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Association Between Stress and Decisional Procrastination in Parents of Children With Down Syndrome During Their Developmental Transitions

Laurel Zeisler
Seton Hall University

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ASSOCIATION BETWEEN STRESS AND DECISIONAL
PROCRASTINATION IN PARENTS OF CHILDREN WITH DOWN
SYNDROME DURING THEIR DEVELOPMENTAL TRANSITIONS

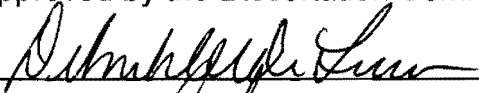

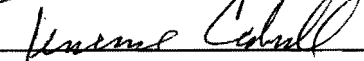
BY

Laurel Zeisler

Dissertation Committee:

Dr. Deborah DeLuca, Chair
Dr. Andrew McDonough
Dr. Terrence Cahill

Approved by the Dissertation Committee:

	Date <u>6/9/2011</u>
	Date <u>6/9/2011</u>
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Seton Hall University
2011

DEDICATION

This dissertation is dedicated to my parents, John and Dorothy Grasso. By playing “good cop, bad cop” they gave me the encouragement to persist as well as the love and support to end this journey at any time, if that was my choice. Thank you. I love you both tremendously.

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And finally, I'd like to thank Arthur for hanging in there all these years with me. Having you by my side always cheered me up. This journey has aged both of us, but we did it!

ABSTRACT

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Laurel Zeisler

Seton Hall University
2011

Background & Purpose of the Study: Decisional procrastination (DP) is a coping method used during times of high stress. It is unclear whether previous research linking cognitive overload and DP would be supported in a population prone to high stress, namely parents of children with Down syndrome. Also, parental stress and decision making was examined based on the child's developmental transition stage.

Methods: The study design was descriptive, exploratory and cross-sectional. The sample consisted of parents or primary caregivers of children with Down syndrome with email address listed with the National Down Syndrome Congress and had a child with Down syndrome aged 3-21 years old living at home. Participants completed an online survey, which included demographic questions, a stress questionnaire, and two decisional procrastination questionnaires. Data for 106 participants was obtained for this study.

Results: Non-parametric data analysis supported differences in parental decisional procrastination for the 3 developmental age groups of children. Also, parents of females were found to have higher decisional procrastination rates than parents of males, thus reflecting a new finding. The association between decisional procrastination and stress was supported in this exploratory study of parents of children with Down syndrome. More than half of the parents or primary caregivers believed that stress influenced their decision making. Ninety-six percent of participants believed that their life experiences have been helpful in their decision making, thus supporting previous decisional confidence research.

Conclusion: This research was the first exploration of decisional procrastination in a truly stressed sample, whereas previously, stress or cognitive overload was artificially induced in a clinical setting to study the association between stress and DP. These results were supportive of the theoretical framework by Janis and Mann. My data also supports that differences in parental decisional procrastination exist during different developmental transitions of their children with Down syndrome.

TABLE OF CONTENTS

DEDICATION	2
ACKNOWLEDGEMENTS	3
TABLE OF CONTENTS	5
LIST OF TABLES	8
LIST OF FIGURES	9
ABSTRACT	10
I. INTRODUCTION	12
Introduction to the Problem	12
Significance of the Study	14
Statement of the Problem	18
Purpose of the Study	19
Research Questions	19
Hypotheses	20
Nature of the Study	20
Definition of Terms	21
Summary	22
II. REVIEW OF RELATED LITERATURE	23
Introduction	23
Theoretical Framework	25
Decisional Procrastination	32
Demographics	32
Clinical Diagnoses	35
Stress	38
Decision Process	40
Summary	44
Parental Stress	46
Disability vs. No Disability	47

- Maladaptive Behaviors49
- Disability Diagnosis51
- Child’s Age/Developmental Transitions54
- Parental Factors55
- Summary57

- III. METHODS59
 - Introduction to the Methodology59
 - Research Design59
 - Pilot Study60
 - Modifications62
 - Sample Population63
 - Procedure64
 - Instrumentation65
 - Research Questions69
 - Hypotheses69
 - Data Analysis Procedures69

- IV. RESULTS72
 - Characteristics of the Sample72
 - Data Set and Normality77
 - Results of the Tests of Hypotheses81
 - Hypothesis 182
 - Hypothesis 283
 - Hypothesis 384

- V. DISCUSSION93
 - General Discussion of Study Findings93
 - Limitations98
 - Implications99

- VI. CONCLUSIONS103
 - Future Directions105

REFERENCES	107
APPENDICES	114
A. Approval to Conduct Research at Site	114
B. IRB Approval	115
C. Letter of Solicitation.....	116
D. Questionnaire on Resources and Stress (QRS-F)	117
E. Decisional Procrastination scale (DP)	120
F. Indecisiveness scale (IS)	121
G. Demographic Questionnaire	122

LIST OF TABLES

Table I.	Conflict Theory of Decision Making	28
Table II.	Demographic Characteristics of Participants	74
Table III.	Kruskal-Wallis Results for IS.....	82
Table IV.	Kruskal-Wallis Results for QRS-F	83
Table V.	Kruskal-Wallis Results for Other Variables.....	86

LIST OF FIGURES

Figure 1.	Age of Child with Down syndrome.....	75
Figure 2.	Age Groups of Child with Down syndrome	76
Figure 3.	Data Distribution for QRS-F	78
Figure 4.	Data Distribution for DP	79
Figure 5.	Data Distribution for IS	80
Figure 6.	Kruskal-Wallis Results for Stress and DP Association	85
Figure 7.	Stress and Decision Making	90
Figure 8.	Life Experiences and Decision Making.....	91

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Chapter I

INTRODUCTION

Introduction to the Problem

Meetings, multitasking, deadlines, information overload...In our fast paced society, individuals are confronted with numerous stressful situations which require decisional action on a daily basis. When individuals are bombarded with daily decision making choices, different patterns of coping may be used during the decision making process. The pattern of defensive avoidance (delaying the decision) includes decisional procrastination which is the coping pattern applied during times of high stress, and with no deadline pressures, and is associated with information evasion (Janis & Mann, 1977). Parents of children with disabilities are one group of individuals prone to high degrees of stress due to their demanding care giving responsibilities.

Parents need to make many daily decisions on behalf of their children with disabilities, and when high levels of stress cause them to delay their decisions, there may be negative consequences, such as a medical emergency later. Researchers have identified that the maladaptive behavior of children is associated with increased family stress (Hayden & Goldman, 1996). As a result, parental focus, specifically the primary caregivers, may shift to daily concerns rather than decision making for the future.

Additionally, the importance of the decision weighs heavily on the decision making process, such that when there is intense conflict regarding a major decision, the decision maker tries to escape the conflict (Janis & Mann, 1977). When a proper information search has not been conducted prior to making a decision, faulty decisions are often the result (Mann, Burnett, Radford & Ford, 1997). Not only do parents of children with Down syndrome have to make numerous daily decisions on their behalf, but specific important decisions regarding schooling and housing options also need consideration during transitional periods.

Children and their families experience many transitions over the years. Although these are normative developmental changes, these periods do increase stress in families as well as the children with Down syndrome. These transitions include: leaving early intervention services at age 3, moving from preschool programs to kindergarten at age 6, approaching adolescence, preteens, transitioning towards adulthood, teenage years, and post school planning, 18-21 ((McCubbin & Figley, 1983; Berry & Hardman, 1998, Blacher, 2001; Turnbull, Turnbull & Wehmeyer, 2007).

As medical advances have increased the lifespan of individuals with Down syndrome, parents will be making decisions for and with their children for a lifetime. If the parents have a great deal of daily stress and/or conflict about decisions, they may be fearful of making the wrong choice, and therefore avoid thinking about or discussing the topic. While there have been

many studies examining the stress of parents of children with Down syndrome, there is no research to date attempting to link the parental stress levels of this population and the impact, if any, it has on their decision making abilities during their child's developmental transitions.

Significance of the Study

Decisional procrastination is defined as a maladaptive pattern of postponing a decision when faced with conflicts and choices (Ferrari, Johnson & McCown, 1995). Decisional procrastination occurs when there is intense conflict regarding an important decision, such as relocation or a career change. The decision maker is fearful of making the wrong choice, and therefore avoids the topic, also known as defensive avoidance. Defensive avoidance is the coping pattern used during times of high stress and no deadline pressures, and is associated with information evasion. Defensive avoidance is one coping pattern utilized when there is intense conflict regarding an important decision, and the decision maker tries to escape the conflict. This is based on Janis and Mann's (1977) Conflict Model of Decision Making, which was founded upon previous research regarding the coping processes individuals use to deal with stress. Stress is defined as an emotional state evoked by threatening events or stimuli, and a stressful event is any change in the environment that induces a high degree of negative emotion, such as anxiety, guilt, or shame (Janis & Mann, 1977). This

unpleasant emotion affects normal patterns of information processing, where extremely low stress and extremely high stress are likely to result in defective information processing and decision making. According to Janis and Mann, intermediate levels of stress are associated with the ideal form of decision making, vigilance.

The majority of research on decisional procrastination has been conducted on university students and females primarily (Effert & Ferrari, 1989; Ferrari & Olivette, 1993; Harriott & Ferrari, 1996; Ferrari & Dovidio, 2000). Application of the Decisional Procrastination (DP) Scale (Mann, 1982) with clinical populations, such as adults with obsessive-compulsive disorder and adults with attention deficit hyperactive disorder, is also found in the literature (Ferrari & McCown, 1994; Ferrari & Sanders, 2006).

Several researchers have attempted to develop a demographic profile of the type of individual who engages in decisional procrastination as a mode of decision making. Using the DP scale (Mann, 1982), Ferrari and colleagues (Harriott & Ferrari, 1996; Hammer & Ferrari, 2002; Diaz-Morales, Ferrari, Argumedo & Diaz, 2006) examined decisional procrastination in individuals based on the following variables: gender, age, marital status, and education and type of work.

Marital status was another variable considered to influence decision making. Hammer and Ferrari (2002) did not discover any notable differences in decisional procrastination scores based on marital status. However,

married people were found to have higher indecision rates than those no longer married (Diaz-Morales, Ferrari, Argumedo & Diaz, 2006), while Harriott and Ferrari (1996) reported the exact opposite findings. It would seem logical that married people would be less decisive due to the possible negotiation and/or disagreement between the couple.

The stress associated with raising a child with disabilities has been thoroughly researched (Carr, 2008; Hodapp, Ricci, Ly & Fidler, 2003; Lopez, Clifford, Minnes & Oullette-Kuntz, 2008; Roach, Orsmond & Barratt, 1999). Hayden and Goldman (1996) examined the relationship between the individual's maladaptive behavior and the parental stress levels in their study of 105 caregivers of individuals with mental retardation. They found that marital status was significant, such that single women had higher stress scores than their married counterparts. Also noteworthy was the finding that families of adults who exhibited one or more maladaptive behaviors experienced significantly more stress than those families with no maladaptive behaviors (Hayden & Goldman, 1996). In another study, parents and siblings of individuals with intellectual disabilities were interviewed regarding out of home placement of their family member. Mothers were the primary caregivers in this sample and they described the enormous physical and emotional stress associated with caring for their children with disabilities (Mirfin-Veitch, Bray & Ross, 2003). The issues associated with care giving increased over time as the children grew and their behavior became less manageable.

Although the mothers reported taking responsibility for making the final decision about when to seek out of home placement for their child, they also reported feelings of guilt, remorse, and second guessing their choice (Mirfin-Veitch, Bray & Ross, 2003). There have been many studies researching parental stress and raising a child with disabilities; however, investigation of parental stress levels based upon which developmental transition the child is currently experiencing is warranted.

Much of the disability research has been conducted on individuals with mental retardation, whereby the findings will be relevant to individuals with Down syndrome, as cognitive impairment is one characteristic of the syndrome. Also, there is a large body of literature specific to individuals with Down syndrome and their primary caregivers (Carr, 2008; Corrice & Glidden, 2009; Dykens, 2007; Dykens & Kasari, 1997; Dykens, Shah, Sagun, Beck & King, 2002; Hodapp, 2007; Hodapp, Ricci, Ly & Fidler, 2003). Recruitment of parents of children with a specific disability will also provide this researcher with access to a larger pool of potential participants by looking into the well established disability population of Down syndrome.

While there have been many studies examining the stress of parents of children with Down syndrome, there is no research to date attempting to link the parental stress levels of this population and the impact, if any, it has on their decision making abilities. Decisional procrastination literature is very limited in quantity and researchers, reflecting a large void in this field of

research. New decisional procrastination studies on different populations will not only broaden the literature base, but also potentially spark the interest of researchers from other disciplines. Further research is warranted to examine the relationship between parental stress and decisional procrastination in parents of children with Down syndrome during their developmental transitions.

Statement of the Problem

Parents of children with disabilities have to make numerous daily decisions on their behalf. Children and their families experience many transitions over the years. Although these are normative developmental changes, these periods do increase stress in families as well as the children with Down syndrome. These transitions include: a. leaving early intervention services at age 3, b. moving from preschool programs to kindergarten at age 6, c. approaching adolescence, preteens, d. transitioning towards adulthood, teenage years, e. and post school planning, 18-21 (Berry & Hardman, 1998, Blacher, 2001).

When a proper information search has not been conducted prior to making a decision, faulty decisions are often the result (Mann, Burnett, Radford & Ford, 1997). And as medical advances have increased the lifespan of individuals with disabilities, parents will be making decisions for and with their children for a lifetime. The National Down Syndrome Society states the

life expectancy for individuals with Down syndrome to be 60 years today (www.ndss.org, 2011). Parents overwhelmed by daily stress may be unable to make proactive decisions for their child with Down syndrome.

Purpose of the Study

Decisional procrastination is one subtype of defensive avoidance, and it is marked by high conflict, loss of hope for a better solution, no tight deadline, and associated with high stress (Janis & Mann, 1977). In 1982, Mann developed a measurement tool to determine an individual's decisional procrastination tendencies. The purpose of this study was to determine if associations exist between the level of stress in parents of children with Down syndrome and decisional procrastination, specifically during their child's developmental transitions.

Research Questions

1. Are there differences between decisional procrastination in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years)?
2. Are there differences between stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years)?

3. Is there an association between decisional procrastination and stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years)?

Hypotheses

H₁ There are differences between decisional procrastination in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

H₂ There are differences between stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

H₃ There is an association between decisional procrastination and stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

Nature of the Study

A descriptive, exploratory research design was used for this online survey. Participants completed a demographic questionnaire, a parental stress measure, and two measures of decisional procrastination. Research participants were identified through a national organization, National Down Syndrome Congress (NDSC) that maintains a website focusing on information, advocacy, and support for families of individuals with Down syndrome (www.ndsccenter.org). Parents or primary caregivers of children

with Down syndrome comprised the sample from which data was collected. Participants were included in this research study if they met the following criteria: primary caregiver of a child with Down syndrome between 3 and 21 years of age, and the child resided in the family home.

Participants were excluded from participating in this study if any of the following criteria were true: their child with Down syndrome was younger than 3, older than 21, or lived in an out of home placement. Additionally, if the parent or primary caregiver reported a medical diagnosis that affected their stress level, they were excluded from this study. The literature reports a correlation between decisional procrastination and Obsessive Compulsive Disorder (Ferrari & McCown, 1994) and decisional procrastination and Attention Deficit Hyperactive Disorder (Ferrari & Sanders, 2006). The elimination of confounding variables strengthened the research design.

Definition of Terms

Decisional Procrastination (DP): is a maladaptive pattern of postponing a decision when faced with conflicts and choices (Ferrari, Johnson & McCown, 1995).

Stress: is an emotional state evoked by threatening events or stimuli, and a stressful event is any change in the environment that induces a high degree of negative emotion such as anxiety, guilt, or shame (Janis & Mann, 1977).

Developmental Transitions: Normative stages of childhood development (Turnbull, Turnbull & Wehmeyer, 2007).

