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PERCEPTION OF RESOURCES AND PSYCHOLOGICAL ADJUSTMENT OF
PARENTS RAISING A CHILD WITH AND WITHOUT AUTISM
AND/OR OTHER DEVELOPMENTAL DISABILITIES

A Thesis

Presented to the Faculty of
California State University,
San Bernardino

In Fulfillment
of the Requirements for the Degree
Masters of Arts
in
Psychology:
General/Experimental

by

Jonathan Francis William Doti

September 2004

PERCEPTION OF RESOURCES AND PSYCHOLOGICAL ADJUSTMENT OF
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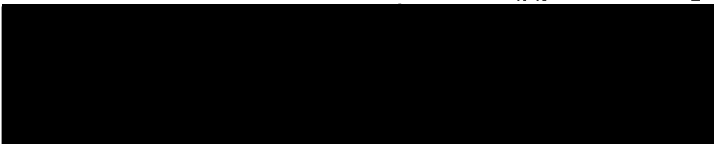
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September 2004

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ABSTRACT

Autism, one of many Pervasive Developmentally Disabilities (PDD), is associated with greater childcare complications. The research literature most notable indicates that, raising a child with autism has associated negative psychological consequences among parents. The most consistent parental complications include depression, somatization, and anxiety. Prior research indicates that resources in parents' lives such as: emotional, financial, and health factors buffer some of the negative effects of PDD childcare. These aforementioned examples are representative of a larger array of resources that may ameliorate the substantial responsibilities of raising a child with autism. This current study sought to investigate the perceptions of resources among parents' and implications for psychological complications. Resource perception was measured through the Perceived Adequacy of Resources (PAR) scale; giving a global resource score and seven sub domains of specific resource. Psychological functioning was ascertained through the Symptom Assessment 45 (SA-45) scale; giving a global mental health score and nine sub-domains of mental health functioning. All items of the SA-45 and PAR were administered as part of a larger

battery of tests in the course of a program evaluation at a University based treatment facility. Comparison data of typically developing children and their families was collected also for comparison purposes. Data analyses indicate that both parental groups had equal perceptions of resources. However, parents raising a child with autism actually reported less mental health complaints than a comparison group. Initial evaluation of these findings suggests that parents are receiving effective treatments through a university-based program. Additional, this population of parents, receiving services, may be a self-selecting group. Thus, they may not be representative of the larger set of parents suffering with the implications of PDD childcare.

ACKNOWLEDGMENTS

"Man's main task in life is to give birth to himself, to become what he potentially is."

-Erich Fromm

"Man's happiness lies not in finding himself internally--that is only a mental exercise. He finds the meaning of his life by being present and loving in the lives of others."

-Buddhist teaching

I would like to thank the members of my thesis advisory board for their countless hours of help. I would like to especially thank Dr. Yu-Chin Chen for her kind and intelligent assistance with the statistical analyses. Without her this thesis would have been delayed. Additionally, I would like to thank Dr. David Chavez for reminding me the place a thesis holds when considering the larger picture. But mostly I want to thank him for his warm encouragement during times of stress--this meant more to me than he realized.

These pages before you reveal little about my work values or academic abilities and very little about my character. Clearly, I did spend many hours on them but this thesis is also a direct result of another person. This person would never acknowledge this but her unwaveringly support has made this thesis a reality rather than a

collection of ideas. Her support has included encouraging words, clear advice, review of academic work, countless meals, laughter, needed hugs as well as much needed ridicule, life saving candy bars, cooking skills, and the innumerable small and great considerations that can never fully be repaid.

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Over the years I have observed her calm patience, love of family, self-respect, and belief in God. I have learned to value these qualities through her. I leave this university appreciating not what the academic program has taught me or this degree confers. Rather, I leave with the knowledge, the greater lessons that are only learned through the presence of a caring and genuine person. For these things I truly thank her.

Lastly, Cinder, you know who you are—thank you for teaching me to realize that love does not always arrive in the form we expect.

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CHAPTER ONE

INTRODUCTION

Parenting has been described as a second career with child-care responsibilities often comparable to the time and energy demands associated with fulltime employment. Amongst a variety of domains, parents will be tasked with new and considerable responsibilities--rarely is childcare trouble-free. Rather, these new responsibilities will require adjustments of individuals, and as a holistic system of interdependent members within a family (Shapiro, 1989). Although most adults enthusiastically adjust to their new parental roles surrounding childcare--even the most well equipped and adjusted families can be psychologically and materially overburdened (Cox, Owen, Lewis, & Henderson, 1989). Attempting to manage the multiple domains of marriage, interpersonal, career, financial, as well as childcare concerns that are sure to arise, may tax the coping capacity of even the most well adjusted and equipped families (Bristol & Schoper, 1984; Seltzer & Heller, 1997; Allard, Gottlieb, & Hart, 1993). Without contention, the birth and care of a child is considered a universally rewarding event. And while meeting

the needs of a child can be one of the most rewarding accomplishments for an adult, clearly, there are also significant related stressors.

In the case of a child who is diagnosed with a Pervasive Developmental Disability (PDD), typical child-care responsibilities are greatly increased (Cutler, Kozloff, 1987; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). Compared to typical levels of time and energy associated with being a parent of a typically developing child--raising a child with developmental difficulties may drastically alter child care responsibilities. Research consistently indicates that the diagnosis of a developmental disability in one's child "...provokes intense, jarring, and often debilitating reactions among parents" and has been aptly described as a, "...psychological assault" (Hauser-Cram, et al, 2001 p. 19). Issues surrounding time, physical energy, medical, behavioral, educational along with inflated financial burdens will demand consideration. Furthermore, parents of a child with a PDD will require the need for increased resources, such as expert care, beyond those related in caring for a typically developing child (Seltzer & Heller, 1997; Warfield, Krauss, Hauser-Cram, Upshur, Shonkoff, 1999).

Unlike the transitory adversities of a crisis nature such as many medical emergencies, the long term care of a child with a PDD can have negative chronic features of cumulative psychological, emotional, financial, and physical effects. These cumulative effects are especially true for parents who shoulder the brunt of child care responsibilities. Unlike a typically developing child where portions of childcare requirements begin to lessen due to developmental gains--the same is not true of a child with a PDD. There is strong evidence that as a child with a PDD matures, instead of a waning of responsibilities, there may actually be increases in care burdens and complications that may further impact parental abilities to cope (Selter, Greenberg, Floyd, Pette, & Hong, 2001). However, age related care responsibility difference among children and adults with a PDD is not yet conclusive (Seltzer & Krauss, 1989; Whittick, 1988). Nonetheless, Suelze and Keenan (1981) indicate that parents of adult children with a PDD required greater resources when compared to young children with a PDD. These parents report less overall support, and access to professional services that result in feelings of social isolation. Further, social isolation has been associated with components of stigmatization of PDD child-

care. This stigma can contribute to overall negative effects upon family functioning (Dyson, 1993; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Crnic, Friedrich, & Greenberg, 1983). Additionally, aspects of PDD child-care are often mired with the knowledge that developmental conditions may not significantly improve as one's child becomes chronologically older (Crnic, Friedrich, & Greenberg, 1983). Therefore, unlike a disease, a PDD has no cure. Rather, childcare for this affected population is a life-long condition that is accommodated by parental abilities. Thus, parents of a child with a PDD may be assigned a life-long responsibility of childcare (Cameron, Armstrong-Stassen & Marjorie, 1991). Parenthood for this population of affected children, in the most severe cases, can be a lasting condition, unrelenting in its scope of responsibilities and aptly described as a second career (Seltzer & Heller, 1997).

One specific PDD garnering mounting national attention is autism. In the last ten years over 2,000 scholarly articles have been written on the subject of autism. This large body of research indicates that autism has had significant impact upon families, service providers, and researchers across a range of disciplines (Tanguay, 2000).

Currently, autism is the third largest identified childhood developmental disorder in the United States with estimates of 2 to 6 per 1,000 children diagnosed (Centers for Disease Control and Prevention, 2001). However, compiled epidemiological studies from the last thirty years in the field of developmental disabilities, estimates the rate of bona fide autism is approximately 1 in 2000 children when using more strict criterion (Fombonne, Du, Cans, & Gradjean, 1997).

