

CAREGIVER DEPRESSION AND SOCIAL SUPPORT
IN FAMILIES WITH CHILDREN WITH AUTISM

by

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DISSERTATION ABSTRACT

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Title: Caregiver Depression and Social Support in Families with Children with Autism

Parents of young children with autism spectrum disorders (ASDs) often report heightened levels of parental distress. An increasing amount of attention is being directed to parental mental health and addressing the well-being of the entire family system. In order to best serve families raising children with ASDs, the present study sought to better understand the relation between social support, various risk factors, and caregiver depression. Data were collected from 60 families with children 2 – 7 years with ASDs through the use of extensive, in-home interviews with primary caregivers. Mothers reported the availability and helpfulness of both formal and informal supports. Similar to previous research, mothers also reported elevated levels of depression. In the present sample, more than half of mothers reported depressive symptoms at or above the cut-off for mild depressive symptomatology. Both child-related variables (autism symptomatology, atypical behavior) and service-related variables (satisfaction with the education eligibility process, satisfaction with sources of information about ASDs) were predictive of maternal depression. Social support and maternal depression were not related.

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DEDICATION

For our Oregon Early Autism Project families, whose time and participation in the project has benefitted the larger autism community and future families in Oregon raising children with autism.

TABLE OF CONTENTS

Chapter	Page
I. INTRODUCTION	1
II. REVIEW OF THE LITERATURE	4
Guiding Theoretical Framework.....	4
Construct of Social Support	6
Importance of Social Support	6
Formal and Informal Supports	7
Key Social Support Literature	9
Dunst, Trivette, & Cross (1986)	9
Bromley, Hare, Davison, & Emerson (2004)	10
Caregiver Depression.....	11
Risk Factors for Depression.....	11
Depression and Parenting	12
Key Caregiver Depression Literature	13
Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy (2004).....	13
Hodge, Hoffman, & Sweeney (2011)	14
Depression and Social Support	14
Conclusion	15
III. METHOD	16
Participants.....	16
Procedure	17
Measures	18

Chapter	Page
Demographics and Service History	18
Adaptive Behavior	18
Autism Symptomatology	19
Atypical Behavior	20
Social Support.....	20
Maternal Depression.....	21
IV. RESULTS.....	23
Data Analysis.....	23
Question 1	23
Question 2	24
Question 3	24
Question 4	25
Question 5	26
Question 6.....	29
Predicting Maternal Depression.....	29
Predicting Total Social Support.....	30
Predicting Total Family Support.....	31
V. DISCUSSION	32
Addressing the Research Questions.....	32
Question 1	32
Question 2	33
Question 3	35

Chapter	Page
Question 4	36
Question 5	39
Question 6	41
Guiding Theoretical Framework.....	42
Limitations	43
Implications and Future Research.....	44
APPENDICES	47
A. TABLES.....	47
B. OEAP RECRUITMENT COVER LETTER.....	65
C. OEAP PHONE SCREEN.....	66
D. OEAP MAIL PACKET COVER LETTER.....	68
E. OEAP INFORMED CONSENT FORM.....	69
F. OEAP FAMILY DEMOGRAPHIC QUESTIONNAIRE	71
G. OEAP INTERVIEW	83
REFERENCES CITED.....	88

LIST OF TABLES

Table	Page
1. Child-Related Demographics.....	47
2. Family- and Service-Related Demographics	48
3. Sources of Support Reported as Available or Helpful.....	49
4. Maternal Depression and CES-D Cut-Scores.....	50
5. Bivariate Correlations Among Social Support and Child-Related Variables.....	51
6. Bivariate Correlations Among Social Support and Parent-Related Variables.....	52
7. Family Demographic Differences in Total Social Support.....	53
8. Bivariate Correlations Among Social Support and Service-Related Variables....	54
9. Bivariate Correlations Among Maternal Depression and Child-Related Variables	55
10. Bivariate Correlations Among Maternal Depression and Parent-Related Variables	56
11. Family Demographic Differences in Maternal Depression	57
12. Bivariate Correlations Among Maternal Depression and Service-Related Variables	58
13. Bivariate Correlations Among Maternal Depression and Social Support- Related Variables	59
14. Group Differences on Child, Family, Service, and Social Support-Related Variables for Mothers with (16+) and Without (Less than 16) Mild to Severe Depressive Symptoms.....	60

Table	Page
15. Group Differences on Child, Family, Service, and Social Support-Related Variables for Mothers with (27+) and Without (Less than 27) Severe Depressive Symptoms.....	61
16. Linear Regression Results for Child and Service Variable Predictions to Maternal Depression.....	62
17. Hierarchical Linear Regression Results for Child and Service Variable Predictions to Maternal Depression.....	63
18. Linear Regression Results for Child, Family, and Service Variable Predictions to Social Support.....	64

CHAPTER I

INTRODUCTION

Raising a child with a developmental disability presents unique challenges and has a significant impact on family functioning and well-being (Olsson & Hwang, 2001; Singer, 2006). Parents of children with disabilities often experience heightened levels of stress and depression (Benson & Karlof, 2009), lower levels of family adaptability and cohesion (Higgins, Bailey, & Pearce, 2005), and greater negative social and psychological impact (Baker, Blacher, Crnic, & Edelbrock, 2002; Emerson, 2003) when compared to parents of typically developing children. Research suggests that parents of children with autism spectrum disorders (ASDs) may be particularly vulnerable to negative outcomes and decreased well-being. Compared to parents of children with other developmental disabilities, parents of children with ASDs report greater levels of depressive symptoms (Abbeduto et al., 2004), heightened stress (Weiss, 2002), and greater negative impact (Blacher & McIntyre, 2006).

With growing public awareness and professional knowledge of ASDs, research within the past several decades has increased dramatically. In an effort to treat the child and remediate concerns in the areas of communication, social interactions, and restricted or repetitive behaviors, much research has focused on child-centered interventions (e.g., Koegel & Frea, 1993; Martins & Harris, 2006; Whalen & Schreibman, 2003). In recent years, caregiver well-being and family functioning has garnered increasing levels of attention and research. Research has found that addressing the entire family system, rather than focusing exclusively on the child, may result in improved outcomes for the family (Smith et al., 2010). A better understanding of family processes and parent well-

being for families with children with ASDs may lead to more effective and comprehensive interventions for this population.

Recent research has investigated child, family, and parent-related variables that may be predictive of better parent and child outcomes; Bromley, Hare, Davison, and Emerson (2004) identified social support as one possible factor influencing family and child outcomes. Indeed, Sharpley, Bitsika, and Efremidis (1997) described three sources of stress when raising a child with an ASD, including the permanency of the condition, lack of understanding by family and society, and very low levels of social support. Both forms of social support, formal (e.g., doctor, school/daycare center, professional agencies) and informal (e.g., spouse, relatives, friends, other parents, parent groups, social groups/clubs, co-workers), may serve important roles in family functioning and caregiver well-being. For caregivers, low levels of social support may result in low levels of activity involvement in the community, which may in turn increase stress levels and perpetuate a cycle of low support and high stress (Sanders & Morgan, 1997). Alternately, families with higher levels of social support report greater family adjustment to the stresses associated with raising a child with a disability (Henderson & Vandenberg, 1992).

Depression, or depressive symptomatology, may be another important variable in the prediction of parent and child outcomes in families with children with ASDs. In a population-based study, mothers of children with ASDs were more likely to experience high levels of parenting stress *and* report poor or fair mental health than mothers in the general population (Montes & Halterman, 2007). Even compared to mothers of children with other disabilities, mothers of children with ASDs report more depressive symptoms

(e.g., Abbeduto et al., 2004; Weiss, 2002). Depression also appears to be importantly related to social support in these families. Gray and Holden (1992) found that the most robust predictor of depression and anxiety in caregivers of children with ASD was low levels of social support.

In order to best serve families raising children with disabilities, we need a better understanding of the relations between social support, various risk factors, and maternal depression. In the reviewed past research, there exists disagreement related to which forms of social support families utilize most and which forms are most helpful. Additionally, the majority of the research investigating social support and caregiver depression in samples of families raising children with ASDs has focused primarily on samples of children in late childhood, adolescence, and early adulthood. Very few studies have investigated these constructs in families raising preschool-aged children with recent autism diagnoses. The present study was designed to add to and extend the growing body of literature related to social support and caregiver depression in families with young children with ASDs. In particular, this study aimed to address the following questions: (a) Which forms of social support are most available to families with young children with ASDs? (b) Which forms of social support are most helpful? (c) Do mothers report elevated levels of depressive symptomatology? (d) Which child-, family-, and service-related variables are related to social support availability and helpfulness? (e) Which child-, family-, and service-related variables are related to maternal depression? (f) Which child-, family-, and service-related variables predict social support and maternal depression?

CHAPTER II

REVIEW OF THE LITERATURE

This review of the literature articulates key concepts and highlights past and current research relevant to social support, depression, and parenting children with ASDs. First, a discussion of the present study's guiding theoretical framework is provided. Second, an introduction to the construct and importance of social support, both formal and informal, is detailed. Next, a review of depression/depressive symptomatology and relevant risk factors within this population is provided. Finally, the relatedness of depression and social support in caregivers with children with ASDs is discussed.

Guiding Theoretical Framework

The primary guiding theoretical framework of the present investigation is ecological-systems theory outlined by Bronfenbrenner (Bronfenbrenner 1977; 1986) in which human development is considered in the context of the interaction between the individual and the changing environment in which he or she lives and develops. In describing this nested arrangement of structures, Bronfenbrenner (1977) describes four systems: (a) the microsystem, (b) the mesosystem, (c) the exosystem, and (d) the macrosystem. In the microsystem, interactions between the individual and the immediate environment are considered. For young children, this microsystem often consists of the child's immediate family, the home environment, and the child's classroom. The mesosystem consists of the interrelations among two or more settings in which the individual participates. For young children, this can include the relation between home and school, home and neighborhood, and school and peer group, for example. The exosystem involves one or more settings in which the individual is not an active

participant. However, the events that occur among such settings have an effect, or are affected by, the settings in which the individual is an active participant. Finally, the macrosystem consists of the broader culture or subculture including the systems (economic, social, education, legal) of which the micro-, meso-, and exosystems are all manifestations. Units within the entire system do not operate in isolation, but rather operate reciprocally and interact within and between levels so that changes reverberate throughout the entire system. Developmental processes are not limited to only the immediate setting, as the interconnection between settings and the larger surroundings is emphasized.

The present study examines child-, family-, and service-related variables associated with parental social support and depression. Child and family variables are consistent with microsystem variables in that they may have a more proximal influence on developmental outcomes. Service-related variables are consistent with both microsystem variables (e.g., school-based service hours) and mesosystem variables (e.g., parent satisfaction and involvement in special education process). Social support may cut across systems in that the degree to which families are supported may be associated with both proximal and more distal outcomes for children. Finally, caregiver depression may likely cut across systems in that depression may impact parenting (microsystem), family-school partnerships (mesosystem), parental employment (exosystem), and access to affordable healthcare (macrosystem). Thus, an ecological systems perspective informs the present study and highlights the myriad influences on developmental outcomes.

Construct of Social Support

Social support may be one key to supporting caregivers and families of children with ASDs. Social support has been defined as a multidimensional construct that includes physical, emotional, and psychological support (Dunst, Trivette, & Cross, 1986). Further, social support is commonly conceptualized into two categories: formal support and informal support. Bristol and Schopler (1983) described formal support as assistance that is typically provided through an organization or agency in the form of social, psychological, physical, or financial support. Informal support was defined as assistance that comes from a network that may include family, friends, neighbors, and parents of other children with disabilities. Both formal and informal support may play an important role in the adaptability and well-being of families with children with ASDs. Past research has identified social support as an important resource that families can utilize, potentially reducing the negative psychological impact that is often associated with raising a child with an ASD (Bromley et al., 2004).

Importance of Social Support

Research has found significant relations between social support and factors that are integral to family and caregiver well-being. For example, Henderson and Vandenberg (2002) identified a positive association between family adjustment and social support, in that families reporting more social support reported better adjustment to having a child with an ASD. Similarly, hardiness (Weiss, 2002) and physical and emotional well-being (Trivette & Dunst, 1992) have also been found to positively relate to social support in families with children with ASDs. The literature to date has also established a strong relation between social support and parental stress, suggesting that

social support may perhaps serve as a buffer of negative parent mental health outcomes (e.g., Dyson, 1997; Sharpley et al., 1997). Thus, within the literature, an inextricable link between social support and various indicators of family functioning and well-being has been established.

Formal and Informal Supports

Formal supports, which are those supports typically provided through an organization or agency, may be supports to which the family is entitled or to which the family otherwise has access. Further, such supports are usually best provided on a cohesive continuum of support, rather than distinct and separate from one another (Cooley, 1994). Although some families may have access to such services free of cost, there are barriers to receipt of formal supports that may influence utilization including lack of awareness of services or inaccessibility due to location or transportation. Formal supports, however, meet certain needs in families that other forms of support may not reliably provide. For example, formal supports can provide families with assistance in understanding autism as well as needs specific to their child (Whitaker, 2002).

Unfortunately, compared to parents of children with other disabilities, Sanders and Morgan (1997) found that parents of children with ASDs reported the greatest difficulty in obtaining social support within the community. Recognizing the unique contribution of various formal supports and problem solving around some of the barriers to accessing such supports are two important steps in increasing formal support utilization.

