“MY BABY COULD LIVE THE BEST LIFE”: FAMILY PERSPECTIVES ON SERVICES FOLLOWING A PRENATAL DIAGNOSIS OF DOWN SYNDROME

By

Zachary Bryson Martin

A thesis submitted to the faculty of
The University of North Carolina at Charlotte
in partial fulfillment of the requirements
for the degree of Master of Education in
Child and Family Studies

Charlotte

2018

Approved by:

____
Dr. JaneDiane Smith

____
Dr. Sue Rebich

____
Dr. Larissa Huber

____
Dr. Bonnie Keilty

ABSTRACT

ZACHARY BRYSON MARTIN. “My baby could live the best life”: Family perspectives
on services following a prenatal diagnosis of Down syndrome. (Under the direction of
DR. JANEDIANE SMITH)

Screenings and diagnostic tests provide individuals the opportunity to receive a prenatal diagnosis of Down syndrome as early as the first trimester of pregnancy. Post-diagnosis, families are presented with opportunities for services and supports to help them prepare for the birth of their child. Families have expressed concerns regarding the services and supports provided prenatally. The aim of this study was to investigate what services and supports are being provided following a prenatal diagnosis of Down syndrome, what are families’ perceptions of these services and supports, and what recommendations families suggest to enhance the services and supports. A researcher-developed questionnaire was used to survey 18 families who have children with Down syndrome to collect the data for this study. Data in this study were analyzed using descriptive statistics and quantitative categorical coding. This study discovered that services being provided are similar to what past research has reported and familial positive perceptions are increasing, but there is still a need for improvement. Limitations for this study were the researcher-developed questionnaire, sample size, families already connected with Down syndrome organizations, and inclusion criteria. Future research should be conducted to explore the effectiveness of support groups and meeting other families who have a child with Down syndrome, training professionals are receiving on interacting with families, and methods Down syndrome organizations and medical agencies can use to collaborate and support families. Implications for future practice for medical professionals are included, such as providing information on positive outcomes, increased training for professionals providing the diagnosis, and increased knowledge of local resources.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1: INTRODUCTION

Down syndrome is the most common chromosomal disorder occurring in the United States today (National Down Syndrome Society (NDSS), 2012). According to the National Down Syndrome Society (2012), approximately 6,000 infants are born with Down syndrome each year, which accounts for about one in 700 children. Given the prevalence of Down syndrome and other chromosomal or genetic disorders in the United States, a variety of diagnostic tests and screenings have been developed in order to predict the chances of a child being born with a chromosomal disorder. According to the American College of Obstetricians and Gynecologists (ACOG), screenings discover the likelihood of having a chromosomal disorder while diagnostic tests can provide mothers with a prenatal diagnosis of Down syndrome or another chromosomal disability rather than waiting until birth to discover the chromosomal condition (ACOG, 2016a; ACOG, 2016b). These screenings and diagnostic tests are especially critical due to the developmental delays and health concerns experienced by many children with Down syndrome because it allows the opportunity for families to prepare for their future child if they choose to continue the pregnancy (Keilty, 2008).

Screenings such as maternal serum markers, ultrasounds, and non-invasive testing can be utilized during the first and second trimesters to identify risks of developmental disabilities that could possibly lead to a diagnosis of Down syndrome (Latendresse & Deneris, 2015). Following a positive screening result, diagnostic tests such as chronic villus sampling, amniocentesis and chromosomal microarray analysis can be offered to confirm a prenatal diagnosis of disability (Latendresse & Deneris, 2015). Families receiving a positive Down syndrome diagnosis have the option to continue or terminate the pregnancy. Depending on when they received their prenatal diagnosis, families who choose to continue the pregnancy will have several months to prepare for life with their child with Down syndrome.

1.1 Statement of the Problem

Having knowledge of their child's prenatal diagnosis provides time for families to prepare for their child (Keilty, 2008). This study did not examine the decision of whether or not to continue pregnancy, but rather the period of time in which families could receive services and supports between the diagnosis and the birth of the child. This period between diagnosis and birth allows ample time for services and supports to be provided to families such as information, genetic counseling, resources and interventions (ACOG, 2016a; ACOG, 2016b; Choi, Riper & Thoyre, 2012; Helm, Miranda & Chedd, 1998; Hippman, Inglis & Austin, 2011; Hodgson, Gillam, Sahhar & Metcalfe, 2010; Hodgson & Weil, 2012; Hurford, Hawkins, Hudhins and Taylor, 2013; Johnston, Huebner, Anderson, Tyll & Thompson, 2006; Keilty, 2008; Love et al., 2002; Marshall, Tanner, Kozyr and Kirby, 2014; Roberts, Stough & Parrish, 2002; Sheets et al., 2011; Skotko, 2005; Skotko, Kishnani & Capone, 2009a; Skotko, Kishnani & Capone, 2009b) in order to enable them to prepare for having a child with Down syndrome. Choi et al. (2012) report:

> In 2008, the Prenatally and Postnatally Diagnosed Conditions Awareness Act was signed into law. This act requires that families who receive a diagnosis of DS [Down syndrome] or another condition, prenatally or up until a year after birth, be given accurate, up-to-date information and support.

With this act, families have the right to information and support in order to prepare for their child's birth. However, studies report that information provided to these families is not up-to-date (Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). These results are concerning considering some of the research (Choi et al., 2012; Hippman et al., 2011; Sheets et al., 2011; Skotko et al., 2009a; Skotko et al., 2009b) reporting lack of up-to-date information was published more recently than the legislation was enacted. Genetic counseling is another possible supportive role for families following a prenatal diagnosis of Down syndrome (Cleary-Goldman et al., 2006; Hippman et al., 2011; Hodgson et al., 2010; Hodgson & Weil, 2012; Hurford et al., 2013; Roberts et al., 2002; Sheets et al., 2011). Following a prenatal diagnosis, many families are referred to genetic counselors to discuss the disability and to answer questions the family has (Roberts et al., 2002). However, genetic counseling has been revealed to not meet the emotional, informational, and psychosocial needs of the families it serves due to narrow descriptions of Down syndrome, focus on negative aspects, and lack of discussions regarding how the child with Down syndrome would function within the family (Hodgson et al., 2010).

Prenatal services and supports have been shown to be beneficial to the children in related literature (Johnston et al., 2006; Love et al., 2002). Both Early Head Start and the Healthy Steps prenatal component of their programs produced positive effects on the children whose parents participated during the prenatal period (Johnston et al., 2006; Love et al., 2002). Healthy Steps found that the children whose parents participated prenatally exhibited larger vocabularies were more likely to attend their two-year-old well-child check, and were more likely to have their full immunization schedule completed by two years of age (Johnston et al., 2006). Likewise, the Early Head Start prenatal participants' children demonstrated increased effects in persistence, engagement, cognition, and less negativity toward parents (Love et al., 2002). Parenting behavior also differed as emotionally supportive parenting and reduction in spanking were more positive for the parents who participated prenatally (Love et al., 2002). These programs are not specific to children with disabilities or Down syndrome, but they demonstrate that participating in prenatal interventions can provide positive results for both the parents and the children.

Down syndrome is considered an "established" condition under Part C of the Individuals with Disabilities Education Act (IDEA), which assists states in providing early intervention services to children from birth to age three (IDEA, 2004). Under this act, however, these services do not begin until the child is born**.** Part C services are supports that serve children from birth to three years old who are at-risk or have disabilities and their families (IDEA, 2004). There are only a few states providing early intervention services for these families prenatally (Keilty, 2008). These services range from service coordination, writing the Individualized Family Service Plan (IFSP), transportation to appointments, and support groups (Keilty, 2008). Without services flowing from the prenatal to the postnatal period in the majority of the United States, gaps are created in services between the child being born until they are referred to and enrolled in early intervention (Keilty, 2008). This gap in services may decrease the progress that could be seen if professionals were serving families continually from the prenatal period to birth (Keilty, 2008). Knowing this, the question arises as to what services and supports should be provided for families during this period.

Parents’ perceptions of services and supports received following a prenatal diagnosis can provide valuable information on desired services and supports that could be provided during the prenatal stage. Provided with parents’ perceptions, professionals will have input as to what services could be beneficial and how existing services could be improved. Several studies investigate parents’ perceptions of the diagnosis process and interactions with healthcare professionals (Helm et al., 1998; Hippman et al., 2011; Roberts et al., 2002; Skotko et al., 2009a; Skotko et al., 2009b). Families’ perceptions reported in the literature have the potential to help professionals to improve the current services provided prenatally if needed. Individual experiences of services and supports received between will vary, but one study reported that each of the ten mothers who participated, all of European descent, had at least one negative experience with the healthcare professionals serving them (Helm et al., 1998). Several studies demonstrated that medical personnel report experiencing difficulty communicating the diagnosis and providing support for families (Elwy, Michie & Marteau, 2007; Hodgson & Weil, 2012). Considering a crucial amount of family’s services will be provided in the medical setting, by genetic counselors, doctors, nurses and other medical personnel, this causes concern. If families are undergoing negative experiences while receiving services and supports, they may not be prepared for the birth of their child with a disability because they will not have adequate information, resources or counseling. Families’ perceptions of the prenatal services and supports provided must be investigated in order to improve services and the overall experience following a prenatal diagnosis.

