Developmental Disabilities:
An Emphasis on Autism Spectrum Disorders
and Family Functioning from an Adlerian Perspective

A Research Paper

Presented to

The Faculty of the Adler Graduate School

In Partial Fulfillment of the Requirements for

the Degree of Master of Arts in

Adlerian Counseling and Psychotherapy

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April 2008
Acknowledgements

Many threads of encouragement have been woven together to allow for the completion of this paper. My thanks extend to those who have taught and nurtured me:

- My family. Special thanks to my husband, Steve, for becoming chief homemaker and motivator during this time; my mother, Mabel, and Wil for understanding my unavailability; Matt and Leah for providing inspiration through my first grandchild-to-be; my sister and sister-in-law, Carla and Erna, for their long-distance support; and Preston, my canine writing companion.

- The entire faculty, staff, and student body of the Adler Graduate School. Every one is filled with *Gemeinschaftsgefühl*, Adler’s term for Social Interest, and is therefore an encourager and role model extraordinaire. Special thanks to Dr. Marina Bluvshtein for gently urging me to start writing and to stop writing, as well as for her care, guidance, inspiration, and many contributions to this paper; Catherine Hedberg and Scout for allowing me to join them to complete internship requirements and for final polishing of this paper; Jana Goodermont for “Graceful Presence” and for the group didactic experience; Dr. Roger Ballou for his introduction to Alfred Adler, Individual Psychology, and APA format; Evelyn Haas for answering every question; and Earl Heinrich for his patient help with research and most everything else.

- My internship supervisors, families, and colleagues. Special thanks to Kathleen Cornelius at Harvest Preparatory School; Jeffrey Postuma and Debbie Mason-Moore at Perspectives Family Center; and Pastor Matt Anderson at Calvary Lutheran Church of Golden Valley.

- My colleagues and mentors, Pastors Lynn Peterson and Mary Brown.
Abstract

The focus of this literature review is on how family functioning is affected when a child is diagnosed with chronic emotional, developmental, or behavioral problems. Particular attention has been given to families of children diagnosed with Autism Spectrum Disorders and viewing the effects from an Adlerian perspective. This review explores the disorder, models of stress and sources of stress in families of children with the disorder, the resources and supports that mediate and moderate these stressors, and the importance of perception and appraisal in coping with the disorder and its impact on the family. Alfred Adler’s theory of Individual Psychology, commonly known as Adlerian psychology, has been used as a framework for understanding, coping with, and responding to the stress ASD diagnoses bring to families.
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The Challenge of Developmental Disabilities

A pregnancy is anticipated and the image of a child enters the family’s thoughts, images of what the child will look like, be like, and do. The pregnancy is confirmed, and, almost immediately, hopes and dreams for the child begin to dominate thoughts. Family life, celebrations, and vacations with the child are imagined throughout the nine months. Finally, the child is born and the family welcomes its newest member. Weeks, months, or even years may pass before parents recognize or admit that something is not “normal.” The family finds itself facing circumstances they had not imagined: the diagnosis of a chronic illness or disability.

The number of families facing this diagnosis has swelled in recent decades. Berge and Holm (2007) reported estimates indicating that between 10 and 30% of American children have chronic health conditions or disabilities, perhaps due to advances in medicine and technology that have made it possible for children with previously fatal health conditions to survive, albeit sometimes with chronic, incurable illnesses. Under the federal Individuals with Disabilities Education Act (IDEA), the number of children with “developmental delay” being served in schools has increased 633% between 1997-1998 and 2000-2001, and the number of children with “autism” has increased more than 400% since first reported in 1992-1993 (Blanchard, Gurka, & Blackman, 2006).

In 2003-2004, the Maternal and Child Health Bureau of the Health Resources and Services Administration sponsored a nationwide telephone survey, the National Survey of
ASDs and Family Functioning

Children’s Health (NSCH). The survey interviewed parents of 102,353 children in the 0 to 17 age range, making it the largest and most comprehensive survey of the health of children in the United States (U. S.) to date. It was unique in that it included all children, not only those with special health needs (Blanchard et al., 2006).

In identifying children with special health needs, the NSCH’s definition of “problem” required that children have “chronic (i.e. lasting ≥12 months and warranting treatment or counseling) emotional, developmental, or behavioral problems” (Blanchard et al., 2006, p. e1204). Using this restrictive definition, just over 5% of children aged 0-17 years, or about 1.5 million American children, fit the criteria. The percentage was higher (6.7%) in the school-age population (6-17 year-olds). Of these children with developmental problems, nearly two-thirds were male (Blanchard et al.).

These prevalence rates differed from earlier surveys that placed them as high as 17%. Blanchard et al. (2006) listed possible reasons for the discrepancy, including (a) more restrictive diagnostic criteria, (b) delay between the onset of symptoms and diagnosis, (c) parents’ inability to recognize the severity of the problems, and (d) limited developmental assessments in primary care settings. Schieve, Blumberg, Rice, Visser, & Boyle (2007) analyzed the NSCH data and suspected under- or delayed diagnoses in populations with less access to services because of the diagnosis’ dependence on in-depth behavioral observation by specialized health care professionals. As another example of underdiagnoses, in 6 to 17- year-olds, 41% of parents of school-aged children expressed concerns about learning difficulties versus 11.5% being professionally diagnosed, and 36% expressed concern about depression or anxiety versus 5.4% professionally diagnosed. The actual frequency of developmental problems is probably somewhere in between the two percentages (Blanchard et al.).
Overall, the NSCH reported that about 1 in 200 (0.5%) children was diagnosed with autism, although in school-aged children, the rate rose to 0.6% (Blanchard et al., 2006). Schieve, et al. (2007) emphasized that the survey specifically asked about “autism” and that children with related developmental disorders may not have been reported. Of the children who were reported to have problems, 7.2% had a diagnosis of autism.

Although early diagnosis and intervention has been shown to significantly improve outcomes in children with autism, it is estimated that only 50% of children are diagnosed before entering kindergarten (National Institute of Mental Health [NIMH], n.d.). Realmulto (2007) reported that the age at time of diagnosis is decreasing due to a greater awareness of the disorder by parents, primary care medical professionals, and preschool program staff, as well as the incentive for identification and increasing access to autism professionals that IDEA entitlements for services have brought. For example, in California in 1987, the mean age of diagnosis was 6.8 years; by 1994 it had decreased to 3.3 years. This decrease in age results in a larger proportion of children with Autism Spectrum Disorders (ASDs) being counted, as the NSCH’s 0.1% difference in prevalence rate between preschool and school-aged children indicated would be significant.

The NSCH’s prevalence rate of about 5 per 1000, up from 0.3 – 1.1 cases per 1000 in the 1980s and 90s, is consistent with other recent reports. Blanchard et al. (2006) suggested that this increase could be due to (a) a more all-encompassing definition of autism, (b) more awareness of the condition, (c) an actual increase in the number of cases, or (d) any combination of these factors. In more recent reports, Weiss et al. (2008) reported a prevalence rate of 0.6%, matching the NSCH’s statistics for school-aged children. The Centers for Disease Control and Prevention (2007) currently places the prevalence rate at 1 in every 150 American children (nearing 0.7%), and more alarmingly, 1 in 94 boys (over 1%). Of note is the Autism Society of America’s (ASA;
n.d.) current statistics, stating that as many as 1.5 million Americans have some form of autism, the same number the NSCH found for the total number of children with developmental problems. The ASA stated that the U. S. Department of Education and other governmental agencies report a growth rate of 10-17% per year. At this rate as many as 4 million Americans could have some form of autism by the end of the next decade.

Autism can affect any child regardless of racial, ethnic, or social background and regardless of family income, lifestyle, or educational level (ASA, n.d.). This problem is international in scope, indicated by research contributing to this paper from Australia, Canada, Hong Kong, Israel, The Netherlands, Sweden, Turkey, and the United Kingdom, in addition to the U. S. The financial burden to families and government agencies is staggering. It is estimated that the lifetime cost of caring for a child with autism ranges from $3.5 million to $5 million. The U. S. is facing almost $90 billion in annual costs for autism, including the costs of research, insurance and non-covered expenses, Medicaid waivers, educational spending, housing, transportation, employment, therapeutic services, and caregiver costs (ASA).

In what seems to be an epidemic, educators and mental health professionals are struggling with how best to help children with these developmental problems. Recent research interested in the psychological and social impact of chronic conditions on children and their families has shown that common stressors and similarities in family adjustment are found across a wide variety of childhood chronic health conditions. Researchers in the psychosocial field have embraced this noncategorical approach, shifting away from the disease-specific approach necessary in biomedical research (Berge & Holm, 2007).

Researchers are finding that potential interventions must go beyond the child’s deficits to addressing the impact on the family and the community. Blanchard et al. (2006) advised:
“Without success in improving these collateral problems, the likelihood of success in treating the primary problems may be diminished” (p. e1210). Other researchers agree. Berge and Holm (2007) predicted that research will move beyond focusing on the illness itself, or even the symptoms of psychological distress that occur in response to dealing with a chronic illness, and will expand to encompass how the family context and family relational processes affect living with a chronic health condition. (p. 131)

In keeping with this research, the focus of this literature review is on how family functioning is affected when a child is diagnosed with chronic emotional, developmental, or behavioral problems, which subsequently will be referred to as Developmental Disabilities (DDs). Particular attention will be given to families of children diagnosed with ASDs and viewing the effects from an Adlerian perspective. A definition of terms as they have been used in this paper has been included prior to exploring the disorder, models of stress and sources of stress in families of children with the disorder, the resources and supports that mediate and moderate these stressors, and the importance of perception and appraisal in coping with the disorder and its impact on the family.

Definitions of Terms

Adjacency structures. Patterns of conversational sequence and structure in which what one participant says or does shapes the other participant’s response (Stiegler, 2007)

Ambiguous. “Doubtful or uncertain…inexplicable… [or] capable of being understood in two or more possible senses or ways” (Merriam-Webster Online Dictionary, 2005)
Attachment. The affectional bond that infants develop with their primary caregivers; the cumulative outcome of interactions between parents and children in the first year of life (Rutgers, Bakermans-Kranenburg, van IJzendoorn, & van Berckelaer-Onnes, 2004)

Attributions. Attempts to explain and find meaning in stressful life events (Dale, Jahoda, & Knott, 2006)

Authoritarian (parenting) style. “Authoritarian control and supervision of the child, and control through anxiety induction” (Rutgers et al., 2007, p. 863)

Authoritative (parenting) style. “Indexes rational guiding of the child, encouraging independence and open expression of affect” (Rutgers et al., 2007, p. 863)

Boundary ambiguity. “A state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system” (Boss and Greenberg, 1984, as cited in Carroll, Olson, & Buckmiller, 2007, p. 211)

Family priorities. “[Reflect] underlying values; they might involve taking on certain roles in life, such as helping others through volunteer or advocacy roles, or involve everyday choices about family activities” (King et al., 2006, p. 357)
Family quality of life. “Conditions where the family’s needs are met, family members enjoy their life together as a family, and family members have the chance to do things that are important to them” (Poston et al., 2003, as cited in Poston & Turnbull, 2004, p. 96)

Family values. “The operating principles by which people conduct their lives and organize the lives of their families” (King et al., 2006, pp. 356-357)

Family world view. “The family’s assumptions about the social and cultural environment and beliefs about its place in the world” (King et al., 2006, p. 356)

Identity ambiguity. The extent of perceived overlap or confusion between parents’ own identities and those of their children with ASDs (O’Brien, 2007)

Joint attention “Behaviors used to follow or direct the attention of another person to an event or object to share an interest in that event or object” (Siller & Sigman, 2002, p. 77).


Mediator: A third variable that carries the effect of one variable (i.e., A) on another variable (i.e., X) and explains why A and X are related (Hastings, 2002)
Membership ambiguity. “Unclear perceptions about whether the chronically ill child is psychologically included in the family” (Berge & Holm, 2007, p. 124)

Moderator. A variable that changes the relationship between A and X (Hastings, 2002)

Parental sensitivity. “The parents’ ability to perceive and interpret their children’s attachment signals accurately and to be able and willing to respond promptly and adequately to those signals” (Ainsworth, Blehar, Waters, & Wall, 1978, as cited in van IJzendoorn et al., 2007, p. 598)

Religion. “The institutionalized and organized patterns of beliefs, morals, rituals and social structures that people create to help fulfill their spiritual quest” (Canda; Fitzgerald, 1997; as cited in Poston & Turnbull, 2004, p. 96)

Role ambiguity. “Unclear expectations about the performance of parental roles within the family” (Berge & Holm, 2007, p. 124).

Self-efficacy. “Feelings of competence in the caretaking role” (Kuhn & Carter, 2006, p. 565)

Spirituality. “The area of life that includes the need to find meaning in our existence; a search for fulfilling relationships between oneself and others, the universe, and reality as one views and understand it; as well as the way that we respond to the sacred”(Canda, 1999; Fitchette, 1993; Gaventa, 2001, as cited in Poston & Turnbull, 2004, p. 96)
**Autism Spectrum Disorders**

In the current *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; 4th ed. text revision, American Psychiatric Association [APA], 2000)*, ASDs are classified as Pervasive Developmental Disorders (PDDs). This cluster of neurodevelopmental disorders with a wide severity range (Schieve et al., 2007) includes Autistic Disorder (AD), a severe form sometimes known as classic or strictly defined autism; two rare but very severe disorders, Rett’s Disorder and Childhood Disintegrative Disorder (NIMH, n.d.); Asperger’s Disorder, a milder form; and PDD Not Otherwise Specified (PDD-NOS), diagnosed when symptoms of either disorder are present but the specific criteria are not met.

Terminology for these disorders has been changing as research progresses but remains imprecise because of the ambiguity and wide range of functioning still found in these diagnoses. The concept of “spectrum” as applied to autism was not in use at the time of *DSM-IV-TR* (2000). Therefore, in this paper, “autism” may refer to any diagnosis on the autism spectrum except when AD or Asperger syndrome is specifically indicated. In general, the terminology of the research cited has been used. In keeping with current usage, this paper uses “Asperger syndrome” versus Asperger’s Disorder, as well as “Rett syndrome” versus Rett’s Disorder. “Syndrome” and “Disorder” have been used interchangeably.

ASDs usually manifest in the first three years of life. Some parents notice their children’s lack of interest in social interaction shortly after birth (*DSM-IV-TR*, 2000). Other parents report typical development for the first year or two of life, begin to notice differences as their children reach a plateau, and then become concerned as their children begin to lag behind other children of the same age. In some cases, the change is gradual; in others it is sudden (NIMH, n.d.).
Because ASDs were once referred to as “psychosis” or “childhood schizophrenia” (DSM-IV-TR, 2000), the diagnosis still can carry a stigma. As recently as 1981, autism was described as a behavioral syndrome (Hartshorne & Herr, 1983). Current research clearly shows that the disorder does not result from poor or inadequate parenting, but is a genetic disorder, “possibly triggered by pre- or postnatal environmental events that are out of the control of parents” (Rutter, 2000, as cited in O’Brien, 2007, p. 144).

Research into the etiology of autism has been problematic because of the wide range of developmental and cognitive differences in the population (Williams, Goldstein, & Minshew, 2006). While chromosomal abnormalities are thought to play a role, only about 10% of cases can be explained by genetic syndromes and known chromosomal anomalies. A recent breakthrough in genetic research has accounted for another 1% of cases (Weiss et al., 2008). Without known biological markers, drugs have not been developed to treat the underlying conditions and, currently, treatment is primarily limited to behavioral interventions where progress is painstakingly slow and results are subtle. Medications have been approved to treat symptoms such as irritability, including aggression, deliberate self-injury, and temper tantrums; obsessive-compulsive disorder; depression and anxiety; seizures; and inattention and hyperactivity (NIMH, n.d.). Relying on these drugs is less than optimal (Blanchard et al., 2006) and presents an additional challenge in today’s cultural context where not only are all conditions expected to be fixed, but quick fixes are demanded.

Because ASDs are lifelong and pervasive, they have a poor prognosis. Research shows that only a small percentage of those with the disorder are able to live and work independently as adults. Some degree of partial independence is possible in about one-third of the cases (DSM-IV-TR, 2000).
Core Deficits

Three distinctive behaviors, ranging from mild to disabling, characterize ASDs: (a) difficulties with social interaction, (b) problems with verbal and nonverbal communication, and (c) repetitive behaviors or narrow, obsessive interests (DSM-IV-TR, 2000; NIMH, n.d.; National Institute of Neurological Disorders and Stroke [NINDS], 2006). AD is the most prototypic form within the PDD cluster (van IJzendoorn et al., 2007). It requires impairment in all three developmental areas.

Social interaction problems. ASDs feature a lack of social or emotional reciprocity. Parents may first notice that their infants display “a failure to cuddle; an indifference or aversion to affection or physical contact; a lack of eye contact, facial responsiveness or socially directed smiles; and a failure to respond to their parents’ voices” (DSM-IV-TR, 2000, p. 72). They may seem indifferent and passively accept or even resist attention. “Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of the expected and typical attachment behavior” (NIMH, n.d.). As they grow, children may become more interested in social interaction, but they tend to have little sense of others’ boundaries and may be inappropriately intrusive or demanding (DSM-IV-TR).

The social deficits of ASDs are particularly challenging in our present cultural context where social norms and standards for behavior have radically changed in recent decades. In today’s society, entertainment and its required socialization are cultural priorities and science and math skills are not as highly valued. For even very young children, day care and extra-curricular activities have replaced quiet time at home alone or with one’s family. There is little tolerance for deviations from the norm. Therefore, children who are socially immature; who do not have a fun, entertaining persona; who have strengths in science and math rather than in social
engagement; and who need mentoring, guidance, and extra attention must be explained (Realmuto, 2007).

**Communication problems.** The development of spoken language in children with ASDs may be delayed or totally lacking in some children (*DSM-IV-TR, 2000*), while others may have precocious language and unusually large vocabularies. Those who do speak may not be able to combine words into meaningful sentences and may speak only single words or repeat phrases over and over, a condition know as echolalia. There are difficulties in initiating or sustaining conversations, again displaying the lack of social reciprocity. The tone of voice may not reflect feelings, and nonverbal behavior is also impaired. Body language is difficult to understand and seldom matches verbal speech, making it challenging for children with ASDs to express their needs (NIMH, n.d.).

**Repetitive Behaviors.** Children with ASDs exhibit “restricted, repetitive, and stereotyped patterns of behavior, interests, and activities” (*DSM-IV-TR, 2000, p. 71*). Behavioral abnormalities include odd repetitive motions, such as hand flapping or walking on tiptoe, and preoccupations with parts of objects, movement of objects, and nonfunctional routines or rituals. They may insist on sameness, become upset over trivial changes in the environment, or have difficulty with transitions. They are often obsessed with one narrow interest or have exceptional command of tasks involving long-term memory, such as historical dates, chemical formulas, or song lyrics (*DSM-IV-TR*).

**Associated Problems**

In addition to the core deficits of ASDs, other problems may accompany the disorder. The majority of children (75%) have some degree of mental retardation (MR; Rutgers et al., 2004), the exception being most of those diagnosed with Asperger syndrome (*DSM-IV-TR,*
Although males are four times more likely to have autism than females (ASA, n.d.; NINDS, 2006), females are more likely to exhibit more severe MR (DSM-IV-TR). Two genetic conditions are sometimes present as well. Fragile X syndrome, the most common inherited form of MR, affects about 5% of people with ASD. Tuberous sclerosis, a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs, affects 1 to 4% of people with ASD. Seizures are developed by about 25% of children, often starting in early childhood or adolescence (NIMH, n.d.).

Sensory problems are apparent in many children. They may demonstrate hypersensitivity to certain sounds, textures, tastes, or smells, indicating that the brain is “unable to balance the senses appropriately” (NIMH, n.d., p. 10). Other behavioral symptoms include hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors, and temper tantrums. Because children with ASDs appear to be healthy, people observing and experiencing these behaviors may react negatively, not realizing that they are due to a disability (Norton & Drew, 1994). Mood disorders such as anxiety and depression, abnormal mood or affect, a lack of fear or excessive fear (DSM-IV-TR, 2000), and erratic sleep patterns are also common and create disruptions in family routines (Norton & Drew).

The core deficits and associated problems of ASDs have the potential to severely impact not only children with the disorder but the functioning of their parents and their entire families. Alfred Adler’s theory of Individual Psychology, commonly known as Adlerian psychology, will be used as a framework for understanding, coping with, and responding to the stress ASD diagnoses bring to families.
An Adlerian Perspective on Autism

Adler (1870 – 1937) believed that people are socially embedded in a network of relationships. In this network, families play a central role, with children and parents influencing each other in orienting themselves toward others, maintaining health, and fostering growth (Oberst & Stewart, 2003). Adler was especially interested in helping families successfully manage the challenges of family life and established the first school-based child-guidance centers in his home of Vienna, Austria, in 1922. A particular focus of Adlerian family therapy is in “making fundamental changes in family functioning so that the negative effects of family dysfunction can be minimised and more healthy relational patterns can be established” (Oberst & Stewart, p. 86).

Because people are socially embedded, Adler believed that their problems are rooted in relationships. Psychological problems are a consequence of the negative appraisal of one’s significance in relation to others. These feelings of inferiority go beyond envy to feelings of personal worthlessness and arise when people are discouraged (Oberst & Stewart, 2003). Compensation and over-compensation are basic responses to these feelings of inferiority (Hartshorne, 2002).

Another core belief of Adler was that life is expressed “‘in movement and direction toward a successful solution of outer and inner confrontations’” (as cited in Ansbacher & Ansbacher, 1956, p. 163). From this, Hartshorne & Herr (1983) assumed that “all behavior is movement, directed toward finding a way to belong” (p. 397). This Adlerian viewpoint assumes that a positive resolution is always possible and that a diagnosis of any kind runs the risk of excluding individuals and families from a society of “normals.” Research has shown that this exclusion is often deeply experienced in families of children with DDs and especially those with
ASDs. This review will feature two key Adlerian concepts, family environment and Lifestyle, and two key elements of Lifestyle, Social Interest and the five life tasks.

*Family Environment*

Because of Adler’s emphasis on social embeddedness, he recognized that families have profound influence on individual family members’ development. Dreikurs (1964) identified three major influences in children’s family environment. The first, family atmosphere, has to do with the family’s (a) mood, the overall emotional tone; (b) order, the structural hierarchical relationships; and (c) relationships, the patterns of interaction (Shulman & Mosak, 1998, as cited in Eckstein & Kern, 2002). Adler believed that successful family environments are warm and friendly and instill cooperation, a crucial life skill: “All of life’s problems demand an ability to cooperate if they are to be resolved” (Adler, 1998, p. 18).

The second influence is the family constellation, which Eckstein and Kern (2002) deemed one of Adler’s most significant contributions to psychology. Family constellation has to do with birth order, both actual and perceived, and the relative positions of each family member in relation to the other members.

