

THESIS

KNOWLEDGE OF SYMPTOMS, SOCIAL SUPPORT, AND PARENTING STRESS IN  
FATHERS OF CHILDREN WITH ASD: IMPLICATIONS FOR IMPROVED AFFECTIVE  
WELL-BEING

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## ABSTRACT

### KNOWLEDGE OF SYMPTOMS, SOCIAL SUPPORT, AND PARENTING STRESS IN FATHERS OF CHILDREN WITH ASD: IMPLICATIONS FOR IMPROVED AFFECTIVE WELL-BEING

Parents of a child with Autism Spectrum Disorder (ASD) will likely experience a more challenging and stressful parenting experience than the average parent (Hayes & Watson, 2013). Previous literature has demonstrated that parenting a child with ASD can be highly stressful for mothers, yet there is scant literature on the experiences of fathers. With such little information, it is unclear what contributes to promoting fathers' affective well-being when caring for a child with ASD. The present study examines the associations between knowledge of ASD symptoms, perceived social support, parenting stress, and both positive and negative affect of fathers of a child with ASD within the context of the ABC-X model. Additionally, this study explores which variables predict fathers' positive affect and negative affect. Fifty-two fathers of individuals with ASD completed a battery of confidential online surveys measuring parenting stress, social support, knowledge of ASD symptoms, and positive/negative affect. Correlational analyses and regression analyses were conducted. Results suggest that fathers experience high levels of parental stress, and this parental stress is associated with overall affective well-being. Perceived social support is associated with negative affect and knowledge of ASD symptoms was found to not be associated with any of our variables. Limitations, implications for clinical interventions, and future directions are explored.

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## **Introduction**

Autism spectrum disorder (ASD) is a lifelong neurodevelopment disorder that is characterized by qualitative impairments in social reciprocity, social-communication, and behavioral flexibility (American Psychiatric Association, 2013). Parents who have a child with ASD are often met with specific challenges that may cause greater stress than parents of children without a developmental disability (Hayes & Watson, 2013). Some of these additional stressors may include limitations in work, unpredictability of child behavior, social isolation, difficulty knowing how their child feels due to communication impairment, and negative social reactions by outsiders (Bayat & Schuntermann, 2013).

Parental stress can be conceptualized as parental perceptions of disparities between the resources available to an individual and the demands of parenting (Hsiao, 2017). Chronic stress for parents can have significant adverse impacts on parent health and well-being (Hsiao, 2017; Smith et al., 2010). Chronic stress can also adversely impact family functioning (Solomon & Thierry, 2006). For example, Hartley and colleagues (2010) found that parents with a child with ASD had a higher divorce rate (23.5%) in comparison to the control group of families raising a child with another developmental disability (13.8%).

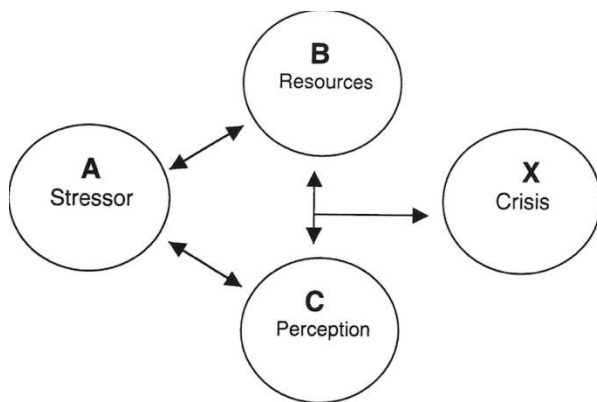
Yet, if we understood more about the nature of parental stress and the resources that parents can mobilize to reduce this stress, we may be able to support parents of children with ASD more effectively. Helping parents manage their stress is important in increasing child well-being, parental well-being, and overall family functioning (Lindo et al., 2016).

In this section, we rely upon Family Stress Theory as an overarching framework for summarizing the literature on the often stressful experience of parenting a child with ASD. In the

context of parenting a child with ASD, we will discuss the role of the stressor, resources, definition of the situation, and outcome measure of either crisis or management. Following this review, we will address a significant gap in the literature on Family Stress Theory and parents of ASD—our overall understanding of fathers’ experiences raising a child with ASD. This will lead us to the current study, and how we aim to bridge the gap in understanding fathers’ experiences.

### **Family Stress Theory**

Family Stress Theory (Hill, 1949) posits a concept based on the ABC-X model, where A is the stressor event, B is the family’s resources or strengths, C is the family’s perception of the event, and X is stress and crisis (see Figure 1; McCubbin & Patterson, 1983; Smith & Hamon, 2012). When a family is unable to immediately figure out a solution to the event, then it will lead to a crisis, or X (Smith & Hamon, 2012). In this section, we discuss each element of the ABC-X theory and integrate what is currently known about stress in families of children with ASD.



**Figure 1:** ABCX Model from Hill (1949)

#### **A: The Stressor**

The stressor can be defined in several ways, and each way will impact the family differently (McCubbin & Patterson, 1983; Smith & Hamon, 2012). The stressor event is neither positive nor negative, as it is simply a neutral situation before it is interpreted. However, how



individuals feel about the stressor is relevant to its potential impact (Hill, 1949; Smith & Hamon, 2012). Stressors can be both normative and non-normative, where normative stressors (i.e. puberty) are predicted and non-normative stressors (i.e. a fatal car accident) are not predicted (Boss, 2002). Stressors can also be ambiguous (i.e. we do not know the basic details about it) or non-ambiguous, where the details are clear (i.e. a loved one who has died from diagnosed terminal cancer). Finally, volitional stressors occur when we want to make something happen (i.e. starting a new job) and non-volitional stressors just happen to an individual (i.e. losing a job; Boss, 2002; Smith & Hamon, 2012). Stressors can be either chronic or acute, depending on how long they last.

Much of what we know about family stress and ASD focuses on mothers, and very little is known about the stressors that fathers experience or how they interpret those stressors. Mothers of a child with ASD experience significantly higher stress than mothers of a child without ASD (Smith et al., 2010; Seymour et al., 2013; Siu et al., 2019). Decreases in psychological well-being, lower levels of positive affect, and higher levels of negative affect have been reported for mothers of a child with ASD in comparison to mothers without a child with ASD (Smith et al., 2010). This could potentially be due to the frequency of stressful daily events. Mothers tend to spend less time in leisure activities (Smith et al., 2010) and experience more daily stressors than comparison mothers (Bayat & Schuntermann, 2013). When compared to their husbands, McStay and colleagues (2014) concluded mothers of children with ASD reported significantly higher levels of stress, as well as lower family quality of life.

Although similarities have been found, the experiences a mother and father have can differ. Faso and colleagues (2013) concluded that hope and vicarious futurity (the combined feeling of hope and despair a parent feels for a child's future) were important in examining

parent depression and stress. However, the authors determined that for fathers in specific, hope and vicarious futurity were particularly important (Faso et al., 2013). Hastings (2003) concluded while there was no difference in the level of stress between mothers and fathers, mothers experienced higher levels of anxiety than their husbands. Gerstein and colleagues (2009) posited that mothers' daily parenting stress increases over time while fathers' stress remains more consistent. Furthermore, decreases in mothers' daily stress was associated with mother and father well-being, marital adjustment, and a positive father-child relationship. For fathers, decreases in stress were associated with the mother's well-being and the parents' perceived marital adjustment (Gerstein et al., 2009). Furthermore, fathers parenting stress was found to decrease his involvement in both care and play (Ahnert et al., 2017). It is clear that while both mothers and fathers have been studied, it is often in comparison to one another, rather than focusing on fathers in specific. Given that fathers are experiencing a potentially qualitatively different kind of stressful experience, more information is needed to fully understand their experience of caregiving for a child with ASD.

## **B: The Resources**

After the specific stressor has affected a family, they must decide how to deal with the specific situation, mainly by accessing resources, or letter B (Hill, 1949; McCubbin & Patterson, 1983; Smith & Hamon, 2012). Resources can be from one of three categories: individual, family, and community (McCubbin & Patterson, 1985). Social support has been found to be one of the most important resources that individual has access to (Smith & Hamon, 2012). Additionally, the more resources an individual can employ, the better one is able to cope, so a variety of resources is often useful (Smith & Hamon, 2012).