Recommendations families report based on their experiences in receiving prenatal services and supports are critical to enhancing practices used and the perceptions families have. Several studies indicated recommendations to improve medical personnel interactions and communication (Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). The mothers participating in the study by Helm et al. (1998) provided advice regarding information sharing and counseling for professionals such as providing nonjudgmental information and avoiding assumptions. Studies collectively support the recommendation from families of providing up-to-date information as well (Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). Other recommendations for potential supports provided by families included local resources, support groups, and access to families of children with Down syndrome (Hippman et al., 2011; Roberts et al., 2002; Skotko, 2005). Advice from parents can guide professionals in the medical field to make improvements if necessary in order to provide the best services possible to enable parents to have competence and confidence in raising their soon to be born child with Down syndrome.

1.2 Purpose and Research Questions

The purpose of this study is to investigate perceptions of parents who have received a prenatal Down syndrome diagnosis in order to offer more current information regarding the services and supports families are receiving and the families' perspectives which may help determine how services and supports can, if at all, be enhanced. The questions this study answered are: A) What prenatal services and supports are provided to families following a diagnosis of Down syndrome? B) What are families' perceptions of the services and supports provided during the prenatal period following diagnosis? And

C) What services and supports do families recommend in order to enhance the process from diagnosis to birth?

CHAPTER 2: LITERATURE REVIEW

To identify relevant literature on families with a prenatal diagnosis of having a child with Down syndrome, the following databases were used: ERIC Database (via EBSCOhost), PsychINFO, and Google Scholar. A literature search was conducted using the following terms: *prenatal diagnosis and disability, prenatal diagnosis and Down syndrome, Down syndrome, genetic counseling, genetic counseling and Down syndrome, parent perspective and prenatal diagnosis, perspective and prenatal diagnosis, prenatal services, prenatal services and Down syndrome, prenatal services and disability, prenatal screening, prenatal screening and Down syndrome, parent perspective and prenatal services, prenatal Part C services,* and *Bronfenbrenner ecological systems theory.*

Results of the review of the literature are described as follows: prenatal screening and diagnostic testing, current services and supports provided to families prenatally, genetic counseling, family perceptions of services and supports provided, and recommendations of professionals and families regarding services and supports.

2.1 Prenatal Screening and Diagnostic Testing

As previously stated, there are a variety of screening and diagnostic tests that can be provided in the medical setting during a pregnancy. ACOG clarifies that screening tests can provide insight about the chances of the fetus having a disorder or aneuploidy whereas diagnostic tests can inform if the fetus actually has a disorder (ACOG, 2016a). Blood samples, tissue samples, cell-free DNA testing and ultrasounds are examples of screening tests that can be provided during the first two trimesters (ACOG, 2016a). These screenings are not definite diagnoses of the fetus' medical condition, however, and they can produce false-positive and false-negative results (ACOG, 2016a). Depending on the results of the screening, the health care professional may feel a diagnostic test is necessary and provide that option to the family. The two diagnostic tests performed are amniocentesis and chronic villus sampling (CVS; ACOG, 2016b). Amniocentesis analyzes amniotic fluid from the placenta while CVS examines a tissue sample from the placenta (ACOG, 2016b). Amniocentesis and CVS increase the chances of pregnancy loss, but can be reduced if the procedure is performed by experienced medical personnel (Roberts et al., 2002). CVS can be performed as early as ten weeks and amniocentesis as early as fifteen weeks (ACOG, 2016c), which means that those families who receive positive diagnoses of Down syndrome could have up to 25 or 30 weeks to prepare for their child provided they choose to continue the pregnancy.

2.2 Current Services and Supports

Supports and services for families actually begin before the prenatal diagnosis has been made. For example, prenatal screening and diagnostic testing are services provided to find out if the fetus has Down syndrome, therefore, it is prior to the diagnosis (ACOG, 2016a; ACOG, 2016b). Prenatal screening and diagnostic testing are crucial to mention due to the fact that they are required to provide the family with a prenatal diagnosis of Down syndrome. Genetic counseling can also be provided before, after, or before and after the diagnosis has been received (Hodgson & Weil, 2012; Roberts, et al., 2002). Genetic counselors provide the family with information regarding the results of the screening, diagnostic testing, pregnancy, and possible disabilities their child may have (Hodgson et al., 2010; Roberts et al., 2002). Once a prenatal diagnosis has been confirmed, a variety of services can take place. One valuable service medical professionals provide is sharing information with families whether it be about the diagnosis, development, resources or a variety of other topics (Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Hodgson et al., 2010; Hodgson & Weil, 2012; Hurford et al., 2013; Keilty, 2008; Marshall et al., 2014; Roberts, et al., 2002; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). Providing information to families is a crucial service and enables families to develop knowledge in order to best care for their child. In some cases, medical providers may make referrals for families to meet other parents who have children with Down syndrome (Helm et al., 1998). Several mothers in a study by Helm et al. (1998) found this support to be very helpful. Although it is not a federal law, some locations throughout the United States do provide some prenatal services that would be considered under the category of Part C such as providing a service coordinator to aid the family as well as providing interventions, information, and resources (Keilty, 2008).

2.3 Theoretical Support

These services and supports may be extremely crucial to the development of the family and their future child with Down syndrome. Prenatal services and supports can be applied to Bronfenbrenner's (1974, 1977, 1979, 1986) ecological systems theory. The ecological systems theory consists of five systems: microsystem, mesosystem, exosystem, macrosystem and chronosystem (Bronfenbrenner, 1974, 1977, 1979, 1986). These systems hold supports at each level and the systems interact with one another reciprocally (Bronfenbrenner, 1974, 1977, 1979, 1986). In this case, the subject in the microsystem would be the family and the supports would be in each system surrounding them. These systems interact with one another to either directly or indirectly impact the family. Each system needs to have supports within it for the families impacted by prenatal diagnoses of Down syndrome to best meet the needs of the family to help them support their child’s development to reach his or her highest potential.

2.4 Genetic Counseling

During the prenatal period, families are interacting with many medical professionals such as physicians, nurses, gynecologists, obstetricians, and genetic counselors. Families are often referred to a genetic counselor during the prenatal period for screening, diagnostic testing, and discussing results of said procedures (Roberts et al., 2002). Roberts et al. (2002) discovered that 87% of participants attributed participating with a genetic counselor to their doctors referring them while 52% of participants indicated they chose this option on their own. The percentages add up to more than 100%, due to the researcher encouraging participants to choose more than one answer if applicable (Roberts et al., 2002). The participants in the study had not yet received a prenatal diagnosis; rather these participants were selected due to being at-risk for having a child with a disability such as spina bifida or Down syndrome based on their maternal age or results of their screening (Roberts et al. 2002). Another study by Cleary-Goldman et al. (2006) discovered that the majority of the participating physicians referred patients to genetic counselors. The high level of referrals to genetic counselors could be explained by studies reporting that physicians and other medical professionals do not feel well trained in counseling to support families following a prenatal diagnosis (Cleary-Goldman et al., 2006). Cleary-Goldman et al. found that 45% of the physicians participating in the study felt that their training was minimal or that they were not even trained in the area of counseling. Many professionals in another study explained that they had little experience with individuals with Down syndrome and often used a “checklist” method to counsel the families (Williams, Alderson, & Farsides, 2002). These studies provide evidence that genetic counselors are often referred to as the experts in counseling families following a prenatal diagnosis of a disability.

According to Sheets et al. (2011), genetic counseling can be defined as “…a communication process that incorporates education about genetic conditions with counseling to promote autonomy and adaptation to the diagnosis”. Considering that Down syndrome is a genetic disorder, it can be assumed that genetic counseling can play an integral role in the prenatal process by assisting the families and educating them. Studies have shown that genetic counselors may not be prepared for such in-depth and personal counseling (Hodgson & Weil, 2012; Roberts et al., 2002). These results are unfortunate, considering a family’s time with a genetic counselor following a diagnosis or prior to testing is their first access to information regarding the disability (Roberts et al., 2002). Time with genetic counselors also provides families the opportunity to talk about the risks and benefits of having a child with Down syndrome (Hurford et al., 2013). Genetic counselors are given the task of attempting to provide information as well as meet the families psychosocial needs (Hodgson & Weil, 2012). This task is made even more challenging considering that counselors are not given standards as to what to share or control over the information provided (Roberts et al., 2002).

Prior to the testing, many families meet with a genetic counselor but data suggest that disabilities are not often mentioned in these discussions with families (Hodgson & Weil, 2012). A study by Hodgson et al. (2010) demonstrated that women with a risk of having a child with Down syndrome were provided with limited information that pertained to the negative consequences such as learning delays or physical effects. Information provided by genetic counselors has been seen as limited and often only addressing the medical side of information, which does not necessarily provide the adequate knowledge the families need (Hodgson & Weil, 2012). Information regarding quality of life is also not typically included in these sessions with genetic counselors (Roberts et al., 2002). Roberts et al.'s (2002) study discovered that 91% of the women participating found the genetic counselor's information helpful but over 80% reported that they were not given quality-of-life information or balanced views of having a child with a disability. Though providing quality-of-life information for families can be difficult considering the individuality of children with Down syndrome such as physical appearances and difference in cognitive abilities (Hodgson & Weil, 2012). This individuality can make it difficult for professionals to paint a clear picture of the child's future for the families, but possible outcomes could reasonably be provided to families.