Summary

This dissertation will be presented in six sections. The next section will be the literature review section and will include the theoretical framework, and research related to decisional procrastination, and parental stress. The third section will discuss the methodology used for this study. The research questions, hypotheses, instrumentation and data analysis procedures will be outlined here. The fourth section will discuss the results of the data collection. The fifth section will be a discussion of the findings. The final section of this paper will be a summary and conclusions about stress and decisional procrastination in parents of children with Down syndrome. Suggestions for future research will also be included in this section.

Chapter II

REVIEW OF RELATED LITERATURE

Introduction

This chapter will be divided into two distinct sections. The first section will introduce the reader to the types of procrastination, explain the theoretical framework of decision making, and discuss the literature related to decisional procrastination. The second section will focus on the research regarding stress in parents of children with disabilities. There will be instances when these sections will be linked together for the purpose of integrating the literature from two diverse fields of research.

“Procrastination” is derived from the Latin root “procrastinare,” translated as “forward + tomorrow”, meaning to put off or postpone until another day (Ferrari, Johnson & McCown, 1995). Through their research, Dr. Ferrari and his colleagues have determined that procrastination is more than inefficient time management. It involves behavioral and cognitive components, also referred to as task delays and decisional delays. (Ferrari, Johnson & McCown, 1995).

In the research literature, there are two areas of procrastination studied: behavioral procrastination and decisional procrastination (Effert & Ferrari, 1989). Behavioral procrastination, consisting of task delay, is further divided into two components, namely avoidant procrastination and arousal

procrastination (Ferrari, Johnson & McCown, 1995). The avoidant procrastinator tends to avoid tasks due to low self-confidence and self-esteem (Hammer & Ferrari, 2002). For example, a student who would rather attribute a poor grade to a lack of effort rather than a lack of ability uses avoidant procrastination to protect his self-esteem. On the other hand, the arousal procrastinator delays tasks until the last minute purposely to experience a euphoric rush during task completion. This individual enjoys having a deadline and working under pressure (Hammer & Ferrari, 2002). Individuals who engage in behavioral procrastination reportedly have a fear of failure and low self-esteem (Lay, 1988) and negative life satisfaction (Effert & Ferrari, 1989). Behavioral procrastination has been the main focus of the research literature as reported by Effert and Ferrari (1989). A primary explanation for this focus is the ready availability of subjects, specifically college students procrastinating over numerous deadlines.

The second area of procrastination is the primary focus of this research paper. Decisional procrastination is defined as a maladaptive pattern of postponing a decision when faced with conflicts and choices (Ferrari, Johnson & McCown, 1995). Decisional procrastination occurs when there is intense conflict regarding an important decision, such as relocation or a career change. The decision maker is fearful of making the wrong choice, and therefore avoids the topic. This is also known as defensive avoidance. Defensive avoidance is the coping pattern used during times of high stress

and no deadline pressures, and is associated with avoidance of information. The Conflict Model of Decision Making (Janis & Mann, 1977) is the theoretical framework of decisional procrastination. The essence of the theory states that there are five patterns of coping behavior that affect the quality of decision making. Each pattern will be fully described in depth.

Theoretical Framework

In making an important decision, intense conflict is likely to arise. Social psychologists Janis and Mann (1977) viewed stress resulting from decisional conflict to be a major determining factor of failure to achieve high quality decisions. The Conflict Model of Decision Making (Janis & Mann, 1977) is based on the presence or absence of three antecedent conditions which determine reliance on a particular pattern of coping with stress. The first condition is the awareness of serious risks about preferred alternatives. For example, the conflict intensifies as the decision maker becomes aware of the risk of suffering losses from whatever choice is selected. Second, the existence of hope (or lack of) of finding a better alternative affects conflict level. The third condition is the belief that there is adequate time to search and to deliberate before a decision is required. Choices to be made in the distant future without immediate time deadlines reduce conflict; however, the individual may be hindered by the lack of a deadline (Mann, Burnett, Radford

& Ford, 1997). Not only can the decisional process be slowed due to the lack of the urgency, but procrastination may result.

The Conflict Model of Decision Making (Janis & Mann, 1977) consists of five types of decision patterns and specifies the conditions that produce each one and its associated level of psychological stress. (See Table 1.) Full descriptions of the five patterns of coping with stress now follow:

Unconflicted adherence: The decision maker ignores information about the risks and losses and decides to continue the present course of action. This is also known as complacency.

Unconflicted change: The decision maker adopts whichever new course of action is most relevant or most strongly recommended.

Defensive avoidance: The decision escapes conflict by procrastinating, shifting responsibility to someone else, or bolstering the least objectionable alternative without considering other options. Incomplete and/or a biased evaluation of information are markers of this coping pattern. Faulty decisions are often the result, due to the defective informational search.

Hypervigilance: The decision maker searches frantically for a way out of the dilemma. It includes a deadline and time pressures, as may be the case in an out of home placement decision based on a medical crisis, such as the sudden transition of an elderly parent being discharged from the hospital to a nursing home. The decision maker

will be in a state of panic and make impulsive decisions that promise immediate relief.

Vigilance: According to Janis and Mann (1977), this is the ideal style of coping in conflict decision making, because it includes a thorough search of information, appraisal, and contingency planning. The decision maker who incorporates vigilance clarifies the objectives, considers the alternative choices, evaluates the consequences, and then proceeds to implement the chosen option.

Table I. *Conflict Theory of Decision Making (Janis & Mann, 1977)*

Coping Pattern	Dominant Information Mode	Characteristics Information Preferences	Levels of Interest in Information
A. Unconflicted adherence	Indifference	Associated with very low stress Nonselective exposure	Low
B. Unconflicted change	Indifference	Associated with very low stress Nonselective exposure	Low
C. Defensive avoidance		Associated with very high stress	
C-1 Procrastination	Evasion	Passive interest in supportive information; avoidance of all challenging information	Low
C-2 Shifting responsibility	Evasion	Delegation of search and appraisal to others	Low
C-3 Bolstering	Selectivity	Selective exposure: search for supportive information and avoidance of discrepant information	Medium
D. Hypervigilance	Indiscriminate search	Associated with very high stress Active search for both supportive and non-supportive information, with failure to discriminate between relevant and irrelevant, trustworthy and untrustworthy	Very high
E. Vigilance	Discriminating search with open mindedness	Associated with moderate stress Active search for supportive and non-supportive information, with careful evaluation for relevance and trustworthiness; preference for trustworthy, non-supportive information if threats are vague or ambiguous	High

Janis and Mann based their Conflict Model of Decision Making (1977) on previous research regarding the coping processes individuals use to deal with stress. Stress is defined as an emotional state evoked by threatening events or stimuli, and a stressful event is any change in the environment that induces a high degree of negative emotion, such as anxiety, guilt, or shame (Janis & Mann, 1977). This unpleasant emotion affects normal patterns of information processing, where extremely low stress and extremely high stress are likely to result in defective information processing and decision making. According to Janis and Mann, intermediate levels of stress are associated with the ideal form of decision making, vigilance.

The Conflict Model of Decision Making (Janis & Mann, 1977) is a valid model with a strong theoretical foundation. This model draws on Lazarus' pioneering work of psychological stress and the coping process in individuals (1966). In 1984, Folkman and Lazarus expanded upon the previous work by distinguishing between problem focused strategies to modify the stressor and emotion focused strategies to regulate fear and anxiety. Problem solving is in concert with Janis and Mann's concept of vigilance whereby the decision maker conducts a thorough search of information, clarifies the objectives, considers the alternative choices, evaluates the consequences, and then proceeds to make a decision. Emotion focused strategies, such as denial and reducing worry by distancing oneself from the decision are similar to the defensive avoidance pattern of coping (Mann, Burnett, Radford & Ford, 1997).

Decisional procrastination is one of the three types of defensive avoidance (Janis & Mann, 1977). Decisional procrastination consists of a cognitive delay and a maladaptive pattern of postponing a decision when faced with conflicts and choices (Ferrari, Johnson & McCown, 1995). This coping pattern may be utilized when there is intense conflict regarding an important decision, and the decision maker tries to escape the conflict (Janis & Mann, 1977). One such difficult decision is faced by parents of young adults with disabilities when determining whether out of home placement is the correct choice when the young adult completes his/her formal schooling (Kazemi & Hodapp, 2006). The decision maker, or parent, may be fearful of making the wrong choice, and therefore avoids thinking about or discussing the topic. Or the decision maker may believe the prospects of finding a good solution are unrealistic and therefore does not seek information regarding options. When a proper information search has not been conducted prior to making a decision, faulty decisions are often the result (Mann, Burnett, Radford & Ford, 1997). With regard to the parent of the young adult with disabilities, the decision for or against an out of home placement is not the issue to consider, but whether or not the parents conducted a thorough informational search before making their decision.

Three essential components of decisional procrastination are high stress, loss of hope for a better solution, and no tight deadline (Janis & Mann, 1977). Although high stress is also associated with hypervigilance, the

difference is that the absence of a deadline provides opportunities for the decision maker to procrastinate. When someone exhibits this decisional procrastination behavior, it can have long reaching detrimental effects. For example, parents who delay the preparation of transitioning their young adults with disabilities into society may be inadvertently doing harm to them. A vigilant decision would more likely result in a planned, gradual transition to a new residence and be less likely to upset the young adult with disabilities. By contrast, a hypervigilant decision made as the result of a parent's illness or death, could lead to a frantic, hurried, immediate transition to a new residence and potentially greatly upset the individual.

Although the Conflict Model of Decision Making (Janis & Mann, 1977) has been the foundation for numerous research studies, there have been a limited number of studies specific to decisional procrastination research. A review of literature regarding decisional procrastination will emphasize what has been discovered and uncover the gaps that justify future research.

Decisional Procrastination

Demographics

Although decisional procrastination research is sparse, several trends are present. The majority of research on decisional procrastination has been conducted on university students and females primarily (Effert & Ferrari, 1989; Ferrari & Olivette, 1993; Harriott & Ferrari, 1996; Ferrari & Dovidio, 2000). Application of the Decisional Procrastination scale (DP) (Mann, 1982) with clinical populations, such as adults with obsessive-compulsive disorder and adults with attention deficit hyperactive disorder, is also found in the literature (Ferrari & McCown, 1994; Ferrari & Sanders, 2006). Two other areas of research include: stress interfering with the information gathering process of decision making (Ferrari & Dovidio, 2001; Rassin, Muris, Booster & Kolsloot, 2008), and decisional procrastination with regard to specific decisions (Germeijs & DeBoeck, 2002).

Due to the fact that decisional procrastination can affect anyone, researchers have attempted to develop a demographic profile of the type of individual who engages in decisional procrastination as a mode of decision making. Decisional procrastination is a coping strategy and coping is linked to personality traits. Using the DP scale (Mann, 1982), Ferrari and colleagues (Harriott & Ferrari, 1996; Hammer & Ferrari, 2002; Diaz-Morales, Ferrari, Argumedo & Diaz, 2006) examined decisional procrastination in individuals

based on the following variables: gender, age, marital status, and education and type of work.

In two studies, women were found to be more indecisive than men (Rassin & Muris, 2005a; Diaz-Morales, Ferrari, Argumedo & Diaz, 2006). Rassin and Muris (2005a) studied 135 university students (mean = 20.8 years) and females were found to be more indecisive than males; however, 78.5% of the sample was female. Diaz-Morales et al (2006) studied 446 Spanish individuals (mean = 49.78 years), which was comprised of an equal number of males and females. This study also compared subjects by age and did not discover any differences in decisional procrastination between the two groups (31-49 years) and (50-64 years). A third study (Harriott & Ferrari, 1996) examined gender differences in 122 female and 89 male "blue-collar" adults (mean = 47.6), and no difference in decisional procrastination based on gender was found.

Hammer and Ferrari (2002) studied 141 individuals (mean = 42 years) and also did not find any differences based upon gender, although their results showed "white collar" workers scoring higher on the procrastination scale than compared to the "blue collar" workers from Harriott and Ferrari's study (1996). One may hypothesize that individuals with college or post college education reported higher levels of decisional procrastination than individuals with a high school diploma or less education. This may be related to higher stress due to decision making responsibilities in their careers. This

supports the important role stress plays in decisional procrastination as previously mentioned (Janis & Mann, 1977).

Marital status was another variable considered to influence decision making. Hammer and Ferrari (2002) did not discover any notable differences in decisional procrastination scores based on marital status. However, married people were found to have higher indecision rates than those no longer married (Diaz-Morales, Ferrari, Argumedo & Diaz, 2006), while Harriott and Ferrari (1996) reported the exact opposite findings. It would seem logical that married people would be less decisive due to the possible negotiation and/or disagreement between the couple. If a married couple was to disagree about a major decision, such as type of schooling for their child with Down syndrome, then decisional procrastination would be a coping method to avoid the conflict.

In summary, two of the four studies revealed higher decisional procrastination rates in women than men (Rassin & Muris, 2005a; Diaz-Morales, Ferrari, Argumedo & Diaz, 2006). This may be due to reduced decision making experiences, resulting in lower decisional confidence in women. Although no differences in decisional procrastination were found between the two age groups of 31-49 and 50-64 years old (Diaz-Morales, Ferrari, Argumedo & Diaz, 2006), further research should be conducted to explore decision making coping styles at different life stages. There was no consensus with regard to marital status and decisional procrastination

tendencies, suggesting the need for further research, such as examination of marital status and specific decisions. Finally, the education level of individuals does appear to affect decisional procrastination. Hammer and Ferrari's study (2002) found higher decisional procrastination in college graduates as compared to high school graduates. These researchers hypothesized that college graduates may have jobs with more responsibilities and higher stress levels leading to increased decisional procrastination. One could also hypothesize that other individuals with many responsibilities and high stress levels, such as parents of children with Down syndrome, would also have high levels of decisional procrastination.

Clinical Diagnoses

In a further attempt to describe the individual who is prone to decisional procrastination, researchers have studied individuals with clinical diagnoses that may interfere with decision making (Ferrari & McCown, 1994; Ferrari & Sanders, 2006).

In the earliest clinical study, sixty-five adults diagnosed with obsessive-compulsive disorder (OCD) (mean = 41.7 years) and their biologically related family members were examined. They were studied regarding both behavioral and decisional procrastination tendencies (Ferrari & McCown, 1994) based on the premise that obsessions and compulsions may be strategies used to avoid unpleasant situations. Avoidance and decisional procrastination

measurements were administered, specifically the Adult Inventory of Procrastination (McCown & Johnson, 1989), and Decisional Procrastination scale (Mann, 1982). Compulsive acts were related to both forms of procrastination, but obsessive thoughts were only found to be correlated to decisional procrastination and not avoidant procrastination. An unexpected finding was that there was no significant difference ($p < .10$) in self-reported avoidant procrastination between the adults diagnosed with OCD and their non-diagnosed related family members (Ferrari & McCown, 1994). Therefore, the assumption that adults with OCD engage in behavioral procrastination as an avoidance strategy is not supported by this research. However, the correlation between obsessive thoughts and decisional procrastination is important because becoming stuck on one idea does not allow the individual to consider the alternatives, which is necessary to make a vigilant decision based on the Conflict Theory of Decision Making (Janis & Mann, 1977).

More recently Rassin and Muris (2005a) explored the relationship between decisional procrastination and obsessive-compulsive tendencies. One hundred and thirty five university students (mean = 20.8 years) not clinically diagnosed with OCD, were given an inventory to measure degrees of compulsive washing and checking, rumination, impulses, and precision (Rassin & Muris, 2005a). The IS (Frost & Shows, 1993) also was administered to assess decisional delay including decisional difficulty and anxiety, worry, regret and low confidence. Correlations were found between

indecision and checking, rumination, impulses, and precision, but no correlation was found between indecision and compulsive washing (Rassin & Muris, 2005a). These two studies confirm the link between decisional procrastination and individuals with obsessive compulsive disorder, both clinically diagnosed and undiagnosed but with OCD tendencies.