Similar to the unique contributions of formal supports, informal supports play an important role helping caregivers reduce the feelings of isolation and helplessness often associated with raising a child with a disability (Cooley, 1994). In fact, low levels of

family support may be related to greater psychological distress in caregivers (Bromley et al., 2004). In a study by Mackintosh, Myers, & Goin-Kochel (2006), other parents of children with ASDs were the most frequently endorsed source of social support. Support from a partner/spouse may also be an important source of support. Indeed, Boyd (2002) found that a spouse was reportedly the best source of support, as they provide respite support and are able to assume many household responsibilities. Additionally, research has identified support groups for parents of children with ASDs as particularly helpful, offering the opportunity for caregivers to engage with similar parents, reduce stress and social isolation, and perhaps increase access to other services or formal supports (Mandell & Salzer, 2007). Informal supports appear to impact several areas of need and functioning in this population.

In addition to these highlighted differences in formal and informal supports, there also exists an important distinction between available support and helpful support, and research is currently somewhat mixed in this area. Suggesting that not all supports are created equal, mothers who reported high levels of negative support (support that is available, but not helpful) were more likely to experience increases in depression and negative affect along with decreases in positive affect (Smith, Greenberg, & Seltzer, 2011). White and Hastings (2004) found that parents reporting greater levels of *helpful* support also reported greater well-being, although it did not appear that the number of informal supports was associated with well-being. Similarly, Konstantareas and Homatidis (1989) discovered that, for mothers, the extent to which supports were useful was a better indicator of stress, rather than the number of supports that were reportedly available. These studies highlight the possibility that having *helpful* supports is more

important than having *many available* supports. However, Salisbury (1990) found that maternal stress levels were reduced by larger networks of social support. More research is needed to better understand the impact of available and helpful supports on parent well-being.

Key Social Support Literature

Dunst, Trivette, & Cross (1986). In an early seminal study by Dunst, Trivette, and Cross (1986), the unique mediational influences of social support on parental, family, and child functioning were examined in a sample of 137 families (96 mothers, mean age = 28.98 years; 41 fathers, mean age = 33.17 years) raising preschool-aged children (mean age = 37.52 months) with intellectual disability, physical impairment, or developmental delay. Several self-report instruments assessing parent reports of social support satisfaction and number of sources of support utilized were gathered, as measured by the Family Support Scale. In addition, parent well-being (as measured by the Questionnaire on Resources and Stress; Holroyd, 1973), parental attitudes toward their child, child functioning and development (as measured by a variety of different standardized assessments), and parent-child play opportunity data (as measured by the Parent-Child Interaction Rating Scale; Dunst, 1984) were collected. When controlling for child and family demographics (SES, child sex, child chronological age, child developmental quotient), analyses revealed both direct and indirect effects of social support. Parents reporting greater social support tended to describe their children as more physically capable, more socially accepted by others, and having fewer behavior problems. As Dunst and colleagues describe, social support networks influence both real and perceived behavior characteristics of their child. Further, children were more likely to make

developmental progress if their parents had more supportive networks. Social support was also related to parent variables, including associations between more supportive social networks and better parent well-being and positive attitudes. These findings reveal that social support exerts influence on parent, parent-child, and child functioning in families raising children with developmental delays and disabilities.

Bromley, Hare, Davison, & Emerson (2004). Bromley and colleagues (2004) sought to examine the impact of a range of variables on parental psychological well-being in families raising children with ASDs. Of primary interest were various aspects of social support. To that end, Bromley and colleagues conceptualized social support into three main categories: formal support, family support, and other informal support. Seventy-one mother-child dyads participated (children were 80% male, 75% Caucasian). Most children were school-aged, although participants ranged in age from less than 5 years to 18 years of age. In addition to utilizing a modified version of the Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984), child adaptive behavior (as measured by the AAMR Adaptive Behavior Scale; Lambert et al., 1993), problem behavior (as measured by the Developmental Behaviour Checklist; Einfeld & Tonge, 1994), family unmet needs and parental general health (as measured by the General Health Questionnaire 12; Goldberg & Williams, 1988) measures were completed. Single mothers reported less overall social support. Families accessing more supports over the course of the previous six months tended to have children that were younger, with greater language delays, less independent functioning, and poorer socialization. Additionally, families receiving more support were more likely to be satisfied with their child's educational services. Perhaps one of the most important findings of Bromley and

colleagues was the association of high levels of parental psychological distress and both lower levels of family support and more challenging child behavior. Although the provision of parent-based mental health services is not necessarily a component of the service-delivery process for families raising children with ASDs, the findings highlight that it may be an important area to consider and further develop.

Caregiver Depression

High levels of risk for mental health problems exist in parents of children with ASDs, particularly in mothers, perhaps because they often assume primary caregiving responsibilities (Hastings & Brown, 2002). One psychological outcome that is especially relevant for parents of children with ASDs is depression. Parents of children with ASDs often report heightened levels of depression. In comparison to a national sample of adults, Benson and Karlof (2009) found that parents of children with ASDs report heightened levels of anger and depressed mood. Mothers of adolescents and young adults with ASDs report greater levels of depressive symptoms than mothers of children with Down syndrome (Abbeduto et al., 2004) and other intellectual disabilities (Olsson & Hwang, 2001). In a study by Benson (2006), almost half of the mothers of children with ASD scored at or above the cutoff for depressive symptomatology. The heightened prevalence of these symptoms in caregivers of children with ASDs again underscores the need to address the entire family system rather than focus exclusively on child functioning.

Risk Factors for Depression

Within the past decade, researchers have sought to better understand this heightened risk for depression in caregivers of children with ASDs. Research has

identified variables that are likely to predict heightened levels of depression including challenging child behavior (Bromley et al., 2004), lower family income (Mackintosh et al., 2006), a higher number of children in the family with disabilities (Ekas, Lickenborck, & Whitman, 2010), greater autism symptomatology, and fewer maternal coping strategies (Abbeduto et al., 2004). Knowledge of such influential factors has important clinical implications; recognizing and understanding these risk factors, professionals working with these families can provide supports that target some of these areas, such as support in handling challenging behavior, accessing government support for low-income families, and increasing coping strategies.

Depression and Parenting

Children of depressed mothers, regardless of developmental status, are at an increased risk for a variety of negative outcomes (Cummings, Keller, & Davies, 2005). In a comprehensive meta-analysis of the literature, Lovejoy, Graczyk, O'Hare, and Neuman (2000) sought to better understand the mediating role of parenting behaviors, which may be one important variable in better understanding the relation between maternal depression and child outcomes. Lovejoy and colleagues found that mothers that were more depressed were more likely to be irritable and hostile toward their child, and mother-child interactions in depressed mothers were more likely to be characterized as negative and coercive than mothers in the control group. Overall, it was found that younger children appear to be experiencing the effects of depressed parents' impaired parenting more so than older children. Perhaps, younger children depend more on their caregivers to initiate and maintain positive interactions and thus, are more likely to experience the negative parenting associated with depression. Increasingly, parental

behaviors are implicated in the relation between maternal depression and child outcomes. Parenting behaviors may be particularly amenable to intervention and, thus, the importance of taking a family-centered approach in the provision of supports is again emphasized.

Key Caregiver Depression Literature

Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy (2004). Abbeduto and colleagues (2004) sought to identify predictors of maternal well-being in a sample of adolescents (approximately 16 years old on average) categorized into three non-overlapping diagnostic groups: Down syndrome, fragile X syndrome, and ASD. All caregivers were biological mothers and married. The contributions of several maternal- and child-related variables were investigated in the prediction of maternal well-being, including depression, pessimism, the closeness of the mother-child relationship, and coping style. When all three groups were considered together, the average depression score for mothers was below the cut-off score for clinical depression on the Center for Epidemiological Studies-Depression (CES-D; Radloff, 1977). However, mothers of children with ASDs reported significantly more depression, with 33% those mothers scoring in the clinical range compared to approximately 18% and 10% of mothers of children with fragile X syndrome and Down syndrome, respectively. Predictors of elevated depressive symptomatology included lower income, the presence of a sibling in the home with a disability, and less adaptive maternal coping. However, the most consistent and robust predictor of maternal well-being was the child's behavior problems. These findings presented by Abbeduto and colleagues highlight the susceptibility of mothers raising children with disabilities, and particularly ASDs. Further, the findings

support the notion of taking a whole-family approach in the provision of services and supports, such as providing services for both caregivers and children.

Hodge, Hoffman, & Sweeney (2011). In an effort to investigate common psychopathologies and the mechanisms of risk in parents of children with ASDs, Hodge and colleagues (2011) compared two samples of biological parents: mothers and fathers of children with ASDs and mothers and fathers of typically developing children. Target children ranged in age from 3 to 18 years, with an average age of approximately 8 years. As is consistent with past research, both mothers and fathers of children with ASDs reported greater depression than parents of typically developing children. However, only mothers of children with ASDs reported greater levels of anxiety when compared to their typically develop counterparts. Interestingly, Hodge and colleagues found that the burden of raising a child with ASD did not increase maternal risk of psychopathology. This finding suggests that it may be genetic factors (or the broader autism phenotype) that predispose parents raising children with ASDs to certain psychopathologies, specifically depression, anxiety, and obsessive-compulsive behaviors. The findings presented by Hodge and colleagues again highlight the necessity of addressing the mental health and overall well-being of both mothers and fathers raising children with ASDs.

Depression and Social Support

Aside from the many risk factors these past studies have identified, some research has also attempted to identify and better understand protective factors; social support is one of these notable factors. Informal support, in particular, has been found to significantly decrease parent depression over time (e.g., Benson, 2006; Benson & Karlof, 2009). In a study by Ekas and colleagues (2010), informal supports (such as a partner,

family member, friend) were associated with lower levels of depression, negative affect, and parenting stress. Further, many of these informal supports were related to increased life satisfaction, positive affect, and overall psychological well-being. Within a caregiver's network, Benson (2012) found that the emotional support garnered from the network was related to increases in maternal perception of support that, in turn, resulted in decreases in depressed mood.

Conclusion

There exists a significant body of research suggesting that caregivers of children with ASDs are at a greater risk of experiencing negative psychological outcomes in comparison to parents of typically developing children (e.g., Baker et al., 2002; Benson & Karlof, 2009; Emerson, 2003; Higgins et al., 2005) and parents of children with other developmental disabilities (e.g., Abbeduto et al., 2004; Blacher & McIntyre, 2006; Weiss, 2002). Recognizing the importance of social support within this population, it is imperative to fully understand this construct and its relation to child, family, and parent outcomes. Caregiver depression is also a salient issue for parents of children with ASDs, and more knowledge surrounding risk and protective factors associated with depressive symptomatology may lend well to intervention and improving outcomes for this population. The proposed study was designed to evaluate social support, maternal depression, and relevant risk factors in a sample of families with young children with ASDs.

CHAPTER III

METHOD

Participants

A sample of 60 families with young children (1 to 6 years) with ASDs was recruited through local agencies and programs providing services to families with children with disabilities in Oregon. These agencies included Early Childhood CARES and the Eugene satellite Child Development and Rehabilitation Center (CDRC) affiliated with the Oregon Health & Science University. Table 1 displays child demographics and Table 2 displays family and service demographics (see Appendix A for all tables). Children were an average age of 53.78 months ($SD = 14.55$). The majority of children (83.3%) were boys. Seventy percent of the sample identified as White/Caucasian, consistent with the demographics of the region from which the data were collected. Nearly all (91.7%) children were reported to have a special education eligibility of ASD, and 78.3% were reported to have a medical diagnosis of an ASD. The special education eligibility and medical diagnostic categories are not mutually exclusive. The child's biological mother served as primary caregiver in 83.3% of families, with the majority of other primary caregivers being another female caregiver (adoptive mother, $n = 9$, 15.0%; other female relative, $n = 1$, 1.7%), heretofore referred to as "mothers". Mothers were an average age of 35.2 years and the majority (90.0%) was married or living with a partner. The majority of mothers (60%) had a high school diploma/GED equivalent or less. More than half of mothers (56.7%) did not work, with the remaining working either full-time or part-time. The majority of children (81.7%) had at least one sibling living in the home. The average household size was about 4 people ($M = 4.28$), and 78.3% of families

qualified for government aid or support. Families had a median income of \$30,000 and 28.3% of families fell below the US Department of Human & Health Services poverty guideline.

Procedure

Participant recruitment was initiated upon receiving approval from the University of Oregon's Institutional Review Board. In collaboration with local agencies, recruitment materials were mailed via US mail to families who had children identified with an ASD aged 6 years old or younger. Recruitment materials included a brief description of the study and ways to contact the project office to learn more about participating in the study (see Appendix B).

Mothers interested in learning more about participating in the study completed a brief telephone interview to determine whether the family met inclusionary criteria. Inclusionary criteria included: (a) child has a medical diagnosis of an ASD (i.e., autistic disorder/autism, Pervasive Developmental Disorder-Not Otherwise Specified, or Asperger's Disorder) or special education eligibility under the disability category "Autism", (b) child is six years old or younger, and (c) child has lived with the primary caregiver for a minimum of one year prior to participating in the study. An overview of the study and participation requirements were discussed briefly with mothers who met inclusionary criteria (see Appendix C).

Upon meeting inclusionary criteria and expressing interest in participation, a follow-up telephone interview and an in-home interview were scheduled on a day/time that was convenient for the family. An adaptive behavior assessment was administered over the telephone to mothers during the 30-45 minute follow-up telephone interview.

The in-home interviews lasted approximately 1.5-2 hours in which two researchers interviewed the primary caregiver and administered several assessments. Mothers also received a packet in the mail including a cover letter (see Appendix D), informed consent (see Appendix E), and two brief measures of parent and family well-being to complete prior to the in-home interview. Participants received a small monetary honorarium (\$25 gift card to a retail store) for their participation.

