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**CONTINUITY AND SUSTAINABILITY WITHIN THE DISABILITY WORLD**

**By**

**JAIMEE SABATO, M.Ed.**

**A Dissertation**

**Submitted in Partial Fulfillment of the Requirements for the**

**Doctorate in Educational Leadership**

**Department of Education**

**Lynn University**

**May 2021**

## ABSTRACT

Raising a healthy child has its joys and challenges; however, raising a child or caring for someone with special needs brings a new set of obstacles. Parents and caregivers of children and individuals with special needs do not have the same selection of available resources as typical parents of healthy children. These challenges are approached with an entirely different perspective with its own joys and challenges that can be demanding. The purpose of this study was to research the usefulness of an iBook, *Navigating Life in the World of Disabilities*, by providing accurate and helpful information from an empirical approach with valuable stories, anecdotes, and information to be shared with those who face similar struggles. By researching the iBook's effectiveness, the researcher discovered that heightening awareness and educating others in this unique area led to a better understanding of ways to navigate the turbulent times while raising a child with special needs. It also increased the sensitivity and compassion of those inside and outside the disability world.

The researcher created an online survey using the Likert Scale and open-ended questions to determine the iBook's usefulness through qualitative research. The researcher decided what components the participants believed to be focal points and examined areas that needed to be included to create a well-rounded iBook that can be used as a valuable resource for those struggling with the same challenges.

Based on the survey results, the researcher concluded that iBook Navigating Life in the World of Disabilities is a useful resource that can assist parents and caretakers on the journey of raising and caring for a child and individual with special needs. This helpful guide can help provide the much-needed resource to parents, caretakers, and educators to help navigate the rough waters on the journey while raising a child with special needs. This iBook can also be translated into different languages and help broaden the community globally. Sharing struggles and offering beneficial advice can help the disability world grow, become stronger, and master any situation.

***Keywords:*** *special needs, disability, parents*

### **Acknowledgments**

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I would like to thank my parents for their endless support and belief in me. I just could not have done this without your love, support, understanding and patience. I am grateful to you for helping me with Allie whenever I needed it, and for telling me how proud I made you. Thank you for believing in me and giving me the strength, love and encouragement.

Finally, I dedicate this research to my children, Allie and UGS. You are my light and my inspiration, and you are both my reason why. Ulises Gabriel, your support encouragement from day one with your most amazing meals, helped get me through when I had class or was in my writing mode. Allie, your snuggles gave me strength, and Blanca, family, and friends for being a part of this journey. .

### **Dedication**

This dissertation is dedicated to my parents Terry and Lucienne Peters, my children Alexia Chiara and Ulises Gabriel Sabato.

This dissertation is also dedicated to those who have walked in my shoes and those who one day will. Your journey may be different than whatever you expected or hoped for, but always remember you are blessed. You may at times feel like you cannot continue, but you can. You may feel overwhelmed, but remember to take things one day at a time. You may feel alone but remember you are not. Roll with whatever comes your way. Lean on those around you who are your rocks. Enjoy the journey, all of it, because it is yours. And to Casey, though I never met you, your legacy lives on and continues to inspire to help heighten awareness and make a difference.

*Alone we can do so little; together we can do so much.*

*~Helen Keller~*

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## Chapter I: Introduction

### Personal Narrative

All I can remember from that day on July 24, 1996, was the overwhelming silence in the delivery room. I was exhausted from 12 hours of labor and the excruciating pain of my child's birth. All I wanted to hear was, "It's a healthy baby." Instead, the room was quiet. I remember Alexia's birth like it was yesterday, and it is hard to believe that it was over 24 years ago. "Where is the baby?" I asked my husband, who had a concerned look on his face. He kept saying, "she's coming, she's fine." I couldn't see what the doctors were doing but my husband could see her little body was purple and flaccid. There was no crying. After a short while, which felt like an eternity, my little bundle of joy rested on my belly and it was then that I met my beautiful daughter. I thought she was perfect. "Such a good baby, she isn't even crying," I thought, not realizing a healthy baby should be exercising her lungs. From that moment, nothing was typical or normal for my little girl. I didn't know it at the time, but we were embarking on the most challenging journey of our lives.

At two days old, Alexia stopped breathing and ended up in the Neonatal Intensive Care Unit (NICU) for weeks. I had to go home without my newborn. My husband and I fought back the tears as we drove home in silence with the empty baby car seat in the back. It was at the NICU that her journey of endless tests and inconclusive results began. We were told to take her home and given no guidance other than to follow up with a pediatrician. At home, Allie cried and cried. She was inconsolable. Doctors, family, friends told us she had colic, or maybe she was hungry. What we did not know at the time was that she was having dozens of seizures a

day, but all we saw were quick shakes as if she had been startled, followed by crying for hours on end.

Then, on Memorial Day, as we were all sitting outside, we heard a shrilly scream from Allie. Her carriage began to shake uncontrollably. I had no idea what was happening, but my husband, who is an adult neurologist, recognized immediately that she was having a grand mal seizure. At ten months, Allie was getting a full workup of tests from head to toe. All I remember from that period was going from doctor to doctor and getting no help. No doctor had any explanation for the seizures, which developed into what is called “infantile spasms” which interfere with brain development. One doctor warned us that Allie wouldn’t make it to her second birthday. Today I can tell you we lost the battle in the first year; the damage to her brain was irreversible. But we did not give up. Allie underwent 11 surgeries to curtail the seizures, which continue to this day, although less in severity and frequency. Over the years, she’s been given 26 different medications to help control the frequency of the seizures.

For more than 21 years, we have had to find ways to educate Allie, to give her the constant physical therapy, occupational therapy, and speech therapy she needs. When Allie was a baby, we hit so many dead-ends in the U.S. Therapy was only offered a couple of times a week, and even then, it was only 30 minutes per session. We also were not able to get the non-FDA drugs that she so desperately needed to stop the seizures, finally, upon hearing the news that she would not make it past her second birthday that gave me the gumption to look elsewhere and make a major life change. All out of options here in the states, Allie and I moved to Argentina for a few years to get her the kind of care and the medication she needed, at a fraction of the

price for therapy that was offered here. In addition, the medication she so desperately needed was accessible.

After a few successful years of therapy and medication, we returned to the US. Allie had entered into the public school system and remained there until she was 22. Allie still continued to have uncontrollable seizures during this time, and we were left with no other choice other than to have several brain surgeries. Navigating the disability world with physical ailments is one challenge, but we were dealing with a much more complicated situation than seizures as Allie had cognitive and physical disabilities as well. As a result of some medications needed for her seizures, Allie developed heart issues, pulmonary problems, and diabetes. I experienced first-hand what many parents do of special needs children. At the same time, I was met with constant struggles to fight for and find services, programs, therapists, nurses, and doctors. This fight became a full-time job along with caring for Allie.

As I look back on the 24 years I have dedicated to caring for Allie - it is my hope that what I have learned can be turned into an iBook that may give accurate and useful information, with stories and anecdotes to be shared with parents, caregivers, educators, family members, friends, and medical professionals, who face similar struggles. Heightening awareness and educating others in this unique area will lend itself to better understanding and compassion. I do not want any other parent to endure the same struggles that Allie or I dealt with. I wish at the time that there was a guide or a book that I could have followed to have helped me navigate the rough waters. Our struggles together helped us grow, become stronger, and master any situation that we faced. I did it on my own without any guide over this long course of time. The internet

20 years ago was not what it is today, and the resources are far greater, but finding useful/accurate resources amid the plethora of information is still no easy task.

Now that Allie has “aged out” from high school (graduated) and is too old to continue within the public school system, we are faced with new challenges. Allie, along with other young adults that are disabled find themselves lost without direction, and at home without a program. What happens to students that are severely and multiply disabled after they are required to leave the public school system due to their age? There are not enough programs in place and the ones that do exist are filled to capacity or have a long waiting list. The transitional process is daunting and overwhelming for parents and students alike. Something needs to be done.

### **Background of the Problem**

Parents, guardians, and families are tasked with creating care plans, fashioning, and equipping their homes, as well as navigate the disability terrain with little to no assistance (Aging & Disability: Addressing the Needs of a Growing Population 2019). This situation is compounded when the families are in lower socio-economic categories and must work two or three jobs without access to resources to continue to care for a child with special needs (Westling, 1997). In addition, across the United States, there is a gap in programs that offer services to individuals who “age out” of the special education programs before the age of 22. Though the transitional process is well established in the public school system (preparing a child in aging out) there are limited programs available for the severely disabled post-high school. This is significant because individuals that graduate from high school with services from

individual educational programs (IEP) do not have a new program to transition into after aging out of their high school programs. Once the student exits school, there are no defined pathways established and those with severe physical and intellectual disabilities end up staying at home after they graduate. This leads to a myriad of problems not only for the students (atrophy of muscles because of a decline of services for physical therapy, occupational therapy, speech therapy, and social interactions) but also for their families. Families are now the sole providers and individuals that are faced with 24 hours of caring for their child. The parent is now faced with the challenge of how they will care for their child while providing services that their child has been accustomed to and has been receiving through their school program for their entire life. Parents are also faced with a host of new challenges mentally, physically, and emotionally as they continue to hold a full-time job while caring for their child who is now at home.

### **What is Aging Out?**

“Aging out” of the public school system occurs just before the student’s 22nd birthday. (U.S. Department of Education: IDEA 2020) It is important to note that the Individuals with Disabilities Education Act (IDEA) is a law that provides free appropriate education to children with disabilities throughout the nation. This law provides special education and related services to those children that are eligible. IDEA governs how states and public agencies provide early intervention, special education, and services to more than 6.5 million eligible infants, toddlers, children, and youths with disabilities. Under IDEA part C, early intervention services are provided, followed by IDEA part B which provides special education and services for children and youth ages 3 - 21 or just before the student’s 22nd birthday. (U.S. Department of Education:

IDEA 2020) There is an exception for those students who are born in July or August as that child may be entitled to an extra year of schooling. The education entitlement ends at the end of the fiscal school year in which the child turns 21. (U.S. Department of Education: IDEA 2020)

IDEA requires schools to provide all students with a free education that is appropriate for the student and provided in the best environment. This might mean you take all general classes but go to a resource room for special help, or it might mean that you receive all instruction in general classrooms. IDEA serves students from ages 3 to 21 and requires transition services. School services under IDEA are something that every student with a disability is entitled to. This means that no matter who you are, what your income or your family's income is, or what kind of disability you have, the school is required to provide free, appropriate education. You are only entitled to these services, however, while you are still in school, typically until age 18 to 21. (U.S. Department of Education: IDEA 2020)

### **Facing the Demands of Raising a Child with Special needs: Coping Strategies, Ideas, Acceptance, Options and the Reality**

As joyous as the privilege is to be a parent, it still comes with its demands. However, when discussing parenting of an exceptional child, there are a number of additional layers of circumstances that require attention and there are a different set of rules. It is a completely different world and difficult to understand unless you live it or choose to live it; by becoming an advocate, working in the field, or adopting a child with special needs (SN). While much

research exists regarding mothers of children (e.g., Loukisas & Papoudi 2016) and older adults (e.g., Knox & Bigby 2007) with intellectual disability, there is a less in-depth exploration of their lived experiences with their son or daughter at the young adult stage. (Rieck, Shakespeare-Finch, Märtsin, & Knox, 2019)

There are different approaches, steps, and levels of acceptance. Some families embrace their situation, by including their child in all of the activities and participate in life alongside the family, as it should be. Others simply do not or cannot because they are incapable. Perhaps a parent may not possess the same coping skills as the other. There might be a parent who embraces the circumstance and the other does not have the capacity to deal with it. Or, in some unique cases, it might be considered a failure if a parent gives up. Perhaps it is due to a lack of resilience and the inability to accept or cope with their situation. It is important to recognize that this is not a judgment call, rather it depends on a host of different factors. When dealing with the special needs world, it is important to remember the unspoken rule of non-judgment. Humans possess various coping skills and what makes us unique are the ways we choose to deal with things. The way in which a parent addresses his unique situation depends on their own life experience which includes a variety of different factors including but not limited to: core values, beliefs, ideas, upbringing, family support, financial accessibility, awareness, relationships, philosophies, and social environmental acceptance to name a few. “ Resilience implies rather more than merely coping with a situation. For Hawley & DeHaan (1996) it suggests a capacity to surface in the face of hardship in ways conducive to well-being. ‘Thriving’ might be more suitable for describing families in these situations, as suggested by Dykens (2005). However,

resilience reflects a primary concern for the accomplishment of wellness in the face of difficulties.” (Grant, Ramcharan, & Flynn, 2007)

When expecting your first child, there are a number of books to help guide you through your pregnancy and advise you of what to be expecting or anticipating in your first year of life with your child. Yet, when it comes to the child with special needs, and what to expect before, during, and after, resources are limited and few are available. There is a need to have a book in place that can help navigate not just at the beginning of birth, but through the years and into adulthood. As a mother of a special needs child, I see the need for a book, a book to explore and address everything that parents would want and need to know when they have a child with special needs. An interactive book may be helpful to access information immediately to help guide and offer advice to those parents, caregivers, family members, and educators that are dealing with similar sensitive issues. Perhaps even a story of a similar situation that was experienced before to lend a new perspective and relate to the situation that they are going through. Presently, there are no iBooks to offer such information in one place. This iBook would offer free immediate access and address up to date issues for families experiencing life with a special needs child. Since early intervention of mental health for the parent is paramount to the success of the care for the child, a special area in the book will be dedicated to mental health issues of the parents and siblings as a result of the stressors they experience with the demands of a child of special needs.

**Purpose**

The purpose of this dissertation in practice is to survey parents, caregivers, educators, families, and friends of individuals with special needs and determine if this iBook is useful by examining what areas are missing, and areas that still need to be addressed. Once successfully completed this iBook may be a free resource offered to the public to provide free useful and meaningful tool available to those that may need guidance. This book may be beneficial to parents, caregivers, families, and educators, in the same situation. The book may also be beneficial to those entering the field of special education and advocacy, or to those living with a similar experience. This iBook may offer solutions, ideas, and practical pieces of information to parents coping with the demands of a special needs child or a chronically ill child. It may offer a broad view of different issues and may provide potential interventions and suggestions in achieving a buoyant positive approach to life and navigating situations that may arise. The strain on relationships both personal and work-related are affected on many levels and parents need support, techniques, and tools to identify common stress triggers that can be avoided (Kish et al., 2018). According to the Centers for Disease Control and Prevention, 15 percent of U.S. families have a chronically ill child with special needs. The researchers found that the demands of care created greater stress than the severity or length of their child's illness (Cousino & Hazen, 2013). When raising a child with special needs, there are additional demands in addition to the typical needs of parenting. Additional responsibilities may include therapy appointments, doctor appointments, and also special medical treatments. In many of these cases, parents reported suffering added stress from watching their child in pain, and from worrying about the child's

vulnerability and explaining the health problems to those outside the family (Cousino & Hazen, 2013).

The purpose of this study is to get expert opinions to determine how useful this iBook, *Navigating Life in the World of Disabilities* is and what additional material should be included or excluded. The goal of this study is to provide an iBook that may assist parents, caregivers, family members, educators, and guardians by offering problem-solving solutions for navigating the world surrounding special needs. This iBook may offer options and ideas to families with individuals that have severe disabilities. This iBook may offer assistance addressing a host of issues and challenges faced by the family and their child. The goal of this interactive iBook addresses the child's journey from birth to diagnosis, and span through the educational years to "aging out at 22" of the school system. The purpose of this study is to review this iBook to ensure that all important topics are covered in a dignified and thorough manner. The intent of the researcher is to provide guidance on a variety of areas including how to create a safe place where they can receive necessary therapies (occupational, physical, and speech therapy ) and continue to grow and participate in the community in which they live to have a fruitful life experience. The iBook may also examine the demands of raising an exceptional child and the importance of mental health on the parents and family. Feedback from the research from the study will help guide and synthesize the most common issues as well as address more complex issues.

