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PARENT/CAREGIVER KNOWLEDGE AND SATISFACTION OF INFORMATION AND
REFERRALS RELATED TO SPEECH-LANGUAGE PATHOLOGY SERVICES FOR
CHILDREN WITH DOWN SYNDROME

THESIS

A thesis submitted in partial fulfillment of the
requirements for the degree of Master of Science in the
College of Health Sciences
at the University of Kentucky

By

Erin K. Salmons

Lexington, Kentucky

Director: Dr. Jane O'Regan Kleinert, Associate Professor of Communication Sciences and
Disorders

Lexington, Kentucky

2015

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ABSTRACT OF THESIS

PARENT/CAREGIVER KNOWLEDGE AND SATISFACTION OF INFORMATION AND REFERRALS RELATED TO SPEECH-LANGUAGE PATHOLOGY SERVICES FOR CHILDREN WITH DOWN SYNDROME

Down syndrome, also known as Trisomy 21, is the most commonly occurring chromosomal abnormality present at birth. The Centers for Disease Control and Prevention estimates that there are approximately 6,000 diagnoses of Down syndrome per year in the United States, further indicating that 1/700 infants are born with Down syndrome. A diagnosis of Down syndrome can be made either prenatally or postnatally. Early intervention services will be warranted to address underlying deficits associated with the syndrome, (i.e., speech-language/feeding/swallowing). Communicative disorders are among the most prominent concomitant deficits associated with Down syndrome. Therefore, it is critical that parents/caregivers of children with Down syndrome be provided with information and referrals specifically related to speech-language pathology services in a timely manner. This study surveyed parents/caregivers of children with Down syndrome, from various Down syndrome associations (5) in the state of Kentucky and the Down Syndrome Association of Greater Cincinnati, located in Ohio, to assess parent/caregiver overall satisfaction of information and referrals received specifically related to speech-language pathology services, including the types and time at which the information and referrals were received. Implications of the results of this study and areas for future research are discussed.

KEY WORDS: Down syndrome, speech-language pathology, parents/caregivers, satisfaction, information and referrals

Erin K. Salmons

April 10, 2015

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CHAPTER ONE: INTRODUCTION

Down syndrome [DS] is the most commonly occurring chromosomal abnormality present at birth (Burgoyne, Duff, Clarke, Buckley, Snowling, & Hulme, 2012; Levis, Harris, Whitehead, Moultrie, Duwe, and Rasmussen, 2012; National Down Syndrome Society [NDSS], 2012.a). The Centers for Disease Control and Prevention currently estimates that there are approximately 6,000 diagnoses of DS per year in the United States, further indicating that one of every 700 infants born are born with DS (Centers for Disease Control and Prevention [CDC], 2014). Down syndrome occurs when an extra copy (full or partial) of the twenty-first (21) chromosome is replicated in the deoxyribonucleic acid [DNA] of an individual. Down syndrome is also referred to as Trisomy 21; 'trisomy,' meaning 3, refers to an extra copy (full or partial) of a chromosome. The presence of additional genetic material alters both the course of development and is the foundation of those characteristics commonly associated with individuals with DS (NDSS, 2012.a).

Diagnosis of DS can be performed before birth, prenatally, or at/following, postnatally, the birth of a child. Screening and diagnostic tests are available for prenatal diagnosis while the observation of certain physical traits and chromosomal analysis are performed to confirm a diagnosis of DS postnatally. Minimal literature exists in recommendation of how parents prefer to be informed of a diagnosis of DS and what types of information they should receive (Sheets, Best, Brasington, & Will, 2011); however, limited literature exists to determine their overall satisfaction with the types of information parents/caregivers receive, whether that information be general information regarding DS or more specific and targeted information related to deficits associated with the syndrome (Sheets et al., 2011; Levis et al., 2012). This paper will investigate and assess the overall satisfaction of the information and referrals received by parents/caregivers

of children with Down syndrome as it relates specifically to speech-language pathology services, including the types and times of receipt of that information.

CHAPTER TWO: RATIONALE FOR THE STUDY

Review of the Literature

As Down syndrome is the most commonly occurring chromosomal abnormality (Burgoyne, et. al., 2012; Levis, et al., 2012; NDSS, 2012.a), it is critical that the parents/caregivers of children with Down syndrome be provided with accurate and up-to-date information and referrals for both the syndrome, as a whole, and the specific needs of services a child with Down syndrome may require to address underlying deficits associated with the syndrome.

Down syndrome can be diagnosed either before birth, prenatally, or following birth, postnatally. There are several ways to screen and diagnose Down syndrome prior to the birth of a fetus, during pregnancy. Both screening tests and diagnostic tests exist in the interest of determining whether or not a fetus is likely to have, or has Down syndrome. Prenatal screenings estimate the likelihood that a fetus will be born with Down syndrome and most will involve a blood test and ultrasound (NDSS, 2012.a), while diagnostic tests identify whether or not a fetus has Down syndrome (Mayo Clinic, n.d.). Results of the screenings, in combination with a woman's age, are used to estimate the chance of a child being born with Down syndrome. Screening tests are often offered within the first and second trimesters of pregnancy (NDSS, 2012.a). Positive indicators that a fetus will be born with Down syndrome will further warrant diagnostic testing. Diagnostic tests that can identify the presence or absence of Down syndrome are: amniocentesis, chorionic villus sampling (CVS), and cordocentesis (Mayo Clinic, n.d.; NDSS, 2012.a) and are almost 100% accurate in identifying the presence or absence of Down syndrome (NDSS, 2012.a). CVS is typically performed within the first trimester between nine to

fourteen weeks gestation (NDSS, 2012.a), while amniocentesis is usually performed during the second trimester of pregnancy between fifteen and twenty-two weeks gestation (NDSS, 2012; Mayo Clinic, n.d.).

Postnatal diagnosis of Down syndrome is largely based on appearance and chromosomal analysis. However, features commonly associated with Down syndrome can be identified in infants without Down syndrome; therefore a blood test, chromosomal karyotype, will likely be performed to analyze the infants chromosomal make-up (Mayo Clinic, n.d.), and determine whether or not a full or partial third copy of the twenty-first chromosome is present.

The receipt of a diagnosis of Down syndrome may come as a shock to some parents. Results of a study conducted by Nelson Goff et al., (2013), indicated the importance of positive early experiences when receiving a diagnosis of Down syndrome and emphasize the importance of providing effective education, resources, and practical information from reliable sources. Providing reliable sources of information and referrals must be at the forefront of consideration when a diagnosis of Down syndrome has been confirmed.

Down syndrome is commonly characterized by a flattened face, upward slant of the eyes, a short neck, small ears, protrusion of the tongue, tiny white spots on the iris of the eye, small hands and feet, palmar crease, small pinky fingers that may curve toward the thumb, hypotonia (low muscle tone), and short stature (CDC, 2014). Notably, Down syndrome is the most common genetic cause of intellectual disability (Sheets et al., 2011). While the severity of impairment varies considerably among individuals, early intervention services such as occupational therapy, physical therapy, and speech therapy will be warranted to address underlying deficits associated with the syndrome (Hines & Bennett, 1996).

The NDSS (2012.b) reports that at least half of all children and adults with Down syndrome will face major mental health concerns at some point in their lives. Children and adults with multiple comorbidities are found to have an increased rate of mental health problems.

The most common mental health concerns include:

- General anxiety,
- Repetitive and obsessive-compulsive behaviors,
- Oppositional, impulsive, and inattentive behaviors,
- Sleep related difficulties,
- Depressions;
- Autism spectrum conditions; and
- Neuropsychological issues characterized by progressive loss of cognitive skills.

Early intervention services are critical in the development and success of children with Down syndrome. The Individuals with Disabilities Act [IDEA] is a United States federal law that governs how states and public agencies provide early intervention, special education, and related services to children with disabilities (U.S. Department of Education, 2011). Part B offers support and services for individuals with disabilities and developmental delays from the ages of three to twenty-one. However, Part C, is a program developed for infants/toddlers from birth through age two. First Steps, a statewide early intervention system that provides services to children with developmental disabilities from birth to age three and their families, under the authority of Part C, is a main source of both information and services for children with Down syndrome. The Kentucky Cabinet for Health and Family Services (2015) report that “children who participate in early intervention experience significant improvement in development and learning.” The provision of early intervention services has a positive impact on the overall

growth and development of individuals with disabilities. Research has also “suggested that early intervention for infants and toddlers with Down syndrome is critical in achieving developmental milestones and intensive early intervention may be related to enhanced brain development” (Brighter Tomorrows, 2014). Examples of services that early intervention programs may provide include physical therapy, occupational therapy, or, specifically related to this research study, speech-language therapy. Wright, Kaiser, Reikowsky, Roberts and Oetting, 2013, report the following:

“Children diagnosed with Down syndrome (DS) experience delays in all areas of development; however, they have specific deficits in developing spoken language skills beyond what is expected of their mental age. (Miller, 1999). Children with DS typically have poor speech intelligibility complicated by motor development delays, problems in phonological memory and/or auditory processing, anatomical and physiological differences in the mouth and throat, and sometimes, hearing impairment (Chapman & Hesketh, 2000; Kumin, 1996; Roberts, Price, & Malkin, 2007; Stoel-Gammon, 2001)” (p. 994).

The National Down Syndrome Congress (2013), a national organization for individuals with Down syndrome and their families, as well as Brighter Tomorrows (2014), which provides information related to the diagnosis of Down syndrome and is funded the by the Human Development Institute at the University of Kentucky, reports that communicative disorders are among the most prominent concomitant deficits associated with Down syndrome. As such, speech-language pathology services are critical to the overall success of children with Down syndrome; including services related to both overall communication and feeding/swallowing. Difficulty in spoken communication may noticeably impede the participation and inclusion of individuals with Down syndrome in social, educational, and vocational activities (Kent, Vorperian, Krieman, & Maassen, 2013), thus having a life-long impact on the individual and their families.

Concerns related to speech and language development, as well as feeding and swallowing disorders in this population, have been identified as an area of concern for the development of a child with Down syndrome. In a study conducted by Cleland, Wood, Hardcastle, Wishart, and Timmins (2010), results indicated that children with Down syndrome present with speech disorders that include errors that are both typical errors given developmental age and atypical errors, which are not only a result of delayed cognitive development. For young children with Down syndrome, an increased likelihood in the “development of hearing loss has been found to have significant impact on speech and language development” (Brighter Tomorrows, 2014; Laws & Hall, 2014, p. 333). Results of this same study suggest that speech and language therapy should continue to be provided when children are identified as having chronic hearing difficulties. While hearing loss may contribute to decreased intelligibility due to articulation errors and the distortion of sounds, it may also impact language development due to decreased exposure of correct modeling of language and vocabulary. Decreased intelligibility is reported to be one of the most difficult areas of speech/language for individuals with Down syndrome (NDSS, 2012.c). “Many individuals have difficulty with the strength, timing, and coordination of muscle movements” (NDSS, 2012.c) required for speech, likely due to the hypotonic nature of musculature associated with the syndrome. Abbeduto, Warren, and Connors (2007), reported that language is among the most impaired domain of functioning in children with Down syndrome, and possibly, the greatest barrier to independent inclusion within the community. Children with Down syndrome are found to have a lower vocabulary size than their typically developing children at the same developmental age (Zampini & D’Odorico, 2013). Areas of syntax and morphology prove to be more difficult due to their abstract and complex nature (NDSS, 2012.c). Overall, almost all children with Down syndrome will have varying degrees of

intellectual disability, resulting in a slower learning rate as compared to their typically developing peers, and frequently experience difficulty in understanding *abstract, language-based concepts* (Brighter Tomorrows, 2014).

Additionally, children with Down syndrome may experience difficulty with feeding and swallowing. Many individuals with Down syndrome have anatomical and structural differences that predispose them to potential feeding difficulty (Van Dyke, Peterson, & Hoffman, 1990). Swallowing difficulties may lead to aspiration. Radiographic studies (modified barium swallow studies) have shown individuals with Down syndrome to have abnormalities in various stages of a swallow (Cooper-Brown et al., 2008). Aspiration of a bolus, food or liquid that has been swallowed, can potentially lead to pneumonia and result in frequent hospitalizations, or if left untreated, death.

The American Speech-Language-Hearing Association [ASHA], the governing body for nationally certified speech-language pathologists, details the scope of practice under which speech-language pathologists may evaluate and treat an individual with communication disorders. ASHA states that speech-language pathologists may address typical and atypical communication and swallowing in the following areas: speech sound production, resonance, voice, fluency, language (reception and expression), cognition, and feeding and swallowing (ASHA, 2007). As such, children with Down syndrome may be evaluated and treated by a speech-language pathologist to address deficits related to speech/language and feeding and swallowing disorders. Feeding and swallowing difficulties are documented in the population of children with Down syndrome. The ability of a speech-language pathologist to make recommendations regarding the management of feeding and swallowing disorders in infants with Down syndrome is of great importance (Lewis & Kritizinger, 2004).

It is critical that the families (i.e. parents/caregivers) of children with Down syndrome be provided with specific information and referrals related to Down syndrome and speech-language pathology. As information is more readily accessible via technology, professionals, especially those in the field of speech-language pathology, must continually analyze and assess the delivery and quality of information and referrals received by parents/caregivers and their satisfaction with those resources. Lawson, Carlson, and Shynkaruk (2012) found that information provided to pregnant women does not appear to provide a complete and overall portrayal of Down syndrome.

Little, if any, literature exists to determine if parents/caregivers are satisfied with the information and referrals they receive related to speech-language pathology services for children with Down syndrome.

Skotko (2005), conducted a research study that assessed the satisfaction of mothers who received a diagnosis of Down syndrome for their infant. Of the total 1126 surveys that were returned, 141 indicated they received a prenatal diagnosis. These respondents further indicated they were satisfied with the care received; however, concerns related to the way in which a diagnosis was provided and the types of information and referrals were provided were among the most frequent suggestions. Research is limited in its review of what types of information is provided to parents/caregivers, as well as when information related to specific needs for children with Down syndrome should be provided. Speech-language pathologists must provide appropriate and current information to provide the best recommendations for parents/caregivers. Sheets, Best, Brasington, and Will (2011), concluded that healthcare providers should include clinical features, developmental abilities, a range of prognostications, and informational resources related to Down syndrome at the time of initial diagnosis, to specifically include,

“medical complications that require immediate intervention, prognosis regarding intellectual abilities and available therapies” (p. 1256).

In light of the need to determine what information is provided to families of newly diagnosed children with DS related to speech-language pathology services, the lack of investigation regarding when and what information is provided to families regarding potential communication and feeding needs for children with DS, and the importance of early intervention following the provision of a diagnosis, this study was designed to assess parent/caregiver knowledge and satisfaction of the information and referrals received related to speech-language pathology services for their children with Down syndrome. In addition, the study attempted to identify the type of information received, as well as, what and when information and referrals are provided specifically related to speech-language pathology services. Specific questions for this study’s investigation included:

1. When do parents of children with Down syndrome receive information and referrals specific to speech-language services?
2. What information and referrals do parents of children with Down syndrome receive when they receive a diagnosis of Down syndrome?
3. What is the overall satisfaction of parents and caregivers regarding information and referrals provided to them regarding speech-language pathology services for their child with Down syndrome?

CHAPTER THREE: METHODOLOGY

Overview

This study is an analysis of parent/caregiver responses to a survey related to the knowledge and satisfaction of information and referrals received by parents/caregivers of children with DS specifically related to speech-language pathology services. This survey examined the responses of parents/caregivers of children with DS to determine: (1) the overall satisfaction of parents/caregivers related to information and referrals regarding DS and speech-language pathology services; (2) what specific information was included in the information and referrals provided to parents/caregivers of children with DS; and (3) when the information and referrals were provided to parents/caregivers.

This study was approved by the University of Kentucky Institutional Review Board [IRB], which reviewed all components of this study, as well as the additional documentation submitted to modify the existing application and extend the survey deadline. A copy of the IRB documentation is included in Appendix A.

An undergraduate research assistant, Sarah J. Haynes, was recruited to assist in the development of the online survey and analysis of the data set (quantitative and qualitative sets).

Survey Instrumentation

A 35 question survey was developed by the principal investigator [PI], henceforth referred to as investigator, to be distributed to parents/caregivers of children with Down syndrome to assess their *satisfaction* with information and referrals received regarding speech-language pathology services for children with DS; *what* specific information was included in the information and referrals provided; and *when* the information and referrals were received

regarding DS and speech-language pathology services. The survey was divided into five distinct sections: (1) Background Information, (2) If you learned your child's diagnosis before birth, (3) If you learned your child's diagnosis at/following birth, (4) Information regarding speech-language pathology services, and (5) Receiving information regarding speech/language services. A section for additional comments was provided at the conclusion of the survey to allow respondents the opportunity to provide any other additional information they wanted to provide. A copy of the survey instrument is located with the IRB documentation included in Appendix B.

