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# Children with Special Needs and the Effect on the Family

Taylor N. Downey

*Eastern Illinois University*

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Children with Special Needs and the Effect on the Family

(TITLE)

BY

Taylor N. Downey

**THESIS**

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF

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Children with Special Needs and the Effect on the Family

Taylor Downey

Eastern Illinois University

Dedication

This research is dedicated to all individuals with special needs and their families. You may face difficult times but the love and support you have for one another will conquer all.

### Acknowledgements

I would like to recognize many individuals in my life for their support and love through this process:

My son: Bodhi, you have brought so much joy and happiness into my life. I am so blessed that you are my son. I hope all of my hard work pays off and I am able to give you the life you deserve. You have been my biggest motivation to finish my thesis and graduate. I love you with all my heart.

My parents: You have always encouraged me to do what I want to do in life. You have been by my side through every grade, college, and graduation. I hope I have made you proud.

My brother: Payton, you have inspired me to pursue research in children with special needs. You have taught me so much in the short time you have been part of our family. You have showed me love and happiness in the simple things in life.

My professors: I would not have been able to write this thesis without the help and push from all of my professors at EIU. Because of every single one of them, I am able to say I am a better person, student, and professional than the day I was when I started graduate school. You have all made my time at EIU a memorable one.

**Abstract**

The purpose of this study was to examine the family unit after the addition of a child with special needs. Additional stressors, positive and negative emotions were also explored in this study. The results of this study suggested that all families have different experiences with their child but they may feel similar emotions, feelings, and face the same characteristics depending on their child's diagnosis.

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## **Chapter One**

### **Introduction**

When the family dynamic changes with the addition of a child, things can become intimidating and stressful. First time parents tend to worry about bathing procedures, diaper changing, feedings and so many other parenting customs. However, the addition of a child with special needs can affect the family beyond the basics and is often overlooked. There are challenges associated with a child's diagnosis that can add a significant amount of physical stress and psychological stress for not only the parents, but for the entire family (Spratt, Saylor, & Macias, 2007). Each diagnosis is different and can cause varying stress factors on the family. Stress is a common experience for any and all parents. When there are high stress levels involved, it can lead to an increased use of undesirable parenting strategies, suppressing and voicing problems, as well as lower social skills within the children (McLennan, Doig, Rasumssen, Hutcheon & Urichuk, 2012).

### **Need for Study**

There is little research that explains how a child with special needs affects the family unit. It is important to understand all aspects of the diagnosis process as well as the family after the diagnosis occurs. In addition to the diagnosis, a key factor to remember is that all diagnoses are different and each individual person and diagnosis have their own unique characteristics. Having a child with special needs can create changes within the family, but there are resources for families to utilize. This study was needed to examine how the family is impacted as well as what resources are beneficial to families that have a child with special needs. This study attempted to contribute to the

growing body of research based upon the increasing number of individuals diagnosed with special needs.

### **Purpose of the Study**

The purpose of this study was to explore how having a child with special needs affects the family. In addition, the stressors within the family were examined. The emotions and feelings that arise surrounding a diagnosis were investigated.

### **Research Questions**

The overarching research question that guided this study was the following:

How does a child with special needs affect the family?

### **Research Hypotheses**

H1. Additional negative family stressors can arise from having a child diagnosed with special needs.

H2. An array of positive emotions can arise from a child's diagnosis.

H3. An array of negative emotions can arise from a child's diagnosis.

### **Definitions of Key Terms**

Terms used throughout this study include:

1. Special needs- "a wide range of physical disabilities, medical conditions, intellectual difficulties, or emotional problems, including deafness, blindness, dyslexia, learning difficulties, and behavioral problems" that negatively impact functioning in some manner (dictionary.com)
2. Operational Definition of Special Needs- "Children with identified disability, health, or mental health conditions requiring early intervention,

special education services, or other specialized services and supports”  
(ccfc.ca.gov)

3. Mild- “A mild intellectual disability is defined as an IQ between 50 and 70. A person with a mild intellectual disability participates in and contributes to their families and their communities and may live and travel independently but will need support and help to handle money and to plan and organize their daily life.” (CDDH.monash.org)
4. Moderate- “A moderate intellectual disability is defined as an IQ between 35 and 50. A person with a moderate intellectual disability understands daily schedules or future events if provided with pictorial visual prompts such as daily timetables and pictures and may develop independence in personal care.” (CDDH.monash.org)
5. Severe- “A severe or profound intellectual disability is defined as an IQ below 35. A person with a profound or severe intellectual disability requires lifelong help with personal care tasks, communication and accessing and participating in community facilities, services and activities.” (CDDH.monash.org).
6. Relationship strain- “to be subjected to tension or stress; suffer strain”  
(dictionary.com)
7. Support group- “a group of people who meet regularly to support or sustain each other by discussing problems affecting them in common”  
(dictionary.com)

## **Chapter Two**

### **Review of Literature**

Parents of children with special needs often experience increased levels of stress compared to parents of children without disabilities. “Excessive caregiving demands, lack of child responsiveness, and unusual behavior patterns have been closely associated with both increased stress levels and depression in the parent of chronically disabled children” (Slavik Cowen & Reed, 2002, p. 272). This study attempted to examine how a child with special needs can affect the family as a unit. This chapter will address contemporary literature related to children with special needs. Terminology and characteristics related to special needs, the process of diagnosis, stress, emotions/feelings, relationship strain, Family Stress Theory and resources will be discussed.

### **Special Needs**

Autism, Down syndrome (DS), and Cerebral Palsy (CP) are just a few of the diagnosis that will change the dynamics of a family forever. It is important for parents, and professionals to be educated on specific needs and their characteristics when working with families. The number of children diagnosed with special needs such as, Autism, DS, and other neurological disorders continue to increase each year, the disruptions in the equilibrium of those connected to the child are unmistakable, as well as the costs to provide care for the child (Brinker, 2011).

As reported by the Autism and Developmental Disabilities  
Monitoring Network in April of 2010, as many as 1 out of  
110 children are born today with an autism spectrum

8. Respite- “to relieve temporarily, especially from anything distressing or trying; give an interval of relief from” (dictionary.com)
9. Stress- “to subject to stress or strain” (dictionary.com)
10. Feelings- “an emotion or emotional perception or attitude”  
(dictionary.com)
11. Diagnosis- “the process of determining by examination the nature and circumstances of a diseased condition.” (dictionary.com)
12. Emotions- “any strong agitation of the feelings actuated by experiencing love, hate, fear, etc., and usually accompanied by certain physiological changes, as increased heartbeat or respiration, and often overt manifestation, as crying or shaking” (dictionary.com)

The following chapter will address the contemporary literature related to the focus of this study.

disorder. That number has increased from 1 out of 150, which was only five years ago (Brinker, p 10, 2011).

With the increasing numbers, more families are affected by the challenges of having a child with special needs in the home. From specific health issues, negative behaviors, and diagnostic testing, children with special needs go through a range of challenges in their first few years of life and well on into adulthood. However, not only are the children learning how to manage their diagnosis but the parents and other siblings are as well.