Given that parents who are caregiving for a child with ASD are experiencing a stressful situation, having the appropriate resources is imperative. These resources will become essential for an individual's coping and overall perception of the situation. Support network, family communication, and flexibility, defined as a family's ability to rebound and reorganize amidst challenges, while keeping continuity, were identified as protective resources (Black & Lobo, 2008). In addition, a positive belief system, or the ability to remain positive amidst challenges, and a high nurturing parent style, were also identified by parents as factors leading to positive adaptation. Positive reframing, compromise coping, and emotional regulation were also found to help increase an individual's daily positive mood (Pottie & Ingram, 2008). Suzuki and colleagues (2015) conducted analyses that revealed when both knowledge of the child's characteristics and positive perceptions of parenting were high, psychological distress was low, but when perceived social supports were low, psychological distress demonstrated an increase (Suzuki et al., 2015). Smith and Hamon (2012) posit that social support is one of the most important resources an individual has access to. Social support can also be found at an individual, family, and community level, which is important when looking for resources.

May and colleagues (2015) conducted a study in which they tested associations between coparenting quality, ASD-specific parenting self-efficacy, and parenting stress in both mothers and fathers of a child with ASD. Although both mothers and fathers experienced high levels of parenting stress and a distinct relationship between coparenting quality and parenting stress, this link between parenting stress and coparenting quality was strong among fathers (May et al., 2015). Thus, fathers' experiences of stress and his sense of parenting competence were reliant upon the quality of their parenting partnership (May et al., 2015). Perhaps then, one of the most important factors to fathers' well-being is a sense of partnership and social support. It may also

be true that fathers' parenting competence is in part determined by his knowledge of ASD symptoms. In another study done specifically with fathers, Frye (2016) assessed the roles of fathers in raising a child with ASD, concluding that their experience was similar to that of a mother's experience. Money, teamwork, honesty, information, and time were specific needs that fathers referenced when caregiving for their child with ASD (Frye, 2016).

As utilized in Family Stress Theory, effective coping can help a family to experience support, warmth, and family cohesion in times of stress (Black & Lobo, 2008). Having the appropriate resources are essential to coping successfully and the use of effective coping skills could be instrumental to how an individual appraises the stressor. Conversely, there are coping patterns that are less effective and at times, detrimental. When compared to fathers of children without disabilities, fathers of a child with a special need reported lower levels of overall family coping (Darling et al., 2012). Another study conducted with both mothers and fathers of preschool and school-aged children with ASD concluded that there are four common coping strategies (Hastings et al., 2005). These four common strategies are: problem-focused coping (problem solving, seeking social support), positive coping (reframing, humor, acceptance), religious/denial coping (using religion and pretending the problem does not exist), and active-avoidance coping (substance use, self-blame). The authors concluded active-avoidance coping was related to more stress and mental health difficulties in both fathers and mothers, whereas positive coping was associated with lower levels of depression in both parents (Hastings et al., 2005). Positive coping, and more specifically the employment of positive reframing, is an effective coping strategy under an extreme condition where it can be difficult to reduce the impact of the actual stressor (Hastings et al., 2005). Positive reframing can be beneficial in

thinking of a negative or challenging situation, such as parenting a child with ASD, in a more positive way (Hastings et al., 2005).

Previous literature has identified potential risk factors associated with having a child with ASD that could ultimately lead towards a lack of management. These include factors such as the child's externalizing behavior, low levels of parental coping, and poor parenting (McStay et al., 2014). Lane and St. George (2020) found that although parenting stress was not directly associated with child behavior, it is associated with parenting behaviors. These parenting behaviors may still ultimately impact the child. Less effective coping skills may be evoked when an individual is under stress. Two examples of less effective coping strategies include substance use and active-avoidance coping due to parental fatigue from child behavior, or engaging in emotion-focused coping strategies (Seymour et al., 2013). The latter strategy left parents with more stress, false beliefs, and guilt than parents who used other forms of coping (Cappe et al., 2011). Additionally, decreases in daily positive mood was associated with escape, blaming, withdrawal, and helplessness, indicating higher levels of negative mood and less effective coping responses (Pottie & Ingram, 2008).

Research demonstrates that mothers and fathers engage in different coping strategies. Hastings and colleagues (2005) determined that while fathers engaged in active-avoidance coping, mothers tended to more frequently use problem-focused coping and active-avoidance coping. This suggests that mothers may utilize more than one type of coping style, potentially due to the increased stressors a mother experiences (Hastings et al., 2005). However, with such limited literature on fathers' coping styles, it is imperative to learn about what factors are associated with fathers' coping styles, as well as how these are associated with fathers' affective well-being. Knowing what resources are beneficial to an effective coping style in fathers will aid

in the understanding of how a father appraises the situation. This appraisal, in turn, will likely be associated with their overall affective well-being, as well as the positive and negative affect they are experiencing.

### **C: Definition of the Situation**

The definition of the situation, or letter C, is important in determining how a family or individual may interpret the stressor situation (McCubbin & Patterson, 1983). In order to assess one's adaptation to a stressful event, Family Stress Theory posits that a family will perceive the event as either stressful or under control. This perception, or lack thereof, of control may then lead to an individual's or family's ability to manage the situation or go into crisis. Individuals who are coping effectively will likely have a more positive definition of the situation. In fact, an individual's appraisal of the event will influence their thoughts and behaviors that are used to manage the stress or during coping (Smith & Hamon, 2012).

It has been found that cognitive appraisal and coping processes can be mediators of individual psychological responses to stressors, like being diagnosed with and living with cancer (Folkman, 1999; McCubbin & Patterson, 1983; Smith & Hamon, 2012). Furthermore, cognitively reframing the situation to something that an individual can handle helps to manage the stressor. Breaking down tasks into manageable pieces can also help an individual feel less overwhelmed by the stressor at hand (Smith & Hamon, 2012).

One way of appraising the situation may be by taking action. A meta-analytic review of interventions targeting stress management in parents of children with developmental disabilities indicated behavior parents training and coping strategies interventions as the two dominant effective interventions in stress reduction for parents of a child with a developmental disability (Lindo et al., 2016). Studies about coping strategies focused on addressing parental stress

through parent perceptions (Lindo et al., 2016). Interventions ranged from self-monitoring, cognitive reframing, and progressive muscle relaxation (Singer et al., 1988), as well as group counseling for problem solving strategies, conflict resolution, and decision-making techniques (Kirkham & Schilling, 1990).

Bourke-Taylor and colleagues (2019) implemented an intervention that used an effective evidence-informed health and empowerment group-based workshop program. Mothers of a child with a disability reported significant change across four time points, including participation in a healthy activity, depression, anxiety, stress symptoms, and empowerment. This indicates that this specific intervention can be effective at improving both health and well-being outcomes for mothers of a child with a disability (Bourke-Taylor et al., 2019).

In a recent study by May and colleagues (2021a), fathers in a text-based program received messages about formal support, understanding ASD, coping, relationships with their parenting partner, and father-child interaction. For fathers who completed the program, there were reports of a significant reduction in parenting stress, as well as an increase in autism-parenting self-efficacy (May et al., 2021a). The partner publication further posits that these fathers were actively participating in the program and applied information into their own parenting behavior (May et al., 2021b). Furthermore, Iida and colleagues (2018) applied an intervention that incorporated parent training to improve stress-coping style while simultaneously decreasing both depression and anxiety. Both interventions utilized a combination of social support and individualized training to most effectively support parents while promoting resilience. The authors concluded for mothers of a child with ASD, the parent training program significantly increased the use of ‘positive appraisal’ stress-coping style while significantly decreasing the use of ‘escape/avoidance’ stress-coping style. Additionally, the Beck

Depression Inventory Second Edition and trait anxiety scores significantly decreased. The authors stated that this indicates parent training may be effective for mothers of children with ASD to improve their stress-coping style while also working to decrease a mothers' depression and trait anxiety (Iida et al., 2018). As can be seen in these examples, when presented with a stressor, those who utilized resources such as social support and knowledge building (parent-training) were able to define the situation in a way in which they took action. This action taking helped to de-stress and at times, decrease depression and anxiety and increase well-being. The decrease in stress is likely associated with more positive affect, and likely greater well-being. It is possible that these individuals are more likely to feel balanced and as though the situation is under control.

### **X: Crisis or Management**

The final letter in Family Stress Theory's ABC-X model is the crisis, or X. Those who are able to manage their situation will not fall into a state of crisis, while those who cannot manage the situation go into crisis (Hill, 1949; McCubbin & Patterson, 1983). That is not to say that families or individuals who fall into crisis will fall apart, but they will learn to function with the stressor in their life (Smith & Hamon, 2012). Thus, following this idea, the stressor of having a child with ASD may lead an individual to crisis, or management. Well-being will be used as a proxy for the X variable of crisis, where crisis is defined as lower levels of well-being, and thus, individuals who are in crisis are not meeting the ideal balance of positive and negative affect, and they are likely experiencing more negative affect. More specifically, it seems as though the stressor of having a child with ASD may lead an individual to either experience crisis (and a less balanced affect), or to manage the situation (a more balanced affect). The stressor may also result



in a differing end result for fathers than for mothers. Perhaps mothers are more able to maintain balance in this stressor, but fathers are more likely to have a decrease in positive affect.

