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The Effects of Communication Disorders in Individuals with Down Syndrome and How to Help Them Succeed

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SENIOR THESIS APPROVAL

This Honors thesis entitled

“Effects of Communication Disorders in Individuals with Down Syndrome and How to Help Them Succeed”

written by

Shelby Louise Bradley

and submitted in partial fulfillment of
the requirements for completion of
the Carl Goodson Honors Program
meets the criteria for acceptance
and has been approved by the undersigned readers.

Dr. Nancy Hardman, thesis director

Professor Carol Morgan, second reader

Dr. Allyson Phillips, third reader

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April 30, 2020

Effects of Communication Disorders in Individuals with Down Syndrome and

How to Help Them Succeed

Shelby Bradley

Honors Senior Thesis, Ouachita Baptist University

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Abstract

According to recent studies conducted by the Centers for Disease Control and Prevention, nearly 1 in every 700 babies born is diagnosed with Down syndrome, resulting in almost 6,000 babies diagnosed in the U.S. every year. Down syndrome, also referred to as DS, comes with some physical and mental differences. Because of these differences, individuals with Down syndrome and their families face many challenges when communicating, and these challenges affect all aspects of life. An increased awareness and knowledge could hopefully and effectively address some of these communication challenges for patients with whom the speech-language pathology profession may work with in the future. Through interviewing five families who have a child with Down syndrome and looking at background research, first-hand knowledge was gained regarding these challenges and how one can help toward alleviating them. These interviews revealed the true difficulties these individuals and families face and the way they perceive they are viewed by society. By using this information, the hope is that professionals and other individuals can aim to better include and help people with Down syndrome succeed in all situations.

Introduction

The topic of communication disorders in individuals with Down syndrome is one closely tied to my educational, future professional, and personal life. Studying speech-language pathology while also minoring in psychology has opened my eyes to a world of disabilities and isolation I had never known existed. Speech therapy was a profession I knew would be geared toward helping others, but the last four years of learning have revealed a vast list of individuals this profession can serve in a variety of ways. Many of these individuals and families seek a speech-language professional's help in order to participate in everyday activities and interactions that most take for granted.

My work as a Supportive Living Companion for a girl with Down syndrome is what initially sparked such a great interest in this topic and offered me firsthand observations of the effects any sort of disability, especially a communication disorder, can have on someone's life. The world around us is not always kind to those who are have a disability nor does it always know how to best aid these individuals in making communicating easier. This is exactly why this topic needs to be addressed so there can be a better way for all individuals to succeed and be welcomed into society. My past work experience, coupled with my studies toward my future profession, are what directed me to my topic for this thesis.

Down syndrome ranks as the most common genetic cause of intellectual disability today. In the United States, approximately 6,000 babies born every year are diagnosed with DS (Center for Disease Control and Prevention, 2019). In other words, 1 in every 700 babies born, will have Down Syndrome. Down syndrome is a chromosomal abnormality; rather than the usual 23 pairs of chromosomes, those with DS have an extra copy of chromosome 21. So instead of a total of 46 chromosomes, a child with Down syndrome has 47. A medical term for having an extra copy

of a chromosome is 'trisomy;' so DS is also referred to as Trisomy 21 (Baksi, 2005). This one extra chromosome results in mental and physical changes that can present life-long challenges. Some physical differences that may be present are facial structure variations, shorter height, low muscle tone, potential hearing loss and other hearing complications, sleep apnea, and heart defects (Center for Disease Control and Prevention, 2019). Additionally, mental challenges are present such as learning disabilities due to longer processing time, IQ in the mildly-to-moderately low range, and difficulty handling large amounts of information at once (Baksi, 2005). These intellectual deficits affect language skills and overall communication. For someone with Down syndrome, processing complex language or large amounts of information may be difficult if they are not provided with the time to process and given the tools needed to respond or communicate in the most effective way possible. Lack of communication skills affects every aspect of that person's life and makes it more difficult for them to succeed in their home and social environments. Communication disorders that are common for this population are stuttering, articulation (speech sound) disorders, language disorders (receptive and expressive), and some individuals even remain non-verbal and need other means of communication such as sign language or communication devices. Although most individuals with DS express a desire for interaction, communication difficulties greatly affect their ability and often hinder their efforts to interact at all. Down syndrome is a life-long condition, but intervention and services can be started immediately after birth and continued throughout the child's development to help these individuals develop their communication abilities and reach the potential that offers them the highest quality of life as possible.