Currently, 1.5 million Americans have some form of this spectrum disorder with escalating rates of approximately 10%-17% per year (Sontag, 1996). This calculates to nearly 4 million Americans as being diagnosed with some form of autism in the coming decade (Centers for Disease Control and Prevention, 2001). In the state of California, autism has become the number one diagnosed childhood developmental disability (Autism Society of America, 2002). The California Department of Developmental Services (CDDS) has experienced an increase of 273% from 1987 through 1998 of individuals identified as eligible and seeking services (Centers for Disease Control and Prevention, 2001). With artifacts of improved diagnosis and growth in state population accounted, this CDDS (2001)

statistic should be alarming to agencies offering services to individuals with autism and their families that care for them. This data (CDDS, 2001) also belies a large and growing population of adults with autism who are functionally dependent upon family and outside services to meet many daily needs and will contribute to the overall federal, state, city, family, and parental obligations (Autism Society of America, 2000).

The Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition indicate that a diagnosis of autism is assigned to children that display major difficulties in core areas of normal development in the use of language, relating appropriately in social situations, and changes in routines (DSM-IV, 1997). Autism is a spectrum disorder diagnosed before the age of three and depending upon severity, typically poor prognosis, reflecting severe detrimental and lifelong impairments of learning and social interaction. Prototypical behaviors of autism include: insistence on sameness, strong attachment to unusual objects, repetitive and stereotypical physical movements of a non-useful nature marked by ritualistic or peculiar displays. Often these behaviors are also of a self-stimulating nature with aspects of echolalia, severe

deficiencies of reciprocal social interactions/joint attention, and exhibiting very little or no signs of emotional affection; commonly failing to form normal emotional attachments to caregivers or parents (DSM-IV, 1997; Simpson & Ziants, 1999). Approximate half of all children with autism never develop spoken language-- compared to other developmental disorders of less severe etiology autism involves numerous and austere core developmental deficiencies (Simpson & Ziants, 1999). Regardless of claimed results, long-term prognosis of the autistic population is relatively poor with improvements in children by specific treatment programs/methodologies generally failing to report lasting effects upon follow-up (Donnellan, 1999; Dunlap, 1999; Sheinkopf & Siegal, 1998; Tanguay, 2000).

Thus, autism has characteristics that make it an exceptionally unremitting condition when compared to other childhood developmental and physical disabilities (Holroyd & McArthur, 1976). Unlike other disabilities such as mental retardation, Down syndrome, and learning disorders, though notable, autism posses intense, unique, and chronic facets for care givers (Sigman & Ruskin, 1999) that accentuate the demands placed upon caregivers, parents, and families that

can result in extraordinary stress (Cohen & Donnellan, 1987; Cutler & Kozloff, 1987). Furthermore, the lack of social reciprocity from their affected child robs parents of emotional processes vital to healthy parent child relationships. Therefore, a child diagnosed with autism intensifies the daily demands placed upon parents' abilities to adjust and cope effectively while returning little or no emotional compensation. Parents report that their children with autism require more time, energy, and effort than they had expected with child-care resulting in higher stress (Bristol & Schopler, 1984; Donovan, 1988; Schopler & Mesibov, 1984). Retarded developmental progress, increased stereotypic behaviors, reduced social interaction, and demandingness of offspring all have been linked with high levels of parental stress (Beckman-Bell, 1980). These aforementioned descriptions of child characteristics are similar to some core features of autism and may account for a portion of parental stress etiology. Consequently, a child with autism may be unique in their capacity to significantly and negatively impact parental coping. A recent longitudinal study focused on child development and parental well-being reveals that a child with autism impacts parents and care-givers severely when

compared to other developmental disorders (Hauser-Cram et. al, 2001). Therefore, further investigation of the implications of child-care associated autism and similar PDD(s) and the effects upon parents and other family members is warranted.

Allied with the growing understanding that family psychosocial and interpersonal processes are fundamental to ameliorating family stress—a conceptual shift in service foci have been undertaken (Bronfrenbrenner, 1992; Hauser-Cram et. al 2001; Hoffman, Sweeney, Gilliam, McDonald, & Palafox, 2003). One manner that child and parental factors can be conceptually framed and methodologically measured is through an ecological based model (Hoffman, et. al, 2003). In this model, child development is considered contextually within a family system (Bronfrenbrenner, 1992; Minuchin, 1988). The adoption of Bronfrenbrener's (1979) ecologically based family model captures the confidence that child development occurs contextually and thus, may be improved contextually. Bronfenbrenner (1979) and Minuchin (1988) recognize the bi-directional and interdependent process that occurs among family members. Further, Minuchin (1988) emphasizes the psychosocial reciprocity of family environments and their ability to affect change among

individuals in a multiply nested manner (Powell-Smith & Stollar, 1997; Hinde & Stevenson-Hinde, 1988; Seligman & Donling, 1997).

The latest suggestions by Hauser-Cram et. al (2001) further reinforce that a family is an interactive unit with change in one individual "resonating" and affecting other family members. This concept is consistent with Bronfrenbrenner's (1978) descriptions of bi-directionality and interdependent family processes. Consequently, child-parent interactions may be a powerful correlated mechanism through which long-term adjustment occurs (Sontag, 1996). Like Bronfrenbrener's (1979) ecologically based theory, Minuchin's (1988) 'family systems' theory; emphasizes the central backdrop of human development occurs through the family, principally so during early childhood. Furthermore, Sontag (1996) sees the family ecology as a practical matter to understanding, "... a theoretically useful concept for studying children with disabilities because it supports the search for protective factors that are capable of modifying developmental risk".

Recognizing development through the lens of the family ecology, recognizes that changes in behaviors follow changes in family environments (Bibby, Eikeseth, Martin,

Mudford, & Reeves, 2001; Bronfenbrenner, 1979; Hoffman, Sweeney, Gilliam, McDonald, & Palafox, 2003; Seligman & Donling, 1997). Appreciating the fundamental supporting role that family members provide, many treatment approaches have allied individuals in target families as cohorts in long-term treatment plans (Bronfenbrenner, 1986; Prizant, & Rubin, 1999; Dunst, & Trivette, 1990). Attempts to affect change in children with autism include family members and their ability to cope with their child's developmental conditions and limitations (Bell, 1968; Bronfenbrenner, 1979; Minuchin, 1986). Therefore, bolstering the abilities of parents and families in meeting their child's developmental needs should be a primary goal. One area that appears useful to investigate is the role parental stress plays in family ecology.

It has been suggested that any successful child treatment intervention should also address root causes of parental distress as one of its primary goals (Fishman et. al, 2000). Parental distress may come in many forms when caring for a child with autism or other PDD. There are reports of loss of self-esteem, social isolation, social stigma, guilt, financial burdens, and respite needs that are impacted due to child care responsibilities (Hauser-

Cram et al., 2001). Moreover, research among this population of parents, reinforce other findings that significant increased rates of depression, guilt/shame, poor physical health, and reduced feelings of self-efficacy are clearly evident (Duis, S., Summers, M., & Summers, C. R., 1997; Juvonen, J, & Leskinen, M., 1994).

Parental stress has been implicated in precursors of depression and decreased feelings of effectance in meeting the demands of a child with a disability (Dyson, 1997; Koeske & Koeske, 1990; Paterson, 1980; Marcus, 1984; Suarez & Baker, 1997). More recently, parents of children with a PDD report, reduced levels of parental satisfaction, control, and poor health in addition with greater distress and maternal dysphoria as compared to parents caring for a child with mental retardation and typically developing controls (Hauser-Cram et. al., 2001; Fishman, et al., 2000). Evidently, caring for a developmentally disabled child produces a characteristic profile of parental stress and distress that has troubling consequences. This may further impact parental abilities in meeting long term child-care needs and has the potential to negatively effects on the family ecology (Hauser-Cram, 2001; Juvonen, & Leskinen, 1994).

By systematically rallying resources, a family may be able to function more efficiently during times of stress (Kreppner, 1990; Minuchin, 1990; Quittner & DiGiramo, 1998). A systemic response to adjust patterns of interpersonal dynamics and rallying of resources is needed (Kreppner, 1990) to enable a family to adapt and function as efficiently as possible (Minuchin, 1990; Quittner & DiGiramo, 1998; Quittner, Glueckauf & Jackson, 1990). If parents were able to access fundamental resources such as social support and financial assets, the burden or at least the perception of stress might be reduced. Moreover, it has been found that resource availability is fundamental to adequately handle the demands and complexities of family life and directly impacts family functioning (Powell-Smith & Stollar, 1997; Rowland, Dodder, & Nickols, 1985).