### **Significance of Study**

Presently, there are no iBooks to offer such information in one place. This iBook may offer immediate access and address up to date issues for families experiencing life with a special

needs child. Since early intervention of mental health for the parent is paramount to the success of the care for the child. A special area in the book will be dedicated to mental health issues of the parents and siblings as a result of the stressors they experience with the demands of a child of special needs. In addition, there are not many transition programs to support the various levels of disabilities that exist. There is an early intervention program followed by the public educational ESE program which addresses K - 12th grade. In the State of Florida, there are several transitional programs for 19 - 22-year-old students with disabilities. These transitional programs are geared toward students who are coming from ESE programs that are on the higher-functioning spectrum of the disabled population. These transitional programs all have the same goal which is to teach skills so that the students can learn appropriate work-related behaviors and social skills. At the end of the program, the main goal is to help these individuals integrate into society in a meaningful way. The programs are designed for students with disabilities who have a goal of employment and are in their last year of high school. They must also demonstrate social and communication skills, have independent toileting and feeding skills, and meet necessary requirements. Program goals are to support students in becoming independent, contributing members of the community, and in gaining and maintaining employment. However many parents of students with IEPs have experienced frustrations with the transition process after high school. This is due to the fact that the transition programs do not address all of the needs of the severely disabled. There is a concern regarding the lack of information concerning transition planning and adult services. Integrated referral systems for health and social care need to be developed, with links to clear care pathways and individual and systemic outcomes should be monitored (Bhaumik et al., 2011). What about those students who

are not high functioning and are not able to participate on the same level in these transitional programs? What happens to them and how can they participate in society with meaning and purpose? Presently, there are very few programs that are available such as ARC, Exceptionalities, Florida Mentor, United Community Options, and Sunrise Community. However, the only programs that remotely address this specific population are the United Community Options program and the Sunrise Community. These programs teach individuals with varying exceptionalities to become more independent and contributing members of society. Note that there are waiting lists for these institutions which can take years. What is a parent to do in the meantime?

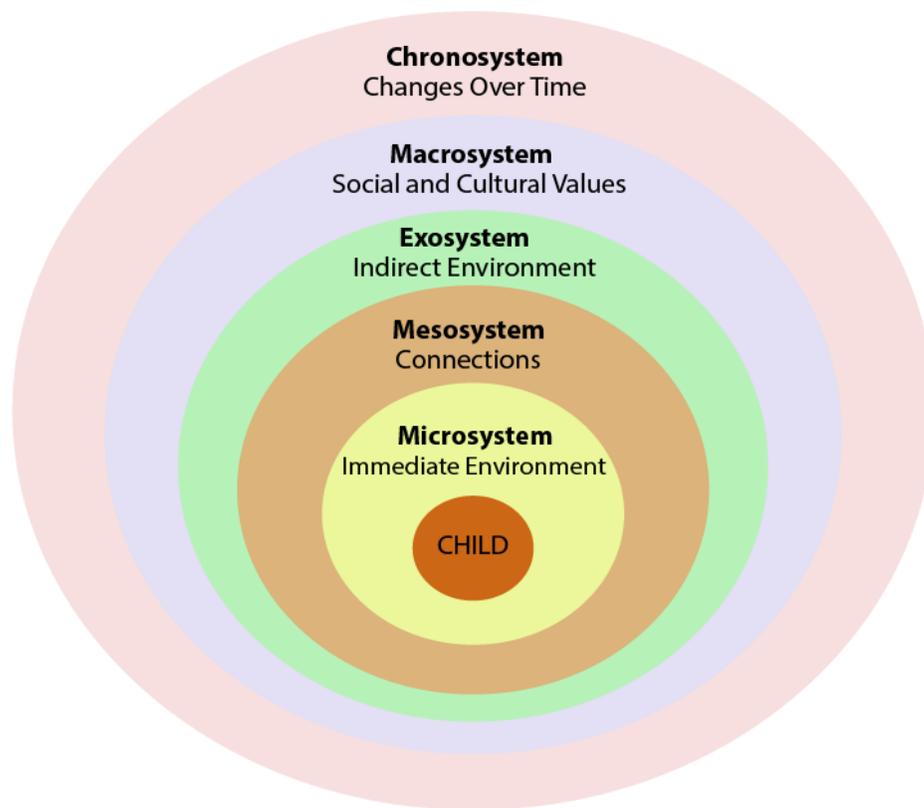
### **Theoretical Framework**

This research is enfolded in the theoretical framework of Bronfenbrenner's Ecological Systems Theory (1990). **Microsystem:** Refers to the institutions and groups that most immediately and directly impact the child's development including family, school, religious institutions, neighborhood, and peers. **Mesosystem:** Consists of interconnections between the microsystems, for example between the family and teachers or between the child's peers and the family. **Exosystem:** Involves links between social settings that do not involve the child. For example, a child's experience at home may be influenced by their parent's experiences at work. A parent might receive a promotion that requires more travel, which in turn increases conflict with the other parent resulting in changes in their patterns of interaction with the child. **Macrosystem:** Describes the overarching culture that influences the developing child, as well as the microsystems and mesosystems embedded in those cultures. Cultural contexts can differ based

on geographic location, socioeconomic status, poverty, and ethnicity. Members of a cultural group often share a common identity, heritage, and values. Macrosystems evolve across time and from generation to generation. Chronosystem: Consists of the pattern of environmental events and transitions over the life course, as well as changing socio-historical circumstances. For example, researchers have found that the negative effects of divorce on children often peak in the first year after the divorce. By two years after the divorce, family interaction is less chaotic and more stable. An example of changing sociohistorical circumstances is the increase in opportunities for women to pursue a career during the last thirty years. Figure 1 below represents Bronfenbrenner's Ecological Systems Theory and the relationship to the current study.

(Figure 1.)

### Bronfenbrenner's Ecological Systems Theory



**Research Questions**

RQ1: In what ways would an interactive guide iBook be helpful for individuals navigating the disability world?

RQ2: How useful would this guide be for the general public in helping caregivers to assist those with disabilities?

RQ3: Given a draft of an iBook as a resource for navigating the disability world, what components are missing that would make this iBook useful? What additional information needs to be added for parents, families, and caregivers of children and adults with severe disabilities?

**iBook - Product**

The researcher created an iBook to assist parents and families of children and adults with severe disabilities and would like to get feedback from the experts, parents, and families that have the lived experience of creating a viable environment for their children. This iBook may provide a how-to resource that offers information to help parents, caregivers, families, and educators understand how to navigate and face challenges with an expert who has walked the path before them. It may offer a sense of comfort and belonging as well as useful tips, suggestions, and resources that can be used to make life living with a child with special needs easier.

**Limitations of the Study**

Limitations of the study that identify potential weaknesses of the research include the following: Potential limitations of the study may be the possibility of non-responders, as well as

interviewees having a personal affiliation with the interviewer due to the interviewers previous and current involvement as a participant as a board member of a foundation or organization (FACES Finding a Cure for Epilepsy and Seizures) and Horses for the Handicapped.

Additionally, the interviewee may feel compelled to answer a certain way because of the interviewer's bias according to Hawthorne's effect (Mccambridge et al., 2014). Additional potential limitations may be participants answering the survey and participating in the interview without reviewing the book or reading the book and not participating in the survey or interview and finally, the sample size may not be generalizable as the number of participants will be between 5 - 25 participants. Due to COVID 19 and distance of participants, methods that will be utilized to conduct research will be limited to an online platform and in-person and face to face interaction is limited.

### **Definitions of Terms**

**Accommodation:** This is a change to or in a student's learning environment. Accommodations help students learn and show what they've learned by removing barriers. For instance, students who take longer to answer questions because of learning differences might be allowed extra time to take a test. Even with accommodations, students are expected to learn the same content as their peers.

**Aging out:** When a student reaches the age of 22 and is no longer a responsibility of the school district.

**Annual goals:** The IEP document lists the academic and functional (every day) skills the IEP team thinks a student can achieve by the end of a school year. These goals are geared toward

helping students take part in the general education curriculum. IEP goals need to be realistic and measurable. Many schools write SMART goals. (SMART stands for Specific, Measurable, Attainable, Results-oriented and Time-bound.)

**Assistive technology (AT):** Any device, equipment, or software that helps students learn, communicate, and function better in school. AT ranges from simple tools (like highlighters) to high-tech software (like apps that read text aloud).

**Behavior Intervention Plan (BIP):** A plan designed to proactively teach and reinforce positive behavior. Typically, the plan uses strategies to prevent and address behavior that gets in the way of learning. It may also have supports and aids for the student. A BIP is often included as part of an IEP.

**Due Process Safeguards** - Schools must provide due process safeguards to protect the rights of children with disabilities and their parents. Parental consent must be obtained for initial and all subsequent evaluations and placement decisions regarding special education. Schools must maintain the confidentiality of all records pertaining to a child with disabilities and make those records available to the parents. When parents of a child with disabilities disagree with the results of an evaluation performed by the school, they can obtain an independent evaluation at public expense.

**ESE- Exceptional Student Education** – The purpose of ESE is to help each child with a disability progress in school and prepare for life after school. ESE services include specially designed instruction to meet the unique needs of the child. The special help they are given at school is called exceptional student education (ESE). The purpose of ESE is to help each child with a disability progress in school and prepare for life after school. ESE services include

specially designed instruction to meet the unique needs of the child. ESE services may also include technology devices, therapy, special transportation, or other supports. There is no charge for ESE services. A team of people makes decisions about the child's needs and ESE services. The child's parents are part of this team (Florida Dept of Education, 2020).

**Individuals with Disabilities Education Act (IDEA)**- The federal law that was signed into law in 1975 by President Gerald Ford. The tenets of the law are to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living; to ensure that the rights of children with disabilities and parents of such children are protected; to assist States, localities, educational service agencies, and Federal agencies to provide for the education of all children with disabilities; to assist States in the implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families; to ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting system improvement activities; coordinated research and personnel preparation; coordinated technical assistance, dissemination, and support; and technology development and media services; to assess, and ensure the effectiveness of, efforts to educate children with disabilities.

**Individual Education Plan** - specifies the child's unique educational needs, states present levels of performance, identifies measurable annual goals and short-term objectives, and describes the specific special education and related services that will be provided to help the child attain those goals and benefit from education.

**Least Restrictive Environment (LRE)-** IDEA mandates that students with disabilities be educated with children without disabilities to the maximum extent appropriate and that students with disabilities be removed to separate classes or schools only when the nature or severity of their disabilities is such that they cannot receive an appropriate education in a general education classroom with supplementary aids and services.

**Supplementary aids and services:** These are support services to help students learn in the general education classroom. They can include equipment or assistive technology, like audiobooks or highlighted classroom notes. They may also include training for staff members to help them learn how to work with students based on their specific needs.

**Related services:** Any support services a student needs to benefit from special education. One possible example is transportation. Another is occupational therapy.

**Transition plan:** This part of the IEP lays out what a teen will learn and do in high school in order to thrive as a young adult. The IEP team and the student develop the plan together before it kicks in at age 16. The transition plan includes goals and activities that are academic and functional. But they extend beyond school to practical life skills and job training. (Lee, 2020)

## **Summary**

Presently there is little to no assistance, or iBook that is available that may help parents, guardians, and families of children and adults with severe disabilities create care plans by fashioning, and equipping their homes, as well as navigate the disability terrain (Baumbusch et al., 2018). This situation is compounded when the families are in lower socio-economic categories and must work two or three jobs without access to resources to continue to care for a

child with special needs. In addition, extra demands on parents of chronically ill children cause stress that affects the whole family, according to a systematic review conducted by Case Western Reserve University, (date). The theoretical framework used for purposes of this study will be Bronfenbrenner's ecological theory. It is an appealing conceptual tool for this study as it may provide guiding public health information, interventions and opinions in order to constructively assess the usefulness of the iBook as it addresses simple answers to complicated questions. The researcher created an iBook to assist parents and families of children and adults with severe disabilities and would like to get feedback from the experts, parents and families that have the lived experience of creating a viable environment for their children.

## Chapter II: Literature Review

### Introduction

This research study seeks to fill the gap in assistance to parents and guardians that care for children, youth, and adults with severe disabilities by creating an interactive iBook to assist in the care of these individuals. The intent is to create a product with the expertise of families that navigated this lived experience. The remainder of this chapter will outline the various complexities that families experience when caring for individuals with severe disabilities.

### Background and Historical Overview

In September of 1973 Section 504 of the Rehabilitation Act became law as the first national law to prohibit discrimination against people with disabilities. (Florida, *News Room* 2013). This movement changed history and then paved the way for the 1990 Americans with Disabilities Act, and the Individuals with Disabilities Education Act (IDEA).

*“The individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children.*

*The IDEA governs how States and public agencies provide early intervention, special education, and related services to more than 7.5 million (as of school year 2018-19) eligible infants, toddlers, children, and youth with disabilities.*

*Infants and toddlers, birth through age 2, with disabilities and their families receive early intervention services under IDEA Part C. Children and youth ages 3 to 21 receive special education and related services under IDEA Part B. In 2004 Congress amended the IDEA through Public Law 114 - 95, the Every Student Succeeds Act, and December 2015.” (About IDEA, n.d)*

*In the law, Congress states:*

*Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities. (About IDEA, n.d.)*

Children with disabilities and their families continue to face significant barriers to accessing inclusive high quality early childhood programs and too many preschool children with disabilities are only offered the option of receiving special education in setting separate from their peers without disabilities. (U.S. Department of Education, 2015)

It is for this reason that a guide would be helpful and assisting families that are caring for individuals with special needs

### **Aging Out Historical Overview**

According to a 2017 Disability Statistics Report, 12.5% of the population in the state of Florida is disabled (Institute on Disability, 2018). However, there are not many programs to support the various levels of disabilities that exist. There is an early intervention program followed by the public educational ESE program which addresses K - 12th grade. In the State of Florida, there are several transitional programs for 19 - 22-year-old students with disabilities. These transitional programs are geared toward students who are coming from ESE programs that are on the higher-functioning spectrum of the disabled population. These transitional programs all have the same goal which is to teach skills so that the students can learn appropriate work-related behaviors and social skills. There are several programs that offer a variety of different classes, each with their own objectives. At the end of the program, the main goal is to help these individuals integrate into society in a meaningful way. The programs are designed for students with disabilities who have a goal of employment and are in their last year of high school. Students must be at least 18 years-old, demonstrate a desire to work and be able to follow directions. They must also demonstrate social and communication skills, have independent toileting and feeding skills and meet dress code requirements. Program goals are to support students in becoming independent, contributing members of the community and in gaining and maintaining employment. Once the students finish this transitional program, they are placed into an appropriate job in which they can participate in the community. However “many parents of students with IEPs have experienced frustrations with the transition process after high school. This is due to the fact that the transition programs do not address the needs of the severely disabled” (Ragan, 2018).

**Parent Perspective of Aging Out**

According to Burell (2011), his wife had to “give up her job to become a fulltime fighter for their daughter, who is blind, unable to walk or talk and suffers from complex epilepsy. Every day, week and month, there were meetings with doctors, nurses, teachers, therapists, social workers and council officials. Burell also said that during 15 years of our daughter’s life, he and his wife were pushed close to breaking point, caring for a child with complex needs and a life-threatening condition. He concluded in saying that, “ Hopefully we are learning from the mistakes of the past, so that life is made easier for the next generation of children with disabilities and their parents” (Burell, 2011).