The third influence is the methods of training. Of these, encouragement is the most important (Dreikurs, 1964). Two other factors in the family environment are family values and parenting styles. Of these, parenting styles will be featured the most prominently in this review. Dreikurs identified four parenting styles: democratic, laissez-faire (including both pampering and neglect), and autocratic. The preferred democratic style features mutual respect, trust, and teamwork.
Lifestyle

“Lifestyle” is a term Adler used as a synonym for character or personality (Oberst and Stewart, 2003). Lifestyle develops in early childhood, shaped by aspects of the family environment, and influences a person’s view of oneself and the world. “‘Experiences become assimilated and utilized according to the style of life…. To facilitate this activity personal rules and principles, character traits, and a conception of the world become elaborated. A well-determined schema of apperception…is established’” (Adler, as cited in Ansbacher & Ansbacher, 1956, p. 182).

King et al. (2006) recognized a family version of Lifestyle and termed it a family belief system. They described it as being comprised of world views, values, and priorities and recognized this as being among the most important factors affecting a family’s overall resilience. These belief systems serve as “cognitive maps that guide the choices families make for their everyday activities” (p. 354). Thus, individuals’ Lifestyles and family belief systems affect attitudes toward life and methods of facing problems.

Social Interest. “Social Interest” is a component of one’s Lifestyle and has to do with feelings of belonging and community. Oberst and Stewart defined Social Interest as feeling like a part of a family, a group, a couple, and the human community…. It means to participate, to contribute, to share; to feel accepted, appreciated, and loved, as well as to accept, appreciate and love other people…. It also means being able to cope with the obstacles and misfortunes of life in a socially adaptive way; not by seeking one’s self-interest and personal advancement, but by pursuing, at the same time, the benefit of – theoretically – the whole of humankind. (p. 17)

The five life tasks. Lifestyle and Social Interest both influence how individuals approach the essential tasks or responsibilities of life. Adler identified three life tasks, those regarding: (a) social relations, known as the friendship task; (b) occupation, the work task; and (c) marriage or intimacy, the love task (Ansbacher & Ansbacher, 1956; Oberst & Stewart, 2003). Two additional
life tasks have been added by Adlerian theorists Dreikurs and Mosak: (d) those of developing and getting along with oneself, the self task, and (e) those involving “spiritual and existential efforts to developing life meanings” (Oberst & Stewart, p. 202), the spiritual task. The birth of a child with a chronic illness or disability can present a higher degree of challenge in navigating all five of the life tasks. Adler also believed that “‘everything can also be different’” (Adler, as cited in Ansbacher & Ansbacher, p. 194). Therefore, these challenges can also present opportunities for enriching each life task experience.

The friendship task encompasses all social relationships that do not have a marital, sexual, or familial commitment (Witmer & Sweeney, 1992). This task may be challenged because the demands of raising children with disabilities often places limits on the time available for social life. Families may withdraw or realize smaller friendship networks if they do reach out, quickly discovering which friends can be counted on to provide support (Hartshorne, 2002). The NSCH data indicated that children with DDs were significantly less likely to participate in sports or social activities outside of school (Blanchard et al., 2006), common social networks for typical families. This task may be enhanced as families develop new circles of support and friendship with other families of children with DDs. In one study, almost 24% identified other parents of children with autism as a source of support (Tarakeshwar & Pargament, 2001).

The work task entails everything people do to support themselves and others economically, psychologically, and socially. It includes not only employment but childrearing, homemaking, volunteering, education, and, in the case of children, playing (Witmer & Sweeney, 1992). The NSCH survey effectively documented the challenge to the work task of having children with developmental problems. Among parents of preschool children with DDs, more than 26% had quit a job, not taken a job, or greatly changed a job in the past 12 months because
of problems with finding appropriate and dependable childcare arrangements. In school-aged children with developmental problems, almost 24% had missed more than 10 days of school and over 62% of their parents had been contacted more than once concerning problems in school (Blanchard et al., 2006). The required flexibility indicated by these responses limits employment and career options. In addition, Hartshorne (2002) noted that a parent may need to continue in a job in order to maintain insurance, rather than staying at home to care for a child or seeking a more satisfying position. This task may also be enhanced: Parents’ newly acquired knowledge and advocacy skills may prepare them for new career opportunities.

The love task involves intimate marital and familial relationships. Successful expressions of the love task display positive family processes and communication that feature trust, self-disclosure, cooperation, and commitment (Witmer & Sweeney, 1992). Extensive research has documented that elevated levels of conflict and marital dissatisfaction are often experienced by parents of children with chronic health conditions, but in some families, children with disabilities may bring parents and families closer together (Konstantareas, 1991; Norton & Drew, 1994). Couples who can cooperate, maintain positive interaction patterns, and minimize conflict can reduce the impact of stress on a family system (Berge & Holm, 2007).

The self task is comprised of three main elements: (a) self-esteem; (b) beliefs about personal control, including a sense of mastery; and (c) a congruence of reality and personal beliefs, known by Adlerians as private logic (Witmer & Sweeney, 1992). Mastery is a cultural priority in the U. S., and parenting children with ASDs constantly challenges parents’ feelings of competency. An example of enhancement in this life task is children who report pride in their ability to help their siblings with disabilities (Rivers & Stoneman, 2003).
The spiritual task involves “ethical, moral, and legal codes, all of which in part are intended to protect and sustain the sacredness of life” (Witmer & Sweeney, 1992, p. 141). As such, the meaning of life, hopes for the future, and values that guide relationships and decisions fall under this life task. Religiosity is one dimension and refers to public expressions of spirituality (Witmer & Sweeney). For some families, raising children with ASDs has fostered deeper examinations of fundamental moral values or experiences of transcendence (Gray, 2001).

Hartshorne (2002) noted that cooperation and courage are key components of success in the life tasks and coping with stressful situations: “The ability to cooperate with one’s spouse, with the demands of work, and with friends assists in making resources available for coping with stressful situations” (p. 268). Adler believed that cooperative activity, along with Social Interest, led to courage. Hartshorne elaborated: “Individuals who have enough confidence in themselves and their abilities to contribute and cooperate demonstrate courage. Courage is embedded in encouragement and discouragement. The former increases confidence and cooperative action; the latter reduces it” (p. 268).

Courage may be the most important trait to foster in parents of children with ASDs. Dreikurs (1964) stated that courage is found in individuals who can make mistakes and fail and yet maintain their self-esteem. This “courage to be imperfect” is a necessary antidote to the high expectations of mastery set by our culture. In parenting children with ASDs, regaining a sense of mastery usually requires letting go of the need to find a perfect solution (Berge & Holm, 2007). The goal is improvement rather than perfection. It is only with this attitude that parents can function, progress, and grow (Dreikurs).

Therefore, encouragement is a technique that underlies all interventions in Adlerian therapy. Encouragement avoids criticism, acknowledges efforts more than results, and focuses on
emphasizing positive aspects and the social or functional value of behavior. Dreikurs (1964) viewed encouragement as “a means to restore that patient’s faith in himself, the realization of his strength and ability and the belief in his own dignity and worth” (p. 272). Encouragement may be crucial to family systems facing the stressors of unexpected and unplanned for diagnoses of ASDs.

Stress in Families of Children with Developmental Disabilities

The diagnosis of an ASD in a family member introduces stress into the family system and will affect family functioning and quality of life. To assess family functioning, the NSCH asked parents questions about (a) the closeness of their relationships with their children, (b) their perceived ability to cope with the day-to-day demands of parenthood, (c) how often they felt their children were much harder to care for than most children of that age, (d) how often they felt they were giving up more of their life than expected to meet the child’s needs, and (e) if they had someone to turn to for day-to-day emotional help in raising their children (Blanchard et al., 2006). To assess family quality of life, Poston and Turnbull (2004) identified 10 domains: “advocacy, daily family life, emotional well-being, family interaction, financial well-being, health, physical environment, productivity, parenting, and social well-being” (p. 101).

As previously mentioned, behavioral interventions for the children with disabilities have been the primary treatment offered to families. Although parent training has been employed, its focus has been on managing the children. Both parents and children have displayed desirable changes in behavior, but studies found that after one year, most parents were not using the techniques. In examining this limitation, researchers realized that other “family issues were likely to arise from, or be intensified by, the extraordinary stress of raising a handicapped child” (Harris, 1984). In a study of 52 caregivers of children with ASDs, 41% reported “some form of
physical emotional, financial or marital relationship stress” (Higgins, Bailey, & Pearce, 2005, p. 132).

**Family Stress**

To understand family stress, this review will introduce four conceptualizations of stress along with Perry’s (2005) application of them to families of children with DDs. Next, models of family stress will be discussed along with Perry’s perceived limitations in these models. Finally, three more recent models of family stress will be presented.

*Conceptualizations of Stress*

Perry (2005) identified four conceptualizations of family stress and applied them to families of children with DDs. These approaches largely focus on measuring stress at an individual level and, as such, would be influenced by an individual’s Lifestyle and success in the five life tasks.

“Stage” models were one of the earliest theories. Stress was understood “as the physiological and psychological reactions that an organism goes through, usually in stages, to adapt to a stressful situation” (Selye, 1980, as cited in Perry, 2005, p. 2). An example of therapy based on this model is grief work, where parents are expected to go through stages of shock, denial, anger, bargaining, working through, and acceptance (Siegel, 1997; Perry & Condillac, 2003, as cited in Perry). Bonanno (2004) reviewed meta-analyses that showed that this type of grief work is largely ineffective and may even be harmful, especially in the case of traumatic loss. It appears that this could be the case in families of children with ASDs (O’Brien, 2007).

A second conceptualization is the “stressful life events” paradigm, which assumes that stressful life events will have a negative impact on mental and physical health. Studies have shown this relationship to be weak. Significant stress and negative outcomes have been reported,
but because of the many intervening variables, many families of children with DDs report coping very well and even report positive effects (Perry, 2005).

Another approach, the “daily hassles” paradigm, suggests that it is the everyday frustrations and hassles associated with the life event that are stressful. Parents often report that it is the cumulative effect of daily hassles associated with caretaking that contributes to parental stress. This definition highlights the difficulty in discriminating between perceptions or appraisals of stress and the actual stressors (Perry, 2005).

A final definition of stress “involves the concept of a ‘resource imbalance’ between the demands of a situation (stressors) and a person’s resources or coping ability” (Perry, 2005, p. 3). In this understanding, moderators such as the family’s coping abilities, resources, and supports are taken into account (Perry, 2005).

Models of Family Stress

One of the first models of stress at the family level was Hill’s ABCX model of family stress. In this model, “A” represents the event or stressor, in this case, the child with a DD; “B” is the family’s coping resources; and “C” is the family’s perception of the event. These three factors contribute to either produce or prevent a family crisis, “X” (Hartshorne, 2002; Pakenham, Samios & Sofronoff, 2005; Perry, 2005).

In the Double ABCX model, McCubbin and Patterson expanded the original model to include additional factors contributing to family adjustment and demonstrating the process of adaptation over time. This model has been widely used, including studies reviewed in this paper by Jones and Passey (2005), Konstantareas (1991), Pakenham et al. (2005), and Tobing and Glenwick (2006). These additions allowed for possible mediator and moderator effects and for
variables to act as mediators in some circumstances and as moderators in others (Hastings, 2002). Pakenham et al. noted these additions in the Double ABCX model:

- the severity of the stressors and the pile-up of demands and additional life stressors (aA);
- the resources that families apply in order to manage a crisis (bB);
- the changes that families make to their definition of the situation to help understand the situation (cC);
- the coping strategies employed (BC);
- and the outcomes of the family’s efforts/adjustment (xX; p. 194)

Perry (2005) recognized several limitations in these theories. First, she disagreed with the common implication that the X factor is a crisis or adaptation (xX) to a crisis, stating that “this does not appear to be the only or most helpful assumption to make regarding families of children with DD” (Perry, p. 4). Second, as previously noted in the description of the daily hassles paradigm, there is confusion between C and A in studies using these models. Hartshorne (2002) questioned the linear arrangement of the ABCX model, finding that for families of children with DDs, “the actual order was ACBX…. the perception of the event, or its appraisal, was the first step in coping with an event like the birth of a child with disabilities, followed by an analysis of resources” (p. 266).

A third limitation identified was that the B factor was broad and unspecific. The models did not make a distinction between the individual resources of parents such as beliefs and coping styles versus family system resources such as cohesion and family harmony, nor separate these inner family resources from social and professional resources outside the family. From an Adlerian perspective, they would not take into account Lifestyle, Social Interest, success at the five life tasks, and family environment. Perry (2005) also questioned whether these were truly family models because they typically include individual measures and whether they were truly useful because they include a number of variables that are difficult to measure.
Perry (2005) proposed a new model drawing from research in “family stress, systems, coping, social support, ecological theory, and developmental psychopathology” (p. 11). The new model consisted of four major components: (a) stressors, including child characteristics as well as other life stressors; (b) resources from individual parents’ and the family; (c) supports from outside the family from both informal and formal sources; and (d) outcomes, which is what is left over after considering the impact of the stressors, mediated and/or moderated by the resources and supports. An important realization was that all components have the potential for having positive or negative influences and can produce outcomes that are positive and/or negative.

At about the same time that Perry (2005) was developing her model, other researchers also advised that positive factors should be measured in addition to family problems (Taunt & Hastings, 2002). Patterson and McCubbin and their colleagues also went on to develop more fluid and positive models. The Family Adjustment and Adaptation Response model (Patterson, 1988, 1989, 1993, as cited in Hastings & Taunt, 2002) focuses on processes that minimize families’ experiences of stress by restoring the balance between demands and capabilities (Hastings & Taunt). The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin et al., 2001, as cited in Twoy, Connolly, & Novak, 2007) is “a strength-based model expanded from the family stress theory…. [and emphasizes] family resiliency or their ability to maintain equilibrium of health in spite of adversity” (p. 253). These later models, along with Perry’s, have the capacity to provide encouragement and to recognize the influences of Lifestyle, Social Interest, the five life tasks, and family environment. They also maintain an ecological view of stressors and resources that are available to the family (Perry; Twoy et al.). Some are at
the individual or family level (microsystem) and others are at the community level (mesosystem).

**Stressors at the Individual Level – Child Characteristics**

Researchers have found great variability in the effects of child characteristics on family stress. Potential child characteristic stressor variables for families of children with DDs include (a) age and gender; (b) dependency in self-help tasks; (c) severity of the disorder, indicated by the diagnosis or type of DD and cognitive or developmental level; and (d) the frequency and severity of maladaptive behavior. Perry (2005) tested her model with families of children with autism and found that child characteristics were responsible for the largest overall variance in stress, 27 to 34%. Interestingly, the influence of Lifestyle is apparent, as Perry observed that parents’ perceptions of the children’s characteristics, actually stress responses or outcome measures, were probably more relevant than the “objective” variables of the children’s characteristics.

**Age and Gender**

Studies have shown that the impact of age and gender of the child varies but in most cases does not significantly impact stress in families. Rutgers et al. (2004) found that the chronological age of children did not affect attachment security, and age was not found to be significantly related to any variables predicting psychological distress in Tobing and Glenwick’s (2006) study of mothers of children with PDDs. O’Brien (2007) did find that mothers of older children reported fewer symptoms of depression. In a study assessing family functioning, mothers and fathers raising children with DDs reported a possible trend toward higher levels of family harmony in families with younger children and with children with milder disabilities, although no significant group differences emerged (Perry, Harris, & Minnes, 2005). In contrast,
Gray (2002, 2006) conducted longitudinal studies with families of children with autism 8 to 10 years after initial assessments. He found that family situations were usually better than at the time of the original assessments when the children would have been younger, although, as we shall see, other variables would also affect these results. Perry et al. posited that

Variables related to age, rather than age itself, serve to increase stress in families. For example, older children are physically larger and their externalizing behaviour may be more difficult to manage, thereby increasing stress levels. On the other hand, sometimes children display lower activity levels as they get older which may serve to lessen the stress reported by parents. (p. 26)

Earlier studies suggested that male children with autism could increase marital disharmony and family stress, possibly due to “culturally based expectations for greater achievement and success for boys” (Farber, 1959, as cited in Konstantareas, 1991, p. 366). After looking at other research, Konstantareas went on to conclude that gender seems to be unrelated, although the children’s ages and degrees of handicap may affect whether this is true. In more recent research, O’Brien (2007) studied mothers of children with ASDs and found that child gender did not affect maternal depressive symptoms.

Dependency in Self-help Tasks

Children with ASDs require significant parental assistance and supervision with basic tasks of daily self-care like toileting, bathing, and dressing even through adolescence (Larson, 2006). Mothers of children with autism reported spending 50% more time with their children than parents of typical children, an average of 9.7 waking hours per day as compared to 6.1 hours (Tunali & Power, 2002, as cited in Larson). These extra time demands place added stress on parents, especially mothers.

Schieve et al. (2007) used the NSCH data to assess parents’ abilities to cope with daily parenting demands by using the Aggravation in Parenting Scale (Macomber & Moore, 1999).
Parents reported on how often in the past month they had felt that (a) their children were more difficult to care for than other children of similar ages, (b) they were bothered a lot by things the children did, (c) they were giving up more of their life than expected to care for their children, and (d) they were angry with their children. They combined the 4 parental coping indicators into a single measure by using established criteria for the Aggravation in Parenting scale. On the composite, parents of children with autism were more likely to score in the high-aggravation range (55%) than parents of children with other developmental problems (44%), parents of children with health care needs that are not developmental (12%), and parents of children without special health care needs (11%). However, one of the individual indicators was interesting: While parents of children with autism were more likely to report feeling that their children were harder to care for, they demonstrated a greater understanding of their children’s impairments in that they were less likely than parents of children with other DDs to report being bothered by things their children did and feeling angry with their children (Schieve et al.).

Concerns about their children’s future self-sufficiency were revealed as prominent stressors by Nachshen, Woodford, & Minnes (2003) in validating 23 variables on the Family Stress and Coping Inventory. They reported that planning for children’s long-term accommodations and their emotional and social support received the two highest parental stress ratings. This is not surprising, as numerous studies have found that only 28% to 50% of adolescents and young adults with autism are independent in the most basic self-care skills (as cited in Larson, 2006). Related to this, safety concerns and a fear of children hurting themselves or others are of major concern to parents (Hutton & Caron, 2005).
Severity of the Disorder

The severity of children’s cognitive, developmental, and communication impairments has been shown to affect family functioning. In initial studies on attachment, Rutgers et al. (2004) found that the severity of the disorder and mental development indicated less secure attachment behavior. O’Brien (2007) also found that more severe impairment correlated with elevated maternal depressive symptoms, although not significantly, but Tobing and Glenwick (2006) found significant positive relationships among children’s functional impairment, parenting stress, and maternal psychological distress.

Tobing and Glenwick (2006) also found an interesting contradiction in mothers of children with Asperger syndrome. These mothers reported greater parenting stress than mothers of children with autism or PDD-NOS. The authors surmised that the ambiguous nature of Asperger syndrome may result in greater stress because many of these children’s intellectual capacities allow them to attend regular public schools, yet their social impairments make functioning in mainstream classrooms difficult. Other studies have also shown that high-functioning children with ASDs may have particular behavior problems (Tonge et al, 1999, as cited in Higgins et al., 2005).

The severity of the disorder may also affect sibling adjustment. Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev (2004) compared siblings of children with autism, MR, and Developmental Language Disorder (DLD)’s attitudes and perceptions toward their siblings with disabilities. They found that sibling adjustment in both the autism and the MR group was related to the children with impairments’ verbal ability, suggesting that a more severe phenotype may affect sibling adjustment either because of an increased genetic liability or because of more daily challenges.
Frequency and Severity of Maladaptive Behavior

Maladaptive behaviors, such as aggressive behavior and misbehavior in public, are of significant concern to parents. One study of 52 caregivers reported on five of the most common characteristics that their children (median age 10:10 years) with ASDs displayed: (a) fascination with topics, people or objects (76%); (b) repetitive behavior (69%); (c) temper tantrums (66%); (d) repetitive talking about a topic (62%); and (e) lack of eye contact in communication (61%). Three other particular behaviors identified were (f) misbehavior in public (67%), (g) withdrawal behavior (64%), and (h) aggressive behavior (62%). Of all of these, the ones of greatest concern to the caregivers were aggressive behavior, with 100% of the caregivers expressing concern, and misbehavior in public, with 95% expressing concern (Higgins et al., 2005). Aggressive behavior appeared to be more prevalent in older rather than younger children, although it was unclear if this was an objective observation or more of a subjective concern explained by Perry et al.’s (2005) previous hypothesis on variables related to age.

The authors suggested that the misbehavior in public was particularly troubling because of “the notion of being judged as a parent by the community and perhaps being viewed as not being able to manage one’s children” (Higgins et al., 2005, p. 131). Clearly, parents’ sense of mastery and self-esteem, components of the self life task, are threatened by their children’s misbehavior and studies have revealed that this affects parental adjustment and psychological distress. In studying the adjustment of mothers of children with Asperger syndrome, Pakenham et al. (2005), found that better maternal adjustment was related to lower levels of child behavior problems. They found that the degree of behavior problems (stressor severity) accounted for 17% of the variance in social adjustment and 11% of the variance in depressive symptoms. Similarly, two other studies agreed. Hastings (2002) cited numerous studies that have shown that “where
children with developmental disability engage in more problem behaviours, their parents are also likely to report more stress and other minor psychiatric problems such as depression and anxiety” (p. 151). Nachshen et al. (2003) found that parents of individuals with more severe maladaptive behavior experienced more stress than parents of those with mild or moderate maladaptive behavior.

Hastings et al. (2005) found this to be true only in mothers. In studying parents of preschool children with autism, they found that the only child characteristic strongly correlated with maternal stress was the behavior problems of their children. Paternal stress was not associated with any child characteristics, including behavior problems. As a possible explanation, the team suggested that this could be due to the fact that mothers typically report more involvement in the care of their children while fathers often bring more adaptive coping strategies. However, these coping strategies could include avoiding their children and doing other activities, leaving the greater burden of care to mothers and adding to their stress.

In another study, Hastings (2002) focused on the relationships among behavior problems in children with DDs, stress, and parenting behaviors. His underlying assumption was based on previous research that indicated that (a) children with DDs are at an increased risk of developing behavioral and emotional problems; (b) genetic, neurological, socio-economic, and motivational variables may account for such differences; and (c) psychological processes, especially social environment effects, have been implicated in the development of these behavior problems. The researcher drew from a model that shows that children and parents reciprocally influence each other:

Antecedent conditions for problem behavior (e.g., deprivation of attention, presence of demands) result in certain events (i.e., parent attention, removal of requests for compliance) being established as reinforcing, making problem behaviours similarly reinforced in the past more likely to occur. Problem behaviours in turn are aversive to
parents, and their presence makes escape from these behaviours available as a reinforcer. Parent behaviour previously reinforced by escape from problem behaviours is then more likely to occur. (Oliver, 1995, as cited in Hastings, 2002, p. 150)

From this, Hastings (2002) introduced a simple model that proposed that children’s behavior problems lead to parental stress, and parents under stress adopt parenting behaviors that reinforce the child’s behavior problems. He reviewed available research that supported each of the three relationships in the model and, although he found few empirical studies to support all of the elements of the model, he felt that it provided a starting point for further research. To support the directionality of the model, he cited other researchers who have found “that hassle associated with the child’s behaviour problems predicted these family accommodations over time…. supportive of a child-driven model where their behaviour problems temporally precede impact on the family” (Hastings, p. 152). Hastings proposed that his model suggested possible mediator and moderator affects. Parental stress may lead to changes in parenting behavior, therefore mediating children’s behavior problems. Because parents are stressed by these problems, children’s behavior affects parenting behaviors. As a moderator, in circumstances where parents are highly stressed, they may respond to children’s behavior coercively, while under lower levels of stress might be able to be more proactive and respond more positively.

