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A Caregiver's Perspective of Caring for Children with Intellectual Disabilities

LaJoy Johnson Law
Walden University

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Walden University

College of Health Sciences and Public Policy

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LaJoy Johnson-Law

has been found to be complete and satisfactory in all respects,
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Walden University
2025

Abstract

A Caregiver's Perspective of Caring for Children with Intellectual Disabilities

by

LaJoy Johnson-Law

MPhil, Walden University, 2023

MPA, University of Phoenix, 2019

BS, University of Phoenix, 2017

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Policy and Administration

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Abstract

Current estimates reported by the National Institute of Health suggest that between 1.4 and 2.2 million children in the United States have some form of intellectual disability. These children need caregivers, yet in the literature there is a lack of studies focusing on the experiences of caregivers raising children with intellectual disabilities. Further, there is a lack of public policies and programs for Washington, D.C. caregivers. The purpose of this general qualitative study was to explore the lived experiences of these caregivers in Washington, D.C. and to identify what policies, programs, and services are needed to support them. Guided by the social model of disability and critical disability theory, this study was conducted to answer two questions: (a) How do Washington, D.C. caregivers of a child with an intellectual disability describe the experience of providing adequate care under the current laws, policies, and programs available to them? and (b) What policies, programs, or services do these caregivers recommend to inform future policy change? Semi structured interviews were conducted with 10 caregivers residing in Washington, D.C. Thematic analysis was used to analyze the data using Braun and Clarke's six-step process. Five major themes emerged: (a) the emotional weight of caregiving; (b) systems that fall short; (c) community and connection; (d) love, joy, and purpose; and (e) a call for policy change and inclusion. Positive social change may result from elevating caregiver voices in policy creation, particularly in under-resourced communities like Wards 7 and 8 in Washington, D.C., where future research is needed to address deeper disparities.

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Dedication

This dissertation is dedicated to every single caregiver of children and individuals with disabilities. The caregiving journey is often a difficult and lonely road—one filled with sacrifices, quiet struggles, and moments when we feel misunderstood, unheard, and unseen. Yet, within that journey lies incredible strength, unwavering determination, and deep resilience. My hope is that this work reflects the power you hold, affirms your experiences, and empowers you to continue caring for your loved ones with grace and compassion.

There are countless complexities in providing care—balancing the needs of our children while trying to hold on to pieces of ourselves. Too often, our voices are left out of the policy-making process, yet our lived experiences shape the very systems meant to support us. It is time for policymakers to recognize our influence and create policies that protect, uplift, and truly serve us.

Most importantly, I dedicate this study to my daughter, Abria. You are my guiding light, my greatest teacher, and the heartbeat of my purpose. From the moment you entered this world—at 1 pound and 6 ounces, fighting for life at just 23 weeks—you have been a living example of courage and perseverance. You have inspired me to become an elected official and now a Doctor of Philosophy, using my platform to ensure caregivers are included in our democracy and that policies reflect their realities. Your light has ignited my mission, and your strength reminds me every day why I fight for change. This work is for you, and for every fighter like you.

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I also want to acknowledge my Mom, Lisa and our family. I especially want to acknowledge, my Dad—Daddy, I miss you with all my heart. We DID IT! I carry your spirit with me everywhere I go. I also want to thank my mentor, Dr. Jacque Patterson. Thank you, Dr. Patterson, for your constant encouragement, for cheering me on to the finish line. Your belief in me has been a steady anchor.

Lastly, my deepest gratitude to the incredible souls who participated in this study and shared their caregiving journeys. Your stories are powerful, and I am honored to help uplift your voices in the pursuit of policies that will better serve caregivers across Washington, D.C., and the nation. This work would not exist without your courage, honesty, and trust.

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Chapter 1: Introduction to the Study

In the book *Disability, Civil Rights and Public Policy*, Stephen Percy (2018) highlighted the dynamic nature of policy development in implementing disability rights laws. His words remain relevant today as the United States stands at a crucial juncture in defining its disability policy landscape. Due to decades of advocacy, disability policy continues to evolve, with many stakeholders calling for more inclusive measures, particularly those addressing the needs of caregivers (Vadivelan et al., 2020). This study was conducted to understand the perspectives and experiences of caregivers of children with intellectual disabilities as they navigate existing programs and policies in Washington DC.

Background

Throughout the history of disability policy, there has been a deficit in public policies and programs to include and aid caregivers of children with intellectual disabilities. This problem is due in large part to the shortage of research studies investigating caregivers' perspectives and experiences caring for a child with an intellectual disability (Sadiki & Mashegoane, 2019). Furthermore, there has been a gap in family support policies and research that includes family members taking care of individuals with disabilities (Hewitt et al., 2013).

The catalyst for my study is the absence of comprehensive policies, stakeholder awareness, and support programs within Washington DC tailored to aid caregivers of children with intellectual disabilities through public services and initiatives. Presently, it is uncertain whether available public or nonprofit programs are effective in addressing

the multifaceted needs of caregivers concerning their financial, emotional, and mental well-being (Sadiki & Mashegoane, 2019). This predicament significantly burdens caregivers of children with intellectual disabilities, who contend with heightened caregiver responsibilities (Paterson & Larios, 2020). A myriad of factors contribute to this challenge, including the lack of insight or acknowledgment among government agencies, policy stakeholders, and nonprofit entities into the experiences of caregivers of children with intellectual disabilities. This study will help to close this knowledge gap.

Problem Statement

The specific research problem that addressed through this qualitative study is the need for more responsive public policies and programs to assist caregivers of children with intellectual disabilities. This problem, specifically, is due to the lack of studies that have explored caregivers' perspectives and experiences caring for a child with an intellectual disability (Vadivelan et al., 2020). While prior research has examined facets of caregiver experience, perspective, and long-term care policies for the elderly and individuals with other disabilities (Cohen & Benvenisti, 2020), there remains a notable dearth of studies focusing on the intricate experiences of caregivers raising children with intellectual disabilities. Although researchers have investigated various caregiver-related studies, there has been a noticeable absence of relevant research studies, particularly in the last 5 years exploring caregivers' perceptions and recommendations on policy and programmatic matters as they relate to assisting this specific population (Paterson & Larios, 2020). For example, researchers have investigated various forms of caregiver experience, perspective, and long-term care policies for the elderly and other disabilities

(Cohen & Benvenisti, 2020; McKenzie & McConkey, 2016), but few studies have explored the detailed perception of experiences of caregivers raising children with intellectual disabilities to assist with the recommendations to improve public policies, programs, and services that are needed to assist the familial caregiver. Such insights are imperative for informing recommendations aimed at enhancing public policies, programs, and services tailored to support familial caregivers.

Purpose Statement

The purpose of this general qualitative study was to understand the experience of raising a child with an intellectual disability, and to discover what policies, programs, and services are needed for caregivers of these children in Washington DC.

Research Questions

The research questions that guide this study are:

RQ 1: How do Washington DC caregivers of a child with an intellectual disability describe the experience of providing adequate care under the current laws, policies, and programs available to them?

RQ 2: What policies, programs, or services do Washington DC caregivers of a child with an intellectual disability recommend, that could inform the development of policy changes for caregivers?

Conceptual Framework for the Study

The conceptual framework for this study is comprised of the social model of disability (Dowling & Dolan, 2001) and critical disability theory (Siebers, 2008). These theories have been used in a variety of disability research and critical disability studies

that have affected public policies and advocacy efforts (Hughes, 2015; Runswick-Cole, 2010; Sousa, 2022; Von Benzon, 2010). This conceptual approach provides guidance on how a child's disability can have a social influence on parents and family dynamics and the inclusion of caregivers in disability policy.

The social model of disability enhances the qualitative direction of this study—exploring how the child's intellectual disability affects the caregiver's perspective, experience, and identity. In addition, this guidance was also combined with the public policy theory of critical disability theory, which states that individuals with disabilities experience civil rights, equity, and equality challenges that can prevent them from participating in the political democratic process. This also relates to children with disabilities and their caregivers.

Caregivers need policies, laws, and programs to protect and assist them so they can receive accommodations, equity, and equality to be able to participate in the democratic process on behalf of their child with a disability in order to effect policy, programs, and service recommendations. The social impact (social model of disability) on the caregiver affects their ability to be able to participate in the democratic process (critical disability theory) to effectively create and recommend policy, program, and service recommendations. The social model of disability helped guide RQ 1, and the critical disability theory helped guide RQ 2.

Nature of the Study

To address the research questions in this qualitative study, the specific research design included a general qualitative study focusing on the experiences and perceptions

of the caregivers of children with intellectual disabilities with in-depth semi structured interviews (Patton, 2015). The key phenomenon was the caregivers' daily life experiences caring for a child with an intellectual disability under Washington DC's current policies and programs. The results of this exploratory study can be used to develop policy and programmatic recommendations.

Definitions

Caregiver: an individual providing care or attending to the requirements of a child/children who have an intellectual disability at least 85% of the time (Johns Hopkins Medicine, n.d.).

Child: Children ages birth to 22 years of age. Under the Individuals with Disabilities Education Act, children with disabilities are considered children up until the age of 22, and this includes children with intellectual disabilities (U.S. Department of Education, n.d.).

Intellectual disability: An individual that has a notable below-average level of overall intellectual abilities, coupled with challenges in adapting to daily tasks, which arise during childhood and impact the child's daily life (U.S. Department of Education, n.d.).

Assumptions

Since this is a general qualitative study, there are assumptions inherent in qualitative research that must be considered, even though they cannot be demonstrated to be true (Ospina et al., 2018). For example, qualitative research assumes there is no one objective way to analyze the data; it explores multiple realities and truths, and all are true

simultaneously (Adler, 2022). Next, when completing interviews, there is an assumption that the participants tell the researcher the truth, but this cannot be demonstrated to be actually true (White, 2018). Moreover, since the participants were caregivers and living in Washington DC, there was an assumption that they have some experience with Washington DC policies and programs.

Scope and Delimitations

The boundaries of this study include caregivers of children with intellectual disabilities living in Washington DC. The term “caregiver” is the primary population used for data collection for this study. The term caregiver is a very broad term that encompasses and includes many family members who are caring for children with intellectual disabilities. This study does not focus on one type of caregiver but on anyone over 18 who provides full-time (85% of the time) care. Though caregivers were included in this study, there are some exclusions. For example, this study is only specific to caregivers of children with intellectual disabilities, excluding caregivers of children with other disabilities and caregivers for adults with disabilities, the elderly, or veterans.

Ensuring transferability is crucial for establishing the reliability of a study, as it relates to the potential for replication with comparable populations and demographics, yielding similar outcomes (Lincoln & Guba, 1985). However, it remains uncertain whether the findings of this study can be generalized to other similar populations or to the broader caregiver community. The caregiver demographic is highly diverse, encompassing various cultural backgrounds, socioeconomic statuses, and other factors that could significantly influence the outcomes of a different study. This limitation

extends to other populations due to the purposeful sampling method employed in this study, which may not be universally applicable or transferable.

Limitations

As mentioned, generalizability was limited. Another possible barrier that could arise in this study is the difficulty of accessing and recruiting participants for primary data collection. Moreover, a challenge may arise in identifying organizations to assist in participant recruitment, particularly those with which the researcher does not currently collaborate. This situation may pose a challenge in maintaining a clear separation between the researcher's roles as a disability advocate and as a researcher. Furthermore, as a caregiver of a child with an intellectual disability, my biases will be addressed in Chapter 3 to ensure reliability, validity, and trustworthiness in the study.

Significance

This study is significant in that it fills a gap in understanding by providing information on the experiences and perspectives of caregivers who are raising children with intellectual disabilities to assist with a much-needed improvement to policies, programs, and services to assist (overall) caregivers of children with disabilities (Cantero-Garlito et al., 2020). Because caregivers have many responsibilities and duties, the results of this study can help develop, create, and fund policies and programs to assist caregivers with multiple social services.

This study is about positive social change through aiding caregivers to access programs to help with the potential burden of raising children with intellectual disabilities. Furthermore, this study may promote inclusion of caregivers of children with

intellectual disabilities as a part of disability advocacy, identity, and culture to help with the creation and implementation of public policies, programs, and services. Lastly, this study can also assist policymakers in helping caregivers of children with varying disabilities to ensure they are included in the democratic process. As Leakes (2019) noted, “The time has come to recognize the rights for caretakers” (p. 736).

Summary

It is imperative that caregivers are included in disability policy to ensure equity and equality in the democratic process. But there has been a lack of studies and policies to include caregivers, in particular, caregivers of children with intellectual disabilities (Sadiki & Mashegoane, 2019). Disability rights have been a trailblazer in public policy over the last several decades, but caregivers seem to be absent in disability policies. Despite researchers’ inquiries into this matter, there is still a lack of research studies around public policies and programs to assist caregivers of children with intellectual disabilities.

The purpose of this qualitative study was to gain a deeper understanding of the experiences of caregivers of children with intellectual disabilities who live in Washington DC by exploring the caregivers’ viewpoint of their daily experiences and recommendations on policies, programs, and services to address the specific needs of this population. Therefore, this study is important to bridge the knowledge gap and provide insights into the experiences and perspectives of caregivers, thereby aiding in the enhancement of policies, programs, and services for caregivers overall. Lastly, this study

can help ensure and foster social change by amplifying the voices of caregivers to be included in disability advocacy, identity, and culture.

Chapter 1 provided a comprehensive overview of the research problem and its significance. In Chapter 2 I provide the literature review, including prior research, and a background review of current disability policies locally, nationally, and internationally. Then in Chapter 3 I present the methodology, research design, trustworthiness, ethical concerns, and procedures. Finally, in Chapters 4 and 5, I present the results, findings and recommendations.

Chapter 2: Literature Review

In any examination of disability research and policy formulation, it is imperative to recognize caregivers as a part of the historical disability journey. Often, society and culture will focus on the individual or child with a disability but not have much focus on the caregiver. The current literature provides background surrounding the day-to-day and economic experiences of caregivers caring for children with intellectual disabilities and similar disabilities and can be used to inform policymakers and stakeholders about legislative and programmatic social change. While this study addresses the specific research problem of the insufficient public policies and programs available to support caregivers of children with intellectual disabilities—these issues stem from a lack of studies that have examined the perspectives and experiences of these caregivers (Sadiki & Mashegoane, 2019).

Chapter 2 is organized into several sections, each focusing on critical aspects of disability policy and research. The section on literature search strategy outlines the comprehensive search methods and databases used to collect literature on caregivers of children with intellectual disabilities, including the recent impact of Covid-19. The Theoretical Foundation/Conceptual Framework section discusses the social model of disability and critical disability theory, which guided the study's examination of the intersection between disability policy and caregiver experiences. The Literature Review section provides an extensive analysis of disability policies, including federal policies from the 20th and 21st centuries, such as the Social Security Act, Rehabilitation Act, Individuals with Disabilities Education Act (IDEA), American with Disabilities Act

(ADA), and Family Medical Leave Act (FMLA). It also compares U.S. policies with international ones and reviews recent caregiver research. The chapter emphasizes the evolving role of policy in supporting caregivers and calls for inclusive policies that address the needs of caregivers of children with intellectual disabilities.

