Evaluating Level of Crisis in Caregivers of Children with Intellectual and Developmental Disabilities

THESIS

Presented in Partial Fulfillment of the Requirements for the Degree Master of Arts in the Graduate School of The Ohio State University

By

Tara L. Benninger, B.S.
Graduate Program in Psychology

The Ohio State University
2015

Master's Examination Committee:
Andrea Witwer, Advisor
Luc Lecavalier
Susan Havercamp
Abstract

Parents caring for a child with an intellectual or developmental disability experience significant stress and potential crises, which can contribute to poorer outcomes for the whole family. While previous research has examined parental stress, the experiences of parents with a child in crisis are poorly understood. This study’s objective was to begin to clarify a family’s experience of crisis as well as examine psychometric properties of a measure designed to assess crisis.

Parents and caregivers of children and adolescents, age 5 to 17 and diagnosed with an Intellectual or Developmental Disability including Autism Spectrum Disorder completed all measures, reporting on their level of caregiver strain within the past 30 days on the Caregiver Strain Questionnaire (CGSQ) and their current level of crisis on the Brief Family Distress Scale (BFDS).

Psychometric data from the BFDS and CGSQ were analyzed to examine aspects of reliability and validity. Additionally, exploratory analyses examined the relationship between demographic characteristics, strain and crisis level. A total of 55 parents/caregivers completed study materials; 52 met eligibility criteria and had usable data on all measures. On average, children were 13.7 years old, and 73.1% were male; 73.1% were the children’s mothers.
Results from analyses indicated a strong positive relationship between the CGSQ and BFDS \( r(52) = .67, p=.000 \) as well as excellent overall internal consistency within the CGSQ (\( \alpha = .95 \)). Additionally, the BFDS was able to detect differences between inpatient and outpatient conditions \( t (50) = 2.905, p=.005 \), as well as previously established crisis groups validly categorizing participants through scores on the CGSQ \( F(2, 49) = 16.04, p=.000 \). Finally, exploratory analyses suggested no differences in stress or crisis level between parents of children with ASD compared to those without ASD, as well as a positive relationship between crisis level and number of comorbidities.

This study was able to further validate a brief measure of crisis with the intent of demonstrating potential clinical utility. This study also helps clarify the experience of parents of children with I/DD in times of crisis and may assist in guiding parent resources and family intervention strategies. Limitations are discussed and include unequal sample sizes between inpatient and outpatient participants. Due to excessive burden, a measure of problem behavior was not included in this study but should be examined in future studies. Future research should examine the utility of the BFDS as a measure of change as well as in control clinical populations.
Dedicated to my parents, William and Patricia Benninger, who have supported me unconditionally in everything I do.
Acknowledgments

I would first and foremost like to thank my advisor, Dr. Witwer, for her ongoing support, encouragement, advice, feedback and willingness to review numerous drafts of this project. I would also like to thank my committee members, Dr. Lecavalier and Dr. Havercamp, for their invaluable guidance suggestions and time.

I would like to thank faculty and staff within the Dual Diagnosis Clinic, specifically Dr. Hellings and Kayla Cardenas; the Child Behavior Supports Specialists, and the Social Workers and staff within the Child Inpatient Unit at Harding Hospital. They provided great assistance through allowing me to recruit their patients and through distribution of study information to potential participants. This study would not have been possible without them. I would also like to thank the caregivers and families who took the time out of their busy lives to complete the study materials.

This project was supported in part by the Nisonger Center Research Fund, for which I am quite grateful. Lastly, I would like to thank my family and friends for their constant encouragement and unwavering love and support.
Vita

March 1991 .................................................................Born, Columbus, OH

May 2013 .................................................................B.S. Psychology, *cum laude*, with honors in the Arts and Sciences, with honors Research Distinction in Psychology, The Ohio State University

September 2013-- August 2014 .......................University Fellow, The Ohio State University

August 2014-Present ..............................................Graduate Teaching Associate, Department of Psychology, The Ohio State University

Fields of Study

Major Field: Psychology

Specializations: Intellectual and Developmental Disabilities; Quantitative Psychology

Concentration
Table of Contents

Abstract ........................................................................................................................................ ii

Dedication ...................................................................................................................................... iv

Acknowledgments .......................................................................................................................... v

Vita ................................................................................................................................................ vi

Table of Contents ............................................................................................................................ vii

List of Tables .................................................................................................................................... ix

List of Figures .................................................................................................................................... x

List of Abbreviations ....................................................................................................................... xi

Chapter 1: Introduction .................................................................................................................. 1

Chapter 2: Methods ....................................................................................................................... 23

Chapter 3: Results ......................................................................................................................... 31

Chapter 4: Discussion .................................................................................................................... 44

References ....................................................................................................................................... 54

Appendix A: Demographics Form .................................................................................................. 65

Appendix B: Brief Family Distress Scale (BFDS) ................................................................. 68
Appendix C: Caregiver Strain Questionnaire (CGSQ) ................................................................. 70
Appendix D: Cover Letter for Participants .................................................................................. 73
Appendix E: Consent Form for Inpatient Participants ................................................................. 76
Appendix F: Additional Data to Collect from Medical Records .................................................. 81
Appendix G: Incentive Form ......................................................................................................... 83
List of Tables

Table 1: Parent Reported Demographic Information, Child Characteristics .......................... 34
Table 2: Parent Reported Demographic Information, Respondent ........................................... 35
Table 3: Average Scores on the CGSQ and BFDS ...................................................................... 38
Table 4: Correlations among CGSQ subscales and BFDS scores ................................................ 38
Table 5: One-way ANOVA comparing crisis group means ......................................................... 40
Table 6: Levels of Strain and Crisis for ASD and no-ASD ......................................................... 42
Table 7: Pearson Product Moment Correlations between BFDS and demographic variables .......................................................... 43
List of Figures

Figure 1: Histogram showing the frequency distribution of scores on the BFDS between inpatient and outpatient settings........................................................................................................ 37
List of Abbreviations

ADHD...........................................Attention Deficit Hyperactivity Disorder
ASD.......................................................Autism Spectrum Disorder
BFDS....................................................Brief Family Distress Scale
BSI.......................................................Brief Symptom Inventory
CGSQ...................................................Caregiver Strain Questionnaire
D/CHC..................................................disabilities or chronic health conditions
DD.......................................................developmental disability
ED.......................................................Emergency Department
ID.......................................................Intellectual Disability
I/DD.....................................................Intellectual and Developmental Disability
LES.....................................................Life Expectancy Survey
OCD.....................................................Obsessive Compulsive Disorder
PSI......................................................Parental Stress Index
PSI/SF..................................................Parental Stress Index-Short Form
PSS......................................................Perceived Stress Scale
QRS.....................................................Questionnaire on Resources and Stress
SES……………………………………………………………..Socio-economic status
Chapter 1: Introduction

Parents caring for a child with an Intellectual or Developmental Disability (I/DD) are under significantly more stress than parents of typically developing children. Valid measures exist to assess levels of parental stress and contributing factors (Abidin, 1995; Brannan, Heflinger, & Bickman, 1997; Cohen, Kamarck & Mermelstein, 1983). However, few measures exist that examine the construct of parents in crisis. This is of note because those with I/DD and their families are at increased risk to experience crises related to physical and mental health factors. Validating a measure of crisis is necessary to accurately assess a parent’s experience in order to enhance communication with clinicians as well as further research in this area. This is the primary focus of the current study in addition to exploring the nature of crisis within families including a child with an intellectual or developmental disability.

Children with an Intellectual or Developmental Disability

A significant number of children in the United States are reported to have an intellectual or developmental disability. Specifically, 15% of children aged 3 to 17 years, or nearly 10 million children from 2006-2008 were reported to have some type of developmental disability. This includes children with Autism Spectrum Disorder (ASD), Cerebral Palsy, Intellectual Disability, and developmental delays among others (Boyle et
al., 2011). Children with these types of disabilities are at increased risk for health problems, psychopathology, and problem behaviors. Parents of children with an intellectual disability (ID) are more likely to report their child has poorer health than parents of a child without ID (Emerson & Hatton, 2007; Krahn, Hammond & Turner, 2006; Ouellette-Kuntz et al., 2005). Children with an ASD also have higher rates of respiratory, food and skin allergies and are more likely to receive physical therapy, occupational therapy or speech therapy compared with children in general (Gurney, Mcpheeters & Davis, 2006). As a result, children with Autism Spectrum Disorder use, on average, more health services including physician and hospital use compared with children in general (Croen et al., 2006; Gurney, Mcpheeters & Davis, 2006; Liptak, Stuart, & Auinger, 2006).

In addition to increased health problems, children with an intellectual or developmental disability are at higher risk for psychiatric disorders compared with their non-I/DD peers (Dykens, 2000). They have significantly higher reported rates of depression and anxiety as well as increased risk of developing behavioral and emotional problems (Gurney, Mcpheeters & Davis, 2006; Lach et al., 2009). Common examples of externalizing problem behavior include aggression, tantrums, non-compliance and hyperactivity (Keller & Fox, 2009). Numerous studies have shown children with developmental disabilities or delays are three to four times more likely to display clinically significant levels of problem behavior than children without delays (Baker, Blacher, Crnic & Edelbrock, 2002; Emerson, 2003; Tonge & Einfeld, 2000;).
This increased risk of health problems, psychopathology and problem behaviors in children and adolescents with I/DD, results in increasing parenting demands compared to a typically developing child. Lecavalier, Leone and Wiltz (2006) found a transactional relationship exists between problem behaviors and parental stress. Parent report of stress levels and child behavior problems were found to exacerbate one another over time. Given these increased parenting demands combined with the significant number of children diagnosed with I/DD, it is important to examine the experience of their parents and caregivers.

_Parenting stress associated with caring for a child with an Intellectual or Developmental Disability_

As a result of the myriad of supports required by children with I/DD, it is no surprise that parents and caregivers of children with I/DD report higher levels of stress than parents of typically developing children. This finding has been well established over time and is supported by studies comparing parents of children with disabilities to those without disabilities in matched/comparative groups (Baker et al., 2003; Dyson, 1997; Eisenhower, Baker & Blacher, 2005; Emerson, 2003; Lecavalier, Leone & Wiltz, 2006; Neece, Green & Baker 2012). Families face many unique challenges associated with caring for a child with an intellectual or developmental disability that contribute to increased stress. These can include financial stress, restriction in social activities and psychological distress (Kogan et al., 2008; Lecavalier, Leone & Wiltz, 2006). Various parent and child factors can contribute to the severity of stress experienced by a caregiver such as gender of the parent reporting, social support and amount of child problem
behaviors (Baker et al., 2002; Hastings, 2002; Lecavalier, Leone & Wiltz, 2006; Orsmond, Seltzer, Krauss & Hong, 2003; Woodman, 2014).

**Parental factors impacting stress**

Studies have shown that level of parent education, amount of financial resources and social support all impact parental stress (Hauser-Cram et al., 2001; Minnes, Woodford & Passey, 2007). Additionally, mothers of children with I/DD are also affected to a greater extent than fathers. Hastings (2002) found that mothers’ stress levels were uniquely impacted by behavior problems of the child with a disability. Mothers’ depressive symptoms and perceived burdens of care are also impacted by having a child with a disability (Singer, 2006; Woodman, 2014). Duarte and colleagues (2005) isolated the challenge of caring for a child with I/DD as the main factor contributing to mothers’ presenting stress. Overall, the existing research indicated that aspects individual to each parent can impact their reported stress levels.