**Autism.** “About 1 in 68 children were identified with Autism based on tracking in 11 communities across the United States in 2012” (Center for Disease Control, 2016). Autism spectrum disorders (ASD) have their own unique characteristics. Individuals may face “social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviors” (Symptoms, n.d.). Symptoms, and their severity, may vary widely across these areas, from mildly challenging to more severe.

Children diagnosed with Autism often face social challenges and struggle with every day human interactions. Children may fail to respond to their name, have no interest in the people in their surroundings, and have delayed speech. Difficulty in regulating emotions may also be a challenge. Someone who does not have knowledge on Autism may see these emotions as “immature behavior” or inappropriate outbursts. These children tend to lose control and become frustrated in many situations. When a child is frustrated, this can lead to “self-injurious behaviors such as head banging, hair pulling or self-biting” (Symptoms, n.d.).

Individuals with Autism tend to face challenges related to communication. Younger children diagnosed with Autism are often delayed in speaking and using gestures. Some significant language delays start early in an infant's life and many do not begin speaking until much later in their life. Speech therapy is often used to help individuals with autism to develop spoken language and work on their communication skills. Children who are non-verbal, use communication systems such as "pictures, sign language, electronic word processors or even speech-generating devices" (Symptoms, n.d.).

Repetitive behaviors is often a common characteristic of Autism in individuals. These behaviors are seen as unusual and include, "hand flapping, rocking, jumping, and twirling, arranging and rearranging objects, and repeating sounds, words, or phrases" (Symptoms, n.d.). Children with Autism may spend more time lining up and arranging toys than actual pretend play with them. Often times a disruption in these behaviors can cause a child to be extremely upset because their routine and consistency is interrupted. These repetitive behaviors can become obsessions and result in an extreme interest in objects, numbers, and symbols.

**Down syndrome.** Each year, almost 6,000 infants are born with DS (Birth defects, 2014). Almost half of these individuals will face a major mental health concern during their lifetime. The most common of these health concerns include, "general anxiety, repetitive and obsessive-compulsive behaviors; oppositional, impulsive, and inattentive behaviors; sleep related difficulties; depression; Autism spectrum conditions; and neuropsychological problems characterized by progressive loss of cognitive skills" (National Down Syndrome Society, para. 2 n.d.).



Situational Anxiety is a major issue in individuals with DS. Anxiety occurs during transitions from one place to another, or if experiencing new situations and surroundings. Examples that may cause anxiety include, “transitions from home to school, meals or bed times, as well as being in an unfamiliar environment” (National Down Syndrome Society, para 16, n.d.).

In addition, individuals with DS may show obsessive-compulsive symptoms. When an individual with anxiety faces a disruption to a comfortable routine, they can feel unhappy or fearful of situations, because they are accustomed to ritualistic behaviors. The individual who is disruptive and oppositional tends to act silly, happy, and excited when changes occur. In either situation these behaviors can be difficult for parents or caregivers to manage.

Depressive symptoms can also occur in individuals with DS. They may show social withdrawal, sadness, and the inability to enjoy once loved activities (National Down Syndrome Society, n.d.). Often times these individuals never typically showed signs of depression, according to their caregivers. A common issue that rises with depression and anxiety is disrupted sleep, which causes issues distinguishing what is causing the sleep issues.

**Cerebral Palsy.** “An estimated 8,000 babies and infants, plus 1,200 to 1,500 preschool–age children are diagnosed with cerebral palsy every year in the United States” (Kriger, 2006, p. 91). CP is a permanent neurological disorder that occurs from brain injury prior to the cerebral development being finished. The entire body can be effected by CP. Decreased body movement, muscle control, muscle coordination, muscle tone,

reflex, posture and balance can all occur. In addition, fine motor skills, gross motor skill, and oral motor functioning can all be impacted.

Physical impairments will appear slowly over time. Different limbs and the extent of impairment will differ from one individual to another. Arms, legs, and the face can be individually affected or the body as a whole. Those diagnosed also can lose the ability to control their muscles. They can have issues contracting their muscles too much or too little. This causes limbs to be stiff or forced into uncomfortable and painful positions. Other complications such as intellectual impairment, seizures, and vision or hearing loss are also common in individuals with CP (Definition of cerebral palsy: What is cp? n.d.)

Every case of CP is different and unique. “An individual may have total paralysis and require constant care, while another may have partial paralysis and require little assistance” (Definition of cerebral palsy: what is cp? n.d.). The timing of the injury plays an important role or the severity of the diagnosis. The injury to the brain happens when the brain is still developing, whether it is before birth, during birth, or immediately after birth.

### **Diagnosis**

Every type of disability is diagnosed differently. Some can be clear and concise and others may be more complicated and involve multiple steps such as observations and collaboration from a team of professionals. There currently is not a medical test that is used to diagnose Autism. Unlike a disability that is evident and presents specific symptoms, autism is more difficult to diagnose because it is a spectrum of closely related symptoms. There are specially trained doctors that administer an Autism-specific behavioral evaluation. A typical evaluation for a diagnosis involves a multi-disciplinary

team of doctors including a pediatrician, psychologist, speech and language pathologist and occupational therapist (How is Autism Diagnosed, n.d.).

The first step to diagnosis is often when parents begin to notice their child is showing atypical behaviors, which seem unusual to them. These include failure to make eye contact, not responding to their name, playing with toys in an unusual way, or repetitive behaviors. Autism is a life-long condition, diagnosed children and adults benefit greatly from interventions, or therapies, that can help them work on reducing these symptoms and help them increase their daily life skills (How is Autism Diagnosed, n.d.).

The diagnosis for DS typically occurs at birth. Doctors recognize features immediately after the birth of the infant. Features often include a “flattened face, upward slant to the eyes, a short neck, abnormally shaped ears, and a single deep crease on the palm of the hand” (Down Syndrome Diagnosis, n.d.). If DS features are present doctors can perform a blood test which can confirm whether the infant in fact has DS. This test is known as chromosomal karyotype, which means that the doctors will allow the blood to “grow” for almost two weeks. Then the blood is examined under a microscope and they will look for extra material from chromosome 21 (Down Syndrome Diagnosis, n.d.).

According to Krigger (2006), CP is diagnosed by observation of slow motor development, abnormal muscle tone, and unusual posture. Physician’s go through a testing strategy and that is based on the development of symptoms, family history, and other factors influencing the probability of the diagnosis. Since Cerebral Palsy is damage that occurred to the brain, it cannot currently be fixed. There are treatment and therapies that help manage the effects that occur on the body (Definition of cerebral palsy: what is cp? n.d.).

### **Stress**

The impact of parenting a child with a disability can be stressful and potentially negative. This impact is not as severe as what is often believed (Staats et al., 2015). Families that include a child with special needs can face additional stressors on top of the traditional factors that occur. Once a child is born and the diagnosis has been made, many emotions arise as well as the increase in stress levels.