Methods

I interviewed and video recorded five different families, all who have a child with Down syndrome. Ages ranged between two and forty years old. These families were recruited from my home church, my high school, past family relationships, and my summer job experience. The families chosen had varied demographic backgrounds. Two of the couples were pregnant with their child later in age while the other couples were in their early twenties. They also all had other children aside from their child who has Down syndrome, varying in amount from one to 3. Family members were asked twelve questions (APPENDIX F) pertaining to common challenges that research suggests individuals with DS can experience. These included communication challenges for and with the child and how these challenges affect the different aspects of the child's life and the lives of their families. They were also asked to reflect on their reactions when given the news their child would be born with or had Down syndrome, and what knowledge they had about DS prior to the diagnosis. Additionally, the families were asked what advice or words they would share with families and their child with DS based on personal experiences at home and within their community. I wanted to add their shared knowledge, experiences, and words of advice with the research I pursued in professional sources about Down syndrome.

Disclosure of Diagnosis

The first topic these families were asked to speak about was the very first instance they were told that their child had the diagnosis of Down syndrome. Living in an age of more advanced medicine and knowledge about DS and disabilities, I assumed most parents receive a diagnosis prenatally and are counselled through what life will be for them in the future. However, all five families were given the diagnosis after the birth of their child. These families reported no complications or early signs to alert them that something might be different about their child. One couple, whose pregnancy occurred in later age, were aware of the increased risks and completed a screening specifically for Down Syndrome, but results were negative.

Each family was told of the diagnosis by either a doctor or nurse, most of which were not necessarily positive or encouraging about their circumstance. In two instances, these health professionals referred to the child as a “mongoloid,” which is a term referring to a person having the physical features of a group of people originating from Asia and is also used as an offensive term for someone with a mental disability. In another instance, a nurse told one of the mothers that her husband would leave her because she gave him a “less than perfect child.” One couple, serving as missionaries in Korea when their child was born, experienced firsthand the cultural differences associated within the medical and social community. They explained how blunt the Korean culture is and how their doctor simply told them that their child has Down syndrome and then directly walked out without any other information or show of emotion. The father said that even though they knew something was wrong they “weren’t ready to hear it so bluntly.” None of these parents had prior knowledge that the child they had planned for would be different than anticipated, nor were they prepared for the manner and frequency with which others would continually point out that difference as well.

Reactions

The families reported various reactions upon being told in the hospital of the child's diagnosis. One mother said she saw "nothing wrong with her perfect baby" and could not understand what disability others were seeing that she did not. Two families said that their children had other health complications comorbid with Down syndrome that commanded more of the parent's attention and steered them away from initially worrying about the diagnosis. Others distanced themselves from friends and family in order to grieve and shelter themselves from the comments made by others about how wonderful or how hard their lives were going to be. One mother said she cried for two weeks or more. She said that support groups and other parents would call to tell about their own experiences of developmental milestones occurring late or struggles she needed to prepare herself but then would talk about how much of a blessing their child is, which sent an extremely mixed message and only caused her more confusion. Another mother described her feelings as "grieving your dreams for what you thought you were getting and what you thought their life would be." She also referred to an essay by Emily Perl Kingsley, *Welcome to Holland*, that put into words what she could not herself.

"When you're going to have a baby, it's like you're planning a vacation to Italy. You're all excited. You get a whole bunch of guidebooks, you learn a few phrases so you can get around, and then it comes time to pack your bags and head for the airport.

