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# RELATIONSHIPS BETWEEN PARENTAL SELF-EFFICACY AND POSTTRAUMATIC GROWTH IN MOTHERS OF CHILDREN WITH DOWN SYNDROME

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RELATIONSHIPS BETWEEN PARENTAL SELF-EFFICACY AND  
POSTTRAUMATIC GROWTH IN MOTHERS OF CHILDREN WITH DOWN  
SYNDROME

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DISSERTATION

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A dissertation submitted in partial fulfillment of the  
requirements for the degree of Doctor of Philosophy in the  
College of Education  
at the University of Kentucky

By  
Amanda A. Smith

Lexington, KY

Director: H. Thompson Prout, Professor of School Psychology

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## ABSTRACT OF DISSERTATION

### RELATIONSHIP BETWEEN PARENTAL SELF-EFFICACY AND POSTTRAUMATIC GROWTH IN MOTHERS OF CHILDREN WITH DOWN SYNDROME

The purpose of this dissertation is to explore the relationships between maternal variables (mother status (biological or adoptive), birth order of the child with Down syndrome, timing of diagnosis (in utero or at birth), mother's age at time of birth or adoption, time elapsed since diagnosis and maternal psychological variables (parenting self-efficacy, and Posttraumatic growth). The current study hypothesizes that maternal variables will be positively related to parenting self-efficacy and that parenting self-efficacy will explain a significant portion of the variance in maternal Posttraumatic growth. Results indicated that maternal self-efficacy as measured by the Parenting Sense of Competence Scale was not significantly related to maternal perceived growth following their child's diagnosis of Down syndrome. Time passed since diagnosis was also not significantly related to either self-efficacy or perceived growth. Limitations and future directions are discussed.

*Keywords:* Down syndrome, Mothers, Parenting, Competence, Posttraumatic Growth, Posttraumatic Growth Inventory

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DOWN SYNDROME

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*This work is dedicated to my mom, dad, sisters, and Justin.*  
*You were the best support group I could have ever asked for.*

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## **Chapter One**

### **Introduction**

Parents have expectations and beliefs about parenting before their child is born. These beliefs and expectations are typically based on preconceived notions about their role as a parent and their own upbringing, previous parenting experiences, and interactions with children. Therefore, the expectations and beliefs about raising a child with a developmental disability may also affect parents' perceived competency and parenting experiences (Kuhn & Carter, 2006). In addition, the manner in which the diagnosis is provided may influence whether a mother 1. Continues or terminates the pregnancy and 2. Raises the child or gives the child up for adoption. Changes in the medical and psychological fields overtime have created a positive shift to viewing parenting a child with a developmental disability such as Down syndrome in a positive manner. Bittles and Glasson (2004) reviewed life expectancy shifts for people with Down syndrome. In the United Kingdom, in 1929, the life expectancy of a child with Down syndrome was 9-years. That has increased in developing countries to a reported 60-year life expectancy in 2000 in Australia (Bittles & Glasson, 2004). Along with the increased survival rates, an increased period of specialized care may be required. Adults with Down syndrome have also been changing expectations. According to Esbensen, Bishop, Seltzer, Greenberg, and Taylor (2010), the majority of adults with Down syndrome were rated by their mothers to have a "moderate" or "high" level of independence compared to 37.4% of adults with Autism Spectrum Disorder. In the Esbensen et al. study adults with Down syndrome were also rated significantly higher in the areas of functional abilities, literacy,

typical tasks of daily living, compared with adults with Autism Spectrum Disorder, even when controlled for intellectual disability.

### **Characteristics of Down syndrome**

According to the Centers for Disease Control and Prevention (CDC, 2014), common physical features often associated with the syndrome include: A flattened face, especially the bridge of the nose, almond-shaped eyes that slant up, a short neck, small ears, a tongue that tends to stick out of the mouth, tiny white spots on the iris of the eye, small hands and feet, a sling line across the palm of the hand, poor muscle tone or loose joints, and shorter in height as children and adults.

### **Prevalence**

Down syndrome is said to be the “most common chromosomal cause of intellectual disabilities” (Norizan & Shamsuddin, 2010, p. 993). It is also the “...most commonly inherited form of learning disability...” (Bittles & Glasson, 2004, p. 282). Down syndrome is also the most common genetic disorder (Choi, Lee, & Yoo, 2011; Sheets et al., 2011).

According to Presson et al. (2013), there are approximately 6,000 children born with Down syndrome annually in the United States. In 2008, the estimated prevalence of Down syndrome in the United States was 8.27 per 10,000 compared to an estimated prevalence of 10.3 per 10,000 in 2002 (Shin et al., 2009), 8.3 per 10,000 in 2003 (Besser, Shin, Kucik, & Correa, 2007), and 13.56 per 10,000 live births during the 2004-2006 time period after adjustment for maternal race and ethnicity (Parker et al., 2010). After adjusting for maternal age, estimated Down syndrome prevalence increased to 14.47 per 10,000 (Parker et al., 2010) or 1 in 691 (National Down Syndrome Society [NDSS],

2012). The national prevalence estimates published by the National Birth Defects Prevention Network include live births and stillborn births. The estimated prevalence was based on 12,515,956 live births during the years 2004-2006 (Parker et al., 2010).

National population-based prevalence estimates are generated from birth defect surveillance programs in the United States; however, the surveillance programs only receive information from approximately “one-third of US births” (Presson et al., 2013, p. 1163). Parker et al. reported that since 1997, the National Birth Defects Prevention Network has been collecting the data from surveillance programs to provide annual information regarding birth defects. Currently, the National Birth Defects Prevention Network collects and publishes data for 45 major birth defects. Parker et al. described major birth defects as “...structural malformations with a significant impact on the health and development of a child...” (p. 1008). In addition, the registry systems do not receive all data about deaths of people with Down syndrome. Without all the information about births and deaths of people with Down syndrome, the prevalence estimate is unreliable.

### **Prenatal Testing**

Prenatal screening and testing has been described as both a positive and negative medical advancement. Sheets et al. (2011) reported that all pregnant women should be “offered prenatal screening and diagnostic testing” (p. 436). Prenatal invasive diagnostic testing such as chorionic villus sampling, which is chromosomal testing of the chorionic tissue, is completed between the 8<sup>th</sup> to 11<sup>th</sup> weeks of pregnancy. During the 2<sup>nd</sup> and 3<sup>rd</sup> trimester, chromosomal testing via amniocentesis can be completed. However, women under the age of 35-years-old are not usually offered or elect to have such testing completed. Skotko and Bedia’s (2005) study suggests that even with availability of

prenatal diagnostic tests and noninvasive screeners, 87% of mothers continue to receive the diagnosis of Down syndrome for their infant at the time of birth.

Kellogg, Slattery, Hudgins, and Ormond (2014) conducted a study using a survey asking 67 mothers of children with Down syndrome about their attitudes toward Noninvasive Prenatal Testing (NIPT). NIPT is a genetic screening that is expected to become more prevalent in use. NIPT carries no risk of miscarriage, compared to chorionic villus sampling and amniocentesis procedures which are not screeners but diagnostic tests that are invasive and increase the likelihood of spontaneous abortion (Kellogg et al., 2014; Skotko & Bedia, 2005). The majority of mothers (88%) in the Kellogg et al. study believed that the use of NIPT would lead to the termination of more Down syndrome pregnancies. The factors the mothers believed would be the most influential factors in whether a mother would terminate a pregnancy were moral or religious beliefs (36%), information provided at the time of prenatal diagnosis (30%), or the availability of NIPT (16%). Of the participants included in the study, 81% of the women had their child with Down syndrome between the ages of 26-40, with 44% of the mothers 36-years-old and older, and 56% were 35-years-old or younger at the time of their child's birth. Although the majority of women (60%) believed noninvasive testing is a good thing for reasons such as having time to prepare and learn about Down syndrome, 28% of the women reported they believe the only purpose of NIPT is to terminate pregnancies of fetuses with Down syndrome. Kellogg et al. discussed that information mothers receive at the time of diagnosis is important to facilitate decisions of continuing or terminating pregnancies.

Of the 467 mothers included in the Skotko and Bedia (2005) sample, 45 mothers or approximately 10%, received prenatal screenings which were false negatives. The other 90% did not have any prenatal screening or testing. Of the 467 participants, 456 mothers answered the question about their age at the time of their child's birth; 39% were over the age of 35 and the average age of the mothers was reported to be 33.7 years (Skotko & Bedia). Of the 1126 mothers in the Skotko and Bedia 2005 study, 141 (12.5%) received a prenatal diagnosis. Of those 141 mothers, 71% learned of the diagnosis without their partners present. The average age of the mother was 35.4 years with 53% older than 35 years.

Skotko (2005a) reported that a majority of mothers who had triple screening did not know they had an "...increased risk of having a child with Down syndrome" (p. 67). The mothers didn't realize that there was also a chance for a false negative. One mother reported that her doctor told her "The results came back fine," and another reported the doctor said, "Well, at least that is one less thing you have to worry about" (p. 67). However, even if the mothers received a false negative or the doctor did not explain in detail the chances of having a child with Down syndrome, the mothers who had screening were more positive and were less anxious at the time of the birth.

Goff et al. (2013) conducted a qualitative study to assess how parents coped with their child's diagnosis, initial responses to and attitude toward diagnosis, and the parents' relationship as a couple. The respondents were first divided into when they received the diagnosis (either prenatal ( $n = 46$ ) or postnatal ( $n = 115$ )). The results of the participant responses were coded into three primary themes: prenatal screening/testing decisions by parents, adjustment process for parents, and post-diagnosis resources and supports. Of the

46 participants who received prenatal diagnosis, 67% would make the same decision in future pregnancies. The participants' rationale for having prenatal diagnosis included: medical problems, maternal age, to be better prepared, and because of previous pregnancies with abnormalities. In the postnatal group, 35% did not have any prenatal screening and would not have prenatal screening in any future pregnancies, 39% reported they had received false negative screening results or did not have full testing, and 13% did not have any screening or testing and would not do so in the future. According to Goff et al., the rationales provided by respondents for not having prenatal testing included: avoiding worry and stress, risks in testing, would not impact decision to continue or terminate pregnancy, previous healthy pregnancies, mother's young age, testing not available, religious beliefs, and/or lack of knowledge of pregnancy risks.

