear ones! Praised are You, O God, who gives strength to the weak, who raises the lowly, who comforts the mourner, who gives hope to those in despair. Amen.

A Prayer for Wise Choices (From Session #5)

May the choices that we make as we leave this room be choices that allow us to see the goodness in all people, not only our special needs children, but everybody, because, as someone once said, "Life is a spectrum disorder" and if we scratch below the surface, everyone has special needs or special wants. Dear God, grant us the ability to discern the good and the right, so that the decisions that we make will be wise and correct. Give us faith to walk in the path before us and hope to face the uncertainties of

the future with confidence and clarity. Let our choices be life enriching and life affirming: בחרת בחיים, "Choose life!" Amen.

A Prayer for Optimism (From Session #6)

אל רחום וחנן, the ways of God are "gracious and compassionate, patient, abounding in kindness and faithfulness, assuring love and forgiving ... sin." Therefore, teach us *Adonai* to be gracious and compassionate as You are. Teach us to be kind and patient; give us faith and assure us of your love. May we take to heart the words of the Psalmist: צדיק ה' בכל דרכיו, "*Adonai* is faithful in all His ways and loving in all His deeds." And may so we blessed! Amen.

A Prayer for Openness (From Session #7)

May it be your will *Adonai* our God and God of our ancestors, to open the gates of learning, love and harmony for us. Grant us insight and peace of mind. May we know the joy of parenting and the celebration of our children's milestones and triumphs, rejoicing in their accomplishments! May we be חזק ואמץ, "strong and of good courage," as we face the future with open hearts, open minds and open arms. Amen.

A Prayer for Group Support and Mutual Caring (From Session #8)

All of us bring something to the table. Through that, we create a sense of community and are strengthened by each other. We find strength by the support that we give to each other, by the insight that we give to each other, and simply by our presence that lets each other know that we care. When we finish reading a book of the Torah, we

say: *נאנוּן קמ קמ*, "May we find strength and be strengthened by each other!" As we conclude our sessions together, may we find support from one another and help each other as we face life's uncertainties, not only with our children with autism, but all life's uncertainties. May we find strength in God and in our tradition, for they are always with us and thus we are never really alone! Amen.

GLOSSARY:
THESE ARE THE WORDS.

(Deuteronomy 1:1)

GLOSSARY

Adonai. (Hebrew). Literally, "My Lord." Used as a pseudonym for the Tetragrammaton, the four-letter Hebrew word for God's name often rendered as Yahweh or YHWH in English.

Aharon. (Hebrew). Literally, "last."

Aleinu. (Hebrew). Literally, "upon us" it refers to the opening words of a prayer calling upon worshipers to praise God. The first paragraph celebrates the distinctiveness of the Jewish people and its unique relationship with God. The second speaks eloquently of our universal hope that someday God will be worshiped by all humanity.

Amidah. (Hebrew). Literally, "standing." It refers to the silent devotional prayer at the core of every Jewish worship service and is said while standing. The weekday version consists of 19 prayers and the holy day version consists of seven. It is usually repeated aloud by the cantor.

Autism. A developmental disorder that appears by age three and that is variable in expression but is recognized and diagnosed by impairment of the ability to form normal social relationships, by impairment of the ability to communicate with others, and by stereotyped behavior patterns especially as exhibited by a preoccupation with repetitive activities of restricted focus rather than with flexible and imaginative ones.

Beit Knesset. (Hebrew). Literally, "house of gathering," it refers to the synagogue, which is from the Greek *synagoga*, meaning "gathering place."

Beit Miqdash. (Hebrew). Literally, "house of holiness" or "sanctuary," it refers to the ancient Temple that stood in Jerusalem, also known as King Solomon's Temple. The First Temple was destroyed by the Babylonians in 586 BCE and the Second Temple, built to replace it in 517 BCE was destroyed by the Romans in 70CE.

Beit Midrash. (Hebrew). Literally, "house of study," it refers to one of the common uses of the synagogue, namely a place of study and learning. The term also denotes a "study hall."

Beit Tefillah. (Hebrew). Literally, "house of prayer," it refers to the chapel or sanctuary of a synagogue in which members of the Jewish faith come to pray.

Ben adam lehavero. (Hebrew). Literally, "between man and his fellow." A phrase connoting the ethical commandments of the Bible.

Betokham. (Hebrew). Literally, "in them" or "in their midst."

B'tzelem Elohim. (Hebrew). Literally, "in the image of God."