### **Emotions/Feelings**

The beginning months after the birth of a child can be an emotional and chaotic time for parents. Feelings of isolation are common and there is a lot of concern for the future for their family and their child (Kerr & McIntosh, 2000). Those families that have positive coping strategies have better adjustment to adapt to the stressors involved in raising their child and understanding their disability. “The experience of receiving a prenatal diagnosis often varies among parents, but any report encountering an array of emotions, including stress, disbelief, sadness, anger, and confusion” (Staats et al., 2015, p. 84).

Hope is a positive mindset that some parents have. It helps parents to transform and reframe their lives around their child. Parents often report their lives are full of empathy, hope. Love, care, compassion, and value, as result of having a child with special needs. They often credit their child and the disability for their personal growth (Staats et al., 2015).

Siblings also experience an array of emotions and feelings once there is a child with special needs added to the family. Often times, siblings become more caring and compassionate towards their sibling and others around them. Children may display feelings of empathy towards their sibling. They also have a heightened appreciation for

their own health and abilities (Dyke et al., 2009). Family resilience is another feeling that siblings portray. Being placed in a situation such as this, the siblings are able to adapt to the change and dynamic of the family and cope with the additional stress in the future.

From the negative feeling standpoint, some parents felt that their other children had a sense of embarrassment in front of their peers because of their sibling's behavior. Some parents noticed their children felt an increased burden and responsibility to help care for their disabled sibling (Dyke et al., 2009). These negative feelings may be reduced when a child with special needs is born into a larger family because there are more individuals to help provide care.

### **Relationship Strain**

All aspects of the family are affected when a child with special needs is added. This includes the family, parents, siblings, and friends. Family functioning is impacted in both a negative and positive manner. Positive outcomes include an increased inner strength, resilience, cohesion, and community connection. Researchers also noted the negative effects on a family. These include strained marital relationships, financial pressures, sibling adjustment, and decreased parent efficiency (Lindo et al., 2016).

It is common for parents of the child to experience a strain on their relationship, especially since they have a child who needs additional attention and care. Some parents may have less time for each other after the child is born. "Family members who are tired, depressed, or in need of health care often must sacrifice their own health and well-being to meet the extraordinary care needs of their child when support is lacking" (Slavik Cowen & Reed, 2002, p. 273).

Parents also noted that spontaneous and thought out recreational trips and the typical family outings were limited. “Financial restraints limited family holiday opportunities, educational opportunities and material goods” Dyke et al., 2009). These circumstances cut out quality family time as well as time with other children which can increase the negative effects for siblings.

In addition, parents of children with special needs tend to rely heavily on their significant other for support. According to Staats et al. (2015), parents of children with DS have a lower rate of divorce than parents of children with another developmental disability. Parents who are at a younger age and have less education are factors that increase the probability of divorce. “In past research it has been suggested that there are few differences in family and marital functioning when comparing families of children with DS to families of children without disabilities” (Staats et al., 2015 p. 85).

Not only are parents immediately affected by the addition of a child with special needs but siblings are as well. Siblings of children with a developmental disability often face an adjustment period following a diagnosis. According to Biasi et al. (2016), siblings may have higher levels of depression and are at a higher risk for internalizing and externalizing problems. In addition, siblings may face social and behavioral change problems, hassles with sibling behavior, and distressing emotions such as guilt (Green, 2013).

Having to meet the high demands that come with having a child with special needs parents may find themselves having little time to spend with friends outside of the family. These relationships may suffer or they may become beneficial in decreasing the stress levels in parents. Research states that parents of older children with a

developmental disorder have a higher rating of satisfaction with their friendships and because of this relationship; they experienced less stress as a result (Lindo et al., 2016).

### **Resources Available to Families**

Often times, there are resources to help parents adapt to the lifestyle changes of a child with special needs. These resources include, counseling, support groups, and respite programs. Resources that are taken advantage of by families often have great success in reducing the caregivers stress levels and worries.

### **Respite Program**

This type of program is part of a comprehensive approach to early intervention as well as preventing child maltreatment. Respite programs are often used by caregivers in order to receive a break from the constant care of their child. These programs are seen to help reduce caregivers stress (McLennan, Doig, Rasmussen, Hutcheon & Urichuk, 2012). Respite programs are often taken advantage of by families and paid for by a particular program the family uses or is in contact with. Often times families are prioritized based on their child's mental and/or developmental issues for respite care due to the fact they may be experiencing higher stress levels than others.

### **Support Groups**

According to Kerr and Macintosh (2000), "social support can be an effective buffer against the stress and isolation faced by individuals in this population" (p.310). Research suggests that parents have reduced stress levels when they are able to share and compare their experiences with other parents/guardians who share a similar situation. Parents who have contact with other parents of children with special needs, experience

influences that decreased their stress levels and also provide emotional, social and practical support (Kerr & Macintosh, 2000)

### **Family Stress Theory: ABC-X**

Reuben Hill's ABC-X model of family stress, is the foundation of family stress theory. Family stress theory revolves around central components from Hill's model. These components include, A as the stressor event, B, the family resources or strengths, and C, as the family's perception of the event. When a family is unable to adapt or solve the problem it can lead to a crisis, which is the X component (Smith & Hamon, 2012).

#### **Stressor Event (A)**

When using the ABC-Z model it is important to remember that the stressor event in the situation can either be positive or negative. These all depend on how a family interprets the situation, as well as the type of stressor. There are three types of stressors within this model, normative stressors, non-normative stressors, and chronic stressors. There are ways to categorize or define these stressors, each depends on how the event impacts the family. The first criteria looks at whether the stressor is internal or external to the family unit. The second being if the event is focused on one member or all of the members of the family. In addition, the onset of the event can affect how much time the family has to adapt. Whether it be a gradual onset or a sudden onset. The severity of the stressor will also play a role in adaptation and whether it was expected or not. Stressors can also be natural or artificially made. The type of stressor will also affect the significance of the impact on the family unit. Finally, the perception of whether or not they are able to solve the crisis situation can determine how the family will react to the sudden change (Smith & Hamon, 2012).



### **Normative Stressors**

Normative Stressors are events that are natural to the typical family's everyday life or a long term transition throughout a family life course (Price, Price, & McKenry, 2010). Daily hassles fall under the normative category. Hassles could include caregiving demands and pressures that arise from everyday tasks that involve children. Some hassles can be infrequent or situational, where others are reoccurring hassles of everyday life.

Developmental transitions are another type of normative stressors. These are defined as the developing characteristics of the young and the social aspects of these transitions. "Developmental transitions have the potential to result in accumulating stressors that can be perceived collectively disruptive change and contribute to psychological distress" (Price, Price, & McKenry, p. 32, 2010). One of the major transitions in a family's life, is adjusting to the period of their children going through the adolescent years. The key issue for parents is allowing their children to gain independence and make decisions. The process of letting-go causes potential stressors for parents.

### **Non-normative Stressors**

Families also face stressor events that are non-normative, unpredictable occurrences that are disruptive to the everyday life. These events are often sudden, dramatic and have considerable potential to cause chaos in families (Price, Price, & McKenry, 2010). Most often, these types of stressors are a result of a unique situation that is unlikely to reoccur.