A letter to participants, outlining the purpose of the study and procedures related to the study, and a participant recruitment flyer were developed by the investigator to assist in the recruitment of study participants. The letter to participants was developed and then submitted to the IRB as supplemental documentation to be used in the recruitment of participants. The participant recruitment flyer was submitted to Kristi Lopez, Director of the University of Kentucky Medical Center Public Relations Department for approval. Following minor revisions, the participant recruitment flyer was approved for distribution to the participating Down syndrome associations in order for the distribution of the information to members. A copy of the letter to participants and participant recruitment flyer are located with the IRB documentation included in Appendices C and D.

Criteria for inclusion in the study were: (1) the respondent must be the parent/caregiver of a child with DS, and (2) over the age of 20 years old.

Distribution of the Survey

The online survey instrument, Qualtrics, licensed product of the University of Kentucky, was used to develop and distribute the online survey while hard-copy forms of the survey, letter

to participants, and participant recruitment flyers were provided to each of the participating Down syndrome associations in Kentucky and the Down Syndrome Association of Greater Cincinnati, located in Cincinnati, Ohio.

The letter to participants and participant recruitment flyer outlines what the research study was investigating as well as how to access the survey, either electronically or in hard-copy form. Documentation was disseminated through the local Down syndrome associations in the state of Kentucky and the local Down syndrome association in the Greater Cincinnati area. The participating Down syndrome associations were: the Down Syndrome Association of Central Kentucky [DSACK], the Down Syndrome of Louisville [DSL], the Down Syndrome Association of Western Kentucky [DSAWK], the Green River Area Down Syndrome Association [GRADSA], the Down Syndrome of South Central Kentucky [DSSCK], and the Down Syndrome Association of Greater Cincinnati [DSAGC]. Each association was contacted by both telecommunication and e-mail by the investigator following IRB approval. Electronic copies of both the letter to participants and participant recruitment flyer were provided to each contact at the associations for review (see Appendices B and C).

Following correspondence with each Down syndrome association and acceptance of participation in the study, each association was provided with electronic and hard-copy forms of supporting documentation for the research study. Survey packets were compiled prior to forwarding hard-copy forms which included a pre-addressed/stamped envelope, a letter to the participant, and a participant recruitment flyer. An additional set of participant recruitment flyers (10) were provided to aid in the recruitment of participants. The Down Syndrome of South Central Kentucky did not respond to investigator communication; however, several survey respondents reported their association with the DSSCK. The investigator attempted

communication with the DSSCK prior to mailing hard-copy forms to the association with no success. Nevertheless, the investigator, making the assumption that the information was disseminated by the association, shipped hard-copy packets to the association.

Postage for the pre-addressed envelopes was purchased at the United States Postal Service [USPS] in which an individual survey packet was weighed to determine the amount of postage required for return to the investigator. Return postage for each envelope was determined to be \$1.19/envelope. The DSACK, DSL, DSSCK, and DSAGC were provided with six complete survey packets and ten additional participant recruitment flyers which were mailed via the USPS in flat rate shipping envelopes for a total of \$5.75/package. The DSAWK was provided with eight complete survey packets and ten additional participant recruitment flyers which were mailed via USPS in a flat rate shipping envelope for a total of \$5.75/envelope. Complete survey packets were not provided to the GRADSA as it was requested by the GRADSA contact that the investigator directly mail survey packets to possible respondents. To ensure the anonymity of the respondent, survey packets and additional participant recruitment flyers were not provided. Detailed contact and shipping information is provided in Appendix E.

Three weeks following initial correspondence with the various Down syndrome associations, an additional e-mail was sent to each contact at the various Down syndrome associations to request participant recruitment materials be again disseminated to members of each of the associations. Participating Down syndrome associations disseminated the participant recruitment materials via electronic media utilized by the association (i.e. e-mail correspondence, social media sites, association websites) and word of mouth. Members of the Down syndrome associations were encouraged to share the information with friends/family that may be interested in participating in the survey.

Data Set

The data set was comprised of responses of up to 35 survey questions and included the following: demographic information of the respondents and their dependent with DS, information regarding the time of diagnosis (prenatally or postnatally), information regarding when the parents/caregiver received information about DS, and when the parent/caregiver received referrals for intervention. Additionally, the respondent was invited to provide narrative remarks to indicate what information the parent/caregiver believes should be provided to new parents/caregivers regarding the need for speech-language services and how professionals can better provide new parents/caregivers with specific information related to speech-language pathology services. Responses to specific questions, such as “Did you receive a prenatal diagnosis?” directed the respondent to a select set of questions pertaining to information related to a prenatal diagnosis, if answered ‘yes’. However, if a respondent answered ‘no’, the respondent was directed to another set of questions pertaining to the receipt of a postnatal diagnosis of Down syndrome.

The total number of respondents to the survey was twenty-three. Fifteen responses were received via the online survey instrument, Qualtrics, while eight surveys were returned as hard-copies. Survey participants were given the option to skip questions if they did not wish to provide a response to a given question; therefore, every question may not reflect all twenty survey participants.

Data Analysis

Data were analyzed both quantitatively and qualitatively. Quantitative data included responses to demographic questions, multiple choice questions, and yes/no questions. Some

multiple choice questions allowed for the respondent to select more than one of the choices provided in the question.

Quantitative data were analyzed using frequency counts and percentages. The total number of responses was calculated for every question answered on the surveys. The number of respondents, and their responses to a given question were recorded on a Microsoft Word Excel Spreadsheet, developed by the investigator. The frequency count for a given response was then divided by the total number of respondents per question to determine a simple percentage. Qualitative data were recorded by the investigator and a trained assistant. Narrative remarks and responses were then placed on an excel spreadsheet, and were reviewed by the investigator. The investigator then identified recurring themes found in the narrative remarks and responses to the qualitative questions, which were then developed into theme categories. The narrative remarks and responses were then sorted into the developed categories. A frequency count was conducted to determine the frequency of occurrence across respondent responses for each theme identified.

Reliability for Qualitative Analysis

A second reviewer was trained to identify the categories and themes identified by the investigator as described above. The trained second reviewer was asked to review each of the narrative remarks and responses provided by survey respondents and sort the remarks and responses into the most appropriate identified category(s) for the identified themes. Agreement between the investigator and the second reviewer was then calculated to determine inter-rater reliability. Initial inter-rater reliability was 87.8%. The investigator and second reviewer then discussed each narrative remark and response identified in each selected theme category and came to a consensus on any disputed items until 100% agreement was achieved.

CHAPTER FOUR: RESULTS

Results of this research study are described below. The following results reflect both the quantitative and qualitative analysis of responses provided by each survey respondent.

Number of Responses

The total number of surveys obtained was twenty-three; fifteen of which were collected via Qualtrics, and eight were returned as hard-copies. Eighteen surveys were reported to have been started electronically; however, three survey participants did not complete the survey. Consequently, the results reported here are based on the fifteen completed electronic surveys. While all survey responses that were collected were analyzed, if a survey respondent did not provide a response to a given question, responses to each question may not reflect all twenty-three participants per survey question.

Quantitative Analysis

Respondent demographics.

Demographic information of survey participants is displayed in Table 4.1 and Figures 4.1 and 4.2. Demographic information for all of the respondents included information on the survey respondent's relation to the dependent (child with Down syndrome), age of both the survey respondent and dependent, affiliation with a local Down syndrome association, location of residence, either urban or rural, and gender of the dependent. Twenty-three out of twenty-three respondents provided an answer to the following questions in the demographic information portion of this survey: relation to child, approximate age of respondent, state of residence, affiliation with a Down syndrome association, and age of dependent (child with Down

syndrome). Twenty of twenty three total respondents indicated whether they lived in an urban or rural area and twenty-two of twenty-three indicated the gender of their dependent. Survey participants included twenty mothers (87%), two fathers (9.0%), and one grandparent (4.3%). Of the twenty-three survey respondents, twenty-one (91.3%) reported to reside within the state of Kentucky and two (9.0%) reported to reside within the state of Ohio. The majority of respondents, twenty (87%) reported themselves to be affiliated with a Down syndrome association within the state of Kentucky, while three (13.0%) reported themselves to be affiliated with the DSAGC located in Cincinnati, Ohio. Specifically for those participants affiliated with a Down syndrome association in Kentucky, eight (34.8%) participants were affiliated with the Down Syndrome Association of Central Kentucky, seven (30%) were reported to be affiliated with the Down Syndrome of South Central Kentucky, and five (21.7%) reported affiliation with the Down Syndrome Association of Western Kentucky.

The average age of a dependent was 8.34 years. However, a wide span of ages in dependents was reported, ranging from one year to twenty-two years of age; twelve (54.5%) dependents were reported to be male, while ten (45.5%) were reported to be female. Similarly, a wide span of age in survey respondents was reported, ranging from 20-30 years to 50-60 years of age. The most frequently occurring age range of respondents was reported as being 40-50 years of age, with eleven of the total number of participants, or 61% of total respondents in that age range.

Slightly over half, thirteen (56.5%), of the respondents reported themselves to reside in an urban area. The remaining ten respondents, equivalent to 39.1%, identified their location of residence to be a rural area.

Prenatal diagnosis.

Table 4.2 and Figures 4.3, 4.4, and 4.5 display the total number of individuals who did or did not receive a prenatal diagnosis of Down syndrome and the responses to each of the questions contained within the respective section of the survey for those respondents who received a prenatal diagnosis. Of the total number of survey participants (23), four (17.4%) reported the receipt of a prenatal diagnosis of DS. A prenatal diagnosis of DS can be determined during either the first, second, or third trimester of pregnancy. One of the four (25%) who received a prenatal diagnosis indicated having received a prenatal diagnosis during the first trimester of pregnancy. Two of the four respondents (50%) reported to have received a diagnosis of DS during the second trimester of pregnancy. The remaining respondent reportedly received a prenatal diagnosis during the third trimester of pregnancy.

Three, 75%, of the total respondents (4) who received a prenatal diagnosis indicated they received information about DS at the time of diagnosis while one, 25%, respondent did not receive any information regarding the syndrome. Only one respondent, 25% of respondents, reported the receipt of information *specific to the needs* of an individual with DS. General information regarding DS was provided to each of the four respondents (100%); however, information regarding early intervention services (e.g., First Steps) was provided to only one respondent at the time of diagnosis. Of the information provided regarding early intervention services, two respondents (50%), reported to have received information regarding First Steps, a statewide early intervention system that provides services to children with developmental disabilities from birth to 3 years and their families, prior to the birth of their child (Kentucky Cabinet for Health and Family Services, 2015). Information specific to (re)habilitation services

(speech-language pathology, physical therapy, and occupational therapy) was not provided to any of the respondents in the information received regarding DS.

As a prenatal diagnosis occurs prior to birth during any of the three trimesters of pregnancy, the receipt of information may vary from one individual to another, in which varied amounts of time exists between the receipt of a diagnosis and the birth of a child. One respondent (25%), received information regarding DS within 24 hours of receiving a diagnosis while two survey respondents (50%) reported to have received information within one week of receiving a prenatal diagnosis. The remaining respondent could not recall the approximate length of time that lapsed from receiving a diagnosis of DS to the receipt of information. Various sources were reported to have provided information regarding Down syndrome to parents/caregivers. Two respondents (50%) reported they received information about DS from a genetic counselor. Additionally, two respondents indicated they received information from friends. Only one respondent (25%) indicated receiving information from a hospital staff member. Despite the limited sources reported to have provided information to the parents/caregivers, overall, three of the total number of respondents who received a prenatal diagnosis (75%) felt they were equipped and prepared to access services for their child due to the length of time between the diagnosis of DS and the birth of their child.

Postnatal diagnosis.

Nineteen of the twenty-three total respondents did not receive a prenatal diagnosis; instead, they received a postnatal diagnosis of DS. The responses of those survey respondents who responded to questions pertaining to a postnatal diagnosis and their responses are displayed in Table 4.3 and Figures 4.6, 4.7, and 4.8.

As previously stated, the amount of time that lapses between receiving a diagnosis of DS and the birth of a child varies from individual to individual. Similarly, the amount of time that elapses between receiving a postnatal diagnosis of Down syndrome and the receipt of information about Down syndrome varies as well. Nineteen of the twenty-three respondents answered questions seventeen and eighteen, which requested that the survey respondent indicate the approximate length of time that elapsed from receiving a diagnosis of DS to the time they received information about the syndrome, and if they received information for services specific to the needs of a child with DS at the of the birth of their child. Results pertaining to the approximate length of time that elapsed from receiving a diagnosis of DS and receiving information about DS are as follows: (1) within 24 hours, eight of nineteen (42.1%), (2) within 72 hours, six of nineteen (31.6%), (3) within 1 week, one of nineteen (5.3%), (4) within 1 month, one of nineteen (5.3%), (5) other, two of nineteen (10.5%), and (6) cannot recall, one of nineteen (5.3%). Most respondents (83.3 % or 15 total) who received information about DS only received *general information* about the syndrome. Slightly under half, eight (42.1%), respondents reported that they did not receive information *specifically related to the needs* of children with Down syndrome. Eighteen of the twenty-three respondents provided a response to indicate the type of information they received about DS. Only one respondent, 5.6% of total respondents, reported to have received information specific to physical therapy, while twelve (66.7%) respondents reported they received information regarding early intervention services (e.g., First Steps). Four respondents indicated that they received additional forms/types of information (i.e., a packet of information from a Down syndrome association, information for a local support group, or medical/healthcare related information). Only twelve of the nineteen respondents (63%) reported that they received information regarding early intervention services. Fourteen of

the nineteen respondents (74%) who specified which early intervention program they were informed about, indicated that they received information regarding First Steps, Kentucky's state funded early intervention program, and Help Me Grow, Ohio's state funded early intervention program.

Eighteen respondents provided responses regarding who provided information related to Down syndrome following a postnatal diagnosis. Nine, or 50%, of survey respondents indicated that the main source for providing information was a pediatrician. Other sources of information were provided by social workers (38.9%), genetic counselors (16.7%), nurses (27.8%), local Down syndrome associations (16.7%), self-researched (16.7%), friends (5.6%), or via alternative sources (e.g., neonatologist, First Steps, or hospital referrals).

Finally, eighteen of the nineteen respondents (94.7%), who received a postnatal diagnosis provided a response to indicate if they did or did not feel they were equipped and prepared to access services for their child following a diagnosis of Down syndrome. The majority of respondents, 66.7%, equivalent to twelve survey respondents, felt they were equipped and prepared to access services for their child; three of these respondents, 16.7%, indicated that they independently sought out information related to Down syndrome. Six respondents (33.33%), reported that they did not feel they were equipped and prepared to access services for their child following a diagnosis of Down syndrome.

Information regarding speech-language pathology services.

Table 4.4 and Figures 4.9, 4.10, 4.11, 4.12, 4.13, 4.14, and 4.15 display the total number of respondents that provided responses to questions pertaining to information regarding speech-language pathology services. Seventeen of the twenty-three respondents, 73.9%, reported they

did not receive information regarding speech-language pathology services. The remaining six respondents, 26.1%, reported that they did receive information specific to speech-language pathology services. Nine of the full twenty-three respondents, 39.1%, provided a response to indicate which areas of speech-language pathology services were addressed in the information they received.

Of the nine respondents who indicated they received information regarding speech-language pathology services, survey respondents were given the option to select the following: 1) information about speech/language, 2) information about feeding and swallowing, or the option to indicate both areas. Two respondents, 22.2%, indicated they received information about speech/language, while two different respondents indicated they received information about feeding and swallowing. The remaining three respondents, less than half, 33.3%, indicated that they received information about *both* speech/language and feeding and swallowing.

In regards to when information on speech and language services was received, all twenty-three respondents indicated when they received information related to speech/language and feeding services for children with DS at some point. A small percentage of respondents (8.7%, equal to two responses) received information specific to speech/language services prior to being discharged home from the hospital. Less than half of respondents (43.5%, equal to 10 respondents) indicated that they received information within 1 week (13.0% of respondents) or within 1 month (30.4% of respondents) of the birth of their child. Eleven respondents (47.1%) indicated that the information specifically related to speech-language pathology services was provided *later* than one month following the birth of a child with Down syndrome and three respondents reported that they did not receive information prior to the age of one.

Next, respondents were asked to indicate in what form of media that the information regarding speech/language services was presented. Twenty-two respondents provided a response to this question. A large number of respondents (thirteen, 56.5%) received the information from a medical/other professional, which was not otherwise specified. Printed materials were provided to eight respondents (34.8%). Of these printed materials, respondents were asked to report whether that information was presented in the form of a pamphlet, book, or other. Five respondents, 62.5%, indicated the information they received was in the form of a pamphlet, while an additional 25% received information through First Steps and an information packet provided by a local Down syndrome association. Three respondents, 37.5%, indicated the printed information received was presented as a book. Thirteen respondents, 56.5%, indicated that the information was presented by a medical or other professional. A small percentage of respondents, 13.0%, three respondents, received information via a telephone call from a parent affiliated with a local Down syndrome association; two (8.7%) of which received a personal visit from a parent with information from a local Down syndrome association. Only one respondent, (4.3% of the total respondents) received a personal visit from a speech-language pathologist. However, when asked to indicate the professional/peer who provided the information specific to speech-language pathology services, none of the twenty-three respondents indicated that the information was received from a speech-language pathologist (despite the one respondent who indicated the information was presented via a personal visit from a speech-language pathologist). Of the eight respondents who indicated 'other' as the source of information received, seven respondents (34.8%) received the information from First Steps. Six respondents, 26.1%, indicated they received information from a pediatrician, and, five respondents, 21.7%, independently sought out information regarding speech-language pathology services. Additional

sources of information were provided as follows: nurse, three of twenty-three (13.0%), genetic counselors, three of twenty-three (13.0%), local Down syndrome association, five of twenty-three (21.7%), social worker, one of twenty-three (4.3%), family, one of twenty-three (4.3%), and friends, one of twenty-three (4.3%).

