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PSYCHOLOGICAL WELL-BEING IN PARENTS OF
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**PSYCHOLOGICAL WELL-BEING IN PARENTS OF CHILDREN WITH
PERVASIVE DEVELOPMENTAL DISORDERS AND ATTENTION-DEFICIT /
HYPERACTIVITY DISORDER**

By

Lisa Choy Tang

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ABSTRACT

PSYCHOLOGICAL WELL-BEING IN PARENTS OF CHILDREN WITH PERVASIVE DEVELOPMENTAL DISORDERS AND ATTENTION-DEFICIT / HYPERACTIVITY DISORDER

By

Lisa Choy Tang, M.A.

This study drew on theories of psychological well-being, stress, and coping to examine profiles of psychological well-being among parents of children with pervasive developmental disorders (PDD) as compared to parents of children with attention-deficit/hyperactivity disorder (ADHD) and of normally developing children. A total of 91 parents (38 PDD, 26 ADHD, 27 typical) were recruited from across the state of Michigan. Measures of child behavioral and emotional problems were obtained using parent and teacher reports on the *Behavioral Observation Scale for Children, 2nd Edition*. Parents also completed adapted versions of the *Brief COPE* and *Brief RCOPE* as well as questionnaires regarding services and supports accessed by their family. Psychological well-being was measured using the 9-item version of the *Ryffe Scales of Psychological Well-being* and additional measures of spiritual well-being, happiness, depression, and anxiety. Principal components analysis was used to reduce the number of variables for analysis. Although children with PDD and ADHD showed differing clinical profiles which indicated increased delays, behavioral problems, and emotional problems relative to the children represented in the typical control group, parents of children with PDD and ADHD did not differ in any aspects of psychological well-being. The PDD and ADHD groups combined showed higher levels of depression than the typical parent group, but did not differ on any other aspects of psychological well-being. Hierarchical regression

analyses indicated that child externalizing problems, attention problems, and internalizing problems were related to increased anxiety and depressive symptoms after controlling for household income. Avoidant-aggressive coping, social support, positive parent-child relationship, and household income predicted 35% of the variance in general psychological well-being. Active-positive coping, avoidant-aggressive coping, and household income accounted for 22% of the variance in parent depression scores. None of the coping or resource variables moderated the relationship between child diagnostic status and parent well-being. Active-positive coping moderated the relationship between child internalizing problems and parent depression. Substance-abuse / humor coping strategies moderated the relationship between child internalizing problems and parent anxiety. Clinical implications of findings and directions for future research are discussed.

In dedication to my family who taught me the greatest lessons in life.
To my father, Tung, whose courage, dedication and love for our family endured
through the hardest times and who will forever inspire me to appreciate
the opportunities that I have been granted.
To my mother, YukWah, who's compassion and strength
have been an example for me.
To my brother, Ricky, who I will always admire and love.

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KEY TO SYMBOLS OR ABBREVIATIONS

Δ = Delta; change

β = Standardized beta; multiple regression coefficient

ADHD = Attention-Deficit / Hyperactivity Disorder

ANCOVA = Analysis of covariance

ANOVA = Analysis of variance (univariate)

B = Unstandardized beta; multiple regression coefficient

BAI = *Beck Anxiety Inventory*

BASC-2 = *Behavior Assessment System for Children, Second Edition*

CARS-P = *Childhood Autism Rating Scale- Parent Form*

CESD = *Centers for Epidemiological Studies Depression Scale*

DD = Developmental Disability

df = *Degrees of freedom*

F = Fisher's F ratio

HLM = Hierarchical linear modeling

M = Mean

MANCOVA = Multivariate analysis of covariance

MANOVA = Multivariate analysis of variance

p = Probability

PAI = *Positive Affect Index*

PDD = Pervasive Developmental Disorder

r = Pearson product-moment correlation

R = Multiple correlation

R^2 = Multiple correlation squared

n = Number in a subsample

N = Total number in a sample

SD = Standard deviation

SE = Standard error of measurement

t = Computed value of a t test

χ^2 = Computed value of a chi-square test

Introduction

Developmental Disabilities such as Pervasive Developmental Disorders (PDD) and Attention-Deficit / Hyperactivity Disorder (ADHD) are life-long conditions that interfere with a wide array of cognitive, psychological, and behavioral functions. Each of these diagnoses presents unique and huge challenges for parents. Although parents often worry that something may be wrong with their child, the majority of parents are not prepared for a reality where something is wrong with their child. Parents of children with Developmental Disabilities are thus at increased risk for mental health problems and compromised well-being. Less talked about, however, is that raising a child with a disability can involve joys and even improved psychological well-being.

Approximately 17% of children have a developmental disability, of which pervasive developmental disorders represent 2% and are the most severely debilitating (Boyle, 2000). This study will examine how parents of children with developmental disabilities, particularly PDD and ADHD, have attempted to adjust to the unique challenges that these children present and the impact of these attempts on their own psychological well-being as parents.

Attention-Deficit / Hyperactivity Disorder occurs in approximately 3-7% of school-aged children (American Psychiatric Association, 2000). The various similarities that children with ADHD share with those with PDDs (e.g., behavior problems, similar executive functioning profiles, ambiguity in etiology, chronicity) and shared treatment modalities sought by their parents make parents of children with ADHD an ideal control group to isolate unique aspects of parenting a child with PDD that has yet to be explored in the literature.

Research on parents of children with PDD has consistently reported higher rates and severity of depressive and anxious symptoms as well as greater general psychological distress in comparison to parents of normally developing children (Bitsika & Sharpley, 2004). Although less consistent, there is also evidence that parents of children with PDDs experience higher risk for mental health problems than parents of children with other chronic disabilities (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Donovan, 1998).

Researchers have mostly approached the experience of raising a child with a PDD as tragic and thus the questions asked and the methodology employed has not allowed room for accounts of resilience or positive adaptation. This traditional deficit model has historically confined psychological research for most of the past century. However, findings from the deficit based tradition have, as a byproduct, shown that all parents do not respond to stressors in the same way. In addition to understanding the specific stressors that these parents experience, it is more crucial to identify how the varying ways that parents attempt to cope with specific stressors influence a complete array of positive and negative mental health outcomes.

Although the research literature is beginning to report accounts of resilience and positive psychological growth related to having a child with a disability, this research is predominantly qualitative and anecdotal rather than empirical. Qualitative methods offer rich accounts of parental experiences, but progress requires use of quantitative research methods that allow for generalizable and rigorous findings to develop and maintain appropriate support programs for parents.

The proposed study will incorporate current theories of psychological-wellbeing to investigate a more realistic range of experiences related to raising a child with a developmental disability (DD) using quantitative research methods. Further, parents of children with PDD versus ADHD will be compared to identify unique experiences in parenting a child with PDD. The study will explore effectiveness of various coping strategies and resources among parents across groups, then identify if there is a unique coping and resource profile for parents of children with each of the diagnoses and the impact of these differences on parental outcomes. Additionally, this study will look at moderators that have previously been neglected in research such as the parent-child relationship, religious coping, parental causal attribution for the child's disability, and the role of child-directed treatment.

The methodology proposed in this research will contribute to a more complete understanding of experiences of parents of children who have DDs. This research is also indirectly relevant to child outcomes. Parental mental health has long been identified as influencing parenting ability and has recently been identified as influencing outcomes among children with mental retardation (Orsmond, Seltzer, Krauss, & Hong, 2003). Ultimately, it is hoped that this research will inform treatment and services for parents of children with developmental disabilities as well as for their children.

Psychological and Behavioral Profiles of Developmental Disorders

Pervasive Developmental Disorders

Although the term Pervasive Developmental Disorder (PDD) includes a variety of disorders, of focus here are autism, Asperger syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS). These three disorders are also collectively

referred to as the autism spectrum disorders. Whether the disorders represent distinct disabilities or varying degrees of severity on a single autism spectrum remains a topic of debate (see Szatmari, 2000 for review). Regardless of diagnosis, PDDs are characterized by impairments in reciprocal social interaction, communication, behaviors, and interests relative to chronological and mental age (American Psychiatric Association, 2000).

Researchers from the United States Centers for Disease Control and Prevention estimate that prevalence for the Autism Spectrum Disorders is at 60 cases per 10,000 (Bertrand, Mars, Boyle, Bove, Yeargin-Allsopp, & Decoufle, 2001). There have been numerous reports world-wide of increased incidence of PDDs (see Fombonne, 2005 for review), including the 237% increase between 1987 and 1998 reported by the California Department of Developmental Services (1999) that sparked the attention of the world. Although some of the increase has been attributed to increased awareness and improved diagnostic validity, there appears to be a real increase in PDDs (California Department of Developmental Services, 1999). At present, there has not been any identified cause for this increase. The Autism Society of America estimates that between 1 to 1.5 million Americans have an autism spectrum disorder (Autism Society of America, 2005). At present, there is no scientifically proven cure for PDDs and information about the effectiveness of early intensive behavioral treatments in managing the disorders has been poorly disseminated to professionals and parents. Thus a growing number of parents are faced with a chronic condition with which they struggle to understand and cope with.

Autism is the most widely known and researched of the PDDs. Estimates of prevalence range from 5 cases per 10,000 (American Psychiatric Association, 2000) to 40 cases per 10,000 (Bertrand et al., 2001). The disorder is 3-4 times more common in

males than females (Fombonne, 2003). Onset occurs before 30 months. Asperger's disorder / syndrome and pervasive developmental disorder not otherwise specified are less common, occurring in 2.6 per 10,000 and 21 per 10,000 individuals, respectively (Fombonne, 2003).

To appreciate the impact of PDDs on parents, it is important to review the behavioral and psychological profiles of these children. Deficits associated with PDDs are highly variable across individuals. Generally, children with autism show the most severe impairments of the three disorders. Roughly 70% of individuals with autism have mental retardation (Fombonne, 2003), individuals with Asperger's disorder generally have normal to above average intelligence, and intellectual profiles for those with PDD-NOS varies widely. Note that the high comorbidity between autism and mental retardation should be interpreted with caution and is likely an overestimate due to questionable validity of IQ assessments for this population and improved treatments for these children. Impairments across social, communicative, and behavioral skills are generally more pronounced among children with comorbid mental retardation.

The hallmark deficit in PDDs is impaired social functioning. Children with PDD have impaired ability to understand, anticipate, and identify thoughts and feelings in themselves and others (Bauminger & Kasari, 1999). These skills are collectively referred to as theory of mind and are difficult for even the most intelligent individuals with a PDD. Children with PDDs have poor orientation to social gestures from others. For example, a child with autism may not respond to his name being called or his parents speaking to him. Reciprocal social interactions such as sharing in play, joint attention, and eye contact are also impaired. Parents of children with PDDs often report difficulties

connecting emotionally with their child and feeling as if their child does not need them emotionally. This sentiment is apparent in a mothers' description of her relationship with her child who has autism, "I am only important to him as one who fulfills his needs. If it were not me, then it could just as well be a total stranger" (Schreibam, 1988, p. 15).

Communication skills are also impaired. At the mild end of the spectrum, a child with PDD may have limited, if any, non-verbal communication, exhibit flat affect, show exaggerated or flat tone of voice, speak excessively, and show poor pragmatics. Children with Asperger disorder often have advanced vocabularies and speak incessantly without attending to if their conversational partner is interested or even physically present. At the more severe end, children with autism have delays in developing functional verbal language; approximately 40% of individuals with autism never achieve functional speech (Utah Department of Health, 2003).

Emotionally, children with PDDs show flattened, excessive, or contextually inappropriate affect. A child with a PDD may become extremely upset in response to normally minor disappointments. Disturbances in daily routines or corrections of mistakes by a well-meaning teacher may result in biting, hitting, and screaming. They may also laugh hysterically when someone trips. In addition to emotional outbursts, a child with autism may lack appropriate safety behaviors and wander off in public places (i.e., shopping malls, grocery stores, parks), thus limiting parents from going to these places.

Self-stimulatory and stereotypic behaviors are common. These behaviors may take the form of echolalia, rocking, whirling, and even self injurious behaviors such as head banging. More impaired children may spend hours engaging in any one of these

behaviors. Children with PDDs also tend to have focused interests that vary in quality. For example, hours may be spent spinning objects, studying door hinges, or learning about trains.

Executive functioning problems in the areas of cognitive flexibility, abstraction, attention, impulsivity, and ability to plan ahead are also common. Children with PDDs have difficulty adjusting to change and tend to perseverate in their thoughts and behaviors. Some children with PDDs are hypersensitive to sounds, textures, or tastes, thereby limiting the clothes they will wear, foods they will eat, and places they will go. Under-sensitivity to physical pain and lack of caution in physically dangerous situations are also common.

Attention-Deficit / Hyperactivity Disorder

Attention-Deficit / Hyperactivity Disorder (ADHD) is another developmental disorder of unknown etiology. Although symptoms can be treated pharmacologically, there is no cure for ADHD and there is increasing evidence that the disorder is a chronic one. Parents of children with ADHD have also been identified as experiencing increased distress relative to parents of typically developing children. However, sources of this distress, coping strategies, and predictors of psychological well-being may be different than among parents of children with PDDs.

The disorder is characterized by age inappropriate inattention, hyperactivity, and impulsivity (American Psychiatric Association, 2000). Attention-deficit / hyperactivity disorder is more common in males than females, occurring at a ratio of 2:1 to 9:1 (American Psychiatric Association, 2000). Children with ADHD have difficulty

sustaining attention, are easily distracted by irrelevant stimuli, and have decreased attention capacity. Poor regulation of motor behaviors and cognitive and behavioral impulsivity are also symptoms of ADHD. Many children with ADHD have comorbid oppositional defiant disorder. These children are defiant with adults, refuse to comply with rules, can be easily annoyed or angered by others, and can be aggressive (American Psychiatric Association, 2000).

Children with ADHD and PDD have overlapping deficits in several domains of executive functioning, including inhibition, planning, and cognitive flexibility (Geurts, Verte, Oosterlaan, Roeyers, & Sergeant, 2004; Goldberg, Mostofsky, Cutting, Malone, Astor, Denckla, & Landa, 2005). Intellectual functioning is generally in the below average range, however functioning is complicated by difficulties applying their intellect in school and to their day-to-day lives (Barkley, 1997).

Children with ADHD tend to have social functioning deficits due to impulsivity and inattention to social cues. For example, they may speak out of turn, be disruptive in class, blurt out embarrassing comments about themselves or others, and have difficulty following rules. Unlike children with PDDs, these children do not lack fundamental sociocognitive abilities such as theory of mind (Perner, Kain, & Barchfeld, 2002). Rather, impairments in social functioning appear to be secondary to symptoms of ADHD.

Parenting Stress

Research on stress and coping among parents of children with PDDs began in the 1970s and has been limited by methodological problems. One major problem with the research has been the operationalizing of stress. Thus, prior to beginning discussion on

stress among parents of children with DDs, it is critical to first have a clear understanding of what stress is. Stress has been a well-researched phenomenon and continues to have strong theoretical relevance to psychopathology. Although commonly used in the psychological literature, the definition of stress is too often vague.

Stress has most commonly been defined as being either a stimulus or response. Dual use of the term confuses the understanding of underlying processes. For example, the *Parenting Stress Index* (Abidin, 1995) is a common measure of both child-related stressor stimuli (Nachshen & Minnes, 2005) and of stress response (Harrison & Sofronoff, 2002; Tomanik, Harris, & Hawkins, 2004). Another problem with the index is that the parenting stress model the index is based on assumes that difficult child characteristics such as poor adaptability, mood problems, behavior problems, and demandingness directly produce and represent parenting stress responses (Abidin, 1995). Current understanding of parenting stress suggests that Abidin's (1995) model is too simplistic to derive useful interventions to support parents aside from pointing the blame on the child's symptoms. Additionally, it artificially increases the relationships between child characteristics and parent outcomes in research.

As argued by Lazarus and Folkman (1984), mixed stimulus-response definitions of stress have limited utility due to their mutual dependence. For example, whether a stimulus is considered to be a stressor depends on the response to that stimulus. However, responses to various stressors are individually variable due to differences such as coping, appraisal, and resources. Similarly, a response definition of stress cannot be determined without first identifying the antecedent stressor.

In an effort to make a clear distinction between these two categories of definitions, stress stimuli will herein be referred to as *stressors*. Stressors are internal drives and external events that exert demands on the person (Lazarus & Folkman, 1984). Stress as a response will be referred to using the general term *distress* as well as the more specific identifiers of depression and anxiety. Having a child with a DD represents a potentially chronic stressor involving continuous demands as well as a series of acute demands across the child's development.

One popular method of determining the presence of a stressor and measuring its severity is via psychophysiological measures. This method was introduced by Hans Selye's (1936) General Adaptation Syndrome, which is a set of generalized physiological reactions and processes initiated in response to demands. These responses have been measured via secretions of the hormone cortisol. Reliance on cortisol levels to measure stress is problematic because it is not a precise measure of either stressors or a stress response. For example, cortisol levels naturally vary throughout the day and are responsive to various events such as sleep cycles, eating, and emotional distress. Without investigating the activating event, physiological arousal in and of itself cannot be inferred to represent a stress response. Additionally, stress and distress are broad concepts that represent specific emotional and physical characteristics, such as depression, anxiety, and tension.

In order to inform treatment efforts and research on adaptational processes, specific identifiers of psychopathology need to be used rather than a broad distress concept. This study will rely on parent self reports of specific psychological symptoms of depression and anxiety. Direct responses to questions about emotional well-being will

bypass the inference that needs to be made from psychophysiological measures of distress that are impacted by non-emotionally related variables. Additionally, outcomes in this study will be investigated in the context of a theoretically driven model where child and family characteristics influence a variety of processes leading to adaptation.

Psychological Well-being among Parents of Children with Developmental Disabilities

The past three decades of research on parental responses to having a child with a disability has focused on a loss model. This historically simple and truncated understanding of the human experience as only being negative severely limits our ability to help people achieve well-being (Seligman & Csikszentmihalyi, 2000). Identification of strategies and resources that have helped parents adapt positively to having a child with a disability allows for empirically driven interventions to help support parents experiencing difficulty adjusting to raising a child with a disability. Recently, research has begun to focus on positive experiences of having a child with a disability. However this research is limited in that it has been mostly qualitative and anecdotal. Due to these various limitations, this review will draw upon empirical literature as well as personal accounts reported in books written by parents of children with disabilities and reported in the research literature in order to more completely review experiences of parents of children with Developmental Disabilities.

Models of Psychological Well-being

The structure of psychological well-being has been a topic of debate for the past half of the century (see Kafka & Kozma, 2002 for review). There is general agreement that psychological wellbeing has both affective and cognitive components. Affective

wellbeing refers to subjective feelings of various emotions, including sadness, anxiety, and happiness. Traditionally, positive and negative affect have been thought of as lying on a single continuum. Not only has research shown that positive and negative emotions co-occur, positive emotions have been found to serve as protective factors against chronic stressors (see Folkman & Moskowitz, 2000 for review). Measurement of positive and negative affect as separate constructs is thus important. The cognitive component of wellbeing involves evaluation of satisfaction with various aspects of one's life.

Ryff (1989) proposes a separate multidimensional model of well-being that draws upon humanistic theory and integrates mental health, clinical, and developmental approaches to wellbeing comprised by key life attitudes. The *Ryff Scales of Psychological Well-being* (Ryff & Keyes, 1995) is the product of Ryff's (1989) 6-factor construct of well-being consisting of self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth. Confirmatory factor analysis showed the 6 factor model to be the best fit with data collected from a large nationally representative sample of adults. These factors also joined together to form a single higher-order factor of well-being, although this single higher-order factor loading has not been found in other research (Kafka & Kozma, 2002). Van Dierendonck (2004) proposed that spiritual well-being is an additional key component of psychological well-being.

Overall, there is limited coherence in theories of the structure of psychological well-being. Theoretical and empirical disagreements may stem from differences in values rather than set human functions of well-being. Definitions of well-being are likely also to be ecologically dependent. Thus, values of what is important likely differ from

system to system (see Bronfenbrenner's Ecological Systems Model, 1979). Definitions of well-being likely differ by culture, community, and individual. To establish relevance to this research, information was drawn from review of the existing literature and this researcher's own clinical, research, and personal experiences with parents of children with PDDs. Based upon this analysis, affect, life-satisfaction, environmental mastery, purpose in life, personal growth, spirituality, and social functioning seem to be aspects of psychological well-being most relevant to parents of children with PDDs. The relevance of these various components is further established in the following review of outcomes among parents of children with DDs.

Distress and Grief

Children represent the future of their parents' lives and to learn that something is wrong with one's child introduces a profound loss and feeling of uncertainty about one's future. Parents of children with chronic disabilities are often reported to experience a loss of the dream of having a perfect child (Naseef, 1991, 2001; Whelan & Hudson, 1987). Most expectant parents look forward to having a perfect child who will be successful in all the areas that they wished for themselves but did not achieve and who will consummate their marriage. Concerns that something might be wrong with their child loom in the background, but are overshadowed by preparations for the best hopes and dreams. When parents learn that something is wrong, these images of perfection "die" and are matched with a grief that pervades every layer of their being. When something is wrong with the child, there is not only concern for the child's future, but also a seemed loss of the possibility that the parent could ever be the perfect parent that he or she so hoped to become. Images of the perfect family are temporarily, and even

forever, crushed and the parent is faced with a daunting challenge that he or she is likely unprepared to cope with. Life, hopes, and dreams must be reconstructed.

The complex emotions experienced by parents of children with chronic disabilities are often compared to Elizabeth Kubler-Ross's (1969) grief cycle. Although progression through these emotions is a natural process, sometimes parents become stuck in stages that either lead to maladaptation or that in and of themselves represent maladaptation. Denial occurs when parents reject that anything is wrong or that the diagnosis is absolute; this period could last from a moment to never accepting the diagnosis. Common emotions reported among parents of children with developmental disabilities are anxiety, depression, anger, shame, loss, and hopelessness. These painful emotions may be experienced in any combination over time.

Research has widely reported that parents of children with Developmental Disabilities experience increased mental health problems in comparison to parents of typically developing children (Bitsika & Sharpley, 2004; Dyson, 1997; Podolski & Nigg, 2001). In a sample of 107 parents of children with an Autism Spectrum Disorder residing in the Gold Coast areas of Australia, Bitsika and Sharpley (2004) found staggeringly high rates of mental health problems in comparison to population base rates within the country. Particularly, they found that 70.5% of the parents reported experiencing between High to Very High levels of daily stress, 67.1% scored in the High to Severe ranges on a self-report anxiety scale, and 39% scored in the High to Severe ranges on a self-report depression scale. The numbers varied from a similar study of parents of children with autism from another area of Australia and, although the authors did not specifically address sources of this variance, they speculate that differences related to unequal access

to services. Although the study had a number of methodological weaknesses, including lack of controls for important sources of variance in mental health (i.e., parent life stressors, socioeconomic status), the numbers reported are disturbingly high and call attention to the need for services for parents of children with PDDs.

Research has frequently reported that parents of children with autism are at greater risk of becoming socially isolated in comparison to parents of children with other disabilities (Kazak & Wilcox, 1984; Rodrigue, Morgan, & Geffken, 1990; Sivberg, 2002; Trute & Hauch, 1988). Shame related to their child's socially inappropriate behaviors combined with the burden of dealing with a society that is intolerant of their child's disability and that blames parents for the child's offensive behaviors could result in social isolation (Gray, 2002a; Jones & Passey, 2005).

Positive Adaptation

Despite the great challenges that having a child with a developmental disability presents, many parents do not experience mental health problems and even rise above the experience, reporting improved quality of life, improved purpose in life, and that their children have made them better people. In an analysis of publication trends between the 1970s and 1990s Helff and Glidden (1998) found that although emphasis on negative outcomes among parents of children with disabilities has decreased, research on positive adaptation has remained sparse. Most often, psychological wellbeing or positive adaptation is studied by looking at the absence of psychopathology. Neglect of positive aspects of wellbeing not only limits the understanding of health, but also the ability for researchers and practitioners to identify and build upon strengths among parents of children with disabilities.