Resources have been considered essential by many professionals when formulating overall long-term treatment strategies of families raising a disabled child (Seligman & Donling, 1979). Findings suggest, that resource access and allocation to be one of the single most important factors that predict healthy family social intra-dynamics (Dunst, Trivette, & Jodry, 1997). Friedrich, Wiltturner, and Cohen (1985) report that resources were equally accurate

predictors as were child variables on measures of family coping abilities. Dunst, Trivette, and Deal (1994) define the central purpose of resource support is to "enable and empower" individuals with the goal to increase family functioning to meet current and future stressors. Hauser-Cram et al. (2001) found that social and financial resources were strong mediators of family functioning and were associated with improved parental well-being and subsequent child improvements.

Conceptually, resources can be broadly delineated into terms of tangible and intangible items, skills, and or support (Dunst, Trivette, & Deal, 1990). Examples of tangible resources include financial assets, home/space requirements, and transportation. While intangible examples include specialized knowledge, time, techniques, and social support (Dunst, Trivette, & Deal, 1990). Many studies have defined the term 'resource' rather unevenly and inconsistently. Nonetheless, parental stress has been ameliorated due to adequate resources. Reducing financial burdens, social isolation, and deficiency of knowledge surrounding their child's disability are examples of the benefits adequate resources (Powell-Smith & Stollar, 1997).

It is important to note that the terms 'coping', 'resources', and 'social support' are often intertwined and loosely defined—suggesting that resources are a multi-faceted construct not easily described or measured. Within the field of family research, there is a dearth of literature that clearly, consistently, and operationally defines the term resource. Often, terms such as social support or emotional encouragement tends to tacitly imply a collection of more specific resources not directly measured. As an example, social support has been variably identified as including emotional, friendship, familiar, and even spousal support. This reflects the nebulous construct of the term resources and the difficult nature of prioritizing which specific items are essential to optimal family functioning during times of stress. Thus, identifying specific types of resources and under which conditions that they are best applied may hold promise in understanding family functioning under conditions of stress.

Regardless, research attests that parents of children with greater developmental difficulties over time indicated the least amount of social support (Sontag, 1997). Similarly, Dunst, Trivette, and Jodry (1997) findings have

emerged to confirm the ameliorating effects of support in reducing stressful factors for parents and families (Bronfenbrenner, 1986; Colletta, 1981; Quitter & DiGirolamo, 1998; Minnes, 1988; Quitter, Glueckauf, & Jackson 1990). Accordingly, access to essential social support is accepted as a crucial factor when considering the coping ability of families-"...a fact that should not be lost to those in a position to affect public policy" (Effects on the Family as a System, 1995). Additionally, social support appears to have encouraging effects--where higher levels of social support appear to reduce the effects of high stress (Johnson & Sarason, 1978). Social support has also been found to be a powerful tool in reducing family stress (Dyson, 1996; Beckman & Porkorni, 1988) and makes a persuasive case for augmenting positive family processes (Dunst, Trivette, & Cross, 1986).

However, the lack of adequate resources may have serious consequences for parents and other family members who may suffer significant complications. Hauser-Cram et al. (2001) report dramatic longitudinal increases of mothers reporting clinically significant problems due to the stress associated with raising a child with autistic or other PDD. High levels of parental stress are correlated

with lowered perceptions of social support that in turn were associated with increased reports of anxiety (Quittner, Glueckauf & Jackson, 1990; Sontag, 1996).

Although not all evidence indicates such clear and negative effects (Holroyd & McArthur, 1976), many findings do report increased levels of negative psychological symptomology when compared to controls (Cohen & Willis, 1985 Cobb, 1976). It is clear that children with autism, their typically developing siblings, and their parents represent a population that is at risk for psychological difficulties (Hauser-Cram et. al, 2001). Consistently, this population of disabled children and their families are diagnosed more often with psychological problems as compared to individuals in comparison groups (Hauser-Cram et. al, 2001; Quitter & DiGirolamo, 1998).

Clearly, these negative psychological effects upon parents can amplify an already undesirable situation in meeting childcare needs. Further, impaired psychological health has negative consequences for the ecological functioning of a family (Hauser-Cram et. al 2001; Webster-Stratton, 1990). These negative effects among parents can result in the use of poor coping skills, formation of maladaptive behaviors, or in some cases, emergence of

clinical levels of psychopathology (Hauser-Cram et. al, 2001). Thus, the triggering antecedents of parental psychopathology holds importance as it is likely to effect affect family ecology (Fiese & Sameroff, 1989; Seligman & Donling, 1997). Therefore, factors that might ameliorate some of the negative affects of child-care associated with raising a child with autism and or other developmental disability are certainly desirable.

One factor that has been suggested in ameliorating stress, links perception of resources and increased feelings of efficacy/control with better family functioning (Dyson, 1997). Parental perceptions of resource availability are strongly correlated with general reduced levels of psychopathology such as better emotional health (Cameron & Armstrong-Stassen, 1991). The literature clearly supports the important role resources play in managing the heavy child-care responsibilities of children with autism and other PDDs (Hauser-Cram et. al, 2001). Parents and families without the proper levels of resources to meet the chronic stress associated with child-care may subsequently be at risk for clinical levels of depression, anxiety, and somatoform complaints. In this vein, parents who are able to secure adequate resources will have the means to better

deal with the inherent stress of raising a child with autism or other PDD. Therefore, parents more able to meet the needs of their developmentally disabled child will maintain a sense of control and buffer the negative psychological impact of severe stress.

To date, few studies have examined the relationship resources play in the psychological adjustment of parents and families when raising a child with autism or other PDD present. Therefore, this study is exploratory in nature, seeking to better differentiate, which resources as measured through the Perceived Adequacy of Resources Scale (PAR) (Rowland, Dodder & Nickols, 1985) affect specific psychological sub domains as measured by the Symptom Assessment-45 (SA-45) (Davidson et al. 1997). Based upon previous research, the following is hypothesized:

It is hypothesized that both parental groups (consumer and comparison) will have relatively equal perceptions of resources. These perceptions of resources will be measured through global/total and domain specific sub scores (interpersonal/social, financial, and health) of the PAR. However, it is expected that there will exist significant parental group (consumer and comparison) differences on measures of mental health functioning. These group

differences will be measured through global and domain specific sub scores (depression, anxiety, and somatoform) of the SA-45. Specifically, it is expected that the parental consumer group (sampled from the UCDD) will have higher scores on the SA-45 mental health measures.

Revealing greater mental health problems/complications contrasted with the comparison parental group who will reveal less mental health problems/complications.

Further, it is hypothesized that there will be significant correlations among PAR (interpersonal/social, financial, and health) and SA-45 sub scores (depression, anxiety, and somatoform) for both parental groups.

Indicating support for specific resources having important impact on specific mental health domains.

Among the three sub scales of the PAR

(interpersonal/social, financial, and health), it is hypothesized that interpersonal resource can best predict each of the three SA-45 subscales (depression, anxiety, and somatoform). And that the remaining PAR subscales (financial and health) domains will be respectively less able to predict the three sub scales of the SA-45 sub scores (depression, anxiety, and somatoform).

Additionally, when examining both parental groups, the three subscales of the PAR (interpersonal/social, financial, and health) will significantly predict mental health scores measured by the three subscales of the SA-45 (depression, anxiety, and somatoform).

Therefore, analysis of the data will allow direct comparisons (consumer and comparison) on global and sub scores of the PAR and the SA-45. Further, data analysis will also allow, to some degree, to estimate if the services/programs of the UCDD are effective in meeting the needs of consumer parents raising a child with pervasive developmental disabilities.

CHAPTER TWO

METHOD

Participants

Participants consisted of parents of developmental disabled children enrolled in the University Center for Developmental Disabilities (UCDD) program. The UCDD is a supplemental behavioral intervention and parent support and education program. This program provides one-to-one behavioral interventions, and parent education and support for families with children and/or adolescents with developmental disabilities (consumers) who display a wide range of behavioral problems, and/or deficits. Approximately 85 % of consumers currently attending the UCDD have at least a partial diagnosis of autistic spectrum disorder (Hoffman, et al., 2003).

These individuals are referred to the UCDD through the Inland Regional Center (IRC), a division of the state of California's Department of Developmental Services (CDDS), which contracts with Regional Centers (RC) consisting of 21 non-profit agencies. IRC serves the Southern California inland area of San Bernardino and Riverside counties-an area encompassing nearly 28,000 square miles and serving

approximately 16,000 individuals. Due to the fluid referral process of families into the UCDD program, the number of families participating at the UCDD can fluctuate.