### **Diagnosis of Down syndrome**

The purpose of Skotko and Bedia's (2005) survey research was to 1) Investigate mothers' perceptions of medical support, 2) Determine how physicians delivered the news to the mothers, 3) Determine what it was like to receive a diagnosis of Down syndrome for their infant, and 4) Determine whether mothers' emotions were affected by setting, printed materials, or information about support groups. The survey included yes/no questions, open-ended questions, and Likert questions ranging from 1-7.

After receiving the diagnosis, some of the mothers expressed disbelief that the child was their child, surprise, betrayal, and disappointment that they were not able to prepare emotionally for raising a child with Down syndrome. Some mothers also reported frustration with their physician since further testing was discouraged after receiving negative screening results. The most common reported feelings were guilt, fear of the

future, and anxiousness. For this sample, first time mothers were statistically more frightened than mothers who already had children. There were no significant differences between the feelings of mothers who had received the prenatal screening and those who did not. Skotko and Bedia (2005) also reported that physicians were not trained or prepared in how to provide the diagnosis to the parents. Some mothers reported that they were informed of the diagnosis by their husband who had received the diagnosis from the doctor. One mother reported “my attending physician and his team disappeared” (Skotko & Bedia, 2005, p. 203). The majority of the mothers reported they had received little to no information from their physicians about Down syndrome. First time mothers who reported they had no prior knowledge of Down syndrome were statistically more frightened and anxious than mothers who had previous pregnancies. The majority of mothers also reported their physicians did not give them enough up-to-date information on Down syndrome, provided the diagnosis in a “quick and sterile manner,” and focused on the negative aspects of Down syndrome (Skotko & Bedia, 2005, p. 206).

Skotko (2005a) reported that physicians’ behaviors have changed overtime. Skotko reported that mothers who received diagnoses more recently compared to mothers who had older children, were more likely to report their physicians talked about positive aspects of Down syndrome. Skotko provided anecdotal comments from mothers from the 1970’s through the early 2000’s. Mothers over time also reported that they wished they would have received the diagnosis earlier. However, one mother said “I strongly feel that if a mother has no idea about her child having Down syndrome or any other disability, she should not be told seconds after delivery” (p. 70). Mothers who perceived their physician pitied them were more likely to feel frightened or anxious. Some mothers also

reported that their doctor blamed them for not having prenatal testing and the pregnancy “...could have prevented or discontinued...” (p. 70). Skotko also reported that the majority of the mothers were less than 35 when they had their child. In summary, Skotko reported that the majority of mothers in his study did not have a positive birthing experience.

Poehlman, Clements, Abbeduto, and Farsad (2005) completed a qualitative study using open-ended interviews to ask mothers ( $n = 21$ ) about both the positive and challenging experiences in receiving a diagnosis of Down syndrome or Fragile X for their child. The majority of mothers reported they were provided the diagnosis by an obstetrician or pediatrician at the birth of their child or the following day. A small number of mothers ( $n = 3$ ) were told about the diagnosis from their husband, who had already learned of the diagnosis from a physician. Mothers of children with Down syndrome reported more family support than mothers of children with Fragile X. Mothers in the Fragile X group reported changes in their concern and adjustment to the diagnosis and developmental challenges their child faced as they learned information from professionals. In comparison, mothers in the Down syndrome group reported they experienced a change in their feelings about the diagnosis as they received more support from other parents of children with Down syndrome and as the child responded to various interventions. Most mothers who experienced denial and chronic mourning at the time of diagnosis began to accept the child’s diagnosis by the time the child reached adolescence (Poehlman et al., 2005).

Whenever the diagnosis is provided, the act of receiving or delivering the news to families can be difficult. The manner in how it is provided is critical for parents to adapt

and cope with the diagnosis (Choi et al., 2011; Sheets et al., 2011; Skotko & Bedia, 2005). The initial parent response to receiving the diagnosis of a developmental disability is usually intense and negative (Flaherty & Glidden, 2000). Parents experience a range of reactions and emotions from acute grief, chronic sorrow, and disappointment, and an overall feeling of being overwhelmed by the diagnosis (Choi et al., 2011). Choi et al. acknowledged that positive parental relationships with their physician or health care provider (i.e., the health care provider answered parents' questions and held a more positive attitude at the time of diagnosis) had an impact on parent reactions to the diagnosis. Skotko (2005b) reported that mothers "...thought their obstetricians had failed to provide enough up-to-date printed material on Down syndrome" (p. 672).

Sheets et al. (2011) provided recommendations for health care personnel to follow or consider when providing the diagnosis of Down syndrome. The authors cited "The Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008" in support of their recommendations for communication about the diagnosis between health care personnel and the parents. The Prenatally and Postnatally Diagnosed Conditions Awareness Act (2008) was written as an amendment to the Public Health Service Act to specifically address "information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally and postnatally diagnosed conditions." Sheets et al. reported guidelines for discussing the three different options (continuing the pregnancy and raising the child, continuing the pregnancy and using an adoption agency, and termination of the pregnancy) after receiving diagnosis. The information the health care providers give to parents needs to be a balance between positive and challenging

outcomes of raising a child with Down syndrome (Ahmed, Bryant, & Hewison, 2007; Hippman, Inglis, & Austin, 2012; Sheets et al., 2011).

Hippman et al. (2012) sent members of the Lower Mainland Down Syndrome Society in British Columbia, Canada, a survey to explore what parents perceived as balanced. The 79 participants, who were either a parent or step-parent of an individual with Down syndrome, provided an opinion about a balanced description of Down syndrome. The participants were provided a scenario of a couple receiving genetic counseling following a diagnosis by amniocentesis. Following the scenario the participants were asked via open-ended question what would make the description of Down syndrome a balanced description. The responses were reviewed by the authors and coded on a 5-point scale 1 (*entirely negative*) to 5 (*entirely positive*). Of the responses, four (7%) were rated as entirely negative, five (10%) mostly negative, 12 (24%) as balanced, 25 (49%) as mostly positive, and five (10%) as entirely positive. The responses were not related to severity ratings (i.e., medical problems, whether or not their adult child was working, and final level of education of their child). Hippman et al. concluded that parent perceptions of what is balanced “varied widely” (p. 39). As perceptions and experiences vary between all people, Sheets et al. (2011) recommended that health care providers discuss how raising a child with Down syndrome may impact the family, the parents’ relationship with each other, and any siblings.

### **Perceptions of Parenting a Child with Down syndrome**

With a diagnosis of Down syndrome or any other significant genetic or health problem, the parents can choose to either “prepare for a life parenting a child with special needs, or to terminate the pregnancy” (Lawson, 2006, p. 43). According to Lawson,

terminations of pregnancies are highest after a prenatal diagnosis of Down syndrome as compared to terminations following diagnoses of other disabilities such as spina bifida or hemophilia. Lawson connected this fact to previous research suggesting that parents view Down syndrome as a more serious condition and/or have a negative perception of parenting a child with cognitive impairments (Lawson, 2006). Challenges that parents of children with Down syndrome and other disabilities face more often when compared to parents of typically developing children include developmental delays in meeting milestones, educational challenges, and medical challenges (Goff et al., 2013).

Lawson (2006) compared perceptions of parenting a child with Down syndrome, a child with muscular dystrophy, and a child with no disability. The participants were randomly selected mid-Western Canadian university employees. The goal of the study was to examine stereotypes and therefore participants who were parents of a child with mental retardation or serious physical disability were excluded from analysis. The participants were provided with one of three vignettes and then a questionnaire to answer based on whether their hypothetical child was healthy and expected to meet all developmental milestones, a child with Down syndrome, or a child with muscular dystrophy. Lawson reported that global perceptions of parenting a child with Down syndrome were significantly less positive than those for parenting a non-disabled child, but not significantly different from parenting a child with muscular dystrophy. Lawson concluded that parenting a child with Down syndrome is perceived as less rewarding and more costly (i.e., financial, emotional, socially) compared to raising a child without a disability.

Lawson (2006) also reported that selective abortion is likely influenced by the loss of parenting rewards and not by the higher costs (i.e., financial, emotional, socially) of raising a child with Down syndrome. Differences between perceived levels of social support available to the individual were not significantly different between the Down syndrome and muscular dystrophy groups; however, perceived social support of parenting a child with Down syndrome accounted for 6.5% of the variance when considering selective termination, while perceived social support was not significant in the muscular dystrophy group. Lawson's results were commensurate with previous research in the fact that, when given the hypothetical situation, the willingness to terminate a pregnancy was low and divergent from actual rates of termination. Lawson attributed this to the hypothetical nature of the study in which people may "underestimate the extent to which they would actually undergo a termination" (p. 54).

Mansfield, Hopper, and Marteau (1999) reported that termination rates following a prenatal diagnosis of Down syndrome were highest when compared to terminations following diagnoses of four other conditions: Spina Bifida, Anencephaly, and Turner and Klinefelter syndrome. Termination of pregnancy may be highest with Down syndrome in response to how the diagnosis is provided as well as to how supported the mother feels. Mothers who choose termination may be influenced by their physician, particularly if the physician or mother, view a diagnosis of Down syndrome through a medical mode (Alderson, 2001). Alderson (2001) attributed the differing views in the literature about prenatal screening and testing to the differences in viewing the diagnosis through the medical model vs the social model. The medical model, Alderson argues, implies that the purpose of prenatal screening and testing is to prevent a child being born with a non-

treatable genetic condition versus the social model which aims to change society's attitudes and environment to be more inclusive. The intent is what drives the screening and testing, according to the medical vs social model. The intent to prevent or the intent to prepare for and provide supports for the family.

