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Families with Neurodevelopmental Disorders and Society Response

By

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Submitted in partial fulfillment

of the requirements for

Honors in the Department of Psychology and Sociology

UNION COLLEGE

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Abstract

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It is estimated that 1 in 10 children, almost 240 million children, live with disabilities around the world (UNICEF Division of Global Communication and Advocacy, 2022). The purpose of this study is to explore the relationships between disability stigma, parental stress, and anxiety levels of the neurotypical siblings of children with disabilities and the community response to these issues. Participants in this study included parents of families characterized by at least one child with a neurodevelopmental disability and one neurotypical child. Parents completed the Parental Stress Scale (Berry & Jones, 1995), the Spence Children's Anxiety Scale (Spence, 1997) regarding their neurotypical child, and the PROMIS Pediatric Stigma – Short Form 8a (The National Institutes of Health, 2022) regarding their child with a neurodevelopmental disability. In addition, information on policies dealing with families with disabilities as well as available federal and community programs were collected and an interview was conducted with a director of community support. Results suggest a positive correlation between parental stress and neurotypical child anxiety, whereby greater parental stress was associated with increased anxiety in the neurotypical siblings of children with a disability. In addition, findings also suggest that programs not only benefit the individual with a disability but are beneficial to the whole family. Addressing parental stress and its impacts on all family members may be a key factor to consider in designing and funding interventions.

Table of Contents

Chapter 1: Definitions, Background, and Theory	5
Defining Disabilities	5
Definition	5
Disabilities Statistics/Trends	8
Historical Approach	10
Pre-Nineteenth-Century	11
Nineteenth-Century	12
Twentieth-Century	13
History of Stigma	19
Understanding Families with Disabilities	23
Ecological Systems Theory	23
Families	25
Parent-Child Relationships	26
Sibling Relationships	27
Chapter 2: Societal Responses and Community Outreach	30
The Americans with Disabilities Act	30
Coverage	30
Title I	31
Title II	32
Title III	33
Title IV	34
Title V	34
Programs and Policies	34
Education	35
Employment	36
Housing	37
Healthcare	39
Caregiver Support	39
Community Support through Federal Programs	40
American Association on Intellectual and Developmental Disabilities	41
Special Olympics	43
The Arc of the United States	45
Chapter 3: Methods and Results	49
Quantitative Study Methodology	50
Participants	50

Procedure	51
Measures	53
Study Results	56
Preliminary Analyses	56
Descriptive Statistics	57
Pearson Product-moment Correlation Coefficients	57
Interview Methodology	59
Interview	59
Interview Results	60
Schenectady ARC	60
Programs	61
What works	62
Challenges	63
Mission and Impacts	64
Impact of Programming on the Family	64
Reaction to Research	65
Discussion	67
Quantitative Study	67
Interview	73
Chapter 4: Conclusion	76
References	79
Appendix A: Study Materials	90
Appendix B: Study Results	105
Appendix C: Outline of Interview Questions	109

Chapter 1: Definitions, Background, and Theory

Defining Disabilities

Definition

Many different disorders fit under the term disability, and previous literature focuses on a wide range of disorders. It is useful to define the term more specifically as it will be used in the present paper. The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) uses the term “neurodevelopmental disorders” to encompass a variety of different disabilities. The DSM-5 defines neurodevelopmental disorders as “a group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning” (American Psychiatric Association [APA], 2013, p. 31). This definition includes a variety of disorders including intellectual disorders, communication disorders, language disorders, Autism Spectrum Disorder, Attention-Deficit/Hyperactivity Disorder (ADHD), specific learning disorders, motor disorders, tic disorders, and other neurodevelopmental disorders (American Psychiatric Association [APA], 2013). It is important to note that various terms are sometimes used interchangeably and have overlapping but distinct meanings. Additionally, different fields tend to use different terminology. For instance, the language used by a teacher in the education sector can differ from that of a psychiatrist in the clinical sector, which may differ from a lawyer in the legal sector, which may also differ from an advocate in the philanthropic sector. In order to gain a better

understanding of the disorders that are included in this study, I will define a few of the terms that neurodevelopmental disorders encompass.

Developmental disability (DD) is a broad term used to encompass many different disabilities that vary in severity and impact. Nonetheless, developmental disabilities, as defined as a range of conditions due to an impairment in physical, learning, language, or behavioral areas. These conditions can begin at any time during the developmental period of childhood, typically persist throughout a person's life, and often impact their day-to-day functioning (Rubin & Crocker, 1989). Although many conditions fit under the term developmental disabilities, the main conditions that focus most on ADHD, Autism Spectrum Disorder, Cerebral Palsy, hearing loss, intellectual disability, learning disability, vision impairment/blindness, and other developmental delays. Most developmental disabilities are present before the child is born but sometimes they can form after birth due to an injury, infection, or another factor. The exact cause of developmental disabilities varies for each condition and many of the causes are unknown. But for most, they are thought to be caused by a complex array of factors including genetics, parent health, behaviors during pregnancy, birth complications, infections the mother might have during pregnancy or the baby might have very early in life, and exposure of the mother or child to high levels of environmental toxins (CDC, 2022).

Intellectual disabilities (ID) is one of the disorders that is included under the DSM-5 category of neurodevelopmental disorders. The DSM-5 defines intellectual disabilities as impairing the general mental abilities that impact adaptive functioning in three areas including the conceptual domain, social domain, and practical domain (American Psychiatric Association [APA], 2013). There are three criteria a person must meet to be diagnosed with an intellectual

disability: (1) a deficit in intellectual functioning including “reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning from experience” as confirmed by clinical evaluation and individualized standard IQ testing; (2) deficits in adaptive functioning that cause the failure to meet developmental and sociocultural standards for personal independence and the ability to meet their social responsibility; (3) the onset of these deficits is during the developmental period (American Psychiatric Association [APA], 2013). In the majority of cases, the cause of IDs is unknown, but ID can be caused by injuries, diseases, or brain problems (CDC, 2022). Some commonly known pre-birth causes include genetic or chromosomal conditions, such as Down syndrome, fragile X syndrome, or other genetic conditions or birth defects, or acquired causes, such as those that are seen in fetal alcohol syndrome, and result from infections (CDC, 2022). There are also causes that can occur when the child is older such as head injury, stroke, or certain infections.

Additionally, there are a few additional constructs that are useful to define when studying disabilities. The first is the general term “disability”. Disability is typically used in a broader social context and more importantly in a formal legal context (Srivastava, 2022). The Americans with Disabilities Act defines disability as a “(A) physical or mental impairment that substantially limits one or more major life activities; (B) a record of such impairment; or (C) being regarded as having such impairment an impairment” (ADA, 1990, p. 7). Some other terms that are typically used when discussing disabilities are condition, disorder, syndrome, and disease. A condition is a “state of health” (Amastyleinsider, 2011), a disorder refers to an “irregularity, disturbance, or interruption of normal functions” (Nasrallah, 2009, p. 14), a syndrome is “a recognizable complex of symptoms and physical findings which indicate a specific condition for

which a direct cause is not necessarily understood.” (Calvo et al., 2003, p. 802), and “a disease is a condition that not only disrupts an individual's functioning but also causes structural changes in the body” (Srivastava, 2022, p. 352). For the purpose of this paper, the term disability is what will be used in reference to neurodevelopmental disorders.

Disabilities Statistics/Trends

According to the United Nations Department of Economic and Social Affairs, about 15 percent of the world’s population, around 1 billion people, live with disabilities making it the world’s largest minority (United Nations, 2022). Additionally, the World Health Organization stated that the majority of people are likely to experience some form of disability – temporary or permanent – at one point in their lives (World Health Organization, 2022). This means that disabilities affect a large number and a wide variety of people. But these numbers also include disabilities other than neurodevelopmental disorders such as physical or temporary disabilities. As there are so many disabilities that are encompassed within neurodevelopmental disorders, I will focus on a few of the various conditions that fit under the umbrella term neurodevelopmental disorders, according to the DSM-5, including Attention-Deficit/Hyperactivity Disorder (ADHD), specific learning disorders, Autism Spectrum Disorder (ASD), and intellectual disorders (ID).

Starting broadly with statistics on developmental disabilities, which is a term that is used to encompass ADHD, Autism Spectrum Disorder, intellectual disability, learning disability, and other developmental delays, about 1 in 6 (17%) children aged three to seventeen years old were diagnosed with a developmental disability in 2022 (Cogswell et al., 2022). Even more staggering

is that this percentage has increased from the 2009-2011 time period to the 2015-2017 time period. More specifically for ADHD, in 2019 it was reported that 9.9% of the proportion of children ages 5 to 17 years reported having ever been diagnosed with attention-deficit/hyperactivity disorder (ADHD), and the percentage of boys reported having ADHD was 14.2% while the rate for girls was 6.8%. Additionally, the racial and ethnic breakdown of children ages 5 to 17 years to have reported having ADHD was 12.9% of children of “All Other Races,” 12.8% of Black non-Hispanic children, 12.2% of White non-Hispanic children, 7.3% of Hispanic children, and 2.5% of Asian non-Hispanic children (EPA, 2022). Additionally, for children ages, 5 to 17 years 13.3% of children from families living below the poverty level were reported to have ADHD while only 10.0% of children from families living at or above the poverty level were reported to have ADHD (EPA, 2022). Zablotsky and Alford (2020) found for the NCHS Data Debrief, that children located in rural areas as compared to urban areas and children with public health insurance compared to children who are uninsured or have private insurance are more likely to be diagnosed with ADHD.

For learning disabilities, the rate of children ages 5 to 17 years who had ever been diagnosed with a learning disability was 7.1% in 2019 with 10.1% of boys compared to 6.1% of girls. The racial and ethnic breakdown of children ages 5 to 17 years reported to have a learning disability is 10.2% for Black non-Hispanic children, 8.7% for Hispanic children, 8.1%, for children of all other races, 7.9% for White non-Hispanic children, 7.5% for American Indian or Alaska Native non-Hispanic children, and 2.4% of Asian non-Hispanic children (EPA, 2022). For children ages, 5 to 17 years 13.1% of children from families living below the poverty level were reported to have a learning disability as compared to 7.1% of children from families living

at or above the poverty level (EPA, 2022). In regards to Autism Spectrum Disorder, the rate of children ages 5 to 17 years who had ever been diagnosed with autism was 2.9% in 2019 with 4.0% of boys compared to 1.2% of girls. The racial and ethnic breakdown of children ages 5 to 17 years reported to have autism is 4.6% of Puerto Rican children, 2.9% of White non-Hispanic children, 2.8% of children of all other races, 2.7% of Black non-Hispanic children, 2.3% of Hispanic children, and 1.7% of Asian non-Hispanic children. For autism, there were similar levels of prevalence for children living below the poverty level and children living at or above the poverty level.

For intellectual disabilities, 1.7% of children ages 5 to 17 years were reported to have ever been diagnosed with intellectual disability in 2019 (EPA, 2022). The Special Olympics reported about 6.3 million people in America to have intellectual disabilities. Additionally, the NCHS Data Brief by the CDC found that the prevalence of Intellectual Disabilities was higher among boys than girls, with intellectual disability being 1.48% for boys and 0.90% for girls (Zablotsky, et al., 2017). They also found that the prevalence of IDs was lower in younger children as compared to older children. The racial and ethnic breakdown is 0.6% Asian non-Hispanic children and between 1.2% and 1.6% for all other race/ethnicity groups, excluding Puerto Rico (EPA, 2022).

Historical Approach

Views of disabilities and behaviors towards individuals with these diagnoses in the United States have come a long way and progressed greatly. In the present day, individuals with disabilities are protected by laws and supported by numerous programs and there are fewer

stigmas surrounding them. That being said, the historical practice toward those with disabilities was often poor and varied at different points in time.

Pre-Nineteenth-Century

From the founding of America in the late 15th century until the 19th century, the view of individuals with disabilities, unfortunately, did not make much progress. As Jordan A. Conrad put it, they were seen as being “totally and permanently unable to participate in rational deliberation in a way that was characteristic of being human, and as a result, they ought to be treated charitably but without any pretense of equality or justice that might generate duties of the state toward them” (Conrad, 2018, p.13). During this time there were two classifications of those with disabilities which included “idiots” and “lunatics”. The biggest distinction between the two terms was that “idiots” were seen as permanent and impossible to cure so they were given to the government, while “lunatics” were allowed to stay on their property as it was believed to be temporary and treatable (Conrad, 2013). Up until the mid-eighteenth century, disabilities were associated with sin, moral failing, or mark of wrongdoing and often led to stigma, shame, and abuse (Andrews et al., 2022). Terms used during this time included “gimp,” “cripple,” “handicap,” or “imbecile”. Some of these terms were traced back as early as the 9th century and were not seen as stigmatized till the 17th century. During this time, in the late 1800s, asylums were built in order to treat these individuals but in actuality, it was to remove them from society (Conrad, 2013).

Nineteenth-Century

In the mid-nineteenth century, due to the development of a training program for the blind and deaf by Jean Marc-Gaspard Itard, many asylums in America started educational programs for their patients (Conrad, 2013). By the mid-1880s there were schools and educational programs, often focused on vocational training as opposed to academics, for individuals with disabilities in 11 states. This was thanks to Samuel Gridley Howe who appealed that the state has a duty to help these individuals. Although these asylums and educational programs showed progress in societal responses, similar to the pre-nineteenth century, they still segregated individuals with disabilities from the rest of the population. An important note is that during this time, *Pless v. Ferguson* (1896) ruled that separate but equal segregation served a public good. Additionally, there was still much mistreatment in many of these institutions. During this time, people associated disabilities with sin, moral failing, or marks of wrongdoing which often led to stigma, shame, and abuse. At this point, a wider range of terminology began to develop including the term “idiocy” which was defined as the most severe, and “imbeciles” who were seen as having the potential to learn (Conrad, 2013). Although these terms are now offensive, they still represent the beginnings of the understanding of a spectrum of disorders.

In the late 19th century and the early 20th century, there was a rise in restrictions on immigrants let into the country due to concerns with the quality of the would-be citizens and their ability to work. Starting with the Immigration Act of 1882 and continuing through the Immigration Act of 1924, the 1960s became the most restrictive immigration law in US history. These restrictions excluded “undesirable” immigrants including people with disabilities who

were deemed defective morally, physically, or intellectually. The Immigration Act of 1882 denied entry to “lunatics”, “idiots”, and people who were unable to take care of themselves without becoming a public charge. These laws became even more restrictive later by also excluding any person who was likely to become a public charge in 1891 (Nielsen, 2012). By 1907 restrictions included rejecting all immigrants judged to be “mentally or physically defective, such mental or physical defect being of a nature which *may affect* the ability of such aliens to earn a living” (Nielsen, 2012, p. 103). This same mindset is shown again during this time through the rise in eugenics, those with disabilities, and many other different populations. This was because during this time disabilities were seen as hereditary traits and were blamed for the disparities between the small number of rich individuals and a large number of poor individuals. By the 1960s sixty-five thousand Americans were sterilized by force (Nielsen, 2012). Unfortunately, due to poor economic and political conditions during this time, institutions began to exhibit much abuse and neglect.