Measures

Demographics and service history. Family demographics and service history questionnaires created for this study were completed as an interview with the primary caregiver (see Appendix F & G). Parent and child demographic information was collected, along with a history of early intervention and current services. When possible, this information was verified through a review of the child's individualized education plan (IEP) or individualized family service plan (IFSP). Demographic variables of interest from these questionnaires included child age, family income, marital status, and total service hours. Satisfaction variables, including satisfaction with the care provided by a pediatrician/physician, sources of information about autism, the medical diagnostic process, the education eligibility process, and the child's current services were measured utilizing a 5-point Likert-type scale ranging from 1 (dissatisfied) to 5 (very satisfied). Final family variables of interest included the presence of a sibling with autism, learning problems, and/or behavior problems. Descriptive statistics for these family- and service-related variables are presented in Table 2.

Adaptive behavior. Researchers administered the Survey Interview Form of the Vineland Adaptive Behavior Scales 2nd edition (Vineland-II; Sparrow, Cicchetti, & Balla,

2005) via telephone interview with the primary caregiver to assess the child's adaptive functioning. This measure was chosen because it is norm-referenced and has well-established reliability and validity for the targeted age group (Salvia, Ysseldyke, & Bolt, 2010). The Survey Interview Form consists of 413 questions distributed among five domains: (a) communication, (b) daily living skills, (c) socialization, (d) motor skills, and (e) maladaptive/problem behavior. For the present study, only the four adaptive domains were administered and scored, as these four domains combine to yield an overall Adaptive Behavior Composite (ABC) standard score, with a mean of 100 and standard deviation of 15. Individual items are scored on a 4-point scale of 2 (usually), 1 (sometimes or partially), 0 (never), and DK (don't know).

Autism symptomatology. During the in-home interview, researchers administered the Childhood Autism Rating Scale – 2nd edition (CARS 2; Schopler, Van Bourgondien, Wellman, & Love, 2010) to rate children's autistic symptoms in 15 areas. This measure was chosen because it is a commonly used measure of autism symptomatology. Additionally, the CARS-2 is norm referenced and has excellent psychometric support (Ozonoff, Goodlin-Jones, & Solomon, 2005). Ratings on the CARS-2 are made on a 7-point scale reflecting numerical values of 1 to 4 (higher scores indicate greater impairment). Scores reflect the degree to which the child's behavior deviates from that of a typically developing child of the same age. Scores on the 15 items are summed to form an overall score ranging from 15 to 60, with corresponding cut-scores reflecting symptom severity (<30 Non-Autistic; 30 - 36.5 = Mild to Moderate; 37 - 60 = Severe). Internal consistency reliability for the CARS-2 in the present sample was $\alpha = .87$.

Atypical behavior. During the in-home interview, researchers administered the Temperament and Atypical Behavior Scale (TABS; Bagnato, Neisworth, Salvia, & Hunt, 1999) to assess atypical behaviors considered to be developmentally dysfunctional. This measure was chosen because it is norm-referenced and has moderate to strong psychometric properties (Bricker, Davis, & Squires, 2004). The TABS is a 55-item checklist comprising four subtests: (a) Detached (20 items; $\alpha = .79$), (b) Hypersensitive/Active (17 items; $\alpha = .82$), (c) Underreactive (11 items; $\alpha = .49$), and (d) Dysregulated (7 items; $\alpha = .64$). For each item, the caregiver is asked to indicate if the behavior is present or absent (rated as “yes” or “no”). In each subtest, items are summed to provide a raw domain score, which is then converted to a T-score ($M = 50$, $SD = 10$). Raw domain scores are summed to form the Temperament and Regulatory Index (TRI) or total raw score, which is converted to a standard score ($M = 100$; $SD = 15$). Higher raw scores and lower standard scores (or T-scores) are indicative of more atypical behavior. Internal consistency reliability in the present sample for the TABS was $\alpha = .87$.

Social support. Mothers received the Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984) via US mail. The FSS is an 18-item self-report questionnaire that measures different sources of informal (e.g., spouse, parents, friends) and formal (e.g., parent groups, early intervention program, professional helpers) support that parents may draw upon when raising a child with developmental disabilities. The measure asks parents to evaluate how useful such supports are. In addition, the scale provides 2 open items for parents to describe other sources of support not included in the 18 items. This measure was chosen because it is one of the most routinely utilized measures of social support in the reviewed literature and has well-established reliability and validity (Dunst,

Trivette, & Jenkins, 1988; Frey, Greenberg, & Fewell, 1989). Respondents rate the helpfulness of each source of support for the family within the past 3 to 6 months, with items ranging from 1 (not at all helpful) to 5 (extremely helpful) and N/A (not available).

An overall score of social support availability was generated by summing scores on all items (20 items). Internal consistency reliability for the FSS Total Score was calculated using the first 18 items and was acceptable ($\alpha = .75$). The two open-ended response items (items 19 and 20) were not included due to low response rate. A measure of available support was generated by summing the number of items that received a rating of 1 to 5 (any item that is reportedly available), with individual scores ranging from 0 to 20. A measure of helpful support was generated by summing the number of items that received a rating of 3 (Generally Helpful) to 5 (Extremely Helpful), with individual scores ranging from 0 to 20. Separate total scores, available support scores, and helpful support scores were calculated for informal support (12 items; $\alpha = .73$) and formal support (6 items; $\alpha = .60$), as well as informal family support (6 items; $\alpha = .58$) and other non-family informal support (6 items; $\alpha = .77$). Family sources of support included spouse/partner, relatives, parents, spouses' parents, spouses' relatives, and children. Other non-family informal sources of support included friends, other parents, spouses' friends, parent groups, social groups/clubs, and co-workers. Informal sources included both informal family support and non-family informal support. Formal sources of support included family doctor/pediatrician, professional helpers, school/daycare center, early intervention, professional agencies, and church/minister.

Maternal depression. Mothers received the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) via US mail. The CES-D is a 20-item self-

report scale designed to measure depressive symptomatology. This measure was chosen because it is one of the most commonly utilized measures of depressive symptoms in nonclinical samples, and has strong reliability and validity (Devins et al., 1988; Radloff, 1977). Mothers are asked to indicate how frequently they experienced a variety of symptoms during the last week utilizing a 4-point Likert-type scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Total scores from the CES-D are obtained by summing all 20 items (some with reverse codes) and can range from 0 to 60, with higher scores indicating a greater degree of depressive symptomatology. A cut-score of 16 to 26 indicates mild depressive symptomatology, and a cut-score of 27 or higher indicates major depressive symptomatology (Zich, Attkisson, & Greenfield, 1990). Internal consistency reliability for the CES-D in the present sample was $\alpha = .91$. A missing response for an item on the CES-D was replaced by the participant's mean score across all relevant items for the scale; missing values were infrequent, with less than one-percent of the values (5 items) being coded as missing.

CHAPTER IV

RESULTS

Data Analysis

Question 1. *Which forms of social support are most available to families?*

Descriptive statistics were run in order to identify which forms of social support mothers reported as most available (see Table 3). The top four most commonly available forms of social support included spouse (95.0%), friends (95.0%), early childhood intervention (93.3%), and physician/pediatrician (88.3%). These four forms of available support included both formal and informal supports, suggesting that almost all families had access to supports from both categories. Further, given that almost all mothers in the present sample were married or living with a partner (90.0%), it is not surprising that this form of social support was the most available. The least available forms of social support included parent groups (46.7%), social groups/clubs (41.7%), church/minister (40.0%) and co-workers (28.3%). Three of the four least available supports are categorized as other non-family informal supports, suggesting that these forms of social support are less available to families than formal or family supports. Additionally, given that only approximately 43% of mothers were employed, it is not surprising mothers reported co-workers as the least available form of support.

The FSS also provides two optional items for the respondent to add in additional sources of support. Only 5% of mothers completed one or two of these additional items. Additional sources of support that mothers identified as available included books (1.67%), University of Oregon HEDCO Clinic (1.67%), Bridgeway House (1.67%), and

OHSU Child Development and Rehabilitation Center (1.67%). All of these items were given a score of a 4 or 5, indicating that they are very helpful supports.

Question 2. *Which forms of social support are most helpful?* Descriptive statistics were run in order to identify which individual forms of social support were most helpful (see Table 3). The most helpful forms of social support included early childhood intervention (90.0%), spouse (81.7%), professional helpers (70.0%) and school/daycare program (70.0%). Three of the four most helpful forms of support represent formal supports. Thus, it appears that in early childhood it is primarily the support provided through professionals or agencies that families found most helpful. The least helpful forms of social support included spouse's parents (21.7%), church/minister (20.0%), and co-workers (5.0%). Forms of formal, family, and other non-family informal supports were all represented as some of the least helpful supports.

Question 3. *Do mothers report elevated levels of depressive symptomatology?* Descriptive statistics were run in order to evaluate the presence and severity of depressive symptomatology in mothers (see Table 4). Mothers had an average score on the CES-D of 17.82 ($SD = 11.18$), which falls above the clinical cut-score for mild depressive symptomatology. This suggests that mothers in the present sample reported elevated levels of depressive symptomatology. Utilizing the cut-scores for low (less than 16), mild (16 to 26), and severe (above 27) depressive symptomatology, 45.0%, 36.7%, and 18.3% of mothers fell into these groups, respectively. More than half (55.0%) of mothers scored above the cut-score for mild depressive symptomatology, suggesting this is a highly impacted sample.

Question 4. *Which child, family, and service-related variables are related to social support?* Bivariate correlations and independent samples *t*-tests were run to identify child, family, and service-related variables related to key social support variables. First, bivariate correlations were run to identify the association between child-related variables and total social support, total formal support, total family support, and total other informal support (see Table 5). Social support was related to child age, such that mothers with younger children reported more total support ($r = -.27, p = .04$) and more family support ($r = -.25, p = .05$). Social support was also related to children's adaptive behavior, such that mothers of children with more adaptive behavior reported more total support ($r = .28, p = .03$) and family support ($r = .31, p = .02$). Social support was not related to child sex or child autism symptomatology. Because there was so little variability in the T-scores and standard scores on the TABS, the raw scores were used in all subsequent analyses. Social support was not related to child temperament and atypical behavior.

Next, bivariate correlations were run to identify the association between parent-related variables and total social support, total formal support, total family support, and total other informal support (see Table 6). Social support was related to maternal age, such that younger mothers reported more family support ($r = -.41, p = .001$). This relation also held true for paternal age ($r = -.37, p = .004$). Further, mothers who worked fewer hours per week reported greater total support ($r = -.26, p = .05$) and other informal support ($r = -.36, p = .004$). Social support was also related to the father's education, such that mothers reported greater other informal support when the father had more

education ($r = .26, p = .05$). Surprisingly, social support was not related to gross annual income.

To investigate the relation between various family demographic variables and total social support, several independent samples T-tests were run (see Table 7). Compared to families where there was a sibling without ASDs, mothers whose target child had a sibling with ASD reported significantly less social support ($t(47) = 2.00, p = .05$). Similarly, compared to families with siblings without behavior problems, mothers of families with siblings with behavior problems also reported significantly less social support ($t(27) = 2.67, p = .01$). The categories for sibling behavior problems, learning problems, and ASD diagnosis were not mutually exclusive. There was no significant difference in social support between mothers who were married or living with a partner and those who were not.

Finally, bivariate correlations were run to investigate the relation between service-related variables and total social support, total formal support, total family support, and total other informal support (see Table 8). The only variable of significance was parental satisfaction with the current services their child was receiving, such that mothers who were more satisfied reported receiving more total social support ($r = .34, p = .01$), formal support ($r = .48, p = .00$), and family support ($r = .27, p = .04$).

Question 5. *Which child, family, and service-related variables are related to maternal depression?* Bivariate correlations and independent samples *t*-tests were run to identify child-, family-, and service-related variables related to maternal depression. First, bivariate correlations were run to identify the association between child-related variables and maternal depression (see Table 9). Unlike social support, maternal

depression was not related to child age or adaptive behavior. Maternal depression was not related to child sex. Maternal depression was, however, related to autism symptomatology, such that mothers reporting higher levels of depressive symptomatology had children with more autism symptomatology ($r = .30, p = .02$). Maternal depression was also strongly related to child atypical behavior, such that mothers with more depressive symptomatology had children with more overall atypical behavior ($r = .53, p = .00$), as well as children that were more detached ($r = .37, p = .004$), hyper-sensitive/active ($r = .53, p = .00$), and dysregulated ($r = .40, p = .002$). Next, bivariate correlations were run to identify the association between parent-related variables and maternal depression (see Table 10). No caregiver variables, including parental age, employment status, education, and annual income, were related to maternal depression.

To investigate the relation between various family demographic variables and maternal depression, several independent samples T-tests were run (see Table 11). Compared to families where the target child had a sibling without ASDs, mothers whose target child had a sibling with ASD reported significantly more depressive symptomatology ($t(47) = -2.30, p = .03$). Again, the categories for sibling behavior problems, learning problems, and ASD diagnosis were not mutually exclusive. Similar to total social support, there was no significant difference in maternal depression between mothers who were married or living with a partner and those who were not.

Further, bivariate correlations were run to investigate the relation between service-related variables and maternal depression (see Table 12). Maternal depression was related to parental satisfaction with the sources of information specific to ASDs, such

that mothers reporting more depressive symptomatology were less satisfied with their sources of information ($r = -.27, p = .04$). Interestingly, maternal depression was related to parental satisfaction with the special education eligibility process, such that mothers reporting more depressive symptomatology reported greater satisfaction with the education eligibility process ($r = .28, p = .03$). Bivariate correlations were also run to evaluate the relation between social support variables and maternal depression (see Table 13). Maternal depression was not related to any social support variables, including measures of total support and number of sources of support.