The majority of the literature on positive accounts among parents of children with disabilities has been narrative. Robert Naseef (1991, 2001), a psychologist and father of a non-verbal adolescent with Autism writes about hope and positive growth derived from personal, clinical, and research experiences. He writes to his son, “I have tried so hard to change you, and in the end it was you who changed me. Instead of becoming the son I wanted you to be you made me become the man I needed to be” (Naseef, 2005).

Although narrative accounts provide a wealth of information about individual experiences, it is now time to explore these positive experiences empirically so that robust support for predictors of resilience and positive adjustment can be established.

The sparse descriptive and empirical research on parents of children with various DDs has suggested that many of these parents do experience positive adaptation. Based on a two phase study where interview and survey data were collected from 95 parents of children with a variety of disabilities (i.e., Autism, ADHD, Down Syndrome) about how their lives have changed as a result of their child, Scorgie and Sobsey (2000) identified several themes of positive adjustment. Specifically, parents reported that they were more tolerant of diversity in others, experienced personal growth, and changes in their philosophical and spiritual values. In the only research to examine positive affect among parents of children with disabilities, Turnbull, Behr, and Tollefson (1986) interviewed 18 parents of children with a disability and identified reports of increased happiness, greater love, and strengthened religious faith (as cited in Summers, Behr, & Turnbull, 1989).

Empirical research on wellbeing among parents of children with DDs has been inconsistent and at times at odds with narrative accounts by parents. Sivberg (2002) compared parents of children with autism and without autism on the *Purpose in Life Test*

(Frankl, 1958) and found that not only did the autism group experience *less* purpose in life than the non-autism parent control group, the autism group scored in the low purpose in life range. Sivberg (2002) also found that parents of children with autism scored lower on a measure of perceived meaning in life, manageability of problems, and comprehensibility of one's environment. In another empirical study, Nachshen and Minnes (2005) found that parents of children with DDs (including DS and Autism) experienced less caregiver well-being on the *Family Member Well-being Scale* (McCubbin & Patterson, 1982) than parents of typically developing children.

In contrast, Seltzer, Greenberg, and Floyd (2004) found no between group differences in levels of wellbeing (Environmental Mastery and Self-Acceptance scales of the *Ryff Scales of Psychological Wellbeing*; Ryff, 1995) between parents of children with DDs compared to typically developing children. Because Seltzer et al. (2004) did not report diagnostic characteristics of any of the children, it is unclear if and to what degree results are representative of parents of children with PDDs or ADHD. Tunali and Power (2002) found no difference in self-reported life satisfaction from interviews with mothers of children with autism compared to mothers of normally developing children.

Differences in measurement and participant inclusion criteria likely contributed to these varying findings among empirical studies. Failure to survey areas of wellbeing identified in descriptive and narrative reports such as personal growth, spiritual growth, and increased social tolerance suggests that these researchers excluded relevant components of positive wellbeing in their designs and thus cannot make adequate conclusions about the state of wellbeing in general among parents of children with DDs.

Nachshen and Minnes' (2005) study presents with another common problem with the literature on positive outcomes in general- wellbeing was operationalized as being on the same continuum as maladaptation. The *Family Member Well-being Scale* (McCubbin & Patterson, 1982) that Nachshen and Minnes (2005) used to measure well-being aggregated items tapping health, tension, energy, cheerfulness, fear, anger, sadness, and general concern to produce a general wellbeing score. As described earlier, positive and negative affect are omnibus constructs that can co-occur. Additional support for an omnibus model of affect is found in Scorgie and Sobsey's (2000) findings that parents emphasized the importance of balancing positive transformations with negative challenges they experienced as a result of parenting a child with a disability. An additional importance of studying positive and negative affect separately is that it is unclear from current research if predictors of these constructs are the same (see Hastings & Taunt, 2002, for review). Thus, in addition to considering a complete picture of mental health that includes positive adaptation, these experiences must be measured as separate from negative mental health outcomes to better understand correlates of parental outcomes. There has been no empirical research on the impact of children with PDDs on positive affect among parents.

In sum, narrative accounts of parents of children with autism and descriptive research on parents of children with DDs consistently report positive life changes related to having a child with a DD. These positive accounts include improved social relations, increased purpose in life, positive changes in spiritual and philosophical outlook, and personal growth. Descriptive research on parents of children with disabilities in general has identified accounts of increased happiness, greater love, and strengthened religious

faith. Few studies have looked at positive experiences among parents of children with PDDs and the empirical research that has been done report inconsistent findings regarding the positive impact of these children on their parents' well-being. Problematic operationalizing of well-being, varying inclusion criteria, and failure to incorporate relevant variables may account for the varying findings. At present, it is unclear if having a child with a PDD is related to compromised well-being in comparison to having a normally developing child. Inclusion of a normal control group would inform this question.

Unique Experiences of Distress among Parents of Children with PDD

Some studies have compared parents of children with PDDs with parents of children with other disabilities in order to identify unique experiences of raising a child with a PDD. By including children with separate constellations of overlapping symptoms, the researcher can statistically and/or methodologically control for confounding factors to identify correlates of core symptoms of interest by controlling for variance associated with the confounding factors.

Donovan (1998) compared mother of adolescents with autism and mothers of adolescents who had mental retardation and found that parents of adolescents with autism reported greater family stress. Addebuto, Seltzer, Shattuck, Krauss, Orsmond, and Murphy (2004) measured group differences in depressive symptoms, pessimism, and closeness of the mother-child relationship among 174 mothers of children with a PDD (Autism, Asperger Syndrome, and PDD-NOS), 22 mothers of children with Fragile X, and 39 mothers of children with Down syndrome. Results indicated that the PDD group of mothers reported higher levels of pessimism about their child's future, more distant

relationships with their child, and more depressive symptoms than mothers in the Down syndrome group. Mothers of children with Fragile X reported comparable levels of depressive symptoms and pessimism about their child's future to the PDD group. Additionally, higher portions of mothers in the PDD group (33.3%) reported experiencing depressive symptoms in the clinical range than the DS group (10.3%) and the Fragile X group (18.2%).

Neither Donovan (1998) nor Abbeduto et al. (2004) precisely controlled for adaptive functioning or behavior problems. Abbeduto et al. (2004) attempted to control for child behavior problems using the *Autism Behavior Checklist* (Krug, Arick, & Almond, 1980), a screener instrument for Autism with five subscales. However, rather than controlling for behavior problems, Abbeduto et al. (2004) effectively controlled for PDD diagnosis and may therefore have underestimated group differences in outcomes. Also, rather than incrementally add predictors to their hierarchical regression analysis, Abbeduto et al. (2004) added several independent variables at a time. It is thus unclear if and how much of the group differences in outcomes they found could be attributed to behavioral and/or adaptive functioning deficits among these groups of children.

Mothers of children with Down Syndrome are most often used as a comparison group to methodologically control for low intellectual ability, which is related to parental burden and distress via adaptive functioning deficits associated with intellectual impairment (White & Hastings, 2004). However there are important differences in these two conditions that limit what research using only Down syndrome control groups can tell us about experiences specific to having a child with a PDD. Unlike PDDs, which have ambiguous etiology, Down syndrome is a chromosomal disorder that clearly cannot

be cured. Ambiguous events have been identified in the coping literature as being the most difficult to adjust to (Taylor, 2006). Hope for a cure is also prevalent among parents of children with PDDs, which can potentially influence outcomes. Additionally, behavioral, intellectual, and social skill profiles are very different between these two diagnostic groups. Whereas children with PDDs vary widely in intellectual ability, intellectual functioning among children with Down syndrome is consistently below average. Behaviorally, children with PDDs often have behavior problems; children with Down syndrome are typically experienced as friendly with few behavior problems. In fact, the Abbeduto et al. (2004) study's measure of behavioral symptoms showed lower variance in *Autism Behavior Checklist* scores in the DS group ($\sigma = 180.9$) than the PDD group ($\sigma = 657.4$). As will be discussed later, behavior problems of the child are a major source of distress for parents and thus it is important to also take these into account in the research design aimed at understanding unique experiences of distress among parents of children with PDDs by using a comparison group with comparable variability in behavior problems.

Controlling for behavior problems and limitations in intellectual functioning are both important steps in isolating the impact of a core feature in PDDs on parenting that has yet to be explored- social cognitive dysfunction. Controlling for intellectual functioning using standardized assessments is not relevant to parenting a child with PDDs. Standardized assessments of intellectual functioning such as the Wechsler Intelligence Scales or the Stanford-Binet scales frequently underestimate intellectual ability among those with PDDs due to difficulties getting the child to cooperate and attend to the testing procedures. The relationship between parent outcomes and their child's IQ would most

likely be mediated by the functional impairment that is inherent with low IQ. Rather than an intangible IQ value of questionable validity for children with PDDs, parents are most likely to be impacted by behavioral indicators of their child's likelihood to function well in the future. Verbal language ability is the most reliable predictor of children with autism's outcomes (Szatmari, Bryson, Boyle, Streiner, & Duku, 2003). In fact, research has found that for children with autism or PDD-NOS, ability to communicate is highly predictive of IQ (Bölte & Poustka, 2002). Considering these various factors, functional communication abilities will be controlled for in this study rather than IQ.

Rather than include a Down syndrome comparison group that is radically different from the PDD group, it is suggested here that language functioning be statistically controlled for and that ADHD be used as a comparison group. Attention Deficit Hyperactivity Disorder is a good comparison group that has yet to be used in research on parents of children with PDDs. As described earlier, children with ADHD tend to have comorbid behavior problems, social skills deficits, and impairments in executive functioning. These characteristics overlap with children with PDDs (Goldberg et al., 2005). However, the severity of social functioning deficits is generally not considered to be at a level that interferes with parental closeness to the child, as is the case with the deficits found among those with PDDs (Nixon, 2001).

There has been no research comparing parents of children with PDDs to those of children with ADHD. However Holroyd and McArthur's (1976) finding that mothers of children with autism ($n = 22$) experienced more family integration problems compared to mothers of children with general neuropsychiatric conditions may inform comparisons.

Parents of children with autism may experience more distress than parents of children with ADHD.

Unique Experiences of Positive Adaptation among Parents of Children with PDD

Only two studies were found that compared parental wellbeing among parents of children with DDs in comparison to other diagnoses using positive measures. In the only study that separately included parents of individuals with autism, Greenberg, Seltzer, Krauss, Chou, and Hong (2004) found no between group differences on a composite measure of wellbeing of three scales of the *Ryff Scales of Psychological Wellbeing* (Personal Growth, Self-Acceptance, and Purpose in Life) among the parents of adults with autism, Down syndrome, and schizophrenia groups. Seltzer, Greenberg, and Floyd (2004) also failed to find any between group differences in the Environmental Mastery or Self-Acceptance scales of the *Ryff Scales of Psychological Well-being* (Ryff & Keyes, 1995) among parents of children with DDs compared to the parents of children with a severe mental health problem. Both studies suggest that having a child with a PDD versus another disability may not differentially impact wellbeing. Due to lack of inclusion of a normal control group, it is unclear if having a child with a disability negatively or positively impacts positive wellbeing. However, based on the previously reviewed studies suggesting that there is some impact on wellbeing, these studies suggest that this impact occurs equally across parents of children with various psychiatric diagnoses. However, before making this conclusion it is crucial to include appropriate control groups and appropriate measures that are informed by clinical and narrative accounts from parents of children with PDDs.

In sum, having a child with a DD, especially with a PDD, is a potential risk factor that significantly increases risk for depression and anxiety. Although sometimes at odds, research and parental narrative accounts suggest that many parents experience positive life changes as a result of raising the child with the DD as well. Due to overly general and limited grouping of parents in previous research, it remains unclear what the unique positive and negative outcomes are among parents of children with PDDs. There is a dearth of research looking at positive adaptation and the methodology used in the research completed to date has left the question of how parents of children with PDD compare in the area of positive adaptation to other parents. The research that has directly looked at positive adaptation is especially lacking in quality and quantity and has provided no useful information on positive adaptation of parents of children with PDDs in comparison to other disabilities. Several remedies are proposed for this research: 1) inclusion of parents of children with ADHD and parents of typically developing children as comparison groups 2) include a broad assessment of psychological wellbeing incorporating affect, life satisfaction, and attitudinal components relevant to parenting a child with a disability, and 3) use of empirical measures to assess outcomes.

Framework for Understanding the Stress and Coping Process

Research has often used the ABCX model and variants of it as an organizing framework to understand family adjustment to raising children with disabilities. Originally proposed by Hill (1949), the letter A represents the stressor stimulus (the child with a DD), B represents the family's resources to meet the demands of the stressor, C represents the meaning that is prescribed to the stressor, and X represents the resulting

crisis outcome. The model posits that X is influenced by A, B, and C factors, with B and C factors partially mediating the relationship between A and X. McCubbin and Patterson (1983) revised Hill's model to incorporate a pile-up of stressors and readjustment of resources and perceptions over time. According to McCubbin and Patterson's Double ABCX model, family reactions to the stressor of the child having a disability can lead to an upward spiral of growth (a concept termed "bonadaption") if resources adequately meet the demands of the stressor. A downward spiral of crisis and dysfunction (maladaption) would result if the resource factors do not meet the demands of the stressor. The ABCX framework has guided research on parents and families of children with Autism, Asperger Syndrome, Learning Disabilities, and DDs in general (Nachshen & Minnes, 2005; Pakenham, Samios, & Sofronoff, 2005). Although derived from the family systems literature, the model can be applied to understand individual experiences within the family.

As reflected in the varying methods used to operationalize the components of the ABCX models in research, the model is too general to consistently guide research paradigms. The resource factor, for example, has been measured using social support, coping styles, personality, characteristics, employment status, and socio-economic status (see Konstantareas, 1991 for examples). Also, distinguishing between C and A factors has been confused due to reliance on parent reports of both A and C factors and due to overlapping constructs being measured for A and C. Even in Pakenham et al.'s (2005) design where A (obtained via maternal ratings on a behavioral rating scale incorporating severity and frequency of the child's behavior problems) and C (obtained via maternal ratings on a separate measure of perceived stress related to behavior problems) appeared

to be theoretically separate, the C factor did not obtain significance in predicting maternal adjustment after covarying the A factor due to A and C being moderately correlated. This study supports that A and C need to be derived from different sources and/or constructs within these factors need to be conceptually distinct. McCubbin and Patterson's (1983) conceptualization of outcomes as being either bonadaptation *or* maladaptation has also been shown in research to be inaccurate. Recall research reviewed supporting an omnibus model of psychological well-being. Lastly, the idea of having a child with a disability being representative of a crisis situation is a biased perspective on the parenting experience.

Perry (2005) proposes an alternate model that addresses some of the various critiques of the traditional ABCX frameworks. His model separates stressors into child-related and other life stressors. Resources (individual and family system) and supports (informal and formal) jointly moderate outcomes, which are conceptualized as either positive or negative. Although Perry's (2005) model improves on the traditional ABCX models in that it is more specific, the model drops the parental perceptions component. Research on parents of children with disabilities has found that parent appraisals and perceptions impact their well-being (Hassall & Rose, 2005). Like the ABCX models, Perry's (2005) model also does not incorporate current evidence suggesting an omnibus model of psychological wellbeing.

The guiding framework proposed herein draws upon the ABCX legacy and Perry's (2005) model. Child and family characteristics are met with various internal coping and external resource factors to influence varying aspects of psychological well-being. Parent perceptions play a role in the framework in that they contribute to coping

and resource factors. Before describing the specific components of each factor in the framework, existing literature on the varying relationships between child characteristics, family characteristics, resources, coping, and outcomes are reviewed in the following sections.

Child Characteristics- Sources of Distress when Raising a Child with a DD

Having a child with a DD introduces chronic challenges for those charged with their care. Research has found that a child with a DD introduces both chronic challenges and developmental period-specific challenges across the lifespan (Gray, 2002b; Wikler, Wasow, & Hatfield, 1981). Wikler et al. (1981) reported that some parents experience chronic sorrow. Parents have an internal template of what 'normal' children are and what a typical parenting experience should be like. Whenever experiences with their own child with a DD depart from this template (e.g., first words, choosing a lunchbox for the first day of school, birthdays, graduations, senior prom), the cycle of loss is retriggered in parents by disappointment (Wikler et al., 1981).

Having a child with a DD introduces increased burden of care in comparison to parenting a typically developing child (Barkley, Anastopoulos, Guevremont, & Fletcher, 1992; Barnett & Boyce, 1995; Rodrigue et al., 1990; Rodrigue, Morgan, & Geffken, 1992). Various stressors related to the child and related to societal attitudes and behaviors in response to the child are present. Gray (2002a) interviewed parents of children with autism and found that parents frequently reported being victims of enacted stigma. Specifically, they reported being yelled at for being bad parents, experienced hostile staring from others, and being avoided socially.

Among child characteristics, behavior problems have been consistently identified as the strongest source of distress for parents of children with DDs. Baker, Blacher, Crnic, and Edelbrock (2002) found that child internalizing and externalizing behavior problems were stronger predictors of child-related parent distress than mental delay and accounted for statistically large portions of variance in parent distress independent of mental delay. Tomanik, Harris, and Hawkins (2004) found that child hyperactivity, noncompliance, and irritability were positively related to distress among mothers of children with autism. Pakenham et al. (2005) found small to moderate partial correlations between behavior problems among children with Asperger syndrome and maternal social adjustment and depression after controlling for income, maternal age, and gender of the child such that more severe behavior problems predicted poorer outcomes. In a sample of parents of children with and without DDs, Nachshen and Minnes (2005) found a large negative correlation between child behavior problems and parent well-being (combined positive and negative affect). One study (Jones & Passey, 2005) failed to find an association between behavior problems and parent distress, but this was likely due to their inadequate measuring of behavior problems as based on frequency rather than a combined frequency and severity rating. Externalizing behavior problems have also been linked to parenting distress among parents of children with only ADHD (Podolski & Nigg, 2001).

Over time, the behavior problems of the child represent chronic sources of distress. In a descriptive longitudinal study, Gray (2002b) found that families of children with autism who had externalizing behavior problems experienced higher levels of distress and social isolation over time than those of children who were not

aggressive/violent. In a longitudinal study of mothers of adults with mental retardation, internalizing and asocial behavior problems of their child positively predicted maternal depression, burden, and pessimism (Orsmond et al., 2003). The severity of the impact of externalizing behavior on parents is portrayed in the following quote by a father about his daughter with autism:

You can't exaggerate [the impact]. Friends of [my wife] just burst into tears at times ... when she just starts doing something or attacks [my wife]. It's just horrifying. It's like a very nasty accident, an assault. If someone assaults you, it traumatizes you. If someone assaults you every day, I'm not sure what it does to you. But we get attacked, one way or another, every day. (Gray, 2002b, p. 220)

Less researched is the role of functional communication in predicting parenting distress. In a descriptive study of parents of children with autism in the Philippines, Liwag (1989) reported that the child's lack of speech was among the top sources of distress for parents. Naseef (2001) writes about difficulties he experiences as a parent of a non-verbal child with autism. Although there is no empirical research on the relationship between functional communication and parent distress, a child's failure to communicate with his / her parent likely interferes with parenting gratification and contributes to concerns about the child's ability to function independently in the future, which is an identified source of anxiety for parents (Liwag, 1989). Failure to achieve verbal language is a clear sign of compromised outcome for the child in the future.

Thus, research suggests that children with DDs introduce increased burden of care for parents due mostly to behavior problems and lack of functional communication. The

behaviors of the child with a DD lead to felt and enacted stigma against parents, who may as a result become socially ostracized. Longitudinal research suggests the importance of controlling for age of the child with a DD because of the additional impact of a pile-up of stressful interactions associated with having a child with behavior problems.

Family Characteristics

Socio-demographic variables are often controlled for in social sciences research due to known correlations with mental health outcomes. Family income and parent education influence child and parent outcomes due to their impact on available resources. In a study of 252 parents of children with chronic mental or physical disabilities, socio-economic status was found to predict maternal mood (Williams, Williams, Graff, Hanson, Stanton, Hafeman, Liebergen, Lueunberg, Setter, Ridder, Curry, Barnard, & Sanders, 2002). Controlling for number of other children in the household is also important due to increases in burden of care related to having more children. Similarly, whether or not the other children in the household have a disability also should be considered.

Moderators of Psychological Well-being in Parents of Children with DDs

Although sometimes considered to be one and the same, coping and resources are distinguished here for practical intervention reasons. The concept of coping will be discussed in more detail, but the definition used here involves the cognitive and behavioral efforts within an individual used to manage emotional and structural demands of a stressor event. Resources are defined here as external sources of formal and informal support available to the individual that are sought in order to manage emotional and structural demands presented by stressors. Using these definitions, the findings of this

research can be clearly translated into either individual-level or community-level interventions.

Coping. Prior to describing the coping literature related to DDs, it is important to first understand how coping is conceptualized. The literature is fraught with disagreements and contradictions about the definition of coping, how to conceptualize it within the person and environment, how to categorize it, how to measure it, and how to evaluate it. Here I will attempt to aggregate this literature in terms of its relevance to parental coping in response to having a child with a chronic mental disability.

Lazarus and Folkman (1984) define coping as a dynamic interchange between the person and the stressor. Coping is “constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141).

The stress and coping process has been among the most avidly researched areas of psychology. The hope has been that this research will be pivotal in developing prevention and treatment programs for those at risk for mental health problems. Proportionally, however, the quantity of this research has not been matched by its quality, resulting in the now widespread criticism of the literature (Lazarus, 2000; Parker & Endler, 1996). “Decades of concentrated research have yielded relatively little of either clinical or theoretical value” (Somerfield & McCrae, 2000, p. 620).

Two main approaches to understanding how people cope with situations have arisen from the literature: 1) the intra-individual approach and 2) the inter-individual approach. Early research on coping emphasized an intra-individual, or contextual, approach to the concept of coping. This approach has been the most popular in the

literature and embodies the idea that people have a repertoire of coping strategies from which they select the best strategy to combat the demands of specific stressors. Thus, this idea suggests that there is a commonality in coping responses among people facing the same stressors. Additionally, coping strategies are thought to adapt to the demands of the stressor and are thus involved in a dynamic process between the person and the stressor (Lazarus & Folkman, 1984). An alternative approach that has risen out of trait theories of personality is the inter-individual approach, sometimes referred to as the dispositional approach.

Most contemporary theorists recognize the complementary strengths of both the dispositional and contextual approaches. Person and situational factors are likely to play a role in normal daily stressors that people experience. Parker and Endler (1996), suggest that “life-threatening or extreme situations typically permit only a narrow range of possible coping responses” (p. 10). Having a child with a chronic disability may qualify as an extreme situation whereby situation-specific coping is most relevant. Thus, it is important to separately examine the coping strategies employed by parents of children with PDDs, ADHD, and no DD. Moreover, the unique coping profiles among parents from each diagnostic group may account for the differing outcomes reviewed earlier among parents of children with DDs and between parents of children with DDs versus no disability. This research will attempt to identify shared coping strategies among parents of children with DDs as well as unique strategies used by parents of children with PDDs. Additionally, this research will examine if the same relationships between coping strategies and components of parent well-being occur across all parent groups or if types of coping are differentially effective across different parent groups.

Organization of Coping. Early coping research organized coping strategies into styles based on the focus of action: emotion-focused and problem-focused. Problem-focused coping, also known as active coping, involves strategies focused directly on solving or reducing the problem at hand. Examples of problem focused coping include parents seeking out resources to treat problems associated with their child's disability or working with the school board to obtain services for their child. Emotion-focused coping describes a method of coping where the focus of action is on the management of emotions associated with the problem. An overlapping dichotomy with emotion-focused coping is active versus avoidant coping. Active coping is essentially the same as problem-focused coping, however emotion-focused coping can be active or avoidant. Avoidant coping is when a person avoids, withdraws from, or tries to escape from the stressor situation. Blaming others or oneself for the child's disability, retreating into fantasies that the child will be cured, and substance abuse are examples of emotion-focused avoidant coping. Examples of active emotion-focused coping would be when parents practice relaxation techniques to manage distress associated with their child or when parents seek emotional support from friends and family to release feelings of distress associated with having a child with a chronic disability.