### **Gaps in the Literature**

Overall, there is a striking lack of empirical knowledge about the stress, coping, and adaptation of fathers of children with ASD (Hayes & Watson, 2013; Gerstein et al., 2009; Braunstein et al., 2013). Part of the disconnect between research on fathers and mothers may be in part due to the fact that mothers are providing direct caregiving more frequently than fathers. Pisula and Kossakowska (2010) conducted a study in which mothers of children with ASD completed self-reports. The authors concluded that mothers of children with ASD identified spending almost twice the amount of time per day on direct care when compared to fathers. Mothers reported approximately nine and a half hours of direct childcare and fathers reported just below five hours (Pisula & Kossakowska, 2010). In another study done by Potter (2017), fathers of children with ASD report being involved in child-care routines, but they reportedly spend the majority of their time with their child in leisure or play activities. Culturally, mothers are more often the caregivers, which could partially explain the variance in the amount and type of evidence on a mother or father's experience parenting a child with ASD. Though fathers may overall be less involved than mothers, fathers' interactions were found to have strong influences on children with a disability (Lane & St. George, 2020).

Given that there is insufficient information regarding fathers' roles in caregiving, in comparison to a mother's, it is unclear exactly what contributes to promoting fathers' affective well-being when caring for a child with ASD. Previous studies have shown that while there are similar important aspects for mothers and fathers in this stressful experience, fathers have a unique experience that is worthy of further research (Frye, 2016; May et al., 2015; Hayes &

Watson, 2013; Hastings et al., 2005). Given that this stressor may result in a different end result for fathers than for mothers, this imbalance of research warrants additional research in which fathers' experiences can be identified. Additional research can explore the impact of stress on parenting in general, and affective well-being, in specific.

### **The Current Study**

The aim of this study is to add to the understanding of families of children with ASD by focusing on the experiences of fathers. Specifically, the authors will use the ABC-X model to determine whether factors that are associated with maternal well-being are relevant to fathers' well-being. Extending the work of Suzuki and colleagues (2015), this study evaluates the extent to which knowledge of a child's ASD symptoms, parental stress, and perceived social support are associated with fathers' affective well-being.

Therefore, our first research question is: *How strongly are knowledge of a child's ASD symptoms, parental stress, perceived social support, and affective well-being associated with one another?* Given this research question, we aim to look at associations between all variables (i.e. parental stress and knowledge, parental stress and social support, parental stress and positive and negative affect, etc.). We hypothesize that knowledge of ASD symptoms will be associated with greater affective well-being (higher positive affect and lower negative affect). We also hypothesize that greater perceived social support will be associated with greater affective well-being (higher positive affect and lower negative affect). Additionally, we hypothesize that parental stress will be lower when either social support and/or knowledge of ASD symptoms is higher, and that affective well-being will be lower when parental stress is higher.

Our second research question is: *To what extent do knowledge of ASD symptoms, parental stress, and perceived social support predict fathers' affective well-being?* We

hypothesize that a combination of social support and parental stress will be most important to fathers' affective well-being, accounting for the most variance. We also hypothesize that variance in well-being will be predicted by social support and stress, even when adjusting for caregiver status or living situation. We have chosen these two covariates of caregiver status and living situation, as previous research has suggested they have an impact on well-being (Pisula & Kossakowska, 2010; Suzuki et al., 2015).

## **Method**

### **Study Design**

This was a survey study that examined associations amongst variables of interest. Survey research involves using standardized questionnaires to collect data about people, as well as their preferences, thoughts, and behaviors (Bhattacharjee, 2012). This type of study design allows for measurement of a wide variety of data, as we collected data on five separate measures in one sitting. More specifically, we used an online survey questionnaire, allowing respondents to receive the survey directly to their phone or computer, rather than through the mail. In doing so, we were able to continue collecting data even when fathers were unable to come into the lab, as survey research tends to be unobtrusive and allows the participant to respond in their own time. Given the short amount of time for data collection and low budget, survey research allowed us to capture a lot of data efficiently and inexpensively.

### **Participants**

Participants were recruited to this study through an existing research database of parents of children with ASD. These parents have participated in research studies previously through the Autism Research Group that is based in the Department of Human Development and Family Studies at Colorado State University. Additionally, 3,400 families of individuals with a variety of developmental disabilities were contacted through the JFK Partners database located within the University Centers for Developmental Disability Program housed within the Department of Developmental Pediatrics of the University of Colorado School of Medicine. Approximately 30% of these families have a child with ASD (approximate  $n = 1,030$ ); however, the listserve is not organized by condition and we were not able to send the notice only to those families who

have a child with ASD. Potential participants were also contacted through the University of Wyoming's WIND listserv. The parents in these databases previously agreed to be contacted by the Principal Investigator (Committee Chair of this Masters' committee) to be invited to participate in future research studies. Participants were also contacted through word of mouth. This included individuals in the family support community and psychologists or therapists who were contacted by the Principal Investigator.

Inclusion criteria for this study were: (1) fathers of at least one child with an ASD diagnosis; (2) adult between the ages of 18 and 80; and (3) access to online service and willingness to complete a confidential online survey regarding their parenting experiences. Additionally, when considering the relational status to the biological mother of their child, fathers who are married, divorced, or cohabitating were eligible.

Exclusion criteria for the study were: (1) child does not have ASD; (2) parent is not the father of the child; and (3) father cannot read or write in English; however, in future studies and with funding opportunities, we hope to learn from parents who have a primary language other than English.

We endeavored to recruit a sample of fathers that is representative of the population of the greater Denver Metropolitan area (80.9% White alone, 9.8% Black or African American alone, 1.7% American Indian or Alaska Native alone, 4.1% Asian alone, 0.2% Native Hawaiian and Other Pacific Islander alone, 3.3% Two or More Races, 29.3% Hispanic or Latino, and 54.9% White alone, not Hispanic or Latino (U.S. Census Bureau QuickFacts: Denver County, Colorado, 2019).

Our sample included 67 fathers of one or more children with ASD. Of the 67 fathers who completed the survey, four were eliminated due to not being the father (i.e. a spouse reporting for

their husband) and 11 were eliminated due to incomplete data (i.e., missing one or more measures entirely), resulting in 52 participants for analysis. The majority of participants were white (92.0%), and many were between the ages of 46 and 55 (38.5%), and had a Bachelor's or Masters degree (40.4% for both). Additionally, the majority were the biological father (92.3%), and they were currently married and living with the biological mother (75.1%). Of those divorced from the child's mother, 48.1% had joint custody of their child. Approximately 80% were employed at the time of the survey (78.8%). The majority of participants had two children (55.8%), of which one child had an ASD diagnosis (88.5%). Participants' children with ASD were most commonly a son (83.0%). Approximately 70% of the offspring with ASD were children and 31% were over the age of 18 years. Most fathers reported that their child with ASD could communicate by speaking in full sentences (63.0%). Out of all of the fathers, over a half (57.7%) were not the primary caregiver. See Table 1 for more demographic information.