The first relationship in Hasting’s (2002) model is between child behavior problems and parental stress. The model identified child behavior problems as a causal factor in parental stress. Hastings supported this assumption with research showing that stress in parents of children with DDs is similar to stress reported by parents of children without disabilities but with significant behavior disorders. He also cited correlational studies showing that children’s behavior problems predict parental stress when other variables, such as socio-economic status (SES), family size, and social support, have been controlled. Another source was research on staff working in
Staff day-to-day negative emotional reactions to residents’ behaviour problems mediate the impact of such behaviours on care staff psychological well being. Thus, behaviour problems elicit negative emotional reactions (e.g., sadness, helplessness, and fear) which accumulate over time to affect staff well being. (p. 155)

Herring et al. (2006) applied Hastings’ model of parent-child interaction to parents of toddlers (aged 20-51 months) who were suspected of having DDs. They assessed and diagnosed and then divided the children into two groups, those with PDD and those without. In addition, they evaluated parental mental health, family functioning, and parenting stress and repeated the process 12 months later. No differences in child behavior and emotional problems emerged between the PDD and non-PDD groups at the initial assessment (T1) or significantly changed over time for either group at 12 months post diagnosis (T2). However, the PDD group had a higher mean total behavior problem score at T2, suggesting that behavior becomes more problematic as the children aged (Herring et al.), matching Higgins et al.’s (2005) and Perry et al.’s (2005) observations.

On parental measures, no significant differences on parental variables of stress, mental health, or reported family dysfunction transpired at T1, although mothers in both groups reported significantly more stress than fathers in both groups. The level of maternal stress for the PDD group declined slightly at T2 but was still higher than that of all the others. Fathers in the PDD group reported significantly more stress than those in the non-PDD group and their overall mental health score increased, indicating more distress, while in all the others it decreased. While not significant, family functioning scores increased for both mothers and fathers of the PDD group, indicating increasing distress, while the scores of parents in the non-PDD group either decreased or stayed the same. These results indicate that children’s behavior and emotional
problems may have the most significant impact on family functioning and parental stress and mental health, as no parental outcomes were associated with the children’s diagnoses or degrees of developmental delay (Herring et al., 2006).

**Stressors at the Family Level - Other Life Stressors**

As has been shown, children’s maladaptive behaviors are a major source of stress in families of children with ASDs. These behaviors have the capacity to disrupt family routines and often require the development of alternate routines to accommodate the children’s demands. Like other families, these also experience other types of stressors including those related to employment, illness or death in other family members, moving, and financial problems. In addition, these families may have additional challenges such as costs of special treatments, renovations of the home to accommodate special needs, or other family members with DDs (Perry, 2005). It is estimated that approximately 5% of siblings also have AD or other developmental problems (*DSM-IV-TR*, 2000).

**Disruption of Family Routines and Rituals**

One of the most significant ways maladaptive behavior impacts family functioning is in the disruption of family routines and rituals. Functional family routines have been “viewed as a gauge of the achievement of a sense of normalcy in family life” (Gray, 1997, as cited in Larson, 2006). Gray (1997) highlighted the importance of everyday rituals:

Regularly patterned family interactions such as eating together, children’s bedtime routines, the ritualized treatment of guests and engaging in joint leisure activities, constitute a largely unplanned, but highly significant means for families to construct a common identity and demonstrate their shared beliefs. (p. 1102)

Aggressive tendencies in their children threaten families’ ability to do these activities by restricting spontaneity and producing the potential for disruption (Gray, 1997). Hutton and Caron (2005) found that more than half of the parents they interviewed talked about the need to adapt
the family’s schedules and routines: “The impact of having a child with autism on the family can be tremendous, including having to plan ahead for simple trips, not having free time alone to relax, and making family vacations and fun virtually impossible” (p. 188).

Gray (1997) interviewed parents in 33 families of children with high functioning autism or Asperger syndrome to assess their ideas about “normal family life.” He acknowledged that this is an “elusive goal,” making the term itself problematic. The primary reasons that emerged as evidence for or against a family’s normal character had to do with daily activities in the everyday environment where they had to deal with work, school, and interactions with other people. The number one reason, mentioned by 32 of the 33 families, was “whether or not [the family] could engage in a series of standard social outings and activities. These activities included dining at a restaurant, shopping and visiting friends” (Gray, p. 1101). The second most frequent barrier to “normal family life” was the relationships among family members, and the third concerned family rituals (Gray).

Larson (2006) discussed family routines in in-depth interviews with 9 mothers of children with various ASDs, and indeed, they reported that they were unable to participate in standard family activities as much as they desired. They also reported that celebrations with extended family were difficult and they often avoided them. They mourned this loss of tradition as well.

Alternate Routines

Larson’s (2006) interviews revealed that alternate routines were developed, usually by mothers, “to be responsive to the child’s emotional and developmental needs and create a livable family life for other family members” (p. 72). These routines were used (a)“to provide regular expectations, ease transitions, and manage the child’s anxiety” (Larson, p. 73); (b) when cyclic variations, such as changes from weekends to weekdays, summer/winter school schedules, and
holidays, occurred; or (c) when the children had difficulties in performance and refused to participate.

These routines also had the capacity to be barriers to “the improvisation required in daily life, such as when there was an alternate caregiver or schedule change” (Larson, 2006, p. 73). New strategies were often required for these irregularities in the schedule, and the need for their constant development left mothers exhausted. Mothers mentioned using “strategies such as foreshadowing the event, tricking the child into agreement or compliance, appealing to a specialized interest, or offering desired activities after completion of the infrequent one that ensured compliance” (Larson, p. 75). Mothers advised, “‘You have to pick your battles’…. and made decisions based on their energy, their judgment of the need for change, and the child’s readiness for new skills” (Larson, pp. 75-76). Mothers’ anxiety was provoked when “children’s inflexibility and inability to improvise when daily events required it, intolerance of additional demands, or fatigue evoked emotionally charged responses or behavioral meltdowns” (Larson, p. 78).

Larson’s (2006) interviews exposed two interesting observations. One was regarding alternate routines. Once they worked, several mothers wondered who was insisting on the sequence, themselves or their children. The other was that several families possessed the self-confidence and courage to work months or even years on training sessions to gradually acclimate their family members with disabilities to new experiences. One mother realized that “‘the little bit I’ve tried in the past is going to help me when I try it again’” (p. 76). Other families with less courage never again attempted these traumatic experiences.
Employment and Financial Problems

As previously stated, in the NSCH families of children with autism were even more likely than parents of children with other DDs to have difficulties with job maintenance. Of all parents, they also had the greatest challenges in day-to-day care and child care. This may result from children with DDs having multiple problems at school, missing more school, and being less involved with community activities than children without problems (Blanchard et al., 2006).

O’Brien (2007) found that family income did not affect maternal depressive symptoms, but Pakenham et al. (2005) found better adjustment in mothers of special needs children when there are fewer financial worries. The Pakenham team found that mothers who had higher incomes tended to report less severe depression and anxiety. One exception was in poorer families that received financial assistance. They may be better off than those not receiving assistance because of the less significant financial burden (Singer & Farkas, 1989, as cited in Pakenham et al).

Affecting finances, the NSCH found that households with children with DDs were twice as likely to be one parent households (Blanchard et al., 2006), but the data was not able to show that having a child with autism increases the probability of living in a single-parent home (Montes & Halterman, 2005). Significantly more of these one-parent families were insured by public sources and lived in “working poor” households. This would likely impact finances, employment, and caregiver burden (Blanchard et al.).

Stressors at the Community Level

Experiences with professionals, particularly at the time of diagnosis, “can have a long-term influence on parents’ attitudes, families’ level of stress and acceptance, and coping strategies” (Hutton & Caron, 2005, p. 180). Incorrect diagnoses can lead to confusion, despair,
blame, and guilt and lead to isolation from friends and relatives, difficulties in marital
relationships, and doubts about diagnoses (Hutton & Caron). Following the diagnosis, the need
for intervention services and the coordination of these services can be sources of family stress.

Diagnosis

The recognition and diagnosis of autism has been a frustrating journey for parents, with
many regarding it as the most stressful point of raising a child with a disability (Baxter,
interviews, parents reported recognizing that something was different about their child very
early, some even reporting they knew on the day of birth. Their perception of the system for
diagnosis was that it “results in months of waiting, numerous referrals, and, in some cases, very
late and inaccurate diagnoses” (Hutton & Caron, p. 187), highlighting the need for professionals
to listen to parental concerns and make early referrals for assessment. Many parents wished that
they would have had someone to talk with, highlighting the need for referrals to counseling
services and support groups. Hutton and Caron recounted:

Most of the parents reported acceptance of the diagnosis when it was finally confirmed.
More than half of the parents felt relieved, whereas others felt feelings of despair,
sadness, and even devastation. Although the diagnosis of autism may seem tragic and
overwhelming at first to a parent, there is, in many cases, a drive to move forward and do
what is needed to help the child improve. (pp. 187-188)

Parental satisfaction increases with earlier diagnosis. Although it is now improving,
delays in obtaining diagnoses have been a source of frustration for parents. Studies have shown
that less than 10% of families received a diagnosis when they first sought advice and “more than
one third of parents surveyed were told either not to worry or to return if the problems
persisted…. More than half did not receive a diagnosis of autism until the child was 6 years old”
were a mean age of 18.6 months old when mothers reported noticing problems, but the mean age of diagnosis of autism was 42.3 months.

**Special Needs and Services**

In the study of NSCH data looking at parental stress and aggravation, Schieve et al. (2007) noted previous studies suggesting psychological distress among parents of children with autism varied by the severity of the disorder, but they hypothesized that other factors might also impact parents’ stress levels. They looked at “indicators of autism severity and/or current special service needs, [other] factors related to severity…, and factors related to SES and culture that might impact resources, access to services, and care-seeking behavior” (p. S116). They formed 4 groups, those of children (a) with autism, (b) with other developmental problems necessitating treatment/counseling, (c) with special health care needs but without developmental problems, and (d) without special health care needs (Schieve et al.).

Within the autism group, the most striking correlation was between the need for special services such as physical therapy, medical equipment, special education, and counseling and high levels of aggravation. Of parents whose children needed special services in the past 12 months, 66% had high aggravation versus 28% of those whose children did not need special services. In the other three comparison groups, high aggravation was only slightly associated with special services. Schieve et al. (2007) acknowledged that they could not discern whether the need for special services was related to (a) the children’s severity of behavior and cognitive functioning; (b) stability, or lack of stability, in the children’s functioning; (c) the parents’ perception of severity and stability; or (d) some combination of these factors.

Experiences with these intervention services can also contribute to a family’s frustrations. One study revealed that “on average, these families received six different services from four or
more agencies, involving seven or more professionals and approximately 37 hours of intervention each week” (Hutton & Caron, 2005, p. 181). More than half of the parents interviewed recounted problems with the services they received, most typically not being able to find the professionals they needed or not receiving enough hours of service each week, probably more common in the rural area of this study than in more urban areas. The most common services were “(a) speech therapy, (b) occupational therapy, (c) in-home behavior specialist support, (d) developmental therapy, (e) applied behavior analysis, (f) physical therapy, (g) respite, and (h) one-on-one classroom support” (Hutton & Caron, p. 185). Of the services, speech therapy was considered to be the most valuable (Hutton & Caron).

Understandably, parents cited a lack of interagency collaboration in receiving these services as a source of frustration. Transportation for services, paperwork and filing, and attending meetings for their children were also challenging. More than two thirds of the parents felt that the services that their children received greatly reduced their stress, but almost one third felt that they caused more stress due to the time required for paperwork and providers coming and going from their homes (Hutton & Caron, 2005).

It is clear that ASDs present daunting challenges to families because their symptoms are disruptive to most of the basic routines of daily family life. Characteristics of the children, as well as family issues such as employment and finances, interface with the experiences of diagnosis and special needs and services in the community to potentially create stress in families. In most cases, numerous resources and supports are available that mediate and moderate how these stressors affect family functioning.
Resources that Mediate and Moderate Stress in Families

While there are numerous sources of stress in families of children with ASDs, an even greater number of variables interact with these stressors to impact family functioning. Family members’ levels of Social Interest affect their ability to access these resources, as Hartshorne (2002) pointed out: “People with higher levels of social interest would have different beliefs, coping patterns, and psychological status than those with lower social interest, and they would be more likely to avail themselves of support systems” (pp. 266-267). Parents’ levels of success on the five life tasks can also influence their capacity to locate and accept support from others in the family and in the community. These resources and support systems are present at the individual level of the parents, at the family level, and at the community level.

Resources at the Individual Level – Parents’ Personal Resources

Parents’ personal resources include psychiatric health, parenting styles, and coping strategies, as well as more demographic factors such as education and employment status. Of these, parenting styles may have the most significance. Reciprocal influences found in parental sensitivity, synchronization, and communication show promise in improving outcomes.

Psychiatric Health

The psychiatric health of parents of children with ASDs has been widely studied, although most research has been with mothers only. A limitation of the NSCH was that it interviewed only 1 parent and it is recognized that the feelings of one parent may not reflect the feelings of another (Schieve et al., 2007). Many studies have shown differences in the experiences and perceptions of mothers and fathers (Hastings et al., 2005; Herring et al., 2006).

From a genetic standpoint, more psychiatric difficulties in parents of children with ASDs, as compared to parents of other clinically diagnosed children, are attributable to the genetic risk
associated with autism. Yirmiya and Shaked (2005) did a meta-analysis on 17 studies in which the psychiatric difficulties of parents of children with autism were compared to the difficulties of parents of children with Down syndrome, MR of unknown etiology, language/learning disabilities (LD), other psychiatric diagnoses, and typically developing children. The results showed that parents of children with autism demonstrated more psychiatric difficulties than parents of children with no presently known genetic liability (Down syndrome, MR of unknown etiology, and typically developing). In contrast, parents of children with autism had fewer difficulties than parents of children with LD and other psychiatric disorders with a known genetic liability. The authors advised that these findings are preliminary and should be evaluated cautiously, but they suggest that genetic liability is an important factor to consider.

Another interesting trend, matching the findings of O’Brien (2007) and Tobing and Glenwick (2006), indicated that parents of low-functioning children revealed more psychiatric difficulties than those with high-functioning children, although they cautioned that environmental effects could not be ruled out, as Tobing and Glenwick noted might be the case for mothers of children with Asperger syndrome. From an environmental standpoint, the differences may be due to the stressful experience of raising children with the disorder, affecting the parents’ well-being and resulting in increased parental vulnerability to psychiatric difficulties (Yirmiya & Shaked, 2005).

It is presently nearly impossible to study genetic and environmental influences separately. Parents’ psychiatric difficulties would need to be examined before their children were born and before their children received the diagnosis of an ASD. In recognition of the influence of Lifestyle, Yirmiya and Shaked (2005) wrote that data has suggested that “retrospective life events are colored and reinterpreted by later experiences…. Furthermore, the diathesis – stress
model (Bauminger & Yirmiya, 2001) suggests that genes and environment transact differently for different individuals” (p. 70). This recognizes, as Adler did, the creative capacities of individuals to decide for themselves and change their appraisals of situations.

Yirmiya and Shaked (2005) recognized that the method for assessing parents’ psychiatric outcomes appeared to be a significant moderator variable in their meta-analysis. Self-report measures uncovered more psychiatric difficulties than clinical diagnoses. Montes and Halterman (2007) also saw self-report as a limitation of the NSCH and stated that although research has shown that parent report of autism is fairly reliable, “it is possible that mothers with a child with autism report domains of psychological functioning differently than other mothers because mental health problems and a diagnosis of autism may influence recall bias” (p. e1045). In their analysis of NSCH data, Schieve et al. (2007) acknowledged that while the survey disclosed parents’ self-reported feelings toward their children with autism, data was not available “to assess how those feelings translated into specific interactions with the child or impacted family functioning in other ways” (p. S121).

Higgins et al. (2005) found no evidence of lower self-esteem in caregivers of children with ASDs. They cautioned that their results may have been positively skewed and representative of families who are coping well and have had access to government-supported services. Other caregivers, who may not be coping as well, may not have had the time and energy to complete the lengthy surveys, as only 52 out of 134 were returned. An alternate reason given for the positive results was that some participants may have responded positively because “they felt they ‘should,’ rather than as they actually believed. Due to the negativity that often appears to surround ASD, some caregivers may have felt pressure to present a socially desirable image of themselves and their families” (Higgins et al., p. 135).
Trute, Hiebert-Murphy, and Levine (2007) found that parental self-esteem appeared to be a significant issue specifically at the outset of entry into childhood disability services, emphasizing the role of parents’ Lifestyle, Social Interest, and success in the five life tasks. Lower levels of self-esteem appeared to predict lower levels of overall family functioning in the longer term. In their study of mothers of children with PDDs, Tobing and Glenwick (2006) made an interesting discovery:

[While] higher levels of parenting satisfaction predicted lower levels of psychological distress, higher levels of parenting efficacy predicted higher levels of psychological distress. This latter, unexpected, finding may be explained by a possible association between a greater sense of parenting efficacy and a greater level of awareness regarding the nature and prognosis of PDDs, as parents who may have received parenting skill training are likely to have been educated regarding the nature of their children’s impairments and probable prognoses for individuals with PDDs. (pp. 15-16)

**Parenting Styles**

While professionals have been careful to emphasize that parenting practices have not caused ASDs, research has shown that parenting practices can affect outcomes. A team led by Rutgers has done extensive research on parenting practices as they relate to attachment issues. In one study, they examined parental psychological functioning; parental feelings of efficacy, particularly their ability to empathize with their children’s feelings and behaviors when stressed; parenting stress; and parenting styles. They did not find parental psychological functioning to be a significant factor, but they did find that “parenting [while not a causal factor] may play a decisive role in the further development and the symptomatology of children with ASD” (Rutgers et al., 2007, p. 868).

They identified two parenting styles: the Authoritative style and the Authoritarian style (Rutgers et al., 2007). Hastings (2002) cited a study that agreed: “Associations were found between the children’s behaviour problems and parents’ behaviour management struggles
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(efforts to direct and control the child’s behaviour), and their use of coercive parenting behaviours” (Floyd & Philippe, 1993, as cited in Hastings, p. 153). From an Adlerian perspective, Dreikurs (1964) referred to these two parenting styles as democratic and autocratic.

The Rutgers team’s comparison study did not find large differences in parenting stress. They reported similar parental efficacy with non-clinical controls and parents who “perceived themselves as rather healthy and balanced” (Rutgers et al., 2007, p. 868). This study assessed parenting at the children’s age of 27-32 months and the authors speculated that parents may not yet realize the impact of the effects of ASDs on the children’s social relationships at this early age. The most significant difference between the clinical and the non-clinical groups was lower levels of authoritative parenting (Rutgers et al.). Recent research focusing on parental sensitivity and communication interaction support this finding.

**Parental sensitivity.** It appears that ASDs do alter the behavioral patterns that express attachment security, yet many children show signs of typical attachment behavior even with impairments in reciprocal social interaction. The Rutgers team’s research suggested that parental sensitivity could be responsible for moderating ASDs’ effects on attachment security (Rutgers et al., 2004; Rutgers et al., 2007). Autism has been described as

a dysfunction or disturbance in the emotional exchanges that regulate the contact between mother and baby. Average babies are born with a very complex emotional set-up and method of functioning in how to regulate communication and contact with other human beings. As this is very delicate and fairly easy to disrupt, the rhythm of interaction and the mother’s sensitivity to the infant’s cues are critical, forming reciprocal interaction when the different partners in communication adapt to each other’s rhythm. (Trevarthen, 1979, 2004, and Trevarthen et al., 1998, as cited in Hedenbro & Tjus, 2007, p. 204)

It has been documented that parental sensitivity has a role in attachment security (van IJzendoorn et al., 2007). One of the Rutgers team’s early studies was a meta-analysis that included a measure of maternal sensitivity on attachment security in children with ASDs. Results
suggested that “if sensitive parents are able to promote secure attachment relationships with their children with autism, this may function as a protective factor and provide children with autism a better prognosis for social development” (Capps et al., 1994; Willemsen-Swinkels et al., 2000, as cited in Rutgers et al., 2004, p. 1132).

Following this meta-analysis, van IJzendoorn et al. (2007) did another comparison study including children (mean age of 28.4 months) with ASD, MR, LD, and typical development to investigate the association between parental sensitivity and children’s attachment security. They posited that “because ASD has been found to be genetically transmitted (Rutter, 2000), parents of children with ASD may run the risk of displaying less social interactive abilities than parents of typically developing children or other clinical groups” (van IJzendoorn et al., p. 598).

Research focusing on genetic and behavioral genetic data has indicated a continuum with autism as the most severe phenotype. It has been proposed that “siblings and parents may show less severe phenotypes, manifesting what is termed today ‘the lesser variant’ or ‘the broad phenotype’” (Yirmiya & Shaked, 2005, p. 69). Numerous researchers have suggested that “the broad phenotype involves certain personality traits such as aloofness, rigidity, anxiety, and hypersensitivity to criticism; pragmatic language and speech impairments; difficulties in interpersonal relations; lower performance IQ; and certain lower neuropsychological abilities” (as cited in Yirmiya & Shaked, p. 70). Van IJzendoorn et al. based their hypothesis on that possibility:

Parents of children with autism may be less sensitive to their children’s needs because of the inborn social impairment with which these children and their social environment have to struggle or because of traces of social impairment in the parents themselves. (p. 600)

Unexpectedly, the van IJzendoorn team found that the sensitivity of parents of children with ASD did not differ significantly from that of parents of children without ASD and that more
parental sensitivity was not associated with more attachment security in children with ASD. The expected correlation between parental sensitivity and attachment security did hold true for the other clinical and non-clinical children. The authors speculated that “children with ASD may challenge the established role of sensitive parenting obtained in studies on typically developing children” (van IJzendoorn et al., 2007, p. 604). The researchers offered two alternate explanations: It could be a matter of problems in assessment of sensitivity and attachment in children with ASD and their parents or it could be that attachment security has different manifestations or functions in these children (van IJzendoorn et al.).

The Rutgers team’s second meta-analysis showed that “the parent-child relationship reflected less flexible, sensitive, and synchronous interactive behaviors as a result of the social impairment of children with autism” (Rutgers et al., 2007, p. 860). Siller and Sigman (2002) also found this to be true. They studied the extent to which caregivers’ behavior is synchronized with the child’s focus of attention and ongoing activity during play interactions.

Synchronization. Siller and Sigman (2002) noted that the nonverbal communication of children with ASDs is characterized by a lack of joint attention. Research has shown that children with ASDs respond less to joint attention as well as initiate it less than do typically developing or children with developmental delays. Responding to joint attention could involve behaviors such as following an adult’s gaze or pointing to an object. Initiating could involve pointing, showing, or alternating gaze between an object and the person’s eyes (Siller & Sigman). They also noted that children with ASDs develop language later and at slower rates and that outcomes vary greatly:

Attempts to explain the variability of the language outcome have investigated the relations between the children’s initial abilities and their consequent level of language acquisition. One relation that is widely established is that the child’s language skills
Siller and Sigman (2002) believed that “given that there are predictive relations between parental styles of interaction and their children’s communication skills for both typically developing children and children with Down syndrome, it seems likely that such relations should exist for children with autism” (p. 78). Limited studies have shown that parents of developmentally delayed as well as children with ASDs are more directive and controlling, possibly as a result of professional advice and training designed to accommodate children’s demands for consistency and routine.