Although useful at a theoretical level, reliance on such broad categories such as coping styles limits the clinical utility of stress and coping research (Zeidner & Saklofske, 1996). Reliance on broad categories has likely contributed to the small and disappointing effect sizes in coping research (see Zeidner & Saklofske, 1996 for review). Each coping style is comprised of various cognitive and behavioral strategies describing what people do to combat stressors. A particular coping style may include strategies that are

effectively different from one another, thereby resulting in misleading findings in research. For example, emotion focused coping could involve positive reinterpretation or denial, each of which could result in very different outcomes. The focus of evaluation must be on more specific behavioral and cognitive strategies used by people in response to stressors.

Measuring Coping. Measurement of coping has faced the numerous difficulties described thus far: reliance on broad coping styles versus specific strategies, inter-individual versus intra-individual scales, and tapping theoretically relevant constructs. A popular measure of coping styles is the *Ways of Coping Scale* (WAYS; Folkman & Lazarus, 1980, 1985). The most recent edition of the measure consists of 50 thoughts or behaviors directed at managing stressful events. The items were designed to tap either problem-focused or emotion-focused coping, although more than 2 factors have been extracted using factor analytic techniques. Current use of the measure relies on the 8 empirically derived scales by Folkman and Lazarus (1988): Confrontive Coping, Distancing, Self-controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem-solving, and Positive Reappraisal. The WAYS is considered to be a measure of dispositional coping because it asks respondents to report how they generally cope with stressful situations.

The most salient critique of the WAYS is that the dimensions are atheoretical and fail to account for relevant coping strategies that people use to combat problems. Research has identified varying factor structures by sample and by stressor (Carver, Scheier, & Weintraub, 1989). Confirmatory factor analysis has failed to replicate the 8 dimensions that Folkman and Lazarus (1988) put forth (Edwards & O'Neill, 1998). The

validity and applicability of the 8 dimensions is thus questionable. Contributing to these varying results in factors is probably that people responding to items on the WAYS may be thinking of differing stressful situations. As discussed earlier, people may respond to different situations with different coping strategies. Another critique relates to the conceptualization of social support. Some have argued that social support is better conceptualized as a resource factor rather than a coping factor (Parker & Endler, 1992). The social support dimension of the WAYS also does not capture the multiple functions of social support, such as solving problems, obtaining information, and venting emotions (Schwarzer & Schwarzer, 1996).

In response to these various criticisms of the WAYS, Carver et al. (1989) developed the COPE based on 13 dimensions derived from existing literature as being relevant to coping practices: active coping, planning, suppression of competing activities, restraint coping, seeking social support for instrumental reasons, seeking social support for emotional reasons, positive reinterpretation and growth, acceptance, turning to religion, focus on and venting of emotions, denial, behavioral disengagement, mental disengagement, and alcohol-drug disengagement. The instrument consists of 60 items and can be used to tap situation specific or general / dispositional coping. A brief version of the COPE, with slightly modified scales, has also been developed (Carver, 1997).

Coping Effectiveness. Coping can be effective or ineffective in managing problems associated with stressors. Active/problem-focused coping is often thought of as *better than* emotion-focused coping. However, evaluation of coping must take into account adaptational outcomes. Coping effectiveness should be evaluated based on the

degree to which a person experiences resilience from negative outcomes and achievement of psychological well-being.

Both emotion and problem-focused coping strategies serve valuable and reciprocal purposes. Whereas emotion-focused coping serves to manage emotional experiences related to a stressor and can in turn place a person in a better state of mind to engage in problem solving, removal of the stressor situation via problem-focused strategies also serves to alleviate emotional distress. It follows that people use a mixture of coping strategies to combat different stressors and this is especially true for complex stressors (Zeidner & Saklofske, 1996). Having a child with a chronic disability represents a complex stressor where it would be expected that emotion and problem focused coping strategies would simultaneously used.

That being said, coping effectiveness is situation specific. Distancing and emotion focused strategies can be effective in situations where the source of distress is unclear, there is a lack of knowledge or ability to solve the problem, and when the situation is unalterable (Lazarus & Folkman, 1984). However, active problem solving tends to be more effective in situations that are ameliorable (Lazarus & Folkman, 1984). In terms of childhood disabilities, both problem-focused and emotion-focused coping strategies may be effective. Disorders such as ADHD and PDD generally cannot be cured, suggesting that emotion focused coping might be effective. However, various methods can be used to effectively treat behavior problems and social skills problems among children with ADHD and PDDs. Thus parents who actively problem-solve around these symptoms may have more positive outcomes.

Most research on coping among parents of children with disabilities has looked at broader styles rather than specific strategies. Additionally, this research tends to rely on dispositional measures of coping such as the WAYS. This reliance on broad definitions and general rather than situation-specific coping has likely contributed to the varying and confusing findings related to outcomes.

Using the WAYS, several researchers have found that reliance on Escape-Avoidance coping is positively correlated with depression, social isolation, and family strain among parents of children with PDDs (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Sivberg, 2002). Dunn et al. (2001) also found negative correlations between Confrontive Coping and depression and between Positive Reappraisal and social isolation. Dunn et al. (2001) was able to conclude that coping moderates the relationship between reported life stressors among parents of children with autism and parent outcomes. In a study of parents of children with various disabilities (mental retardation, learning disabilities, or emotional/behavioral disorders), Malka and Dee (1991) found that parents of children with disabilities were more likely than parents of children without disabilities to rely on an avoidant coping style, which in-turn predicted negative affect in the prior group.

Hastings, Kovshoff, Brown, Ward, Espinosa, and Remington (2005) used principal components factor analysis with varimax rotation to extract 4 factors from Carver's (1997) brief COPE inventory (situational format): Active Avoidance Coping, Problem-Focused Coping, Positive Coping, Religious/Denial Coping. In order to fit in this rubric of factors, 2 items from the original inventory and some of the original coping dimensions were collapsed across the 4 factors. Hastings et al. (2005) found moderate to

large positive correlations between Active Avoidance coping and anxiety, depression, and stress. Positive Coping (use of humour, positive reframing, acceptance, and emotional social support) was negatively correlated with depression, and Religious/Denial was positively correlated with depression. Contrary to their hypothesis, Problem-focused coping was not related to any of the three outcomes.

The primary problem with Dunn et al. (2001), Malka and Dee's (1991), and Sivberg's (2002) research is that they relied on dispositional measures of broad coping styles. It is unclear based on their methodology which stressors in their lives were referred to when answering the coping questionnaire. Thus, neither the conclusion that an escape-avoidance style is ineffective at all times nor the conclusion that an escape-avoidance style is ineffective for parents faced with stressors associated with having a child with a PDD can be made. Although Hastings et al. (2005) measured coping related to stressors associated with having a child with PDD, they collapsed the specific dimensions of the COPE into broad coping styles using exploratory factor analytic techniques.

The broad coping styles used in these prior studies make it difficult to derive specific clinical interventions from the results. For example, the definition of confrontive coping is the aggressive / impulsive efforts to alter the stressor situation at hand; it is unclear how this definition might be translated into interventions for depression. Similarly, Active Avoidance coping includes substance use, behavioral disengagement, self-blame, and venting of emotions; it is unclear which of these more specific strategies relates to negative outcomes. The operationalization of religious coping as being in the same factor as denial is also questionable.

Additional problems with the above research are that the assessed outcome dimensions fail to take into account a complete psychological well-being model. Lack of control groups in the Dunn et al. (2001) and Hastings et al.'s (2005) research also limits inferences about the unique implications of the results for parents of children with PDDs and limits the ability to address why parents of children with PDD experience increased distress in relation to other parents. Finally, the researchers failed to control for socio-demographic variables.

Pakenham et al. (2005) surveyed mothers of children with Asperger syndrome (10-12 years old) using the stressor-specific version of the COPE as a predictor of social adjustment, depression, anxiety, and subjective physical health. Hierarchical multiple regression where family income, maternal age, gender of the child, severity of the stressor, other life stressors, and quality of social support were entered as covariates indicated that only Behavioral Disengagement significantly predicted depression; prediction of anxiety approached significance. They found no correlations between coping and social adjustment or subjective physical health status after controlling for said variables. Similar to the previously reviewed studies, they failed to find a relationship between problem-focused coping strategies and adjustment. Pakenham et al. (2005) also failed to include a control group or measure more positive aspects of psychological well-being.

Research comparing coping profiles of parents of children with PDDs to other groups of parents has indicated differential coping patterns in conjunction with different mental health outcomes, suggesting that coping may be a moderator of outcomes. However, not all studies tested this moderator effect. Donovan (1998) found that

mothers of adolescents with autism are less likely to cope by maintaining a social support system, self-esteem, and maintaining their own psychological stability than were mothers of adolescents with mental retardation. Rodrigue, Morgan, and Geffken (1990) found that mothers of children with autism and Down syndrome relied more on wish-fulfilling fantasy, self-blame, and information seeking (6-factor structure of WAYS) than mothers of normally developing children and that mothers of children with autism relied less on cognitive restructuring than mothers of children with Down syndrome. It is difficult to make sense of these findings, as neither Rodrigue et al. (1990) nor Donovan (1998) relate coping styles with outcomes. Sivberg (2002) found that parents of children with PDDs used withdrawal coping strategies (Distancing and Escape dimensions of WAYS) more frequently than parents of children without PDDs. Social support, self-control, and problem solving were used more frequently by parents of children without PDDs. Recall that Sivberg (2002) found that escape coping moderated family strain in the PDD group. It is unclear if social support, self-control, and problem solving were related to outcomes among the PDD group of parents because the researchers did not do this analysis. Across groups, however, these methods of coping were unrelated to family strain, purpose in life, perception of the world to be comprehensible, perceived manageability of problems, and perceived meaning in life.

Using a combined descriptive and empirical research design, Tunali and Power (2002) found that mothers who successfully coped with having a child with autism had redefined what constituted fulfillment in their lives. Whereas the only positive correlate of life satisfaction among parents of children without autism was the degree of understanding of the child's behavior, life satisfaction among parents of children with

autism was correlated with leisure activities with family, understanding of the child's behavior, rated importance of understanding of the child's behavior, rated importance of being a successful parent, stronger orientation to home than career, and a belief that other mothers should stay at home with their children rather than work outside of the home.

It is difficult to draw conclusions from the existing coping research on parents of children with PDDs due to reliance on different coping measures, reliance on broad coping styles, and differing controls variables across studies. Overall, it appears that parents of children with PDDs rely more heavily on emotion-focused and avoidant coping strategies than parents of typically developing children and that these styles of coping are in-turn related to depression, anxiety, and distress. Findings regarding the effectiveness of problem-focused types of coping are inconsistent, with only one study finding that Confrontive Coping is related to less depressive symptoms, but the rest finding no relationship between any of the positive coping styles and parent adjustment. Positive reappraisal, redefining what is important in life, and Positive Coping appear to protect against depression and to promote social adjustment and life satisfaction. These findings are highly tentative due to varying use of controls for relevant demographic and child variables which, as reviewed earlier, impact parent adjustment. Most of the studies rely on dispositional measures of coping rather than situation-specific measures, limiting implications that might be made about how specifically to intervene and where. Lack of appropriate control groups has also limited the utility of the coping research.

Religious Coping. The low prevalence of research on religion in psychology is a glaring oversight in the investigation of the human experience. Earliest accounts of human history reveal that an enduring search for meaning in life and a belief in a higher

power has existed as part of human cultures around the world. As reviewed, narrative accounts by parents of children with DDs indicate spiritual growth as an important outcome of their parenting experience. None of the above reviewed coping research looked at religious coping, with the exception of Hastings et al. (2005) and Pakenham et al. (2005), who took a peripheral look at religious coping as being among many other strategies.

Hastings et al. (2005) conceptualized religious coping as being in the same factor as denial and found that this factor was positively related to depression. The conceptualization of religion as being in the same factor as a strategy typically thought of as unproductive and related to negative outcomes reflects a bias that should not be present in research. It is unclear from their findings if either denial or religious coping separately accounted for the variance in depression. Pakenham et al. (2005) found no correlation between religious coping and any of their outcome measures. Initially, these findings appear to be at odds with parent narrative accounts. However, neither Pakenham et al. (2005) nor Hastings et al. (2005) measured personal growth, spiritual growth, or life-satisfaction- all outcomes that might be theoretically linked to religious coping. Additionally, both sets of researchers used items from the COPE inventories (Carver, 1997; Carver et al., 1989) to measure religious coping. The items may be too broad to capture the complex ways that people turn to religion to cope with stressors.

Religion can have many positive and negative functions. Pargament, Koenig, and Perez (2000) describe five functions relevant to coping: 1) religion as a framework for understanding and interpreting meaning 2) religion as a means to achieve a sense of control and mastery 3) religion as a source of comfort 4) religion as a source to develop

intimacy and kinship with others 5) use of religion as a support through life changes.

Pargament and colleagues (2000) also suggest potentially destructive methods of religious coping, including redefining stressor situations as punishment from God or by demons, expressions of dissatisfaction of one's religion, and expression of discontent with God or a Higher Power.

Tarakeshwar and Pargament (2001) conducted the only study to include a comprehensive measure of religious coping that incorporates positive and negative categories by which religion could impact parental well-being (RCOPE; Pargament et al., 2000). After controlling for number of problems parents experienced, age of the child at diagnosis, severity of perceived stress, and global religiosity, Positive Religious Coping predicted religious / spiritual growth and stress-related growth, but not depression or anxiety. No significant correlations were found between Negative Religious Coping and outcomes.

Unfortunately, Tarakeshwar and Pargament's (2001) measures of psychological well-being were limited and primarily deficit oriented. Although they included a religious growth measure, wording was biased for use with Christian populations. For example, the questionnaire included the words "God" and "church." Wording of the RCOPE is similarly biased for use with people ascribing to monotheistic religions. These measures likely alienated people who are self-described as being spiritual or who belong to polytheistic religious groups. In fact, 28.6% of their sample reported being affiliated with a religion other than protestantism, catholicism, or Judaism and 2.4% of the participants were Jewish. Formatting of the questions may thus have contributed to Type II error.

Causal Attributions. The role of causal attribution, conceptualized here as an internal coping strategy, for the child's disability has yet to be investigated in the research on parents of children with PDD. Despite decades of fervent research on etiology, presentation, and treatment, there is much about PDD that remain a mystery. At present, research has supported genetic and neurodevelopmental influences on the development of the disorders (Rutter, 2005) however the exact etiology remains unknown. The etiopathology of ADHD is similarly vaguely understood.

Combined with the poor dissemination of this research to parents and professionals, the continued lack of a consistent treatment that would cure PDD or ADHD leaves parents vulnerable to unsupported treatments claiming to offer a cure (Green, Pituch, Itchon, Choi, O'Reilly, & Sigafoos, 2006; Jacobson, Foxx, & Mulick, 2005). Alternative treatments include chelation therapy, chiropractic treatments, sensory integration therapy, megavitamin therapy, elimination diets, EEG neurofeedback, and withholding vaccinations (Jacobson et al., 2005; Schechtman, 2006). These treatments are based on theories that developmental disabilities are caused by metabolic deficiency, pollution, overgrowth of yeast in the colon, prenatal exposure to teratogens, spinal misalignment, mercury poisoning via vaccinations, and allergies (Jacobson et al., 2005; Kozlowski, 1992). Although occasionally helping a few, these treatments generally do not help children with PDD or ADHD.

The impact of the positive causal attribution that alternative treatments offer has yet to be explored in relation to parental adjustment. Knowing what caused the disorder and beliefs that the child will be cured may help parents gain a sense of control over their child's treatments and over their own lives as a whole. Conversely, ascribing the

disability to scientifically unsound causes with therapies that probably will not help the child, are expensive, and that could be dangerous for the child could also be harmful to parental well-being in the long run. Given the high frequency of use of these alternative treatments (Green et al., 2006), it is important to investigate the impact of the treatments on children but also the parents who choose to implement these treatments. The following paragraphs review evidence suggesting that causal attribution may be a crucial component to parent psychological well-being.

A sense of failure and guilt over having produced a “damaged child” is common (Naseef, 2001; Whelan and Hudson, 1987). Blaming of parents, particularly mothers, is most prevalent for disorders that have ambiguous etiology, such as PDDs and ADHD. Parents of children with PDDs in particular may experience strong guilt over having caused their child’s disability (Rodrigue et al., 1990). In fact, psychologists have specifically blamed mothers for their children’s autism. The legacy of mother blaming was perpetuated by Bruno Bettelheim’s publication of *The Empty Fortress: Infantile Autism and the Birth of the Self* (1967). Bettelheim’s ideas remained the dominant theory of autism’s etiology throughout the late 1960s and 1970’s and mothers of children with autism were shamed for failing their children. Although Bettelheim’s theories have been largely discredited, the continued failures to find the cause of autism results in lingering a possibility that parents could have caused the disability. Although the medical model offsets some of the blame away from parents of children with ADHD, poor parenting continues to be a popular theory for the cause of behavior problems among children with ADHD. Parents of children with ADHD are often blamed for their children’s behavior problems.

Ambiguous situations have been identified in the stress and coping literature as the most difficult to adjust to due to the threat to personal locus of control (X- see Taylor Textbook). One study supporting this trend among parents of children with DDs found that parents reported more disrupted family harmony if their child had a DD of unknown etiology versus Down syndrome (Perry, Harris, & Minnes, 2005).

Gray (2002a) interviewed 53 parents of children (ages 5 – 26) diagnosed with either high functioning autism or Asperger's syndrome. He quotes a common experience of being embarrassed as a parent when their child with autism acts out in public, yet looks physically normal:

I can walk through shopping centre after shopping centre and no one knows my child's autistic or he's got a problem. So, if he sees a drink machine and he wants a drink, and I haven't got the right change and he stands there . . . and screams, 'I want a drink!', it runs through my mind, 'What must some people be thinking?' . . . Do you say to them the reason he's carrying on like this is because he is autistic? . . . Actually, there were times when I thought, 'God! I wish he were Down's syndrome', because people would leave me alone. They would see the Down's syndrome [and] know there was a problem. (Gray, 2002a, p. 743)

As the quote above demonstrates, having a child who looks normal, but behaves inappropriately can be especially distressing for parents. This experience is likely shared between parents of children with PDDs and ADHD.

In sum, parental attribution of cause of their child's DD may influence how they adjust via personal and societal pathways. Particularly, knowing what has caused one's

child's disability may dispel feelings of guilt and blame, which have been categorized under avoidant emotional coping. As reviewed earlier, avoidant emotional coping styles tend to be related to increased depression, anxiety, and social isolation. Additionally, knowing what has caused the disability may help parents regain a sense of control over their lives. Even if attribution is to a false cause, it is possible that the false sense of hope may improve parental psychological well-being as a whole.

External Resources and Supports

The literature on social support among parents of children with PDDs has reported inconsistent results related to outcomes. Inconsistencies may be due to measurement differences. Social support can be divided into 1) professional social support, including various professional services directed at the child or the parent (therapy, educational services, respite care, psychiatric care) and 2) informal social support (extended family, friends, spouse, children). Additionally, people may seek social support for instrumental (informational, services) or emotional needs. Most research has used measures that incorporate several types and uses of support to achieve a general measure of social support. Using general measures, social support has been found to be inversely related to anxiety and depression (Gray & Holden, 1992), positively related to parental well-being (Nachshen, 2005), and to be positively related to life satisfaction (Milgram & Atzil, 1988) among parents of children with PDDs. Additionally, social support has been found to moderate the relationship between child-related stressors and social isolation such that presence of social support buffers the negative impact of stressors on social relationships (Dunn et al., 2001).

Some researchers have taken a closer look at the role of sources and uses of social support. This research has resulted in varying findings. When parents perceive that family members care for and understand the child with PDD, support from these members has been related to lower levels of anxiety and depression (Bitsika & Sharpley, 2004). Similarly, White and Hastings (2004) found that when informal social support was viewed as helpful, it was associated with decreased anxiety, depression, and general distress among parents of children with intellectual disabilities (most had autism). Despite a majority of the sample reporting using formal social supports, neither number of services nor perceived helpfulness of these services were related to parent depression, anxiety, or distress in the White and Hastings (2004) study. Pakenham et al. (2005) found that seeking social support for emotional reasons was related to poorer social adjustment among mothers of children with Asperger syndrome, but unrelated to depression or anxiety. Pakenham and colleagues found no relationships between seeking social support for instrumental / practical support and any of their outcome measures.

These various findings may be explained by negative experiences often reported by parents of children with DDs with informal and formal supports. In a qualitative study of parents of children with DDs, 66.7% of parents found dealing with friends, family, and neighbors on a day-to-day basis to be extremely stressful (Jones & Passey, 2005). Parents reported experiencing lack of understanding by others and negative social attitudes. In terms of formal social supports, 82.4% reported that dealing with doctors and other professionals was extremely stressful. Parents perceived professionals to be unsupportive, 'talking above their heads,' and to not listen to them.

Parents of children with DDs have less access to social supports than other parents (Donovan, 1998; Gray, 2002a; Nachshen & Minnes, 2005). Social isolation is likely due to a combination of avoidance of difficult social situations and others avoiding them due to uncomfortable experiences with the child with DD. Further research on social support among parents of children with PDDs using more specific measure is needed to clarify how professional services and society may be more supportive of parents, rather than an additional source of distress.

Perceived Closeness to Child

One major source of support for parents, or disappointment when not felt, is the affection shared with their child. The bond between a parent and his / her child is among the strongest and important bonds that human beings form in their lifetime. Research has yet to explore the role of this critical relationship as a resource for parents of children with PDDs.

The role of parent-child closeness is especially relevant for parents of children with PDDs. Impairments in social functioning among these children interfere with their ability to form close reciprocal relationships with others, their parents included. Children with PDDs are able to develop secure attachments (Rutgers, Bakermans-Kranenburg, van IJzendoorn, & van Berckelaer-Onnes, 2004). However, they are less likely than normally developing children to be securely attached and co-morbid mental retardation decreases the likelihood of being securely attached. Expression of affection among children with PDDs is different from normally developing children, making these behaviors less recognizable. For example, children with PDDs are less likely to seek and maintain contact with their parents and tend to avoid eye-contact. Instead, they may show subtle

or apparently a-social behaviors (e.g. tugging on a parent's shirt when anxious, engage in self-stimulatory behaviors).

Parents of children with PDDs are less likely to feel close with their child with PDD than parents of children with other DDs (Abbeduto et al., 2004). Although Abbeduto et al.'s (2004) study was the only study to compare perceived closeness among parents of children with PDDs compared to other parents, additional support comes from related research. Parents of children with autism perceive their children to show more negative and less positive emotions in comparison to parents of normally developing children (Capps, Kasari, Yirmiya, & Sigman, 1993). Conversely, prosocial behavior among children with DDs is inversely related to maternal distress (Beck, Hastings, & Daley, 2004).

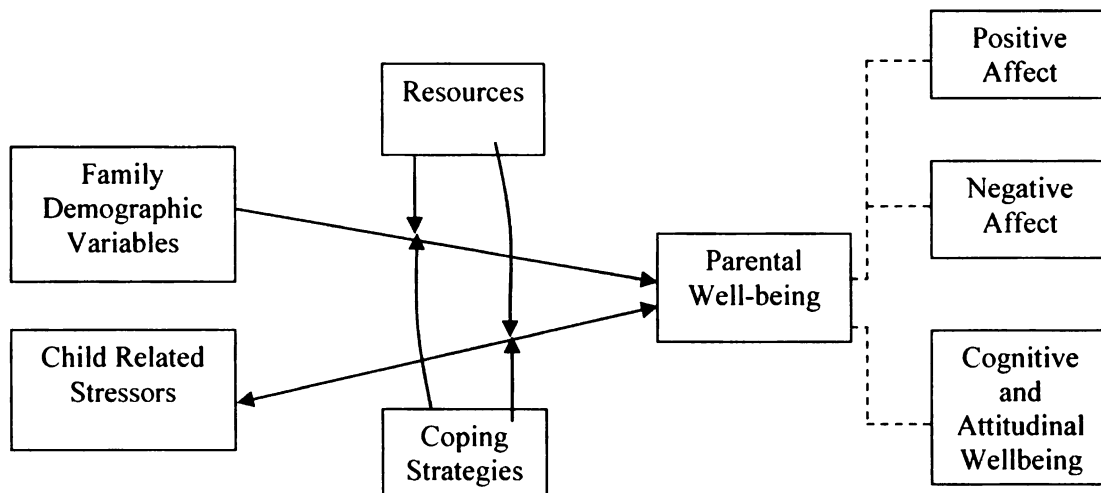
The child with autism's apparent retreat into his own world is an especially difficult characteristic for parents to cope with. In the only study to relate parenting distress to child social behaviors, Kasari and Sigman's (1997) found that child related stress on the *PSI* was inversely related to social responsiveness during a play interaction. Recall that the child-related stress measure on the *PSI* is confounded with child behavior problems, thus this finding can only be assumed to be tentative. Kasari and Sigman (1997) also found that parents of children with autism who viewed their child to be more difficult in temperament were less likely to engage with their children in play and that this relationship was not significant for parents of typically developing children or children with mental retardation. This finding suggests not only relevance for child outcomes, but also introduces that parent perceptions are especially relevant among parents of children with autism.