Elwy, Mitchie, and Marteau (2007) conducted a study with 97 neonatologists. After being told to read the vignette as if they were the health care provider providing the diagnosis, they were provided one of three different vignettes: (a) The mother was not offered prenatal screening, (b) The mother refused screening, or (c) The mother received a false negative result of screening. In each of the vignettes the mother gave birth to a child with Down syndrome. The neonatologists were then asked on a 5-point scale from 1 (*strongly disagree*) to 5 (*strongly agree*) how likely they would use the 10 given statements on the Information on Down Syndrome Scale. The Information on Down Syndrome Scale included five statements that emphasized problems associated with having a child with Down syndrome (i.e., Having a child with DS can be very stressful for families) and five statements that downplayed problems (i.e., Having a child with DS can be a very positive experience for families). The other items targeted the participants' attributions of perceived controllability and blame for the birth of a child with Down syndrome. One item asked how much the participants blamed the mother for the birth of a child with Down syndrome from 0 (*do not blame at all*) to 7 (*completely blame*). The second was how much control they perceived the mother had over having a child with Down syndrome from 0 (*no control at all*) to 7 (*complete control*). The neonatologists who received the vignette, in which the mother refused the screening, perceived the birth of a child with Down syndrome as more controllable and reported attributing more blame

towards the mother. It was also noted that the neonatologists who blamed the mother, while in the minority, were also more likely to emphasize problems associated with Down syndrome. This suggests that choice of prenatal screening may influence the manner in which the physician communicates with parents.

While the degree to which a physician believes a mother has control over the birth of a child with Down syndrome is suggested as a factor in parent self-efficacy, the manner in which physicians communicate with mothers before or after the birth experience will also likely impact their outlook with regard to raising a child with Down syndrome. The timing of the diagnosis is likely important as well. Receiving a diagnosis during pregnancy allows time for parents to prepare for parenthood. Flaherty and Glidden (2000) reported that most children with Down syndrome are identified at birth. Most often children with Down syndrome who are put up for adoption or given to foster care, have this happen while the child is in infancy. Due to this timing, adoptive and birth families may have been raising the child for approximately the same amount of time. This is in opposition to different developmental disabilities that may not be diagnosed until later in life and may not be placed in an adoptive or foster family until later.

In summary, for parents who choose to continue the pregnancy, having the prenatal diagnosis of Down syndrome provided time for parents to 1) acquire knowledge about Down syndrome, 2) address medical planning issues, and 3) plan ahead for financial costs associated with therapies that children with Down syndrome often require. Health conditions that often accompany a diagnosis of Down syndrome can be anticipated, detected, and/ or avoided with advanced medical planning and care. In addition to intellectual disabilities, individuals with Down syndrome may have a range of

health difficulties related to congenial heart disease, hearing, vision, periodontal disease, weight, muscle tone, stomach problems, celiac disease, thyroid problems, and skeletal problems. Infants and children with Down syndrome are also 10 to 15 times more likely than other children to develop leukemia (Roizen, 2001).

### **Adaptation to having a child with Down syndrome**

Goff et al. (2013) reported that grief was the primary reaction to the diagnosis regardless of the timing of the diagnosis (i.e., prenatal vs. postnatal). The researchers coded responses provided by 161 parents about initial reactions to diagnosis. The majority of responses indicated that “grief, fear, mourning, overwhelmed, denial, guilt, [and] anger” (p.451) were the emotions experienced at time of diagnosis. The length of time it took for participants to adjust to the diagnosis ranged from “almost immediately” (p. 451) to several years. Among the primary factors identified in the adjustment process were medical factors. Some participants reported that their child’s heart problems put the Down syndrome diagnosis in perspective. The greatest impact on adjustment, as reported by parents, was meeting with other parents who had a child with Down syndrome and meeting their child.

In a study of birth and adoptive parents conducted by Flaherty and Glidden (2000), 52 birth and 53 adoptive families were raising at least one child between ages 1 and 12-years with Down syndrome. The prediction provided by Flaherty and Glidden was that adoptive parents would report better functioning and emotional responses than birth parents soon after the arrival or diagnosis of Down syndrome. The researchers’ hypothesis was supported by the data, which indicated birth mothers showed significantly higher levels of depression at birth compared to adoptive mothers at the time the child

entered the family. However, after five and a half years, both birth and adoptive mothers had low levels of depression. Mothers who previously had reported high levels of depression at the birth of their child had adjusted well to the challenges of raising a child with Down syndrome (Flaherty & Glidden, 2000).

Kuhn and Carter (2006) conducted a study of self-efficacy using the maternal efficacy scale with mothers of children with autism spectrum disorders. The authors reported that maternal self-efficacy was negatively correlated with the presence of another child with a disability ( $r = -.21, p < .01$ ) and positively correlated with the time elapsed since diagnosis ( $r = .25, p < .01$ ).

Raising a child with a disability has been shown to be stressful to parents. Sloper and Turner (1993) reported that up to 70% of mothers and 40% of fathers report feeling stress from raising a child with a disability. Baker, Blacher, Crnic, and Edelbrock (2002) further elaborated that parents of children who display behavior problems have more parental stress than parents of typically developing children. Based on the high occurrence of health problems in infants and children with Down syndrome, it would make sense that parents of children with high health needs would also have high levels of stress. Although individuals with Down syndrome are more likely to have significant illnesses, the life expectancy and prognosis for a productive and positive life experience have increased over time. Hanson (2003) reported that parents face difficult challenges such as “medical complications, teasing or ostracism, disappointments in their children’s ability to achieve some adult milestones and lack of adequate services and supports when the children reached adulthood” (p. 363). Although Down syndrome is “diagnostically

homogeneous,” every family has a unique experience in having a child with a disability (Richman, Belmont, Kim, Slavin, & Hayner, 2009, p. 540).

Van der Veek, Kraaij, and Garnefski (2009) pointed out that having a child with Down syndrome is “...not an event one deals with in isolation...” (p. 217). Having a child with Down syndrome is a lifelong change, which may require significant reliance on resources and supports, as well as cognitive coping strategies such as positively reframing beliefs about having a child with Down syndrome. The stress-coping model originally presented by Lazarus and Folkman (1984) suggests that when people evaluate stressful situations, they may experience additional emotional, behavior, and cognitive consequences. In addition, Van der Veek et al. (2009) reported that “experiencing more support from the environment has been found to be related to less psychological distress and more adaptive coping in parents of children with Down syndrome” (p. 217). Van Der Veek et al. used an updated model as a framework to explain the variance in emotional well-being of parents of children with Down syndrome. Van der Veek et al. reported having positive feelings about having a child with Down syndrome was significantly related to coping self-efficacy. Variations in parent stress and coping depend on the child’s severity of disability, as well on the child’s behavior and medical issues, and result in varying levels of parent self-efficacy. Based on this information, it would make sense that a mother who finds out during pregnancy that she will be having a child with Down syndrome will have more time to prepare and seek out environmental supports. Parents of children with developmental disabilities have been consistently identified as having more stress and burdens than parents of typically developing children resulting from communication, emotional, and behavioral needs that accompany children with

developmental disabilities (Dabrowska & Pisula, 2010). As an example, King, Baxter, Rosenbaum, Zwaigenbaum, and Bates (2009) interviewed parents of children with Autism Spectrum Disorder and Down syndrome in an effort to understand family perspectives and belief systems. Although both sets of parents described strategies that included optimism, acceptance and appreciation, and striving (goal-oriented, problem focused), parents of children with Down syndrome reported more positive appraisals and less negative appraisals, when compared to parents of children with Autism Spectrum Disorders.

### **Parenting Self-Efficacy**

Self-efficacy is a belief a person has about his or her ability to successfully engage in a task. Self-efficacy is assessed in a particular context as it is not reasonable for any rational human being to believe he or she is competent, can be successful, and can master every domain (Bandura, 2006). Self-efficacy will increase and/or decrease based on four sources of influences (a) performance accomplishments, (b) vicarious experience, (c) verbal persuasion, and (d) physiological states (Bandura, 1977). It is not necessary for each of the four sources of influence to be present to increase efficacy. In addition, each of the four sources of influence have varying degrees of influence on a person's behavior (Bandura, 1977).

The performance accomplishment influences a person to engage in activities in which he or she believes he or she is competent and will be successful (Bandura, 1977; Pajares, 2006). Thus, if an individual achieves success repeatedly, an occasional failure is less likely to reduce the individual's beliefs in his or her ability to achieve a certain outcome. Vicarious experiences will influence individuals through their observations of

others being successful in certain areas. Observing others succeed particularly in changing domains, can increase a person's own belief that he or she will be successful in similar situations (Bandura, 1977; Pajares, 2006). Pajares (2006) referred to learning through vicarious experiences as learning from "actions of models" (p. 346). Pajares suggested that vicarious experiences are particularly helpful for individuals who have limited experience in certain domains, which would restrict their ability to judge their own competence. For example, parents who participate in social support groups are likely to hear about and learn about successful parenting practices from other parents of children with Down syndrome. Bandura (1977) noted that although vicarious experiences can be influential, this source of influence is not as effective as individual success.

Bandura (1977) suggested that individuals who are persuaded that they have the ability and also receive external help or aids to overcome challenges, are more likely to be successful, and in turn, are more likely to experience an increase in their sense of self-efficacy. Verbal persuasion influences the self-efficacy of individuals by suggestion. Verbal persuasion may be a weaker influence compared to the others, because the individuals who are being persuaded may not believe what is being told to them. Verbal persuasion may also be focused on increasing an individual's outcome expectation rather than on his or her level of self-efficacy (Bandura, 1977).

Emotional arousal is the fourth source of influence (Bandura, 1977). According to Bandura (1977) individuals rely on their anxiety and vulnerability to stress when evaluating their abilities to perform in challenging situations. Bandura (1977) elaborated that individuals who are confident that their levels of stress and anxiety will not prohibit

them from being successful will have higher self-efficacy compared to individuals with high levels of stress and anxiety.

Pajares (2006) made the argument that individual expectations play a large role in motivating individuals to make changes in their behavior, as opposed to solely relying on consequences such as rewards or punishments. This represents a different theoretical framework than the behavioral theory that suggests consequences of behaviors will determine whether an individual engages in a certain behavior. An outcome expectancy which is defined by Bandura to be "...a person's estimate that a given behavior will lead to certain outcomes" (p. 193) is arguably more important than the actual reinforcement itself. Based on this outcome expectancy, an individual will make an evaluation of his or her abilities and determine whether or not he or she will be able to perform the behaviors that lead to the desired outcome. This belief is called an efficacy expectation (Bandura, 1982). The difference between an outcome expectancy and an efficacy expectation is that, for the outcome expectancy, the individual believes a certain behavior will produce a certain outcome, regardless of whether or not he or she believes in his or her ability to engage in that behavior. If he or she strongly believes in his or her abilities, he or she is more likely to engage in the behavior and persist at the behavior. This is intuitive because a person who does not believe in his or her own abilities is not likely to continue to engage in a behavior. A person's self-efficacy in a particular domain, or belief that he or she can succeed, will influence whether that person will choose to engage in certain activities, environments, and/ or situations. Of course, when a person finds him or herself in a challenging situation and is successful the positive outcome will reinforce the behavior and in turn increase self-efficacy. The higher the level of self-efficacy, the more

likely a person is to work through challenges and persist. However, individuals need to have a reason to want to put in the effort and to engage in the behavior to obtain a positive outcome.