2.5 Family Perceptions

This lack of training in communicating information about disabilities has affected the way families perceive the services and interactions they have with medical professionals when they receive a prenatal diagnosis (Helm et al., 1998; Hodgson & Weil, 2012; Marshall et al., 2014; Roberts et al., 2002; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). Many perceptions regarding the information were mentioned previously including lack of information and the quality of information (Hodgson & Weil, 2012; Hodgson et al., 2010; Roberts et al., 2002). Nearly all of the participants in a study by Skotko (2005) felt that they were given information that was out of date. The ten mothers in the study by Helm et al. (1998) reported that they encountered healthcare professionals who did not seem to support their decision to continue their pregnancy following the prenatal diagnosis. More than half of the participants in the same study felt that the reactions of their obstetricians were cold and distant during screening and diagnostic testing (Helm et al., 1998). Discussions were also perceived to be overly negative and the implication of the child being a burden was present in reports of discussions between genetic counselors and families (Hodgson & Weil, 2012). These discussions could explain why 95.7% of participants in a study by Roberts et al. (2002) anticipated an increased burden as parents of a child with Down syndrome. Parents expressed that communication between different specialists as well as communication between providers and parents was inconsistent (Marshall et al., 2014).

All perceptions were not negative, however. In a study by Skotko et al. (2009a), mothers who were provided with up-to-date information were satisfied with their physicians' services. Another study by Skotko (2005) discovered that mothers agreed their obstetricians were supportive of their decisions to continue the pregnancy. Others expressed that they were pleased with their services when they were provided with the opportunity to meet other parents who had children with Down syndrome (Helm et al., 1998; Skotko, 2005). One study comparing satisfaction levels of mothers receiving prenatal diagnoses in 1983 to 2003 indicated that satisfaction has increased (Skotko, 2005). Mothers who had received their prenatal care in the five years prior to 2003 appeared to be exceptionally satisfied (Skotko, 2005). The numerous perceptions have led several studies to search for suggestions from the families and professionals in order to better improve their experiences (Helm et al., 1998; Hippman et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). The differences in perceptions appear to be related to the quality of information, the referral to resources such as support groups, and how recently they received their prenatal diagnosis.

2.6 Recommendations from Families and Providers

Research provides recommendations for medical professionals regarding the types of services and supports provided (e.g., genetic counseling, information provision, and referrals to support groups) and how they are implemented (e.g., meeting in person, quality of information, and attitude of the professional) (Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Roberts et al., 2002; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). Considering many of these recommendations result directly from families who experienced either a prenatal or postnatal diagnosis of a child with Down syndrome, one assumption is that these recommendations reflect the families' desires for types of services and supports and how they should be implemented to better meet families' needs.

To begin with, the need for up-to-date information was recommended in many of the studies (Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). Lack of up-to-date information again appears to be a critical issue. When discussing the diagnosis, Skotko et al. (2009a; 2009b) reported that the clinician most knowledgeable on Down syndrome should be the one to discuss the diagnosis with the family. This knowledgeable clinician should also be trained on how to deliver the news of the prenatal diagnosis in the most helpful and appropriate way (Skotko et al., 2009a). This recommendation is supported by Hippman et al.'s (2011) proposition that clinicians gather knowledge about real life experiences with individuals with Down syndrome in order to provide better descriptions about having a child with Down syndrome and avoid a medical model description. Physicians should be careful with their words by using sensitive language that will not offend the families (Skotko et al., 2009a; Skotko et al., 2009b). Examples of this would be to exclude using phrases such as “I am sorry” or negative labels such as “mongolism” (Skotko et al., 2009a; Skotko et al., 2009b). In addition, providers should allow the discussions to be parent-driven in order to best meet the families’ needs (Hippman et al., 2011). Allowing parents to lead the discussion could help physicians avoid giving their own personal opinions, which mothers recommend against (Skotko, 2005).

Physicians should provide up-to-date resources for families at each visit such as resources available by the National Down Syndrome Society or the National Down Syndrome Congress (NDSC) (Skotko et al., 2009a; Skotko et al, 2009b). This recommendation from families may well be supported by Hippman et al.’s (2011) suggestion of genetic counselors building and focusing on strong relationships with Down syndrome support organizations. Skotko (2005) recommended that families be offered contact with Down syndrome support groups that are local to the family. This recommendation correlates well with findings associated with participants in a study by Hippman et al. (2011) who recommended that parents be offered the opportunity to meet with other parents who had children with Down syndrome. This recommendation is reinforced by the Roberts et al. (2002) study that reported that 91.3% of participants in their study had not been offered the opportunity to meet other parents of children with Down syndrome. Sheets et al. (2011) found that over 96% of parents in their study described that discussing how children with Down syndrome are more like typically developing children than different was essential. Information regarding early intervention centers that were available was reported to be extremely valuable as well (Hippman et al., 2011). Personal stories from parents of children with Down syndrome and videos of what life is like with a child with Down syndrome were also suggested to be helpful (Hippman et al., 2011).

Keilty (2008) proposes the idea of providing Part C services prenatally. Although support services do not exist under Part C currently, Keilty (2008) highlights how these services could be provided by focusing on anticipatory guidance, family priorities, and parental confidence and competence. Anticipatory guidance is already being utilized in the pediatric health field and provides families with knowledge and resources in order to enable families to focus on their child's health and development (Dworkin, 2000). Therefore, early intervention providers could provide training on anticipatory guidance to medical providers in order to facilitate this service (Keilty, 2008). Keilty (2008) discusses the importance of focusing on family's priorities to allow families to concentrate on their child's development. Parental confidence and competence would include providing families with information, resources, and interventions so that families would not need to depend on professional help (Keilty, 2008). This outline of Part C prenatal services depends on Banduras' (1977) social learning theory, which emphasizes self-efficacy in order for families to believe that they can in fact reach their goals. When families feel that they have the competence to achieve their goals, they will show perseverance and continue their efforts (Keilty, 2008). This concept of prenatal Part C services may well be the most crucially needed recommendation discussed.

2.7 Conclusion

It is clear that services and supports may not meet the needs of families in the prenatal period following a diagnosis of Down syndrome. Current services and supports provided to families following a prenatal diagnosis may consist of genetic counseling, information sharing, resources, and interventions (Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Hodgson et al., 2010; Hodgson & Weil, 2012; Hurford et al., 2013; Johnston et al., 2006; Keilty, 2008; Love et al., 2002; Marshall et al., 2014; Roberts et al., 2002; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). Several studies found that many family perceptions of these prenatal services are negative leading one to assume families are not pleased with the current services and supports. While services and supports are in place that could be beneficial to families during the prenatal phase, recommendations indicate that both families and medical providers see areas for improvement (Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Roberts et al., 2002; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; Skotko et al., 2009b). While prior studies have investigated services and supports, families' perceptions, and recommendations for services, few studies have been conducted in the past decade. This literature provides an exceptional opportunity to be applied in research to investigate what services and supports are currently being provided following a prenatal diagnosis of Down syndrome, what are the families' perceptions of the services and supports, and what are their recommendations for prenatal services and supports. Once it becomes clear what services and supports are needed currently, professionals have an opportunity to implement these services and supports to meet families' needs.

CHAPTER 3: METHOD

The method discussed will include the participants the researcher identified, the instrument used, the procedure for the study, how the data were analyzed, and limitations of the study.

3.1 Participants

The goal of this study was to recruit 100 participants to complete the survey questionnaire provided by the researcher. The researcher contacted Down syndrome organizations in one Southeastern state in an effort to recruit participants for the study. Only organizations located in the Southeastern state were approached for participants in order to focus on the perspectives of families within that state considering supports and services differ by states. Participants were required to meet the criteria of being a parent of a child with Down syndrome who either received a prenatal diagnosis or have a child with Down syndrome and would have preferred to have learned of the diagnosis prenatally. Participants were required to be 18 years or older, English-speaking, and have a child ten years of age or younger at the time of the survey. Only one parent per family could participate. English speaking was a component of the inclusion criteria because the materials for the study were not translated into other languages. Only families with children 10 years of age or younger could participate in order to collect information from families who experienced the services and supports recently. By collecting data from families with children 10 years of age or younger, it allowed the data to reflect how perspectives have changed in the last decade considering the Prenatally and Postnatally Diagnosed Conditions Awareness Act was signed in 2008 (Choi et al., 2012).

After recruitment, 46 participants either completed or partially completed the questionnaire, and 73.9% (*n* = 34) of those participants met the inclusion criterion. Data were only analyzed for the participants who reported receiving a prenatal diagnosis of Down syndrome (*n* = 18). Participants in this study represented a sample of convenience. Participants were recruited by providing the survey link to Down syndrome organizations and requested the organizations distribute the link via email, listserv, or social media to their members.

3.2 Instrument

The participants in the study were surveyed using a researcher-developed questionnaire titled “Family Perspectives” using Qualtrics software (Qualtrics, Provo, UT) (see Appendix A for instrument). Questions were created using information discovered while reviewing literature. These included questions regarding families’ perceptions on the quality and quantity of information provided by medical professionals (Hodgson & Weil, 2012; Hodgson et al., 2010; Roberts et al., 2002). The format of questions included Likert scale, multiple choice, and open-ended responses. Participants reviewed a statement of consent at the beginning of the survey, indicating that by completing the questionnaire they are providing consent (See Appendix B for consent form). The survey questions included: (a) demographic information, (b) information concerning the diagnosis, (c) what services and supports were provided prenatally, (d) families perceptions of services and supports provided prenatally, (e) family recommendations for services and supports provided prenatally and (f) support systems for the families. Participants who did not receive a diagnosis during the prenatal period could not participate in questions regarding information concerning the prenatal diagnosis, what services and supports were provided prenatally, families' perceptions of services and supports provided prenatally and support systems. These questions were avoided using skip logic on the Qualtrics software (Qualtrics, Provo, UT). The questionnaire was estimated to take ten to fifteen minutes for participants to complete and consisted of 64 questions.