**Table 1**

*Participant Demographic Information*

| Characteristic                         | <i>n</i> | percent |
|--|----------|---------|
| Parent                                 |          |         |
| Father                                 | 52       | 100.0%  |
| Age                                    |          |         |
| 18-25                                  | 0        | 0.0%    |
| 26-35                                  | 2        | 3.8%    |
| 36-45                                  | 17       | 32.7%   |
| 46-55                                  | 20       | 38.5%   |
| 56-65                                  | 11       | 21.2%   |
| 66-75                                  | 1        | 1.9%    |
| 75 or more                             | 1        | 1.9%    |
| Race/Ethnicity                         |          |         |
| American Indian or Alaska native       | 0        | 0.0%    |
| White                                  | 48       | 92.0%   |
| Asian                                  | 2        | 4.0%    |
| Middle Eastern or North African        | 0        | 0.0%    |
| Black or African American              | 0        | 0.0%    |
| Native Hawaiian/other Pacific Islander | 0        | 0.0%    |
| Biracial                               | 1        | 1.9%    |

|   |    |       |
|---|----|-------|
| Not known                               | 2  | 3.8%  |
| Hispanic or Non-Hispanic                |    |       |
| Hispanic, Latino, or Spanish            | 3  | 5.7%  |
| Non-Hispanic                            | 49 | 94.3% |
| Another race or ethnicity not listed    | 0  | 0.0%  |
| Education                               |    |       |
| Less than a high school diploma         | 0  | 0.0%  |
| High school diploma/GED                 | 2  | 3.8%  |
| Some college or associate/trade degree  | 8  | 15.4% |
| Bachelor's degree                       | 21 | 40.4% |
| Master's degree or higher               | 21 | 40.4% |
| Biological father                       |    |       |
| Yes                                     | 48 | 92.3% |
| No                                      | 4  | 7.7%  |
| Primary Caregiver                       |    |       |
| Yes                                     | 22 | 42.3% |
| No                                      | 30 | 57.7% |
| Relationship to the biological mother   |    |       |
| Currently married and living together   | 39 | 75.1% |
| Currently married and living separately | 2  | 3.8%  |
| (at least 6 months)                     |    |       |
| Divorced/Separated and living together  | 0  | 0.0%  |
| Divorced/Separated and living apart     | 9  | 17.3% |
| Never lived together                    | 2  | 3.8%  |
| Mother has passed away                  | 0  | 0.0%  |
| Current custody status of child         |    |       |
| Sole custody                            | 6  | 11.5% |
| Joint custody                           | 25 | 48.1% |
| No custody                              | 2  | 3.8%  |
| Not applicable/Other                    | 16 | 30.8% |
| Missing                                 | 3  | 5.8%  |
| Employment Status                       |    |       |
| Employed                                | 41 | 78.8% |
| Working part-time                       | 3  | 5.8%  |
| Unemployed                              | 8  | 15.4% |
| Children                                |    |       |
| 1                                       | 9  | 17.3% |
| 2                                       | 29 | 55.8% |
| 3                                       | 8  | 15.4% |
| 4                                       | 3  | 5.8%  |
| 5                                       | 2  | 3.8%  |
| 6 or more                               | 0  | 0.0%  |
| Missing                                 | 1  | 1.9%  |
| Children diagnosed with ASD             |    |       |
| 1                                       | 46 | 88.5% |
| 2                                       | 4  | 7.7%  |
| 3 or more                               | 0  | 0.0%  |
| Missing                                 | 2  | 3.8%  |

|   |    |       |
|---|----|-------|
| Gender of child with ASD                |    |       |
| Son                                     | 43 | 83.0% |
| Daughter                                | 12 | 23.0% |
| Both a son and a daughter               | 3  | 6.0%  |
| Age of child diagnosed with ASD         |    |       |
| 0-3                                     | 6  | 12.0% |
| 4-7                                     | 7  | 13.0% |
| 8-12                                    | 10 | 19.0% |
| 13-17                                   | 14 | 27.0% |
| 18+                                     | 16 | 31.0% |
| Communication style of child with ASD   |    |       |
| My child is still learning how to comm. | 10 | 19.0% |
| Pictures or augmentative comm.          | 5  | 9.6%  |
| Sign language and gestures              | 2  | 3.8%  |
| Single words/simple sentences           | 12 | 23.0% |
| My child speaks in full sentences       | 33 | 63.0% |

## Procedures

Study procedures were approved by the Institutional Review Board (IRB) at Colorado State University (CSU). Parents in the Autism Research Group, JFK Partners database, and WIND database were sent a recruitment email describing the study. Interested individuals were directed to a secure and confidential Qualtrics portal where they could provide participation consent. They were then able to complete the survey anonymously via Qualtrics, which has a secure portal overseen by the IT department at CSU. Initiation of the survey constituted informed consent per clear guidance in the survey introduction, which was written at a 6<sup>th</sup>-grade reading level. Participation was completely voluntary, and participants were able to stop the online survey at any time. No identifying information about participants was gathered as part of this study, so risks to violation of confidentiality were limited. The survey ended with a statement of completion and statements of gratitude for participation.

## Measures

The measures embedded within the online survey included: (1) demographic questionnaire (created for this project by the lead author), (2) The Autism Survey (assessing for



knowledge of ASD symptoms; Stone, 1987), (3) The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988), (4) Autism Parenting Stress Index (APSI; Silva & Schalock, 2012), and (5) Positive and Negative Affect Schedule (PANAS; Carstensen et al., 2000). All of the scales were in Likert-scale format, and the demographic questions were in short-answer or multiple-choice question form.

Care was taken to present items that do not contain sensitive content and the information obtained was similar to what one would share in a therapy visit. Based on prior literature, the demographic questionnaire was developed from an existing lab measure and included items that were relevant to this study. All other measures have been psychometrically validated and their psychometric properties are outlined below. All items for each measure can be found in the appendices.

### ***Demographic Questionnaire***

Items in the Demographic Questionnaire included: participant age, race/ethnicity, education, relational status to the child's biological mother, diagnosis of child(ren), age of child, gender of child, communication status of their child, and number of children, as well as number of children with an ASD diagnosis. The child's communicative ability was used in the study as a proxy for ASD severity. The items included in the demographic questionnaire were essential for confirming eligibility in the study, as well as gathering information for the analysis of covariates (e.g., living situation and caregiver status). See Appendix A for the demographic questionnaire.

### ***The Autism Survey (Heidgerken et al., 2005; Stone, 1987)***

The Autism Survey is a measure that assesses knowledge and beliefs about ASD and was originally created for professionals in four disciplines (pediatricians, clinical psychologists, speech/language pathologists, and school psychologists) across both community- and school-

based professions (Stone, 1987). The measure we used was adapted in 2005 by the Christian Sarkine Autism Treatment Center HANDS in Autism Team. This measure can be found in Appendix B and includes 20 statements about conceptions or misconceptions about ASD. Ratings are indicated on a six-point Likert scale and the labels are as follows: 1 (*Fully Agree*), 2 (*Mostly Agree*), 3 (*Somewhat Agree*), 4 (*Somewhat Disagree*), 5 (*Mostly Disagree*), and 6 (*Fully Disagree*). For example, respondents were asked to rate how much they agree or disagree with the statement ‘Autism is an emotional disorder’ or ‘All children with autism display poor eye contact’ (HANDS in Autism Team, 2005). As recommended by the authors and the developer of the measure, scores with 3 or less indicates disagreement and 4 or more indicates agreement with a statement (Stone, 1987; Heidgerken et al., 2005). Higher total scale score indicates more ASD knowledge, therefore, items phrased in the opposite direction were recoded.

Campbell and colleagues (1996) identified The Autism Survey to have acceptable to good internal consistency (Cronbach’s  $\alpha = .66$ ). They completed a second analysis after identifying three rogue items. The authors deleted the three rogue items from subsequent analyses, completing the secondary analysis and concluding there was higher internal consistency (Cronbach’s  $\alpha = .74$ ). This improved version will be used in the present study.

***Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988)***

The MSPSS is a brief, norm-referenced parent checklist that assesses the subjective adequacy of one’s social support. It was originally tested among undergraduate students (Zimet et al., 1988) and has subsequently been used in other populations, including studies of parenting (Wang et al., 2017) and incarcerated individuals (Wittenborn et al., 2020). The MSPSS specifically attempts to address the subjective assessment of social support adequacy, while including three specific sources of social support: family, friends, and significant other (Zimet et

al., 1988). This scale, found in Appendix C, has a total of 12 items (e.g. ‘There is a special person who is around when I am in need;’ ‘My family really tries to help me.’), each with a response range from 1 to 7. The Likert scale item labels are as follows: 1 (*Very Strongly Disagree*), 2 (*Strongly Disagree*), 3 (*Mildly Disagree*), 4 (*Neutral*), 5 (*Mildly Agree*), 6 (*Strongly Agree*), 7 (*Very Strongly Agree*). Total scores range from 1 to 7 and higher scores indicate higher perceived social support. Scores can be calculated overall, for a Total Scale Score, as well as by subscales, for Significant Other Subscale, Family Subscale, and Friends Subscale. Higher scores on both Total Scale Score and Subscales indicate more perceived social support.

The MSPSS was chosen as it was found to have very good internal consistency (Cronbach’s  $\alpha = .88$ ) and high test-retest reliability,  $r = .85$  (Zimet et al., 1988). Additionally, Wittenborn and colleagues (2020) assessed the convergent and discriminant validity of the individual MSPSS scale items by evaluating the strength of associations between items using inter-item correlation coefficients. The authors tested inter-correlations for items that belonged to the same subscale, and correlations for items belonging to different subscales. Average inter-item correlations equaled .50 and individual inter-item correlations about this value were appropriate (Wittenborn et al., 2020).