Parenting behaviors have been reported to be the most influential determinant in parent self-efficacy. Belsky (1984) and Seigny and Loutzenhiser (2009) used a three determinant model of parenting that assessed predictors of parenting behaviors and reported parent characteristics which accounted for the majority of variance in parenting self-efficacy scores. Bandura (1997) reported that previous parenting experiences, perceived to be positive or negative, were a strong predictor of parent self-efficacy. Employment status and postsecondary education were not significant in influencing parenting stress levels which, as mentioned before, have, in turn, been shown to influence self-efficacy (Webster, Majnemer, Platt, & Shevell, 2008).

Parental self-efficacy has been studied in research as an independent variable, a transactional variable, and as a dependent variable, as it has been found to be related to methods of discipline, parenting behaviors, involvement in education, and interactions between mothers and toddlers. In a study conducted by Scheel and Rieckmann (1998), parenting stress predicted parental self-efficacy with 15% of the variance. Bandura (1982) proposed that in stressful situations, individuals with low self-efficacy give up easier, internalize failure, report an increase in depression and anxiety, and experience a decrease in role satisfaction.

Bandura (2006) published a guide to constructing self-efficacy scales and stated: “there is no all-purpose measure of perceived self-efficacy” (p. 307). Bandura suggested that scales of perceived self-efficacy should be tailored to the explicit domain of interest.

Bandura continued that all items should be phrased in terms of “can do” as opposed to “will do” as self-efficacy is the measure of perceived capability and not intention (p. 308). Self-efficacy scales should include behavior factors that have impact on the domain of interest and also the level of difficulty needed to overcome to be successful. Bandura stated the standard method for measuring self-efficacy beliefs should include levels of ability that the person believes he/she can do, usually a 100-point scale in 10-unit intervals. He reported that measures of self-efficacy are more sensitive and reliable than scales with fewer intervals. Efficacy scales are unipolar as a person cannot have less confidence than zero confidence. Self-efficacy scales should also have face validity. However, a scale that has already been identified and determined to be a valid measure of parenting self-efficacy will be utilized for this dissertation. Rogers and Matthews (2004) reported that the Parenting Sense of Competence Scale (PSOC) is general and broad enough to make it a particularly useful measure of parenting satisfaction and efficacy. The PSOC is a domain-general assessment of PSE as the questions focus on parents’ overall sense of efficacy in their parenting role versus their self-efficacy in specific parenting tasks. In the previous research conducted with parents of children with Down syndrome, the PSOC has been frequently used. In fact, “The PSOC is the scale used most frequently in previous studies of PSE” (Coleman & Karraker, 1997; Jones & Prinz, 2005; Troutman, Moran, Ardnt, Johnson, & Chmielewski, 2012).

The 17 questions on the PSOC are score on a 6-point Likert scale ranging from 1(*strongly agree*) to 6 (*strongly disagree*). Items which load on the Efficacy factor 6, 10, 11, 13, 15, and 17 are reversed scored to indicate positive parental experience. The Efficacy factor, as reported by Johnston and Mash (1989) had an internal consistency

alpha coefficient of  $\alpha = .76$ . The Satisfaction factor internal consistency alpha coefficient was reported to be  $\alpha = .75$ . Ohan, Leung, and Johnston (2000) used the mother data to report internal consistency of .80 for both Efficacy and Satisfaction scales. Johnston and Mash (1989) reported that item 17 did not load onto either factor and recommended that the item be omitted in future use and therefore, will not be included in this study.

Rogers and Matthews (2004) used an exploratory method of analysis and completed a principal component analysis and analyzed mother and father data separately. Using the mother data, the authors reported a three factor model with the factors accounting for 51.6% of the variance. The first factor, Satisfaction, accounted for 28.2% of the variance with an Eigenvalue of 3.95. The second factor, Efficacy, accounted for 14.6% of the variance with Eigenvalue of 2.03. The authors introduced a third factor, Interest, which accounted for 8.8% of the variance and had an Eigenvalue of 1.23. The Interest factor reported by Rogers and Matthew (2004) was created by items 12 and 14. According to Johnson and Mash (1989) and Ohan et al. (2000), items 12 and 14 loaded onto the Satisfaction factor. According to Gilmore and Cuskely (2008), the PSOC has a three-factor structure: Satisfaction, Efficacy, and Interest. Gilmore and Cuskely (2012) utilized the PSOC for a longitudinal study and reported the Cronbach alpha coefficients for each of the factors at both time 1 and time 2, which was approximately 8-years later. Satisfaction had Cronbach alpha coefficients of  $\alpha = .73$  and  $\alpha = .78$  at time 2. Efficacy had Cronbach alpha coefficients of  $\alpha = .74$  (time 1) and  $\alpha = .65$  (time 2). Gilmore and Cuskelly (2012) did not include the items that loaded on the Interest factor as the Cronbach alpha coefficients in the Gilmore and Cuskely (2008) study were  $\alpha = .75$  and  $\alpha = .54$  and those were considered to be “unacceptably low.” Construct validity of the

PSOC was reported to be to be clinically significant ( $r = .48$ ) with the Self-Efficacy for Parenting Tasks Index-Toddler Scale (Coleman & Karraker, 2003; Troutman et al., 2012). Discriminant validity was established by Erdwins, Buffardi, Casper, and O'Brien (2001) as the PSOC was weakly correlated ( $r = .26$ ) with an assessment of self-efficacy in the work domain. In addition, Lovejoy, Verda, and Hayes (1997) demonstrated that the PSOC was weakly correlated with scales assessing parental locus of control, indicating that the PSOC discriminates between PSE and other types of parenting cognitions.

Rogers and Matthews (2004) also reported the alpha coefficients for internal consistency for the subscales. The alpha coefficients were: Satisfaction  $\alpha = .77$ , Efficacy  $\alpha = .78$ , and  $\alpha = .58$  for Interest. Additionally, Rogers and Matthews reported in their discussion that the Interest factor doesn't belong with the original purpose of the PSOC, which was to measure parent self-esteem via perceived efficacy and satisfaction. Rogers and Matthews suggested that, for future use of the PSOC, the items that created the Interest factor should be deleted if the intent is to keep with the original purpose of the PSOC measure. For the purposes of this dissertation, items 12 and 14 were omitted from this study as the interest factor is outside the scope of this dissertation.

Coleman and Karraker (1997) suggest that, in order for parents to have efficacy in regards to parenting, parents need to have: "(a) knowledge of appropriate child care responses, (b) confidence in their own abilities to carry out such tasks, and (c) the beliefs that their children will respond contingently and that others in their social milieu, including family members and friends, will be supportive of their efforts" (p. 50).

Research on parenting children with disabilities has primarily focused on the negative aspects, such as stress, depression, and challenges faced by families and

members of the family. However, it is likely that parents feel a variety of emotions when it comes to having a child with Down syndrome. Spielman and Taubman-Ben-Ari (2009) stated that pregnancy allows for the parents to prepare for parenthood and when this time is cut short by having a pre-term delivery - even for babies who are not at-risk or have a medical complication - parents still experience the birth as a crisis. Experiencing this as a crisis is common among pre-term parents, but how the parents experience and cope with the crisis varies. The authors hypothesized that parents of pre-term babies would report lower self-efficacy and higher stress related growth compared to parents of full-term babies (Spielman & Taubman-Ben-Ari, 2009). The Parenting Sense of Competence Scale and Posttraumatic Growth Inventory were two of the measures used in the study. Using ANOVAs for data analysis, the researchers reported that parents of pre-term babies reported significantly greater stress-related growth than parents of full-term babies. Using Pearson correlations, the researchers reported that earlier age of gestation at birth, weight at birth, and the baby's APGAR scores were all correlated with the mother's sense of growth (Spielman & Taubman-Ben-Ari, 2009).

### **Posttraumatic Growth**

The positive psychology movement seeks to maximize the positive benefits that stem from negative situations or circumstances. What a person experiences following a traumatic event or crisis has been labeled in a few different ways in the research. Frazier et al. (2009) reviewed research on the growth following an adverse event and identified the labels as: stress-related growth, Posttraumatic growth, perceived benefits, or growth following adversity. For the purposes of this dissertation, Posttraumatic Growth (PTG) will be used to define the phenomenon of positive change following an event that causes

cognitive restructuring of one's core beliefs of the assumptive world (Lindstrom, Cann, Calhoun, & Tedeschi, 2011). Lindstrom et al. (2011) noted that the assumptive world is based on a person's belief system and assumptions about the world and his or her purpose in it. Triplett, Tedeschi, Cann, Calhoun, and Reeve (2011) reported that it takes cognitive effort for a person to redefine belief systems, rebuild his or her life, and find meaning in life. Lindstrom et al. reported two cognitions that likely influence the process of PTG; rumination and self-disclosure. Lindstrom et al. hypothesized that people who discuss the event they've experienced in a positive manner would experience more growth than those who talk to others about their experience in a negative manner. The authors reported that 98% of their study population was exposed, via reading about it or hearing about it, to people who had experienced positive change or growth as a result of their own encounter of an adverse event. The authors did not elaborate on whether the stories they heard or read about were related to the same adverse event, or if the stories were about other adverse events. At any rate, the authors indicated that positive experiences following an adverse event are readily available. The authors also noted that their participants who had disclosed the positive consequence of their experience reported more deliberate rumination and less stress related to the event. These results suggest that positive growth is aided by deliberate and conscious thinking about the positive consequences following an event and sharing those thoughts with others.