Twentieth-Century

World War I began on July 28, 1914, with America joining on April 6, 1917. World War I, also known as The Great War, created lasting consequences that were felt around the world, including views on disability in America. The scale of World War I was unparalleled at the time. According to the Gilder Lehrman Institute of American History, it was reported to have killed more than 14 million people, involved 28 countries, cost \$337 billion, and left at least 7 million men permanently disabled (Mintz). With such a large portion of the population left with some sort of disability after serving the country, there was an increase in disability advocacy after this

world war. Organizations such as the American Legion, founded in 1919, and The Disabled American Veterans (DAV), founded in 1920, began forming to provide veterans as well as their families support and advocacy (Maloney, 2017). Due to the efforts of these organizations, the U.S. government established the United States Veterans Bureau, the precursor to the U.S. Department of Veterans Affairs, in 1921. Additionally, the Federal Board for Vocational Education was established by the government in 1917, leading to the first studies on veterans' disabilities (Maloney, 2017). In 1918, the Smith-Sears Vocational Rehabilitation Act was passed which offered rehabilitation and vocational training for disabled veterans. This program not only shows an increase in advocacy for individuals with disabilities, but it laid the groundwork for future legislation that would address the needs of the broader disability community. For instance, this legislation was later amended in 1943, to include individuals with intellectual disabilities and mental illness. A similar effect happened following WWII, where in the conclusion of WWII there was an increase in disabled veterans and advocacy which greatly aided disability movements. In fact, despite forced sterilizations being legal until 2003, its popularity in the United States decreased significantly after World War II due in part to the use of eugenics in Nazi Germany as well as due to a greater sensitivity toward those with disabilities due to many soldiers returning with physical and emotional disturbances (Conrad, 2013).

Later in the late 20th century, there was much progress made for the rights of those with disabilities, leading some to call this time a disabilities movement. This movement may have in part been due to another movement that began in the mid-twentieth century. The 1960s were marked by the Civil Rights movement which sought to end segregation, discrimination, and disenfranchisement in the United States. While a large part of this political movement focused on

racial inequalities, it also affected other minorities including women and people with disabilities. During this time, citizens with disabilities began protesting using methods taken from anti-war and racial freedom movements to demand opportunities and protections of full citizenship (Nielsen, 2012). This movement was not only helpful in accomplishing political reform, but gave people with disabilities hope, a community, and organizational strength that allowed them to explore their identities.

An example of the shift that occurred in the late 20th century due to this political movement was caused by the case of *Brown v. Board of Education* and Eunice Kennedy Shriver, President John F. Kennedy's sister, who initiated a research panel to study and develop educational training programs for individuals with intellectual disabilities. *Brown v. The Board of Education* created a precedent that "state-sanctioned segregation based solely on a person's unalterable characteristics (e.g. race, gender, disability) was unconstitutional" (Conrad, 2018, p. 7). This led to an increase in higher education for those with physical disabilities. Thanks to Eunice Kennedy Shriver's work, the Community Mental Health Act (CMHA) of 1963 was developed and provided grants for research facilities, community-based centers, and facilities, and to train educators with methods for working with those with disabilities.

An example of a disability movement that gained traction during this time was the independent living movement. Beginning at the University of California, Berkeley in the late 1960s and later spreading across the nation, this movement promoted deinstitutionalization and self-determination. The movement would also contribute to the development of the Architectural Barriers Act of 1968 which was one of the amendments to the Social Security Act. The other amendments to the Social Security act included the 1971 amendment to finance Intermediate

Care Facilities for the Mentally Retarded (ICF/ID), and the Medicaid Home and Community-Based Services (HCBS) waiver program. All of these programs were aimed at supporting those with disabilities. But the provisions and legislation that protected the rights of individuals with disabilities came later, in part as a result of the civil rights movement

The 1970s was a big decade for legislation involving disabilities. A major provision to protect individuals with disabilities that resulted from the disabilities rights movement was Section 504 of the Rehabilitation Act of 1973. This provision “prohibited discrimination on the basis of race by recipients of federal funds” (Scotch, 2009, p. 20). This had many implications for establishing the rights of people with disabilities including federal funds for schools, colleges, public transportation systems, hospitals, social service agencies, and government offices. Although this was a major step forward in protecting the rights of individuals with disabilities, it was only accomplished as a side effect of provisions meant for racial discrimination. Another major program was started two years later in 1974, Supplemental Security Income (SSI). According to the Office of Retirement and Disability Policy, Supplemental Security Income was first started in 1974 and was aimed to provide income support to people who are older than 65, blind or disabled adults, and blind or disabled children. This was an extremely useful program as it gave financial assistance to disabled adults who had no work history. Additionally, in November of 1975, the Education for All Handicapped Children Act (Public Law 94-142), or the EHA, was signed into law by President Gerald Ford. This law provided funding for all the states in order to guarantee free and appropriate public education to all children with special needs. Also in 1975, the Individuals with Disabilities

Education Act (IDEA) was passed by congress which promoted equal access to education for students.

Moving past the 1970s and into the 1980s, the Civil Rights Restoration Act of 1984, which overturned the court decision that had restricted the enforcement of institution-wide civil rights protections in programs that received federal funds, was the first time the disability community had been explicitly stated as part of a civil rights effort (McGuire, 1994). Another provision that resulted from the movement was the Fair Housing Amendments Act of 1988, which added revisions to the original act that prohibited housing discrimination on the basis of disability, race, religion, gender, familial status, or national origin. The Americans with Disabilities Act (ADA) of 1990 was a major milestone for individuals with disabilities as it was the first major civil rights initiative that was disability-focused and had the broadest range of coverage with protections in employment, telecommunications, transportation, and public accommodations (McGuire, 1994).

On a broader scale, in 1980 the World Health Organization introduced the "International Classification of Impairments, Disabilities, and Handicaps" which introduced a conceptual framework that allowed for further classification of disablement including impairment, disability, and handicap. This framework states that an impairment is any loss or abnormality of physical bodily structure or function, a disability is any limitation or lack of ability deriving from an impairment that prevents the performance of an activity in the time range considered normal for a human being, and handicap is a disadvantaged condition caused by an impairment or disability limiting or preventing a person performing a role considered normal (Andrews et al., 2022). This classification was important to note because it greatly reflected changes in ways of thinking

about people with disabilities. This framework focuses on the diagnosis as “a deficit orientation that situates disability as a problem within the person” (Andrews et al., 2022, p. 2). The terminology tends to be clinical, all-encompassing categories. Examples of common terminology during this time include “the blind” or “the mentally ill”. Additionally, “first-person” language has been rising in usage during this time. This is important because it reflects the positive progress made in society's views on individuals with disabilities as it “emphasizes distinguishing the person from the disability by referring to those with disabilities first as individuals and then mentioning their disability second and only when needed ” (Andrews et al., 2022, p. 2). One example of this would be “people with disabilities” rather than “disabled person”. This model of language has been widely adopted in many disability language guidelines including the 1990 Americans with Disabilities Act and is widely used in today’s society.

Additionally, organizations such as the National Association for Retarded Children (now ARC of the United States) were founded in 1950. All of these programs and organizations aided in the slow and proper deinstitutionalization of individuals with disabilities. Most recently, in 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities. There were also monumental court cases during this time that supported the rights of those with disabilities including Wyatt v. Stickney, Halderman v. Pennhurst State School & Hospital, and Olmstead v. L.C. Wyatt v. Stickney ruled that when being involuntarily committed to a state-run facility, people with disabilities had the constitutional right to a “humane psychological and physical environment, (2) qualified staff in numbers sufficient to administer adequate treatment and (3) individualized treatment plans” (Wyatt v. Stickney, 334 F. Supp 1341, 1343 (M.D. Ala. 1971)). The court ruled in Halderman v. Pennhurst State School & Hospital ruled that the

patients had a right to “minimally adequate habilitation” in the “least restrictive environment” (Halderman v. Pennhurst State School & Hospital, 446 F. Supp. 1295, 1322 (E.D. Pa. 1977)). Lastly, Olmstead v. L.C. acknowledged sheltered workshops and segregated day programs as a form of “unnecessary[segregation]” (Conrad, 2018, p.12). These most recent court cases, organizations, and legislation have all worked to reduce the stigmas surrounding those with disabilities and give them more rights. Despite how far society has come, there is still a long way to go, especially to destigmatize. Historically, there has been much stigma directed toward both individuals with disabilities and their families that have continued into the modern day. To fully understand the stigma faced by individuals with disabilities, it is important to understand the history of stigma as a social and cultural construct.

History of Stigma

As seen by the negative historic treatment of people with disabilities, there is much stigma surrounding these individuals. Additionally, an abundance of research shows the negative effect of disability stigma on children with a disability (López et al., 2017) and their parents (Green, 2003). But before getting into detail about the stigmatization around individuals with disabilities, it is important to first define stigma and the ideology surrounding it.

To fully understand stigma, one first must understand deviance. Deviance is a behavior that violates social rules or norms and stimulates negative social reactions (University of Minnesota, 2016). Deviance goes along with the idea of social control which refers to the ways society attempts to prevent and sanction behavior that violates norms (University of Minnesota, 2016). French sociologist Durkheim viewed deviance as an important function of society and

believed that it served several functions. According to Durkheim, deviance clarifies norms and increases conformity, it strengthens social bonds among the people reacting to the deviant, and it can help lead to positive social change (University of Minnesota, 2016).

It is also important to note that deviance is relative and depends on context. For instance, depending on things such as location and time period, the same action can be considered deviant in one context and not another. Labeling theory is a sociological theory that has been developed to explain this variation of deviance in different contexts. Labeling theory was developed by Howard Becker in 1963. Becker (1963), explains his theory as follows:

Social groups create deviance by making the rules whose infractions constitute deviance, and by applying these rules to particular people and labeling them as outsiders. From this point of view, deviance is not a quality of the act the person commits, but rather a consequence of the application by others of rules and sanctions to an “offender.” The deviant is one to whom that label has successfully been applied; deviant behavior is behavior that people label so (p. 9)

Labeling theory is essentially the idea that labeling someone as deviant increases the likelihood that the person continues to be deviant because the societal label affects the individual’s self-image creating a self-fulfilling prophecy. Edwin Lemert introduced the idea of primary and secondary deviance within labeling theory. Primary Deviance is acts of deviance that do not result in stigmatization which is typically the case because the acts of deviance either occur often or are unknown to be deviant by the committer. Alternatively, secondary deviance is when a person is already labeled as deviant and engages in deviant behavior because of the negative social label already assigned to them. This negative label is a stigma. The labeling theory

emphasizes how this stigma affects both the way the individual labeled thinks and acts as well as how other members of society think about and treat them.

According to Michaels et al., the word stigma was originally used to describe marks that were used as visible testaments to a person's marginal social status or deviance (2012). But by the 18th century it was, in part, used to describe signs of disease or physical degeneration and in the 20th century was used in sociological theory as physical and symbolic marks of social deviance or disapproval. Michaels goes on to describe how contemporary definitions of stigma are a “socio-cultural process by which members of marginalized groups are labeled by other people as abnormal, shameful, or otherwise undesirable” rather than being an inherent flaw in the individual or groups it is directed towards (Michaels et al., 2012, p.2). This is an important distinction as in this paper the idea of stigma will be used to define stigma as a “problem that does not reside within marked individuals but rather stems from the stigmatizing community that has labeled people with mental illness as damaged” (Michaels et al., 2012, p.2). Stigma can be further classified into public and self-stigma. Public stigma is when the general public makes assumptions about a person based on their diagnosis. While self-stigma is when the public stigma is internalized and they accept it as an accurate representation of themselves and others within the same group (Michaels et al., 2012).

People with disabilities are often seen with stigma and are discriminated against, but this is even more evident when looking at children with disabilities and their relationships with their peers. Stigma towards children with special needs is related to several social problems including social isolation, exclusion, and bullying. An abundance of research has shown that compared to students without special needs a larger proportion of students with special needs experience

difficulties in social participation, have a lower number of friends, have fewer interactions with classmates, are less accepted, and are more likely to report being bullied (Koster et al., 2010, Fink et al., 2015). These are significant issues because, as previous studies have shown, there are associations between children's social relationships that were associated with social-emotional adjustment (Murray & Greenberg, 2006) and life satisfaction (Pgam & Murray, 2015).

While a number of studies have been done on the perceptions and effects of discrimination and stigma concerning the child with disabilities, less has been done on the perception and effects in regard to their family members. Oftentimes, parents and neurotypical siblings are the ones that observe the stigma and discrimination towards their loved ones which can have a great effect on those family members. For instance, according to Cantwell et al. parents of children with disabilities report a greater amount of depressive symptomatology, which was associated with stigma, self-esteem, and social support (Cantwell et al., 2015). Many other studies explore these topics including studies that controlled for the effects of the increased care responsibilities, sometimes termed “hassle,” of caring for a child with a disability. Green (2003) finds that even while controlling for this hassle, “maternal perceptions that individuals with disabilities are devalued and discriminated against (stigmatized) by others increases maternal distress (subjective burden)” and those children whose mothers perceive more stigma, interact less with peers in informal settings like homes and neighborhoods (Green, 2003, p.1). More specifically, parents that reported a higher level of stigma were lower in self-esteem and more depressed (Cantwell et al., 2015). Another study was done specifically on affiliate stigma which is defined as the “internalized stigma by association” (García-Ael and Pérez-Garín, 2020). García-Ael and Pérez-Garín (2020) found that discrimination increases affiliate stigma in parents

of children with Autism Spectrum Disorder and Intellectual Disabilities, affiliate stigma negatively relates to parents' self-esteem, affiliate stigma mediates the effect of discrimination on parents' self-esteem, and social support is a protective factor against the negative effects of discrimination on parents' self-esteem. Additionally, it was found that mothers were more likely to feel stigmatized than fathers and that parents with a more severely disabled child were more likely to perceive themselves as stigmatized (Gray, 1993). This abundance of research shows just how much-perceived stigma can affect the parents of children with disabilities and even has the opportunity to indirectly affect the children through their parents.

As stigma affects the parents and caretakers of children with disabilities, it makes sense that their siblings would be affected as well. Primarily due to the idea of stigma by association also known as courtesy stigma. But there is a gap in research on this topic as there is little to no literature on it. There was a study done on siblings of those with Down syndrome, it was shown that levels of courtesy stigma were higher in adolescence than adulthood but they did find overall relatively low levels of courtesy stigma and that participants still reported strong positive relationships with their sibling with Down syndrome (Fulk, 2014). Further research needs to be done on the effect of stigma on siblings of children with disabilities, which is one of the goals of the present project.

Understanding Families with Disabilities

Ecological Systems Theory

An abundance of existing research focuses on the influence members of a family have on one another. More specifically, literature has shown that parents greatly influence their children,

children also influence their parents, and siblings influence each other. This effect can be explained by the Ecological Systems Theory which emphasizes the importance of social environments on human development.