### ***Autism Parenting Stress Index (Silva & Schalock, 2012)***

The Autism Parenting Stress Index (APSI) is a measure of parenting stress specific to both the core and co-morbid symptoms of ASD. The measure is intended for use by clinicians who want to identify areas to target for parent-focused interventions. It can also be used for assessing the effect of an intervention on parenting stress. Items fall into three different categories: Social Disability, Difficult-to-Manage Behavior, and Physical Issues. Respondents are asked to rate the aspects of their child’s health according to how much stress it causes them

or their family. Examples include ‘Your child’s social development’ or ‘Self-injurious behavior.’ Respondents rate items on a Likert-scale, with responses ranging from ‘*Not Stressful.*’ ‘*Sometimes creates stress,*’ ‘*Often creates stress,*’ ‘*Very stressful on a daily basis,*’ to ‘*So stressful that sometimes we feel we cannot cope*’ (Silva & Schalock, 2012). Higher scores indicate less stress, therefore all items were recoded in the opposite direction for ease of interpretation of analyses for this study. See Appendix D for the Autism Parenting Stress Index.

Silva and Schalock (2012) evaluated internal consistency for the overall measure, as well as for the three sub-categories mentioned above. For children with ASD, there was good internal consistency, (Cronbach’s  $\alpha = .83$ ). Additionally, for parents of children with ASD, alphas were generally lower at the construct level. Specifically, on the factors of core ASD behaviors, co-morbid behaviors, and co-morbid physical issues, Cronbach’s  $\alpha = .79, .76$ , and  $.67$ , respectively. Furthermore, test-retest reliability was found to be high,  $r = .88$  (Silva & Schalock, 2012).

#### ***Positive and Negative Affect Scale (PANAS; Carstensen et al., 2000)***

Created to sample emotional experiences in everyday life, the PANAS assesses the degree to which an individual experiences specific emotion or feeling states. Participants rate the extent to which they experienced both positive (pride, calm, joy, contentment, relaxed, excitement) and negative (anger, sadness, fear, anxiety, frustration, embarrassment, and boredom) emotional states on a seven-point Likert scale. The scale ranges from 1 (*not at all*) to 7 (*extremely*; adapted from Carstensen et al., 2000). Ratings that are greater than 1 indicate that an emotion was present, and frequency and intensity of such emotions are able to be captured in a single rating as well. Therefore, higher ratings indicate greater frequency and intensity of experiencing an emotion (Castensen et al., 2000). Higher positive affect indicates greater

affective well-being, while higher negative affect indicates lower affective well-being. See Appendix E for the Positive and Negative Affect Scale.

Luong and Charles (2014) evaluated the internal consistency of PANAS subscale ratings at baseline, task, and posttask. Cronbach's  $\alpha$ s were .92, .91, and .93, respectively, for positive affect and .90, .86, and .84, respectively, for negative affect. Furthermore, Watson and colleagues (1988) found convergent correlations ranging from .89 to .95 and low discriminant correlations ranging from -.02 to -.18, indicating good scale validity.

### ***Caregiver Status and Living Situation***

We chose to include two covariates in our analyses (i.e., living situation, primary caregiver status). The first covariate (living situation) was dichotomized and dummy-coded, where two of the six potential answers (i.e. married and living together and separated and living together) were assigned a code of 1. Those answers where the father was not living with another individual (i.e. married and not living together; separated and not living together; never lived together; and mother passed away) were coded as a 0. Therefore, those who had a higher score of 1 were living with another individual. Primary caregiver was determined based on whether a father answered yes (1) or no (0).

### **Statistical Analysis**

Preliminary analyses examined the distributions of all variables. The authors confirmed participant eligibility, checked for data completion, and replaced missing values for each participant with the group mean of each score for the missing item. There were a total of seven missing items, distributed fairly equitable across measures.

This is a study of associations amongst constructs, therefore we will present correlational analyses for all hypothesized associations, followed by a multiple regression analyses to

determine which predictor (social support, parental stress, knowledge of ASD symptoms) accounts for the most variance in affective well-being. In this analysis, living situation (or cohabitation status measured as living with another individual) and being the primary caregiver were controls.

## Results

### Descriptive Statistics

Descriptive analyses and tests measuring skewness and kurtosis indicated that the dependent variables approached normality, allowing for parametric correlations to be conducted. Means, standard deviations, and ranges were analyzed for relevant total or subscale total scores for each measure. The Autism Survey has a maximum score of 120, with higher scores indicating greater knowledge of ASD symptoms. The Multidimensional Scale of Perceived Social Support has a maximum score of 84, with higher scores indicating greater perceived social support. The Autism Parenting Stress Index has a maximum score of 65, with higher scores indicating less stress. The Positive and Negative Affect Scale was separated into positive and negative subtotals, with a maximum high score of 42 for the positive scale and 49 for the negative scale. Higher scores on both positive and negative affect scales indicate greater positive or negative affect, respectively. Means, standard deviations, and ranges can be found in Table 2.

**Table 2**

*Descriptive Statistics of Relevant Variables*

| Measure                   | <i>M</i> | <i>SD</i> | Range        |
|---------------------------|----------|-----------|--------------|
| Knowledge of ASD Symptoms | 85.50    | 9.17      | 67.00-103.00 |
| Social Support            | 61.77    | 15.09     | 12.00-81.00  |
| Parental Stress           | 36.77    | 11.80     | 13.00-59.00  |
| Positive Affect           | 22.62    | 7.16      | 8.00-39.00   |
| Negative Affect           | 23.04    | 8.01      | 9.00-42.00   |

### Correlational Analyses

The aim of this study were twofold: (1) to examine associations between all variables, and (2) examine the hypothesized factors associated with an increase in fathers' affective well-

being (increase in positive affect and decrease in negative affect). Correlational analyses were used to examine our first aim and research question: *How strongly are knowledge of a child's ASD symptoms, parental stress, perceived social support, and affective well-being associated with one another?* Correlations were analyzed amongst all measures, with the alpha criteria set at .01, due to multiple comparisons. As shown in Table 3, correlations between these variables are small (.1-.3), medium (.3-.5), or large (.5-1.0) effects (Cohen, 1988).

**Table 3**

*Correlation Matrix of Knowledge of ASD Symptoms, Social Support, Parental Stress, and Affect*

|                                 |                     | 1.   | 2.     | 3.     | 4.     | 5. |
|---------------------------------|---------------------|------|--------|--------|--------|----|
| 1. Knowledge of ASD Symptoms    | Pearson Correlation | 1    |        |        |        |    |
|                                 | Sig. (1-tailed)     |      |        |        |        |    |
| 2. Social Support               | Pearson Correlation | .16  | 1      |        |        |    |
|                                 | Sig. (1-tailed)     | .130 |        |        |        |    |
| 3. Parental Stress <sup>a</sup> | Pearson Correlation | .30  | .39**  | 1      |        |    |
|                                 | Sig. (1-tailed)     | .016 | .002   |        |        |    |
| 4. Positive Affect              | Pearson Correlation | .23  | .30    | .33**  | 1      |    |
|                                 | Sig. (1-tailed)     | .052 | .016   | .008   |        |    |
| 5. Negative Affect              | Pearson Correlation | -.27 | -.45** | -.67** | -.55** | 1  |
|                                 | Sig. (1-tailed)     | .026 | <.001  | <.001  | <.001  |    |

<sup>a</sup>Higher scores of parental stress indicate lower parental stress.

\*\* . Correlation is significant at the 0.01 level (1-tailed);  $p < .001$

### ***Knowledge of ASD Symptoms***

We hypothesized that knowledge of ASD symptoms would be associated with greater affective well-being (higher positive affect and lower negative affect). Knowledge of ASD symptoms was found not to be significantly related to perceived social support, parental stress, or positive or negative affect.



### ***Perceived Social Support***

We hypothesized that greater perceived social support would be associated with greater affective well-being (higher positive affect and lower negative affect). Perceived social support was found to have a medium, significant association with parental stress, such that as perceived social support increased, parental stress increased. Additionally, though perceived social support was not significantly associated with positive affect, there was a medium, significant association with negative affect. It was determined that as perceived social support increases, negative affect significantly decreases.

### ***Parental Stress***

We hypothesized that parental stress would decrease when either social support or knowledge of ASD symptoms increased. We also hypothesized affective well-being would be lower when parental stress was higher. Parental stress was significantly associated with both positive affect and negative affect. More specifically, it was found that as parental stress increases, positive affect significantly increases. Along similar lines, as parental stress decreases, negative affect significantly increases. The relationship between parental stress and positive affect had a medium effect size, while the relationship between parental stress and negative affect had a large effect size.