However, as of November 2002, UCDD served 115 consumers (affected children), (80% male and 20% female) who ranged in age from 3 through 17 years old (31% under the age of six, 47% between the ages of 7 through 11, and 22% 12 years or older). Of the total families attending the program at UCDD, approximately 90% have agreed to participate in this project. Preliminary collected demographic information reveals: Caucasian, 35%; Hispanic/Latino, 18%; African American, 13%; Asian American, 13%; Pacific Islander, 4%; Native American, 2%, and other /mixed 16%. Extensive demographic information was collected of all family members and consumers across a variety of domains and will be used for later program evaluation, research and implementation. The California State University San Bernardino has reviewed and approved all aspects of this and other research associated with collection of these datum and subsequent UCDD programs.

Participation within this research program was strictly voluntary and did not affect services provided to family consumers or members. No monetary or other

compensation was provided for research participation. All participants were debriefed following administration of all measures and were treated in accordance with the, "Ethical Principles of Psychologists and Code of Conduct" (APA, 1992).

Participants for the comparison families will come from local Southern California Communities and the campus of California State University San Bernardino (CSUSB). Other demographic information will include number of children in the family and ages, total household income, educational level of parent(s), and marital status. These items will be collected to ascertain any significant correlated factors that might also influence parental functioning.

Procedures

Parents currently attending or initially entering the UCDD program were invited to participate in the research project. Participants (parents); were individually assessed in a quiet room free of distractions by UCDD research staff members. To maintain consistency and due to the varying reading competencies of participants, staff member read aloud all directions and questions of assessment measures.

The staff member will read an informed consent statement explaining the general purpose of the data collection and the parents will be asked to sign this statement confirming that they have understood the informed consent prior to the administration of the assessments. An 8x10 inch foldout display holding each scale was presented. This display served to clearly show the range of each Likert for a particular measure. Due to the sensitive nature of questions asked, this display also served to provide privacy for participant responses as recorded on standardized answer sheets. At the end of the assessment session, all answer sheets will be immediately sealed in a plain unmarked manila envelope identified with a five digit alphanumeric code to ensure anonymity. There are no time constraints to complete measures; however, pilot testing of these measures typically took approximately 1.5 through 2 hours to complete the full parent assessment packet. Upon completion of datum collection, staff member will then debrief the participant. Data for this particular study will be collected from a larger (687 items), ongoing program evaluation project at UCDD. Measures of test packets include: the Parent Stress Index (PSI), the Family Environment Scale (FES), the Dyadic Adjustment Scale (DAS),

Coping Scale for Adults (CSA), Perceived Adequacy of Resources (PAR), Symptom Assessment-45 (SA-45), the Rosenberg Self-Esteem Scale (ROS), Doti/Armstrong Attribution Scale (DAAS), Behavioral Vignettes Test (BVT), the Therapy Attitudes Inventory (TAI), the Child Behavior Checklist (CBCL), and the Hoffman-Moon Parentification Scale (HFP).

The PAR, and the SA-45, the two principle measured used for this specific study, were therefore embedded as part of a larger battery of measures used in evaluation of treatment programs offered to parents and their autistic children through the UCDD. The PAR and the SA-45 alone collectively take approximately 20 minutes to complete.

Due to the drastically reduced scoped and scale of the number and type of questions collected from the comparison group, questionnaires will be read and completed by parents alone. Since the comparison group parents will only be answering items from the PAR and the SA-45, these brief questionnaires will be handed out and returned to researchers as they are completed by parents. No complications are expected due to this adjustment in procedures--owing to the relatively simple, direct, and

reduced nature of questions employed within both measures (73 items) versus the total 687 items.

Materials

The Perceived Adequacy of Resources (PAR) Scale will be used to examine parental perceptions of resources. The PAR Scale measures how respondents feel about the adequacy of family or personal resources. This measure consists of 28 items covering 7 resource concepts: 1. Physical Environment, 2. Health/Physical Energy, 3. Time, 4. Financial, 5. Interpersonal, 6. Knowledge/Skills, and 7. Community). A 7-point Likert scale ranging from 1 (strongly agree) through 7 (strongly disagree) will be used to evaluate items (Rowland, Dodder, & Nickols, 1995). Sample questions for each of the respective subscales are: 1. "Space inside my home is adequate for my needs", 2. "My health allows me to do my work", 3. "I have enough time to do the things I want", 4. "I have enough financial resources to meet unexpected needs", 5. "I have neighbors that I can call on for help", 6. "I have enough education to meet my long term needs", and 7. "My community is a good place to live".

The Symptom Assessment-45 (SA-45) is a 45-item questionnaire that requires approximately 10 minutes to

complete. The SA-45 was designed to provide a relatively quick assessment of psychiatric symptomology. It provides a global severity index of psychological health, broken down into 9 sub areas of psychological functioning. The nine subscales of the SA-45 are: 1. Anxiety, 2. Depression, 3. Hostility, 4. Interpersonal Sensitivity, 5. Obsessive-Compulsive, 6. Paranoid Ideation, 7. Phobic Anxiety, 8. Psychoticism, and 9. Somatization. Employing a 5-point Likert scale ranging from 1 (not at all) through 5 (extremely), respondents are asked to rate their symptom prevalence based upon how much a problem has bothered or distressed them in the last seven days (Davison, Bershadsky, Bieber, Silversmith, Maruish, & Kane, 1997). Sample questions for each respective subscale are: 1. "Feeling afraid in open spaces or on the streets", 2. "Feeling hopeless about the future", 3. "Shouting or throwing things", 4. "Feeling inferior to others", 5. "Having to check and double check what you do", 6. "Feeling that people are unfriendly or dislike you", 7. "Spells of terror or panic", 8. "The idea that someone else can control your thoughts", and 9. "Numbness or tingling in parts of your body".

Statistical Analysis

T-test analysis will be employed to uncover group differences (consumer and comparison) on measures of PAR and SA-45 global and sub scores. Additionally, correlations among the sub scales of the PAR (interpersonal/social, financial, and health) and the SA-45 (depression, anxiety, and somatoform) will be calculated. Further, hierarchical regression analyses will be run to determine predictive value of sub categories of the PAR (interpersonal/social, financial, and health) as contributing to each of the criterion scores of the SA-45 (depression, anxiety, and somatoform).

CHAPTER THREE

RESULTS

Chi square analyses were conducted on seven sets of demographic data to examine the comparability between the consumer and the comparison groups: (1) number of children living at home under the age of eighteen, (2) marital status, (3) sex of the parent who provided the PAR and the SA-45 data, (4) total household income, (5) education level, (6) ethnicity, and (7) age of the parent. As can be seen from the summarized results in Table 1, significant between-group differences were found for four (i.e., marital status, total household income, education level, and age of the parent) of the seven sets of demographic data. Because of the problematic nature between consumer and comparison groups on demographic backgrounds, the major results surrounding comparability in this study need to be interpreted with caution.

Global score and sub-domain scores were calculated for both the PAR and the SA-45 measures. The global PAR score is the sum of its seven sub-domain scores: (1) physical environment, (2) physical health, (3) time, (4) financial, (5) interpersonal/social, (6) knowledge/skills, and (7)

community. The global SA-45 score is the sum of its nine sub-domain scores: (1) anxiety, (2) depression, (3) obsessive-compulsive, (4) somatization, (5) phobic anxiety, (6) hostility, (7) interpersonal sensitivity, (8) paranoid ideation, and (9) psychotism. For current research interests, only the global PAR score and its three sub-domain scores (interpersonal, financial, and health physical) and the global SA-45 score and its three sub-domain scores (depression, anxiety, and somatization) will be reported.

T-tests were conducted to test between-group differences (consumer group vs. comparison group) for the above-mentioned measures. The mean scores and the standard divisions for the global PAR and its three sub-domain scores and the global SA-45 and its three sub-domain scores are summarized in Table 2 and Table 3, respectively. As can be seen from Table 2 and Table 3, no significant between-group (consumer vs. comparison) differences were found for the global PAR score and its three sub-domain scores (the interpersonal, financial, and health physical) or the global SA-45 score and its three sub-domain scores (depression, anxiety, and somatization).

Further, to determine the relationship between each of the sub-domains of the PAR (perception of resources: interpersonal, financial and health) and each of the sub-domains of the SA-45 (mental health measure: depression, anxiety and somatization), bivariate correlation coefficients were calculated for the consumer group and the comparison group, respectively. The results are summarized in Table 4 and Table 5.

As can be seen from Table 4, for the consumer group, each of the three sub-domains of the PAR and each of the three sub-domains of SA-45 was negatively correlated. Significant negative relationships were found between interpersonal/social resources and two of the SA-45 sub-domains (depression and anxiety). Significant negative relationships were also found between financial resources and the same two SA-45 sub-domains (depression and anxiety). Moreover, significant negative relationships were found between health resources and all three of the SA-45 sub-domains (depression, anxiety and somatization).