Only when you land, the stewardess says, 'Welcome to Holland.'

You look at one another in disbelief and shock, saying, "Holland? What are you talking about? I signed up for Italy."

But they explain that there's been a change of plan, that you've landed in Holland and there you must stay.

"But I don't know anything about Holland!" you say. "I don't want to stay!"

But stay you do. You go out and buy some new guidebooks, you learn some new phrases, and you meet people you never knew existed. The important thing is that you are not in a bad place filled with despair. You're simply in a different place than you had planned. It's slower paced than Italy, less flashy than Italy, but after you've been there a little while and you have a chance to catch your breath, you begin to discover that Holland has windmills. Holland has tulips. Holland has Rembrandts.

But everyone else you know is busy coming and going from Italy. They're all bragging about what a great time they had there, and for the rest of your life, you'll say, "Yes, that's what I had planned."

The pain of that will never go away. You have to accept that pain, because the loss of that dream, the loss of that plan, is a very, very significant loss. But if you spend your life mourning the fact that you didn't get to go to Italy, you will never be free to enjoy the very special, the very lovely things about Holland." (Kingsley, 1987)

Prior Knowledge

Four sets of the parents had limited or no prior knowledge about Down syndrome before the birth of their child. The parents said they may have met a few children with DS throughout the years or knew other parents who had a child with this diagnosis but thought it would "never end up being them." One of the mothers said she had majored in sociology and minored in psychology in college and she knew her classes covered the topic of DS, but she never fully

understood it or thought it would ever apply to her. Another mother, a physical therapist, was the only parent who had any real knowledge of this syndrome but again, never considered social and communicative complications it could bring.

Lack of Professional Support

While still in the hospital, the parents reported that they received no consultation from professionals such as speech-language pathologists, a counselor, a doctor, or other professional to explain expectations or what life would look like for their child for the days, months, and years to come. There was no discussion about future therapy that would be needed, or delayed milestones, or possible resources such as support groups of other parents with children with Down syndrome. Instead, they received negative comments from nurses and healthcare professionals calling their baby names such as “mongoloid” or expressing pessimism towards the goals their child would be able to accomplish by saying that they will have a “happy child” or they “know some that work at McDonalds.” All that the parents were told before leaving the hospital was that their child had Down syndrome. In all of these cases, the parents had to seek out information and professional help on their own.

At Home - Alone

The first few months at home can be chaotic and life-altering for any parents bringing home their newborn. For these parents I interviewed, a few of them said the first few months were cherished times; their child seemed just like any other baby. One mother said she listened to a lot of music, sang to her baby, and cried many tears over him. To her, this was a time she could close out the world and “overcome his diagnosis with love.” Two of the couples had never

had a baby before and these parents adapted to having a newborn in the home, changed diapers, went without sleep – just as any parent does with a newborn.

In addition to the usual changes brought to a family with a newborn, other parents were dealing with health complications such as colostomy bags, prematurity, skull surgery, and a heart defect that added stress with ongoing medical appointments and continual worry about their child's health. These health issues may have initially distracted the parents from the Down Syndrome diagnosis because of their focus on their child's overall health.

Overall, this was an extremely emotional time for all of the parents. It was also a time the parents began hearing and thinking about future decisions and resources. Two of the couples had friends who worked as speech-language pathologists and offered advice such as early intervention and treating their child just like any other baby. Whether these parents were trying to navigate health complications, spending long periods of time in hospitals, trying to make decisions for their child's future, or spending time desiring to be alone without any of the outside comments or suggestions, it was a life transforming time for each family.

Therapy and Support Services

One of the most common denominators among individuals with Down syndrome is the multitude of various therapies received throughout their lives. These therapies include occupational therapy, physical therapy, sensory therapy, and of course, speech and language therapy. All of the interviewed parents said that their child started receiving early intervention services and therapy around six-months of age.