**Child Factors impacting parenting stress**

A variety of child factors also influence severity of parental stress such as child age, diagnosis and problem behaviors. For example, parenting stress was found to increase between early and middle childhood then decrease through adolescence in a study of children with developmental disabilities (Woodman, 2014). Most early research focused on differences in diagnosis and severity of disability as potential drivers of parental stress (Frey, Greenberg & Fewell, 1989; Minnes, 1988; Woodman, 2014). Some evidence suggests parents of children with an Autism Spectrum Disorder experience more stress than parents of children with other disabilities (e.g., Down syndrome;
Dabrowska & Pisula, 2010; Griffith, Hastings, Nash & Hill, 2010; Sanders & Morgan, 1997); recently this discrepancy between diagnoses has been more accurately explained by the amount of problem behavior (Blacher & McIntyre, 2006; Dunn, Burbine, Bowers & Tantleff-Dunn, 2001; Eisenhower, Baker & Blacher, 2005; Estes, Munson, Dawson & Koehler, 2009; Koegel et al., 1992; Moes, Koegel, Schreibman & Loos, 1992; Osborne & Reed, 2009). Child behavior problems can consist of both internalizing and externalizing issues. Internalizing problem behaviors include sadness, anxiety, fearfulness and social withdrawal. Examples of externalizing problem behaviors include hyperactivity, poor impulse control, noncompliance, tantrums, self-injury and aggression (Keller and Fox, 2009; Woodman, 2014). Overall, problem behaviors have proven the most important predictor of parental stress in children with an intellectual or developmental disability (Baker et al., 2002; Lecavalier, Leone & Wiltz, 2006; Orsmond et al., 2003). Research has indicated problem behaviors as more predictive of lower psychological well-being and higher stress than severity of child’s intellectual functioning or severity of disability. (Abbeduto et al., 2004; Hastings, 2002; Hastings et al., 2005; Woodman, 2014). In addition to problem behavior, lower child adaptive behavior and communication skills have both been associated with higher stress among parents (Hanson & Hanline, 1990).

Interestingly, although child problem behaviors are related to higher levels of parent stress, a study of children with Smith-Magenis Syndrome and their parents examined the relationship between family functioning, parental stress and child behavior problems. Authors found that maladaptive behaviors predicted higher levels of parental stress, but higher levels of general family functioning moderated this effect. These
findings suggest overall more positive family functioning may protect parents from some of the negative effects of stress. (Morse, Rojahn & Smith, 2014). This warrants the continued study of parent stress and family functioning in order to improve outcomes and direct interventions as first-step in a family-oriented treatment plan.

Impact of parental stress on the child and family

Evidence for a transactional model supports the idea that high-parenting stress can contribute to a worsening in problem behavior; as well as higher levels of problem behavior contributing to more parental stress (Baker et al., 2003; Lecavalier, Leone & Wiltz, 2006). This model is further supported by a recently published longitudinal study of the transactional nature of relationships between mothers and their children with an intellectual or developmental disability. Results indicated the presence of a bidirectional reciprocal relationship of internalizing behaviors in early childhood which moves to a child-driven model of parenting stress in middle childhood. Authors also examined children from mid-late adolescence and found a parent-driven model; suggesting after middle childhood parent stress levels drive child internalizing behaviors. In contrast, within externalizing behaviors in early and middle childhood, researchers found a primarily child-driven model suggesting child externalizing behaviors predicted later higher parent stress levels. Similar to internalizing models, from mid-late adolescence results indicated a primarily parent driven model. Research examining children across the lifespan allowed for observation of specific effects when separating externalizing and internalizing behavior. This additionally allows for examination of these relationships across different life phases (Woodman, Mawdsley & Hauser-Cram 2015). As parental
stress increases over time, additional considerations are necessary to ensure family well-being. Within any proposed model of parental stress and family functioning, high levels of parental stress can have a negative, lasting impact on the child and family.

Parental stress is associated with numerous undesirable outcomes. High amounts of parental stress contribute to a decrease in psychological well-being for both children and parents. It has been established that caring for a child with I/DD is associated with increased risk for depression and poorer physical health (Gallagher & Whiteley, 2013; Singer, 2006). This includes a higher risk for diabetes, greater reported specific debilitating health problems (back problems; arthritis) and often reported lower general health (Allik, Larsson, & Smedje, 2006; Hedov, Anneren, & Wikblad 2000; Pinquart and Sorensen, 2003). A meta-analysis of parents of children with disabilities or chronic health conditions (D/CHC) compared to parents of children without D/CHC found parents of children with D/CHC had higher levels of health problems as measured by the Parenting Stress Index (PSI) Health domain compared with parents of children without these conditions (Miodrag, Burke & Hodapp, 2015). Parents of children with I/DD are also more likely to report health problems related to sleep, headaches, gastrointestinal issues and upper respiratory infections compared to controls (i.e., parents of typically developing children) (Gallagher & Whiteley, 2013). In addition to the health of the parents, high levels of parental stress can contribute to adverse outcomes for the whole family. It has been associated with marital conflict, higher likelihood of divorce (Risdal and Singer, 2004) as well as less effective parenting.
Of additional concern is the finding that higher levels of parental stress often interact with and can lead to increased child behavior problems due to the transactional relationship mentioned above (Baker et al., 2003; Briggs-Gowan, Carter, Skuban & Horwitz, 2001; Donenberg & Baker, 1993; Johnston & Mash, 2001; Neece, Green & Baker, 2012). Families with children demonstrating high amounts of child behavior problems contribute to increased parental stress, which over time contributes to worsening in child behavior problems, promoting the cyclical nature of negative effects experienced by families. Finally, parenting stress is related to decreased family quality of life (Baker et al., 2003, Hastings, 2002, Lecavalier, Leone & Wiltz, 2006). Because parent stress has the potential to negatively impact the family, it is important to measure these stress levels among parents of children with I/DD.

**Measurement of Parental stress**

Measuring stress is not a simple task. Stress involves both the occurrence of events and the individual’s perception of these events (Innocenti, Huh, & Boyce, 1992). There are a variety of measures used to estimate levels of parenting stress. The measures differ based on the various conceptualizations of stress. Perry (2004) separated stress into four categories including a grieving model, stressful life events, daily hassles and resource imbalance. The “grieving model” is understood as physiological and psychological reactions an organism progresses through to adapt to a stressful situation. The “stressful life events” paradigm suggests a relationship between negative life events and mental/physical health problems. Examining parents’ daily frustrations as opposed to major life events is central to the “daily hassles” model. A final way to conceptualize
stress is the presence of a “resource imbalance” between demands and the persons’ resources and coping abilities. These distinctions mirror several existing measures of stress which often combine one or more of the above models (Abidin, 1995; Brannan, Heflinger, & Bickman, 1997; Cohen, Kamarck & Mermelstein, 1983). Existing scales differ on a number of variables including informant (e.g. self-report vs. clinician), measuring stress as a single-construct vs. multi-faceted, and examining a combination of subjective or objective stress. The Parenting Stress Index (PSI, Abidin 1995) is a common measure used to assess potential parent-child system dysfunction (Innocenti, Huh, & Boyce, 1992; Lecavalier, Leone & Wiltz, 2006; Woodman, 2014). The Brief Symptom Inventory is a measure of symptoms of psychological distress such as depression and anxiety (BSI; Derogatis & Melisaratos, 1983; Estes et al., 2009). The Perceived Stress Scale has also been used in caregiver research (including those with a child with a disability) to measure stressful experiences (PSS; Cohen, Kamarck, & Mermelstein, 1983; Gallagher & Whiteley, 2013; Phua, Reid, Walstabh & Reddinhough, 2005). The PSS is a 4-item scale that measures how stressful individuals perceive situations they have experienced to be over the last month. It has strong psychometric properties with good test-retest reliability ($r = .80$) and internal consistency reliability (Chronbach’s $\alpha = .75$) (Cohen et al., 1983). Gallagher & Whiteley (2013) used the PSS to measure psychological stress in caregivers for children with intellectual disability and found parents reported higher perceived stress than control parents. They also found that perceived stress, in addition to challenging behavior problems, was most predictive of poorer physical health in parents. Stress categorized by “stressful life events” has been
measured by the Negative Life Changes scale of the Life Expectancy Survey (LES; Sarason, Johnson, & Siegal, 1978; Estes et al., 2009). Past research has also measured stress by examining resource availability and coping skills. Estes et al., (2009) used the *Questionnaire on Resources and Stress* (QRS; Konstantareas, Homatidis, & Plowright, 1992) to assess stress and burden of care in families of children with disabilities. Researchers found that mothers of children with ASD showed higher parenting stress scores than mothers of children in the DD group. The QRS is a self-report questionnaire that measures stress and burden of care. The QRS has shown adequate psychometric properties including acceptable internal consistency (Chronbach’s $\alpha=.680$), construct validity, concurrent validity and discriminant validity. Gallagher & Whitley (2013) assessed social support with the 12-item *Support Functions Scale* (Dunst, Trivette & Deal, 1988) which asks parents to rate sources of support available to them. It has shown to have good internal consistency (Cronbach’s $\alpha=.86$). Examiners found parents of children with intellectual disability reported lower levels of social support than controls.

Another more recent measure of parent stress is the Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger, & Bickman, 1997). Originally designed for parents of children with severe emotional and behavioral disorders, the CGSQ captures both objective and subjective strain. It has been validated and widely used in parents of children with a serious emotional or behavior disorder (Blader, 2006; Brannan and Heflinger, 2001; Heflinger & Taylor-Richardson, 2004; Kang, Brannan & Heflinger, 2005; Sales & Greeno, 2004; Taylor-Richardson, Heflinger & Brown, 2006).
The CGSQ is a 21 item scale rated on a five-point scale ranging from 1 (not at all a problem) to 5 (very much a problem). During development, exploratory factor analysis was performed to identify underlying latent factors. Results indicated two subscales including one that measured objective caregiver strain while the other included subjective aspects of caregiver strain. Within the subjective scale two dimensions emerged including internalized strain and externalized strain. Internalized subjective strain captured feelings such as worrying about family, feeling sad etc., while externalized strain focused on negative feelings directed at the child. Subscale scores are calculated as means of items on each subscale as well as a global measure of caregiver strain being calculated from the CGSQ items. The scale as a whole, in addition to its’ subscales, demonstrated adequate internal consistency, measured by Cronbach’s alpha (.93 entire scale, .92 objective strain, .74 for externalized subjective strain and .86 for internalized subjective strain). Further support for its validity comes from correlations with related constructs. It was correctly hypothesized that the CGSQ would have a negative relationship with family functioning (FAD) and a positive relationship with the BSI (Brief Symptom Inventory) (Brannan, Heflinger, & Bickman, 1997). The CGSQ has also been used in caregivers of children with I/DD. The CGSQ has shown adequate reliability and validity in determining caregiver strain in Autism (Khanna et al., 2012; Stuart & McGrew, 2009). The CGSQ demonstrated high internal consistency (α=.94) in a sample of caregivers of children recently diagnosed (within the past 6 months) with an Autism Spectrum Disorder (Stuart & McGrew, 2009). Khanna and colleagues assessed the factorial validity, convergent validity, internal consistency reliability, and floor and ceiling effects of the CGSQ in a
population of caregivers of children with Autism. Using confirmatory factor analysis, this study confirmed from the original study that a three-factor structure was best fit for the CGSQ, within a population of children with ASD. The objective strain subscale was moderately correlated with subjective externalized strain (r=.49) and strongly correlated with subjective internalized strain (r=.77). Externalized and Internalized strain were also correlated (r=.56). Convergent validity based on the correlations with child’s Autism severity and extent of behavioral problems was adequate (.13-.45 for severity and .33-.58 for behavior problems). Kirby, White & Baranek (2015) recently demonstrated the utility of using the CGSQ within a population of parents of children with ASD. This study found that subjective internalized strain was reported at the highest rate, followed by objective strain, and finally subjective externalized strain. Additionally, parents of children with ASD reported significantly higher levels of subjective internalized strain and objective strain than parents of children with other DD diagnoses. Authors also explored sensory features in relation to caregiver strain and found that as hyper- or hypo-reactivity to sensory features increased, level of objective strain also increased in parents of children with ASD. Overall, the psychometric properties of the Caregiver Strain Questionnaire are adequate when used with caregivers of children with emotional and behavior problems as well as Autism Spectrum Disorder. It has not yet been validated in multiple clinical contexts within a sample of children with other various intellectual or developmental disabilities.