In studying how different family members interact with children with autism, El-Ghoroury and Romanczyk (1999) observed that parents exhibited more play behaviors toward children than did siblings, possibly compensating for their children’s disability level. In so doing, they may be limiting their children’s opportunities to initiate social interactions. In contrast, children with autism exhibited more vocal and verbal initiations toward their siblings than toward their parents, indicating that the sibling behavior allowed the children greater opportunities to initiate play and social interactions. Siller and Sigman (2002) hypothesized:

Caregivers of children with autism who spend a higher proportion of the play engagement targeting objects that are already the focus of the child’s attention, trying to maintain the child’s ongoing activity, will have children with superior communication skills at later ages. (p. 79)

To validate their theory, Siller and Sigman (2002) followed children with autism and developmental delay, as well as children with typical development, over a period of 1, 10, and 16 years. They found that children with autism spent the same amount of time attending to toys as did children in the other groups, and their parents synchronized their behaviors as much as those in the other groups. As expected, those parents “who showed higher levels of synchronization...
during initial play interactions had children who developed superior communication skills over a period of 1, 10, and 16 years compared with children of caregivers who showed lower levels of synchronization initially” (Siller & Sigman, p. 85). Their results showed that parents of children with ASDs do a remarkable job in the difficult task of determining what their children are attending to and intending to do and are able to successfully adapt their interactive behavior to the language level of their children. The caregiver’s own tendency to initiate joint attention in a synchronized way was the strongest predictor of the child’s nonverbal communication gains. It did not predict gain unless caregivers chose to show, point, or offer an object that was already the focus of the children’s attention, suggesting that “children with autism are able to learn by modeling if the activity selected is part of their attentional focus” (Siller & Sigman, p. 85).

Children’s gains in language skills were associated with caregivers’ verbal rather than nonverbal behaviors, not surprising, considering the difficulty children with ASDs have in noticing and interpreting non-verbal cues. Parents’ utterances that were synchronized with children’s focuses of attention as well as being undemanding in quality were the strongest predictors of the children’s future gains in language skills. Two distinct features of undemanding utterances might explain this finding:

First, undemanding utterances by definition not only match the toy to which the child is attending but also the toy-directed activity in which the child is engaged. Demanding utterances, however, describe, suggest, or demand an activity that is different from the child’s ongoing activity. If we think of the child’s focus of attention as a “focus on a certain activity with an object” rather than just a “visual focus on a certain object,” the match between caregiver utterance and the child’s focus of attention is better for undemanding synchronized utterances. Also, it has been reported in the literature that children with autism are less compliant and demonstrate atypical gaze and affect patterns when confronted with interpersonal demands (Arbelle, Sigman, & Kasari, 1994; Lemanek, Stone, & Fishel, 1993). It might be easier for a child with autism to process utterances that do not involve interpersonal demands. (Siller & Sigman, 2002, p. 86)
The authors cautioned that perfect synchronization without verbal demands is not the goal, only that parents of children with ASDs may show too little synchronization and too many demanding verbalizations. The interactive style identified as being beneficial for the development of communication skills is similar to the concept of “child choice” which has been shown to promote language development in children with language delay and is a basic tenet of many interventions that consider the child’s motivation and the sharing of control over materials and tasks as basic considerations (Siller & Sigman, 2002). This corresponds with the Rutgers team’s findings of the benefits of the authoritative style of parenting and, as Adler recognized, is probably central for learning and language acquisition for all children. He wrote that in order to attract children’s interests, teachers must discover and build on children’s successes and confidence in previous interests:

If anyone is to blame for educational failures, it is the teachers and the parents who have not found the right way to interest the children…. Any interests that children have developed should be used to motivate them toward other interests also (Adler, 1998, p. 130).

This research shows that this may be even more crucial for children with ASDs.

Siller and Sigman (2002) concluded with three reasons why it is important for caregivers of children with ASDs to be sensitive to their children’s focuses of attention. These reasons recognize goal-directed behavior and significance and belonging, elements of Social Interest: “Naturally occurring communication always has a goal and is therefore closely related to the motivation of the person who wants to communicate” (p. 87). First, engaging with or talking about an object that the child is already attending to might model social and language experiences while compensating for attentional deficits. Second, demonstrating the shared intentional state might help the child understand that other persons have intentions about external objects or events, a necessary understanding for the development of joint attention and language.
Third, being sensitive to the child’s interest might show that interacting and sharing an interest with another person can be fun and motivating instead of frustrating (Siller & Sigman).

Hedenbro and Tjus (2007) also looked at synchronization in their investigation into how communication is established between newborns and their parents. They observed the interactions between a girl and her parents when the child was three, nine, 16, and 48 months of age. They analyzed videotapes of the family and compared their interactions to those of typical families, looking at the quantitative variables of verbal and nonverbal contributions, affirmation, clarification, turns and turn-taking sequences, triangulation, shared focus, and eye contact, as well as the qualitative variables of synchronization and inclusion versus exclusion. They operated under the premise that

The central problem in early childhood autism is “an impairment of complex symbolic function affecting all forms of communication”. According to Wing (1996) the interaction between average infants and their parents is supposed to consist of two-way communication, in which the infant responds with happiness and excitement. In this way, the parents get positive reinforcement, which strengthens the reciprocal bonds between the parents and the child which is lacking when the child has an autistic spectrum disorder. (Ricks and Wing, 1975, as cited in Hedenbro & Tjus, p. 203)

In the Hedenbro and Tjus (2007) case study, dyadic, but not triadic, synchronization started positively at three months. The child vocalized and made positive, although short and abruptly-ending facial expressions. The qualitative observations indicated that the child did demonstrate social capacity by seeking to establish contact with her mother, but her mother initiated a high number of turn-taking sequences rather than affirming and supporting the child’s contributions.

At nine months, synchronization was difficult in the mother-child dyad and was not achieved in the other subsystems. The child’s contributions more often included attention to objects rather than attention to her parents. The child’s vocalizations were less frequent and had a
tone of negative affect, and her facial expressions were strained. There were fewer turn-taking sequences and most were initiated by the parents. The mother seemed stressed (Hedenbro & Tjus, 2007).

At 18 months, no synchronization was observed and the extreme discouragement of all family members was evident. The child differed from other children in shared focus and eye contact. She was less active in playing and her facial expressions were neutral and difficult to interpret. Her father was active in attempting to engage his daughter in play, but he did not attend to the child’s focus. There was no sign of joint attention and shared emotions. Her mother was less active and had a tense facial expression. The observers interpreted that the child “was trying to show that she recognized and followed her parents’ interaction, although she had given up her efforts to start an exchange” (Hedenbro & Tjus, 2007, p. 218).

At 48 months, the triad showed better synchronization than any of the dyadic subsystems:

[The child] appeared to act much younger than her age and could speak only a few words…. She was able to follow her parents’ interactions but only took the initiative to interact a few times. Her facial expression could be described as blank. She smiled only once. Her mother acknowledged the smile and asked her to invite her father to join her in play. [She] simultaneously smiled, looked at her father, and asked him to join her in play…. [Her mother] appeared to enjoy playing and invited [the child] to join, but did not allow enough time for [her] to respond, almost as if she did not expect any response. (Hedenbro & Tjus, 2007, p. 215)

In retrospect, the mother commented that “she had felt rejected by the child, which gave her the same feeling as when she felt rejected by her own mother as a child. She added that this might have influenced her behaviour toward her daughter” (Hedenbro & Tjus, 2007, p. 217).

This young mother’s comments reveal her sense of discouragement and the absence of feelings of significance and belonging. As Adler recognized, these feelings were rooted in her family of origin environment and experience. Her daughter needed more encouragement that typical children and she was unable to provide it.
Communication sensitivity. In related research aimed at improving communication skills, Stiegler (2007) found that children with ASDs “can and do communicate in an orderly manner” (p. 407). Recognizing the role others may play in exchanges, she described communicative competence as “the ability to collaborate with another person to exchange meaning and to be a communicating member of society” (p. 401), a clear complement to the Adlerian concepts of cooperation and Social Interest. Stiegler also recognized purposeful behavior, as did Siller and Sigman, and based her research on the assumption “that although nonspeaking children with ASD may communicate in ways that seem bizarre or mysterious by conventional standards, these behaviors must be accomplishing some type of pragmatic work or they would disappear from the child’s repertoire” (Damico and Nelson, 2005, as cited in Stiegler, p. 407).

Stiegler (2007) demonstrated communicative competency by analyzing an interaction with a nonspeaking child diagnosed with autism using adapted conversation analysis (CA) and speech act analysis (SAA). Acts were considered to be communicative if they met more than one of the following criteria:

- was directed toward the interactant by means of gaze, body orientation, or gesture; (b) had an effect on the interactant; (c) conveyed a recognizable message that could be “translated” into words; and (d) was persistent…. Communicative acts included socially significant movements and postures, gazes directed at the partner or at relevant objects (e.g., the shoes), a small variety of vocalizations, smiles and laughs, conventional gestures, pitch changes, duration changes, intensity changes, vocal quality changes, mild self-injury paired with direct gaze, mild aggression paired with direct gaze, giving objects, object manipulation, one formal sign, several echolalic utterances featuring word approximations, and speech. Noncommunicative acts included incidental gazes away from the interaction, incidental shifts in body position, self-regulatory behavior, and self-help behavior. (Stiegler, p. 404)

In the exchange, Stiegler (2007) looked at the use of adjacency structures which are similar to Hedenbro and Tjus’ (2007) term of turn-taking sequences. Common adjacency structures include greetings, questions, requests, and demands. Analysis revealed that the child
demonstrated several communicative competencies, including an awareness of his responsibilities in terms of conversational sequence and structure; an ability to initiate communicative interactions; an appropriate use of gaze and smile behavior; and an interest in regulating the other’s behavior, using demands, protests, and warnings.

Adlerians Hartshorne & Herr (1983) made a similar observation and recognized “autistic-like behaviors as serving the purpose of exerting control over the environment, and as being highly significant to the child” (p. 400). They posited that these behaviors keep environmental stimuli and other people under constant control. They described an intervention in which they imitated exactly what the child was doing instead of struggling against the behaviors and concluded: “By accepting the importance of these behaviors and engaging in them with the children, the therapist encourages, reduces the power struggle, and elicits cooperation” (p. 400).

Although Stiegler is a professional speech-language pathologist and the interaction analyzed was a professional intervention, the clinician was hopeful that this work with adapted CA and SAA could be extended to work within families, leading to “a more accurate interpretation of unconventional nonverbal communicative behaviors as well as a scrutiny of the pragmatic acts being modeled by interventionists, caregivers, and even peers in a child’s daily environment” (Stiegler, 2007, p. 407). Informed communication partners increase the likelihood of successful interactions. Analysis might point out practices and environments that could be adjusted to lessen undesirable behavior or communication patterns and provide clues to a child’s own style and strengths. An understanding of adjacency principles could lessen communication breakdowns that occur when a behavior is not interpreted correctly and an expected response does not follow the initial expression (Stiegler).
Coping Strategies

As has been shown, higher levels of parental stress and mental health problems in families of children with autism are not uncommon. However, in the NSCH, significantly more parents of children with autism (48% versus 39% of parents of children with other DDs) reported they were able to cope “very well” with the day-to-day demands of parenthood (Blanchard et al., 2006). In the NSCH data, Montes and Halterman (2007) recognized the Adlerian principle of compensation in that

these mothers show remarkable strengths in coping, parent-child relationship, and psychological functioning. Given the challenges of parenting a child with autism this suggests that families use compensatory strategies to maintain family stability in the context of poorer mental health and higher stress. (p. e1045)

The coping strategies of parents of children with DDs have been amply studied but results vary widely. Jones and Passey (2005) studied the impact of levels of coping resources, strategies, and perceptions on the stress experienced by parents of children with DDs who had significant behavior problems. They found:

Coping strategies involving the maintenance of family integration, co-operation and optimism were strongly associated with reduced stress relating to overall family cohesiveness, the parent’s perceptions of reward or satisfaction in caring for their child, and their concerns regarding future care of their child and the possibility of institutionalization. Trute and Hauch (1988) found a strong correlation between family cohesion and coping strategies such that parents reporting active coping skills could discuss and debate alternative choices while maintaining a high commitment and responsibility to one another. (p. 41)

Ergüner-Telkinalp & Akkök (2004) interviewed mothers of children with autism to explore the effects of a coping skills training program. The eight-session cognitive behavioral training program consisted of intervention techniques that were designed to teach about stress and its effects; general coping strategies, including problem solving, social support, and avoidance; problem solving skills; relaxation training; positive thinking, including training in differentiating self-defeating and self-enhancing thoughts; and developing social support. After
completion of the program, they assessed mothers for (a) coping strategies, including problem solving, exploring social support, and avoidance, and (b) hopelessness, including measuring feelings, thoughts, and motivations toward the future.

The training did not have any effect on reducing the stress levels of the mothers and did not produce any significant differences in the use of avoidance coping. They speculated that these mothers may have adapted to and accepted the condition because the median age of the children with disabilities in this study was 15.2 and all mothers had previously received training, matching the results of Gray’s (2002, 2006) longitudinal studies.

The training program did reduce the level of hopelessness in the mothers. They indicated that by learning to relax as an alternative response when experiencing difficulties with their children, they learned that they could control their feelings in other situations. This helped them develop a more optimistic view toward their future. While not shown in the objective measures, interviews and observations revealed that mothers indicated feeling more relaxed, had a more positive viewpoint, used less negative words, and “stressed the growth that the child brought to their lives” (Ergüner-Telkinalp & Akkök, 2004, p. 264).

Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) studied the relationships among stressors, social support, locus of control, coping styles, and negative outcomes in parents of children with autism and found that coping styles had more influence on outcomes than social supports or locus of control. The emotion-focused coping styles of escape and avoidance, “including hoping for miracles, having fantasies, using food or drugs, and avoiding others” (p. 49) corresponded with more depression, isolation, and spousal relationship problems. Another emotion-focused style, distancing, also corresponded to increased depression and feelings of isolation but was sometimes helpful in social relationships when it decreased the domination of
conversations about the family situation. Distancing can include “going on as if nothing has happened, trying to forget the situation, and making light of the situation” (p. 49). Pakenham et al. (2005) found that problem-focused coping was not related to maternal adjustment, but “higher levels…of emotional approach coping (positive reinterpretation and seeking social support for emotional purposes)...and lower levels...of passive avoidant coping (venting of emotions and behavioural disengagement;” p. 202) did predict better maternal adjustment.

Dunn et al.’s (2001) study also revealed three coping styles that would increase the likelihood of positive outcomes, but when not used, led to negative outcomes. Not using the emotion-focused style of positive reappraisal, including “such things as growing as a person, finding new faith, rediscovering the important things in life, and being inspired to be creative” (p. 50), and not seeking social support led to isolation and spousal relationship difficulties. Not using the problem-focused style of confrontive coping, including “fighting for what is wanted, expressing anger to the cause of the problem, letting feelings out somehow, and taking chances,” (p. 50) led to depression.

In the Dunn et al. (2001) study, the mean age of the children was 7.47 years. The authors cautioned that “coping behavior might be a short-term mechanism…. The most critical period of adjustment and coping may occur before the age of three and different relationships among these variables may be observed in this time frame” (Dunn et al., 2001, p. 50). The authors recognized that this warranted further research.

Sivberg (2002) compared the coping behaviors of 37 families of children with an autistic disorder with those of parents with children without autism. The researcher looked at families from a family system perspective and hypothesized that higher levels of coping would yield
lower levels of strain on the family system and that the types of coping behaviors would differ between the two groups. He used four test instruments to test the hypothesis:

1. Sense of Coherence Test (SOC; Antonovsky, 1987) measuring (a) comprehensibility, the tendency to expect the world to be ordered, structured and clear; (b) manageability, the tendency to expect the demands of problems to be manageable and to be able to be resourced; and (c) meaningfulness, the tendency to see life as being meaningful, which encourages the confrontation of problems.

2. Purpose in Life Test (PIL-R; Frankl, 1958; 1962) measuring the general level of coping similarly to the SOC.

3. Family Relations Scale (FARS; Höök & Cederblad, 1992) measuring family systems and family pathology to assess the level of strain on the family system. The test has five subscales: (a) attribution, referring to the degree to which one attributes the family’s problems to a specific child; (b) joint interest, referring to the lack of joint activities within the family; (c) isolation, referring to separation of the spouses from each other and from other family members; (d) chaos, referring to the level of chaos in the family; and (e) intrusion, referring to the difficulties of family members in maintaining their own separate spheres of activity.

4. Ways of Coping Questionnaire (WOC; Lazarus & Folkman, 1984) measuring eight different dimensions: confrontation, distancing, self-control, social support, accept responsibility, escape, problem solving, and reappraisal.

As expected, Sivberg (2002) found a negative relationship between the level of strain on the family system, as indicated by the FARS score, and the level of coping, as indicated by the SOC and PIL-R scores. Families of children with ASDs had much higher levels of strain, and the
score on the intrusion subscale was particularly high. The author attributed this to the great
difficulties children with disabilities have “in the process of becoming an independent person”
(p. 406), a concern of parents that has been expressed previously in this paper.

Also as expected, the coping behaviors as measured by the WOC were markedly
different. Parents in the group of children with ASDs scored higher on the distancing and escape
dimensions, both of which involve avoidance of difficulties and are considered to be non-
constructive. In contrast, parents in the other group scored higher on self-control, social support,
and problem solving, all of which are considered to be constructive (Sivberg, 2002) and
demonstrated higher levels of Social Interest and success in the life tasks. One interesting
observation was that in early accounts of the etiology of autism, researchers linked its
development to mothers with the trait of distancing, therefore “hindering the child in developing
adequate object relations and object constancy” (Sivberg, p. 407). Sivberg’s results suggested
that “parents of a child with an ASD readily develop distancing and escape in reaction to the
strain on the family system which the problems connected with the child with the ASD tend to
bring about” (p. 407).

Gray (2002) conducted a study of parents of children with autism 8 to 10 years after they
had participated in an initial study. He found that the outcomes for families had been “relatively
favorable” (p. 222) and about two-thirds of the parents thought that their situation was better than
it had been at the time of the earlier study. Like Ergüner-Telkinalp & Akkök (2004), Gray
concluded that it was likely that a process of successful coping was operating. In contrast to
Dunn et al.’s (2001) appraisal of coping behavior as a short-term mechanism, Gray referred to
Berry and Hardman’s (1998, as cited in Gray) description of coping as “a long-term process
where the affected family members gradually accumulate skills and develop perspectives on their
situation that helps them to manage the problem” (p. 222). Blackledge and Hayes (2006) also found this to be true. An Acceptance and Commitment Therapy for parents decreased distress and depression levels, and levels improved even more at a 3-month follow up, suggesting that the active coping components may take time to develop.

In another longitudinal study of the social experiences of families of children with autism, Gray (2006) examined how parental coping strategies change over time. The initial study included 35 families and took place when most of the children were between 6 and 12 years of age (T1). The follow-up study (T2), with 28 of the families, was conducted 8 to 10 years later. At T2, the median age of the children was 18; all were still living with their families. Eight individuals were enrolled at a special school for children with disabilities, 8 were receiving some form of community service support, and 2 were receiving no services. One was attending a regular school. None of those who had finished school were employed in regular jobs.

The results revealed that parents were using far fewer coping strategies than they had at T1, and the strategies had shifted from problem-focused to emotion-focused coping. This suggested less emotional distress, with most noting that their children were significantly easier to live with, and indicated that both the children’s living skills and parental adaptations were more advanced. At T1, treatment services and support from other family members were the most popular strategies. At T2, none of the children were enrolled in the treatment center (Gray, 2006).

Social withdrawal and individualism also declined over time, but this may not necessarily indicate more family social engagements. Gray (2006) proposed that this could be the result of more orderly habits and improved public behavior of the children in combination with parental adjustment to the restrictions. The other category that was popular at T2 was “other” coping
strategies. Responses pointed to more emotion-focused coping strategies, such as parental attachment to their children and appreciation of their good qualities and achievements (Gray).

Demographic Variables

O’Brien (2007) found that mothers with higher levels of education reported fewer symptoms of depression. Both O’Brien and Pakenham et al. (2005) found that older mothers reported better social adjustment. While not the only variable, Gray’s longitudinal studies indicated that adjustment improves as parents age, but this may be true in the general population as well.

Resources at the Family Level

Family system resources are those that involve marital status and satisfaction, family functioning, and demographic variables such as SES. Hastings (2003) studied the adjustment of siblings of children with autism whose families were involved in an intensive (40 hours per week) training program and found that where there are ample financial resources, siblings may be less affected than when families are struggling financially. Higher SES seemed to indicate that families had the financial and psychological resources to sustain intensive intervention models. Curiously, in Pilowsky et al.’s (2004) study, the families of children with autism had higher levels of education and income.

Marital Status and Satisfaction

O’Brien (2007) found that partner status did not affect maternal depressive symptoms in mothers of children with ASDs, but Perry (2005) found family systems resources, especially the spousal relationships, gave substantial variance (20 to 24%) in family stress. In a systemic analysis of psychological functioning in families of children with autism, Hastings et al. (2005) found that both maternal and paternal stresses were correlated with their partners’ depression, but
Trute and Hiebert-Murphy (2002) found that in families of children with DDs, it may have less impact on the well-being of fathers than of mothers.

In Higgins et al.’s (2005) study with a group of 52 caregivers of children with ASDs, 87% were in a stable relationship and of those, 67% had never been separated or divorced. Similarly, Konstantareas (1991) reported that the divorce rate in families with children with disabilities was actually lower than a state or province average. Possible explanations were that parents may overlook their personal dissatisfaction and stay together for the sake of their needy children, or the shared stress may bring them together, building an emotional bond and providing a very tangible meaning for their relationship or helping the family grow in ways that are accepting of differences (Konstantareas; Norton & Drew, 1994).

Although they were in stable relationships, Higgins et al. (2005) found that the overall marital happiness rating for respondents was somewhat lower than the norm, not surprising given that the extra time and attention required by children with disabilities could put parents at risk of disregarding their own relationship needs and the needs of their partners. Another researcher found that while general ratings of marital happiness do not differ, parents of children with autism have more extremely unhappy marriages and parents of typical children have more extremely happy marriages (DeMyer, 1979, as cited in Harris, 1984). It may be the “weak or shaky marriages that suffer most” (Gath, 1978, as cited in Harris, p. 130).

Rivers and Stoneman (2003) found that as marital stress increased, sibling relationship quality declined and typically-developing siblings reported that they directed more negative behaviors toward their siblings with disabilities. The researchers speculated that it is possible that negative, conflicted sibling relationships could create marital stress, but it was more likely that children were emotionally affected by their parents’ difficulties and negative reactivity spilled
over into the sibling relationship. Children would then model the negative exchanges that they witnessed in their parents’ relationship, clearly highlighting the influence of family atmosphere.