The Ecological Systems Theory was developed by Urie Bronfenbrenner in 1979 to understand a child's development through the context of the individual's relationships within communities and the wider society (Ryan, 2001). According to the Ecological Systems Theory, there are five environmental systems that individuals interact with including the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Bronfenbrenner, 1979). The macrosystem involves the structures that the child has direct contact with and includes systems such as the child's family, school, and neighborhood. The Ecological Systems Theory states that, at this level, the child is not only affected by their environment but the child also affects their environment. For example, the stress of a parent can affect the child's behavior but the child's behavior can also affect the parent's stress. This is the idea of bi-directional influences which can occur on all system levels and between systems but is most prominent in the microsystem. The mesosystem is what interconnects the microsystems. For instance, the connection between the family and teachers or their peers and parents. The ecosystem involves the larger social systems that do not involve the child. An example would include a parent getting laid-off from their place of work. Although the child may have never come in direct contact with their parent's place of work, they are still affected by it. The macrosystem is the layer that makes up the overarching culture that influences children. This includes cultural values, customs, and laws. For example, if a culture believes that a parent should be the ones responsible for supporting their child, then they are less likely to provide resources to help the parents. Lastly, the chronosystem

encompasses the pattern of environmental events and transitions over their life. This can include things such as the time of a parent's death.

This theory is important as it explains how a child's microsystem, including their family and peers, affects a child's development bi-directionally. This includes how a parent can affect the child and vice versa as well as how a child can affect their sibling and vice versa. The exosystem can explain how a child can be affected by the experiences on their microsystem including the experiences of their siblings or parents. The macrosystem also highlights the impact that societal views and responses such as laws and organizations can have on a child. The Ecological System Theory highlights the importance of the environment in the development of a child, including the relationships with people in those environments. The following sections will highlight the importance of the interactional relationships between a child with disabilities and their family.

Families

From this theoretical perspective, the parents and siblings have a great impact on a child's development as they are a part of the child's microsystem and have direct contact with them. This idea is in concurrence with a vast amount of pre-existing literature in the field of both psychology and sociology as it is well-established in both these fields that family relationships can affect each member of the family. For example, previous research has shown that parental stress levels can have effects on the children of the family. Christina M. Rodriguez (2010) studied the association between maternal parental stress and children's internalizing symptomatology by sampling 92 mother-child dyads and found that maternal parental stress, from both child and parent sources, was significantly associated with symptoms of anxiety in

their children. Parents can so greatly affect their children that there have been works of research that show it can moderate the relationship between stressors, such as trauma exposure, and child stress. Cho et al., (2020) found that the relationship between parental trauma exposure and child separation anxiety was significant when parental stress was moderate to high, but not when parental stress was low.

Parent-Child Relationships

In concurrence with the bidirectional influences of the Ecological Systems theory, existing literature has shown that not only do parents affect the children but the children also affect each other as well as their parents. So for instance, a child can cause an increase in stress in their parents. One situation where children have been shown to increase their parent's stress is when a child has a disability. This stress can be attributed to a multitude of factors, some more direct, such as stress due to the level of care required for the child, and some indirect, such as stress due to the stigma of others. A number of studies have been done showing that parents of children with a disability have a greater amount of stress. One study done by Dyson (1993) found that families with disabilities have a greater amount of stress than families with children without disabilities. Further, Ren et al. (2020) found differences in the parent's state of anxiety among children with different types of disabilities. More specifically, the parent's state of anxiety was significantly higher in parents of children with autism than in parents of children with visual impairments. This is likely due to differences in symptoms, level of care required, and severity of the disability. For instance, children with intellectual disabilities have greater emotional and behavioral difficulties which predict lower caregiver mental well-being (Salomone et al., 2018),

and child maladaptive and adaptive behavior accounted for a significant proportion of the variance in maternal stress (Tomanik et al., 2004). Additionally, it was also found that social (Ren et al., 2020) and informal social support (Benson, 2006) reduce levels of parent stress proliferation and parent depression. But this stress can be attributed to a multitude of additional factors including as well and requires more research.

Sibling Relationships

Siblings are another part of the microsystem that has a large effect on a child's development. Sibling relationships are oftentimes the longest relationship in a person's life starting with an extensive amount of contact with one another throughout childhood and adolescence, so it would be logical that siblings have a great effect on each other's behavior and socio-emotional development and adjustment. But there is surprisingly little research on how siblings affect one another. The literature that does exist shows that siblings can influence each other in both direct and non-direct ways within the family. Some examples of direct ways siblings can influence each other include sibling interactions influencing children's social-cognitive development, sibling influences on adjustment problems, and sibling differentiation (McHale et al., 2012). Some examples of indirect sibling influences include parents' learning from experience, parents' differential treatment, and resource dilution (McHale et al., 2012).

As siblings have a large effect on each other, logically, a child having a disability would also affect their sibling. Despite the vast amount of research done on children with disabilities and even on the effect it has on their parents, less research has been conducted on the effects it

has on their siblings. The research that does exist focuses on both positive and negative effects. Dautz Williams et al. (2010) performed a content analysis on forty studies performed between 1970 and 1995 and found that out of 363 themes, 61.1% reflected negative manifestations of increased risk in good siblings while 37.2% reflected positive outcomes. One positive effect of having siblings with a disability includes a greater amount of cognitive empathy (Rum, et al., 2022). Barak-Levy et al. (2010) compared parents' self-reports with self-reports from children who have siblings with Autism Spectrum Disorder (ASD) and children with no disabled sibling. They found that 59.2% of parents of those with children with ASD described "being helpful/responsible" as the most important positive attribute of their healthy child while only 14.8% of parents with neurotypical children emphasize this category. Interestingly this same quality may be a source of distress for children with a sibling with ASD. There are many negative effects that can arise in siblings of those with disabilities including lower participation levels in extracurricular activities (Barak-Levy et al., 2010) and, in a study of siblings of children with disabilities, including Autism Spectrum Disorder, Prader-Willi syndrome, and a developmental disability but with unknown etiology have reported significantly higher levels of anxiety and depression than the control group. Of the minimal existing research on qualities that may result, even less research focuses on the reason behind these trends. But one possible explanation is the increase in parental stress caused by having a child with a disability.

As the Ecological Systems Theory shows with the mesosystem, exosystem, macrosystem, and chronosystem, a multitude of other factors outside of a child's family can affect the development of a child. For instance, the ecosystem involves larger social systems that do not directly involve the child so this can include things that affect the microsystem of the

child. A more specific example includes a child's sibling with a disability causing their parents more stress which in turn affects them. Another example could be a child being affected by courtesy stigma due to their sibling having a disability. The macrosystem, the overarching culture that influences children, is another significant layer to take into account with the child's development and can include societal responses such as governmental policies and organizations. This is in line with current research that shows that support services are beneficial to both people with disabilities but also their families.

Chapter 2: Societal Responses and Community Outreach

This chapter will look at both federal programs and community outreach through federal programs designed to help people with disabilities and their families.

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal civil rights law that was a major milestone for making the United States more equitable and inclusive for individuals with disabilities. The passing of the ADA in 1990 by congress was not only monumental due to the new protections it brought but also due to the fact it also meant that the United States recognized that historically, a large population of the nation was being excluded and discriminated against. The ADA prohibits discrimination against people with disabilities in everyday activities and guarantees that those individuals have the same opportunities as everyone else to enjoy employment opportunities, purchase goods and services, and participate in state and local government programs (U.S. Department of Justice Civil Rights Division, 1/19/23). The ADA is broken into five different sections named titles. Title I covers employment, Title II covers public services, Title III covers public accommodations, Title IV covers telecommunications, and Title V is miscellaneous.

Coverage

The Americans with Disabilities Act has a definition of disability and who qualifies to be protected in its laws. According to the 1990 Americans with Disabilities Act, a person with a disability is someone who has a “physical or mental impairment that substantially limits one or more major life activities of such individual; record of such an impairment; or being regarded as

having such an impairment” (U.S. Department of Justice Civil Rights Division, 1/19/23, Sec. 12102). To ensure that there is no confusion about this definition, Congress has also further broken down the definition. The term “substantially limits” is a broad term that includes but is not limited to “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working” and the term “major life activities” includes the operation of a major bodily function and includes but is not limited to “includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions”. The idea of having a “record of such an impairment” is included so that the act can cover people who were once impaired but no longer are. One example is someone who had cancer but is now in remission not being hired due to the fact the employer worries that their cancer will return. Although individuals may not have cancer anymore, they can still be discriminated against and are still under the protection of the ADA. The idea of “being regarded as having such an impairment” is included to protect people who may not have any impairment but are discriminated against because the discriminator believes that they do. For instance, if an employee is fired because there was a rumor that they had HIV, they will still be protected regardless of if they actually had HIV or not.

Title I

Title I of the ADA covers employment and applies to employers who have 15 or more employees and covers the private sector, state and local governments, and labor unions (U.S. Department of Justice Civil Rights Division, 1/19/23, Sec. 12111.). The title requires employers

to provide equal opportunity to benefit from the employment-related opportunities that are available to others. This includes but is not limited to recruitment, hiring, promotions, training, pay, and social activities. These equal opportunities must be given to qualified applicants or employees through employers providing reasonable accommodations. A “qualified individual” is defined by the ADA as “an individual who, with or without reasonable accommodation, can perform the essential functions of the employment position that such individual holds or desires” (U.S. Department of Justice Civil Rights Division, 1/19/23, Sec. 12111.). And a “reasonable accommodation” is a change to accommodate the qualified employee so they can do the job without causing the employer “undue hardship”. Undue hardship is defined by the ADA as “an action requiring significant difficulty or expense” (U.S. Department of Justice Civil Rights Division, 1/19/23, Sec. 12112.). Additionally, title I of the ADA also addresses medical examinations and inquiries by specifying prohibited discrimination inquiries and acceptable inquiries. Lastly, Title I of the ADA is regulated and enforced by the U.S. Equal Employment Opportunity Commission.

Title II

Title II involves public services and is meant to require public entities to provide qualified individuals with disabilities an equal opportunity to benefit from all of their services, programs, and activities, including transportation. The ADA defines a public entity as “any State or local government; any department, agency, special purpose district, or other instrumentality of a State or state or local government; and the National Railroad Passenger Corporation, and any commuter authority” (U.S. Department of Justice Civil Rights Division, 1/19/23, Sec. 12131.). Some examples of state and local government services, programs, and activities include public

education, transportation, recreation, health care, social services, courts, voting, emergency services, and town meetings (U.S. Department of Justice Civil Rights Division, 1/19/23). As the title requires state/local governments to give individuals with disabilities an equal opportunity, they require them to make “reasonable accommodations” when necessary to provide this equal opportunity. An example of a reasonable modification is a situation where a public museum doesn’t allow food and the museum allows an individual with diabetes to bring in snacks to maintain their blood sugar (.S. Department of Justice Civil Rights Division, 1/20/23). Typically, the U.S. Department of Justice regulates and enforces Title II but the U.S. The Department of Transportation, Federal Transit Administration, focuses specifically on transportation.

Title III

Title III encompasses public accommodations and requires businesses and nonprofits to provide individuals with disabilities an equal opportunity to access the goods, services, facilities, privileges, advantages, or accommodations that they offer in public accommodations. Examples of these businesses and nonprofits include restaurants, hotels, retail stores, movie theaters, private schools, doctors’ offices and hospitals, daycare centers, gyms, and organizations offering courses or examinations. Additionally, privately operated transit and commercial facilities must adhere to some of the requirements. Title III also sets the minimum standards for accessibility for alterations and new construction of facilities, requires public accommodations to remove barriers in existing buildings, and requires businesses to make "reasonable modifications" to their typical ways of doing things when those with disabilities including taking steps to be able to communicate with customers with vision, hearing, and speech disabilities (Department of Justice

Civil Rights Division, 1/19/23). Title III is also regulated and enforced by the U.S. Department of Justice.

Title IV

Title IV addresses telecommunications and amended the Communications Act of 1934 to provide equal services to individuals with disabilities. It requires telephone and internet companies to provide a nationwide system of interstate and intrastate services that allow individuals with hearing or speech disabilities to communicate (ADA National Network, 1/20/23). One example of this is the requirement of captioning federally funded public service announcements. Federal Communication Commission regulates and enforces Title IV.

Title V

Lastly, Title V is miscellaneous that provides a place for the provisions relating to the ADA as a whole. This includes explaining the ADA's "relationship to other laws, state immunity, its impact on insurance providers and benefits, the prohibition against retaliation and coercion, illegal use of drugs, and attorney's fees" (Department of Justice Civil Rights Division, 1/19/23).

Programs and Policies

The passing of the Americans with Disabilities Act was a milestone in the rights of people with disabilities and mandated equal opportunities for individuals with disabilities. Since its passing in 1990, many different government programs have been made available for both children and adults with disabilities. This section will go more into depth about the current

government and local programs for families with disabilities. These programs fall under a few major categories including education, employment, housing, health care, and caregiver support.

Education

Education is an important factor in the development of children as it helps to set them up for their future endeavors. This is why it was such an important moment when President Gerald Ford signed the Education for All Handicapped Children Act into law in 1975. Guaranteeing a free and appropriate public education to every child with a disability in the country, was the first step in establishing all of the programs currently offered today. The Individuals with Disabilities Education Act (IDEA), originally known as the Education for All Handicapped Children Act, was enacted in congress in 1975 (Individuals with Disabilities Education Act, 1/20/23). It was meant to do a few different things to support infants, toddlers, children, and youth with disabilities as well as their families. Firstly, IDEA was aimed at ensuring that every child with a disability has a free and appropriate public education available which includes special education and related services that are designed to meet their unique needs. Secondly, it was meant to protect the rights of children with disabilities as well as their parents. Third, it was enacted to assist States and localities in providing equal education for those with disabilities. Lastly, it was aimed to assess and ensure the effectiveness of the efforts in educating all children with disabilities. Since then there have been multiple reauthorizations that added things such as mandating earlier intervention options for children with disabilities, greater support for students transitioning to post-education, a higher standard for teachers, greater accountability for educational outcomes, and greater rights for parents advocating for their children. An essential part of IDEA is the student's individualized education program (IEP) which is a plan created by a

child's teachers and parents in order to best meet the child's needs. Additionally, there is an individual transition plan (ITP) which is similar but geared toward the child's transition out of education to achieve their career goals. In addition to the Individuals with Disabilities Education Act, each state in the United States had its own set of programs and additional education rights for people with disabilities.

Employment

As a child gets older and passes beyond primary and secondary education, the next thing they must worry about is finding employment. Employment is also an important part of a person's life as it is what can be the difference between being able to support oneself or not. The government offers a number of programs that help individuals develop their skills, search for jobs, train for jobs, and protect themselves from discrimination. Starting with programs that help to develop individuals with disabilities skills, there are many different programs that the United States Government provides to explore careers, find training, search for jobs, and prepare for interviews (USA Gov, 1/20/23). One example of a program is the State Vocational Rehabilitation Agencies which, according to the Rehabilitation Services Administration, provides grants "to formula grants to Vocational Rehabilitation (VR) agencies to administer the State VR Services, State Supported Employment Services, and Independent Living Services for Older Individuals Who Are Blind programs in all 50 states, the District of Columbia, Puerto Rico, and four Territories" (U.S. Department of Education, 1/20/23). An example of another one is the Ticket to Work program which trains Social Security disability recipients aged 18 - 64 to work. The United States Government also promotes getting a government job as they provide a less competitive hiring process and reasonable accommodations. Many online resources direct

individuals with disabilities regarding their rights and how to file a proper complaint or lawsuit if they feel their rights have been violated.