Literature Search Strategy

Disability policy and research have evolved over the last several decades. However, limited policies and research relate to the caregivers of children with intellectual disabilities. I had to expand the search to similar topics, such as caregivers of children with autism, cerebral palsy, developmental disability, or another similarly related disability. Furthermore, there was also a limited number of official laws or bills that affected caregivers and children with intellectual disabilities. The literature search strategy involved collecting literature through extensive searches in various libraries. The keywords that were searched in various databases, including the Walden Library, to help find numerous articles were related to *mother or maternal, parent, caregiver, caregiver experience, caregiver perception, caregiver burden, caregiver stress, children with disabilities, caregiver, children with intellectual disabilities, disability, disabilities, or special needs, parent, caregiver, child or youth, and policy, bill, law or legislation and covid19*.

I also searched the following research and policy databases: ProQuest, Walden (EBSCO Advanced Thoreau) Library Search, Taylor and Francis, EBSCO Public Administration Review, Journal of Public Administration Research and Theory, and Sage Journals, Nexis, Caregiver USA Gov, Google, Google Scholar. I searched for articles

ranging from 2017 to 2024 and reviewed numerous documents. I found various research articles examining caregivers of children with various or similar disabilities and caregivers of aging adults or seniors with disabilities but limited articles on specific connections to policy to assist caregivers of children with disabilities. The policy journals searched for were the *Journal of Public Administration Research and Theory*, *Public Administration Review*, and *Public Administration-Wiley Online Library*.

When I first started researching, I started with a narrow search. I was not finding many relevant articles within the last 5 years and opened the search to relevant articles in the last 10-15 years. Though it was difficult to find peer-reviewed policies and research pertinent to my topic, this study will help fill some of the scholarly gaps and assist other researchers as this topic becomes more significant to solve problems affecting the disability caregiver population.

Additionally, Covid-19 exacerbated many ongoing issues that have now been brought to the surface and caregiving is one of those topics. It is important to recognize and take part in the solution of helping caregivers of children with intellectual and all other disabilities and value their contributions to this world (Embregts et al., 2021). Therefore, it is essential to include Covid-19 throughout this chapter to give a holistic viewpoint of the caregivers to effectively inform research, policy and programs.

Conceptual Framework

This study was guided by two theories as part of a conceptual framework. The first theory is the social model of disability (Dowling Dolan, 2001; Oliver, 1983), and the second theory is the critical disability theory (Siebers, 2008). These two theories are

appropriate for this study due to the inclusion of disability policy and rights while highlighting equity and equality challenges. If there are no concrete policies to extend equitable accommodations to disabled individuals, then not only will individuals with disabilities and their families not be able to participate as citizens in a democracy, but they will not be able to participate in the democratic process to make social change. The social model of disability and critical disability theory revolutionized the political power and inclusiveness of the disability community.

Social Model of Disability

Mike Oliver was one of the first constructionists of the social model disability theory. This was transformative in studying the social constructs of society. Oliver found that parents and families and other members that interact with an individual with a disability are affected by the individual's disability and how they socialize with individuals that have disabilities (Oliver, 1983, 1990). In addition, Oliver (1990) also found that "disability is defined by public policy" (p. 78) and contended that disability is the intersection of socialism, social change, and public policy. Later, Dowling and Dolan (2001) incorporated the social model of researched families' respite experiences caring for children with disabilities. The social model of disability is vital to my research to guide how the child's intellectual disability affects the caregiver.

Critical Disability Theory

Critical disability theory is a theoretical framework from critical theories and the social model of disability (Hosking, 2008). Individuals with disabilities have struggled to feel accepted and included in society and policies; thus, many disability studies were

derived from an emancipation viewpoint (Meekosha & Shuttleworth, 2009; Siebers, 2008). In addition, disability rights can transcend norms, and it is crucial to recognize disability rights as an identity. This concept can also apply to children with disabilities, but since they are children, then, this can also apply to the parents or caregivers of the child.

According to critical disability theory, parents need policies, legislation, and programs to protect them so they can also receive accommodations, equity, and equality to participate in the democratic process on behalf of their child with a disability (Siebers, 2008). Together the social model of disability and critical disability theory provide a public policy and qualitative research lens. This study was conducted to explore the caregiver's experience (social model of disability) and the recommendations for public policies, programs, and services to assist caregivers (critical disability theory). Together, these two major disability theories helped shed light on the caregiver's experience to support this population in hopes of significant social change.

Literature Review Related to Key Variables and/or Concepts

In this literature review, I will review current literature and provide an overview of disability policy formulation and how it has affected children with intellectual disabilities, and if it has affected caregivers. I will explore disability policy and research by examining current federal (20th and 21st century) policies through a timeline to show the progression of disability. Also, there will be an examination of Washington DC disability policies and the intersectionality of children with intellectual disabilities and caregivers. Lastly, I will compare international disability policies to U.S. disability

policies and review recent caregiver research studies and the challenges to including caregivers in disability policy. For example, Cantero-Garlito et al. (2020) explored the daily experiences of mothers of children with disabilities in Spain and confirmed that mothers experienced both positive and negative occurrences with higher experience of burden challenges. Similarly, Ejiri and Matsuzawa (2017) examined Japanese mothers through a cross-sectional study and found that mothers caring for children with intellectual disabilities had decreased participation in employment activities and a higher unemployment rate than mothers caring for children without an intellectual disability.

Researchers noted that the intersectionality of disability policy and caregiver support should be outlined by government entities through caregiver benefits, external resources, and social support to assist the caregiver with the responsibility of raising a complex child (Cantero-Garlito et al., 2020). Before beginning the federal historical timeline of disability policy, it is important to note that while numerous policies extend to individuals, including children, with disabilities, a limited amount of both policies and research included caregivers (Sadiki & Mashegoane, 2019).

20th Century U.S. Federal Disability Policies

To understand the current state of policies affecting individuals and children with intellectual disabilities and their caregivers in the current 21st century, it is important to examine 20th-century U.S. federal disability policies that have affected policies today. This timeline includes the Social Security Act, Vocational Rehabilitation Act, Individuals with Disabilities Education Act, American with Disabilities Act, and the Family Medical Leave Act, since these policies have paved the way and opened the door for the creation

of more disability policies that affect individuals and children with intellectual disabilities and their caregivers.

Social Security Act 1935

One of the major federal social policies that have impacted individuals with intellectual and other disabilities and their families (even until the present day) is the Social Security Act of 1935. The Social Security Act financially assists individuals with disabilities, and if the individual is a child, they receive supplemental security income from their legal guardian (National Archives, 2022). In 1935, after fighting the second world war and enduring the Great Depression, many individuals suffered disabling injuries, including elderly individuals, children with special health care and educational needs, individuals experiencing deafness and blindness, and unemployed individuals (Keesler, 2015).

The Social Security Act was enacted as an insurance financial assistance program to help individuals with disabilities with financial living costs and general well-being (Hole et al. 2013). President Franklin signed the social security act into law on Aug 15, 1935, and this landmark act became one of the first federal income support policies extended to the elderly, children with special health care and educational needs, and individuals with qualifying disabilities, including individuals with intellectual disabilities, to provide financial assistance for daily living (Percy, 2018).

Financial burden is a major concern for individuals with intellectual disabilities as they age due to the stress of maintaining financial stability (Hole et al., 2013). Currently, the number of individuals with disabilities is on the rise, so there is an ever more pressing

need to ensure Social Security be continually efficient and proactive with resources for social security recipients and their families (Keesler, 2015). The Social Security Act serves as a model for new federal, state and local policy and legislation to provide financial assistance, that includes the caregivers of children with intellectual disabilities.

Rehabilitation Act of 1973

The next major federal policy development extended to individuals with disabilities and intellectual disabilities was the Vocational Rehabilitation amendment of 1943, also known as the Barden-LaFollette Act. It was reauthorized in 1973 and renamed the Rehabilitation Act of 1973 (U.S. Equal Employment Opportunity Commission, n.d.). The Rehabilitation Act of 1973 allows state-level disability departments to have vocational services, which included many new employment opportunities for individuals with intellectual disabilities (U.S. Equal Employment Opportunity Commission, n.d.). In addition to ensuring the ability to participate in the everyday workplace, it also provided workforce training and coaching to individuals with disabilities, along with financial assistance to eligible rehabilitative programs (Griffin et al., 2010).

This act also signaled an important shift in disability rights, ensuring youth with intellectual and other various disabilities who are aging out have a transitional pathway forward to adulthood (Wicker et al., 2022). According to Sarrett (2022), this is the instrumental legislation that guarantees children with an Individualized Education Plan (IEP) are able to access vocational programs to help prepare for the transition into young adulthood.

Numerous children with disabilities start the rehab process around the age of 14 to get ready for the transition to adulthood—for example, DC Department on Disability Services- Rehabilitation Service Administration (RSA) helps youth with disabilities starting at the age of 14 with transition services to employment, college, and other career trades (DC Department on Disability Services, n.d.). The Rehabilitation Act has helped an increasing number of individuals with intellectual disabilities obtain access to college, trades, employment, and various vocational services (Sarrett, 2022).

This policy provides an example of how caregivers might be included in the vocational policies, so they can also access vocational services to assist with employment. Employment and finances can be a barrier for families due to caring for a child with an intellectual disability (Griffin et al., 2010). An inclusive vocational policy may be a way to help lift the financial stress and burden of the caregiver.

Individuals with Disabilities Education Act of 2004

One of the most important civil rights laws surrounding individuals with intellectual and other related disabilities is the Individuals with Disabilities Education Act (IDEA). Formerly known as The Education for Handicapped Children Act of 1975, this policy was revolutionary in protecting the rights of children with disabilities to receive an appropriate education along with their non-disabled peers and being provided a “free appropriate public education (FAPE)” (U.S. Department of Education, n.d., sec. 1).

The Individuals with Disabilities Education Act is a federal policy implemented nationwide across every state’s public education system, and under IDEA, there are 13 qualifying disabilities (U.S. Department of Education, n.d.). One of the qualifying 13

disabilities is intellectual disability. Upon reviewing this law, I wanted to highlight a disability population that is currently recognized by the federal government and has a direct intersection with children and often is not studied as much as other disabilities associated with children.

While the Individuals with Disabilities Education Act is one of the few policies that mandates parental participation in the special education process, families are typically not considered for input on a policy and legislative level (Robinson & Mueller, 2020; Rossetti et al., 2021). The IDEA was reauthorized in 2004 and is expected to be reauthorized in the upcoming years (Burke et al., 2022), which would provide an opportunity to include the caregiver's perspective in the legislation, and could potentially serve as a model for caregiver policy inclusion.

American with Disabilities Act of 1990

Another groundbreaking federal disability policy was the Americans with Disabilities Act (ADA), signed into law in 1990. This historic piece of legislation protects the civil rights of individuals, including children with disabilities, from discrimination in many aspects of public life, such as the inclusion in recreational and employment opportunities (ADA, 1990; Lease, 2019). The ADA also provides reasonable accommodations and modifications for individuals with a disability, in that state, local, and city government programs must have reasonable accommodations for individuals with disabilities to be able to access programs (Lorr, 2022). For instance, state and local governments must ensure all government materials are accessible to the blind

and deaf, or an out-of-school-time program must be accessible to children with disabilities.

The ADA was instrumental in helping protect many individuals with intellectual disabilities, and included protections against discrimination in government and public education programs, in addition to those in the IDEA. However, certain discriminatory protections do not cover the caregivers for the individual with the disability. There is a small provision called the associated provision, which disallows employers to be unfair or prejudiced in hiring an individual with a direct link or association with an individual with a disability (Leakes, 2019). But according to Lease (2019), federal laws such as ADA “do not specifically prohibit discrimination against caregivers as a protected class and are inadequately addressed in policy” (pp. 709-710). It is my hope that this study will raise awareness around caregivers and not only including them in disability policies but considering them a protected class whose civil rights deserve to be protected in addition to their children that have disabilities.

Federal Medical Leave Act 1993, Amended in 2015

Family—rather, caring for one’s family has always been the backbone of the United States. Still, caregiving was not truly recognized on a public policy scale until Congress passed the Federal Medical Leave Act (FMLA) in 1993. According to the U.S. Department of Labor (n.d.), employees (under eligible employers) can take unpaid time off to provide caregiving activities to care for family members due to medical reasons. To access FMLA, an employee must be eligible and have worked for an employer for a specific amount of time or worked a specific number of hours (Pilapil et al.,

1993). However, there are often barriers for many individuals in accessing FMLA, due to consistent caregiving and challenges in initially qualifying.

Many caregivers are not able to qualify because they cannot comply with the length of employment requirement, due to taking off to care for a sick or disabled child or relative (Chou et al., 2018). Additionally, while FMLA does provide up to 12 weeks of leave, the leave is unpaid, which is not sustainable for a caregiver caring for child with a chronic disability or chronic illness (Lease, 2019). Despite the many restrictions within the FMLA policy, it can still provide a policy model to help protect the employment of caregivers of children with intellectual disabilities.

21st Century U.S. Federal Disability Policies

The Developmental Disabilities Assistance and Bill of Rights Act of 2000

The 21st century began with one of the first pieces of legislation to specifically include families of individuals with intellectual disabilities in the policy. Early in 2000, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) was established to assist individuals with developmental and similar disabilities with independent living skills and help with integration into the community and other programs (Nevada Center for Excellence in Disabilities, 2023). The legislation funded advocacy and support programs to help inspire individuals with developmental disabilities and their families to help mold policies for the developmental disability community (Association of University Centers on Disabilities, n.d.). The DD Act is a monumental start to caregiver and family inclusivity. We still have numerous challenges to conquer but, the DD Act, opened up the policy perspective of caregiver inclusion.

Recent U.S. Federal Disability Policies Affecting Caregivers

Since the DD Act was passed at the start of the 21st century, there have been a few other policies that address the needs of caregivers. For example, the Recognize, Assist, Support, and Engage (RAISE) Act was established in 2018 and “requires the Department of Health and Human Services Secretary to develop a national caregiving agenda and recommends policies and resources” (Administration for Community Living, 2022). This federal law is very promising to issue guidance on statutes, legislation, and programming that should be passed to help caregivers nationally. The council finalized a set of recommendations in November 2020 (note this in the height of the Covid-19 pandemic) and delivered them to Congress in September 2021 (Administration for Community Living, 2022).

The council made several recommendations, but the most critical recommendations that will assist with policy formulation is there needs to be increased public responsiveness and mindfulness of the various demands, concerns, and burdens of caregiving. In addition, to the increased response from the public, there also needs to be an increase in support services such as financial, workplace and human service support (Administration for Community Living, 2022).

More recently there has been progress towards passing federal policies for caregivers of children with disabilities. One example of proposed legislation is the Autism Family Caregiver Act (AFCA) of 2022. In February 2022, the Congressional Autism Caucus introduced a bipartisan bill that would assist caregivers and provide access to “caregiver skills training” (Autism Family Caregiver Act, 2023, sec. 2) for

direct caregivers of children with autism and other similar learning and developmental disabilities.