Off-time developments are classified as a non-normative stressor. These are typical events that happen at an unanticipated time, which then become disruptive and

cause stress for families. These events could include, retirement, death of an elderly family member, and becoming a grandparent.

Another category that falls into non-normative stressors can be the initial awareness or diagnosis of a family member. This would include delinquency, conduct disorders, attention deficit behavior, physical illness, poor mental health, and birth defects. Along with a diagnosis parents often experience distress, worry, edginess, and feelings of devastation (Price, Price, & McKenry, 2010).

### **Chronic Stressors**

“Chronic stressors are atypical circumstances that occur over extended periods of time, are difficult to amend, and may have debilitating effects, both for parents and for the parent-child relationship” (Price, Price, & McKenry, p 34, 2010). These type of stressors could include a parent’s employment that affects their parenting abilities, poverty, and marital conflict. Another example of chronic stressors could include the physical, financial, and emotional demands that parents encounter when they have a child whom suffers from a long-term illness or have persistent abnormal qualities (Price, Price, & McKenry, 2010).

### **Resources (B)**

Once a family encounters a stressor they must then determine how to manage the event. Accessing resources is one way of doing this. Resources are defined as “the potential strengths of individuals, families, and other systems that may act as vehicles through which parents can obtain what they value” (Price, Price, & McKenry, p 35, 2010). There are positive and negative resources within a family unit. Resources that are positive include traits, qualities, characteristics, and abilities of parents that have the

ability to address the demands of the stressors. The negative resources would be the family's vulnerabilities of parents and the parent-child relationship (Price, Price, & McKenry, 2010). This model contains two types of resources, personal resources and family/social resources.

### **Personal Resources**

Resources that are considered personal to a family include economic well-being, education, interpersonal skills, and physical health. Self-efficacy and positive self-esteem are considered to be personal resources, and they can help empower parents and family members to manage stressful circumstances.

### **Social Resources**

Social support is one of the most important resources a family can access. Support helps build an individual's self-esteem. Social support can also come from community resources, such as the opportunity for networking and assistance in finding valuable resources (Smith & Hamon, 2012). "Having good social support from friends, neighbors, and family can lead to more positive parenting practices and can minimize the effects of environmental stress" (Smith & Hamon, p 119, 2012).

### **Definition of the Situation (C)**

According to Smith & Hamon (2012), the manner in which individuals interpret a stressor is just as important as accessing resources when determining how a family will respond to a crisis situation. "Cognitive appraisal and coping processes are thought of as mediators of individual psychological responses to stressors" (Smith & Hamon, p 119, 2012). A families' outlook on crisis can vary from others. Some may see life changes as

challenges for them to overcome or they might interpret the stressor as uncontrollable and see it as damaging to the family's well-being.

### Stress and Crisis (X)

The previously mentioned parts of the model all determine if a family enters a state of crisis. A family will reach this stage if they are unable to maintain their usual family balance because of the stressor event. If a family reaches this crisis stage, it does not mean that they will not survive it. Often times, families function better after a crisis than they previously were (Smith & Hamon, 2012).

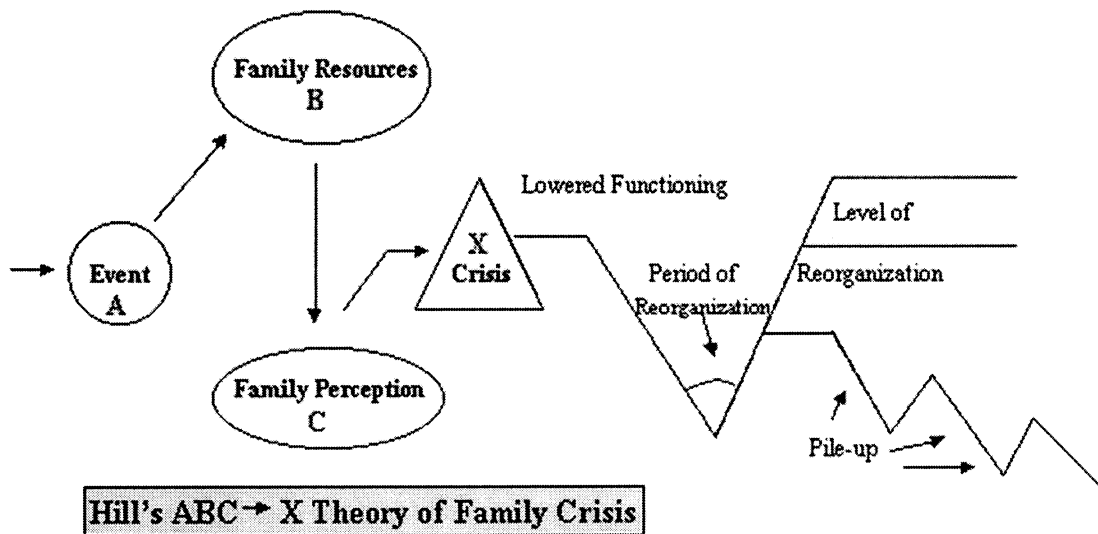


Figure 1. Reuben Hill's ABC-X Theory

### Conclusion

No matter what developmental disability a child has, the family is sure to encounter challenges and changes after the diagnosis. It is important for families to remember that there are resources available for them as long as they are willing to take advantage of them.

When parents are coping with their child's condition, understanding what developmental limitations exist, identifying and accessing necessary specialized care and medical services, locating community resources and support, and planning for the future are common demands described by parents of children with special needs (Nelson, Goff et al., 2013).

A family's experience raising a child with special needs will be unique compared to those without a child with a developmental disability. The experience is impacted by their specific situation, the external environment, and support. Not all families experience the same negative emotions, feelings, and stressors related to a diagnosis of special needs, but it is important to remember there can also be positives along the way.

The following chapter will describe the methodology that is used in the study, including the design of the study, sample, and selection of the sample, description of the sample, instrumentation/measurement, data collection, and analysis.

## **Chapter Three**

### **Methodology**

The purpose of the study was to explore the impact of child with one of the three focused special needs on a family unit. In addition, the stressors within the family were examined. The emotions and feelings that arise surrounding diagnosis were investigated.

The research questions are as follows.

1. How does a child with special needs affect the family?

The research hypothesis are as follows.

H1. Additional negative family stressors can arise from having a child with special needs.

H2. An array of positive emotions can arise from a child's diagnosis.

H3. An array of negative emotions can arise from a child's diagnosis.

### **Design of the Study**

The researcher utilized a qualitative research approach for this study. A convenience sample of participants engaged in individual interviews with the researcher. The interviews were guided by the use of the Downey Survey (Appendix A), developed by the researcher to elicit information used to gain an understanding of how a child with special needs affected the family unit. Qualitative data were analyzed using the constant comparative approach. "Qualitative research allows researchers to get at the inner experience of participants, to determine how meanings are formed through and in culture and to discover rather than test variables" (Corbin & Strauss, p. 12, 2008).