To further investigate the relation between maternal depression and child-, family-, service-, and social support-related variables, two groups of mothers were compared: low depression (scoring less than 16 on the CES-D) and mild to severe depression (scoring 16 or higher on the CES-D). Independent samples T-tests were run to evaluate differences on key variables between these two groups (see Table 14). Mothers in the mild to severe depression group had children with significantly less adaptive behavior ($t(58) = 2.07, p = .04$), significantly more autism symptomatology ($t(58) = -2.81, p = .01$), and significantly more atypical behavior ($t(58) = -4.26, p = .00$) when compared to the low depression group. Mothers in the mild to severe depression group, however, reported more satisfaction with the education eligibility process ($t(54) = -2.22, p = .03$). The two groups of mothers did not significantly differ on any family or social support-related variables.

In order to evaluate variables associated with severe depression, two different groups of mothers were compared: low to mild depression (scoring less than 27 on the CES-D) and severe depression (scoring 27 or higher on the CES-D). Independent

samples T-tests were run to evaluate differences on child, family, service, and social support-related variables between these two groups (see Table 15). Mothers in the severe depression group had children with significantly more autism symptomatology ($t(58) = -2.38, p = .02$) and significantly more atypical behavior ($t(58) = -3.28, p = .00$) when compared to the low to mild depression group. Mothers in the severe depression group also reported significantly less satisfaction with their sources of information about ASDs ($t(58) = 2.08, p = .04$). The two groups of mothers did not significantly differ on any family or social support-related variables.

Question 6. *Which child, family, and service related variables predict social support and maternal depression?* Linear regression analyses were run to identify child, family, service, and social support variables predictive of maternal depression. Only variables with significant bivariate correlations were included in the regression analyses.

Predicting maternal depression. A linear regression was run to investigate the relations between significant demographic variables and maternal depression (see Table 16). CARS-2 Total Score, TABS TRI raw score, satisfaction with sources of information, and satisfaction with education eligibility process were entered together as the independent variables. Maternal depression (CES-D total score) was entered as the dependent variable. The overall equation was significant, accounting for a total of 30.9% of the variance in maternal depression ($p = .001$). Among the demographic variables, TABS TRI raw score ($\beta = .51, p = .002$) and parental satisfaction with the educational eligibility process ($\beta = .27, p = .03$) contributed significantly to the prediction of maternal depression. CARS-2 Total Score and parental satisfaction with sources of information about ASDs did not contribute meaningfully when entered with the other variables. Post

hoc power analysis indicated that the power to detect obtained effects at the $\alpha = .05$ level was .99 for the overall regression in prediction of maternal depression.

Given the aims of the present study and the emphasis placed on supporting the entire family rather than focusing specifically on child-directed interventions, a hierarchical regression was run to investigate the contribution of demographic variables above and beyond those that are child-related (see Table 17). The child variables, CARS-2 Total Score and TABS TRI raw score, were entered together on the first step. Parental satisfaction with sources of information and satisfaction with education eligibility process were entered together on the second step. Again, maternal depression was entered as the dependent variable. Results indicate that the overall equation was significant, accounting for 30.9% of the overall variance in caregiver depression. Parental satisfaction with the education eligibility process maintained a significant prediction to maternal depression even after controlling for the child-related variables ($\beta = .51, p = .002$). These service-related variables accounted for 7.1% of the variance in this model. Post hoc power analysis indicated that the power to detect obtained effects at the $\alpha = .05$ level was .57 for the overall hierarchical regression in prediction of caregiver depression, indicating that the analysis was under-powered to detect significant effects. In future investigations, a sample size of 100 would be necessary to detect significant effects given the same predictors, $\alpha = .05$, and the same effect size as the present study.

Predicting total social support. A linear regression was run to investigate the relations between significant demographic variables and total social support (see Table 18). Child age, VABS-II Adaptive Behavior Composite, mother's hours worked per week, and satisfaction with the child's current services were entered together as the

independent variables. Total social support was entered as the dependent variable. The overall equation was significant, accounting for a total of 24.4% of the variance in total social support ($p = .004$). Among the demographic variables, hours/week mother works ($\beta = 0.26, p = .04$) and satisfaction with current services ($\beta = .29, p = .02$) contributed significantly to the prediction of total social support. Child age and VABS-2 ABC did not contribute meaningfully when entered with the other variables. Post hoc power analysis indicated that the power to detect obtained effects at the $\alpha = .05$ level was .94 for the overall regression in prediction of total social support.

Predicting total family support. Finally, a linear regression was run to investigate the relations between significant demographic variables and total family support (see Table 18). Child age, VABS-II Adaptive Behavior Composite, maternal age, paternal age, and satisfaction with the child's current services were entered together as the independent variables. Total family support was entered as the dependent variable. The overall equation was significant, accounting for a total of 29.1% of the variance in total family support ($p = .002$). Among the demographic variables, VABS-2 ABC was the only variable that contributed significantly to the prediction of total family support ($\beta = 0.25, p = .05$). Child age, maternal age, paternal age, and parental satisfaction with current services did not contribute meaningfully when entered with the other variables. Post hoc power analysis indicated that the power to detect obtained effects at the $\alpha = .05$ level was .97 for the overall regression in prediction of caregiver depression.

CHAPTER V

DISCUSSION

This investigation sought to examine the presence and correlates of social support and caregiver depression in a sample of families with young children with ASDs. Although some past research has examined these constructs in families with children and adolescents with ASDs, there is little research investigating the relation between social support and caregiver depression in an early childhood sample. This study aimed to identify the availability and helpfulness of social supports, as well as the presence of elevated caregiver depression. Similar to past research, more than half of the mothers in the present study reported mild to severe depressive symptomatology. Contrary to past research, results from the present study did not suggest a relation between social support and maternal depression.

Addressing the Research Questions

Question 1. *Which forms of social support are most available to families?*

Research has identified social support as an integral component of family and caregiver well-being (e.g., Henderson & Vandenberg, 2002; Trivette & Dunst, 1992; Weiss, 2002). Some past research has suggested that social support may even serve as a buffer of negative mental health outcomes in caregivers (e.g., Dyson, 1997). First and foremost, the present study sought to identify which forms of social support were most available to families.

Among the most available were both formal and informal supports, including spouse, friends, early childhood intervention, and physician/pediatrician. Given that 90% of mothers in the present sample reported that they were married or living with a partner,

it was not surprising that a spouse was the most available form of social support. Further, despite the often isolating nature of raising a child with a disability (Cooley, 1994), almost all mothers reported friends to be an available support. When considering formal supports, it was also not surprising that early childhood intervention and the family physician or pediatrician were most often available. Data from the present sample were drawn from a county whose early childhood intervention program often served as the first contact and service provider for families who suspected their child had a developmental delay or disability. Further, given that the present sample is an early childhood sample, it was not surprising that the early childhood intervention program was a readily available source of support. Similarly, at a young age, children often visit their pediatrician on an annual or bi-annual basis. Thus, it is not surprising that the family physician or pediatrician is one of the most available forms of social support.

Among the least available supports were parent groups, social groups/clubs, church/minister, and co-workers. Other non-family informal supports accounted for the majority of the least available supports. Co-workers were reportedly the least available form of social support, which is not surprising given that less than half of mothers were currently employed. The other least available supports, including parent groups, social groups/clubs, and church or minister, may have been less accessible to families. Given that they all place a demand on the caregiver's time and often do not involve the child, finding the time and the help of an alternative caregiver to seek out these supports may be unrealistic for many families raising children with ASDs.

Question 2. *Which forms of social support are most helpful?* Past research has also sought to evaluate the construct of social support not only by identifying what

supports are available, but also by considering which supports are reported to be helpful. There is research supporting the notion that not all supports are created equal (Smith et al., 2011) and a greater level of helpful support may be a better indicator of caregiver well-being than the total number of supports (e.g., Konstantareas & Homatidis, 1989; White & Hastings, 2004).

Mothers in the present sample reported early childhood intervention, spouse, professional helpers, and school or daycare program as the most helpful forms of support. In addition to being the most commonly available support, a spouse or partner was also one of the most helpful supports. This is consistent with past research that has identified the positive support benefits associated with spouses (Herman & Thompson, 1995) and the finding that a spouse may be the best form of social support, as he or she is able to provide respite support and help with household duties (Boyd, 2002). The other three most helpful supports are all formal supports. Given the early childhood sample this may not be surprising, though it is inconsistent with some past research that suggested that informal supports may be more beneficial to families (Herman & Thompson, 1995). With a young child with a disability, it is likely that caregivers are relying heavily on professionals to navigate the diagnostic and service delivery process. It is the formal supports such as professional helpers, early childhood intervention, and school programs that may be best equipped to educate families about ASDs and help them access other necessary supports and services.

Among the least helpful supports were spouse's parents, church/minister, and co-workers. These supports represent all three types of support, family, formal, and other informal support, suggesting that the helpfulness of social supports may be very source

specific. Parent groups were almost among some of the least helpful supports. This is inconsistent with some previous research that has suggested that parent groups may be particularly helpful as they offer the opportunity for parents to engage with others caregivers raising children with disabilities, which in turn can reduce stress, increase social connectedness, and increase access to other services (Mandell & Salzer, 2007). Perhaps, the finding may be a product of the region from which the data were drawn; parent groups may not be routinely available or accessible to families in the present sample.

Question 3. *Do mothers report elevated levels of depressive symptomatology?* Mothers raising children with ASDs are particularly susceptible to parental distress (Hasting & Brown, 2002). Depression is one indicator of parental distress that is especially relevant for caregivers with children with ASDs. Past research has suggested that mothers of adolescents and young adults with ASDs report greater levels of depressive symptomatology than mothers of children with Down syndrome and other disabilities (Abbeduto, 2004). In one study, almost half of mothers scored at or above the cut-off for depressive symptomatology (Benson, 2006). Mothers in the present study reported even greater levels of depression, with more than half of mothers (55%) reporting depressive symptomatology at or above the cut-off for mild depressive symptoms (≥ 16) on the CES-D). Although this finding is similar to past research, mothers in the present sample are certainly more impacted. This may be due to the early childhood nature of the present sample, as past research has focused on school-age through adult child populations. Even more problematic is the percentage of mothers reporting depressive symptoms above the cut-off for severe depression on the CES-D.

Almost 20% of mothers reported severe depressive symptomatology (scores ≥ 27). Given the relatedness of parental depression, parenting behaviors, and child outcomes, this finding is particularly concerning. As past research has identified, mothers that are more depressed are more likely to engage in parenting behaviors that are negative, hostile, and coercive (Lovejoy et al., 2000). Providing support to parents to manage depressive symptoms and engage in more positive parenting behaviors may be of top intervention priority for families raising children with ASDs.

Question 4. *Which child, family, and service-related variables are related to social support?* In addition to identifying which forms of social support were most available and helpful, the present study sought to identify variables predictive of social support, including child, family, and service-related variables. Past research has identified barriers to the utilization of social support. Sanders and Morgan (1997) reported that, when compared to parents of children with other disabilities, parents of children with ASDs reported the most difficulty in accessing social support. Identifying these unique barriers and examining factors related to social support is among the first steps in increasing the availability and usefulness of social supports for families with children with ASDs.

First, child-related variables, including age, adaptive behavior, autism symptomatology, and atypical behavior/temperament, were considered. Mothers of younger children reported more total social support and more family support. It is unknown if parents more readily seek out support when their children are younger, or if there are simply more supports that are relevant and available. Perhaps, mothers of younger children reported more family support because relatives were more likely to

provide support to caregivers raising younger children with recent diagnoses of ASDs, such as a grandparent moving in with the family to provide respite care. The child's adaptive behavior was also related to total social support and family support, such that mothers with children with higher adaptive behavior scores reported more support. Although children with less adaptive behavior likely require more support, it appears that mothers were not receiving support consistent with the needs of their child.

Parent-related variables, including age, income, employment, and education were evaluated in order to understand their possible relation to social support. Parental age was related to family support, such that younger mothers, and mothers with younger partners, tended to report more support from family. As parents age, they may be less able to access family supports because their parents and other relatives are aging themselves and are decreasingly able to provide support. Further, younger parents may be less financially independent or still living with their own parents and, thus, report more family support. Mothers who worked fewer hours per week reported more total support and other informal support. Perhaps, mothers who worked less have more time to seek out support and access services, such as attend parent groups, apply for government services, or spend time with friends. Quite surprisingly, social support was not related to gross annual income, qualification for government aid, or federal poverty guideline status. Intuitively, one would suspect that families with more financial means would have the ability to access more supports. However, considering the region from which the data were drawn, the majority of services available to families were those that were provided free-of-charge through the county and disability services. Additionally, while there are some (but limited) private agencies that provide services to children with

ASDs, the majority of families in the present sample do not report accessing these supports.

Given the increased caregiving burden of raising more than one child, and particularly more than one child with special needs, several family-related variables were investigated. Considering only those mothers with more than one child in the home, mothers of families with siblings with ASDs reported significantly less social support. Mothers of families with siblings with behavior problems also reported less social support. With this increased caregiving burden, parents may have felt more isolated, or had less time to access social supports. Unfortunately, although mothers raising multiple children with special needs are likely to need more formal and informal support, it does not appear that they had increased social supports. Such information is important for professionals to be mindful of when working with families with multiple children.