Respondents were then requested to rate their overall satisfaction with the information they received regarding speech-language pathology services for children with DS using a Likert scale, where 1 indicated they were not at all satisfied and 5 indicated they were very satisfied. All twenty-three respondents provided a rating for the information they received. Seventeen respondents, equivalent to 73.9%, reported that they would rate the information they received as a '1' (13.04%- 3 respondents), '2' (26.1%- 6 respondents), or '3' (38%- 8 respondents). Only three, 13.0%, respondents indicated that they were very satisfied with the information they received specifically related to speech-language pathology services.

The point in which a referral for speech-language pathology services is received is critical to the overall satisfaction of parents/caregivers regarding speech-language pathology services. Twenty-three responses were recorded for the analysis regarding the time at which a referral for speech-language pathology services was received. A significant percentage of respondents, eleven (47.8%) indicated they received a referral for speech/language services within 6-12 months after the birth of their child. Five respondents, 21.7%, reported they received a referral between the ages of two and five. A total of six respondents, 26.1%, received a referral within the first six months following the birth of a child with Down syndrome. One respondent, 4.3%, reported that they never received a referral for speech-language pathology services. Twenty-two total responses were recorded to determine who provided the referral for speech-language pathology services. Referrals were provided predominantly by early

interventionists and pediatricians, as indicated by twenty respondents, 87% (56.5%- Early Interventionist and 30.4%- Pediatricians). Referrals from a local Down syndrome association (three responses or 13.0%) and First Steps (2 responses or 8.7%) were also indicated in the results. Four respondents, 17.4%, independently researched information regarding a referral for speech-language pathology services. No respondent indicated that a referral was provided by a speech-language pathologist for services.

Twenty-two respondents provided the age at which their child began receiving speech-language pathology services. A significant number of respondents, 45.5%, equivalent to ten respondents, indicated their child began receiving services between the ages of 6-12 months. For six respondents, 27.3%, speech-language pathology services began within the first six months after birth. Three respondents, 16.7%, reported their children began receiving services between the ages of two and five years of age.

Finally, survey respondents were asked to utilize a Likert scale to indicate to what degree the information they received regarding speech/language needs for children with Down syndrome assisted in the advocating for appropriate services for their children, where '1' indicated not at all helpful and '5' indicated very helpful. Twenty-two of the twenty-three total survey respondents indicated a satisfaction rating regarding the referral for speech-language pathology services. Only eight respondents, 36.4%, indicated that the information provided was helpful in their advocating for speech/language services; seven respondents, (31.8%) indicated 4 on the Likert scale while one (4.3%) respondent indicated a 5 on the scale. The remaining respondents specified '1' (18.2%- 4 respondents), '2' (22.7%- 5 respondents), or '3' (22.7%- five respondents) for a total of 63.6% of respondents who indicated the information they received did not assist advocating for services for their child.

Qualitative Analysis

Respondents were both requested and invited to provide a response to a single multiple choice question and open-ended questions to convey the point at which they feel parents/caregivers should receive information regarding the needs for speech-language pathology services for children with DS and what information should be included and how that information should be conveyed. Narrative remarks and responses were analyzed for shared themes and content. Each comment was reviewed individually and then all comments were analyzed for recurring themes. A total of twenty-one respondents provided narrative remarks and responses to determine recurring themes for the question: *‘What information do you think should be provided to new parents regarding the need for speech/language services for children with Down syndrome?’*. Twenty survey respondents also provided responses to the following question: *‘How could professionals better provide new parents with specific information related to speech-language pathology services for children with Down syndrome?’*. Finally, at the conclusion of the survey, respondents were also invited to provide any additional comments related to the content of the survey.

Themes from responses receiving information on speech-language pathology services.

Table 4.5 and Figures 4.16, 4.17, and 4.18 display the analysis of information regarding the time at which survey respondents feel parents/caregivers should receive information regarding speech-language services for children with Down syndrome and the recurring themes that emerged following the analysis of narrative remarks and responses.

Twenty-two responses were recorded to determine the time at which parents/caregivers believe new parents/caregivers of children with Down syndrome should receive information

about Down syndrome regarding speech-language pathology services. Ten respondents (45.5%), indicated that parents should receive information about speech-language pathology services at the time of the initial diagnosis of Down syndrome, either prenatally or postnatally. Six respondents selected 'other' as a response to when the information should be provided to new parents/caregivers. These six respondents reported that parents should receive the information at the time of the initial diagnosis or within the first month postnatally, unless feeding/swallowing issues necessitated the immediate need for speech-language pathology services following the birth of their child. Eighteen of the twenty-two respondents indicated that information should be received at the time of diagnosis up to one month postnatally is 18 of the 22 respondents which is equivalent to 82% of the total number of respondents.

Following the analysis of each set of narrative remarks and responses, four primary themes emerged from the analysis of the narrative remarks and responses provided by survey respondents. Most notably, survey respondents indicated the need for increased information related to available services (i.e., First Steps, in-home treatment options, etc.) and counseling. The second and third most frequently occurring themes were the increased need for provision of information pertaining to the scope of practice of speech-language pathologists to include their expertise for feeding/swallowing issues and treatment and the need for increased early intervention services (including the establishment of a communication system and implementation of therapy during early development). The fourth and final theme that emerged was the need for increased support group(s)/system(s) for parents/caregivers of children with Down syndrome.

During the analysis of the survey question, *'What information do you think should be provided to new parents regarding the need for speech/language services for children with*

Down syndrome?” survey respondents did not include suggestions for specific information that should be included when providing information to new parents. However, the two most commonly occurring themes were: (1) the need for to provide increased information related to available services and counseling, and (2) the need for the provision of information pertaining to the scope of practice of speech-language pathologists to include their expertise for feeding/swallowing issues and intervention. Eleven of the twenty responses, 52.4%, commented on the need for increased information related to the available services and counseling. Eight of the eleven narrative responses (72%) addressed the need to provide information as to what services are available and/or are necessary for a child with Down syndrome and the need for information regarding general developmental milestones, as well as basic information regarding common communication deficits for children with Down syndrome. Nine of the twenty respondents (42.9%) indicated the need to provide information regarding feeding and swallowing, in which nine (47.4%) of the nineteen respondents, cited concern that the majority of parents/caregivers are unaware that speech-language pathologists are qualified to assess and treat feeding/swallowing disorders. Multiple respondents commented that they were unaware speech-language pathologists were qualified to address issues related to feeding and swallowing disorders. Other remarks and responses also indicated the increased need to provide information about feeding/swallowing services available for the treatment of these disorders. Six respondents, 28.6%, noted concern regarding the need for increased early intervention services; while one respondent, 4.8%, also indicated that parents/caregivers should be provided with information about support group(s)/system(s) for parents/caregivers of children with DS.

The four primary themes, previously stated, were also identified in remarks and responses to the question: *‘How could professionals better provide new parents with specific information*

related to speech-language pathology services for children with Down syndrome?': the need for increased information regarding available services and counseling, the need for increased early intervention services, the need for provision of information pertaining to the scope of practice of speech-language pathologists to include their expertise for feeding/swallowing issues and treatment, and the need for increased support group(s)/system(s), with the most prevalent being the increased need for providing information regarding available services and counseling.

Again, survey respondents did not provide any specific information as to how information should be provided to new parents of children with DS. However, thirteen of the twenty respondents, 65%, reported that professionals could better provide information to new parents by providing specific information regarding available services for children with DS, both printed and orally, and via face-to-face communication. Two themes both occurred in 25% of responses, equivalent to five respondents per theme, which were the increased need for information regarding early intervention services and the need for information pertaining to the scope of practice of speech-language pathologists. One respondent stated, 'I had no idea that a speech therapist worked with feeding issues,' while another reported that information regarding speech-language pathology services need be 'provid(ed) earlier, and more frequently.' One survey respondent cited their concern regarding delayed early intervention services, while another referenced concerns that many children with DS are not treated using individualized treatment plans. The final theme that was identified in two (10%) respondents' remarks and responses was the need for information regarding support group(s)/system(s) for parents/caregivers of children with DS.

Open response.

Table 4.6 displays the analysis of the open responses remarks that were provided by the four survey respondents. Four narrative remarks and responses were provided in the ‘Additional Comments’ portion of the survey. Three of the primary themes were identified in the analysis of the narrative remarks and responses. As in the previous analysis of remarks and responses, the need for increased information related to available services and counseling is at the forefront of concerns for parents/caregivers of children with DS; two respondents, 50%, narrative responses included cited this as a need when receiving information about speech-language pathology services. The remaining themes that were identified were: 1) the need for increased early intervention services and 2) the need for the provision of information related to the scope of practice of speech-language pathologists. Each of these themes was identified for 25% (one of four) of the remarks and responses provided by the survey respondent.

Table 4.1 Demographic information of survey respondents

<i>Demographic Information</i>								
								Total # Respondents/Question
Question 1	Mother	Father	Grandparent	Caregiver				
	20 (86.95%)	2 (8.69%)	1 (4.34%)	0				23
Question 2	20-30 years	30-40 years	40-50 years	50-60 years	60+ years			
	2 (8.69%)	7 (30.43%)	11 (47.82%)	3 (13.07%)	0			23
Question 3	Kentucky	Other						
	21 (91.30%)	2 (8.96%)						23
Question 4	DSACK	DSL	DSSCK	GRADSA	DSAWK	DSAGC	NA	
	8 (34.78%)	0	7 (30.43%)	0	5 (21.73%)	3 (13.04%)	0	23
Question 5	Urban Area	Rural Area						
	13 (65%)	9 (39.13%)						20
Question 6	Male	Female						
	12 (54.54%)	10 (45.45%)						22
Question 7	Age 1: 1 (4.34%)	Age 2: 5 (21.73%)	Age 3: 2 (8.69%)	Age 4: 1 (4.34%)	Age 5: 1 (4.34%)	Age 6: 1 (4.34%)	Age 7: 2 (8.69%)	Average Age: 8.34 years
	Age 8: 1 (4.34%)	Age 9: 1 (4.34%)	Age 12: 3 (13.04%)	Age 14: 1 (4.34%)	Age 18: 2 (8.69%)	Age 19: 1 (4.34%)	Age 22: 1 (4.34%)	23
Acronym Key								
DSACK: Down Syndrome Association of Central Kentucky								
DSL: Down Syndrome of Louisville								
DSSCK: Down Syndrome of South Central Kentucky								
GRADSA: Green River Area Down Syndrome Association								
DSAWK: Ups-N-Downs Down Syndrome Association of Western Kentucky								
DSAGC: The Down Syndrome Association of Greater Cincinnati								
NA: None at this time								

Table 4.2 Prenatal diagnosis

<i>Prenatal Diagnosis</i>													
Question 8	Yes	No											Total # Respondents/Question
	4 (17.39%)	19 (82.60%)											23
Question 9	1st Trimester	2nd Trimester	3rd Trimester										
	1 (25%)	2 (50%)	1 (25%)										4
Question 10	Yes	No											
	3 (75%)	1 (25%)											4
Question 11	Yes	No											
	1 (25%)	3 (75%)											4
Question 12	General Information about Down syndrome	Information specific to speech-language pathology services	Information specific to physical therapy	Information specific to occupational therapy	Information regarding Early Intervention Services (e.g., First Steps)	Other							
	4 (100%)	0	0	0	1 (25%)								4
Question 13	Recurring Response												
	First Steps: 2												2
Question 14	Within 24 hours	Within 72 hours	Within 1 week	Within 1 month	Other	Cannot Recall							
	1 (25%)	0	2 (50%)	0	0	1 (25%)							4
Question 15	OB/GYN	Pediatrician	APRN/PA	Nurse	Social Worker	Genetic Counselor	Family	Friends	Local Down syndrome	Self-researched	Other		
	0	0	0	0	0	2 (50%)	0	2 (50%)	0	0	1 (25%)		4
Question 16	Yes	No											
	3 (75%)	1 (25%)											4
					Key								
					APRN: Advanced Practice Registered Nurse								
					PA: Physician Assistant								

Table 4.3 Postnatal diagnosis

<i>Postnatal Diagnosis</i>												
Question 17	Within 24 hours	Within 72 hours	Within 1 week	Within 1 month	Other	Cannot recall						Total # Respondents/Question
	8 (42.10%)	6 (31.57%)	1 (5.26%)	1 (5.26%)	2 (10.52%)	1 (5.26%)						19
Question 18	Yes	No										
	11 (57.89%)	8 (42.10%)										19
Question 19	General Information about Down syndrome	Information specific to speech-language pathology services	Information specific to physical therapy	Information specific to occupational therapy	Information regarding Early Intervention Services (e.g., First Steps)	Other						
	15 (83.33%)	0	1 (5.55%)	0	12 (66.66%)	4 (22.22%)						18
Question 20	Recurring Responses											
	First Steps- 13 (92.85%)	Help Me Grow- 1 (7.14%)										14
Question 21	OB/GYN	Pediatrician	APRN/PA	Nurse	Social Worker	Genetic Counselor	Family	Friends	Local Down syndrome association	Self-researched	Other	
	0	9 (50%)	0	5 (27.77%)	7 (38.88%)	3 (16.66%)	0	1 (5.55%)	3 (16.66%)	3 (16.66%)	4 (22.22%)	18
Question 22	Yes	No										
	12 (66.66%)	6 (33.33%)										18
					Key							
					APRN: Advanced Practice Registered Nurse							
					PA: Physician Assistant							

Table 4.4 Information related to speech-language pathology services

<i>Information Regarding Speech-Language Pathology Services</i>																	Total # Respondents/Question
Question 23	Yes	No															23
	6 (26.08%)	17 (73.91%)															
Question 24	Information about speech/language	Information about feeding and swallowing	Information about speech/language and feeding and swallowing														9
	2 (22.22%)	4 (44.44%)	3 (33.33%)														
Question 25	Prenatally	At birth	Within 24 hours	Before discharge home from the hospital	Within 1 week	Within 1 month	Later										23
	0	0	0	2 (8.69%)	3 (13.04%)	7 (30.43%)	11 (47.08%)										
Question 26	Internet	Printed Material	i. Pamphlet	ii. Book	iii. Other	Personal visit from a parent with information from a local Down syndrome association	Telephone call from a parent with information from a local Down syndrome association	Medical professional/ other professional	Personal visit from a speech-language pathologist								22
	3 (13.04%)	8 (34.78%)	5 (62.5%)	3 (37.5%)	2 (25%)	2 (8.69%)	3 (13.04%)	13 (56.52%)	1 (4.34%)								
Question 27	Speech-language Pathologist	OB/GYN	Pediatrician	APRN/PA	Nurse	Social Worker	Genetic Counselor	Family	Friends	Local Down syndrome association	Self-researched	Other					23
	0	0	6 (26.08%)	0	3 (13.04%)	1 (4.34%)	3 (13.04%)	1 (4.34%)	1 (4.34%)	5 (21.73%)	5 (21.73%)	8 (34.78%)					
Question 28	1	2	3	4	5												23
	3 (13.04%)	6 (26.08%)	8 (34.78%)	3 (13.04%)	3 (13.04%)												
Question 29	Prenatally	Within a week of the birth of your child	Within a month of the birth of your child	Within 3-6 months after the birth of your child	Within 6-12 months after the birth of your child	By age 2	Within 3-5 years	5+ years	Never								23
	0	0	2 (8.69%)	4 (17.39%)	11 (47.82%)	4 (17.39%)	1 (4.34%)	0	1 (4.34%)								
Question 30	Speech-Language Pathologist	Early Interventionist	OB/GYN	Pediatrician	APRN/PA	Nurse	Social Worker	Genetic Counselor	Family	Friends	Local Down syndrome association	Self-researched	School	Pre-school teacher	Teacher	Other	22
	0	13 (56.52%)	0	7 (30.43%)	0	0	0	0	0	0	3 (13.04%)	4 (17.39%)	0	0	0	2 (8.69%)	
Question 31	Within a week after birth	Within a month after birth	3-6 months	6-12 months	By age 2	3-5 years	5+ years										22
	0	1 (4.54%)	5 (22.72%)	10 (45.45%)	4 (18.18%)	1 (4.54%)	0										
Question 32	1	2	3	4	5												22
	4 (18.18%)	5 (22.72%)	5 (22.72%)	7 (31.81%)	1 (4.54%)												
<div> <div>Key</div> <div>APRN: Advanced Practice Registered Nurse</div> <div>PA: Physician Assistant</div> </div>																	