### **Sample Selection**

Sample selection for this study began after permission was obtained to conduct research with human subjects from Eastern Illinois University's Institutional Review Board, #16-077. The sample was one of convenience and participation in the study was voluntary. Participants were recruited from the population of parents served by the special education program in an elementary school in a small Midwestern town through a letter from the researcher (Appendix B). This school housed Kindergarten through 6<sup>th</sup> grades. However, the special education classroom served students of a variety of age groups, ranging from 6 to 11 years at the time of the study.

After initial contact with the population, the researcher used the snowball approach to solicit further participation in the study, asking the parents to recommend other families that would be willing to participate. The goal was a minimum of six. Upon the agreement to participate, the researcher determined whether individuals fit the parameters for the study. The parameters of this study were that participants have a child with special needs. If individuals were deemed appropriate, a face-to-face interview was scheduled at which time informed consent was explained (Appendix C) and obtained.

### **Instrument Description**

The researcher developed the Downey Survey after a thorough review of contemporary literature regarding the topic. The literature includes references by Corbin & Strauss, Kerr & McIntosh, and Smith & Hamon. The instrument included open-ended questions addressing the research questions for the study. Three professors in the School of Family and Consumer Sciences at Eastern Illinois University deemed the interview questions valid and appropriate for the study.

### **Procedure for Data Collection**

Parents of children with special needs were asked to participate in this study through the use of the snowball method. Interested participants that met the criteria for the study were contacted by the researcher and face-to-face interviews were scheduled. The risks and benefits of the study were discussed and informed consent was obtained; each participant was told that he or she could withdraw from the study at any time.

The researcher performed each interview using the Downey Survey. The interviews were voice-recorded using equipment provided by the researcher. Each interview was stored in the personal computer of the researcher, to which only she had access.

### **Data Analysis**

Qualitative data were analyzed using the constant comparative approach based on Corbin & Strauss's work (2008). The researcher started analysis by transcribing each interview from the recorded data. As themes appeared in data, either through over-reaching ideas or the use of specific terminology, they were organized into categories of similar information. As the researcher moved through each interview she constantly compared new interview data to existing categories in order to either support or delete categories. Upon the completion of a qualitative analysis a commonality of thought is identified.



## **Chapter Four**

### **Results**

The purpose of the study was to explore the impact a child with one of the three focused special needs has on a family unit. In addition, the stressors within the family were examined.

This chapter discusses the results of the study. Qualitative data were gathered through interviews with parents of a child with special needs and was analyzed using the constant comparative method. The design of the study allowed the researcher to better understand how the family unit was impacted by the addition of a child with special needs. Research questions addressed the diagnosis of a condition leading to a special need, how the diagnosis was made, feelings regarding the diagnosis, family stress levels, relationships, child care, resources, and overall experience with children with special needs.

The research question and hypotheses are as follows.

#### **Research Question**

1. How does a child with special needs affect the family unit?

#### **Hypotheses**

H1. Additional negative family stressors can arise from having a child with special needs.

H2. An array of positive emotions can arise from a child's diagnosis.

H3. An array of negative emotions can arise from a child's diagnosis.

#### **Instrumentation**

A total of six participants were interviewed using the Downey Survey (Appendix A). Each question revolved around the families' individual experience with their child.

Current research on this topic lacks information on stress levels and strains on not only the parent's relationship but with other siblings, family and friends. Therefore, the researcher created instrument questions based on the lack of information in hopes to expand knowledge on those topics.

### **Data Analysis**

The constant comparative method was used to analyze the qualitative data (Corbin and Strauss, 2008). The researcher first used microanalysis, which is where the researcher created ideas from a sample of questionnaire responses. Using this method allowed the research to look for similar responses with in participant's interviews. Common responses found repeatedly were grouped into broad categories. Responses continued to be analyzed in broad categories and broke down into common themes. Through the data analysis process, an abundant of support emerged for the overall research question. In addition, the themes of: diagnosis, advice, resources and support emerged.

### **Children's Diagnosis and Additional Needs**

Participants were asked one question regarding their child's diagnosis and what additional needs come with it. Data indicated that three children were diagnosed with Down syndrome, one Autism, one ODD, RAD, ADHD, and one child in the middle of the diagnosis process.

Along with the child's initial diagnosis, each child may have unique needs because of their diagnosis. Two out of three children in this study with Down syndrome had no additional needs or health concerns. The remaining child had to have corrective eye surgery along with heart surgery at a very young age. Families noted that heart defects were a common trait in individuals with Down syndrome. This child also had

digestive issues. Her family has to keep on top of her bowel movements to ensure she does not become constipated, because it happens very easily.

The child diagnosed with Autism had no additional needs that were present from the diagnosis. The two remaining children had unique characteristics that presented. The child diagnosed with Oppositional Defiant Disorder, Reactive Attachment Disorder, and Attention Deficit Hyperactivity Disorder had a plethora of additional needs. One issue the family faces on a daily basis is their child having Pica.

The final child had yet to receive a diagnosis; they were currently in the long process of discovering why their child behaved the way she did. The family has faced an issue with her speech. They have difficulty understanding what she needs which in turn makes it difficult to help her.

### **Diagnosis Process and Feelings**

Each child's diagnosis was made in their own unique way. There are specific tests for one and observational cues for another, yet parent's feelings are the same. Each parent noted that it is a scary feeling to go through the diagnosis process because of the unknown. Research shows that parents expecting a child tend to hope that they are a healthy and typical infant, therefore when they receive the news of a special need, many emotions come about. Parents often experience feelings of anger, fear, and shock. Some parents asked themselves "why us" (Kuhn, 2016)?

*"With our son, we did not receive a diagnosis until he was a couple years old; the doctors put him through a set of activities and observed his behaviors. Once we received the diagnosis, we had feelings of sadness and anxiety for quite a while, until we fully educated ourselves on Autism."*

*“Once we found out we were pregnant the doctors ran blood work since I was over 35. The test showed that our baby had a 1% chance of having Down syndrome. We wanted further testing so we went to Champaign for the gender determination. They told us it was a girl and it was a quick downslide from then on. They told us she had a heart defect that would require surgery, this is a major marker for Down Syndrome. They did a procedure called an amniocentesis to test her chromosomes. We had to wait an agonizing 5 days for the results. They called and said yes she had Down syndrome and Turner syndrome and we were instantly sad and angry.”*

*“The diagnosis process was a breath of fresh air because we finally knew why our daughter acted the way she did. We finally had the answer we had been looking for. Once we received the diagnosis then we could go educate ourselves on how to manage and handle her behaviors”*

*“We didn’t know or expect him to have Down syndrome; all of our tests came back negative. We did not know anything about the Down syndrome. We were under the impression he was a typical child. We did not know until the minute we had him, then we were told about it. It was not a nice way to find out but that is how it happened. We were upset, scared, mad, and I think we were feeling just about every feeling you could feel”*

A diagnosis can be made with ease or it can be a lengthy process. This process can be very stressful for parents as well as siblings. Going through this stressful time can be hard on a family but several participants noted that finally receiving the diagnosis and allowing ourselves to do research helped lessen the stress.

### **Communication of Diagnosis**

Communication of diagnosis varied from family to family. The majority of families felt the need to share the diagnosis right away with family and friends. They felt that it was important for all members in the child's life to know and understand the diagnosis. They wanted to educate these individuals on the diagnosis as well as how to care and interact with their child. This also gave family members an idea of what to expect in the future.