Occupational therapy dealt with fine motor skills and building muscle tone for activities such as breast feeding or visual tracking. The focus of physical therapy worked on motor skills

such as rolling over, sitting up, walking, skipping, going up and down stairs and catching and throwing a ball. Sensory therapy focused on an early feeding problems or sensory aversions. Speech and language therapy focused on overall communication skills by using sign language as well as talking. Additionally, speech therapy worked with the parents and their child on feeding and swallowing issues, tongue placement, and later, on articulation (speech sounds), stuttering, and improving their language skills. Some of the parents whose children are older, reported that therapy continued up until college age, while other parents were in the beginning stages of therapy. Regardless of what stage they were in, all the parents agreed that therapy, no matter what kind, has been extremely helpful in their child's growth and development.

Speech and Language Skills

Although all of the therapies mentioned above have an important place in the development of children with Down syndrome, because of my future profession as a speech-language pathologist I was especially interested in the family responses outlining their experiences in regard to their child's speech and language skills.

Speech and language skills for children with Down syndrome, as with all children, will vary in levels of development. Overall, development of speech and language skills is delayed when compared to their peers with typically developing skills. Some children will be delayed in acquiring speech skills and will initially communicate through simple signs and/or gestures. For those children who do start using speech sounds, due to weakened muscle tone they will often have difficulty with producing clear speech. The parents interviewed reported that clarity of speech had been one of the main issues with their child's communication. This lack of clarity may have been due to speaking too quietly, speaking too quickly, or stuttering. One of the

families, aside from speech therapy, coupled sign language with verbal speech to provide another source of explanation when their child was difficult to understand. All families have dealt with struggles in their child's speech and language skills and continue to provide them with the resources and professional help they need to be effective communicators.

Education

Education is a large aspect of any individual's life but determining the right route becomes more challenging when a disability is involved. For all of the families interviewed, several school options were explored in order to find the best fit. The first family placed their child in a mother's day out program. They then moved to a preschool where the teacher, having a child with Down Syndrome herself, was very helpful and accommodating to children with special needs. They then put her in public school from 1st through 5th grade, which went well except for repeating 1st grade due to the parent's impression of an unpleasant teacher and school experience that ultimately led to switching schools after that first year. Going into 6th grade, the rest of her school career was spent at a private school for children with disabilities, which she thoroughly enjoyed and from which she graduated. She is now enrolled in a two-year culinary program for individuals with special needs and will graduate this year.

The next family's child also started with a day school and then jumped into public school. However, the school setting began to present difficulties for him beginning in the 4th grade and they eventually pulled him out in the 8th grade after an instance of abuse. He then attended a private school for children with disabilities for a little over a year until it was no longer financially possible, yet his parents say it taught him more in that short amount of time than public school ever did. After reaching college age, he attended Barnabas Preparatory, a two-year

college program that equips individuals with special needs with new skills. He lived on campus and had the college experience he had always wanted.

The third family's child began at a special needs school staffed by teachers who were highly certified. Although this family said their child learned a lot, their daughter was one of the highest functioning students and the parents wanted her to be in a more educationally challenging environment. They decided to put her in public school, but that resulted in behavior problems followed by no consequences or reinstruction and school-work that was above her ability at the time. After much deliberation, the parents changed her placement to the special education self-contained classroom located in the mainstream school she currently attends.

Education was especially socially difficult for one of these families. After kindergarten, they wanted to place their child in public school; however, this caused an uproar in the community they lived in because people in the community wanted to push him into a school specifically for special needs children instead. Many meetings were spent advocating for their child and when he did start public school, the school did not require him to follow the same rules and behave according to the same standards as the other students. The parents were not satisfied with this response to their child so they changed public schools where their child's placement was shared between the mainstream classroom and the special education classroom. Their child was given many educational opportunities, but also social opportunities which was important to their child and to the family. He served as a basketball manager for the basketball team, earned a letterman jacket, and participated in senior night with his teammates his senior year. His positive high school experience prompted his desire to attend college, which seemed very unattainable with the resources that were available. However, his family found an adult special needs program

that he now attends a few days each week. Although it is not a college experience, this program provides him a post-high school experience that meets his needs at this time.