If this bill becomes a law, many communities serving children with autism and other similar disabilities will receive grant money to implement caregiver skills training (Autism Family Caregiver Act, 2023). This bill focuses primarily on helping the caregiver with specific skills to improve the “mental and physical well-being” of the autistic or disabled child (Autism Family Caregiver Act, 2023, para. 5). While the bill is an step in the right direction for caregiver-inclusive policies, the policy does not address the caregiver’s wellbeing and/or specific emotional, social, financial, and mental support to help the caregiver of children with varying disabilities including intellectual disabilities.

The Impact of Covid-19 on Federal Caregiver Policy

As the world evolves, caregiver communities continuously advocate for families caring for children with intellectual and other similar disabilities, especially since the Covid-19 pandemic. The pandemic is worth noting since this study is being conducted post-Covid-19. While this study does not particularly focus on the effects of the Covid-19 pandemic and caregivers’ experiences—there is an intersection between caregivers caring for their children with intellectual disabilities and the experience of caring for their children through and post-pandemic. Before the pandemic occurred, numerous caregivers were already experiencing struggles within their families and their experiences and level of burden was exasperated when the pandemic first occurred in 2020 (Houtrow et al., 2020).

For example, during the Covid19 pandemic, caregivers experienced increased depressed symptoms, higher physical, emotional, and mental stress, and overall burnout (Shapiro & Bassok, 2022). Additionally, minority and low socioeconomic status caregivers were disproportionately affected during the pandemic because of existing inadequacies access to healthcare, financial opportunities and social opportunities that widened even further (Houtrow et.al., 2020). I believe it is indispensable to touch upon the disproportionate effects the pandemic had on minority and low socioeconomic status caregivers since this study is being conducted in a high urban area that does include minority communities. While this study will not be examining the effects or comparison of race of the caregivers, it is always important to keep in mind the effects of race and class in this country, especially in the caregiver community.

Increasing Access to High-Quality Care and Supporting Caregivers 2023 Executive Order

As the nation continues to recover from the effects of Covid 19 there have been some national policies that have been created to be more inclusive of caregivers. The increased inclusivity was due to the to the advocacy and unfortunate effects of covid19 on many disability households. For example, in 2023 during the Joseph Biden presidential administration, the High-Quality Care and Supporting Caregivers 2023 Executive Order was created to provide guidance to the U.S. Department of Education and U.S. Department of Health and Human Services surrounding affordable child-care, long-term care and guidance to assist caregivers of elderly adults, children and individual with disabilities (The White House, 2023).

An optimistic measure of the executive order includes an official inclusion of family caregivers and their struggles with not receiving adequate support, training, and chances to obtain breaks and respite. For instance, countless family caregivers care for their elderly parents and children with and without disabilities and do not have the proper financial support (The White House, 2023). This is an official government recognition of the multiple struggles that numerous caregivers experience daily. This executive order also gives credibility and validity to the caregiver's experience on a national platform. This study hopes to also highlight the daily experiences of the caregivers in an urban area to explore the positive and challenging daily experiences to inform public policies and programs.

Lastly, this executive order also provides a favorable public policy example of executive guidance to federal agencies on how to provide education intervention assistance to family caregivers with children with disabilities---such as early intervention services and programs (The White House, 2023). While this scholarly proven guidance will be beneficial to education and human service federal agencies, many of the agencies are currently overseeing several evidence-based early intervention programs for children with disabilities under the part C of the Individuals with Disabilities Education Act (IDEA) (U.S. Department of Education, n.d.). For caregivers to be more included in policy, federal policies should focus on new, innovative, and evidence-based training, financial, mental, social and support for the caregiver to be properly supported (Dawson et al., 2020).

State and Local Caregiver Policies

Caregiver Policies in Washington DC (District of Columbia)

With the major federal disability policies and legislative milestones that have affected children with intellectual disabilities and caregivers as a foundation, in this section I will present local Washington DC disability legislation and policies that have affected children with intellectual disabilities and caregivers. Despite the limited number of official laws or bills that affected caregivers and children with intellectual disabilities, one policy did expressly include caregivers for individuals with intellectual disabilities.

In 2019, the DC Council established the Grandparent and Close Relative Caregiver Subsidy Pilot Program to help grandparents and close family members or relatives who gained custody of their grandchildren to receive subsidy monthly payments to help care for their grandchild or familial related child and added amendments to help more close-related caregivers gain access to the program (Cuccia, 2022; Weerasingha-Cote, 2021). While this policy focused on the grandparents and close relatives who have assumed the role of a legal guardian to care for the child, it could provide a template for future caregiver policies, since many families caring for children with intellectual disabilities experience financial burdens (Sadiki & Mashegoane, 2019).

Caregiver Policies in Other States

Other state jurisdictions have enacted policies that could be examples for Washington DC in developing policies that center the needs of caregivers. New York, Virginia, Florida, and Washington State have policies surrounding individuals being able to take advantage of being personal assistants (home care assistance) to their chronically

ill family members (NY State Senate, n.d.). These consumer personal assistant policies usually are funded through state Medicaid dollars (Dawson et al., 2020). Giordono (2020) found that Washington and Pennsylvania states gave employment preferences to individuals with disabilities. Although these policies are not directed specifically at caregivers, they provide models that could be used to assist caregivers of children with intellectual disabilities financially, and through employment preference policies.

International Disability and Caregiver Policies

Disability-related and caregiver policies are present worldwide, and many could be a helpful model for policies in both Washington DC and at the federal level in the United States. For example, in Israel, Cohen (2020) conducted a secondary data analysis policy study on long-term care for seniors and found that Israel needed an increase in long-term policies that can help with funding staff to help care for the seniors. Countries in Africa found a similar need for more long-term policies that specifically focus on caregivers of children raising intellectual disabilities (Mkabile et al., 2021). Caregivers in Spain benefit from the Promotion of Personal Autonomy and Care of Dependent Persons, also known as the Dependency Act (Cantero-Garlito et al., 2020, p. 2). This legislative policy was initially created for families caring for elderly individuals but was eventually amended to include families caring for children with disabilities, and it provides access for caregivers to social services and grant funding (Cuevas Fernández-Gallego et al., 2012).

Caregivers and children with disabilities need holistic policies for the entire family, funding proper external support and putting “families first” (Olin & Dunér, 2019,

p. 113). Policymakers in African areas are recognizing the great public need for more programs for caregivers raising children with intellectual disabilities that address caregiver burnout (Mkabile et al., 2021). France has an inclusive holistic program at the L'Arche, which offers an employment program for individuals with intellectual disabilities and provides community meetings, food meals, care coordination, political education, and engagement outreach coordinators to help with the public interest of individuals with Intellectual disabilities (McCray, 2021).

Some countries are exploring innovative ways to assist caregivers through policies and programs. For example, Paterson and Larios (2020) examined using empathy and compassion to inform Canada policymakers perspectives and opinions to bridge the gap between quantitative and qualitative insights. It is essential policymakers have proper information to cognitively understand the social dynamics of an issue. Although many policymakers may not have a full understanding of the experiences of caregiving, there is power in the policymaker relating to the experience of burnout, exhaustion, or underappreciation---this is the relational experience that led to the passing of the Canadian Caring for Children Program and Canadian Caring for People with High Medical Needs Program in 2014 (Hango, 2020).

The innovation of having policymakers realize their own challenging experiences and relate them to the experiences of others is the power of social policy making to be able to aid caregivers and their families. I believe Gerdes et al. (2011) said it best “once we have empathic insights into discrimination, injustice, or inequality, we are better able to take action that promotes social justice” (p. 117). The lack of inclusion of caregiving is

a grave injustice for the ability of caregivers to be included in the democratic process, financial and social aspects of society (Siebers, 2008). If policies are more inclusive of caregivers, not only will this assist their children with intellectual and other similar disabilities—the policies can assist the entire family. This will be a great benefit to the disability movement in culture and society.

As one can see, there are numerous international policies and programs that focus on caregiver inclusive policies, however, more caregiver-related research and policy studies are needed to understand and take action on this issue. Whether international or national, caregivers can feel a sense of a holistic healthy life, when the caregiver and the entire family feel supported.

Research Studies on Caregivers

To this point I have presented background and context on disability and caregiver-related policies, but it is also important to examine the research focused on caregivers of children with intellectual disabilities or similar related disabilities that can potentially influence and create policies and programs for caregivers. To date there have been few research studies that focus on caregivers of children with intellectual disabilities, but there have been several recent studies about caregivers for children with chronic and other parallel conditions, such as cerebral palsy, learning disabilities, etc. Moreover, this section will also feature studies that were conducted over the last ten years due to the lack of research studies conducted in the last 5 years.

A theme I found throughout this research was the level of caregiver burden and managing daily activities for the child or individual with the disability. Caregivers

experienced significant burdens while caring for children with intellectual and similar disabilities (Mak et al., 2007, McKenzie & McConkey, 2016). According to Vadivelan et al. (2020), caregivers of children with cerebral palsy experienced increased burden and intersectional challenges with poverty and stigmas. In their studies of caregivers of children with intellectual disabilities, Marsh et al. (2020) and Mkabile et al. (2021) also found that caregivers experienced caregiving burdens and burnout as social, emotional, and mental challenges.

Caregivers are constantly managing finances, behavior, other children, doctors and therapeutic visits, transportation and much more to ensure the child with the disability has appropriate and adequate support—which is a significant amount of burden and stress (Dreyfus & Dowse, 2018). It is important to note the theme of caregiver burden to emphasize this experience in order for policymakers to assist in providing public policy and programmatic relief.

Additionally, several researchers articulated the need to understand why the caregiver perspective is critical in the development of policies (Robinson & Mueller, 2020), specifically on the levels of burden experienced by caregivers of children with intellectual disabilities (Aldersey et al., 2020; Ingolfssdottir et al., 2018). Hewitt et al. (2013) examined families caring for individuals with intellectual disabilities experiences and found many families struggled with their children in school, increased physical and mental caregiver burden, economic instability and strain, and dysfunctionality in immediate familial households. While this provides great insight into caregivers' day-to-day challenges, this study was conducted 10 years ago and is an example of how there

needs to be an increased focus on families caring for children with intellectual disabilities and what programs and policies they will find helpful in their household.

Challenges to the Inclusion of Caregivers in Disability Policy

There is a clear lack of public policies and programs to assist caregivers of children with intellectual disabilities, and one reason for this is the lack of studies that have explored caregivers' perspectives and experiences caring for a child with an intellectual disability (Sadiki & Mashegoane, 2019). There have been only a handful of policy and general research studies surrounding the perspective of caregivers caring for children with intellectual disabilities.

The most notable was Marsh et al. (2020), who examined the perspectives of fathers of children with intellectual disabilities through a qualitative synthesis review of articles over the last 20 years on a global scale. However, their study was a literature review of international articles to understand Fathers' perspectives through themes and not an actual study of the father's experiences and their policy and programmatic outlook. The paucity of research studies in the last 5 years examining the caregiver's perspective and experience of raising children with intellectual disabilities, especially in an urban setting like Washington, DC, is almost non-existent. This study will help fill the gap in knowledge of the caregiver's day-to-day experience of raising a child with an intellectual disability, in order to help provide recommendations to inform public services, programs, and policies.

Summary and Conclusions

Caregivers should be in every room where decisions about our children are made. It is striking that not many policies and programs are inclusive to caregivers of children with intellectual disabilities. There has been numerous research in the health and education industry—however, there is still a low volume of studies examining public policies to help caregivers care for children with intellectual disabilities. Due to the numerous responsibilities and duties of caregivers, the results of this study can develop and create policies and programs to assist caregivers with multiple social services. Vadivelan et al., 2020 said, “Caregivers of children with cerebral palsy have unique burdens that include poverty, stigmatization, and non-inclusive public policy, which need to be addressed to improve the quality of life of caregivers” (p. 8). This powerful parallel quote exhibits the unique challenges caregivers face accessing public policy and programs to help raise their children with chronic conditions and related disabilities. Chapter 2 showed the literature search strategies and review; local, national and international intellectual and disability related services; caregiver related research studies and the challenges with caregiver inclusive public policies.

This study aims to bring social change by aiding caregivers to access programs to help with the potential burden of raising children with intellectual disabilities through future policy and programmatic development. The methodological approach to achieving this is in greater detail in chapter 3. Though many of the research articles were found during the research for this dissertation topic, there was a common theme found among

many different countries surrounding caregiver stress, burnout, financial assistance, and emotional support.

Chapter 3: Research Method

As mentioned in Chapter 1, the purpose of this study was to understand the experience of raising a child with an intellectual disability and to discover what policies, programs, and services are needed for caregivers of these children in Washington DC. In this chapter, I present the research design. I also discuss procedures, recruitment, methodology, data collection, and issues of trustworthiness.

Research Design and Rationale

This study will be guided by the following research questions (RQ):

- RQ 1: How do Washington DC caregivers of a child with an intellectual disability describe the experience of providing adequate care under the current laws, policies, and programs available to them?
- RQ 2: What policies, programs, or services do Washington DC caregivers of a child with an intellectual disability recommend, that could inform the development of policy changes for caregivers?

To understand the phenomenon of caring for a child with an intellectual disability in the Washington DC area and to inform the development of policy for caregivers of these children, a general qualitative design was used to structure this research. This study was conducted to understand the experiences and perceptions of the caregivers raising a child with intellectual disabilities; however, each caregiver has their own perspective of their experience and their own perception of policy and programs that should be provided for caregivers. Since qualitative designs are rooted in the process of filling in the information gap with new knowledge and understanding that knowledge is rooted in the

individual experience or an individual's truth and how they view the world (Ravitch & Carl, 2021), and given the nature of the relativist-constructivist view, it is appropriate that this study has a general qualitative methodology (Burkholder et al., 2020).

Research Tradition and Approach

Qualitative research is used to explore and investigate people's social interactions, perceptions and how they make sense of the world through their own experiences (Mohajan, 2018). Initially, qualitative research originated from aspects of psychology, sociology, and the natural sciences (Jovanović, 2011). Paul Lazarsfeld advocated for another research approach besides quantitative methods and wanted science to investigate another perspective of the world—a psychological perspective (Bailey, 2014). In qualitative research, it is critical to understand that each person has their own social reality.

The social aspect of qualitative research designs aligns with the social model of disability as a framework for this study. The social model of disability complements the study's qualitative direction to examine the social interaction between the child with an intellectual disability and their caregiver (Dowling & Dolan, 2001). This approach allowed me to capture the human experience through interviewing, which can help explain “why” someone is having a certain experience (Bailey, 2014). Though the data collection process with the participant caregivers, I was able to understand the “what” and “why” of their experience raising a child with intellectual disabilities. Additionally, diverse qualitative approaches are all about investigating human nature and exploring different cultures and how they connect with the world (Potter, 2013). I wanted this study

to connect and show the world a different perspective that is often unknown, shown, or talked about on a large scale. Pauly (1991) described the qualitative process as finding a specific issue to research, develop a research question, gather the data, analyze the data, and then share the results to help tell a story that fills the world with another perspective that the world needs to see and learn from. This study was intended to share the perspectives of caregivers caring for children with intellectual disabilities with the world on how to improve public policies and programs and value them as subject matter experts.