An additional focus of the study by Rassin and Muris (2005a) was to investigate if indecisiveness negatively correlated with life satisfaction, and if indecisive individuals were prone to avoid decision making. The results showed there was a negative correlation between satisfaction with life and indecisiveness; however, the researchers noted that causality could not be determined. To test the possible avoidance of decision making, fifteen statements about society were presented to the participants, and they were instructed to write "agree, disagree, or do not know." Even with the variable of time eliminated from the experiment, indecisiveness correlated positively with the number of "do not know" answers, suggesting that indecisive individuals actually fail to reach decisions (Rassin & Muris, 2005a). These researchers suggested furthering their research by investigating whether indecisiveness is associated with specific decisions. Specific decisions for their children with Down syndrome during developmental transitions will need to be made by parents.

In another clinical study, Ferrari and Sanders (2006) compared a convenience sample of 29 adults clinically diagnosed with attention deficit

hyperactive disorder (AD/HD) (mean = 48.6 years) to a control group of 167 adults without the diagnosis (mean = 44.1 years). This exploratory study included administration of three procrastination diagnostic tools: Adult Inventory of Procrastination (McCown & Johnson, 1989), General Procrastination Scale (Lay, 1986), and Decisional Procrastination scale (Mann, 1982) to assess avoidant, arousal, and decisional procrastination respectively. Results confirmed the hypothesis that adults with AD/HD reported significantly higher procrastination than adults without an AD/HD diagnosis (Ferrari & Sanders, 2006). Both behavioral (avoidant and arousal) and cognitive (decisional) procrastination affects adults with AD/HD. Future researchers need to be aware of the correlations between decisional procrastination and individuals with clinical diagnoses, such as OCD and AD/HD, in order to develop exclusionary criteria for their samples.

Stress

Stress is defined as, "an emotional state evoked by threatening events or stimuli," (Janis & Mann, 1977) and when an individual is fearful of the outcome of their decision they may utilize decisional procrastination coping skills. Ferrari and Olivette's 1993 study of 86 adolescent females explored this concept. The relationship between parental authority styles (authoritarian, authoritative, and permissive) and female decisional procrastination was investigated. Daughters raised in a two parent household completed the DP

(Mann, 1982) and a parental authority questionnaire, and as expected high authoritarian households produced daughters who reported significantly more indecision (Ferrari & Olivette, 1993). Possibly, their indecision relates to being fearful of the consequences of making the wrong decision, resulting in decisional procrastination. These individuals would demonstrate high levels of indecision regardless of the actual decision.

The possible link between fear and indecision is supported by the findings from another study (Rassin & Muris, 2005b) whereby 50 female university students were assessed with regard to their perceptions of ambiguous situations. Scores on the Indecisiveness Scale (Frost & Shows, 1993) were compared with scores from a measurement tool consisting of 28 short situation descriptions, with 7 positive, 7 negative, and 14 ambiguous and implying a possible threat. After controlling for confounding variables of anxiety and depression, indecisiveness correlated with the number of ambiguous situations that were labeled as concerning (Rassin & Muris, 2005b). This finding suggests that indecisive individuals are more likely to perceive situations as threatening or stressful, and likely to influence their decision making process either by delay or avoidance.

These findings support the relationship between stress and general indecision. While the Conflict Model of Decision Making (Janis & Mann, 1977) relates the stress or conflict of the actual decision to decisional procrastination, these two studies (Ferrari & Olivette, 1993; Rassin & Muris,

2005b) confirm that individuals who are fearful of the consequences of their decisions are likely to delay or avoid decisions, and be generally indecisive. By contrast, an individual may be generally decisive but due to the high stress of a specific decision (relocation, medical issues) he/she may cope by using decisional procrastination. Therefore, the relationship between stress and decisional procrastination should be studied with parents' general decision making as well as specific decision making during children's developmental transition periods.

Decision Process

Decisional procrastination research consists of the examination of individuals, as well as the decision making process. Early research focused on identification of personality correlates of individuals engaged in decisional procrastination. Subsequently, the focus shifted toward understanding differences in the decision making process between procrastinators and non-procrastinators (Ferrari & Dovidio, 2000; Ferrari & Dovidio, 2001; Rassin, Muris, Booster & Kolsloot, 2008). Because decisional avoidance is associated with incomplete and/or biased evaluation of information, and is influenced by high stress (Janis & Mann, 1977), the examination of decision making with time constraints has been the focus of several procrastination studies. By definition, decisional procrastination is a maladaptive pattern of postponing a decision when faced with conflicts and choices (Ferrari, Johnson & McCown,

1995). This delay in decision making is also one component of Janis and Mann's theory (1977), whereby decisional avoidance occurs when there is no deadline.

To investigate the decision making process, Ferrari & Dovidio (2000) examined the relationship between behavioral styles and decisional procrastination in 130 university students as they chose college courses from an informational board. Specific course information was written on index cards and participants were instructed to turn over as few or as many cards as they needed before making their decision. The amount of information varied from eight to thirty pieces of data in the four groups. The process used to reach the decision with regard to time and amount of information searched was of primary interest, and not the specific decision. The Decisional Procrastination scale (Mann, 1982) in this study had moderate reliability with a Cronbach alpha of .70 (Ferrari & Dovidio, 2000). Decisional procrastination was treated as the independent variable and multiple regressions were used to analyze the data. As hypothesized, the individuals scoring higher in decisional procrastination took longer overall to reach their decision, especially when more data was available for consideration (Ferrari & Dovidio, 2000). They were not distracted in their information search, but used a systematic and in depth approach before making their choice. This desire for a large amount of information about limited choices is suggestive of a cautious approach, and

does not support the thorough informational search needed to make a vigilant decision.

To simulate a more realistic decision making experience, a follow-up study conducted a year later (Ferrari & Dovidio, 2001) included the addition of distracter tasks to increase the participants' cognitive load and thereby increase their stress. Participants were given the DP scale (Mann, 1982) and were divided into two groups based on a median split procedure. The group of indecisives scored at or above the median of 11, while the group of decisives scored below 11. The distracter tasks included remembering random digits, counting clicks, or both tasks combined. Participants were to choose college courses from an informational board consistent with the procedure from the previous experiment. There were no significant differences in the amount of time it took individuals in the decisives group and individuals in the indecisives group to complete their search process; however, individuals in the combined cognitive load condition searched significantly less of the information than those in the other two groups (Ferrari & Dovidio, 2001). Under the conditions of high cognitive demand, a much narrower search strategy was utilized, supporting Janis and Mann's (1977) theory that individuals under high stress engage in an incomplete and/or biased evaluation of information. As a result, poor decisions are to be expected due to the absence of knowledge about all the viable options and their benefits and consequences.

Further exploration of the decision making process was conducted in the Netherlands (Rassin, Muris, Booster & Kolsloot, 2008) with a close replication of Ferrari and Dovidio's study (2000). However, these researchers substituted the Indecisiveness Scale (Frost & Shows, 1993) for the Decisional Procrastination scale (Mann, 1982) used by Ferrari and Dovidio (2000; 2001). The results from their sample of 50 university students (mean = 21.5) fully support the correlation between indecisiveness and narrowed information seeking (Ferrari & Dovidio, 2000), also known as "tunnel vision". "Tunnel vision" is a form of defective information gathering, whereby individuals do not explore many possible options. These participants gathered more information about the course they finally chose compared to the other options (Rassin, Muris, Booster & Kolsloot, 2008).

Indecision and indecisiveness are two distinct terms, specifically because the former addresses procrastination related to important decision making situations (Ferrari, Johnson & McCown, 1995) while the latter refers to general, daily decisions. Because not all decisions are equally important, decisional procrastination may be evidenced in situations where deciding is difficult and stressful (Janis & Mann, 1977). An individual may have little difficulty making daily decisions, and would have a low decisional procrastination score, but at the same time may have difficulty making one or two major specific decisions.

Summary

The concept of decisional procrastination warrants further research, as evidenced by the high percentage of studies involving young university students and the lack of literature involving adult populations. New populations for examination could include adult populations prone to high stress or the study of several generational groups. Research of specific decisional procrastination is in the early stages, suggesting room for growth. Implications of stress levels in parents and decisional procrastination regarding daily decisions could be compared to decisional procrastination regarding specific decisions they are facing based on their child's developmental stage.

Much of the research has centered on demographic profiling, such as the individual's gender, age, marital status and education level. Rassin and Muris (2005b) have also suggested building the literature base by furthering their research and investigating whether general decisional procrastination is correlated with specific decisional procrastination. An extension of this study could include an exploration of a possible relationship of decisional procrastination to other life specific decisions regarding education, vocations, and housing options.

A study of stress and decisional procrastination in parents of children with Down syndrome during their developmental transitions is warranted. The research is limited concerning decisional procrastination in adults. Given that

a main component of decisional procrastination is high stress, it stands to reason to study a population prone to stress, namely parents of children with disabilities. Although there is some research regarding the transition of young adults with disabilities from school, there is limited research devoted to other developmental transitions throughout a child's life. The combination of these topics would add to the existing body of literature in both fields. In addition to these theoretical implications, the practical implications of this research could include the need for more assistance provided to parents of children with disabilities during stressful transition times based on their ages. Parents would then have information presented to them about their options as opposed to having to do an information search by themselves after becoming frustrated.

The following section will discuss the literature related to parents of children with disabilities and the variables associated with parental stress. The research will demonstrate that this population may engage in higher rates of decisional procrastination than the general population due to their higher stress levels. Therefore, the relationship between stress and decisional procrastination should be examined in this population.

Parental Stress

This section will discuss the literature related to parents of children with disabilities and the variables associated with parental stress. The research will show that due to their high stress levels, parents of children with disabilities are likely to engage in higher rates of decisional procrastination than the general population. Therefore, the relationship between stress and decisional procrastination should be explored in this population.

According to the U.S. Bureau of the Census, as of 2004, in the United States there were an estimated 5 million children under age 18 with disabilities (www.census.gov). The stress associated with raising a child with disabilities has been thoroughly researched (Cole & Meyer, 1989; Dykens, Shah, Sagun, Beck & King, 2002; Hodapp, Dykens & Masino, 1997; Hodapp, Ricci, Ly & Fidler, 2003; Lopez, Clifford, Minnes & Oullette-Kuntz, 2008; Orr, Cameron, Dobson & Day, 1993; Pisula, 2007; Ricci & Hodapp, 2003; Roach, Orsmond & Barrett, 1999; Weiss, Sullivan & Diamond, 2003). The findings have uncovered several factors that are correlated with parental stress. These factors include both child and parent related factors, which will be thoroughly discussed in this section.

Although it can be joyful, the responsibility of raising a child is one that is inherently stressful. Furthermore, the degree of parental stress increases when the child has a disability (Lopez, Clifford, Minnes & Oullette-Kuntz, 2008; Roach, Orsmond & Barrett, 1999). Disability is defined as, "having a

physical, mental, or emotional impairment which is expected to be of long, continued and indefinite duration” (U.S. Department of Housing and Urban Development (HUD), 2010). Stress is defined as, “an emotional state evoked by threatening events or stimuli, and a stressful event is any change in the environment that induces a high degree of negative emotion such as anxiety, guilt, or shame” (Janis & Mann, 1977).

Disability vs. No Disability

In their 2008 study, Lopez and colleagues compared 29 parents of preschool children with disabilities to 17 parents of preschool children without disabilities. The group of children with delays had a variety of diagnoses, including Down syndrome and autism. Caregivers were interviewed by telephone to examine parental stress and to investigate the relationship between child and family characteristics and stress. Parents of children with disabilities reported significantly more stress ($M=22.90$; $SD =8.47$) than parents of children without disabilities ($M=13.76$; $SD =7.62$), ($p<.001$) (Lopez, Clifford, Minnes & Oullette-Kuntz, 2008). The children with disabilities also had more maladaptive behaviors than children without disabilities. This supports the findings from a previous parental stress study by Roach, Orsmond and Barrett (1999).

In that study, 41 two-parent families of preschool children with Down syndrome were compared to 58 two-parent families of typically developing

preschool children (Roach, Orsmond and Barrett, 1999). These researchers used the 101 item Parenting Stress Index (PSI) (3rd ed.) (Abidin, 1995) to assess factors of both child and parent related stress in both groups of mothers and fathers. Findings showed that parents of children with Down syndrome perceived more stress on measures of children's distractibility, acceptability, and demandingness than did parents of typically developing children. Additionally, as the number of siblings increased, these parents were more likely to perceive more stress associated with their disabled child's demandingness. An additional finding was that mothers of older children with disabilities perceived more health difficulties than did the mothers of younger children from this group. Reasons for parental stress also differed between mothers and fathers of both groups. Group status (Down syndrome and typically developing children) was a significant predictor of fathers' parental stress. Mothers' stress was associated with children's care giving difficulties. These studies (Lopez, Clifford, Minnes & Oullette-Kuntz, 2008; Roach, Orsmond & Barrett, 1999) demonstrate increased parental stress due to the day to day demands of raising a young child with a disability. Additionally, potential stressors, such as maladaptive behaviors, are likely to increase as the child with disabilities ages.

Maladaptive Behaviors

The presence of one family member's negative behaviors may increase the demands placed on the family and increase their overall stress. Hayden and Goldman (1996) examined the relationship between the individual's maladaptive behavior and the parental stress levels in their study of 105 caregivers of individuals with mental retardation. Maladaptive behaviors were described as physical aggression toward self, others, or property, self stimulation, pica, incontinence, and temper tantrums. The caregivers who responded were primarily mothers (86.7%), with fathers (6.7%), siblings (2.9%), and extended family members (1.9%). The majority of caregivers (62.9%) ranged from 50 to 69 years old and 70.5% of the entire sample was married (Hayden & Goldman, 1996). The sample of young adults with mental retardation was equal with regard to gender and the majority (58.1%) was between the ages of 20 and 29 years old. Severity of retardation included mild (47.6%), moderate (21.9%), severe (20.0%), profound (5.7%), and unknown (4.8%) (Hayden & Goldman, 1996).

The stress instrument used was the Questionnaire on Resources and Stress-Short Form (QRS-SF) (Holroyd, 1987). The QRS-SF has an extensive research base in the disability literature (Glidden, 1993; Glidden & Floyd, 1997). Eleven six-item subscales were used which were based on factor analysis of the original 285 items. Total QRS-SF scores were compared with the independent variables by means of ANOVA. Of significance was marital

status, such that single women had higher QRS-SF scores than their married counterparts. Also noteworthy was the finding that families of adults who exhibited one or more maladaptive behaviors experienced significantly more stress than those families with no maladaptive behaviors (Hayden & Goldman, 1996). This may burden parents to the extent that their daily stress impacts future planning for their child as expressed by parental decisional procrastination.

The correlation between maladaptive child behaviors and parental stress is further supported by research by Weiss, Sullivan and Diamond (2003). They studied parents of 97 individuals with developmental disabilities. These individuals with disabilities ranged in age from 9.3 to 42.5 years, with a mean age of 24.9 years. Since the majority of the children were adolescents or adults, the Parenting Stress Index (PSI) (3rd ed.) (Abidin, 1995) was modified to be age appropriate. The Personal Adjustment factor emerged as a significant predictor of parental stress. This child related factor reflects behaviors that are repetitive and maladaptive, but not antisocial or aggressive. These findings suggest that maladaptive behaviors of individuals with disabilities continue throughout their lifespan, and in turn continue to contribute to parental stress.

This is further evidenced in a study of mothers of children (aged 2 to 18 years) with developmental delays (Orr, Cameron, Dobson & Day, 1993). Parental stress was measured by use of the Parenting Stress Index (PSI)

(Abidin, 1986) in three groups divided by child's age. Mothers of children in preschool (2-5) (N=39), middle childhood (6-12) (N=40), and adolescence (13-18) (N=33) were compared to explore age related changes in parental stress. As expected, behavioral problems were highly correlated with maternal stress in both older groups. Data was not collected for behavioral problems in the preschool group. An unexpected finding was that PSI scores in the adolescent group were consistently lower than the middle childhood group. Parents experienced the most stress during the middle childhood period. These researchers hypothesized that parents learn to adapt to their child's disability over time.