In a review of 39 empirical studies as conducted by Linley and Joseph (2004), positive change following trauma and adversity were inconsistently associated between growth, socio-demographic, and psychological distress variables. In the review, the authors noted that participants ranged from mothers bereaved of a child, husbands of

women with breast cancer, and survivors of natural disasters, plane crashes, and mass shootings. Linley and Joseph suggested that it is not the traumatic or adverse event itself which affects differences in growth, but rather individual characteristics, as everyone experiences the event in a different manner. Tedeschi and Calhoun (1996) suggested that surviving and living through traumas provide individuals feedback about their own performance and competence in handling adverse situations. Thomas, DiGuilio, and Sheehan (1991) suggested that people who experience traumatic events may develop confidence that could be generalized to all kinds of situations. Helgeson, Reynolds, and Tomich (2006) completed a meta-analysis of the relationship of benefit finding and growth to psychological and physical health. A total of 235 studies were reviewed and 87 were included in the meta-analysis. Inclusion criteria were: adult population, clear measure of benefit finding, experience of a stressful event, and a measure of physical or mental health. Of the 87 studies, three studies were related to parents of children with a disability: two of the studies included parents of children with Autism Spectrum Disorders, and one included parents of children with Down syndrome. Helgeson et al. (2006) did not include longitudinal studies in the meta-analysis, as there were not enough longitudinal studies for statistical analysis. The results indicated that benefit finding was associated with better mental health; benefit finding may be related to positive outcomes as time from the event increases, (specifically two or more years,) and the authors suggested that benefit finding may be an outcome measure that reflects positive benefits from trauma as opposed to a lack of exposure to a traumatic event.

Vishnevsky, Cann, Calhoun, Tedeschi, and Demakis (2010) also conducted a meta-analysis of PTG and reported the most common traumatic events studied in research

are: cancer, bereavement, terrorism, and natural disaster. In addition, Vishnevsky et al. (2010) also reported that women consistently report more growth than men, which led the author to suggest that there are real differences in women and men reporting post traumatic growth, and that the results are not due to biased measures.

Following three studies by Taubman-Ben-Ari, Findler, and Sharon (2011), the authors determined that PTGI was an appropriate and effective measure of motherhood. The first study included first time mothers ( $n = 150$ ) who completed an open-ended question about the changes they had experienced since transitioning to motherhood. First time mothers had given birth within 3-24 months. The researchers conducted a content analysis and determined that the mothers' responses reflected four of the five dimensions on the PTGI. The dimension that was not reflected was related to increased spirituality and religious faith. The second study was designed to be longitudinal and originally 400 mothers gave consent to be included. However, when contacted when their child was 4-years-old, the final sample was 157 mothers. The mothers again answered open-ended questions and the content of their responses reflected four of the five dimensions on the PTGI. The results of the second study indicated that increased spirituality and religious faith was the dimension again not reflected in the mothers' open response. Based on the results of the first two studies, the authors reported that both mothers who had recently given birth and those who had been mothers for a few years experienced positive growth following the birth of their child. The third study conducted by Taubman-Ben-Ari et al. (2011) included mothers who had given birth within 24 months prior to participating in the study. In addition to the mothers, participants also included maternal grandmothers. The criterion for the grandmother was that the target grandchild had to be her first

grandchild. Both the mother and grandmother completed the PTGI. The mothers reported their own growth since giving birth and the grandmothers reported on the changes they perceived in their daughters since giving birth. The domains of the PTGI, as completed by the child's mother and their mothers, were positively and significantly related. The authors reported that the PTGI is compatible with mothers in general and sub-groups of mothers in measuring PTG. The take away from this research was that not only do the individuals who experience a major life event experience change, but the changes individuals experience in the different domains of PTG are also noticeable by people close to them.

In order to measure “perceptions of benefits” of individuals who have encountered a traumatic or life changing event, Tedeschi and Calhoun (1996) developed the Posttraumatic Growth Inventory (PTGI). Tedeschi and Calhoun believed that the perceptions of benefits fit into three broad categories: Changes in Self-Perception, Changes in Interpersonal Relationships, and Changes in Philosophy of Life. In general, Tedeschi and Calhoun believed that living through a traumatic event makes people change. Tedeschi and Calhoun, in sync with the positive psychology movement, believed that people can change for the better; people become stronger, people seek out new meaning in their lives, make sense of what happened, rearrange their priorities, and place a stronger value on relationships with others. Tedeschi and Calhoun designed the PTGI to target these areas of change. The PTGI is a 21-item measure that measures five factors; New Possibilities, Relating to Others, Personal Strength, Spiritual Changes, and Appreciation of Life. Descriptions of the five factors are self-explanatory. New possibilities is looking at life in a new way; Relating to Others is looking for positives in

people, learning to rely on others for support, and the appreciation of others; Personal Strength is the awareness that one is stronger than he or she might have previously believed (the motto “What doesn’t kill you makes you stronger,” applies to this experience); Spiritual Changes are feelings of increased faith and understanding of a higher power; and Appreciation of Life is creating new priorities, as well as restructuring of priorities in life (Lindstrom et al., 2011). In the development of the PTGI, Tedeschi and Calhoun (1996) reported an internal consistency of  $\alpha = .90$  and acceptable test-retest reliability of  $\alpha = .71$ . In addition, the PTGI was not correlated with social desirability ( $r = -.15, p < .01$ ), as measured by the Marlowe-Crowne Social Desirability Scale. The purpose of the PTGI is to measure perceived benefits from surviving a traumatic event. Therefore, people who have experienced and survived a traumatic event should indicate more perceived benefits than those who have not had that experience. Overall, women reported more benefits than men and people who experienced trauma reported more benefits than those who had not. Tedeschi and Calhoun reported that PTG has been used as an outcome variable, but suggested that the PTG may be tapping a cognitive effort to positively reinterpret the traumatic event. They also noted that it is possible that a person’s personality may allow for an individual to more frequently see benefits.

Religiousness and rumination are two areas of cognitive processing that may be related to self-efficacy. Martin and Tesser (1996), as cited in Calhoun, Cann, Tedeschi, and McMillan (2000), defined rumination as a variety of repetitive cognitive thinking related to a specific event. Rumination has been found to be related to experiencing posttraumatic growth (Calhoun et al., 2000). Ruminating about the birth of a child with Down syndrome may be likely to increase self-efficacy as rumination may be related to

evaluating one's efficacy in caring for his or her child. The area of religiousness may be related to growth as some people may have religious beliefs against abortion, and some individuals may turn to faith to make sense of the diagnosis. Calhoun et al. (2000) investigated rumination and religiousness in a small sample of 54 college students. Religious participation (e.g., frequency of attendance at religious services and importance of religion) as well as positive reframing (e.g., trying to make sense of it, thinking about the meaning of life, making good come out of the struggle of the event) and negative (intrusive thoughts) aspects of rumination were the independent variables, with the total score of the PTGI as the dependent variable. There was no significant correlation between the amount of religious participation and the total posttraumatic growth score.

### **Statement of Purpose**

It is important to identify variables that may be associated with positive growth in mothers following a diagnosis of their child with Down syndrome. Past research has shown that parents have a strong impact on their child's development and achievement (Bandura, 1997; Coleman & Karraker, 1997, 2003). Understanding how to support mothers and increase their chance of experiencing positive growth regarding their child's diagnosis will not only impact the mother but also the child's outcomes. King et al. (2009) suggested that understanding parent perspectives and values is crucial in providing effective service delivery and engaging parents in therapy and may be crucial in developing rapport and relationships with families. Hodapp, Ly, Fidler, and Ricci (2001), as cited in King et al. (2009), suggested that parents of children with Down syndrome, mothers in particular, report "more rewarding parenting experiences than do parents of children with other disabilities" (p. 51). Therefore, the parents who received

the diagnosis and chose to continue with the pregnancy will have lower levels of growth as it is possible that the parents did not view the birth of their child to be an adverse event. The importance of this research is to better understand the sources of parental self-efficacy and sources of post traumatic growth in mothers who receive a diagnosis of Down syndrome prenatally and mothers who receive the diagnosis postnatally. Parental self-efficacy has been linked to child outcomes and student performance, so it can be expected that by understanding parent experiences, the community-at-large can allow for interventions to help parents and, in turn, help their children.

### **Hypothesis One**

As they have not had time to prepare for a diagnosis of Down syndrome, mothers who receive the diagnosis at birth are hypothesized to report less parenting self-efficacy than mothers of children who received a diagnosis of Down syndrome prenatally. The timing of diagnosis will also influence parenting self-efficacy as research suggests parent self-efficacy increases over time. As the literature suggests, mothers' self-efficacy will be influenced by previous parenting experiences through having children with or without disabilities prior to the target child.

### **Hypothesis Two**

Mothers who report higher levels of total PSE will also report higher levels of PTG. To examine the relationship between PSE variables and PTG, bi-variate correlations will be run to test this hypothesis.

### **Hypothesis Three**

It is hypothesized that once maternal variables have been entered as control variables, PSE will account for a significant amount of variance in PTG. A stepwise regression will be used to test this hypothesis.

## Chapter 2

### Method

#### Participants

The target population was English-speaking mothers who have children with Down syndrome. There were no exclusionary criteria based on race or ethnicity and that information was also not asked on the survey. Age of the mother and child were not exclusionary factors and they were included in the study. Mothers who did not have a child with Down syndrome were excluded from the study as well as people who did not self-identify as a biological or adoptive mother of a child with Down syndrome. Five participants were not included in analyses as they self-reported they were legal guardians and therefore, their participation was discontinued. In this study, 9 participants (5.5%) self-identified as an adoptive mother and 153 participants (93.9%) self-identified as a biological mother. One participant did not answer the item and was excluded from data analysis. The average age of the mothers at time of diagnosis was ( $M_{\text{age}} = 32.54$ , age range: 18-50 years) and the average current age of children with Down syndrome ( $M_{\text{age}} = 11.11$ , age range: 1-54 years). The age of the mothers when they became the mother of their child ranged from 18 to 50-years-old with an average age of 32.54.