What about those students who are not high functioning and are not able to participate on the same level in these transitional programs? What happens to them and how can they participate in society with meaning and purpose? What programs are in place for the disabled dependent population? Presently, there are very few programs that are available such as Association of Retarded Children, Exceptionalities, Florida Mentor, and United Community Options. However, the only program that remotely addresses this specific population is the United Community Options program. This program teaches individuals with varying exceptionalities to become more independent and contributing members of society. Individuals participate in meaningful day training and recreational activities that strive to honor consumer choice and promote independence. Daily living skills including social and behavioral skills, money management, fitness and health, and self-advocacy are key components to program success. United Community Options has a large fleet of vans for transporting individuals and is available in most areas in South Florida (Ragan, 2018).

In South Florida, there is a need for a daily program that services the needs of the severely disabled 22-year-olds that age out of their transitional programs and that are cognitively and physically disabled. These individuals are unable to be placed in the workforce environment because of their special needs and limitations. However, these individuals need a program that can help them participate in life in a meaningful and productive way. Presently there are no programs in place for these severely disabled young adults. These individuals are in need of a program that provides services including; occupational therapy, speech therapy, and physical therapy to name a few. In addition to these services, additional services such as music therapy, art therapy, hydrotherapy, hippotherapy, socialization therapy, and animal therapy can be included as well.

### **Programs that assist families of children and adults with severe disabilities**

Below are a few organizations listed that may be contacted for those that are dealing with a child or young adult with special needs. In addition, these organizations are always interested in those who are seeking to help or volunteer their time.

#### **Council for Exceptional Children**

The Council for Exceptional Children is the largest international professional organization dedicated to improving the educational success of children with disabilities. By advocating for successful governmental policies, setting standards for professionals in the education industry, and providing professional development seminars, the organization helps

teachers, administrators, parents, related students and other educational support staff to best support and educate the children with special needs with whom they work.

### **National Youth Leadership Network**

Led by young citizens, the National Youth Leadership Network works to build strength and "break isolation" among people with disabilities who are between the ages of 16 and 28. They try to create a culture of full inclusion, sparking new ideas about how to measure success and ability and supporting youth with disabilities in leadership roles. The group hosts workshops around the country for young people to learn how to develop leadership skills.

### **National Collaborative on Workforce and Disability for Youth**

NCWD/Youth focuses on young teens and helps them to learn how to cope with their disability and find their place in the workforce. The group also teaches kids to access the education they need. Once the young adults are able to achieve their educational and employment goals, NCWD/Youth works to assist them with living as independently as possible.

### **The M.O.R.G.A.N. Project**

The M.O.R.G.A.N. Project stands for Making Opportunities Reality Granting Assistance Nationwide. This group, established by parents Robert and Kristen Malfara, supports families in their journey of raising a child with special needs, be that child biological, adopted or within the foster care system. In addition to having a large library of resources and information on their website, the group also assists families with travel expenses for medical treatments and gifts of medical equipment that aren't covered by insurance, such as wheelchairs. It works to create a group of parents who are supportive of each other in difficult times.

### **Federation for Children With Special Needs**

Headquartered in Boston, the Federation for Children with Special Needs is a national organization that provides information, support and assistance to parents of children with disabilities, their professional partners and their communities. By allowing these families to more fully participate in community life, children with special needs are able to grow to their full potential. The Federation promotes the active and informed participation of parents of children with special needs in shaping and influencing public policies that affect their families. The peer support network the group provides allows for families to meet with those who can relate and understand.

### **Family Voices**

Family Voices, which, according to the Parenting Advocacy Network, aims to achieve family-centered care" for all children with special needs. Family Voices provides families with the "tools to make informed decisions" about healthcare and education, build partnerships between families and their service providers and serve as a trusted resource on healthcare. They also help families learn to advocate for improved policies to best serve children with special needs. One of their main goals is to empower young people with disabilities so that they may become self-advocates for various causes that affect those with special needs.

### **Parent to Parent USA**

Parent to Parent USA is a group that matches each parent with a fellow parent who has a child with the same special healthcare need, disability or mental health concern, allowing each parent or family to have a contact for sharing information, receiving support and creating new friendships. Parent to Parent USA has local groups in almost all states and is great for connecting families with each other for emotional support.

**Disabled Sports USA**

Everyone deserves to have a fun time playing sports, according to Disabled Sports USA. Founded by injured Vietnam War veterans, the organization has expanded to anyone with a permanent disability who wants to play sports but hasn't been able to in a standard setting. Using sports as rehabilitation, many children and young adults with special needs gain confidence and dignity through their teamwork and active exercise. Disabled Sports USA also works with the United States Olympic Committee to help choose athletes to compete in the Paralympics.

**Best Buddies**

Best Buddies is a great organization for helping kids with special needs develop friendships and stay social,” says Dr. Jen Trachtenberg, a board-certified pediatrician in New York City. Best Buddies works to end the “social, physical and economic isolation of the 200 million people with intellectual and developmental disabilities” by helping them form meaningful one-to-one friendships with peers. Through these relationships, Best Buddies works to help those with special needs improve their communication skills, secure jobs and develop the necessary skills to live independently.

**Friendship Circle**

Friendship Circle emphasizes the importance of friendship in the special needs community. Friendship Circle, which has locations throughout the country, pairs teen volunteers with a child with special needs in order to form “lasting friendships” and help teens reap the

rewards of “selfless giving.” Most programs take place either after school or on Sundays but include a number of sports, activities, social circles and trips for older kids. (Care.com, 2020)

### **The Arc (Association for Retarded Citizens)**

The ARC is to promote and protect the human rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community throughout their lifetimes.

### **The Unicorn Foundation**

The mission of the Unicorn Foundation is to redefine what is possible by creating cradle to career pathways that help kids and young adults with special needs excel in their communities.

### **United Spinal Cord Foundation**

The United Spinal Cord Foundation Association is a national 501(c) (3) nonprofit membership organization dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders by providing support and information to loved ones, care providers and professionals.

### **Funding & Grants Available For Families With Children and Young Adults With Disabilities**

There are several organizations that provide funding and grants for children and young adults with disabilities. These organizations cover a wide array of funding purposes such as therapy, equipment, accessibility, medications, recreational opportunities, and many other items and services. These organizations have certain grant/funding criteria; therefore it is important to check their website for further funding details.

**Challenged America**

Challenged America offers funding to disadvantaged, physically or developmentally challenged children (or their parents). You can submit requests for medical attention, rehabilitative therapy, and/or assistive devices they would otherwise be unable to obtain. The benefits to the children go far beyond the physical. Assistance from Challenged America can improve their quality of life, help them gain confidence and self-esteem, and ease their reentry into the community.

**Disabled Children's Fund**

Disabled Children's Fund (DCF) is a humanitarian organization committed to serving the indigent and oppressed children and their families worldwide. Disabled Children's Fund provides about two million dollars' worth of humanitarian services annually at no charge for children and adults and provides braces, wheelchairs, crutches, walkers, and rehabilitative services globally.

**The First Hand Foundation**

The First Hand Foundation is a public 501(c)(3) organization that provides funding for individual children both domestically and globally who need assistance with clinical necessities (such as surgery, medication and therapy), medical equipment and travel related to care. They provide both domestic and global funding.

**Giving Angels Foundation**

The mission of the Foundation is to assist special needs children with a physical disability or illness aged 21 or younger throughout the United States. The Foundation awards grants to lower income families to enhance the everyday life of the child. Funds are awarded on a case by case basis. Families who wish to receive assistance must complete an application and

demonstrate financial need. Applications are accepted throughout the year. Grants are only to be awarded once per child (for clarification, families who have multiple children who qualify are eligible to be awarded once per child)

### **Gracie's Hope Inc.**

A non-profit organization committed to help improve the lives of children with special needs. They help provide funding for therapies such as, but not limited to, PT, OT, Speech, Chelation, and Hyperbaric Oxygen Therapy. They also help provide needed equipment and assist families in finding respite care, and other needed services.

### **The Kiddie Pool**

The Kiddie Pool program is an online fundraiser. Your family joins the program and a custom webpage is created for your child with special needs. Included on the webpage is a photograph of your child, your child's story, products desired for your child and fun facts about your child. This webpage is designed to be shared with friends and family through an email campaign. Once friends and family members visit your child's webpage, they can read about your child and learn about the products he/she needs. They can then make a donation for your child that will be put into an account on [Adaptivemall.com](http://Adaptivemall.com). You will receive an email each time someone has donated to your child's fund so that you can keep track of where you are with your goal. Once your child has received enough donations, you can redeem them for the products desired.

### **Kiddos' Clubhouse Foundation**

Kiddos' Clubhouse Foundation provides therapy scholarships to help families pay for critical therapies.

**Maggie Welby Foundation**

Offers grants for children and families that have a financial need for a particular purpose. Grants may extend to children and families in need of help with bills, athletic opportunities, medical needs, or an opportunity that a child would not otherwise have. All grants are awarded to the family but are paid directly to the specific purpose for which the grant was applied.

**National Downs Syndrome Society**

The National Down Syndrome Society is the leading human rights organization for all individuals with Down syndrome. <https://www.ndss.org/>

**Parker's Purpose Foundation Assistance**

Parker's Purpose Foundation Assistance offers funding/grants to any family who has a minor (18 and under) with a life altering illness or disability that is in an immediate financial crisis due to unforeseen medical expenses. Families who live in Ohio will be first priority in providing assistance but will extend outside the state if deemed necessary.

**Prayer Child Foundation**

The Foundation seeks to provide assistance to living children that are eighteen years old and younger with physical and emotional challenges. The Foundation provides support to national children's charities, individuals and organizations located within supporters' local communities.

**Sunrise Foundation**

Sunrise is one of the largest, private 501(c)(3) not-for-profit organizations in the country dedicated to serving people with intellectual and developmental disabilities. Much of the organization's early growth can be attributed to assisting state agencies with deinstitutionalization efforts, and in more recent years, Sunrise has welcomed smaller companies in need of assistance or support into the Sunrise Group. As a result, over the last 50 years Sunrise has increased the number of persons served from 50 people in just South Florida to over 2,000 across several states with over 3,000 exceptional employees. Sunshine Foundation answers the dreams of chronically ill, seriously ill, physically challenged and abused children, ages three to eighteen, whose families cannot fulfill their requests due to the financial strain that child's illness may cause.

#### **UnitedHealthcare Children's Foundation**

UnitedHealthcare Children's Foundation is a 501(c)(3) non-profit charity dedicated to facilitating access to medical-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child and that are not fully covered by the available commercial health benefit plan. This "support" is in the form of a medical grant to be used for medical services not covered or not completely covered by commercial health benefit plans. <http://www.uhccf.org/>

#### **Variety the Children's Charity**

Variety's Freedom Program delivers vital life-changing equipment and services for mobility, independence and social inclusion to individual children and children's organizations. Together through the Freedom program, we change children's lives by granting items and

services that provide independence, mobility and freedom. Grants under the Freedom program are made to individual children and children's organizations. <http://usvariety.org/>

### **Wheel to Walk Foundation**

A non-profit organization that helps children and young adults (20 years and younger) with disabilities obtain medical equipment or services that is not provided by their insurance companies. We purchase items such as therapy tricycles, adaptive strollers, shower chairs, pumper cars, zip zac chairs, selective communication devices, gait trainers, speech therapy and wheelchairs, to name a few. Our organization strongly believes that no child or young adult with special needs go without items that could improve the quality of his or her daily life. If you live in Oregon, Washington, Idaho or California and need assistance with anything from leg braces, bath chairs, gait trainers to therapy tricycles and wheelchairs, please contact us.

<http://www.wheeltowalk.com/>

### **Wheelchairs 4 Kids**

Although our name may be Wheelchairs 4 Kids, our plan involves so much more than providing wheelchairs for America's disabled children. Our goal is to give every child with mobility challenges the best opportunity to live life at its fullest. Wheelchairs 4 Kids will help them by providing not only well fitted, well equipped wheelchairs, but also assist with ramps, wheelchair lifts, home modifications and hopefully in the future, playgrounds. <http://wheelchairs4kids.org/>

(United Spinal Resource Center - United Spinal Association 2020)

### **National Autism Association**

The mission of the National Autism Association is to respond to the most urgent needs of the autism community, providing real help and hope so that all affected can reach their full

potential. NAA achieves its mission through six areas: advocacy, research, education, direct tools (direct tangible tools to families and schools in all fifty states) thoughtful awareness, and hope.

<https://nationalautismassociation.org/>

### **LDonline.Org**

LD OnLine seeks to help children and adults reach their full potential by providing accurate and up-to-date information and advice about learning disabilities and ADHD. The site features hundreds of helpful articles, multimedia, monthly columns by noted experts, first person essays, children's writing and artwork, a comprehensive resource guide, very active forums, and a Yellow Pages referral directory of professionals, schools, and products.

More than 2.9 million school-age children in the United States – approximately five percent of the student population – are diagnosed with learning disabilities. Many more struggle in school but never receive a formal diagnosis. LD OnLine provides educators with accurate, authoritative information about learning disabilities so they can obtain the help they need.

LD OnLine also serves adolescents and adults with learning disabilities. Our site offers information and resources on the transitions from school to college and from school to the workplace, and on the issues faced by adults with learning disabilities.

LD OnLine is a national educational service of WETA-TV, the PBS station in Washington, D.C.

### **Understood.Org**

Understood.Org is dedicated to growing and shaping a world where everyone who learns and thinks differently feels supported at home, at school, and at work; a world where people with

all types of disabilities have the opportunity to enjoy meaningful careers; a world where more communities embrace differences.

### **Council of Parent Attorneys and Advocates - COPAA**

COPPA's mission is to protect and enforce the legal and civil rights of students with disabilities and their families. Our primary goal is to secure high quality educational services and to promote excellence in advocacy. COPAA works to: Enable parents to work more effectively with school personnel to plan and obtain effective educational programs for their children with disabilities; Encourage more attorneys and advocates to undertake representation of parents of children with disabilities in their efforts to plan and obtain effective educational programs; Provide advocate, attorney, parent and other professional COPAA members with the practical resources and information they need to obtain effective educational programs for students with disabilities; Enable members to network and share information and legal resources; Provide training for special education advocates on all aspects of special education advocacy and informal conflict resolution; Provide training for attorneys on legal practice: including due process, litigation, and informal conflict resolution; Enable parents to locate advocates, attorneys, and related professionals through COPAA's website directory; and file amicus curiae briefs in cases of national significance. <https://www.copaa.org/default.aspx>

### **Finding a Cure for Epilepsy and Seizures - FACES**

The mission of FACES is to improve the quality of life for all those affected by epilepsy and seizures. FACES is affiliated with NYU Langone Health and its Comprehensive Epilepsy

Center. FACES funds research to improve epilepsy care, advances new therapies, and fosters a supportive community for children, families and caregivers who live with the challenges of epilepsy.