*“We told all of the family right off the bat, it was somewhat sad. I remember crying a lot every time we told somebody. Everybody was saying do not worry about it, everything will be ok and we will still love him. Family was eager to work with them and learn. His grandparents were looking stuff up on the internet to see what we needed to do and what kind of things we needed to work with in case he gets behind so we can keep him on track. One set of grandparents were out buying black and white books and working on that. They wanted to make sure we had all the things we needed and that we knew what to do.”*

One family in particular took a different route to sharing the diagnosis. All parents take this type of news differently. It can be hard to process for the parents so it may interfere with when and how they share the news.

*“That took us some time. Because it was super important because I did not want to tell anybody until we had fully come to terms with it. I did not want the “everything happens for a reason” or just all those comments because you are angry and sad and I did not want to lash out at someone like “yeah right”. I wanted to come to terms first. Of course we told my parents but I lost a best friend at the time. I had told her we had some rough news and I needed to process it before we could talk about it. I probably took two weeks to just sit with it and then I checked in with her and told her I was ok but she could not understand why I took the time to. So anyways, our friendship was completely severed at the time because she said I was being selfish and not talking with her. She said that even then when I told her that this is why, because I found out my daughter has down syndrome and a heart condition and has surgery, she even then didn’t back down or was more understanding. That was the first time we realized yeah friendships are going to change but that is just the part of it. It is not as if anybody we told said anything that was harsh. We just needed to come around to ourselves first off.”*

### **Strain on Siblings, Family, and Friends**

In a situation such as having a child with special needs, parents, siblings, family, and friends can all be affected and all in different ways. Having a child with special needs

who requires additional care and attention from the parents can place a strain on the parents and other sibling's relationship. Families with a child with special needs may also not have a lot of spare time for extended family and friends, which may cause distance between individuals.

*“I think we were both on the same page with our emotions. It was a roller coaster but we communicated well and I think that was super important. Family, I think there was not a strain I think it got a little frustrating because my parents were still saying things about abortion type of things. Like you guys, that's a lot of work, taking on a lot type of thing. I finally had to say were are not doing that, it's not an option and we are moving on. Friends, I lost a friend but I gained friendships that I had originally lost contact with but then they were there to help and be by my side and help with my baby shower.”*

Not all families face this type of strain. In some circumstances, families may grow and become closer and a stronger unit. Participants noted that they received help from family and friends who went above what they could have ever hoped for.

*“I feel that our son's diagnosis brought us much closer together because it was a time where we needed each other for support. Our other children love their brother very much and their relationship has not changed. Our family and friends were wonderful; they researched Down syndrome themselves and learned all about the diagnosis in order to understand him”*

### **Experience with Special Needs**

When a family's child is diagnosed with special needs, they can be terrified, but if a parent has experience working with a child with special needs they may feel more educated or prepared. Half of the participants reported that they had no experience working with special needs before their child was born.

*“No real experience with children but my wife and I both used to work with special needs adults.”*

The remaining half of the participants had worked with or had been around a child with special needs. They noted that it was a blessing to have this experience because they had an idea of what the diagnosis entailed for the child. Participants also felt scared and worried because they have seen how some children behaved due to their diagnosis.

*“We had some experience working with a child with special needs and that scared us when we were told of her diagnosis, Down syndrome, because we instantly thought she would be just like this child we knew, whom was severely disabled and had anger issues.”*

### **Stress Levels**

It is very common for families raising any child to experience stress. When that child has a diagnosis and requires extra care and attention it is more than likely the parents will have higher stress levels than those whom have a child without a diagnosis. Participants noted that these stress levels can decrease over time.

*“Of course, we experienced higher stress levels, but what parent would not. Once you get into a routine and become more aware of*



*what it takes to care for the child, you tend to see stress levels decrease.”*

Participants noted that many factors could be linked to the increased stress levels. Factors such as doctors' appointments, health concerns, and behavioral issues are just a few mentioned. All of these factors require more of the families' attention and time, which leads to less time for daily tasks.

*“...We had three kids. She is not a big stressor. It is mostly the special needs aspect with the doctors' appointments we have to go to, along with speech therapy, physical therapy, and occupational therapy. It is not as easy with an average child. WE have come to adapt to her and how she is. We can communicate with her even though she cannot talk very well, we know what she is saying. Most people would not be able to understand but we can because we are with her all the time.”*

### **Partner Alone Time**

Any family having young children, parents find themselves with little alone time, or not as much as before. As stated before children with special needs may require a lot of attention and supervision, which makes it hard for parents to have time to themselves.

Participants noted that they had to be creative to get any partner time.

*“Pretty hard and still is. We just tell ourselves that she is almost like a 2.5 half year old so it is hard to find people we trust for a long period of time because she can be so needy and cannot entertain herself*

*until recently she can play with her kindle a little bit. I know for the first month was always the hardest, it was with Henry too. You think yeah I cannot do this and James and I were just constantly feeding and changing diapers and then it starts to let up a little bit and now we can breathe and go out for dinner. Your baby is usually easy to tout around and they sleep while you eat. However, yes, it is definitely something we have to work hard on to get time together even if it is just a family walk or in the evenings after the kids go to bed at 10. We always say it's not always going to be like this and you have lots of family help."*

A common response for participants was, "what alone time". Participants said that in the beginning you do not get very much alone time or none at all. You have to set a routine for yourself and the child. If you get the child on a routine, then it is easier to have time by ourselves. One participant noted that it is very important for parents to take care of themselves and their relationship so they can provide the best care for their child.

### **Daily Care and Child Care**

Along with any child, there are typical tasks that parents help children with but if a child has special needs, there may be additional care they require. The majority of parents noted that their child requires more doctors' appointments and checkups than a child without special needs does.

*"The care for him is pretty typical to any other child, just a few more doctors' checkups and that's it."*

Parents also noted their child requires a strict routine in order to keep them from “falling apart”. Having a strict routine helps their child to know what they must do each morning when they wake up and each night before bed. Parents who have a consistent routine notice their child will transition better to new tasks or places.

*“We keep a very strict routine for him because that works best for him. It helps us to get him ready each day and that way he knows what to expect and where he is going.”*

Other parents noted that their child could function well on their own with majority of day-to-day tasks but need to be reminded to perform them. Children who cannot perform these tasks have the assistance of their parents while using the restroom, brushing teeth and getting dressed.

### **Additional Support and Resources**

Parents of children with special needs have the opportunity to receive help as long as they want it. Resources that parents can use include their child’s doctor, school teachers, and their therapist’s. There are other resources and support for families but these were the resources mentioned by participants.

*“We use the birth through two programs to help with her therapy outside and inside our home. Her doctors in St. Louis at the Children’s Hospital are also a great resource and support.”*

There are participants who did not use many resources but relied on family and friends for a lot of support. Having the help from resources and other individuals, participants can experience less stress when caring for their child.