As noted above, many different tools have been developed to assess stress and to a lesser extent to specifically measure parental stress. Even fewer measures have been
utilized in populations of parents of children with I/DD. The wide variety of measurement tools used to assess caregiver/parent stress supports the assertion that parental stress is complex and we lack a universal measure to most accurately depict this construct. While each of the above tools accurately measures stress, at times children and their families may escalate from stress to crisis. There is a lack of psychometrically valid measures examining a family’s level of crisis. This is a relatively new area of interest and needs further exploration to establish a standard of measurement.

Measure development begins with first understanding the population and context of interest. For this study it is relevant to gain background knowledge of children and their parents in crisis. This includes examining variables surrounding prevalence, preceding and maintaining factors in addition to existing measures available to parents and caregivers to measure level of crisis.

*Children in Crisis*

Given the rising prevalence of intellectual and developmental disabilities in addition to high rates of comorbid psychiatric disorders in this population, it likely that children with I/DD receive psychiatric treatment, including possibly hospitalization in an emergency department or inpatient unit. The frequency and severity of behavior problems children exhibit (i.e. physical aggression, disruptive behavior, self-injury and elopement) contribute to behavioral episodes escalating to crisis (Mandell et al., 2012).

Increasingly, general hospital emergency rooms are used to treat individuals with behavioral health emergencies such as aggressive behavior and suicide risk. Children with an intellectual or developmental disability are admitted to the hospital more often
and have greater length of hospital admission compared to children without I/DD (Gurney, McPheeters & Davis, 2006; Iacono and Davis, 2003; Mahon & Kibirige, 2004). Croen et al., 2006 found that children with an ASD used 12 times more psychiatric inpatient hospital days compared to those without an ASD. Children with I/DD were also found to be 2.5 times more likely to have an extended stay in the pediatric emergency department while awaiting a psychiatric inpatient bed compared to children without a disability (Wharff, Ginnis, Ross & Blood, 2011). A recent evaluation of psychiatric inpatients with an ASD found that number of challenging behaviors upon admission and severity of behavior problems correlated with a longer inpatient stay (Guinchat et al., 2015).

Factors contributing to admission to the ED or inpatient unit for children with I/DD include comorbid psychiatric diagnoses, externalizing behavior problems, availability of community resources and type of insurance (Kalb et al., 2012; Mandell et al., 2012). Research has examined predictive factors among adults with ID and more recently, youths with an ASD. Prichard, Palucka, Reid & Lunsky (2007) reviewed admission of 20 clients to a dual diagnosis inpatient program and found that the chief complaint upon admission was challenging behavior and threat/danger to others. Guinchat and colleagues (2015) collected data on 58 patients with ASD admitted for behavioral crises with ages ranging from 10.9-37 years. Researchers looked specifically at etiologies of behavioral crises and found almost half (47%) were psychiatric in nature, followed by organic causes such as seizures (28%) and environmental such as disruption in treatment (25%). Kalb et al., 2012 reviewed almost 4 million visits to the ED for
children aged 3-17 and found that 13% of the visits among children with an ASD were due to a psychiatric problem compared to 2% of visits of youths without an ASD. Externalizing behavior problems including aggression and self-injury were the most common chief complaint at admission to an inpatient unit among children with autism and developmental disorders (Mandell, 2008; Siegel et al., 2012). A gap in the literature exists regarding children with any intellectual or developmental disability and factors that contribute to their admission to a psychiatric inpatient unit.

As children escalate to crisis, parental stress follows suit. Considering the available information surrounding children in crisis, it is evident the number of parents or caregivers affected would be significant, and consequences would be severe. Gathering more information around parents in crisis is essential to improving communication within families, between families and clinicians and ultimately improving outcomes for children.

**Parents in Crisis**

It is evident that individuals with intellectual or developmental disabilities have potential problem behaviors and additional stressors that may necessitate hospitalization. It is important to quickly identify when families are approaching or are in crisis to respond appropriately (Weiss & Lunsky, 2011). Roberts’ work on crisis intervention (2000) categorizes crisis as a significant disruption of psychological equilibrium, often including failure of current coping mechanisms, experiencing acute distress and functional impairment. White, McMorris, Weiss & Lunsky, (2012) expanded upon this understanding by specifically investigating the antecedents, behaviors and consequences involved in crises experienced by families of individuals with an ASD across the lifespan.
Qualitatively, the authors compiled consistent themes highlighted by families such as problem behavior, comorbid psychopathology and lack of services, consistent with other research on parent stress, as precursors to crisis. Interestingly, this study also found differences in families’ reported experience of crisis relative to age; where families of older individuals were more negatively impacted than families of younger children.

Other studies have examined the caregiver experience when their child with I/DD is admitted to the ED or inpatient unit. Qualitative studies have outlined parents’ perspectives of hospital visits for their child with I/DD. These highlighted the importance of communication with both the child and the parent, the burden placed on the parent to continually provide care for the child while in the hospital, and the lack of knowledge and training nurses and other professionals had in regards to caring for a child with a disability (Avis & Reardon, 2008; Brown & Guvenir, 2009; Weiss et al., 2009). A recent review of studies examining parent stress found ‘Crisis Management’ as a key theme of concern identified by parents caring for an individual with Intellectual Disabilities and challenging behavior. This review explored this theme through parents’ qualitative accounts of experiencing crisis but provided no quantitative measure of crisis (Griffith & Hastings, 2014). Few studies have measured parent stress during their child’s hospitalization. Phua et al., (2005) assessed parents’ perceptions of their child with cerebral palsy’s experience in an inpatient unit and measured parental stress. They used the Perceived Stress Scale, (PSS-10; Cohen et al., 1983) which was designed to measure the degree to which situations in a person’s life are perceived as stressful. Overall, parents of children with cerebral palsy scored significantly higher on the PSS compared with
controls, implying a higher level of perceived stress over the previous month. While it assessed perceived stress over the past month, this scale does not specifically address stress in a time of crisis (i.e. during an inpatient hospitalization for their child). The Parenting-Stress Index Short Form (PSI/SF; Abidin, 1990) was used as a measure of change in a study examining how respite care for children affected psychological distress in their parents. The PSI/SF is a 36-item self-report instrument designed to measure relative magnitude of stress as well as identify sources of stress. While this measure has been validated in parents of children with developmental disabilities it also does not specifically assess the family’s level of crisis. Accurately measuring this experience during crisis would be beneficial for clinicians to assess a families perceptions’ and more effectively meet their needs. Studies have suggested the utility of collecting additional data within outcome measures including assessments of parent stress and satisfaction, especially within randomized controlled trial research, but which are infrequently implemented in research or practice (Chaplin, 2004).

The Brief Family Distress Scale

Weiss & Lunsky (2011) recognized the need for a quick assessment to gauge the crisis experience from the perspective of the individual in or approaching crisis. For families of children with I/DD, as previously demonstrated, measures of stress exist but are lengthy and usually assess stress over time. Evidence suggests families in or approaching crisis need a tool to quickly and accurately communicate their needs upon admission to the Emergency Department or an inpatient unit. This information would be valuable to the family and the clinician. Weiss and Lunsky (2011) designed a 1-item self-
report measure to assess the experience from the perspective of the caregiver. Distress was conceptualized from previously mentioned Roberts’ (2000) idea of crisis, defined specifically as

“An acute disruption of psychological homeostasis in which one’s usual coping mechanisms fail and there exists evidence of distress and functional impairment. The subjective reaction to a stressful life experience that comprises the individual’s stability and ability to cope or function. The main cause of a crisis is an intensely stressful, traumatic, or hazardous event…”

(Roberts 2000, p.516).

The measure is designed on a continuum of distress, from mild stress to qualitatively distinct and immediate periods of crisis. It was designed to be brief in order to be accessible to families even in severe distress. The nature of crisis requires a quick response. Previously mentioned measures may assess caregiving strain or even crisis but haven’t been incorporated into clinical practice because of time constraints. Weiss & Lunsky (2011) piloted their measure in an online community sample including parents of children with an Autism Spectrum Disorder. They found that the Brief Family Distress Scale had good construct validity with significant correlations in expected directions. The measure was also able to validly distinguish families into groups based on level of crisis, the majority of the sample (50%) experienced a “Moderate” level of impairment (family is managing stress with significant effort) while 16% reported a Marked level of impairment (being close to or in crisis).
While Weiss & Lunsky (2011) successfully implemented a measure to assess crisis in families with children with an ASD, there were a number of limitations. The sample was a voluntary, community and online sample. The population of interest was parents of children with an ASD. It is unknown if the measure can be used in a different setting such as an inpatient unit where more individuals would presumably be in crisis. It is also unknown if the BFDS can be used with parents of other clinical populations such as children with an intellectual disability or other developmental disability. Consequently, the focus of this study will be adapting the Brief Family Distress Scale, implementing it in a variety of clinical populations, and assessing its’ validity and reliability. This measure could be implemented in clinical settings and would be a useful tool for professionals who work with families to prevent crisis as well as those working with families during and after crisis (Weiss & Lunsky, 2011). An assessment of crisis is necessary to accurately gauge the individual’s perception of severity, gather information for intervention and monitor progress (Lewis & Roberts, 2001). Given that the most common complaint among family members while their child with I/DD is hospitalized is ineffective communication, establishing a valid measure could bridge that gap, enhancing communication between families and clinicians.

Validating Measures

To be effective, a measure of crisis should maintain certain psychometric properties. The science of psychometrics is usually focused on the type, reliability, and validity of the data. If a measure or test is psychometrically sound it will be reliable and useful in future research (Furr & Bacharach, 2008). Weiss & Lunsky (2011) and Khanna
and colleagues (2012) evaluated psychometric properties of measures of stress and crisis under the constraints of reliability and validity. Reliability measures consistency or repeatability, while validity describes whether a measure does what it is intended to do. There are various forms of reliability and validity designed to serve distinct purposes. Examples of validity include construct, face and concurrent validity. Examples of reliability include inter-rater and test-retest reliability and internal consistency. Researchers employ some combination of these tests to ensure their measures are psychometrically sound. Additional considerations are necessary when evaluating the psychometric properties of a single-item measure. Although occasionally viewed as psychometrically weak, many single-item measures are still used frequently within clinical practice. Previous research has examined psychometrics of many single-item measures and discussed various benefits to their use. Overall some conclude that properties of these measures are stronger than previously thought and consideration should be given to the balance between scale length and psychometric quality (Dollinger & Malmquist, 2009; Zimmerman et al., 2006). Psychometrically sound measures can be used to measure crisis in parents of children with I/DD, such as the one discussed in previous paragraphs.