*Family Functioning*

Harris (1984) considered the impact of children with autism on the family life cycle. The researcher observed that parents of infants and preschoolers may find that day-to-day care does not differ significantly from care for typical young children, although some young children with autism may be “far more exhausting” (Harris, p. 131). Families face more challenges as the child reaches school age, a time when demands for physical care would ordinarily diminish. The additional time demands especially limit mothers in their development of other life roles and increase the potential for isolation in relation to other mothers of children of the same age. At the time of adolescence, “little of the pressure to grow, open up to new experiences, and reexamine their marriage is afforded the parents…who find that their child grows older, but not much more self-sufficient than in the past” (Harris, p. 131). These issues intensify as parents age and may be less able to care for their children and siblings may feel pressured to assume responsibility for their brothers or sisters (Harris).

*Family environment and family harmony.* Perry et al. (2005) assessed family functioning as perceived by parents raising children with Down syndrome, Fragile X syndrome, Rett syndrome, autism, and DD of unknown etiology. The assessment tool included subscales in three dimensions that parallel aspects of Adlerian family atmosphere: (a) relationships, in which cohesion, expressiveness, and conflict are rated; (b) personal growth, in which independence, achievement orientation, intellectual-cultural orientation and moral-religious affiliation are rated; and (c) system maintenance, in which organization and control are rated.
The researchers also used a score based on the relationship dimension, the Family Relations Index, to measure family harmony. The family harmony score was derived by subtracting the level of conflict in a family from the level of cohesion and expressiveness. Family harmony, over and above child characteristics, individual coping style, and social and community supports, has been found to be a good predictor of family stress and its outcome (Perry et al., 2005). They found that these families were doing as well or better compared to typical families. While families raising children with DDs did report higher levels of stress, it did not necessarily mean that it would result in negative family outcomes. They found one significant difference among the groups: a declining trend in parent perception of family harmony as the etiology of the disorder became more ambiguous. Higher levels of family harmony were reported by parents of children with Down and Fragile X syndromes, where the etiology is better established, than parents of children with DD of unknown etiology and autism (Perry et al.).

*Family cohesion.* Higgins et al. (2005) looked at family adaptability and family cohesion in families of children with ASDs as measures of family functioning and found them to be below the norm. These families demonstrated less flexibility and a lack of warmth and connection when compared with families in the norm group. It is understandable that the characteristics of children with ASDs and the ramifications of their behavior for the family system would likely put them at risk of falling outside of the healthy family functioning range. Matching findings by Gray (1997) and Larson (2006) on the importance of family outings, the authors explained that families that cannot engage in activities with all family members risk disconnection and unresponsiveness to all members’ needs.
Schieve et al. (2007) used the NSCH data to compare parents’ “perception of closeness and ability to share ideas or talk about things that matter with the child” (p. S115). Surprisingly, parents of children with autism reported that their relationship with their children were “very close” more often than parents of children with other DDs and as often as those with special health care needs but without DDs and those without special health care needs.

However, Schieve et al. (2007) found that parents in the autism group were less likely than those in other groups to feel that they were able to share ideas or talk about things that matter with their children. It appears that another reciprocal process is in place: Children have difficulty responding to sharing, so mothers feel that they can’t share with them and don’t. Children have fewer experiences with sharing and lack opportunities to learn how to respond, so they continue to not respond.

Attachment. Next to Schieve et al.’s (2007) report of close parent-child relationships, research suggesting that “children with autism show most difficulties with behaviours that necessitate a working model of the self, the other, and their interdependence” (Rutgers et al., 2004, p. 1132) seems contradictory, making attachment an interesting theory to explore with this population. Attachment behavior reveals trust in the availability of caregivers and expectations about caregivers’ reactions (Rutgers et al.). The attachment system is activated when a child is tired, distressed, or threatened and seeks comfort from the caregiver. These experiences guide children’s strategies for regulating negative emotions and managing stress (Rutgers et al., 2004; Rutgers et al., 2007).

The Rutgers team conducted a meta-analysis on ten studies on attachment in children with ASDs. Most of the studies assessed attachment behavior using a modified version of the Strange Situation Procedure (SSP; Ainsworth et al., 1978, as cited in Rutgers et al., 2004) in
which behavior in children’s reunions with their caregivers is rated after two brief separations, one in which a stranger is present. An underlying assumption of the SSP is that children are able to give meaning to the parent’s departure, and as a consequence may show secure attachment. The studies indicated that children with ASDs tended to display less contact seeking and contact maintaining with their mothers than control children, but they demonstrated clear preferences for their mothers over a stranger and showed an increase in proximity seeking with their mothers after a separation. The meta-analysis found that 40% to 63% (53% overall) showed secure attachment behavior, as compared to 65% in normative, non-clinical samples (Rutgers et al.).

They observed two factors that moderated the results. One was the severity of the disorder. Children with more strictly-defined autism (AD) were less securely attached and showed less responsiveness in their contact with caregivers, possibly indicating that the severity of the impairment in reciprocal social interaction affected the parents’ ability to establish a secure attachment relationship. The other factor was mental development. Children with lower mental development showed more signs of insecurity, and, in fact, those with higher mental development did not differ from their non-clinical comparisons in secure attachment behavior. The chronological age of the child, although previously suggested as a factor, was not confirmed to affect attachment security (Rutgers et al., 2004).

Noting results that indicated that children with ASDs display less contact seeking and contact maintaining with their mothers, the authors questioned the validity of these studies using the SSP where attachment security was measured in stressful laboratory conditions or in free play. They speculated that children with ASDs “might be more affected by a somewhat stressful context than normal children” (Rutgers et al., 2007, p. 860). As an alternative, the authors looked
at an assessment that was used by one of the studies in the meta-analysis, the Attachment Q-Sort (AQS; Waters, 1987, as cited in Rutgers et al., 2007).

They used a modified version of the AQS in a subsequent study comparing preschool children with ASD with non-clinical children and children with MR and LD, two other clinical disorders featuring a less disturbed capacity for social relatedness. This study found that ASD rather than MR was responsible for less secure attachment behavior. Even the high-functioning children with ASD showed low security in comparison with non-clinical children, affirming the more secure-base or context-dependent attachment behaviors (Rutgers et al.).

A possible explanation for this less people-secure versus more context-secure attachment behavior may be found in research showing that high-functioning children with AD have poor memory for both complex visual and complex verbal stimuli as well as poor spatial working memory (Williams et al., 2006). In a press release, one of the authors described how this affects behavior:

“People with autism don’t have the automatic cross talk between brain systems – the reasoning and the memory systems – that tells their brain what is most important to notice or how to organize it thematically…. If the brain does not, from the start, automatically identify and store key information, that seriously impairs the capacity to interact, communicate and solve problems…. Typical people automatically notice and focus on what’s important or relevant, but because people with autism focus on details instead, they can’t recall or respond to what most people think are important.” (Minshew, as cited in APA, 2006)

Adjustment of siblings. Siblings have a complex role in families of children with ASDs and present opportunities as well as additional challenges for parents. As an opportunity, siblings provide experiences that affirm and encourage parental competencies. One challenge includes assisting siblings in coping with their roles in the family in addition to coping themselves (Harris, 1984). Another is altered family power structures when older siblings sometimes assume


more power because of parental time focused on the sibling with disabilities (Hardman et al., 1983, as cited in Norton & Drew, 1994).

In interviewing parents of high functioning children with autism, Gray (1997) found that over half of the respondents were concerned about the quality of the emotional relations among family members. As previously reported, Rivers and Stoneman (2003) found that marital stress negatively impacted sibling relationship quality. Pilowsky et al. (2004) also found that parental stress was related to socialization difficulties among the siblings. This association may be attributed to the relation between parent-child interaction and peer-related social competence (Guralnick, 1999), where stress may play a role either by impacting on parent’s availability to model social rules and cues during interactions, affecting the child’s knowledge of such social beads, or through negative emotions experienced during the interaction, that may affect vulnerability to emotional regulation difficulty, and then in turn affect peer relationship. (pp. 862-863)

The families interviewed by Hutton and Caron (2005) “reported that the siblings of their children with autism experienced jealousy or resentment due to attention…. Other feelings included sadness and fear. Very few siblings were accepting” (p. 188). Breslau, Weitzman, and Messenger (1981) studied siblings of children with disabilities and found that while they did not show higher rates of severe psychological impairment or greater overall symptomatology, they scored significantly higher on interpersonal aggression with peers and in school.

They found an interesting interactive effect between birth order and sex: “Among siblings younger than the [children with disabilities,] male siblings had greater impairment than female siblings, whereas among siblings older than the [children with disabilities,] female siblings were psychologically worse off” (Breslau et al., 1981, p. 350). Their findings contradicted previous research, and they hypothesized that this may be true only when the disability is congenital, suggesting that “the observed impact is of the earliest life experience” (Breslau, 1982, p. 93).
Their results replicated a previous study by Breslau that also found that age-spacing affects sibling well-being. Males less than 2 years younger than the children with disabilities had lower levels of psychological functioning and exhibited more aggressive behavior. Females less than 2 years younger scored higher on depressive-anxious feelings (Breslau).

Evidence has shown that typically developing siblings are more satisfied with their sibling relationship when the sibling with autism is chronologically younger (Rivers & Stoneman, 2003). Pilowsky et al. (2004) also reported that older siblings provided a more positive emotional description of their siblings with disabilities. Similarly, Rivers and Stoneman reported that older siblings were more satisfied with the sibling relationship when the sibling with autism was younger, but as the siblings grew older, their satisfaction declined. A possible explanation is that “as children with autism become older, their atypical behavior becomes more pronounced and difficult for the typically developing sibling to accommodate” (Rivers & Stoneman, p. 392).

Most of the siblings of children with autism (86.7%) were surprisingly well functioning considering “the genetic, familial, and social stresses they face” (Pilowsky et al., 2004, p. 863). Contrasting with Rivers and Stoneman’s (2003) findings, their circumstance may be “positively modulated revealing, as siblings grow older, an enhanced empathic ability toward their sibling” (Pilowsky et al., p. 862). Other positive findings have revealed that siblings are important social agents. As previously mentioned, children with autism make more vocal and verbal initiations towards their siblings than towards their parents (El-Ghoroury & Romanczyk, 1999), and siblings report “being proud of their ability to ‘teach’ their younger siblings with autism” (Bristol & Schopler, 1984, as cited in Rivers & Stoneman, 2003, p. 384).
Resources at the Community Level

Outside the immediate family, parents may receive support from informal social networks or from formal support services (Perry, 2005). As previously mentioned, Social Interest influences how and if resources and support are accessed. The Rutgers team’s comparison study found that parents of children with ASDs reported even more social support than the other clinical groups (Rutgers et al., 2007). The NSCH data agreed: A majority of the parents of children with DDs (83%) “felt they had the help of an emotional support system consisting of family, friends, and health care professionals” (Blanchard et al., 2006, p. e1206). The rate was even higher in parents of children with autism (90%; Blanchard et al.).

Dunn et al. (2001) found that social support moderated the influence of stressors on negative outcomes, matching Jones and Passey’s (2005) findings that “parents who valued social support had lower stress relating to finances, and both support services and family support were associated with lower stress related to lack of parental reward” (p. 42). Rivers and Stoneman (2003) found that more use of informal social support acted as a buffer for sibling positive behavior and sibling satisfaction but did not protect from the effects of marital stress on negative behaviors. Dunn et al. (2001) found that higher levels of social support corresponded to fewer spousal problems, although it was less important than coping styles.

Informal Social Supports

Informal social support comes from extended family members, friends and neighbors, and social and religious organizations. Perry (2005) noted that this emotional support or tangible help may be actual or perceived. Several studies have shown that quality rather than quantity is important in social supports. Pakenham et al. (2005) reported that better maternal adjustment was related to higher levels of qualitative social support, but that quantitative social support was
unrelated. Tobing and Glenwick (2006) agreed, reporting that greater satisfaction with social support, but not the number of supports, was associated with lower levels of maternal psychological distress. Considerations in this crucial issue include:

- the quantity versus quality issue (small but supportive networks may be best);
- the utility of the concept of perceived support (versus actual support obtained);
- the valence of contacts with the social network (helpful or stressful);
- and the issue of a threshold model of support (social isolation is harmful, but beyond that, more is not necessarily better; Tobing & Glenwick, p. 8)

Dunn et al (2001) found no direct relationship between social support and isolation, suggesting that some parents feel isolated despite receiving social support. They did find that social support may be particularly important in more difficult times. As previously mentioned, Ergüner-Telkinalp & Akkök (2004) found that the use of social support reduced mothers’ levels of hopelessness. Contrary to Dunn et al.’s findings, they believed that the buffer of social support was most important as an escape from isolation. In their study, it was observed that meeting with mothers and “sharing feelings, ideas and experiences seemed to promote social cohesiveness and support” (p. 265) and mothers felt less lonely.

While social support is valued, many parents (66.7%) reported that dealing with friends, neighbors, and family on a daily basis was “extremely stressful” (Jones & Passey, 2005). Lack of understanding and negative social attitudes were the most common challenges, agreed upon by 22% of parents in Higgins et al.’s (2005) study. To deal with this, 55.6% of respondents listed their spouses as sources of support, 26.7% recognized themselves, and 20.0% relied on their parents to help them. Explaining their children’s disabilities to others and accepting their situations as difficult were reported as successful strategies by the majority of parents, but others felt that ignoring or avoiding their situations by not going to certain places or not including the children with disabilities was helpful (Jones & Passey).
Formal Supports and Services

Professional interventions include education/treatment programs for the child as well as family interventions such as individual, marital, or family counseling; respite care; behavior management training; and parent support groups and organizations (Perry, 2005). Key are “their quality and effectiveness, their suitability for the family’s needs and values at the time, and their impact on parental levels of satisfaction” (Perry, p. 9). Pilowsky et al. (2004) found that stress experienced by parents of children with autism, MR, and DLD did not differ among the three groups. They posited that this was true despite higher levels of stress because support groups and extended schooling are more available for families of children with autism than for the other groups. Nevertheless, Perry found that formal supports did not add at all to the variance in family stress. Similarly, Tobing and Glenwick’s (2006) study suggested that mothers of more functionally impaired children may have more formal supports, but these additional supports do not reduce their stress.

As with informal social supports, Rivers and Stoneman (2003) found a similar buffering effect for mobilizing formal resources on the effects of marital stress on sibling positive behaviors and satisfaction. However, contrary to their prediction, “Families experiencing high marital stress who sought greater support from professionals and formal resources external to the family had typically developing siblings who reported more, rather than fewer, negative sibling behaviors” (p. 391). They posited that this could be due to the fact that more distressed families may turn to outsiders more for help. Their problems could be unrelated to the sibling relationship, or conversely, as other research has shown, heavily accessing the service system could “compromise, rather than enhance, positive family functioning” (Rivers & Stoneman, p. 391). Hastings (2003) found that when children with autism had less severe symptoms, “their
siblings were less at risk for behavior problems when the family also received high levels of formal social support” (p. 148).

Jones and Passey (2005) reported that 82.4% of parents rated dealing with doctors and other professionals more “extremely stressful,” a higher percentage than had rated dealing with family and friends as “extremely stressful” (66.7%). They reported a lack of support, difficulty in obtaining a diagnosis and agreement among professionals, and not being listened to and understood as major concerns. In dealing with professionals, parents rated sources of support as their partner (37.8%), other professionals (28.9%), themselves and their parents (both 26.7%), and other mothers of children with DDs (8.9%).

Parents reported that active/external strategies such as independently seeking more information and support, doing things themselves, and perseverance were successful strategies. Similarly, Tarakeshwar and Pargament (2001) found that nearly 43% of parents claimed it was more useful to educate themselves about the disorder than to rely on professionals for help. Others reported that passive/internal strategies, such as accepting things as they are and expecting the worst were helpful. Several others recommended getting a second opinion as a strategy, one reported that luck was necessary, and three felt that taking legal action to advocate for changes to services such as educational supports was beneficial.

The utilization of resources that mediate and moderate stress in families of children with ASDs begin to impact outcomes. Contrary to what may be expected, the personal resources of parents, especially psychiatric health and coping strategies, may have a greater impact on outcomes than the degree of children’s impairment or informal or even formal social supports and services. These personal resources are greatly influenced by Lifestyle and degree of Social Interest and are significant in the perception and appraisal of the family situation that lead to
consequent meaning. The Adlerian view states: “The individual’s experiences cannot be changed; what can be changed is the individual’s opinion of them. The past is unalterable, but the future is open” (Oberst & Stewart, 2003, p. 48). This awareness is particularly appropriate for parents of children with a chronic, incurable disorder.

Perception and Appraisal of the Family Situation

Numerous reports have suggested that the “severe emotional and behavioral difficulties [of children with DDs] create negative impacts on home lives, friendships, learning, and recreational activities, as well as place considerable burden on families and communities” (Blanchard et al., 2006, p. e1203). Of the 52 caregivers in the study by Higgins et al. (2005), 25% described ASDs as having a negative effect on family life. They measured three primary coping factors in their study of family functioning: self-esteem, optimism, and spousal support. The coping strategies “were at least moderately helpful” (p. 132), but no significant differences or predictions in marital or family adjustment were revealed, nor was there evidence of lower self-esteem in these parents. This implied that either the measure was not specific enough to assess the particular coping strategies, the coping strategies were not able to mediate the situations faced by these parents, or “it may not be coping strategies per se, but the cognitive appraisal of the situation that mediates the relationship” (p. 134).

It has also been found that stressors do not directly predict negative outcomes (Dunn et al., 2001). Reports of positive family functioning have been noted in previous research, despite the widespread documentation of higher levels of stress in families of children with disabilities (O’Brien, 2007). O’Brien cited studies showing that with effective intervention and supports, “many families of children with disabilities adapt successfully to their child’s needs and manage to function well” (p. 135). Perry et al. (2005) studied mothers and fathers raising children with
DDs and found that these families “are generally doing as well as or better than the norm and did not resemble distressed families at all” (p. 25). Hutton and Caron (2005) advised that

If anything can be learned, it is that families are strong and adaptable to the challenges and joys of having a child with autism. Furthermore, they are remarkable in the ways in which they coped with uncertainty and a diagnosis that still has no known cure. (p. 189)

In the NSCH, parents of children with autism reported that their problems were similar but more severe when compared with parents of children with other developmental problems, but 50% of them (versus 39% of parents of children with other developmental problems) also reported being able to cope “very well” with the day-to-day demands of parenthood (Blanchard et al., 2006; Schieve et al., 2007). Hutton & Caron (2005) found that despite intense stress, parents were able to talk about their children with great fondness and hold onto hope for them. Most parents believed that “they were successful in coping with their child’s disorder and that they led lives that were rewarding and valuable” (p. 181).

Perry (2005) noted that “Most family stress research has focused on negative outcomes…in that the outcome was termed ‘parenting distress’” (p. 10). She stated that research has shown that both positive and negative outcomes are possible and that they are not mutually exclusive or even negatively correlated with one another. Similarly, Hastings and Taunt (2002) found that families often identified positive attitudes alongside typical negative and stressful experiences and that each is associated with different variables. Perry used the previously mentioned concept of resource imbalance in defining outcomes:

Outcomes…may be thought of as what is left over after considering the primarily negative (but also potentially positive) impact of the Stressors, mediated and/or moderated by the primarily positive (but also potentially negative) influences of the various Resources and Supports available. This residual quantity consists of emotional states and cognitive appraisals and attributions about those emotional states, and can be positive and/or negative. (p. 5)
In attempting to identify why some families adapt more successfully than others, recent research has pointed to the importance of meaning and perception in determining how families respond to stressful events or situations (Berge & Holm, 2007). Perry (2005) suggested that research is needed to ascertain “the particular internal resources, beliefs, and coping abilities (e.g., hardiness, optimism, religious faith, task-oriented coping, etc.) that are most effective for reducing stress” (Perry, p. 7). Clearly, an exploration of parents’ Lifestyles would be beneficial in this analysis, as Hartshorne (2002) stated, “Parents will appraise the birth of a child with severe disabilities based on their lifestyles” (p. 274).

In the study on the relationships among children’s behavior problems, parental stress, and parenting behavior, Hastings (2002) deduced that parental appraisal processes may identify “the mechanisms via which children’s behaviour problems affect parental stress…. More severe child behaviour problems led to less problem-focused and/or more emotion-focused coping by parents which impacted negatively on parental stress” (p. 155). Further study has shown that parental appraisal variables such as parental beliefs and self-efficacy are significant and that these variables may act as moderators under some circumstances but as mediators under others. Hastings recognized that cultural and socio-economic factors likely affect these parental beliefs, coping methods, and approaches to parenting. In another study, Hastings found that parents who held positive beliefs about their children’s early intervention programs were less affected by their children’s autistic symptoms.

King et al. (2006) cited research on adaptation, adjustment, and resilience in families of children with autism and Down syndrome. They interviewed 15 parents to investigate their world views, values, and family priorities and how these beliefs might change over time. They found parents’ beliefs and priorities to be diverse, but four main themes emerged. The first was their
initial reactions to parenting a child with a disability. Two commonly discussed topics were the diagnosis of ASD or Down syndrome as a life-changing experience and the relinquishment of some of their hopes, expectations, and dreams for their children’s futures. A second theme had to do with how the family adapted over time. Common topics were becoming more aware of their beliefs, the importance of maintaining hope, and gaining a sense of control about how they viewed their situation.

A third theme consisted of world views and values that were strengthened, broadened, adapted, or relinquished over time. Parents reported an increased understanding of themselves as well as of societal issues. They mentioned positive things they had learned, including patience, acceptance, tolerance, perseverance, compassion, and unconditional love. They spoke of learning what is important in life, seeing strengths rather than deficits, and recognizing the worth of all individuals and all accomplishments, no matter how small (King et al., 2006).

A fourth theme concerned priorities that had changed in relation to their changes in world views and values. They were able to give up “trying to fix the child” and focus on what their children needed and could do rather than on what they couldn’t do. Parents reported being able to shift their focus from solely concentrating on the child with disabilities to balancing that child’s needs with those of other family members or their own growth and development (King et al., 2006). This equilibrium correlates with Adler’s (1998) advice on mothers’ relationships with their children: “Where one problem is overstressed, all other problems suffer from neglect, and even the single problem we are focused on cannot be tackled as effectively if we attach too much importance to it” (p. 101).
Protective Processes: Adaptation

King et al. (2006) identified three processes and factors that have been found to be important in assisting individuals and families in successful adaptation and establishment of a sense of coherence and control: (a) protective processes, (b) fundamental ways of thinking, and (c) positive appraisal. First, protective processes have been found to be important for adults with disabilities and likely could also be important for parents and families of children with disabilities. In earlier research, King et al. (2003, as cited in King et al.) identified “replacing a loss with a gain (transcending), recognizing new things about oneself (self-understanding), and making decisions about relinquishing something in life (accommodating;” p. 364) as protective processes.

Gray (2001) examined how parents of children with autism “attempt to construct coherence out of the disorder their child’s disability brings to their families and their own identities as parents” (p. 1247). He interviewed 32 parents representing 23 families of children (median age of 8) with autism whose impairments ranged from moderate to severe. He especially focused on the moral qualities of the experience of illness and disability and highlighted three reasons why, in Western cultures, children with ASDs are threats to parents’ moral status: (a) a lingering belief from the Puritan tradition that views illness as an indication of sinfulness; (b) the value placed on self-control; and (c) the value placed on “normality.” For these reasons, the diagnosis of an illness often initiates an examination of fundamental moral values:

The loss of taken for granted assumptions about good health, and the inability to continue with normal activities, requires the individual to reflect upon the things he or she values in life and to assess their responsibility for the illness and the meaning it will have for the future. (Gray, p. 1248)

Gray (2001) found three main themes that are similar to the protective processes identified by King et al. (2006). Accommodation was the theme of the majority of the parents’
narratives; resistance and transcendence were the two most common alternatives. Parents aligned themselves with specific communities of support according to the path they followed.