Additionally, two programs aid individuals with income. Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). The SSDI is meant to help disabled or blind individuals who are "insured" by workers' contributions to the Social Security trust fund by providing them benefits. The contributions are based on the earnings of either that individual, their spouse, or parents (Social Security Administration, 2/5/23). Alternatively, the SSI program gives cash assistance payments to "aged, blind, and disabled persons (including children)" that have limited income and resources. The money comes from the Federal Government's general tax revenues (Social Security Administration, 2/5/23). Many states have their own supplemental benefits that they may provide separately or combined with the Federal SSI. The key differences between the two programs are that the SSDI is meant for disabled workers and those who have been disabled since childhood regardless of income and resources but requires a work history and is wage based. While the SSI is meant for disabled adults and children who are unable to work and are in financial need but do not require any work history,

Housing

Housing is a basic need that can be a challenge for individuals with disabilities for a variety of different reasons. These challenges can differ depending on both the type of disability and the age of the individual. For instance, the issue may be about finding housing with the proper accommodation that allows them to live an independent life, or it may be an issue with finding affordable housing, or it may be that they might need assisted living. The United States government has a variety of housing programs at the federal, state, and local levels to help

individuals find affordable housing through both renting and buying, modifying an existing home, or developing their skills to live independently (USA Gov, 1/20/23). Individuals with disabilities are eligible for public housing programs, rental assistance or subsidized housing, and housing choice voucher programs.

There are a few key federal housing initiatives that were created specifically to aid those with disabilities in finding affordable housing. The Section 811 Project Rental Assistance (PRA) Program was authorized by the Frank Melville Supportive Housing Investment Act of 2010. It seeks to “expand the supply of supportive housing that promotes community integration for low-income people with disabilities by leveraging mainstream affordable housing, Medicaid, and other community-based supportive service resources” (The HUD Exchange, 2/5/23). Another key program is the Section 8 Housing Choice Voucher program which is meant to assist very low-income families, the elderly, and the disabled in affording decent, safe, and clean housing in the private market (U.S. Department of Housing and Urban Development, 2/5/23). Lastly, the National Housing Trust Fund (NHTF) is a dedicated fund that provides grants to states to produce and preserve affordable housing for the lowest-income households (The HUD Exchange, 2/5/23).

Additionally, state and local independent living centers can help individuals with disabilities develop skills to live on their own. Furthermore, individual states have departments of human services or disabilities offices that may be able to assist with living modifications, housing counseling, locating rental housing, and independent living skills.

Healthcare

In terms of healthcare programs, the government offers programs to improve well-being. These resources include informational websites and tools to teach you about disabilities, how to stay healthy and prevent healthcare-related discrimination, and resources to connect people to knowledge about additional programs. Additionally, there are health insurance programs for individuals with disabilities including Medicaid, Medicare, and Affordable Care Act Marketplace (USA Gov, 1/20/23). Medicaid provides free or low-cost medical benefits to those eligible, including people with disabilities, adults with a low income, children, pregnant people, and people over 65. It is administered by states in accordance with federal requirements and is funded jointly by state and federal governments (Medicaid, 2/5/23). Medicaid generally includes hospital insurance, medical insurance, and drug coverage (Medicaid, 2/5/23). Medicare provides federal health insurance for people either older than 65, below 65 with certain disabilities, or people of any age with end-stage renal disease. Medicare generally includes hospital insurance, medical insurance, and drug coverage (Medicare, 2/5/23). The Affordable Care Act is for people who need health coverage but do not qualify for disability benefits as it expanded the Medicaid program to cover all adults with incomes below 138% of the federal poverty line (Healthcare, 2/5/23).

Caregiver Support

In addition to offering support for those with disabilities, the government also offers programs geared toward their caregivers. These caregivers, who are oftentimes family members, may need help. Being a caregiver requires the individual to take on a lot of responsibilities that can be emotionally, physically, and financially taxing. When caregivers do not have the support

they need, they often experience burnout which can be detrimental to the well-being of both the caregiver and the individual in their care. There are two main ways the government provides support to these caregivers. Firstly, the federal government offers resources that give advice on how to cope, protect their own health, prevent and relieve stress, and how to overall provide good support. The second main way the government provides support to caregivers is by having a program that pays caregivers. The role of caregiving can be a large time commitment that can prevent them from maintaining employment which can further inhibit them from having the resources to provide for themselves and the individual to whom they are providing care. So the government has many programs that allow the family members of those with disabilities to get paid for acting as caregivers. An example of this type of program is Long-Term Care Insurance (USA Gov, 1/20/23).

Community Support through Federal Programs

There have not only been changes in the stance of the United States government on disabilities but in the stance of the general population. As the Ecological Systems Theory states, a person's development is affected by their environment (Ryan, 2001). Not only can governmental laws, policies, and programs affect an individual's environment, but so can the community. Since individuals with disabilities are an underserved population, often communities organize themselves to provide the support that the government does not. This support can be in many different forms including non-profit organizations. This section will explore three examples of non-profit organizations dedicated to helping those with disabilities and their families: The American Association on Intellectual and Developmental Disabilities, The Special Olympics, and The Arc of the United States.

American Association on Intellectual and Developmental Disabilities

The American Association on Intellectual and Developmental Disabilities (AAIDD) was founded in 1876 by Edouard Seguin, M.D., and is headquartered in Washington, DC. They have approximately 3,500 interdisciplinary members all over the United States and 55 other countries (Tassé & Grover 2013). Since its founding in 1876, the organization has gone through several name changes including the Association of Medical Officers of American Institutions for Idiotic and Feeble-minded Persons in 1876, the American Association for the Study of the Feeble-minded in 1906, the American Association on Mental Deficiency in 1933, the American Association on Mental Retardation in 1987, and finally the current name as the American Association on Intellectual and Developmental Disabilities in 2007. The AAIDD is the world's largest and oldest interdisciplinary professional organization devoted to intellectual and developmental disabilities (MentalHelp, 2019). The organization has many purposes including researching intellectual disabilities; increasing social awareness; promoting progressive governmental policy; supporting families; and developing rehabilitative strategies for persons with intellectual and developmental disabilities (MentalHelp, 2019)

More specifically, the AAIDD's mission is to promote "progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities" (American Association on Intellectual and Developmental Disabilities, 2023). They have their main goals listed on their website which are to (1) enhance the capacity of professionals who work with individuals with intellectual and developmental disabilities; (2) promote the development of a society that fully includes individuals with intellectual and developmental disabilities; and (3) sustain an effective, responsive, well

managed, and responsibly-governed organization (American Association on Intellectual and Developmental Disabilities, 2023).

The way that the AAIDD accomplishes its mission is by acting as a membership organization and source of information for those in the field of intellectual and developmental disabilities. The AAIDD provides its members with professional resources and tools to help them improve the lives of people with intellectual and developmental disabilities. They do this by offering educational opportunities, hosting events and webinars, publishing books and journals, and overall promoting information sharing, networking, and collaboration amongst its members. Some specific examples of what the organization accomplished in 2021 include presenting 32 educational webinars attended by over 10,000 learners, having over 1,000 learners enrolled in their online courses, publishing 105 articles in their three peer-reviewed journals, training over 300 professionals in the use of SIS-A and SIS-C, and submitting comments on proposed federal rules regarding the use of electric shock (American Association on Intellectual and Developmental Disabilities, 2022). Some of the AAIDD's landmark contributions include being a leader in the field in establishing the definition and diagnostic criteria for intellectual disabilities. Most notably, the AAIDD's definition of intellectual disability has been adopted by all federal and state governments as well as the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) (Tassé & Grover 2013). The AAIDD has also been known for influencing legislation and social action toward improving the treatment and support of individuals with intellectual and developmental disabilities. This includes serving as *amicus curiae* in numerous cases for the rights of individuals with intellectual disabilities. Additionally, they have recently formed the Consortium for Citizens with Disabilities. Which is a coalition of

similar national organizations, including the American ARC, that advocates for federal public policy that empowers people with disabilities (The Consortium for Constituents with Disabilities, 2023).

Special Olympics

The Special Olympics was founded by Eunice Kennedy Shriver, sister of President John F. Kennedy, in 1968. Shriver started a day camp in her backyard named Camp Shriver in 1963 for children with intellectual and physical disabilities to allow disabled children the opportunity to participate in something they normally were not given the chance to, sports and physical activities. The first official International Special Olympics Summer Games was held at Soldier Field in Chicago on July 20th, 1968. The event had over 200 events including broad jump, softball throw, 25-yard swim, 100-yard swim, high jump, 50-yard dash; and water polo. Following the event, Shriver stated that more games would be held every two years from then on. On December 2nd, 1968, Senator Edward Kennedy announced the formation of Special Olympics, Inc (Special Olympics, 2023).

The mission of the Special Olympics is to “provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community” (Special Olympics, 2023). They accomplish this mission through their many various programs and initiatives. Special Olympics categorizes its efforts under six categories on its website. These categories include sports, games

and competitions, inclusive health, youth and schools, leadership, and a campaign named The Revolution is Inclusion.

The sports category includes their support of over a “million athletes, 1 million coaches and volunteers, more than 100,000 competitions each year, and 32 Olympic-type sports through programs in more than 170 countries” (Special Olympics, 2023). Their games and competitions category refers to the year-round Olympic-type sports training and athletic competition that Special Olympics provides for both children and adults with intellectual disabilities. These events provide opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in the sharing of gifts, skills, and friendships (Special Olympics, 2023).

Due to the fact that those with intellectual disabilities are often denied health services and die on average 16 years sooner than the general population, the inclusive health initiative is an important aspect of the Special Olympics. This initiative refers to their Special Olympics Health program and partners with the U.S. Centers for Disease Control and Prevention to give individuals with intellectual disabilities an equal opportunity to be healthy. They do this by focusing on “improving the physical and social-emotional well-being of people with ID by increasing inclusion in health care, wellness, and health systems for Special Olympics athletes and others with ID. Learn how we are making a difference” (Special Olympics, 2023).

Another focus of the Special Olympics is on youth and schools. In order to promote inclusion, they start by promoting it in schools and communities. A youth-led projects for inclusion; school programs to promote inclusive communities; their Global Center for Inclusion that supports education research, policy, and practice; youth leadership summits; early childhood play programs; grassroots movements; their Generation Unified resource that empowers students

to become agents of change; USA Unified Champion Schools model which aims to build accepting school environments; and connecting college students with Special Olympics athletes (Special Olympics, 2023).

Their leadership categories include programs that focus both on building leadership qualities in their athletes but also programs that are aimed at educating people without disabilities to be more inclusive. These programs include Athlete Leadership which makes leadership opportunities for individuals with intellectual disabilities, Unified Leadership which is meant to train leaders to build environments where individuals can succeed in a meaningful way, and the Special Olympics Leadership Academy which provides support, training, and mentoring to their leaders (Special Olympics, 2023). Lastly, the Revolution is Inclusion initiative is a global movement that the Special Olympics started more than 50 years ago and is meant to try to “break down barriers and end discrimination against people with intellectual disabilities” (Special Olympics, 2023).

The Special Olympics has accomplished much since its founding in 1968. One of the most impressive aspects of the Special Olympics is the size and reach of its programs. According to their 2021 Global Reach Report, they had programs in 201 countries and jurisdictions, 3,724,760 total participants, 33,742 competitions, 46,997 athlete leaders, 18,496 healthy athletes screenings, and 15,008 unified schools (Special Olympics, 2023).

The Arc of the United States

The Arc of the United States (The Arc) was founded in the 1950s by parents of people with intellectual and developmental disabilities and is based in Washington, D.C. The Arc of the United States has gone through many name changes since its founding in order to change with

the times. These names included the National Association for Retarded Children (NARC) from 1953 to 1973, the National Association for Retarded Citizens (NARC) from 1973 to 1981, the Association for Retarded Citizens of the United States (ARC) from 1981 to 1992, and has been The Arc of the United States (The Arc) since 1992. The Arc was the first organization that put money towards research on intellectual and developmental disabilities and is currently the world's largest community-based organization of and for people with intellectual and developmental disabilities. With over 140,000 members affiliated through over 700 state and local chapters nationwide (The Arc, 2023). The mission of the ARC is that it “promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes” (The Arc, 2023). Their vision is “for people with intellectual and developmental disabilities (IDD) to be valued members of their communities, with the opportunity to realize their full potential and a future that is secure” (The Arc, 2023). Additionally, they have eight core values including human dignity, personhood, choice, rights, community, support, equity, and diversity.

In order to accomplish these goals, the ARC has developed a strategic framework composed of five strategies: build the movement, speak the truth to anyone who will listen, advocate, extend our reach, and innovate. The strategy of building the movement refers to organizing and mobilizing a national movement of people to advocate for change. The strategy for speaking the truth to anyone who will listen involves working with people with intellectual and developmental disabilities and their families to amplify their stories. Strategy three of advocacy involves advancing the interest of people with disabilities and their families before the executive and legislative branches of government in the courts as well as influencing the

practices of private and public sector organizations. Strategy four is extending their reach which is the ARC's goal of being present in the communities where people with intellectual and developmental disabilities live. Lastly, their fifth strategy of innovation refers to The Arc utilizing their knowledge and creativity to "envision, pilot, and implement new and improved programs, supports, and services and to create new opportunities for people with intellectual and developmental disabilities and their families" (The Arc, 2023). The Arc has hundreds of state and local chapters across the country, with each of the chapters providing a variety of services, support, and advocacy for individuals with intellectual and developmental disabilities and their families. These vary by chapter but include but are not limited to "individual and public policy advocacy; residential, educational, and vocational services; person-centered and financial planning; recreational activities; and other supports that meet the unique needs of the community" (The Arc, 2023).

The Arc has had many accomplishments in the past several years including being represented on the first President's Panel on Mental Retardation (PPMR) in the 1960s and advocating that have contributed to the enactment and amendment of programs such as Medicare, Medicaid, the Supplemental Security Income program, and the Fair Housing Act to protect individuals with disabilities. But more recently, the 2021 annual report released by the Arc reports many accomplishments including that their advocacy has contributed to \$12.7 billion in new federal funding for home and community-based services, that they told 7,500 stories in front of the U.S. Capitol, 3 million views on their educational videos regarding disabilities services (The Arc, 2023).

Each of these organizations has accomplished much in the field. Whether that be because of their focus, reach, advocacy, or fundraising efforts. Despite the fact, each of these organizations is a pioneer in the field, they all still continue to grow and improve to better serve individuals and families with disabilities. In order to do this, research must be done in order to understand what changes would lead to improvement. My research is looking to better understand how the entire family unit is affected by a disability. Chapter three presents my findings in this area and chapter four presents these finds to a program director at the ARC program in Schenectady.

The Schenectady Arc has a person-centered planning process where they work with the individual with a disability and their family or other advocates in order to discover the best combination of supports and services to help the individual achieve their goals. More specifically, they assist individuals with “seeking employment, residential services, day services, medical or other clinical services, recreation programs, and respite services” (The Schenectady Arc, 2023). Additionally, the Schenectady ARC supports individuals of all ages and ability levels.