**Summary**

Caring for a child with an intellectual or developmental disability comes with numerous challenges. These include increased health problems, higher rates of problem behavior and co-morbid psychiatric diagnoses (Emerson, 2003; Tonge & Einfeld, 2000). These factors in addition to others such as financial strain and availability of resources
contribute to level of parental stress (Lecavalier, Leone & Wiltz, 2006). High levels of parental stress are in turn associated with decreased quality of life, lower overall general health and increased child behavior problems. When stress escalates to crisis some children with I/DD are admitted to the emergency department or an inpatient unit. While existing measures assess levels of parent stress over time and in other contexts, we lack a valid measure to assess relative stress of families in varying degrees of crisis. Validating such measures will provide a precise depiction of the family’s perception of crisis and their relative distress. This will ideally improve communication and enable clinicians to better meet the needs of families.

**The Proposed Research**

In light of the aforementioned gap in the current literature on measures of crisis for parents of children with intellectual and developmental disabilities, the following hypotheses are being proposed for further investigation:

**Primary Hypothesis**

- Hypothesis 1: The Brief Family Distress Scale (BFDS) will demonstrate acceptable construct validity by showing a significant positive correlation with the Caregiver Strain Questionnaire (CGSQ global score in addition to the CGSQ subscales).

**Secondary Hypotheses**

- Hypothesis 2: The Brief Family Distress Scale will be able to distinguish between settings-those in an inpatient setting vs. an outpatient setting.
Hypothesis 3: Using Weiss & Lunsky’s (2011) previously designated categories (ex: those in crisis [6-10], those approaching or close to crisis [4-5], and families under stress but not near crisis [1-3]) scores on the Brief Family Distress Scale will predict scores on the CGSQ; indicating the BFDS can adequately distinguish between groups at different levels of crisis.

Hypothesis 4: The CGSQ will be psychometrically valid within a sample of children with various intellectual and developmental disabilities by demonstrating adequate reliability (internal consistency) and validity.

Exploratory analyses will examine relationships between demographic factors, crisis level, caregiver strain and further explore relationships between the BFDS and subscales of the CGSQ.
Chapter 2: Methods

Participants

Inclusion criteria for participants consisted of parents or primary caregivers of children/adolescents (between 5-17 years old) diagnosed with an intellectual or developmental disability, including Autism Spectrum Disorder. Eligibility was based on the following criteria: parent reported previous diagnosis of Intellectual disability, developmental disability (this may include for example children/adolescents with a diagnosis of ASD, Cerebral Palsy, Down Syndrome, Language Disorder, ADHD, Fragile X), or a previously established IQ<70. Due to the nature of the survey at this time only English-speaking parents/guardians were included. Only one caregiver per family was able to participate. Families with more than one child with an I/DD diagnosis only completed study materials once. Participants included individuals from several clinical settings in order to examine the presence of a meaningful difference in crisis severity between groups. Participants were recruited from outpatient behavior clinics including a psychiatric clinic for individuals with DD and a community-based behavioral support program. Recruitment also occurred at The Ohio State University Wexner Medical Center’s inpatient psychiatric unit at Harding Hospital. Of the 12 total parents/caregivers contacted within the inpatient unit, all consented to participate. A total of 25 parent/caregivers were contacted through the psychiatric clinic for individuals with DD.
and 24 agreed to participate. Packets were distributed to approximately 50 families through the community-based behavioral support program and 17 were returned.

**Measures**

*Demographics*

A demographic form (see Appendix A) for each child was completed with all other measures. This form requested information about current diagnoses, medications, age, race, gender, in addition to information about the parents and other family members such as socioeconomic status, education level and information on who is living in the home. Additional data was collected from medical records of those admitted to the inpatient unit including reason for admission and length of stay.

*Crisis Experience*

Parents’ subjective experience of crisis was measured by the Brief Family Distress Scale (see Appendix B). This provided a rating of the caregiver’s perceived level of crisis on a 10-point scale. Each point represents a statement ranging from no stress to complete crisis, shown in Appendix B. Weiss and Lunsky (2011) validated this measure in a community sample of parents with children with Autism Spectrum Disorders. They presented descriptive data as well as examined construct validity of the measure. Their data were normally distributed around a mean of 4.28 (SD= 1.65), median of 4, and mode of approximately 4.5. This data reflects expectations for a non-referred community sample. Pearson’s product moment correlations and Spearman’s rho were calculated among stressor, coping, and positive and negative adjustment variables. Significant moderate-sized correlations were found between all variables and crisis severity
(magnitudes: .29-.45) except positive parenting experience and SES. Their findings were not related to age or gender. Respondents were categorized into crisis groups: No impairment (1-3), Moderate impairment (4-5), or Marked impairment (6-10). Analyses confirmed significant differences between meaningful groups based on crisis severity across all variables, except positive parenting experiences and SES. Post hoc analyses indicated parents in the Marked impairment group had significantly more negative events, mental health problems, and burden compared to parents at No or Moderate impairment. Their results support good construct validity for the Brief Family Distress Scale (BFDS).

In order to use the measure in a sample of families with a high likelihood of currently experiencing crisis, it was necessary to adapt the measure to reflect subtle differences families may report while still being in crisis. The original measure specifies that a score of “9” indicates “We are currently in crisis, and have asked for help from crisis services (Emergency room, hospital, community crisis supports)” while a score of “10” indicates “We are currently in crisis, and it could not get any worse”. Although these scores may identify families in crisis, they do not meaningfully distinguish between individuals currently in crisis. It is anticipated that the sample collected from the inpatient unit would produce homogenous ratings on the BFDS (i.e., all individuals admitted would have “asked for help from crisis services”). After consulting with the original authors, the measure was adapted to reflect these meaningful differences. Item 9 now reads “We are currently in crisis, have asked for help from crisis services but are hopeful for a resolution”. Item 10 now reads “We are currently in crisis, have asked for help from
crisis services and it could not get any worse” This adjustment aims to accurately
distinguish between these two groups within the inpatient setting.

Caregiver Strain

Discussed earlier, the Caregiver Strain Questionnaire (see Appendix C) was
originally developed to assess strain experienced by parents of children and adolescents
with serious emotional and behavioral disorders (BFDS; Brannan, Heflinger, & Bickman,
1997). The CGSQ is a 21-item scale divided into three dimensions, which assess strain
over the previous 30 days. Each item is ranked on a five-point Likert-scale ranging from
1 (not at all a problem) to 5 (very much a problem). The three dimensions assessed are
objective caregiver strain, internalized subjective strain and externalized subjective strain.
The objective strain subscale captures the negative consequences of caregiving such as
disruption of personal time and financial strain. Internalized subjective strain captures
negative feelings such as worry or guilt and is internal to the caregiver. The Externalized
subjective strain subscale aims to assess negative feelings directed toward the child such
as anger, embarrassment or resentment. Scores for each subscale are calculated as the
mean of the items in the subscale. An overall score is calculated by summing the three
subscale scores. Higher total scores indicate greater levels of caregiver strain. The
Caregiver Strain Questionnaire (CGSQ) has been successfully used in a variety of
populations including ADHD, OCD, Substance Abuse Disorder and most recently
Autism Spectrum Disorders (Khanna, 2012; Kirby, White & Baranek, 2015; Lowry,
Schatz & Fabiano, 2015). In a population of parents with children with an ASD, the
CGSQ demonstrated adequate convergent validity. The objective strain subscale had a
moderate correlation with the subjective externalized strain (r=.49; p<.01) and a strong
correlation with subjective internalized strain (r=.77; p<.001). Subjective externalized
and internalized strain subscales were also correlated (r=.56; p<.01). The subscales had
significant correlations with health related quality of life (r=-.25 to -.58), maladaptive
coping, and unhealthy family functioning (.21-.35). Convergent validity based on
correlation with Autism severity (.13-45; low to moderate) and extent of behavior
problems (.33-.58; moderate to strong) were adequate. Khanna and colleagues (2012)
also demonstrated excellent internal consistency (Cronbach’s α = .94). The CGSQ was
chosen for this study as a measure of convergent validity for the BFDS. It also will give
additional information on parents’ level of strain and the relationship between strain,
diagnosis and other variables. The CGSQ was also chosen because it is brief in nature
and has been used in a population of children with Autism Spectrum Disorders. While
many studies have successfully evaluated caregiver strain using the CGSQ few have
examined score differences between subscales across groups or in different contexts
(Kirby, White & Baranek, 2015). Brannan, Heflinger & Bickman (1997) highlighted the
importance of these different scores as a means of qualifying differences between
caregivers to more accurately direct interventions and identify specific areas of need. In a
study comparing parents of children with an ASD (n=71) to those with a DD (n=36) on
different strain types, results found higher levels of caregiver strain among caregivers of
children with an ASD than those of children with a DD (Kirby, White & Baranek, 2015).

Procedures

Recruitment.
As mentioned above, all participants were recruited from either two outpatient settings or one inpatient setting. Recruitment also occurred at The Ohio State University Wexner Medical Center’s inpatient psychiatric unit at Harding Hospital. Potential participants were identified with the assistance of the clinicians in each setting. Social Workers within the inpatient unit were able to identify potential participants based on diagnoses at intake. All parents of children within the outpatient clinic were eligible as long as children were between 5 and 17 years old. Within these two settings parents completed study materials and returned them immediately. All parents of individuals within the community-based behavioral program (under 18) were also potentially eligible to participate since diagnoses of I/DD is implied. Clinicians within the community-based behavioral program provided eligible participants with a packet containing relevant information. If interested in participating, parents in this outpatient setting completed and returned measures through the mail.

Consent.

Documentation of consent was waived for the outpatient settings of this study. Instead, a cover letter (see Appendix D) was provided in each packet with a description of the study, incentive, risks and benefits. Within the psychiatric clinic the investigator went over elements of this letter with participants as well as encouraged them to read it on their own. Within the community-based setting, specialists instructed parents to read over the materials carefully and use the return addressed envelopes included in the package if they wanted to participate. Parents in these outpatient settings implied consent by completing and returning study measures. Parents who did not want to participate
could simply decline or discard the materials. Within the inpatient unit consent was obtained by the investigator. The investigator reviewed consent information (see Appendix E) with families and explained all relevant and possible risks and benefits to the study. Participants signed consent forms along with the investigator in order to participate. All data collected were de-identified and coded. All data coded were stored in password protected computers on the OSU Wexner Medical Center campus. Hard copies were kept in a locked file cabinet in a locked office. Only the PI and key personnel listed in the IRB Application had access to the data.

Incentive

With partial funding support from the Nisonger Center Research Fund caregivers were offered incentive of a $10 giftcard for their participation. This information was included on the cover sheet which all participants received as well as told verbally to participants in Inpatient and outpatient psychiatric clinic settings. Within the outpatient community based behavioral program setting all packets included an incentive form (see Appendix F). This form was not numerically coded so personally identifiable information was not linked with study participation. Upon receipt of incentive form and completed measures, a $10.00 Target gift card was mailed to the participant’s provided address.