Despite possible adaptation over time, major changes in the family are expected to increase parental stress. One may hypothesize that the uncertainty and changes associated with transitioning from school to work and community life are an added burden upon the individual with disabilities who craves routine and control. Inability to cope with this disruption may manifest as increased behavioral issues (Kazemi & Hodapp, 2006). The stress resulting from these increased behavior problems (frequency and/or intensity) may hinder parental decision making.

Disability Diagnosis

With the knowledge that parents of children with disabilities experience greater stress than parents of children without disabilities, researchers have

attempted to ascertain if specific disabilities cause more parental stress than others. Several comparative studies have examined this concept (Hodapp, Ricci, Ly & Fidler, 2003; Pisula, 2007; Ricci & Hodapp, 2003). A comparison between 25 mothers of children with autism and 25 mothers of children with Down syndrome was made regarding parental stress (Pisula, 2007). The children's age ranged from 4-20 years with a mean of 11 years for each group. The children with Down syndrome were equally split with respect to gender, but the children with autism were 66% male, which is typical of the larger population. Parents were given a Polish version of the 15 scale QRS (Holroyd, 1987). Although this stress tool has not been fully adapted in Poland yet, the researcher felt confident based on the pilot testing, that the validity was good enough for comparative analyses (Pisula, 2007). Parents of children with autism showed higher stress levels than the parents of children with Down syndrome on seven of the 15 QRS scales. The two main scale differences were: Overprotection/Dependency and Difficult Personality Characteristics. These findings may suggest that children with autism cause their parents more stress than children with Down syndrome; however, gender was not analyzed separately. Larger, stronger young adult males with autism would most likely be more difficult to manage than shorter stature young adults with Down syndrome.

Researchers have hypothesized that due to their social nature children with Down syndrome are easier to parent than children with other

developmental disabilities. In 2009, Corrice and Glidden conducted a study to determine if there is a “Down syndrome advantage” as children aged from 12 to 18 years. One hundred twenty mothers (N=56 Down syndrome; N=64 other disabilities) were given subscales of the QRS (Holroyd, 1987) and the Transition Daily Rewards and Worries Questionnaire (TDRWQ) (Glidden & Jobe, 2007). Mothers of children with Down syndrome did report more personal reward rearing of their children than mothers of children with other developmental disabilities. However, no differences were found between the two groups regarding stress levels. An additional finding was maternal age as a confounding factor, such that when it was controlled for there was no difference between the two groups in personal reward. Corrice and Glidden (2009) remarked that because mothers of children with Down syndrome are generally older, they may be better able to handle the stresses and demands of raising children. This may be a partial explanation of why young adults with Down syndrome continue to live with their parents after exiting from school. That is not to say decisional procrastination coping in these parents can be ruled out. Additionally, due to the fact that older mothers are caring for individuals with an expected lifespan 60 years (www.ndss.org), it is crucial that vigilant decision making about out of home placement options be conducted prior to a medical crisis.

Child's Age/Developmental Transitions

One child related factor that has an influence on parental stress is the child's age. In a comparative study of children with Prader-Willi syndrome, Down syndrome, and nonspecific mental retardation, researchers found a within group difference for the children with Down syndrome (Dykens & Kasari, 1997). The 129 participants ranged from 4-19 years (mean = 11 years) and were matched across groups on both gender and age. Based on scores from the Child Behavior Checklist (Achenbach, 1991), age emerged as a significant correlate of maladaptive behavior only in the children with Down syndrome. As these individuals aged, their anxiety/depression, and withdrawal increased ($r_s=.31$ and $.42$, $p_s < .01$, respectively) (Dykens & Kasari, 1997). Higher rates of internalizing problems may be less stressful for parents than increased externalizing problems, such as aggressive behavior. These age related findings were later corroborated in a study of 211 children and adolescents with Down syndrome aged between 4 and 19 years (mean=9.74) (Dykens, Shah, Sagun, Beck & King, 2002).

Dykens et al. (2002) found decreases in externalizing behaviors in the 37 adolescents (14-19 years) as compared to the 174 children aged 4-13 years. Additionally, the adolescents showed age related increases in their internalizing behaviors, especially withdrawal, being more secretive, and preferring to be alone. These age related patterns require further investigation. Withdrawal, anxiety and depression may be a response to

limited social opportunities with one's peers, or may be related to the onset of depression or other problems of adults with Down syndrome (Dykens, 2007). Also, this age related change has been found to influence parental attitudes towards their children with Down syndrome. Older children with Down syndrome were found to be less reinforcing and less acceptable to their fathers (Ricci & Hodapp, 2003) and mothers (Hodapp, Ricci, Ly & Fidler, 2003)

Parental Factors

In addition to the child related factors associated with parental stress (disability vs. no disability, maladaptive behaviors, disability diagnosis, and child's age), researchers have examined parent related factors. Marital status and age of parent have been found to be correlated with stress levels (Hayden & Goldman, 1996; Carr, 2008).

Hayden and Goldman (1996) examined parental stress levels in their study of 105 caregivers of individuals with mental retardation. The majority of caregivers ranged from 50 to 69 years old and the sample of young adults with mental retardation was between the ages of 20 and 29 years old. Even though 70% of the sample was married, marital status was of significance, such that single women had higher QRS-SF (Holroyd, 1987) stress scores than their married counterparts. The correlation between marital status and stress may influence major decisions such as out of home placement of the

young adult with disabilities. A large study by Sherman (1988) compared 154 families who placed their family member with disabilities out of home to 377 families who provided care for them at home. In the case where the family member with disabilities was placed out of home, parental separation or divorce was more prevalent. It was not determined if the stress of caring for the child with disabilities impacted the marriage, or if the stress of caring for the child as a single parent factored into the out of home placement decision, but this provides support for the importance of marital status as a variable of interest.

An additional key variable in parental stress research is parental age. Over the decades as the lifespan of individuals with developmental disabilities has increased, there has been a growing number of aging parents whose care giving responsibilities extend into their old age (Hodapp, 2007). In a longitudinal study of parents of individuals with Down syndrome (Carr, 2008) parents of 28 surviving 40 year olds with Down syndrome were compared to parents of 16 individuals in the non disabled control group. In the Down syndrome group, the average age of mothers was 75.9 years (range=59-87) and the average age of fathers was 75 years (range=65-88). For the first time in the study, mother's age was significantly associated with malaise, older mothers having a higher mean score ($p < .05$).

Researchers have remarked on the increased age of parental caregivers. If offspring with Down syndrome will live into their 50s and 60s

and have parents 30-40 years older, then we will have many families who will need to prepare for care giving after the death of the parents (Hodapp, 2007). Noteworthy in the Carr study (2008) is the finding that although 21 of the 28 individuals with Down syndrome had at least one living parent, 11 (52%) still lived at home, and 4 (19%) lived with a sibling. Only 29% of individuals with a living parent resided in an out of home placement. This supports decisional procrastination coping in these parents of advanced age. It was not specified if the seven individuals with Down syndrome who outlived both parents had a smooth, planned transition to a new residence or a hurried one resulting from crisis and hypervigilant decision making.

In 2001, Blacher states that the stress associated with parents during the launching stage of their young adults into the community deserves further research. However, there are several other specific stressful transitional periods of a child's life that require attention from researchers in the disability field. These developmental transitions include: a. leaving early intervention services at age 3, b. moving from preschool programs to kindergarten at age 6, c. approaching adolescence, preteens, d. transitioning towards adulthood, teenage years, e. and post school planning, 18-21 (Berry & Hardman, 1998).

Summary

The stress associated with raising a child with disabilities has been thoroughly researched. Research has documented the association between

child and parent related factors regarding stress in parents of children with disabilities. The key child related factors include: maladaptive behaviors, disability diagnosis, and age. The main parent related factors include: marital status, and age. Marital status and age are also key variables in the decisional procrastination literature (Diaz-Morales, Ferrari, Argumedo & Diaz, 2006). The population of parents of children with Down syndrome requires examination to determine if daily care giving burdens and increased stress levels affect decision making negatively.

Decisional procrastination researchers need to expand upon their laboratory studies of artificially induced stress via cognitive overload tasks (Ferrari & Dovidio, 2001). Now that they've determined a relationship between stress and defective information seeking leading to decisional procrastination, we need to examine this construct in a population prone to high stress, i.e. parents of children with disabilities. Daily parental stress may interfere with decision making throughout the child's lifetime. The research methodology will be described in detail in the next section.

Chapter III

METHODS

Introduction to the Methodology

The purpose of this study was to assess decisional procrastination levels in parents of children with Down syndrome, because daily stress may be negatively influencing their decision making. This research examined decisional procrastination and stress in parents of children with Down syndrome during their developmental transitions. Also, this study explored the association between decisional procrastination and parental stress with regard to general decision making. This study attempted to determine if the association between parental stress and decisional procrastination differed based upon which developmental transition period their child is currently in.

Research Design

A descriptive, exploratory, cross-sectional design was used in this study to explore the association between stress and decisional procrastination in parents/primary caregivers of children with Down syndrome during their developmental transitions. According to Alreck and Settle (2004), personal interviewing, telephone interviewing, postal mail, and online surveys are the four main methods of data collection in survey research. For the pilot study, telephone interviewing and postal mail were used to gather the data.

For this dissertation study, online surveying was chosen to collect data from a large sample.

Pilot Study

The pilot study entitled “An exploratory pilot study of a relationship between stress and decisional procrastination of parents of children with disabilities” was conducted in Spring 2010. A two part mixed methods design was used to explore a possible relationship between stress levels in parents of children with disabilities (ages 5-21 years old) and decisional procrastination. A secondary goal of the pilot study was to test the research methodology regarding recruitment and data collection. A phone interview was conducted with those participants who returned a signed informed consent form. Participants provided demographic information about their child with disabilities aged 5-21 years old, consisting of: child's age, child's gender, nature of the disability, and number of siblings. General questions regarding stress and decision making and residential placement were also asked. Phone interviews were tape recorded (with consent of each participant). These recordings were used for transcription and accuracy of data collection solely. For the second portion of this research study, participants received a written transcript of the phone interview via mail and were instructed to add, delete, or change any items. They also received 3 short questionnaires: Questionnaire on Resources and Stress (QRS-F), Indecisiveness Scale, and Decisional Procrastination Scale. Parents returned

paperwork via mail. Twenty research envelopes were distributed and four primary caregivers chose to participate, for a 20% response. The sample consisted of two mothers, one father, and one female guardian, ranging in age from 40's to 60's, with high school or college degrees, and currently married. These caregivers had three (25%) or more children (75%), and their child with a disability was more likely to be male (75%). Only two diagnoses were reported, Down Syndrome (75%) and Cerebral Palsy (25%).

Themes resulting from that pilot research included: 1. The concept of stress was agreed to influence decision making; however, 50% of the participants mentioned other children in the family provided them with stress too. Family size should not be overlooked as a contributing variable to stress. 2. Life experiences may account for decisional confidence. During the short phone interview, these experiences were mentioned: "other daughter survived cancer," "son went to war for 8 months," "put grandmother in a rest home," and "adopted 7 children in addition to our 3 biological ones." When asked if stress played a role in decision making, participants answered, "I don't think so," "Absolutely, absolutely, stress plays a big role," "Yes," "Stress is a main thing." Several of the participants mentioned being "prepared," or "cushioned," for raising a child with disabilities due to having certain life experiences previously.

The two main limitations to this pilot study were decreased participation and small sample size. Although a survey response of 20% is considered

good in the literature (Alreck & Settle, 2004), a higher percentage would have provided additional data to analyze. Correlations could not be made from such a limited response.

Modifications

Based on the results of the pilot study, five specific modifications were made to improve the methodology for the dissertation study. First, parents of children with a specific disability, namely Down syndrome, were recruited. This was done to narrow the focus of this exploratory research. The second modification was to focus on parental decision making during specific developmental transitions of their children. The quantity and importance of decisions made for children with Down syndrome varies according to their stage in life. Third, the age range was broadened to include parents of children 3 and 4 years old, where previously the cutoff was 5 years old. This was done to include parents of children in the very important developmental transition of preschool. Fourth, the two-part data collection used for the pilot study was condensed into a single data collection for each participant. This modification was made in order to limit participant procrastination during the second phase of data collection. The fifth and final modification to the pilot study methodology was the use of electronic surveys as opposed to mailed paper surveys. Not only did this reduce researcher expenses and minimize scoring errors, it also enabled the survey to be easily distributed to a national organization. As a result, recruitment of participants from the National Down

Syndrome Congress increased the total number of participants for the dissertation study.

Sample Population

The data was collected from a sample of parents or primary caregivers of children with Down syndrome. Participants were identified through a national agency, National Down Syndrome Congress (NDSC), which maintains a website for education and support of parents of children with Down syndrome (www.ndsccenter.org). Minimum participation of 102 parents/primary caregivers was the objective in order to have a sufficient sample pool.

Participants were included in this research study if they met the following criteria: primary caregiver of a child with Down syndrome between 3 and 21 years of age, with the child residing in the family home. Participants were excluded from participating in this study if any of the following criteria were true: their child with Down syndrome was younger than 3, older than 21, or lived in an out of home placement. Additionally, if the parent or primary caregiver reported a medical diagnosis that may affect their stress level, they were excluded from this study. The literature reports a correlation between decisional procrastination and obsessive compulsive disorder (Ferrari & McCown, 1994) and decisional procrastination and attention hyperactive

deficit disorder (Ferrari & Sanders, 2006). Elimination of confounding variables strengthened the research design.

Procedure

The National Down Syndrome Congress agreed to facilitate this research (Appendix A). They assisted by announcing this research to their 13,000 members through an e-mail notification with a link to the electronic survey host, ASSET. This email invitation included: Letter of solicitation (Appendix C), and a link to the survey on ASSET (electronic survey host). Once Seton Hall University IRB approval was received (Appendix B) the survey commenced, and was available for the entire month of November 2010. Three reminders were sent at one week intervals. Due to the anonymity of the survey, all members of the NDSC received the survey reminders, whether they had already participated or not. Parents/primary caregivers completed four short questionnaires via computer. Completion of surveys was expected to take approximately 30 to 45 minutes, and this was explained in the letter of solicitation.

The four surveys consisted of a demographic questionnaire and three validated tools; one measured parental stress and two measured decisional procrastination. The Questionnaire on Resources and Stress (QRS-F) included 52 true or false questions, such as: "It is easy for me to relax." (See Appendix D). The Decisional Procrastination Scale included five questions

such as: "I put off making decisions." (See Appendix E). The Indecisiveness Scale included 11 questions such as: "I find it easy to make decisions." (See Appendix F). The demographic questionnaire included 13 questions related to: parental age, gender, education level, ethnicity, child's age, child's gender, and number of siblings (See Appendix G). Upon completion, participants submitted their answers via computer on the electronic survey host, ASSET.

Instrumentation

The three validated instruments that were used were the following:

1. Short Form of the Questionnaire on Resources and Stress (QRS-F)

(Friedrich, Greenberg & Crnic, 1983)

2. Decisional Procrastination Scale (Mann, 1982)

3. Indecisiveness Scale, revised

(Frost & Shows, 1983; Rassin, Muris, Franken, Smit & Wong, 2007)

These three tools have all been published in textbooks, and are able to be used for education and research purposes free of charge. However, as a courtesy, the living authors were contacted and informed of this dissertation study and the use of these tools. No objections were voiced, and several expressed their pleasure about expanding the research base on this topic.