Given the dual-pronged purpose of this study to both explore caregivers' experiences and their perspectives on policy and programmatic recommendations, use of a general qualitative design was more appropriate than other qualitative designs such as a phenomenology or a narrative approach. In a phenomenological approach, the researcher focuses on a specific occurrence in the participants' lives and examines the occurrence through someone else's outlook to gain understanding and knowledge of the occurrence (Worthington, n.d.).

Phenomenological research is used to understand exactly how someone else feels, thinks, operates, and experiences life events (Patton, 2002). While I considered using a phenomenological design because of the focus on "lived experience" (Worthington, n.d., p. 77), the need to also understand the participants' beliefs, opinions, perspectives, and internal/external reflections of an experience and how that relates to culture and humanity (Percy et al., 2015) was necessary in order to answer the second research question about their recommendations on policies and programs. I also considered a narrative

approach—in which the participants would chronicle their stories/experiences from the point of becoming a caregiver with a child with an intellectual disability to the current state of raising their child. According to Creswell et al. (2007), a narrative design depicts an individual's experience over a consecutive period of time. While crafting my research questions and researching caregiver topics, I asked myself what I wanted to know about caregivers raising children with intellectual disabilities. The research questions I am asking do not warrant a narrative approach since the research questions focus on the caregivers' experience, opinions, perspectives, and reflections and are not in an explicit time order (Percy et al., 2015). Moreover, narrative qualitative designs recount the experience in a historical or biographical fashion (Lewis, 2015). While this is a notable approach, it was not the appropriate qualitative design for my study. A general qualitative design is the best fit for this study to examine both the caregivers' experiences and how those experiences can be used to make recommendations for policy and programmatic change.

Role of the Researcher

In qualitative research, it is critical to understand the role of the researcher and how this affects the entirety of the research project. The researcher is the main tool of data collection and analysis (Ravitch & Carl, 2021). As the sole researcher in this project exploring the experiences of caregivers and their recommendations, my role was to serve as the researcher and observer.

Managing Biases

In qualitative research, it is imperative that the researcher examines their own biases. As the caregiver of a child with an intellectual disability, I have direct lived experience that runs parallel with this research, so it was important for me to acknowledge and mitigate my own biases in order to maintain objectivity. One of the recommended ways for a researcher to manage their own biases is with the help of qualitative triangulation. According to Patton (1999), triangulation consists of using multiple techniques to understand and analyze both the data and the researcher's own bias, to ensure the study's validity. Lavee and Itzchakov (2023) recommended three techniques for triangulation: (a) analyzing the participants' interviews—listening intensely to their responses and recording rich, thick descriptions, (b) exploring and comparing current and previous peer-reviewed literature and/or similar studies, and their results, and (c) assessing my own bias through frequent and repetitive journaling.

Assessing my own bias was done through bracketing, which is a process in which the researcher reflects on and acknowledges their own experiences to ensure a trustworthy study (Tufford & Newman, 2012). This was especially helpful after each participant interview. The primary tool I employed during bracketing is journaling, which is a bracketing method that helps with reflexivity and transparency in the study (Korstjens & Moser, 2018). When researchers recognize their own perspectives, experiences, attitudes, and assumptions in the research process, it helps keep them honest to the audience (Ortlipp, 2008). I journaled after each interview to set aside my beliefs and listen to the participant intensely while taking notes, specifically referencing

the answers to the interview questions (Amankwaa, 2016). Journaling can also enable critical self-reflection and help balance out the power dynamic between the researcher and the participants to ensure the researcher shows care, empathy, and compassion toward their participants (Amankwaa, 2016). Since some of the participants' experiences may be overwhelming (Mkabile et al., 2021), protecting the participant was important for them to feel comfortable and safe and also to ensure a smooth conversation in the semistructured interview process.

Use of Incentives

Another ethical consideration that is important to address is the use of a \$25 Visa gift card emailed to participants at the end of the interview completion process. The justification for this decision is that I believe the participants should be compensated for their time and valued as subject-matter experts. Many caregivers are very busy and may have limited time since they are caring for a complex-needed child, and it is critical to value their time since their time may be limited (McKechnie et al., 2018). Since caregivers may have limited time in their day, the gift cards served as an encouragement strategy to help recruit participants and ensure appropriate amounts are given to the participants (Head, 2009). In addition to the gift cards helping recruit the participants, I recognize the ethical and trustworthiness implications of financial compensation.

According to Head (2009), financial incentives should be set to an appropriate amount to help mitigate the appearance of participants being pressured to answer questions in a specific way. Caregivers are a part of the democratic process, and their participation in this study constitutes "socially valuable knowledge" (Gelinis, 2018, p. 770), since this

study will share a perspective that often is not heard in policy and could potentially give public policy stakeholders another outlook on policy that is or is not affecting caregivers. A gift card incentive is a tangible reminder to the caregiver they are a valued member of society and policy stakeholder.

Methodology

Participant Selection Logic

A population is a particular group of people with distinctive traits, and a sample size is an even smaller group of people within that exact population (Casteel & Bridier, 2021). Since this study is using a qualitative design, it is imperative to identify the population or group of individuals (Ravitch & Carl, 2021) and the sampling strategy that used. This study focused on the population of caregivers, and the sample or subset group was selected from caregivers who live in Washington DC and are caregivers of children with intellectual disabilities. Additionally, this particular study is centered around the caregiver, not the child with the intellectual disability; therefore, I used a purposeful sampling technique due to the need for a specific type of participant (the caregiver) to answer the research questions (Ravitch & Carl, 2021).

Selection Criteria

I did not want the definition of a caregiver to be too narrow, which could have the potential to exclude important perspectives and stories that could give insight into how they are experiencing policies and programs raising and caring for a child with an intellectual disability and potentially has great insight into policy and programmatic recommendations to assist the overall caregiver population in Washington DC.

According to Collins and Swartz (2011), a caregiver is a person who provides care and assistance to an individual, usually a family member, who has a chronic or debilitating condition. This could include a grandparent, single parent, two-parent household, mother, father, aunt, uncle, legal guardian, foster parent, adoptive parents, or a family member with legal custody/guardianship. In this study, a caregiver of a child with an intellectual disability could be any of these as long as they are providing care or attending to the requirements of the child with an intellectual disability at least 85% of the time (Johns Hopkins Medicine, n.d.), to ensure the data reflects full-time caregivers.

Potential participants filled out a Google form questionnaire (see Appendix A) to see if they met the criteria to be able to participate in the study. The criteria/questionnaire include the following:

- a current resident of Washington DC
- be 18 years or older
- be a caregiver of a child with an intellectual disability (children ages 3-22).

This age range was selected to align with the Individuals with Disabilities Act (IDEA) criteria for a “Free Appropriate Public Education” (IDEA, Code 300.101), and in Washington DC this is from the age of 3 through 22.

- provide care to the child (who has an intellectual disability) at least 85% of the time

Sample Size

In qualitative research, final sample size is attained at the point of saturation. Saturation is a concept in which the researcher no longer needs to recruit or obtain more

participants after a certain amount of participants has been reached and deemed adequate to obtain data collection—this is rooted in grounded theory, which states that when the researcher completes a coding analysis of each participant’s experience and/or social interactions and there are no new themes or similar groupings of information then saturation has been obtained (Saunders, et al., 2018). Proper identification of saturation is also essential because it reinforces the studies validity and credibility (Rahmi & Khatooni, 2024).

To determine a target sample size, I considered other similar qualitative studies. For example, Aldersey et al. (2020) had a similar study in which they explored the needs of families of children with intellectual and developmental disabilities in Addis Adaba, Ethiopia, and had a 16 family-member sample-size they studied through interviews. In 2016, McKenzie and McConkey had a sample size of 37 South African family caregivers caring for adults with intellectual disabilities through focus groups.

Additionally, Embregts et al. (2021) studied the experiences of mothers caring for children with intellectual disabilities in 2021 (mid-way through the covid-19 pandemic) using semi-structured interviews with five participants as their sample size. For this study and ensuring the data is appropriately analyzed without having unnecessary extra data collection (Saunders et al., 2018), I will plan on a sample size of 10-15 participants. However, the final determinant of sample size for this study is the point saturation is reached.

Instrumentation

In qualitative research, the primary instrument is the researcher for gathering data (Ravitch & Carl, 2021), and the researcher is then responsible for crafting interview. The best way to answer this study's research questions will be through the use of semi-structured interviews—this will enable me to ask open-ended questions, probing questions, and follow-up questions, to make certain the research question is answered. Adeoye-Olatunde and Olenik (2021) highlight many benefits to a semi-structured interview, such as the interview being focused on its specific content while giving the researcher and the participant the flexibility of having a conversation, and the researcher being able to explore more ideas in the conversation that will help answer the research question. This format also allows researchers to highlight experiences that can strengthen the understanding of the participants' experiences (Adeoye-Olatunde & Olenik, 2021).

Interview guides allow researchers to craft specific questions to ask the interviewee and to ensure the interview stays on topic and goes smoothly for the participant, while providing structure (Magaldi & Berler, 2020). For this study I will use a researcher-developed protocol comprised of a semi-structured interview guide to allow for adjustability during the conversation. For example, I can ask the participant to elaborate or explain a specific circumstance that is shared. This method of data collection grants the researcher the opportunity to gather data that will enrich the study and provide more knowledge to assist this population (Kallio et al., 2016).

Interview guides are now a regular mechanism that numerous qualitative researchers use to help support data collection. The questions included in the interview

guide for this study are literature-based and modelled under the study's conceptual framework to help answer each research question. For example, questions like "Describe how caring for your child has affected your family?" or "Tell me about your social experience raising a child with an intellectual disability?" or "Tell me about your financial experiences raising a child with an intellectual disability" or "Do you participate in any current programs that help your family or are you aware of any programs that helps caregivers of children with intellectual disabilities?" are all questions related to the first research question, applying the social model of disability conceptual framework. These questions specifically answer RQ1 by uplifting and exhibiting the caregiver's experience and perspective on raising the child with an intellectual disability. These interview questions also show how the caregiver is directly affected and how the caregiver is functioning in a social construct in the world with the child (Oliver, 1983 & 1990).

The following questions will help answer the second research question regarding the policy and programmatic recommendations by the caregivers. "Do you participate in any current programs that help your family or are you aware of any programs that helps caregivers of children with intellectual disabilities?" also can help answer RQ2 due to the caregiver either knowing or not knowing about specific programs that can lead to certain recommendations. Questions such as "If you had a magic wand, what programs would you create or what programs/policies would you change or recommend?" and "What programs or policies would you like to see implemented?" or "What would make you feel more involved or more engaged in the policy-making process?" or "How important is it

to you to be involved in the policy-making process?” help ascertain the participants’ recommendations to improve policies or programming.

These questions are also guided by critical disability theory, which focuses on how individuals with disabilities are engaged in the civic and policy making process (Siebers, 2008). This theory conjointly can refer to the caregiver that is caring for the child with an intellectual disability (Siebers, 2008), since the caregiver must be engaged in the democratic process as a stakeholder to make recommendations that will benefit the caregiver population. According to Naz and Aslam (2022), sufficiency in data collection is reached when there is plentiful data collected and it is authentic. See Appendix B for the full interview guide with all the interview questions and pre-interview and post-interview checklist.

Content Validity

According to Brod et al. (2014), content validity is an evaluation of the effectiveness and appropriateness of the material that directly affects the participant. Content validity also establishes whether or not the material is a proper reflection of a specific population and encompasses a study’s conceptual framework, research questions and subject matter (Vakil & Jahangiri, 2018). This assures adequate alignment that properly reflects the population being explored in the study. The technique I chose to validate the content within the interview guide was expert validation. Expert validation is used to enhance the study’s credibility with subject matter experts who have direct experience with the study’s population to affirm the sufficiency of the interview questions to answer the research questions (Widodo & Sudiby, 2018). In addition to my

committee, I will consult with a qualitative methodologist, an administrator at a Washington DC school who has direct interaction with caregivers of intellectual disabilities, and a caregiver of a child with a similar disability, to ensure that the interview questions are accessible and appropriate for potential participants. The experts will be asked to examine the interview questions to offer suggestion and feedback to ensure the instrument will answer the research questions (Bord et al. 2014).

Procedures for Recruitment, Participation, and Data Collection

Recruitment and Participation Eligibility

The first step to the identification and recruitment process will be to contact different local partner organizations through an introductory email (see Appendix C) with a flyer attached to the email (see Appendix D) and a social media post (see Appendix E) attached to inform individuals about the study. I will contact organizations in Washington DC such as publicly funded schools that serve children with intellectual disabilities, nonprofit organizations that offer health, education, and services to children with intellectual disabilities, and disability-related community coalitions to inform them of this study and to request they advertise my study by posting the flyer and/or social media post (see Appendix E). Additionally, the flyer will also be physically shared at public libraries in the Washington DC community and will also be shared via my personal social media platforms—Facebook, X formerly known as Twitter, and Instagram.

The recruitment introductory email with the attached flyer will have a general overview of the study and will have a link that will take the participant to the screening questionnaire (Appendix A) to determine the eligibility of potential participants. The link

will also be on the attached flyer and social media posts. Interested participants will go through the screening process via the questionnaire.

Once individuals complete the screening questions and are deemed eligible, then they will be taken to the *Eligibility Met and next steps* section of the Google form (see p.9 of Appendix A), where they will be able to fill out the informed consent form. After consent has been accepted, individuals will be taken to the scheduling section, and select the date and time for their interview and hit the submit button. Then, the prospective participant will be sent an email (see Appendix C), confirming their interview time that includes a calendar invite with the zoom link and information about the study to ensure they have all the information before the interview. In the event there are too few participants recruited for the study then there will be a follow-up plan to expand the geographical area requirement from just participants residing in Washington DC to the greater Washington DC Metropolitan Area (DC, Maryland-MD, Virginia-VA).

If at any point during the screening an individual is deemed ineligible to participate in the study or does not consent, then they will automatically be taken to the *Thank you, ineligible* section (see Appendix A). Those who do continue on to complete the interview will be emailed their \$25 gift card following their completed interview. Participants will also be offered a copy of the study's results when available, to understand how their participation might result in social change and helping shape policies and programs for caregivers in Washington DC.

Data Collection

The semi-structured interviews will be conducted and audio-recorded via Zoom, at a designated time that is agreed upon between the researcher and the participant. Each participant's interview will last between 45 minutes and 1 hour, and will include introductions, ensuring the participant feels comfortable before the interview begins, confirming informed consent is completed, ensuring participants' questions and concerns are addressed by the researcher, and the interview questions.

Per Walden IRB guidelines, participants will only be audio recorded. Subsequently, the interviews were transcribed for data results and analysis purposes, using the transcription functions in Zoom and Grain Intelligence Inc. All the recordings of participants will be stored in a password-protected Google folder and the participants' videos will be labeled Participant A, B, C, D, etc. for confidentiality purposes.

Data Analysis Plan

The data was analyzed using Braun and Clarke's (2021) six-step data analysis process, guided by reflexive and thematic analysis. Reflexive and thematic analysis is the recognition of patterns and themes within the data, to contemplate a deeper understanding of the data (Byrne, 2022). Braun and Clarke (2021) six-step data analysis process is a widely used approach in qualitative methodology due to its fluidity in analysis. The six steps are 1) become aware of the data and take detailed notes, 2) develop a system for coding, 3) search and develop initial themes of data collection, 4) review themes 5) finalize and define the categorization of themes and 6) compose report (Braun & Clarke, 2021). The procedures for each of the steps are detailed in the next section.