Similar results were found for the comparison group, as can be seen from Table 5. Significant negative relationships were found for each of the three sub-domains of the PAR (interpersonal/social, financial, and health)

with each of the three sub-domains of SA-45 (depression, anxiety and somatization).

In addition to the relationship between the sub-domains of the PAR and the sub-domains of the SA-45, the relationship between the global score of the PAR and the global score of the SA-45 was also examined for the consumer and comparison groups. For the consumer group, a significant negative relationship was found between global PAR and global SA-45 scores, $r(89) = -.417$, $p=.000$. This indicated that, for the consumer group, 17.39% of the variance in the global SA-45 scores was accounted for by the variation of the global PAR scores. For the comparison group, a significant negative relationship was also found between global PAR and global SR-45 scores, $r(130) = -.460$, $p=.000$. This indicated that, for the comparison group, 21.16% of the variance in the global SA-45 scores was accounted for by the variation of the global PAR scores.

Lastly, in order to examine the extent to which the participants' sub-domain scores on the Perceived Adequacy of Resources scale (interpersonal, financial and health) were predictive of the sub-domain scores on the Symptoms Assessment-45 (depression, anxiety and somatization), six separate hierarchical multiple regression analyses were

conducted. Three hierarchical multiple regression analyses were conducted for the consumer group and three were conducted for the comparison group. For each analysis, interpersonal scores were entered at the first step as the first predictor variable while financial and health scores were entered at the second and third steps respectively as the second and the third predictor variables. The criterion variables are the three sub-domain scores of the SA-45. The results are summarized in Table 6 to Table 11. Below are the criterion variables of the SA-45 (depression, anxiety, and somatoform) presented individually between groups.

Depression

As can be seen from Table 6, for the consumer group, results at step one indicated that interpersonal resources significantly predicted depression, $F(1,89)=10.14$, $p=.002$, $R^2=.102$, where 10.20% of the variance in depression was accounted for by the variation of interpersonal/social resources. At the second step, financial resources improved prediction, $R^2\text{change}=.023$. Interpersonal resources and Financial resources significantly predicted depression, $F(2, 88)= 6.30$, $p=.003$, where 2.3% of the variance in

depression was account for by the variation of financial resource. In the last step, health resources again significantly improved prediction, $R^2\text{change}=.06$, where health resources accounted for an additional 6% of the variance in depression. The three sub-domains of PAR (interpersonal, financial, and health) significantly predicted depression, $F_{(3, 87)} = 6.57$, $p = .000$.

As can be seen from Table 7, for the comparison group, results at step one indicated that interpersonal resources significantly predicted depression, $F(1,130)= 12.72$, $p=.001$, $R^2=.082$, where 8.2% of the variance in depression was accounted for by the variation of interpersonal/social resources. At the second step, financial resources improved prediction, $R^2\text{change}=.082$. Interpersonal resources and Financial resources significantly predicted depression, $F(2, 129)= 13.28$, $p=.000$, where financial resources accounted for an additional 8.2% of the variance in depression. In the last step, health resources again significantly improved prediction, $R^2\text{change}=.062$, where Health resources accounted for an additional 6.2% of the variance in depression. The three sub-domains of PAR

(interpersonal, financial, and health) significantly predicted depression, $F(3, 128) = 12.95$, $p = .000$.

Anxiety

As can be seen from Table 8, for the consumer group, results at step one indicated that interpersonal resources significantly predicted anxiety, $F(1, 89) = 5.09$, $p = .026$, $R^2 = .054$, where 5.4% of the variance in anxiety was accounted for by the variation of interpersonal/social resources. At the second step, financial resources improved prediction, R^2 change = .028. Interpersonal resources and Financial resources significantly predicted depression, $F(2, 88) = 3.96$, $p = .023$, where financial resources accounted for an additional 2.3% of the variance in anxiety. In the last step, health resources again significantly improved prediction, R^2 change = .025, where Health resources accounted for an additional 2.5% of the variance in depression. The three sub-domains of PAR (interpersonal, financial, and health) significantly predicted depression, $F(3, 87) = 3.45$, $p = .020$.

As can be seen from Table 9, for the comparison group, results at step one indicated that interpersonal resources significantly predicted anxiety, $F(1, 130) = 14.21$, $p = .000$,

$R^2=.099$, where 9.9% of the variance in anxiety was accounted for by the variation of interpersonal/social resources. At the second step, financial resources improved prediction, R^2 change=.080. Interpersonal resources and Financial resources significantly predicted anxiety, $F(2, 129)=14.11$, $p=.000$, where financial resources accounted for an additional 8.0% of the variance in anxiety. In the last step, health resources again significantly improved prediction, R^2 change=.170, where Health resources accounted for an additional 17% of the variance in anxiety. The three sub-domains of PAR (interpersonal, financial, and health) significantly predicted anxiety, $F(3, 128)=22.86$, $p=.000$.

Somatization

As can be seen from Table 10, for the consumer group, results at step one indicated that interpersonal resources did not significantly predicted somatization, $F(1,89)=.366$, $p=.547$. At the second step, financial resources did not improved prediction. Interpersonal resources and Financial resources did not significantly predicted somatization $F(2, 88)=.759$, $p=.471$. In the last step, health resources again did not significantly improved prediction. The three sub-

domains of PAR (interpersonal, financial, and health) did not significantly predicted depression, $F(3, 87)=2.18$, $p=.096$.

As can be seen from Table 11, for the comparison group, results at step one indicated that interpersonal resources significantly predicted somatoform, $F(1,130)=18.76$, $p=.000$, $R^2=.126$, where 12.6% of the variance in somatoform was accounted for by the variation of interpersonal/social resources. At the second step, financial resources improved prediction, $R^2\text{change}=.105$. Interpersonal resources and Financial resources significantly predicted somatoform, $F(2, 129)=19.39$, $p=.000$, where financial resources accounted for an additional 10.5% of the variance in somatoform. In the last step, health resources again significantly improved prediction, $R^2\text{change}=.090$, where Health resources accounted for an additional 9% of the variance in somatoform. The three sub-domains of PAR (interpersonal, financial, and health) significantly predicted somatoform, $F(3, 128)=20.54$, $p=.000$.

Table 1. Chi Square Test Results: Background Comparability
Between the Consumer Group and the Comparison Group

Number of Children Living at Home under the Age of
Eighteen*

	Consumer	Comparison
1-2 children	67	106
3-4 children	24	25

$$\chi^2(1, 222) = 1.66, p = .198$$

*One family (with 5 or more children) from the comparison group was excluded from this χ^2 analysis.

Marital Status*

	Consumer	Comparison
Single	12	35
Married	84	77
Divorced or Separated	3+8	3+17

$$\chi^2(2, 239) = 11.69, p = .003$$

*The Divorced and the Separated categories were combined for this χ^2 analysis due to the low frequencies for the divorced category for each group.

Sex of Parent

	Consumer	Comparison
Female	98	121
Male	14	11

$$\chi^2(1, 244) = 1.15, p = .285$$

Household Income

	Consumer	Comparison
\$0-23,999	11	40
\$24,000-35,999	13	29
\$36,000-47,999	14	14
\$48,000-59,999	8	15
\$60,000-71,999	10	11
\$72,000 or more	33	23

$$\chi^2(5, 221) = 18.90, p = .002$$

Education Level*

	Consumer	Comparison
High School Graduate	29	17
Some College	35	81
College Graduate	15	24
Graduate Degree and Doctoral/Professional	7+1	4+1
Other	13	5

$$\chi^2(4, 232) = 23.73, p = .000$$

*The Graduate Degree category and the Doctoral/Profession category were combined for this χ^2 analysis due to low frequencies for the Doctoral/Professional category for each group.

Ethnicity of Parent

	Consumer	Comparison
African American	13	27
Caucasian	46	62
Hispanic/Latino	32	33
Asian, Pacific Islander and Other	13+1+3	4+1+5

$$\chi^2(3, 240) = 6.77, p = .08$$

*The three categories, Asian, Pacific Islander, and other were combined for this χ^2 analysis due to low frequencies in each category for each group.

<i>Age of Parent (years)*</i>	<i>Consumer</i>	<i>Comparison</i>
18-24 & 25-30	3+29	33+31
25-30	29	31
31-36	28	23
37-42	23	18
43-49 & 50 or older	10+2	19+8

$$\chi^2(3, 227) = 11.82, p = .008$$

*The categories, 18-24 and 25-30, and the categories 43-49 and 50 or older were combined due to low frequencies.