*“We did not really use many resources other than her teacher’s and doctors.  
In a small town, there is not a lot of help outside of those individuals.”*

These resources are not only beneficial for the family but for the child themselves. Using these resources, children can meet and interact with other children sharing the same diagnosis. In addition, parents can meet other parents whom have experienced what they are going through. Communication with other families were often more beneficial to participants than a professional because they live the same life everyday as the participants do.

### **Strained Parent Relationship**

Going through a stressful situation such as having a child with special needs, parents can face a lot of emotions and stressors that can affect their relationship with their partner. The majority of participants noted that they felt the diagnosis brought them closer to one another.

*“As I said earlier, I think the diagnosis brought us together as a couple and as a family.”*

They mentioned that one parent tended to keep the other calm in stressful times. A lot of the time participants were experiencing the same struggles and working together got them through it as a team. They noted they relied on each other a lot to get through difficult times, especially when their child would cry and they could not figure out how to calm them down.

*“My husband seemed to be calmer than me and when I would cry he would talk to me and calm me down. He would tell me that everything would be ok.”*

**Siblings**

Homes that have other children besides the child with special needs often wonder how the siblings will be impacted. All participants who had multiple children noted that the addition of their special needs child had a positive impact on their other children. Parents saw their children become more helpful and understanding of individuals who have disabilities.

*“Her older brother was very understanding when it came to our attention and having to focus on her quite a bit. She demanded a lot of time from us and he knew why.”*

Participants whom had older children found they were very helpful with their sibling when it came to accommodating their needs. Siblings wanted to help take care of the child alongside their parents.

*“His siblings have been great. They are all older and were a great help when he was younger.”*

**Positive Experiences**

Positive experiences happen with any child whether there is a diagnosis present or not. Participants spoke of several positive experiences that affected their whole family and friends, not just themselves.

*“I have seen great sides of people because of him. He brings out the best in all of us.”*

Many participants spoke of emotional and mental experiences not just the physical ones. Parents saw themselves change with how they interact with their child and others around them. They noticed themselves being more calm and relaxed when a

situation is out of their control. Although they do experience stress occasionally their child reminds them that nothing is too big to overcome.

*“I think as a whole family we have a little more patience and understanding of those who are different from us. When he accomplishes things it is an accomplishment for the whole family.”*

### **Personal Experiences**

Participants were asked what they would like to share about their experience. All participants suggested that families should do their research on the child’s diagnosis. Educating yourself and advocating for the child is the best thing a parent can do. Also, looking for resources in the families’ community or surrounding towns. Parents should reach out for help when they need it. No parent should be ashamed to ask for help.

*“Do your research; there is help out there you just have to take advantage of it.”*

Participants wanted to share their experience with not only other parents of children with special needs but also all parents. It is very important for families and individuals to understand and remind themselves that they are just another person.

*“They are no different from anyone else; things just take a little longer.”*

Whether a child has a diagnosis or not, they all develop and mature at their own pace. Children will hit their milestones when they are ready to, it may not be when they are expected to but they will. Several participants noted that moments like these are celebrated in families of children with special needs.

### **Advice**

In unknown situations people often seek for advice from others whom have experienced what they are about to go through. Participants were asked to share advice

they would give to other parents whom are going through the diagnosis process or just finished it.

*“My biggest piece of advice would be to not get discouraged. That was the hardest part for me. It was hard for me to come to grips with the fact that my child would not be able to enjoy a "normal" life.”*

Other participants had simple advice to share with parents.

*BREATH....and relax and don't borrow trouble before it's had, just take everything in stride!*

Advice from other parents can be very helpful because they have experienced situations with their child and have answers that other parents could benefit from. Parents can share what worked for their child to others in hopes that it will help them.

### **Summary**

The current study used interviews to collect information on how a child with special needs affects the family. Despite the differences in diagnoses from child to child, families in this study reported similar feelings regarding the process.

However, children with the same diagnosis may not have similar needs. Each participant noted that it was important for them to educate themselves on the diagnosis, and reach out to find resources such as other families with the same diagnosis. Conversing with other families who have a child with the same diagnosis was said to be very beneficial.

Through this qualitative data analysis, the overall research question, how does a child with special needs affect the family, was answered in a variety of ways. In addition,

the hypotheses were supported with reoccurring responses in regards to positive and negative emotions and family stressors.



## **Chapter Five**

### **Summary of Study**

The purpose of this study was to discover how a child with special needs affects the family. Through the study one research question was answered and three hypotheses were supported.

#### **Research Question**

1. How does a child with special needs affect the family unit?

#### **Hypotheses**

- H1. Additional negative family stressors can arise from having a child with special needs.
- H2. An array of positive emotions can arise from a child's diagnosis.
- H3. An array of negative emotions can arise from a child's diagnosis.

#### **Discussion**

Overall, six participants participated in the current study. Each participant had a child with special needs. Three of the participant's children had Down syndrome, one had Autism, one had ODD, ADHD, and RAD. The final child was in the process of receiving a diagnosis.

#### **Research Question #1: How does a child with special needs affect the family?**

It is difficult to answer this question with one specific answer. Families were all affected differently by the addition of their child. Some experienced similar diagnoses, health concerns, and childcare but depending on the amount of support, resources, and help, families can have different stories.

**Hypotheses #1: Additional negative family stressors can arise from having a child with special needs.**

All families experienced an increase in stress levels in the months following a diagnosis. Many factors play a role in parents increased stress levels and depression such as, excessive caregiving demands, lack of child responsiveness, and unusual behaviors (Cowen & Reed, 2002). Stress tended to level back out to normal once families did their research on their child's specific need and managed the day-to-day experiences that came along with a child needing intervention of some type. Resources and outside support were reported as beneficial to families when questions arrived.

**Hypotheses #2: An array of positive emotions can arise from a child's diagnosis.**

Once negative emotions were dissolved the families in this study reported that they convinced themselves they were given this child for a purpose, to teach them a life lesson and patience. Parents often give credit to their child and the diagnosis for their personal growth (Staats et al, 2015). Not only did parents experience these positive emotions, but siblings did as well. Parents reported that siblings showed more love towards a sibling with special needs. They were very understanding that the child needed more time and attention from parents.

**Hypotheses #3: An array of negative emotions can arise from a child's diagnosis.**

All families reported having similar feelings and emotions after the diagnosis. Found in the literature many parents report they encountered an array of emotions including stress, disbelief, sadness, anger, and confusion (Staats, et al, 2015). Many participants reported being scared and fearful of the diagnosis. They were not sure how they would care for the child because they knew nothing about the diagnosis. A few

parents asked themselves why they were given a child with special needs, as if it were a punishment. However, participants reported that negative emotions subsided after they educated themselves on the diagnosis and reached out for support.

### **Limitations**

One major limitation to this study would be the sample size. The sample size used for this study was six (6) parents of children with special needs. Due to this small sample size, the results only pertain to these participants.

### **Recommendations for Future Research**

This study introduced new insight towards children with special needs and how they influence the family unit. However, future research should use a larger sample size in order to gain a more realistic take on how families were affected with the addition of a child with special needs. In addition, participants should be recruited outside of a small Illinois town. This will allow the researcher to see how families from larger towns or cities adjust to the additional needs of a child. For example, there would be more resources for the family in a larger area, which then may decrease their adjustment and stress levels.