Research on parenting resources must include assessment of the perceived relationship between the parent and the child. This relationship may be especially relevant to parent well-being among parents of children with PDDs.

This Study

The organizing framework guiding this study was drawn from McCubbin and Patterson's (1983) double ABCX model and Perry's (2005) model. A visual representation of the theoretical is depicted in Figure 1. Specific aspects of this model have been derived from review of the research and narrative literature on parents of children with developmental disabilities.

Figure 1. Theoretical Model of Parent Psychological Adjustment



Family and child characteristics are considered here to make-up a context within which parents react. Family demographic variables represent the family context, including socio-economic status and number of children in the household. Family context was expected to influence parent-well-being and was theorized as being independent of what the child brings to parents' experiences.

The primary child related stressor of interest was the child's diagnosis. Participants recruited had children with either ADHD or PDD. Additionally, a comparison group of parents of typically developing children was recruited to enable differentiation of typical parenting experiences versus the unique experiences of parents

of children with DD. As found in prior research, the specific child characteristics such as the child's age, intellectual functioning, communication skills, social skills, behavioral problems, and attention problems were each also expected to influence parental well-being.

The relationship between the family and child context variables to parent well-being was expected to be moderated by external resources and internal coping factors. Separation of the moderators into these two categories was a deliberate attempt to facilitate intervention efforts by clearly delineating support needs at the parent-level or the societal / service level. Resources of interest included the perceived closeness in the parent-child relationship, professional services directed at the child and / or family, emotional support from friends, and instrumental support from friends.

Coping strategies included parental causal attribution for the child's disability and coping strategies specific to parenting the child (positive religious coping, negative religious coping, substance use, planning, causal attribution, behavioral disengagement, venting, self-blame, active coping, denial, self distraction, humor, acceptance, and positive reframing). Due to the large number of coping strategies measured in the scales and risk for committing Type I error, several of the coping strategies were entered into a principal components analysis to reduce the number of analyses. Derived factors were driven by associations within the data as well as coping theories reviewed.

Research Questions and Hypotheses

1. Psychological well-being between groups:
 - a. The PDD parent group was expected to report the most depressive and anxiety symptoms, followed by the ADHD group. Furthermore, the DD

groups combined were expected to show more psychopathology than the normal controls.

- b. Based on literature suggesting that parents of children with PDD tend to be socially isolated compared to other parents, it was expected that Relations to Others would be most impaired among parents of children with PDD after controlling for demographic variables.
 - c. With respect to Happiness and the remaining measures of cognitive and attitudinal well-being, the literature is less clear so this aspect of the study was exploratory.
2. The relationship between diagnostic status of the child and parent well-being was expected to be moderated by coping and resource variables after controlling for demographic variables.
- a. Positive religious coping, planning, active coping, use of humor, positive reframing, and acceptance were each expected to buffer the impact of the child's diagnosis on parent depression and anxiety. In addition, these aspects of coping were expected to positively relate to positive parent well-being.
 - b. Of the parents of children with DD, it was expected that positive causal attribution for their child's disorder and belief in curability of this disorder would predict less negative affect and better well-being. In particular, it was expected that causal attribution among the DD groups would positively impact environmental mastery.

- c. Resource variables were expected to predict parent well-being such that more support and closer parent-child relationships would predict increased positive well-being.
- 3. Unique coping profiles across study groups:
 - a. Parents of children with DDs were expected to rely less on emotional and instrumental sources of support than parents of typically developing children and to use a larger repertoire of coping strategies than parents of typically developing children.
- 4. Relationship between child context and parental well-being:
 - a. Children with DD were expected to have more impairments in behavioral, social, language, and emotional functioning in comparison to the typically developing children. Externalizing and internalizing problems were expected to be similar across children with PDD and with ADHD. However, functional communication and social skills were expected to be more delayed on average among children with PDD.
 - b. The child context variables were expected to be related to parent adjustment, such that more child problems would be associated with increased negative affect and decreased positive affect and well-being. Further, these child context variables were expected to moderate group differences in psychological well-being.
- 5. Effectiveness of coping and resources across groups in managing parent well-being:

- a. Based on currently limited treatments in managing symptoms of PDD in comparison to ADHD, problems associated with PDD might be considered something that parents just need to accept. Thus, it was expected that parents of children with PDD relying on emotion-focused coping strategies would experience more positive outcomes and that this relationship would not be significant for the ADHD or normal parent groups.
- b. The quality of the parent-child relationship among parents of children with PDD was expected to be among the strongest moderators of psychological well-being.

Methods

Participants and Recruitment

Three parent groups were targeted for recruitment: 1) parents of children with an autism spectrum disorder, 2) parents of children with ADHD, and 3) a control group of parents of children without any mental or physical health problems. Recruitment letters were sent to elementary and middle schools, intermediate school districts, and Autism and ADHD support groups across the state of Michigan. Additionally, controls and parents of children with ADHD were referred by researchers from the Michigan State University Attention study. The snowballing method of recruitment was also used, where existing participants referred other potential participants to the study. Parents recruited from schools and community organizations were given lottery entries to win a prize (Apple iPod Nano, Palm Organizer, \$50 Gift Card to Barnes and Noble, tickets to the Statewide Autism and Resource Training Conference). Parents recruited from the Michigan State University Attention Study were given \$15 for their participation in order to provide sufficient incentive because to this population that had received financial compensation when they participated in an earlier study of ADHD.

A total of 91 parents from 66 families were recruited, consisting of 65 mothers and 26 fathers (this includes 3 adoptive mothers, 4 adoptive / step-fathers, and 4 caregivers who identified as being a major parental figure for the child). Forty-eight of the participants were mother-father pairs reporting on the same child. Table 1 outlines specific participant counts per study group. In some cases, both parents of the same child were included. Table 2 indicates specific characteristics of each group in the sample. Mean age of parents was 40.54 years ($SD = 5.78$). At the time of participation in the

study, 85% of the parents were married, 10% were divorced, 4% were single, and 1% were separated. Socioeconomic status was generally high, with 37.4% having graduated from a 4-year college and an additional 33.0% having attained a graduate or professional degree. There were significant differences between groups in mean household income ($F(2, 85) = 4.20, p \leq .05$) such that the control group had a higher mean income than the other two groups, which had comparable income levels. Employment status was 54.4% full time, 13.3% part time, and 25.6% identified as being homemakers. Including the child in question, mean number of children in the household was 2.39 ($SD = 1.03$), with no significant differences across study groups ($F(2,86) = 1.23, p = .296$). Representation of ethnic diversity in the sample was comparable to that in the general population in Michigan (87.5% Caucasian, 3.4% Hispanic / Latino, 5.7% African American, 1.1% Asian, 2.3% Other). The majority of participants endorsed a religious affiliation (22% Catholic, 18.9% Protestant, 24.4% Christian / Non-denominational, 3.3% Baptist, 18.8% other), with only 12.2% indicating no religious affiliation.

A total of 66 children ages 6-12 years old ($M = 9.03, SD = 1.72$) were reported on for the study. Table 3 details of the children included in the study. Intellectual testing results were not available for all children, however there was a significant correlation between parent's perception of the child's intelligence and actual test scores ($r = .967, p \leq .05$). Thus, parent ratings of their child's perceived intelligence were used for analyses in substitution for actual intelligence testing scores. As expected, there were significant differences between groups in children's intelligence such that the control group was reported to be the most intelligent (average parent rating suggested functioning in the Above Average range), followed by the ADHD group, then the PDD groups where

average parental ratings suggested functioning in the Average range, $F(2, 62) = 8.84, p \leq .01$. As previously described, intelligence testing of children with PDD has questionable validity and reliability. Research indicates that speech development is a strong predictor of child outcomes in children with PDD (Sallows & Graupner, 2005). Thus, BASC-2 functional communication scores were also used to estimate the developmental functioning of children across groups. One-way analysis of variance (ANOVA) indicated significant between group differences in mean functional communication score (average parent and teacher reports) across groups, $F(2, 62) = 52.39, p \leq .01$. Post-hoc analyses indicated the PDD group not only had significantly underdeveloped Functional Communication skills relative to the other two groups, mean development of this skill was in the clinically delayed range ($M = 28.57, SD = 9.15$). The ADHD group had more delayed Functional Communication skills than the typically developing children.

Of the 26 children in the PDD group, 19 had a diagnosis of Autism and 7 had a diagnosis of Aspergers Disorder. Additional comorbid diagnoses were ADHD ($n = 4$), Sensory Integration Disorder ($n = 2$), and neurological disorders ($n = 2$). Using the cutoff score of 28 on the CARS-P, 84.6% of the children in the PDD group met the Autism cutoff per parental report. Children in the PDD group had either a medical diagnosis of Autism, Asperger's Disorder, or Pervasive Developmental Disorder Not Otherwise Specified or a special education designation of Autism Impaired from the Michigan Special School district per their parents' report. Diagnoses were confirmed for 18 children by psychological evaluation and school reports. Criteria for Autism Impaired are similar to criteria in the DSM-IV for PDD and the majority of those given a

designation of Autism impaired meet criteria for a PDD. Recruitment of parents of children from public schools was a critical aspect of obtaining a demographically representative sample of parents of children affected with a PDD. Unlike children referred by medical or psychological clinics who are more likely to come from higher socioeconomic backgrounds, children involved in the special education system represent a full range of socioeconomic backgrounds. The sample had the expected gender representation for a diagnosis of autism (88% male).

The 20 children (85% male) in the ADHD group had a parent reported medical diagnosis of ADHD. There was no specific special education category for these children; however obtaining a medical diagnosis for ADHD is more generally accessible by people from all socioeconomic backgrounds. As expected, composite ratings by parents and teachers of the children in the ADHD group on the BASC-2 indicated clinically significant problems with attention ($M = 67.49$, $SD = 7.60$).

A total of 42 teachers (21 for the PDD group, 10 for the ADHD group, and 11 for the Control group) provided ratings for the children's functioning in school. All teachers knew the child for at least 3 months at the time of participation in the study. Teachers were given \$10 for their participation in the study.

Measures

Demographic information and child's developmental history was gathered using the Social History form. Also included in this form were questions about parent perceptions of the child's intellectual functioning, causal attribution, and whether the parent believed the child's disorder could be cured. All questionnaires used in this study,

with the exception of the *Behavior Assessment System for Children- 2nd Edition* are in Appendix A.

Child Related Stressors

The *Behavior Assessment System for Children- 2nd Edition* (BASC-2; Reynolds & Kamphaus, 2004) is a rating scale with a parent rating form (160 items) and companion teacher rating form (139 items) for children. The Child (ages 6-11) and Adolescent (ages 12-21) forms were used in this study. Five scales were used for this study: Social Skills, Functional Communication, Externalizing Behaviors, Internalizing Behaviors, and Attention Problems. All of these scales have acceptable internal consistency and test-retest reliabilities. The Functional Communication scale assesses the child's ability to effectively express and communicate ideas. The Social Skills scale assesses for pro-social behaviors and politeness. The Externalizing Behavior scale measures conduct problems, aggression, and hyperactivity. The Internalizing Behaviors scale measures anxiety, depression, and behavioral withdrawal. Attention Problems measures the child's attentional functioning in his / her environment.

The Childhood Autism Rating Scale-Parent form (CARS-P; Bebko, Konstantareas, & Springer, 1987) was used to assess autistic symptom severity among children with PDD. The CARS-P is a direct adaptation of the Childhood Autism Rating Scale (CARS; Schopler, Reichler, Devillis, & Delay, 1980) to make the scale appropriate for self-administration by non-professional parents. The cutoff score for a positive screen of autism on the original CARS is 30. However, due to the CARS-P having 14 items instead of 15, the cutoff score of 28 was used for this study. Parents in this study were asked to rate the child's behaviors on the 14 domains corresponding to autism

symptomology based on a 4-point scale (1 = normal for chronological age, 2 = mildly abnormal, 3 = moderately abnormal, 4 = severely abnormal). The scale has been used in previous research as a scale of autism severity and has been related to parental distress (Freeman, Perry, & Factor, 1991; Tobing & Glenwick, 2002). Research on psychometric properties of this instrument has yet to be completed. Internal consistency of the total score in this sample was appropriate ($\alpha = .94$ for entire sample, $\alpha = .88$ for children with pervasive developmental disorders).

Coping Strategies

The brief COPE (Carver, 1997) consists of 28 self-report items assessing 14 dimensions of coping: active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame. Wording was changed for easier readability (i.e., change of “I’ve been” to “I”). Instructions were altered such that parents responded according to how they currently deal with stressful situations related to the target child. The social support items are considered resource variables rather than coping variables in the theoretical model. An altered version of the Brief RCOPE (Pargament, Smith, Koenig, & Perez, 1998) was used to assess religious coping. Each of the 14-items represents different ways that people use religion to manage challenging situations. These methods include seeking a spiritual connection, seeking spiritual support, collaborative religious coping, religious forgiveness, benevolent reappraisal, purification, focusing on religion, spiritual discontent, punishment reappraisal, interpersonal religious discontent, demonic reappraisal, and questioning the power of a higher power. Items are divided into positive and negative

religious coping subscales. Cronbach's alphas ranged from .87 to .89 for the positive religious coping dimension and from .67 to .81 for the negative religious coping dimension. Original items were re-worded for this study to accommodate varying religious backgrounds (e.g. "God" was changed to "my God or a Higher Power").

Resources and Supports

A measure of formal social supports was developed based on Dunst, Jenkins, and Trivette's (1994) Family Support Scale (FSS) where parents indicate whether they received any of a list of supports and the degree to which those supports were helpful. The original scale consisted of 5 different professional services, which does not capture the diversity in services that parents of children with developmental disabilities receive. Thus, a new measure, the *Professional Services and Support Questionnaire* (PSSQ), was created for this study. In it, parents indicated if they or their child received any of a list of formal services and the degree to which they perceived the services to be helpful.

Bengtson and Black's (1973) *Positive Affect Index* was used to measure the degree to which parents perceive their relationships with their children to be characterized by trust, love, and understanding. The scale consists of 5 questions asking parents how much they feel positive affect toward their child and 5 questions asking how much they perceive their child expresses positive affect toward them. An additional item asking about degree of closeness parents feel their relationship is with their child. Each item has 6 choices ranging from "not at all" to "extremely much." This measure has been used in previous studies of parents of children with a variety of diagnoses (Abbeduto et al., 2004; Orsmond et al., 2003).

Psychological Well-being

The *Center for Epidemiological Studies Depression Scale* (CESD; Radloff, 1977) is a widely self-report depression scale designed to measure depressive symptoms in community samples. The scale consists of 20-items that have shown to have good internal consistency in a general adult population ($\alpha = .85$). Items tap 6 dimensions of depression: depressed mood, feelings of guilt and worthlessness, feelings of hopelessness and helplessness, psychomotor retardation, loss of appetite, and sleep disturbance. The scale is widely used in clinical and research settings and takes approximately 5 minutes to complete. The standard cutoff score for a significant screen for depression is 16.

The Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988) is a 21-item self-report measure of anxiety symptoms for adults that was designed to discriminate between anxiety and depression. The scale is widely used in clinical and research settings and takes approximately 5-10 minutes to complete. Internal consistency has been found in a non-clinical sample to be excellent ($\alpha = .90 - .91$) (Creamer, Foran, & Bell, 1995).

The *Subjective Happiness Scale* (Lyubomirsky & Lepper, 1999) is a 4-item measure of global subjective happiness. Internal consistency of the instrument is good to excellent ($\alpha = .79 - .94$). Responses are on a 7-point Likert scale ranging from unhappy to very happy.

The *Satisfaction with Life Scale* (Diener, Emmons, Larson, & Griffin, 1985) is a 5-item measure of global satisfaction with life. Internal consistency is good ($\alpha = .87$). Responses are on a 7-point Likert scale ranging from “Strongly Disagree” to “Strongly Agree.”

Attitudinal aspects of psychological well-being were measured using the Environmental Mastery, Personal Growth, Purpose in Life, and Self-Acceptance scales of Ryffe and Keyes' (1995) *Scales of Psychological Well-being*. This study used the 9-item version of the scales, which have good internal consistency ($\alpha = .71 - .82$).

Van Dierendonck's (2004) *Spiritual Well-being scale* will be added to the attitudinal assessment protocol. Van Dierendonck took items from Ellison's (1983) *Spiritual Well-being Scale* and Howden's (1992) *Spiritual Assessment Scale* to compile the 10-item scale that will be used in this study. Internal consistency is appropriate for the Inner Resources Scale ($\alpha = .76$) and the Relationship with a Higher Power Scale ($\alpha = .87$) of the measure. This study aggregated the two subscales into a single Spiritual Well-being measure.

Results

Principal Components Analysis

Coping and Resources

Principal components analysis was used to reduce 10 Brief Cope Dimensions (self-distraction, active coping, denial, substance use, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, self-blame) down to fewer components in order to reduce number of analyses and associated risk for Type I error. The 20 corresponding items were subjected to principal components analysis using SPSS Version 15 (see Table 4 for factor loadings). Inspection of the inter-item correlation matrix indicated that many of the coefficients were .3 and above, indicating appropriateness of the principal components analysis method. Additionally, the Kaiser-Meyer-Olkin value of .65 exceeded the recommended value of .6 and Bartlett's Test of Sphericity reached statistical significance ($p = .00$), further supporting the factorability of the correlation matrix. Examination of the screeplot using Kaiser criterion showed 6 - 8 components, however a large drop was shown in variance explained after 2 components. Analyses were conducted where 8, 5, 4, and 3 components were forced and Varimax rotation was performed to aid interpretations. The three-component solution made most theoretical sense and accounted for 44.39% of the variance, with component 1 contributing 18.23%, component 2 contributing 17.05%, and component 3 contributing 9.11%. Component 1 consisted of the items Carver (1997) designated as active, planning, and positive reframe items. This component was termed Active-Positive Coping for this study. Component 2 consisted of items originally designated as self-distraction, denial, behavioral disengagement, venting, and self-blame items. This component was termed

Avoidant-Aggressive Coping. Component 3 consisted of items originally designated as Substance Abuse and Humor items. Although considered to be a positive coping strategy to be able to laugh at one's troubles (Roussi, Krikeli, Hatzidimitriou, & Koutri, 2007), wording of the humor items may have tapped insensitivity to the child's disability and poor judgment that similarly occurs when under the influence of drugs and alcohol. This component was termed Substance Abuse / Humor for this study.

The Brief R-COPE scale and Brief COPE Religion items were combined in a factor analysis due to the investigator's specific interest in examining the role of religious coping on parental well-being (see Table 5 for factor loadings). Examination of inter-item correlations, Kaiser-Meyer-Olkin measure of sampling adequacy (.88), and Bartlett's test of sphericity ($p = .00$) indicated that principal components analysis was appropriate. The screeplot using Kaiser criterion and number of eigenvalues over 1 indicated that extraction of 2-3 factors was appropriate. Principal components analysis with Varimax rotation and forcing 3 and 2 components were conducted. The 2-component structure made the most theoretical sense given the positive and negative valence of the corresponding questions. The 2-component structure accounted for 68.43% of the variance, with component 1 accounting for 47.13% and component 2 accounting for 21.29%. Items in component 1 were a composite of the Positive Religious coping items identified by (Pargament, Smith, Koenig, & Perez, 1998) and the 2 Religious coping dimension items delineated by Carver (1997). Component 1 was thus termed Positive Religious Coping for this study. Items in component 2 consisted of the Negative Religious coping items identified by Pargament, Smith, Koenig, and Perez (1998) and was so termed for this study.

Resources and Supports

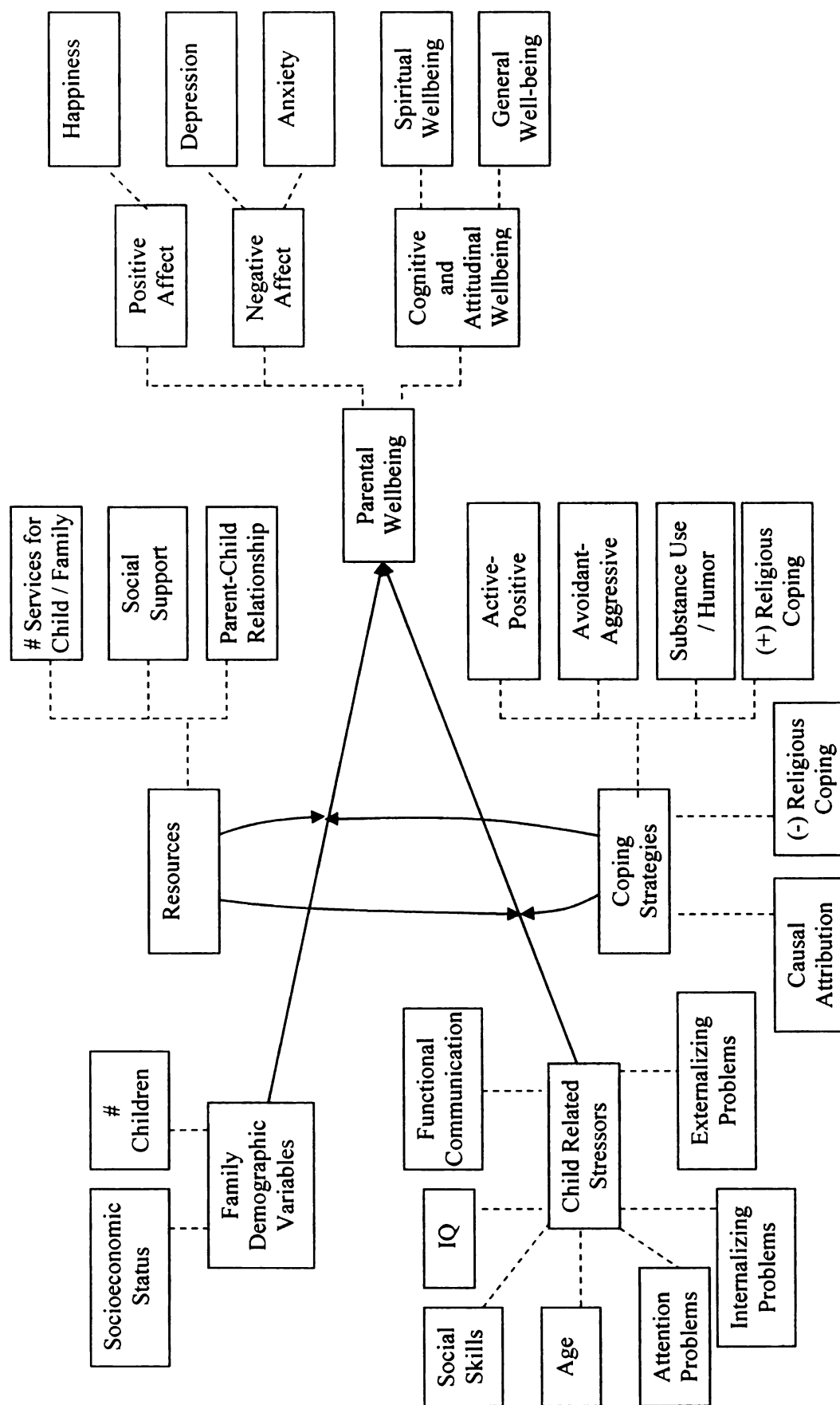
High correlations between the Emotional Social Support and Instrumental Social Support items on the Brief COPE ($r = .63 - .78, p \leq .01$) and extraction of only one component using principal components analysis supports combining these items into a single Social Support composite. The scale reliability for this composite was appropriate ($\alpha = .90$).