Finally, a large significant association was found amongst positive and negative affect, such that as positive affect increases, negative affect decreases.

### ***Regression Analyses***

To analyze our second aim and research question (*To what extent do knowledge of a child's ASD symptoms, parental stress, and perceived social support predict fathers' affective well-being?*) we conducted two multiple linear regressions to assess which variables (i.e. knowledge of ASD symptoms, parental stress, social support, living situation, and caregiver status) accounted for the most variance in fathers' affective well-being (i.e. positive and negative

affect in separate models). The first multiple regression we ran included five predictor variables (i.e. knowledge of ASD symptoms, parental stress, social support, living situation, and caregiver status) and had positive affect as the outcome variable. This regression will be described first. We then used the same predictors in the multiple linear regression as described previously, but negative affect was our outcome variable. This regression will be described second.

We hypothesized that a combination of social support and parental stress would be the best predictors of fathers' affective well-being. We also hypothesized that variance in well-being would be predicted by social support and stress, regardless of caregiver status or living situation. In holding these two contextual variables constant, we further tested our two hypotheses related to our controls. By controlling for living situation, we hoped to determine whether social support was associated with affective well-being, regardless of the current cohabitation status of the father. In addition, we hypothesized that fathers who are married/cohabitating with someone would be likely to consider their partner as a social support and would have increased affective well-being (greater positive affect and decreased negative affect).

Additionally, we chose to control for the factor of whether the father was the primary caregiver, or the adult who spends the most time with the child. We hypothesized that fathers who are the primary caregiver would have greater knowledge of ASD symptoms, as they are more commonly caregiving for their child.

### ***Positive Affect***

Counter to our hypotheses, the results indicated that our model was not a significant predictor of positive affect,  $F(5, 46) = 2.286, p = .061$ . Our predictions were that higher social support would be associated with greater affective well-being. As shown in Table 4, none of the independent variables were statistically significant.

**Table 4***Regression Analysis of Predictor Variables and Positive Affect*

| Variable                  | <i>B</i> | <i>SE</i> | $\beta$ | <i>t</i> | <i>p</i> |
|---------------------------|----------|-----------|---------|----------|----------|
| Constant                  | 3.58     | 9.45      |         | .38      | .706     |
| Parental Stress           | .10      | .09       | .17     | 1.12     | .275     |
| Social Support            | .09      | .07       | .19     | 1.27     | .210     |
| Knowledge of ASD Symptoms | .10      | .11       | .13     | .93      | .357     |
| Living Situation          | 2.32     | 2.46      | .14     | .94      | .351     |
| Caregiver Status          | -1.43    | 2.13      | -.10    | -.67     | .507     |
| $R^2 = .11$               |          |           |         |          |          |

*Negative Affect*

The results indicated that the model was a significant predictor of negative affect,  $F(5, 46) = 9.51, p = .000$ . Overall, our five variables accounted for 46% of the variance in total negative affect. The strongest predictor of affective well-being was parental stress. As can be seen in Table 5, this variable was negatively associated with negative affect and was the strongest of all in the model,  $B(SE) = -.37(.08), p \leq .001$ . We hypothesized that parental stress and social support would be most important to a father's affective well-being. In contrast to results in Table 3 with bivariate correlations, perceived social support was no longer significantly related to negative affect when adjusting for other variables in the model. Similar to what was presented in Table 3, knowledge of ASD symptoms was not a significant predictor of affect when controlling for other variables in the model.

**Table 5***Regression Analysis of Predictor Variables and Negative Affect*

| Variable        | <i>B</i> | <i>SE</i> | $\beta$ | <i>t</i> | <i>p</i> |
|-----------------|----------|-----------|---------|----------|----------|
| Constant        | 49.87    | 8.29      |         | 6.01     | .000     |
| Parental Stress | -.37     | .08       | -.54    | -4.52    | .000     |
| Social Support  | -.12     | .06       | -.23    | -1.97    | .055     |

| Variable                     | <i>B</i> | <i>SE</i> | $\beta$ | <i>t</i> | <i>p</i> |
|------------------------------|----------|-----------|---------|----------|----------|
| Knowledge of<br>ASD Symptoms | -.06     | .10       | -.07    | -.59     | .555     |
| Living Situation             | -1.45    | 2.16      | -.08    | -.67     | .504     |
| Caregiver Status             | .27      | 1.87      | .02     | .14      | .887     |
| $R^2 = .46$                  |          |           |         |          |          |

## Discussion

The aim of this study was to contribute to the understanding of families of children with ASD by focusing on the experiences of fathers. Specifically, the authors used concepts from the ABC-X model to determine whether factors that are associated with maternal well-being are relevant to fathers' well-being. The authors extended the work of Suzuki and colleagues (2015) and applied these findings within the ABC-X model.

As demonstrated in Family Stress Theory, when a family has the appropriate resources (such as knowledge of symptoms and social support), they perceive the event as more in their control and thus are less likely to fall into crisis (McCubbin & Patterson, 1983; Smith & Hamon, 2012). This feeling of control promotes management of the stressor, and likely, psychological well-being and positive coping (Smith & Hamon, 2012). Well-being was used as a proxy for the X variable of crisis. We defined crisis as lower levels of well-being, and thus, individuals who are in crisis are not meeting the ideal balance of positive and negative affect, and they are likely experiencing more negative affect. The authors acknowledge that many other things, such as the economy, the pandemic, among other things can attribute to an individual's overall feeling of well-being, though they may or may not be directly associated with well-being.

When looking at the data, we can see that it may follow a general pattern similar to the ABC-X Model. Specifically, it is clear that fathers in this specific survey population are experiencing parental stress, or letter A, the stressor. Additionally, parental stress is associated with both positive and negative affect, indicating that the stressor does have an association with a fathers' overall outcome, or affective well-being. Furthermore, while the resource of social support is important to the stressor, as well as outcome (Negative Affect), knowledge is not

associated with the stressor or outcome, indicating that when experiencing the stressor of parenting a child with ASD, social support is important to reaching crisis or not, but knowledge of ASD symptoms may not be. These findings align with previous research indicating social support is one of the most important resources individuals can access (Smith & Hamon, 2012). In speculating why we had these results, it may be that social support is important to both resources (B) and coping (C), making it more important than knowledge, which is just a resource (B). Conversely, it may be that knowledge of ASD resources is an important resource, but only if it is able to be a tangible resource, allowing fathers to use it as a daily resource and potential coping strategy. Knowledge is potentially not useful unless it can be applied to their child.

It may be assumed that parents with higher negative affect are not coping as well and using their resources to their advantage. Perhaps, those are the fathers facing greater parental stress and greater negative affect, and the ones who have been unable to manage the situation as well (Hill, 1949; McCubbin & Patterson, 1983). Though these fathers may be experiencing greater negative affect, indicating the potential for crisis, there is also a possibility that they may have learned to function with the stressor in their life (Smith & Hamon, 2012). While no conclusions can be drawn, it does seem as though this model was appropriate in guiding our research in meaningful ways.

### **Knowledge of ASD Symptoms**

In opposition to the study's hypotheses, parental knowledge of ASD symptoms was not significantly correlated with social support, parental stress, or affective well-being. Several ideas come to mind when reviewing these results. First, the measure of choice for ASD knowledge, The Autism Survey, was a survey based on more global traits of ASD and was more generalized knowledge. Perhaps, given an assessment that measures their own child's ASD symptoms,

fathers may identify knowledge of these symptoms as more important to their well-being. This may be because the knowledge they have of their child is more applicable to them, potentially alleviating more stress than knowledge about ASD in general. Knowledge of ASD symptoms may not be a resource unless it is able to be used in day-to-day life.

Additionally, many (57.7%) of the fathers in this study were not the primary caregiver for their child. This makes sense, as past studies have referred to fathers as the primary playmate for their child, much like the mother is commonly the primary caregiver (Roggman et al., 2004; John et al., 2013). Regardless, being the primary caregiver may mean more knowledge of symptoms, treatment, options for support, among other things. Conversely, for fathers who do spend more time actively caregiving for their child and are aware of their own child's symptoms, knowledge of the symptoms may be of particular importance. This is an area for future research and will be discussed below.

Furthermore, this study's findings differ from Suzuki and colleagues' (2015) findings. These authors found when both knowledge of the child's characteristics and positive perceptions of parenting were high, psychological distress was low, but when perceived social supports were low, psychological distress demonstrated an increase. This study's findings indicate knowledge of a child's characteristics were not associated with overall affective well-being. Again, this may be because The Autism Survey measure more global traits of ASD, versus the child's specific traits. Another possibility is because our sample focuses on fathers who were not commonly caregivers, they may have differing experiences from mothers who are more commonly the primary caregiver. Perhaps this trait of the individual is important to determining one's well-being.