#### Procedure

The University of Kentucky Institutional Review Board through the Office of Research Integrity approved all research materials and protocols. Down syndrome societies were contacted via email from information found on the society webpage. Depending on the society, a director, president, or chairperson was contacted via email. In the initial contact, the society representative was asked if there was potential interest in

forwarding the introduction survey and survey link. Following the positive response by the society representative, the email with the introduction to the survey research as well as the link to the electronic online survey was forwarded to its members by the society representative. Direct emails of society members were not obtained by the researcher. One director did not believe there was interest in her society to participate and therefore did not agree to read or forward on the email request. Of the 15 societies and networks contacted, four agreed to participate and forwarded on the email, and no response was received despite follow up emails from 10 societies or networks. The members received an email with a confidentiality notice and the link to the survey within the email. See appendix A for the introduction and confidentiality notice in the email all potential participants received. The participants self-selected to participate in the study by clicking on the link to the online survey. The respondents were able to discontinue their participation at any time.

### **Data Analysis**

The participant responses were exported from Survey Monkey to Microsoft Excel and then imported into IBM SPSS, Version 22. This study was designed using independent t-tests, correlations, and multiple regression analysis to assess for relationships among constructs. The items on the PSOC which load on the Efficacy factor, 6, 10, 11, 13, and 15 were reverse scored to calculate the PSOC total score. In the cells that had no data, which indicated missing information, 999 was entered. When running the analyses, the option to “exclude cases pairwise” was selected to include participants in the analysis for which necessary information was provided. Therefore,

participants who completed all the PSOC items, but not the PTG, would be included in any PSOC analyses. Maternal variables were analyzed using descriptive analysis.

### **Instrumentation**

**Parenting Sense of Competence Scale (PSOC).** For the purposes of this dissertation, the Parenting Sense of Competence Scale (PSOC) was used to assess parenting self-efficacy. The PSOC is a domain-general assessment of PSE as the questions focus on a parents' overall sense of efficacy in their parenting role versus their self-efficacy in specific parenting tasks. The 17 questions on the PSOC are scored on a 6-point Likert scale ranging from 1 (*strongly agree*) to 6 (*strongly disagree*). Items which load on the Efficacy factor, 6, 10, 11, 13, 15, and 17 are reverse scored to indicate positive parental experience.

In the current study and based on the previous mentioned research, the PSOC included 14 of the original 17 items. The Cronbach alpha coefficient for the PSOC total scale was  $\alpha = .81$  ( $n = 146$ ). The Cronbach alpha coefficient for the PSOC efficacy subscale was  $\alpha = .75$  and included the reversed scored items. The Cronbach alpha coefficient for the PSOC satisfaction subscale was  $\alpha = .79$  and included seven of the 14 total items.

**Posttraumatic Growth Inventory (PTGI).** The Posttraumatic Growth Inventory (PTGI), as developed by Tedeschi and Calhoun (1996), is a 21-item measure. The measure is used to assess level of change on a Likert type scale from 1-6, with 1 (*did not experience a change*) to 6 (*experienced a great degree of change*) in the area in question.

The PTGI provides a total score with the higher number indicating higher perceived change. In addition to the total score, each of the five factors receives a score.

The five factors are: New Possibilities, Relating to Others, Personal Strength, Spiritual Change and Appreciation of Life. Tedeschi and Calhoun reported an internal consistency of  $\alpha = .90$ . Tedeschi and Calhoun reported test retest reliability was  $r = .71$ . Analysis of variance indicated that women reported more benefits than men; however, the gender x severity interaction was not significant. Univariate tests showed that women scored significantly higher on four out of five factors: New Possibilities, Relating to Others, Personal Strength, and Spiritual Change, but not on Appreciation of Life. The possible benefits are treated as outcomes of coping with traumatic events. Sheikh and Marotta (2005) examined the correlations of the five factors with each component and with the total PTGI. They reported that each factor correlated with the total PTGI score with  $\alpha = .80$  or above. Sheikh and Marotta reported an internal consistency analysis of the subscales on the total score and reported an alpha value of  $\alpha = .96$ . Sheikh and Marotta ran a principal component analysis with oblique rotation and the results indicated that the PTGI measures the one construct desired, PTG.

In the current study, Cronbach alpha coefficient for the PTGI total score ( $n = 127$ ) was  $\alpha = .93$ .

## Chapter Three

### Results

The results of this dissertation will be presented in order of hypothesis.

#### Demographics

Twenty eight of the participants (17.5%) reported receiving the diagnosis at birth compared to 124 (77.5%) who received the diagnosis in utero. Of the mothers, nine (5.6%) self-identified as an adoptive mother and 151 (94.4%) self-identified as a biological mother. See Table 1 for descriptive of maternal and child age.

Table 1. *Descriptive Table for Maternal Age (in Years) and Child Age (in Months)*

Variable	<i>n</i>	Min.	Max.	Mean	Standard Deviation
Age of Mother at time of birth or adoption	158	18	50	32.51	6.154
Age of Child in Months	159	2	648	127.43	116.62

*Note.* Some mothers reported child's age in months and some reported in years. All ages were recoded into months.

#### Hypothesis One

Hypothesis one was: Mothers who receive the diagnosis at birth will report less parenting self-efficacy than mothers of children who received a diagnosis of Down syndrome prenatally. The subscales and the PSOC total scores had Cronbach alphas of  $\alpha = .75$  and higher, indicating highly correlated scales. An independent-sample t-test was conducted to compare the parenting self-efficacy total score for mothers who received the diagnosis prenatally and at birth. There was no significant difference in PSOC total scores for prenatal diagnosis ( $M = 56.19, SD = 8.53$ ) compared to at birth ( $M = 58.88, SD = 7.75$ );  $t(137) = 1.47, p = .14$  (two-tailed). An independent-samples t-test was conducted to compare the satisfaction subscale score of the PSOC between mothers who

had received the diagnosis prenatally and at birth. There was no significant difference in scores for mothers who received the diagnosis prenatally ( $M = 29.56$ ,  $SD = 6.08$ ) and at birth ( $M = 30.11$ ,  $SD = 5.43$ );  $t(139) = .431$ ,  $p = .667$  (two tailed). An independent-samples t-test was conducted to compare the efficacy subscale score of the PSOC between mothers who had received the diagnosis prenatally and at those who received the diagnosis at birth. The significant difference in scores prenatally ( $M = 31.50$ ,  $SD = 4.70$ ) and at birth ( $M = 33.73$ ,  $SD = 3.57$ );  $t(47.19) = 2.69$ ,  $p = .010$ ,  $d = .54$  (two tailed) indicated that mothers who received the diagnosis at birth reported higher parenting efficacy than the mothers who received the diagnosis in utero. Cohen's effect size value ( $d = .54$ ) suggested a moderate significance (Coe, 2002; Lakens, 2013).

### **Hypothesis Two**

The relationship between perceived parenting self-efficacy (as measured by the PSOC total score,  $n = 146$ ) and posttraumatic growth (as measured by PTGI total score,  $n = 127$ ) was investigated using Pearson product-moment correlation coefficient. The relationship between the two variables approached significance, but was not significant at the .05 level,  $r = .051$ ,  $n = 127$ ,  $p = .570$ . The relationship between the perceived parenting self-efficacy as measured by the PSOC self-efficacy subscale and posttraumatic growth was investigated also using the Pearson product-moment correlation coefficient. The relationship between the PSOC self-efficacy subscale and PTG was positive and significant  $r = .203$ ,  $n = 128$ ,  $p = .021$ . Refer to Table 2 for the correlations with maternal variables (age of mother at time of birth or adoption, age of child in months) with the PSOC total, PSOC self-efficacy subscale, PSOC satisfaction subscale, and PTG.

Table 2. Correlation Matrix for All Continuous Variables

		PTGI Total	PSOC Total	PSOC SE subscale	PSOC Satisfaction subscale	Age of Mother	Age of Child
PTGI Total	Pearson's r	1					
PSOC Total	Pearson's r	.051	1				
subscale PSOC Self-Efficacy	Pearson's r	.203*	.803**	1			
PSOC Satisfaction subscale	Pearson's r	-.091	.867**	.408**	1		
Age of Mother	Pearson's r	-.190*	-.013	-.097	.033	1	
Age of Child	Pearson's r	.075	.092	.056	.059	.071	1

*Note.* Significant correlations between the subscales and the PSOC total are expected to be strongly related as they are a part of the same measure. \* $p < .05$ . \*\* $p < .01$

### Hypothesis Three

To examine the predictive strength of important maternal variables as well as PSE on Posttraumatic growth, a stepwise regression analysis was conducted with maternal variables (timing of diagnosis in utero or at birth, time since diagnosis in months, caregiver category either adoptive or birth, age of mother at birth, and birth order) and PTG total score as the dependent variable. After the maternal variables have been entered as control variables, it was hypothesized that PSE would account for a significant amount of the variance in PTG.

Age of mother, child birth order, time since diagnosis, PSOC satisfaction subscale, PSOC self-efficacy subscale, PSOC total score were used in a stepwise multiple regression analysis to predict PTG total. The prediction model contained two of the six predictors and was reached in two steps with no variables removed. The model was

statistically significant,  $F(2, 107) = 4.538, p = .013$ , and accounted for approximately 8% of the variance of PTG total ( $R^2 = .078$ , Adjusted  $R^2 = .061$ ). The raw and standardized regression coefficients of the predictors together with their correlations with self-efficacy, their squared semi-partial correlations are shown in Table 3.

Table 3. *Stepwise Regression Analysis Predicting Posttraumatic Growth from PSOC Self-Efficacy Subscale and PSOC Total Score*

Model	<i>b</i>	<i>SE-b</i>	Beta	Pearson r	<i>sr</i> <sup>2</sup>
Constant	64.91	14.06			
PSOC subscale Self-efficacy	2.1	.705	.463	.200	.076
PSOC Total	-.805	.382	-.328	.043	.038

*Note.* The dependent variable was Posttraumatic Growth total score.  $R^2 = .134$ , Adjusted  $R^2 = .117$ . *sr*<sup>2</sup> is the squared semi-partial correlation.

## **Chapter 4**

### **Discussion**

The purpose of this dissertation was to determine if and what maternal variables and self-efficacy variables have a relationship with or predict positive growth in mothers, which was referred to as posttraumatic growth in this dissertation. Based on the literature review, this study included mothers' age, age of the child, and timing of diagnosis, as those variables were believed to be influential in the areas of parenting self-efficacy and posttraumatic growth. The average age of the mothers in this study was 33, which is consistent with literature that indicates that the majority of children with Down syndrome are born to mothers under the age of 35 (Skotko & Bedia, 2005). One hypothesis for this is that more mothers over the age of 35 receive in utero diagnosis and choose to terminate the pregnancy (Kellogg et al., 2014; Sheets et al., 2011).