Finally, mothers who were more satisfied with the services their child currently received reported more total support, formal support, and family support, which is consistent with past research (Bromley et al., 2004). Given that this finding is only correlational, it is not possible to draw causal conclusions. Mothers that are more satisfied with their child's services may have a strong history of positive interactions with professionals and service providers, and thus may be more likely to seek out social support. Perhaps mothers who felt supported by family and professionals may have in turn felt more satisfied with the services their child currently received. Indeed, the relation between these variables may be reciprocal. Mothers that were more satisfied may have sought out more support, and mothers with more support may have, in turn, felt more satisfied.

Question 5. *Which child, family, and service-related variables are related to maternal depression?* Research investigating the heightened risk for depression in caregivers raising children with ASDs has increased within the past decade. Significant variables related to caregiver depression include challenging child behavior (Bromley et al., 2006), lower family income (Mackintosh et al., 2006), multiple children in the family with disabilities (Ekas et al., 2010), and greater autisms symptomatology (Abbeduto et al., 2004). The current investigation sought to corroborate and extend this previous research, as knowledge of pivotal factors predicting caregiver depression in early childhood has important clinical implications.

First investigating child-related variables, maternal depression was significantly related to variables that were not related to social support. Maternal depression was not related to child age or adaptive behavior. However, maternal depression was positively related to autism symptomatology, which is consistent with past research (Abbeduto et al., 2004). Child temperament and atypical behavior was also related to maternal depression, such that mothers with more depression reported that their child had a more difficult temperament and more atypical behavior. It appears that challenging child behavior (autism symptomatology and atypical behaviors) is an important variable in understanding mothers' heightened risk for depressive symptoms. Consistent with these correlational findings, when comparing two groups of mothers, those with low depression (CES-D scores of <16) and those with mild to severe depression (CES-D scores of ≥ 16), it appears that the mothers scoring above the cut-off for depression had children with less adaptive behavior, more autism symptomatology, and more atypical behavior. Again, causal relations cannot be drawn. As research has shown, depressed mothers engage in

more negative parenting behaviors, which may result in more challenging child behavior. Or, perhaps, challenging child behaviors put mothers at-risk for depression. Indeed, there may also be a reciprocal relation between maternal depression and challenging child behavior.

Caregiver- and family-related variables, including age, employment, education, gross annual income, qualification for government aid, and federal poverty guideline status were not related to maternal depression. This finding is somewhat unexpected given past research findings (e.g., Mackintosh et al., 2006), but may be a result of the high rates of depression represented in the overall sample. With more than half of the sample reporting elevated depressive symptoms, it may have been difficult to detect some of the statistically significant relations between these family variables and maternal depression.

As was significant for social support, mothers whose children had at least one additional sibling with an ASD reported significantly more depressive symptomatology compared to mothers whose children had a sibling without an ASD. This finding is consistent with the findings of Ekas and colleagues (2010), as well as Abbeduto and colleagues (2004) who found that the number of children in the family with disabilities was a significant predictor of caregiver depression.

Interestingly, mothers married or living with a partner reported no significant differences in depression compared to single mothers. This is inconsistent with past research. For example, in a sample of parents with children with intellectual disabilities, Olsson and Hwang (2001) found that single mothers were more likely to experience

severe depression. Perhaps there were too few single mothers in the present sample to detect a statistically significant difference in maternal depression.

Inconsistent with past research, there were no observed relations between social support and maternal depression. Previous investigations have identified social support as a protective factor, and social support has been found to relate to decreases in parent depression over time (e.g., Benson, 2006; Benson & Karlof, 2009). Informal supports, in particular have been associated with less depressive symptoms as well as decreases in other indicators of parental distress, including parenting stress (Ekas et al., 2010). Again, it is possible that the heightened levels of maternal depression in the present sample accounted for this lack of important relations. Or perhaps, given that the present investigation is an early childhood sample, social support may be operating differently and may not yet be a variable related to caregiver depression.

Question 6. *Which child, family, and service related variables predict social support and maternal depression?* The final aim of the present study was to identify variables predictive of caregiver depression and social support. As previously stated, the current investigation focused largely on family and caregiver well-being. When considering the best ways to support children and families, a whole family approach may result in improved outcomes of the family (Smith et al., 2010). The present study sought to gain a better understanding of family processes and parent-well being in order to support the development and implementation of supports that are designed to support the entire family.

Even after controlling for child-related variables that were significantly related to maternal depression, parental satisfaction with the education eligibility process

maintained a significant prediction to maternal depression. Thus, supporting parents during their diagnostic journey and providing assistance as they navigate the service delivery process may be one key way professionals can support parents and improve outcomes for the entire family. In predicting total social support, when entered with significant child-related variables, the hours per week the mother worked and parental satisfaction with the current services their child received were the only significant predictive variables. Although maternal employment is not a readily amenable intervention target, it is an important contextual variable for service providers to consider when working with families. And again, the importance of supporting parents throughout the diagnostic and service delivery process is highlighted.

In predicting both maternal depression and total family support, child related variables (atypical behavior and adaptive behavior, respectively) were strongly predictive. Children's behavior is clearly associated with parent and family well-being. The importance of child-directed interventions that teach new skills and reduce problem behaviors cannot be overemphasized. It is the addition of supports and services that target parent and family variables that may result in more positive outcomes for the entire family.

Guiding Theoretical Framework

The results of the present study highlight child development within the context of the interaction between the child and his or her changing environment, as described by Bronfenbrenner's ecological-systems theory (Bronfenbrenner, 1977; 1986). Parents reported that both formal and informal supports are available, suggesting that families are accessing supports that cut across the micro-, meso-, and exosystems. Similarly, the

helpful sources of social support also fall across the different ecological systems. Heightened levels of maternal depression also influence variables across systems, as it was related to problematic child behavior (microsystem), siblings in the family (microsystem), and satisfaction with variables related to information and services (mesosystem). Indeed, an ecological systems perspective highlights the numerous influences on child development and family outcomes. This perspective and these findings underscore the importance of addressing family need and well-being across many different levels and systems, rather than focusing specifically on child functioning.

Limitations

It is important to acknowledge several limitations of the present study. First, the sample size was relatively small, although not unprecedented for a sample of families raising children with a low-incidence disability (e.g., Benson, 2006; Bromley et al., 2006; Hastings & Brown, 2002;). Power to detect statistically significant effects was satisfactory for the linear regressions. However, the analysis was under-powered to detect significant effects for the hierarchical linear regression predicting maternal depression. Future investigations should aim for a sample size of at least 100 participants to detect significant effects given the same variables.

Several characteristics of the present sample limit the generalizability of findings. First, the majority of families in the present sample resided in a single county in Oregon. Many families had similar experiences throughout the diagnostic and service delivery process, given that there were limited school and county agencies and professionals working with this population. For example, the majority of families obtained a medical diagnosis of an ASD from one specialty medical clinic. Similarly, the majority of

families went through the process of obtaining a special education eligibility of ASD and received services through the county early intervention/early childhood special education provider. Because of this, the family experiences may not generalize to other geographical locations within the state or country. Additionally, the overwhelming majority of primary caregivers were biological mothers. The findings of the present study may not accurately represent the experiences of fathers serving as primary caregivers. Further, given that the present study focuses on early childhood and these children have received ASD diagnoses at a young age, the present sample may not be representative of all children on the autism spectrum.

The present study also primarily relied on caregiver report. Although attempts were made to corroborate certain family and child information (validated through review of records such as Individualized Family Service Plans (IFSPs) or direct observations), the caregiver served as the primary respondent on all measures. The use of multiple raters and multiple tools to evaluate the same construct would have been ideal, although beyond the scope of the present study. Additionally, the present study did not have measures specific to child problem behavior or parenting stress; both of these constructs may play an important role in the present study given their relatedness in previous research.

Implications and Future Research

Child-, family-, and service-related variables all play an integral role in understanding the availability and usefulness of social support and maternal depression. Considering which forms of social support are available to families and which forms are most helpful to families, professionals working with these families may be positioned to

assist families in the support acquisition and utilization process. Professional helpers themselves are among the most useful supports and can capitalize on their established relationships to help families expand their support networks. Future research should continue to identify barriers to social support utilization and investigate which supports are most beneficial to which families in order to most effectively and efficiently support caregivers. Additionally, more research about how families establish and maintain social support networks and how these networks change over time as children age is needed. Research should evaluate the social support utilization of fathers or secondary caregivers, as the needs of both caregivers are critical since they are a part of the family system.

Another significant finding from the present study is the percentage of mothers reporting elevated levels of depressive symptomatology, and particularly the sub-group of mothers reporting severe depressive symptomatology. Future research on families of children with ASDs could include caregiver depression as a primary intervention target. Interventions with cognitive behavioral strategies and components have demonstrated effectiveness (e.g., Singer, Ethridge, & Aldana, 2007). Such strategies in combination with behavior management techniques or assistance in accessing social supports may be particularly helpful for these caregivers. Similarly, the extent to which the correlates of caregiver depression (including child behavior, satisfaction with aspects of service delivery) can be intervened upon successfully to result in decreases in caregiver depression could be evaluated. Longitudinal investigations could also elucidate the relations between social support, caregiver depression, and other important family variables over time and how they influence one another. With this understanding, we

will be better able to meet the needs of caregivers, prioritize intervention targets and strategies, and provide comprehensive family support.

APPENDIX A

TABLES

Table 1

Child-Related Demographics (N = 60)

Demographic	<i>n</i>	%
Age in months – <i>M (SD)</i>	53.78 (14.55)	
Sex (Male)	50	83.3
Race		
White/Caucasian	42	70.0
Hispanic/Latino	3	5.0
Mixed	15	25.0
Medical Diagnosis (<i>N = 47</i>)		
Autism/Autistic Disorder	19	40.4
PDD-NOS	12	25.5
Asperger’s Disorders	1	2.1
Autism spectrum disorder (ASD)	15	31.9
Education eligibility	55	91.7
VABS-II standard score– <i>M (SD)</i>		
Adaptive Behavior Composite (ABC)	71.88 (10.70)	
Communication	74.15 (16.86)	
Daily Living Skills	75.57 (12.24)	
Socialization	71.37 (9.33)	
Motor Skills	78.58 (13.32)	
CARS-2 Total Score – <i>M (SD)</i>	39.12 (6.51)	
CARS-2 Severity Scores		
Minimal to no symptoms (score of 15 to 29.5)	5	8.3
Mild to moderate symptoms (score of 30 to 36.5)	15	25.0
Severe symptoms (score of 37 and higher)	40	66.7
TABS T- and Standard Scores (SS) – <i>M (SD)</i>		
Temperament & Regulatory Index SS (TRI)	52.73 (5.87)	
Detached (T-score)	3.15 (8.44)	
Hyper-sensitive/active (T-score)	22.03 (11.06)	
Underreactive (T-score)	35.07 (15.36)	
Dysregulated (T-score)	26.67 (18.30)	

Note. CARS-2 = Childhood Autism Rating Scale – 2nd Edition. TABS = Temperament and Atypical Behavior Scale. VABS-II = Vineland Adaptive Behavior Scales – 2nd Edition.

Table 2

Family- and Service-Related Demographics (N = 60)

Demographic	<i>n</i>	%
<i>Family-Related</i>		
Mother's age in years – <i>M (SD)</i>	35.23 (7.95)	
Father's age in years (<i>N = 59</i>) – <i>M (SD)</i>	37.63 (7.98)	
Mother's employment		
Full-time	7	11.7
Part-time	19	31.7
Not employed	34	56.7
Father's employment (<i>N = 59</i>)		
Full-time	43	71.7
Part-time	8	13.3
Not employed	8	13.3
Mother's marital status		
Married or living with partner	54	90.0
Household income/year in USD – <i>M (SD)</i>	\$38,417.67 (22703.72)	
Child/family qualify for government aid	47	78.3
Presence of a sibling (<i>N = 49</i>)		
with an ASD	21	42.8
with a learning problem	28	57.1
with a behavior problem	15	30.6
<i>Service-Related – M (SD)</i>		
Child service hours/week	13.17 (7.60)	
Satisfaction with care from pediatrician	3.22 (1.69)	
Satisfaction with sources of information	3.87 (0.91)	
Satisfaction with medical diagnostic process	3.28 (1.25)	
Satisfaction with education eligibility process	3.96 (1.14)	
Satisfaction with current services	3.92 (1.20)	

Table 3

Sources of Support Reported as Available or Helpful (N = 60)

Source of Support	Available <i>n</i> (%)	Helpful <i>n</i> (%)
Spouse	57 (95.0)	49 (81.7)
Friends	57 (95.0)	27 (45.0)
Early childhood intervention	56 (93.3)	54 (90.0)
Physician/pediatrician	53 (88.3)	31 (51.7)
Professional helpers	51 (85.0)	42 (70.0)
School/daycare program	47 (78.3)	42 (70.0)
Spouse's friends	46 (76.7)	14 (23.3)
Parents	44 (73.3)	20 (33.3)
Relatives	41 (68.3)	14 (23.3)
My own children	41 (68.3)	20 (33.3)
Spouse's parents	40 (66.7)	13 (21.7)
Professional agencies	40 (66.7)	25 (41.7)
Other parents	37 (61.7)	15 (25.0)
Spouse's relatives	36 (60.0)	14 (23.3)
Parent groups	28 (46.7)	19 (31.7)
Social groups/clubs	25 (41.7)	15 (25.0)
Church/minister	24 (40.0)	18 (20.0)
Co-workers	17 (28.3)	3 (5.0)

Table 4

Maternal Depression and CES-D Cut-Scores (N = 60)

Variable	<i>n</i>	%
CES-D Total Score– <i>M (SD)</i>	17.82 (11.18)	
CES-D cut-scores		
Low depressive symptomatology (below 16)	27	45.0
Mild depressive symptomatology (16 to 26)	22	36.7
Severe depressive symptomatology (above 27)	11	18.3

Note. CES-D = Center for Epidemiological Studies Depression Scale.