The QRS-F (Friedrich, Greenberg & Crnic, 1983) is a 52 item shortened measurement tool derived from the original 256 item Questionnaire on Resources and Stress (QRS) (Holroyd, 1974). This true/false self report questionnaire was designed to measure the impact a child who is handicapped, developmentally delayed or chronically ill has upon his/her family members. The QRS-F assesses parental stress in four areas: parent and family problems (20 items), pessimism (11 items), child characteristics (15 items), and physical incapacitation (6 items). This instrument is widely used in the disability research (Ben-Zur, Duvdevany & Lury, 2005; Baker & Blacher, 2002; Hodapp, Dykens & Masino, 1997) due to its sound psychometric properties. Scott, Sexton, Thompson & Wood (1989) tested the reliability of the QRS-F, and found total alpha scores of .92. Individual alpha scores were: parent and family problems (.84), pessimism (.85), child characteristics (.87), and physical incapacitation (.77). According to Portney & Watkins (2000), scales with moderate correlations (between .70 and .90) among the items suggest a scale with strong internal consistency. Validation studies (Friedrich, Greenberg & Crnic, 1983; Scott, Sexton, Thompson & Wood, 1989) provide support for the QRS-F as a reasonably valid measurement tool.

There are two main decisional procrastination assessment instruments, Mann's Decisional Procrastination Scale (DP) (1982) and Frost and Shows' Indecisiveness Scale (IS) (1993). These two instruments were

utilized based on their high reliability and validity, with Cronbach alpha as high as .83 and .87 respectively (Orellana-Damacela, Tindale & Suarez-Balcazar, 2000). Orellana-Damacela and colleagues (2000) also reported a high correlation between the two decisional procrastination scales, $r(181) = .77$, $p = 0.0001$.

The Decisional Procrastination (DP) tool is a self reported 5 item, 5 point Likert scale (Mann, 1982) that is the fundamental instrument used to assess decision making. It was developed to examine procrastinatory behavior related to important decision making situations (Ferrari, Johnson & McCown, 1995). It was derived from Mann's 31 item Flinder's Decision Making Questionnaire (1982), which included Janis and Mann's five coping strategies; however, it is able to stand alone as a valid measurement tool (Mann, Burnett, Radford & Ford, 1997).

The 5 item DP scale (Mann, 1982) has a Cronbach alpha of .72-.80 and retest reliability of .62-.69 as reported by Ferrari, Johnson and McCown (1995). Coefficients above .75 indicate good reliability and values from .50 to .75 suggest moderate reliability (Portney & Watkins, 2000). A substantial number of studies have used the DP scale (Mann, 1982) to assess an individual's use of indecision as a coping strategy (Effert & Ferrari, 1989; Ferrari & Olivette, 1993; Ferrari & McCown, 1994; Harriott, Ferrari & Dovidio, 1996; Ferrari & Dovidio, 2000; Orellana-Damacela, Tindale & Suarez-

Balcazar, 2000; Ferrari & Dovidio, 2001; Hammer & Ferrari, 2002; Patalano & Wengrovitz, 2007).

Frost and Shows (1993) Indecisiveness Scale (IS) is an additional tool designed for the purpose of evaluating an individual's decisional procrastination tendencies. This self reported tool is a 15 item, 5 point Likert scale that not only assesses decisional delay, but also incorporates decisional difficulty and personality traits including anxiety, worry, regret and low confidence (Patalano & Wengrovitz, 2007). A total score is obtained by adding all the items, with higher scores (range: 15-75) reflecting higher levels of indecisiveness (Rassin & Muris, 2005b). This instrument has shown good internal consistency in cross cultural research with Cronbach alpha = .88 for American women and .85 for American men, as well as .83 for Chinese women and .84 for Chinese men (Patalano & Wengrovitz, 2006).

Recently, Rassin and colleagues computed reliability and validity studies on the IS (Frost & Shows, 1993), and discovered four of the fifteen items were omissible (Rassin, Muris, Franken, Smit & Wong, 2007). The items omitted were found to measure specific indecision, such as: difficulty deciding what to order from a menu, or difficulty planning free time. Since the purpose of the Indecisiveness Scale is to measure general indecision, deletion of questions measuring specific indecision will strengthen the tool's validity. The revised 11 item version of the IS, with scores ranging from 11-55,

has been found to possess good four week test–retest reliability ($r = .88$) and internal consistency (Cronbach's alpha = .87) (Rassin et al., 2007).

Research Questions

1. Are there differences between decisional procrastination in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years)?
2. Are there differences between stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years)?
3. Is there an association between decisional procrastination and stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years)?

Hypotheses

H₁ There are differences between decisional procrastination in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

H₂ There are differences between stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

H₃ There is an association between decisional procrastination and stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

Data Analysis Procedures

All recorded and written data was kept in a locked file cabinet in the primary investigator's office, and will remain there for three years. Subjects'

information was anonymous. All demographic data was coded to protect confidentiality. The data was collected by way of an electronic survey tool. The primary researcher exported the data into SPSS 18.0 format for the purpose of analysis. Data was coded and analyzed for differences between parental stress and decisional procrastination based on the child's developmental transition period. Also data was coded and analyzed for associations between parental stress and decisional procrastination scores.

The statistical package, SPSS 18.0 was used to perform all analyses of quantitative data. Frequencies and percentages were reported for nominal level demographic variables. These included: parent's gender, marital status, and child's gender. Medians were reported for ordinal level variables. These included: parental age, education, total number of children, and child's age. Nonparametric tests were used to determine if differences existed between child's age (developmental transition) and parental stress and decisional procrastination scores. Nonparametric data analysis was chosen for three reasons. First, it cannot be assumed that the sample of convenience represented a larger normal distribution. Second, because the data were at the nominal and ordinal level of measurement nonparametric analysis is recommended (Portney & Watkins, 2000). Third, the data weren't normally distributed, and could not be transformed even after several attempts. Therefore, a non-parametric analysis based on rank-ordering was used, as opposed to parametric analysis based on probability.

Chi Square Test of Association was used to analyze relationships between the nominal level variables, such as parental gender and child's gender. Spearman's Rank Correlation Coefficient was used for ordinal level variables to analyze relationships between the dependent variables (QRS-F, IS, and DP scales). Although the QRS-F has nominal level True/False questions, the tool is scored as a whole and treated as ordinal level data in the literature. In order to uncover differences in variables mentioned in the literature, Kruskal Wallis Tests were conducted. The variables of interest included: parental age, marital status, education, total number of children, and child's age.

The three hypotheses were addressed via the data collected from the quantitative measures. This included the three self administered questionnaires related to stress and decisional procrastination. In order to examine developmental transition periods, the ages (in years) of the children originally were categorized into the following groups: a. 3-6, b. 7-10, c. 11-14, d. 15-17, e. 18-21. However, based on the actual data the child's ages were collapsed into 3 groups: a. 3-6 years, b. 7-13 years, and c. 14-21 years. These age groups adequately reflect the major developmental transition periods, as supported by the disability literature (Hodapp, Ricci, Ly & Fidler, 2003).

Chapter IV

RESULTS

Characteristics of the Sample

The original sample included 135 participants; however, the final sample consisted of 106 parents or primary caregivers of children with Down syndrome aged 3-21 years old. The 29 exclusions were due to the participants reporting a medical diagnosis affecting their stress level. The literature supports a relationship between OCD and decisional procrastination, and ADHD and decisional procrastination, so that was the rationale for the exclusion criterion (Ferrari & McCown, 1994; Ferrari & Sanders, 2006).

A median effect size required 352 participants and a large effect size required 102 participants. The small sample may have been due to several factors. The survey was conducted in November, and parents may have been too busy with Thanksgiving plans to participate. When the NDSC announced this study, there were also two other studies recruiting participants simultaneously. Another explanation for the small sample could be that a large percentage of NDSC members were excluded due to having children younger than three years old. New parents of children with Down syndrome may join the national organization for information and support, while parents of older children may participate more with state or local support groups.

The majority of the participants were married (90.6%) white (91.5%) females (92.5%). Due to their homogenous nature, the variables of marital status, ethnicity, and parental gender were not able to be analyzed beyond frequencies and percentages. There was variability with regard to parental age, education level, and total number of children. The majority of the participants were in their forties (51.9%) with an approximately even split between twenties and thirties (26.4%) and fifties and sixties (21.7%). The educational levels were as follows: high school graduates (21.7%), college graduates (42.5%), and masters or doctoral degree recipients (35.8%). The total number of children included: one child (12.3%), two children (34.9%), three children (36.8%), and four or more children (16.0%).

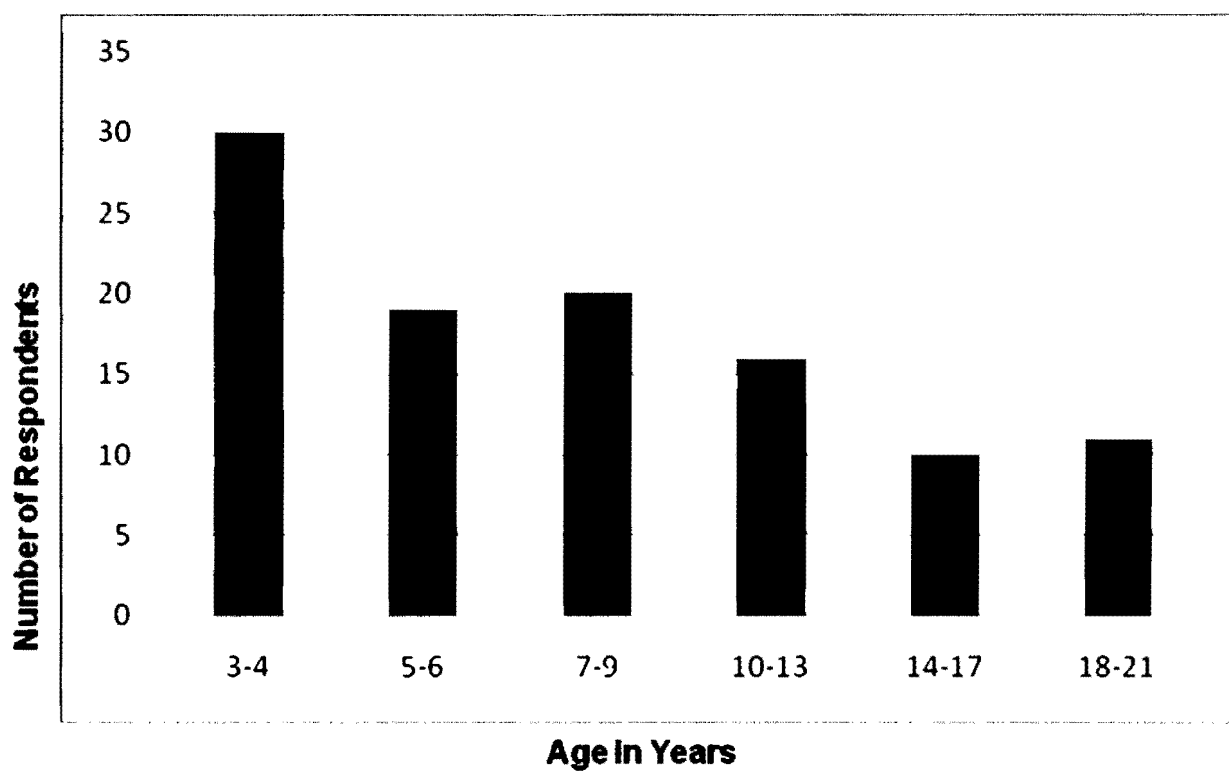
The majority of children attended public school (88.7%), and therefore this variable could not be analyzed further with regard to parental decision making. There was roughly an even split regarding child's gender, with females slightly higher (52.8%) than males (47.2%). The demographic breakdown of the 106 participants can be seen below in Table II.

Table II. Demographic Characteristics of Participants (N=106)

Demographic	<i>f</i>	%
Parental		
Gender		
Female	98	92.5
Male	8	7.5
Age Group		
20s-30s	28	26.4
40s	55	51.9
50s-60s	23	21.7
Marital Status		
Married	96	90.6
Not Married	10	9.4
Ethnicity		
White	97	91.5
Black/African American	4	3.8
Hispanic/Latino	2	1.9
Asian	0	0
American Indian	0	0
Other	3	2.8
Education Level		
High School Graduate	23	21.7
College Graduate	45	42.5
Masters or Doctoral Degree	38	35.8
Total # of Children		
1	13	12.3
2	37	34.9
3	39	36.8
4 or more	17	16.0
Child's		
Gender		
Female	56	52.8
Male	50	47.2
Age Group		
3-6 years	49	46.2
7-13 years	36	34.1
14-21 years	21	19.7
Education Type		
Public	94	88.7
Private	10	9.4
Homeschool	2	1.9
Total	106	

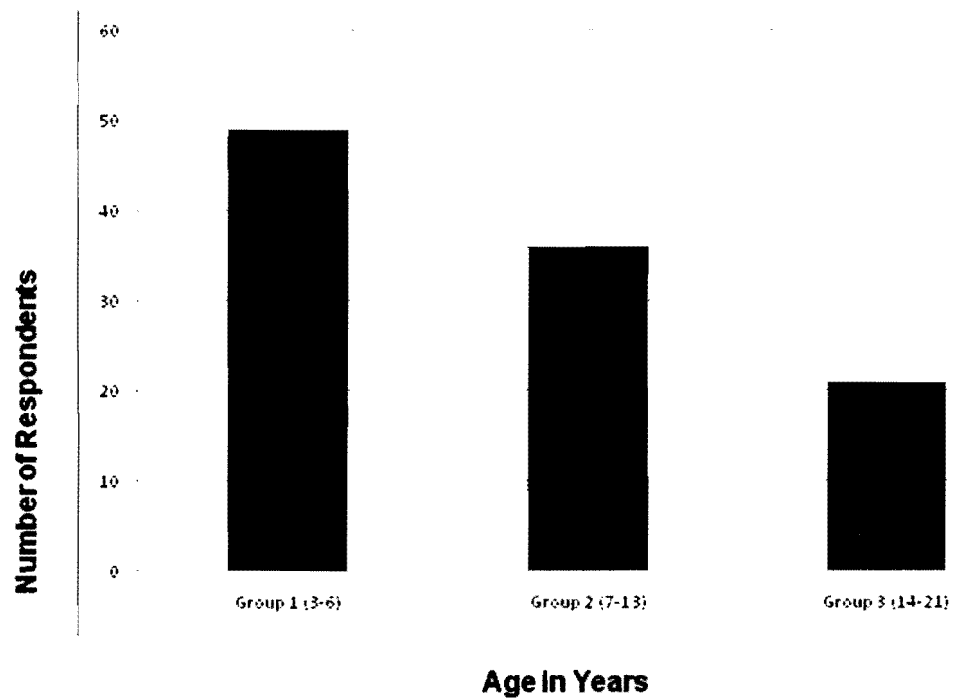
The data collected regarding the children's ages needed to be condensed from five age groups to three age groups in order to use analysis to address the hypotheses regarding stress, decisional procrastination and developmental transitions. The original child age groups are shown below in Figure 1. As you can see, the 30 parents of 3-4 year olds who participated in this research outnumbered all the other groups.

Figure 1. *Age of child with Down syndrome*



In order to analyze the data and form a clearer picture of the developmental transition periods represented by the 106 participants in this study, the data were collapsed into three groups (3-6 year olds, 7-13 year olds and 14-21 year olds). The three collapsed child age groups are shown below in Figure 2. Participants represented in the three groups were: Group 1 = 49, Group 2 = 36, Group 3 = 21.

Figure 2. *Age Groups of children with Down syndrome*



Even after collapsing the age groups, there were only 21 parents in the 14-21 year old group. There are two possible theories for this. First, because the participants were recruited through a parent support group (NDSC), overall membership may be skewed toward parents of younger children trying to learn about Down syndrome and gain support from others. Social support has been shown in the literature to reduce parental stress. Second, parents of older children may either be too stressed from raising teenagers to participate in a survey, or they may actually be the targeted focus of this research, in that they may be using decisional procrastination coping to avoid thinking about critical decisions such as employment and housing options for their young adults. So when a study about decision making was presented to them, avoidance coping was used.