Table 2. Mean Scores, Standard Divisions, and t-test
Results for the Global PAR and its Three Sub-domains

Variable	Consumer (n=91)		Comparison (n=132)	
	M	SD	M	SD
Interpersonal Resources t(221)=1.52, p=.130	18.97	5.26	20.01	4.86
Financial Resources t(221)= 1.57, p=.118	16.70	6.36	15.42	5.71
Health Resources t(221)=.52, p =.605	18.73	5.30	19.08	4.72
Global PAR t(221)=.35, p=.727	126.47	26.13	125.17	28.20

Table 3. Mean Scores, Standard Divisions, and t-test
Results for the Global SA-45 and its Three Sub-domains

	Consumer (n=91)		Comparison (n=132)	
Variable t-tests	M	SD	M	SD
Anxiety t(221)=1.41, p=.159	8.36	3.36	9.11	4.18
Depression t(221)=.50, p=.615	9.49	4.44	9.80	4.53
Somatization t(221)=1.74, p=.084	8.52	4.04	9.54	4.50
Global SA-45 t(221)=1.93, p=.055	71.98	22.85	79.82	33.65

Table 4. Consumer Group (n=91): Correlations Between PAR
(Interpersonal, Financial, Health) and SA-45 (Depression,
Anxiety, Somatization)

	Depression	Anxiety	Somatization
Interpersonal/Social	-.32**	-.23*	-.06
Financial	-.30**	-.27*	-.13
Health	-.38**	-.28**	-.26*

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

Table 5. Comparison Group (n=132): Correlations Between PAR (Interpersonal, Financial, Health) and SA-45 (Depression, Anxiety, Somatization)

	Depression	Anxiety	Somatization
Interpersonal/Social	-.30**	-.31**	-.36**
Financial	-.36**	-.37**	-.42**
Health	-.42**	-.57**	-.51**

** p < .01

Table 6. Hierarchical Regression Analysis for
Interpersonal, Financial and Health Resources Predicting
Depression in the Consumer Group (n=91)

Step Predictor Variables	R	R ²	ΔR^2	F
1. Interpersonal Resources	.320	.102		F(1,89)=10.14**
2. Financial Resources	.354	.125	.023	F(2,88)= 6.30**
3. Health Resources	.430	.185	.060	F(3,87)=6.57*

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

Table 7. Hierarchical Regression Analysis for
Interpersonal, Financial and Health Resources Predicting
Depression in the Comparison Group (n=131)

Step Predictor Variables	R	R ²	ΔR^2	F
1. Interpersonal Resources	.299	.089		F(1,130)=12.72**
2. Financial Resources	.413	.171	.082	F(2,129)=13.28**
3. Health Resources	.483	.233	.062	F(3,128)=12.95**

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

Table 8. Hierarchical Regression Analysis for
Interpersonal, Financial and Health Resources Predicting
Anxiety in the Consumer Group (n=91)

Step Predictor Variables	R	R ²	ΔR^2	F
1. Interpersonal Resources	.233	.054		F(1,89)=5.09*
2. Financial Resources	.287	.082	.028	F(2,88)=3.96*
3. Health Resources	.32	.107	.025	F(3,87)=3.47*

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

Table 9. Hierarchical Regression Analysis for
Interpersonal, Financial and Health Resources Predicting
Anxiety in the Comparison Group (n=131)

Step Predictor Variables	R	R ²	ΔR ²	F
1. Interpersonal Resources	.314	.099		F(1,130)=14.21**
2. Financial Resources	.424	.179	.080	F(2,129)=14.12**
3. Health Resources	.591	.349	.017	F(3,128)=22.85**

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

Table 10. Hierarchical Regression Analysis for
Interpersonal, Financial and Health Resources Predicting
Somatoform in the Consumer Group (n=91)

Step Predictor Variables	R	R ²	ΔR^2	F
1. Interpersonal Resources	.064	.004		F(1,89) = 0.37
2. Financial Resources	.130	.017	.013	F(2,88) = 0.76
3. Health Resources	.264	.070	.053	F(3,87) = 2.18

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

Table 11. Hierarchical Regression Analysis for
Interpersonal, Financial and Health Resources Predicting
Somatoform in the Comparison Group (n=131)

Step Predictor Variables	R	R ²	ΔR^2	F
1. Interpersonal Resources	.355	.126		F(1,130)=18.76**
2. Financial Resources	.481	.231	.105	F(2,129)=19.39**
3. Health Resources	.570	.325	.094	F(3,128)=20.54*

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

CHAPTER FOUR

DISCUSSION

The purpose of this study was to investigate the effects of rearing a child with autism or other pervasive developmental disability (PDD) and its long-term impact upon parents. Specifically, we sought to understand the relationship of perceived resources and parental mental health. Expectations surrounding our study were driven by findings in the research literature, indicating the buffering and ameliorating effects related to resources. Perceptions of resources and mental health functioning were collected from two groups: parents raising a child with a PDD (consumer group) and parents raising a typically developing child (comparison group). Perceptions of resources were expected to have especially notable effects among consumer parents caring for a child with a PDD. In particular, perceptions of resources were expected to have strong effects on subsequent associated measures of mental health (Dyson, 1993; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Crnic, Friedrich, & Greenberg, 1983).

Since consumer and comparison groups were sampled from similar communities located in Southern California, it was anticipated that both groups would report similar levels of perceptions of resource. Consumer and comparison groups reported equal perceptions of resources. Findings surrounding global PAR scores reveal no significant differences between consumer and comparison groups. Nor were there any significant group differences within the target sub domain scores of the PAR (interpersonal, financial, and health) (see Table 2). This suggests comparability between groups.

Research interests surrounding the global and domain specific scores of mental health were also collected to determine psychological functioning between parental groups. The consumer parental group was expected to reveal elevated negative SA-45 mental health scores when contrasted with comparison group scores. However, this expectation was not supported (see Table 3). Consumer and comparison groups reported approximately equal levels of mental health complaints.

Correlation analyses of this study's target sub-domains of the PAR: interpersonal, financial, and health and the SA-45: depression, anxiety, and somatoform renders

many significant negative relationships. Of the possible nine bivariate pair-wise correlations within the consumer group only interpersonal and financial areas failed to significantly correlate with the mental health factor of somatization. Failure of resource items interpersonal and financial to correlate with somatization is not completely unexpected. The literature often mentions physical complaints such as lack of energy and general fatigue as correlaries of PDD child care. However, physical complaints are also often associated with presentations of depression and may be a smaller facet of a larger domain of depleted or overwhelmed coping abilities among parents. The remaining seven significant correlations were inversely related to each other; where decreases in PAR levels were associated with elevated SA-45 levels (see Table 4). Comparison group correlations reveal all nine coefficients were significant and inversely related (see Table 5).

To investigate how resources among consumer parents might be predictive of target mental health domains, three separate hierarchical regression analyses were also conducted. These analyses reveal that social/interpersonal, financial, and health resource domains significantly predicted scores on measures of both

depression and anxiety but not somatoform (see Table 6). Three identical regression analyses were conducted for the comparison group. Revealing that interpersonal/social, financial, and health domains were significantly predictive of all three SA-45 mental health domains of depression, anxiety, as well as somatoform. This further reinforces the notion that there is a robust link between these particular resources with our target domains of mental health functioning.

Past research has sought to investigate the role of resources and its relationship with mental health (Cameron & Armstrong-Stassen, 1991)--mixed results have been reported (Quitter & Di Girolamo, 1998). Some findings have even reported a greater sense of life purpose and better physical and psychological functioning among parents raising a child with a PDD (Jessop, Reissman & Stein, 1988). Along with the results of our current study, it suggests that there are important considerations in measuring parental resource and mental health.

In line with these types of aforementioned findings our findings also reveal that the consumer parental group failed to report significant elevated levels of mental health complications. Factual, both consumer and comparison

groups calculated scores on the SA-45 measure were on the initial criterion for significant negative mental health problems. However, a lack of serious and elevated mental health complications suggest at least two different explanations in light of the majority of research indicating the considerable negative impact of PDD child care. First, it indicates that they have access to adequate resources at least equal to needs of a comparison group. And that consumer resource levels are sufficient in meeting the needs of PDD child care. Since we found that both consumer and comparison groups perceived equal levels of resources some other potent form of ameliorating factor is occurring. The most obvious factor in parents making up our quasi-experimental consumer group is the role of the University Center for Developmental Disabilities.