The other family that was interviewed just started making these types of educational choices; their daughter is not school age yet. Since her father is the head of a Kindergarten through 12th grade school in Korea, they anticipate it will be the appropriate placement for their daughter and will meet her academic and social needs when the time comes to enroll in kindergarten.

Do-Overs

When asked about “do-overs” or decisions they would have made differently to help their child better succeed, many answers had to do with school or services. One family wished they had put their child in a special education school sooner because it gave her greater opportunities and helped her gain confidence socially. While attending public school, their daughter was aware she was different from the other kids, which made her more reserved and shy in social situations. These parents continue to question if they had started her at the special needs school earlier, would she be more outgoing and confident today? Another parent said they wish they would have gotten a second job to keep their child at the special needs school he attended for a year. Most stated they wished they would have started services earlier, and expressed their desire to have learned earlier what they could have done better to help their child. The one answer a parent gave that truly brought all of this into focus is,

“I feel called to have the role of working for his happiness now. He followed all my kids around to their games and activities and now it’s his time. I want him to have all the experiences he can and to have such an awesome life. I don’t know if I’ve done that really well or could have done it differently. We don’t want any special treatment but then we also kind of do because they sometimes need more. I don’t want to limit him but we all have limits. He wants all the things: to get married, to have kids, to have a job like my husband’s, and to have a house. And if I dwell on it, that makes me sad but I just have to remember that we all have our limits.

Asked for Advice

Another question asked was what they would say to a new parent of a child with Down Syndrome who asked for advice. One said, the best advice they ever got was to never think past the next day or stage; just stay focused on getting the child through one more day and then worry about the next. They were also encouraged to simply enjoy their child, because first and foremost they are your child and you need to enjoy your children. Another emphasized the importance that others should wait to be “asked” for advice because several well-intentioned people tried to impose their advice on her long before she was ready to hear it. She said that if someone were to ask her for advice, she would tell them about early intervention and to trust their motherly instincts. Parents who have children with Down syndrome need to be reminded that God gave that child to them instead of letting others dictate their lives. Other advice was to not always trust what your doctor says their life will look like, to remember and enjoy that the baby phase will last a little longer than those of other children, and to not waste time comparing their own child to other kids. Additionally, parents would tell other families to accept the circumstances that are very far from your dreams, so they can confidently make the best choices for them, and it is always okay to cry. One mom said that obviously there is a lot to worry about, but it all just comes back to loving them. She encouraged finding support in the community of special needs and in the town around you. She also said,

“The more you expand your circle, the more people know it isn’t scary. You have to let some dreams go and God gives you different dreams that are going to be awesome. Day by day get all the current information you can. It’s not a death sentence for your family and it’s going to bless you so much. People take cues from you about things like communicating with him and talking directly to him. The more you open up your life and let people in is like educating people on how to treat others.”

If Only They Knew

Overall, language disorders have greatly affected the way these individuals communicate and how others communicate with them as well. With these disorders, come many difficulties the parents wished others knew when communicating with their child. They wanted people to understand how much extra time their child may need to process language in a conversation and that they will not always speak up for themselves when it is needed. They also wanted their children to be treated the same and held to the similar standards as other children rather than people talking around the children as though they were not present or ignoring them just because they were not sure how to communicate with someone with Down syndrome. The parents also said they wanted people to not assume the child is poorly behaved if the child is throwing a tantrum or not responding to someone's questions. Instead, they wished others could understand the continual language difficulties experienced by their child and the frustration that results. They emphasized that their child often times understood much more than people think, but can be difficult to understand, need a little more time to process, or could benefit from additional information or explanation.