*Accommodation*

In Gray’s (2001) study, the majority of cases conformed to the illness ideology of the agency the families were involved and aligned with, therefore displaying accommodation. This ideology included beliefs about the etiology and prognosis of the disorder and assumptions about how clients will adapt to the illness. In this case, the ideology was based on “a biomedical model of autism that assumes it to have a biological, probably genetic etiology, and a poor prognosis” (Gray, p. 1250). The agency’s goals were to assure the parents that autism has a biological base and that they had done nothing wrong as parents; to discourage parents from being obsessed with the cause of the illness and move to the practical problems of treating the disorder; and to convince parents that “despite their child’s autism, they were still a normal family…. to which something abnormal – the birth of an autistic child – had happened” (p. 1250). Families who adapt in this way usually come to accept the situation and are successful at coping with the stress the illness places on the family as well as accessing services to manage the children’s problems.

*Resistance*

Gray (2001) recognized that accommodation requires “a degree of passivity on the part of the parents and it does not provide a moral explanation for their child’s suffering” (p. 1253). Some parents reject this passivity and create an alternative narrative that is more empowering. In Gray’s study, one mother educated herself about the disorder and available services, sought out other parents who were dissatisfied with the services, and became an activist and influenced public policy toward children with disabilities. This mother found support in aligning with a political activist community. This path gave her a sense of control and direction in her own life,
and even though life was still very stressful, she felt empowered. King et al. (2006) stated that advocacy and support are about talking yourself and other people out of thinking negatively about your child and the disability. Another example of empowerment is parents who have been frustrated with the “illusion of inclusion” in traditional schools and have worked to establish charter public schools to better meet their children’s educational needs (Walsh, 2007).

Transcendence

Other parents seek a greater meaning for their children’s disability. Gray (2001) interviewed one mother who turned to her faith and found a transcendent meaning in her family’s situation. She believed that her child had been given to her for a reason and that many people, including her, had been touched and positively changed by contact with her child. This mother’s church was her alternate community of support.

Li-Tsang, Yau, and Yuen (2001) interviewed parents identified as “successful” in their coping mechanisms, attitudes, and help-seeking behaviors. Two of the participants stated “that it was God who gave them this child because God knew that they would be nice to the child. To them, raising a child with a disability became their mission” (p. 66).

Fundamental Ways of Thinking

Fundamental ways of thinking related to family resilience are a second factor in successful adaptation. These include “making meaning from adversity, having a positive outlook, transcendence and spirituality, and religious beliefs” (Bennett et al., 1996; Walsh, 1998, as cited in King et al., 2006, p. 364). Parental attributions, including locus of control and self-efficacy; ambiguous loss; and spirituality and religion are examples of processes that affect fundamental ways of thinking.
Attributions

Attributions have been found to be predictors of parents’ emotional and behavioral reactions to their children (Antshel et al., 2004; Wagner, 1996, as cited in Dale et al., 2006). Weiner (1985, as cited in Dale et al.) identified three dimensions of attributions: (a) locus of cause, involving whether the cause is perceived to be internal or external; (b) stability, involving whether an event is perceived to be chronic or changeable; and (c) controllability, involving whether the event can be changed by personal or external forces.

In a focus group, Dale et al. (2006) interviewed 16 mothers of children who had been diagnosed with an ASD over 1 year prior to the interview. Ages of children at time of diagnosis ranged from 3 to 11 years. Assessment measures showed that mothers in this group had high stress levels but relatively low levels of reported depression and high expectations about their children’s futures.

They asked mothers about their (a) experiences before the diagnosis; (b) reactions and perceptions at diagnosis; (c) feelings about the cause, actions and beliefs that may help their children; and (d) perceptions and concerns about their children’s futures. All mothers speculated about the cause of their children’s disorders, mentioning birth, pregnancy, MMR vaccinations, genetics, biological factors, and maternal behaviors. The majority did not attribute blame for their children’s disorder to a particular source, but their personal theories were linked to their perceptions for their children’s futures and actions that may help them. Curiously, about one third of the group “believed that their children’s condition could be completely overcome in the future” (Dale et al., 2006, pp. 475-476). Highly publicized celebrity cases likely add to this belief. Actress Jenny McCarthy claims that her son with ASD “is in recovery… For the most part he’s a typical child in a normal school” (Harpo Productions, 2008).
Locus of control. Another finding was that mothers who reported higher levels of personal control also reported higher levels of depressed affect, suggesting that they experienced a sense of isolation and were overburdened with too much of the responsibility of helping their children (Dale et al., 2006). In contrast, Konstantareas (1991) found that mothers with an external locus of control reported the greatest stress, but this did not hold true for fathers, and Dunn et al. (2001) agreed, observing that parents “who experience stress and view themselves as having no control over events may be most susceptible to the influences of life stress” (p. 41). Dunn et al. found that parents with internal locus of control had lower levels of depression and isolation, although it “did not buffer the effects of stress or enhance the effects of social support” (p. 49). They likened this to learned helplessness and found a direct relationship between internal locus of control and fewer negative outcomes.

Common challenges to internal control can come from either the children with disabilities or from support systems. Jones and Passey (2005) also found that parents who felt that their parenting was effective and they were in control, rather than their children being in control, tended to have lower levels of stress. This parental locus of control versus child locus of control accounted for 32% of the variance in parental stress. Dunn et al. (2001) posited that locus of control “may help explain the complex effects of social support” (p. 41), matching Dale et al.’s (2006) suggestion that parental wellbeing may be related to balancing personal control with feeling supported by others.

Self-efficacy. In one of the few larger studies, Kuhn and Carter (2006) investigated associations between parenting self-efficacy and parental cognitions of agency, feelings of guilt, and autism knowledge. The type of guilt considered in this study involved mothers’ feelings of not doing enough for their children. The authors designed questionnaires addressing these
cognitions that were completed by 170 biological mothers of children (aged 2.4 to 10.8 years of age) with autism. Mothers were also assessed for depression and parenting stress. The authors cited research that has shown that parents who believe that their efforts will be successful are more likely to persist in their efforts to help their child. They hypothesized that higher self-efficacy can be predicted by maternal agency.

Kuhn and Carter (2006) found that 40% of the mothers reported elevated depressive symptoms and 63% were above the clinically significant stress level on assessment measures. As predicted, “over and above the contributions of depression, parenting stress, time since diagnosis and the presence of another child with a disability, agency and guilt contributed unique variance in the prediction of maternal self-efficacy” (Kuhn & Carter, p. 569). Over 80% of mothers reported feelings of guilt about not doing enough for their children, and 21% of those thought that this interfered with their ability to effectively parent their children. In another study, parental self-efficacy mediated the impact of their children’s behavior problems on mothers’ anxiety and depression, but moderated this relationship for fathers (Hastings, 2002). Autism knowledge was positively correlated with maternal agency, showing that mothers who had more knowledge were more active in promoting their children’s development. Autism knowledge was thought to be a factor in helping parents to attribute their children’s behavior to the disorder rather than to their parenting (Kuhn & Carter).

Ambiguous Loss

Dale et al.’s (2006) interviews with mothers of children with ASDs revealed that the uncertainties regarding cause and prognosis of the disorder were especially difficult, and as previously mentioned, Perry et al. (2005) found a declining trend in parent perception of family harmony as the etiology of the disorder became more ambiguous. Research has shown that
ambiguity “creates a powerful block to coping and grieving, predicting symptoms such as depression, anxiety, loss of mastery, hopelessness, and conflict, all of which erode couple and family relationships” (Boss & Couden, 2002, p. 1151). When losses are ambiguous, it is “the situation and not the person’s psyche [that] makes letting go impossible” (Boss, 1999, p. 5).

Boss (1999) wrote that “the certainty we hunger for in human relationships is most poignantly unachievable when a person we care about is neither clearly absent nor clearly present in our lives” (p. 4). Chronic illnesses, occurring most often because of genetic predispositions that cannot be controlled, can create this situation because they are difficult to diagnose and have no cure. Outcomes are difficult to predict because “genetic factors and personal resilience respond to treatment and bodily insult differently” (Boss & Couden, 2002, p. 1352). Boss and Couden went on to state that

The freezing of family process is less likely the result of illness than from the ambiguity…. [What might be labeled as pathology could be] normal reactions to untenable situations of ambiguity…. Coping is blocked: behavioral adaptations become non-existent or dysfunctional as the family waits and wishes for a miracle to put things right again. (p. 1353)

Boss applied Hill’s ABCX model of family stress to the theory of ambiguous loss and “noted that ambiguity can be introduced into the family system as either the stressor event (A-factor) or the perception of the event (C-factor)…. The meaning they give to it (C-factor) is the critical variable” (Carroll et al., 2007, p. 211). In this discussion, the diagnosis of ASD—the stressor event (A) in which information is unclear or unavailable—is known as ambiguous loss. A possible response stemming from the diagnosis—the perception of the event (C)—is known as boundary ambiguity (Berge & Holm, 2007).

Stressors of ASDs that contribute to ambiguous loss. Boss and Couden (2002) identified five reasons why the ambiguity surrounding an illness contributes to family stress and “can make
people feel helpless and thus more prone to depression, anxiety, and relationship conflicts” (p. 1353). O’Brien (2007) focused on the application of ambiguous loss with families with children with an ASD diagnosis and described how Boss and her colleagues’ five reasons pertain to this situation.

The first area of ambiguity is a lack of clarity in diagnosis. As we have seen, with few known biological markers, diagnosis of ASD must rely on clusters of behavioral symptoms, making it a long and rarely straightforward process. Although recent research has been mentioned, the etiology is still unclear and, as Dale et al.’s (2006) study also confirmed, many parents believe that an action at some point, such as a childhood immunization, might have caused the disorder (O’Brien). A recent case will likely add to this uncertainty. Although studies have discounted the link between autism and thimerosol, a mercury-based vaccine preservative that has since been removed from childhood vaccinations, the U. S. government has recently conceded a case that alleged that the vaccine worsened an underlying disorder that led to autism-like symptoms (Stobbe, 2008).

The second area is a difficulty in predicting outcomes. With ASDs, there is no pattern of symptoms or strengths and the long-term outcome is highly variable. Some children with severe impairments grow up to hold jobs and live independently, while others require substantial lifelong support and intervention (O’Brien, 2007).

The third area is in the day-to-day variability in functioning. Inconsistency in behavior and performance levels “makes it difficult for parents to plan activities or respond effectively to their children’s behavior…. [and] can keep family members feeling off-balance, never quite certain whether the child is truly unable—or just unwilling—to learn certain basic skills”
(O’Brien, 2007, p. 136). This leads to confusion in a basic parental function: how to discipline the child (Berge & Holm, 2007).

The fourth area is in the appearance of health. Among children with chronic illness, this is particularly difficult in ASD diagnoses. Parents may have believed that their children were developing typically and were only a little unusual or more difficult than other children. Family members and friends may undermine parents’ self-confidence by questioning the diagnosis, suggesting that parents are overreacting (O’Brien, 2007), or, as Norton & Drew (1984) reported, expressing criticism of children’s or parents’ behaviors.

The fifth area is in the loss of relationships. “The nature of autism itself, especially the difficulties of individuals with ASDs to perceive others’ feelings and share meaningful experiences with others, creates a situation of considerable ambiguity within the family” (O’Brien, 2007, p. 137). The child is physically present in the household, even requiring increased amounts of parental attention and family resources, but is not psychologically entirely present and able to participate in the family in traditional ways, changing the nature of the family relationships (O’Brien). This area especially relates to the Adlerian concepts of Social Interest and belonging.

O’Brien (2007) interviewed mothers to determine if these issues would come up spontaneously in conversation about experiences in their families with their children with ASDs. It was determined that the following would be interpreted as ambiguity:

Expressions of conflicting thoughts and feelings (ambivalence); hopelessness or helplessness (loss of mastery) alternating with hope or being in control; doubt about one’s identity, role, or relationship with the child; self-blame or incompetence; anxiety about the future; and uncertainty or confusion about the child’s diagnosis. (p. 139)

Analysis revealed that more than half of the mothers interviewed expressed feelings that could be described as arising from ambiguous loss. They frequently expressed “conflicting or
contradictory emotions and ideas about the child and the ASDs, confusion about the child’s and their own future, and alternations between hope and hopelessness, feeling in control and feeling helpless” (O’Brien, 2007, p. 140). The narratives often had to do with “the uncomfortable feeling of being on a roller coaster, not knowing on any given day whether things would go well or be difficult” (O’Brien, p. 141). They tended to cling to their images and expectations from the past when looking to the future. The study concluded that the theory of ambiguous loss “has direct relevance to many families of children with ASDs” (O’Brien, p. 143).

**Boundary ambiguity.** Boundary ambiguity is a family’s possible response to the stressor situation of an ambiguous loss. It is important to view boundary ambiguity as a continuous variable: Higher levels of boundary ambiguity are likely to predict higher levels of family stress (Carroll et al.). Berge and Holm (2007) identified factors both outside and inside the family that might place parents at risk for higher levels of boundary ambiguity.

Outside the family, characteristics of the illness, time and demands of treatment, and the length of the uncertainty affect the degree of boundary ambiguity. Inside the family, the family type, based on Lifestyles and how the family processes information, can influence the response. Families with a rigid need for clarity or a high expectation of mastery and control will have more difficulty in tolerating the ambiguity. If they ignore or deny facts, their interpretation of reality becomes the source of ambiguity (Berge & Holm, 2007)

Berge and Holm (2007) also identified factors that might mediate the relationship between boundary ambiguity and psychological distress. Foremost was the degree to which family members were able to tolerate ambiguity. Differences between family members in this ability may be a source of conflict. Parents who have created family environments that
encourage cooperation, maintain positive interaction patterns, and minimize conflicts will be less susceptible to the distress boundary ambiguity can create.

Of the two dimensions of boundary ambiguity, Berge and Holm (2007) termed the first membership ambiguity. This involves an external family boundary and threatens the Adlerian sense of belonging for the excluded children. They termed the second role ambiguity. This involves an internal family boundary and is the more common and pervasive of the two.

Identity ambiguity. O’Brien (2007) recognized a slightly different dimension of boundary ambiguity and labeled it identity ambiguity. This overlap and confusion between parents’ own identities and those of their children is important from an Adlerian perspective as well.

“Appropriate boundaries increase the chances for the development of a life style which reflects greater degrees of social interest, cooperativeness, and responsibility” (Hirschorn, 1987, p. 209).

A second component of O’Brien’s (2007) study tested the hypothesis that “identity ambiguity would be related to mothers’ depressive symptoms and perceptions of stress connected to her child with an ASD, and this relation would not vary with the severity of the child’s disorder” (p. 143). Two groups were formed on the basis of the number and severity of ASD symptoms displayed by the children. Children in one group had been diagnosed with AD and had significant impairment in all three core areas of autism. In the other group, the children had other ASD diagnoses with fewer or less severe symptoms. Indeed, analysis showed that identity ambiguity was a significant predictor of maternal depressive symptoms and child-related stress and it was the same for both groups. O’Brien’s (2007) research showed that ambiguous loss provides a useful framework for attempting to understand the challenges families of children with disabilities face and their resilience in learning to live with ambiguity. The author concluded:
The inherent ambiguity of autism, related to the lack of knowledge surrounding its etiology, symptoms, treatment, and outcome, suggests that parents whose children are diagnosed with ASDs experience conflicting realities and emotions. Coming to terms with the discrepancies between their initial expectations for their child and family and the altered outlook that is required for a family to continue to function well after a child receives an ASD diagnosis is a process that few families can be expected to negotiate easily (p. 142).

**Spirituality and Religion**

Spirituality and religion have also been recognized as having important roles in finding meaning in and coping with the circumstance of having children diagnosed with DDs (Konstantareas, 1991). King et al. (2006) cited research demonstrating that hope and spiritual beliefs are important factors in people’s ability to meet challenges across the lifespan. Konstantareas clarified that research has shown that parents perceive belief in God, rather than involvement with formal religious structures, to be helpful. Adler recognized that religion is one of the greatest movements in understanding that the meaning of life is found in concern for the welfare of all of humankind, but he also advised that religion can easily be misinterpreted (Adler, 1998).

Researchers have differentiated between spirituality and religion: Spirituality is often expressed through religion and religious practices but can also be expressed in secular forms. It is personal but can also be shared in communities and religious organizations (Canda, 1999, as cited in Poston & Turnbull, 2004). As Gray (2001) pointed out, illness and disability present moral issues and individuals’ religious and/or spiritual beliefs influence their views of it (Zhang & Bennett, 2001, as cited in Poston & Turnbull, 2004). Sevensky (1981, as cited in Poston & Turnbull) identified three functions that religion provides for people with illnesses: (a) “a framework to make meaning of their illness…, (b) practical resources, and… (c) hope” (p. 96).
Poston and Turnbull (2004) interviewed 78 families of children with disabilities in two urban areas in Kansas and Louisiana and in one rural area in North Carolina to ascertain what role spiritual and religious beliefs and practices held in family quality of life. They were asked open-ended questions about their perceptions of family quality of life, about times that go well and times that are tough, and things that contribute to these times. Although not specifically asked about their spiritual or religious affiliations, comments indicated that most of the participants were Christian. Their comments fell into two categories that matched the differentiation of spirituality and religion: having spiritual beliefs and participating in religious communities.

Spirituality and religion played a major role in many families’ experiences. Three areas emerged in the category of having spiritual beliefs: (a) having faith, (b) using prayer, and (c) attributing meaning to disability. Participants expressed the importance of faith in giving them strength and allowing them to rely on something greater than themselves. Prayer was spoken of “as a way to communicate with God and to access their faith” (Poston & Turnbull, 2004, p. 102). In prayer, many asked God for direction, strength, patience, and inner peace and also thanked God for the good things in their lives. About half of the families who spoke about their spiritual life used their faith as a way to make sense of having a child with a disability, albeit in two very different ways: Some viewed it as a blessing; others viewed it as a test of faith (Poston & Turnbull).

Participants joined religious communities to share and develop their spirituality with others and, from this involvement, gained a sense of strength for meeting everyday challenges. Several described their place of worship as “a place of acceptance and unconditional love” (Poston & Turnbull, 2004, p. 103), while others spoke of the difficulties they faced because they
felt their children were not understood and accepted and the church did not have the support to allow families to fully participate (Poston & Turnbull). Similarly, Konstantareas (1991) and Tarakeshwar and Pargament (2001) also reported that many parents complained that their children were perceived as disruptive during religious services and were not welcome. This separated the family because it was necessary for someone to stay home with the child.

Coulthard and Fitzgerald (1999) conducted a study in Dublin, Ireland, investigating the relationships among reported support from organized religion, personal beliefs, and health status. To address this issue, they assessed 54 families of children with autism using a scale that measured support from two dimensions: (a) personal beliefs, an internal coping resource, and (b) organized religion, an institutional or formal resource. The results showed that participants received the most support from their personal beliefs and little support from organized religion.

The majority of parents agreed with five of the six statements on the assessment scale relating to support from personal beliefs, including 66% who reported seeking comfort through prayer. Only 39% felt that having children with disabilities had brought them closer to God and their religion, and 45% felt that it had distanced them. Interestingly, older participants were more likely to report support from their personal beliefs, perhaps reflecting a developmental maturity that might occur in the population as a whole. Better health was correlated with better support from personal beliefs, and those who sought comfort in prayer had significantly better health than those who did not. The authors recognized prayer as a resource and a coping strategy. The act of physically carrying out an activity and deferring to a higher power may lessen feelings of guilt and responsibility and enable parents to cope more adequately (Coulthard & Fitzgerald, 1999).
The majority disagreed with all but one of the six statements on support from organized religion. Forty-six per cent agreed and 10% disagreed that they were satisfied with the availability of religious education for their children, although 28% said it did not apply because they were not interested. Many of the children had participated in rites of passage such as first communion and confirmation, possibly serving as a way of normalizing the family situation by observing the rites of their cultures (Coulthard & Fitzgerald, 1999).

Two results differed significantly from a similar study by Fewell with families of children with Down syndrome. One was that only 7% of participants agreed that their clergy had been helpful at the time of diagnosis, compared to 42% in Fewell’s study and 22% had not told their clergy of the disability. The authors attributed this difference to the recognition of Down syndrome, a less ambiguous and diverse disorder, at birth versus the more ambiguous and diverse ASDs that are not diagnosed until sometimes much later. Therefore, in mainline Christian communities, the disability (Down syndrome) would likely be known by the clergy at the time of baptism (Coulthard & Fitzgerald, 1999).

The second difference was that only 5% of participants agreed that they would seek help from their clergy in contrast to 37.7% in Fewell’s study. Again, the impairments of ASDs may result in families withdrawing from their faith communities. Not surprisingly, more clergy support was reported in smaller, close-knit minority communities (Coulthard & Fitzgerald, 1999).

Tarakeshwar and Pargament (2001) interviewed 45 parents to assess the role of religion in the coping processes of families of children with autism (mean age of 10.29 years) in northwest Ohio. They also examined the association between the use of positive and negative religious coping methods and depression and anxiety in parents as well as the links between the
use of religious coping strategies and parental perceptions of psychological and spiritual growth. Slightly more than 40% declared themselves to be Protestant, 28.6% Catholic, 28.6% “other,” and 2.4% Jewish. They asked about the frequency of attending church and of praying and of their self-rated religiosity.

They also administered a questionnaire consisting of 11 items reflecting the positive dimension and 10 items representing the negative dimension of religious coping. Three items measured religious outcome: “perceived changes in closeness to God, closeness to church, and spiritual growth in response to the stressful experiences in raising a child with autism” (Tarakeshwar & Pargament, p. 251). Parents also selected and ranked the three most severe stressors in raising their children over the past year.

Results were similar to those found with other coping strategies (Dunn et al., 2001; Ergüner-Telkinalp & Akkök, 2004; Higgins et al., 2005; Pakenham et al., 2005) and indicated that greater use of positive religious coping was associated with better religious outcome and greater stress-related growth, but it was not associated with levels of anxiety and depression. As might be expected, greater use of negative religious coping was associated with lower religious outcome, greater depressive affect, and, marginally, greater anxiety. It was not associated with stress-related growth (Tarakeshwar & Pargament, 2001).

A large number of parents (81%) reported that their religion provided meaning to the challenge of raising a child with autism through helping them redefine the stressor as benevolent and potentially beneficial. Twenty per cent of parents reported having a spiritual connection with God, but 25% expressed spiritual discontent. Forty per cent reported looking to clergy and church members for support, but 30% felt that they were abandoned by their church or were not satisfied with the clergy. As previously mentioned, negative aspects of religion such as being
unable to attend worship as a family due to children’s behavior and insensitivity on the part of the church community likely contribute to this dissatisfaction (Tarakeshwar & Pargament, 2001).