Table 5

Bivariate Correlations Among Social Support and Child-Related Variables (N = 60)

Child Variables	Total support	Total formal support	Total family support	Total other informal support
Age (in months)	-.27*	-.12	-.25*	-.16
VABS-II Standard Score- <i>M(SD)</i>				
Adaptive Behavior Composite	.28*	.13	.31*	.19
Communication	.17	.10	.26*	.06
Daily Living Skills	.26*	.13	.23	.23
Socialization	.33*	.25	.34**	.15
Motor Skills	.22	.02	.22	.22
CARS-2 Total Score – <i>M(SD)</i>	-.13	-.08	-.11	-.13
TABS raw scores – <i>M(SD)</i>				
Temperament & Regulatory Index	.01	.04	-.05	.01
Detached	-.03	.09	-.08	-.09
Hyper-sensitive/active	.05	-.06	.00	.12
Underreactive	.06	.10	.05	.02
Dysregulated	-.03	.03	-.13	-.02

Note. CARS-2 = Childhood Autism Rating Scale – 2nd Edition. TABS = Temperament and Atypical Behavior Scale. VABS-II = Vineland Adaptive Behavior Scales – 2nd Edition.

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

Table 6

Bivariate Correlations Among Social Support and Parent-Related Variables (N = 60)

Parent Variables	Total support	Total formal support	Total family support	Total other informal support
Age (in years)				
Mother	-.19	.01	-.41**	.02
Father (<i>N</i> = 59)	-.15	-.03	-.37**	.03
Employment				
Mother	-.20	-.06	-.17	-.18
Father (<i>N</i> = 59)	.04	.00	.02	.09
Hours worked/week				
Mother	-.26*	-.07	-.11	-.36**
Father (<i>N</i> = 59)	.16	.10	.11	.16
Gross annual Income				
	-.10	-.16	.14	-.14
Degree beyond high school diploma				
Mother	-.04	-.10	.05	.00
Father (<i>N</i> = 58)	-.09	-.15	.20	-.20
Highest grade completed				
Mother	-.10	-.03	-.04	-.12
Father (<i>N</i> = 58)	.15	.00	.06	.26*

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

Table 7

Family Demographic Differences in Total Social Support (N = 60)

Family Variables	<i>M(SD)</i>	<i>T</i>
Sibling has an ASD (<i>N</i> = 49)		
Yes	34.10 (9.72)	
No	40.64 (12.39)	2.00*
Sibling has a learning problem (<i>N</i> = 49)		
Yes	36.30 (10.58)	
No	39.73 (12.91)	1.02
Sibling has a behavior problem (<i>N</i> = 49)		
Yes	30.85 (8.89)	
No	40.36 (11.63)	2.67**
Family qualifies for government aid		
Yes	37.68 (12.70)	
No	34.92 (12.24)	-0.70
Family below federal poverty guideline		
Yes	38.18 (9.47)	
No	36.65 (13.67)	-.042
Mother married/living with partner		
Yes	37.22 (12.87)	
No	35.83 (10.07)	-0.26

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

Table 8

Bivariate Correlations Among Social Support and Service-Related Variables (N = 60)

Service Variables	Total support	Total formal support	Total family support	Total other informal support
Child service hours/week	-.16	.00	-.16	-.16
Parental satisfaction				
with care from pediatrician	.09	.19	.06	-.01
with sources of information	-.02	.12	-.02	-.17
with medical diagnostic process	.03	.04	.04	-.02
with education eligibility process	.17	.09	.16	.10
with current services	.34**	.48**	.27*	-.03

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

Table 9

Bivariate Correlations Among Maternal Depression and Child-Related Variables (N = 60)

Child Variables	<i>r</i>
Age (in months)	-.03
Vineland II Standard Score- <i>M(SD)</i>	
Adaptive Behavior Composite	-.17
Communication	-.07
Daily Living Skills	-.18
Socialization	-.15
Motor Skills	-.17
CARS Total Score – <i>M(SD)</i>	.30*
TABS raw scores – <i>M(SD)</i>	
Temperament & Regulatory Index	.53**
Detached	.37**
Hyper-sensitive/active	.53**
Underreactive	.12
Dysregulated	.40**

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

Table 10

Bivariate Correlations Among Maternal Depression and Parent-Related Variables (N = 60)

Parental Variables	<i>r</i>
Age (in years)	
Mother	-.05
Father (<i>N</i> = 59)	-.02
Employment	
Mother	-.10
Father (<i>N</i> = 59)	-.18
Hours worked/week	
Mother	.02
Father (<i>N</i> = 59)	-.16
Gross Annual Income	-.14
Degree beyond high school diploma	
Mother	-.14
Father (<i>N</i> = 58)	-.06
Highest grade completed	
Mother	.05
Father (<i>N</i> = 58)	-.14

Table 11

Family Demographic Differences in Maternal Depression (N = 60)

Family Variables	<i>M(SD)</i>	<i>T</i>
Sibling has an ASD (<i>N</i> = 49)		
Yes	20.85 (11.18)	
No	14.02 (9.54)	-2.30*
Sibling has a learning problem (<i>N</i> = 49)		
Yes	19.36 (10.81)	
No	13.99 (10.07)	-1.79 [†]
Sibling has a behavior problem (<i>N</i> = 49)		
Yes	19.15 (10.52)	
No	16.15 (10.83)	-0.86
Family qualifies for government aid		
Yes	18.56 (11.43)	
No	15.13 (10.17)	-0.98
Family below federal poverty guideline		
Yes	14.80 (9.51)	
No	19.01 (11.67)	1.32
Mother married/living with partner		
Yes	17.62 (11.20)	
No	19.60 (11.81)	0.41

[†]*p* < .10. **p* < .05.

Table 12

Bivariate Correlations Among Maternal Depression and Service-Related Variables (N = 60)

Service Variables	<i>r</i>
Child service hours/week	.17
Parental Satisfaction	
with care from pediatrician	.07
with sources of information	-.27*
with medical diagnostic process	.11
with education eligibility process	.28*
with current services	-.08

* $p < .05$.

Table 13

Bivariate Correlations Among Maternal Depression and Social Support-Related Variables (N = 60)

Social Support Variables	<i>r</i>
Total social support	
FSS total score	-.08
Total formal support	.00
Total informal support	-.11
Total family support	-.12
Total other informal support	-.06
Number of sources of support	
Total number of sources	.09
Total number of helpful sources	-.13
Total number of formal sources	.14
Total number of informal sources	.04
Total number of family sources	.05
Total number of other informal sources	.02

Table 14

Group Differences on Child, Family, Service, and Social Support-Related Variables for Mothers With (16+) and Without (Less than 16) Mild to Severe Depressive Symptoms

Demographic	Low Depression (<i>N</i> = 27)		Mild to Severe Depression (<i>N</i> = 33)		<i>T</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Child-related					
Age in months	55.26	13.71	52.58	15.31	0.71
VABS-II ABC	74.96	9.74	69.36	10.93	2.07*
CARS-2 Total Score	36.65	6.95	41.14	5.42	-2.81**
TABS TRI raw score	19.89	6.89	28.55	8.51	-4.26***
Family-related					
Mother age in years	35.81	8.63	34.76	7.45	0.51
Father age in years (<i>N</i> = 59)	37.59	7.83	37.66	8.23	-.03
Service-related					
Child service hours/week	12.31	7.04	13.87	8.07	-0.79
Satisfaction with care from pediatrician	3.15	1.81	3.27	1.61	-0.28
Satisfaction with sources of information	4.07	0.78	3.70	0.98	1.62
Satisfaction with medical diagnostic process	3.39	1.15	3.21	1.32	0.48
Satisfaction with education eligibility process	3.60	1.16	4.26	1.06	-2.22*
Satisfaction with current services	3.96	1.13	3.88	1.27	0.27
Social support-related					
Total social support	35.52	12.91	38.36	12.31	-0.87
Total formal support	15.37	5.60	17.03	5.84	-1.12
Total informal support	20.15	8.97	20.76	9.19	-0.26
Total family support	12.15	4.98	11.94	5.65	0.15
Total other informal support	8.00	5.96	8.82	5.53	-0.55
Total sources of support	11.74	3.19	12.94	3.31	-1.42
Total helpful sources of support	6.81	3.10	7.55	3.35	-0.87

Note. CARS-2 = Childhood Autism Rating Scale – 2nd Edition. TABS = Temperament and Atypical Behavior Scale. VABS-II = Vineland Adaptive Behavior Scales – 2nd Edition.

p* < .05. *p* < .01. ****p* < .001.

Table 15

Group Differences on Child, Family, Service, and Social Support-Related Variables for Mothers With (27+) and Without (Less than 27) Severe Depressive Symptoms

Demographic	Low to Mild Depression (<i>N</i> = 49)		Severe Depression (<i>N</i> = 11)		<i>T</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Child-related					
Age in months	53.53	14.92	54.91	13.39	-0.28
VABS-II ABC	72.45	11.30	69.36	7.37	0.86
CARS-2 Total Score	38.20	6.70	43.18	3.47	-2.38*
TABS TRI raw score	22.78	8.72	33.00	2.79	-3.82***
Family-related					
Mother age in years	35.33	8.28	34.82	6.59	0.19
Father age in years (<i>N</i> = 59)	37.71	8.11	37.20	7.69	0.18
Service-related					
Child service hours/week	12.79	7.28	14.83	9.08	-0.80
Satisfaction with care from pediatrician	3.10	1.71	3.73	1.56	-1.11
Satisfaction with sources of information	3.98	0.77	3.36	1.29	2.08*
Satisfaction with medical diagnostic process	3.16	1.28	3.70	1.06	-1.22
Satisfaction with education eligibility process	3.91	1.20	4.22	0.83	-0.74
Satisfaction with current services	3.88	1.22	4.09	1.14	-0.53
Social support-related					
Total social support	37.67	12.28	34.45	14.02	0.77
Total formal support	16.06	5.46	17.27	7.10	-0.63
Total informal support	21.22	8.57	17.18	10.63	1.35
Total family support	12.53	5.12	9.82	5.85	1.55
Total other informal support	8.69	5.63	7.36	6.10	0.70
Total sources of support	12.43	3.27	12.27	3.50	0.14
Total helpful sources of support	7.49	3.07	6.00	3.80	1.39

Note. CARS-2 = Childhood Autism Rating Scale – 2nd Edition. TABS = Temperament and Atypical Behavior Scale. VABS-II = Vineland Adaptive Behavior Scales – 2nd Edition.

p* < .05. **p* < .001.

Table 16

Linear Regression Results for Child and Service Variable Predictions to Maternal Depression

	ΔR^2	β
Predictors of caregiver depression	.31***	
Child variables		
CARS-2 Total Score		-.06
TABS TRI raw score		.51**
Service Variables		
Satisfaction with sources of information		-.04
Satisfaction with education eligibility process		.27*

Note. CARS-2 = Childhood Autism Rating Scale – 2nd Edition. TABS = Temperament and Atypical Behavior Scale.

* $p < .05$. ** $p < .01$. *** $p = .001$.

Table 17

Hierarchical Linear Regression Results for Child and Service Variable Predictions to Maternal Depression

	ΔR^2	β
Predictors of caregiver depression		
Step 1 (Child variables)	.24***	
CARS-2 Total Score		-.06
TABS TRI raw score		.53**
Step 2 (Service variables)	.31***	
CARS-2 Total Score		-.06
TABS TRI raw score		.51**
Satisfaction with sources of information		-.04
Satisfaction with education eligibility process		.27*

Note. CARS-2 = Childhood Autism Rating Scale – 2nd Edition. TABS = Temperament and Atypical Behavior Scale.

* $p < .05$. ** $p < .01$. $p = .001$.

Table 18

Linear Regression Results for Child, Family, and Service Variable Predictions to Social Support

	ΔR^2	β
Predictors of Total Social Support	.24**	
Child age (in months)		-.08
VABS-II ABC		.20
Hours/week mother works		-.26*
Satisfaction with current services		.29*
Predictors of Total Family Support	.29**	
Child age (in months)		-.05
VABS-II ABC		.25*
Mother age (in years)		-.24
Father age (in years)		-.15
Satisfaction with current services		-.17

Note. VABS-II = Vineland Adaptive Behavior Scales – 2nd Edition.

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

APPENDIX B

OEAP RECRUITMENT COVER LETTER

Dear Parent/Guardian,

My name is Dr. LauraLee McIntyre and I am a faculty member in the school psychology program in the Department of Special Education and Clinical Sciences at the University of Oregon. I am a child psychologist with a special interest in supporting children with autism spectrum disorders (ASD) and their families. My research team is interested in better understanding the needs of children with ASD and their families in our community. Early Childhood CARES is sending you this letter, on my behalf, because you have a child receiving services. I am inviting you to participate in a study investigating the needs and experiences of families with a young child with ASD.

I am conducting a study to learn more about family experiences surrounding the identification of ASD and early intervention. I invite you to participate in this study. Your participation will involve being interviewed either in person (at your home or child's school) or on the phone. This study will take approximately 2 hours of your time. You will receive a \$25 gift card to Fred Meyer for participating in the interview as our way of saying thank you for your help.

Your participation is *voluntary, so may choose to participate or not*. There will be no adverse consequences should you choose not to participate. The people who are providing care and services to your child will not know whether or not you agreed to be a part of this study. Furthermore, you may choose to withdraw your participation at any time without risk. Your participation is also *confidential, which means names and identifying information will not be used* when our study results and findings are presented to others.