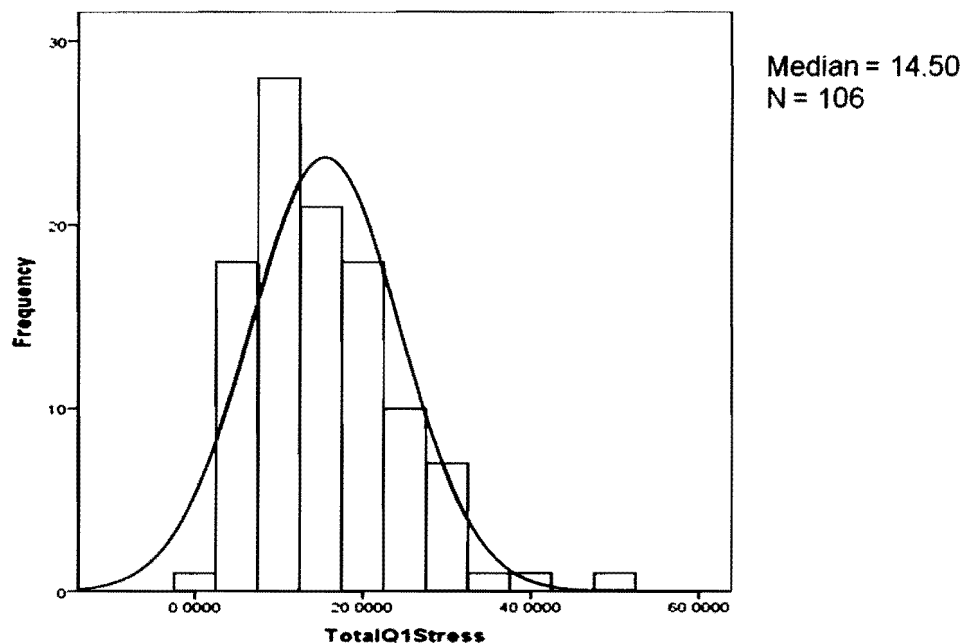
Data Set and Normality

In addition to the demographic data collected from the 106 participants, there was data based on the scores from the three validated measurement tools. In order to convert the paper questionnaires to the online survey format, two of the tools needed to be modified for ease of scoring. The paper versions of both the QRS-F (Friedrich, Greenberg & Crnic, 1983) and the IS (Rassin, Muris, Franken, Smit & Wong, 2007) had reverse coded questions to reduce the likelihood that participants would answer all questions the same. When the tools were modified for the electronic version on ASSET, it was important

to make sure their reliability remained intact. Therefore, SPSS (18.0) was used to conduct a Cronbach's alpha coefficient to test the reliability of the modified tools. The reliability for the electronic instrumentation was as follows: QRS-F (.91), IS (.95), DP (.90). These reliability statistics were consistent with those reported for the paper versions of these measures, and previously mentioned in this dissertation.

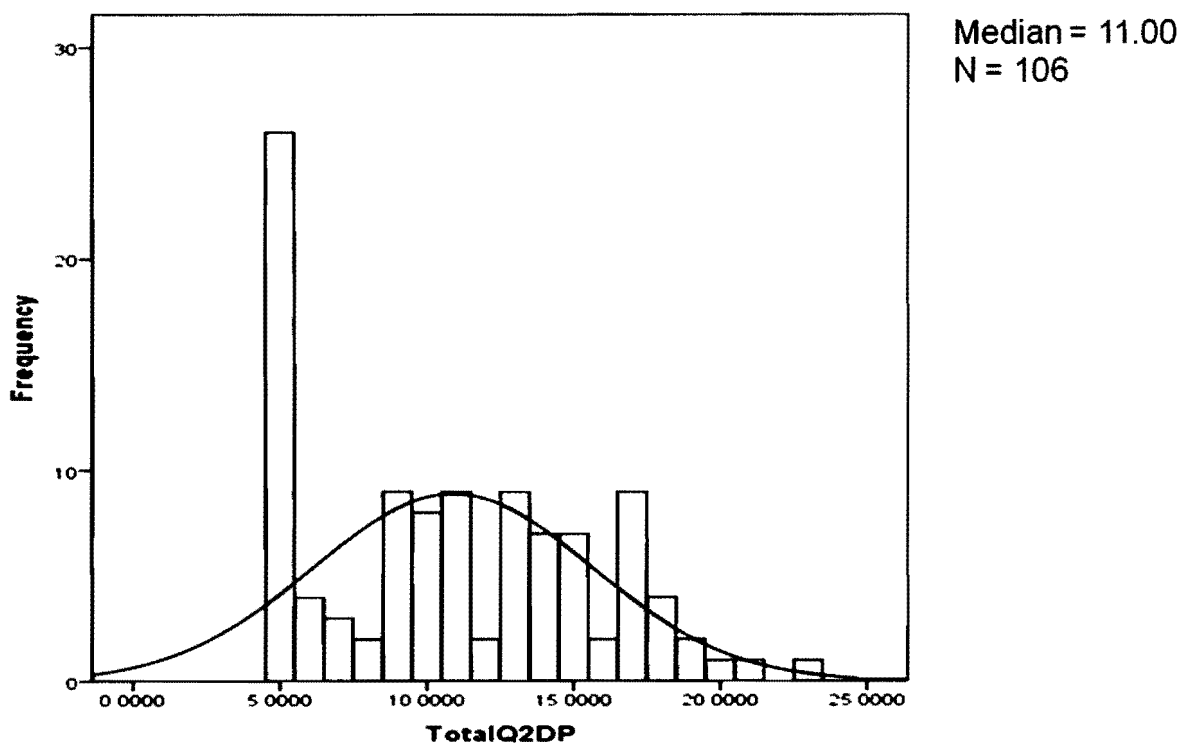
Originally, parametric analysis was the intended form of investigation; however, based on the non-normality of the data sets non-parametric analysis was utilized. The data distribution for the stress measure (QRS-F) is shown in Figure 3. The histogram shows a positive skew as evidenced by a longer tail to the right. Possible scores for this tool ranged from 0-52, and this sample had a median of 14.50.

Figure 3. *Data Distribution for QRS-F*



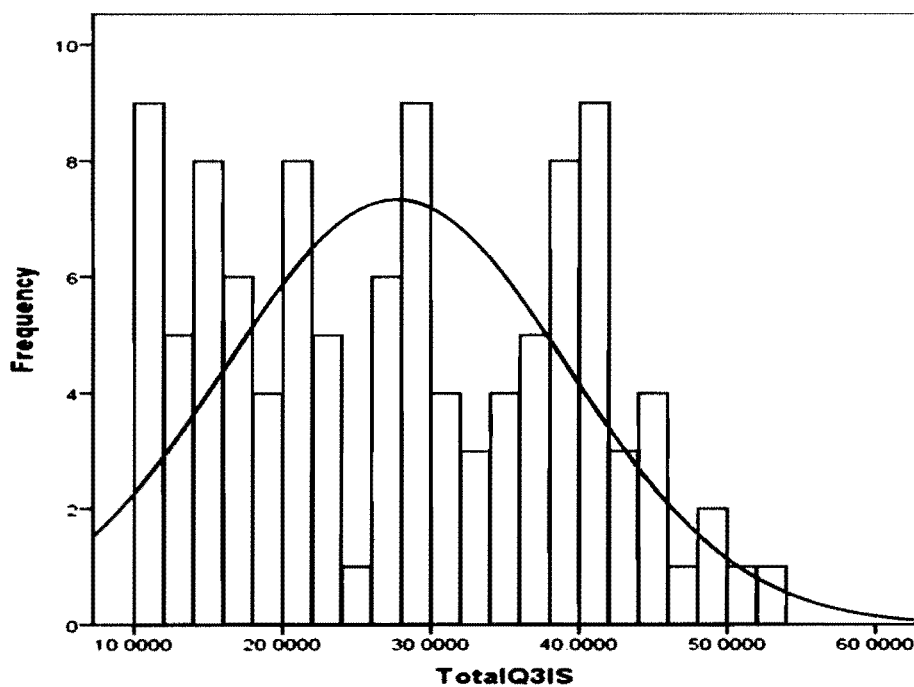
The data distribution for one of the decisional procrastination measures (DP) is shown in Figure 4. Possible scores for this tool ranged from 5-25, and this sample had a median of 11.00. According to Portney & Watkins (2000), the median is a better measure of central tendency than the mean when data are not normally distributed. As you can see, this data set does not have a normal bell-shaped curve.

Figure 4. *Data Distribution for DP*



The data distribution for the second decisional procrastination measure (IS) is shown in Figure 5. Possible scores for this tool ranged from 11-55, and this sample had a median of 28.00. Perhaps this histogram best reflects the fact that the data need transformation. Because the data from the three quantitative tools did not follow the standard bell shaped curve, efforts were made to transform the data to normal distribution.

Figure 5. *Data Distribution for IS*



After examining the data from the three histograms, another test of normality was done. When the skewness ratio (Skewness/Standard Error of Skewness) is less than 2, the data are normal. The skewness ratio was larger than two for each of the three data sets. Then transformation of data was done in order to convert the non-normal data. Each of these options was tried: elimination of outliers, log base 10, square root, squared, and inverse reciprocal. Each time the skew analysis was repeated to determine if it was less than 2. It was not. At the end of this process, it was determined that the data weren't normally distributed and a non-parametric analysis based on rank-ordering would be justified.

Results of the Tests of Hypotheses

The Kruskal-Wallis H Test is used to compare more than two independent groups (Portney & Watkins, 2000). In this study, it was used to look for differences between decisional procrastination in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years). It was also used to look for differences between stress in parents of children with Down syndrome during three developmental transition periods (Group 1 = 3-6 years; Group 2 = 7-13 years; and Group 3 = 14-21 years). Results for the first hypothesis can be seen below in Table III., followed by an explanation of the results.

Hypotheses 1

H₁ There are differences between decisional procrastination in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

Table III. *Kruskal-Wallis Results for IS*

Ranks		
ChildAgeGroup	N	Mean Rank
TotalQ3IS 1	49	58.45
2	36	56.36
3	21	37.05
Total	106	

Parents in Group 1 with a child aged 3-6 years old had the highest decisional procrastination mean rank (58.45). Parents in Group 2 were ranked second with a mean rank of 56.36. And parents of children aged 14-21 years old (Group 3) were ranked third with a mean rank of 37.05. The results of the data analysis do support differences in parental decisional procrastination for the 3 developmental groups. Significance was reached with a p value of 0.02, which was less than the value of $p < 0.05$. Therefore this hypothesis is supported.

The Kruskal-Wallis test only shows that there is an overall difference across the 3 groups. We don't know if each pairwise comparison is significant. So then I used Mann-Whitney test for pairwise comparisons, and to protect against Type 1 error I used a Bonferroni correction, and this was done on

SPSS 18.0. For the pairwise comparisons, parents in Group 1 did score significantly higher than parents in Group 3. The group comparisons were as follows: Groups 1:2 = .772, Groups 1:3 = .007, and Groups 2:3 = .025. Significance was determined by dividing 0.05 by 3, because there were three groups. Therefore 0.0167 was the significance level for these pairwise comparisons. Significance was reached for groups 1 and 3.

Age Group 1 includes 2 transition periods (entering preschool, and entering school) and therefore this result is logical and expected, as supported by Senecal & Guay's study in 2000, which said coping with stressful events delays decision making. Results for the second hypothesis can be seen below in Table IV., followed by an explanation of the results.

Hypotheses 2

H₂ There are differences between stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

Table IV. *Kruskal-Wallis Results for QRS-F*

Ranks			
	ChildAgeGroup	N	Mean Rank
TotalQ1Stress	1	49	57.82
	2	36	55.50
	3	21	40.00
	Total	106	

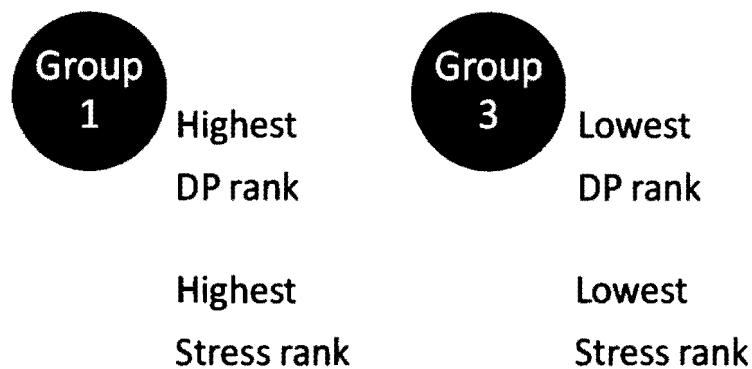
When exploring differences in parental stress for the 3 child age groups, the p value was 0.08. Therefore this hypothesis was not supported. I imagine that a larger sample run in a future study may reflect data that support this hypothesis. Although significance was not reached for this variable, it does not mean the differences do not exist, but merely that this sample did not reflect them.

A point of interest is that in parents of children ages 3-6 years old, their mean rank of 57.82 was the highest, and parents of children 14-21 had the lowest mean rank of 40.00. This order is identical to the order of the decisional procrastination ranking. This leads us to the third hypothesis. Results for the third hypothesis can be seen below in Figure 6, followed by an explanation of the results.

Hypotheses 3

H₃ There is an association between decisional procrastination and stress in parents of children with Down syndrome during three developmental transition periods (3-6 years; 7-13 years; 14-21 years).

Figure 6. *Kruskal-Wallis Results for Stress and DP Association*



With regards to an association between decisional procrastination and stress in parents of children with Down syndrome during three developmental transition periods, my findings were that: age group 1 with parents of children ages 3-6 years old, had the highest ranking for both the decisional procrastination measure and the stress measure. By contrast, age group 3 with parents of children ages 14-21 years old had the lowest ranking for both the decisional procrastination measure and the stress measure. Based on the literature and the rank order of these results, the association between stress and decisional procrastination does exist. And although it was expected that parents of older children would be more stressed and have higher DP during this developmental transition period that required major decisions, the large age range may have been too broad.

A future study could seek more participants from the oldest child age group, and thus have a narrower age range, such as 18-21 years old. For parents of children in their final year or two of school, much higher parental DP and stress ranks would be expected.

In addition to the three hypotheses, differences in other variables mentioned in the literature were examined using Kruskal-Wallis Tests. Due to the nominal level data, the Mann Whitney U Test was used for the child's gender. These results can be seen below in Table V., followed by an explanation of the results.

Table V. *Kruskal-Wallis Results for Other Variables*

Variable of Interest	# of Groups	QRS-F	DP	IS
Parental Age (20s-30s, 40s, 50s-60s)	3	.37	.91	.33
Parental Education (HS and College)	3	.59	.13	.09
Total # Children (1,2,3,4+)	2	.44	.14	.06
Child's Age (3-6, 7-13, 14-21)	4	.36	.17	.07
Child's Gender	3	.08	.35	.02
	2	.85	.02	.06

For the parental age variable, previous research showed that older mothers of children with Down syndrome had higher stress levels than younger mothers of children with Down syndrome (Carr, 2008). These results do not show significant differences in stress between parents in their 20s-30s, 40s, or 50s-60s.

Qualitative data from the pilot study suggested increased stress with increased family size. These results do not support that, and that is why it is important to remember not to generalize qualitative findings. Although significance was not reached for these variables, we cannot conclude that these associations do not exist, but merely that this sample did not reflect them.

The education variable was gleaned from the decisional procrastination research. Hammer and Ferrari's 2002 study found higher DP in college graduates as compared to the high school graduates from Effert and Ferrari's 1989 study. The results from this research did not reflect differences in the three education groups; however, when the groups were collapsed into two groups (high school graduates and college graduates and beyond), the scores on the Indecisiveness Scale approached a significant p value (.06), with higher decisional procrastination in high school graduates than individuals with college and beyond. This contradicts Hammer and Ferrari's findings from 2002.

Differences were detected in child's age and were addressed by the hypotheses. Of the independent variables that were stated in the Method section, parental gender, ethnicity, marital status, and type of child's schooling were not able to be analyzed beyond frequency counts due to their homogenous nature.