Nearly 14% reported that the rituals and hymns of the church had a calming affect on their children, perhaps serving as repetitive auditory or visual stimulation and appealing to their propensity for routines and rituals. Almost 10% described their religion as a way of helping them understand a disease with no identified cause and the same percentage cited their partners’ shared religious faith as a resource, a circumstance that likely decreases marital stress (Tarakeshwar & Pargament, 2001).

In Li-Tsang et al.’s (2001) study, a small sample of parents (10) in an Asian community, “less than half of the informants had a religious background and there [was] no major difference in the coping mechanisms between those parents with a religious background and those without” (p. 66). This matched The Barna Group’s (2007) research that showed that the world view, and therefore attitudes, beliefs, values, opinions, and behaviors, of the vast majority of Christians (96%) does not differ from non-Christians.

In Gray’s (2006) longitudinal study, the number of parents citing religion as a coping strategy remained the same over 8-10 years, but its share of the proportion of all coping activities increased. Gray posited that this could reflect the decline in the importance of the use of treatment services as well as

an acceptance by the parents that their earlier expectations about their child’s improvement will not be fulfilled. Under the circumstance, the parents may have found it more important to acknowledge the permanence of their child’s disability and find a way of thinking about it that will put it into a meaningful perspective. (p. 974)

**Positive Appraisal**

A third factor in successful adaptation is the capacity for positive appraisal and other characteristics that lead to resiliency in families. These include the abilities to balance the child’s
needs with the needs of other family members and the family as a whole and to attribute positive meanings to the situation (Patterson, 1991, as cited in King et al., 2006). Positive perceptions have been shown to contribute to successful coping and adaptation.

Taunt and Hastings (2002) believed that family research should measure positive factors in addition to family problems. They emphasized “the importance of the nature of questions asked about functioning in families of children with developmental disabilities” (p. 417). They cited three predecessor studies that asked family members to describe the positive impact of children with disabilities. Agreement emerged on ten key issues across the three studies:

(a) Pleasure/satisfaction in providing care for the child, (b) The child as a source of joy/happiness, (c) The child provides a challenge or opportunity to learn and develop, (d) Strengthened family and/or marriage, (e) A new or increased sense of purpose in life, (f) Development of new skills, abilities, or new career opportunities, (g) Family members have experienced personal growth (more compassionate, less selfish, more tolerant, increased strength/confidence), (h) Expanded social and community networks, (i) Increased spirituality, and (j) A changed perspective on life (e.g., clarified what is important in life, making the most of each day, living life at a slower pace; p. 411)

Taunt and Hastings (2002) asked two sample groups open-ended questions focusing on positive aspects of caring for children with disabilities and on parents’ perceptions of the future, both for their children and for their family. Themes that emerged as positive impacts on parents in both samples included (a) positive characteristics of the child (80% and 53%), (b) increased sensitivity (60% and 59%), (c) opportunities to learn (30% and 50%), (d) changes in perspectives on life (80% and 72%), and (e) improved family dynamics (10% and 28%). One sample added increased assertiveness/confidence (25%) and strengthened religious faith (12%). Support from other families (50%) and opportunities to expand social networks or make a difference (31%) were mentioned respectively by each sample.

Positive impact on siblings and extended family members showed similar agreement. Both samples mentioned improved extended family dynamics (20% and 28%) and opportunities
to learn (10% and 12%). One sample reported increased sensitivity (90%), positive effect on siblings (50%), and changed perspective on life (20%), and the other sample reported positive attitudes toward others (34%) and a greater sense of responsibility in siblings (12%). As far as parents’ perspective on the future, 30% and 47% were generally hopeful, 20% and 6% were generally fearful or anxious, 20% and 19% expressed hopes and fears, and 20% and 9% did not look to the future (Taunt & Hastings, 2002).

Trute and Hiebert-Murphy (2002) did a longitudinal study of 64 families of children with a primary diagnosis of developmental delay. In addition, almost half had multiple handicaps including physical disabilities and over one fourth were children with Down syndrome. The families were first assessed when the children were 5 years old on average and then 7 years later when they were 12 years old on average. The authors evaluated an assessment tool, the Family Implications of Childhood Disability Scale (FICD), which they developed to reflect both positive and negative parental appraisals of the impact of childhood disability on functioning in the family system and to identify mothers and fathers who might be at risk for long-term parenting stress. Items on the negative scale pertained to time demands, disruptions in family routines and vacations, financial burden, limitations in social contacts outside the home, chronic stress, and marital tension. Items on the positive scale involved bringing the parents closer to God, improved marital relationships, examination of values, and positive personal development.

Like Hastings and Taunt (2002) and Perry (2005), the authors found that both positive and negative appraisals co-occur in families and are not inversely related or negatively correlated (Trute & Hiebert-Murphy, 2002). However, in a later study, Trute et al. (2007) found a more direct, although weak, relationship between fathers’ negative and positive appraisals of the family impact of childhood disability. Cognitive appraisal emerged as “an important factor in
delineating the relationship between a stressor and adjustment” (Trute & Hiebert-Murphy, p. 277). Interestingly, no average change in parents’ cognitive appraisal of the impact of childhood disability on family life transpired over the 7-year interval, suggesting that parental appraisal is formed early on and remains static through to the preadolescent years of the child.

Trute and Hiebert-Murphy (2002) found mothers’ and fathers’ scores to be moderately correlated on the negative subscale score, but not correlated on the positive subscale, suggesting that parents have similar perceptions of the negative impact of the disability on family life, but their views on the positive impact are independent. This matched the findings of Hastings et al. (2005) in a study of parents of preschool children with autism. They found that mothers held more positive perceptions than fathers and these positive perceptions were not correlated with child and father variables. In contrast, paternal positive perceptions were affected by variables such as maternal depression that affect stress. Trute and Hiebert-Murphy, however, showed no significant differences between the appraisals of mothers and fathers when the scores were averaged.

In the later study, Trute et al. (2007) used an expanded version of the FICD to further assess the differences between maternal and paternal cognitive appraisals in 103 families of children with intellectual and developmental disabilities. In this sample, 33% of the children were developmentally delayed (NOS), 19% were diagnosed with autism, 12% with PDD, 10% with cerebral palsy, 9% with Asperger syndrome, 8% with Down syndrome, and 7% with genetic or metabolic delays such as Fragile-X syndrome. This time they assessed parents when children were 4 years old on average at 6 months (T1) and 18 months (T2) after entry into childhood disability services.
The team found that at T1, fathers’ scores on positive appraisal were significantly lower than mothers’ scores, but the differences became non-significant at T2. This suggested that positive perceptions may emerge more quickly in mothers than in fathers but may converge over time. They also found that mothers’ levels of self-esteem over time could be predicted by their early assessment of positive and negative impacts on family life. This study demonstrated that positive parental perceptions and appraisals in the first months following entry into childhood disability services can assist parental coping, while negative parental appraisals can predict lower levels of long-term family well-being (Trute et al., 2007).

Coping strategies that influence perception and appraisal appear to have the most influence on family functioning. Protective processes that lead to successful adaptation; fundamental ways of thinking, most notably influenced by an understanding of ambiguous loss and spirituality; and opportunities for positive appraisal seem to be key elements. This is not surprising, as family members constantly evaluate variables that affect family functioning. Few variables are truly objective.

Summary and Recommendations

This literature review has discussed the nature of DDs with an emphasis on ASDs, common stressors families of children with ASDs face, resources that parents and families may draw upon, and the role of coping strategies that influence perception and appraisal. The emphasis of this research has been on the family rather than on the child with the DD, agreeing with the American Academy of Pediatrics: “Families are the most central and enduring influence in children’s lives…the health and well-being of children are inextricably linked to their parent’s physical, emotional and social health, social circumstances, and child-rearing practices” (Schor, 2003, as cited in Blanchard et al., 2006, p. e1209). The goal of this research has been to assist
families and clinicians in making choices that will improve family functioning, a goal that was shared in analyzing the data in the NSCH:

Analysis...has the potential to provide new information...which might be used to revise clinical practices and reformulate policy to maximize the functional status of children with emotional, developmental, and behavioral problems...and their families. This is consistent with the World Health Organization 2002 International Classification of Functioning, Disability, and Health, which emphasizes an individual’s functional capacity over disability when addressing developmental problems. (Blanchard et al., 2006, p. e1203)

Every effort has been made to locate the most current research available on ASDs and family functioning, however, several limitations must be taken into account in considering results. First, while a great number of studies have been presented, most of them had small sample sizes. This is likely to improve as ASDs become more prevalent. Second, the majority of studies reported on heterogeneous populations that often combined data from children with DDs or the range of phenotypes in ASDs, although in many aspects of family functioning, this is probably not significant. Third, while sibling adjustment has been briefly considered, it was beyond the scope of this review to study siblings in depth. It would also be of value to include grandparents or other extended family members in family functioning research. Fourth, the emphasis has been on parental adjustment and its effects on the family, but much of the data in available research is limited to studies with mothers. This is a noteworthy opportunity for further research. Fifth, this review did not include research on individual and family interventions. This would be a logical and instructive accompaniment to these findings.

In conclusion, this paper will summarize and make recommendations for supporting children, parents, and families keeping the Adlerian perspective in the forefront. Next, the roles of two support resources, family therapists and faith communities, will be discussed. Finally, a brief look at two common illusions will be presented.
Supporting Children

As has been shown, there is a myriad of intervention services for children with ASDs. While beneficial, there is a need to go beyond treating symptoms to considering the quality of life for children and their families. Even with impairments in social interaction, a sense of belonging and community may be especially important for children with ASDs. Nachshen et al. (2003) reported that “creating and/or finding opportunities for [their children] to make friends and participate in activities” received the third highest parental stress rating. There is significant opportunity for community organizations to sponsor activities for children with DDs. Blanchard et al. (2006) recommended:

Participation in everyday activities is considered a vital part of children’s development and is related to quality of life and, possibly, future life outcomes. According to the NSCH, children with developmental problems participated in sports [40.3% versus 58.9% of typically developing children] and social activities outside of school [44.2% versus 53.3%] less frequently than their peers. These findings may account, in part, for parent’s observations that their children had lower self-esteem, were depressed and anxious.... Thus, new approaches are needed to increase these children’s participation in community activities, which may prove to be as important as individual interventions in improving overall development, as well as quality of life. (p. e1209)

Supporting Parents

As mentioned in the limitations of this review, the experiences of parents of children with ASDs are largely reported by mothers only. The available research with both parents indicates that the stress levels, burdens, and perceptions vary significantly between mothers and fathers. It appears that mothers have higher levels of stress (Herring et al., 2006) but their positive perceptions may emerge more quickly (Trute et al., 2007). Curiously, behavior problems are strongly correlated with maternal stress but not paternal stress. It was supposed that this is due to less involvement of fathers with their children, adding to the burden of mothers. This imbalance
and possible resulting maternal resentment or paternal exclusion may be significant for clinicians to address, not only with fathers but with other family members as well.

**Genetic Liability**

While genetic liability may be an important consideration to explore with parents, caution is advised. Some parents may welcome a new way to understand their own lives that provides “a frame in which a whole bunch of seemingly unrelated aspects of my own life growing up fit together for the first time” (Schwarz, as cited in Carey, 2007). Others may not want to be identified in this way and realize responsibility for passing on the problem. If suspected by clinicians, encouraging parents to be assessed and, if diagnosed, sharing it with their children may be an important opportunity for connection between them. One parent described himself as a translator for his more-severely affected child (Schwarz, as cited in Carey).

**Reciprocal Processes**

Kuhn and Carter (2006) advised: “Helping children with autism by empowering parents to adopt more effective behaviors may prove fruitful” (p. 571). As previously noted, care must be taken to assure parents that their actions have not caused their children’s disabilities, but the research reviewed in this discussion certainly points to advising parents that their behavior can impact outcomes as well as offering education and training to facilitate the process. This can be a source of encouragement to parents because it provides hope for improved relationships. Siller and Sigman (2002) cited research that indicated

Genetic research provides compelling evidence for the importance of biological factors in autism…. but it also highlights that the relation between the “autistic genotype” and its manifestation in behavioral deficits is far from being deterministic…. Therefore, findings that the environment does play a role…is consistent with a line of research that has a complex view on the processes that are involved in the initiation, persistence, and desistance of behavioral deficits in childhood psychopathology and a focus on the interaction between biological and environmental factors. (pp. 86-87)
This review has revealed numerous reciprocal and reinforcing processes in parent-child relationships. It is an interesting revelation because it seems to challenge one of ASDs’ core deficits: the lack of social or emotional reciprocity. The reciprocity may not be constructive, but it is nonetheless reciprocity and may be encouraging in that it assumes that children with ASDs have communicative and behavioral competencies that can be extended and built upon.

Reciprocal processes discussed in this review include: (a) parenting styles and children’s behavior (Hastings, 2002; Rutgers et al., 2007); (b) parental sensitivity as it affects attachment (van IJzendoorn et al., 2007); (c) synchronization in attention between parents and children in developing communication skills (Hedenbro & Tjus, 2007; Siller & Sigman, 2002; Stiegler, 2007); (d) the development of distancing and escape coping behaviors (Sivberg, 2002); (e) the role of parental stress in sibling adjustment (Pilowsky et al., 2004); and (f) the perception of closeness and sharing (Schieve et al., 2007).

Hastings (2002) described the reciprocal process well in predictions to explore in future research: (a) Behavior problems will predict parental stress more than measures of the severity of a child’s intellectual or adaptive functioning; (b) Parents who are under increased stress will engage in different parenting behaviors, likely contributing to their children’s behavior problems; (c) Certain parenting behaviors such as a coercive style will be linked to higher levels of challenging behaviors due to reinforcement processes; (d) Psychological variables such as coping, social support, self-efficacy, and other beliefs will mediate and/or moderate the impact of behavior problems on parental well being; (e) Parental negative emotional reactions to behaviors may explain the impact of such behaviors on a day-to-day basis on longer term parental stress responses; and (f) The factors identified interact with a number of other processes, such as parenting practices related to socio-economic or cultural variables that may decrease or increase
the risk of developing behavior problems or neurobiological processes that may explain certain behaviors and be subsequently reinforced by social factors including parental behavior.

Hastings (2002) emphasized two implications for practice from his research. First, assessment and intervention should include the behavior of other people in the children’s environment. Stiegler (2007) emphasized that successful interactions are the responsibility of all family members, not only the children with ASDs:

> We will, I believe, come to the realization that interaction breakdowns are as much the fault of the adult as they are of the child. How autistic of us to place the total blame on the children who…are trying very hard to keep the interaction going. (Duchan, 1983, as cited in Stiegler, 2007, p. 407)

Second, treatment should focus on reducing parental stress, indirectly improving the children’s behavior by improving the quality of parenting behavior. Two recommended methods for supporting parents were behavior management skills training and cognitive-behavioral therapy for increasing positive parental appraisal processes such as coping, self-efficacy, and beliefs. From an Adlerian perspective, this could be accomplished by assessing Lifestyle and subsequently challenging mistaken beliefs. As Adlerians would, Hastings emphasized the value of encouragement: “Even something as simple as encouraging parents to recognise the positive dimension of life with their child may help to reduce the impact of child-related stressors on parental well being” (Hastings & Taunt, 2002, as cited in Hastings, 2002, pp. 157-158).

*Parenting sensitivity and styles.* Rutgers et al. (2007) found “less flexible, sensitive, and synchronous interactive behaviors” (p. 860) between parents and children with ASDs. The discussion seems to imply that less flexible parenting may be less desirable, but clinicians must be cognizant that a seemingly less flexible style may be the only way parents can establish and maintain structure and predictable routines to meet the needs and demands of children with ASDs. As Siller and Sigman (2002) recognized, perfect synchronization without verbal demands
is not the goal, and clinicians would be advised to promote balance between structure/routine/predictability and flexibility/spontaneous sensitivity so that one does not come at the expense of the other.

However, the Rutgers team advised that “longitudinal, prospective studies starting early in the autistic child’s life may be crucial for disentangling the different roles of parental sensitivity and children’s autistic impairments in the emergence of the first attachment relationships” (Rutgers et al., 2004). Parental sensitivity training in interpreting their children’s needs and signals has the potential for fostering improved parent-child relationships and influencing children’s overall communicative functioning. Juffer et al.’s Video-feedback Intervention to promote Positive Parenting protocol has been successfully applied to other families of children with chronic illnesses and was recommended (Rutgers et al., 2007). Training in parenting styles and child-parent transactions may also prove beneficial for parents.

Mansager and Volk (1995) described an Adlerian psycho-educational model for parent training for couples with strained parent-child relationships. In one of the sessions, Dreikurs’ (1964) four parenting styles are presented using a matrix with a vertical “authority” or “firmness” axis, ranging from “over-control” to “leniency,” and a horizontal “nurturance” or “love” axis, ranging from “neglectful” to “indulgent.” Parents are encouraged to recognize themselves and visualize possible change by moving themselves on the matrix.

In the same session, parents share specific examples of disturbing interchanges with their children. These examples are analyzed with a variation of Ellis’ “A-B-C” framework (Ellis & Harper, 1979, as cited in Mansager & Volk, 1995), where “A” is the child’s activating behavior, “B” is the parent’s belief about the behavior, and “C” is the consequent emotional and behavioral response of the parent and the child. Special attention is given to exposing beliefs.
In the next session, the Adlerian technique of Early Recollections (ERs) and the part they play in solutions for current problems are introduced. ERs are then collected using a combination of Willhite’s (1991) procedure and Lew and Bettner’s (1993) Connexions Focusing Technique. Before the next session, co-therapists meet to discuss the ERs and how they relate to the parenting styles of the participants, with special attention given to the nature of any parent-child interactions and the part played by adult or authority figures. In the next session, parents are given an outline with suggestions for reframing and constructively applying the solutions provided in their ERs to the current parenting situations. Challenges to any irrational or mistaken beliefs or private logic are often included (Mansager & Volk, 1995).

This 5-session model has two considerable strengths. First, it presents an efficient way to address parents’ Lifestyles. Hartshorne (2002) advised that identifying and using parents’ Lifestyle assets can help them find faith in their own abilities and the resolve to deal with the uncertainties a family with a child with a severe disability must face.

A second strength of this model is that it is conducted in a group setting with up to six couples, providing an arena for parents to share their experiences with other parents in similar situations. Social isolation has repeatedly been shown to be a concern for parents, and meeting with other parents has been found to reduce parents’ levels of hopelessness and loneliness (Dunn et al., 2001; Ergüner-Telkinalp & Akkök, 2004). This group experience offers an opportunity for parents to both express and cultivate Social Interest.

Hartshorne (2002) directed professionals not only to encourage parents to network with other parents and organizations, but to join them in working to strengthen or create support groups or systems by participating themselves and urging other professionals to do so as well. Blanchard et al. (2006) recommended:
In light of the increasing prevalence of autism…a greater proportion of attention and resources will need to be directed toward this population of caregivers and that family focused interventions, such as referrals to parental support groups, may be as important as those that are focused on the individual child. (p. e1209)

Since Mansager and Volk’s (1995) model was not designed for parents of children with DDs, three additions or adaptations are recommended. First, an exploration of parents’ beliefs about illness and disabilities through the Adlerian technique of genograms may be beneficial. Second, opportunities for parents to express feelings and beliefs about low parenting self-efficacy and guilt that may interfere with effective parenting may provide a normative framework and free energy to adopt more active roles in their children’s lives (Kuhn & Carter, 2006). Third, consideration should be given to format and scheduling. Because of the extreme demands on parents’ time and energy, a workshop format may be more practical. Scheduling one weekend away may be easier than multi-session therapy (Blackledge & Hayes, 2006).

*Coping mechanisms.* Hastings’ (2002) research uncovered a vicious circle where more severe behavior problems led to less problem-focused and/or more emotion-focused coping by parents, then to more parental stress, and then to more behavior problems. This matches the belief that higher levels of expressed emotions in parents positively correlate with childhood psychopathology. Thus, it appears that emotion-focused coping may refuel children’s behavior problems, a striking example of reciprocity.

Studies reviewed have shown the value of acquainting parents with emotional approach coping strategies such as positive reappraisal and seeking emotional social support, as well as other constructive coping mechanisms including self-control, social support, and problem solving. Confrontive coping to fight for what is wanted, express anger and other feelings, and take chances is also recommended. However, it may also be important to help parents recognize non-constructive coping behaviors as well. Escape and avoidance, including hoping for miracles,
having fantasies, using food and drugs, or avoiding others, and passive avoidant emotion-focused coping strategies such as venting emotions and behavioral disengagement should be revealed and discouraged (Dunn et al., 2001; Pakenham et al., 2005; Sivberg, 2002).

Distancing and escape, usually considered to be non-constructive emotion-focused coping behaviors, may play a role in hindering the development of secure attachment behavior. The Rutgers team’s research (Rutgers et al., 2004; 2007) indicated that attachment does develop between parents and children with ASDs, but the impairments of ASDs may affect the process. Both Hedenbro and Tjus (2007) and Sivberg (2002) found that parents may develop distancing and escape coping behaviors in reaction to feelings of rejection fostered by their children’s responses or lack thereof. Clinicians may find it beneficial to assist parents in experiencing more typical responses by role playing or imagining and then practicing those feelings and cognitions in interactions with their children. One technique to consider would be the empty chair, where parents could imagine a reciprocating child and respond to that child.

Courageous Paradox

As a parent of a child with disabilities, Hartshorne (2002) understood that “the world of disability is all about what a person cannot do, dis-abilities” (p. 268). As has been shown, the sources of discouragement and resulting feelings of inferiority are numerous in families of children with disabilities. Hartshorne listed a few examples of how parents may feel:

inadequate to deal with the medical and educational needs of their child; …they failed in not producing a healthy baby; …embarrassed by the notice they and their child receive from others; ….they must rely on what professionals say, because parents are not experts. (p. 269)

Parents strive to compensate for these feelings, and Hartshorne (2002) noted a key Adlerian belief that can enable parents to do that in a positive and productive way: “finding the courage to be imperfect and letting their child be imperfect” (p. 268). Hartshorne wrote:
The parents of a child with disabilities are confronted with what could be called the “courageous paradox.” On the one hand, they need to be realistic about their child and to be able to feel genuinely that if their child never improves, never progresses, never becomes that healthy human being they want their child to be, that this is okay. This is not resignation: This is real acceptance.…

On the other hand, parents of a child with disabilities should never give up the hope that their child will exceed all expectations and make tremendous progress. This is not based on fantasy, but on hope. If the parents give up hope, their child’s future is much less certain. When parents are able to maintain both of these positions at the same time, they are demonstrating what Adler meant by courage based on both social interest and activity. By accepting their child as worthwhile and able to contribute even with no change, they are showing social interest. By never giving up hope for their child’s potential, parents are led to action. Parents with courage will seek out services for their child and push medical and educational institutions to provide what the parents believe their child requires. (pp. 268-269)

O’Brien (2007) concurred: “The challenge for parents whose children have ASDs is to accept the reality of the permanent nature of their child’s condition while maintaining optimism about potential gains that can be made through effective intervention” (p. 136). However, O’Brien’s labeling of the condition as “reality” and “permanent” must be questioned. Reality is a psychosocial construct, and if the disability becomes the paramount focus of the family, then the family may become stuck and unable to move forward. Clinicians may assist families in thinking about the disability as just one component of reality, making room for reconfiguring family/relational systems to accommodate needed changes and for creating goals and incentives for movement. Accepting disability as permanent or terminal turns it into a handicap and limits its potential for becoming an opportunity.