Data Analysis

Both IBM SPSS Statistics 22 and R i386 3.2.2. were used for statistical analyses in this study. Convergent validity of the BFDS was examined based on its correlation to the subscales and total scores of the CGSQ. Pearson product moment correlations were calculated and a positive moderate relationship was hypothesized between the BFDS with
each of the subscales of the CGSQ. T-tests were used to examine relationships between crisis level/caregiver strain and child age or child gender. Concurrent validity was examined by exploring the ability of the BFDS to meaningfully distinguish between groups. Independent samples T-tests examined BFDS score differences between groups at various settings (inpatient versus outpatient). It was hypothesized that the mean score on the BFDS within the outpatient settings would be significantly different than the mean of the inpatient setting. Respondents were also categorized into groups based on their level of crisis as described by BFDS scores: No impairment (1–3), Moderate impairment (4–5), or Marked impairment (6–10). These categories are based on those of Weiss & Lunsky (2011). One-way ANOVAs examined differences between crisis group means and scores on the CGSQ. A significant difference based on caregiver strain between each group was hypothesized. Internal consistency of the CGSQ was evaluated using Cronbach’s alpha. An alpha value of 0.7 is considered satisfactory, greater than 0.7 to 0.9 as adequate, and greater than 0.9 as excellent (George and Mallery, 2003). Exploratory analyses examined in more detail the experience of parents in crisis and looked at the impact of diagnosis as well as comorbidities on perceived level of crisis and caregiver strain.
Chapter 3: Results

Study Sample

Within the inpatient hospital setting, a total of 12 families consented and completed study materials. Within the outpatient clinical setting, 24 families completed study materials. After reviewing study materials on their own, a total of 19 families within the home-based outpatient setting completed and returned study materials. Of the 55 total families who completed study materials, 1 did not meet eligibility criteria and 2 participants had missing data. This left 52 participants for data analysis. Only 2 participants were missing more than 15% of the items on the Caregiver Strain Questionnaire and were excluded. No participants were missing scores on the Brief Family Distress Scale. When participants had less than 15% missing data on the Caregiver Strain Questionnaire and had completed the Brief Family Distress Scale, average scores and standard deviations were calculated. This data was also sorted by setting between inpatient and outpatient participants. Demographic information is summarized below including diagnoses, gender, age, parent SES (socioeconomic status) and education level.

Power Analysis

Before performing any data analyses, a new power calculation was performed since a smaller number of participants were recruited than originally planned. With 52
subjects, assuming the standard type I error rate of 5%, we have 80% power to detect a correlation of $r=.37$. This is within reason, because previous studies done by Weiss and Lunsky (2011) demonstrated adequate convergent validity through significant moderated sized correlations between scores on the BFDS and related variables.

**Child Demographic Information**

Demographic information was provided by parents or primary caregivers. Of the eligible participants, 73.1% were mothers, 13.5% were fathers, 9.6% an adoptive parent and the remainder primary caregivers. On average, children were 13.7 years old (SD=3.09), ranging from 6.4-17.9 years and 73.1% were male. Parents reported that 40 children were diagnosed with an Autism Spectrum Disorder (ASD), 20 with an intellectual disability (ID), 1 with Down syndrome, 4 with a Language Disorder, 16 with Attention Deficit Hyperactivity Disorder (ADHD) and 7 with an ‘other’ Developmental Disability. These total numbers include children with multiple diagnoses. Overall, 51.9% indicated their child had been diagnosed with more than one developmental disability. For individuals with an Autism Spectrum Disorder, the most common comorbid diagnoses reported were ID (n=14) and ADHD (n=9). Additionally, 34.5% of parents indicated their child had also been diagnosed with at least one comorbid mental health disorder. The most commonly reported mental health diagnoses were mood disorders (n=11). Parents reported 80.8% of children took psychotropic medications, with the most common medications being psychostimulants and antipsychotics. According to parents, 65.4% of children were on more than one psychotropic medication. Within the inpatient setting, average length of stay and reason for admission was able to be obtained for 11 of
the 12 participants. The average length of stay was 9.6 days. Out of the 11 inpatient participants 4 were admitted for suicidal ideation, 3 for aggression with or without homicidal ideation or disruptive behavior, 2 for psychosis, 1 for acute mania and 1 for a major depressive episode. Additional child demographic characteristics separated by setting are presented in Table 1. Additional parent and family demographic information including respondent age, race, individuals living in the home, parent reported level of education and income is presented in Table 2.
<table>
<thead>
<tr>
<th>Child Sex</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>male</td>
<td>6</td>
<td>32</td>
<td>38(73.1)</td>
</tr>
<tr>
<td>female</td>
<td>6</td>
<td>8</td>
<td>14(27)</td>
</tr>
<tr>
<td><strong>Child Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>12</td>
<td>36</td>
<td>48(92.30)</td>
</tr>
<tr>
<td>African American</td>
<td>0</td>
<td>3</td>
<td>3(5.8)</td>
</tr>
<tr>
<td>Asian</td>
<td>0</td>
<td>1</td>
<td>1(1.90)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reported number of medications taken</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>2</td>
<td>8</td>
<td>10(19.2)</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>7</td>
<td>8(15.4)</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>7</td>
<td>9(17.3)</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>10</td>
<td>16(30.8)</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>4</td>
<td>5(9.6)</td>
</tr>
<tr>
<td>5</td>
<td>0</td>
<td>3</td>
<td>3(5.8)</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>1</td>
<td>1(1.90)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent Reported Diagnoses</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual Disability</td>
<td>7</td>
<td>13</td>
<td>20(38.5)</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>7</td>
<td>33</td>
<td>40(77)</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>0</td>
<td>1</td>
<td>1(2)</td>
</tr>
<tr>
<td>Language Disorder</td>
<td>0</td>
<td>4</td>
<td>4(7.7)</td>
</tr>
<tr>
<td>Attention Deficit Hyperactivity Disorder</td>
<td>8</td>
<td>8</td>
<td>16(30.8)</td>
</tr>
<tr>
<td>Other Developmental Disability</td>
<td>1</td>
<td>6</td>
<td>7(13.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of IDD diagnoses</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4</td>
<td>21</td>
<td>25(47.2)</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>13</td>
<td>18(34)</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>6</td>
<td>9(17)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of other comorbidities</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>2</td>
<td>32</td>
<td>34(64.2)</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>7</td>
<td>10(18.9)</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3(5.7)</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>0</td>
<td>2(3.8)</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>0</td>
<td>1(1.9)</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>0</td>
<td>2(3.8)</td>
</tr>
</tbody>
</table>
Table 2

*Parent Reported Demographic Information, Respondent*

<table>
<thead>
<tr>
<th>Respondent Race</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>11</td>
<td>37</td>
<td>48(92.3)</td>
</tr>
<tr>
<td>African American</td>
<td>1</td>
<td>1</td>
<td>2(3.8)</td>
</tr>
<tr>
<td>Asian</td>
<td>0</td>
<td>1</td>
<td>1(1.9)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0</td>
<td>1</td>
<td>1(1.9)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Respondent Age</th>
<th>mean(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>44.6(11.1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest level of education mother figure</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some high school</td>
<td>0</td>
<td>2</td>
<td>2(3.8)</td>
</tr>
<tr>
<td>High school graduate or GED</td>
<td>3</td>
<td>8</td>
<td>11(21.2)</td>
</tr>
<tr>
<td>Some college, post high school or 2 year degree</td>
<td>3</td>
<td>13</td>
<td>16(30.8)</td>
</tr>
<tr>
<td>College graduate</td>
<td>3</td>
<td>13</td>
<td>16(30.8)</td>
</tr>
<tr>
<td>Advanced graduate or professional degree</td>
<td>1</td>
<td>4</td>
<td>5(9.6)</td>
</tr>
<tr>
<td>Not in household</td>
<td>1</td>
<td>0</td>
<td>1(1.9)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest level of education father figure</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some high school</td>
<td>1</td>
<td>4</td>
<td>5(9.6)</td>
</tr>
<tr>
<td>High school graduate or GED</td>
<td>4</td>
<td>5</td>
<td>9(17.3)</td>
</tr>
<tr>
<td>Some college, post high school or 2 year degree</td>
<td>2</td>
<td>9</td>
<td>11(21.2)</td>
</tr>
<tr>
<td>College graduate</td>
<td>1</td>
<td>9</td>
<td>10(19.2)</td>
</tr>
<tr>
<td>Advanced graduate or professional degree</td>
<td>1</td>
<td>5</td>
<td>6(11.5)</td>
</tr>
<tr>
<td>Not in household</td>
<td>1</td>
<td>5</td>
<td>6(11.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Household income</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $20,000</td>
<td>2</td>
<td>8</td>
<td>10(19.2)</td>
</tr>
<tr>
<td>$20,001-$40,000</td>
<td>3</td>
<td>5</td>
<td>8(15.4)</td>
</tr>
<tr>
<td>$40,001-$60,000</td>
<td>4</td>
<td>9</td>
<td>13(25)</td>
</tr>
<tr>
<td>$60,001-$90,000</td>
<td>0</td>
<td>9</td>
<td>9(17.3)</td>
</tr>
<tr>
<td>More than $90,000</td>
<td>2</td>
<td>9</td>
<td>11(21.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of additional people living in home</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Total(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>4</td>
<td>5(9.6)</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>13</td>
<td>15(28.8)</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>14</td>
<td>18(34.6)</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>6</td>
<td>10(19.2)</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3(5.8)</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>1</td>
<td>1(1.9)</td>
</tr>
</tbody>
</table>
Demographic Comparisons by Setting

A central focus of the analyses is derived from comparing scores between settings and thus data from the outpatient clinical setting was combined with the outpatient home based setting and will be referred to as the “outpatient” setting or group. Inpatient and Outpatient (outpatient clinical setting plus outpatient home setting) groups were compared on multiple key demographic variables including age, sex, race and diagnoses. Both independent samples-t tests and fisher’s exact tests were used to examine statistical differences. Significant differences were observed in reference to age (t=2.81, p=.007*) and mental health comorbidities (t=6.62, p=.000*). No significant differences were found by sex (p=.06), race (p=1), type of diagnosis (p=.1), number of IDD diagnoses (t=1.18, p=.71) or number of medications (t=.1, p=.25). Within the inpatient setting, mean reported age was M=15.9(sd=1.5) while outpatient mean reported age was M=13.2(sd=3.2). Within the inpatient setting, mean reported comorbidities were M=2.3 (sd=1.8) while outpatient mean reported comorbidities were M=.23(sd=.5).

Psychometrics

The primary goal of this study was to examine the psychometric properties of the Brief Family Distress Scale (BFDS). First, means and standard deviations were calculated for both the BFDS and the Caregiver Strain Questionnaire (CGSQ). Within the inpatient unit, parents/caregivers CGSQ global scores were calculated at (M=9.33, SD=2.42) and in the outpatient setting as (M=9.33, SD=2.53). BFDS scores within the inpatient unit were (M=7, SD=2.25) and outpatient (M=5.3, SD=1.69). A frequency distribution of these scores can be seen in Figure 1. Average scores for each measure,
including subscale scores are presented in reference to each setting in Table 3.

Convergent validity was examined through Pearson correlations between scores on subscales of the CGSQ and score on the BFDS. Scores on the CGSQ were strongly positively correlated with the BFDS. Specifically, $r(52) = .67$, $p = .000$ for the Global Score on the CGSQ and the BFDS. See Table 4 for correlations of all CGSQ subscales and the BFDS.