The benefit of research is that you will be helping us to understand the needs of young children with ASD and their families. This information should help us to develop better early identification and intervention programs for children. This will help children who already have the diagnosis of ASD, but may also benefit those who are not yet diagnosed. The risks to you of participating in this study are minimal. You may feel some discomfort being interviewed (we ask some personal questions about your child and family). If you feel uncomfortable answering any of the questions, you may skip the item(s) without penalty. If you no longer wish to continue, you have the right to withdraw from the study, without penalty, at any time.

If you are interested in participating or learning more about this study, please contact the Oregon Early Autism Project office (541-346-2632) or email Mallory Brown, Project Coordinator, (malloryb@uoregon.edu).

Sincerely,

Laura Lee McIntyre, PhD, BCBA-D

Associate Professor & Director, School Psychology Program

APPENDIX C

OEAP PHONE SCREEN

Hello, my name is _____ from the University of Oregon. You received a letter describing the Early Autism Project, a research project conducted by Dr. Laura Lee McIntyre and our research team in the College of Education at the U of O. I wanted to return your phone call/email and give you some information about this project. Is this a good time to talk? (If not, when would be a better time?).

Let me tell you a little more about this study.

The Early Autism Project is a study funded by a grant from the Fairway Fund and the College of Education at the University of Oregon. Dr. McIntyre is the principal investigator of this study and she is a child psychologist and professor and director of the school psychology graduate training program at the University of Oregon. Our research team is interested in family experiences surrounding the identification process for children with autism. We are also interested in services and care for young children with autism spectrum disorders. As part of this study, we are trying to interview every family in the area who has a child, birth – kindergarten, with autism spectrum disorders, including autism, PDD, and Asperger's Disorder.

Participation in this study is voluntary, so you can choose to participate or not. Additionally, everything that we talk about is confidential. This means that we cannot disclose what you've shared with us. We can't share what you've discussed with us with your child's teachers, service coordinators, therapists, or doctors. Your confidentiality is protected. Should you decide to participate in the study, we will go over an Informed Consent Form which describes everything in more detail. We'll also make sure that you get a chance to have any of your questions answered.

Participation in the Early Autism Project involves participating in an interview with me or a project staff member. We will ask you questions about your child – for example, discuss your child's strengths and skills as well as concerns you may have. We'll ask you questions about your child's educational programming, and we'll also ask you questions about the diagnostic process – for example, we'll have you talk about your first concerns regarding your child's development and who you went to for help. We will also get some family background information.

We would like to conduct an interview with you to get this information. We'll come to your home (or other location) at a time that is convenient for you. Your child does not need to be present during the interview. Our visit with you will take 1 ½ - 2 hours. We will provide you with a \$25 gift card for your time – our way of saying thanks for helping us with this important study.

The findings from our study will be summarized and will be available to families who participate in the project, as well as professionals in the field. We will remove all identifying information from the results so individual families will not be identified.

Our goal is to identify what families are experiencing during the diagnostic and identification process, as well as identify ways that professionals can support families during this time. Ultimately, the results of this study will be used to help make the service delivery system more family-friendly so we can do a better job with early identification and intervention for young children with autism and their families.

Do you have questions at this time? Do you have a few more minutes so I can get some information about you and your family to determine whether you meet eligibility for participation?

APPENDIX D

OEAP MAIL PACKET COVER LETTER

Dear _____,

Thank you for your interest in the Oregon Early Autism Project! We are delighted to include you in this project. Enclosed please find the following three documents:

- 1) Informed Consent Form (please keep this for your records)
- 2) The Family Support Scale questionnaire
- 3) The CESD questionnaire

Please take a moment to review the Informed Consent Form. Please contact the Oregon Early Autism Project office (541-346-2632) or email Mallory Brown, Project Coordinator, (malloryb@uoregon.edu) if you have questions or would like to discuss the study further.

We have scheduled a follow-up phone call with you on: _____.
This phone call will last approximately 30-45 minutes.

Your in-person interview is scheduled for: _____.
This visit will last approximately 90 minutes.

Please don't hesitate to contact us with questions. We look forward to talking with you further and involving you in this study.

Warm regards,

Laura Lee McIntyre, PhD, BCBA-D
Associate Professor & Director, School Psychology Program
Principal Investigator, Oregon Early Autism Project

APPENDIX E

OEAP INFORMED CONSENT FORM

My name is Dr. LauraLee McIntyre and I am an Associate Professor and Director of the School Psychology Program in the Department of Special Education and Clinical Sciences in the College of Education at the University of Oregon. I am inviting you to participate in a research study. Involvement in the study is voluntary, so you may choose to participate or not. This sheet will explain the study to you. If you have additional questions about the research, feel free to ask me. I'll be happy to explain anything in greater detail if you wish.

I am interested in learning more about family experiences surrounding the identification and diagnosis of autism spectrum disorders (ASD) in early childhood. You will be asked to complete an in-person interview where one of our assessors will ask you questions about your child's developmental functioning, early experiences with healthcare providers and early intervention/preschool, general family information. The interview will take approximately 1 ½ hours and will be conducted in person (in your home or other location of your choosing) or over the phone. We will schedule the interview at a time that is convenient for you. We will also ask that you complete two short questionnaires on your own. We will mail these questionnaires to you in advance of our in-person interview. These questionnaires are estimated to take 15 minutes to complete, making the total participation time in this study approximately 2 hours.

All information will be kept confidential. I will assign a number to your responses, and only my research staff and I will have the key to indicate which number belongs to which participant. In any articles I write or any presentations that I make, I will use a made-up name for you, and I will change details about you and your family to protect your identity. *Your information will be disclosed only with your written permission or as required by law.* Under state law, my research staff and I are required to report suspected or known abuse of children or elderly individuals. If any member of my research staff has or is given such information, we are required to report it to authorities.

The benefit of this research is that you will be helping us to understand the experiences of families with a young child identified with ASD. This information should help us provide better early identification and intervention programs in our community. Additionally, you as parent will have the opportunity to share your unique experiences during the "diagnostic journey". The risks to you of participating in this study are very minimal. You may feel some discomfort discussing your child's developmental history or your family situation with me. If you choose to have the interview conducted in person at your home, you may feel that this visit is a slight intrusion of your privacy. I will try to minimize these risks as much as possible. If you feel uncomfortable answering any of the questions during the interview, you may skip the question without penalty. If you wish to have the interview conducted over the phone, you may choose to do so. If you no longer wish to continue with the interview, you have the right to withdraw from the study, without penalty, at any time.

APPENDIX F

OEAP FAMILY DEMOGRAPHIC QUESTIONNAIRE

1. Name: _____
Last, Middle, First
2. Date of Birth: _____ Age: _____
3. Current Education/Therapeutic Placement:
- (1) Early Intervention (birth – 3 years)**
Please specify type of EI: (1) Parent Toddler Classroom
(2) Home only
(3) Combined (classroom + home)
(4) Other _____
(5) N/A (not enrolled in EI)
- (2) Early Childhood Special Education (3 – 5 years)**
Please specify type of ECSE: (1) Segregated program
(2) Inclusive program
(3) Community preschool
(4) Home only
(5) Other _____
(6) N/A (not enrolled in ECSE)
- (3) Kindergarten**
Please specify type of K Prog: (1) General education
(2) Education Resource Room (ERR)
(3) Life skills program
(4) Autism classroom
(5) Other _____
(6) N/A (not enrolled in K)
- (4) Other:** _____
- (5) None (not receiving services)**
4. Education/therapeutic placement is:
(1) Part-time (2.5 hours or less per day) _____
(2) Full-time (5 hours/day and 5 days/week)
(0) N/A (not receiving services)
5. Gender:
(1) Male
(2) Female
6. Race/ethnic background of child:
(1) White/Caucasian
(2) Black/African American
(3) Hispanic/Latino: _____
(4) Asian: _____
(5) Native American: _____
(6) Pacific Islander: _____
(7) Mixed: _____
(8) Other: _____

7. **Education eligibility** of autism?

- (0) No
- (1) Yes
- (2) Don't know

8. **Medical diagnosis** of an autism spectrum disorder?

- (0) No
- (1) Yes _____
- (2) Don't know

9. What is child's **medical diagnosis**?

- (1) Autism (Autistic Disorder)
- (2) PDD or PDD-NOS
- (3) Asperger's Syndrome
- (4) Other _____
- (5) Unknown
- (6) Multiple _____
- (7) None (no medical diagnosis of ASD)

10. When was child identified with **medical diagnosis**? _____ (Specify Date)

- (1) At birth or infancy (0-11 months)
- (2) One-year old (12-23 months)
- (3) Two-years old (24-35 months)
- (4) Three-years old (36-47 months)
- (5) Four-years old (48-59 months)
- (6) Five-years old (60-71 months)
- (7) Unknown
- (8) N/A (no medical diagnosis of ASD)

11. Who identified child (with **medical diagnosis** of ASD)?

- (1) Primary Care Physician/Pediatrician
- (2) Other Physician/Specialist _____
- (3) Psychologist _____
- (4) Other: _____
- (5) Unknown
- (6) N/A (no medical diagnosis of ASD)

12. Secondary Diagnosis: (Please circle one)

- (1) Developmental delay (or MR or ID)
- (2) Sensory dysfunction disorder
- (3) ADHD
- (4) Disruptive behavior disorder
- (5) Seizure disorder
- (6) Other: _____
- (7) None
- (8) Multiple

13. When was child diagnosed with secondary diagnosis?

- (1) At birth or infancy (0-11 months)
- (2) One-year old (12-23 months)
- (3) Two-years old (24-35 months)
- (4) Three-years old (36-47 months)
- (5) Four-years old (48-59 months)
- (6) Five-years old (60-71 months)
- (7) Unknown
- (8) N/A (No secondary diagnosis)

14. Who diagnosed child (with secondary diagnosis)?

- (1) Primary Care Physician/Pediatrician
- (2) Other Physician/Specialist _____
- (3) Psychologist _____
- (4) Other: _____
- (5) Unknown
- (6) N/A (No secondary diagnosis)

15. When was child identified with **education eligibility** of autism? _____
(Specify Date)

- (1) At birth or infancy (0-11 months)
- (2) One-year old (12-23 months)
- (3) Two-years old (24-35 months)
- (4) Three-years old (36-47 months)
- (5) Four-years old (48-59 months)
- (6) Five-years old (60-71 months)
- (7) Unknown
- (8) N/A (no education eligibility of autism)

16. Who identified child with **education eligibility** of autism?

- (1) Early Childhood CARES (EC CARES)
- (2) School district _____
- (3) Other: _____
- (4) Unknown
- (5) N/A (no education eligibility of autism)

17. Does child have medical/health problems (in addition to primary/secondary diagnoses)?

- (1) Yes: _____
- (0) No
- (2) Don't know

18. Is child seen regularly by a physician?

- (1) Yes
- (0) No

19. Is child currently taking any medication (including vitamins/supplements)?

(1) Yes:

Name _____ Reason: _____

Name _____ Reason: _____

(0) No

Interviewers: Please code Complementary and Alternative Medicine (CAM):

(1) Yes (all vitamins but multivitamins, supplements, and/or chelation)

(0) No

20. Does child have health insurance?

(1) Yes

(0) No

21. What type of health insurance?

(1) Private Insurance (e.g., Blue Cross) _____

(2) Oregon Health Plan/State Insurance

(3) Medicaid

(4) Other _____

(5) Multiple _____

(6) None (does not have health insurance)

Early Intervention/Early Childhood Special Education (Preschool) History

22. Did/does child receive Early Intervention services (0-3 yrs)?

(1) Yes

(0) No

(2) Don't Know

23. Is child currently enrolled in preschool or other early childhood education (or received in past)?

(1) Yes

(0) No

(2) N/A (currently too young for preschool/ECSE)

24. Is child enrolled in a program (EI, ECSE, Kindergarten) with special education eligibility (with an IFSP or IEP)?

(1) Yes

(0) No

(2) Don't Know

25. Does child receive related services in addition to special education services?

(1) Yes

(0) No

(2) Don't Know

26. If yes, which related services does your child receive?

Speech therapy

(1) Yes

Frequency (# of sessions/week or # of sessions/month): _____

- Please specify:
- (a) Child direct therapy
 - (1) Yes
 - (0) No
 - (8) N/A (not receiving speech)
 - (b) Parent consultation
 - (1) Yes
 - (0) No
 - (8) N/A (not receiving speech)

(0) No

Occupational Therapy (OT)

(1) Yes

Frequency (# of sessions/week or # of sessions/month): _____

- Please specify:
- (a) Child direct therapy
 - (1) Yes
 - (0) No
 - (8) N/A (not receiving OT)
 - (b) Parent consultation
 - (1) Yes
 - (0) No
 - (8) N/A (not receiving OT)

(0) No

Sensory Integration combined with OT or other therapy (e.g., use of weighted vests, brushing, swinging, body sock, joint compression, sensory table, sensory diet, etc.?)