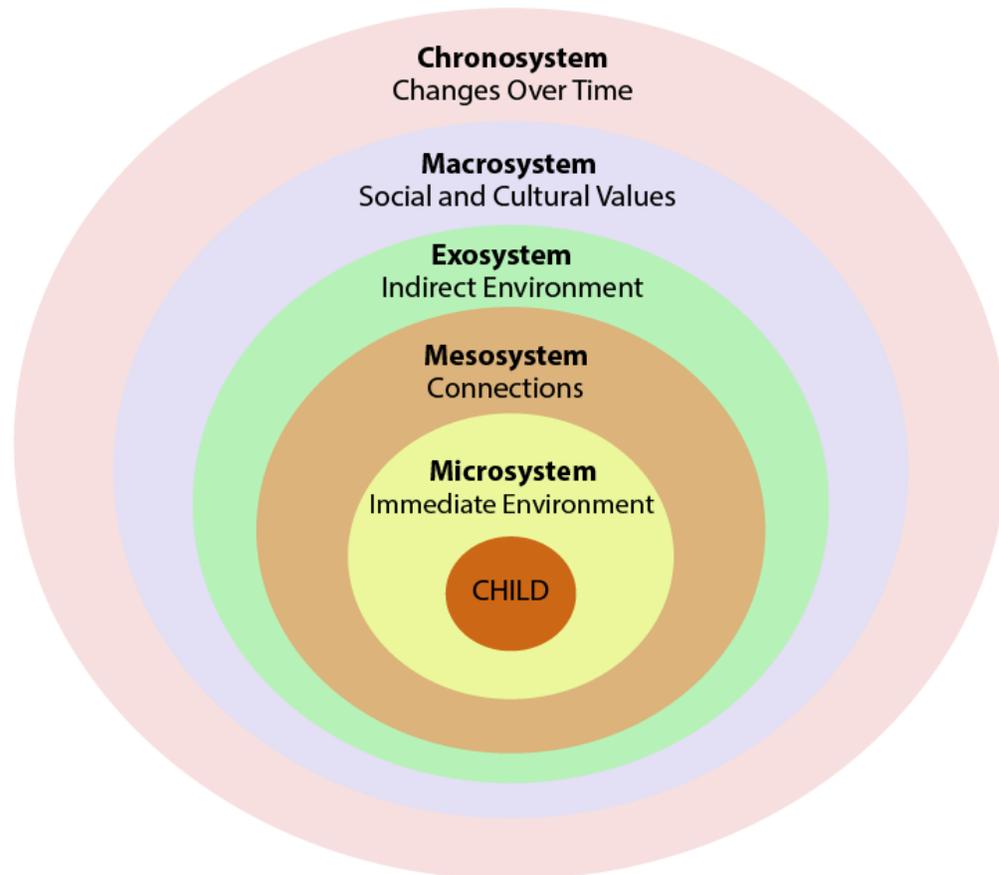
## **Theoretical Framework**

### **Bronfenbrenner's Ecological Systems Theory**

American psychologist, Urie Bronfenbrenner, formulated the Ecological Systems Theory in 1973, to explain how the inherent qualities of children and their environments interact to influence how they grow and develop. The Bronfenbrenner theory emphasizes the importance of studying children in multiple environments, also known as ecological systems, in the attempt to understand their development. According to Bronfenbrenner's Ecological Systems Theory, children typically find themselves enmeshed in various ecosystems, from the most intimate home ecological system to the larger school system, and then to the most expansive system which includes society and culture. Each of these ecological systems inevitably interact with and influence each other in all aspects of the children's lives. (PDF) Ecological Systems Theory n/a) Bronfenbrenner's ecological model organizes contexts of development into five levels of external influence. These levels are categorized from the most intimate level to the broadest. On the next page, Figure 1 illustrates the nested macro and microenvironments included in the model.

(Figure 1.)

### **Bronfenbrenner's Ecological Systems Theory**



(C) The Psychology Notes Headquarters <https://www.PsychologyNotesHQ.com>

#### **The Bronfenbrenner Ecological Model: Microsystem**

The Bronfenbrenner theory suggests that the microsystem is the smallest and most immediate environment in which children live. As such, the microsystem comprises the daily home, school or daycare, peer group and community environment of the children.

Interactions within the microsystem typically involve personal relationships with family members, classmates, teachers and caregivers. How these groups or individuals interact with the children will affect how they grow. Similarly, how children react to people in their microsystem

will also influence how they treat the children in return. More nurturing and more supportive interactions and relationships will understandably foster the children's improved development. One of the most significant findings that Urie Bronfenbrenner unearthed in his study of ecological systems is that it is possible for siblings who find themselves in the same ecological system to experience very different environments (in this case it will be the child that is disabled compared to their siblings.) Therefore, given two siblings experiencing the same microsystem, it is not impossible for the development of them to progress in different manners. Each child's particular personality traits, physical traits, and mental capabilities, as well as temperament, which is influenced by unique genetic and biological factors, ultimately have a hand in how he/she is treated by others.((PDF) Ecological Systems Theory n/a)

### **The Bronfenbrenner Ecological Model: Mesosystem**

The mesosystem encompasses the interaction of the different microsystems which children find themselves in. It is, in essence, a system of microsystems and as such, involves linkages between home and school, between peer group and family, and between family and community.

According to Bronfenbrenner's theory, if a child's parents are actively involved in the friendships of their child, for example they invite their child's friends over to their house from time to time and spend time with them, then the child's development is affected positively through harmony and like-mindedness. However, if the child's parents dislike their child's peers and openly criticize them, then the child experiences disequilibrium and conflicting emotions, which will likely lead to negative development.

**The Bronfenbrenner Ecological Model: Exosystem**

The exosystem pertains to the linkages that may exist between two or more settings, one of which may not contain the developing children but affect them indirectly, nonetheless. Based on the findings of Bronfenbrenner, people and places that children may not directly interact with may still have an impact on their lives. Such places and people may include the parents' workplaces, extended family members, and the neighborhood the children live in. For example, a father who is continually passed up for promotion by an indifferent boss at the workplace may take it out on his children and mistreat them at home.

**The Bronfenbrenner Ecological Model: Macrosystem**

The macrosystem is the largest and most distant collection of people and places to the children that still have significant influences on them. This ecological system is composed of the children's cultural patterns and values, specifically their dominant beliefs and ideas, as well as political and economic systems. For example, children in war-torn areas will experience a different kind of development than children in peaceful environments.

**The Bronfenbrenner Ecological Model: Chronosystem**

The Bronfenbrenner theory suggests that the chronosystem adds the useful dimension of time, which demonstrates the influence of both change and constancy in the children's environments. The chronosystem may include a change in family structure, address, parents' employment status, as well as immense society changes such as economic cycles and wars. By studying the various ecological systems, Bronfenbrenner's Ecological Systems Theory is able to demonstrate the diversity of interrelated influences on children's development. Awareness of

the contexts that children are in can sensitize us to variations in the way children may act in different settings.

For example, a child who frequently bullies smaller children at school may portray the role of a terrified victim at home. Due to these variations, adults who are concerned with the care of a particular child should pay close attention to his/her behavior in different settings, as well as to the quality and type of connections that exist between these settings (Marsh, et al., "What is Bronfenbrenner's Ecological Systems Theory?", 2020). Bronfenbrenner himself acknowledged the latest form of his theory as the most appropriate (Bronfenbrenner and Evans 2000), we adhere to a pragmatic view of knowledge and theory. In line with Bryant (Eriksson et al., 2018), we believe that "knowledge exists in the form of statements or theories which are best seen as instruments or tools; coping mechanisms, not once-and-for-all-time truths. Rather knowledge [or theory, our note] is a web or a network of statements rather than an edifice, and the value of any form of knowledge [or theory, our note] is its usefulness and applicability which may be constrained in terms of time and place and user"(Eriksson et al., 2018). Thus, we believe that even use of earlier concepts from Bronfenbrenner's ecological theory might potentially be useful for guiding public health interventions. This is why it is useful for purposes of the study as the interviewees input and their experience is a form of knowledge.

### **Summary**

This chapter reviewed a myriad of services and groups that work with families who are charged with the care of individuals with severe disabilities. This research study may seek to fill the gap in assistance to parents and guardians that care for children, youth, and adults with severe

disabilities by creating an interactive iBook. The intent is to create a product with the expertise of families that navigated this lived experience. The remainder of this chapter will outline the various complexities that families experience when caring for individuals with severe disabilities. The iBook may offer assistance in the care of these individuals. However, still there is little support that can be found in a free, interactive iGuide for these families. By using Bronfenbrenner's theoretical framework, concepts clearly consider important interactions within the different systems and therefore demonstrate the effectiveness of recommendations that are most useful for guiding public health policy and practice. It is the hope of the researcher and authors of the iBook to demonstrate the effectiveness and utility.

## **Chapter III: Methodology**

### **Introduction**

#### **Philosophical Lens**

As a mother of a special needs child who was given only till she was two years old to live, I can personally share my experience and demonstrate my desire to change the way our system works in the United States through writing my dissertation and creating a program that can be replicated. This program requires funding (public/private/ federal) to ensure its sustainability. I have a 23-year-old daughter with West Syndrome, intractable seizures, CP, and who has endured 11 brain surgeries, I have seen the lack of programs and lack of organization from the perspective of a parent of a special needs child. I often ask myself, “How many others are there in this country and world like my daughter?”. It is time to make a lasting change that can help to improve the lives of severely disabled individuals and their families. Presently, the red tape that exists through the public system makes it virtually impossible to secure an appropriate program within a reasonable amount of time. This is also if an appropriate program exists.

As a researcher and a mother, my philosophical worldview is that of pragmatism (Creswell & Creswell, 2018). I conduct my work and love with a problem-centered, pluralistic, real-world practice approach which best serves my daughter.

### **Proposed Research**

Reviewing the iBook for parents *Navigating Life in the World of Disabilities* is a culmination of the researcher’s lived experiences with her daughter and collection of best practices. In order for this iBook to have the perspective of others it is imperative that those who have shared this lived experience review the iBook and give vital feedback for a well-rounded resource for other parents and families. Therefore, the proposed research design will engage an action research design, (Mertler, 2019).

**Research Design**

The proposed research will implement an action research design (Mertler, 2019). Action research is transformative social learning with a change schema. The generative purpose of action research is to analyze and discuss the data together with stakeholders, taking care that diverse participants' viewpoints are welcomed. Therefore, having key stakeholders evaluating the iBook, *Navigating Life in the World of Disabilities*, is the essence of action research design.

**Research Questions**

**RQ1:** In what ways would an interactive guide iBook be helpful for those navigating the disability world?

**RQ2:** How useful would this guide be for the general public in helping caregivers to assist those with disabilities?

**RQ3:** Given a draft of an iBook as a resource for navigating the disability world, what components are missing that would make this iBook useful? What additional information needs to be added for parents, families, and caregivers of children and adults with severe disabilities?

**Population/Sample**

This research will implement a purposive and snowball sampling (Creswell & Creswell, 2018). The researcher will send personal emails to potential participants as well as through various parent groups of children, youth, adults with disabilities. The number of participants that the researcher anticipates will review the iBook and answer the survey questions will be between 5 - 25 participants.

**iBook Product (Appendix D)**

These are the tentative areas that are going to be addressed in the book

Chapter 1 -Birth to 3

Chapter 2 - Preschool

Chapter 3 - Elementary School

Chapter 4 - Middle School

Chapter 5 - High School

Chapter 6 - Adults

Chapter 7 - What does it mean to be a good advocate? What are some steps I can take ?

Chapter 8 - The Importance of Advocating For Your Child

Here are a few steps that you can take (many of them seem obvious, but simply just gentle reminders to all that are naturally good advocates for their children or for someone they love.

Chapter 9 - Know your child

Know your child's strengths and weaknesses and be able to articulate this during the Individualized Education Program (IEP), or the Individualized Family Service Plan (IFSP) meeting.

Chapter 10 - Know your community / It takes a Village

Chapter 11 - Educate yourself with the law

Chapter 12 - Organization is key

Chapter 13 - Always be Prepared

Chapter 14 - Following up after a meeting

Chapter 15 - What is the next step

Chapter 16 - Always be a step ahead and anticipate

Chapter 17 Mental Health & Resiliency

Chapter 18 - Summary

### **Survey Instrumentation**

The researcher – made survey (See Appendix E) will consist of ten of Likert scale questions and two open-ended questions. Some examples include :

1. Do you have, care for, or help a child or adult with severe disabilities? (yes / no)
2. It was easy to access the iBook from a computer, tablet, phone, or any other device. (Strongly agree - Agree - Neither agree nor disagree - Disagree - Strongly disagree)
3. How well do the topics in the iBook cover your own personal experience with your child?  
(Not well at all - Mildly well - Fairly well - Quite well - Extremely well)

The remainder of the questions will be open-ended and included in the appendix. A sampling of these questions include: 1. When did you realize that your child was having difficulty reaching milestones? Can you describe? 2. Do you have any other children and if so, describe where this child falls in line with your other children being born? 3. Describe how the iBook relates to you and your situation? Please elaborate. 4. Please describe which areas of the iBook were most useful to you ?

### **Procedures**

The following procedures will apply for potential survey and iBook review participants.

1. Receive an email from researcher (appendix A)
2. Flyer posted in parent of children of severe disability social media venues (Appendix B)
3. Participants will be directed to the informed consent form which is the first page of the survey. (Appendix C)

4. After consenting to be a participant, they will be directed to the iBook, “Navigating Life in the World of Disabilities “ ~ An Interactive Guide for Parents Navigating Life with a Child or Adult with Severe Disabilities ” (Appendix D)
5. After reviewing the iBook participants will then be directed to survey (Appendix E)

### **Analysis**

The researcher will run descriptive statistics (i.e. mean, mode, median, average, standard deviation) with the Likert scale questions and organize the open ended responses into codes to generate themes (Creswell & Creswell, 2018). The Likert scale results will then be triangulated with the qualitative themes to make meaning and assist in guiding the improvement of the iBook.

### **Ethical Issues**

The risks of participating in this study are minimal however participants may feel uncomfortable and exit out of the survey at any time without consequence. There are no benefits to taking the survey and reviewing the iGuidebook, however participants may enjoy knowing they are assisting in creating a free iGuidebook that will help other families and individuals navigate the disability world. The participants will be strictly anonymous and no IP addresses will be collected by the researcher. The data will be kept in a locked password protected computer and deleted in one year after the study is completed.

### **Summary**

Presently there is little to no assistance, or iBook that is available that may help parents, guardians, and families of children and adults with severe disabilities create care plans by fashioning, and equipping their homes, as well as navigate the disability terrain.. (Aging &

Disability: Addressing the Needs of a Growing Population 2019) The participants in the study will be individuals that either have children with special needs, are caregivers, family or friends. The theoretical framework used for purposes of this study will be Bronfenbrenner's ecological theory. It is an appealing conceptual tool for this study as it may provide guiding public health information, interventions and opinions in order to constructively assess the usefulness of the iBook as it addresses simple answers to complicated questions. The researcher created an iBook to assist parents and families of children and adults with severe disabilities and would like to get feedback from the experts, parents and families that have the lived experience of creating a viable environment for their children. The researcher will employ an action research analysis to understand the usefulness of the iBook for parents and caregivers, teachers, and future students in the ESE field. The survey will consist of two parts, one is a 12 question Likert Scale and open-ended question instrument through Survey Monkey followed by an online video interview of open ended questions about the usefulness of the iBook that they review. There will be approximately between 5 - 25 participants. Upon the completion of the survey and interviews, the researcher will analyze the findings and present the results.

## **Chapter IV: Results**

### **Introduction:**

The primary purpose of this study was to review and evaluate the iBook “Navigating Life in the World of Disabilities” which is a culmination of the researcher’s lived experiences with her daughter and collection of best practices. In order for this iBook to have the perspective of others and offer guidance to other families, and educators it is imperative that those who have shared this lived experience review the iBook and give vital feedback for a well-rounded resource for other parents and families, and educators. Therefore, the proposed research design will engage an action research design, (Mertler, 2019).