## **Parental Stress and Social Support**

Parental stress was found to be the greatest predictor of negative affect for fathers in this survey. These findings are not surprising, as an individual experiencing stress is likely to have a higher negative affect during this time. Parental stress was also strongly correlated with perceived social support, such that an increase in social support was correlated with an increase in parental stress, indicating that with greater social support present, fathers feel less stress. Past research by Frye (2016) posited that fathers were in need of money, teamwork, honesty, information, and time. Given the relationship we found, it implies fathers are also in need of social support. Perhaps this comes from a partner, friends, colleagues, or professionals helping with caretaking. Parental stress was also positively associated with positive affect and negatively associated with negative affect, suggesting stress is associated with affective well-being in general. We confirmed our hypotheses, finding when parental stress increases, positive affect significantly increases; similarly, as parental stress decreases, negative affect significantly increases. This indicates that when stress levels decrease, positive affect increases, but when stress levels increase, negative affect also increases.

We also confirmed our hypothesis that perceived social support would be associated with negative affect, finding a small to medium negative association between social support and negative affect. As perceived social support increases, negative affect significantly decreases. This may imply that although more stress means greater negative affect, perceived social support may help to alleviate some of the stress, also helping to reduce negative affect. However, given the correlational nature of the data, no conclusions can be drawn.



## **Positive and Negative Affect**

Overall, the study's model for predicting affective well-being was stronger for negative affect than for positive affect. While no significant results were found for positive affect, parental stress accounted for the greatest variance in negative affect. Additionally, contrary to the study's hypotheses and bivariate correlations, social support did not significantly predict negative affect. This is also contrary to results reported by Suzuki and colleagues (2015), in which they found low social support was associated with an increase in psychological distress. Interestingly, the two covariates in this study, living situation and caregiver status, also did not account for much variance in the model. It may be that these are important considerations in our model, but not when accounting for other variables in the model.

The regression model may not have been robust for predicting positive affect as it was at predicting negative affect because there are other aspects that are better at predicting positive affect. For example, Pressman and colleagues (2009) found individuals who engaged in frequent enjoyable leisure activities were found to have better psychological and physical functioning, as well as greater levels of reported positive affect, life satisfaction, and social support. These individuals also reported lower negative affect and depression (Pressman et al., 2009). This implies that activities such as hobbies could be better predictors of positive affect. In fact, engaging in many types of leisure activities can also play a role in buffering the negative psychological impact of stress (Pressman et al., 2009). Fathers who have something enjoyable to look forward to, an activity to share with their child, or at an age where they have more free time on their hands, may be better able to experience more positive affect.

Another possibility is that fathers were experiencing negative sentiment override. Negative sentiment override occurs when there is a high ratio of negative to positive affect and

interactions that an individual has are interpreted as increasingly negative (Gottman & Silver, 1999). Given that data was collected by fathers who were experiencing high levels of stress, it may be that all activities feel stressful, or negative. The data suggest that for this group of fathers, negative affect is most strongly associated with parental stress, rather than knowledge of ASD symptoms or social support. Additionally, data was collected during the COVID-19 pandemic. This has the potential to leave fathers feeling even more stressed, perhaps helping to explain why our model predicted negative affect better than positive affect.

## **Limitations**

Although this survey research was ideal for remote data collection and allowed the authors to capture multiple factors of data at once, there were limitations to this study. First, the generalizability was low in this initial inquiry. The authors were able to conduct convenience sampling in the metro-Denver area, which meant participants were predominantly white and highly educated. Due to this being a Masters thesis, there was no funding, so considerable efforts to make the population more generalizable were not made. Second, the sample size was relatively small, limiting the generalizability. Conclusions made for this population of fathers cannot be extended to fathers all around the country, as there could be several additional variables that are important to affective well-being. Given the short amount of time to complete the study, we were unable to collect data on more participants. Our sample was smaller than we had hoped it would be, so we may not have had the power to detect some associations. Third, the sample did not have as many primary caregivers as desired. Many (31.00%) of the fathers had a child who was 18 or older. Although their child may still need caregiving, depending on their symptoms, this child may need less caring than a young child. Additionally, a father who has been caregiving for 25 years is going to have differing experiences from one who has been caregiving for three years. These varying experiences may alter the way in which the data is viewed, as this study compared individuals with potentially large differences in experiences. Fourth, it is important to note that given the correlational nature of our data, the authors cannot make conclusions in regard to effect, and instead can simply observe associations. This inability to infer causation leaves potential for data to be inferred in different ways, as directions are not fully known. Finally, the survey reached individuals through Listservs in which the authors were

unable to target fathers who specifically had a child with ASD. Instead, the survey was sent to parents of children with varying developmental disabilities. Thus, fathers had to come across the email themselves and then have access to the internet in order to take our survey. Furthermore, the study likely had some sampling bias, which ultimately affects our external validity, because the authors were not be able to reach people who did not have access to email or internet.

## **Future Directions**

In the future, the authors hope to extend this work and complete a study with a more diverse population with a larger sample size. With funding and additional time, a study that targets specific demographic groups can be conducted, hopefully making the sample more generalizable. The authors would also like to be able to include a Spanish version of this survey. Additionally, we are interested in learning more about fathers who are the primary caregiver. Though this study did include both biological and non-biological fathers, extending the study to include more fathers who are biological fathers, stepfathers, adoptive fathers, and foster fathers may reveal patterns in which fathers who are not biologically related to the child have a similar or differing experience to biological fathers. Furthermore, a future study could incorporate live observations, rather than survey research, in order to hopefully decrease the potential for biases such as sampling bias and social desirability bias.

The findings of this study in relation to the ABC-X model may be of particular importance for clinicians, helping to guide future therapeutic interventions. Clinicians could assess for factors that fathers do have (i.e. stressor (A), social support (B), but no coping (C)) and then determine how they can intervene to help with overall affective well-being (X). For example, given that social support is important to fathers' affective well-being, but knowledge of ASD symptoms appears less important, behavioral clinicians may find that taking the time to connect with a father before educating them on interventions or otherwise may be beneficial in communicating social support and reminding fathers they are not in this experience alone. Mental health clinicians may find it significant to take into account whether a father has someone whom he can lean on at home, such as a spouse. For those who do not, specific interventions

targeting validation of stress, need for social support, and understanding of the challenge may be useful. A group therapy for fathers in which they can discuss symptoms, behavioral reactions, and overall stress may be beneficial. Given the chance to learn about ASD symptoms and obtain social support at the same time may be an important clinical implication for fathers. In hosting a group session where fathers feel supported, knowledgeable, and safe, they may experience improved affective well-being. Furthermore, given that this study was robust at predicting negative affect, clinicians may need to inquire more about what it is that affects an individual's positive affect. What factors is it that counteract the negative affect in an individual, lowering the negative affect and increasing the positive affect? In learning these factors, clinicians may be able to provide comprehensive and individualized therapy that works at balancing fathers' overall affective well-being.

## **Conclusion**

For parents of a child with Autism Spectrum Disorder, it is likely they will experience challenges and stressors greater than the average parent (Hayes & Watson, 2013). With the potential added stressors of social isolation, unpredictability of behavior, and negative social reactions by outsiders (Bayat & Schuntermann, 2013), it is possible these parents are in need of strategies or interventions for promoting affective well-being. While there is evidence that mothers of a child with ASD are overly stressed, there is a striking lack of evidence of fathers' experiences (Braunstein et al., 2013). This study illuminated that fathers are also experiencing high levels of stress and it is tied to their affective well-being. Through our findings and within the context of the ABC-X model, it is clear that these fathers are experiencing high stress, and social support appears to be an important resource. Given that these factors are malleable, and an individual can work to improve their social support, stress levels, or knowledge of ASD symptoms, this study's findings could have important implications for improving clinical interventions and parental adjustment, potentially helping to relieve stress for this specific population of fathers.