Figure 1: Histogram showing the frequency distribution of scores on the BFDS between inpatient and outpatient settings.
### Table 3

*Average Scores on the CGSQ and BFDS*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Total</th>
<th>Inpatient</th>
<th>Outpatient</th>
</tr>
</thead>
<tbody>
<tr>
<td>CGSQ</td>
<td>mean(SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Objective Strain</td>
<td>3.2(.96)</td>
<td>3.2(.82)</td>
<td>3.2(1.02)</td>
</tr>
<tr>
<td>Subjective Externalized Strain</td>
<td>2.4(.89)</td>
<td>2.3(1.03)</td>
<td>2.4(.86)</td>
</tr>
<tr>
<td>Subjective Internalized Strain</td>
<td>3.7(.93)</td>
<td>3.8(.88)</td>
<td>3.7(.96)</td>
</tr>
<tr>
<td>Global Score</td>
<td>9.3(2.48)</td>
<td>9.3(2.42)</td>
<td>9.3(2.53)</td>
</tr>
<tr>
<td>BFDS</td>
<td>5.7(1.96)</td>
<td>7(2.25)</td>
<td>5.3(1.69)</td>
</tr>
</tbody>
</table>

### Table 4

*Correlations among CGSQ subscales and BFDS scores*

<table>
<thead>
<tr>
<th></th>
<th>CGSQ_OBJ</th>
<th>CGSQ_SUBJext</th>
<th>CGSQ_SUBJint</th>
<th>CGSQ_Global</th>
<th>BFDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>CGSQ_OBJ</td>
<td></td>
<td>.633**</td>
<td>.756**</td>
<td>.903**</td>
<td>.708**</td>
</tr>
<tr>
<td>CGSQ_SUBJext</td>
<td>.650**</td>
<td></td>
<td>.852**</td>
<td>.458**</td>
<td></td>
</tr>
<tr>
<td>CGSQ_SUBJint</td>
<td></td>
<td>.906**</td>
<td></td>
<td>.617**</td>
<td></td>
</tr>
<tr>
<td>CGSQ_Global</td>
<td></td>
<td></td>
<td>.674**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: CGSQ_OBJ= Caregiver Strain Questionnaire Objective Strain Subscale, CGSQ_SUBJext=Caregiver Strain Questionnaire Subjective Externalized Strain Subscale, CGSQ_SUBJint=Caregiver Strain Questionnaire Subjective Internalized Strain Subscale, CGSQ_Global=Caregiver Strain Questionnaire Global Score, BFDS=Brief Family Distress Scale

**p<.01
In order to examine additional psychometric properties of the BFDS, the CGSQ was first evaluated to confirm reliability within this population and settings. Previous studies have demonstrated excellent internal consistency in a variety of samples (Brannan, Heflinger, & Bickman, 1997; Khanna et al., 2012; Stuart & McGrew, 2009). Internal consistency of the CGSQ was examined using Chronbach’s alpha. The full Caregiver Strain Questionnaire consisted of 21 items (α=.95), the Objective strain subscale consisted of 11 items (α=.93), the Subjective externalized strain subscale consisted of 4 items (α=.72), and the Subjective internalized strain subscale consisted of 6 items (α=.87). Guidelines provided by George & Mallery (2003) suggest the subscales of the CGSQ as well as the total measure have excellent, good and acceptable reliability (> .9 = excellent, > .8 = good, > .7 = acceptable). Additionally, Table 3 highlights the strong positive correlations between subscales on the CGSQ.

T-tests and ANOVAs were used to examine other aspects of validity for the BFDS and CGSQ. An independent samples T-test was conducted to compare scores on the BFDS and the Global Score of the CGSQ for Inpatient versus Outpatient conditions. There was a significant difference in the scores on the Brief Family Distress Scale between the inpatient setting (M=7.0, SD=2.26) and the outpatient setting (M=5.35, SD=1.69); t (50) = 2.905, p=.005. There was no significant difference in Global scores on the CGSQ between the inpatient setting (M=9.34, SD=2.42) and the outpatient setting (M=9.33, SD=2.53); t(50)=.002, p=.998. Respondents were also categorized into crisis groups: No impairment (1-3; 9.6%), Moderate impairment (4-5; 42.3%), or Marked impairment (6-10; 48.1%). These groupings were based on Weiss & Lunsky’s (2011)
recommendations. A one-way ANOVA examined differences between crisis groups relative to Global score on the CGSQ. There was a significant effect of crisis group membership on the Global score at the p<.05 level for the three conditions [F(2, 49) = 16.04, p=.000]. Post hoc comparisons indicated parents at the Marked level of impairment had significantly higher ratings on the CGSQ global score compared to parents at No or Moderate levels of impairment (all p’s<.001). Parents at the Moderate level of impairment also reported significantly higher ratings on the CGSQ global score compared to parents at in the No impairment group (p=.02), listed in Table 5.

Table 5

*One Way ANOVA comparing crisis group membership*

<table>
<thead>
<tr>
<th>Variables</th>
<th>ANOVA</th>
<th>Crisis level</th>
<th>Crisis level</th>
<th>difference (SE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global score</td>
<td>F(2, 49)=16.037**</td>
<td>Marked</td>
<td>None</td>
<td>4.95(.96)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Marked</td>
<td>Moderate</td>
<td>2.15(.56)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moderate</td>
<td>None</td>
<td>2.80(.98)*</td>
</tr>
</tbody>
</table>

Note: p-values adjusted with Bonferroni correction
*p<.01, **p<.001
Exploratory Analyses

Additional exploratory analyses were performed to examine elements of the parent reported experience of stress. Independent samples t-tests were performed to examine differences between children diagnosed with ASD vs. not-ASD on the BFDS (No ASD: M=5.4, SD=1.83; ASD: M=5.72, SD=2.01) and CGSQ global score (No ASD: M=9.09, SD=3.03; ASD: M=9.41, SD=2.33). While small differences were in expected directions, no significant differences were found. These results were inconsistent with previous research and are potentially due to the large discrepancy in group members (ASD (n)=40, no ASD(n)=12). Correlations examined relationships between scores on the Brief Family Distress Scale and Caregiver Strain Questionnaire with number of I/DD diagnoses, number of mental health comorbidities, number of individuals living in the home, number of medications and age. Significant positive correlations were found between the BFDS and number of I/DD diagnoses; r(52)=.377, p=.003 as well as number of comorbid mental health diagnoses; r(52)=.377, p=.003. Additionally significant negative correlations were found between number of people in the home and scores on the CGSQ and BFDS. All exploratory analyses results are presented in Tables 6 and 7.
Table 6
Levels of Strain and Crisis for ASD and no-ASD

<table>
<thead>
<tr>
<th></th>
<th>ASD</th>
<th>no-ASD</th>
<th>t-test</th>
<th>df</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective Strain</td>
<td>3.3(.9)</td>
<td>3.1(1.1)</td>
<td>-0.603</td>
<td>50</td>
</tr>
<tr>
<td>Subjective Externalized Strain</td>
<td>2.4(1.0)</td>
<td>2.5(1.0)</td>
<td>0.329</td>
<td>50</td>
</tr>
<tr>
<td>Subjective Internalized Strain</td>
<td>3.8(.9)</td>
<td>3.5(1.1)</td>
<td>-0.714</td>
<td>50</td>
</tr>
<tr>
<td>Global Score</td>
<td>9.4(2.3)</td>
<td>9.1(3.0)</td>
<td>-0.383</td>
<td>50</td>
</tr>
<tr>
<td>Brief Family Distress Scale</td>
<td>5.7(2.0)</td>
<td>5.4(1.8)</td>
<td>-0.474</td>
<td>50</td>
</tr>
</tbody>
</table>
### Table 7

**Pearson Product Moment Correlations between BFDS and demographic variables**

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>IDD total</th>
<th>MI_comorbid</th>
<th>people_home</th>
<th>med_count</th>
<th>CGSQ_global</th>
<th>BFDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.171</td>
<td>0.184</td>
<td>-0.029</td>
<td>0.284*</td>
<td>0.172</td>
<td>0.242</td>
<td></td>
</tr>
<tr>
<td>IDD total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other comorbid</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People in home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of meds</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CGSQ_global</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.674**</td>
</tr>
</tbody>
</table>

Note: IDD_total=number of IDD diagnoses, MI_comorbid=number of other comorbidities, people_home=number of people in home, med_count=number of medications, CGSQ_global=Global Score on Caregiver Strain Questionnaire, BFDS=Brief Family Distress Score

*Correlation is significant at the .05 level (2-tailed)  
**Correlation is significant at the .01 level (2-tailed)
Chapter 4: Discussion

There are few data on the experiences of families in crisis. Additional data would allow for a better understanding of factors pushing families into crisis as well as how it is resolved. This ultimately results in an absence of resources available to families that would provide support in times of crisis or to those approaching crisis. The findings of this study have important implications regarding the experience of crisis in families with a child with an intellectual or developmental disability.

Specifically, the purpose of this study was to validate a brief measure of crisis in a clinical population. Previous research has supported the use of the Brief Family Distress Scale in an online sample of parents of children with an Autism Spectrum Disorder. The current study contributes to the existing work by extending previous findings to multiple clinical populations where individuals presented with a variety of diagnoses. Working toward establishing convergent validity, this study explored relationships between the Brief Family Distress Scale and the Caregiver Strain Questionnaire. It additionally examined the validity of crisis groups designated by the BFDS. To establish construct validity, differences between individuals in an inpatient unit and outpatient settings were compared. Finally, this study explored relationships of demographic factors to levels of stress and crisis. All proposed hypotheses were well supported. Findings suggest that the
Brief Family Distress Scale is a psychometrically sound instrument with utility in clinical settings.

**Psychometrics**

With regard to convergent validity, correlations reported between BFDS and subscales on the CGSQ were in expected directions and were strong in magnitude. This finding was consistent with previous research, which demonstrated moderate positive correlations between the BFDS and related variables such as problem behavior and negative life events (Weiss & Lunsky, 2011). The CGSQ also demonstrated strong psychometric properties within this sample of children with I/DD. Though originally developed for caregivers of children with serious emotional and behavior disorders, the CGSQ has demonstrated a useful measure in other populations including ASD (Khanna et al., 2012). The reliability of the CGSQ within this population, which includes children diagnosed with various intellectual and developmental disabilities, was excellent (Chronbach’s alpha=.95), aligning with the reported internal consistency from the original study (Chronbach’s alpha=.93; Brannan, Heflinger & Bickman, 1997). Reliability of the subscales was also good, all exceeding .7. Additionally, correlations between the subscales were strong, all significant at the p<.01 level. As the CGSQ has been validated in many populations and settings, it is likely that the strong relationship seen with the BFDS supports its’ validity and overall utility.

Content validity of the BFDS was also well supported within this study. Significant differences were found when comparing the sample of inpatient participants to those in the outpatient settings. It was expected that parents of children within an
inpatient psychiatric hospital would report a more severe experience of crisis than parents of children in an outpatient setting. Results demonstrated parents of children in the inpatient unit were under significantly more acute distress than those in the outpatient settings. This aspect of the BFDS had yet to be explored in previous research as the original sample was drawn from a self-selected online survey and did not have a comparison group. Results also showed that scores on the CGSQ of individuals from the inpatient unit were not significantly different from those in the outpatient settings. This finding was surprising as it was expected that parents reporting more severe experiences of crisis would also report higher levels of strain. It is possible that the BFDS isolates the experience of crisis due to the language used within the measure as well as assessing the respondent’s current situation rather than their experiences summarized over the past 30 days. Although there were not statistical differences between settings, this does not suggest that parents are not under significant amounts of stress. It is likely the reverse is true and parents of children in both inpatient and outpatient settings are experiencing an overall high level of strain.