Cognitive and Attitudinal Well-being

Due to the large number of analyses planned for this study, it was not possible to examine each of the 4 dimensions of the *Ryffe's Scales of Psychological Well-being* used in this study (Environmental Mastery, Personal Growth, Purpose in Life, and Self-Acceptance). Instead, general Well-being was measured by combining the 4 dimensions. This was based on a factor analysis conducted by the authors of the scale (Ryffe & Keyes, 1995) showing that dimensions of the scale joined together to form a single higher-order factor of well-being. High correlation with the *Life Satisfaction Scale* also supported creating a General Well-being scale by re-scaling the items to a consistent 6 point likert scale and aggregating them such that each of the Ryffe scale dimensions and the *Life Satisfaction Scale* had a equal weighting in the overall Well-being scale. Reliability statistics for this combined scale showed good internal consistency for the sample in this study ($\alpha = .94$). The *Scales of Spiritual Wellbeing* were maintained as a separate measure of well-being due to the researcher's interest in this specific aspect of well-being that has yet to be explored among parents of children with developmental disabilities.

A diagram of the scales used for this study positioned with the corresponding aspects of the theoretical model guiding this study is depicted in Figure 2.

Figure 2. Theoretical Model of Parent Psychological Adjustment with Variables Incorporated



Descriptive Statistics

Prior to conducting analyses, the data were examined for data entry errors, missing values, outliers, and adherence to univariate assumptions of normality. Data cleaning was completed using a double data entry system with different people entering the same data into separate SPSS databases. An Excel program was then written to compare discrepancies in entries. All inconsistent entries were corrected. Several items were left blank by participants for the *Scales of Psychological Well-being*. For participants where only 1 item was skipped ($n = 5$), the score was imputed using that participant's average score on items in the same dimension. Dimension scores were not calculated for participants who skipped more than 1 item on the scale ($n = 4$). No data were imputed for the BAI or CESD because no participants skipped more than 3 items on the scales (scale authors indicated a cutoff of 4 missing responses for the scales to be unscorable). Several parents and teachers left items blank in the BASC-2 response scales resulting in some scales not being scored for those participants due to insufficient data.

Univariate outlier analyses identified that one participant in the ADHD group had significantly extreme scores on both the BAI and CESD. The scores were examined to be legitimate. Due to the large difference in the outlying BAI score from the next highest score, the score was reduced to be less extreme as described in Tabachnick and Fidell (2007). Even following adjustment of the outlier scores on BAI and CESD, these variables remained significantly positively skewed and kurtotic. Based on analyses of histograms of normality statistics, a decision was made to use a logarithmic transformation of the BAI variable to correct for non-normality. Following

transformation, this variable conformed to univariate normality assumptions. The outlying CESD score was not extremely different from the next highest 3 scores, thus a decision was made to keep this score and apply a logarithmic transformation to the variable to correct for non-normality. Following correction, the CESD variable conformed to univariate normality assumptions and no outliers were identified.

The PAI Closeness variable showed significant negative skew (-1.18) and positive kurtosis (1.32). Following examination of the shape of the distribution, a reflected square root transformation was applied. Positive Affect From Child on the PAI was also significantly positively skewed (-1.49) and showed positive kurtosis (3.50). A reflected square root transformation was applied following examination of the shape of the distribution of scores. The Substance Abuse / Humor factor showed positive skew (1.24) and kurtosis (1.90) and, following examination of the shape of the distribution of scores, was subjected to logarithmic transformation. Following transformations, the PAI Closeness, PAI Positive Affect from Child, and Substance Abuse / Humor scales all showed normal distributions.

The Negative Religious Coping variable showed positive skew (2.98) and kurtosis (13.48) and included an outlier. Deletion of the outlier did not correct for the non-normality. Logarithmic transformation improved approximation to normality, however skew (1.60) and kurtosis (3.22) remained significant. With the exception of one participant who used this coping method a moderate amount, the majority of participants did not use or only did this a little bit. Thus, due to the non-normality of distribution of the variable, low variance in responses across groups, and violation of homogeneity of variance assumption (Levene Statistic = 3.04, $p \leq .05$), this scale was removed from

further analysis. Positive religious coping was negatively skewed (-1.30) and was thus subjected to a reflected square root transformation. Examination of the histogram showed a high frequency of participants not using this method of coping at all. However, most scored above the lowest possible rating. Transformation of this variable to normality was not possible. Due to there being good variance in scores, a decision was made to analyze between group differences in this variable using nonparametric statistics, however the variable was not included in regression analyses due to violation of normality assumptions.

Tests of Research Predictions

Hypothesis 1- Affective and Cognitive / Attitudinal Well-being Comparisons Between Parent Groups

Table 6 details group means and results of tests for between group differences for psychological well-being and affective well-being variables. Univariate analysis of variance (ANOVA) showed significant group differences across the three groups in depression scores, $F(2, 88) = 3.74, p \leq .05$, however differences did not remain significant after controlling for household income in a univariate analysis of covariance (ANCOVA), $F(2, 84) = 1.99, p = .14$, partial $\eta^2 = .05$. There was a significant relationship between family income and CESD scores, as indicated by a partial η^2 value of .08, $F(1, 84) = 7.32, p \leq .01$. Number of children in the household and age of the child in question were not included as covariates in analyses as originally planned due to these variables not differing significantly across groups. To analyze between group differences in frequency of clinical depression, scores on the CESD were dichotomized into

depressed and not depressed categories based on the widely used cutoff of 16 for this scale (Radloff, 1977; see Table 7 for characteristics of each group on clinical depression). The Chi-Square test for independence indicated no significant association between study group and depression status, $\chi^2 (2, n = 91) = 3.10, p = .21, \phi = .19$. Examination of differences across parents of children with developmental disabilities versus the typical control groups using Chi-Square with Yates Continuity Correction also indicated non-significance, $\chi^2 (1, n = 91) = 1.46, p = .23, \phi = .16$.

Univariate ANOVA indicated no significant between group differences in anxiety (BAI) scores, $F (2,88) = 2.31, p = .11$. Likewise, controlling for family income in an ANCOVA analysis indicated no significant difference between groups on the anxiety scores, $F (2, 84) = .93, p = .40$, partial eta squared = .02. There was a small and significant relationship between Income and BAI scores partial eta² = .06, $F (1, 84) = 4.95, p \leq .05$. To examine between group differences in clinically elevated anxiety, parent scores on the BAI were categorized into Low Anxiety (scores below 22) and Moderate or High Anxiety (scores 22 and above). Chi-Square analysis indicated no significant association between study group and anxiety status, $\chi^2 (4, n = 91) = 1.51, p = .47, \phi = .13$.

A Multivariate analysis of covariance (MANCOVA) was conducted on the remaining well-being variables (Happiness, Spiritual Well-being, Composite Well-being) controlling for family income to examine if there were significant group differences on any of these variables and to minimize Type 1 error from conducting multiple analyses. No significant group differences were found on any of these scales (see Table 6). Another question posed in the hypotheses was whether the *Ryffe's Scales of Psychological Well-*

being dimension of Positive Relations with Others would show poorer adjustment for parents of children with PDD than parents of typically developing children. Univariate ANOVA indicated no significant differences across groups, $F(2, 85) = .02, p = .98$.

Analyses were repeated comparing both of the DD groups (ADHD and PDD) combined to the control group of parents with typically developing children. Univariate ANOVA showed significant between group differences in CESD scores, $F(1, 89) = 7.53, p \leq .01$, and group differences remained significant even after controlling for income in an ANCOVA, $F(1, 85) = 3.99, p \leq .05$. Test of the significance of within family nestedness by examining the variance components indicated that family nestedness did not explain a significant portion of variance in depression scores (8% of variance, Wald- $Z = .53, p = .59$). Thus, multi-level analyses were not needed. Univariate ANOVA comparing the two groups on the BAI was significant, $F(1, 89) = 4.15, p \leq .05$, however this relationship did not remain significant after family income was controlled for in an ANCOVA, $F(1, 85) = 1.60, p = .21$. MANCOVA analyses did not indicate significant differences across the two groups in Happiness, Psychological Well-being, or Spiritual Well-being.

Hypothesis 2. Bivariate Associations Between Coping, Resource, and Parent Well-being

Variance components were calculated using HLM and family nestedness was not related to any of the coping and resource variables, thus indicating that single level analyses would be appropriate. Pearson correlations between coping, service and support, and well-being variables are reported in Table 8. Notable was that total number of services accessed within families showed an expected strong positive correlation with

Active Positive Coping, however was unrelated to any affective or other well-being measures. Also, the three parent-child relationship scales from the PAI showed strong positive inter-correlations with one another and were significantly related to depression and general well-being in the expected direction such that increased quality of the relationship was associated with better adjustment. As expected, several of the coping scales were significantly associated with the affect and well-being measures. Parent affect and well-being scales showed significant inter-correlations with one another in expected directions. Income was positively correlated with parent-child closeness and positive affect felt from the child, though not related to positive affect felt for the child. Income was also positively associated with overall psychological well-being and negatively related to avoidant-aggressive coping, substance abuse / humor coping, depression, and anxiety.

Tests of Coping Strategies as Moderating Child Diagnosis and Parent Well-being

The second hypothesis pertained to whether positive religious coping, planning, active coping, use of humor, positive reframing, and acceptance on the Brief COPE and Brief R-COPE buffered the impact of child diagnosis on parental negative affective well-being. This could only be tested for depression; anxiety showed no differences across groups. Religious coping was not included in regression analyses due to non-normality in distribution of these strategies mentioned earlier. Principal components analysis results (see Table 4) indicated that all of the remaining coping strategies indicated, with the exception of humor, loaded onto the Active Positive Coping factor. As previously discussed, the humor dimension unexpectedly loaded with the Substance Abuse dimension. Pearson partial correlations controlling for household income were calculated

to identify if substance abuse / humor coping and active-positive coping were significantly related to depression. Only active- positive coping (partial $r = -.28, p \leq .01$) was significantly correlated with depression. Active-positive coping and the dichotomous grouping variable (DD or control group) were centered using a z-score transformation and multiplied to create an interaction term. A hierarchical regression analysis with household income entered in Step 1, Active-positive coping and the grouping variable in Step 2, and the interaction term in Step 3 indicated that the interaction was not significant, $\beta = -.04, t = -.39, p = .70$.

The next portion of hypothesis 2 asked whether the positive coping dimensions would predict variance in the positive psychological well-being variables (happiness, general well-being, spiritual well-being). Results of the correlation analysis (see Table 8) indicated the active-positive coping factor as being the sole positive coping dimension. Three separate hierarchical regression analyses were conducted for the affective and well-being scales (see Table 9). Active-positive coping significantly predicted happiness and the two well-being scales after controlling for household income. Because none of these positive adjustment measures significantly differed across study groups, interaction effects were not tested.

Relationship Between Beliefs About Developmental Disabilities and Parent Well-being. The next portion of the hypothesis looked at causal attribution and belief that the child would be cured among the parents of children with developmental disabilities. Overall, 41.9% of parents of children with ADHD or PDD believed that their child could not be cured, 21% stated that they believed their child could be cured, and 37.1% stated that they did not know if their child could be cured. Chi-square analysis indicated that

there were no differences across PDD and ADHD groups in beliefs regarding curability of their child, $\chi^2 (2, n = 62) = 3.41, p = .18, \phi = .23$.

Parent responses to the questions regarding etiology of the child's disorder were coded into 4 categories. Of those who responded, 19% of parents stated they did not know what caused their child's disability. 13.8% identified mercury in vaccines as the causal factor. 22.4% believed that the disorder was inherited or due to a genetic cause. 44.8% stated other causes, including pre-natal or peri-natal insults, other environmental toxins, victimization from early neglect, or a combination of genetic and / or mercury related factors. Chi-square analyses indicated that there were significant differences across PDD and ADHD groups in identified causes for the child's disorder, $\chi^2 (3, n = 58) = 8.02, p \leq .05$. Specifically, more parents of children with PDD identified a mercury related cause ($n = 7$) or Other cause ($n = 19$) than parents of children with ADHD ($n = 1$ and $n = 7$, respectively). These categories were dichotomized into parents who identified some sort of cause (positive causal attribution) versus those who indicated that they did not know the cause.

One-way ANOVA analyses were conducted to test the relationship between parental beliefs related to a cure for their child's disability and parent affect and well-being. Contrary to expectations, no significant relationships were found between belief in a cure and parent affect or well-being variables. One-way ANOVA analyses were conducted to test the relationship between causal attribution for the child's disability and parent affect and well-being.

Relationship Between Service and Support Measures and Parental Well-being.

Another question posed as part of this hypothesis was if number of services accessed,

social support, and parent-child relationship dimensions (positive affect toward child, positive affect from child, closeness) and social support measures would significantly predict outcomes across each of the affective and well-being measures. Hierarchical regression analyses controlling for income in Step 1 and entering each of the independent variables separately to predict happiness, depression, anxiety, general well-being, and spiritual well-being were conducted (see Table 10). Partial support for hypotheses was obtained. Total number of services accessed did not significantly predict any aspects of parent affect or well-being. However, several of the relational variables predicted affect and well-being. In terms of the parent-child relationship, positive affect toward child predicted 7% of the variance in depression scores and 6% of general well-being in the expected direction, but did not significantly predict variance in anxiety, spiritual well-being, or happiness. Positive affect felt from the child predicted 7% of the variance in parental depression, 10% of general well-being, and 9% of spiritual well-being in the expected direction of supporting more positive adjustment, but did not significantly predict scores on happiness or anxiety. Overall perceived closeness with their child predicted 5% of the variance in depression scores, 5% of happiness scores, 10% of general well-being scores in the expected direction, but did not predict variance in anxiety or spiritual well-being scores. Broader social support predicted 6% of the variance in general well-being scores in the expected direction, however failed to predict any other parent outcome scores.

To further analyze the role of the various coping and resource variables in predicting parental well-being, post-hoc analyses were conducted. To minimize problems of multicollinearity, total services accessed was not included in regression analysis due to

it's high significant correlation with active-positive coping ($r = .40, p \leq .01$). Similarly, only the positive affect felt from child scale on the PAI was included due to high inter-correlations between the overall closeness, positive affect toward child, and positive affect felt from child scales (see Table 8). Of the three scales, positive affect felt from child was selected because it had the most consistent relationships to parent well-being of the three PAI scales.

Hierarchical regression analysis controlling for household income in Step 1 and simultaneously entering active positive coping, avoidant- aggressive coping, substance abuse / humor coping, Positive Affect from Child, and Social Support in Step 2 explained 26.2% of the variance in depression, $F(6, 75) = 5.80, p \leq .01$. Removal of the non-significant predictors one at a time, with removal of the smallest individual beta coefficients first, resulted in incremental removal of social support, substance abuse / humor, and positive affect from child. The remaining model with active positive coping and avoidant-aggressive coping and controlling for household income accounted for 22% of the variance in parental depression, $F(3, 79) = 8.72, p \leq .01$, with direction of associations being in the expected directions. Active-positive coping was negatively associated with depression and avoidant-aggressive coping was positively associated with depression. See Table 11 for regression coefficients. Notable is that in the model with active-positive coping, avoidant-aggressive coping, and positive affect from child and controlling for household income, the unique contribution of positive affect from child to the variance in depression scores approached significance ($\beta = .18, t = 1.79, p = .08$), with the overall model explaining 24.1% of the variance in depression scores ($F(4, 78) = 7.52, p \leq .01$).

Prediction of the composite psychological well-being score was also tested. With the three coping variables, and positive affect from child in the model and controlling for household income, 37.1% of the variance in well-being was accounted for ($F(6, 73) = 8.78, p \leq .01$). Incremental removal of predictors that did not provide significant unique prediction of the dependent variable resulted in removal of substance abuse / humor and then active-positive coping. The resulting model (see Table 12) contributed 35% in the prediction of variance in composite psychological well-being ($F(4, 76) = 11.77, p \leq .01$). Direction of association was as expected such that avoidant-aggressive coping was negatively associated with well-being and social support and positive affect from child were positively associated with well-being.

Hypothesis 3- Comparing Coping and Resource Effectiveness Across Groups

Principal components analysis results for the *Brief-COPE* scales did not support a distinction between emotion-focused versus problem-focused types of coping that were part of this hypothesis. Thus, testing of whether reliance on emotional versus problem focused coping strategies differed across PDD and ADHD parent groups could not be conducted. Partial correlations were conducted for each of the coping components with each of the well-being scales, controlling for household income. Although several significant relationships emerged in the PDD parent group, only one relationship (avoidant-aggressive coping and anxiety $r = .47, p \leq .05$) was significant for the control group of parents. No significant correlations emerged for the ADHD group. Comparison of unique effectiveness of coping strategies in each of the study groups thus could not be performed.

Hypothesis 4- Relationship Between Child Context and Parent Well-being

Child Behavioral and Emotional Characteristics. Parent and teacher ratings of the children's social skills, externalizing behaviors, and functional communication were significantly correlated (See Table 13). However, parent ratings of internalizing behaviors were not significantly correlated with teacher ratings. Thus scores for social skills, externalizing behaviors, and functional communication were averaged across parent and teacher raters when available. Internalizing scores were averaged across maternal and paternal reports when available, leaving out teacher reports due non-significant correlations with parental ratings and research evidence indicating that teachers are less accurate raters than parents of children's' internalizing behavior problems (Hinshaw, Han, Erhardt, & Huber, 1992; Thompson, Dubowitz, English, Nooner, Wike, Bangdiwala, Runyan, & Briggs, 2006).

See Table 14 for a summary of behavioral and emotional characteristics by study group. Scores are reported in *T* score format such that for clinical scales (externalizing behaviors, internalizing behaviors, attention problems) above 65 represent clinically severe problems and for adaptive scales (Social Skills, Functional Communication) scores below 40 represent underdeveloped skills relative to other children of the same age.

As expected, on average the children in the PDD group had clinically delayed functional communication skills ($M = 28.57$, $SD = 9.15$) and social skills ($M = 34.38$, $SD = 7.84$). On average, children in the ADHD group had clinically significant levels of externalizing behavior problems ($M = 65.15$, $SD = 13.74$) and borderline delayed social skills ($M = 40.12$, $SD = 10.17$). On average, children of parents in the control group did

not have clinically significant behavioral, social, or communication problems. One-way ANOVAs indicated significant between group differences on the Functional Communication, Social Skills, Attention Problems, Internalizing Problems, and Externalizing Problems scales on the BASC-2 (see Table 14). These differences maintained significance even when income was controlled for and all scales were entered into a MANCOVA to minimize Type 1 error. Post-hoc analyses indicated that children in the ADHD group had more externalizing problems than the PDD and Control groups and children in the PDD group had more externalizing problems than the Control group. Children in the ADHD group had more internalizing problems than the PDD and Control groups and children in the PDD group were not significantly different from controls on this dimension. As expected, social skills and functional communication skills were the most impaired in the PDD group. Further, children in the ADHD group were more impaired than children in the typically developing group on these dimensions.

Relationship Between Child Characteristics and Parent Psychological Well-being.

Table 15 details Pearson correlations for child context (BASC-2 scales) and parental affect and well-being measures. Happiness and spiritual well-being were not significantly related to any of the child context scores. All remaining parent affect and well-being scores were significantly correlated with all of the child context scores in expected directions. Tests of moderation were conducted using hierarchical linear modeling (HLM) regression analysis to control for within family correlations in BASC-2 mean scores. The significant main effect for the grouping variable (DD versus control) onto depression while controlling for family income was previously established (see Hypothesis 1). Due to SPSS not being able to output standardized parameter estimates in

HLM, all variables were centered prior to analyses so that output results would be standardized. Tests of significance of the various BASC-2 problem and adaptive scales were conducted in separate HLM regressions onto depression controlling for household income (see Table 16). All BASC-2 scales except internalizing problems significantly predicted parental depression after controlling for within family correlations and household income. Next, interaction terms were calculated between each of the BASC-2 scales and the dichotomized group variable. Hierarchical linear modeling was used to test the significance of the interaction between study group and child context measures by entering the main effects, household income, and the interaction between the dichotomized group variable with each of the BASC-2 scales (see Table 16 for results). The hypothesis was not supported such that none of the interactions were significant, thus indicating that the influence of diagnostic grouping on depression does not significantly differ across levels of any of the child context variables.

Post-hoc analyses were conducted using HLM regression analyses to further evaluate if the coping and resource variables may buffer the impact of child stressors on parent well-being. Partial Pearson correlations controlling for household income were calculated between the child stressor variables and parent well-being. None of the specific child context variables on the BASC-2 were associated with parental happiness, general well-being, or spiritual well-being. The problem scales of the BASC-2 were significantly related to depression and anxiety (see Table 17). Of these, externalizing problems and internalizing problems were selected due to their stronger correlations with depression and anxiety and in order to reduce number of analyses and risk for type I error. Following, partial correlations were calculated between the coping and resource variables

and parental depression and anxiety. Of the coping and resource variables, only active positive coping (partial $r = -.27, p \leq .05$), avoidant-aggressive coping (partial $r = .32, p \leq .01$), and positive affect from child (partial $r = .27, p \leq .01$) were significantly correlated with depression. The only significant association between resource and coping variables with anxiety were for avoidant-aggressive coping (partial $r = .30, p \leq .01$) and substance abuse / humor coping (partial $r = .21, p \leq .05$). Partial correlations between these coping methods and internalizing problems were not significant.

Thus, to further reduce number of analyses, only moderators of the relationship between child internalizing and externalizing problems and depression were calculated. Regression was conducted using HLM to control for inter-family correlations and household income to test moderation effects between these variables. Results are detailed in Table 18. The only significant moderating relationship was active positive coping on the relationship between child internalizing problems and parent depression. Graphing of the interaction indicates that with increased reliance on active positive coping methods, the association between child internalizing problems and depression is attenuated.

Hierarchical linear modeling regression was conducted to control for inter-family correlations and household income to test moderation of the relationships between child problems and parental anxiety. Results are detailed in Table 19. The only significant moderating relationship was substance abuse / humor on the relationship between internalizing problems and parent anxiety such that higher levels of substance abuse / humor are related to decreased magnitude in the relationship between anxiety and child internalizing problems.

Parent Use of Coping and Support Variables. Table 20 details between group comparisons for each of the coping variables. Several participants submitted incomplete Brief COPE and Brief RCOPE questionnaires. Thus, analyses for the various coping dimensions include different sample sizes. Aside from the active-positive coping variable, where parents in the PPD group were more likely to use this strategy than parents of typically developing children ($t(63) = 3.37, p \leq .01$), no significant differences were identified across groups in coping methods.

Table 21 details support and resource characteristics across study groups and results of tests for between group differences. Univariate ANOVAs were conducted to evaluate if there were significant differences across groups in the various coping and support variables. No between group differences were found for social support, $F(2, 86) = 1.13, p = .33$. Positive affect toward child and positive affect from child both showed differences across groups ($F(2, 88) = 10.34, p \leq .01$ and $F(2, 88) = 6.55, p \leq .01$, respectively). Post-hoc analyses indicated that for both variables there were no differences between the PDD and ADHD groups, but each of the clinical groups were significantly different from the control group in the expected directions such that parents of children with developmental disabilities shared less positive affect with their child than parents of typically developing children. No group differences were found in overall closeness ($F(2, 88) = .82, p = .44$). There were significant differences across groups in number of services accessed $F(2, 88) = 20.09, p \leq .01$. Post-hoc analyses showed that the PDD group accessed the most services, followed by the ADHD group. Analysis of who received these services indicated that only child directed services attained significant differences across groups, $F(2, 88) = 32.58, p \leq .01$. Post-hoc analyses indicated again

that parents in the PDD group accessed the most services, followed by the ADHD group for child-directed services.