### **Research Design**

The researcher implemented an action research design (Mertler, 2019). Action research is transformative social learning with a change schema. The generative purpose of action research is to analyze and discuss the data together with stakeholders, taking care that diverse participants’ viewpoints are welcomed. Therefore, having key stakeholders evaluating the iBook, “Navigating Life in the World of Disabilities” is the essence of action research design. “Action research is done by educators for themselves and is a systematic inquiry into their own practice” (Johnson, 2008).

### **Purpose of the Study**

The purpose of this study was to evaluate the effectiveness of the iBook, “Navigating Life in the World of Disabilities” for families and get vital feedback in an effort to provide a well-rounded resource for parents, educators, families, and caretakers of individuals with special

needs. The researcher's goal is to compile the results of the study by utilizing the answers provided by the participants in the study and identify the key elements and themes from the data collected. The questions on the survey further explored areas that the participants felt would be helpful to include in this iBook and also gauged the effectiveness of the usefulness of this book. The researcher's goal is to provide a well-rounded iBook as a guide to those that care for individuals with special needs from the perspective of lived experiences. The questions on the survey will further explore the opinions of the participants and be used as part of the results.

### **Research Questions**

The questions below guided the study.

RQ1: In what ways would an interactive guide iBook be helpful for those navigating the disability world?

RQ2: How useful would this guide be for the general public in helping caregivers to assist those with disabilities?

RQ3: Given a draft of an iBook as a resource for navigating the disability world, what components make this iBook useful? What additional information needs to be added for parents, families, and caregivers of children and adults with severe disabilities?

### **Summary of Analysis**

The research process began with the researcher posting flyers on specific social media groups as well as sending out blast emails to specific special needs groups (Autism after 21, FACES , Special Compass, public school system ESE Departments, Horses for the Handicapped) and utilized the snowball method of analysis in order to maintain the targeted group. The

researcher used an action research based qualitative assessment using a Likert scale as well as open ended questions to the participants. The email blast that was sent out was geared toward parents, families, friends, and caretakers and teachers of individuals with special needs. The email that was sent out to the specific targeted group included a small note from the researcher stating the purpose of the research and what was required. In addition to the note, the image of the flyer, the iBook link, and the link to Survey Monkey was provided to make the reading and evaluation process simple. The participant was asked to read *Navigating Life in the World of Disabilities* and then evaluate the iBook by completing a 16 questions survey online using SurveyMonkey. The researcher anticipated between 5 - 25 participants, however over a three week period there were a total of 35 participants and exceeded the original estimation. The researcher felt that having more participants would assist in the evaluation and research process. Individuals that did not make the cut off date for the survey, were encouraged to reach the researcher via email to share their thoughts and recommendations. Figure 1 below shows the informed consent for the survey with the exact number of participants that completed the survey.

The first question on the survey was the informed consent. There were a total of 35 respondents and 100 percent agreed to participate in the study. The results listed below on Figures 1a, and 1b. show the data for this question from the survey.

*Informed Consent*

**Navigating Life in the World of Disabilities**

\* 1. Informed Consent

Dear Participant,

The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that you are free to decide not to participate or to withdraw at any time without affecting the relationship with the researcher or study.

The purpose of this study is to evaluate the usefulness of an interactive iBook. The study will provide information as to the usefulness of an iBook provided to parents and caretakers of children and adults with severe disabilities. The information gathered from this online survey may assist future parents in planning and navigating life with a child and adult that is severely disabled.

Participating in this online survey will have minimal risks such as possibly feeling uncomfortable or anxious if certain areas are discussed. Any time, you may stop the online survey and choose not to participate. The online survey will be destroyed. Choosing not to participate will not affect you in any way. This online survey does not have any benefits; however, you may enjoy sharing your lived experiences as a parent or caretaker and knowing you are assisting in the creation of a guidebook.

I will be happy to share my findings with you after the research is completed. The researcher will not know your identity as a participant and your name will not be associated with the research findings in any way. Should you have any questions please feel free to contact at the information below or Dr. Jennifer Lesh, Chair of the Lynn University Institutional Review Board at [jllesh@lynn.edu](mailto:jllesh@lynn.edu)

By marking the I agree, you will give your consent with full knowledge of the nature and purpose of the study. Thank you for your participation,

Jaimee Sabato

Lynn University

[jsabato@email.lynn.edu](mailto:jsabato@email.lynn.edu)



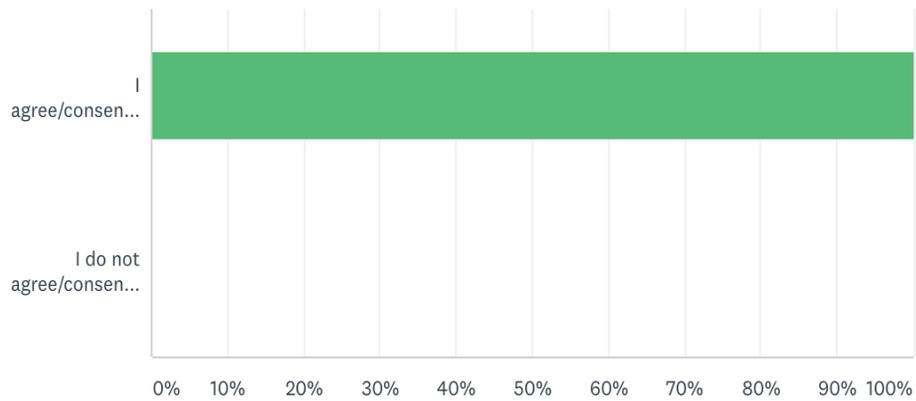
I agree/consent to take the survey. I understand the study and have been given an opportunity to ask questions.

I do not agree/consent to take survey.

Figure 1b.

Participants in the study who answered yes on the informed consent.

Answered: 35 Skipped: 0



ANSWER CHOICES	RESPONSES
I agree/consent to take the survey. I understand the study and have been given an opportunity to ask questions.	100.00% 35
I do not agree/consent to take survey.	0.00% 0
<b>Total Respondents: 35</b>	

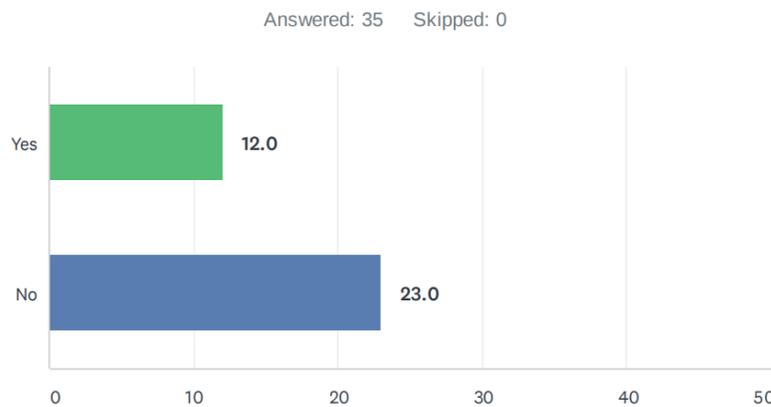
Question number 2 in the survey asked if the participants have, cared for, or helped a child or adult with severe disabilities. The data collected reflects that 12 participants ( 34.29%) of the 35 participants care for a severely disabled child or adult and 23 participants (65.71%) do not care for a severely disabled child or adult. There were no participants that skipped this

question. The results listed below on the graph in Figure 2 show the data for this question from the survey.

Figure 2.

*Participants that have or care for an individual with severe disabilities*

**Q2 Do you have, care for, or help a child or adult with severe disabilities?**



ANSWER CHOICES	RESPONSES	
Yes	34.29%	12
No	65.71%	23
TOTAL		35

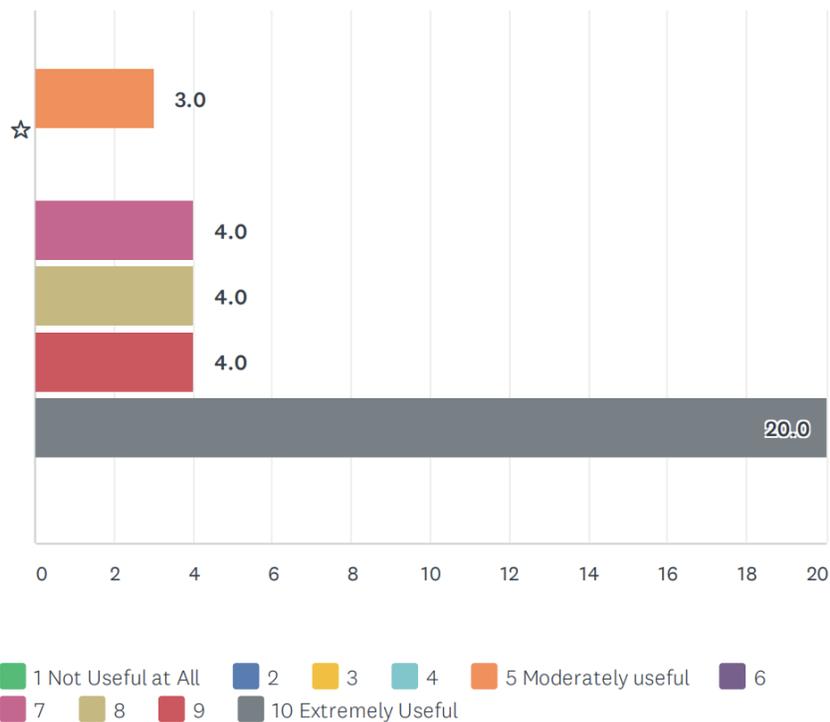
Question number 3 in the survey is designed using a Likert scale, and asks about the usefulness of *Navigating Life in the World of Disabilities* for someone in the disability world. The Likert scale measures the responses by using the ordinal scale (10 = extremely useful; 5 = moderately useful; 1= not useful at all). The total respondents that found the book extremely useful totaled 57.14% representing 20 individuals represents the majority of participants. The weighted average of participants that felt that the book was useful was 8.89 out of 10 on the

Likert scale. There were 4 individuals which represented 11.43% that rated the usefulness of the book at a 9 on the Likert scale, 4 individuals which represented 11.43% that rated the usefulness of the book at 8 on the Likert scale, there were 4 individuals which represented 11.43% that rated the usefulness of the book at a 7 on the Likert scale, no individuals rated the usefulness at a 6 on the Likert scale. There were 3 individuals that rated the book moderately useful = 5 on the Likert scale which represents 8.57% of the 35 participants. There were no ratings below moderately useful = 5 on the Likert scale. Listed below are the results and complete breakdown of the 35 participants. The results listed below on the graph in Figure 3 show the data for this question from the survey.

Figure 3. Survey results for Question 3 Usefulness of iBook

Q3 How useful do you feel Navigating Life in the World of Disabilities is for someone in the disability world?

Answered: 35 Skipped: 0



*Survey results for Question 3 Usefulness of iBook*

*(continued Figure3.)*

	1 NOT USEFUL AT ALL	2	3	4	5 MODERATELY USEFUL	6	7	8	9	10 EXTREMELY USEFUL	TOTAL	WEIGHTED AVERAGE
☆	0.00% 0	0.00% 0	0.00% 0	0.00% 0	8.57% 3	0.00% 0	11.43% 4	11.43% 4	11.43% 4	57.14% 20	35	8.89

Question number 4 in the survey is designed using a Likert scale, and asks how useful *Navigating Life in the World of Disabilities* is for someone who is not familiar with the disability world. The Likert scale measures the responses by using the ordinal scale (10 = extremely useful; 5 = moderately useful; 1= not useful at all). All 35 participants responded. There were 22 respondents that found the book extremely useful for those not familiar with the disability world which represents 62.86% of those individuals that participated in the survey. The remaining individuals that participated in the survey rated the book’s usefulness for those not familiar with the disability world as follows:

8 individuals representing 22.86% rated 9 out of 10

1 individual representing 2.86% rated 8 out of 10

3 individuals representing 8.57% rated 7 out of 10

no individuals rated 6 out of 10

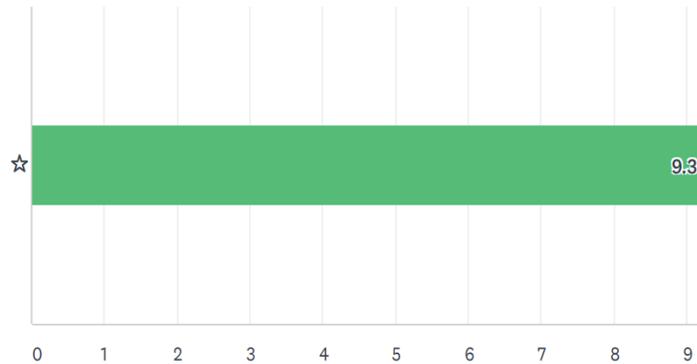
1 individual rated 5 out of 10 (Moderately useful)

no individuals rated lower than 5 out of 10

The results are listed below on the graph in Figure 4 shows the data for this question from the survey.

Q4 How useful do you feel Navigating Life in the World of Disability is for someone who is not familiar with the disability world?

Answered: 35 Skipped: 0



	1 NOT USEFUL AT ALL	2	3	4	5 MODERATELY USEFUL	6	7	8	9	10 EXTREMELY USEFUL	TOTAL	WEIGHT AVERAG
☆	0.00% 0	0.00% 0	0.00% 0	0.00% 0	2.86% 1	0.00% 0	8.57% 3	2.86% 1	22.86% 8	62.86% 22	35	9

Question number 5 in the survey is designed as an open ended question asking what areas of the iBook do you feel can be added? Participants were encouraged to write as much as they wanted. Answered: 35 Skipped: 0

Several of the participants were pleased with the book in its' original form. However, the information the researcher gathered demonstrated several outstanding themes that emerged from the results. **Among these themes were: the focus on family, the support system that is needed, translating the book into different languages, adding more available resources, and information for the parents.**

The majority of participants were pleased with the information supplied. The researcher has included a sampling of several suggestions listed below. It should also be noted that there were emails that were sent to the researcher which assisted in helping to outline the themes.