Finally, the BFDS validly categorized participants into the BFDS crisis groupings designated by Weiss & Lunsky’s (2011) study who differed in scores on the CGSQ. Given the types of clinical settings used to recruit participants, it was not surprising that 48% of our sample fell within the ‘Marked impairment’ group, 42% in the ‘Moderate impairment’ and 10% in the ‘No impairment’ category. This supports the assertion in previous work that data collected from crisis-related services would yield a higher percentages of families endorsing ‘Marked impairment’ (Weiss & Lunsky, 2011).
Additionally, 42% of our sample reported experiencing ‘Moderate impairment’, suggesting most families participating were experiencing a significant amount of stress (e.g. “Things are very stressful but we are getting by with a lot of effort”). These results support the consistent finding that families of children with a variety of developmental disability diagnoses are under significant amounts of stress. When further exploring the distribution of crisis groups within the various settings, the combined outpatient settings were first separated back to their recruitment groups to the psychiatric clinic and community-based program. It was found that of those reporting ‘Marked impairment’, 76% were participants within the inpatient hospital or outpatient psychiatric clinic. This likely is due to the nature of the psychiatric clinic and the characteristics of the patients, who often have multiple diagnoses and are under the care of a psychiatrist. These findings suggest the need for additional family-focused services even within psychiatric outpatient settings.

Although the data demonstrated overall significant mean differences between settings on the BFDS, it is interesting to note that of the 12 total inpatient participants, 2 participants indicated scores of 3 and 4 respectively. This was surprising as scores of 3 and 4 indicate things are “sometimes stressful” or “often stressful”. Another participant was noted to verbally communicate to the examiner that she and her daughter were currently in crisis, but proceeded to indicate a score of a 6 which reads: “we have to work extremely hard every moment of every day to avoid having a crisis”. An alternative explanation for this is participants did not fully read or understand all the options present on the scale. It is more likely that these varied expressions of crisis highlight the element
of subjectivity of the experience of crisis in addition to those present within a parent-reported measure. Additionally, past research has demonstrated that children with disabilities, especially those with an ASD diagnosis, utilize emergency services at higher rates than typically developing children. It is possible families with repeated exposure to crisis services may no longer feel they are in crisis while in those settings (Croen et al., 2006; Gurney, McPheeters & Davis, 2006). This is an important finding to consider when evaluating the utility of the BFDS in a clinical population. It may also be helpful to consider a more objective evaluation from the clinician when determining needs for support.

In summary, consistent with previous research, the BFDS showed adequate psychometric properties within all three clinical settings assessed in this study. Being one of few studies to gather data from families in a time of crisis, this study adds valuable information that should be considered when designing supports or resources for families in crisis. It is supported that this measure can be used among clinicians in various contexts as a tool for effective communication.

Continuing to expand upon these findings, it would be valuable to examine if the BFDS could serve as a measure of change in future research. Patient reported outcomes associated with emergency and inpatient psychiatric care for this population are discouraging, indicating lower patient satisfaction and an increase likelihood of readmission (Iacono and Davis, 2003). Hospital staff have reported lack of knowledge, confidence, training and resources leading to additional challenges caring for children or adults with I/DD (Lunsky, Gracey, & Gelfand, 2008; McConkey & Truesdale, 2000).
Children with disabilities have greater lengths of stays in hospitals and increased use of interventions such as physical and chemical restraints (Lokhandwala, Khanna, & West-Strum, 2012; Palucka & Lunsky, 2007). Implementing a brief, valid measure of crisis as an indicator for change during a patient’s hospital stay would provide important information regarding the efficacy of hospital settings for people with I/DD. The BFDS could also be used as an outcome measure within interventions aimed at improving satisfaction within emergency settings. Another review of children with I/DD within inpatient settings revealed unsatisfactory experiences. A common theme reported for improvement was the need for better communication between staff and parents (Shilling, Edward, Rodgers & Morris, 2012). Using the BFDS as a method of communication could also improve parent and child experiences within emergency/crisis settings.

Factors relating to strain and crisis

Examining elements of the CGSQ can add information relevant to the type of strain experienced by caregivers of children with I/DD. Patterns observed within this study mirrored those of a previous study which found highest levels of subjective internalized strain followed by objective strain and finally subjective externalized strain (Kirby, White & Baranek, 2015). These results were replicated across both inpatient and outpatient groups supporting evidence suggesting caregivers may need the most support with feelings of worry or guilt. The clinical utility of this information should direct interventions or assist with the creation of resources designed for parents and caregivers.

Within exploratory analyses, relationships between types of diagnoses and stress were explored in addition to how other demographic variables related to stress and crisis.
Earlier research has focused on the nature and severity of the disability as a predictor of parent stress (Frey, Greenberg & Fewell, 1989; Minnes, 1988; Woodman, 2014). Some evidence suggests parents of children with ASD experience more stress and less reward than parents of children with other disabilities (e.g., Down syndrome; Dabrowska & Pisula, 2010; Griffith, Hastings, Nash & Hill, 2010; Hodapp, Ly, Fidler & Ricci, 2001). However, within this sample, no differences in crisis or stress level were observed between those with an ASD diagnosis compared to those without an ASD diagnosis. It is possible this is due to the discrepancy in sample sizes between those with and without an ASD diagnosis. Alternatively, more recent research has focused on the link between amount of problem behavior and stress rather than diagnosis (Neece, Green & Baker, 2012). It would have been interesting in this study to examine how levels of child behavior played a role in crisis and stress; but in order to keep participation brief, an additional measure was not included. Future research should weigh the potentially beneficial information gained from a measure of child behavior problems against the cost of adding time to clinical samples or groups within crisis.

Results from this study showed moderate relationships between number of I/DD related diagnoses, number of other mental health comorbidities and level of perceived crisis. Psychopathology, often associated with behavior problems, likely compounds the risk of crisis, and may even contribute to a more severe experience of crisis when compared with children without multiple comorbidities (Neece, Green & Baker, 2012). Finally, a negative association was observed between number of people in the home and overall strain as well as perceived level of crisis. This may be due in part to the
relationship observed between social support and parental stress (Khanna et al, 2012). These exploratory aims have demonstrated that within this sample, there were no differences in parental stress or crisis level between ASD and non-ASD children but instead as comorbidities increased parent perceived crisis increased as well.

Limitations

There are several limitations within this study that should be considered when interpreting findings. First, small sample sizes make it more difficult to observe statistical effects. There were large differences in size comparing inpatient to outpatient as well as ASD to no-ASD participants, reducing the amount and complexity of tests applicable to the data. Furthermore, the sample only included children with one or more I/DD diagnosis and had no comparison group to typically developing children. This has not yet been looked at when evaluating the BFDS and would add valuable information for its validity. Additionally, there was a significant difference between settings in regards to age, with inpatient participants older than outpatient participants. Many studies emphasize the relationship between age and parent stress, thus these differences could complicate interpretation of results. However, within this sample, correlations between age, strain and crisis were small and non-significant. A product of study design, all information collected was parent reported, thus there were no consistent ways of confirming diagnoses. All exploratory correlational analyses should be interpreted with caution as causal inferences cannot be made. Other limitations regarding measurement are important to consider. In general, the PSI (Parental Stress Inventory) is more widely used and validated in samples of children with developmental disabilities. The CGSQ has
been used less frequently with this population as it was originally developed for parents of children with severe emotional/behavioral problems. However, the PSI is only applicable for use in parents of children up to 12 years old and contains 120 items. The CGSQ was chosen because it is brief and could be used and compared across all participants. A previous study using the CGSQ in children with developmental disabilities altered the word “behavioral” to “developmental” when describing child’s problems throughout the measure to make it more applicable. Although this study was published after data collection began, this is a change that should be continued in the future to add clarity. Finally, a measure of problem behavior would be useful in future studies regarding the experience of crisis.

Conclusions

Previous research focused on parents caring for a child with an intellectual or developmental disability (I/DD) has consistently found increased levels of stress compared with parents of typically developing children. Further work has outlined contributing factors and elucidated many of the specific challenges parents face. This study has demonstrated that parents of children with I/DD in multiple clinical settings are experiencing significant levels of strain and would likely benefit from resources designed to address this. While this research contributes to increased understanding of the family system and development of holistic interventions, much of this work focuses on the everyday experiences of stress. It has been shown that many children and adolescents in the I/DD population are at increased risk to utilize crisis services such as emergency rooms and inpatient units. This level of stress goes beyond the everyday experience.
Thus, it is vital to have an understanding of the experience of crisis to aid in its resolution. This study has contributed to the literature through the validation of a brief measure of crisis for families of children with I/DD. Use of a brief, one-item measure is cost-effective and reduces the burden on parents under significant amounts of stress. Putting this measure of crisis into practice will improve communication between clinicians, patients and their families and hopefully improve overall outcomes for individuals with I/DD.
References


57


children with neurodevelopmental disorders. *Disability & Rehabilitation*, 31(9), 741–752. doi:10.1080/08916930802354948


60


Appendix A: Demographics Form
Demographics Form

Data to be collected for research

Child Birth Month and Year ________________________________ Sex: □ Male □ Female

Respondent relationship to child
□ Mother
□ Father
□ Adoptive Parent
□ Primary Caregiver

Child’s current diagnoses:
□ Intellectual Disability
□ [previously Mental Retardation]
□ Autism Spectrum Disorder
□ Cerebral Palsy
□ Down Syndrome
□ Fragile X
□ Language Disorder
□ Developmental Disability

(Specify: __________________)
□ Other: __________________

Child’s Race:
□ White
□ Black or African American
□ Asian
□ Hispanic or Latino
□ Other (specify)________________

Respondent (Parent/Caregiver) Race:
□ White
□ Black or African American
□ Asian
□ Hispanic or Latino
□ Other (specify)________________

Respondent Age: _____________

3. How many people live currently with your child?
   □ Natural mother
   □ Natural father
   □ Foster parents
   □ Adoptive parents
   □ Brothers – Ages: _____________
   □ Sisters – Ages: _____________
   □ Other family members
   Please Specify who: _______________

66
Unmarried partner

4. Language in the home:
   - English
   - Spanish
   - Other: ___________________

5. In current household, Mother/mother figure’s highest level of education
   - Some High school
   - High school graduate or GED
   - Some college or post-high school or 2 year degree
   - College graduate
   - Advance graduate or professional
   - Not in household

6. In current household, Father/father figure’s highest level of education
   - Some High school
   - High school graduate or GED
   - Some college or post-high school or 2 year degree
   - College graduate
   - Advance graduate or professional
   - Not in household

7. Annual Household Income (estimate for last year)
   - Less than $20,000
   - $20,001-$40,000
   - $40,001-$60,000
   - $60,001-$90,000
   - More than $90,000

8. Does your child live permanently outside the home? Yes ☐ No ☐
   If so, please check the type of placement: ☐ Group home ☐ Residential institution
   - Other (please explain) ____________________________________________________

9. Please list your child’s current medications:
   ______________________________________________________
   ______________________________________________________
Appendix B: Brief Family Distress Scale (BFDS)
**Brief Family Distress Scale**

Original Instrument Author: Jonathan A. Weiss; Yona Lunksy (2012)  
Adapted by Tara L. Benninger and Andrea Witwer

On a scale of 1 to 10, please indicate where you and your family currently are right now, in terms of crisis by picking one of the following statements:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Everything is fine, my family and I are not in crisis at all</td>
</tr>
<tr>
<td>2</td>
<td>Everything is fine, but sometimes we have our difficulties</td>
</tr>
<tr>
<td>3</td>
<td>Things are sometimes stressful, but we can deal with problems if they arise</td>
</tr>
<tr>
<td>4</td>
<td>Things are often stressful, but we are managing to deal with problems when they arise</td>
</tr>
<tr>
<td>5</td>
<td>Things are very stressful, but we are getting by with a lot of effort</td>
</tr>
<tr>
<td>6</td>
<td>We have to work extremely hard every moment of every day to avoid having a crisis</td>
</tr>
<tr>
<td>7</td>
<td>We won’t be able to handle things soon. If one more thing goes wrong - we will be in crisis</td>
</tr>
<tr>
<td>8</td>
<td>We are currently in crisis, but are dealing with it ourselves</td>
</tr>
<tr>
<td>9</td>
<td>We are currently in crisis, have asked for help from crisis services (Emergency room, hospital, community crisis supports) but are hopeful for a resolution</td>
</tr>
<tr>
<td>10</td>
<td>We are currently in crisis, have asked for help from crisis services and it could not get any worse</td>
</tr>
</tbody>
</table>
Appendix C: Caregiver Strain Questionnaire (CGSQ)
Caregiver Strain Questionnaire
Brannan, Heflinger & Bickman, 1997

Caregiver Strain Questionnaire

Please think back over the past 30 days and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time.