Step 1: Become Aware of the Data and Take Detailed Notes

The first step in the six-step data analysis process is becoming aware of the data and taking detailed notes (Braun & Clarke, 2021). Each interview in this study will be transcribed, and I will also be taking detailed notes of my first reactions (Maguire & Delahunt, 2017) on a printed version of the interview protocol. In addition to taking detailed notes, I will be reading the transcripts several times, making additional notes, and paraphrase what each participant said. (Maguire & Delahunt, 2017). This will assist me with organizing the data to understand the perspective of the caregiver as it relates to each of the research questions. Additionally, I will be immersing myself in the data to have thorough understanding of what each participant is conveying.

Step 2: Develop a System for Coding

Coding is a technique that is used in qualitative research to help understand, organize and summarize the data (Maguire & Delahunt, 2017), and I am planning to use multiple layers or rounds of coding: Pre-coding, open coding, and axial coding.

Pre-coding is a form of deductive coding that relates to the information previously obtained through themes and concepts that emerged in the literature (Williams & Moser, 2019). My precoding technique will include identifying specific concepts from the literature review and the conceptual framework (see Appendix F). Then, I will complete a round of coding where I search for participants' words and phrases related to these pre-identified concepts, using different colors to highlight each concept and organize the results in an Excel sheet.

Next, I will conduct two rounds of open coding. One round of open coding, to identify specific words and phrases of concepts that emerge from reading and re-reading the transcripts with me as the researcher (Maguire & Delahunt, 2017; Williams & Moser, 2019). For the second round of open coding, I will be using Nvivo 14 computer software as another form of coding; I will use NVivo 14 to help with coding. NVivo 14 is a computer software program that assists with coordinating and visualizing qualitative data (Lumivero, 2023). NVivo 14 will be a great assistance to help with developing a system for coding the data.

Lastly, in qualitative research, there are possibilities of outliers. Outliers are data points that are collected that are different from the other data points---Outliers can also be defined as unexpected knowledge that researchers did not consider in their hypothesis (Aguinis et al., 2013). If the study has an outlier in the data, then the unexpected knowledge will be highlighted and expounded upon. Additionally, unexpected knowledge may help answer the research questions in a unique way and may help with further recommendations for future studies to help create new knowledge and approaches (Mohrman et al., 2012).

Step 3: Search and Develop Initial Themes of Data Collection

I will begin this third step in the six-step data analysis process by critically examining patterns that emerged from the rounds of coding, and by beginning the process of axial coding to develop categories. Axial coding is the second round of coding in which the codes are put into categories to help identify relationships between the initial words and phrases (Williams & Moser, 2019). As a result, initial themes will arise and

develop throughout examining the data (Maguire & Delahunt, 2017). Themes are labels—a direct result of coding and categorizing the data (Saldana, 2015).

Step 4: Review Themes

In this step I will review the initial themes to determine if they are understandable (Carpendale et al, 2022). It is imperative to review the data to ensure there is a flow of comprehension and that themes answer the research questions. In the process of reviewing the initial themes, Byrne (2022) recommends asking questions such as, Are there subthemes that emerged? Or are there overlapping themes? Are the themes too wide in range? and Do the themes generally make sense? This step ensures the data analysis is going in an appropriate direction and completes the iterative process (Williams & Moser, 2019).

Step 5: Finalize and Define the Categorization of Themes

This is the final step in the iterative process before writing the report. This is the step in which I will finalize each theme, categories, and codes and define how the themes relate to each other. During the pre-coding write-up, there will be an Excel sheet that will have a section that defines each category and also have a column for inter-relation to examine if the categories will have relation to each other (Saldaña, 2015). Furthermore, I will be using the NVivo software to assist with the finalization of the different categories that will be placed in themes.

Step 6: Compose Report

The last step in Braun and Clarke's (2021) six-step process is composing or writing up the report of the thematic analysis of the data. The reporting will be captured

in Chapter 4 in the data collections and analysis, and will include tables, summaries and interview quotes to illuminate the categories and the themes.

Issues of Trustworthiness

According to Lincoln and Guba (1985), trustworthiness in qualitative research is the assurance in one's study's findings—findings that are reliable, objective, and valid. Trustworthiness is comprised of four elements: credibility, transferability, dependability and confirmability.

Credibility

In most cases, credibility is analogous with objectivity in quantitative studies (Lincoln & Guba, 1985). To establish that the data collected is honest and trustworthy, I will be using expert validation and saturation (Connelly, 2016). As previously described, expert validation is a strategy that is used to increase a study's credibility through perspectives from subject-matter and scholarly experts that have experience with a study's particular population to validate the overall methodologies and structure of the study (Widodo & Sudiby, 2018). The next technique that will be used to ensure credibility is the study having an appropriate level of saturation. As, previously stated it is imperative to show that when the data is collected, it reaches a position where no new knowledge will be revealed from data collection (Rahmi & Khatooni, 2024). Through expert validation and proper saturation techniques, this will enhance the validity and credibility for this study.

Transferability

The next element of trustworthiness is transferability. Transferability is a study's relevance and ability to be replicated and compared (Amankwaa, 2016). Transferability is also a component of applicability and appropriateness of a study's findings that can be transferred to another setting (Korstjens & Moser, 2018). The results of this study may be applicable to other populations of caregivers and various situations to researchers studying similar populations since this population will strive to include a diverse set of caregivers to ensure the data is as inclusive and representative of the larger caregiver population as possible.

To provide transferability, relevance, and appropriateness I will be using plentiful, rich, and thick descriptions of data collection to help the reader understand and create a vivid picture of the data (Lincoln & Guba, 1985). Journaling and maintaining records will also include handwritten and typed notes of thick descriptions of the interviews including participants' details of event, participants' tone, details of the caregiver's experience, and initial researcher impressions (Amankwaa, 2016). Therefore, transferability strategies such as journaling and maintaining records to provide rich thick descriptions will enhance external validity and credibility for a more trustworthy study (Korstjens & Moser, 2018).

Dependability

The third element of trustworthiness is dependability. Dependability is a study's ability to show consistent and stable findings over time (Lincoln & Guba, 1985). This study's results will be dependable through use of triangulation and audit trail strategies. Triangulation, as mentioned in Chapter 3, will be conducted by analyzing the

participants' interviews (listening intensely to their responses and recording rich, thick descriptions), exploring and comparing current and previous peer-reviewed literature and/or similar studies, and their results, and lastly, assessing my own bias through frequent and repetitive journaling (Tufford & Newman, 2012). Additionally, throughout this chapter, I have provided a detailed description of the research methods, another way to enhance dependability (Ahmed, 2024). Dependability is the foundation of stability for any study. Triangulation and audit trail strategies will be used to provide external validity and credibility for a trustworthy study (Connelly, 2016).

Confirmability

The last element of trustworthiness is confirmability. Confirmability is a study's capability for others to substantiate or verify data collection and findings so that it may be replicated (Connelly, 2016). Similar to dependability, confirmability can also be established in the study with the use of audit trails. As previously mentioned in the dependability section, audit trails are a strategy that will be used for this study by maintaining records that will chronicle detailed notes, memos, and journaling throughout the data collection process (Amankwaa, 2016). Moreover, confirmability will also be produced in this study via reflexivity—a process to help mitigate biases (Lincoln & Guba, 1985). Reflexivity can be accomplished through reflexive journaling—a technique that researchers use to identify first impressions (Korstjens & Moser, 2018). As a caregiver myself, I must ensure that my first impressions are recorded in the notes to effectively manage and determine any biases that may arise to create a trustworthy study.

Ethical Procedures

Treatment of Human Participants

I did not anticipate any ethical concerns related to recruitment. As mentioned previously in this chapter, the recruitment process focused on contacting different local partner organizations to request their assistance in advertising this study. I used templates provided by the Walden IRB. Participants were provided informed consent during the screening process, as described early in this chapter, once a participant was found eligible to participate in this study.

This study did not use any form of coercion of participants. Additionally, I did not interview individuals that I knew personally or professionally, nor did I intentionally recruit anyone in a vulnerable category as determined by Walden IRB. The risks to participants were minimal—none more than their daily living activities. This research should not pose a greater risk of harm or discomfort than what people commonly encounter in their everyday lives or during standard medical or psychological assessments in this study. It is also important to note that most social-behavioral studies involve some forms of minimal risks, and this study falls into that category of low risk.

The Treatment of Data

Participant identities were protected at all times in the study including the audio recording of interviews. Due to Walden IRB requirements, participants were not video recorded, only audio recorded. The participant interview recordings were labeled in a secure password-protected folder and will be labeled as Participants A, B, C, etc. that was only be accessible to myself as the researcher. Additionally, all handwritten notes

(memos and journaling notes) were locked in a secure file cabinet that only I retained the key for. Even throughout any data dissemination, the participants' identities will remain confidential due to privacy reasons as outlined by the Walden IRB. Furthermore, protections were used such as listing participants by pseudonyms (e.g.: Participant A, B, etc.) to keep the data confidential during the reporting process. After 5 years, all files will be permanently deleted.

Summary

Caregivers of children with intellectual disabilities constitute a significant and impactful population whose perspectives merit thorough exploration. Their stories and experiences hold invaluable insights that can inform the development and refinement of public policies, programs, and services tailored to meet their unique needs. This research study is committed to amplifying their voices and experiences, acknowledging their importance in shaping inclusive and effective interventions.

Chapter 3 explains the methodology and research design employed to capture and convey the caregivers' experience, detailing the procedures for recruitment, ethical considerations, and measures to ensure trustworthiness. Subsequently, Chapter 4: Results and Data Collection examine the outcomes of the aforementioned methodologies and procedures, offering a comprehensive analysis of the insights from the caregivers of children with intellectual disabilities.

Chapter 4: Results

Chapter 4 presents the findings of this study based on in-depth interviews with caregivers of children with intellectual disabilities in Washington, D.C. These caregivers offered insights into their daily experiences, emotional journeys, and the systemic challenges they encounter while caring for their children. Their stories, filled with both hardship and resilience, form the foundation for understanding how public policies and programs impact caregiving families.

The purpose of this study was to explore the lived experiences of these caregivers and assess how existing laws, policies, and services shape their ability to provide adequate care. Guided by the social model of disability (Dowling & Dolan, 2001) and critical disability theory (Siebers, 2008), the study was further designed to elevate caregiver perspectives in shaping public policy. Two central research questions framed the analysis: How do Washington, D.C. caregivers of a child with an intellectual disability describe the experience of providing adequate care under the current laws, policies, and programs available to them? and What policies, programs, or services do they recommend that could inform future policy development?

This chapter is organized to first present the research setting, participant demographics, and data collection process. I then describe the six-step thematic analysis that guided data interpretation, followed by an in-depth discussion of the five major themes that emerged. The chapter concludes with a section on evidence of trustworthiness, outlining the strategies used to ensure the credibility, transferability, dependability, and confirmability of the findings.

Setting

This study was conducted virtually following approval from the Walden IRB (IRB #: 09-04-24-1076417). Upon approval, the recruitment process detailed in Chapter 3 was initiated. All interviews were conducted virtually via Zoom, with only audio recordings captured, in accordance with IRB guidance. A total of 11 interviews were conducted, all from my home office to ensure participant privacy and confidentiality. Interviews were conducted one-on-one using a semistructured interview protocol, and participants were briefed on the purpose of the study, interview structure, and compensation process beforehand. Each participant received a \$25 gift card following completion of the interview. There were no personal or organizational disruptions during the study period that influenced participant involvement or data quality. As such, the conditions under which interviews were conducted supported the credibility and integrity of the research findings.

Demographics

Of the 10 people who completed the study, eight were mothers and two were fathers; no grandparents or other caregiver types were interviewed. There is a total of eight wards in the Washington, D.C. area. Participants represented four of the eight wards (see Table 1). No racial or ethnic demographics were collected, and neither was information on socioeconomic status. While marital status was not explicitly collected, several participants revealed their marital status, and there was a blend of married and single parents in the sample.

Table 1*Participant Demographics*

Participants	Caregiver Type	Ward
A	Mother	Ward 2
B	Mother	Ward 6
C	Father	Ward 2
D	Mother	Ward 3
E	Mother	Ward 3
F	Mother	Ward 2
G	Mother	Ward 1
H	NA	NA
I	Father	Ward 3
J	Mother	Ward 2
K	Mother	Ward 1

Note. Participant H was not eligible to be a participant in this study; NA-Not Analyzed

Data Collection

A total of 11 interviews were conducted; however, only 10 interviews were included in the final analysis. One participant (Participant H) was excluded after it was discovered during the data analysis phase that the child in question did not meet the inclusion criteria of having an intellectual disability. Although the participant initially appeared eligible based on their responses, further probing during the interview revealed the child had a different developmental diagnosis. This decision to exclude was made to maintain the trustworthiness and integrity of the study.

All interviews were conducted virtually via Zoom from my private home office to protect participant confidentiality. Each participant engaged in one Zoom audio-recorded interview, which lasted between 45 minutes to 1 hour. The first 10–15 minutes included a review of the study purpose, reaffirmation of consent, and explanation of the interview process as outlined in the interview guide (see Appendix B). Audio recordings were made

using Zoom's built-in recording feature, and no video was captured, as per IRB guidelines.

There were no significant deviations from the data collection plan outlined in Chapter 3. However, an unusual circumstance occurred during the interview with Participant H. Although the participant completed the screening questionnaire and initially appeared to meet the eligibility criteria, it became evident midway through the interview that their child had a diagnosis of autism rather than an intellectual disability. At the beginning of the interview, it was assumed the child had both autism and an intellectual disability due to the questionnaire response. However, as the interview progressed and questions were asked specifically about the child's intellectual disability diagnosis and related experiences, the participant repeatedly referred only to autism.

To ensure accuracy, I asked for clarification regarding the child's diagnosis, and the participant confirmed that the child had been diagnosed with autism, not an intellectual disability. Given that this was discovered halfway through the interview and a significant amount of time had already passed, I allowed the participant to complete the session. But after careful consideration, I determined that the interview would not be included in the final data analysis, as the participant did not meet the inclusion criteria for the study. This decision was made to uphold the trustworthiness and integrity of the research findings.

Data Analysis

Data analysis is a crucial component of the qualitative research process. Data analysis helps understand the data findings by categorizing the data into themes that help

tell a story (Ravitch & Carl, 2021). As mentioned in Chapter 3, the data analysis for this study was conducted using Braun and Clarke's (2021) six-phase thematic analysis process.

Six-Step Thematic Analysis

Braun and Clarke's (2021) method allowed for a thorough and reflexive process that included: familiarizing myself with the interview transcripts through repeated reading and detailed note-taking, generating initial codes with open coding and second round of coding with the aid of NVivo software, identifying potential themes by clustering related codes, reviewing and refining themes for internal consistency, defining and naming final themes, and producing a narrative report that authentically represents the lived experiences of caregivers. Each phase is discussed in detail below.