3.3 Procedure

Following Institutional Review Board (IRB) approval and prior to distributing the link to the questionnaire to the Down syndrome organizations, the researcher conducted a pilot study to establish content and social validity. The inclusion criteria for the pilot participants mirrored the criteria for the general study. Pilot participants were accessed through a Down syndrome organization located in a Northeastern state to avoid depleting the participant pool in the state where the study was conducted. These participants completed or partially completed the questionnaire but did not provide feedback. Since feedback was not received, the researcher contacted five families located in a Southeastern state and asked them to complete the questionnaire. Three of these families completed the questionnaire and provided feedback to the researcher. Based on the feedback, no changes needed to be made to the questionnaire prior to distributing to participants in the study.

The researcher contacted the Down syndrome organizations prior to distributing links to the "Family Perspectives" questionnaire. The researcher did not have prior affiliation with these organizations. The researcher located these organizations using an internet search and contacted the organizations via email. The organizations were provided with an introduction letter (Appendix C), which was the procedure of the study and requested to distribute the “Family Perspectives” questionnaire link amongst their members. All parameters of the data collection process were discussed with the participating organizations before beginning data collection. This included how they could distribute the questionnaire, when they would remind participants, and the timeline of the data collection. This discussion occurred separately from recruitment and only after the organization had provided consent to support the researcher by distributing the “Family Perspectives” questionnaire. Once permission was obtained by the liaison from the participating organizations, the questionnaire link was provided to the members. The organization’s liaisons were members of each organizations leadership or employees of the organizations. The liaisons of each participating organization distributed the information requesting participation to their members via email, listserv, or the organization’s social media pages if applicable. The researcher requested the liaisons provide confirmation and the date in which they distributed the questionnaire to the families with their organizations. Several of the organizations provided confirmation and the date of distribution for the researcher. After one week, the researcher provided the participation recruitment letter and the questionnaire again so the liaison could distribute an email or social media post to all possible participants reminding them to complete the questionnaire if they had not yet responded. After the reminder was sent, data were collected for two more weeks and then another reminder was shared via email or a social media post by the organization liaisons following the same procedures. After the second reminder, data were collected for one more week allowing participants a total of 28 days to respond.

3.4 Data Analysis

Data collected through the researcher-developed questionnaire were uploaded into Statistical Package for the Social Sciences (SPSS) software from Qualtrics for analysis (Qualtrics, Provo, UT). The questionnaire provided data on (a) demographic information, (b) diagnosis information, (c) services and supports provided prenatally, (d) families perceptions of services and supports provided prenatally, and (e) family recommendations for prenatal services and supports. Analyses were conducted using descriptive statistics (frequencies and percentages). Responses from the open-ended questions were coded by the researcher and a professional in the early intervention field in order to establish any themes that were present. Quantitative categorical coding was used to determine the themes present in responses. The themes were compared and discussed by the researcher and early intervention professional to ensure reliability in themes found and frequency of the themes within the responses. The most common themes have been included to enrich the data.

CHAPTER 4: RESULTS

The survey provided insight into families' perceptions of the supports and services they received following a prenatal diagnosis of Down syndrome and answered the following research questions: 1) What prenatal services and supports are provided to families following a diagnosis of Down syndrome? 2) What are family's perceptions of the services and supports provided during the prenatal period following diagnosis? 3) What services and supports do families recommend in order to enhance the process from diagnosis to birth?

Results are presented by research question. Descriptive summaries are provided regarding the services and supports families received following the prenatal diagnosis of Down syndrome and their perceptions of those services and supports. Results specific to the services and supports received only includes families with a prenatal diagnosis of Down syndrome. In this study, 18 of the 34 participants (53%) received a prenatal diagnosis.

Demographic information was collected on participants who met the inclusion criteria for this study (see Table 1 for participant characteristics). Ages of the participants in this study ranged from 30 to 48 years old. The majority of participants' children (88.9%) were born in the Southeastern state the study was completed. The children with Down syndrome from each of these families were born in the range of 2008-2018 and the median household income bracket for the participants' households in this study was $60,000-$79,000. All but one of the participants in this study reported that they had health/medical insurance at the time of their child's birth as well.

TABLE 1

Participant Characteristics

Variable	*n*	Percentage
Role		
Mother	15	83.3%
Father	1	5.6%
Parent	1	5.6%
Chose not to answer	1	5.6%
Ethnicity		
Caucasian	14	77.8%
African American	1	5.6%
Native American or Alaska Native	1	5.6%
Hispanic	1	5.6%
Multi racial/Other	2	11.1%
Marital Status		
Married	16	88.9%
Single	1	5.6%
Divorced	1	5.6%
Education Level		
Some college education, no degree	5	27.8%
Associates degree	3	16.7%
Bachelors degree	7	38.9%
Masters degree	3	16.7%
Employment Status		
Full-time	15	83.3%
Part-time	2	11.1%
Unemployed, not looking for employment	1	5.6%

Note: The ethnicity percentages add up to greater than 100% due to participants being able to choose multiple answers.

4.1 Supports Families Reported Receiving

Research question #1 sought to answer what services and supports families received during the prenatal period following a diagnosis. Support from family, community, church, support groups, friends, and genetic counselors were provided to the majority of participants in this study (see Table 2).

TABLE 2

Services and Supports that Families Receive

Type of Support	n =	Percentage
Support from family members	16	88.9%
Support from community, church, support groups, friends.	15	83.1%
Support from a Genetic Counselor	15	83.3%
Offered the opportunity to meet with another family who has a child with Down syndrome	8	47.1%
Referred to or given information on Down syndrome organizations	9	52.9%
Offered opportunity to participate in a support group	5	29.4%

Meeting other families who have children with similar diagnoses, Down syndrome organizations, and support groups were also described as forms of support (See Table 2 for reported services). However, participants' utilization of these supports differed depending on the type of support. Meeting with other families who have a child with Down syndrome was a support utilized by all participants who were offered the opportunity. This was exceptionally more than the 57.1% who were involved with Down syndrome organizations. The 57.1% participation rate applies to participants (*n* = 14) that were either referred to, given information about, or independently sought Down syndrome organizations. Both of these supports were reported more than support groups, where 40% of participants were offered the opportunity. When asked to share any other services and supports that were provided by professionals, themes emerged that participants (*n* =4) were not provided with other services and supports or that the services were not provided until after their child was born.

Providing information was another service and support reported by the participants in this study, although the results differ depending on the type of information. Information regarding development was provided to 77.8% (*n* = 14) of the participants in this study while 38.7% (*n* = 7) received information on the quality-of-life their child might experience. Information regarding early intervention services was provided to 47.1% (*n* = 8), less than half of the participants. Educational resources such as books, websites, and webinars regarding Down syndrome were provided to 47.1% (*n* = 8) of the participants. All of the participants utilized the resources when provided with them.

4.2 Parent Perception of Services and Supports

The second research question sought to determine how families perceived the services and supports they received following the prenatal diagnosis of Down syndrome (See Table 3). When asked why they were either satisfied or dissatisfied with their genetic counselors, two themes were identified. Both were related to participants' positive perceptions of their genetic counselor. Three participants reported that their genetic counselor was available to serve their families in a variety of ways such as phone conversations, meeting in person, and later appointments during the evening. A second theme, reported by two participants, was that families were provided with literature when being served by their genetic counselor.

TABLE 3

Perceptions of Supports Received

Type of Support	*n* =	Participants who Reported Positive Perceptions
Support from family members and friends	17	65%
Support from a Genetic Counselor	15	55.6%
Support from medical professionals	17	52.9%
Support from meeting other families	8	75%
Support from Down syndrome organizations	14	71.4%
Support from support groups	2	100%

When overall perceptions of support were assessed, 66.7% (*n* = 12) of participants felt that the medical professionals supported their family following the diagnosis (*M* = 3.78, *SD* = 1.40). Several themes were identified regarding the support that families received from medical professionals during the prenatal period. First, five participants commented that medical professionals brought up abortion or termination after the prenatal diagnosis. Examples of comments shared related to this theme were: “First option was termination only,” and “My OB/GYN kept asking me at every appointment if I wanted to continue my pregnancy.” In contrast, seven participants reported that professionals were supportive of the family’s decision to continue the pregnancy. An example of this theme was: “She was reassuring that my baby could live the best life”. A third theme regarded the information that medical professionals provided to families. Based on responses from five participants, perceptions of support from medical professionals were affected depending on if the professionals provided information or were unable or unwilling to provide information. The preference of certain disciplines was common as well as four participants preferred certain professionals such as their genetic counselor to their obstetrician or physician.

TABLE 4

Perceptions of Support from Medical Professionals

Theme	Responses Including the Theme	Percentage of Total Responses
Abortion/Termination	5	29.4%
Supportive of decision	7	41.2%
Information	5	29.4%
Discipline preference	4	23.5%

There was overall agreement that meeting one-on-one with families who have children with similar diagnosis, support groups, and participating with a Down syndrome organization was beneficial. Two themes emerged when participants reported why they felt participating in a Down syndrome organization or association was beneficial or not; both were positive. Eight participants mentioned the benefit of meeting other families who had children with similar diagnoses in their responses and three participants responded that they were able to obtain information by participating with the Down syndrome organization. Examples of comments shared by participants were: "Because it was other parents going through what I was," and "…it was helpful to see parents of older children who were generally happy."