Table 4.5 Receiving Information Related to Speech-Language Pathology Services

<i>Receiving Information Regarding Speech-Language Pathology Services</i>									
									Total # Respondents/Question
Question 33	At the time of initial diagnosis (prenatally or at birth)	1 month after birth	3 months after birth	6 months after birth	1 year after birth	2 years after birth	3 years after birth	Other	
	10 (45.45%)	2 (9.09%)	3 (13.63%)	0	1 (4.54%)	0	0	6 (27.27%)	22
Question 34	Theme	Need for increased early intervention services (including the establishment of a communication system and implementation of therapy during early development)	Need for provision of information pertaining to the scope of practice of speech-language pathologists to include their expertise for feeding/swallowing issues and intervention	Need for increased information related to available services (i.e. First Steps, in-home treatment options, etc.) and counseling for parents/caregivers	Need for increased support group(s)/system(s) for parents/caregivers of children with Down syndrome				
		6 (28.57%)	9 (42.85%)	11 (52.38%)	1 (4.76%)				21
Question 35	Theme	Need for increased early intervention services (including the establishment of a communication system and implementation of therapy during early development)	Need for provision of information pertaining to the scope of practice of speech-language pathologists to include their expertise for feeding/swallowing issues and intervention	Need for increased information related to available services (i.e. First Steps, in-home treatment options, etc.) and counseling for parents/caregivers	Need for increased support group(s)/system(s) for parents/caregivers of children with Down syndrome				
		5 (25%)	5 (25%)	13 (65%)	2 (10%)				20

Table 4.6, Open response remarks and responses

<i>Open Response Remarks</i>						
						Total #Respondents/Questions
Open Response Remarks	Theme	Need for increased early intervention services (including the establishment of a communication system and implementation of therapy during early development	Need for provision of information pertaining to the scope of practice of speech-language pathologists to include their expertise for feeding/swallowing issues and intervention	Need for increased information related to available services (i.e. First Steps, in-home treatment options, etc.) and counseling for parents/caregivers	Need for increased support group(s)/system(s) for parents/caregivers of children with Down syndrome	
		1 (25%)	1 (25%)	2 (50%)	0	4

Figure 4.1, Parent/Caregiver relation to child

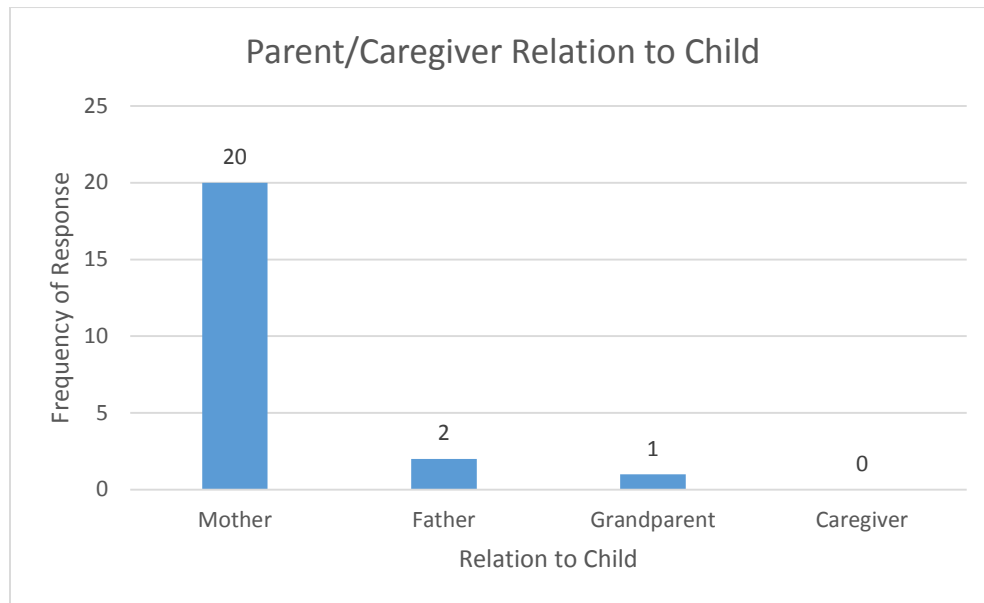


Figure 4.2, Approximate age of Parent/Caregiver

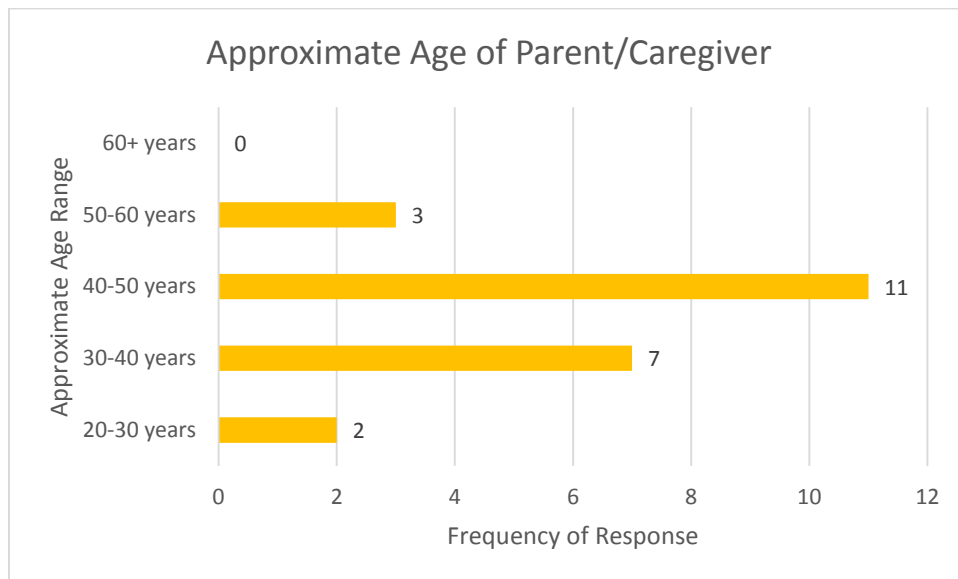


Figure 4.3, Information received regarding DS following *prenatal* diagnosis

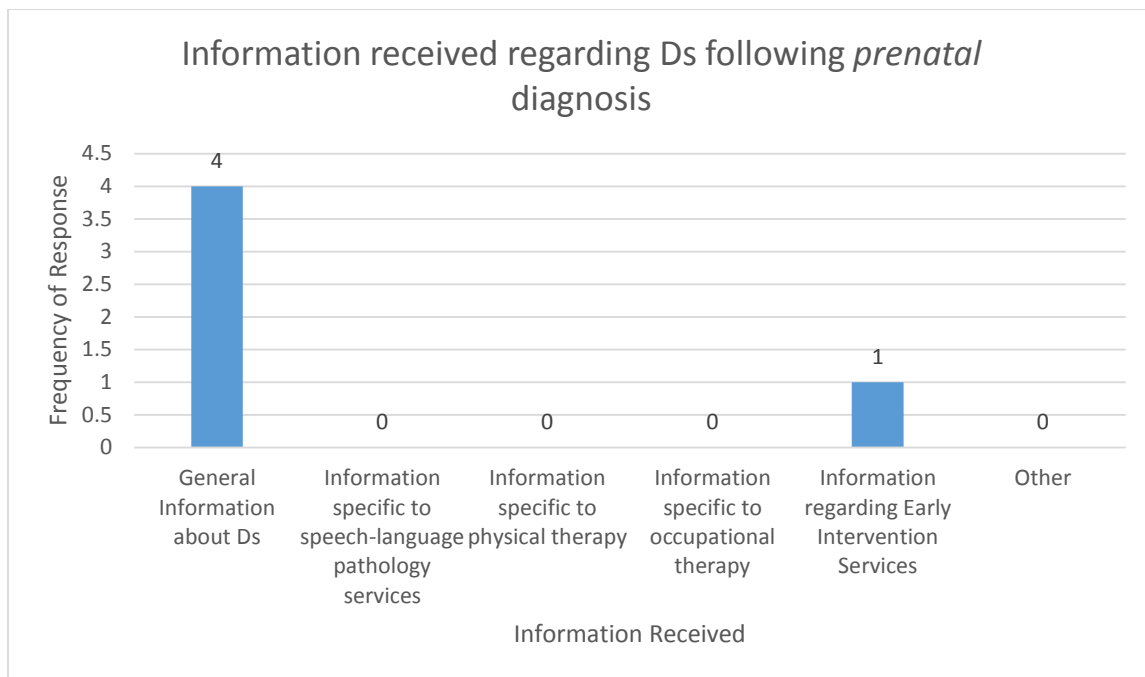


Figure 4.4, Length of time between diagnosis and receipt of information with *prenatal* diagnosis

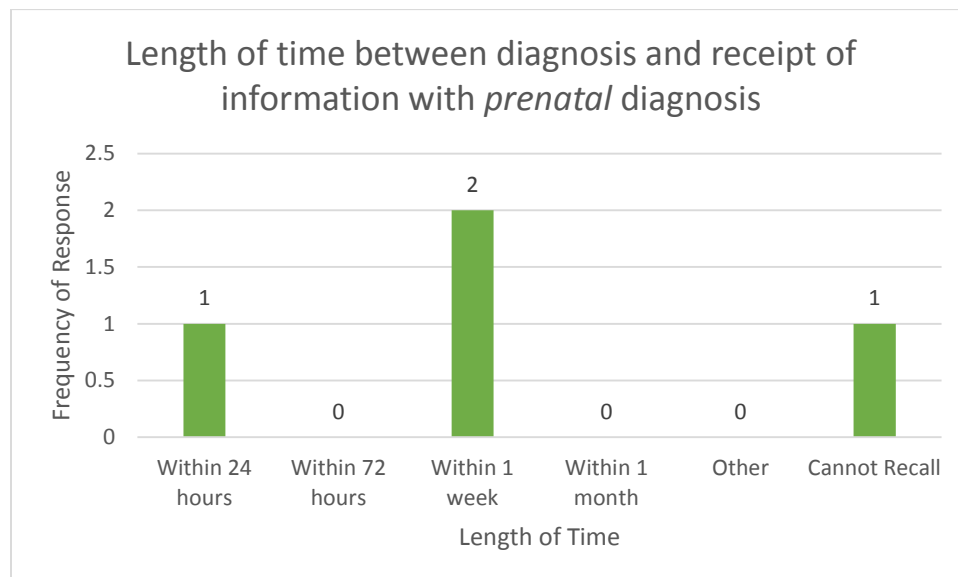


Figure 4.5, ‘Do you feel you were equipped and prepared to access services for your child due to the length of time between the diagnosis of Down syndrome and the birth of your child?’

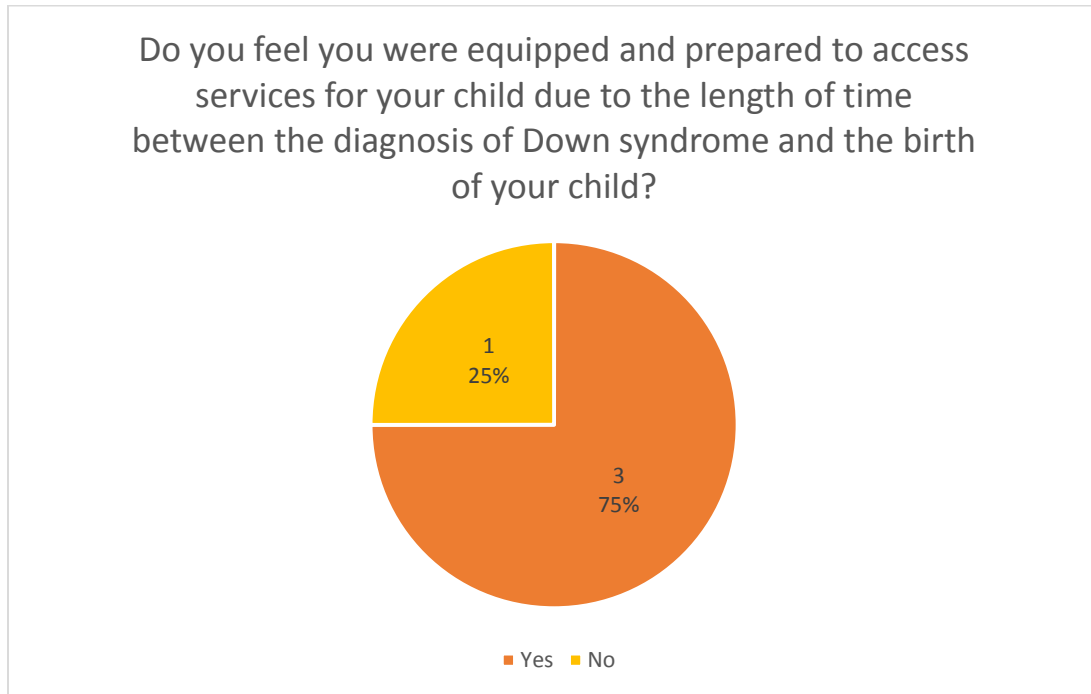


Figure 4.6, Information Received Regarding DS following *postnatal* diagnosis

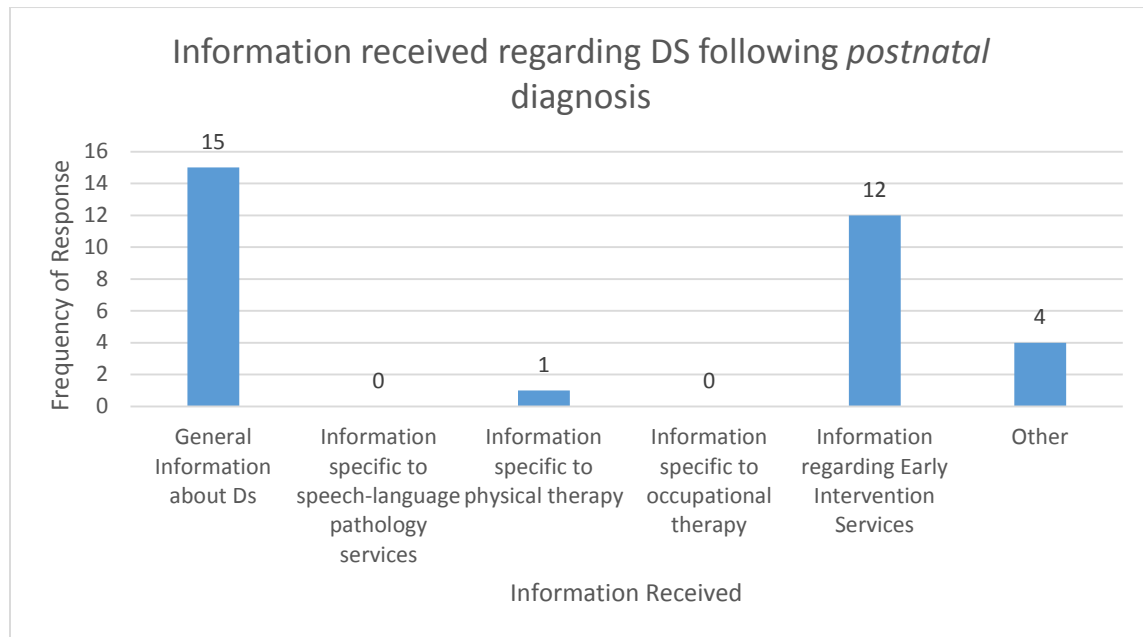


Figure 4.7, Length of time between diagnosis and receipt of information with *postnatal* diagnosis

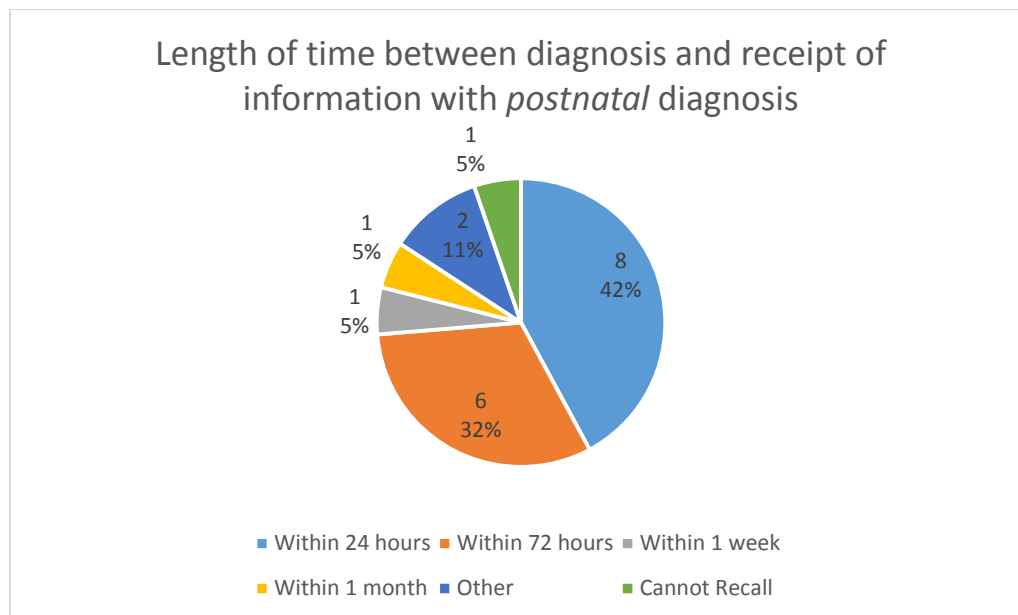


Figure 4.8, ‘Do you feel you were equipped and prepared to access services for your child after receiving information following the birth of your child?’