An unexpected finding was that differences were detected in child's gender with a significant p value (.02) on the Mann Whitney U Test. Parents of females were found to have higher decisional procrastination rates than parents of males. Age was not a factor as male and female children were evenly distributed among parental age groups as well as in the three child age groups. No literature yet looks at parents and why they may be more decisive in making decisions for their sons as compared to their daughters. However, these results provide an additional explanation as to why a larger portion of daughters remain in the family home after age 21 as compared to sons. Previous researchers attributed that finding to larger, stronger males being more difficult to care for physically by their mothers (Blacher, 2001). Now we see that mothers of daughters are more indecisive than mothers of sons. The literature doesn't suggest any reasons why and therefore this is a new finding.

A Spearman's rank order correlation was run to determine if a relationship existed between the 106 parents' stress and decisional procrastination scores. There was a weak, positive correlation between Stress and DP scores, which was statistically significant ($r = .330$, $P = 0.01$) and a

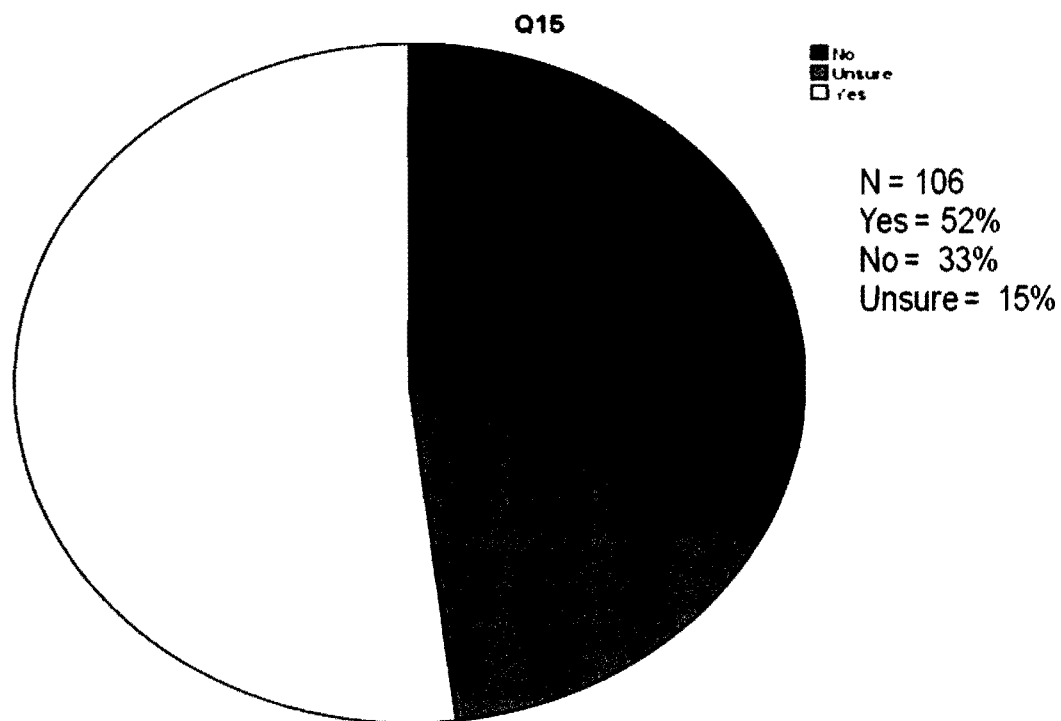
moderate, positive correlation between Stress and IS scores, which was statistically significant ($r = .437, P = 0.01$). There was a strong, positive correlation between DP and IS scores, which was statistically significant ($r = .842, P = 0.01$). Due to this strong correlation, these two decisional procrastination tools are often used together to strengthen the research.

The p value of 0.01, means that there is a 1 out of 100 chance of making a Type I error (Portney & Watkins, 2000). Therefore the probability that these results occurred by chance are very small. These findings do suggest stress, decisional procrastination and IS are inter-related; however, I cannot conclude that research on this topic is complete. A study of parental stress regarding specific decisions and decisional procrastination would be a logical extension of this study. Additionally, qualitative data may flesh out these quantitative findings.

As a result of the pilot study findings, two questions were added to the demographic questionnaire regarding stress and decision making. This was done, because it appeared from the phone interviews that people seemed to think there was some relationship between stress and decision making. This section represents quantitative analysis from the qualitative findings. When parents or primary caregivers were asked if they believed that stress influenced their decision making 52% said Yes, 33% said No, and 15% were unsure or failed to make a decision (Figure 7). This option of "unsure" was drawn from the research literature of Rassin & Muris, 2005a. Their study

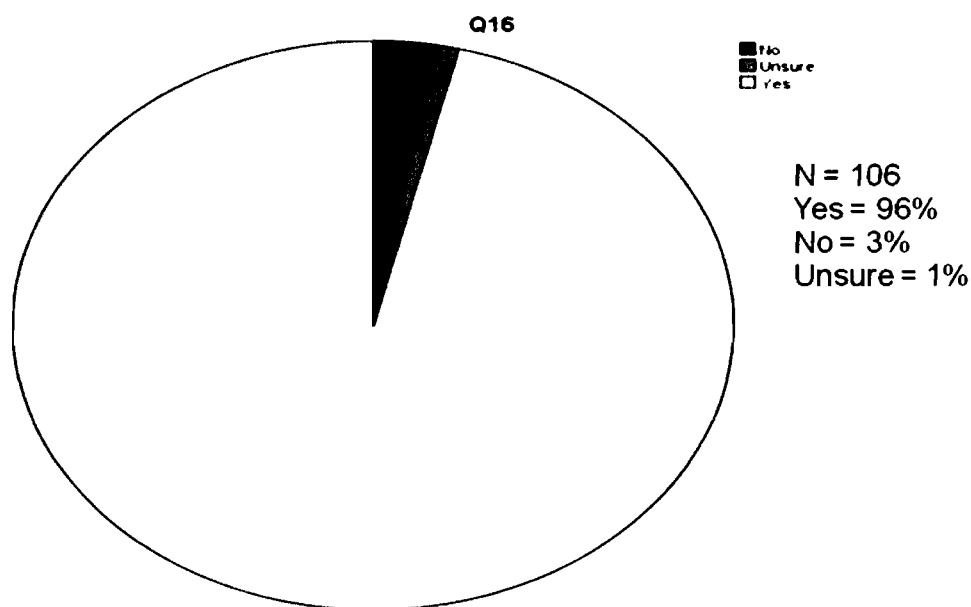
found that indecisive individuals delay as well as cancel decisions. This question yielded similar results to the Spearman correlations obtained, and were mentioned above.

Figure 7. *Stress and Decision Making*



In contrast to the previous slide, the participants were very decisive when answering the question, “Do you believe that your life experiences have been helpful in your decision making? 96% responded Yes, 3% responded No, and only 1% responded Unsure (Figure 8).

Figure 8. *Life Experiences and Decision Making*



This finding supports the previous work by Mann, Beswick, Allouche & Ivey in 1989. They determined that life experiences play a role in how individuals cope during decision making. In addition to reducing daily stress, providing training classes for parents with children with Down syndrome or other disabilities could increase their decisional confidence, and lessen their decisional procrastination coping strategies.

Although the quantitative analysis of parental age and stress levels (Kruskal Wallis Test) did not show significant differences in stress between parents in their 20s-30s, 40s, or 50s-60s, life experiences cannot solely be measured by chronological age. What this finding indicates, is that regardless of one's age, practice making decisions can lead to decisional confidence.

Chapter V

DISCUSSION

General Discussion of Study Findings

Although the sample for this study may not be representative of the larger population, these results are interesting and worthy of further investigation. This summary of results is based upon the independent variables that were analyzed. Regarding parental age, these results do not show significant differences in parental age and stress, which is contrary to previous research where older mothers of children with Down syndrome had higher stress levels than younger mothers of children with Down syndrome (Carr, 2008). As you may recall, Carr's longitudinal study looked at mothers of adults with Down syndrome, and there is a large age difference between mothers of a 40 year old and mothers of a 21 year old.

With regard to education, Hammer & Ferrari's 2002 study found higher decisional procrastination in college graduates as compared to high school graduates. The results from this research did not reflect differences in the three education groups, but when the groups were collapsed into two groups (high school graduates and college graduate and beyond) scores on the Indecisiveness Scale approached a significant p value (.06), with higher DP in high school graduates than individuals with college and beyond. This contradicts the 2002 findings of Hammer and Ferrari. An explanation for this

could be that the individuals with more education had more decisional opportunities in their lives which led to higher decisional confidence, and were therefore more decisive. This trend was also reflected in the 96% of participants who agreed that life experiences are helpful in decision making.

The variable addressing the total number of children in the family was included based on the qualitative pilot study findings. In the original phone interviews, parents reported stress coming from their other children also. However, this variable was not shown to have an effect upon parental stress or decisional procrastination in this study. Perhaps one possibility why parents in larger families may not have more stress is that they may have more support from family members or religious affiliations. Social support has been shown in the literature to moderate stress.

Differences were identified in child's age and parental indecisiveness. This is supportive of the hypotheses. Parental decisions made on behalf of their children throughout their developmental stages will vary in number and importance. And during times of major decision making, such as early childhood, the stress involved with worrying about making the right choice can result in decisional avoidance. And although these results are logical, this research has not been explored before.

A new finding was discovered with regards to child's gender and parental indecision. Parents of females were found to have higher decisional procrastination rates than parents of males. There was nothing in the

literature which would explain why. However, upon reflection this finding makes sense, and in the out of home placement literature, sons are more likely to live outside the family home after exiting schooling. This researcher hypothesizes that mothers may be more protective of their daughters than of their sons, which would lead to worrying and then they may engage in decisional procrastination coping due to the loss of hope about a better solution, which is an antecedent condition of the Conflict Theory. But because this is more anecdotal than evidence based, further research should be conducted in order to provide a stronger explanation.

Due to the lack of demographic variability, parental gender, ethnicity, marital status, and type of child's schooling could not be analyzed beyond frequencies and percentages. However, these independent variables are important and their interactions with parental stress and decisional procrastination should be investigated in future studies on this topic. For example, there is a major difference between public and private school environments. The inclusion level in public school is another level of detail that will affect stressor level in different developmental periods.

An additional variable to include in future research could be a qualitative question related to trust and decisional procrastination. How often do parents trust other facilities and how does that affect decisional procrastination? If a parent doesn't completely trust others, maybe that is why he/she delays making a decision. Fear of making the wrong decision is an

element of decisional avoidance (Janis & Mann, 1977). However, parents who have decisional confidence would be the ones that are making the decisions. In that aspect, maybe they trust themselves enough to weigh all the information provided to them before making their decision. Individuals who have low decisional confidence may use buck passing as their avoidance strategy, because they highly trust the health or educational professional to make the decision for them. The issue of trust would be an excellent element to include in future studies. Qualitative research could be used to delve into this area in depth.

One more variable to include in future research could be a qualitative question related to parental stress and their child's health. Because individuals with Down syndrome have shortened life spans due to medical issues, parental stress may be increased due to health concerns. Additionally, this shortened lifespan may be one reason why they do not plan for any type of adult living arrangements beyond the home environment, figuring that they won't live long enough to warrant the plan, so they subconsciously procrastinate instead of addressing it. On the other hand, with good medical treatment, individuals with Down syndrome can live into their fifties or sixties, according to the National Down Syndrome Congress. When parents are even considering out of home placement options for their young adults, important information such as the quality and availability of medical treatment should be provided to them to assist in their vigilant decision making. They should also

be provided with this information prior to a medical emergency or hypervigilant coping may be the result due to the time pressure.

Limitations

All research has limitations, and there were five main limitations in this research study. They included a small sample size, respondent bias, using an electronic survey vs. a paper survey, inability to generalize to larger population, and limited data for parents of the oldest children.

The first limitation to this study was the small sample size obtained. In a prevalence study in the United States (Shin, Besser, Kucik, Lu, Siffel & Correa, 2009), currently there are an estimated 83,400 children with Down syndrome between the ages of 0 and 19 years of age, and this exploratory study examined less than 1% of that figure. Also a larger sample may have less variability, normalized data, and therefore parametric analysis could have been used.

Secondly, these results may reflect non response bias, whereby parents of older children who did not participate in this survey were the individuals affected by daily stress and decisional procrastination coping.

A third limitation was the method of survey distribution. A mailed survey may have reached a different set of parents. Although 90% of the NDSC members have computer access, they may prefer to complete surveys with pen and paper. Electronic survey was chosen to limit financial expense as well as reduce investigator error in scoring.

A fourth limitation of this study was that it only measured the relationship between stress and decisional procrastination in parents of

children with Down syndrome. Therefore, the results cannot be generalized to parents of children with disabilities of a different diagnosis. An extension of this research to those populations would broaden the literature base. Also, the data are reflective of participants who were members of the National Down Syndrome Congress. The results from this study may not represent the beliefs of parents who are not members of this organization, and therefore no assumptions can be made about stress and decisional procrastination of those individuals. Additionally, these results from this small exploratory study cannot be generalized to all of the members of the National Down Syndrome Congress.

A fifth limitation was that parents of children aged 18-21 were under represented in this survey. Based on the conflict theory of decision making, decisional procrastination could be an issue for these parents because stressful decisions concerning transitions to community life, both residential and vocational would need to be made for these young adults exiting high school.

Implications

The implications of this dissertation research are very important for both theoretical and clinical reasons. The theoretical importance of this research will be discussed first. This dissertation research is the first exploration of decisional procrastination in a truly stressed sample, whereas previously, stress or cognitive overload was artificially induced in a clinical

setting to study the association between stress and DP (Ferrari & Dovidio, 2001; Rassin, Muris, Booster & Kolsloot, 2008). Also, these results are supportive of the Conflict Theory of Decision Making by Janis and Mann (1977). Based on this theoretical framework, benchmarks of decisional procrastination coping include: an incomplete and/or a biased evaluation of information, no time deadline and high stress. Faulty decisions are often the result, due to the defective informational search. Stress can interfere with the active information gathering process needed for vigilant decision making. As the literature suggests, as children pass through different developmental transitions, their parents are faced with varying levels of stress and many decisions to be made. If the decision is too stressful, or parents are overwhelmed with daily stress, they may avoid decisions altogether.

The data revealed an association between parental stress and child's age. My data supports that differences in parental decisional procrastination exist during different developmental transitions of their children. For example, parents of children in the 3-6 year age group need to make decisions about entering preschool, therapies, exiting preschool, and entering elementary school. Additionally, numerous medical decisions are made during this time period. 96% of my sample agreed that stress influences their decision making process. By contrast, parents of children with Down syndrome aged 7-13 may already have the major educational and therapeutic decisions made and in place, and therefore DP would not be as high as the previous group.

A third contribution to the literature provided by my research is the establishment of reliability statistics for the modified QRS-F, DP, and IS, which will be of assistance to others interested in researching decisional procrastination via electronic methods.

The clinical importance of this research is also noteworthy. Based on the results from this research, parents of 3-6 year olds and parents of 14-21 year olds should be provided with additional decision making resources. Nearly 50% of this sample was obtained from parents of children aged 3-6 years old, suggesting that this demographic is actively seeking information or support already. However, parents of 14-21 year olds may need more assistance with the information gathering process, due to burnout from years of caretaking or lack of hope about their child's options. By pinpointing certain developmental transitions that are more stressful, professionals can provide information and options to parents during these difficult decision times.

Decision workshops can also be conducted for the improvement of decision-making skills and confidence, which reduces decisional procrastination as supported by previous research (Mann, Beswick, Allouache & Ivey, 1989). By increasing the amount of information provided to parents during developmental transitions and also teaching them how to make vigilant decisions through workshops, we will be empower parents of children with Down syndrome to make proactive decisions on behalf of their

children, rather than reactive decisions due to procrastination or hypervigilant coping.