TABLE 5

Perceptions of Down Syndrome Organizations

Theme	Responses Including the Theme	Percentage of Total Responses
Meeting other families	8	66.7%
Obtaining information	3	25%

Information was another source of support provided to families during the prenatal period following the diagnosis. Participants (*n* = 14) reported receiving information on the development of children with Down syndrome, although only 50% felt they were provided with an adequate amount of information on the subject. In contrast, 71% (*n* = 7) of participants who received quality-of-life information perceived the information as extremely positive or positive. For those who received information on early intervention (*n* = 8), 75% of participants felt this helped ease the transition into actually receiving the early intervention services after their child was born. Information on resources available for families was provided as well, but only 35.3% of participants reported that they felt they were given an adequate amount of information. In consideration of all the information participants received, 55.6% of participants in this study agreed that the information provided was up-to-date. Overall, 76.5% of participants agreed that the act of providing information to families could be improved and provided suggestions for improvement (refer to section 4.3).

When preparation for their child's birth was assessed, 52.9% (*n* = 9) felt that the services and supports they received prepared their families. Participants were asked to share why they felt prepared or not and three themes were identified. One theme was that participants (*n* = 3) felt prepared based on their own research prior to birth, regardless if support was provided by medical professionals or other sources. Another theme present was that participants (*n* = 2) were prepared for the worst or scared based on the information that had been provided to them by medical professionals. Lastly, two participants reported that they were not prepared for the medical challenges and daily life they encountered when their child was born.

TABLE 6

Perceptions of Preparation for Birth

Theme	Responses Including the Theme	Percentage of Total Responses
Independent research	3	23.1%
Prepared for the worst	2	15.4%
Medical challenges	2	15.4%

4.3 Improvements Suggested for Services and Supports

The third research question's purpose was to investigate what services and supports families recommend to enhance the prenatal period following the diagnosis. When participants were asked what improvements should be made in regard to the information provided following the prenatal diagnosis of Down syndrome, one major theme emerged within the open-ended responses. Eight participants (57%) responded that the information provided to families following the prenatal diagnosis by clinicians should focus more on the positive outcomes (i.e., success in school, independence) that individuals with Down syndrome can have rather than the negative outcomes (i.e. medical challenges, cognitive delays). Some examples of these comments were: “I would suggest to talk about more about what the individuals CAN do…” and “Focus on the fact that your child will be awesome!”

In regard to support groups and Down syndrome organizations, three themes were discovered when participants were asked to share suggestions regarding the services and supports if the participants rated that they were dissatisfied. Two participants responded that there were no local support groups or Down syndrome organizations, which impeded their ability to participate. A second theme was that participants (*n* = 2) obtained information through their own research or request, rather than through support from professionals. Third, two participants responded that there were not enough services prenatally such as early intervention and government assistance.

TABLE 7

Down Syndrome Organization Suggestions

Theme	Responses Including the Theme	Percentage of Total Responses
No local organizations/Support groups	2	33.3%
Independent research	2	33.3%
Lack of services prenatally	2	33.3%

Participant response to what services and supports should be initiated following a prenatal diagnosis generated four themes. First, six participants responded that families should be connected with other families who have children with Down syndrome. A second theme reported by participants (*n* = 5) was that professionals should be more positive when interacting with the families. A response within this theme was: "Giving facts about employment, secondary education. Focusing on the abilities would have been mentally helpful". Third, three participants responded that families should be connected with support groups following the prenatal diagnosis. Lastly, three participants shared that families should be provided with information on local resources such as early intervention and government resources. A comment relating to this theme was: "It is absolutely impossible to understand/figure out what state/government supports are available".

TABLE 8

Suggestions for Prenatal Services and Supports

Theme	Responses Including the Theme	Percentage of Total Responses
Connect with other families	6	42.8%
Positivity	5	35.7%
Support groups	3	21.4%
Local resource information	3	21.4%

CHAPTER 5: DISCUSSION

The purpose of this study was to evaluate the services and supports that families receive following the prenatal diagnosis of Down syndrome and how these services and supports might be improved. The discussion is organized by the research questions this study seeks to answer. The three research questions for this study were: 1) What prenatal services and supports are provided to families following a diagnosis of Down syndrome? 2) What are families' perceptions of the services and supports provided during the prenatal period following diagnosis? 3) What services and supports do families recommend in order to enhance the process from diagnosis to birth?

5.1 Services and Supports Received

The first question the researcher sought to answer related to what services and supports families receive following the prenatal diagnosis of Down syndrome. Most participants (83%) reported receiving genetic counseling services, which is similar to the findings of Roberts et al. (2002) that 87% of the participants reported receiving genetic counseling. This suggests genetic counseling is still a primary source of services and supports for families following a prenatal diagnosis. Most families (66.7%) were satisfied with the services and supports provided by genetic counselors, indicating this service could be beneficial to families. However, this finding also emphasizes the need for improvement considering the relatively low percentage of families who were satisfied with this support. Improving the availability of genetic counseling services could make a large impact in preparing families for the birth of their child with Down syndrome as well.

Like genetic counseling, meeting with other families who have a child with Down syndrome is a common service families reported receiving, although the majority of participants were not offered this opportunity. This is consistent with Hippman et al.'s (2011) recommendation that families should be offered the opportunity to meet with other families who have children with Down syndrome as only 47.1% of participants in this study were offered the opportunity. Participants in this study were less likely to meet families through a support group, but this could be due to limited opportunities to participate in support groups. Only 29.4% (*n* =5) of participants in this study were offered the opportunity to participate in a support group. This finding contradicts recommendations by Skotko (2005) to offer all families contact with Down syndrome support groups.

Similar to support groups and meeting other families, participation in Down syndrome organizations was another source of support reported by participants. Participating in Down syndrome organizations were supports that were utilized at a high rate, yet participants were only referred to this type of support around half of the time. Considering the high rate of participation in this type of support found in results from this study, Hippman et al.'s (2011) recommendation to build a strong relationship with Down syndrome organizations and Skotko's (2005) recommendation to offer families contact with Down syndrome support groups may prove beneficial in supporting families.

Information was provided to participants in this study during the prenatal period as well. Professionals providing quality-of-life information has improved since the Roberts et al. study in 2002, although less than half of the participants in this study were offered the information. This is concerning considering the recommendations from

Hippman et al. (2011) that professionals should gather real-life knowledge about individuals with Down syndrome to provide better descriptions about having a child with Down syndrome. The provision of quality-of-life information continues to be an area that needs improvement based on past research by Hippman et al. (2011) and recommendations from participants in this study (See Section 5.3).

Information regarding early intervention services was provided to fewer than half of the participants in this study. This is concerning considering that children with Down syndrome are automatically eligible to receive early intervention services provided by the Southeastern state this study was completed in. Educational resources were also provided to fewer than half of the participants, but the results also showed that all of the participants provided with these resources utilized them. Considering the universal utilization, providing these resources appears to be a significant way to help families learn more about Down syndrome and prepare them for the birth of their child.

5.2 Family Perceptions

Families' perceptions regarding services and supports they received during the prenatal period were analyzed in this study as well. Families reported satisfaction with meeting with other families who have children with Down syndrome, support groups, and participating in Down syndrome organizations. Themes identified in the open-ended responses support the notion that families were satisfied with the act of meeting with other families who have children with Down syndrome. These results suggest that personal and social interactions played a large role in the satisfactory perceptions from families. This finding is consistent with previous research by Helm et al. (1998) and Skotko (2005) where participants reported they were pleased with services when provided the opportunity to meet parents who had children with Down syndrome. As already reported, participation with Down syndrome associations whether it be through meetings, support groups, or other activities, received positive perceptions in this study. This reinforces past recommendations that families should be given information regarding Down syndrome organization resources, offered contact with Down syndrome support groups, and that genetic counselor's should create strong relationships with these organizations (Hippman et al., 2011; Skotko, 2005; Skotko et al., 2009; Skotko et al., 2009b). Based on the high rates of utilization and positive perceptions, these supports may be important to provide to families during the prenatal period.

Differing from personal and social interactions, past studies have indicated that the act of providing information to families created negative perceptions from families following the prenatal diagnosis (Hodgson & Weil, 2012; Hodgson et al., 2010; Roberts et al., 2002; Skotko, 2005). Perceptions regarding up-to-date information on Down syndrome in this study differed from results obtained by Skotko (2005) where nearly all of the participants felt the information they were given was not up-to-date. The participants' perceptions of the up-to-date information provided to them could possibly have an effect on the perceptions reported regarding the overall support from medical professionals.

Positive correlation between up-to-date information and perceptions of medical professionals is supported by Skotko (2009a), who found that the mothers who were provided with up-to-date information were pleased with their physicians. Similarly, information regarding the local early intervention services is a support that was consistent with Hippman et al.'s (2011) results that families felt the information was valuable. This supports Keilty’s (2008) recommendation of providing Part C services prenatally considering the majority of participants in this study felt the information on early intervention services eased the transition into actually receiving said services. Providing early intervention prenatally could possibly improve supports and information provided to families based on the lack of participants who received information on resources available to them in this study. Overall, the majority of participants in this study still felt the act of providing information could be improved which places an importance on the recommendations by participants in section 5.3.