Beneficial Choices

The last topic discussed in the interviews was what the parents considered as the most beneficial in regards to helping their children be more successful in communicating and improving their overall language skills. One of the parents said that searching out friends and settings that made their child feel comfortable communicating was highly beneficial. Another said "hands down early intervention, specifically speech therapy, helped their child excel in all other areas." Other benefits mentioned were having a regular schedule, plenty of interaction with

others, having expectations, and treating their children as normal as possible. Overall, the most beneficial choice that the parents noted was having a good speech-language pathologist. The stated that even though other skills, such as motor abilities, are hard for them or become harder later in life, they know if they have communication skills, their child will always be able to express their wants and needs to others.

Personal Connection and Conclusion

Choosing this topic was a way for me to interlace several aspects and passions that are present in my life. It has given me the ability to see my future career in another light and to hear from parents and individuals how speech-language pathology has greatly impacted their lives. It has also given me a clearer perspective on the immense effect that any type of communication disorder has on a person's life each day. On a personal note, this research has pushed me to see the world through the eyes of the family I work for and encouraged me to remember that my purpose is to always strive to make communication easier for those with disabilities. It was evident through the interviews that many people see disabilities in a negative or uncomfortable light and that shapes their beliefs regarding the lives these individuals will lead. In my future career as a speech-language pathologist, I will work with individuals with disabilities and will use this information I gained through these interviews to highlight these lives that have meaning and potential. I also will share this information with others in hopes it will lead to more opportunities for success and better means of communication for these precious children who have Down syndrome.

APPENDIX A: Information Sheet

Information Sheet

Project Title: The Effects of Communication Disorders in Individuals with Down Syndrome.

Principle Researcher: Shelby Bradley, CMDS student at Ouachita Baptist University

Supervisors/Other Readers: Dr. Nancy Hardman, Professor Carol Morgan, Dr. Allyson Phillips

Contact Information: email: bra62053@obu.edu

Thank you for being willing to participate in this research study. Participation will involve a series of interview questions that will be videotaped upon permission given in the following forms. It is important to read the following information carefully and fill out all necessary information. If there is anything you do not understand or would like to discuss further, please ask the researcher or contact them through the email above.

Purpose of the Study:

The purpose of interviews for this study is to collect information from personal stories to add to research collected from other research studies and sources. The interview questions will consist of details pertaining to early life of the child, the communication disorders they have, steps taken to address these disorders, and advice and reflection on how to help individuals with Down Syndrome. All information gathered through these interviews and other research will go toward the development of a thesis paper that will be approved by the Carl Goodson Honors Council and will also be presented at OBU Scholar's Day. The hope is that this research project will give others a better understanding of the lives individuals with Down Syndrome lead along with communication disorders, academics, and relationships with others. Through obtaining this broader knowledge, people may more consciously communicate with individuals with Down Syndrome and look for ways that will help them better succeed in a variety of settings.

APPENDIX B: Informed Consent Form

Informed Consent Form

Information and Purpose: The interview for which you are being asked to participate in is a part of a research thesis that is focused on the effects communication disorders have on individuals with Down Syndrome and how to help them succeed in all aspects of life. The researcher is interested in hearing from families who have a family member with Down Syndrome and can first-hand respond to how communication disorders have affected the individual and with this information, how society can then help them better succeed. This study will be presented in a thesis paper and at OBU's Scholar's Day presentations.

Your Participation: Your participation in this study will consist of an interview lasting approximately half an hour. You will be asked at least ten questions along with background information regarding your experience with communication disorders in Down Syndrome and helping these individuals succeed. You are not required to answer the questions and may pass on a question at any time. At any time you may notify the researcher that you would like to stop the interview. There is no penalty for discontinuing participation.

Benefits and Risks: The benefit of your participation is contributing information to other families, students, educators, and speech-language pathologists regarding the effects of communication disorders on individual's with Down Syndrome and how to help them succeed. This may assist others in having a better understanding of Down Syndrome and how they can better communicate with and help these individuals be successful. There are no risks associated with participating in the study.

Confidentiality: The interview will be video-taped; however, names will not be recorded. Your name and identifying information will not be associated with any part of the written report or research unless previous permission is given. All of your information and interview responses will be kept confidential. The researcher will only share your individual responses with the research supervisors and those attending OBU's Scholar's Day presentations.