**Sample of responses to Question 5 (open ended question)**

*“I found the book covered clearly all that was needed.”*

*“Talk more about other disabilities.”*

*“1. University as an option. My daughter went and there were a host of challenges but she persevered graduating with a double major and minor. 2. SSI-information on our government programs. We didn't even know SSI was available to our daughter. 3. Joni Ericson Tada one of the most inspirational women you'll meet 4. MDA resource center 5. Make a wish”*

*“On P. 28 maybe add a bit in about how doctors rely on empirical evidence. They really take into account what can be seen or measured and don't necessarily listen to young mothers.”*

*“I like it as is.”*

*“I may have missed it so I apologize if it was in there, but I was wondering why infants get these seizures? Are they caused from a variety of different reasons or is it unknown?”*

*“More Clinical research.”*

*“Would love more personal stories.”*

*“Perhaps having a section of motivational, self-help for the parents.”*

*“I would add the experiences of other parents and document how they also coped with the challenges they faced.”*

*“No areas”*

*“Personal anecdotes”*

*“Personal anecdotes. Use more of your life stories”*

*“It is perfect.”*

*“N/A”*

*“Perhaps add ways of coping if a parent becomes depressed or feels guilty because of their child's condition.”*

*“Possibly include the special educator aspect... Maybe include what they have found to be most beneficial for their current and/or past students and their families - what advice they may have to contribute.”*

*“More information about IIFSP and iEP process state by state.”*

*“Na”*

*“The bullets should be expanded to include more details I will call you to expand on this.”*

*“This is a wonderful book and it’s perfect as is.”*

*“No area’s”*

*“List of places to contact for help.”*

*“The chapters that are noted in the book as future additions will enhance this valuable work.”*

*“While I'm sure it would be difficult to do, I think finding the perspective of the disabled person would be helpful. I know when I was in a wheelchair, I had a lot to say about what was going on around me (accessibility, etc) and it felt like I was being asked to exist in a world that wasn't setup for my success. I realize the US has amazing ADA laws not present in other countries, but even still - resources are lacking.”*

*“There were a lot of resources available. At several points, I found myself overwhelmed with the information presented. More information about the types of evidence-based therapies that are available (what they address, how to access them), would be helpful. A parent reading this is going to be overwhelmed with the journey in front of them. All of the information, and opinions, they will receive from*

*friends, neighbors, doctors, books, websites, social media pages, etc. will be daunting. Self-care is key! “*

*“This is an incredibly personal book that interweaves Jaimee Sabato's family story with excellent advice for families with disabled members. The interviews are missing. There are some headings that are still "Lorem ipsum..." You could give an example of what a daily journal looks like. When you have figures from another source (like APGAR), be sure to footnote those.”*

*“I thought it was fantastic. Possibly links to agencies by state that might assist families.”*

*“N/A”*

*“I don't know of anything that has been missed.”*

*“On furry friends, less anecdotal more sources - the anecdotes about the dogs are good but talk more about service animals and add a source or two. In the overnight bag part, drop airpods and replace with earbuds, airpods are a specific product. Under “Know Your Community” perhaps tone back a bit on Yiayia and Papou, not everyone is going to have access to such a close and willing family.”*

*“Advocating for rights is such an important section. I think it was informative. From my experience, this is the area that many parents struggle to find help.”*

*“Information on different types of school programs should be included.”*

*“I would love to see pictures of your daughter, and at different stages of her life.”*

Question number 6 in the survey is designed as an open ended question asking what suggestions the participant had for a caregiver, teacher, parent working with an individual with severe disabilities? Participants were encouraged to write as much as they wanted. There were also emails sent to the researcher that further provided a basis along with the sampling of some of the answers below to provide a common thread and theme for this section. The main themes that emerged were:

**the impact of positivity,**

**the importance of educating oneself,**

**having patience and understanding,**

**and the importance of communication.**

This area proved to be more empirical in its approach as many of the suggestions stemmed from a personal experience.

Answered: 35 Skipped: 0

Below is a sampling of some of the responses provided:

*“Patience, understand and educate yourself on the particular disability.”*

*“Much of the behavioral component can be caused by physical pain/infections etc.”*

*“1. Ask others for help. I never did and it made life so much harder then it had to be  
2. Be the advocate for your child. No one knows your child better then you. Don't take no for an answer if you know what is best for your child in a school situation. If your child has the language skills, teach them to be their own advocate. There may come a day when you are not there and they will then know how to advocate for themselves. 3. Before school began I would meet with every teacher and specialist and go over my daughters diagnosis, what it meant and her needs. Part of her condition is hearing loss. I would provide a one page sheet on hearing loss which explained wearing hearing aids is not like wearing glasses. It doesn't correct it perfect. Hearing aids make everything louder so please don't put my daughter next to a window where someone could be cutting the grass, don't put my daughter next to a child that taps a pencil or has other sounds because then she will not hear what you are teaching. I found most teachers receptive to the information provided. 4. Turn negatives into positives. My daughter loves monkeys and when she came to me worried about how she would feed herself when her hands got too weak I told her, “I read an article about people having monkeys for service animals and they feed*

*you.” I showed her the article. She was so happy. My daughter can’t smile due to facial paralysis. I told her well people get Botox to make their lines go away, you will never have a line. When we would park in handicap her brothers and sister would say thanks to her for getting to park close. Everything was met with a positive encouraging outlook. Now that doesn’t mean I didn’t cry my eyes out many times behind closed doors.”*

*“Educate yourself and don’t trust everything.”*

*“I’d keep the guide handy and re-read it often.”*

*“I thought this part was very thorough. As a former case manager for children with psychiatric and behavioral disabilities you hit the nail on the head with needing a village and trusting your gut. Maintaining an empathetic and interdisciplinary approach to helping kids is imperative. I loved how many resources were given.”*

*“Always ask for help.”*

*“N/A”*

*“The fact that you were getting a special job and you were chosen to be a caregiver and advocate for this special human being. Also knowing the fact that you can do it and they were supportive for you as a parent out there.”*

*“I would advise them to make inquiries and then to take advantage of the numerous organizations listed in this book to help their child receive all the help that is available to them.”*

*“N/A”*

*“N/A”*

*“PATIENCE”*

*“Read this book.”*

*“To be patient and try to be empathetic towards the child. Remember it is a struggle for the child to deal with their disability.”*

*“I would suggest that everyone get a chance to read this book. It's a powerful tool for anyone familiar with the world of disabilities or as a tool in diagnosis.”*

*“You touched on it but elaborate a little more on the importance of patience and collaboration. It provides a support system for both the child and everyone involved with the child (parent, caregiver, teacher, etc.).”*

*“Assemble a team you can trust and communicate with them openly.”*

*“N/A”*

*“Keep a positive attitude always Never loose hope Seek help from wherever it may come.”*

*“I don't have any suggestions.”*

*“Be honest even if you are not sure what to do and work together to help everyone involved .”*

*“N/A “*

*“I think the type of disability you're talking about in this book requires training on the part of the teacher. We need to know what can reasonably be expected, how to navigate waters that are foreign to us, and how to empower our students. While I can understand my able bodied students, I sometimes struggle with my adapted students. It's not that I don't want to be their advocate, it's just that I don't know how to be. I have yet to speak the language, and that is a critical point.”*

*“Self-care Behaviors are just a symptom. In order to help your child, look beyond the behavior. Stay away from behavioral approaches that only look at observable behavior. Your child doesn't need help with their behavior, the need help with the things that are causing the behavior (motor skills, sensory processing, emotional regulation, etc).”*

*“This could be a great resource for people who are doing some caregiving for people with severe disabilities, or thinking about it. For example, there will be people who want to enter this care world, either f/t or even as a summer camp counselor (the latter is my own experience) so an intro is helpful.”*

*“None “*

*“N.A.”*

*“Knowledge is key and this book is a road map for new parents.”*

*“So far so good.”*

*“This book would be helpful for any teacher to remember the milestones.”*

*“Constant communication with the family.”*

*“Always try to be caring and compassionate.”*

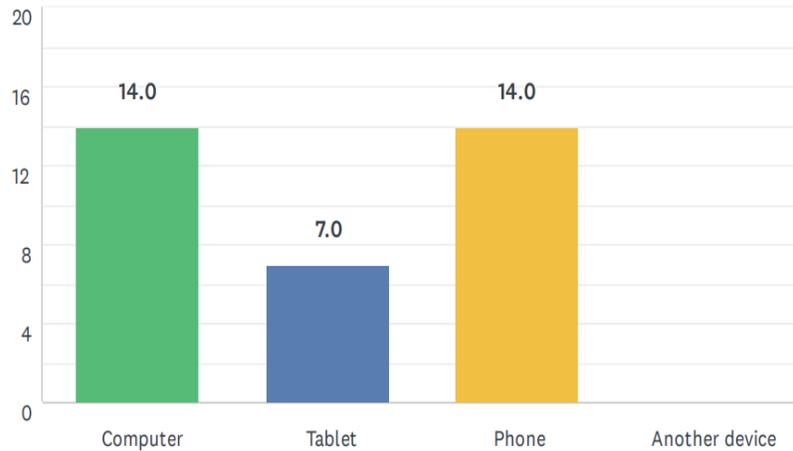
Question number 7 in the survey asked how the participant accessed the iBook. There were no participants that skipped this question. Of the 35 participants, 14 individuals = 40% of

the 35 participants accessed the iBook by computer and 14 individuals = 40%35 accessed the iBook by phone. The major trend was that the iBook was accessed by computer or by a phone. The remaining 7 individuals = 20% accessed the iBook by using a tablet. There were no other methods or tools used to access the iBook. It was evident that there were an equal number of participants that accessed the iBook by computer and by phone with 40% in each group with a total of 80% of the 35 participants being polled. The results are listed below on the graph in Figure 5 shows the data for this question from the survey.

*(Figure 5.)*

### Q7 How did you access the iBook?

Answered: 35 Skipped: 0



ANSWER CHOICES	RESPONSES	
Computer	40.00%	14
Tablet	20.00%	7
Phone	40.00%	14
Another device	0.00%	0
<b>TOTAL</b>		<b>35</b>

Question number 8 in the survey stated, “ It was easy to access the iBook from one of these devices; computer, tablet, phone, or any other device. Participants were given a Likert scale with an ordinal range from 1- 10 (1 not being accessible at all and 10 representing that access was extremely accessible. The researcher’s findings from the data demonstrated that the majority of the individuals that participated in the survey found the iBook easy to access from a computer, a tablet, a phone, or any other device. The results are listed below on the graph in Figure 6 shows the data for this question from the survey. Answered: 34 Skipped: 1

The results were as follows:

Individuals that rated a 10 on the Likert scale: 28 = 82.35%

Individuals that rated a 9 on the Likert scale: 2 = 5.88%

Individuals that rated an 8 on the Likert scale : 2 = 5.88%

Individuals that rated a 7 on the Likert scale : 1 = 2.94%

Individuals that rated a 6 on the Likert scale : no respondents

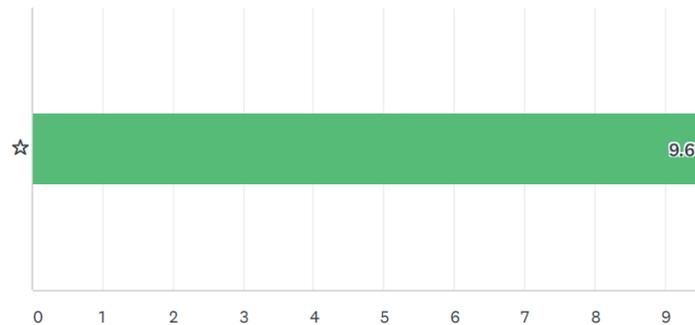
Individuals that rated a 5 on the Likert scale : 1 = 2.94%

There were no individuals that rated lower than a 5 on the Likert scale.

**(Figure 6.)**

Q8 It was easy to access the iBook from one of these devices; computer, tablet, phone, or any other device.

Answered: 34 Skipped: 1



	1 NOT AT ALL ACCESSIBLE	2	3	4	5	6	7	8	9	10 EXTREMELY ACCESSIBLE	TOTAL	WEIGHTED AVERAGE
☆	0.00% 0	0.00% 0	0.00% 0	0.00% 0	2.94% 1	0.00% 0	2.94% 1	5.88% 2	5.88% 2	82.35% 28	34	9.59

Question number 9 in the survey asked how well did the topics in the iBook cover your own personal experience? This question was designed using an ordinal Likert scale (1- 10 ; 1 not covered and 10 all areas covered) The results that were reflected in the survey are listed below. The researcher recognized that not all of the participants had or cared for a child or adult with special needs/ severe disabilities. This proved to be one of the limitations of the study as not all of the participants cared for an individual with special needs, and therefore, their personal experiences varied. The results are listed below on the graph in Figure 7 shows the data for this question from the survey. Answered: 34 Skipped: 1

The total weighted average 8.56 out of 10 on the Likert scale with the results as follows:

The results were as follows:

Individuals that rated a 10 on the Likert scale: 19 = 55.88%

Individuals that rated a 9 on the Likert scale: 3 = 8.82%

Individuals that rated an 8 on the Likert scale: 4 = 11.76%

Individuals that rated a 7 on the Likert scale : 2 = 5.88%

Individuals that rated a 6 on the Likert scale : 4 = 11.76%

Individuals that rated a 5 on the Likert scale : no respondents

Individuals that rated a 4 on the Likert scale : no respondents

Individuals that rated a 3 on the Likert scale : 1 = 2.94%

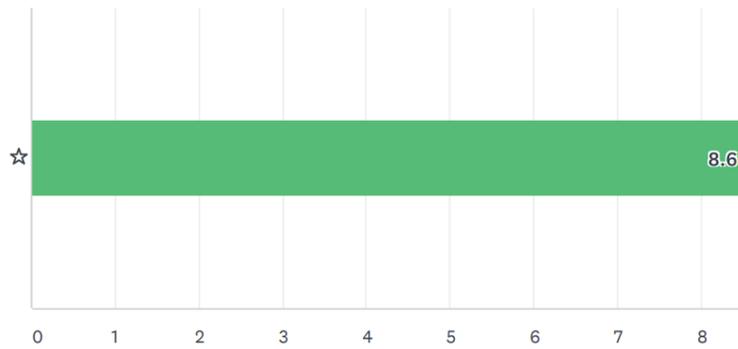
Individuals that rated a 2 on the Likert scale : no respondents

Individuals that rated on the Likert scale: 1 = 2.94%

(Figure 7.)

Q9 How well do the topics in the iBook cover your own personal experience?

Answered: 34 Skipped: 1



1 NOT COVERED	2	3	4	5	6	7	8	9	10 ALL AREAS COVERED	TOTAL	WEIGHTED AVERAGE
2.94%	0.00%	2.94%	0.00%	0.00%	11.76%	5.88%	11.76%	8.82%	55.88%	34	8.56
1	0	1	0	0	4	2	4	3	19		

Question number 10 in the survey asked, “Based upon your own experience, how useful is the iBook?” The major trend of the results of this study revealed that 60% of the participants found the iBook to be extremely useful. Results showed that 34.29% found the iBook useful,

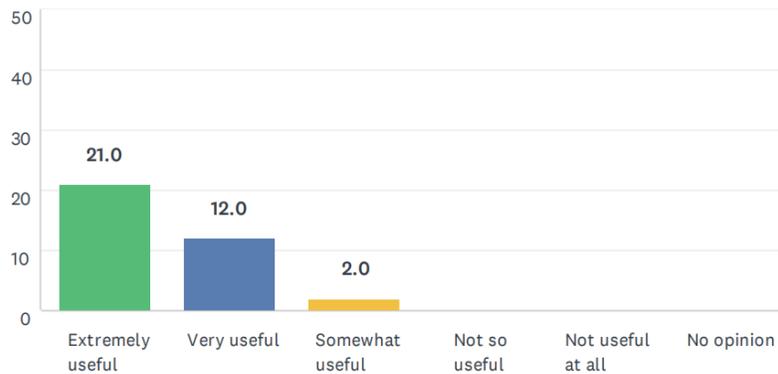
5.71% found the iBook somewhat useful, 0% found the iBook not so useful, 0% found the iBook not useful at all, and 0% had no opinion. The graph in Figure 8 shows the data for this question from the survey.

Answered: 35 Skipped: 0

*(Figure 8.)*

Q10 Based upon your own experience, how useful is the iBook?

Answered: 35 Skipped: 0

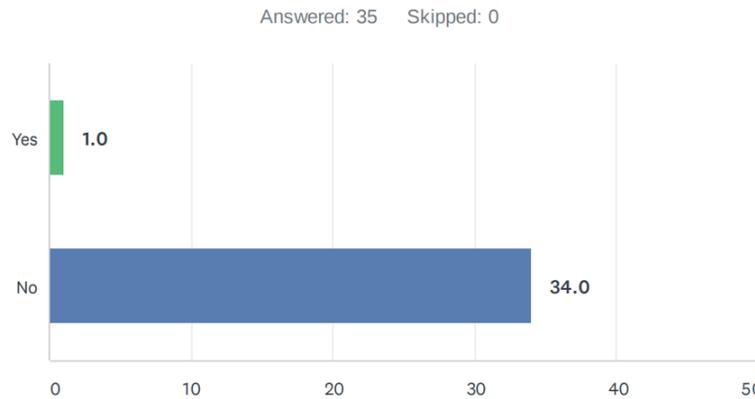


ANSWER CHOICES	RESPONSES	
Extremely useful	60.00%	21
Very useful	34.29%	12
Somewhat useful	5.71%	2
Not so useful	0.00%	0
Not useful at all	0.00%	0
No opinion	0.00%	0
<b>TOTAL</b>		<b>35</b>

Question number 11 was a close ended question. The question posed asked, “ Is there any information that was not useful in this iBook?” The major trend of the results of this study revealed that 97.14% of the participants felt that there was no information in the book that was not useful. The remaining 2.86% felt that there was information in the book that was not useful. Answered: 35 Skipped: 0 The graph in Figure 9 shows the data for this question from the survey.