Phase 1: Familiarization with the Data

Following the completion of interviews, I engaged in a thorough familiarization process by listening to each Zoom audio recording multiple times and reading the full transcripts closely. Initial notes were taken in my journal during this phase to capture early impressions, potential points of interest, and recurring ideas related to the caregivers' lived experiences. During this phase, my initial impression of the caregivers' experiences was that many caregivers were experiencing overwhelming emotions related to raising their child with ID. Still, there was an overarching impression of love for their children. The caregivers were very adamant about a sense of belonging with their child. This stage laid the foundation for a deeper immersion into the data, ensuring I remained closely connected to the caregivers' narratives throughout the analysis.

Phase 2: Generating Initial Codes

Once familiar with the data, I began an initial round of pre-coding manually. During this pre-coding phase, each interview was first coded using the policy pre-codes (see Appendix F). The policy pre-codes determined were *conceptual framework*, *scholarly literature*, *DC Grandparent Policy*, and *IDEA*. It was imperative that this qualitative public policy-focused study also highlighted the policy codes to help understand how the caregivers' experience can help shape current and future policies. Table 2 presents the total number of policy pre-code references across the 10 interviews. The policy pre-code that was referenced the most was the conceptual framework codes, followed by the scholarly literature review pre-codes (see Appendix F). The codes were enlightening and aligned—the conceptual framework combines how the child's disability affects the caregivers' experiences (Dowling & Dolan, 2001) and the policy/programs recommendations uplift the involvement of the caregiver in the democratic process—critical disability theory (Siebers, 2008).

Table 2

Summary of First-Round Open Coding by Policy Pre-Code Category

Policy Pre-Code Category	Total References
Conceptual Framework Codes – Critical Disability Theory and Social Model of Disability	409
Scholarly Literature Review Pre-Codes – Caregiver Burden, Stress, Policy Gaps, etc.	286
DC Grandparent Program/Policy (Model Policy) – Financial Support, Kinship Care	91
IDEA Policy – IEP, 504 Plans, Transportation, Caregiver Advocacy	66

Note. These pre-code categories were developed from Appendix F during the initial round of open coding and reflect prominent themes that emerged across participant interviews. NVivo software was used to support the coding process and ensure transparency and consistency across data analysis.

After the initial pre-coding phase, a round of open coding was conducted to identify specific words and phrases that emerged from repeatedly reading the interview transcripts (Maguire & Delahunt, 2017; Williams & Moser, 2019). During this phase, I highlighted and bolded words that were frequently repeated across participants, and many captured the emotional tone or depth of the caregivers' experience. Throughout many of the participant interviews there were numerous repetitive words and phrases that tied to the caregivers' emotional state. For example, recurring phrases such as "challenges," "exhausted," "I feel anxious and worry," and "shocked" in response to their child's diagnosis were consistently cited. These emotionally charged terms helped illuminate common patterns in how caregivers processed their experience raising their child with intellectual disabilities.

NVivo was then used to conduct a round of open coding to organize, compare, and refine the initial codes, helping ensure consistency and thoroughness across all transcripts. Both manual coding and computer-assisted coding were cross-referenced to validate code accuracy and minimize bias. NVivo was used to organize and visualize the data, making it easier to identify key patterns, for example, through word frequency across participant narratives (see Figure 1). Figure 1 illustrates the most commonly used words across all interview transcripts. The word frequency analysis was conducted to validate and compare findings from the open coding phase.

Figure 1

NVivo Top 20 Most Frequently Used Words Across Participant Interviews

Word	Count	Weighted Percentage (%)
child	236	1.70
family	140	1.01
support	112	0.80
think	104	0.75
children	94	0.68
time	92	0.66
sometimes	90	0.65
school	85	0.61
things	82	0.59
love	81	0.58
always	72	0.52
therapy	72	0.52
husband	71	0.51
help	69	0.50
kind	69	0.50
feel	66	0.47
daughter	63	0.45
try	63	0.45
challenges	61	0.44
disability	60	0.43
going	60	0.43
people	59	0.42
care	58	0.42
make	57	0.41
emphasized	56	0.40

Note. This figure displays the highest frequency terms generated through NVivo’s word frequency query. Words such as “child,” “family,” “support,” and “children” appeared most often across transcripts, reinforcing core themes related to caregiving roles, emotional impact, and the centrality of family dynamics in the experiences of caregivers raising children with intellectual disabilities.

As described previously, open coding allowed for the manual identification of frequently repeated words and phrases, such as “challenges,” “exhausted,” “I feel anxious and worry,” and “shocked.” These terms revealed key emotional undercurrents in the caregivers’ narratives. Interestingly, the NVivo-generated list confirmed several of these insights. For instance, high-frequency terms such as *child* (236 mentions), *family* (140

mentions), *support* (112 mentions), and *children* (94 mentions) closely aligned with the themes identified through manual coding. These results reinforced the importance of caregiving dynamics, emotional labor, and family-centered experiences in the participants' accounts. This triangulation between manual coding and NVivo's automated analysis added an additional layer of credibility to the emergent themes, affirming both the emotional and relational aspects of caregiving for children with intellectual disabilities.

Phase 3: Searching for Themes

Following the generation of initial codes, I grouped similar codes together to begin identifying broader patterns of meaning. Codes that shared conceptual similarities were clustered to form potential themes and subthemes. NVivo's query and visualization features, such as word clouds and code trees, supported the exploration of connections between codes. This phase involved moving from codes to candidate themes that could represent significant aspects of caregivers' experiences across the data set. Figure 2 shows a synthesized version or a word cloud of the caregiver codes based on NVivo coding participant interviews. In addition to Figure 2, NVivo also produced the following number-coded tree to visualize the codes to continue the process of exploring themes, which can be seen in Figure 3.

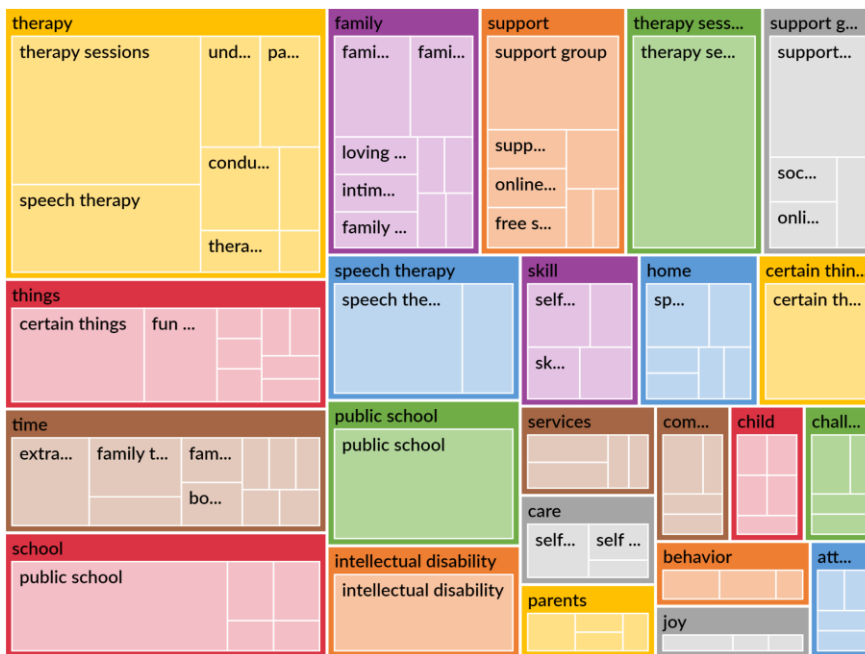
Figure 2

NVivo Word Cloud



Figure 3

NVivo Coding Chart



Note. Figure 3 shows a color and number-based coding chart based on NVivo Coding for Participant Interviews

Phase 4: Reviewing Themes

The candidate themes were then reviewed for coherence, internal consistency, and relevance to the research questions. I engaged in a recursive process of refining and adjusting themes, ensuring that each theme accurately reflected the data and that there was a clear distinction between themes. During this phase, some initial themes were collapsed, split, or discarded as needed. The finalized set of themes captured the richness of the caregivers' experiences while avoiding unnecessary overlap or redundancy.

Phase 5: Defining and Naming Themes

Each theme was clearly defined, refined, and named to succinctly capture the core essence of the caregiver experiences they represented. Participants' words were used to create evocative theme names that captured the essence of the data. Detailed descriptions were developed to articulate how each theme connected to the broader research objectives. Where appropriate, subthemes—such as caregiver burnout, fear, and persistent challenges under the emotional weight of caregiving—were identified to provide greater nuance and depth within the overarching thematic structure.

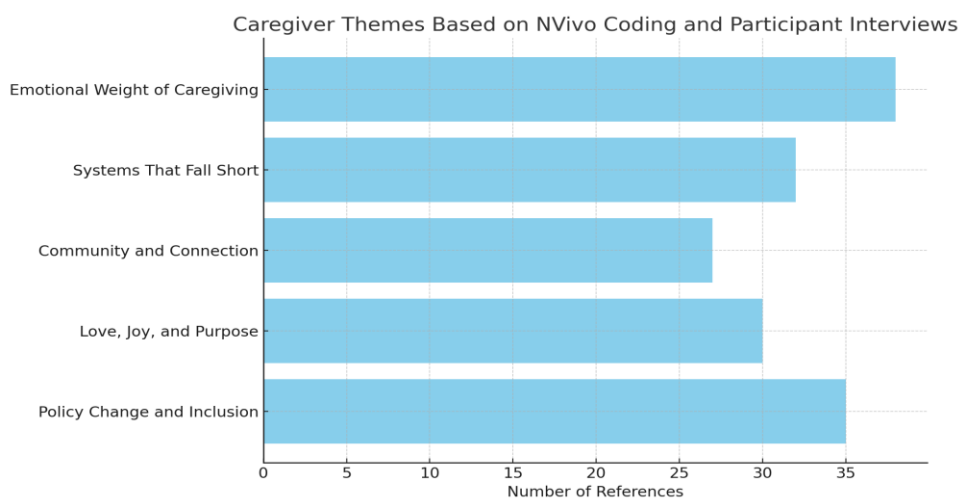
The five final themes that emerged were: (a) emotional weight of caregiving, (b) systems that fall short, (c) community and connection, (d) love, joy, and purpose, and (e) policy change and inclusion. These themes are not only grounded in participant narratives, but also reflect the conceptual framework guiding this study.

As shown in Figure 4, the bar graph visually represents the number of coded references associated with each theme based on NVivo analysis. This visual comparison reinforces the centrality of these themes in caregivers' experiences, with the emotional

weight of caregiving and policy change and inclusion being the most frequently referenced. Together, these themes offer a comprehensive and emotionally resonant portrayal of the caregiving journey for children with intellectual disabilities.

Figure 4

Caregiver Themes based on the number of references in NVivo Coding



Phase 6: Producing the Report

In the final phase, vivid excerpts from participant interviews were selected to illustrate each theme and subtheme. These excerpts were carefully chosen to reflect the diversity and complexity of participants' experiences. A coherent narrative was developed to present the themes in alignment with the study's research questions and conceptual framework. The findings were organized to provide a logical, rich, and compelling account of caregivers' lived experiences.

Evidence of Trustworthiness

In qualitative research, trustworthiness is essential to ensuring that findings accurately and authentically represent participants' lived experiences. As outlined by

Lincoln and Guba (1985), trustworthiness is established through four key components: credibility, transferability, dependability, and confirmability. During the data collection and analysis phases of this study, each of these elements was intentionally upheld to maintain the rigor and integrity of the research. Strategies such as expert validation, rich and thick description, triangulation, audit trails, and reflexive journaling were employed to support these efforts.

As both a researcher and a caregiver of a child with an intellectual disability, I approached this work with a deep personal understanding of the complexities involved. Reflexivity and transparency were central to the process, ensuring that my interpretations remained grounded in the participants' voices rather than my own assumptions (Korstjens & Moser, 2018). The following section outlines how each dimension of trustworthiness was implemented throughout this study.

Credibility

To enhance credibility, I implemented the strategies described in Chapter 3, including expert validation and ensuring data saturation. Prior to data collection, I consulted with subject-matter and scholarly experts familiar with the experiences of caregivers of children with intellectual disabilities. Their feedback validated the methodological design and ensured cultural and experiential alignment with the target population (Rahmi & Khatooni, 2024). During analysis, I confirmed saturation was achieved by identifying recurring themes and noticing when no new information was emerging across participant narratives. Additionally, credibility was strengthened by excluding data from Participant H, whose experience did not align with the study's

inclusion criteria. This decision preserved the integrity and trustworthiness of the findings by ensuring consistency and relevance in the data analyzed.

Transferability

To support transferability, I employed rich, thick descriptions throughout the data collection and analysis process. Interview transcripts captured not only participant responses but also contextual cues such as tone, emotion, and caregiver circumstances (Amankwaa, 2016). I maintained handwritten and typed notes that included detailed observations and initial researcher impressions, offering a vivid picture of each participant's experience. These descriptions allow future researchers to determine the applicability of the findings to similar populations or caregiving contexts (Amankwaa, 2016). By including a diverse sample of caregivers from varied geographic and socioeconomic backgrounds within Washington, D.C., the study enhances its potential relevance to broader caregiving populations.

Dependability

To ensure dependability, I used methodological triangulation and an audit trail. Triangulation was implemented through a multi-step analysis process that included cross-referencing participant narratives with current peer-reviewed literature, researcher journals, and analytic memos (Ahmed, 2024; Molefe et al., 2022; Sanderson et al., 2025). This approach strengthened the consistency and reliability of the emergent themes by drawing from diverse sources of insight. These strategies align with recent qualitative policy studies that emphasize the importance of triangulation in capturing the multifaceted nature of caregiving for children and adults with intellectual and

developmental disabilities. The audit trail—comprised of coding records, reflective journaling, and memo writing—provided transparency throughout the research process and supported the confirmability and replicability of the findings.

Confirmability

Confirmability was supported through the use of reflexivity and audit trail strategies. I maintained a reflexive journal throughout the study to record personal reflections, reactions, and potential biases related to my dual role as both researcher and caregiver (Korstjens & Moser, 2018). This practice helped distinguish participant voices from my own interpretations, ensuring that findings were grounded in the data (Connelly, 2016). The audit trail further substantiates the trustworthiness of the study by documenting the progression of analytic decisions, data interpretation, and methodological choices. Together, these measures enhance the objectivity and confirmability of the study's conclusions.

Results

Raising a child with an intellectual disability is no simple task—it is a journey marked by resilience, sacrifice, and deep love. These sentiments were echoed by participants in this study, whose narratives reflected moments of pride and laughter, as well as raw vulnerability, frustration, and exhaustion.

Caregivers—ranging from married to single parents, across various socioeconomic backgrounds—spoke candidly about their day-to-day realities, their hopes for their children, and their recommendations for improving support systems. Despite their challenges, the overwhelming tone across interviews was one of love and

commitment. What follows is an in-depth analysis of the themes that emerged from these narratives, organized by the two guiding research questions of this study.

Theme 1: The Emotional Weight of Caregiving

Caregivers in this study consistently described their journeys as emotionally demanding and deeply overwhelming. The weight of navigating complex educational and health systems—while managing daily caregiving responsibilities—often left them feeling isolated and exhausted. Participant A shared, “We felt overwhelmed. You know, that feeling of responsibility,” capturing a sentiment echoed by many.