Hypothesis 5- Role of Parent-Child Relationship in Predicting Well-being Among Parents of Children with PDD. Analyses in Hypothesis 2 established a positive association between several of the parent-child relational scales on the PAI with parental well-being (see Table 10). Of the PAI scales, positive affect from child showed the strongest and most consistent prediction of affective and well-being scales in the overall study sample and was thus selected for analysis of potential interaction effects with child characteristics in predicting affect and well-being among parents of children with PDD. Model statistics indicated that 11.4% of the variance in spiritual well-being was explained by positive affect from child and household income and 20.3% of the variance in general well-being was explained by positive affect from child and household income. Prediction of happiness approached significance, $\beta = -.20$, $t = -1.86$, $p = .07$. Recall that the positive affect from child scale was reverse square root transformed to correct non-normality in distribution of scores. Thus, these relationships are in the expected direction of positive affect from child serving as a potential promoter of positive well-being among parents of children with PDD.

Next, to analyze if positive affect from child could buffer the influence of child stressors on parent well-being, main effects for the child characteristics (externalizing problems, internalizing problems, attention problems, social skills, functional communication, perceived IQ) were regressed onto general well-being and spiritual well-being in 12 separate hierarchical regression analyses controlling for household income in

step 1. The only significant child context predictor of spiritual well-being was attention problems ($\beta = -.39, t = -3.20, p \leq .01$), with the overall model explaining 49.9% of the variance in spiritual well-being, $F(2, 33) = 16.44, p \leq .01$. Social skills contributed unique prediction of variance in general well-being, $\beta = .33, t = 2.19, p \leq .05$, with the overall model including household income predicting 29.7% of the variance in the dependent variable, $F(2, 32) = 6.75, p \leq .01$. Functional communication contributed unique prediction in general well-being, $\beta = .34, t = 2.25, p \leq .05$, with the overall model including household income explaining 27.4% of the variance, $F(2, 31) = 5.86, p \leq .01$. Attention Problems contributed unique prediction of general well-being ($\beta = -.40, t = -2.79, p \leq .01$), with the overall model including household income explaining 34.9% of the variance in general well-being, $F(2, 32) = 8.59, p \leq .01$. Tests of models where Attention Problems, Social Skills, and Functional Communication were entered simultaneously into Step 2 after controlling for income in Step 1 indicated that only Attention Problems contributed significant unique prediction of general well-being.

The various significant main effects were centered using z-score transformations and interaction terms between positive affect from child with attention problems, functional communication, and social skills each were calculated. Hierarchical regressions were used to test these interactions after controlling for income and main effects. None of the four hierarchical regression tests showed significant interactions. Thus, there was no support for quality of the parent-child relationship buffering the impact of child disability characteristics among parents of children with PDD on their affective or psychological well-being.

Discussion

Psychological Well-being among Parents Groups

Risk for Psychopathology. A primary focus of this study was to replicate findings that parents of children with developmental delays (DD) are at risk for psychological distress relative to other parents and, further, to examine factors that account for this risk. As a group, parents of children with either ADHD or PDD were more likely to endorse depressive symptoms than parents of typically developing children. The expected findings of risk among parents of children with DD for anxiety were not found. Although not completely replicating prior research findings, this study does support the hypothesis that parents increased distress due to having a child with a DD.

Rates of clinically significant depression (21.1% for PDD group, 30.8% for ADHD group) and anxiety (5.3% for PDD group, 11.5% for ADHD group) in this sample were lower than has been identified in other studies. In particular, the Bitsika and Sharpley (2004) study in Australia identified staggeringly high rates of pathology among parents of children with autism (39% - 67% reporting High to Severe anxiety and depression). There could be several explanations for the divergence of findings here. For one, the Australian sample may have had access to very different supports and resources than has been available to the parents in Michigan represented in this sample. Additionally, the Bitsika and Sharpley (2004) study was published 4 years ago. Over the past few years, there has been an explosion of autism research and increased public awareness about autism. Additionally, although still lagging behind the demand, there are more evidence based services available now to families and these children than in the past. Parents may feel less alone and more like they have treatment options today than in

the past. This may explain why the results from this study also failed to replicate prior studies in finding that parents of children with PDD were more socially isolated. On average, regardless of perceived effectiveness, the parents of children with PDD accessed 7 separate treatment services. All of the children with PDD in the current study received some form of treatment. In comparison, 76.5% of the parents completing Bitsika and Sharpley's (2004) study responded that they had accessed services directed to support them. Although the questions asked here of parents were slightly different, it is possible that the sample in the present study received more services on average than parents participating in prior research.

Previous research comparing parents of children with PDD to children with mixed psychiatric problems suggested that parents of children with PDD could be at increased risk for depression and anxiety relative to parents of children with ADHD. This has been the first study to explicitly compare these two groups of parents. There were no significant differences between parents of children with PDD versus ADHD in the self-reported depression or anxiety levels. Examination of child related stressors sheds some light on why parent differences between these two groups did not emerge. As expected, children with PDD were the most delayed in social and communication skills. However, children with ADHD had, on average, more externalizing and internalizing problems and attention problems than the children with PDD. Each of these specific aspects of the child context predicted anxiety and depression symptoms. Thus, it could be that whereas children with PDD and ADHD have different profiles of challenges, these challenges result in similar overall stressor load on parents and, consequently, similar well-being profiles.

Another explanation for the decreased risk for depression and anxiety relative to other studies may be the specific sample recruited for this study. As a whole, the sample was well educated and household income was high. Although income was statistically controlled for in analyses, it is possible that there is simply a decreased base-rate in depression and anxiety among all parents with high educational and income achievements resulting in the relatively small sample size in this study simply not capturing these parents. Household income in this study was associated with decreased externalizing, communication, and attention problems in children ($|r| = .28 - .33, p \leq .01$), as well as decreased affective problems and increased general well-being and happiness among parents ($|r| = .22 - .35, p \leq .01$). Covarying income in analyses resulted in much of the variance in affective and cognitive / attitudinal well-being being taken by income and problems with multicollinearity in regression analyses, which may have contributed to Type II error.

Positive Adaptation. This study departed from a tradition in the literature to look solely at negative adjustment among parents of children with DD. Assuming only a tragic impact of having a child with a disability on parents is unrealistic and limits the ability of research to help more parents achieve and maintain positive health. Results of this study indicated that parents, regardless of if their child had ADHD or PDD, experienced happiness, general well-being, and spiritual well-being at similarly high levels. This was contrary to qualitative research findings indicating that having a child with PDD resulted in transformative changes in parents' outlook on life (Scorgie & Sobsey, 2000). Other empirical research has either found the same finding here (Seltzer,

Greenberg, & Floyd, 2004) or that parents of children with PDD experienced decreased well-being relative to other parents (Nachshen & Minnes, 2005; Sivberg, 2002).

This research attempted to address a problem in prior empirical research by measuring aspects of well-being parents of children with DD described as having been transformed as a result of having a child with special needs in their lives. Measures for personal growth, relations with others, environmental mastery, and spiritual well-being were planfully included in this research. No significant differences in these aspects of well-being were found across groups. The discordance between what parents are saying and what empirical research has been finding may be due to inappropriate operationalizing of well-being used in the empirical research. Perhaps researchers are still not asking the right questions. Also possible is that the bonadaptation that parents describe in narrative accounts come from an ability to positively reframe life stressors rather than a true transformative improvement in their well-being. In fact, parents of children with PDD were found to rely more on positive and active coping methods than parents of typically developing children. Another possibility for this lack of between group differences in happiness and cognitive and attitudinal aspects of well-being is that perhaps only a small portion of parents rise above the challenges of parenting a child with a developmental delay to experience bonadaptation. If this is indeed the case, it would be important to identify these parents, conduct careful qualitative research on their experiences and coping, and construct measures to capture the positive well-being they describe. Additionally, it is difficult to identify true transformative effects of having a child with PDD without conducting a longitudinal study.

Parents of children with ADHD and PDD were just as happy, just as healthy spiritually, and just as positive in their general attitudes and thinking about their lives as parents of typically developing children. Perhaps one source for the resiliency in parents of children with DD despite significant child stressors is the increased use of active positive coping methods relative to parents of typically developing children. Support for this idea was found in the significant moderating effect, described in more detail in a later section of this discussion, of active positive coping on the relationship between child internalizing problems and parental depression across the entire sample.

Relationship Between Child Characteristics and Parental Well-being

Another aspect of the theoretical model was that child diagnosis would be related to parent well-being. As expected, child externalizing problems, attention problems, internalizing problems, social delays, and communication delays were related to increased anxiety and depressive symptoms among parents. Although not remaining significant after controlling for income, these behavioral and emotional problems were associated with decreased general well-being. Child behavioral characteristics overlapped in children with ADHD and PDD. Specifically, although in different degrees, children with ADHD and PDD often shared deficits in social competence, behavioral, and attentional problems. The considerable overlap suggests nosological issues. Children with PDD often have comorbid ADHD. There is also considerable variability in presentation of children with PDD such that the children in this study presented with a broad range of intellectual and behavioral characteristics. Additionally, children with ADHD often present with social difficulties although these appear to be secondary to

poor attention to social cues and difficulty with behavioral inhibition rather than a fundamental deficit in social cognition as is the case with children with PDD. Many of the children with PDD in this study were also diagnosed with ADHD and had attentional difficulties and externalizing behavior problems. Thus, parents of children with PDD versus ADHD only experience shared stressors which may contribute to the failure to find differences in well-being among the two clinical groups. Rather than focusing on diagnostic group differences to discern parental experiences of stressors, it may be more relevant to focus on the specific child-related stressors.

Association between Coping, Resources, and Parent Psychological Well-being

Regression analyses including the various parent health and coping and resource factors supported that a significant portion of variance in parent health was explained by coping and resource factors. Additionally, predictors of parent psychopathology differed from predictors of positive adjustment. Avoidant-aggressive coping, social support, felt closeness, and household income predicted 35% of the variance in general psychological well-being. Prediction of depression, however, was only associated with income, active-positive coping, and avoidant-aggressive coping, with the overall model accounting for 22% of the variance in depression scores. This finding supports the importance of separately measuring positive affect and well-being from negative affect. Due to the small sample sizes in each of the parent groups relative to number of analyses being performed, unique coping styles and differential effectiveness of coping and resources among parents of children with PDD versus other parents could not be examined. This question remains important because there are aspects of parenting a child with PDD.

Thus these parents may require specific types of support to combat these unique stressors and to promote positive well-being.

Parental Coping Strategies for Child-related Stressors. This research was the first to examine parental coping with the specific stressors that parenting their child introduces to their lives. Prior research has assumed that parents cope with parenting demands in the same manner that they cope with other daily life demands. However, it was argued here that parenting a child with developmental delays introduces unique challenges that may elicit a separate set of coping behaviors from parents. Also proposed was to examine specific coping behaviors rather than broad coping styles. However, given the large number of analyses already needed to examine moderation effects on a large number of psychological well-being variables, decision was made to reduce the number of analyses to enable appropriate focus on whether coping in general had an impact on well-being. Thus, factor analyses were conducted on the 10 coping dimensions of the Brief COPE into 3 broad styles of coping: active positive, avoidant aggressive, and substance abuse / humor coping. As has been found in the coping literature, active positive coping strategies for child related stressors were associated with fewer depressive symptoms, increased happiness, increased general well-being, and increased spiritual well-being after controlling for family demographic characteristics. Avoidant and aggressive coping strategies were related to increased depression and anxiety symptoms and decreased happiness and general well-being. Reliance on substance use and humor was not associated with positive or negative parental adjustment after controlling for household income. This may have been due to only a small minority of parents in this sample

endorsing using substances to cope with child related stressors as well as possible misinterpretation of the questionnaire items tapping humor.

The finding that humor loaded with substance abuse and was negatively related to positive adjustment was unexpected. Examination of the humor items on the Brief COPE in context of the altered instructions in this study to respond to the questionnaire based on specific coping with child-related stressors suggested parents may have interpreted these items as making fun of and laughing at their child. Humor has been identified in research (Roussi et al., 2007) as being an adaptive method to cope with life stressors. Perhaps in context of coping with child-related stressors humor may be representative of an unhealthy defense mechanism that distances parents from problems in a way that exacerbates the impact of stressors. Also possible is that use of humor to cope with child-related stressors presented by children with ADHD and PDD is representative of a failure to appropriately empathize with the child's struggles and inability to modulate ones own stress to maintain appropriate parent-child boundaries.

Of the three groups of parents, parents of children with PDD were found to rely most heavily on active positive methods of coping when dealing with stressors related to their child. It appears that having a child with a developmental delay forces parents to be more active and positive in their coping and that when their child has PDD they are mobilized further in this regard. Presumably, parents of children with DD developed an increased reliance on these methods as a consequence to experiences with their child. Both PDD and ADHD involve lifelong impairments for which there continues to be no cure. Parents of these children are often at odds with schools and their communities to get appropriate educational services and acceptance for their children. In the case of

PDDs, the impairment is often more pervasive and profound and the treatment is more complex and limited in its effectiveness in addressing core symptoms of the disorder. Parents of children with PDD are faced with a sea of treatment options, many of which are costly and lack empirical validation. Access to professionals with expertise in this area is difficult and when there is access, professionals offer them limited answers for what could work. Faced with a circumstance of a child with problems and limited available treatment, parents of children with PDD may feel especially pressed to be actively involved in their child's care, reframe setbacks, plan carefully ahead when interacting with their child.

The study also examined whether a definitive idea about the source of the child's disability would be associated with better parental adjustment. Parents of children with ADHD and PDD are constantly asking why their child developed these conditions. Regardless of motivations, it was expected that having an idea about what caused their child's disability would be related to better adjustment by way of giving parents a sense of control over their lives. This relationship was not supported as no associations with well-being were found with causal attribution or belief in a cure as possible for their child. There was a trend toward parents who had a positive causal attribution about the etiology of their child's disorder being happier. Failure to find a significant effect may be due to the crude measurement of causal attribution used here as well as due to the sample size being too small to detect effects. However, the trend suggests that this aspect of parent adjustment might be explored further in future research using larger sample sizes and more specific measurement strategies. The trend also supports importance of explaining to parents upon diagnosing children what may have caused the child's disorder, even if a

clear causal relationship cannot be identified. In fact, parent responses in this study identified a variety of etiological sources to ADHD and PDD with mixed scientific support.

The positive and negative religious coping scales failed to adhere to statistical assumptions of normality and equality of variance across groups required for parametric statistics. Thus, the scales were not examined for their relationship to parental well-being and affect. Several of the participants also crossed out portions of the text in the scale and replaced them with “God,” indicating that these participants had difficulty relating to the wording of the scales. Although the original intent when re-wording the scale was to make it more inclusive of non-monotheistic faiths, the high prevalence of Christian religious identifications in the current sample may have resulted in the re-wording of the scale alienating some participants in the sample. What was evident, however, in the large font and exclamation marks of participants who had diligently crossed out “my religion,” “my God,” and “or a higher power” and emphatically inserted the word “God” in their place was that religion is an extremely important part of people’s lives that should continue to be explored in research.

External Resources and Supports for Parents. Another source of resilience for both the PDD and ADHD parents groups could be the relatively more frequent use of formal treatment services for the child and the family compared to parents of typically developing children. There was a significant negative association between total services and parental depression and positive association with general well-being. However, when income was controlled in regression analyses, number of services did not predict any of the parent well-being measures. Income was significantly associated with several

of the parent well-being measures as well as number of services accessed. Additionally, income was confounded with group membership such that the control group had a significantly higher family income than the ADHD group. Thus, a definitive conclusion regarding whether or not interventions for children with DD and their families support parent well-being cannot be made. Future research using larger samples sizes where socio-economic status is more equally represented across study groups should examine this important role of interventions for parent health and, specifically, if services are helpful to parents of children with DD.

This study was the first to examine the importance of the parent-child relationship among parents of children with developmental disabilities in determining parent health. Most parents in the study identified as feeling very close to their child. Positive affect felt from the child and toward the child as well as perceived closeness with the child were associated with decreased depression symptomatology, increased happiness, and increased general and spiritual well-being. Thus, as expected, the parent-child relationship is a particularly important aspect of support for parents. General social support, however, was significantly associated with general well-being only, suggesting that the parent-child relationship influences more aspects of parent well-being than general social support.

Parents of children with PDD and ADHD did not differ from one another in the affection shared with their child; however as a group they shared less affection than parents of typically developing children with their child. When looking at just parents of children with PDD, parent-child relationship continued to predict general well-being and

spiritual well-being after controlling for household income. Prediction of happiness in the PDD sample approached significance.

Moderators of Parental Adjustment

Moderation effects of the various coping and resource variables could only be tested for parent depression due to this being the only aspect of well-being that differed across groups (DD versus control group). None of the coping and resource variables were found to buffer the impact of child diagnosis on parental depression. Moderators of the relationship between child diagnosis and positive aspects of well-being could not be tested due to there not being any group differences in positive well-being. As previously discussed, it is possible that child diagnosis itself was not the primary child-context variable to predict parent well-being as originally hypothesized. Thus, post-hoc analyses were conducted to examine if the coping and resource factors would moderate the relationship between the specific child-related stressors and parent well-being. For the prediction of parental depression, active positive coping strategies moderated the relationship between child internalizing problems and parental depression, such that the association decreased with increased use of active positive coping strategies. Although this finding should be interpreted with caution due to the large number of analyses in this study risking Type I error, the finding suggests that taking action to address child related stressors, planning, and positive reframing methods reduces parental depression symptomatology when their child has internalizing emotional problems.

Increased reliance on substance abuse / humor coping was associated with decreased strength in the relationship between parental anxiety and child internalizing

problems. This was contrary to expectation as it was expected that use of substance abuse / humor coping would exacerbate the risk posed by child internalizing behaviors for parental anxiety. The substance abuse / humor factor was a combination of theoretically divergent methods of coping. In fact, substance abuse is considered a maladaptive coping strategy whereas humor has been identified in previous literature as being protective. As previously discussed, parents may have interpreted the humor coping questions in a way such that use of this strategy represented minimizing of the child's problems and being unempathic and emotionally unavailable to their child.

Examination of the quality of shared positive affections between parent and child as a moderator of the relationship between child stressors and parent well-being indicated that there was no significant moderation effect across the entire sample. Moderation analyses for just the ADHD and PDD parent groups were not completed due to lack of power in detecting significant moderator effects with the sample size obtained. Future studies with a larger sample size should investigate if quality of the parent-child relationship does indeed buffer the impact of child related stressors among clinical groups on parental well-being.

Although this study only found that two of the coping and resource variables significantly moderated the effect of one of the child related stressors on parent psychopathology, this should not be taken that these coping and resource variables are unrelated to parent well-being. Despite not finding more of the expected moderation effects, there were significant associations between the coping and resources and parent well-being as expected. Additionally, there was also support for child-related stressors predicting parent well-being. Lack of finding significant moderator effects may have

been due to coping and resources not having specific effects on child related stressors as was modeled in this empirical study. As was discussed in the literature review, the inconsistencies in research on moderators of well-being may also be due to measurement issues where the instruments used may not have reflected the constructs that they aimed to measure. Measures specifically tapping the constructs that were identified in the narrative and empirical research as relevant to the questions posed for this study were carefully selected. However due to the number of analyses planned, some of the variables were subjected to principal components analysis to reduce number of analyses and the risk for Type II error. As previously mentioned, the substance abuse and humor factor of coping was not anticipated to emerge in the principal components analysis and falling together due to these constructs being theoretically divergent. Due to this measurement issue, it remains unclear if substance abuse or humor can independently moderate the relationship between child stressors and parent well-being.

Study Weaknesses and Recommendations for Future Research

Although planning for this research involved considerations of critiques of the existing literature and research design involved many adjustments to remedy the limitations that have existed, there were a number of anticipated and unanticipated limitations that emerged in this study. Some of these limitations came about through the original proposal to be more specific and thorough in measurement, which resulted in an unmanageable number of analyses being proposed and risking statistical problems with Type I error. Following, variables were reduced to a more feasible balance of sample size, number of analyses, and number of variables in an effort to limit Type I error. Thus,

despite efforts to be more specific, this research only partially accomplished this feat. Additionally, there were a number of sampling, measurement, and methodological issues that should be addressed in future research.

Sampling. Prospective power analysis indicated that the sample size was more than sufficient to detect large effects that had been found in prior studies on parental depression and anxiety among parents of children with DD. Failure to replicate group differences in parent psychopathology and general well-being in prior research may be due to the effect size of group differences among the Michigan population of parents being smaller than estimates based on previous research in other geographic areas suggested. Parents of children with DD in Michigan may be better off than parents sampled on other research. Alternatively, the sample size may have been appropriate but sampling biases may have influenced results. Parents struggling may not have been adequately captured in the recruitment process. Despite efforts to recruit a socioeconomically representative sample through using school recruitment methods, the sample recruited was generally well educated with high annual income and was thus not demographically representative of the Michigan population. As previously mentioned, there may be a lower rate of psychopathology among parents at higher socioeconomic levels. Due to the low base-rate of PDD and ADHD in the general child population, it was difficult to locate a large number of parents of children with these clinical diagnoses. The parents who did participate may have been psychologically healthier, thereby having more internal resources to complete demands necessary for participation in a research study. Although income was controlled for in analyses, there were significant group differences in income such that the control group had significantly greater income than

the other two groups, thereby introducing a significant problem with multicollinearity that limited the ability to detect between group differences.

Efforts were made to incentivize parents to participate once located by discussing the potential benefits of the study to families of children with DD and offering parents lottery entries to win substantial prizes. More parents expressed interest and were thus mailed research packets for the study than returned questionnaires. Phone follow-up with parents indicated that most parents who did not return the questionnaires still intended to complete the questionnaires, but had difficulty finding the 1.5 hours of time needed. Obtaining complete data from parents of children with ADHD was most difficult and phone follow-ups were conducted in attempt to obtain responses to questions skipped. Additionally, part way through data collection the incentive for this group was changed to a financial incentive of \$15 for participation. The comparison group of parents was surprisingly the most difficult to recruit, presumably due to decreased motivation to participate in a study where the population of focus did not directly apply to them. Many of the parents in the control group were in helping or scholarly professions (e.g., teachers / professors, special education aides). The final sample obtained was a result of strenuous data collection efforts over a period of 1.5 years. A more representative sample of parents might be obtained in future research through increasing participation incentives and recruiting from more general community venues. Additionally, in-person data collection would likely increase participant engagement, increase standardization and researcher control in data collection, and improve study completion rates.

Another limitation of this study was that diagnostic confirmation and intellectual testing results were achieved for only a small portion of the children reported for in this

study. Correlation analysis supported using parental perceptions of their child's intellectual level for this study, but this method is neither psychometrically valid nor reliable. Future research should obtain confirmations of intellectual testing and diagnostic testing results. Both ADHD and PDD are currently popular diagnoses in medical clinics and in schools, thereby running the risk for over diagnosis or mis-diagnosis of problems. Further, parents may have difficulty understanding clinician and school assessment findings of "features of" a clinical diagnosis versus when actual diagnosis has been made. Parent reported diagnoses in this study may thus represent over-reporting of PDD and ADHD, thus contributing to failure to find significant between group differences in affective and cognitive / attitudinal well-being among parents in these groups versus controls.

Measurement. As previously discussed, coping and well-being variables had intentionally been chosen to identify specific coping behaviors and aspects of well-being relative to parents. However, the large number of variables that resulted made analysis unmanageable and thus in the interest of the primary focus of this study to identify if coping and resource factors moderate aspects of well-being, principal components analysis was used to reduce the number of variables involved in analysis. Thus, it is unclear what aspects of the active positive coping factor (positive reframe, active problem solving, or planning ahead), if not all aspects, were the active agents in predicting positive adaptation. Similarly, it remains unclear if use of humor in managing parenting demands could be adaptive due to these items being clustered with substance abuse items. Additionally, as previously discussed, the wording of the humor items may have been interpreted by parents as laughing at or minimizing their child's difficulties.

Future research might focus on specific coping strategies to identify which aspects of the factors examined in this study influence parental well-being. A larger sample size would also allow for more specific aspects of coping and well-being than was within the scope of possibility for this study due to the large number of planned analyses. Larger sample sizes across groups would permit the examination of unique coping styles and the differential effectiveness of coping and resource supports of parents of children with PDD. Pilot research on use of humor coping strategies for child specific stressors should be conducted to validate the measure for parents of children with DD to ensure that the questions are more clearly and uniformly interpreted by respondents.