Cantor. The Jewish religious official who leads the musical part of a service.

Chelation. (Medicine). The process of removing a heavy metal from the bloodstream by means of a chelate, as in treating lead or mercury poisoning.

Cerebral palsy. A disorder usually caused by brain damage occurring at or before birth and marked by muscular impairment. Often accompanied by poor coordination, it sometimes involves speech and learning difficulties.

Communication disorder. Difficulties in language development and other forms of human interaction, including subtle gestures of facial expression, tone of voice and body language—features of what is commonly called the total communication. For this reason, autism is often called a "communication disorder."

Conservative Judaism. Jews who keep most of the requirements of the Mosaic Law, but allow for adaptation of other requirements to fit modern circumstances when authorized by the Conservative rabbinate.

Cystic fibrosis. A hereditary disease of the exocrine glands, usually developing during early childhood and affecting mainly the pancreas, respiratory system, and sweat glands. It is characterized by the production of abnormally viscous mucus by the affected glands, usually resulting in chronic respiratory infections and impaired pancreatic function.

Davven. (Yiddish). Literally, "pray."

Deliberative theology. The understanding of faith that emerges from a process of carefully reflecting upon embedded theological convictions. This sort of reflection is sometimes called second-order theology, in that it follows upon and looks back over the implicit understandings embedded in the life of faith.

Developmental disability. Problems developing skills common to others of the same age. Since the rate and pattern of development is the primary concern with autism, it is called a "developmental disability."

Down's syndrome. A congenital disorder, caused by the presence of an extra 21st chromosome, in which the affected person has mild to moderate mental retardation, short stature, and a flattened facial profile; also called Trisomy 21.

Embedded theology. The way in which individuals learn about their faith from countless daily encounters, formal and informal, planned and unplanned. It is the theological assumptions they make about why the world works as it does. It is first-order theology or the language of witness, being made up of the most immediate and direct testimonies to the meaning of faith.

Epigenesis. Individuals achieve more advanced levels of ego functioning by mastering successive developmental challenges.

Gemara. (Aramaic). Literally, "completion." The second part of the Talmud, consisting primarily of commentary on the *Mishnah*.

Hassidic Judaism. The beliefs and practices of a sect of Orthodox Jews based on the teachings of the *Baal Shem Tov*, a.k.a. Israel ben Eliezer (1700?-1760), a Polish-born Jewish religious leader and mystic and the movement's founder.

Haviv. (Hebrew). Literally, "most precious," or "dearest."

Kotzker Rebbe. Rabbi Menachem Mendel of Kotzk, better known as the Kotzker Rebbe (1787-1859) was a Hassidic leader. He was known for having acquired impressive Talmudic and Kabbalistic (mystical) knowledge at a young age. He was a student of Rebbe Bunim of Peshischa, and upon the latter's death attracted many of his followers. The Kotzker Rebbe, while not having composed any works himself, is well known for his incisive and down-to-earth philosophies. He appears to have had little patience for false piety or stupidity. It is thought that due to his genius he became very lonely in later life. This led him to leave in seclusion for the last twenty years before his death. He is considered to be the spiritual founder upon which the Ger Dynasty in Poland is based through the teachings of its founder Rabbi Yitzchak Meir Alter

Landsmanschaft. (Yiddish). Literally, "regional affinity group." It is probably better described than defined: folks who came from the same town in the Old Country, settled in one city or another, where they got together to socialize, play cards, and gossip. They also passionately looked out for each other, bailing each other out and financing each other's debts.

Lurianic Mysticism. A body of mystical teachings of rabbinical origin, often based on an esoteric interpretation of the Hebrew Bible, developed by the 16th century Rabbi Isaac ben Solomon Luria (1534-1572).

Libido. The psychic and emotional energy associated with instinctual biological drives, in particular, the manifestation of the sexual drive.

Megillot. The five *megillot* of the Hebrew Bible are Song of Songs, Ruth, Lamentations, Ecclesiastes and Esther. Each is read on a Jewish holy day reflecting its themes: *Pesah* (Passover), *Shavuot* (Pentecost), *Tisha B'Av* (9th of Av), *Sukkot* (Tabernacles) and Purim.

Midrash. (Hebrew). Literally, "exegesis" or "commentary" or "explanation." Any of a group of Jewish commentaries on the *Tanakh* (Hebrew Scriptures) compiled between 400 and 1200 CE and based on exegesis, parable, and haggadic legend.