For some, the emotional toll began at the point of diagnosis. Participant C recalled, “When I first found out about my [child’s] diagnosis, I was really overwhelmed. I didn’t believe that this could actually happen to my child.” Beyond the emotional strain, the financial burden also emerged as a significant stressor. As Participant E explained, “...the financial burden, you know, because of therapy, special education, medical bills, all those things, is actually challenging financially.”

These reflections resonate with the principles of the social model of disability, which frames disability-related stress not solely as a result of the diagnosis, but as a consequence of inadequate societal and systemic responses (Dowling & Dolan, 2001). The emotional weight expressed by participants underscores this model, emphasizing that the child’s disability has a direct social, emotional, mental, and physical effect on the caregiver. This theme directly addresses Research Question 1 and reinforces the SMD’s focus on how intellectual disability shapes the caregiver’s experiences, perspectives, and evolving sense of identity.

Theme 2: Systems That Fall Short

Another central theme that emerged was the persistent inadequacy of systems intended to support children with intellectual disabilities and their families. Caregivers spoke candidly about their struggles navigating public schools, healthcare, and community-based services—systems that often fell short of meeting even the most basic needs. These gaps in institutional support frequently required caregivers to become relentless advocates, resource seekers, and decision-makers, taking on roles well beyond what should be expected of families.

Participant G shared, “My child wasn’t able to get the behavioral support in class. So, the teacher and I had to suggest homeschool,” highlighting the painful reality that when schools fail to provide appropriate services, families are forced to make drastic decisions. Participant I added, “We had to find our own therapy because it was hard navigating the whole process and hard for us to understand,” while Participant J reflected, “We’re worn out. We have spent lots of money trying to find resources and therapy services.” These experiences underscore a recurring pattern of systemic neglect, where caregivers are left to navigate fragmented supports on their own.

This theme aligns with the social model of disability, which critiques the ways that institutional structures contribute to the disabling of individuals through exclusion and inaccessibility (Dowling & Dolan, 2001). It also resonates strongly with critical disability theory, which demands not only individual accommodations but structural change and accountability within public institutions (Siebers, 2008).

The voices of caregivers in this study illuminate how these systemic failures shape their everyday realities, reinforcing that the challenge is not the disability itself, but the inadequacy of systems to equitably respond to it.

Moreover, this theme speaks directly to Research Question 1, offering a deeper understanding of how caregivers' experiences, perspectives, and identities are shaped by their child's intellectual disability. It also sets the stage for themes 3 and 5, where caregivers offer powerful policy and programmatic recommendations for transforming the very systems that have failed them.

Theme 3: Community and Connection

For many caregivers, support groups emerged as an essential source of strength, healing, and solidarity. These spaces offered far more than just practical resources—they provided emotional validation, a sense of shared understanding, and, perhaps most importantly, the reassurance that caregivers were not alone in their journeys.

Participant C reflected on this impact, stating, "Support groups helped me realize I'm not the only one going through this." This sentiment was echoed by others who not only valued these communities but also recommended their expansion. Participant B shared, "Make resources for parents...provide workshops that help them to navigate through their challenges and also advocate effectively for their children." Similarly, Participant K emphasized the need for mental health-specific spaces, stating, "There should be more support groups for parents dealing with depression and anxieties".

This theme aligns closely with critical disability theory, which emphasizes the importance of community, inclusion, and collective identity in navigating the structural

barriers imposed by ableism (Siebers, 2008). Additionally, Theme 3 also answers RQ2 with various programmatic recommendations to assist caregivers. For example, caregiver support groups became spaces where their voices were affirmed, their realities were acknowledged, and their advocacy work was strengthened through shared knowledge and mutual support. These groups fostered a sense of civic belonging—transforming isolation into empowerment—a powerful programmatic recommendation.

Theme 4: Love, Joy, and Purpose

Amid the emotional, financial, and systemic challenges of caregiving, another theme stood out as both grounding and uplifting: the joy, purpose, and deep love caregivers felt for their children. Despite the hardships, participants consistently expressed that their children were a source of strength, growth, and meaning. This theme disrupts the deficit-centered lens so often associated with disability care, reminding us that the caregiving experience is as much about resilience and love as it is about navigating barriers.

Participant D captured this sentiment simply but powerfully: “Have patience, and be loving, no matter the situation.” Others spoke to the emotional strength that emerges in the face of adversity. As Participant A shared, “Even in the face of uncertainty, they should always try to find strength.” Participant B added, “We’ve learned to appreciate the little things and every victory,” reflecting the daily triumphs and moments of joy that can easily be overlooked in policy or academic discourse.

These reflections humanize the caregiving experience and affirm the importance of recognizing not just the burdens, but also the *strengths* of families raising children

with intellectual disabilities. In addition, to answering Research Question 1, this theme also aligns with critical disability theory (Siebers, 2008). This theme underscores the need for policies and supports that honor the full spectrum of caregiving—not only the challenges, but also the love, purpose, and dignity found within it.

Theme 5: A Call for Policy Change and Inclusion

Throughout the interviews, caregivers offered thoughtful and specific recommendations for public policies and programs that could better support families like theirs. These suggestions reflected more than individual needs—they revealed a call for structural transformation. Caregivers repeatedly emphasized that those with lived experience must be included in the design, implementation, and evaluation of policies that directly impact their families. Their responses highlight the importance of recognizing caregivers not only as advocates, but as experts whose insights are essential to meaningful change.

Participant F shared, “The government could, you know, help out parents who has children with disabilities. It would really be helpful for parents who don’t have the financial ability,” underscoring the need for direct support and equity-driven policy solutions. Participant G echoed this sentiment, adding, “Make resources for parents, maybe provide workshops or support groups that helps them to navigate through their challenges and also advocate effectively for their children with disabilities.”

This theme directly addresses Research Question 2, which explores caregivers’ policy and program recommendations, and strongly affirms critical disability theory’s emphasis on participatory democracy and systemic accountability (Siebers, 2008). It also

aligns with Dowling and Dolan's (2001) framing of caregivers as community leaders whose perspectives must shape the environments in which they raise their children. Caregivers in this study were clear: they are not simply navigating broken systems—they are actively envisioning what justice and inclusion should look like.

Summary

The results of this study provide meaningful insight into the caregiving experiences of individuals supporting children with intellectual disabilities in Washington, D.C. In response to Research Question 1, caregivers described emotional, financial, and systemic burdens that often stemmed not from their child's diagnosis alone, but from inadequate support across education, healthcare, and social services. These findings align with the social model of disability, which highlights how structural barriers often exacerbate caregiving challenges (Dowling & Dolan, 2001).

In response to Research Question 2, caregivers proposed actionable policy recommendations including mental health support, caregiver peer groups, and financial relief programs. Their suggestions mirror recent scholarship calling for holistic, family-centered supports and fair compensation for caregivers. Moreover, participants called for greater inclusion of caregiver voices in decision-making processes—underscoring critical disability theory's emphasis on participatory justice and disability advocacy (Siebers, 2008). Chapter 5 will interpret these findings in the context of existing literature, examine their implications for public policy, and offer recommendations for practice, advocacy, and future research.

Chapter 5: Discussion, Conclusions, and Recommendations

This final chapter presents an interpretation of the study's findings, grounded in the lived experiences of caregivers raising children with intellectual disabilities. The purpose of this general qualitative study was to understand the lived experiences of caregivers raising children with intellectual disabilities in Washington, D.C. and to identify the policies, programs, and services needed to better support them. This study was conducted to amplify caregiver voices and explore how current systems and structures either support or hinder their ability to care for their children.

The findings revealed five core themes: (a) the emotional weight of caregiving; (b) systems that fall short; (c) the importance of community connection and support groups; (d) love, joy, and purpose found in caregiving; and (e) a call for policy change and inclusion. These themes are deeply rooted in the conceptual frameworks of the social model of disability (Dowling & Dolan, 2001) and critical disability theory (Siebers, 2008), which together emphasize that the barriers faced by caregivers are often shaped more by inaccessible systems than by the child's disability itself.

This chapter will present the interpretation of these findings in light of existing literature and theory, discuss the implications for practice and policy, offer recommendations for future research, and address the study's limitations. Ultimately, this research aims to contribute to a more equitable and inclusive approach to disability caregiving by centering the expertise and experiences of those most directly impacted—the caregiver.

Interpretation of the Findings

The study's findings confirm, extend, and complicate existing research on caregiving for children with intellectual disabilities, offering critical insight into how systemic barriers, institutional neglect, and intersecting oppressions shape the caregiving experience. Each theme—ranging from emotional burden to calls for policy reform—mirrors key patterns found in the literature, while contributing new, localized understandings rooted in D.C.'s policy context. Together, the findings highlight how caregivers are not only navigating the demands of disability care but are also resisting and adapting to systems that often fail to support them.

Findings in Relation to the Literature

The theme of emotional weight of caregiving supports a growing body of research highlighting the emotional distress, exhaustion, and role overload experienced by caregivers (Hussain & Raihan, 2022; Riches et al., 2023). Participants described balancing multiple roles—parent, advocate, case manager—with limited institutional support. These findings confirm earlier international studies that outline the persistent mental and emotional toll of caregiving in under-resourced environments.

The theme noted that systems that fall short aligns closely with the findings of Molefe et al. (2022), who developed a support framework in South Africa based on the reality that caregivers often operate in silos. In this study, caregivers described gaps across educational, medical, and government systems, and a deep frustration with the lack of cross-agency coordination. Similarly, Sanderson et al. (2025) emphasized that

caregivers—especially those supporting individuals into adulthood—often lack streamlined, comprehensive supports, a challenge mirrored in this study’s data.

Caregivers’ experiences of having to self-educate and become “accidental experts” resonate with findings from Modula and Chipu (2024), who identified information and knowledge sharing deficits as a significant challenge in caregiving. In both studies, families expressed a deep need for timely, accessible, and relevant information, suggesting a broader issue in caregiver communication and training.

The theme “community and connection” reinforces the importance of relational support in the caregiving experience. Riches et al. (2023) observed that peer networks often fill the void left by formal systems. Similarly, participants in this study found comfort, practical advice, and validation through support groups, church communities, and peer mentors.

The theme “love, joy, and purpose” builds on Ahmed’s (2024) framing of qualitative research as a site of strength and resilience. Caregivers in this study shared the joy and pride they feel in their children’s personalities, milestones, and relationships. This dimension adds emotional complexity to the caregiving narrative, challenging purely deficit-oriented accounts of disability (Ahmed, 2004; Siebers, 2008).

Finally, the theme “a call for policy change and inclusion” echoes the advocacy-oriented recommendations found in Sanderson et al. (2025) and Riches et al. (2023). Participants called for actionable changes such as dedicated caregiver supports, more inclusive educational placements, and alternative diploma pathways—demands that reflect an increasing push for caregiver-informed policy transformation.

Interpretation Through the Conceptual Framework

In addition to the literature validating this study, the conceptual framework guided the data analysis and interpretation process. The social model of disability (Dowling & Dolan, 2001) and critical disability theory (Siebers, 2008) are deeply embedded in the study's findings. Caregivers did not view their child's intellectual disability as the main limitation (Dowling & Dolan, 2001). Instead, they identified exclusionary practices, systemic inefficiencies, and barriers as the true sources of difficulty (Siebers, 2008). Their stories underscore the social model of disability premise that disability is constructed through inaccessible environments and inflexible institutions—the caregiver is socially affected by the child's disability and has found the system to be challenging to navigate and not “easily” accessible (Dowling & Dolan, 2001).

Similarly, the findings reflect the tenets of critical disability theory (Siebers, 2008), which centers power, access, and systemic inequity. Many caregivers discussed how disability intersects in discriminatory ways—particularly when navigating public school systems, the health care system, or mental health support. Their lived experiences illustrate the ongoing marginalization of disabled children and their families within governmental systems (Siebers, 2008). Importantly, their advocacy—through calls for diploma reform, community-based solutions, and mental health supports—demonstrates a collective push toward justice, agency, and structural accountability.

Limitations of the Study

While this study provides important insights into the lived experiences of caregivers of children with intellectual disabilities in D.C., several limitations must be

acknowledged. First, the sample size was relatively small and limited to caregivers residing in Wards 1 through 6. As a result, the findings may not fully reflect the experiences of caregivers in the entire city—Wards 7 and 8, unfortunately were not represented in this study. These communities continue to face systemic and well-documented socioeconomic inequities (DC Policy Center, 2021). This gap is further addressed in the recommendations section, where the need for future research in these wards is discussed. This geographic gap limits the study’s generalizability across the full spectrum of caregiving experiences in D.C.

Second, participation was voluntary and relied on community-based recruitment, which may have introduced self-selection bias. Caregivers who were more engaged with advocacy networks or who had the capacity to participate may differ from those who are more isolated, under-resourced, or too overwhelmed in their daily lives, potentially skewing the data toward those with more access or support.

Finally, as a qualitative study, the findings are not intended to be statistically generalizable. Rather, they offer a deep, contextual understanding of a specific group of caregivers at a specific moment in time (Ratvich, 2021). Nonetheless, these limitations present opportunities for future research to broaden and diversify the sample, particularly among underrepresented wards and marginalized caregiving populations.

Recommendations

Given that all participants in this study resided in Wards 1–6, in the District of Columbia, it is critical to consider the stark socioeconomic differences between these wards and those located East of the Anacostia River—specifically Wards 7 and 8.

Median household income in Ward 8 is approximately \$50,855, and \$69,109 in Ward 7, compared to \$93,284 in Ward 1, \$102,214 in Ward 6, and \$122,680 in Ward 3 (Census Reporter, 2023; DC Health Matters, 2025). Similarly, educational attainment varies widely: while approximately 23.5% of adults in Ward 8 hold a bachelor's degree or higher, that figure reaches nearly 60% in wealthier wards such as Ward 3 (DC Policy Center, 2021).

These disparities illustrate the need to replicate this study in Wards 7 and 8, where residents face greater economic hardship, lower access to higher education, and presumably increased caregiving burdens. One can hypothesize that if participants of this study from socioeconomically healthier wards already experience emotional, mental, and financial stress due to caregiving, then the weight on caregivers in communities furthest from opportunity may be even more significant. Uplifting the voices of caregivers in Wards 7 and 8 is essential to understanding and addressing these layered inequities and reaching caregivers across the District of Columbia.

The second recommendation emerging from this study is a targeted policy response to address the financial burdens experienced by caregivers of children with intellectual disabilities. Almost all participants shared the emotional, mental, and financial toll of caregiving, including having to decrease work hours or leave employment altogether to manage their child's needs, and experienced increased medical, therapeutic, and educational bills. These findings support the need for a financial assistance policy specifically for primary caregivers of children with intellectual and/or other related disabilities.

A promising policy model that can be used as a template is the District of Columbia’s *Grandparent and Close Relative Caregiver Subsidy Program* which provides monthly financial assistance to grandparents and close relatives raising children, without interrupting their eligibility for other state and federal benefits such as Temporary Assistance for Needy Families (TANF) or Supplemental Security Income (SSI) (D.C. Child and Family Services Agency, 2023).