Another limitation was that parental coping and well-being ratings were all self-report questionnaire ratings. Although the measures in this study, with the exception of the *Professional Services and Supports Questionnaire* developed for this study, were determined to be valid measures of constructs in previous studies, self-report measures rely heavily on the respondent's ability to be insightful regarding their own functioning. Further, the questions were generally quite face valid and there may have been a halo effect in responding. For example, parents may have felt a strong pull to respond in a religiously faithful manner to questions related to their spiritual coping and health. With respect to the *Positive Affect Index*, it is unclear what criteria parents used to determine how close they felt to their child. Future research might examine these relationships further using clinical measures of the parent-child relationship such as direct observation and rating by a professional trained in evaluating relationship quality. External ratings of parental coping strategies and well-being through clinical interviews may facilitate further validity in measuring these constructs as well.

Qualitative responses offered by participants in the religious coping and well-being questionnaires suggested that religiosity is an important aspect of parents' lives that is relevant to their parenting a child with special needs. The efforts made to adjust the *Brief RCOPE* and *Spiritual Wellbeing Scale* items to be appropriate for non-monotheistic faiths appeared to result in alienation of many participants in this predominantly Christian sample. Future research on highly religious groups should take care to ensure that any measures of religious coping and religious well-being be culturally appropriate to that specific population.

As previously discussed, service utilization was analyzed through a count of number of services accessed and this variable did not independently predict psychological well-being when other variables were included. Analysis of specific types of services accessed may clarify the important question of if and what types of services influence parental well-being. Inclusion of larger sample sizes for clinical groups where socioeconomic status is more equally distributed across groups would be important to addressing this question as well.

Methods. Another risk with having parents provide information on both their coping and well-being is source bias, such that correlations between these variables may have been partially attributed to the fact that the data were provided by the same source. Child adaptive behaviors and problems were also provided by parents, however the source bias effect was partially offset by teacher ratings of the child's functioning. Teacher ratings were only achieved for 64% of the children included in this study. External ratings of parent variables and child functioning would address the problem of source bias in future research to further clarify the relationships between these constructs.

As previously discussed, one explanation for failure to replicate narrative accounts of positive transformation as a result of having a child with PDD is that perhaps only a small subset of parents experience this transformation. If this is indeed the case, it would be important to identify these parents, conduct careful qualitative research on their experiences and coping, and construct measures to capture the positive well-being they describe to ensure that research on positive adaptation includes the relevant well-being constructs. Following, identification of moderators of positive well-being could be re-examined as relevant to the resulting constructs of well-being.

Transformative effects of having a child with special needs cannot be effectively identified without conducting longitudinal research. Data on coping and psychological well-being must be collected prior to experience of child related stressors and parents must be followed during the transformative process. Recruitment of a representative sample would be difficult, however possible through recruiting those with genetic risk of having a child with PDD. Family members of people diagnosed with PDD could be recruited prior to having children. This research may also be accomplished through collaboration with large scale longitudinal child development research, though the low base-rate of PDD makes this method difficult.

Future research might also examine similarities among parents who have shown positive adaptation versus negative adaptation through clustering these two groups. The current study did not have a large enough sample of parents with clinically significant anxiety and depression to accomplish this analysis.

Conclusions.

Despite limitations, this study provides important insight into how research on parental coping with having a child with DD could proceed. Additionally, results provide important implications to policy and practice relative to children with PDD and their families. Although support for specific risk was not found among parents of children with PDD, as a group parents of children with DD experienced increased risk for depression symptomatology relative to parents of typically developing children. This increased risk occurred despite accessing professional services. Findings thus suggest that additional supports are necessary and that parents of children with DD may have limited access to effective treatments across.

This study departed from tradition of focusing on negative outcomes among parents of children with special needs. Positive affect and attitudes toward life are important aspects of parent health that are influenced by having a child with DD. Additionally, the study suggested that predictors of positive adaptation are different from predictors of negative adaptation. Researchers and clinicians should not neglect positive affect and positive attitudes in parent functioning and assume that negative adjustment negates the experience of positive emotions and attitudes. Continued neglect of positive well-being would limit the ability of clinicians to fully understand and support parent's and researcher's ability to identify variables that support parents.

Access to supportive relationships (parent-child relationship included) and abstaining from aggressive and avoidant coping strategies predict positive outlook about one's life. In terms of reduction of risk for depression, abstaining from avoidant and aggressive coping strategies and reliance on positive and active coping methods appear to

be most helpful. Professionals should continue to support parents in to be actively involved in their child's treatment as it appears that parents benefit from these actions. Assuming that more effective services would support additional benefit of active coping methods on parental well-being, additional research on treatment efficacy should be conducted.

Another important contribution of this study was it's inclusion of the parent-child relationship as a major source of support for parents of children with PDD. Results supported that the parent-child relationship is significantly and more broadly related to parent well-being than other social supports. Family-centered treatment involving parents in the therapeutic process with children with PDD as well as targeting the parent-child relationship clinically would not only benefit parental health, but would undoubtedly also benefit the children.

APPENDICES

APPENDIX A

Identifying Information

(This information will be filed separately from questionnaire responses to protect your and your child's confidentiality)

Parent Information:

Name: _____		Age: _____	
Relation to Child:	☐ biological mother ☐ adoptive mother ☐ step-mother ☐ other (please specify): _____	☐ biological father ☐ adoptive father ☐ step-father	
Address: _____ _____			
City: _____		State: _____	Zip Code: _____
Phone: () - _____			

Child Information:

Name: _____		Age: _____	
Date of Birth: _____		Gender: M / F	

Social History Form

Parent Information:

Ethnicity (check all that apply):

- | | |
|--|---|
| ☐ Non-Hispanic / Latino White
☐ Hispanic/Latino
☐ African American
☐ Other: _____ | ☐ American Indian or Alaska Native
☐ Asian
☐ Native Hawaiian or other Pacific Islander |
|--|---|

- Marital Status:**
- | | | |
|-----------------------------------|------------------------------------|----------------------------------|
| ☐ married | ☐ single | ☐ widowed |
| ☐ divorced | ☐ separated | |

Do you have sole or joint custody of this child (circle one)? sole joint

Religious Affiliation:

- | | |
|--|---|
| ☐ Catholic
☐ Lutheran
☐ Baptist
☐ Protestant
☐ Christian, Non-denominational
☐ Mormon | ☐ Agnostic
☐ Muslim
☐ Buddhist
☐ Hindu
☐ Judaism
☐ None
☐ Other: _____ |
|--|---|

Highest educational achievement:

- | | |
|--|---|
| ☐ Less than 9 th grade
☐ Some High School
☐ High School Graduate / GED | ☐ Some college / specialized training
☐ 4 year college graduate
☐ Graduate / professional degree |
|--|---|

Employment Status:

- | | |
|---|--|
| ☐ Full Time
☐ Part Time
☐ Laid Off | ☐ Retired
☐ Homemaker
☐ Other (specify) _____ |
|---|--|

Occupation: _____

Household Income:

- | | | |
|---|---|---|
| ☐ less than \$15,000 | ☐ \$15,000 to \$29,999 | ☐ \$30,000 to \$44,999 |
| ☐ \$45,000 to \$69,999 | ☐ \$70,000 to 100,000 | ☐ Over \$100,000 |

Do you have any physical or mental health problems? (If yes, please list):

Number of other children living in your home (including the child for this study):

How many of these children (including child for this study) have a medical / psychological disability? Please indicate each diagnosis that each child has.

This Child:

Sibling 3:

Sibling 1:

Sibling 4:

Sibling 2:

Sibling 5:

Child Information: (the following are questions involving the child for this study only)

Ethnicity (check all that apply):

☐ Non-Hispanic / Latino White

☐ Hispanic/Latino

☐ African American

☐ Other: _____

☐ American Indian or Alaska Native

☐ Asian

☐ Native Hawaiian or other Pacific Islander

Grade in School: _____

School District: (or name of school) _____

Is your child in a special classroom?

Yes ☐ full day

☐ No

☐ half day

☐ other _____

**Age at
Diagnosis:** _____

Does your child qualify for special education services because he / she was evaluated to be Autism Impaired (AI)? Y / N

Please indicate ALL diagnoses that currently apply to this child and how old the child was when the diagnosis was made: **Age at Diagnosis:** _____

☐ Autistic Disorder

☐ Asperger's Disorder / Asperger Syndrome

☐ Pervasive Developmental Disorder – Not Otherwise Specified

☐ Fragile X syndrome

☐ Down Syndrome

☐ Attention Deficit / Hyperactivity Disorder (ADHD)

☐ Other (please specify): _____

Did your child receive a medical diagnosis from any of the following professionals? (check all that apply)

☐ Family Physician

☐ Psychologist (Psy.D. / Ph.D.)

☐ Psychiatrist (MD)

☐ Neurologist

☐ Other (please specify): _____

Is your child currently taking any prescription medications? (if yes, please list below):

_____	_____
_____	_____
_____	_____

Developmental Milestones:

At what age did your child first do the following? (indicate year/month of age)

Crawl	_____
Walk	_____
Speak first words	_____
Speak in sentences	_____
Toilet Trained	_____

Did your child experience a loss of skills? Y N

If YES, which skill(s)? _____

Does your child use vocabulary that is advanced in comparison other children his / her age? Y N

Which of the following do you believe is representative of this child's intellectual ability?

- ☐ Mentally Impaired ☐ Below Average ☐ Average ☐ Above Average
☐ Superior

Please describe aspects of this child that you enjoy:

What do you believe are strengths that this child has:

If your child has an Autism Spectrum Disorder or ADHD, do you believe that your child can be cured? Yes No Don't Know

If your child has an Autism Spectrum Disorder or ADHD, how do you believe your child developed the disorder?

Professional Services and Support Questionnaire

We are interested in the types of services that parents obtain to help themselves, their families, and their child. The following are a list of services directed at helping you / your family and a list of services directed at helping your child. Please indicate whether you or your child has participated in any of these services now OR in the past. For each service / treatment used, please also indicate how effective you found it to be.

Services for you or your whole family:

	Current	Past	Degree of Helpfulness				
			Extremely Not at all Helpful				
1. Individual counseling / psychotherapy	☐	☐	1	2	3	4	5
2. Psychiatric Medication (i.e., antidepressant, anti-anxiety drugs)	☐	☐	1	2	3	4	5
3. Couples therapy	☐	☐	1	2	3	4	5
4. Family therapy	☐	☐	1	2	3	4	5
5. Parent support group	☐	☐	1	2	3	4	5
6. Respite Care	☐	☐	1	2	3	4	5
7. Parent Training	☐	☐	1	2	3	4	5
8. Other(s) (please specify)	☐	☐	1	2	3	4	5
	☐	☐	1	2	3	4	5

Services for this child:

	Current	Past	Degree of Helpfulness				
			Extremely Not at all Helpful				
1. Individual counseling / psychotherapy	☐	☐	1	2	3	4	5
2. Behavior Therapy (i.e., ABA)	☐	☐	1	2	3	4	5
3. Social Skills Group	☐	☐	1	2	3	4	5
4. Psychiatric Medication	☐	☐	1	2	3	4	5
5. Vitamin Therapy	☐	☐	1	2	3	4	5
6. Chelation / Detoxification Therapy	☐	☐	1	2	3	4	5
7. Disability support group	☐	☐	1	2	3	4	5

8. Sensory Integration Therapy / Occupational Therapy	☐	☐	1	2	3	4	5
9. Relationship Development Intervention (RDI)	☐	☐	1	2	3	4	5
10. Music Therapy	☐	☐	1	2	3	4	5
11. Chiropractic Therapy	☐	☐	1	2	3	4	5
12. Special Diet (e.g. gluten free)	☐	☐	1	2	3	4	5
13. Facilitated Communication	☐	☐	1	2	3	4	5
14. Others (Please Specify)	☐	☐	1	2	3	4	5
	☐	☐	1	2	3	4	5
	☐	☐	1	2	3	4	5
	☐	☐	1	2	3	4	5

POSITIVE AFFECT INDEX

The following questions ask about different aspects of your relationship with your child. Please circle the answer that best describes each aspect of how you view your child or how you believe your child views you.

1. How well do you feel that YOU UNDERSTAND this child? A. Not at all well B. Not too well C. Somewhat well D. Pretty well E. Very well F. Extremely well	6. How well do you feel this child UNDERSTANDS YOU? A. Not at all well B. Not too well C. Somewhat well D. Pretty well E. Very well F. Extremely well
2. How much do you <u>trust</u> this child? A. Not at all B. Not too much C. Somewhat D. Pretty much E. Very much F. Extremely	7. How well do you feel your child <u>trusts</u> you? A. Not at all B. Not too much C. Somewhat D. Pretty much E. Very much F. Extremely
3. How <u>fair</u> do you feel you are toward this child? A. Not at all fair B. Not too fair C. Somewhat fair D. Pretty fair E. Very fair F. Extremely fair	8. How fair do you feel this child is toward you? A. Not at all fair B. Not too fair C. Somewhat fair D. Pretty fair E. Very fair F. Extremely fair
4. How much do you <u>respect</u> this child? A. Not at all B. Not too much C. Somewhat D. Pretty much E. Very much F. Extremely	9. How much respect do you feel from this child? A. None at all B. Not too much C. Somewhat D. Pretty much E. Very much F. Extremely
5. How much <u>love</u> do you feel for this child? A. Not at all B. Not too much C. Somewhat D. Pretty much E. Very much F. Extremely	10. How much love do you feel this child has for you? A. Not at all B. Not too much C. Somewhat D. Pretty much E. Very much F. Extremely

11. Taking everything into consideration, HOW CLOSE do you feel is the relationship between you and your child at this point in your life?

- A. Not at all close
- B. Not too close
- C. Somewhat close
- D. Pretty close
- E. Very close
- F. Extremely close

Adapted from Bengtson & Black (1973).

Brief Cope

We are interested in ways that people deal with difficult or stressful situations related to raising a child with a disability versus a child without a disability. There are lots of ways that people respond to parenting challenges. We are interested in how you try to deal with these situations. This questionnaire asks you to indicate what you generally do in difficult situations related to the child identified for this study.

Each item says something about a particular way of coping. Please circle to what extent you do what each item says. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can as they apply to your parenting of this child.

	I don't do this at all	I do this a little bit	I do this a medium amount	I do this a lot
1. I turn to work or other activities to take my mind off things.	☐	☐	☐	☐
2. I concentrate my efforts on doing something about the situation I'm in.	☐	☐	☐	☐
3. I say to myself "this isn't real."	☐	☐	☐	☐
4. I use alcohol or other drugs to make myself feel better.	☐	☐	☐	☐
5. I get emotional support from others.	☐	☐	☐	☐
6. I give up trying to deal with it.	☐	☐	☐	☐
7. I take action to try to make the situation better.	☐	☐	☐	☐
8. I refuse to believe that it has happened.	☐	☐	☐	☐
9. I say things to let my unpleasant feelings escape.	☐	☐	☐	☐
10. I get help and advice from other people.	☐	☐	☐	☐
11. I use alcohol or other drugs to help me get through it.	☐	☐	☐	☐
12. I try to see it in a different light, to make it seem more positive.	☐	☐	☐	☐
13. I criticize myself.	☐	☐	☐	☐

	I don't do this at all	I do this a little bit	I do this a medium amount	I do this a lot
14. I try to come up with a strategy about what to do.	☐	☐	☐	☐
15. I get comfort and understanding from someone.	☐	☐	☐	☐
16. I give up the attempt to cope.	☐	☐	☐	☐
17. I look for something good in what is happening.	☐	☐	☐	☐
18. I make jokes about it.	☐	☐	☐	☐
19. I do something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	☐	☐	☐	☐
20. I accept the reality of the fact that it has happened.	☐	☐	☐	☐
21. I express my negative feelings.	☐	☐	☐	☐
22. I try to find comfort in my religion or spiritual beliefs.	☐	☐	☐	☐
23. I try to get advice or help from other people about what to do.	☐	☐	☐	☐
24. I learn to live with it.	☐	☐	☐	☐
25. I think hard about what steps to take.	☐	☐	☐	☐
26. I blame myself for things that happened.	☐	☐	☐	☐
27. I pray or meditate.	☐	☐	☐	☐
28. I make fun of the situation.	☐	☐	☐	☐

Adapted from Carver (1997)

Brief RCOPE-revised

We are interested in ways that people deal with difficult or stressful situations related to raising a child with a disability. There are lots of ways that people respond to these challenges. We are interested in how you try to deal with these situations. This questionnaire asks you to indicate what you generally do in difficult situations related to the child for this study.

Each item says something about a particular way of coping. Please circle to what extent you do what each item says. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I don't do this at all	I do this a little bit	I do this a medium amount	I do this a lot
1 Looked for a stronger connection with my God or a Higher Power.	☐	☐	☐	☐
2 Sought love and care from my God or a Higher Power.	☐	☐	☐	☐
3 Sought help from my God or a Higher Power in letting go of my anger.	☐	☐	☐	☐
4 Tried to put my plans into action together with my God or a Higher Power.	☐	☐	☐	☐
5 Tried to see how my God or a Higher Power might be trying to strengthen me in this situation.	☐	☐	☐	☐
6 Asked forgiveness for my sins.	☐	☐	☐	☐
7 Focused on religion to stop worrying about my problems.	☐	☐	☐	☐
8 Wondered whether my God or a Higher Power had abandoned me.	☐	☐	☐	☐
9 Felt punished by my God or a Higher Power for my lack of devotion.	☐	☐	☐	☐
10 Wondered what I did for my God or a Higher Power to punish me.	☐	☐	☐	☐
11 Questioned my God's or a Higher Power's love for me.	☐	☐	☐	☐
12 Wondered whether my church, temple, synagogue, or other place of worship had abandoned me.	☐	☐	☐	☐
13 Decided the devil or an evil spirit made this happen.	☐	☐	☐	☐
14 Questioned the power of my God or a Higher Power.	☐	☐	☐	☐

Adapted from Pargament, Smith, Koenig, and Perez (1998).

CES-D

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week.

	During the Past Week			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	☐	☐	☐	☐
2. I did not feel like eating; my appetite was poor.	☐	☐	☐	☐
3. I felt that I could not shake off the blues even with help from my family or friends.	☐	☐	☐	☐
4. I felt that I was just as good as other people.	☐	☐	☐	☐
5. I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
6. I felt depressed.	☐	☐	☐	☐
7. I felt that everything I did was an effort.	☐	☐	☐	☐
8. I felt hopeful about the future.	☐	☐	☐	☐
9. I thought my life had been a failure.	☐	☐	☐	☐
10. I felt fearful.	☐	☐	☐	☐
11. My sleep was restless.	☐	☐	☐	☐
12. I was happy.	☐	☐	☐	☐
13. I talked less than usual.	☐	☐	☐	☐
14. I felt lonely.	☐	☐	☐	☐
15. People were unfriendly.	☐	☐	☐	☐
16. I enjoyed life.	☐	☐	☐	☐
17. I had crying spells.	☐	☐	☐	☐
18. I felt sad.	☐	☐	☐	☐
19. I felt that people disliked me.	☐	☐	☐	☐
20. I could not get "going."	☐	☐	☐	☐

Beck Anxiety Inventory

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.

	During the Past Month			
	Not At All	Mildly but it didn't bother me much.	Moderately - it wasn't pleasant at times	Severely – it bothered me a lot
Numbness or tingling	☐	☐	☐	☐
Feeling hot	☐	☐	☐	☐
Wobbliness in legs	☐	☐	☐	☐
Unable to relax	☐	☐	☐	☐
Fear of worst happening	☐	☐	☐	☐
Dizzy or lightheaded	☐	☐	☐	☐
Heart pounding/racing	☐	☐	☐	☐
Unsteady	☐	☐	☐	☐
Terrified or afraid	☐	☐	☐	☐
Nervous	☐	☐	☐	☐
Feeling of choking	☐	☐	☐	☐
Hands trembling	☐	☐	☐	☐
Shaky / unsteady	☐	☐	☐	☐
Fear of losing control	☐	☐	☐	☐
Difficulty in breathing	☐	☐	☐	☐
Fear of dying	☐	☐	☐	☐
Scared	☐	☐	☐	☐
Indigestion	☐	☐	☐	☐
Faint / lightheaded	☐	☐	☐	☐
Face flushed	☐	☐	☐	☐
Hot/cold sweats	☐	☐	☐	☐

Subjective Happiness Scale (SHS)

For each of the following statements and/or questions, please circle the point on the scale that you feel is most appropriate in describing you.

1. In general, I consider myself:

1	2	3	4	5	6	7
not a very						a very
happy person						happy person

2. Compared to most of my peers, I consider myself:

1	2	3	4	5	6	7
less happy						more happy

3. Some people are generally very happy. They enjoy life regardless of what is going on, getting the most out of everything. To what extent does this characterization describe you?

1	2	3	4	5	6	7
not at all						a great
						deal

4. Some people are generally not very happy. Although they are not depressed, they never seem as happy as they might be. To what extent does this characterization describe you?

1	2	3	4	5	6	7
not at all						a great
						deal

The Satisfaction with Life Scale

DIRECTIONS: Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number in the line preceding that item. Please be open and honest in your responding.

1 = Strongly Disagree

2 = Disagree

3 = Slightly Disagree

4 = Neither Agree or Disagree

5 = Slightly Agree

6 = Agree

7 = Strongly Agree

_____ 1. In most ways my life is close to my ideal.

_____ 2. The conditions of my life are excellent.

_____ 3. I am satisfied with life.

_____ 4. So far I have gotten the important things I want in life.

_____ 5. If I could live my life over, I would change almost nothing.

Scales of Psychological Well-being

The following set of questions deals with how you feel about yourself and your life. Please remember that there are no right or wrong answers. Circle the number that best describes your present agreement or disagreement with each statement.