For each question, please tell me which response (which number) fits best.

In the past 30 days, how much of a problem was the following:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Interruption of personal time resulting from your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2.</td>
<td>You missing work or neglecting other duties because of your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3.</td>
<td>Disruption of family routines due to your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4.</td>
<td>Any family member having to do without things because of your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5.</td>
<td>Any family member suffering negative mental or physical health effects as a result of your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6.</td>
<td>Your child getting into trouble with the neighbors, the school, the community, or law enforcement?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7.</td>
<td>Financial strain for your family as a result of your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8.</td>
<td>Less attention paid to other family members because of your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9.</td>
<td>Disruption or upset of relationships within the family due to your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.</td>
<td>Disruption of your family’s social activities resulting from your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Copyright 1994 Vanderbilt University (Brannan, Heflinger, & Bickman)

All rights reserved.
In this section, please continue to look back and try to remember how you have felt during the past 30 days.

For each question, please tell me which response (which number) fits best.

**In the past 30 days:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. How isolated did you feel as a result of your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. How sad or unhappy did you feel as a result of your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. How embarrassed did you feel about your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. How well did you relate to your child?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. How angry did you feel toward your child?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. How worried did you feel about your child’s future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. How worried did you feel about your family’s future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. How guilty did you feel about your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. How resentful did you feel toward your child?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. How tired or strained did you feel as a result of your child’s emotional or behavioral problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. In general, how much of a toll has your child’s emotional or behavioral problem taken on your family?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Copyright 1994 Vanderbilt University (Brannan, Heflinger, & Bickman)

All rights reserved.
Appendix D: Cover Letter for Participants
Dear Parent:

Thank you for your interest in this research study. I am a graduate student in the Intellectual and Developmental Disabilities Psychology program at The Ohio State University. For my master’s thesis, I am investigating the quality of a measure designed to assess crisis level in caregivers of children and adolescents with Intellectual or Developmental Disabilities. Dr. Andrea Witwer, my faculty advisor, is supervising this study.

Parents caring for a child with an intellectual or developmental disability can be under a significant amount of stress. Parental stress can result in poorer outcomes for whole family including more child behavior problems, stress within the family and risk of anxiety or depression. Researchers have measures to look at parent stress over time but, we don’t have measures that look at families potentially in crisis. Validating a measure will give a clear picture of a family’s perception of crisis and their stress level to better guide clinicians’ conversations with families under stress.

We are seeking your assistance for this important study. Please carefully read over the following information as you consider participating in the study.

If you choose to participate in this study, we would like you to complete a demographics form and two questionnaires about your stress level and perception of crisis. We estimate that this will take less than 20 minutes of your time. If you choose to participate, please complete and return the enclosed study materials.

You will be compensated for participating in this study. For completing and returning the study materials enclosed in this packet, we will provide you with a $10.00 gift card to Wal-Mart

Your participation is voluntary. We hope that after reading this information, you will choose to complete and return the materials in this packet. If you decide not to participate, there will be no penalty or loss of benefits to which you are otherwise entitled. You may choose not to participate in this study and discard all study materials. Additionally, you may choose to skip any questions or stop participating at any time.

As this study involves research, there is some risk involved. While we believe that this study presents no more than minimal risk to you, there is concern for unauthorized disclosure of your information. However, we have taken steps to prevent this from occurring as much as is possible. Additionally, no information will be linked to your child’s personally identifiable information, such as his or her name. If you have any concerns or feel harmed by this study, please contact one of the researchers listed below. For questions about your rights as a participant in this study or to discuss other study-related concerns or
complaints with someone who is not directly involved with the study, you may contact the Office of Responsible Research Practices at 1 (800) 678-6251 or (614) 688-8457.

We are asking you to provide your child’s month and year of birth, current diagnoses, race, information about your household and your contact information. We are requesting that you provide this information to ensure that your child is eligible for the study, to accurately score questionnaires and to ensure that you receive your gift card. This information will not be shared or disclosed with individuals who are not involved with the study. If you choose to complete this study and would later like to revoke the authorization to use this information, please contact one of the study investigators listed below.

To maintain confidentiality, we will maintain strict control of all information collected. However, in certain circumstances, this information must be released. For example, information regarding this study may be disclosed if required by state law. Also, the information you provide may be reviewed by the following groups: the Office for Human Research Protections or other federal, state, or international regulatory agencies; The Ohio State University Institutional Review Board; or the Office of Responsible Research Practices.

We hope that you will take the time to complete and return the enclosed questionnaires. This study would not be possible without your help! If you have questions or would like more information regarding the study, please contact one of the investigators below. We appreciate your help as we investigate a parent/caregiver of a child with intellectual or developmental disability’s experience of stress and crisis. Thank you.

Sincerely,

Tara Benninger, B.S.
Graduate Student
I/DD Psychology
Nisonger Center, room 279
The Ohio State University
1581 Dodd Drive, Columbus OH 43210
Tara.Benninger@osumc.edu
(614) 247-8028

Andrea Witwer, Ph.D.
Assistant Professor
Psychiatry & Behavioral Health
Nisonger Center
The Ohio State University
1581 Dodd Drive, Columbus OH 43210
Andrea.Witwer@osumc.edu
614-685-8721
Appendix E: Consent Form for Inpatient Participants
The Ohio State University Consent to Participate in Research

Study Title: Evaluating Level of Crisis in Caregivers of Children with Intellectual and Developmental Disabilities

Researcher: Tara Benninger, B.S. and Andrea Witwer, PhD.

Sponsor:

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose:
Parents caring for a child with an intellectual or developmental disability can be under a significant amount of stress. Parental stress can result in poorer outcomes for whole family including more child behavior problems, stress within the family and risk of anxiety or depression. Researchers have measures to look at parent stress over time but, we don’t have measures that look at families potentially in crisis. Validating a measure will give a clear picture of a family’s perception of crisis and their stress level to better guide clinicians’ conversations with families under stress.

We are seeking your assistance for this important study. Please carefully read over the following information as you consider participating in the study.

Procedures/Tasks:
If you choose to participate in this study, we would like you to complete a demographics form and two questionnaires about your stress level and perception of crisis. We estimate that this will take less than 20 minutes of your time. If you choose to participate, please complete and return the enclosed study materials.

We will be accessing your child’s medical records to gain relevant demographic information for study. This information includes your child’s age, diagnoses, race, reason for admission, length of stay in the unit, members who live in the household, household education level, language in the home, and income. We are collecting this information to ensure that your child is eligible for the study, to accurately score and analyze questionnaires. This information will not be shared or disclosed with individuals who are not involved with the study. If you choose to complete this study and would later like to revoke the authorization to use this information, please contact one of the study investigators listed below.
Duration:
We estimate that this will take less than 20 minutes of your time.

You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits:

Your participation is voluntary. We hope that after reading this information, you will choose to complete and return the materials in this packet. If you decide not to participate, there will be no penalty or loss of benefits to which you are otherwise entitled. You may choose not to participate in this study and discard all study materials. Additionally, you may choose to skip any questions or stop participating at any time.

As this study involves research, there is some risk involved. While we believe that this study presents no more than minimal risk to you, there is concern for unauthorized disclosure of your information. However, we have taken steps to prevent this from occurring as much as is possible. Additionally, no information will be linked to your child’s personally identifiable information, such as his or her name. If you have any concerns or feel harmed by this study, please contact one of the researchers listed below. For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not directly involved with the study, you may contact the Office of Responsible Research Practices at 1 (800) 678-6251 or (614) 688-8457.

Confidentiality:

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:

You will be compensated for participating in this study. For completing and returning the study materials enclosed in this packet, we will provide you with a $10.00 gift card to Target.
Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:
For questions, concerns, or complaints about the study, or you feel you have been harmed as a result of study participation, you may contact

Andrea Witwer
1581 Dodd Drive, Columbus OH 43210
Andrea.Witwer@osumc.edu
614-685-8721

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.
Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

<table>
<thead>
<tr>
<th>Printed name of subject</th>
<th>Signature of subject</th>
<th>AM/PM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Date and time</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Printed name of person authorized to consent for subject (when applicable)</th>
<th>Signature of person authorized to consent for subject (when applicable)</th>
<th>AM/PM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Date and time</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relationship to the subject</th>
<th>AM/PM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Date and time</td>
</tr>
</tbody>
</table>

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

<table>
<thead>
<tr>
<th>Printed name of person obtaining consent</th>
<th>Signature of person obtaining consent</th>
<th>AM/PM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Date and time</td>
<td></td>
</tr>
</tbody>
</table>
Appendix F: Additional Data to Collect from Medical Records
Additional Data to be collected for research from Medical Records

Code:

Diagnoses:

IQ (if available):

Reason for admission:

Length of stay:
Appendix G: Incentive Form
**Incentive Form**

If you choose to participate in this study, you are entitled to receive a $10.00 gift card. However, in order to provide you with this incentive, we need to collect some basic information. If you do not wish to receive the $10.00 gift card, please do not complete this form.

Where should the gift card be sent?

First and Last Name: ____________________________

Street Address: ________________________________

City, State, Zip: ________________________________

You should receive your gift card within a few weeks after submitting this form. After sending the gift-card, this information will be destroyed. If you have any questions regarding this incentive, or any other aspect of the study, please contact either of the study investigators:

Tara Benninger, B.S.  Andrea Witwer, Ph.D.
Graduate Student  Associate Professor
I/DD Psychology  Psychology and Psychiatry
Nisonger Center, room 279  Nisonger Center
The Ohio State University  The Ohio State University
1581 Dodd Drive, Columbus OH 43210  1581 Dodd Drive, Columbus OH 43210
Tara.Benninger@osumc.edu  Luc.Lecavalier@osumc.edu
(614) 247-8028  614-685-872