The support received from medical professionals following the prenatal diagnosis of Down syndrome was also addressed with this study. Several themes emerged in the open-ended responses that may provide some insight as to why families perceive support or not. Several participants reported that medical professionals would present termination of the pregnancy as their first option. Based on the corresponding Likert scale responses regarding overall support from medical professionals, presenting the option of abortion to families could be a reason as to why familial satisfaction levels were less positive. Several participants in this study responded they felt supported when professionals were in agreement with the family’s decision to continue the pregnancy. It could be possible that the medical professionals mentioned within the theme regarding abortion did not follow the recommendations from past literature that professionals should allow the families to lead the discussions to better meet the families needs and avoid giving personal opinions (Hippman et al., 2011; Skotko, 2005).

Participants also reported that information provision was a reason in perceiving support or not. The presence and quality of information appears to continue to be a hindrance in familial perception of support, which is similar to findings by Choi et al., 2012; Helm et al., 1998; Hippman et al., 2011; Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009a; and Skotko et al., 2009b. An interesting theme also emerged regarding the familial perceived levels of support among different disciplines. For example, a participant reported feeling supported by their genetic counselor but was not pleased with the support of their OB/GYN. This could possibly be due to the specific professionals having more knowledge and training on Down syndrome and delivering the diagnosis rather than certain disciplines in general. Skotko et al. (2009a; 2009b) reports that hospitals should allow the most knowledgeable clinician to discuss the diagnosis and be trained on how to best deliver the news in an appropriate and helpful way.

Looking at medical professional support more closely, the perceived support by genetic counselors was also analyzed. Participants reported that the most common form of support that genetic counselors provided is literature. Participants indicated positive responses, indicating that the literature provided was helpful. This differs from past research where information was reported to be limited from genetic counselors (Hodgson et al., 2010; Hodgson and Weil, 2012) but mirror findings by Roberts et al. (2002) that the majority of the participants perceived the information provided by genetic counselors to be helpful. Perhaps negative familial perceptions pertaining to information provision in prior studies (Hodgson & Weil, 2012; Hodgson et al., 2010; Roberts et al., 2002; Skotko, 2005) compelled genetic counselors to increase the literature they provide to families.

Families responded why they did not feel prepared for the birth of their child based on the supports and services they received prenatally. Interestingly, participants did not include the higher-rated supports such as meeting other families, support groups, and

Down syndrome organizations in their reasons explaining their perceived level of preparedness. Those who did not feel prepared (47.1%) reported they were expecting "the worst" or did not feel ready for the daily rhythms of care and medical challenges. This is consistent with findings by Hodgsen et al. (2010) that information provided to participants pertained to negative consequences such as learning delays or physical effects. This theme is consistent with findings by Roberts et al. (2002) where 95.7% of participants anticipated an increased burden as parents of a child with Down syndrome. It is clear that the current prenatal services and supports are not adequately preparing families for life with their child after birth.

5.3 Recommendations from Families

Participants suggested improvements that could be made in regard to the information provided to families following the prenatal diagnosis. One theme that emerged was that information provided should focus more on positive outcomes that individuals with Down syndrome experience rather than the negative outcomes, such as medical challenges and cognitive delays. Participants indicated a desire to be presented with what their child could do rather than what medical professionals forecasted their child would not be able to do. These recommendations mirror findings from previous studies that are parents of children with Down syndrome described their children more alike than different from typically developing peers (Sheets et al., 2011). The information participants received during this study appear to be similar to findings by Hodgson and Weil (2012) that discussions with medical professionals were perceived to be needlessly negative. Hipmman et al.'s (2011) recommends that clinicians should gather real-life knowledge regarding individuals with Down syndrome to better provide descriptions to families. Perhaps a dearth of strengths-based information is still a barrier preventing families from feeling supported.

A second theme suggests that families should be connected with other families with children with Down syndrome, which echoes recommendations Hippman et al. (2011) for families to be offered contact with other families who have children with Down syndrome. This suggestion could be based on participants' desire to be connected with families to learn information from other families that they are not receiving from medical professionals. Hipmman et al. discovered that parents found personal stories from other parents of children with Down syndrome to be helpful. Obtaining information from other families was also a reported benefit of meeting other families found in the results from this study.

Participants also provided suggestions for Down syndrome organizations and support groups. A common response was that there were no local support groups or Down syndrome organizations for the families to actively participate. This response is interesting because the researcher recruited participants through Down syndrome organizations located in a Southeastern state, implying that the participants were familiar with the organization that they were recruited from. However, participants were not asked when they became involved with the organization, indicating that perhaps they became involved after their child was born. Based on the responses by participants regarding the lack of local resources, the recommendation by Skotko et al. (2009a; 2009b) that physicians should provide information on up-to-date resources appears pertinent. This directly relates to another theme that there were not enough prenatal services available for families. The lack of prenatal services reported could be supported by Keilty's (2008) proposal to provide early intervention services prenatally to better support families during this period. Both of these themes could be the reason that families reported they completed their own research and obtained their own information instead of being supported by support groups and Down syndrome organizations.

Overall, participants were also asked to recommend what services and supports should be initiated following a prenatal diagnosis. One emerging theme was that families should be connected with support groups and other families who have children with Down syndrome. Meeting other families was a common theme in the open-ended responses across the questionnaire implying that this could be an important support to provide families during the prenatal period. This reiterates recommendations by Skotko (2005) and Hippman et al. (2011) that families should be offered contact with support groups and other families who have children with Down syndrome.

Another theme that was identified was that professionals should be more positive when interacting with families after the diagnosis. This idea has also been recommended in past articles that are 20, 13, and 9 years old, respectively (Helm et al., 1998; Skotko, 2005; Skotko et al., 2009b), so it is concerning that this continues to be a needed recommendation for professionals. The third theme that emerged was that professionals need to provide more information on local resources. Keilty’s (2008) proposal of prenatal early intervention services could possibly benefit families in this matter considering providing information on resources is an aspect of early intervention.

5.4 Limitations

This study had several possible limitations, beginning with the instrument being a researcher-developed questionnaire. In an effort to provide content and social validity, the researcher piloted the questionnaire. After piloting the questionnaire, no changes needed to be made and pilot participants made no recommendations for improvement. The sample for this study was a limitation as well because it was a convenience sample from one Southeastern state. The sample was a limitation due to results that may not be generalizable for other states in the United States. However, this could also be a strength considering it may have more clearly represented the supports and services in this particular Southeastern state compared to past research, which represented multiple states. The convenience sample was also collected from Down syndrome organizations within the Southeastern state, which would exclude families who are not already involved with those organizations, lowering the sample frame size. The participants' involvement with these organizations may have also produced more positive results compared to participants who were not involved with Down syndrome organizations. Lastly, inclusion criteria for the questionnaire required participants to be fluent English speakers, since the questionnaire was conducted in the English language without a translation option, which could have limited the total sample frame. Accessing only English-speaking families could have also reduced the ability to generalize the information to families speaking other languages as well.

5.5 Implications for Future Research

Several implications from this study could guide research in the future. Prior studies have recommended that families have the opportunity to meet with other families who have children with Down syndrome and support groups; these supports both received positive perceptions in this study. Research should be conducted to investigate the importance and nature of relationships with other parents of children with Down syndrome and the activities they engage in when participating in these supports. Future research should also be completed to determine how professionals are being trained to interact with families and determine why families often perceive professionals as being unsupportive and negative. This research would be supported by Cleary-Goldman et al.'s (2006) findings that 45% of physicians in their study felt their training was minimal. Skotko et al. (2009a; 2009b) also recommended that clinicians should be trained on how to deliver the news of the diagnosis in the most helpful and appropriate way. The results of this study provided positive perceptions regarding participating with Down syndrome organizations, but almost half of the participants were not referred to these organizations. Research should be completed on how Down syndrome organizations and medical professionals are collaborating to better support families. This research would be supported by Hippman et al.'s (2011) recommendation that genetic counselors build and focus on strong relationships with Down syndrome support organizations.

5.6 Implications for Future Practice

This study also suggests important implications for future practice. First, all professionals should ensure that they provide families with information about the positive outcomes for individuals with Down syndrome instead of pressuring families into terminating the pregnancy post-diagnosis. Providing information on positive outcomes has been a concern in several studies over the past two decades (Helm et al., 1998; Skotko, 2005; Skotko et al., 2009b). Increased training for medical professionals regarding delivering the diagnosis and communicating with families would be beneficial in this respect. This is supported by Skotko et al.'s (2009a) study recommending the most knowledgeable clinician be trained on how to best deliver the diagnosis. Current information on a variety of topics addressing a Down syndrome diagnosis (i.e. development, resources, and quality-of-life) should continue to be provided to families. Medical professionals should understand and communicate the resources available to families, such as early intervention services and financial support. Similar to Skotko (2005) and Skotko et al.'s (2009b) recommendation, medical professionals should familiarize themselves with local Down syndrome organizations in an effort to increase referrals to support groups, other families with children who have Down syndrome, and the organizations themselves.

REFERENCES

ACOG. (2016a). Prenatal genetic screening tests. Retrieved on January 20, 2017 from https://www.acog.org/Patients/FAQs/Prenatal-Genetic-Screening-Tests.

ACOG. (2016b). Prenatal genetic diagnostic tests. Retrieved on January 20, 2017 from https://www.acog.org/Patients/FAQs/Prenatal-Genetic-Diagnostic-Tests.