**(Figure 9.)**

**Q11 Is there any information that was not useful in this iBook?**

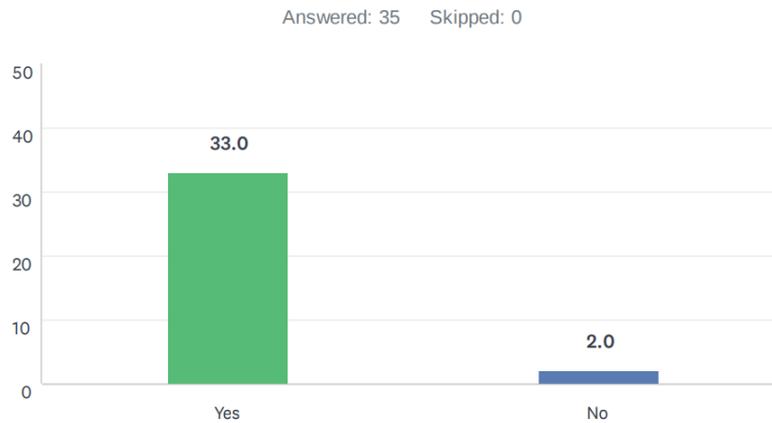


ANSWER CHOICES	RESPONSES
Yes	2.86% 1
No	97.14% 34
TOTAL	35

Question number 12 was a close ended question. The question asked, “ Is there any information that was useful in this iBook? The major trend of the results of this study revealed that 94.29% of the participants felt that the information provided in the book was useful. The remaining 5.71% felt that the information provided in the iBook was not useful. The results to this question align with the prior question and both results are comparative with 97.14 % compared to 94.29% (leaning toward a trend which felt the information in the iBook was useful. There was only a small discrepancy of 2.85 % between the two numbers. The graph in Figure 10 shows the data for this question from the survey.

**(Figure 10.)**

**Q12 Is there any information that was useful in this iBook? If so, please explain.**



ANSWER CHOICES	RESPONSES	
Yes	94.29%	33
No	5.71%	2
TOTAL		35

Question number 13 was an open ended question which asked, “ What suggestions can you offer to make this iBook more useful? The answers revealed a trend which suggested that more personal stories along with additional resources and contact information for parents would be useful. There was mention of self care for the mother specifically and also a suggestion to “give examples of other families and how they were able to navigate the system to obtain the optimal care for their child.” Answered: 35 Skipped: 0

The following were some of the responses submitted:

*“If the target audience will be a combination of caregivers, parents, school personnel and parents’ friends and relatives, more lists/charts/anecdotes might be useful.”*

*“None it covered to me what I needed to know.”*

*“Just more general about special needs and less specific about seizures.”*

*“To add a few other organizations. I suggested a few above. To add or discuss options for the disabled child that goes to college.”*

*“This iBook was full of great advice.”*

*“None”*

*“I found the whole book easy to follow and useful. I don’t have any suggestions. I can’t wait to share it with parents that can benefit from it.”*

*“Causes of the disabilities.”*

*“I think a section on mom self care would be great.”*

*“Great job and you cover so many wonderful points that need to be said out loud.”*

*“I would give examples of other families and how they were able to navigate the system to obtain the optimal care for their child.”*

*“N/A”*

*“More personal anecdotes.”*

*“Touch more on the special education teacher piece.”*

*“It is perfect as is.”*

*“Maybe be a little more specific on the Always Be Prepared Section and the organization is the key section.”*

*“Interviews with parents of children with disabilities.”*

*“Maybe vignettes from other parents or educators”.*

*“N/A”*

*“N/A”*

*“Websites of people to contact for help.”*

*“The book is excellent as is.”*

*“I think you did a great job with it, Sabato. maybe a Table of Content for easy reference (I may have missed it), but beyond that, well done!”*

*“There were some formatting challenges that might just be because of the current stage of the book. Reading a book on a computer is not my first choice.”*

*“Perhaps hyperlinks to online resources for more, as one can't possibly include everything in an iBook.”*

*“I think it’s amazing as is!! “*

*“N/A “*

*“I don't have any additions.”*

*“I put my notes up earlier.”*

*“Maybe some type of training for the mental health of caregivers, as this is a large responsibility.”*

*“Add different educational programs available .“*

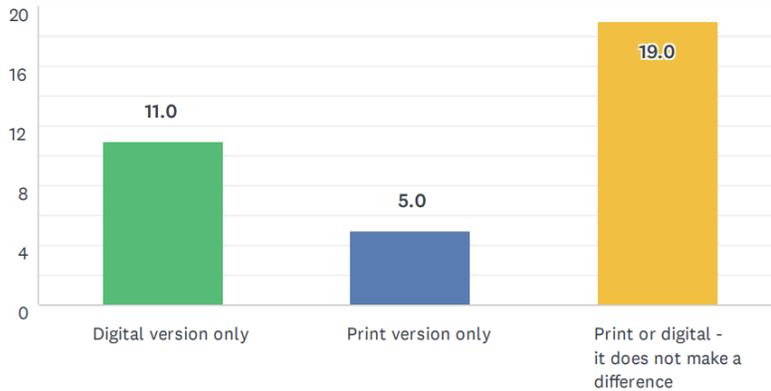
*“add in information from JAFCO”*

Question number 14 was a close ended question,“ Would you prefer to read the iBook digitally or do you prefer a print version? Three choices were offered: digital version only, print version only, print or digital - it does not make a difference. The major trend of the results of this study revealed that 54.29% of the participants replied that it did not make a difference if the iBook was in a digital version or a print version. The second largest group responded with a 31.43% that preferred a digital version only. The smallest percentage of participants that chose the print version only had 14.29% of the 35 participants. The graph in Figure 11 shows the data for this question from the survey.

*(Figure 11.)*

Q14 Would you prefer to read the iBook digitally or do you prefer a print version?

Answered: 35 Skipped: 0



ANSWER CHOICES	RESPONSES	
Digital version only	31.43%	11
Print version only	14.29%	5
Print or digital - it does not make a difference	54.29%	19
<b>TOTAL</b>		<b>35</b>

Question number 15 was a close ended question,“ How likely are you to recommend this book to someone? The answer choices were: Highly likely, Somewhat likely, Neutral ,Somewhat not likely, and Highly unlikely. The responses were : (77.14% )Highly likely, (20%) Somewhat likely, (0%) Neutral , (0%) Somewhat not likely, (0)% Highly unlikely, (2.86%) If somewhat not likely to highly unlikely, please explain why.The major trend of the results of this study revealed that 77.14% were highly likely to recommend this iBook to someone, 20% being somewhat likely to recommend this iBook to someone they know.

One participant (representing 2.8% of the 35 participants ) answered “if somewhat not likely to highly recommend this book” the response to explain why was the following:

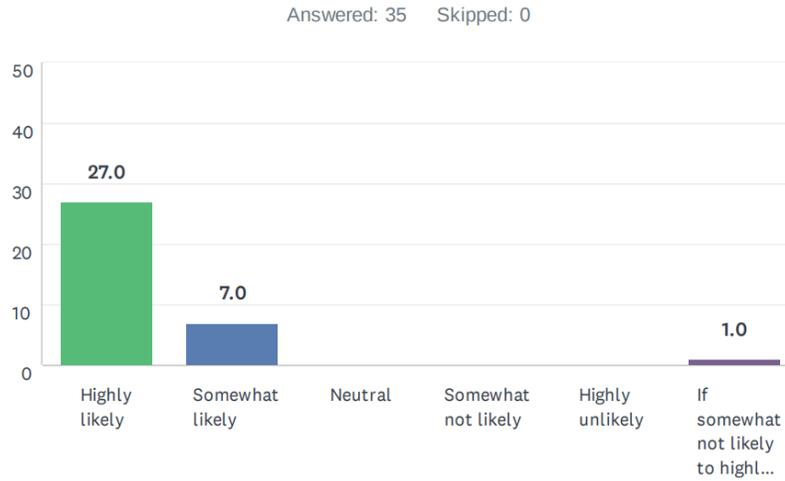
*“If somewhat not likely to highly unlikely, please explain why.:*

*I find that other parents of children with special needs would connect with your personal story, helpful information etc. I also feel like others can learn more in depth about disabilities as a result of reading your book.”*

The researcher made the assumption that it was likely the participant answered incorrectly based upon the participant’s answer. The graph in Figure 12 shows the data for this question from the survey.

***(Figure 12.)***

Q15 How likely are you to recommend this book to someone?



ANSWER CHOICES	RESPONSES	
Highly likely	77.14%	27
Somewhat likely	20.00%	7
Neutral	0.00%	0
Somewhat not likely	0.00%	0
Highly unlikely	0.00%	0
If somewhat not likely to highly unlikely, please explain why.	2.86%	1
<b>TOTAL</b>		<b>35</b>

Question 16 asked “If you are interested in contributing to the content of this iBook please email the researcher at [jsabato@email.lynn.edu](mailto:jsabato@email.lynn.edu) All 35 participants skipped this question, however, the researcher did receive emails that contained information that assisted in this research. It is the researcher’s feeling that the participants did not want to participate in the book but rather chose to give feedback that would assist in shaping the iBook via email and did not choose to fill out their personal information on the survey.

**Q16 \*\*\*If you are interested in contributing to the content of this iBook please email the researcher at [jsabato@email.lynn.edu](mailto:jsabato@email.lynn.edu)**

Answered: 0 Skipped: 35

ANSWER CHOICES	RESPONSES	
Name	0.00%	0
Company	0.00%	0
Address	0.00%	0
Address 2	0.00%	0
City/Town	0.00%	0
State/Province	0.00%	0
ZIP/Postal Code	0.00%	0
Country	0.00%	0
Email Address	0.00%	0
Phone Number	0.00%	0

In conclusion, the researcher can conclude that the iBook is a useful tool for parents, caregivers, educators, family members, friends, therapists, and medical professionals. The researcher concluded that the iBook can also be used as a tool of reference as a guide for those involved in the disability world as it helps heighten awareness and educate others in this unique area and can ultimately lend itself to better understanding and compassion.

## CHAPTER V

### Conclusions

#### Introduction

The field of special needs is wide in range and there are not many iBooks to support parents and families on their journey with a child that has special needs. The primary purpose of this study was to review and evaluate the iBook *Navigating Life in the World of Disabilities* which is a culmination of the researcher's lived experiences with her daughter and collection of best practices. The study focused on the effectiveness of the iBook, *Navigating Life in the World of Disabilities*, from the perspective of others using an empirical approach from the participants. It was imperative that those who have shared this lived experience review the iBook and give vital feedback for a well-rounded resource for other parents and families, and educators. The researcher used an action research design (Mertler, 2019). The main themes that emerged from the study reflected the need for a book of this type, its usefulness, the importance of relationships, coping mechanisms, and resources. Based on the compilation of data and themes, the researcher could draw conclusions and make interpretations to provide additional information to make the iBook a more well-rounded resource for families and individuals dealing with those in the world of disabilities.

## **Summary of Results**

The original survey was to consist of two parts; a 12 question Likert Scale and open-ended question instrument through Survey Monkey followed by an online video interview of open ended questions about the usefulness of the iBook that they reviewed. However, the researcher augmented some of the questions in the survey to make it a total of 16 questions instead of 12 questions. These questions included both Likert scale questions along with open ended questions. By doing this, the researcher gathered enough substantial data to draw conclusions and make interpretations to establish common themes. The researcher also had informal follow up interviews with some of the participants which added more data to the survey questions.

The original number of participants that the researcher estimated was between 5 - 25 participants. This research implemented a purposive and snowball sampling (Creswell & Creswell, 2018). By using the snowball method the researcher found that the number of participants exceeded its original desired number of 5 - 25 participants. The researcher welcomed additional participants to a total of 35 participants which provided additional data.

The results were triangulated and the researcher was able to evaluate the effectiveness of the iBook, "Navigating Life in the World of Disabilities". The researcher was able to get vital feedback and compare it with additional resources from parents, educators, families, and caretakers of individuals with special needs. The questions on the survey further explored the opinions of the participants and were used as part of the results.

The researcher compiled the results of the study by utilizing the answers provided by the participants in the study and identified the key elements and themes from the data collected.

Based on the Likert scale and the informal interviews, and emails, the researcher was able to conclude that Navigating the Life in the World of Disabilities is an effective resource for families, parents, educators, and caretakers. There were suggestions made to include , “additional information for different disabilities, add individual state resources for those with special needs, include more personal stories of the researchers own experience, and stories from other families as well as educators and caretakers, and add photographs.

### **Research Question One**

**RQ1:** In what ways would an interactive guide iBook be helpful for those navigating the disability world?

Through triangulation the researcher was able to conclude various ways that the iBook would be helpful for those navigating the disability world. The majority of participants 65.71% who cared for a child or adult with severe disabilities felt that it provided easy access to the content. It proved to be most convenient and easily accessible using different tools (computer, tablet and phone). The main theme emerged was that the participants felt they could access various areas and not have to read the book cover to cover. The interactive part made it easy to find and access certain categories that were needed by simply typing in the topic.

### **Research Question Two**

**RQ2:** How useful would this iBook be for the general public in helping caregivers to assist those with disabilities?

The researcher concluded through data that the majority of participants felt that the iBook would be useful for the general public as well as those being a helpful resource to caregivers to assist those with disabilities. Of the participants, 57.14% felt that the iBook was extremely useful (10 on the Likert scale and the remaining participant scored anywhere between 5 and 9 on usefulness for the iBook. Concluding that this iBook would be helpful to the general public in helping caregivers assisting those with disabilities.

### **Research Question Three**

**RQ3:** Given a draft of an iBook as a resource for navigating the disability world, what components are missing that would make this iBook useful? What additional information needs to be added for parents, families, and caregivers of children and adults with severe disabilities?

The common themes that emerged from this question focused on adding more personal stories from the researcher, from other families that have children with disabilities, coping skills for parents, additional information for siblings of individuals with special needs, interviews with parents of children with disabilities, and maybe vignettes from other parents or educators. The majority of participants felt that the iBook covered many areas and felt that it was complete.

### **Limitations of the Study**

There were many factors that contributed to the limitations in this study. Among some of the limitations were the sample size of the participants. Since the researcher wanted to target a narrow group dealing with issues that pertained to those in the world of disabilities this may have

affected the number of results. Despite the fact that the number of participants that were involved in the study, the researcher also felt that time could have been a factor as well. The survey was open for a limited amount of time and then once closed no more data was collected. The researcher also found that some of the results of the survey may be biased due to the fact that many of the individuals were familiar with the researcher. The majority of individuals that were surveyed did have or care for an individual with special needs and this too may have been a limitation. The survey was sent out during COVID - 19 and many individuals were over saturated with information from the internet, whether it be with their own personal work or perhaps virtual learning for their children. The researcher feels that this is a factor because some of the respondents were limited in their answers as they may have felt overwhelmed with providing additional feedback. Results came in at varied times during the day and this too could have contributed to the limited answers, for example, those that answered during the evening provided more elaborate answers and also emails, whereas those that responded during the day were quick to answer the questions. There were also a certain number of characters to respond to certain answers and this would be considered a limitation as well. The final limitation the researcher found was the differences in tools used to read the iBook as well as how the survey was taken. Some of the participants found it easier to read the iBook on the computer and some participants found it easier to read the iBook on their phone or tablet. The same circumstance applied to the taking of the survey. found it easier to take the survey on the computer versus a tablet or phone.