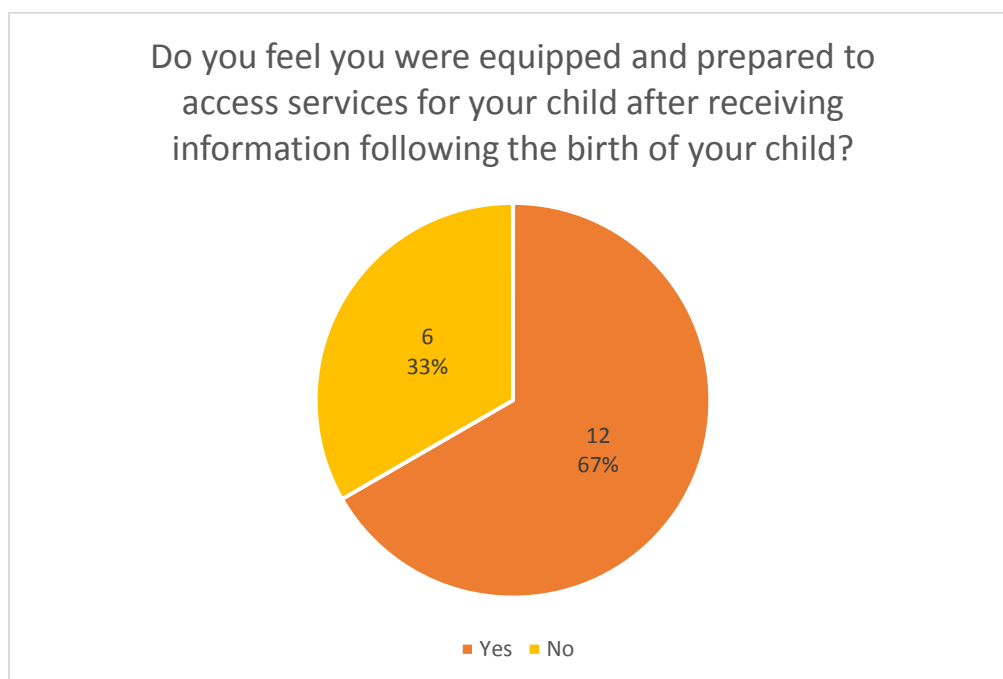


Figure 4.9, Number of respondents that received information specific to speech-language pathology services

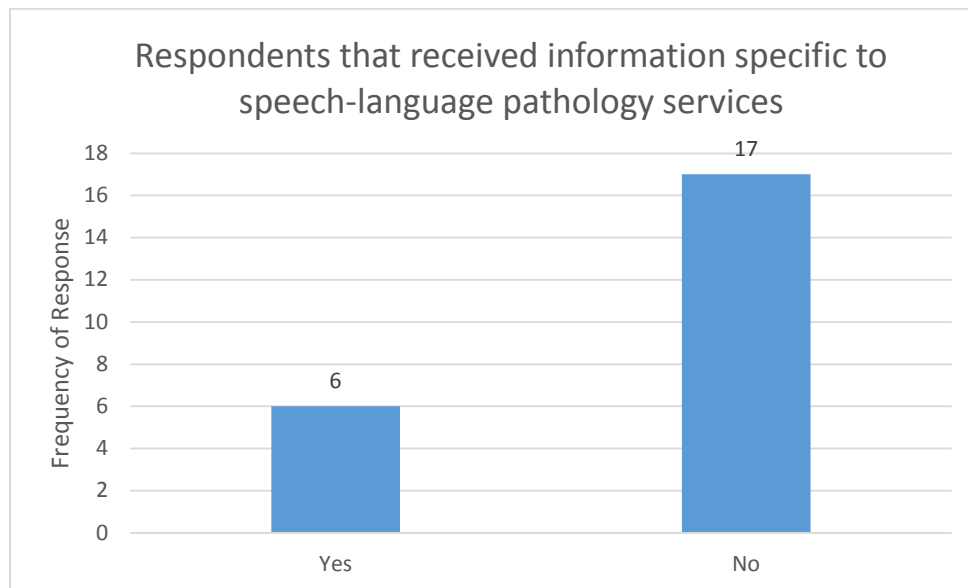


Figure 4.10, Area of speech-language pathology services addressed in the information received by parents/caregivers

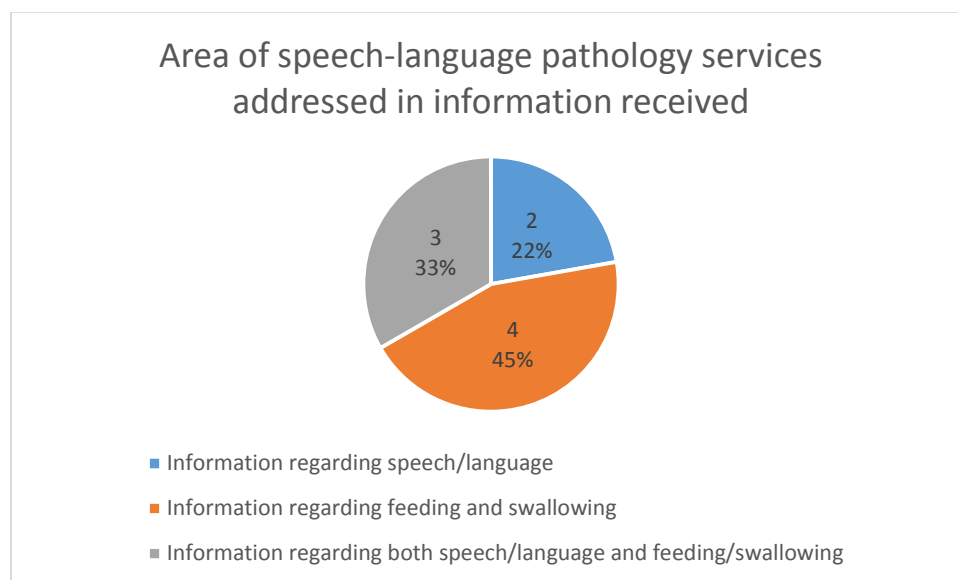


Figure 4.11, Time of receipt of information related to speech language-pathology services

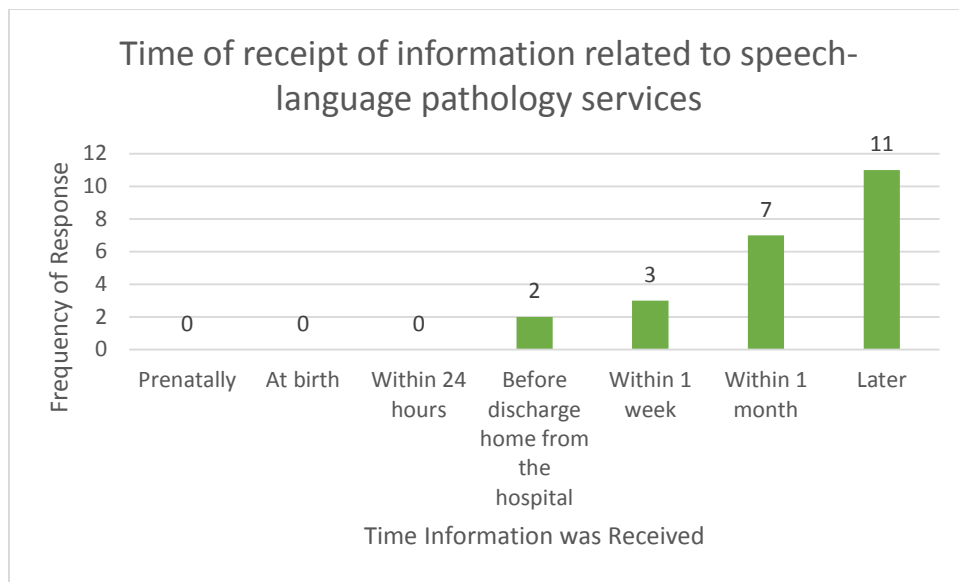


Figure 4.12, Overall Satisfaction with information and received regarding speech-language pathology services

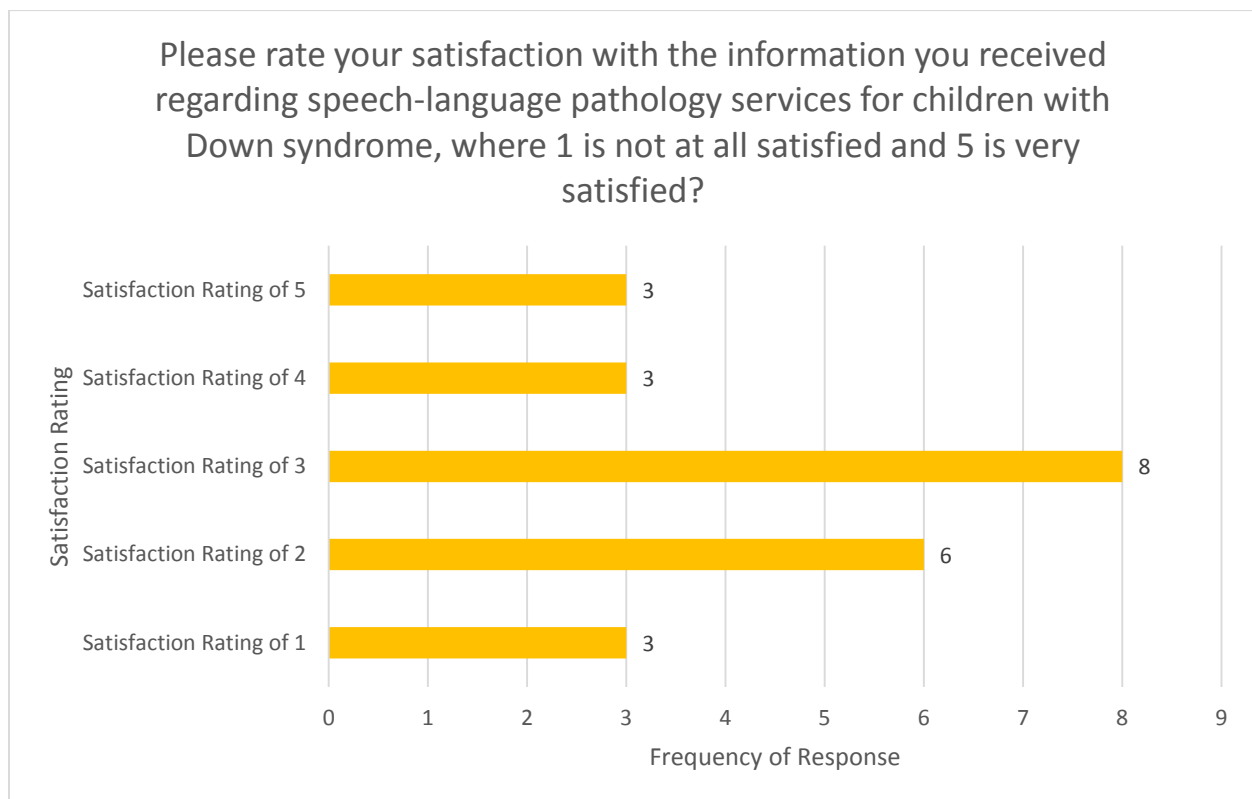


Figure 4.13, Time of receipt of referral related to speech-language pathology services

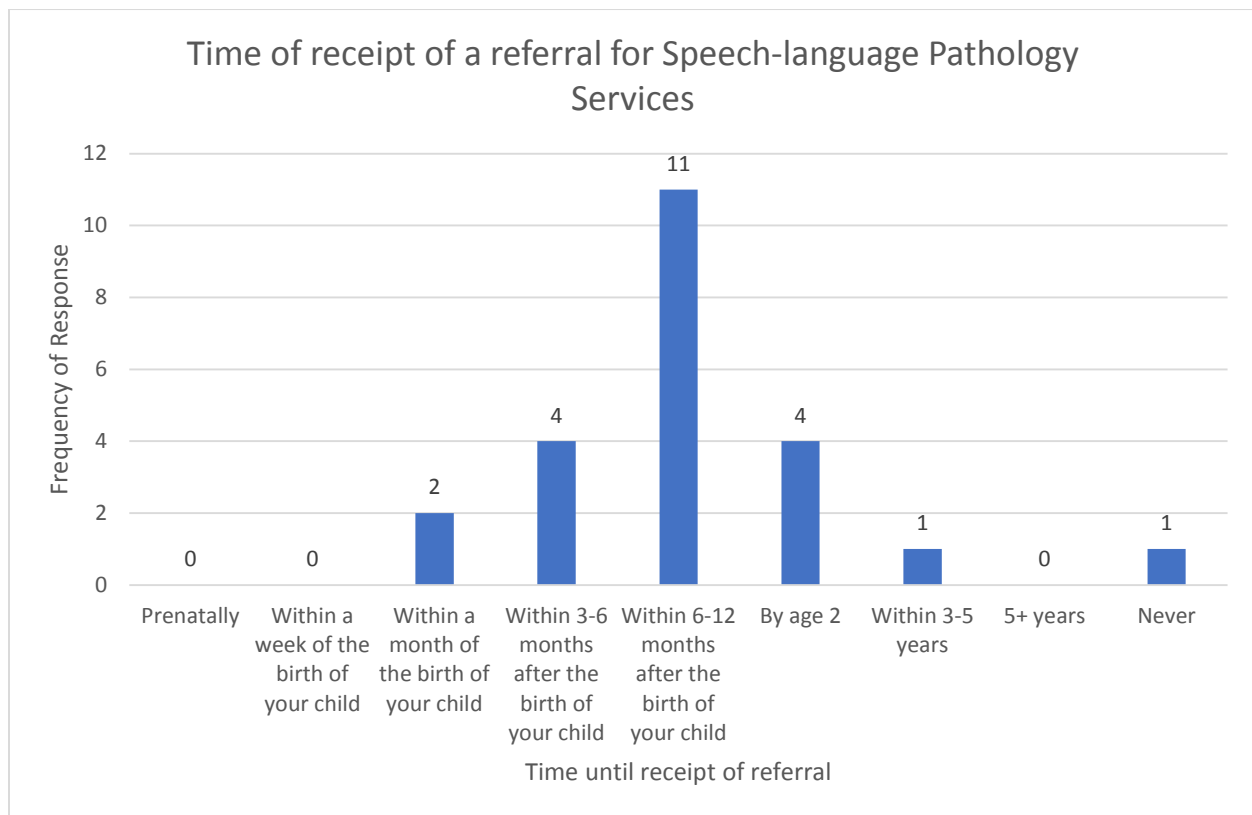


Figure 4.14, Age at which a child began receiving speech-language pathology services

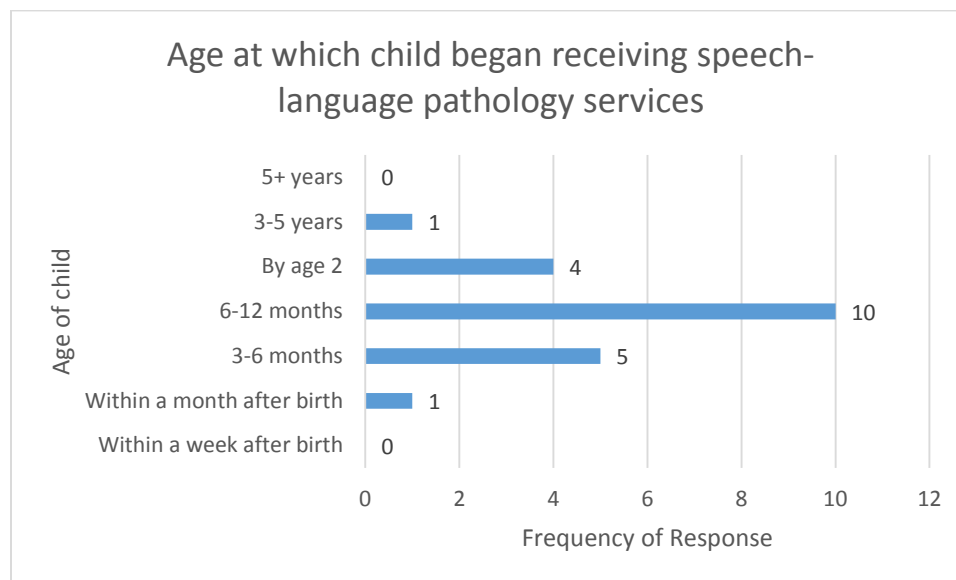


Figure 4.15, Degree of satisfaction regarding, information related to speech-language pathology needs for children with DS, advocating for services