Hartshorne (2002) showed that the behavior of courageous parents can be misunderstood. The researcher administered a commonly used questionnaire on resources and stress to 27 parents of preschool children with disabilities. In the interviews, he recognized that parents’ “responses were influenced by the overall level of courage and that in some cases parents who were very encouraged about their child were receiving scores that reflected more stress” (Hartshorne, p. 270). He identified questions that presume that parents who are realistic about
their situations are therefore under a great deal of stress, ignoring the possibility of the parent having less stress because of encouragement and missing the effect that Lifestyle and Social Interest can have on the outcome of the experience. Hartshorne, like Taunt and Hastings (2002), advised that research should measure positive factors in addition to family problems.

Hartshorne (2002) believed that “a parent who perceives the event as having potentially positive meaning and who is able to identify resources to support their child and family will be under less stress, even while answering the questions realistically” (p. 272). Because Hartshorne’s study probably predated the more positive models cited in this paper, his experience was that much of the literature on stress in families of children with disabilities is based on scales that presume stress and negative outcomes. He concluded that this may account for the discrepancy between the widespread documentation of high levels of stress in these families and the reports of positive family functioning and explained:

Professionals may conclude from such studies that these parents are inevitably strained and in need of remedial treatment (Glidden, 1993). Such treatment aimed at addressing primary deficits may, in fact, increase feelings of inadequacy and discouragement in families who are trying to develop the courage to raise the child. (p. 272)

Parents Helping Parents, a family resource and service center for parents of children with special needs and the professionals who serve them, maintains that “there is a stage of adaptation beyond acceptance; a stage that might be called the ‘appreciation’ or the ‘all right’ stage” (Poyadue, 1993, as cited in Taunt & Hastings, 2005, p. 419). This stage would indicate:

The unhappy and apparently discouraged parent may in fact be so, or he or she may be past denial and starting to struggle with the development of courage. The extent to which the parent becomes courageous will depend on lifestyle, social interest, and the amount of encouragement he or she receives from others, particularly his or her social support system and professionals. (Hartshorne, 2002, p. 269)
Other instances of paradox

This study has revealed several other instances of paradox that generate questions. One is the question of the validity of parent self-reports: Are they positively or negatively skewed? Do parents feel “pressure to present a socially desirable image of themselves and their families” (Higgins et al., p. 135)? Are they displaying courage or a lack of it?

Other questions come from seemingly paradoxical correlations. First, how is it that higher levels of parenting satisfaction predicted lower levels of psychological distress, but higher levels of parenting efficacy predicted higher levels of psychological distress (Tobing & Glenwick, 2006)? Clinicians need to be aware that low levels of expressed distress may not necessarily mean high parental efficacy and high levels of distress may not mean a lack of parental efficacy. It is known that individuals who are depressed may have greater insight and hold a more accurate appraisal of the world than non-depressed individuals who hold unrealistic appraisals.

In related but contrasting findings, one study found that higher levels of personal control predicted higher levels of psychological distress and feelings of isolation (Dale et al., 2006), and others found that higher levels of personal control predicted lower levels of depression and isolation (Dunn et al., 2001; Konstantareas, 1991). It may be that both are true, even in the same individuals, depending on the day and circumstances. Depressed affect could be related to the necessity to constantly maintain the level of perceived control from either internal or external sources.

Two other questions emanate from Scheive et al.’s (2007) research: (a) How is it that parents of children with ASDs scored high on the Aggravation in Parenting scale, yet reported being less bothered by the things their children did and were less likely to feel angry with their
children? (b) How is it that parents rated their relationships with their children as being very close, yet felt less able to share ideas or talk about things that matter with their children?

It is important for clinicians to be cognizant of these questions and view them as opportunities to offer encouragement. They relate to ambiguous loss, and simply being aware of them may be normalizing and encouraging.

Supporting Families

Hartshorne (2002) quoted Turnbull’s description of raising children with disabilities as a long-term, or marathon, activity: “The real issue for families…is to be able to remain intact as a family over time, meet the developmental needs of the child over time, and develop the kinds of relationships that remain resilient and vital over time” (Turnbull, 1988, as cited in Hartshorne, p. 275). Opportunities for families to have fun together are crucial in establishing this kind of family atmosphere. Clinicians might assist and encourage families in locating and participating in activities such as family retreats offered by Joni and Friends, an organization dedicated to ministering to people with disabilities (www.joniandfriends.org).

As with parents, exploring perceptions and appraisals of the family situation with siblings would be beneficial. An assessment of perceived psychological birth order would be one method of addressing this. In light of Breslau’s (1982) and Breslau et al.’s (1981) research, it would be interesting to explore the relationships between birth order and sex. A possible issue might be different capacities in adjustment, awareness, and insight in males and females. It would also be interesting to examine how Rivers and Stoneman’s (2003) observations of sibling relationship satisfaction relate to Pilowsky et al.’s (2004) findings that, as children, sibling adjustment is related to the child’s verbal ability. Would this change later in life when emotional closeness would be more desired but impossible for the child with an ASD to offer?
Teaching families about ambiguous loss should be a priority for clinicians. Ambiguous loss provides a framework for understanding many of the issues and paradoxes that have been discussed, particularly uncertainty or confusion with diagnoses; parental self-efficacy, mastery, and control; identities, roles, and relationships in the family; family routines and rituals; and conflicting thoughts and feelings. Identifying the situation as ambiguous loss can energize and help parents reorganize their thinking, make decisions that can improve family functioning, and employ constructive coping mechanisms rather than remaining stuck in a pattern that is not effective in their changed family circumstances. It can also be very encouraging, allowing parents to attribute their distress, confusion, and immobility to the inherently ambiguous situation instead of themselves (O’Brien, 2007).

Ambiguous loss affects not only children and parents, but the whole family. With this in mind, Boss and Couden (2002) proposed that intervention should go beyond individuals and their symptoms to take into account “the family’s unique ways of coping with ambiguity and how they make sense out of it” (p. 1353). In line with Adlerian therapists, they recommended family meetings with conversations among several generations of family members to discuss and reach agreement not only on what has been lost but on how to enjoy the capabilities the family still has. They must realize that the assumption of perfect health is gone, but they can still have many good days together once they learn to reduce the impact of the illness on their daily lives. Parents must come to realize that “they still have their child to love and touch and interact with, but they have to let go of their dream that their child has robust health” (p. 1354). As has been mentioned, encouraging them to meet with other families experiencing similar loss can often help in this process. Boss and Couden believed that a realistic clinical goal is to help a family learn how to live well with the stress of long-term ambiguity…. A kind of healing is possible if interventions are constructed using a family-stress management
model rather than a medical model. When a family member has a physical condition that won’t get better, the only window for change lies in the family’s perception of the ambiguity. The clinical goal is to enable family members—the patient and family caregivers—to remain as self-determined as possible in spite of progressive debilitation and ambiguity of status. (p. 1354)

In applying Boss and Couden’s (2002) research to families with children with chronic illnesses, Berge and Holm (2007) agreed that managing boundary ambiguity was a primary treatment goal, seeking both to reduce the extent of ambiguity and to help family members learn to tolerate it. They discussed five steps for effective intervention. The first step in managing boundary ambiguity is assessment. They used an assessment process that included questions to assess role ambiguity, focusing on the parent-child roles and expectations such as discipline and parents’ abilities to attend to other responsibilities and relationships, and membership ambiguity, focusing on the way the children fit into the family. Parents responded on a scale of 1 – 10 to describe the extent to which the perception is true and also the extent to which it is bothersome or stressful, assessing both the degree of boundary ambiguity and their ability to tolerate it.

Next, parents and families can be assisted in managing the boundary ambiguity issues identified in the assessment questions. Berge and Holm (2007) discussed five techniques that may be helpful: (a) perception sharing, (b) labeling the problem, (c) gathering information, (d) reconstructing, and (e) dialectical thinking.

Perception sharing is beneficial in managing boundary ambiguity because it is likely that each family member has different tolerance levels and different views of the child, the diagnosis, and the effects on the family. From an Adlerian perspective, this makes sense due to each person’s unique Lifestyle. The strength of the marital relationship, an indication of the partners’ success with the love task, impacts this communication process. When perceptions are shared and discussed, it is possible to find agreement. Agreement helps improve the decision-making
process and helps the family restructure roles and create new rituals that can decrease role ambiguity (Berge & Holm, 2007).

Labeling the problem as boundary ambiguity reduces the likelihood of depression, anxiety, and self-blame that parents may feel as a result of the challenges in their parent-child relationship. Instead of viewing their feelings as an inability to cope with the situation or as a relationship problem, an understanding of boundary ambiguity encourages parents to be more resourceful in managing their stressful situation (Berge & Holm, 2007). Parents of children with ASDs become proficient in labels and labeling; this may be an exercise that demonstrates the positive value of labeling.

Information gathering through talking directly with health care professionals; researching via the internet, books, periodicals, and national organizations and associations; and networking with other parents can “add a layer of certainty that can counteract some of the helplessness parents experience because of ambiguity” (Berge & Holm, 2007, p. 128). Kuhn and Carter (2006) found that autism knowledge was thought to be a key factor in helping parents attribute their children’s behavior to the disorder rather than to their parenting.

Hartshorne (2002) connected parents’ ability and interest in accessing information with their degree of Social Interest. In previous studies by Hartshorne, parents identified the need for information as most important, but Hartshorne cautioned professionals about providing too much information, as this can overwhelm, and in turn, discourage, parents. Instead, he recommended that they encourage parents by supporting them in developing their own skills to locate and access information. It appears that parents do become proficient in this, as Twoy et al. (2007) reported that up to 93% of parents turned to others facing similar problems for information.
One important part of information gathering may be to assist parents in thinking and planning for their children’s futures. As Nachshen et al. (2003) found, this is a source of considerable stress for parents. Acquainting them with resources that could facilitate the process may alleviate some of this distress.

Reconstructing perceptions, as has been presented as important in this review, is another way to manage boundary ambiguity. For parents, an ASD diagnosis in their child presents a situation over which they have little control, defeating their sense of mastery. Berge and Holm (2007) wrote:

Reconstructing includes realizing that the experience of confusion is attributable to the ambiguity rather than something parents or other family members did or neglected to do. Once the source of the helplessness is known, the coping process can begin; that is, parents and family members can assess the situation, begin revising perceptions, and gradually change family roles, rules, and rituals. Finally, parents and family members can make active decisions about the roles they choose to incorporate into their identity, even though uncertainty persists. (p. 128)

Berge and Holm (2007) recognized that considerable reconstructing may be necessary in a family with a chronically ill child. Roles traditionally belonging to one parent can be divided into smaller roles undertaken by several family members. Families may need assistance in designing new rituals and traditions that can bring order, comfort, and certainty to the ambiguous situation, while at the same time having opportunities to mourn traditions that have been relinquished. By discussing values and priorities with families, clinicians can help families identify and articulate them, provide families with a feeling of being understood, inform their decisions regarding interventions for their children, and increase the likelihood of successful interventions (King et al., 2006). The use of contextual reframing strategies involving “transcending events, devaluing the importance of particular goals, and refocusing priorities can assist families to establish a sense of coherence and control” (King et al., p. 364).
Helping families see the positive aspects of having a family member with a disability is of prime importance. Two possible ways to do this are acquainting the family with affirmations and modeling and practicing rituals that provide opportunities to verbalize positive feelings toward other family members. Newly designed rituals such as candle-lighting ceremonies may be one way to celebrate this recognition and appreciation. Taunt and Hastings (2002) found that exposure to positive attitudes in parent-to-parent support programs fostered the development of positive attitudes in other parents. Sharing experiences with other families in similar circumstances may be especially beneficial for siblings. Family situations, as Gray’s (2002; 2006) longitudinal studies revealed, seem to improve with time. Pairing families of children who have been recently diagnosed with families that have years of experience may be a worthwhile endeavor for agencies, clinics, associations, or faith communities.

A final technique for managing boundary ambiguity is dialectical thinking, very much in line with Hartshorne’s (2002) idea of courageous paradox. As opposed to absolute thinking that “can lead to either acting as if the child is not ill or closing the child out of the family while he or she is still alive” (Berge & Holm, 2007, p. 129), dialectical thinking “allows parents who are experiencing boundary ambiguity to combine optimistic and realistic thinking at the same time, which can ultimately add to their ability to stay engaged in life despite the presence of ambiguity” (Boss, 1999; 2002; 2006, as cited in Berge & Holm, p. 129). With dialectical thinking, parents can evaluate roles, adjust roles that are not optimal to family functioning, and keep roles that are satisfying (Berge & Holm). On a hopeful note, Boss and Couden (2002) concluded by pointing out some advantages of living with ambiguous loss:

It brings surprises, it challenges, it rewards creativity for thinking up new ways to handle the work, leisure, intimacies, and rituals of family life…. Those not insistent on mastery and finding perfect solutions to every problem can live with ambiguous losses without negative effects to themselves or the patient. (p. 1360)
Despite the many services available, parents have reported a lack of support, not being listened to and understood (Jones & Passey, 2005), and difficulties in the coordination of services (Hutton & Caron, 2005). Many parents (82.4%) perceived working with professionals to be very stressful (Jones & Passey) and many (43%) claimed it was more useful to educate themselves about the disorder than to rely on professionals for help (Tarakeshwar & Pargament, 2001). Clearly, improvement is needed. Family therapists and faith communities may be underused resources that could assist families. Hutton and Caron advised:

Raising a child with autism is a full-time job. Increased services, more efficient ways of doing paperwork, and increased funding for respite care and other services are needed for these parents who never get to go home from work. (p. 189)

Family therapists are uniquely equipped to fulfill many roles that could improve services for families of children with DDs. It would be beneficial for families to be connected with family therapists as soon as there are concerns about their children’s development. Medical professionals, usually the first service providers to be involved with the family, should be made aware that in retrospect, parents have reported that they would have liked to have had someone to talk with (Hutton & Caron, 2005).

At the time of diagnosis, there seems to be as great a value in working with the parents as with the children with disabilities. As we have seen, the time of diagnosis is particularly stressful for families (Hutton & Caron, 2005; Kuhn & Carter, 2006) and parental appraisals made at the time of diagnosis tend to endure (Dunn et al., 2001; Trute & Hiebert-Murphy, 2002), making it particularly crucial to take parents’ beliefs about the disorder and their attempts at making sense of the information into account. Being mindful of parents’ self-esteem and sense of control are
especially important when presenting diagnostic information, assessment results, and treatment options. Involving both parents in meetings will assist them in developing common goals and understandings that may reduce marital stress (Perry, 2005). Family therapists can assist parents and families in changing perceptions and gaining courage and hope at these times:

[This process] may provide families with a sense of realistic hope for the future, and may validate their perspectives by showing that they are not alone in their experiences and challenges…. Parents may find it useful to know that it is common to feel a lack of control, and disappointment and sadness due to lost dreams. Over time, many families gain new dreams, develop new understandings of their child and of the world, manage life effectively by adjusting their priorities, and report life-changing benefits for themselves, other family members, and members of the broader community. (King et al., 2006, pp. 364-365)

The importance of early intervention and parents’ initial satisfaction with services cannot be overemphasized. Early interventions to reduce children’s behavior and emotional problems and to provide additional support, education, and skills training for parents have the potential to improve family outcomes (Herring et al., 2006). It has been shown that parents who hold positive beliefs about their children’s early intervention programs are less affected by their children’s autistic symptoms (Hastings, 2002). Being aware of parents’ attributions may provide an understanding of the decision-making processes in regard to education and interventions (Dale et al., 2006). King et al. (2006) agreed, pointing out the significance of identifying values because they are linked to priorities and affect parents’ choices of supports and opportunities for their children as well as their goals for therapeutic interventions. Attention to family life cycle stages may also inform the development of effective interventions (Kuhn & Carter, 2006).

Families’ frustrations with services also cannot be overlooked. As Rivers and Stoneman (2003) found, it is possible that heavily accessing the service system may impede positive family functioning. Jones and Passey (2005) called for adopting a multi-dimensional and inclusive approach to research and practice with families, including the recognition of the importance of
parental perceptions and the awareness of the potential for professionals to be a cause of
increased stress. Care must be taken to avoid overloading the family system with time and
energy requirements. An issue to consider in family quality of life is whether families should be
encouraged to move beyond “more is better,” as is now happening in end-of-life decisions on
treatment (Marcotty, 2008).

One way to ensure this would be to review strengths and needs and then set appropriate
goals (Perry, 2005). Hartshorne (2002) agreed: “To facilitate greater family resilience,
professionals need only encourage parents to build on their own strengths. From the lifestyle
framework, one would work with assets instead of mistakes” (p. 272). Schieve et al. (2007),
recognizing that numerous therapies from several different disciplines are often necessary,
reported that

shifting treatment from expert-driven or provider-based models which are child-centered
to models emphasizing a collaborative team approach, in which families are integral
members, is gaining attention (Becker-Cottrill, McFarland & Anderson, 2003). Such
family centered models consider family concerns and quality of life in developing
treatment plans. (p. S120)

The Role of Faith Communities

Faith communities are also uniquely equipped to reach out to families of children with
DDs. Poston and Turnbull (2004) denoted three things that families are looking for from their
faith communities: “(a) acceptance of their child, (b) spiritual and emotional support for
themselves, and (c) supports for their child during services so that both their child and
themselves can have meaningful participation in religious activities” (pp. 103-104). To address
these issues, clergy, staff, and congregants must be educated and sensitized to the challenges and
demands facing families of children with DDs. Inviting parents of children with DDs to share
can be encouraging, empowering, and validating.
There are numerous ways for faith communities to provide spiritual and emotional support to families. Lay ministries such as BeFrienders (www.befrienderministry.org) or Stephen’s Ministries (www.stephenministries.org) train and equip volunteers to walk alongside families or reach out in times of crisis. Matching families with other parents who may be facing similar problems or providing opportunities for parents to express negative religious appraisals such as feelings of anger toward God or of being punished by God can assist families in dealing with their struggles.

Other means of support include sponsoring parents’ nights out, respite care for other events, or family events for children with disabilities. Recognizing that families need support in order to participate, one-on-one support for children must be available during church activities (Poston & Turnbull, 2004; Tarakeshwar & Pargament, 2001). These services not only assist families of children with DDs, but they provide other congregants with avenues for expressing their faith and Social Interest in caring and serving ministries.

Poston and Turnbull (2004) advised that families also have a role in making partnerships with their faith communities successful. Families need to “(a) set aside time for spiritual or religious practice, (b) ask for support from their religious community, and (c) ask for support from their community disability organization or child’s school” (p. 104). Another important suggestion was for families of children with disabilities to volunteer in other areas of ministry, such as food drives, ushering, or greeting. Research has shown that serving as a family promotes healthy youth as well as family relationships (Search Institute, 2007).

Professionals are well advised to be aware and respectful of the capacity of faith communities to positively impact family functioning. Tarakeshwar and Pargament (2001) wrote: “The church and its beliefs can be regarded as a resource for the parents’ emotion-focused
coping efforts because they help to minimize stress by providing parents with alternative ways of interpreting the challenges of parenting an autistic child” (p. 256). It has been reported that frequent church attendees “are seven times more likely to seek assistance from clergy for their marriage and family problems than the assistance of a nonreligious mental health specialist” (Privette, Quackenbos, & Bundrick, 1994, as cited in Tarakeshwar & Pargament, p. 257). In the U. S., this may be especially true for non-English speakers. Twoy et al. (2007) found that spiritual support was statistically significant for parents who indicated that English was their second language. A possible explanation may be that addressing concerns through spiritual advisors does not require the expense of and reliance on a hired interpreter.

**Illusions**

In conclusion, two issues that have been encountered in this research are of note. Courageous parents have referred to them as illusions. One is the “illusion of inclusion.” One parent who is working to start a charter public school for older children with ASDs said, “‘We just want them to reach their potential, but we just didn’t see it happening’” (Waisbren, as cited in Walsh, 2007). It is this group of parents that termed their experience in the public schools as the “illusion of inclusion.” Mainstreaming has been the protocol in public schools for decades, but these parents are questioning whether it’s really working or if it is the best or only option. Children’s self-esteem and sense of belonging are challenged when they are expected to constantly compete and be compared to typically-developing children. The pressures of No Child Left Behind to raise student achievement and the financial burden of special education services are straining school districts. These parents are courageous enough to ask if there is another way. Alternative schools may provide more opportunities to focus on the abilities and strengths rather than on the disabilities and weaknesses of these students who are differently abled. Their ability
to experience the world in an unusual way may uniquely equip them to find solutions to
problems that have eluded others.

It may also be helpful for clinicians to challenge the illusion of inclusion in families. Parents may hold the mistaken belief that their children with disabilities must be included in all activities, limiting the family’s participation in many desired outings and events. Parents who would not consider these outings appropriate for preschoolers may believe that it is necessary to include their older children with disabilities when developmentally they may not be any more appropriate. This may require greater availability of respite care, another opportunity for associations, agencies, and faith communities to offer assistance. Perhaps assisting parent groups in forming cooperative child care exchanges could be one solution.

The other illusion is the “illusion of normalcy.” Challenging the value our culture places on normalcy or broadening its scope by lifting up the value of other strengths is one of the most important roles of professionals and communities of influence. A vision of Parents Helping Parents (2007) is “a world where our communities are not afraid of differences.” Normalcy is related to prejudice and implies that one individual or family is better than another; one is included and one is excluded. One professional, a family/psychosocial researcher, professor of family medicine, and practicing family therapist, also is a parent of a son with chronic illness and a daughter with autism. He poignantly spoke of normalcy:

Chronic illness…is omnipresent…. Facing chronic illness means moving swiftly from the cosmic concerns of life and death to the embattled mundane routine of medication compliance, coupled with the…aching thirst for normalcy—sweet, blessed, boring normalcy….

Perhaps it is normalcy, and all it may entail, that provides the seemingly most enticing goal of families with chronic illness. And yet, for all its allure, normalcy is something that perhaps because of its illusiveness becomes almost unappealing, certainly overrated…. As our lives continue, the challenges we face are certainly different from our friends and neighbor’s, but no less enriching and perhaps even more so. (Holloway, 2007, p. 244)
This review has demonstrated that parents of children with ASDs diligently work on their relationships and don’t take these relationships for granted. Schieve et al.’s (2007) research suggested that there is room for improvement in these skills and attitudes in parents of children without special health care needs. Calling on parents of children with ASDs to encourage and train others may in turn encourage, affirm, and foster and provide opportunities for them to express Social Interest.

Adler believed that finding true meaning in life depended on contribution and cooperation, two key elements of Social Interest (Adler, 1998). Many individuals in our present society are searching for meaning. Many are engaging in behaviors that are destructive to themselves, their families, and their communities because they have unrealized hopes and dreams and have not found meaning and purpose.

Perhaps families of children with ASDs may be uniquely equipped to be a resource for all others. In order to survive and grow, they have no choice but to rely on and extend contribution and cooperation. They have realized that hopes and dreams may need to be relinquished, but many have learned, as King et al. (2006) reported, that new hopes and dreams can be life-changing as well as life-giving. As Holloway (2007) inferred, they have found meaning and purpose.
References


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