Chapter 3: Methods and Results

An abundance of research explores the negative effects of disability stigma on children with disabilities (e.g., López et al., 2017) and their parents (e.g., Green, 2003), but less is known about the impact it has on the neurotypical siblings of children with disabilities. There is, however, an abundance of research and theories that suggests stressors experienced by one family member can affect the other members of that family system. The purpose of the study presented in this chapter is to examine the ways caregivers and neurotypical siblings of children with disabilities are affected by having a child with a disability as part of their family system and examine the community response. Firstly, a qualitative study was done that examines the relationships between stigma towards a child with a disability, parental stress, and neurotypical child anxiety levels in the neurotypical sibling. I hypothesize that perceived stigma towards the child with the disability, parental stress, and neurotypical child anxiety levels of the neurotypical sibling will be related, with higher levels of the perceived stigma being associated with higher parental stress and higher neurotypical child anxiety. Additionally, I hypothesize a potential moderating role of parental stress, whereby low levels of parental stress may protect against the impact of stigma on neurotypical child anxiety. In addition to the quantitative study, an in-depth interview was conducted with an employee of a community program. The goal of the interview was to gain an understanding of the community response to the problems discussed in this thesis and to understand the institutional response to the findings of this study. This interview will be discussed in more detail later in this chapter.

Quantitative Study Methodology

Participants

Participants were parents or caregivers of multiple children (at least two) under the age of 18, including a child with a neurodevelopmental disorder and a neurotypical child. The term parent will be used throughout the study description for efficiency but may include parents and other caregivers. As described in more detail in the description of the procedures below, originally, 99 parents attempted to self-select to participate in the study. 32 of the participants were removed because they indicated not having two or more children under the age of 18, 3 cases were removed as they indicated that the children they kept in mind were not under the age of 18, and 7 of the participants did not qualify for the study because (1) they did not report having a child under the age of 18 with a neurodevelopmental disorder ($N=5$), or (2) did not report having a child under the age of 18 with neurotypical development ($N=2$). Additionally, 16 participants were dropped from the study because they began the study but did not complete the study measures. The final sample included 41 parents/caregivers of both a child with a neurodevelopmental disorder and a child with neurotypical development, including 39 (95.1%) female and 2 (4.9%) male caregivers, aged 32 to 58 years ($M= 44.3$ years). The participants reported having 3 to 5 children under the age of 18 with participants having a mean of 3.2 children. There were 37 biological mothers (90.2%), two biological fathers (4.9%), one adoptive mother (2.4%), and one other (2.4%). When asked to choose which of the categories best described them, the majority of the participants identified as white 80.5%, 9.8% as Asian, 9.8% as other, and no participants identified as Black or African American, American Indian or Alaska

Native, or Native Hawaiian or Pacific Islander. Additionally, 7.3% of participants reported being of Hispanic, Latino, or Spanish origin.

Parents also reported demographic information about their children. Specifically, parents were asked to respond to demographic questions about their child with a disability and their neurotypical child. For parents who endorsed more than one child who met the category requirements, they were asked to keep only one child in mind when answering study questions. Of the children with a disability, there were 29 males and 12 females who were aged 2 to 17 with a mean age of approximately 10.7 years. Parents reported the diagnoses of their child with a disability and were able to select multiple diagnoses if applicable. The sample included 12 diagnoses of Intellectual Disability, 12 of Communication Disorder, 21 of Autism Spectrum Disorder, 23 of Attention Deficit/Hyperactivity Disorder, 15 of Specific Learning Disorder, and 5 of Motor Disorders. Of the neurotypical children, there were 14 males and 24 females (data missing for 3) who were aged 2 to 17 with a mean age of 10.0 years.

Procedure

All procedures followed guidelines for the protection of human subjects and were approved by the College's Human Subjects Research Committee. Parents were recruited via promotional posts on social media platforms of various parenting interest groups, including those of organizations directed toward parents and caregivers of children with disabilities and professionals with which they come in frequent contact (e.g., The American Association on Intellectual and Developmental Disabilities and Bridge Kids NY), and informal parenting support sites such as Facebook group pages. A URL link was provided in all study recruitment

material, which directed participants to an informed consent document and a series of questionnaires that were administered on Qualtrics, an online research platform. Participants did not receive any direct benefit for their participation but they were able to select an organization from a list of non-profit organizations with a mission to serve families of individuals with disabilities to receive a donation of \$3 in honor of participants' participation in aggregate. These non-profit organizations included the Special Olympics, the Arc of the United States, and the American Association on Intellectual and Developmental Disabilities.

As described above, informed consent was obtained from each participant. Participants were prescreened for the study via a set of initial self-report questions to determine if they qualified as both (1) a parent of a child under the age of 18 who has received a neurodevelopmental disorder diagnosis and (2) a parent of a child under the age of 18 who has not received a neurodevelopmental disorder diagnosis. Parents self-reported their child's disorder status based on a list of disorders included in the American Psychiatric Association's definition of Neurodevelopmental disorders as cited in the DSM-5 (American Psychiatric Association [APA], 2022). Participants who reported having at least one child, under the age of 18, with any of the qualifying diagnoses and one child, under the age of 18, who did not have any of the diagnoses continued on in the study. If participants reported having more than one child with a qualifying disorder (i.e., more than one child with a disability) they were asked to respond to all questions in the study with only one of the children in mind. If participants did not endorse that their child had a diagnosis among the qualified disorders, then they were disqualified from the study. Next, the parent was asked if they had a child without any of the qualifying diagnoses. If they answered yes they would qualify for the survey. If parents had more than one neurotypical

child, they were asked to keep one child in mind when responding to questions related to their neurotypical child. If they did not endorse having a neurotypical child, then they were disqualified from the study. All qualified participants were asked to complete all of the study measures, which included demographic questions and measures of disability stigma, parental reports of neurotypical child anxiety, and parental stress.

Measures

Each participant was asked to provide information regarding their age, gender, relationship to the children of focus in the study, ethnic and racial background, as well as their children's ages, genders, disability status, and related diagnoses, as applicable. As previously described, participants first completed questions to determine if they met the study inclusion criteria (detailed in the Disability Check section below). Participants who met inclusion criteria completed measures of disability stigma, parental stress, and parental report of neurotypical child anxiety in that order. After completing the measures, participants were provided with an electronic debriefing statement that provided them with additional information about the nature of the study, thanked them for their participation, and provided them the opportunity to select the non-profit organization they would like their participant remuneration to go towards if they desired.

Disability Check. Participants were first asked to answer a series of questions to assess whether the following participant inclusion criteria were met: Participants are a parent or caregiver of (1) a child under the age of 18 years old with a neurodevelopmental disorder and (2) a child under the age of 18 years old with neurotypical development. The Diagnostic and

Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013) lists eight categories under their definition of Neurodevelopmental Disorders including intellectual disorders, communication disorders, Autism Spectrum Disorder, Attention-Deficit/Hyperactivity Disorder, specific learning disorders, motor disorders, tic disorders, and other neurodevelopmental disorders. Participants were first asked to self-report if they had a child with a disability. If they did not endorse having a child with a disability, they were redirected to a message that thanked them for their interest in the study and informed them that, based on their responses, they did not qualify for the study and did not proceed with the study. If they endorsed having a child with a disability, they were provided a list of the DSM-5 Neurodevelopmental Disorders categories along with a few examples for each category and asked to select all that applied to their child with a disability. If they selected any of the categories of inclusion, then they would be classified as meeting the first criteria of inclusion as having a child with a disability. If they selected “none of the above,” participants were disqualified from the study. To determine if participants met the second condition of study inclusion, they were asked if they had a child without a disability as defined in the question as “a child without a diagnosis of Intellectual Disabilities, Communication Disorders, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Specific Learning Disorder (SLD), or Motor Disorders.”. If they selected “no” they were eliminated from the study. If they selected “yes,” then they would continue in the study.

Disability Stigma Measure. Perceived stigma was measured using the PROMIS Pediatric Stigma – Short Form 8a (The National Institutes of Health, 2022). This measure is an 8-item questionnaire, which asks participants to report their perceptions of the stigma

experienced by their child with a developmental disability on a five-point scale including never (1), rarely (2), sometimes (3), often (4), and always (5). The lowest possible score is 8 and the highest possible score is 40. The National Institutes of Health provides a scoring service that provides the raw score, theta, *t*-score, and standard error for each participant. The current sample demonstrated good internal consistency in their responses (Cronbach's $\alpha = .91$).

Neurotypical Child Anxiety. Parents were asked to report on the anxiety of their neurotypical child (the sibling of the child with a neurodevelopmental disorder). Sibling anxiety was measured using the Spence Children's Anxiety Scale (SCAS; Spence, 1997), which asks parents 38 questions about their child on a four-point scale including never (0), sometimes (1), often (2), and always (3). The measure includes 6 subscales of panic attack and agoraphobia, separation anxiety, physical injury fears, social phobia, obsessive-compulsive, and generalized anxiety disorder/overanxious disorder. The total score of all six subscales is calculated by summing all items with possible scores ranging from zero to 114; this score was used in the present analysis. Additionally, the Spence Children's Anxiety Scale website provides automatic scoring forms for children ages 7-9. This form provides the participants' *t*-scores and whether the *t*-score is in a normal or elevated range. *t*-scores and ranges were calculated for 18 of the 41 participants who met the age requirements of the Spence Children's Anxiety Scale automatic scoring forms. Internal consistency of the SCAS, as measured by Cronbach's alpha, is reported as $\alpha = .89$ (Nauta et al., 2004). Responses for the current sample demonstrated good internal consistency as well (Cronbach's $\alpha = .91$).

Parental Stress. Parent stress was measured using the Parental Stress Scale (PSS; Berry & Jones, 1995), which asks parents 18 questions on a five-point scale including strongly disagree

(1), disagree (2), undecided (3), agree (4), and strongly agree (5). Parental Stress scores range from 18 to 90, with 18 being the lowest possible stress score and 90 being the highest possible stress score. The parental stress score is calculated by first reverse scoring items 1, 2, 5, 6, 7, 8, 17, and 18, then summing up all item scores. Internal consistency of the PSS, as measured by Cronbach's alpha, is reported as $\alpha = .83$, and 6-week test-retest reliability as $r = .81$ (Berry & Jones, 1995). Responses for the current sample demonstrated good internal consistency as well (Cronbach's $\alpha = .89$).

Study Results

Preliminary Analyses

Prior to analyses regarding the hypotheses, the data were screened for participants who did not meet study inclusion criteria and for missing data, outliers, and normality. A total of 58 of 99 cases were removed from the analysis. Forty-two cases were removed for not meeting the study inclusion criteria. Specifically, of those 42 cases, 32 were removed for not having two or more children under the age of 18, 5 were removed for not having a child with a neurodevelopmental disorder, two were removed for not having a neurotypical child, and three cases were removed because the participants indicated that the children they were reporting on in the study were over the age of 18. Additionally, 16 of the 58 cases were excluded from the analyses due to the participant starting but not completing the survey, which resulted in insufficient data for those participants to score all the measures. The final sample following data screening included 41 parents and caregivers, including 39 (95.1%) women and 2 (4.9%) men between the ages of 31 and 58, with a mean age of 44.3 years. The distribution of each variable was evaluated for skewness and kurtosis. The skewness of disability stigma was found to be .26,

indicating that the distribution was symmetric. The kurtosis of disability stigma was found to be $-.67$, indicating that the distribution was normal. The skewness of neurotypical child anxiety was found to be 1.2 , indicating that the distribution was highly right-skewed with the distribution of scores more heavily loaded in the lower anxiety range. The kurtosis of neurotypical child anxiety was found to be $.61$, indicating that the distribution was normal. The skewness of parental stress was found to be $-.03$, indicating that the distribution was symmetric. The kurtosis of parental stress was found to be $-.31$, indicating that the distribution was normal.

Descriptive Statistics

The means and standard deviations of the study measures are presented in Table 1. These represent the raw scores for all the measures. Further, the t -scores were calculated for disability stigma using a scoring service provided by The National Institutes of Health. The stigma t -score for each diagnosis is shown in Table 2. Additionally, the neurotypical child anxiety levels, normal or elevated, for the neurotypical child were calculated for 18 of the 41 participants with t -scores between 0-59 being normal and t -scores between 60-100 being elevated. Of those 18 participants, 10 participants were classified as having anxiety in the normative range and 8 participants had an elevated anxiety level, with a range of scores from 36.80 to 65.80 ($M = 49.28$).

Pearson Product-moment Correlation Coefficients

Three Pearson product-moment correlation coefficients were conducted to evaluate the hypothesis that stigma towards a child with a disability (i.e. disability stigma), neurotypical child anxiety levels and parental stress are related ($N = 41$). The variables of disability stigma, parental stress, and neurotypical child anxiety were analyzed by their overall scores on the measures. The

relationship between parental stress and neurotypical child anxiety levels of the neurotypical sibling was evaluated first. There was significant evidence to conclude that there was a strong positive association between parental stress ($M = 68.51$, $SD = 6.36$) and neurotypical child anxiety levels of the neurotypical sibling ($M = 17.37$, $SD = 12.19$), $r(39) = .45$, $p = .003$. Higher levels of parental stress were associated with higher neurotypical child anxiety. The relationship between parental stress and stigma towards the child with the disability was evaluated next. The results show that there was no significant correlation between parental stress ($M = 68.51$, $SD = 6.36$) and disability stigma ($M = 19.12$, $SD = 7.06$), $r(39) = .24$, $p = .135$. Lastly, the relationship between neurotypical child anxiety and disability stigma was evaluated next. The results show that there was no significant correlation between neurotypical child anxiety ($M = 17.37$, $SD = 12.19$) and stigma towards the child with the disability ($M = 19.12$, $SD = 7.06$), $r(39) = .10$, $p = .521$. A table summarizes the results (Table 3). Additionally, as there was no significant correlation between parental stress and disability stigma or neurotypical child anxiety and disability stigma, moderation was not possible.

Parental stress and Neurotypical Child Anxiety. The relationship between parental stress and neurotypical child anxiety was evaluated first. As hypothesized, there was significant evidence to conclude that there was a strong positive association between parental stress ($M = 47.39$, $SD = 10.50$) and neurotypical child anxiety ($M = 17.37$, $SD = 12.19$), $r(39) = .53$, $p < .001$. A scatter plot summarizes the results (Figure 1). Higher levels of parental stress were associated with higher neurotypical child anxiety levels.

Parental stress and Disability Stigma. The relationship between parental stress and disability stigma was evaluated next. Contrary to the study hypotheses, the results show that

there was no significant correlation between parental stress ($M = 47.39$, $SD = 10.50$) and disability stigma ($M = 19.12$, $SD = 7.06$), $r(39) = .26$, $p = .10$. A scatter plot summarizes the results (Figure 2).

Neurotypical Child Anxiety and Disability Stigma. Lastly, the relationship between neurotypical child anxiety levels and disability stigma was evaluated next. Contrary to the hypotheses, the results show that there was no significant correlation between neurotypical child anxiety levels ($M = 17.37$, $SD = 12.19$) and disability stigma ($M = 19.12$, $SD = 7.06$), $r(39) = .10$, $p = .521$. A scatter plot summarizes the results (Figure 3).