Midrash Tehillim. An early Rabbinic commentary on the Book of Psalms. The Rabbinic era begins with the close of the Hebrew Bible in 444 BCE and continues through the period of the Talmud, closing c. 500 CE. It is divided into three sub-periods: Saboraic (444-135 BCE), Mishnaic (135 BCE-180 CE) and Talmudic (180-500 CE).

Mishnah. (Hebrew). Literally, "second" or "repeat." The first section of the Talmud, being a collection of early oral interpretations of the *Tanakh* (Hebrew Scriptures) as compiled about 200 CE. Called *Mishnah* because it is second in authority to the Torah and was taught orally through repetition and memorization.

Muscular dystrophy. Any of a group of progressive muscle disorders caused by a defect in one or more genes that control muscle function and characterized by gradual irreversible wasting of skeletal muscle.

Narcissism. A psychological condition characterized by self-preoccupation, lack of empathy, and unconscious deficits in self-esteem. Erotic pleasure derived from contemplation or admiration of one's own body or self, especially as a fixation on or a regression to an infantile stage of development.

Ontogeny. The origin and development of an individual organism from embryo to adult. Also called ontogenesis.

Orthodox Judaism. Jews who strictly observe the Mosaic Law as interpreted in the Talmud and Code of Jewish Law.

Phylogeny. Relating to or based on evolutionary development or history.

Psychogenic. Originating in the mind or in mental or emotional processes; having a psychological rather than a physiological origin. Used of certain disorders.

Qabbalah. A body of mystical teachings of rabbinical origin, often based on an esoteric interpretation of the Hebrew Bible.

Reconstructionist Judaism. The beliefs and practices of a sect of liberal Jews based on the teachings of Rabbi Mordecai M. Kaplan (1881-1982), a Polish-born Jewish religious leader and the movement's founder.

Reform Judaism. The branch of Judaism introduced in the 19th century that seeks to reconcile historical Judaism with modern life and does not require strict observance of traditional religious law and ritual.

Secretin. A polypeptide hormone produced in the duodenum, especially on contact with acid, which stimulates secretion of pancreatic juice.

Shiva. (Hebrew). Literally, "seven." A period of seven days of mourning after the death of close relative (spouse, child, parent, sibling); "the family is sitting *shiva*"

Sitra ahra. (Aramaic). Literally, "the other side," the side of God that brings evil into the world.

Talmud. (Hebrew). Literally, "learning" or "instruction." The collection of ancient Rabbinic writings consisting of the *Mishnah* and the *Gemara*, constituting the basis of religious authority in Judaism.

Tanakh. (Hebrew acronym). The sacred book of Judaism, consisting of the Torah, the Prophets, and the Writings; also referred to as the Hebrew Scriptures. The word is comprised of the first letter of each section: *Torah* (Pentateuch), *Nevi'im* (Prophets), and *Ketuvim* (Writings).

Theophany. A visible (but not necessarily material) manifestation of God to human beings.

Torah. (Hebrew). Literally, "instruction." Refers to the Pentateuch, the Five Books of Moses, or the Hebrew Bible. It consists of Genesis, Exodus, Leviticus, Numbers and Deuteronomy. In a wider context, Torah refers to any type of Jewish learning that brings one closer to God and Jewish Tradition.

Unetaneh Toqef. A prayer in the High Holy Day liturgy of the Jewish people said to be composed by Rabbi Amnon and introduced into the liturgy by the poet and cantor, Kalonymos ben Meshullam of Mayence (ca. 1100). The prayer expresses a dramatic awareness of the unpredictability and uncertainty of human life.

Yad. (Hebrew). Literally, "hand." The hand-shaped pointer used while reading from Torah scrolls.

Yahweh. (Hebrew). The sacred name of God in Jewish scriptures and tradition; also known as the Tetragrammaton. Since Hebrew was written without vowels in ancient times, the four consonants YHWH contain no clue to their original pronunciation. Contemporary scholarship generally renders it "Yahweh." In traditional Judaism, the name is not pronounced, but *Adonai* ("Lord") or something similar is substituted. In most English versions of the Bible the Tetragrammaton is represented by "LORD" (or less frequently, "Jehovah"). Synonyms: YHWH, Yahwe, Yahveh, Yahve, Jahweh, Jehovah, JHVH.

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HE WROTE DOWN ON THE TABLETS THE TERMS.

(Exodus 34:28)

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