If you have any questions or concerns, please contact the researcher.

By signing below, I acknowledge that I have read and understand the above information. I am aware that I can discontinue my participation in the study at any time.

Signature: _____ Date: _____

APPENDIX C: Parent Permission Form

**Parent Permission Form
(for children under 18)**

I, _____

(first and last name of parent/guardian)

give permission to the researcher, Shelby Bradley, to interview and video tape

my child(ren) _____

(first and last name(s) of children)

for the purpose of fulfilling the Carl Goodson Honor's Program Senior Thesis

requirements and giving the researcher the ability to present the thesis at

OBU's Scholar's Day.

Parent Signature: _____ Date: _____

APPENDIX D: Video Release Form

Video Release Form

As a part of this research project, the participant will be videotaped while answering a series of interview questions. I would like you to indicate what use of this video you are willing to consent to by initialing below. You are free to initial any number of spaces from zero to all of the spaces and your response will in no way affect your credit for participating. The researcher will only use the video in ways that you agree to.

- **The interview can be videotaped by the researcher**

Please initial: _____

- **The video can be studied by the researcher for use in the research project.**

Please initial: _____

- **The video can be seen by supervisors involved in the research project.**

Please initial: _____

- **The video can be referred to in the researcher's written thesis paper.**

Please initial: _____

- **The video can be shown in public at OBU's Scholar's Day presentations.**

Please initial: _____

I have read the above description and give my consent for the use of the video as indicated above.

Signature: _____ Date: _____

APPENDIX E: Background Information

Background Information

1. Age of child: _____

2. Number of siblings: _____

3. Birth order of child: _____

4. Age of parents when child was born:

Father: _____

Mother: _____

5. Medical History Information:

APPENDIX F: Interview Questions

Interview Questions

1. Tell about when you were told your child has Down Syndrome.
Was it during pregnancy or after ____ was born? Who told you? How did they tell you? Where were you? Who was with you?
2. Tell me about your reaction(s).
3. Tell me what you knew about Down Syndrome before _____ was born.
4. Before you left the hospital, did an SLP talk to you or work with you or meet w/ you about what to expect down the road in regard to developmental milestones such as walking, talking, etc?
If yes, tell me about that experience.
If no, did anyone talk to you about the future? What did they tell you?
5. Coming home from the hospital, tell me about your first few months with ____.
6. Tell about the different therapies ____ has &/or continues to receive.
When did you start therapy? What was the main focus of these @ the beginning as compared to later?
7. Tell me about your experiences with ____ language skills.
What has been the biggest struggle? What continues to be difficult?
8. Tell me about educational experiences – starting w/ preschool or kindergarten to current.
What kind of education did they have or currently have? Public, special education?
9. Is there anything you would have done differently to help them better succeed?
If you could have a “do-over” in regard to __’s educational experiences, tell me about how or what you would do differently.
10. If a new parent w/ a child w/ Down Syndrome were to ask you for advice, tell me what you would say to them.
And specifically, what would you say to them about working with their child & other professionals to improve overall communication/language skills?
11. How have their language disorders affected the way you communicate with them?
Tell me what you wish others knew about communicating with your child.
What advice would you give to others about communicating with your child and helping them succeed?
12. Tell me what you think were the most beneficial in regard to helping ____ be more successful in communicating – w/ improving their overall language skills.

APPENDIX G: Institutional Review Board Human Subjects Application

**Ouachita Baptist University
Institutional Review Board
Human Subjects Review Application Cover Sheet**

Submission Date:

Project Title: Effects of Communication Disorders in Individuals with Down Syndrome.