Interview Methodology

An interview with a program director that works with families with disabilities, at an organization in Schenectady NY was conducted. The purpose of the interview is to examine community response to the problems discussed in this thesis and to better understand the institutional response to the data collected from family members in the quantitative study.

Interview

For my in-depth interview, I contacted a local Director at Schenectady ARC to speak with them about the programs they offer, what works about them, what the biggest challenges are, and their reaction to the results of my study. The interview participant was recruited through an existing contact that I had through a club, Good Eats, at Union College that partners with Schenectady ARC. After emailing the participant and their agreement to participate in the interview, we schedule the interview to be conducted over a video call. Once obtaining oral consent to record the interview, the interview was conducted in a conversational manner with a

pre-prepared list of questions and follow-up questions if more detail was needed. Participation in the interview was voluntary and the information was kept confidential. Despite only interviewing one participant, the participant has extensive experience in working in various roles at the organization and provided detailed and informative responses.

The interview was a guided conversation that began by asking for a job title and the responsibilities that the director had. Next, the interviewee was asked to provide some basic information about their education and professional experience that led them to their current role. The participant was asked to give an overview of the programs that the Schenectady ARC provides. To follow up the interviewee was asked what works about their programs as well as what could improve about the programs. Additionally, the participant was asked what are the biggest challenges more generally as an organization. Lastly, the participant was given an overview of the quantitative study and the results that were presented earlier in Chapter 3. The participant was asked to give their reaction to the quantitative study. Lastly, the participant was asked if they had any thoughts about the siblings of individuals with disabilities. (See **Appendix** for an outline of interview questions).

Interview Results

Schenectady ARC

The Interviewee is a Director of Community Support at Schenectady ARC. The role's duties and responsibilities include overseeing anything that is built as a community habilitation service or respite care. Prior to working at Schenectady ARC, the interviewee received their Bachelor's degree in Communication Disorders at the College of Saint Rose. They have worked at Schenectady ARC since 1984 and before entering the Director position, they worked in 9

different capacities at the organization. Even now they work in multiple roles and with almost every program they offer due to understaffing.

According to the interviewee, Schenectady ARC was founded in the 50s by parents who stood on street corners and worked with the post office to raise money to open their first school. This is due to the fact at the time schools did not allow children with disabilities to be educated in their settings, rather they would institutionalize them. Parents did not want this fate for their children and got together to open the “Little Red School House”. Since then they’ve grown significantly. But due to the pandemic, they are unfortunately getting smaller.

Programs

The respondent described the programs offered by the Schenectady ARC in two general categories. This includes the programs for the individuals and what is done within Schenectady ARC so that it can function. The first category they described was programming for individuals with disabilities. This includes housing programs which include 21 Residential houses people live in and over 20 apartments. There are also several day habilitation services which are when individuals go to a non-residence setting during the day to get support to build life skills in those settings. These skills include hygiene, personal care, money management, social skills, job skills, and more. This service is provided not only to teach skills but also so that individuals do not have to stay home all day. Another program they have for individuals has supported employment programs where they work with people to develop job skills to find employment. They also have recreation and community habilitation programs, which are classified as “without walls program” because it is community-based. The organization essentially goes wherever it can get services. Some examples include going to Union College for Good Eats, to the bowling alley to

bowl, and other recreational opportunities in the community. For community habilitation, the participants with disabilities are out all day long, wherever they can find things to do with the participants depending on their needs and interests. One instance of a day habilitation program includes Discovery Academy where individuals go to Union College to socialize with students, use classroom space, and learn academics. Additionally, Schenectady ARC also operates a clinic at their 214 state street site that offers physical therapy, occupational therapy, speech, psychology, psychiatry, podiatry, and primary care.

The second category they describe is everything that Schenectady ARC needs to do in order to run. One of the largest aspects of this is grant writing to help raise money. According to the Interviewee, 90% of how the Schenectady ARC staff get paid is with Medicaid dollars. They describe this as one of the challenges of the program. Since Medicaid is funded to help people, staff does not get paid if the individuals cancel and do not show up:

So not only are we paid at a Medicaid rate which is not substantial, the individuals have the right to cancel or decline services whenever they want. So we are kind of at that mercy. there is no extra money out there to just go ‘oh let's pay them more. There is no extra money out there to get paid more. These are not state-funded dollars, just Medicaid dollars.

What works

In regards to what works about the programming that Schenectady ARC offers, the interviewee stated that “people are looking for things to do during the day now more than ever”. They gave some context and stated that following the pandemic, a lot of programs shut down and are not coming back. Due to the pandemic, a lot of individuals with disabilities are home now

which has not been the case before. In fact, since some of the programs closed down due to the pandemic, many of these individuals' parents are no longer able to work full-time jobs because they can not leave their loved ones alone at home. Additionally, the interviewee expressed the belief that the state is no longer funding "bricks and mortar" programs as they believe that the government does not want to pay for people to stay in buildings. Rather, they want programs to be community-based. "So what works is that we actually have a place to go where people can socialize and build on life skills" stated the director.

Challenges

The respondent also stated what the biggest struggles of the programs are, "but what doesn't work is where we have our hands tied". From the interviewee's perspective, the funding available does not allow for the programs to grow, despite the need. Additionally, due to the local economy and current employment rate, they have not been able to hire and they are very short-staffed. According to the director, "we spend a lot of days getting by on the bare minimum and making the best of what we can but it is a struggle".

Another struggle that they face with programming is the changing demographic, specifically in the residential homes they run. Issues arise when there is a mismatch in age and impairment level between the current residents and prospective residents. Since Schenectady ARC has been supporting a lot of the same people from the community for decades, those individuals are aging and going to nursing homes or dying. So they must fill those vacancies, typically with youths. But the issue arises when they have vacancies in over 20 homes with people over the age of 50, but can only fill them with youths around the age of 21-year-old. Additionally, conflicts can also arise when trying to put a minimally disabled person into a house with people who are very

disabled. The director stated that “There is not enough funding out there to build and grow these residential programs but the need is substantial and we do not know how to make it work”.

Mission and Impacts

When asked about what they believe the mission and impact of Schenectady ARC and its programming to be, the interviewee referred to the organization's website. According to the website the Schenectady ARC’s mission is “Schenectady ARC is committed to helping people in the Capital Region enjoy healthy, rewarding lives as members of their community. Schenectady ARC brings staff, families, and the community together to encourage dreams and respond to each person's life choices by offering high-quality services, resources, and supports” (The Schenectady Arc, 2023). Additionally, their website states that the impact of Schenectady ARC is that “Schenectady ARC is committed to creating and fostering partnerships to create the power for people with intellectual and other developmental disabilities to live, learn, work and play as fulfilled members of our community. We greatly appreciate our community partners who support our mission and vision. In addition to these partnerships, there are many ways that we, as an agency, impact our greater Schenectady community” (The Schenectady Arc, 2023).

Impact of Programming on the Family

When asked if they believed their organization and its services impact the rest of the family, the respondent stated that yes. They said that

ARC is an acronym for Advocacy, Resources, and Choices. Our agency provides advocacy and resources for parents of children/adults with ID/DD. Such advocacy/resources provide parents with choices they can consider when raising a

family composed of disabled and non-disabled siblings. When parents utilize our supports, they are able to find time to manage the needs of all of their children which ultimately impacts the entire family in a positive way. Our supports is also life-long, meaning, once parents are no longer able to attend to the needs of their disabled children, SARC can assist families in exploring/obtaining/maintaining resources necessary to continue to support disabled individuals without burdening siblings.

Despite the fact that none of the services of the Schenectady ARC are directly aimed to help the non-disabled members of the family, the director highlights the indirect benefit that the programming and services provided to the entire family.

Reaction to Research

In reaction to the findings presented in Chapter 3, the participants gave their insight into their own experiences with families of individuals with disabilities and the stigma they face. The respondent first stated that in their previous role as a case manager for Schenectady ARC, they were assigned to visit the homes to visit individuals with a disability but would always make sure to also ask how everyone else is doing. They stated:

Because you become so consumed by the person with the disability, you sometimes lose sight of the rest of the family. If that family dynamic or those supports falls apart, then the individual with a disability is even worse off.

Specifically, in regard to siblings of individuals with disabilities, they said that they had always been greatly impressed by the siblings. In their experience, the siblings they interacted with always had a great ability to protect and look out for their siblings with a disability. They even

stated that “In all my years, I have not run into a situation where the child is resentful. I am sure there are times and thoughts but in general, I find them to be very supportive”. In their experience, they did bring up one issue that they think should be addressed more, the parent's expectations of the sibling over the long run. The director said that they run into a lot of parents who think, or even say outright, that their neurotypical child will take care of their child with a disability if they are no longer around. But more often than not, when the parents are gone, the neurotypical sibling will say that they can not do it. It is a difficult situation to put that neurotypical sibling into because they do not know what their circumstances will be when the time comes and it is a lot to ask of them. For instance, if the neurotypical sibling has their own disabled child and needs to focus their care on them or if their partner is not patient and they can not bring that dynamic into their home. They believe that it is important that the parents are realistic about what to expect in the future from the nondisabled child. While they believe that being a health care proxy or even guardian would be a good role to ask of the neurotypical child, having to be legally responsible for housing and raising them is a lot to ask.

They also gave their insight into how they noticed, over time, the stigma toward individuals with disabilities has changed. The interviewee said that they believe we are living in a time when people are less ignorant and are more educated on disabilities. They stated that when they grew up a few decades ago, people knew very little about disabilities. The interviewee reported that during that time, people with disabilities were often hidden. They gave a more specific example of the school setting, “special education classes used to be in the basement as compared to now where they are more integrated”. The director went on to say that when they were growing up, people did not know the difference between different diagnoses and they just

knew them as “disabled”. They believe that this shift is due to the fact that children are taught from a very early on to be more patient, tolerant, open, and empathetic. The interviewee observed that there are more programs now that teach and inform children about these disabilities and how to interact with individuals with disabilities. According to them, society as a whole is more aware as well.

Despite the fact the interviewee believes that people are more accepting of children with disabilities, they believe there is a larger judgment passed to the parents and how they are handling their child with a disability. They believe that people do have to understand and respect parents of children with disabilities and want to be there for them, but they still judge them on their parenting skills. The interviewee says that most judgment is passed onto parents in situations where others are affected and that the judgment is towards how the parent handles the situation. For instance, the interviewee gave an example of a child with Autism having a meltdown at a school event they attended. In their opinion, people did not confront the parent as they understand that the child has a disability, but they believe people still pass judgment on the parent for not teaching the child or handling the situation better. Overall, the interviewee believes that stigma towards individuals with disabilities has decreased in recent years, but increased towards their parents.

Discussion

Quantitative Study

Although not all of the results were statistically significant, this study still gives important information to base future research. Despite the small sample size, the results show that there was a strong positive association between parental stress and neurotypical child

anxiety levels. That is, greater parental stress was associated with increased anxiety levels in the neurotypical sibling of children with a disability. This is consistent with Rodriguez's (2010) findings that show that parental stress is associated with symptoms of anxiety in their children. While there are multiple possible explanations for this relationship as there is no data showing the direction of the relationship or whether it is due to a third factor, one possible explanation is the role parents play in their child's adjustment. A study by Cho et al. (2020) found that the relationship between parental trauma exposure and child separation anxiety was only significant when parental stress was moderate to high and not when parental stress was low. This study demonstrates that parental stress may have a significant effect on a child's adjustment. The finding is significant as it can help to develop better strategies to help parents and their children better adjust to stressors. For instance, although it may not be possible to stop or change mutual stressors affecting a parent and their child, such as a traumatic event, it is possible to help parents cope with it in a healthy manner. Which in turn, based on the presented explanation, could help their child better adjust.

This idea can be valuable in the application to families of children with disabilities as research by Dyson (1993) found that families with disabilities have a greater amount of stress than families with children without disabilities. This increased parental stress could be important in considering how neurotypical siblings are affected by having a sibling with a disability. Research by Barak-Levy et al. (2010) found that siblings of those with disabilities reported significantly higher levels of anxiety than the control group. Although it is not possible to avoid or prevent the diagnosis of a disability, it is possible to better help the parents cope with the diagnosis and decrease their parental stress. For instance, it was also found that social (Ren et al.,

2020) and informal social support (Benson, 2006) reduce levels of parent stress proliferation. This implies that providing support to parents that reduce parental stress can aid not only the parents' well-being but their children's as well. As the director at Schenectady ARC explained, when parents get support, they are able to find time to manage the needs of all of their children and experience less stress. Consequently, benefiting the entire family, including decreasing neurotypical child anxiety. This can aid in demonstrating how supporting a child with a disability and relieving stress off of the parent can also aid the neurotypical sibling. These findings provide insight into creating better strategies for helping families with disabilities.

The other two relationships explored in the present quantitative study were not significantly significant. More specifically, parental stress and stigma were not correlated. This finding contradicts previous studies that have shown a parent's perceived stigma on their child with a disability was associated with increased distress in the parent (Green, 2003). Similarly, there was no correlation between the neurotypical child's anxiety levels and stigma towards the child with the disability. There are many possible reasons for these results. One large limitation of the study is the small sample size, which reduced statistical power, making it difficult to find significant effects. As it is possible there are relationships that the current sample size is too small to detect, it is recommended that future studies replicate this study with larger sample sizes. Another possible reason for insignificant results may be an artifact of the level of stigma perceived by the current sample. Specifically, the stigma for all of the participant's scores in the present study did not, on average, seem to be elevated beyond normal levels. One possible explanation for the low stigma scores is the fact that the PROMIS Pediatric Stigma – Short Form 8a was created for children with chronic conditions, more specifically chronic medical

conditions such as skin disorders. Therefore, it is possible that this measure may not fully account for the stigma that is directed toward children with neurodevelopmental disabilities. Future research can redesign the study with a measure that was specifically designed to detect stigma in children with disabilities. Another possible explanation for the low stigma scores was presented by the director of Schenectady ARC who stated that they believe that stigma towards children with disabilities has decreased in recent years due to greater education and advocacy. Future research can evaluate the current level of stigma families with disabilities are facing as compared to families without disabilities to see if the results are still consistent with previous findings. Similarly, there seemed to be low overall neurotypical child anxiety, with preliminary analysis showing the scale to be highly right-skewed with the average score being 17.38 out of 114. This contradicts previous studies that showed siblings of children with disabilities had elevated anxiety levels (Barak-Levy et al., 2010). Based on this, the study's current sample may not be representative of the anxiety levels experienced by siblings of children with disabilities in the general population. Since the parent version of the Spence Children's Anxiety Scale was used, it is possible that parents did not accurately portray the neurotypical child's anxiety levels. Anxiety is an internal experience that can be difficult for others to properly gauge, even parents. Additionally, another possible explanation for an inaccurate measure of the parent proxy anxiety measure is that if a parent is preoccupied with the needs of stigma faced by their child with a disability, they may not notice the anxiety levels of their neurotypical child as much or they may seem minimal in comparison. This is one possible explanation for why the neurotypical child anxiety scores were low for all of the participants, and future studies can have siblings complete a self-reported measure of anxiety. This idea is supported by the director of Schenectady ARC

who observed that when a caretaker is so consumed by the needs of an individual with a disability they sometimes lose sight of the other members of the family. Another possible reason for the low anxiety scores and low parental stress scores is the fact that the participants were recruited through parenting and community social media groups. So it is possible that there was a selection bias and parents from these groups who voluntarily chose to take the survey had lower parental stress levels and/or perceived less stigma. Prior research has shown that social (Ren et al., 2020) and informal social support (Benson, 2006) reduce levels of parent stress proliferation, therefore it is possible that the parents who are in these parenting and community groups have more social support and less parental stress. Another possible explanation is that if the participants had the time to voluntarily take this survey, it is possible that they are dealing with less stress as compared to parents/caregivers who chose not to or did not have time to participate. Additionally, as this study implies, these measures are correlated so it is possible that the reduced parental stress might also mean a decreased neurotypical anxiety level. Future research should explore other, more general, recruitment tactics.