- (1) Yes
- (0) No

Physical Therapy (PT)

(1) Yes

Frequency (# of sessions/week or # of sessions/month): _____

- Please specify:
- (a) Child direct therapy
 - (1) Yes
 - (0) No
 - (8) N/A (not receiving PT)
 - (b) Parent consultation
 - (1) Yes
 - (0) No
 - (8) N/A (not receiving PT)

(0) No

Behavioral programming (e.g., ABA) – either home- or center-based

(1) Yes

Frequency (# of hours/week): _____

(0) No

DIR/Floortime – either home- or center-based

(1) Yes

Frequency (# of hours/week): _____

(0) No

Other: _____

(1) Yes

Frequency (# of sessions/week or # of sessions/month): _____

If yes, specify “other” category:

- | | | |
|-----------------------|---------|--------|
| 1:1 Aide | (1) Yes | (0) No |
| Adaptive P.E. | (1) Yes | (0) No |
| Play Therapy | (1) Yes | (0) No |
| Music Therapy | (1) Yes | (0) No |
| Therapeutic Listening | (1) Yes | (0) No |
| Other | (1) Yes | (0) No |

(0) No

27. Special Diets (e.g., Gluten Free/Caeson Free)

(1) Yes

(0) No

28. Do any of these related services/therapies cost you money (out-of-pocket)?

(1) Yes

(0) No

29. Name of School Program (ECSE or Elementary):

30. Name of School District family resides in:

Mother/Mother Figure Information

31. Name of Mother:

_____ Last, _____ Middle, _____ First

32. Mother’s Date of Birth: _____ Age: _____

33. Is Mother/Mother Figure the Primary Caregiver?

(1) Yes

(0) No

If no, who is?: _____

34. Race/Ethnic Background of Mother:

(1) White/Caucasian

(2) Black/African American

(3) Hispanic/Latino: _____

(4) Asian: _____

(5) Native American: _____

(6) Pacific Islander: _____

(7) Mixed: _____

(8) Other: _____

35. Status of Mother Figure

(1) Biological

(2) Step

(3) Adoptive

(4) Female relative (aunt, grandmother)

(5) Other: _____

(6) No mother-figure present in home

36. Current Marital Status of Mother/Mother Figure

(1) Married or Living With Partner

(2) Unmarried - Single

(3) Separated

(4) Divorced

(5) Widowed

(6) Other _____

37. How long has child been living with mother figure?

(1) Less than 6 months

(2) 6-12 months

(3) 1-2 years

(4) 2+ years

(5) All/most of child's life (all but a few months)

(6) Child does not live with mother figure

38. Mother's Highest Grade Completed: (1-12=HS; 13-16=College; 16+ Post college)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

39. Mother's Highest Degree Obtained

- (0) None
- (1) HS Diploma/GED
- (2) Vocational Degree/Certificate
- (3) Associates Degree (2-year college degree)
- (4) Bachelor's Degree (4-year college degree)
- (5) Master's Degree
- (6) Doctorate (e.g., Ph.D, Ed.D., J.D., M.D, etc.)
- (7) Other: _____

40. Mother employed?

- (2) Yes; Full-time
- (1) Yes; Part-time
- (0) No

41. Mother location of employment?

- (1) Home
- (2) Out-of-home
- (8) N/A (not employed)

42. Mother's Job Title:

43. How many hours worked per week? _____

Father/Father Figure Information

44. Name of Father/Father

Figure: _____
Last, Middle, First

45. Father's Date of Birth: _____ Age: _____

46. Race/ethnic background of father:

- (1) White/Caucasian
- (2) Black/African American
- (3) Hispanic/Latino: _____
- (4) Asian: _____
- (5) Native American: _____
- (6) Pacific Islander: _____
- (7) Mixed: _____
- (8) Other: _____

47. Status of Father Figure

- (1) Biological
- (2) Step
- (3) Adoptive
- (4) Male relative (uncle, grandfather)
- (5) Other: _____
- (6) No father figure present in home

48. Current Marital Status of Father/Father Figure

- (1) Married or Living With Partner
- (2) Unmarried - Single
- (3) Separated
- (4) Divorced
- (5) Widowed
- (6) Other _____

49. How long has child been living with father figure?

- (1) Less than 6 months
- (2) 6-12 months
- (3) 1-2 years
- (4) 2+ years
- (5) All/most of child's life (all but a few months)
- (6) Child does not live with father figure

50. Father's Highest Grade Completed: (1-12=HS; 13-16=College; 16+ Post college)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

51. Father's Highest Degree Obtained

- (0) None
- (1) HS Diploma/GED
- (2) Vocational Degree/Certificate
- (3) Associates Degree (2-year college degree)
- (4) Bachelor's Degree (4-year college degree)
- (5) Master's Degree
- (6) Doctorate (e.g., Ph.D, Ed.D., J.D., M.D, etc.)

52. Father employed?

- (2) Yes; Full-time
- (1) Yes; Part-time
- (0) No

53. Father location of employment?

- (1) Home
- (2) Out-of-home
- (8) N/A (not employed)

54. Father's Job Title:

55. How many hours worked per week? _____

56. Annual total family (combined) income

- (1) \$14,999 or less
- (2) \$15,000-24,999
- (3) \$25,000-34,999
- (4) \$35,000-44,999

- (5) \$45,000-54,999
- (6) \$55,000-64,999
- (7) \$65,000-74,999
- (8) \$75,000-84,999
- (9) \$85,000-99,999
- (10) \$100,000-\$114,999
- (11) \$115,000-\$129,999
- (12) \$130,000+

57. Does family and/or child qualify for government aid programs?

- (1) Yes
- (0) No
- (2) Don't Know

58. If yes, which government aid programs does the family and/or child receive?

TANIF Temporary Assistance to Needy Families (i.e., welfare/public assistance)

- (1) Yes
- (0) No

Supplemental Security Income (SSI)

- (1) Yes
- (0) No

Social Security

- (1) Yes
- (0) No

Medicaid (and/or Medicaid Waiver)

- (1) Yes
- (0) No

Caregiver Disability Pension

- (1) Yes
- (0) No

Women, Infants, and Children (WIC)

- (1) Yes
- (0) No

Oregon Health Plan (OHP)

- (1) Yes
- (0) No

Other: _____

- (1) Yes
- (0) No

59. Total number of adults (age 18+) currently living in the home _____

60. Total number of children currently living in the home _____

Sibling Information

61. Does child have siblings living in the home?

- (1) Yes
- (0) No

62. How many siblings living in the home? _____

Sibling Name: _____
Date of Birth: _____ Age _____

Sibling Name: _____
Date of Birth: _____ Age _____

Sibling Name: _____
Date of Birth: _____ Age _____

63. Do any of the siblings have learning problems?

- (1) Yes _____
- (0) No

64. Do any of the siblings have behavior problems or mental health problems?

- (1) Yes
- (0) No

65. Do parent(s)/caregiver(s) have history of learning problems?

- (1) Yes
- (0) No

66. Do parent(s)/caregiver(s) have history of mental health problems?

- (1) Yes
- (0) No

67. Any family history of autism spectrum?

- (1) Yes _____
- (0) No _____

68. If yes, is the family history of autism spectrum in the immediate family (parents or siblings of target child)?

- (1) Yes
- (0) No
- (8) N/A (no family history of ASD)

Family Contact Information

Home address: _____

Phone number (home): _____

Phone number – work (please circle: Mother/Father): _____

Phone number – cell (please circle: Mother/Father): _____

Email address (please circle: Mother/Father): _____

How long have you lived here? _____ How long lived in Oregon? _____

APPENDIX G

OEAP INTERVIEW

1. What concerns did you first have about your child's development?
 - (1) Yes (0) No **Speech and Language Development**
 - (1) Yes (0) No **Hearing**
 - (1) Yes (0) No **Social Development (e.g., poor eye contact)**
 - (1) Yes (0) No **Play Skills (e.g., inappropriate toy play)**
 - (1) Yes (0) No **Behavioral Concerns** _____
 - (1) Yes (0) No **Feeding**
 - (1) Yes (0) No **Sleeping**
 - (1) Yes (0) No **Other** _____

2. How old was your child when differences were *first noticed* in his or her development? _____ (specify age)
 - (1) At birth (birth – 1m)
 - (2) Less than a year old (1m – 11m)
 - (3) Between 1st and 2nd birthdays (12m – 24m)
 - (4) Between 2nd and 3rd birthdays (25m – 36m)
 - (5) Between 3rd and 5th birthdays (37m – 60m)

3. How old was your child when concerns about his or her development were *first discussed* with another person? _____ (specify age)
 - (1) At birth (birth – 1m)
 - (2) Less than a year old (1m – 11m)
 - (3) Between 1st and 2nd birthdays (12m – 24m)
 - (4) Between 2nd and 3rd birthdays (25m – 36m)
 - (5) Between 3rd and 5th birthdays (37m – 60m)

4. Who first raised concerns about your child's development? (*Circle one*)
 - (1) Myself/Spouse
 - (2) Another family member
 - (3) Daycare/childcare provider
 - (4) My child's pediatrician/ primary care provider
 - (5) A provider in a specialty clinic
 - (6) A friend
 - (8) ASQ Oregon website (online evaluation)
 - (7) Other _____

5. How old was your child when concerns about his/her development were *first discussed* with your child's pediatrician/primary care provider? _____ (specify age)
 - (1) At birth (birth – 1m)
 - (2) Less than a year old (1m – 11m)
 - (3) Between 1st and 2nd birthdays (12m – 24m)
 - (4) Between 2nd and 3rd birthdays (25m – 36m)
 - (5) Between 3rd and 5th birthdays (37m – 60m)

6. Did your child's pediatrician/primary care provider use any screening instruments or questionnaires to find out more about your concerns?

- (0) No
- (1) Yes _____
- (2) Don't Know

7. After concerns were first discussed with your child's pediatrician/primary care provider, what happened?

- (1) **Don't Worry:** My child's pediatrician/primary care provider told my family not to worry about my child's development.
- (2) **Wait and See:** My child's pediatrician/primary care provider told my family that we should wait until the next well child appointment to see how my child continued to develop.
- (3) **Scheduled Follow-Up Visit:** My child's pediatrician/primary care provider scheduled a follow-up visit to discuss concerns about my child's development further.
- (4) **Referred to Specialist:** My child's pediatrician/primary care provider made a referral to another physician or agency for further evaluation.
- (5) Other (Please describe) _____

8. Overall, how satisfied are you with the care you received from your child's pediatrician?

- (1) Dissatisfied
- (2) Somewhat Dissatisfied
- (3) Neutral
- (4) Satisfied
- (5) Very Satisfied

9. Other comments about child's pediatrician or experiences with pediatrician:

10. How old was your child when he/she first started receiving services? _____

(specify age)

- (1) At birth (birth – 1m)
- (2) Less than a year old (1m – 11m)
- (3) Between 1st and 2nd birthdays (12m – 24m)
- (4) Between 2nd and 3rd birthdays (25m – 36m)
- (5) Between 3rd and 5th birthdays (37m – 60m)

11. How old was your child when he/she first identified with an ASD? _____ **(specify age)**

Please specify if response pertains to:

- (1) Medical diagnosis
- (2) Education eligibility

- (1) At birth (birth – 1m)
- (2) Less than a year old (1m – 11m)
- (3) Between 1st and 2nd birthdays (12m – 24m)
- (4) Between 2nd and 3rd birthdays (25m – 36m)
- (5) Between 3rd and 5th birthdays (37m – 60m)

12. Was your child on a waiting list to be evaluated/diagnosed?

- (0) No
- (1) Yes
- (2) Don't Know

13. If your child was on a waiting list, how long did you wait? _____

14. **Intervention/Treatment Supplemental Question:** After your child was identified, what did they tell you or recommend to you for intervention/services for your child?

15. Changes in services since being identified with autism?

- (0) No
- (1) Yes
- (2) Don't Know

16. If yes, change in services, was the change an increase or decrease in services?

Decrease

- (0) No
- (1) Yes

Increase _____

- (0) No
- (1) Yes

17. How do you gain information about autism? (please circle response)

- (1) Yes (0) No **Teachers/School**
- (1) Yes (0) No **Therapists**
- (1) Yes (0) No **Pediatrician/Physician**
- (1) Yes (0) No **Internet**
- (1) Yes (0) No **Books/Magazines**
- (1) Yes (0) No **Conferences**
- (1) Yes (0) No **Autism parent support groups (ASO, FEAT of Oregon)**
Do you attend regularly? __ (1) Yes __ (0) No __ (8) N/A
- (1) Yes (0) No **Family members/friends**

(1) Yes (0) No **Other parenting groups** (e.g., Birth to 3)

(1) Yes (0) No **Other:** _____

Interviewers: Please tally the total number of sources of information (above)

18. How satisfied are you with your information and/or source(s) of information?

- (1) Dissatisfied
- (2) Somewhat Dissatisfied
- (3) Neutral
- (4) Satisfied
- (5) Very Satisfied

SUMMARY/OPEN-ENDED QUESTIONS

19. Describe your experiences with other professionals (healthcare and education):

20. Barriers to earlier identification/diagnosis:

21. Family changes made since child was identified (or diagnosed):

22. Have you (or spouse/partner) changed work (e.g., took a 2nd job, stopped working, etc.)?

- (0) No
- (1) Yes _____

23. Have you (or spouse/partner) made changes regarding family planning (e.g., decided to have another child, decided to not have another child)?

- (0) No
- (1) Yes _____

24. Overall level of satisfaction with the educational (IFSP/IEP) identification/evaluation process

- (1) Dissatisfied
- (2) Somewhat Dissatisfied
- (3) Neutral
- (4) Satisfied
- (5) Very Satisfied
- (8) N/A (child does not have autism education eligibility)

25. Overall level of satisfaction with the medical diagnosis/evaluation process

- (1) Dissatisfied
- (2) Somewhat Dissatisfied
- (3) Neutral
- (4) Satisfied
- (5) Very Satisfied
- (8) N/A (child does not have a medical diagnosis)

26. Overall satisfaction with current services.

- (1) Dissatisfied
- (2) Somewhat Dissatisfied
- (3) Neutral
- (4) Satisfied
- (5) Very Satisfied

27. Any thing else you wish to share? _____

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