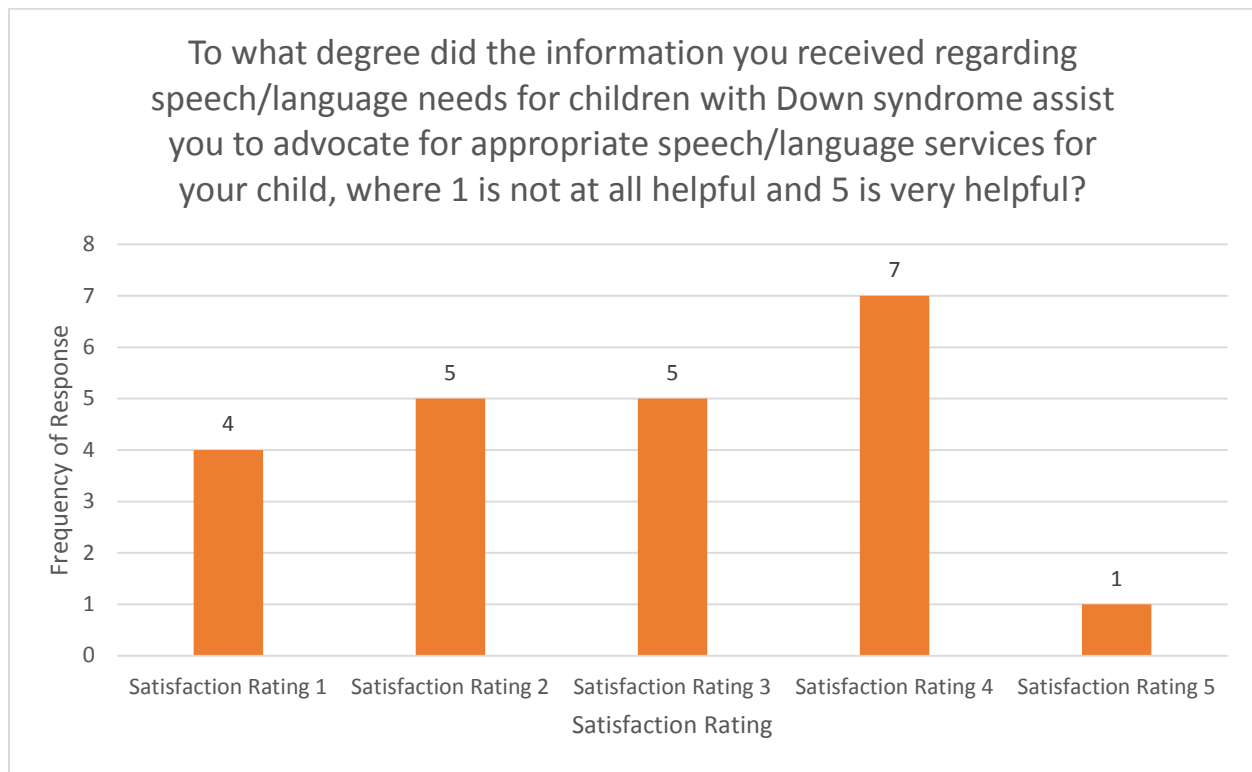


Figure 4.16, Time at which parents/caregivers believe new parents/caregivers should be provided with information regarding speech-language pathology services for children with DS

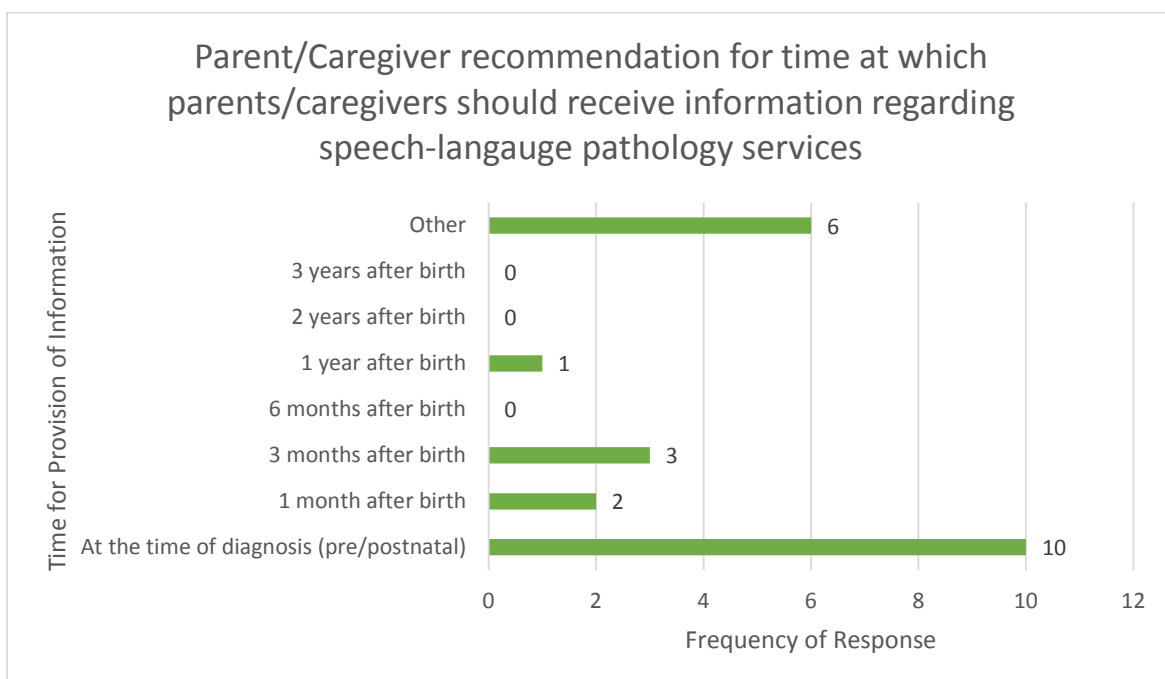


Figure 4.17, ‘What information do you think should be provided to new parents regarding the need for speech/language services for children with Down syndrome?’

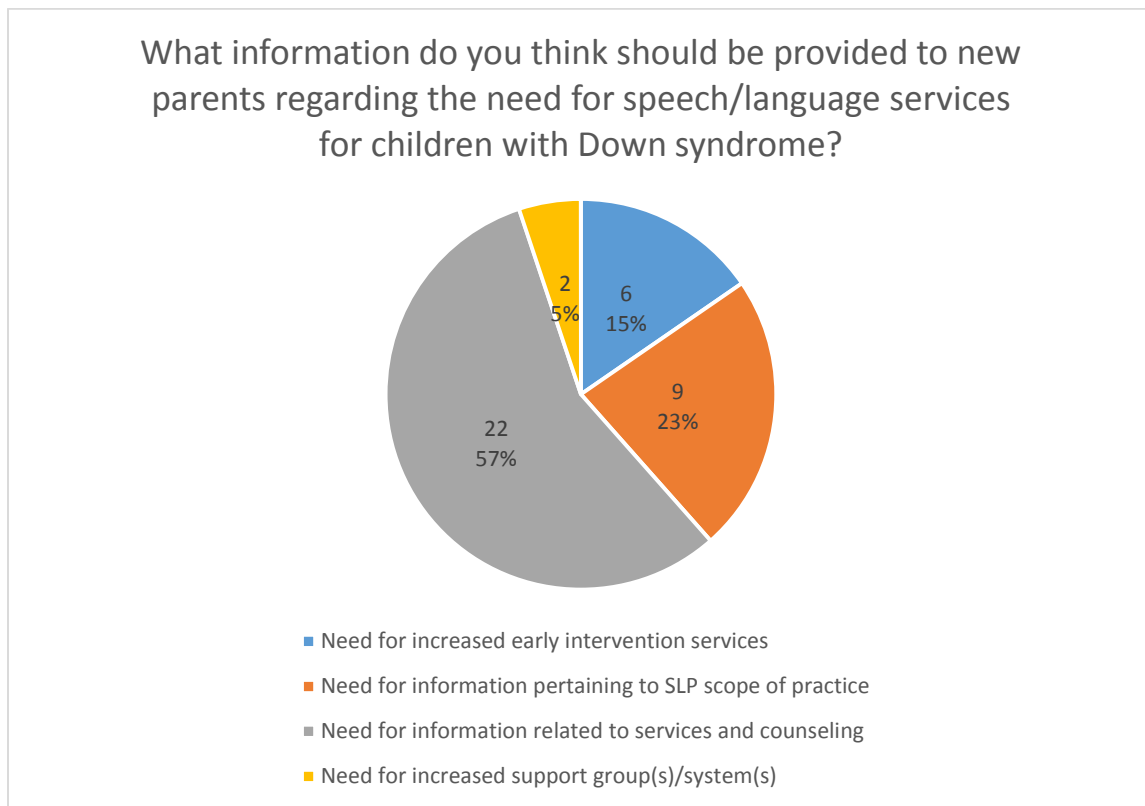
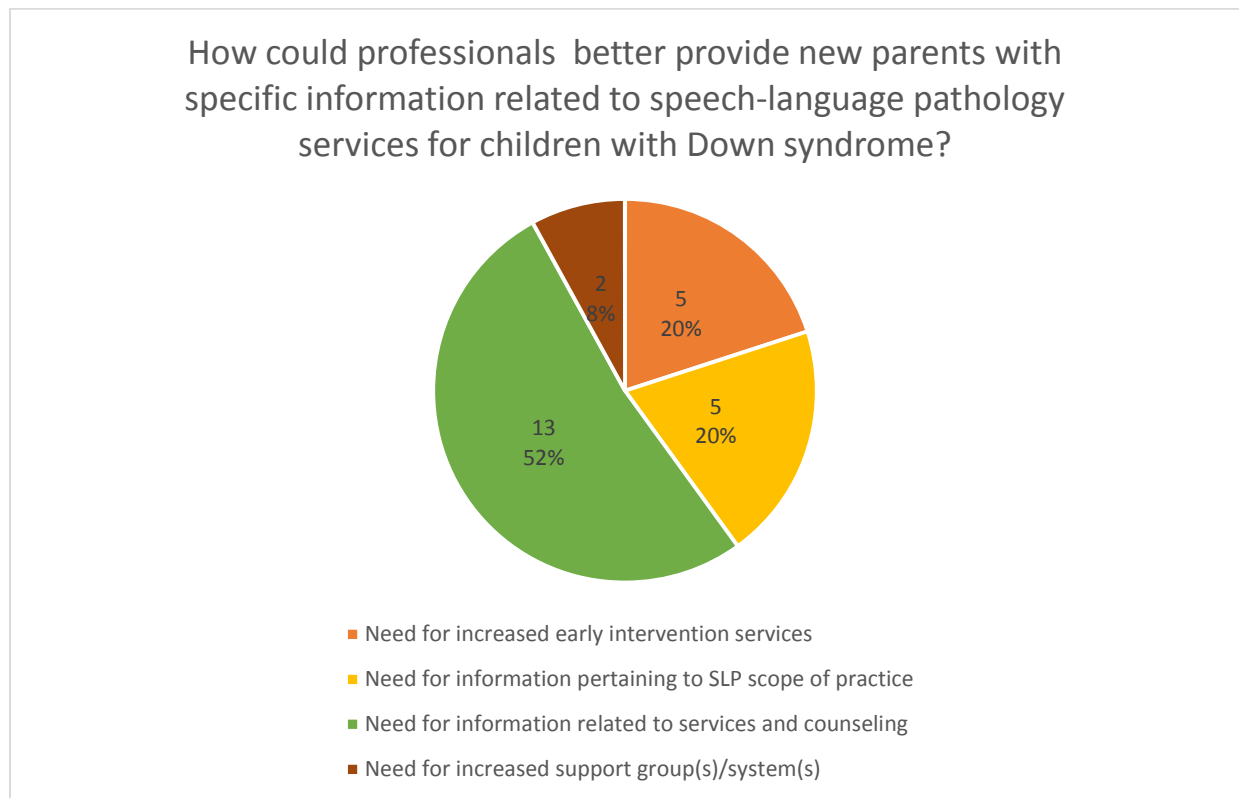


Figure 4.18, ‘How could professionals better provide new parents with specific information related to speech-language pathology services for children with Down syndrome?’



CHAPTER FIVE: DISCUSSION

This study was conducted for three primary purposes: 1) to determine the overall satisfaction of parents/caregivers related to information and referrals regarding Down syndrome and speech-language pathology services; 2) to determine what specific information was included in the information and referrals provided to parents/caregivers of children with Down syndrome; and 3) to determine when the information and referrals were provided to parents/caregivers.

Respondent Demographics

Of the twenty-three completed surveys, twenty, 87%, of survey respondents were the mother of a child with Down syndrome. Two, 8.7%, of the survey participants were fathers. One survey respondent, 4.3%, reported themselves as a grandparent of a child with Down syndrome. As anticipated a greater proportion of respondents were mothers. These results may suggest that mothers are more apt to assume responsibility in this area. Also, this study did not request that the respondent indicate whether or not they are a single parent. One might also wonder, if this information suggests that mothers of children with Down syndrome are more informed when it comes to the services a child with Down syndrome receives and the information and referrals that assisted in the procurement of those services.

The majority of survey respondents reported themselves to be within the age range of 40-60 years. The limited number of respondents coupled with results of the age of respondents may impact results as a prenatal diagnosis may or may not have been available to the respondent at the time of diagnosis or that with increased age the likelihood of a child being born with DS increases. As new technology has improved the methods of detection of fetal abnormalities over the last 20 years (Leshin, 2011), the reliability of results and risk of miscarriage associated with

receiving a prenatal diagnosis may or may not have an effect on the likelihood of an individual to receive a prenatal diagnosis. Nevertheless, the sample population represented a broad age range, which included parents/caregivers who did receive a prenatal diagnosis (4 respondents) and those who received a postnatal diagnosis (19 respondents). Similarly, survey respondents were asked to provide the age of their child with Down syndrome. The average of dependents was 8.34 years. The youngest age reported was 1 year of age while the oldest was 22 years of age. This information may play an important role in determining the overall satisfaction of parents/caregivers regarding the receipt of information and referrals, as information today is more readily available with the aid of technology and an increased importance placed on the need for early intervention services.

The majority of respondents indicated that they lived within the state of Kentucky, while two reported they lived in Ohio and each indicated an affiliation with a local Down syndrome association. Survey respondents from the Down Syndrome Association of Central Kentucky, the Down Syndrome of South Central Kentucky association, Down syndrome Association of Western Kentucky, and the Down Syndrome Association of Greater Cincinnati comprised the sample population. Slightly over half of survey respondents reported they lived in an urban area, while the remaining respondents indicated they lived in a rural area. These findings are critical to consider when assessing overall satisfaction as well. The availability of professionals and resources in a rural area may play a role in the overall satisfaction of parents/caregivers as it relates to the accessibility of that information and professionals qualified to provide it. As reported in one of the narrative responses, one individual cited some concern regarding how and where to access services which was particularly frustrating as they lived in a rural area.

Prenatal Diagnosis

A small percentage of respondents, four of the twenty-three, indicated they received a prenatal diagnosis. As information and referrals, as well as early intervention services, are critical to the development and success of individual with Down syndrome, it may be possible that the amount of time that exists between the receipt of diagnosis and the provision of information and referrals, regarding Down syndrome and speech-language pathology services, may better prepare parents/caregivers to access and secure services for their children with Down syndrome. However, one respondent indicated that they did not feel they were equipped and prepared to access services for their child. This respondent received a diagnosis of Down syndrome within the third trimester of pregnancy, did not receive information at the time of diagnosis and was not provided with information specific to the needs of a child with Down syndrome. This respondent's dissatisfaction with the information received could be attributed to the limited amount of time between the diagnosis of Down syndrome and the birth of their child, or simply due to the lack of information received following a diagnosis of Down syndrome. However, when compared to those who did not receive a diagnosis of DS prenatally, this could simply be due to a limited time to adjust to the diagnosis. It was interesting to note that while only one respondent reported receipt of information on early intervention at diagnosis, two others reported receiving information regarding the First Steps program. It might be concluded that parents/caregivers did not recognize First Steps as an early intervention services program when provided with information following a diagnosis of Down syndrome, or that First Steps is viewed as a separate entity, not to be included with early intervention services. Surprisingly, no respondent was provided with information from a source other than a genetic counselor, friend, or hospital staff member (provided in the space 'other'). Given the importance of early

intervention and accessing and procuring early intervention services for children with Down syndrome, especially speech-language pathology services, it would appear that speech-language pathologists and other professionals are lacking in the provision of information to those parents/caregivers who receive a prenatal diagnosis.