The study was designed to encompass the diagnoses included in the DSM-5 definition of neurodevelopmental disorders. This was done due to the fact that each of these different diagnoses has different symptoms and displays themselves differently. Leading to various levels of care, therefore evoking different amounts of parental stress. Additionally, as each diagnosis displays itself differently, it may lead to different stigma levels depending on how many of the symptoms are outwardly displayed. This was done intentionally as it would be interesting to compare the different levels of disability stigma, parent stress, and parental report of neurotypical sibling anxiety. The comparison between differences in diagnosis was not possible in the current

study due to a limited sample size, but future studies can collect data from a large enough sample to compare the results by diagnostic category. Similarly, the sample also includes a large range in age of children, from 2 to 17 years old. Future research might include a study that focuses on one range of ages that may have more significant results or a study that collects data from a large enough sample to compare the results of the different age groups. Additionally, the study data was based on parent self-reports, including parent-report of the child's diagnosis status and child anxiety. Future studies can be done in a more clinical setting with more controlled and accurate results. For instance, a future study can be done that either requires the proper review of medical records proving the diagnosis of the child with a disability or where the study includes an in-person diagnostic evaluation. Additionally, an in-person evaluation in a controlled environment could allow for more flexibility in the type of measure used to evaluate parental stress levels and neurotypical child's anxiety levels.

In summary, this research provides support for the idea that parental stress and the anxiety levels of neurotypical children are related. While the present study did not support an association between parental stress and stigma towards the child with the disability nor between stigma towards the child with the disability and anxiety levels of the neurotypical sibling, the lack of association should be interpreted with caution as it is inconsistent with previous research and is the result of a study with limited statistical power. These findings are important as it has implications for understanding the ways in which a neurotypical child is impacted by having a sibling with a disability. Despite the limitations, this study brings attention to an under-addressed research topic and helps to lay the foundation for how other studies might be designed, including

using different measures, a larger sample size, and being conducted in a more controlled environment.

Interview

The interview with the Director at Schenectady ARC helped to add depth to the project by adding a professional perspective as well as demonstrating an application of community support by federal programming. We discussed the history of the Schenectady ARC, the programs it offers, what works about it, and what its greatest challenges are. While Chapter 2 offers background information on the federal laws that allow this program to run as well as information on community outreach organizations, including the national Schenectady ARC, the interview was able to show an application of these federal programs and how local/regional chapters may differ from the national organization. As seen in Chapter 1, the United States has come a long way in improving its views of disabilities and behaviors toward individuals with disabilities. Public opinion is often reflected in societal responses including governmental policies. Chapter 1 introduces the Medicaid program which was enacted in the twentieth century and Chapter 2 presents some examples of applications of Medicaid including aid in funding for housing and healthcare. The director of ARC speaks about how Schenectady ARC is funded by Medicaid, meaning that is how they finance their programs and pay their staff. This is a great example of how Medicaid is being used to help individuals with disabilities as the Schenectady ARC runs programs to provide housing, life skill training, and day services through programs, job training and placements, and healthcare through their own clinic. The existence of Schenectady ARC and how it gets its funding not only benefits individuals and families with

disabilities but also represents how far society has come in its decreasing stigma toward disabilities.

Another notable finding from the interview was that the Schenectady ARC programs and services provided differ slightly from the ones presented in Chapter 2 according to the national organization's website. The national organization's website puts a large emphasis on advocacy while also mentioning general programs, supports, and services offered. This is likely due to the fact that each chapter across the country offers a different set of services, support, and advocacy. Another notable fact is that the Schenectady chapter of ARC has a mission statement that is different from the national one. Most notably, the Schenectady ARC mission statement contains the line, "In addition to these partnerships, there are many ways that we, as an agency, impact our greater Schenectady community" (The Schenectady Arc, 2023), while the national ARC does not have an equivalent line. This emphasizes the difference in goals and programs of the national ARC and the local chapter. This difference can be seen when examining the answers of the director. When asked whether they believed their organization and its services benefited the other members of the family beyond the individual with a disability, the director answered yes. They stated that the advocacy and resources provided by the Schenectady ARC not only benefit the individual with a disability but also alleviate some of the burdens from their parents allowing them to better care for the rest of the family. This answer, as well as their other answers regarding the families of the individual with a disability, represents the employee's awareness of the greater benefits of the organization's programs. This answer implies that there is a much greater benefit to these programs than most people might see. That is that the programs not only benefit the individual with a disability but are beneficial to the whole family. This finding would

be supported by prior research that shows that a family system can affect one another. More specifically, parents' stress can affect their children (Rodriguez, 2010), children can affect their parents' stress levels (Dyson, 1993), and siblings can affect one another (McHale, et al., 2012). Even more so, this implication is supported by the results of the quantitative study conducted in chapter three, which were that parental stress and neurotypical child's anxiety levels are correlated. This suggests that if the programs and services provided by Schenectady ARC alleviate some of the parent's stress, then it is possible it might, in turn, decrease the anxiety of the neurotypical sibling.

Chapter 4: Conclusion

About one billion people, 15 percent of the world's population, live with disabilities. (United Nations, 2022). As disabilities affect such a large portion of the population, it is important to understand their effects. An abundance of research and theory that suggests stressors experienced by one family member can affect the other members of the family system (Rodriguez, 2010). This idea can be applied to families of children with disabilities, including to the aspect of disability stigma. Prior research displays a negative effect of disability stigma on the child with a disability (López et al., 2017) and their parents (Green, 2003), but little research has been done on examining how this in turn impacts the neurotypical siblings of children with disabilities.

This thesis explored how a family system is affected by having a child with a disability and how to utilize this knowledge to better help both the individual with a disability and their family. The research included two components— a quantitative study and a qualitative interview— which built upon one another. My quantitative study examined the relationships between stigma towards a child with a disability, anxiety levels in the neurotypical sibling, and parental stress. While further research should be conducted with larger sample sizes and with different measures, the current findings suggest that there is a significant relationship between parental stress and neurotypical child anxiety. This result, coupled with previous findings that parents of children with disabilities have greater stress levels, demonstrates that parental stress is an important construct to understand, particularly with regard to understanding the ways in which having a child with a disability affects not only the individual with a diagnosis but the entire family system (Dyson, 1993). Previous research suggests that social support for parents of children with

disabilities acts as a protective factor for parents of children with disabilities against things such as perceived discrimination and self-esteem (Recio et al., 2020). This implies social support is likely important not only for the child with a disability but for their parents and siblings as well. My interview with a Director at Schenectady ARC was aimed at exploring community responses designed to help individuals with disabilities as told by a director of such a program. The findings of the interview coupled with the information on related policies and available federal and community programs allowed a comprehensive understanding of what societal responses are in place to aid individuals with disabilities and their families. The results of the interview combined with research results imply that these programs not only benefit individuals with a disability but are beneficial to their families as well. This interview was conducted with one employee of a singular organization, future research can replicate the interview with employees in various positions at a variety of programs to see if the responses are consistent.

Based on the results of this interview combined with the results of the study as well as existing research, I recommend that more funding should be allocated to programs that help individuals with disabilities as it would not only benefit those individuals but also their families. As the Ecological Systems Theory states and the findings of this research and previous research support, members of a family system affect one another. More specifically, the presented research implies that programs aimed at helping individuals with disabilities are not only benefitting the individual with a disability but the whole family. This knowledge is important as it highlights the importance of these programs. Based on the reports of the program director, what works best about the Schenectady ARC program is that it addresses the needs of individuals with disabilities and provides them with solutions. Many of the greatest struggles of

the programs revolve around a lack of resources, including funding and staffing, available to match the level of need. Based on this, I recommend that the federal government increase funding for these programs, such as Medicaid, aimed to help individuals with disabilities.

The findings of this paper explore the under-examined research topic of how neurotypical siblings are affected by having a sibling with a disability and provide valuable insight into how to better help them. But there is still research to be done on the topic. Future research should replicate the quantitative study with a larger sample size, using more accurate measures, and in a more controlled environment to see if the results stay the same. More interviews should also be conducted to understand if the opinion shared by the program director is shared by employees of other community response organizations. Additionally, new research can be conducted to learn more about this research topic beyond what was done for this paper. For instance, additional interviews can be conducted with parents and neurotypical siblings of families with disabilities in order to further understand them. This paper provides crucial insight and attention to an underrepresented research topic and opens the door for much future research.

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Appendix A: Study Materials

Informed Consent

My name is Nova Shek, and I am a student at Union College. I am inviting you to participate in a research study about families with children with disabilities. Involvement in the study is voluntary, so you may choose to participate or not. A description of the study is written below.

I am interested in learning more about how having a child with developmental disabilities affects a family, including parents and siblings. You will be asked to complete a series of questionnaires about your experience as a parent and the experiences of your children. Specifically, the questions included in this study will ask about parenting and your children's adjustment, as well as basic demographic questions about you and your children's age, race, and gender. This will take approximately 30 minutes. All information will be collected anonymously and kept confidential.

Your participation helps us to learn more about families with disabilities and ways in which families can be better supported to reduce negative experiences. There are no foreseeable risks to you of participating in this study, however, this survey asks questions that have you recall potentially negative experiences involving your children. For some participants, these questions may be sensitive or create discomfort. If you no longer wish to continue, you have the right to withdraw from the study, without penalty, at any time.

At the end of the survey, you will be provided with more information about the survey and its purpose.

If you have any questions about the research please contact Nova Shek (shekn@union.edu), Professor Jennifer Malatras (malatraj@union.edu), and Professor Ilene Kaplan (kaplani@union.edu). If you have any questions concerning your rights as a research participant that has not been answered by the investigator or if you wish to report any concerns about the study, you may contact the Union College Human Subjects Review Committee Chair Joshua Hart (hartj@union.edu).

By continuing, you indicate that you understand the information printed above and that you wish to participate in this research study.


☐ Yes, I consent to participate in this study

☐ No, I do not consent to participate in this study

Check

Please fill out the following

☐ I'm not a robot


reCAPTCHA
[Privacy - Terms](#)

Disability Check

The following questions are designed to determine if you meet the criteria for this study.

How many children do you have under the age of 18?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5+

Do you have a child with a disability?

- ☐ Yes
- ☐ No

Do you have **multiple children** with a disability?

- ☐ Yes
- ☐ No

For the purpose of this study, please only think of **one** of your children with a disability and keep them in mind for the remainder of the study.

Does your child with a disability have any of the following diagnoses? Please check all that apply.

- ☐ Intellectual Disabilities (i.e., Global Developmental Delay, Unspecified Intellectual Disability, etc.)
- ☐ Communication Disorders (i.e., Language Disorder, Speech Sound Disorder, Childhood-Onset Fluency Disorder, etc.)
- ☐ Autism Spectrum Disorder (ASD)
- ☐ Attention-Deficit/Hyperactivity Disorder (ADHD)
- ☐ Specific Learning Disorder (SLD) (i.e., Dyslexia, Dysgraphia, Dyscalculia, Language Processing Disorder, Nonverbal learning disabilities, Auditory Processing Disorder, Visual Perceptual/Visual Motor Deficit, etc.)
- ☐ Motor Disorders (i.e., Developmental Coordination Disorder, Stereotypic Movement Disorder, Tic Disorders, Tourette's Disorder, etc.)
- ☐ None of the above

Do you have a child **without** a disability?

For the purpose of this study, we are defining a child without a disability as a child without a diagnosis of Intellectual Disabilities, Communication Disorders, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Specific Learning Disorder (SLD), or Motor Disorders.

- ☐ Yes
- ☐ No

Do you have **multiple** children **without** a disability?

- ☐ Yes
- ☐ No

For the purpose of this study, please only think of **one** of your children without a disability and keep them on mind for the remainder of the study.

To avoid confusion, for the remainder of the study we will refer to your child who you indicated as having a disability as "**child with a disability**".

Similarly, for the remainder of the study we will refer to your child who did not qualify as having a disability as "**child without a disability**".

Stigma

Please respond to the following questions with your **child with a disability** in mind

Lately (in the last 1-2 months)...

	Never	Rarely	Sometimes	Often	Always
Other children avoided my child because of his/her condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child felt left out of things because of his/her condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other children were mean to my child because of his/her condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other children made fun of my child because of his/her condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child felt embarrassed in front of other children because of his/her condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child was treated unfairly by other children because of his/her condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child felt different from other children because of his/her condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child avoided making new friends to avoid talking about his/her condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Transition

We just asked you questions regarding your **child with a disability**. Now we are going to

ask you a series of questions regarding your **child without a disability**.

Child Anxiety

The following is a list of items that describe children. For each item please select the response that best describes your **child without a disability**. Please answer all the items.

BELOW IS A LIST OF ITEMS THAT DESCRIBE CHILDREN. FOR EACH ITEM PLEASE CIRCLE THE RESPONSE THAT BEST DESCRIBES YOUR CHILD **WITHOUT A** DISABILITY. PLEASE ANSWER ALL THE ITEMS.

	Never	Sometimes	Often	Always
My child worries about things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is scared of the dark	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child has a problem, s(he) complains of having a funny feeling in his / her stomach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child complains of feeling afraid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child would feel afraid of being on his/her own at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is scared when s(he) has to take a test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is afraid when (s)he has to use public toilets or bathrooms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child worries about being away from us / me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child feels afraid that (s)he will make a fool of him/herself in front of people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child worries that (s)he will do badly at school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Sometimes	Often	Always
My child worries that something awful will happen to someone in our family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child complains of suddenly feeling as if (s)he can't breathe when there is no reason for this	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child has to keep checking that (s)he has done things right (like the switch is off, or the door is locked)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is scared if (s)he has to sleep on his/her own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child has trouble going to school in the mornings because (s)he feels nervous or afraid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is scared of dogs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child can't seem to get bad or silly thoughts out of his / her head	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child has a problem, s(he) complains of his/her heart beating really fast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child suddenly starts to tremble or shake when there is no reason for this	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child worries that something bad will happen to him/her	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is scared of going to the doctor or dentist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my child has a problem, (s)he feels shaky	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Sometimes	Often	Always
My child is scared of heights (eg. being at the top of a cliff)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child has to think special thoughts (like numbers or words) to stop bad things from happening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child feels scared if (s)he has to travel in the car, or on a bus or train	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child worries what other people think of him/her	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is afraid of being in crowded places (like shopping centers, the movies, buses, busy playgrounds)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All of a sudden my child feels really scared for no reason at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is scared of insects or spiders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child complains of suddenly becoming dizzy or faint when there is no reason for this	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child feels afraid when (s)he has to talk in front of the class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's complains of his / her heart suddenly starting to beat too quickly for no reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child worries that (s)he will suddenly get a scared feeling when there is nothing to be afraid of	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Sometimes	Often	Always
My child is afraid of being in small closed places, like tunnels or small rooms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child has to do some things over and over again (like washing his / her hands, cleaning or putting things in a certain order)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child gets bothered by bad or silly thoughts or pictures in his/her head	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child has to do certain things in just the right way to stop bad things from happening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child would feel scared if (s)he had to stay away from home overnight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Parent Stress

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

I am happy in my role as a parent.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

There is little or nothing I wouldn't do for my child(ren) if it was necessary.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

Caring for my child(ren) sometimes takes more time and energy than I have to give.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

I sometimes worry whether I am doing enough for my child(ren).