### **Implications for Future iBooks**

Based on the results, the researcher concluded that the iBook, *Navigating Life in the World of Disabilities* has the potential to help many parents, families, educators, and caretakers as well as people with disabilities nationally and globally. This iBook has the potential to be used for Professional Development for educators and caretakers in order to heighten awareness. The researcher is fully aware that keeping the iBook current will also offer opportunities for others to add new knowledge, experiences, and information to continue to assist those challenged on their journey. It also has the potential to be used for college and university courses for those students seeking to pursue a career in special education. *Navigating Life in the World of Disabilities* has the potential to broaden the scope of what is being taught in a traditional course as it focuses on the lived experiences through an empirical approach of research. These results are consistent with previous research and would provide a useful tool for those in need of guidance, advice or direction.

There is also an opportunity to help unite the disability community by inviting individuals to communicate with others. Through this effort, individuals can offer advice through participating in sharing ideas, experiences and current information with respect to keeping the book fluid and using the iBook as a platform to unite families and individuals in the disability world. By translating *Navigating Life in the World of Disabilities* into different languages (for example, Spanish, Creole, Mandarin, French, and Greek) there is greater opportunity to reach a broader audience and continue to add to the platform that was originally designed. This will lend itself to a continual process of advancement for the researcher and further unite parents, families, educators, and those with disabilities globally in the world of disabilities. This can impact future

research by broadening this unique community based upon the data that was evaluated previously. Sharing knowledge is the key to opening up new worlds by heightening the awareness that is so greatly needed.

By offering *Navigating Life in the World of Disabilities* in the format as an iBook, it will allow for the researcher to continue to expand the book with new knowledge in the essence of a continual improvement process.

### **Recommendations for Future Studies**

The researcher recommends further research for studies that will further explore and enhance areas surrounding navigating life in the disability world. In addition, coping skills and mental health support for families dealing with challenges of raising and caring for individuals with special needs requires more attention. The impact of mental health on families that care for individuals with special needs continues to grow. The researcher feels that different avenues can be explored in order to face the current issues with the mental health of families for those that care for individuals with special needs as well as for the individual that has special needs. The researcher hopes that through providing research, future resources and programs can be made readily available. By doing this it will assist in keeping information and programs current and fluid and will help those families in need of guidance. At the same time it may offer a platform that will encourage other families and individuals to add their experiences, stories and references. It is the researcher's hope to create a gold standard as a resource and help cultivate a new way of thinking by acceptance and understanding. By doing this in our society we will be able to create a global ripple effect and create the change that is so desperately needed.

**Summary**

In almost fifty years we have witnessed significant advancement with more equal treatment and better education. However, the road ahead still remains full of challenges with obstacles to overcome. Society still lacks the compassion, understanding and education so greatly needed and more attention to individuals with disabilities needs to be highlighted. More improvements need to be made to change the biases linked to individuals and families with special needs and more resources need to be available. It is the hope of the researcher that the iBook that is created, *Navigating Life in the World of Disabilities*, as a product of this dissertation may fill the gap that exists in our society by providing a resource specifically created for those families faced with challenges while raising their child with disabilities. Educating the parents is the necessary tool needed in order to assist parents on their journey.

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### **Appendix A: Participation Invitation Letter**

Dear Invitee,

My name is Jaimee Sabato. I am a doctoral student at Lynn University's Ross College of Education Program. I am kindly requesting your participation in a doctoral research study that I am conducting titled: *An Interactive Guide for Parents Navigating Life with a Child or Adult with Severe Disabilities*.

The intention is to assess how and why this interactive book is a useful guide for those navigating the landscape in the disability world and what components can be added or removed. The study involves completing basic demographic information and a survey on Google Forms.

Participation is completely voluntary and you may withdraw from the study at any time. The study is completely anonymous; therefore, it does not require you to provide your name or any other identifying information.

If you would like to participate in the study please read the Informed Consent letter below. To begin the study, click the survey link at the end.

Your participation in the research will be of great importance to assist in ensuring that all individuals and families will have access to a useful iBook in assisting with navigating life in the disability world and make experiences easier and more manageable.

Thank you for your time and participation.

Sincerely,  
Jaimee Sabato, Doctoral Student, Lynn University

**Appendix B**

**Flyer**

# ***Volunteers Needed***

**Survey an iBook for Special Needs**

**all surveys must be submitted by September 25, 2020**

**Click here to get  
access to iBook and  
online survey**

Questions:  
[jaimeesabato.com](http://jaimeesabato.com)  
email me at  
[jsabato@email.lynn.edu](mailto:jsabato@email.lynn.edu)

**Appendix C: Informed Consent**

Dear Participant,

The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that you are free to decide not to participate or to withdraw at any time without affecting the relationship with the researcher or study.

The purpose of this study is to evaluate the usefulness of an interactive iBook. The study will provide information as to the usefulness of an iBook provided to parents and caretakers of children and adults with severe disabilities. The information gathered from this online survey may assist future parents in planning and navigating life with a child and adult that is severely disabled.

Participating in this online survey will have minimal risks such as possibly feeling uncomfortable or anxious if certain areas are discussed. Any time, you may stop the online survey and choose not to participate. The online survey will be destroyed. Choosing not to participate will not affect you in any way. This online survey does not have any benefits; however, you may enjoy sharing your lived experiences as a parent or caretaker and knowing you are assisting in the creation of a guidebook.

I will be happy to share my findings with you after the research is completed. The researcher will not know your identity as a participant and your name will not be associated with the research findings in any way. Should you have any questions please feel free to contact at the information below or Dr. Jennifer Lesh, Chair of the Lynn University Institutional Review Board at [jlesh@lynn.edu](mailto:jlesh@lynn.edu)

By marking the I agree, you will give your consent with full knowledge of the nature and purpose of the study. Thank you for your participation,

Jaimee Sabato  
Lynn University  
[jsabato@email.lynn.edu](mailto:jsabato@email.lynn.edu)

\_\_\_\_\_, I agree/consent to take the survey. I understand the study and have been given an opportunity to ask questions.

\_\_\_\_\_, I do not agree/consent to take the survey.

**Appendix D**

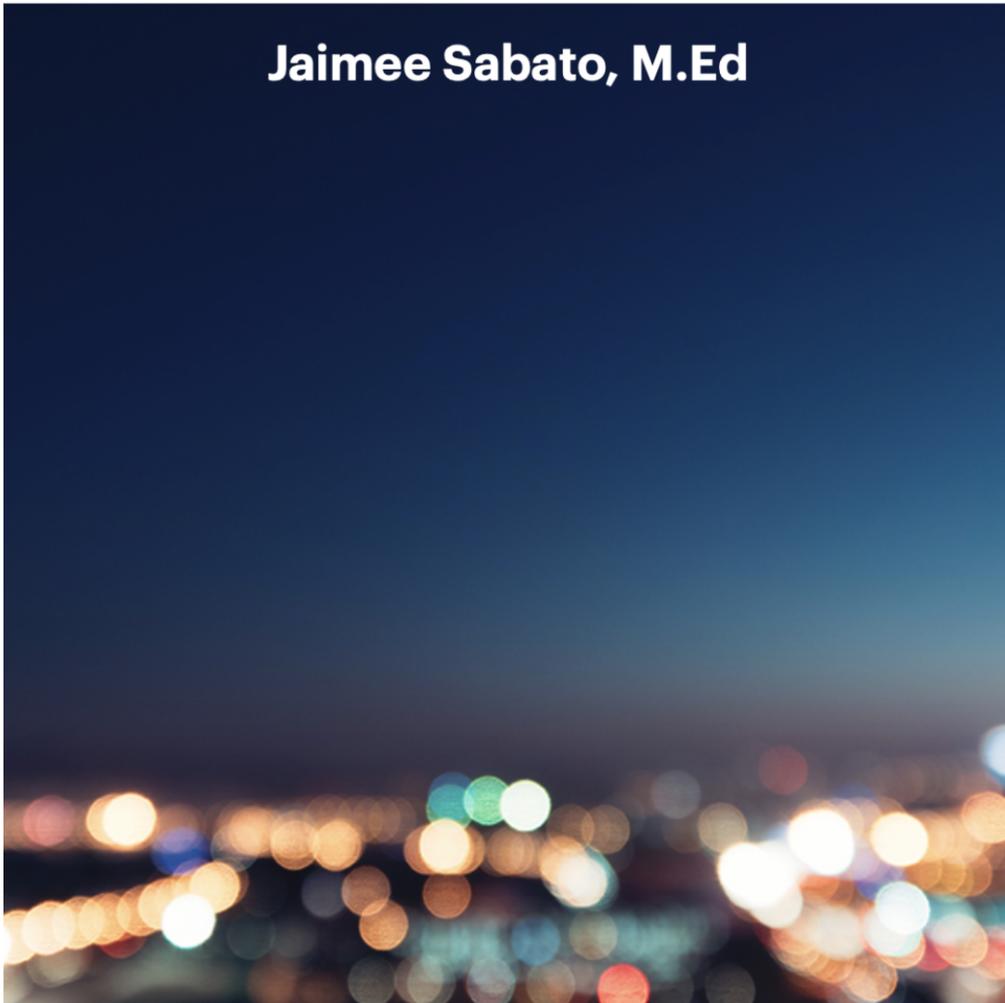
**iBook: Navigating Life Within the Disability World**

(Link to iBook )

[iBook for Survey Navigating Life in the World of Disabilities .pdf](#)

**Appendix E**  
**Copy of Online Survey**

**Jaimee Sabato, M.Ed**



**A GUIDE TO**

**NAVIGATING LIFE  
IN THE WORLD OF  
DISABILITIES**

\* 1. Informed Consent

Dear Participant,

The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that you are free to decide not to participate or to withdraw at any time without affecting the relationship with the researcher or study.

The purpose of this study is to evaluate the usefulness of an interactive iBook. The study will provide information as to the usefulness of an iBook provided to parents and caretakers of children and adults with severe disabilities. The information gathered from this online survey may assist future parents in planning and navigating life with a child and adult that is severely disabled.

Participating in this online survey will have minimal risks such as possibly feeling uncomfortable or anxious if certain areas are discussed. Any time, you may stop the online survey and choose not to participate. The online survey will be destroyed. Choosing not to participate will not affect you in any way. This online survey does not have any benefits; however, you may enjoy sharing your lived experiences as a parent or caretaker and knowing you are assisting in the creation of a guidebook.

I will be happy to share my findings with you after the research is completed. The researcher will not know your identity as a participant and your name will not be associated with the research findings in any way. Should you have any questions please feel free to contact at the information below or Dr. Jennifer Lesh, Chair of the Lynn University Institutional Review Board at [jlesh@lynn.edu](mailto:jlesh@lynn.edu)

By marking the I agree, you will give your consent with full knowledge of the nature and purpose of the study. Thank you for your participation,

Jaimee Sabato

Lynn University

[jsabato@email.lynn.edu](mailto:jsabato@email.lynn.edu)



I agree/consent to take the survey. I understand the study and have been given an opportunity to ask questions.

I do not agree/consent to take survey.

\* 2. Do you have, care for, or help a child or adult with severe disabilities?  

- Yes
- No

\* 3. How useful do you feel *Navigating Life in the World of Disabilities* is for someone in the disability world?  



\* 4. How useful do you feel *Navigating Life in the World of Disability* is for someone who is not familiar with the disability world?  



\* 5. What areas of the iBook do you feel can be added? Please feel free to write as much as you want.  

\* 6. What suggestions do you have for the caregiver, teacher, parent working with an individual with severe disabilities? Please feel free to write as much as you want.  

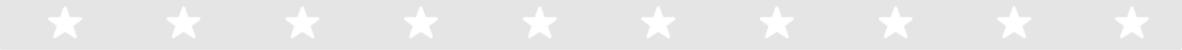
\* 7. How did you access the iBook?  

- Computer
- Tablet
- Phone
- Another device

\* 8. It was easy to access the iBook from one of these devices; computer, tablet, phone, or any other device.

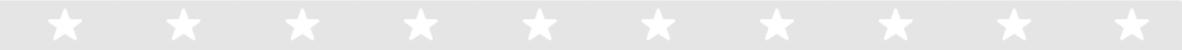
🗨 0

1 Not at all accessible      2      3      4      5 Moderately accessible      6      7      8      9      10 Extremely accessible



\* 9. How well do the topics in the iBook cover your own personal experience? 🗨 0

1 Not covered      2      3      4      5 Moderately covered      6      7      8      9      10 All areas covered



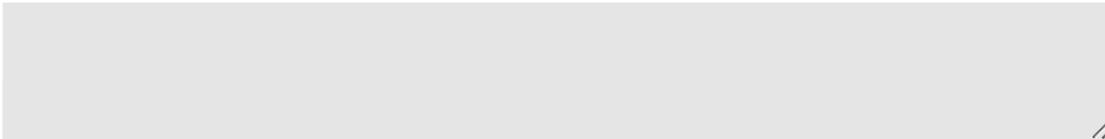
\* 10. Based upon your own experience, how useful is the iBook? 🗨 0

- Extremely useful
- Very useful
- Somewhat useful
- Not so useful
- Not useful at all
- No opinion

\* 11. Is there any information that was not useful in this iBook? 🗨 0

- Yes
- No

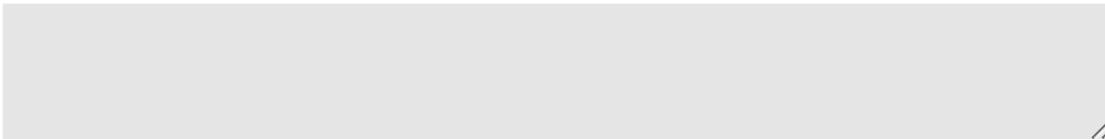
Comment



\* 12. Is there any information that was useful in this iBook? If so, please explain. 🗨 0

- Yes
- No

Comment



\* 13. What suggestions can you offer to make this iBook more useful? Please feel free to write as much as you want.  0

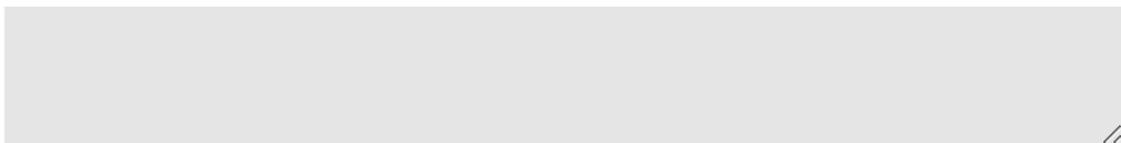


\* 14. Would you prefer to read the iBook digitally or do you prefer a print version?  0

- Digital version only
- Print version only
- Print or digital - it does not make a difference

\* 15. How likely are you to recommend this book to someone?  0

- Highly likely
- Somewhat likely
- Neutral
- Somewhat not likely
- Highly unlikely
- If somewhat not likely to highly unlikely, please explain why.



\* 16. \*\*\*If you are interested in contributing to the content of this iBook please email the researcher at [jsabato@email.lynn.edu](mailto:jsabato@email.lynn.edu)  0