Hypothesis one was: Mothers who receive the diagnosis at birth will report less parenting self-efficacy than mothers of children who received a diagnosis of Down syndrome prenatally. The total score of the Parenting Sense of Competence scale was used as the initial measure of parenting self-efficacy. Even though there were no significant differences between the PSOC total and PSOC satisfaction subscale scores in mothers who received a prenatal diagnosis compared to those who received the diagnosis at birth, there was a significant moderate difference between mothers' self-efficacy subscale scores. Mothers who receive the diagnosis at birth are likely to report higher self-efficacy subscale scores, which is not consistent with previous research that suggests self-efficacy increases with time. It is possible that because the participants were not administered the measure at birth, that mothers may not have remembered their emotions

at the time of the birth of their child. It is possible that mothers rate their parenting self-efficacy skills different from their being a parent specifically to their child with Down syndrome. In future studies, research may consider including both a general measure of parenting self-efficacy and a specific measure to target their self-efficacy belief of parenting a child with Down syndrome.

The self-efficacy subscale, even though highly correlated with the total ( $\alpha = .81$ ) and satisfaction score ( $\alpha = .79$ ), may be more sensitive to changes in time or some other characteristic of mothers that differ between the two groups.

Hypothesis two was: Mothers who report higher levels of Parenting Self-Efficacy will also report higher levels of Posttraumatic Growth. The relationship between the PSOC total score and posttraumatic growth was insignificant. However, the relationship between the PSOC self-efficacy subscale score and posttraumatic growth total was positive and significant which supported the hypothesis. The mothers who had higher levels of belief in their ability to be successful as a mother experienced a greater degree of positive change over time. However, in future studies, it may be important to break down the self-efficacy construct into the four influences described by Bandura (1977). The mothers included in this study were contacted via support groups, which may inflate a mother's self-efficacy via vicarious experiences, verbal persuasion, and emotional state. These individual influences may each influence posttraumatic growth in different ways.

The age of the mother, was significantly, but negatively, correlated with the PTGI total, but not correlated with PSOC total or PSOC subscales. The average age of the mothers in this study, at time of diagnosis, was approximately 33-years-of-age. As mothers age, concerns about their own health may increase. They may also have concerns

about who will take care of their child after they are no longer living, and may be experiencing new transitions themselves, or with their child (i.e., leaving high school, trying to get a job, determining whether guardianship is appropriate) that decrease their positive perceptions about being a parent to a child with Down syndrome.

Hypothesis three was: When controlling for maternal variables, Parenting Self-Efficacy will account for a significant amount of variance in Posttraumatic Growth. A stepwise regression was used to test this hypothesis. The maternal variables entered into the regression were: timing of diagnosis in utero or at birth, time since diagnosis in months, caregiver category either adoptive or birth, age of mother at birth, and birth order. The resulting prediction model contained two of the six predictors and was reached in two steps with no variables removed. These two predictors were PSOC efficacy subscale and PSOC total, which were highly correlated. Even though the model was statistically significant, the predictors only accounted for 8% of the variance in posttraumatic growth. The five factors of posttraumatic growth, New Possibilities, Relating to Others, Personal Strength, and Spiritual Change, and Appreciation of Life were not separated out in this dissertation; however, the individual factors may be related to self-efficacy. It is also possible that this measure of self-efficacy is not a true measure of self-efficacy.

### **Summary**

In summary, the participants in this dissertation were different from previous research as these participants received diagnosis or highly likely results from screenings prenatally versus the majority of research that has mothers who received diagnosis at or shortly after birth. The mothers in this study also opted to have a child with Down

syndrome. There is no comparison group to mothers who opted to not continue pregnancy or give the child to another family via adoption. These differences may be a factor in the minimal significant findings in this dissertation.

Research suggests that having more time to prepare for a child with a disability is important to mothers adapting and coping with the diagnosis; however, the time since diagnosis was not significant in this study (Goff et al., 2013; Kellogg et al., 2014). It is possible that access to resources (i.e., financial/social), religiosity/spirituality, or education levels account for higher self-efficacy than actual time past.

The research included in the literature review also suggested that the majority of mothers of children with disabilities have a negative birthing experience. The mothers in the current study may not have perceived the birth of their child as being a negative experience. This may be in part due to changing expectations for life and success for children with Down syndrome. It is also possible that the mothers in this study received the diagnosis in a balanced manner, were connected to support groups, and connected with medical specialists; which would make the experience more positive instead of more negative (Goff et al., 2013; Poehlman et al., 2005; Skotko, 2005a, Skotko, 2005b, Skotko & Bedia, 2005).

### **Limitations and Future Directions**

The PSOC in previous research has been reported to measure the self-efficacy construct (Coleman & Karraker, 1997; Jones & Prinz, 2005; Rogers & Matthews, 2004; Troutman, Moran, Ardnt, Johnson, & Chmielewski, 2012). However, the questions included in the self-efficacy subscale are not consistent with Bandura's self-efficacy scales (Bandura, 2006). Self-efficacy is defined as the belief a person has in their ability

to be successful given a particular task. The wording of the self-efficacy items on the PSOC (See Appendix A) do not specifically target mothers' belief in their abilities to perform parenting tasks or target their knowledge of appropriate caregiving responses. In addition the questions are not specific to being a mother of a child with Down syndrome. The PSOC includes the satisfaction and self-efficacy subscales; however, in reading the questions of the PSOC, it is difficult to determine which questions go with which scale. A measure of self-efficacy with questions that are consistent with Bandura's recommendations may provide different results in relation with the posttraumatic growth inventory.

Although researchers have used PSOC and PTGI scales with similar sample sizes as in this dissertation, Skotko 2005a was able to obtain a sample size of 1,126. The methodology of the Skotko studies was delivering packets to support groups and having the participants complete hard copy surveys. This dissertation relied on internet connections and for the society representatives to forward on the survey link. In the future, both paper and internet surveys may receive more responses. It is possible that adoptive mothers don't tend to join or participate in support groups or find support in other ways. Future research may consider being more targeted and deliberate in obtaining adoptive mother participants.

Future research may include other comparison groups and other disability groups. For example, Poehlmann et al. (2005) included mothers of children with Fragile X and reported that mothers of children with Fragile X had more time with their child before diagnosis. The length and experiences between birth and diagnosis may influence

perceived growth. Along with comparison groups, mothers who chose to not be a parent to a child with Down syndrome should be included.

The current study did not ask about the experience mothers had in receiving the diagnosis. Specifically, this study did not ask how the mothers were provided the diagnosis, who provided the diagnosis, and how the participants felt at the time of diagnosis. It is possible that posttraumatic growth may be influenced by the perception of the physician's message and less about the actual diagnosis. It is possible that the mothers in this study did not perceive their birth or the diagnosis as a negative or traumatic experience. Future research conducted in the area of posttraumatic growth with mothers of children with Down syndrome should include a measure about the feelings and experiences of the mother at the time of diagnosis and then over time. Although it would have been anecdotal in nature, asking the mothers in this sample why they had participated in prenatal screening and diagnosis may have also provided insight into possible differences between this population, compared to other mothers. The results of this study may not be generalizable to the majority of mothers of children with Down syndrome, as the majority in this study received the diagnosis prenatally.

Another limitation in this study was the participants. The women each made the choice to continue their pregnancy or to raise their child after receiving the diagnosis. It is plausible that the women in this study differ in their beliefs about their ability to raise the child compared to mothers not included in this study. Future research should include a group of mothers who either chose to terminate the pregnancy or to give their child up for adoption.

Findings from this study add to the research, as previous research has not examined the relationship between self-efficacy with posttraumatic growth with the population of mothers of children with Down syndrome. This is the first study to compare parenting self-efficacy between mothers who received the diagnosis of Down syndrome prenatally versus mothers who received the diagnosis postnatally. This result provides further support for giving diagnoses as early and as soon as possible for the benefit of the mother and child outcomes. This dissertation adds to the current literature as this was the first study to compare parenting self-efficacy and posttraumatic growth in mothers who received the diagnosis prenatally and postnatally.

## Appendix A

### Invitation/Welcome to the survey:

Hello!

As a caregiver of a child with Down syndrome you know firsthand the trials and successes you feel as a parent and for your child. Being a mother gives you experiences that are identical to no one else. I have really appreciated and learned a lot about the relationships between mothers and their children through my participation in a developmental disabilities certificate through the University of Kentucky, participation in Jesus Prom, and working and volunteering alongside families and individuals with Down syndrome.

As part of my dissertation, I am hoping to learn more about the experiences of mothers in regards to parenting in general and your experiences in regards to parenting a child with Down syndrome. This research will hopefully provide practitioners with information about how to better interact with mothers. This survey may take you between 5 and 10 minutes.

Of course, you have a choice about whether or not to complete the survey/questionnaire, but if you do participate, you are free to skip any questions or discontinue at any time. This study is anonymous, which means that no one will know that the information you give came from you or even whether you participated in the study. Please be aware, while we make every effort to safeguard your data once received from the online survey/data gathering company, given the nature of online surveys, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey/data gathering company's servers, or while enroute to either them or us. The final data will be retained for 6-years after the study is over.

Although we have tried to minimize this, some questions may make you upset or feel uncomfortable and you may choose not to answer them. If some questions do upset you, we can tell you about some people who may be able to help you with these feelings.

I would like to thank you in advance for your consideration to participate. If you have questions about the study, you may contact the investigator, Amanda Smith. If you have any questions about your rights as a volunteer in this research, contact the staff in the Office of Research Integrity at the University of Kentucky at 859-257-9428 or toll free at 1-866-400-9428.

Thank you in advance for your assistance with sharing your invaluable experiences!  
Amanda A Smith, Ed.S.  
Doctoral Candidate  
School Psychology Program, University of Kentucky

## Appendix B

I am the \_\_\_\_\_ of my child with Down syndrome (check all that apply)

Legal Guardian

Foster parent

Grandparent

Adoptive Mother

Biological Mother

If known: was the diagnosis of Down syndrome provided:

In utero

At birth

If adopted did you choose to adopt a child specifically with Down syndrome

Yes

No

How old were you when you became pregnant or the parent/guardian of your child with Down syndrome?