Assumed earlier in this study, we believed that specific resources such as social support and financial assets would hold greater influence than other resources areas. However, our results do not paint a clear and unambiguous rendering of the effects of these resources. True, there were significant correlations between PAR and SA-45 sub domains investigated—nevertheless these findings cannot designate direct causality of resources and mental

health. When considering the hierarchical regression analyses, interpretation of our findings lend support to the predictive value of social support and financial assets on measures of depression and anxiety. Social support upon depression has clear face validity benefits.

Depression and anxiety are often intertwined presentations associated with high and chronic levels of stress. Repeatedly, the diagnosis of depression has been indicated not under acute conditions. Rather, it is the long term and unrelieved nature of even moderate stress that often leads to clinical levels of depression. Financial stress can also be considered a more precise and quantifiable measure that reveals a value or indicator of stress experiences. Therefore, reduced financial resources are a marker revealing just one more facet of stress that compounds other deficits in family functioning.

However, the link between anxiety and finances is not well known but the relationship between these items also appears to have face validity. When considering the extra demands of PDD child care, financial considerations must be a constant concern for parents. Parents attempting to manage all the components of PDD child care along with typical mundane factors such as work and household

maintenance would leave little extra time or income for entertainment or relaxation to recharge their ability to cope. Therefore, raising their levels of depressions and anxiety. Plainly, the tangled nature of these domains and constructs are not without their problematic interpretations and the explanations offered can only be considered speculative.

However, this population of parents at the UCDD appears to be functioning relatively well. It may be that the lack of negative effects/affects among parents most probably is not the result of intellectual processes taking place. Rather, they may involve aspects of direct assistance. Social support and respite care as offered through the UCDD are closely linked and consistently shown to recharge parents' coping capacity in the literature (Abelson, 1999). Bristol and Schopler (1984) claim that without social support and respite care, "...parents might become isolated...marital conflicts may escalate...(and) financial strains may increase".

Parents who seek services for themselves and their children suggest that they are in need of assistance across a range of domains. It has been suggested among the staff of the UCDD that knowledge of a particular resource without

the chance of access to it elicits negative consequences. These consequences are often expressed in language describing depression and anxiety among parents of PDD children. Suggesting that knowledge of resources without hope of securing a particular resource may actually raise levels of depression and anxiety in this population.

However, something appears to be occurring after parents and their families enter the program. There appears to be a knowledge hope of true resources being accessible. Services/programs offered at the UCDD and similar facilities are possibly making a positive difference for parents caring for a child with a PDD. Thus, the moderate scores on the SA-45 mental health measure for the consumer parental group that are comparable to the comparison group evidence ameliorating processes are occurring. Even in a restrained evaluation, the UCDD can be credited with at least a portion of the positive effects in parents caring for a child with a PDD.

When considering the summation of our results the limitations of this current study are worthy of note. Parents seeking services at the UCDD may be a self-selecting group by the fact they even seek extra or outside services. Parents may also go to extra efforts to make all

appointments and thus reap the full benefits of treatment. Moreover, the lack of significant negative effects in the consumer group may not be attributed alone to the programs at the UCDD and other factors or programs may be responsible.

Results involving the comparison group were also unforeseen. Demographic information collected, in order to evaluate group comparability, may also have been a limitation of this current study. Across the seven demographic areas analyzed--four demographic areas were significantly different (see Table 1). Difference in many core demographic areas limits the direct comparability of group responses and results need to be interpreted with some caution.

One potential explanation for the comparison group's relatively elevated SA-45 scores involves the compounded responsibilities of being a student and parent. Clearly, student and parental responsibilities are substantial when combined. In addition, this comparison group's significant correlations and regression analyses on measures of somatization may be explained in terms of the time period data was collected. Data collected at the end of an academic year and term/quarter implies possible the highest

cumulative levels of physical, intellectual, and psychic attrition. Clearly, students look forward to a break over the summer months to recharge their physical and mental reserves depleted over the academic year and may well reflect rising stress levels. Moreover, pooled comparison data collected from the local community reflects a sample that is made up of a modest socioeconomic status and possibly reflects the stress associated with a lower SES. Combined parental, school, and socio-economic stressors may partially explain the comparison group's slightly higher scores on the SA-45 measure.

Since this was an exploratory study, the total number of independent variables employed was limited. Investigation of the interactions among sources and mediators of parental stress needs increased attention. Thus, increased family characteristic including child attributes such as severity of autism, age, and sex may reveal alterations in child care responsibilities. Parenting styles may also illuminate other facets of family dynamics affecting child care. These additional variable items would afford a more holistic and comprehensive understanding of mediating factors associated with stress, resources, and family characteristics. In the future, data

collection needs to include groups outside the UCDD in diverse programs to discern the effect of similar and dissimilar programs among parents.

Although the literature specifies the negative impact of child care associated with a PDD, we did not find this effect in our treatment population. However, this does not implicitly suggest that this population of parents is free of mental health burdens, have access to special resources, or even that they are an unusual set of individuals. Rather than viewing the parents of the UCDD as a uniquely capable group they most likely are a burdened population. One that is receiving consistent and effective services from a range of service providers that act to offset some of the burdens of PDD child care. Our findings may be due to parents' levels of resource and mental health also needs to be established upon entering a program. This would illuminate whether parents are truly improving over time once participating in services such as the UCDD provides or if they are somehow inherently more capable due to self selecting for services. Thus, a longitudinal study that captures parental data prior to program start and over long-term set points is needed to reveal programs effectiveness and parental characteristics. This schedule

of sampling would indicate when and if treatment effects are occurring. In addition, whether there might be rebounds and general trends in parental functioning over the course of program inclusion. Historically, parents often report increased anxiety as their two year involvement with the UCDD comes to an end. Currently, this type of longitudinal data is being collected as part of the UCDD program evaluation but is not yet fully compiled.

Although this study did not find absolute and definitive results, there are implications worthy of mention. Clearly, the literature would indicate that considering all resources as equal in their effect as inaccurate. Resources need to be ranked or evaluated according to their value to parents under the stress of PDD child care. True, this ranking of resources would not take the form of a laundry list of first through last. However, there are items of resource that are taken for granted that should be paramount when hoping to assist parents under stress. The most overriding of these, and it is an intuitive one, points to the needs of interpersonal/social support.

Individuals derive the bulk of their ability to combat negative stress by rallying the supports of friends,

family, and services. Without this vital resource, individuals and families would soon find themselves overwhelmed and unable to meet the challenges of daily life much less the significant burdens of PDD child care. Even the counseling sciences have long recognized the value of social presence in ameliorating negative psychological implications (Rogers, 1942; Kahn, 1997).

Secondly, financial resources have long been thought to hold the largest benefit across a range of stress domains. Clearly, adequate levels of financial resource are necessary for daily and long term management of life factors, especially so in the face of PDD child care. But it would be too simplistic to say that money cures all things. Instead, financial resource has its place but is superceded by elements of social interaction that holds the most promise. Social support, however, is not without its cost. Programs like that at the UCDD clearly cost a considerable amount of money. But when considering the benefits it provides over the long term it may cost very little in comparison to not having such programs in parents' and children's lives.

If any recommendations from this study to service providers stand out: that families clearly are an

interactive unit with parental and child characteristics interacting with levels of resources. A univariate approach attempting to understand family factors will fail to understand the nested and reverberating effects of individuals and their unique characteristics. Further, resources are not capricious or equal in their ability to ameliorate life stressors that can trigger acute and chronic repercussions of mental health associated with a PDD in one's child.

When looking at social support, and financial, and health assets, there is a clear intuitive hierarchy of value placed upon these items in the face of stress. No amount of financial assets will alleviate all aspects of the strains of PDD child care. Nor will health and physical energy effect the negative effect of long term stress. True, financial resources can buy many components of practical care such as expert advice, special equipment and even in home care visits. But it is the human touch, concern, and presence of friends and family that reassures, calms, and offers hope to those who may be facing obstacles. These obstacles may look overwhelming when faced alone. However, with some measure of social support, obstacles are not reduced--rather, individuals are

strengthened to meet the burdens of their experiences through the help of important people in their lives. With social support, parents do not have to be all things at all times to care for their child with a PDD--others help carry this load. Therefore, items such as social support are prominent in the literature and in this current study as having important implications for family functioning.