	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Some what	Strongly Agree
In general, I feel I am in charge of the situation in which I live.	1	2	3	4	5	6
The demands of everyday life often get me down.	1	2	3	4	5	6
I do not fit very well with the people and the community around me.	1	2	3	4	5	6
I am quite good at managing the many responsibilities of my daily life.	1	2	3	4	5	6
I often feel overwhelmed by my responsibilities.	1	2	3	4	5	6
I generally do a good job of taking care of my personal finances and affairs.	1	2	3	4	5	6
I am good at juggling my time so that I can fit everything in that needs to get done.	1	2	3	4	5	6
I have difficulty arranging my life in a way that is satisfying to me.	1	2	3	4	5	6
I have been able to build a home and a lifestyle for myself that is much to my liking.	1	2	3	4	5	6
I am not interested in activities that will expand my horizons.	1	2	3	4	5	6
I don't want to try new ways of doing things--my life is fine the way it is.	1	2	3	4	5	6
I think it is important to have new experiences that challenge how you think about yourself and the world.	1	2	3	4	5	6
When I think about it, I haven't really improved much as a person over the years.	1	2	3	4	5	6
I have the sense that I have developed a lot as a person over time.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
I do not enjoy being in new situations that require me to change my old familiar ways of doing things.	1	2	3	4	5	6
For me, life has been a continuous process of learning, changing, and growth.	1	2	3	4	5	6
I gave up trying to make big improvements or changes in my life a long time ago.	1	2	3	4	5	6
There is truth to the saying you can't teach an old dog new tricks.	1	2	3	4	5	6
Most people see me as loving and affectionate.	1	2	3	4	5	6
Maintaining close relationships has been difficult and frustrating for me	1	2	3	4	5	6
I often feel lonely because I have few close friends with whom to share my concerns.	1	2	3	4	5	6
I enjoy personal and mutual conversations with family members or friends.	1	2	3	4	5	6
I don't have many people who want to listen when I need to talk.	1	2	3	4	5	6
It seems to me that most other people have more friends than I do.	1	2	3	4	5	6
People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6
I have not experienced many warm and trusting relationships with others.	1	2	3	4	5	6
I know that I can trust my friends, and they know they can trust me.	1	2	3	4	5	6
I live life one day at a time and don't really think about the future.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
I tend to focus on the present, because the future nearly always brings me problems.	1	2	3	4	5	6
My daily activities often seem trivial and unimportant to me.	1	2	3	4	5	6
I don't have a good sense of what it is I'm trying to accomplish in life.	1	2	3	4	5	6
I used to set goals for myself, but that now seems like a waste of time.	1	2	3	4	5	6
I enjoy making plans for the future and working to make them a reality.	1	2	3	4	5	6
I am an active person in carrying out the plans I set for myself.	1	2	3	4	5	6
Some people wander aimlessly through life, but I am not one of them.	1	2	3	4	5	6
I sometimes feel as if I've done all there is to do in life.	1	2	3	4	5	6
When I look at the story of my life, I am pleased with how things have turned out.	1	2	3	4	5	6
In general, I feel confident and positive about myself.	1	2	3	4	5	6
I feel like many of the people I know have gotten more out of life than I have.	1	2	3	4	5	6
I like most aspects of my personality.	1	2	3	4	5	6
I made some mistakes in the past, but I feel that all in all everything has worked out for the best.	1	2	3	4	5	6
In many ways, I feel disappointed about my achievements in life.	1	2	3	4	5	6
My attitude about myself is probably not as positive as most people feel about themselves.	1	2	3	4	5	6

The past had its ups and downs, but in general, I wouldn't want to change it.	1	2	3	4	5	6
When I compare myself to friends and acquaintances, it makes me feel good about who I am.	1	2	3	4	5	6

Spiritual Well-being Scale

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
I can turn to a spiritual dimension within myself for guidance.	1	2	3	4	5	6
I have an inner strength.	1	2	3	4	5	6
I have experienced my own strength in times of struggle.	1	2	3	4	5	6
I have a sense of harmony or inner peace.	1	2	3	4	5	6
My innerness or an inner resource helps me deal with uncertainty in life.	1	2	3	4	5	6
I rely on an inner strength in hard times.	1	2	3	4	5	6
I experience a spiritual dimension that gives me strength and love.	1	2	3	4	5	6
Frequently meditating or praying gives a sense of inner peace.	1	2	3	4	5	6
I get personal strength and support from my God or a Higher Power.	1	2	3	4	5	6
I have a personally meaningful relationship with God or a Higher Power.	1	2	3	4	5	6

CARS – PARENT:
Symptom and Stress Rating Scale

SYMPTOMS	SYMPTOM RATING (Please rate each symptom in your child) 1 = Normal for chronological age 2 = Mildly abnormal 3 = Moderately abnormal 4 = Several abnormal	STRESS RATING (How stressful is this symptom for you?) 1 = None at all 2 = A little bit 3 = Quite a bit 4 = Extreme
1. Ability to relate to people (example: does not return interest others show in him / her)		
2. Imitation (extent to which child imitates, verbal or motor)		
3. Appropriateness of emotions (example: giggling, crying, etc.)		
4. Unusual body movements and/or repetitive motions or routines		
5. Unusual ways of relating to objects (example: spinning cups, lining up objects)		
6. Difficulty with change in the environment (example: new living room furniture)		
7. Interest in visual information (example: staring at lights, avoiding eye contact)		
8. Response to sounds (example: overreacts or under-reacts)		
9. Use of other senses (example: mouthing, licking, smelling, rubbing)		
10. Anxiety reaction (example: separation from parents, unusual fears, or absence of reaction)		
11. Verbal communication (example: mute, echoes, pronoun reversal, repetitive language)		

SYMPTOMS	SYMPTOM RATING (Please rate each symptom in your child) 1 = Normal for chronological age 2 = Mildly abnormal 3 = Moderately abnormal 4 = Several abnormal	STRESS RATING (How stressful is this symptom for you?) 1 = None at all 2 = A little bit 3 = Quite a bit 4 = Extreme
12. Nonverbal communication (example: use of or response to gestures)		
13. Extremes of activity level (example: high or low activity level)		
14. Intellectual abilities (example: a rating of 2 means an even impairment in all intellectual areas; a rating of 4 means some areas very impaired, other areas normal or higher)		

From: Bebko, Konstantareas & Springer (1987) Journal of Autism & Developmental Disorders

APPENDIX B

Table 1.

Number of parents and children per study group

	PDD	ADHD	Controls	Total
	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i> (%)
Gender				
Mothers	26	20	19	65 (71%)
Fathers	12	6	8	26 (29%)
Girls	3	3	13	19 (29%)
Boys	23	17	7	47 (71%)

Table 2.

Characteristics of Parent Sample

	PDD		ADHD		Controls		F or χ^2
	M	SD	M	SD	M	SD	
Age of Parent	41.73	5.42	40.04	6.76	39.41	5.12	$F(2,87) = 1.41$
Mean Household Income ^a							$F(2, 85) = 4.20^*$
Less than \$15,000	3 (8.1%)		1 (3.8%)		1 (4%)		
\$15,000 - \$29,000	4 (10.8%)		5 (19.2%)		1 (4%)		
\$30,000 – \$44,999	--		2 (7.7%)		1 (4%)		
\$45,000 - \$69,999	12 (32.4%)		11 (42.3%)		5 (20%)		
\$70,000 - \$100,000	12 (32.4%)		6 (23.1%)		7 (28.0%)		
Over \$100,000	6 (16.2%)		1 (3.8%)		10 (40.0%)		
Number Children in Home	2.45	1.13	2.58	1.1	2.15	.77	$F(2, 86) = 1.23$

^a Household income is presented in frequencies and percentages within study groups.

* $p \leq .05$, ** $p \leq .01$

Table 3.

Characteristics of Children

	PDD		ADHD		Controls		<i>F</i> or <i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Mean Age of Child	8.73	1.76	9.55	1.43	8.91	1.88	$F(2,63) = 1.38$
Mean Age of Diagnosis	3.84	1.81	6.80	2.24	--	--	$t(44) = 4.95^{**}$
CARS-P Score	32.86	8.40	22.16	5.31	14.56	1.12	$F(2, 83) = 66.95^{**}$
Perceived Child Intelligence (<i>n</i>) ^a							$F(2, 62) = 8.84^{**}$
Mentally Impaired	4 (15.4%)		--		--		
Below Average	6 (23.1%)		3 (15%)		--		
Average	6 (23.1%)		7 (35%)		2 (10%)		
Above Average	6 (23.1%)		9 (45%)		13 (65%)		
Superior	3 (11.5%)		1 (5%)		5 (25%)		

Note. All analyses on children except CARS-P scores were conducted using maternal reports, with paternal reports substituted when maternal reports were missing.^a Perceived intelligence scores are presented in frequencies and percentages within study groups and were based on maternal report, with paternal reports substituted when maternal ratings were unavailable.

* $p \leq .05$ ** $p \leq .01$

Table 4.

*Principal Components Analysis using Varimax Rotation for**Brief COPE items*

Item	Factor 1	Factor 2	Factor 3
14	.82		
7	.77		
2	.68		
25	.64		
20	.62	-.23	
24	.5		
17	.52		.23
12	.50		.40
6		.68	
16		.64	
26		.60	.21
8		.60	
9		.59	.38
13		.59	
19		.55	
21		.55	.25
3		.49	-.20
1		.24	
4			.83
11			.82
18	.38	.26	.53
28	.29	.33	.50

Note. Religion and social support items were removed from analyses.
Factor Loadings below .2 are not presented in this table for easier interpretability.

Table 5.

*Principal Components Analysis using Varimax Rotation
for Brief R-COPE and religion items in Brief COPE*

Item	Factor1	Factor 2
22	.86	
27	.89	
1	.95	
2	.95	
3	.94	
4	.94	
5	.90	
6	.85	
7	.84	
8		.77
9		.69
10		.82
11		.66
12		.76
13	.29	.21
14		.78

Note. Items 22 and 27 are from the Brief COPE and the remaining items are from the Brief R-COPE. Factor Loadings below .2 are not presented in this table for easier interpretability.

Table 6.

Means, Standard Deviations, and AN(CO)VA and MAN(CO)VA Analyses for Parent Psychological-Wellbeing Variables

	PDD		ADHD		Control		<i>F</i> ^a	<i>F</i> ^b
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
BAI	8.53	6.86	10.04	9.07	6.07	7.03	(2, 84) = .93	(1, 85) = 1.60
CESD	12.03	7.90	13.08	11.31	7.56	7.94	(2, 84) = 1.99	(1, 85) = 3.99*
Happiness	20.23	5.01	18.81	3.81	20.04	5.44	(2, 81) = .41	(1, 82) = .08
Well-being ^c	4.64	.77	4.56	.66	4.85	.83	(2, 81) = .17	(1, 82) = 1.54
Spiritual Well-being	4.41	1.09	4.38	1.14	4.24	1.35	(2, 81) = .80	(1, 82) = .34

Note: ^a *F*-tests for differences between all three groups. ^b *F*-tests for differences between the combined PDD and ADHD groups versus the Control group. ^c The

Well-being variable is a composite of the 5 Ryffe scales and the Life Satisfaction Scale, with scaling standardized to a 6 point likert type scale where larger values correspond to more positive well-being. *F* statistics for the BAI and CESD are from univariate analyses controlling for family income. *F* statistics for the remaining scales were obtained from a multivariate analysis controlling for family income.

p* ≤ .05 *p* ≤ .01

Table 7.

Group Frequencies for Clinically Significant Depression and Anxiety and Chi-Square Analyses

	PDD	ADHD	Control	χ^2 ^a	χ^2 ^b
CESD					
Not Depressed	30 (78.9%)	18 (69.2%)	24 (88.9%)	3.10	1.45
Depressed	8 (21.1%)	8 (30.8%)	3 (11.1%)		
BAI ^c					
Low Anxiety	36 (94.7%)	23 (88.5%)	26 (96.3%)	1.51	.07
Moderate Anxiety	2 (5.3%)	2 (7.7%)	1 (3.7%)		
High Anxiety	0 (0%)	1 (3.8%)	0 (0%)		

Note. ^a χ^2 comparing across three study groups. ^b χ^2 across developmental disabilities and typical control group. ^c Scores below 22 indicate Low anxiety, 22-35 indicate Moderate anxiety, and scores above 36 indicate high anxiety. Chi-square analyses for BAI were conducted by collapsing Moderate and High Anxiety groups together due to low frequency of High anxiety scores across groups.

* $p \leq .05$, ** $p \leq .01$

Table 8.

Pearson Correlations and Reliabilities for Coping, Service, Support, and Parent Affect, Well-being, and Income Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Total Number of Services	--													
2. Pos. Affect Toward Child	.05	(.80)												
3. Pos. Affect From Child	.10	-.72**	(.87)											
4. Parent-Child Closeness	-.13	-.66**	.64**	--										
5. Social Support	.07	.03	-.10	-.28**	(.90)									
6. Active Positive Coping	.40**	.11	-.06	-.12	.26*	(.80)								
7. Avoid-Aggressive Coping	-.06	-.27*	.22*	.29**	.28**	-.06	(.74)							
8. Sub. Abuse / Humor Coping	.15	.05	.10	.08	.11	.25*	.33**	(.75)						
9. CESD	.16	-.29**	.35**	.30**	-.13	-.18	.39**	.27*	(.91)					
10. BAI	.16	-.19	.26*	.18	.00	-.05	.36**	.29**	.65**	(.89)				
11. Happiness	.04	.14	.25*	.26*	.18	.29**	-.35**	-.32**	-.63**	-.40**	(.87)			
12. Psychological Well-being	.04	.30**	.41**	-.39**	.27*	.26**	-.44**	-.25*	-.75**	-.48**	.71**	(.95)		
13. Spiritual Well-being	.06	.20	-.33**	-.24*	.19	.23*	-.32**	-.41**	-.42**	-.44**	.54**	(.92)		
14. Household Income	-.06	.16	-.30**	-.22*	.04	-.21	-.31**	-.36*	-.34*	-.29*	.22*	.32*	.16	--

Note. Positive Affect from Child and Parent-Child Closeness variables are reverse transformed.

* $p \leq .05$, ** $p \leq .01$

Table 9.

Hierarchical Regression Analyses Statistics Showing the Relationship of Active Positive Coping on Each Positive Affect and Wellbeing Measure Controlling for Household Income

	<i>B</i>	<i>SE B</i>	β	$R^2\Delta$	$F\Delta$
Happiness	3.10	.91	.35	.12	(1, 82) 11.66**
General Well-being	.47	.14	.34	.11	(1, 80) 11.33**
Spiritual Well-being	.60	.23	.28	.08	(1, 82) 6.78**

* $p \leq .05$, ** $p \leq .01$

Table 10.

Hierarchical Regression Analyses Statistics Showing the Relationship Between Resource and Support Measures on Parental Affect and Wellbeing Measures Controlling for Household Income

	<i>B</i>	<i>SE B</i>	β	$R^2\Delta$	<i>F</i> Δ
CESD ^a					
Total Services	.00	.00	.13	.12	(2, 85) = 1.65
Positive Affect Toward Child	-.04	0.2	-.25	.06	(2, 85) = 6.15*
Positive Affect From Child	.11	.04	.28	.07	(2, 85) = 7.28**
Parent-Child Closeness	.08	.04	.24	.05	(2, 85) = 5.39*
Social Support	-.13	.01	-.10	.01	(2, 83) = .93
BAI ^b					
Total Services	.00	.00	.15	.02	(2, 85) = 2.06
Positive Affect Toward Child	-.02	.01	-.13	.02	(2, 85) = 1.45
Positive Affect From Child	.06	.04	.18	.03	(2, 85) = 2.76
Parent-Child Closeness	.04	.03	.12	.01	(2, 85) = 1.31
Social Support	.00	.01	.02	.00	(2, 83) = .04
Happiness ^c					
Total Services	.08	.14	.06	.00	(2, 84) = .35
Positive Affect Toward Child	.67	.69	.10	.01	(2, 84) = .93
Positive Affect From Child	-3.44	1.85	-.20	.04	(2, 84) = 3.47
Parent-Child Closeness	-3.29	1.55	-.23	.05	(2, 84) = 4.52*
Social Support	.87	.60	.15	.02	(2, 82) = 2.07
General Well-being ^d					
Total Services	.01	.02	.06	.00	(2, 82) = .33
Positive Affect Toward Child	.25	.10	.25	.06	(2, 82) = 5.85*
Positive Affect From Child	-.89	.27	-.34	.10	(2, 82) = 10.51**
Parent-Child Closeness	-.73	.23	-.32	.10	(2, 82) = 10.04**
Social Support	.21	.09	.24	.06	(2, 80) = 5.55*
Spiritual Well-being ^e					
Total Services	.03	.03	.08	.01	(2, 84) = .57
Positive Affect Toward Child	.27	.17	.17	.03	(2, 84) = 2.56
Positive Affect From Child	-1.30	.45	-.31	.09	(2, 84) = 8.45**
Parent-Child Closeness	-.71	.39	-.20	.04	(2, 84) = 3.34
Social Support	.23	.15	.17	.03	(2, 82) = 2.14

Note. Positive Affect from Child and Parent-Child Closeness variables are reverse transformed. ^a R^2 for Step 1 = .12. ^b R^2 for Step 1 = .08. ^c R^2 for Step 1 = .05. ^d R^2 for Step 1 = .10. ^e R^2 for Step 1 = .02.

* $p < .05$, ** $p < .01$

Table 11.

Hierarchical Regression Analysis for Support and Coping Styles onto Depression

	<i>B</i>	<i>SE B</i>	β	$R^2 \Delta$	<i>F</i> Δ
Step 1.				.11	9.91**
Household Income	-.03	.01	-.33**		
Step 2.				.14	7.35**
Household Income	-.02	.01	-.29**		
Active Positive Coping	-.05	.02	-.24*		
Avoidant-Aggressive Coping	.07	.03	.28**		

* $p \leq .05$, ** $p \leq .01$

Table 12.

Hierarchical Regression Analysis for Support and Coping Styles onto Composite Well-being Score

	<i>B</i>	<i>SE B</i>	β	$R^2\Delta$	$F\Delta$
Step 1.				.10	8.63**
Household Income	.17	.06	.31**		
Step 2.				.28	11.77**
Household Income	.06	.05	.12		
Avoidant-Aggressive Coping	-.75	.17	-.44**		
Social Support	.28	.08	.33**		
Positive Affect from Child	-.57	.26	-.21*		

Note. To correct for non-normality, positive affect from child was reverse logarithmic transformed. Thus, interpretation of the negative direction of the beta weights here should be that greater felt affect from child was associated with increased well-being. Total model adjusted $R^2 = 0.35$.

* $p \leq .05$, ** $p \leq .01$

Table 13.

Inter-rater correlations for BASC-2 scales

Variable	Maternal	Paternal
Internalizing Behaviors		
1. Maternal	--	
2. Paternal	.79**	
3. Teacher	.20	-.21
Externalizing Behaviors		
4. Maternal	--	
5. Paternal	.73**	--
6. Teacher	.41**	.09
Social Skills		
7. Maternal	--	
8. Paternal	.75**	--
9. Teacher	.73**	.55**
Functional Communication		
10. Maternal	--	
11. Paternal	.79**	--
12. Teacher	.83**	.73**

* $p \leq .05$, ** $p \leq .01$

Table 14.

Means, Standard Deviations, and ANOVA Comparison Statistics for BASC-2 scales

	PDD		ADHD		Control		<i>F</i> or χ^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Internalizing Behaviors ^a	46.81	9.69	55.30	13.44	48.30	7.80	7.95*
Externalizing Behaviors ^a	56.45	7.43	65.15	13.74	46.12	6.63	42.45**
Attention Problems	61.62	5.53	67.49	7.60	43.38	6.80	73.71**
Social Skills	34.38	7.84	40.12	10.18	54.10	7.29	31.47**
Functional Communication	28.57	9.15	42.18	10.74	56.33	6.78	52.39**

Note. Analyses conducted using average ratings across parent and teachers (maternal and paternal ratings averaged for Internalizing Behaviors) for each child, except 1 child in the PDD group whose mother skipped too many items on this scale for it to be scoreable. Mean scores are reported in *T* score format. Sample size for each analysis was 64. ^a Due to non-homogeneity of variance across groups, the Kruskal-Wallis Test was used for these analyses.

* $p \leq .05$, ** $p \leq .01$

Table 15.

Pearson Correlations for BASC-2 scales and Parental Affective and Psychological Well-being

	Externalizing		Internalizing		Attention		Social Skills		Functional	
	Problems		Problems		Problems		Problems		Communication	
CESD	.33**		.27**		.37**		-.28**		-.26*	
BAI	.30**		.32**		.28**		-.25*		-.21*	
Happiness	-.14		-.16		-.16		.12		.10	
Well-being	-.28**		-.23*		-.28*		.28*		.27*	
<u>Spiritual Well-being</u>	-.04		-.16		-.08		.14		.11	

Note. Higher scores on the problem scales indicate more pathology and higher scores on the adaptive scales (Social Skills and Functional Communication) indicate more positive development.

* $p \leq .05$, ** $p \leq .01$

Table 16.

Regression Analyses Using Hierarchical Linear Modeling Statistics Showing the Relationship Between BASC-2 Child Problems and Adaptive Skills onto Parental Depression Controlling for Household Income

	β	F
Internalizing Problems	.19	(1, 85) = 3.57
Internalizing Problems X Group	-.19	(1, 83) = .42
Externalizing Problems	.25	(1, 85) = 5.73*
Externalizing Problems X Group	.58	(1, 83) = 2.06
Attention Problems	.33	(1, 85) = 10.58**
Attention Problems X Group	-.29	(1, 83) = .51
Social Skills	-.27	(1, 85) = 6.99**
Social Skills X Group	.40	(1, 83) = 1.29
Functional Communication	-.21	(1, 84) = 3.98*
<u>Functional Communication X Group</u>	<u>-.06</u>	<u>(1, 82) = .02</u>

Note. Due to missing data, sample sizes for these analyses varied.

* $p < .05$, ** $p < .01$

Table 17.

Pearson Partial Correlations for BASC-2 scales and Parental Well-being, Controlling for Household Income

	Externalizing		Internalizing		Attention		Social Skills		Functional	
	Problems		Problems		Problems				Communication	
CESD	.33**		.42**		.26*		-.20		-.08	
BAI	.30*		.41**		.17		-.13		-.07	
Happiness	-.03		-.13		-.07		.03		.01	
Well-being	-.17		-.24		-.20		.17		.15	
Spiritual Well-being	-.09		-.23		-.09		.11		.05	

Note. Higher scores on the problem scales indicate more pathology and higher scores on the adaptive scales (Social Skills and Functional Communication) indicate more positive development.

* $p \leq .05$, ** $p \leq .01$

Table 18.

Results of Hierarchical Linear Modeling Regressions Testing Moderation of Child Stressors onto Parental Depression

Predictor	Moderator	β	t
Externalizing Problems			
	Active Positive Coping	-.04	-.44
	Avoidant-Aggressive	-.07	-.78
	Positive Affect from Child	.04	.42
Internalizing Problems			
	Active Positive Coping	-.19	-2.0*
	Avoidant-Aggressive	-.06	-.74
	Positive Affect from Child	.07	.76

Note. The positive affect from child variable was reverse logarithmic transformed to correct for non-normality.

* $p < .05$, ** $p < .01$

Table 19.

*Results of Hierarchical Linear Modeling Regressions Testing Moderation
of Child Stressors onto Parental Anxiety*

Predictor	Moderator	β	t
Externalizing Problems			
	Avoidant-Aggressive	.05	.53
	Substance Abuse / Humor	-.17	-1.83
Internalizing Problems			
	Avoidant-Aggressive	-.05	-.62
	Substance Abuse / Humor	-.21	-2.56*

* $p < .05$, ** $p < .01$

Table 20.

Mean Coping Strategies by Group and Between Group One-Way ANOVA Comparisons

	PDD		ADHD		Control		<i>F</i> or χ^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Active-Positive Coping	3.22	.46	2.98	.52	2.79	.57	(2, 86) = 5.74**
Avoidant- Aggressive Coping	1.84	.36	2.01	.52	1.87	.42	(2, 83) = 1.24
Substance Abuse / Humor	1.68	.57	1.68	.58	1.70	.52	(2, 87) = .02
Positive Religious Coping ^a	2.26	1.08	2.34	.88	2.14	1.16	(2, <i>n</i> = 90) = .96
Negative Religious Coping	1.30	.37	1.30	.54	1.14	.22	

Note. The scales presented above are composite scales derived through principal components analyses of Brief COPE and the Brief RCOPE items. Ratings are presented on a 4 point likert scale format, with 1 = I don't do this at all, 2 = I do this a little bit, 3 = I do this a medium amount, 4 = I do this a lot. ^a Due to non-normal distribution of the Positive Religious Coping variable, the Kruskal-Wallis Test was used to evaluate differences across groups.

** $p \leq .01$

Table 21.

Mean Services and Supports by Group and Between Group ANOVA Comparisons

	PDD		ADHD		Control		F
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Social Support	2.47	.88	2.75	.81	2.74	.90	(2, 86) = 1.13
<i>Positive Affect Index</i>							
Feel Toward Child	4.94	.71	4.58	.81	5.41	.44	(2, 88) = 10.34**
Expressed From Child	4.67	1.06	4.38	.86	5.19	.47	(2, 88) = 6.55**
Overall Closeness	5.08	.97	5.08	.93	5.33	.96	(2, 88) = .82
Difference Received vs. Feel	-.27	.90	-.19	.49	-.22	.40	(2, 88) = .119
PSSQ							
Number Services for Family	2.55	1.83	2.15	1.71	1.78	1.83	(2, 88) = 1.49
Number Services for Child	4.50	2.75	2.27	2.09	.22	.51	(2, 88) = 32.58**
Total Number Services	7.05	3.68	4.42	3.40	2.00	2.00	(2, 88) = 20.09**

Note: Social Support was scored on a 4-point Likert Scale with larger numbers signifying increased access of social support. The *Positive Affect Index* is scored on a 6-point Likert Scale with larger numbers indicating increased positive affect. The Difference variable was computed through subtracting parent positive affect felt toward their child from child expressed positive affect toward the parent, such that negative values indicate parents feeling more positive affect toward their child than received from their child.

** $p \leq .01$

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