Postnatal Diagnosis

Surprisingly, most respondents indicated that they received information about Down syndrome within twenty-four hours of receiving a diagnosis of Down syndrome. Specifically, the majority of respondents indicated they received information more than 24 hours after a diagnosis but less than 72 hours after receiving a diagnosis of Down syndrome. These results indicates that information is provided in a seemingly, timely manner following the receipt of Down syndrome. However, slightly under half of the survey respondents reported that they did not receive information *specifically related to the needs* of children with Down syndrome. These results are telling of the need for an increased effort to provide information specifically related to the needs of a child with Down syndrome including information related to occupational therapy, physical therapy, and speech-language pathology services. Of the information that was received by parents/caregivers, the vast majority of respondents reported to have received general information about Down syndrome and information regarding early intervention services. One respondent received information specific to physical therapy services, while four of the respondents reported they received information about support groups and possible health concerns. These findings are critical when assessing the provision of information to access and secure services following a diagnosis of Down syndrome. Professionals within the (re)habilitation sciences must be proactive in the provision of information to parents/caregivers to allow them to access and procure speech-language pathology services. Of the ten respondents

who indicated they received information about early interventions service programs, all indicated they received information regarding First Steps (with two others, again, apparently not realizing that First Steps was early intervention). This information is significant in recognizing that information about early intervention services seems to be widely provided to parents/caregivers and is critical in the beginning stages of development.

Postnatally, an increased number of sources were indicated in providing information to parents/caregivers which included pediatricians, nurses, social workers, genetic counselors, friends, local Down syndrome associations, information that was self-researched, and alternative sources (hospital employees and First Steps). This increase in sources that provided information may be due to the larger medical team involved in sustaining care after, than before, the birth of a child. Prior to the birth of course, services are not required. However, once a child is born and is in need of services, a multidisciplinary team is required to assist in the treatment of that child. Specifically, this information indicates that professionals and those that assist in the care and treatment of children with Down syndrome must play a more active role following *both* a prenatal and postnatal diagnosis of Down syndrome.

Information Regarding Speech-Language Pathology Services

As previously stated, speech-language pathology services are critical to the development and success of children with Down syndrome. Only a small percentage of respondents indicated that they were satisfied with the information they received specifically related to speech-language pathology services; with the majority of the total respondents also rating their overall satisfaction as poor to neutral (1-3 on the Likert scale). This finding may indicate that even when such information is offered, it unfortunately may be inadequate in its overall benefit and assistance to parents/caregivers of children with Down syndrome. Speech-language pathologists,

as the professionals charged with the assessment and treatment of disorders related to communication and feeding and swallowing, must provide better information, referrals, and resources for parents/caregivers, and the professionals, and colleagues who advise parents, to better address the lack and quality of information and referrals provided to parents/caregivers.

Only a few respondents (four) indicated that they received information related to speech-language pathology services. Slightly under half reported they received information related to both speech/language and feeding and swallowing. However, the majority of survey respondents indicated they only received information regarding speech/language or feeding and swallowing, not information related to both speech/language *and* feeding and swallowing needs for this population. Only half of the four respondents reported they received information related to speech/language, while the other respondents indicated they received information regarding feeding and swallowing. This information is crucial to the understanding of how and what information should be provided to parents/caregivers. Speech-language pathologists must provide information regarding both speech/language and feeding and swallowing services; as this population has an increased risk to require services for both speech/language and feeding and swallowing. Analysis of these narrative responses which were a recurrent theme, may reflect a lack of knowledge in speech-language pathologists who work in early intervention in the area of feeding and swallowing disorders. It may be that these professionals are not addressing feeding and swallowing disorders with children with DS, then the parents would, of course, be unaware that feeding and swallowing *should be* in their scope of practice. It is the obligation of the speech-language pathologist to promote and advocate for speech-language pathology services, including *all* aspects of the field. This may include taking a proactive role in seeking continuing education for themselves and then providing accurate information to families,

via community resources for parents/caregivers of children with Down syndrome. Opportunities for dissemination of such information may include providing educational seminars for parents/caregivers, colleagues, and members of an inter-disciplinary team, participating in local Down syndrome association conferences/seminars to provide education regarding ‘hot topics’ associated with speech-language pathology services for children with Down syndrome, or conducting open forums or in-service workshops regularly for parents/caregivers.

While understanding the importance of providing specific information, it is also important to note when that information is provided. The most frequent response provided by respondents when answering when speech-language pathology service information was provided was selected as, ‘Later.’ This refers to receiving information later than 1 month following receipt of a diagnosis of Down syndrome. A very small percentage of survey respondents indicated they received information prior to discharge home from the hospital. This may be attributed to feeding difficulties experienced by the infant warranting specific speech-language pathology services; however this is a very small percentage of individuals who received information related to speech-language services that will be needed as the child ages.

Information regarding speech-language pathology services for children with Down syndrome was provided in many forms, via technology, printed materials, friends, family, or a healthcare professional. Information was reportedly received from a medical professional/other professional for slightly fewer than half of survey respondents. As such, in order for families to receive quality information about speech-language services, speech-language pathologists must continually provide medical professionals with accurate and current information so it may be relayed to parents/caregivers. As only one respondent reported to have received information from a speech-language pathologist, this marginal number indicates that speech-language

pathologists are not the primary source of information regarding services related to their scope of practice. It is therefore especially important that speech-language pathologists take a proactive role in the dissemination of information and referrals about this very important area of service provision. It is imperative for speech-language pathologists to be at the forefront of providing the most current, up to date, and evidence based research and information.

First Steps was indicated as being a main source in providing information specific to speech-language pathology services. Speech-language pathologists must be attuned to the programs and services provided by First Steps and communicate with all professionals within that program to provide current and critical information regarding speech-language pathology services. Again, it is critical that speech-language pathologists work closely with other professionals as a part of an interdisciplinary team in order to provide information regarding speech-language pathology services to parents/caregivers, and to advocate for these services for families who need them.

When asked to rate their satisfaction regarding the information received specific to speech-language pathology services, the majority of respondents, 7, or 35%, indicated that they were neutral in terms of their satisfaction. However, nine respondents, 45%, indicated they would rate their satisfaction as a '1', or not at all satisfied, or a '2'. Overall, the information that parents/caregivers received regarding speech-language pathology services was unsatisfactory to those parents/caregivers who will require those specific services. It is crucial that parents/caregivers recognize the importance of speech-language pathology services, and 'buy-in' to services in order to motivate them to access and procure services for their child. Therefore, speech-language pathologists must consider other opportunities to connect with parents/caregivers of children with Down syndrome in order to relay information specific to

speech-language pathology services. Opportunities for this may include attending and presenting at meetings/conferences/seminars held by local Down syndrome associations. Additionally, speech-language pathologists must take a proactive role in the reform of legislation related to (re)habilitation services for children with disabilities, which may include partnering with local advocacy groups and Down syndrome associations in their community.

The receipt of information is critical to empower parents/caregivers to educate themselves regarding the importance of speech/language services for children with Down syndrome. However, a referral to receive services is also crucial in the procurement of services in a timely manner. Some survey respondents reported they received a referral between the ages of two and five, which is actually rather late in the early intervention time frame. However, the majority of survey respondents indicated their child received a referral for speech-language services within 6-12 months following the birth of their child. This information could play a large role in the reports of many parents/caregivers receiving information from the First Steps program, which services children from birth to 3 years of age. As referrals are being provided within this critical period, it is again, important that parents/caregivers have access to *high quality* information regarding speech-language pathology services *including their role in feeding and swallowing* and direct contact with a speech-language pathologist.

The overall goal in providing information regarding the needs for speech-language pathology services is to procure necessary services for a child with Down syndrome. Survey respondents were asked to again utilize a Likert scale and indicate to what degree the information they received regarding speech/language needs for children with Down syndrome assisted them in advocating for appropriate speech-language pathology services. The majority of respondents again indicated that the information they received was not at all helpful, as indicated

by a '1' on the scale, a '2', or '3,' to indicate neutrality. Slightly below 40% of respondents indicated the information they received was helpful in advocating for appropriate speech-language pathology services. This information is important in the understanding of how parents view the importance of speech-language pathology services, as well as the analysis of how information and referrals are provided to parents. It is evident by the dissatisfaction of parents/caregivers that information regarding speech-language pathology services is not being provided appropriately, adequately, or effectively. It is critical that parents be empowered to advocate for services for their children but they must first be provided with current and adequate information describing the need for these services. However, this lack in satisfaction may be due to a lack in appropriate information that is provided to parents/caregivers regarding the importance of speech-language pathology services for children with Down syndrome.

Receiving Information Regarding Speech-Language Pathology Services

Parents/caregivers were asked to indicate when *they* felt a new parent/caregiver should be provided with information and referrals regarding speech-language pathology services. Of all responses provided, only a minute percentage of respondents indicated that this information should be provided one year after birth. A significant percentage, and vast majority of respondents, indicated that information regarding speech-language pathology services should be provided at the time of initial diagnosis (either prenatally or postnatally). It can be concluded that parents/caregivers feel information regarding speech-language pathology services is critical to provide to new parents/caregivers. For those survey respondents that indicated information should be provided at a time other than the initial diagnosis, the majority indicated that information should be provided with the first month of receiving a diagnosis of Down syndrome. Speech-language pathologists must be prepared to provide parents/caregivers with information

and referrals, available services, and recommendations of strategies to use within the home to assist in the development of a child with Down syndrome. Narrative comments were also provided by respondents who were requested to indicate what information should be provided to new parents/caregivers regarding the need for SLP services and how professionals could better provide new parents/caregivers with information regarding SLP services. Four recurring themes emerged in the analysis of these responses:

- The need for increased early intervention services (including the establishment of a communication system and implementation of therapy during early development),
- The need for provision of information pertaining to the scope of practice of speech-language pathologists to include their expertise for feeding/swallowing issues and intervention,
- The need for increased information related to available services (i.e. First Steps, in-home treatment options, etc.) and counseling for parents/caregivers, and
- The need for increased support group(s)/system(s) for parents/caregivers of children with Down syndrome.

Upwards of 50% of respondents indicated that new parents/caregivers should be provided with information related to available services and counseling services related to speech-language pathology services. Therefore, it would be prudent to assume that speech-language pathologists must maintain a working knowledge of services that are available for children with disabilities, as well as be able to provide counseling regarding speech-language pathology services and the development of a child with Down syndrome. Speech-language pathologists must be able to communicate the needs of a child with Down syndrome and what services will assist in

addressing those needs. A second theme identified by slightly less than half of respondents indicated that parents/caregivers should be informed of speech-language pathologist's expertise in the assessment and treatment of feeding and swallowing disorders. Again, self-advocacy on the part of speech-language pathologists must be considered with the understanding that many parents/caregivers are unaware of the services they provide. Multiple respondents commented that they were unaware speech-language pathologists were qualified to address issues related to feeding and swallowing. Other responses also indicated the need to provide information about feeding and swallowing and services available for feeding and swallowing issues. It is necessary to both inform parents/caregivers of the need for speech-language pathology services and what services are provided by that professional.

The need for increased information related to available services and counseling was noted by the majority of respondents pertaining to how professionals could better provide information about speech-language pathology services. As this information is clearly identified as a concern of parents/caregivers, speech-language pathologists must assess the reasons as to why parents/caregivers consider this information as extremely important to provide. This could be due to complexity of processes in order to receive services or due to the lack of awareness on the part of speech-language pathologists and parents/caregivers regarding services that are available. It may also be due to the lack of understanding of speech-language-feeding service on the part of those who provide parental information within the medical or early intervention (First Steps) system. Counseling must be provided to *both professionals and parents/caregivers* in order to ensure their understanding of options related to the treatment and success of children with Down syndrome. In regards to parents/caregivers, the cliché, 'knowledge is power' seems fitting when

understanding why receiving information about available services and counseling of parents/caregivers is so important.

The need for increased early intervention services was also noted in both sets of narrative responses. The small percentages of those respondents who indicated this theme in their comments, indicate that speech-language pathologists must provide the information about treatment options followed by specific programs and services that will aid in the development of their child. Lastly, the need for increased support group(s)/system(s) was indicated by a marginal percentage in both sets of questions. Those respondents who indicated these themes in their responses noted that it is important to connect with another parent/caregiver of a child with Down syndrome. With this information, speech-language pathologists may consider it to be a wise decision to provide resources which a new parents/caregivers of a child with Down syndrome may access other parents/caregivers, i.e., ‘veteran’ parents of children with Down syndrome, as one respondent noted.

Open Responses

Again, the most frequent response provided by survey respondents indicated the need for increased information related to available services and counseling for parents/caregivers. The need for increased early intervention services was noted in one of the narrative remarks and responses, while the need for provision of information regarding the scope of practice of speech-language pathologists was also noted in one response. The recurrence of the need for increased information related to available services and counseling appears to be at the crux of concerns of parents/caregivers of children with Down syndrome when being provided with information and referrals related to speech-language pathology services.

The high frequency of occurrence regarding the need for increased information related to available services and counseling for parents/caregivers indicates that SLPs must be prepared to provide appropriate and current information regarding the services that are provided to address speech-language pathology needs, while providing counseling services regarding the needs of a child with Down syndrome specific to speech-language pathology services. Knowledge of the information and services available may assist the SLP in allowing the parent/caregiver the opportunity to educate themselves on the importance of speech-language pathology service for children with Down syndrome.

Limitations

Several limitations exist within the current study that may have impacted results. First, a very limited number of respondents participated in and completed this survey. Due to this small sample size, results of this survey may not generalize to the population of parents/caregivers of children with Down syndrome at large or be representative of all parents/caregivers. Survey participants were only recruited by means of an affiliation with a local Down syndrome association. This may have impacted results as participants affiliated with a Down syndrome association may potentially be more proactive in the procurement of information and referrals, as opposed to those with no connections or ties with an association. Likewise, respondents affiliated with only four of the six Down syndrome associations contacted participated. Continuation of this research study to include more participants from additional Down syndrome associations would allow for more generalization of results. Furthermore, it is possible a larger sample size was not accessed as participants only associated with a local Down syndrome association were invited to participate. Differences in the experiences and attitudes of

parents/caregivers may have impacted the overall level of satisfaction in the receipt of information and referrals received.

Future Research

More research is needed to determine the overall satisfaction of parents/caregivers related to information and referrals specifically related to speech-language pathology services. While this study showed the overall satisfaction of parents/caregivers regarding information and referrals related to speech-language pathology services is neutral to poor, the limited number of responses does not allow for a generalization of results, nor is it representative of the population at large. More research is needed to validate the results of this research study. Specifically, a larger sample size must be obtained in order to generalize the results obtained by this study. Similarly, a follow-up study to determine the reason as to why the overall satisfaction of information and referrals was rated as neutral to poor may also provide further insight as to how this information should be provided and presented to parents/caregivers of children with DS. Further research in this area may spur professionals, namely speech-language pathologists, to take action in the delivery of information and referrals regarding speech-language pathology services for children with Down syndrome. Research is also needed to assess the satisfaction of speech-language pathologists as related to the information and referrals that are provided to parents/caregivers, both for children with Down syndrome and as a whole. Determining the overall satisfaction of both parents/caregivers and speech-language pathologists may prove to be the catalyst in changing the way information and referrals are disseminated regarding speech-language pathology services.

Implications and Conclusions

Despite the limited number of responses to this survey, a total of seventeen of twenty-three respondents, 74%, indicated that they did not receive any information regarding speech-language pathology services for children with Down syndrome. These results point toward the need for increased advocacy on the part of speech-language pathologists to report and provide information to other professionals and parents/caregivers regarding the need for speech-language pathology services. Speech-language pathologists must work to ‘brand’ their profession in an effort to increase awareness regarding the scope of practice of speech-language pathologists. Similarly, the majority of respondents indicated that information and referrals for speech-language pathology services should be provided at an earlier date in time following the receipt of a diagnosis of Down syndrome.

Results of this research study indicate that further action must be taken to address the identified deficits in the provision of information and referrals related to speech-language pathology services. Specifically, action must be taken in doing the following:

- Expansion and continuation of the study to allow for additional respondents to allow for generalization of results,
- Development of workshops and seminars for professionals to address the need for improved counseling of parents/caregivers when providing information and referrals,
- Inclusion of coursework in graduate study programs or training programs pertaining to counseling parents/caregivers,
- Provision of education to parents/caregivers, healthcare professionals, early interventionists, and peers regarding the specific needs of children with Down

syndrome related to speech-language pathologists including their expertise in the assessment and treatment of feeding and swallowing disorders,

- Development of educational materials to provide information related to the communication development of children with Down syndrome,
- Increased promotion of parent advocacy in order to access and secure speech-language pathology services for children with Down syndrome,
- Continuing education developed and provided by speech-language pathologists pertaining to feeding and swallowing treatment and intervention with the birth to 3 population, and to
- Assist in the development of community outreach programs for local Down syndrome associations to connect new parents/caregivers with ‘veteran’ parents/caregivers of children with Down syndrome to conduct question and answer sessions.