In future research, the study should focus on a wider variety of developmental disabilities. This research study focused solely on Autism, Down Syndrome, and Cerebral palsy, as these diagnoses were prevalent in the geographical area of the study. This will help to gain more knowledge about other family's adjustments that have a child with a different diagnosis. With further research, more families and professionals will know how to educate others on developmental disabilities, a specific diagnosis, and how to adjust to this family change. Siblings themselves should be interviewed to gain their

perspective on the family unit. Parents often think they know how their children feel but interviewing the siblings themselves may reveal a different story. In addition, researchers should identify resources available to families to assist with the child, medical issues, behavioral issues, and negative stressors that families may face.

### **Recommendations for Professionals**

Professionals in the field of education, childhood intervention, and other field that work with individuals, families and communities should be thoroughly educated on children with special needs and their family. It is important for professionals to be aware of factors such as the diagnosis process and the common characteristics of each diagnosis. These individuals may be those educating parents and family members on specific care for their child and resources available to them for assistance.

It is also very important for educators, especially those in special education, to have the knowledge of these factors as well. Educators are those who work one on one with students in the school system as well as with their parents whom continue teaching at home. Special education teachers are often those who implement intervention plans within the classroom and see what additional services they may need. Teachers also work with therapists within the school system who provide physical, speech, and occupational therapy for at risk children.

Professionals in the family services field may offer counseling to families who have trouble with the adjustment and need additional help in finding services. That is why it is important for individuals working in this field to have an understanding of developmental disabilities and how to help parents cope with stress.

### **Conclusions**

This study focused on the effect of a child with special needs on a family. As special needs continue to be a growing topic more professionals should be educated on developmental disabilities and how the whole family is impacted. There is limited research on the topic of children with special needs and how their family unit is affected in regards to stress levels, care of the child, and relationships within the family. Research that has been done focuses solely on stress levels of the parents verses the family as a whole, including siblings, extended family members, and friends. The results from this study has provided a better understanding of how the family adjusts and changes with the addition of their child with special needs.

**Appendix A: Downey Survey**

1. What diagnosis was your child given?
  - a. What additional needs come with the diagnosis?
2. Walk me through the process of the diagnosis.
  - a. Feelings
  - b. What were you thinking?
3. Did you communicate diagnosis with others?
  - a. If so, how?
  - b. If not, why not?
  - c. What did this feel like?
4. Did the diagnosis place a strain on:
  - a. Partner
  - b. Children
  - c. Family
  - d. Friends
5. What type of experience do you have working with or caring for a child with special needs prior to the birth of your child?
6. What did you notice regarding your stress levels once your child was born?
7. What does alone time with your partner after your child was born look like?
8. What does the daily care for your child look like?
  - a. Who provides care for your child?
9. What type of additional support from resources outside of family and friends that you receive?

10. Do you feel that your relationship has been strained due to your child's diagnosis?
11. Does the child with special needs affect the sibling, if so in what way?
12. What positives have you experienced with your child?
13. What would you like to tell others about your experience?
14. What advice would you give a family that just received a diagnosis for their child?

**Appendix B**

Hello Parents/Guardians,

It is that time, the start of another school year! I hope you all had a wonderful and exciting summer with your child/children. My name is Taylor Downey and I am a student at Eastern Illinois University and I am needing your help! I am currently working on my Master's degree in the Family and Consumer Sciences program.

As a graduate student we have the option to write a thesis in order to graduate and I am doing such that, which is why I am reaching out to you. My thesis topic is on Children with Special Needs and how they impact the family unit. I am looking for volunteers to complete an interview with me in order for me to gain more knowledge about how your family was impacted.

This interview is completely confidential and no names will be released within the thesis. Interview responses will be used to gain a better understanding of how different families are impacted in their own unique ways. Your help will be very beneficial to my thesis. At any time throughout the interview you may withdraw if you feel necessary.

If you agree to participate please sign below and include your contact information that you wish to be reached at. Return back to school with your child by August 24<sup>th</sup>. Also, if you have any questions about this project please feel free to contact me via phone, text, or email.

Thank you for your help and have a great school year!

Taylor Downey

(217)-663-2584

[tndowney@eiu.edu](mailto:tndowney@eiu.edu)

Signature \_\_\_\_\_ Phone Number \_\_\_\_\_

Please circle how you would like to be contacted: Call or Text



## Appendix C

### CONSENT TO PARTICIPATE IN RESEARCH

#### Children with Special Needs and the Family

You are invited to participate in a research study conducted by Taylor Downey and Dr. Miki Sherwood, from the department of Family and Consumer Sciences at Eastern Illinois University. Your participation in this study is entirely voluntary. Please ask questions about anything you do not understand, before deciding whether or not to participate. You have been asked to participate in this study because you are the parent of a child diagnosed with a special need.

The purpose of this study is to explore how having a child with special needs affects the family. In addition, the stressors within the family will be examined. The emotions and feelings that arise surrounding a diagnosis will be investigated.

If you volunteer to participate in this study, you will be asked to complete an interview with the researcher and describe how having a child with special needs has impacted your family. All interviews will be recorded and kept confidential by the researcher.

At any time you feel uncomfortable you may withdrawal from the study and the interview will stop immediately. Anything recorded prior to withdraw will be deleted and not used for the study.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of keeping all interview recordings and transcribed records contained on the researcher's locked personal computer.

Participation in this research study is voluntary and not a requirement or a condition for being the recipient of benefits or services from Eastern Illinois University or any other organization sponsoring the research project. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind or loss of benefits or services to which you are otherwise entitled. There is no penalty if you withdraw from the study and you will not lose any benefits to which you are otherwise entitled.

If you have any questions or concerns about this research, please contact:  
Taylor Downey, Primary Investigator, (217)-663-2584, [tndowney@eiu.edu](mailto:tndowney@eiu.edu)  
Dr. Mikki Sherwood, Co-Investigator, (217)-581-6349, [mlsherwood@eiu.edu](mailto:mlsherwood@eiu.edu)

If you have any questions or concerns about the treatment of human participants in this study, you may call or write:

Institutional Review Board  
Eastern Illinois University  
600 Lincoln Ave.  
Charleston, IL 61920  
Telephone: (217) 581-8576  
E-mail: [eiuirb@www.eiu.edu](mailto:eiuirb@www.eiu.edu)

You will be given the opportunity to discuss any questions about your rights as a research subject with a member of the IRB. The IRB is an independent committee composed of members of the University community, as well as lay members of the community not connected with EIU. The IRB has reviewed and approved this study.

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I voluntarily agree to participate in this study. I understand that I am free to withdraw my consent and discontinue my participation at any time. I have been given a copy of this form.

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Printed Name of Participant

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Signature of Participant

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Date

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[Health-Issues--Down-Syndrome](http://www.ndss.org/Resources/Health-Care/Associated/Conditions?Mental-Health-Issues--Down-Syndrome)

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