APPENDIX
RESEARCH PACKET

Informed Consent

Thank you for participating in this study, the study in which you are being asked to participate is about your beliefs and perceptions concerning yourself and your family. My name is Jonathan Doti and I am a graduate student at California State University, San Bernardino (CSUSB) under the direction of Dr. Charles Hoffman. Specifically, we are interested if resources in your life, such as finances and emotional support, could buffer some of the normal difficulties of raising a child. You will be answering some demographic information and then a series of questions and marking your corresponding answers. Please answer all questions as honestly as possible—we are very interested in what you think.

The entire questionnaire will take approximately 15 minutes. Your participation is completely voluntary and you may choose to discontinue at any time for any reason. Students at CSUSB may receive extra credit points at the discretion of their instructor. Complete confidentiality will be assured—no name or identification is required with the information you provide. Therefore, we will not be looking at individual responses.

There are no foreseeable risks associated with participation. This study has been reviewed and approved by the Institutional Review Board, at California State University, San Bernardino. If you have any questions or comments concerning this study, please contact Dr. Charles Hoffman in the department of psychology at CSUSB (909) 880-7305 or e-mail at choffman@csusb.edu.

By marking in the appropriate box below, you will be giving permission to use the data that you provide. Further, you acknowledge that you are at least 18 years of age and have at least one child and who lives at home with you without any known developmental disability or significant medical condition. Again, thank you for your participation.

I Agree to Participate; mark here:

☐

Date: ____/____/03

dd / mm / yy

1. Total number of your children (under the age of 18 years) living in your home: ____.

2. Age(s) of your child(ren) living at home: _____.

3. Your marital status:

☐ Single ☐ Married ☐ Divorced ☐ Separated

4. Your sex:

☐ Female ☐ Male

5. Total household income (yearly):

☐ less than \$24,000 ☐ \$24,000 to \$35,999 ☐ \$36,000 to \$47,999
☐ \$48,000 to \$59,999 ☐ \$60,000 to \$71,999 ☐ \$72,000 or greater

6. Your education level:

☐ H. S. Graduate ☐ Some College ☐ College Graduate
☐ Graduate Degree ☐ Doctorate, Professional ☐ Other

7. Your ethnicity:

☐ African American ☐ White/Caucasian ☐ Hispanic/Latino
☐ Asian ☐ Pacific Islander ☐ Other

8. Your age: _____.

Directions: *After reading each statement, please respond by indicating the extent to which you agree or disagree with each statement.*

Circle 1 if you strongly disagree
 Circle 2 if you disagree
 Circle 3 if you somewhat disagree
 Circle 4 if you neither agree nor disagree
 Circle 5 if you somewhat agree
 Circle 6 if you agree
 Circle 7 if you strongly agree

1. I have enough time for leisure activities.	1	2	3	4	5	6	7
2. I have enough finances to meet unexpected expenses.	1	2	3	4	5	6	7
3. Space inside my home is adequate for my needs.	1	2	3	4	5	6	7
4. My knowledge is adequate for the work I do.	1	2	3	4	5	6	7
5. I have friends who can help me.	1	2	3	4	5	6	7
6. Community facilities are adequate for my needs.	1	2	3	4	5	6	7
7. My income covers my expenses.	1	2	3	4	5	6	7
8. I have enough time to do the things I want to do.	1	2	3	4	5	6	7
9. My energy is adequate for my activities.	1	2	3	4	5	6	7
10. Professional people in my community are helpful to me.	1	2	3	4	5	6	7
11. My health allows me to do my work.	1	2	3	4	5	6	7
12. My relatives are helpful to me.	1	2	3	4	5	6	7
13. Equipment in my home is adequate for my needs.	1	2	3	4	5	6	7
14. The housing I have meets my needs.	1	2	3	4	5	6	7
15. I have neighbors I can call on for help.	1	2	3	4	5	6	7
16. I have enough education to meet my long-term goals.	1	2	3	4	5	6	7
17. I know how to take care of financial matters.	1	2	3	4	5	6	7
18. I have adequate credit for my needs.	1	2	3	4	5	6	7

<u>19. I have enough time for household work.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>
20. My community is a good place to live.	1	2	3	4	5	6	7
<u>21. I know how to perform household repairs.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>
22. I have enough time to help others.	1	2	3	4	5	6	7
<u>23. I know persons whose judgment I trust.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>
24. I have enough energy for recreation.	1	2	3	4	5	6	7
<u>25. Government programs help me.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>
26. I have enough income to save money regularly.	1	2	3	4	5	6	7
<u>27. Space surrounding my home meets my needs.</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>
28. My health allows me to do what I want.	1	2	3	4	5	6	7

Directions: The following is a list of problems and complaints that people sometimes have. Please read each one carefully. After each one, circle the number that best describes how much that problem has bothered or distressed you during the past 7 days, including today. Circle only one number for each problem, and do not skip any items.

Circle 1 for not at all
 Circle 2 for a little bit
 Circle 3 for moderately
 Circle 4 for quite a bit
 Circle 5 for extremely

1. Feeling lonely.	1	2	3	4	5
2. Feeling blue.	1	2	3	4	5
3. Feeling no interest in things.	1	2	3	4	5
4. Feeling fearful.	1	2	3	4	5
5. The idea that someone else can control your thoughts.	1	2	3	4	5
6. Feeling others are to blame for most of your troubles.	1	2	3	4	5
7. Feeling afraid in open spaces or on the streets.	1	2	3	4	5
8. Hearing voices that other people do not hear.	1	2	3	4	5
9. Feeling that most people cannot be trusted.	1	2	3	4	5
10. Suddenly scared for no reason.	1	2	3	4	5
11. Temper outbursts that you could not control.	1	2	3	4	5
12. Feeling afraid to go out of your house.	1	2	3	4	5
13. Other people being aware of your private thoughts.	1	2	3	4	5
14. Feeling people do not understand you or are unsympathetic.	1	2	3	4	5
15. Feeling that other people are unfriendly or dislike you.	1	2	3	4	5
16. Having to do things very slowly.	1	2	3	4	5
17. Feeling inferior to others.	1	2	3	4	5
18. Soreness of your muscles.	1	2	3	4	5
19. Feeling that you are watched or talked about by others.	1	2	3	4	5
20. Having to check and double-check what you do.	1	2	3	4	5

21. Difficulties making decisions.	1	2	3	4	5
22. Feeling afraid to travel on buses, subways, or trains.	1	2	3	4	5
23. Hot or cold spells.	1	2	3	4	5
24. Having to avoid places or activities because they frighten you.	1	2	3	4	5
25. Your mind going blank.	1	2	3	4	5
26. Numbness or tingling in parts of your body.	1	2	3	4	5
27. Feeling hopeless about the future.	1	2	3	4	5
28. Trouble concentrating.	1	2	3	4	5
29. Feeling weak in parts of your body.	1	2	3	4	5
30. Feeling tense or keyed up.	1	2	3	4	5
31. Heavy feelings in your arms or legs.	1	2	3	4	5
32. Feeling uneasy when people are watching or talking about you.	1	2	3	4	5
33. Having thoughts that are not your own.	1	2	3	4	5
34. Having urges to beat, injure, or harm someone.	1	2	3	4	5
35. Having urges to break or smash things.	1	2	3	4	5
36. Feeling very self-conscious with others.	1	2	3	4	5
37. Feeling uneasy in crowds, such as shopping or at a movie.	1	2	3	4	5
38. Spells of terror or panic.	1	2	3	4	5
39. Getting into frequent arguments.	1	2	3	4	5
40. Others not giving you proper credit for your achievements.	1	2	3	4	5
41. Feeling so restless that you couldn't sit still.	1	2	3	4	5
42. Feelings of worthlessness.	1	2	3	4	5
43. Shouting or throwing things.	1	2	3	4	5
44. Feeling that people will take advantage of you if you let them.	1	2	3	4	5
45. The idea that you should be punished for your sins.	1	2	3	4	5

Debriefing Statement

Thank you for taking the time to answer these questions. We are interested in the effects of raising children and the impact it may have upon parents. Specifically, we are interested if resources, as perceived by parents, would affect parental psychological functioning.

As you know, raising a child can very rewarding. However, child-care, at times, can be associated with stress that might have negative implications. We hope to improve our understanding of parents and the impact of child-care. Your participation has contributed and expanded understanding in this field of research. All information collected from you will remain anonymous. All data will be analyzed on a group level and thus; no individual responses will be examined.

This experiment is being conducted through the psychology department at California State University San Bernardino (CSUSB) under the direction of Dr. Charles Hoffman. Results of this study will be available by June 2003. If you have any questions or comments concerning this study, please contact Dr. Charles Hoffman through the psychology office at (909) 880-7305 or e-mail: choffman@csusb.edu.

Thank You

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