Chapter VI

CONCLUSIONS

Decisional procrastination (DP) is a coping method used during times of high stress. The decisional procrastination literature tells us that general cognitive overload or stress interferes with the information gathering process (Ferrari & Dovidio, 2001; Rassin, Muris, Booster & Kolsloot, 2008). The process of gathering information is crucial to making vigilant decisions (Janis & Mann, 1977). Parents of children with disabilities are reported to exhibit higher levels of stress than parents of children without disabilities (Roach, Orsmond & Barratt, 1999; Lopez, Clifford, Minnes & Oullette-Kuntz, 2008). If decisional procrastination is linked to stressors in one's life situation, then an individual under high stress conditions will not be able to make vigilant decisions. It was unclear whether previous research linking cognitive overload and decisional procrastination would be supported in a population prone to high stress, namely parents of children with Down syndrome.

As children pass through different developmental transitions, their parents are faced with varying levels of stress and many decisions to be made. Therefore, parental stress and decision making was examined based on the child's developmental transition stage. The three groups of children that were studied were ages 3-6 years, ages 7-13 years, and ages 14-21 years. Due to the small sample, the original five transition stages were

collapsed into these main three groups representing early childhood, middle childhood, and adolescence and young adulthood. Differences were found between parental decisional procrastination rates of the three age groups. Parents of the youngest children were found to be more indecisive than parents of the oldest children. Due to the many educational and medical decisions that need to be made for preschool aged children, these results were expected and logical. As the majority of decisional procrastination research was conducted on college aged participants, this research was noteworthy. Additionally, a new finding was added to the research base, because this study uncovered that parents of daughters with Down syndrome were more indecisive than parents of sons with Down syndrome. The results from this dissertation open the door to the possibilities of future studies on the topic of parental stress and decisional procrastination.

Future Directions

The findings from this decisional procrastination study can be further expanded upon in several different ways. This was an exploratory study whereby I applied decisional procrastination research to a stressed group, in this case parents of children with Down syndrome. To move forward, parents of children with autism or other disabilities could be studied regarding parental stress and decision making.

The finding of parents of daughters being more indecisive than parents of sons was a new finding and deserves further study. Further exploration of the variable of child's gender and parental decisional procrastination may add a theoretical basis to the anecdotal notion of mothers being more protective of their daughters than of their sons. The relationship between the child's gender and the parent's indecision may be a factor in the higher rate of out of home placement for male children.

In order to investigate specific decisions, such as the one mentioned above, an English tool to measure specific indecision needs to be created. The only tool to measure specific indecision is in Dutch (Germeijs & DeBoeck, 2002). Possibly a modified Indecisiveness Scale could be tested for specific decisions. This tool could then be used for the general population for major life milestones, such as getting married, moving, or deciding to go back to school.

Finally, a further area of decisional procrastination research could examine individuals who have leadership positions. Would people who are decisive at work also be decisive at home with personal decisions? Or would the stress of making so many professional decisions result in higher personal procrastination in decision making? While this dissertation research is important and adds to the existing body of literature, there are many future studies that can be conducted on the topic of decisional procrastination.

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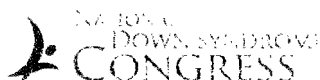
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Appendix A
Approval to Conduct Research at Site



NATIONAL CENTER
1370 Center Drive, Suite 102
Atlanta, Georgia 30338
phone: 800-232-NDSC toll free
fax: 770-604-9898
e-mail: info@ndscenter.org
www.ndscenter.org

THE NATIONAL ORGANIZATION
OF POLYMERASE CHAIN REACTION

May 7, 2010

Laurel Zeisler
1400 County Hwy 9
Schenevus, NY 12155

Dear Ms. Zeisler:

Thank you for your interest in the area of Down syndrome research. While we value the effort you are putting forth, we discourage research-related studies, materials, sampling, etc. to take place during the convention.

However, the NDSC center would be willing to assist you by announcing your research to our families through an email notification as well as alert affiliate leaders to your need for parent participation.

Please send us your official research project details and the information our families will need to participate at your convenience and we will spread the word as widely as possible.

Thanks again for your time and consideration and best of luck.

Sincerely,

Coleen Popp

Coleen Popp
Convention Coordinator

Appendix B

IRB Approval

SETON HALL UNIVERSITY

1 8 5 6

Letter of Solicitation

November, 2010

Dear Parent,

I am a Doctoral Candidate in the Department of Graduate Programs in Health Sciences at Seton Hall University. I am also a speech language pathologist practicing in Delaware County, NY. I would like to invite you to participate in a dissertation research study I am conducting. The purpose of this study is to explore stress levels in parents (or primary caregivers) of children with Down syndrome (ages 3-21 years old) and possible relationships with decisional procrastination.

This study will consist of demographic questions about yourself and your child with Down syndrome (for example, age and gender). Then you will have 3 short questionnaires. The Questionnaire on Resources and Stress (QRS-F) includes true or false questions, such as: "It is easy for me to relax." The Indecisiveness Scale includes questions such as: "I find it easy to make decisions." The Decisional Procrastination Scale includes questions such as: "I put off making decisions." Upon completion, you will submit your survey electronically.

Completion of surveys is expected to take approximately 45 to 60 minutes. There are no known risks or discomforts associated with your involvement. Also, it is not anticipated that you will benefit directly by participating in this research study. There will be no costs involved in participating in this research. You will not receive financial compensation for your participation.

Your identity will be kept confidential. Your information will be assigned a code number. The data will be kept in a locked file cabinet in the principal investigator's office for three years. The information obtained is solely for research purposes to determine if relationships exist between stress levels in parents and decision making patterns. No identifying information will be used and all information will be used in aggregate. After three years, all data will be destroyed.

Your participation in this study is completely voluntary. There is no penalty for not participating. You can discontinue completing the survey at any time without consequence. This research has been approved by the Institutional Review Board of Seton Hall University. Thank you for your participation in my dissertation research. Please ask me any questions you may have:

Principal Investigator: Laurel Zeisler, Doctoral Student, Department of Graduate Programs in Health Sciences, Seton Hall University, NJ phone 607-278-5271 e-mail: laurel.zeisler@student.shu.edu

Faculty Advisor: Valerie Olson, Ph.D., Associate Professor, Department of Graduate Programs in Health Sciences, Seton Hall University, NJ phone 973-275-2086 e-mail: olson.val@shu.edu

IRB Office: Mary Ruzicka, Ph.D., Director, Seton Hall University Institutional Review Board
phone 973-313-6314 e-mail: irb@shu.edu

Agreement: I have read the procedure described above. I voluntarily agree to participate in the procedure and by completing and submitting the survey, I am giving my consent to participate.

Seton Hall University
Institutional Review Board

OCT 18 2010

School of Health and Medical Sciences
Department of Graduate Programs in Health Sciences
tel. 973 275 2076 • Fax 973 275 2171
400 South Orange Avenue • South Orange, New Jersey 07079 • shu.edu

Approval Date:

Seton Hall University
3/2005

Appendix C

Letter of Solicitation

Dear Parents/Primary Caregivers,

<http://asset.tlhc.shu.edu/servlets/asset.AssetSurvey?surveyid=4190>

I am a Speech Language Pathologist in my final year of study in the School of Health and Medical Sciences at Seton Hall University, completing my Doctoral research project. I am seeking to understand the relationship between stress and decisional procrastination in parents of children with Down syndrome. I hope this information will help to uncover patterns of stress during different developmental transitions and provide information regarding when future support and information should be increased.

Your involvement in the study is completely voluntary and anonymous.

Participation in this research activity will entail completing a survey regarding stress and decision making. Withdrawal from this study can be done at any time without any penalty.

There are no foreseeable risks associated with the survey. The survey is expected to take approximately 30-40 minutes to complete. There are no direct benefits from participating in this study. The results of this study may help to determine whether or not daily parental stress affects decision making, and if the relationship differs depending on the child's developmental time frame (ages 3-21 years).

The survey will be completed using the ASSET online survey system. No personal information will be collected from the participants, thus ensuring that responses remain anonymous. The data will be stored by the principal investigator in a secure, locked site. Completing the survey is considered voluntary consent to participate in the study. This study was approved by the Institutional Review Board of Seton Hall University. To ensure anonymity, there is no username required for log-in purposes. Please complete this survey only once. Thank you for your help.

All questions or concerns about the survey may be referred to the research team: Laurel Zeisler, Principal Investigator (laurel.zeisler@student.shu.edu) and Dr. Valerie Olson, Research Faculty Advisor (olson.val@shu.edu).

Appendix D

Questionnaire on Resources and Stress (QRS-F)
(Friedrich, Greenberg & Crnic, 1983)

Stress Questionnaire: Please answer the questions with regard to your child with Down syndrome.

True False

- | | | |
|--|-----------------------|-----------------------|
| 1. <i>My child doesn't communicate with others of his/her age group.</i> | <input type="radio"/> | <input type="radio"/> |
| 2. <i>Other members of the family have to do without things because of him/her.</i> | <input type="radio"/> | <input type="radio"/> |
| 3. <i>Our family disagrees on important matters.</i> | <input type="radio"/> | <input type="radio"/> |
| 4. <i>I worry about what will happen to my child when I can no longer take care of him/her.</i> | <input type="radio"/> | <input type="radio"/> |
| 5. <i>The constant demands for care for my child limit growth and development of someone else in our family.</i> | <input type="radio"/> | <input type="radio"/> |
| 6. <i>My child is limited in the kind of work he/she can do to make a living.</i> | <input type="radio"/> | <input type="radio"/> |
| 7. <i>I have accepted the fact that my child might have to live out his/her life in some special setting.</i> | <input type="radio"/> | <input type="radio"/> |
| 8. <i>My child can't feed himself/herself.</i> | <input type="radio"/> | <input type="radio"/> |
| 9. <i>I have given up things I have really wanted to do in order to care for my child.</i> | <input type="radio"/> | <input type="radio"/> |
| 10. <i>My child is unable to fit into the family social group.</i> | <input type="radio"/> | <input type="radio"/> |
| 11. <i>Sometimes I avoid taking my child out in public.</i> | <input type="radio"/> | <input type="radio"/> |
| 12. <i>In the future, our family's social life will suffer because of increased responsibilities and financial stress.</i> | <input type="radio"/> | <input type="radio"/> |
| 13. <i>It bothers me that my child will always be this way.</i> | <input type="radio"/> | <input type="radio"/> |
| 14. <i>I feel tense when I take my child out in public.</i> | <input type="radio"/> | <input type="radio"/> |
| 15. <i>I can't go visit friends whenever I want.</i> | <input type="radio"/> | <input type="radio"/> |
| 16. <i>Taking my child on vacation spoils the pleasure for the whole family.</i> | <input type="radio"/> | <input type="radio"/> |
| 17. <i>My child doesn't know his/her address.</i> | <input type="radio"/> | <input type="radio"/> |
| 18. <i>The family doesn't do as many things together now as we ever did.</i> | <input type="radio"/> | <input type="radio"/> |
| 19. <i>My child isn't aware of who he/she is.</i> | <input type="radio"/> | <input type="radio"/> |

20. *I get upset with the way my life is going.*
21. *Sometimes I feel very embarrassed because of my child.*
22. *My child doesn't do as much as he/she should be able to do.*
23. *It is difficult to communicate with my child because he/she has difficulty understanding what is being said to him/her.*
24. *There aren't many places where we can enjoy ourselves as a family when my child comes along.*
25. *My child is over-protected.*
26. *My child isn't able to take part in games or sports.*
27. *My child has too much time on his/her hands.*
28. *I am disappointed that my child does not lead a normal life.*
29. *Time drags for my child, especially free time.*
30. *My child can't pay attention very long.*
31. *It isn't easy for me to relax.*
32. *I worry about what will be done with my child when he/she gets older.*
33. *I get almost too tired to enjoy myself.*
34. *His/Her confidence is not one of the things I appreciate about my child.*
35. *There is a lot of anger and resentment in our family.*
36. *My child is not able to go to the bathroom alone.*
37. *My child cannot remember what he/she says from one moment to the next.*
38. *My child cannot ride a bus independently.*
39. *It is not easy to communicate with my child.*
40. *The constant demands to care for my child limit my growth and development.*
41. *My child does not accept himself/herself as a person.*
42. *I feel sad when I think about my child.*
43. *I often worry about what will happen to my child when I can no longer take care of him/her.*

44. *People can't understand what my child tries to say.*
45. *Caring for my child puts a strain on me.*
46. *Members of our family do not get to do the same kinds of things other families do.*
47. *My child will always be a problem to us.*
48. *My child is not able to express his/her feelings to others.*
49. *My child has to use a bedpan or diaper.*
50. *I often feel blue.*
51. *I am worried much of the time.*
52. *My child cannot walk without help.*

Appendix E

Decisional Procrastination scale (DP)
(Mann, 1982)

Decisional Procrastination scale	<i>Not true for me</i>	<i>Often untrue for me</i>	<i>Sometimes true/false for me</i>	<i>Often true for me</i>	<i>True for me</i>
<i>1. I waste a lot of time on trivial matters before getting to the final decision.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>2. Even after I make a decision I delay acting on it.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>3. I don't make decisions unless I really have to.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>4. I delay making decisions until it's too late.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>5. I put off making decisions.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix F

Indecisiveness Scale (IS), revised
(Frost & Shows, 1983; Rassin, Muris, Franken, Smit & Wong, 2007)

Indecisiveness Scale	<i>Highly disagree</i>	<i>Somewhat disagree</i>	<i>Neutral</i>	<i>Somewhat agree</i>	<i>Highly agree</i>
<i>1. I try to put off making decisions.</i>	○	○	○	○	○
<i>2. I don't always know exactly what I want.</i>	○	○	○	○	○
<i>3. I find it difficult to make decisions.</i>	○	○	○	○	○
<i>4. I don't like to be in a position to make decisions.</i>	○	○	○	○	○
<i>5. Once I make a decision, I don't always feel confident that it is a good one.</i>	○	○	○	○	○
<i>6. I usually don't make decisions quickly.</i>	○	○	○	○	○
<i>7. Once I make a decision, I worry about it.</i>	○	○	○	○	○
<i>8. I become anxious when making a decision.</i>	○	○	○	○	○
<i>9. I often worry about making the wrong choice.</i>	○	○	○	○	○
<i>10. After I have chosen or decided something, I often believe I've made the wrong choice or decision.</i>	○	○	○	○	○
<i>11. It seems that deciding on the most trivial things takes me a long time.</i>	○	○	○	○	○

Appendix G

Demographic Questionnaire

1. **What is your relationship to the child?**
 - Mother* *Father* *Sibling*
 - Grandparent* *Aunt* *Uncle*
 - Other*

2. **What is your gender?**
 - Male* *Female*

3. **What is your age?**
 - 20s* *30s* *40s*
 - 50s* *60s*

4. **What is your level of education?**
 - I was unable to complete high school* *High school graduate* *College graduate*
 - Masters or doctoral degree*

5. **What is your current marital status?**
 - Single, never married* *Currently married* *Currently separated*
 - Divorced* *Widowed*

6. **What is your ethnicity?**
 - White* *Black/African American* *Hispanic/Latino*
 - Asian* *American Indian* *Other*

7. **How many children do you have in total?**
 - 1* *2* *3*
 - 4* *5* *6*
 - 7* *8* *9*
 - 10* *More than 10*

8. **What is the gender of the child with Down syndrome?**
 - Male* *Female*

9. ***What is the age of the child with Down syndrome?***
 3 4 5
 6 7 8
 9 10 11
 12 13 14
 15 16 17
 18 19 20
 21
10. ***What type of schooling does your child attend?***
 Public *Private* *Homeschool*
 Schooling completed
11. ***Do you have any medical diagnoses that you believe may affect your level of stress?***
 No *Yes*
12. ***Do you believe stress influences your decision making?***
 No *Yes* *Unsure*
13. ***Do you believe that your life experiences have been helpful in your decision making?***
 No *Yes* *Unsure*