If you have more children, biological/adoptive, what is the birth order of your child with Down syndrome?

How old is your child with Down syndrome?

## Appendix C

### Parenting Sense of Competence Scale

**1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildly Disagree    Disagree    Strongly Disagree

**2. Even though being a parent is rewarding, I am frustrated now while my child is at her/her present age**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildly Disagree    Disagree    Strongly Disagree

**3. I go to bed the same way I wake up in the morning, feeling I have not accomplished a whole lot**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildly Disagree    Disagree    Strongly Disagree

**4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildly Disagree    Disagree    Strongly Disagree

**5. My mother was better prepared to be a good mother than I am**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildly Disagree    Disagree    Strongly Disagree

**6. I would make a fine model for a new mother to follow in order to learn what she would need to know in order to be a good mother**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildly Disagree    Disagree    Strongly Disagree

**7. Being a parent is manageable, and any problems are easily solved**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildly Disagree    Disagree    Strongly Disagree

**8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildly Disagree    Disagree    Strongly Disagree

**9. Sometimes I feel like I am not getting anything done**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildy Disagree    Disagree    Strongly Disagree

**10. I meet my own personal expectations for expertise in caring for my child**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildy Disagree    Disagree    Strongly Disagree

**11. If anyone can find the answer to what is troubling my child, I am the one**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildy Disagree    Disagree    Strongly Disagree

**12. Considering how long I have been a mother, I feel thoroughly familiar with this role**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildy Disagree    Disagree    Strongly Disagree

**13. I honestly believe I have the skills necessary to be a good mother to my child**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildy Disagree    Disagree    Strongly Disagree

**14. Being a mother makes me tense and anxious**

1                      2                      3                      4                      5                      6  
Strongly Agree    Agree    Mildly Agree    Mildy Disagree    Disagree    Strongly Disagree

## Appendix D

### Posttraumatic Growth Inventory

Indicate for each of the statements below the degree to which this change occurred in your life as a result of becoming a mother to a child with Down syndrome

#### 1. My priorities about what is important for life:

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

#### 2. An appreciation for the value of my own life

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

#### 3. I developed new interests

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

#### 4. A feeling of self-reliance

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

**5. A better understanding of spiritual matters**

1= I did not experience this change as a result of becoming a mother to a child with Down syndrome

2= I experienced this change to a very small degree

3= a small degree

4= a moderate degree

5= a great degree

6= a very great degree as a result of becoming a mother to a child with Down syndrome

**6. Knowing that I can count on people in times of trouble**

1= I did not experience this change as a result of becoming a mother to a child with Down syndrome

2= I experienced this change to a very small degree

3= a small degree

4= a moderate degree

5= a great degree

6= a very great degree as a result of becoming a mother to a child with Down syndrome

**7. I established a new path for my life**

1= I did not experience this change as a result of becoming a mother to a child with Down syndrome

2= I experienced this change to a very small degree

3= a small degree

4= a moderate degree

5= a great degree

6= a very great degree as a result of becoming a mother to a child with Down syndrome

**8. A sense of closeness with others**

1= I did not experience this change as a result of becoming a mother to a child with Down syndrome

2= I experienced this change to a very small degree

3= a small degree

4= a moderate degree

5= a great degree

6= a very great degree as a result of becoming a mother to a child with Down syndrome

**9. A willingness to express my emotions**

1= I did not experience this change as a result of becoming a mother to a child with Down syndrome

2= I experienced this change to a very small degree

3= a small degree

4= a moderate degree

5= a great degree

6= a very great degree as a result of becoming a mother to a child with Down syndrome

**10. Knowing I can handle difficulties**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome  
2= I experienced this change to a very small degree  
3= a small degree  
4= a moderate degree  
5= a great degree  
6= a very great degree as result of becoming a mother to a child with Down syndrome

**11. I'm able to do better things with my life**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome  
2= I experienced this change to a very small degree  
3= a small degree  
4= a moderate degree  
5= a great degree  
6= a very great degree as a result of becoming a mother to a child with Down syndrome

**12. Being able to accept the way things work out**

- 1= I did not experience this change as result of becoming a mother to a child with Down syndrome  
2= I experienced this change to a very small degree  
3= a small degree  
4= a moderate degree  
5= a great degree  
6= a very great degree as a result of becoming a mother to a child with Down syndrome

**13. Appreciating each day**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome  
2= I experienced this change to a very small degree  
3= a small degree  
4= a moderate degree  
5= a great degree  
6= a very great degree as a result of becoming a mother to a child with Down syndrome

**14. New opportunities are available which wouldn't have been otherwise**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome  
2= I experienced this change to a very small degree  
3= a small degree  
4= a moderate degree  
5= a great degree  
6= a very great degree as a result of becoming a mother to a child with Down syndrome

**15. Having compassion for others**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

**16. Putting effort into my relationships**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

**17. I'm more likely to try to change things which need changing**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

**18. I have a stronger religious faith**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

**19. I discovered that I am stronger than I thought I was**

- 1= I did not experience this change as a result of becoming a mother to a child with Down syndrome
- 2= I experienced this change to a very small degree
- 3= a small degree
- 4= a moderate degree
- 5= a great degree
- 6= a very great degree as a result of becoming a mother to a child with Down syndrome

**20. I learned a great deal about how wonderful people are**

1= I did not experience this change as a result of becoming a mother to a child with Down syndrome

2= I experienced this change to a very small degree

3= a small degree

4= a moderate degree

5= a great degree

6= a very great degree as a result of becoming a mother to a child with Down syndrome

**21. I accept needing others**

1= I did not experience this change as a result of becoming a mother to a child with Down syndrome

2= I experienced this change to a very small degree

3= a small degree

4= a moderate degree

5= a great degree

6= a very great degree as a result of becoming a mother to a child with Down syndrome

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**Vita**  
**Amanda A. Smith**

**Education**

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12/2008–8/2011	Educational Specialist Degree in School Psychology University of Kentucky, Lexington, Kentucky
8/2008–06/2010	Developmental Disabilities Certificate University of Kentucky, Human Development Institute, Lexington, Kentucky
8/2007–12/2008	Master of Science in School Psychology University of Kentucky, Lexington, Kentucky
8/2002–5/2006	Bachelor of Arts in Psychology State University of New York at Geneseo, Geneseo, New York
7/2005-8/2005	Oxford University, New College, England

**Professional Positions Held**

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9/2011-current	<i>Certified School Psychologist, Fayette County Public Schools, Lexington, KY. Supervisor: Diann Shuffett, Associate Director of Special Education</i>
8/2010–6/2011	<i>School Psychology Intern, Fayette County Public Schools, Lexington, KY. Site Supervisor: Diann Shuffett, Associate Director of Special Education. University Supervisor: Rachel Hammond, Lecturer</i>
8/2010–6/2011	<i>School Psychology Intern, Nelson County Public Schools, Bardstown, KY. Site Supervisor: Stacie McCune, School Psychologist. University Supervisor: Rachel Hammond, Lecturer</i>
8/2009–5/2010	<i>Advanced Practicum, Madison County Public Schools, Richmond, KY. Supervisor: April Walters, School Psychologist. University Supervisor: Lisa Ruble, Professor</i>

## Research Experience

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- Fall 2008 to December 2009: *Research Assistant*: COMPASS Grant, Department of School Psychology, University of Kentucky, Supervisor: Lisa Ruble, Ph.D.
- Fall 2007 to Spring 2010: *Research Assistant*: Examining Caregiver Variables in the Development of Early Number Sense in Young Children, Department of School Psychology. University of Kentucky, Supervisor: Kristen Missall, Ph.D.
- Fall 2006 to Summer 2007: *Research Assistant*: Studies to Advance Autism Research and Treatment. University of Rochester, Supervisor: Tristram Smith, Ph.D.
- Fall 2005 to Spring 2006: *Research assistant*: Early Family Parentification/role reversal and Social Adjustment. Department of Psychology, SUNY Geneseo. Supervisor: Jennifer Katz, Ph.D.
- Spring 2006: Research seminar: Sexual Aggression in couple relationships. Department of Psychology, SUNY Geneseo. Supervisor: Jennifer Katz, Ph.D.

## Research Presentations

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- Smith, A. A.** (April 2010). *Self-efficacy and Determination of Parents' of Individuals with Intellectual Disabilities*. Poster presented at the NADD 2010 International Congress & Exhibit Show: Innovations and Interventions (MH/IDD), Toronto, Ontario, Canada.
- Smith, A. A., & Ruble, L. A.** (March 2010). *Caregiver and Teacher Verbal Interactions during Consultation on Child Outcomes*. Poster presented at the National Association of School Psychologists, Chicago, IL.
- Smith, A. A., Ruble, L. A., Toland, M. D., Kirk, A., & Birdwhistell, J. L. (May 2009). *The Influence of Caregiver Verbal Interactions during Conjoint Consultation on Child Outcomes*. Poster presented at the International Meeting for Autism Research, Chicago, IL.
- Hojnoski, R., Missall, K. N., **Smith, A. A.**, & Polignano, J. (April 2009) *What Shall We Play? Gender and Early Math Performance*. Poster presented at the Society for Research in Child Development, Denver, CO.
- Smith, A. A., & Thomas, M. K., Missall, K., & Hojnoski, R.** (February 2009). *Children's Play with Toys Eliciting Math Talk and Play*. Poster presented at the National Association of School Psychologists, Boston, MA.

- Thomas, M. K., **Smith, A. A.**, Missall, K., & Hojnoski, R. (February, 2009). *Relations Among Caregiver Self-Efficacy, Self-Efficacy-Building Experiences, And Child Math Performance*. Poster presented at the National Association of School Psychologists, Boston, MA.
- Rooks, E., **Smith, A.**, & Kimberly, C. (February, 2008). *Individual Academic Consultations: Discussions about Study Strategies to Enhance Academic Life*. Concurrent session presented at the Annual First Year Experience Conference, San Francisco, CA.
- Kenien, T., **Smith, A.**, Petracca, M., & Katz, J. (November 17, 2006). *Early family and parentification and social adjustment*. Poster presented at the Association for Behavioral and Cognitive Therapies Conference, Chicago, IL.