Bronfenbrenner, U. (1974). Developmental research, public policy, and the ecology of childhood. *Child Development, 45(1),* 1–5.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32(7),* 513– 530.

Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22(6),* 723–742.

Choi, H., Van Riper, M., & Thoyre, S. (2012). Decision making following a prenatal diagnosis of Down syndrome: An integrative review. *Journal of Midwifery & Women's Health*, *57*(2), 156-164. doi:10.1111/j.1542-2011.2011.00109.x

Cleary-Goldman, J., Morgan, M. A., Malone, F. D., Robinson, J. N., D'Alton, M. E., & Schulkin, J. (2006). Screening for Down syndrome. *Obstetrics & Gynecology*, *107(1),* 11-17.

Elwy, A. R., Michie, S., & Marteau, T. M. (2007). Attribution and reported communication of a diagnosis of Down syndrome. *Health Communication*, *22*(2), 115-121. doi:10.1080/10410230701453975

Helm, D. T., Miranda, S., & Chedd, N. A. (1998). Prenatal diagnosis of Down syndrome: Mothers' reflections on support needed from diagnosis to birth. *Mental Retardation*, *36*(1), 55-61. doi:10.1352/0047-6765(1998)036<0055:PDODSM>2.0.CO;2

Hippman, C., Inglis, A., & Austin, J. (2012). What is a 'balanced' description? Insight from parents of individuals with Down syndrome. *Journal of Genetic Counseling*, *21*(1), 35-44. doi:10.1007/s10897-011-9417-2

Hodgson, J. M., Gillam, L. H., Sahhar, M. A., & Metcalfe, S. A. (2010). "Testing times, challenging choices": an Australian study of prenatal genetic counseling. *Journal of Genetic Counseling*, *19(1),* 22-37.

Hodgson, J., & Weil, J. (2012). Talking about disability in prenatal genetic counseling: A report of two interactive workshops. *Journal of Genetic Counseling*, *21*(1), 17-23. doi:10.1007/s10897-011-9410-9

Hurford, E., Hawkins, A., Hudgins, L., & Taylor, J. (2013). The decision to continue a pregnancy affected by Down syndrome: Timing of decision and satisfaction with receiving a prenatal diagnosis. *Journal of Genetic Counseling*, *22(5),* 587-593.

Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Johnston, B. D., Huebner, C. E., Anderson, M. L., Tyll, L. T., & Thompson, R.S. (2006). Healthy steps in an integrated delivery system. *Archives of Pediatrics and Adolescent Medicine, 160*, 793-800.

Keilty, B. (2008). Earlier intervention: Prenatal initiation of IDEA, Part C supports and services. *Early Childhood Services: An Interdisciplinary Journal of Effectiveness*, *2*(4), 195-206.

Latendresse, G., & Deneris, A. (2015). An update on current prenatal testing options: First trimester and noninvasive prenatal testing. *Journal of Midwifery & Women's Health*, *60*(1), 24-36. doi:10.1111/jmwh.12228

Love, J. M., Kisker, E. E., Ross, C. M., Schochet, P. Z., Brooks-Gunn, J., Paulsell, D., et al. (2002). *Making a Difference in the Lives of Infants and Toddlers and Their Families: The Impacts of Early Head Start. Volumes I Final Technical Report*. Princeton, NJ: Mathematica Policy Research, Inc.

Marshall, J., Tanner, J. P., Kozyr, Y. A., & Kirby, R. S. (2015). Services and supports for young children with Down syndrome: Parent and provider perspectives. *Child: Care, Health and Development*, *41(3),* 365-73.

National Down Syndrome Society. (2012). *Down Syndrome Facts.* Retrieved February 4, 2016 from http://www.ndss.org/Down-Syndrome/Down-Syndrome-Facts/

Roberts, C. D., Stough, L. M., & Parrish, L. H. (2002). The role of genetic counseling in the elective termination of pregnancies involving fetuses with disabilities. *The Journal of Special Education*, *36*(1), 48-55. doi:10.1177/00224669020360010501

Sheets, K. B., Crissman, B. G., Feist, C. D., Sell, S. L., Johnson, L. R., Donahue, K. C., et al. (2011). Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome: Recommendations of the national society of genetic counselors. *Journal of Genetic Counseling, 20(5),* 432-41.

Skotko, B. G. (2005). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics and Gynecology*, *192(3),* 670-677.

Skotko, B. G., Kishnani, P. S., & Capone, G. T. (2009a). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics Part A*, *11*, 2361-2367.

Skotko, B. G., Capone, G. T., & Kishnani, P. S. (2009b). Postnatal diagnosis of Down Syndrome: Synthesis of the evidence on how best to deliver the news. *Pediatrics*, *124*(4), e751-e758. doi:10.1542/peds.2009-0480

Williams, C., Alderson, P., & Farsides, B. (2002). What constitutes 'balanced' information in the practitioners' portrayals of Down syndrome? *Midwifery, 18,* 230–237.

APPENDIX A: QUESTIONNAIRE

Family Perspectives

Start of Block: Demographics

We would like to invite you to participate in a study regarding the services and supports for families who have children with Down syndrome.

The purpose of this questionnaire is to obtain information regarding the prenatal services and supports your family received following a diagnosis of Down syndrome, your family's perceptions of those services and supports, and your recommendations to enhance the prenatal services and supports provided. If you did not receive a prenatal diagnosis of Down syndrome, this questionnaire will be used to investigate what services and supports you would have liked to receive if you had learned about your child's diagnosis during the prenatal period. The information gathered during this research may help to improve prenatal services and supports. With the information obtained from this questionnaire, professionals could enhance prenatal services and supports enabling families to be prepared for the birth of their child with Down syndrome. The inclusion criteria for participation is that you are a parent who received a prenatal diagnosis of Down syndrome or would have liked to have received a prenatal diagnosis of Down syndrome. Other inclusion criteria includes: participants must be 18 years or older, English speaking, the child with Down syndrome must be ten years or younger, and only one parent per family can participate. The questionnaire should only take about 10 minutes of your time, and it is completely voluntary. Your participation is completely anonymous and the researcher will have no way to connect data to participants. Thank you in advance for your help with this study.

○ I agree to participate in this study.

○ I prefer not to participate in this study.

Skip To: End of Survey If Dear Participant, We would like to invite you to participate in a study regarding the... = I prefer not to participate in this study.

What is your relationship to the child with Down syndrome?

____

Please select your race (select all that apply)

- ☐ Asian/Pacific Islander
- ☐ Black/African-American
- ☐ Caucasian
- ☐ Native American/Alaska Native
- ☐ Hispanic
- ☐ Multi-Racial/Other
- ☐ Prefer not to answer

What is your age?

____

What is your marital status?

- ○ Single
- ○ Married
- ○ Widowed
- ○ Divorced
- ○ Prefer not to answer

Please select the highest level of education you have completed.

- ○ Some high school, no diploma
- ○ High school diploma/GED
- ○ Some college, no degree
- ○ Associate degree
- ○ Bachelor degree
- ○ Master degree
- ○ Doctorate degree or other professional degree

Please select your employment status at the time of your child's birth.

- ○ Employed full time
- ○ Employed part time
- ○ Unemployed looking for work
- ○ Unemployed not looking for work
- ○ Retired
- ○ Student
- ○ Prefer not to answer

What is your household income level?

- ○ Less than $20,000
- ○ $20,000 - $39,999
- ○ $40,000 - $59,999
- ○ $60,000 - $79,999
- ○ $80,000 - $99,999
- ○ $100,000 and above

In what year was your child with Down syndrome born?

____

In what state was your child with Down syndrome born in?

____

Does your child reside in the state they were born in?

- ○ Yes
- ○ No

Did you have medical insurance at the time of the child's birth?

- ○ Yes
- ○ No

Did you participate in a screening test during your prenatal period? (Screening tests do not provide a diagnosis, they provide insight regarding the chance of an abnormality. Examples of screening tests include: Blood samples, tissue samples, cell-free DNA testing, and ultrasounds.)

○ Yes

○ No

Did you participate in a diagnostic test? (Diagnostic tests do provide a diagnosis. Examples of diagnostic tests: Amniocentesis and Chronic Villus Sampling.)

○ Yes

○ No

Did you receive a prenatal diagnosis of Down syndrome?

○ Yes

○ No

Skip To: Q7 If Did you receive a prenatal diagnosis of Down syndrome? = Yes

---

What services and supports would you have liked to receive if you had learned of your child's diagnosis during the prenatal period?

____

____

____

____

____

Skip To: End of Survey If What services and supports would you have liked to receive if you had learned of your child's dia... Is Displayed

---

During what trimester did you receive the prenatal diagnosis?

- ○ 1st Trimester
- ○ 2nd Trimester
- ○ 3rd Trimester

Who delivered the news of the prenatal diagnosis?

- ○ Physician
- ○ Gynecologist/Obstetrician
- ○ Nurse
- ○ Genetic Counselor
- ○ Other ____________________

How was the diagnosis delivered to you?

- ○ In person
- ○ In a form other than in person (eg. phone call, in writing, etc.)

Please select your level of agreement with the statement below.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I feel that the medical professionals supported me following the prenatal diagnosis.	○	○	○	○	○

Please explain why you selected the level of agreement you selected in the previous question regarding the support your family received from medical professionals after the diagnosis.

____

____

____

____

____

Following the prenatal diagnosis, were you provided with services and supports from genetic counselors?