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## Appendix A

### The Demographics Questionnaire

1. I am reporting for:
  - a. Myself
  - b. Someone else (i.e. spouse)
2. Which category below includes your age?
  - a. 18-25
  - b. 26-35
  - c. 36-45
  - d. 46-55
  - e. 56-65
  - f. 66-75
  - g. 75 or more
3. With which racial and ethnic group(s) do you identify? *(Mark all that apply)*
  - a. American Indian or Alaska native
  - b. Hispanic, Latino, or Spanish origin
  - c. White
  - d. Asian
  - e. Middle eastern or North African
  - f. Black or African American
  - g. Native Hawaiian or other Pacific Islander
  - h. Another race or ethnicity not listed above \_\_\_\_\_
4. If you chose 'another race or ethnicity not listed above' please answer here:
5. What is your highest level of education?
  - a. Less than a high school diploma
  - b. High school diploma/GED
  - c. Some college or associate/trade degree
  - d. Bachelor's degree
  - e. Master's degree or higher
6. I am the biological father of a child with ASD:
  - a. Yes
  - b. No
7. The relationship to the biological mother of my child can be best described as:
  - a. Currently married
  - b. Divorced/Separated
  - c. Living Together, but not married
  - d. Mother has passed away



8. What is the current custody status of your child?
- a. Joint custody
  - b. Sole custody
  - c. Other
9. If you chose 'other' please respond here:
10. Please select which applies to you best. I am currently \_\_\_\_\_.  
a. Employed  
b. Working part-time  
c. Unemployed

About your Son/Daughter:

11. How many children do you have? \_\_\_\_\_
12. How many children are diagnosed with Autism? \_\_\_\_\_
13. Check all that apply:
- a. I have a son with autism
  - b. I have a daughter with autism
14. How do you and your child communicate?
- a. My child is still learning how to communicate
  - b. Pictures or augmentative communication
  - c. Sign language and gestures
  - d. My child speaks in single words or simple sentences
  - e. My child speaks in full sentences
15. How old is your child with autism?
- a. 0 – 3
  - b. 3 – 7
  - c. 7 – 12
  - d. 13 – 17
  - e. 18+
16. Are you the primary caregiver (with the child the most out of any adult)?
- a. Yes
  - b. No

## Appendix B

### The Autism Survey

Stone (1987) adapted by Christian Sarkine Autism Treatment Center, HANDS in Autism Team, 2005.

1. Autism is an emotional disorder

| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| 1           | 2            | 3              | 4                 | 5               | 6              |

2. Early intervention can lead to significant gains in children's social and communication skills.

| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| 1           | 2            | 3              | 4                 | 5               | 6              |

3. All children with autism display poor eye contact.

| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| 1           | 2            | 3              | 4                 | 5               | 6              |

4. Children with autism typically perform better when tasks are presented visually than when tasks are presented verbally.

| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| 1           | 2            | 3              | 4                 | 5               | 6              |

5. Problems with social relatedness that are present in autism are different from social problems seen in other psychiatric conditions.

| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| 1           | 2            | 3              | 4                 | 5               | 6              |

6. Autism is more frequently diagnosed in males than in females.

| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| 1           | 2            | 3              | 4                 | 5               | 6              |

7. Children with autism do not show attachments, even to parents/caregivers.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

8. Research indicates that sensory integration therapy is an effective treatment for autism and its symptoms.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

9. Children with autism are deliberately uncooperative.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

10. Most parents/caregivers of children with autism report their first concerns were related to the child's social behavior.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

11. Autism tends to run in families.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

12. We now have treatments than can cure autism.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

13. Children with autism can grow up to live independently.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

14. There is one approach/program that works for all children with autism.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
|-------------|--------------|----------------|-------------------|-----------------|----------------|

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|

15. It is important that all children diagnosed with autism receive some form of special education services at school.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

16. Autism occurs more commonly among higher socioeconomic and educational levels.

17. Autism can be diagnosed as early as 18 months.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

18. With the proper treatment, most children with autism eventually outgrow the disorder.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

19. Children with autism do not show affection.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

20. The need for routines and sameness is one of the earliest behavioral features of autism.

|             |              |                |                   |                 |                |
|-------------|--------------|----------------|-------------------|-----------------|----------------|
| Fully Agree | Mostly Agree | Somewhat Agree | Somewhat Disagree | Mostly Disagree | Fully Disagree |
| 1           | 2            | 3              | 4                 | 5               | 6              |

## Appendix C

### Multidimensional Scale of Perceived Social Support

1. There is a special person who is around when I am in need.

| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

2. There is a special person with whom I can share joys and sorrows.

| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

3. My family really tries to help me.

| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

4. I get the emotional help and support I need from my family.

| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

5. I have a special person who is a real source of comfort to me.

| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

6. My friends really try to help me.

| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

7. I can count on my friends when things go wrong.

| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

8. I can talk about my problems with my family.

|                           |                      |                    |         |                 |                   |                        |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

9. I have friends with whom I can share my joys and sorrows.

|                           |                      |                    |         |                 |                   |                        |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

10. There is a special person in my life who cares about my feelings.

|                           |                      |                    |         |                 |                   |                        |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

11. My family is willing to help me make decisions.

|                           |                      |                    |         |                 |                   |                        |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

12. I can talk about my problems with my friends.

|                           |                      |                    |         |                 |                   |                        |
|---------------------------|----------------------|--------------------|---------|-----------------|-------------------|------------------------|
| Very Strongly<br>Disagree | Strongly<br>Disagree | Mildly<br>Disagree | Neutral | Mildly<br>Agree | Strongly<br>Agree | Very Strongly<br>Agree |
| 1                         | 2                    | 3                  | 4       | 5               | 6                 | 7                      |

## Appendix D

### Autism Parenting Stress Index

1. Your child's social development.

|               |                          |                      |                                 |  |
|---------------|--------------------------|----------------------|---------------------------------|--|
| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
| 1             | 2                        | 3                    | 4                               | 5  |

2. Your child's ability to communicate.

|               |                          |                      |                                 |  |
|---------------|--------------------------|----------------------|---------------------------------|--|
| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
| 1             | 2                        | 3                    | 4                               | 5  |

3. Tantrums/meltdowns.

|               |                          |                      |                                 |  |
|---------------|--------------------------|----------------------|---------------------------------|--|
| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
| 1             | 2                        | 3                    | 4                               | 5  |

4. Aggressive behavior (siblings, peers)

|               |                          |                      |                                 |  |
|---------------|--------------------------|----------------------|---------------------------------|--|
| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
| 1             | 2                        | 3                    | 4                               | 5  |

5. Self-injurious behavior.

|               |                          |                      |                                 |  |
|---------------|--------------------------|----------------------|---------------------------------|--|
| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
| 1             | 2                        | 3                    | 4                               | 5  |

6. Difficulty making transitions from one activity to another.

|               |                          |                      |                                 |  |
|---------------|--------------------------|----------------------|---------------------------------|--|
| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
| 1             | 2                        | 3                    | 4                               | 5  |

7. Sleep problems.

|               |                          |                      |                                 |  |
|---------------|--------------------------|----------------------|---------------------------------|--|
| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
| 1             | 2                        | 3                    | 4                               | 5  |

8. Your child's diet.

| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
|---------------|--------------------------|----------------------|---------------------------------|--|
| 1             | 2                        | 3                    | 4                               | 5  |

9. Bowel problems (diarrhea, constipation).

| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
|---------------|--------------------------|----------------------|---------------------------------|--|
| 1             | 2                        | 3                    | 4                               | 5  |

10. Potty training.

| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
|---------------|--------------------------|----------------------|---------------------------------|--|
| 1             | 2                        | 3                    | 4                               | 5  |

11. Not feeling close to your child.

| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
|---------------|--------------------------|----------------------|---------------------------------|--|
| 1             | 2                        | 3                    | 4                               | 5  |

12. Concern for the future of your child being accepted by others.

| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
|---------------|--------------------------|----------------------|---------------------------------|--|
| 1             | 2                        | 3                    | 4                               | 5  |

13. Concern for the future of your child living independently.

| Not stressful | Sometimes creates stress | Often creates stress | Very stressful on a daily basis | So stressful sometimes we feel we can't cope |
|---------------|--------------------------|----------------------|---------------------------------|--|
| 1             | 2                        | 3                    | 4                               | 5  |



## Appendix E

### Positive and Negative Affect Schedule

This survey consists of a number of words that describe different feelings and emotions. Read each item and then circle the appropriate answer next to that word. Indicate to what extent you are experiencing these feelings and emotions DURING THE PAST WEEK.

|                   | Not at<br>All |   |   |   |   |   | Extremely |
|-------------------|---------------|---|---|---|---|---|-----------|
| 1. Anger          | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 2. Pride          | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 3. Sadness        | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 4. Fear           | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 5. Calm           | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 6. Anxiety        | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 7. Joy            | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 8. Contentment    | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 9. Frustration    | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 10. Relaxed       | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 11. Embarrassment | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 12. Boredom       | 1             | 2 | 3 | 4 | 5 | 6 | 7         |
| 13. Excitement    | 1             | 2 | 3 | 4 | 5 | 6 | 7         |