Project Personnel

<u>Name</u>	<u>Dept.</u>	<u>School</u>	<u>Faculty, staff, student</u>
Principle Investigator			
Shelby Bradley	CMDS	Natural Sciences	Student

PI contact information:

e-mail- bra62053@obu.edu telephone- 501-4995604 campus box- 3086

Suggested project classification: Exempt _____ Nonexempt _____

Estimate of risk to subjects: None Low _____ Moderate _____ High _____

Proposed Project Dates: 12/01/19 to 04/24/20

Estimated number of participants 20

Funding Agencies or Research Sponsors: **Dr. Nancy J. Hardman, CCC-SLP**

Submission Status:

New Project
_____ Renewal or Continuation
_____ Change in Procedure for Previously Approved Project
_____ Annual Review
_____ Resubmission

Action of the Research Committee

Project Number _____ Approve _____
Approve with minor revision _____ Defer for revisions _____ Disapprove _____

Human Subjects Application Checklist

Detailed project description

Selection of subjects

- Method of recruitment & selection

Student researcher will gain permission from five families to participate in video interviews for the study. These families all include a child who has Down Syndrome.

- Recruitment advertisements or script

NA

- Demographics- Ages and gender, etc.

North Little Rock, AR

Conway, AR

Searcy, AR

Pyeongtaek, South Korea (Missionaries)

- Compensation

- Compensation conditions and schedule of payment

Participants will receive no compensation for participating in the study.

- Location and duration of experiment

A private, quiet environment for videoing (possibly my own home or participant's home) where interviewing will last at least 15-30 minutes.

- Investigator's relationship to subjects

Researcher's hometown is Conway, AR. Participants are known family friends varying from areas such as church, high school, and employment experiences.

- Alternatives to participation

Participation is voluntary.

Purpose of Study

To determine the effect of communication disorders for those with Down Syndrome and how to best support their communication efforts.

Research Procedures

- Physical/Behavioral aspects

NA

- Deception or Coercion

There is no intentional deception or coercion.

- Debriefing opportunities

Participants will be given the option of viewing results by attending the poster session presentations at Ouachita Baptist University during Scholars Day, April 2020.

Survey/Assessment Instrument(s)

The interviews will take approximately 30 minutes and will be video recorded for later transcription. Ten questions regarding the individual's experience with communication disorders, services, education, success, effect on the family and social life, and demographics (age, gender) will be asked to family members and the individual(s) with Down Syndrome.

Required policy statements

Benefits to the individual and to the university and to humanity

The research will allow this researcher the opportunity to compare family experiences from those who have a child with Down Syndrome. I hope it will raise awareness about the effect communication disorders have on these families and individuals as well as provide tangible ways to improve their communication skills to participate more fully in activities of their choosing.

Risks to the participant **No known risks.**

Comparison of risks and benefits **NA**

Procedures for minimizing risk **NA**

Procedures for maintaining confidentiality of data

Researcher will gain signatures on an Informed Consent document from each family participating.

Procedures for final disposition of data

As a requirement of the Carl Goodson Honors Program, the student researcher will participate in the Senior Thesis Poster Session presentation at Scholars Day at the end of next semester.

Conflict of interest statement

Elements of Informed Consent Included:

Informed Consent Form **X**

Parental permission form **NA**

Assent form for minors ages 7-17 **X**

Justification for waiver of consent or signed consent **NA**

Cover letter for mail surveys **NA**

Telephone script for telephone surveys **NA**

Information sheet **X**

Videotape/audiotape release form **X**

REFERENCES

- Baksi, Leela (2005). "Supporting people who have Down's syndrome to overcome communication difficulties." Down's Syndrome Association. Retrieved from: http://downsyndromedevelopment.org.uk/wp-content/uploads/2013/03/Overcoming_communication_difficulties.pdf
- Center for Disease Control and Prevention (2019). "Down Syndrome." Retrieved from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>
- Kingsley, Emily Perl. (1987). "Welcome to Holland."

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Lastly, I would like to thank the families that were willing to participate in this study. Without the understanding, transparency, and personal experience they freely offered, I would have never been able to complete a project such as this one. The level of admiration I have for you all is incomparable. Thank you for all of your help.