○ Yes

○ No

Skip To: Q47 If Following the prenatal diagnosis, were you provided with services and supports from genetic couns... = No

Please rate your level of satisfaction with the services and supports you received from genetic counselors.

	Extremely dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Extremely satisfied
Genetic counseling	○	○	○	○	○

Please explain why you were either satisfied or dissatisfied with the services and supports you received from a genetic counselor.

____

____

____

____

____

Did you receive support from your family during the prenatal period?

○ Yes

○ No

Did you receive support from others such as the community, church, support groups, friends, and such?

○ Yes

○ No

If so, please explain who you received support from and what support did they provide?

Please select your level of agreement for the following statement

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
The information I was given regarding Down syndrome was up-to-date information.	○	○	○	○	○

Following the prenatal diagnosis, were you provided with information about the development of individuals with Down syndrome?

○ Yes

○ No

Skip To: Q32 If Following the prenatal diagnosis, were you provided with information about the development of ind... = No

Do you feel you were provided with an adequate amount of information about the development of individuals with Down syndrome?

○ Yes

○ No

Following the prenatal diagnosis, were you provided with information or a description regarding the quality of life (what daily life would be like for you and your child)?

○ Yes

○ No

Skip To: Q54 If Following the prenatal diagnosis, were you provided with information or a description regarding t... = No

---

Please select the rating that most accurately describes the information given regarding the quality of life your child might have.

	Extremely positive	Somewhat positive	Neither positive nor negative	Somewhat negative	Extremely negative
	○	○	○	○	○

Do you feel that the act of providing information to families could be improved?

○ Yes

○ Maybe

○ No

If you were dissatisfied with the information provided to you following the prenatal diagnosis, what improvements would you suggest?

____

____

____

____

____

During the prenatal period, were you offered the opportunity to participate in a support group?

○ Yes

○ No

Skip To: Q40 If During the prenatal period, were you offered the opportunity to participate in a support group? = No

Did you participate in a support group?

○ Yes

○ No

Skip To: Q40 If Did you participate in a support group? = No

Did you find the participation in a support group to be helpful?

○ Yes

○ Maybe

○ No

Please explain why you feel the support group was helpful or not helpful.

____

____

____

____

____

During the prenatal period, were you offered educational resources such as books, websites, webinars on the subject of Down syndrome?

○ Yes

○ No

Skip To: Q50 If During the prenatal period, were you offered educational resources such as books, websites, webin... = No

Please list the educational resources you were offered such as books, websites, and webinars on the subject of Down syndrome. (If possible, please list the specific resource such as the title of the book, website, or webinar.)

____

____

____

____

____

Did you utilize any of the educational resources?

○ Yes

○ No

Skip To: Q50 If Did you utilize any of the educational resources? = Yes

---

Please list the educational resources you utilized such as books, websites, and webinars. (If possible, please list the specific resource such as the title of the book, website, or webinar.)

____

____

____

____

____

Did you find any of the educational resources to be helpful?

○ Yes

○ No

Please explain why you felt the educational resources were helpful or not helpful.

____

____

____

____

____

During the prenatal period, were you referred to or given information on a Down syndrome organization or association?

○ Yes

○ No

Skip To: Q51 If During the prenatal period, were you referred to or given information on a Down syndrome organiza... = Yes

During the prenatal period, did you independently seek contact with Down syndrome organizations or associations?

○ Yes

○ No

Skip To: Q23 If During the prenatal period, did you independently seek contact with Down syndrome organizations o... = No

If so, please list the organizations or associations.

____

____

____

____

____

Did you participate in any of the organizations or associations you listed above?

○ Yes

○ No

Please explain why you felt participating in a Down syndrome organization or association was beneficial or not.

____

____

____

____

____

Did you find participation in a Down syndrome organization or association to be beneficial?

○ Yes

○ No

Were you offered the opportunity to meet one-on-one with other parents who had children with Down syndrome?

○ Yes

○ No

Did you actually meet with other parents one-on-one who have children with Down syndrome?

○ Yes

○ No

Skip To: Q29 If Did you actually meet with other parents one-on-one who have children with Down syndrome? = No

---

Please rate how useful this support was for you.

	Not at all useful	Slightly useful	Moderately useful	Very useful	Extremely useful
Meeting one-on-one with other parents of children with Down syndrome	○	○	○	○	○

Please select your level of agreement for the following statement

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I was given an adequate amount of information on resources available to me (ex. support groups, websites, books, families with children with Down syndrome).	○	○	○	○	○

During the prenatal period, were you provided information on the North Carolina Infant-Toddler Program, the Children's Developmental Services Agency, or other services provided to families and children with disabilities birth through the age of three once the child was born?

○ Yes

○ No

Skip To: Q25 If During the prenatal period, were you provided information on the North Carolina Infant-Toddler Pr... = No

Who provided the information on these services?

○ Medical personnel

○ NC Infant-Toddler Program professionals (e.g. a service coordinator from the CDSA)

○ Family members

○ Other, please specify ____

Did the information on these services ease the transition into receiving services such as therapy or evaluations following the birth of the child?

○ Yes

○ No

Please list any other services and supports that professionals provided you with during the prenatal period

____

____

____

____

Please rate your overall level of satisfaction with the services and supports provided to you by medical professionals following the prenatal diagnosis of Down syndrome.

	Extremely dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Extremely satisfied	I did not receive services or supports from medical professionals
	○	○	○	○	○	○

Please rate your overall level of satisfaction with the services and supports provided to you by family and friends following the prenatal diagnosis of Down syndrome.

	Extremely satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Extremely dissatisfied	I did not receive services or supports from family and friends.
	○	○	○	○	○	○

Please rate your overall level of satisfaction with the services and supports provided to you by support groups or Down syndrome organizations following the prenatal diagnosis of Down syndrome.

	Extremely satisfied	Moderately satisfied	Slightly satisfied	Neither satisfied nor dissatisfied	Slightly dissatisfied	Extremely dissatisfied	I did not receive services or supports from support groups or Down syndrome organizations
	○	○	○	○	○	○	○

If you were dissatisfied, what suggestions do you have regarding the services and supports (such as the frequency of supports provided, the amount of information, etc.) you received following your prenatal diagnosis of Down syndrome?

____

____

____

____

____

Do you feel that the services and supports provided to you following the prenatal diagnosis prepared you for the birth of your child?

○ Yes

○ No

Please explain why you selected yes or no.

____

____

____

____

____

What services and supports should be initiated following a prenatal diagnosis of Down syndrome in order to enable families to prepare for the birth of their child?

____

____

____

____

____

End of Block: Demographics

APPENDIX B: PARTICIPANT CONSENT

UNC CHARLOTTE

Dear Participant,

We would like to invite you to participate in a study regarding the services and supports for families who have children with Down syndrome.

The purpose of this questionnaire is to obtain information regarding the prenatal services and supports your family received following a diagnosis of Down syndrome, your family's perceptions of those services and supports, and your recommendations to enhance the prenatal services and supports provided. If you did not receive a prenatal diagnosis of Down syndrome, this questionnaire will be used to investigate what services and supports you would have liked to receive if you had learned about your child's diagnosis during the prenatal period. The information gathered during this research may help to improve prenatal services and supports. With the information obtained from this questionnaire, professionals could enhance prenatal services and supports enabling families to be prepared for the birth of their child with Down syndrome. The inclusion criteria for participation is that you are a parent who received a prenatal diagnosis of Down syndrome or would have liked to have received a prenatal diagnosis of Down syndrome. Other inclusion criteria includes: participants must be 18 years or older, English speaking, the child with Down syndrome must be ten years or younger, and only one parent per family can participate. The questionnaire should only take about 10 minutes of your time, and it is completely voluntary. Your participation is completely anonymous and the researcher will have no way to connect data to participants. Thank you in advance for your help with this study.

APPENDIX D: LETTER TO ORGANIZATION LIASIONS

UNC CHARLOTTE

Dear ___________________

My name is Zachary Martin and I am currently in the final phase of the Master in Child and Family Development program at the University of North Carolina at Charlotte. I am writing to ask for your support in a study I am conducting under the supervision of Dr. JaneDiane Smith at the university. The purpose of the study is to investigate what prenatal services and supports are being provided to families following a diagnosis of Down syndrome, what are families perceptions of the prenatal services and supports provided, and what do families recommend to improve prenatal services and supports following a diagnosis of Down syndrome? The information gathered during this research may help to improve prenatal services and supports. With the information obtained from this study, professionals could enhance prenatal services and supports enabling families to be prepared for the birth of their child with Down syndrome. If you agree to offer support with this study, you would receive an email with an electronic questionnaire link that you could share with the members of your organization or post to your organizations social media accounts in order to reach possible participants. The inclusion criteria for participation is that the family member who has a child with Down syndrome and received a prenatal diagnosis or that the family member has a child with Down syndrome and would have preferred to receive a prenatal diagnosis. Other inclusion criteria includes: participants must be 18 years or older, English speaking, the child with Down syndrome must be ten years or younger, and only one parent per family can participate. The questionnaire should only take about 10 minutes of participant’s time, and it is completely voluntary. The questionnaire is anonymous so participation and data will not be connected to any participants. I hope that participants find this to be a valuable opportunity to voice their thoughts and feelings about prenatal services and support provided following a prenatal diagnosis of Down syndrome. Participant’s opinions on this topic are very important to us and this research can only be successful with the generous help of people like you.

Thank you for your support,

Zachary Martin
Zmartin3@uncc.edu
980-581-7408