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

I feel close to my child(ren).

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

I enjoy spending time with my child(ren).

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided

- ☐ Agree
- ☐ Strongly agree

My child(ren) is an important source of affection for me.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

Having child(ren) gives me a more certain and optimistic view for the future.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

The major source of stress in my life is my child(ren).

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

Having child(ren) leaves little time and flexibility in my life.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

Having child(ren) has been a financial burden.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

It is difficult to balance different responsibilities because of my child(ren).

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

The behavior of my child(ren) is often embarrassing or stressful to me.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

If I had it to do over again, I might decide not to have child(ren).

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

I feel overwhelmed by the responsibility of being a parent.

- ☐ Strongly disagree

- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

Having child(ren) has meant having too few choices and too little control over my life.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

I am satisfied as a parent.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

I find my child(ren) enjoyable.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Undecided
- ☐ Agree
- ☐ Strongly agree

Demographics

Please answer the following questions about yourself

Please enter your age (in years) in the space below.

Please select your gender

- ☐ Male
- ☐ Female
- ☐ Non-binary / third gender
- ☐ Prefer not to say

Please select your relationship to your children

- ☐ Biological father
- ☐ Biological mother
- ☐ Step father
- ☐ Step mother
- ☐ Adoptive father
- ☐ Adoptive mother
- ☐ Foster father
- ☐ Foster mother
- ☐ Other

Are you of Hispanic, Latino, or of Spanish origin?

- ☐ Yes
- ☐ No

How would you describe yourself?

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Pacific Islander
- ☐ Other

Please answer the following questions about your **child with a disability**

Please enter the age of your child (in years) with a disability in the space below

Please select the gender of your child with a disability

- ☐ Male
- ☐ Female
- ☐ Non-binary / third gender
- ☐ Prefer not to say

Please answer the following questions about your **child without a disability**

Please enter the age of your child (in years) without a disability in the space below

Please select the gender of your child without a disability

- ☐ Male
- ☐ Female
- ☐ Non-binary / third gender
- ☐ Prefer not to say

Donation

For your participation in this study, you may select an organization from our list of non-profit organizations with a mission to serve families of individuals with disabilities to receive a donation of \$3 in honor of your participation.

Please note as all information will be collected anonymously and kept confidential, your name and other identifying information will not be shared with the agency.

Please select a non-profit agency from the list below that you would like your donation to go towards

- ☐ Special Olympics
- ☐ The Arc of the United States
- ☐ American Association on Intellectual and Developmental Disabilities

If you wish to receive an email confirmation of the donation made in aggregate at the conclusion of data collection, please enter your email bellow

Debrief

In this study, you were asked to complete three different measures—one measuring the level of stigma you perceive is experienced by your child with a developmental disability, one that measured the anxiety of your neurotypical child, and one that measured your parental stress. The results of this study will help us better understand the impact of disability stigma on the family system, including the relationships to parenting stress and sibling anxiety. This information may be relevant to efforts intended to better support children with disabilities and their families.

If you would like to receive a report of this research when it is completed or a summary of the findings, please contact Nova Shek at shekn@union.edu. If you have concerns about your rights as a participant in this experiment, please contact the Union College Human Subjects Review Committee Chair Joshua Hart (hartj@union.edu) or the Office for Human Research Protections (<https://www.hhs.gov/ohrp/>).

Thank you again for your participation.

Disqualification Message

Thank you for your interest in this study. This study is interested in understanding more about families with disabilities, particularly the effects on the siblings and parents of children with disabilities. Based on your responses, you do not qualify for this study at this time. Thank you again for your interest.

Appendix B: Study Results

Table 1

Means and Standard Deviations for Measures of Disability Stigma, Child Anxiety, and Parental Stress

Measure	<i>M</i>	<i>SD</i>
Disability Stigma (PROMIS)	19.12	7.06
Neurotypical Child Anxiety (SCAS)	17.37	12.19
Parental Stress (PPS)	47.39	10.50

Note. *M* and *SD* were used to represent mean and standard deviation, respectively. Measures used were the PROMIS Pediatric Stigma – Short Form 8a (PROMIS), Spence Children's Anxiety Scale (SCAS), and Parental Stress Scale (PPS).

Table 2

*Means *t*-Score for Stigma by Neurodevelopmental Disorders Disability.*

Measure	Total
Intellectual Disability	51.12
Communication Disorder	49.14
Autism Spectrum Disorder	50.10
Attention Deficit/Hyperactivity Disorder	50.57
Specific Learning Disorder	51.79
Motor Disorders	56.84

Note. Scores were generated using the National Institutes of Health scoring service.

Table 3

Correlations Between Disability Stigma, Neurotypical Child Anxiety, and Parental Stress

Measure	1	2	3
1. Disability Stigma (PROMIS)	-		
2. Neurotypical Child Anxiety (SCAS)	.10	-	
3. Parental Stress (PPS)	.26	.53**	-

** Correlation is significant at the 0.01 level (2-tailed).

Figure 1

Scatter Plot Depicting the Scores on Parental Stress and Neurotypical Child Anxiety for Each Participant

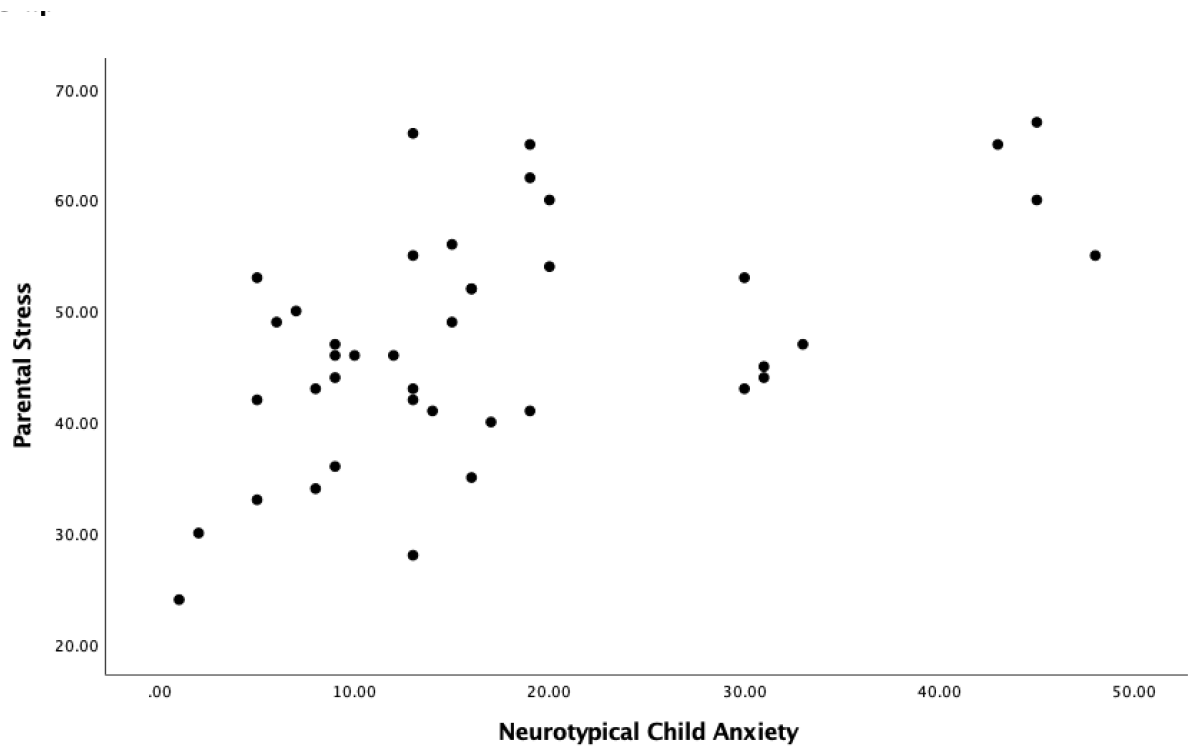


Figure 2

Scatter Plot Depicting the Scores on Parental Stress and Disability Stigma for Each Participant

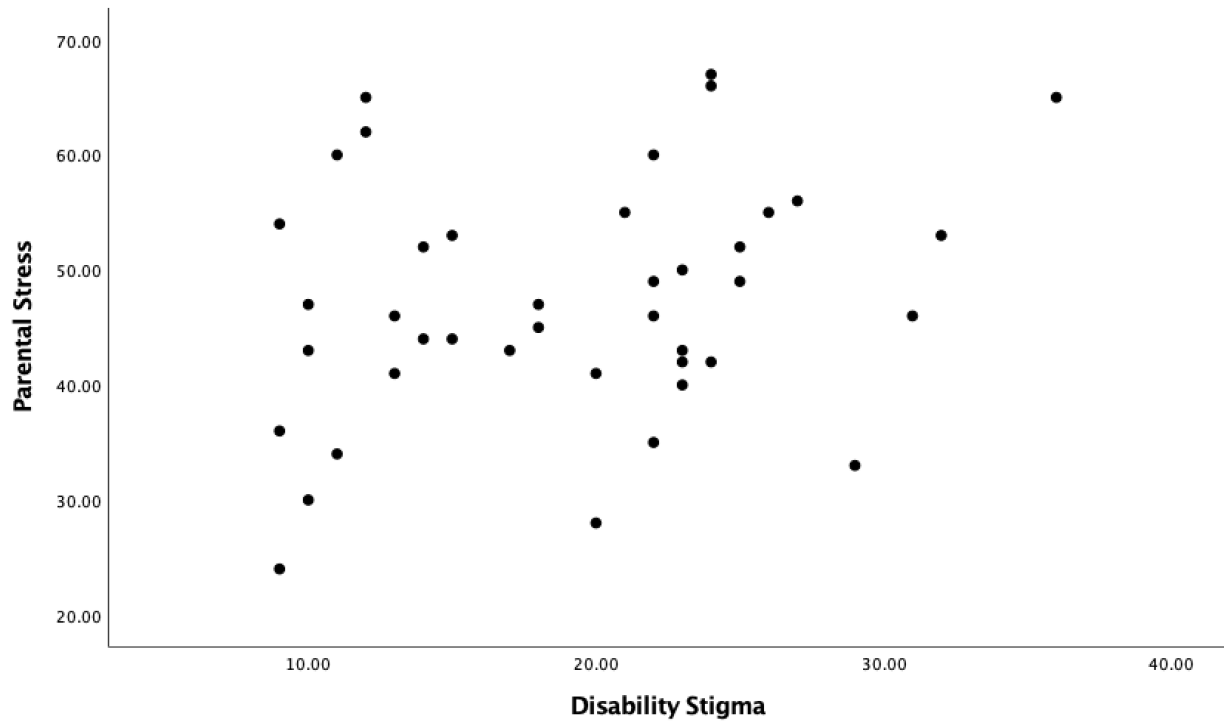
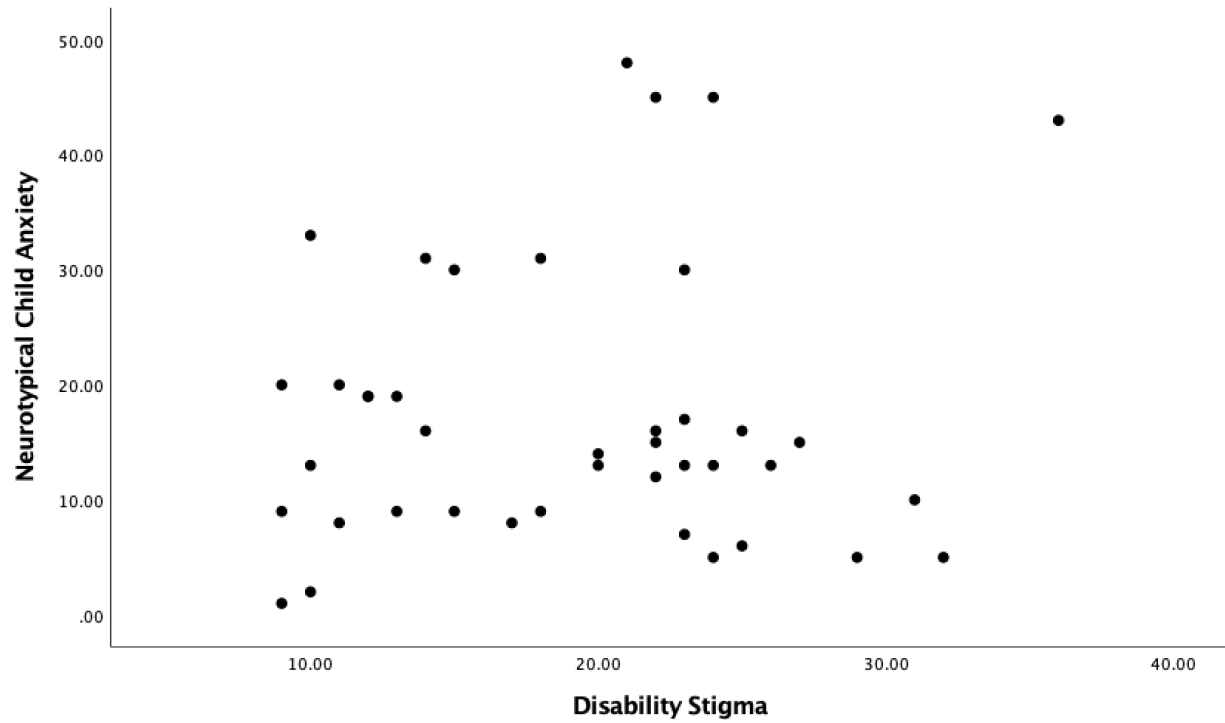


Figure 3

Scatter Plot Depicting Neurotypical Child Anxiety and Disability Stigma for Each Participant



Appendix C: Outline of Interview Questions

Basic Information-

- What is your job title and what responsibilities does it entail?
- What is your educational background?
- What work experience did you have prior to this role?

Specific Questions

- Can you give an overview of the programs at Schenectady ARC
- What works about these programs?
- What can be improved about these programs?
- What are the biggest challenges?
- What is the mission or impact of the Schenectady ARC and its programs?
- Do you believe your organization and its services impact the rest of the family (I.e. their parents/siblings)? If so, what do you believe this impact is?