Appendix A: IRB Exemption Certification Approval and Modification of Study Approval



EXEMPTION CERTIFICATION

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PI phone #: (859)797-3999

FROM: Institutional Review Board
c/o Office of Research Integrity

SUBJECT: Exemption Certification for Protocol No. 14-0942-X3B

DATE: December 9, 2014

On December 9, 2014, it was determined that your project entitled, *Parent/Caregiver Knowledge and Satisfaction of Information and Referrals related to Speech-Language Pathology Services for Children with Down Syndrome*, meets federal criteria to qualify as an exempt study.

Because the study has been certified as exempt, you will not be required to complete continuation or final review reports. However, it is your responsibility to notify the IRB prior to making any changes to the study. Please note that changes made to an exempt protocol may disqualify it from exempt status and may require an expedited or full review.

The Office of Research Integrity will hold your exemption application for six years. Before the end of the sixth year, you will be notified that your file will be closed and the application destroyed. If your project is still ongoing, you will need to contact the Office of Research Integrity upon receipt of that letter and follow the instructions for completing a new exemption application. It is, therefore, important that you keep your address current with the Office of Research Integrity.

For information describing investigator responsibilities after obtaining IRB approval, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" from the Office of Research Integrity's IRB Survival Handbook web page [<http://www.research.uky.edu/ori/IRB-Survival-Handbook.html#PIresponsibilities>]. Additional information regarding IRB review, federal regulations, and institutional policies may be found through ORI's web site [<http://www.research.uky.edu/ori/>]. If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at (859) 257-9428.



Office of Research Integrity
IRB, IACUC, RDRC
315 Kinkaid Hall
Lexington, KY 40506-0057
859 257-9428
fax 859 257-8995
www.research.uky.edu/ori/

Changing end date

Modification Review

IRB Number
14-0942-X3B

TO: Erin Salmons
Communication
Department of Rehabilitation Sciences
313 Manhattan Dr.
Lexington, KY 40505
PI phone #: (859)797-3999

FROM: Chairperson/Vice Chairperson
Institutional Review Board (IRB)

SUBJECT: Approval of Modification Request for Protocol 14-0942-X3B

DATE: February 18, 2015

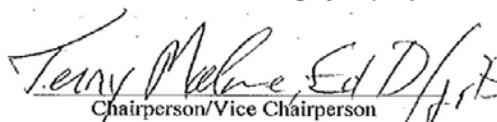
On February 13, 2015, the Institutional Review Board approved your request for modifications in your protocol entitled:

*Parent/Caregiver Knowledge and Satisfaction of Information and
Referrals related to Speech-Language Pathology Services for Children
with Down Syndrome*

If your modification request necessitated a change in your approved informed consent/assent form(s), attached is the new IRB approved consent/assent form(s) to be used when enrolling subjects. [Note, subjects can only be enrolled using informed consent/assent forms which have a valid "IRB Approval" stamp, unless waiver from this requirement was granted by the IRB.

Note that at Continuation Review, you will be asked to submit a brief summary of any modifications approved by the IRB since initial review or the last continuation review, which may impact subject safety or welfare. Please take this approved modification into consideration when preparing your summary.

For information describing investigator responsibilities after obtaining IRB approval, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" from the Office of Research Integrity's Guidance and Policy Documents web page [<http://www.research.uky.edu/ori/human/guidance.htm#PIresp>]. Additional information regarding IRB review, federal regulations, and institutional policies may be found through ORI's web site [<http://www.research.uky.edu/ori/>]. If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at (859) 257-9428.


Chairperson/Vice Chairperson

Appendix B: Survey Instrumentation

Background Information

Respondent Information

1. Relation to Child:

Mother Father Grandparent Caregiver (Please specify relation to child): _____

2. Approximate Age: (please circle)

20-30 years 30-40 years 40-50 years 50-60 years 60+ years

3. State of Residence:

Kentucky Other (Please specify the state): _____

4. Please indicate which, if any, Down syndrome association your family is affiliated with:

- a. Down Syndrome Association of Central Kentucky
- b. Down Syndrome of Louisville
- c. Down Syndrome of South Central Kentucky
- d. Green River Area Down Syndrome Association
- e. Ups-N-Downs Down Syndrome Association of Western Kentucky
- f. The Down Syndrome Association of Greater Cincinnati
- g. None at this time

5. Do you live in an urban or rural area? (please circle)

Dependent Information

6. Is your child male or female? (please circle)

7. Age: _____

***If you received a prenatal diagnosis, please continue to question 8 on page 2.**

***If you did *NOT* receive a prenatal diagnosis, please continue to question 17 on page 4.**

If you learned your child's diagnosis before birth

8. Did you receive a pre-natal diagnosis of Down syndrome? (please circle)

Yes or No

9. Please indicate during which trimester you received a pre-natal diagnosis of Down syndrome.
(please circle)

1st Trimester 2nd Trimester 3rd Trimester

10. Did you receive information about Down syndrome at the time of diagnosis? (please circle)

Yes or No

11. Did you receive information for services specific to the needs of a child with Down syndrome at
the time of diagnosis? (please circle)

Yes or No

12. Please indicate the type of information you received. (please circle all that apply)

- a. General Information about Down syndrome
- b. Information specific to speech-language pathology services
- c. Information specific to physical therapy
- d. Information specific to occupational therapy
- e. Information regarding Early Intervention Services (e.g. First Steps)
- f. Other services: (please list)

13. If you received information regarding early intervention or other services (for example, First Steps), what programs did you receive information about? (please list)

14. Please indicate the approximate length of time that went by from receiving a diagnosis of Down syndrome to the time you received information about Down syndrome. (please circle)

- a. Within 24 hours
- b. Within 72 hours
- c. Within 1 week
- d. Within 1 month
- e. Other (please list): _____
- f. Cannot recall

15. Please indicate who provided this information. (please circle all that apply)

- a. OB/GYN
- b. Pediatrician
- c. Advanced Practice Registered Nurse (APRN)/Physician Assistant (PA)
- d. Nurse
- e. Social Worker
- f. Genetic Counselor
- g. Family
- h. Friends
- i. Local Down syndrome association
- j. Self-researched
- k. Other (please list): _____

16. Do you feel you were equipped and prepared to access services for your child due to the length of time between the diagnosis of Down syndrome and the birth of your child?

Yes or No

*If you received a prenatal diagnosis and have answered questions 1-16 please turn to question 23 on page 6.

If you learned your child's diagnosis at/following birth

17. Please indicate the approximate length of time that went by from receiving a diagnosis of Down syndrome to the time you received information about Down syndrome. (please circle)

- a. Within 24 hours
- b. Within 72 hours
- c. Within 1 week
- d. Within 1 month
- e. Other (please list): _____
- f. Cannot recall

18. Did you receive information for services specific to the needs of a child with Down syndrome at the time of the birth of your child? (please circle)

Yes or No

19. Please indicate the type of information you received. (please circle all that apply)

- a. General Information about Down syndrome
- b. Information specific to speech-language pathology services
- c. Information specific to physical therapy
- d. Information specific to occupational therapy
- e. Information regarding Early Intervention Services (e.g. First Steps)
- f. Other services: (please list)

20. If you received information regarding early intervention or other services, what programs did you receive information about? (please list)

21. Please indicate who provided this information. (please circle all that apply)

- a. OB/GYN
- b. Pediatrician
- c. Advanced Practice Registered Nurse (APRN)/Physician Assistant (PA)
- d. Nurse
- e. Social Worker
- f. Genetic Counselor
- g. Family
- h. Friends
- i. Local Down syndrome association
- j. Self-researched
- k. Other (please list): _____

22. Do you feel you were equipped and prepared to access services for your child after receiving information following the birth of your child? (please circle)

Yes or No

*If you learned your child's diagnosis after their birth and have answered questions 1-7 and 17-22 please continue to question 23 on the next page.

Information regarding speech-language pathology services

23. Of the information you received, did you receive information specific to speech-language pathology services? (please circle)

Yes or No

24. Please indicate which areas of speech-language pathology services were addressed in the information you received. (please circle all that apply)

- a. Information about speech/language
- b. Information about feeding and swallowing

25. Please indicate when you received information regarding related to speech/language and feeding services provided to children with Down syndrome. (please circle)

- a. Prenatally
- b. At birth
- c. Within 24 hours
- d. Before discharge home from the hospital
- e. Within 1 week
- f. Within 1 month
- g. Later (please indicate): _____

26. Please indicate in what form of media the information you received was presented. (please circle all that apply)

- a. Internet
- b. Printed Material:
 - i. Pamphlet
 - ii. Book
 - iii. Other (please list): _____
- c. Personal visit from a parent with information from a local Down syndrome association
- d. Telephone call from a parent with information from a local Down syndrome association
- e. Medical professional/other professional
- f. Personal visit from a speech-language pathologist

27. Please indicate who provided this information. (please circle all that apply)

- a. Speech-language Pathologist
- b. OB/GYN
- c. Pediatrician
- d. Advanced Practice Registered Nurse (APRN)/Physician Assistant (PA)
- e. Nurse
- f. Social Worker
- g. Genetic Counselor
- h. Family
- i. Friends
- j. Local Down syndrome association
- k. Self-researched
- l. Other (please list): _____

28. Please rate your satisfaction with the information you received (pamphlets, word of mouth, reading materials, etc.) regarding speech/language pathology services for children with Down syndrome, where 1 is not at all satisfied and 5 is very satisfied?

1 2 3 4 5

29. Please indicate at what point in time you received a **referral** for speech/language services.
(please circle)

- a. Prenatally
- b. Within a week of the birth of your child
- c. Within a month of the birth of your child
- d. Within 3-6 months after the birth of your child
- e. Within 6-12 months after the birth of your child
- f. By age 2
- g. Within 3-5 years
- h. 5+ years
- i. Never

30. Please indicate who provided the referral. (please circle all that apply)

- a. Speech-language Pathologist
- b. Early Interventionist
- c. OB/GYN
- d. Pediatrician
- e. Advanced Practice Registered Nurse (APRN)/Physician Assistant (PA)
- f. Nurse
- g. Social Worker
- h. Genetic Counselor
- i. Family
- j. Friends
- k. Local Down syndrome association
- l. Self-researched
- m. School
- n. Pre-school teacher
- o. Teacher
- p. Other (please list): _____

31. At what age did your child begin receiving speech-language pathology services? (please circle)

- a. Within a week after birth
- b. Within a month after birth
- c. 3-6 months
- d. 6-12 months
- e. By age 2
- f. 3-5 years
- g. 5+ years

32. To what degree did the information you received regarding speech/language needs for children with Down syndrome assist you to advocate for appropriate speech/language services for your child, where 1 is not at all helpful and 5 is very helpful?

1 2 3 4 5

Receiving information regarding speech/language services

33. At what point should parents receive information regarding the need for speech/language services for their child with Down syndrome? (please circle)

- a. At the time of initial diagnosis (prenatally or at birth)
- b. 1 month after birth
- c. 3 months after birth
- d. 6 months after birth
- e. 1 year after birth
- f. 2 years after birth
- g. 3 years after birth
- h. Other (please list): _____

34. What information do you think should be provided to new parents regarding the need for speech/language services for children with Down syndrome?

35. How could professionals better provide new parents with specific information related to speech-language pathology services for children with Down syndrome?

Any other comments:

Appendix C: Letter to Participants

To Whom It May Concern:

Down syndrome is the most commonly occurring chromosomal abnormality present at birth. Speech-language pathology services, in combination with early intervention services, for children with Down syndrome are important; as are appropriate information and referrals that allow families to advocate and obtain needed services for their children. This survey will be used to: (1) determine when parents/caregivers of children with Down syndrome receive information and materials related to both Down syndrome and the need for speech-language pathology services; (2) determine what specific information was included in the information and referrals provided to parents/caregivers; and (3) to determine parents/caregivers overall satisfaction regarding information and referrals provided for children with Down syndrome. Hopefully, the survey will serve as a means for professionals, especially those working within the field of speech-language pathology, to better provide parents/caregivers of children with Down syndrome with appropriate information and referrals specifically related to the field of speech-language pathology.

We hope to obtain as many responses as possible so your answers are important to us. This survey is strictly anonymous and confidential, which means no names or identifying information will appear or be used on the survey, in research documents, or any other outcomes from the study. It is your right to discontinue your participation in this study/survey at any time. It is also your right to skip any questions on the survey if you desire. Although you will not get personal benefit from taking part in this research study, your responses help us understand more about how professionals, particularly speech-language pathologists, may better provide information and referrals to parents/caregivers of individuals with Down syndrome. There are no known risks to participating in this study.

The survey/questionnaire should take approximately 30 minutes to complete.

If you have questions about the study, please contact Erin K. Salmons at (859) 797-3999 or email her at eksalm2@uky.edu or contact Dr. Jane Kleinert at (859) 218-0568 or email her at jklei2@uky.edu.

If you have complaints, suggestions, or questions about your rights as a research participant, please contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428 or toll-free at 1-866-400-9428.

Thank you in advance for your assistance with this important project. To ensure your responses/opinions will be included, please complete the online survey/questionnaire or use the enclosed postage-paid envelope to return your completed survey/questionnaire by **February 15th, 2015**.

Sincerely,

Erin K. Salmons

Department of Rehabilitation Sciences/College of Health Sciences, University of Kentucky

PHONE: 859-797-3999

E-MAIL: eksalm2@uky.edu

Appendix D: Participant Recruitment Flyer

Survey participants are needed for a research study to assess Parent/Caregiver satisfaction with Information and Referrals related to Down syndrome and Speech-Language Pathology

You may be able to participate in this survey study if you are over the age of 20 and are the parent/caregiver of an individual with Down syndrome. The survey is completely voluntary and anonymous.

The purposes of this study are: 1) to determine the overall satisfaction of parents/caregivers related to information and referrals regarding Down syndrome and speech-language pathology services; 2) to determine what specific information was included in the information and referrals provided to parents/caregivers of individuals with Down syndrome; and 3) to determine when the information and referrals were provided to parents/caregivers.

We hope to determine how professionals can better provide parents/caregivers of children with Down syndrome with the information necessary to access and secure speech-language pathology services for their children.

If you are interested in completing this survey, you have several options to participate:

Follow the link to begin and complete the survey:

https://uky.az1.qualtrics.com/SE/?SID=SV_cCMVtKZZYlkfegp

Or

Obtain a hard copy of the survey along with a self-addressed and stamped envelope from your Down syndrome association.

If you are interested in receiving more information about this study, please contact

Erin K. Salmons at (859) 797-3999 or email her at eksalm2@uky.edu or contact

Dr. Jane Kleinert at (859) 218-0568 or email her at jklei2@uky.edu.



Appendix E: Contact and Shipping Information for each participating Down syndrome association

Down Syndrome Association	Contact	Number of Complete Survey Packets Mailed	Number of Additional Copies of Participant Recruitment Flyers	Carrier of Mailing
Down Syndrome Association of Central Kentucky (DSACK)	Traci Brewer, Executive Director E-mail: traci.dsack@gmail.com Brooke Grow, Communications/Office Coordinator E-mail: dsack.org@gmail.com Phone: 859-494-7809 Website: www.dsack.org	6 Return postage purchased and placed on return envelopes at \$1.19/envelope	10	USPS via Flat Rate Envelope at \$5.75/package
Down Syndrome of Louisville (DSL)	Diana Merzweiler, Executive Director dianam@downsyndromeoflouisville.org Phone: 502-495-5088 Website: www.downsyndromeoflouisville.org	6 Return postage purchased and placed on return envelopes at \$1.19/envelope	10	USPS via Flat Rate Envelope at \$5.75/package
Down Syndrome Association of Western Kentucky (DSAWK)	Amy Elliott, Secretary, amy.elliott83@gmail.com Phone: 270-705-8353 Website: www.dsawk.com	8 Return postage purchased and placed on return envelopes at \$1.19/envelope	10	USPS via Flat Rate Envelope at \$5.75/package
Green River Area Down Syndrome Association (GRADSA)	Carla Renfrow, Executive Director, E-mail: crenfrow@roadrunner.com Phone: 270-925-0195 or 270-852-6518 Website: www.gradsa.org	0	0	N/A
Down Syndrome of South Central Kentucky (DSSCK)	General Information E-mail: info@dssky.org Phone: 800-807-3531 Website: www.dssky.org	6 Return postage purchased and placed on return envelopes at \$1.19/envelope	10	USPS via Flat Rate Envelope at \$5.75/package
Down Syndrome Association of Greater Cincinnati (DSAGC)	Kathleen Ferrara, Medical Outreach Coordinator E-mail: kathleenf@dsagc.com Phone: 513-265-0883 Website: www.dsagc.com	6 Return postage purchased and placed on return envelopes at \$1.19/envelope	10	USPS via Flat Rate Envelope at \$5.75/package

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Vita

Place of birth:

Lexington, Kentucky

Educational Institutions attended and degrees already awarded:

Bluegrass Community and Technical College, 2007-2008, No degree awarded

Transylvania University, 2008-2009, No degree awarded

University of Kentucky, 2010-2013, Bachelor of Science in Health Sciences,
Summa Cum Laude

Erin K. Salmons