I highly recommend that a similar caregiver-centered DC local policy be developed to provide flexible financial support to families raising children with disabilities. This recommendation aligns with recent national calls to action to recognize the financial burden of unpaid caregiving labor and to prevent families from experiencing a “benefits cliff” (National Council on Disability, 2023, that forces them to choose between insufficient support and losing vital assistance (National Council on Disability, 2023).

Policymakers must ensure that this economic support is not disruptive to existing benefits, accessible across income levels, and responsive to the long-term demands of caregiving. Implementing such a policy would not only promote economic justice and wealth for the families but also affirm the essential role of caregivers within the disability ecosystem—particularly in under-resourced communities like Wards 7 and 8, where caregiving demands are often compounded by systemic socioeconomic inequities (Siebers, 2008).

In addition to public policy recommendations, this study also offers guidance for public administration to ensure the implementation of programs that effectively support

caregivers. Participants emphasized the importance of building stronger community connections. As such, I recommend partnerships with community-based organizations to create and sustain caregiver support groups for families of children with intellectual and related disabilities—helping them feel more connected, supported, and less isolated in their journey.

The last recommendation is to build more community for caregivers, such as support groups and caregiver navigators. The support groups and caregiver navigators could be provided by Community-Based Organizations. This study revealed that many caregivers wanted more peer- to -peer support with other caregivers. While some were already in connected neighborhood groups, many stated that there are no formal support groups designated for caregivers as a whole around the city.

Even though this study is focused solely on caregivers of children with intellectual disabilities, these results bring up many questions about how other caregivers are experiencing daily life raising their children with other similar disabilities, such as autism, developmental delays, cerebral palsy, etc. In Chapter 2, the literature review began with limited research on articles that contained studies with caregivers of children or individuals with intellectual disabilities. But, due to the limited amount of both qualitative and policy research, the search was widened to include caregivers of children with autism, developmental delays, and/or cerebral palsy. One could make an educated guess about the daily life these caregivers are experiencing. Therefore, there may need to be more policy and programmatic support for caregivers of children with disabilities in

general, and this should be implemented by an office that includes human and health services programs specifically for caregivers and the children.

Implications and Positive Social Change

This study affirms the power of storytelling and research as tools for social change—particularly for caregivers raising children with intellectual disabilities. By centering their lived experiences, this study brings attention to the realities too often ignored in public discourse, policy development, and academic literature. These voices are not only valuable, they are necessary to shaping inclusive systems that reflect the full spectrum of caregiving labor, love, and resilience. In doing so, this research contributes to a growing movement within disability advocacy that recognizes caregivers as part of the broader disability community and as key agents of change within it.

Beyond the lived experiences of the participants, this study carries important methodological, theoretical, and empirical implications for social change. Theoretically, it draws from the social model of disability (Dowling & Dolan, 2001; Oliver, 1990), which reframes disability not as an individual deficit, but as a condition shaped by systemic barriers. Oliver (1990) powerfully noted that “disability is defined by public policy” (p. 78), pointing to the intersection of social structures, disability, and the need for policy reform. By including the perspectives of caregivers within this framework, the study challenges systems to become more inclusive—not only of disabled individuals but of those who provide critical daily care.

As previously stated in Chapter 1, this study is grounded in critical disability theory (Siebers, 2008), which demands that we interrogate the systems and structures that

have historically excluded caregivers—particularly those raising children with intellectual disabilities—from democratic participation and public policymaking. From a social change perspective, this exclusion is not merely a gap in representation; it is a structural injustice that must be addressed. By documenting the compounding emotional, financial, and social burdens caregivers face, this research helps fill a long-standing empirical gap and positions their experiences as central to any conversation about equity and reform.

Methodologically, this study affirms the transformative power of qualitative inquiry in surfacing the lived realities of those too often invisible in data-driven decisions. Caregivers are not passive recipients of systems—they are frontline experts whose insights are essential to building public policies that are not only inclusive, but just. In this way, the study actively contributes to a more democratic, humane, and socially responsive framework for disability justice.

Conclusion

“The time has come to recognize the rights for caretakers” (Leakes, 2019, p. 736). This is the message that resonates with the participants of this study. Therefore this study stands as both a love letter and a call to action—a declaration that caregivers of children with disabilities deserve to be seen, heard, and respected not just in private spaces but in the halls of power, where policies are shaped and futures are decided.

Caregivers are not asking for pity—they are demanding partnership. They are not burdens on the system—they *are* the system’s backbone. They are educators, nurses,

therapists, advocates, and above all, parents doing everything in their power to give their children a meaningful life in a world that often overlooks them.

We must do more—as policymakers, as practitioners, and as a society—to center caregivers in the democratic process, not as an afterthought, but as co-creators of the policies and services that directly impact their lives and their children’s futures. Their lived experiences are not anecdotal—they are expertise.

This research is a beginning, not an end. It is a reminder that when we uplift caregivers, we strengthen families, schools, and entire communities. Caregivers are powerful, resilient, and worthy of more. It is time the systems around them reflect that truth.

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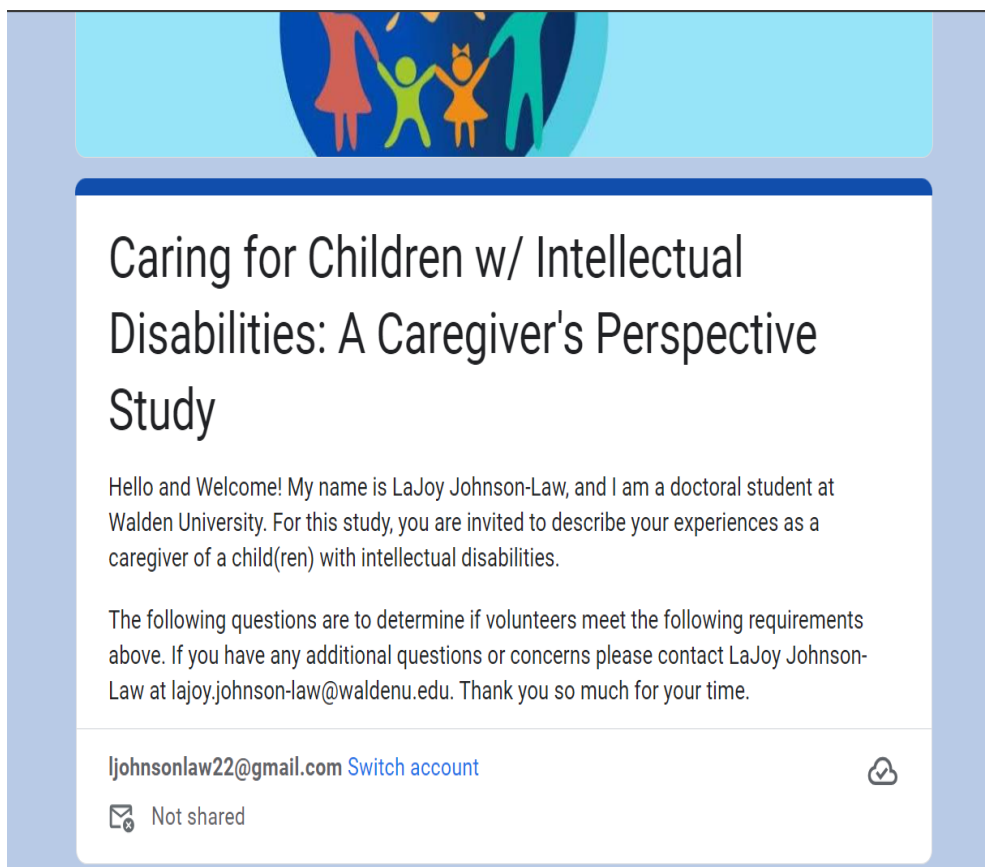
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Appendix A: Screening Questionnaire

The screening questions are in a Google Form to make it easier for participants to fill out.

The link takes participants to the Google Form. Screenshots are provided in Appendix A.

Page 1



Page 2

Caring for Children w/ Intellectual Disabilities: A Caregiver's Perspective Study

ljohnsonlaw22@gmail.com [Switch account](#)

Not shared

* Indicates required question

Age Determination

Are you 18 years old or older? *

Yes

No

[Back](#) [Next](#) [Clear form](#)

Never submit passwords through Google Forms.

*Disclaimer: If a participant selects “no” at any time during the responses, they will be taken to this page (**thank you - ineligible page**) and exit the survey. Please note that if a participant says no to any of the screening questions, then this screen will appear.

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Thank You

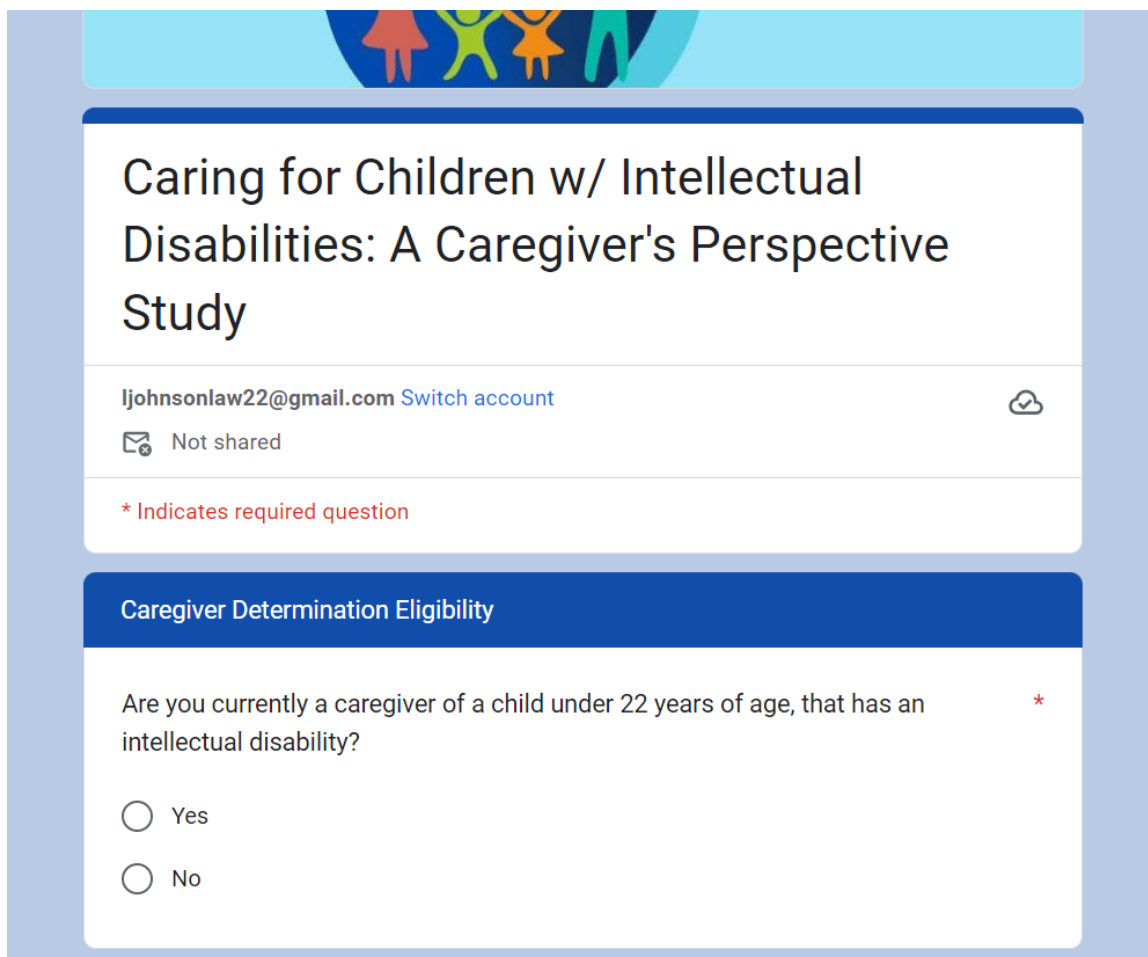
Thank you for taking out time in your busy schedule to complete this questionnaire for this study. Unfortunately, you do not meet the volunteer requirements but appreciate your interest. If you know anyone that would want to participate in the study, please share the study flyer or social media post. Thank you. Have a great day. Please hit the submit button. We may be able to contact you for a future opportunity. Thank you.


[Back](#) [Submit](#) [Clear form](#)

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***For the remaining pages, the screenshots and presume the participants selected the “yes” response for all responses.**


Page 3





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* Indicates required question


Caregiver Determination Eligibility

Are you currently a caregiver of a child under 22 years of age, that has an intellectual disability? *


Yes


No

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Caregiver Determination Eligibility Continued...

Do you provide care to the child (that has an intellectual disability) at least 85% of * the time?


Yes


No

[Back](#) [Next](#) [Clear form](#)



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Residency Determination

Do you currently reside in the District of Columbia (D.C.) ? *

Yes

No


Back


Next

Clear form

Note: This is the eligibility determined page, once a potential participant has met all the eligibility requirements to potentially participate in the study.

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* Indicates required question

Eligibility Met

Thank you, you meet the volunteer qualifications for this study. The following section will take you through informed consent, compensation and next steps. Thank you so much!

*

Informed Consent

You are invited to take part in a research study that will better understand the experiences and perspectives of caregivers of children (ages 3-21) with intellectual disabilities that could help better understand their experiences to help

You can ask questions of the researcher by emailing lajoy.johnson-law@waldenu.edu. If you want to talk privately about your rights as a participant or any negative parts of the study, you can call Walden University's Research Participant Advocate at 612-312-1210. Walden University's approval number for this study is **IRB will enter approval number here**. It expires on **IRB will enter expiration date**.

You might wish to retain this consent form for your records. You may ask the researcher or Walden University for a copy at any time using the contact info above.

Obtaining Your Consent


If you feel you understand the study and wish to volunteer, please indicate your consent below by clicking the "yes, I consent" option.

Yes, I consent


No, I do not consent


Back
Next
Clear form

*Disclaimer: If a participant selects **“No, I do not consent”** at any time during the responses, they will be taken to this page and exit the survey. Please note that if a participant says **no** to any of the screening questions, then this screen will appear.



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Thank You

Thank you for taking out time in your busy schedule to complete this questionnaire for this study. Unfortunately, you do not meet the volunteer requirements but appreciate your interest. If you know anyone that would want to participate in the study, please share the study flyer or social media post. Thank you. You do not have to hit the Submit button, please close this browser.

[Back](#) [Submit](#) [Clear form](#)

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* Indicates required question

Next Steps (Compensation and Schedule of Interview)

Thank you so much for completing the informed consent. I am so grateful for you. The next step is to schedule an interview date and time. Once your interview is complete, you will be emailed a \$25 Visa gift card for your volunteered participation. Thank you.

Please select an interview time below. If none of these times works for your schedule, please email me at lajoy.johnson-law@aje-dc.org to schedule a time that will be more convenient for you. Thank you. *

Interview Date and Time


Option 2

Option 3

If none of these times work for your schedule, email the researcher at lajoy.johnson-law@waldenu.edu


[Back](#) [Next](#) [Clear form](#)

***Note, that participants will have eight options (interview dates and times will span over a 2-week period) to choose from to complete their interview.** As stated, if the interview date/time options conflict with the participant's schedule, participants can email the researcher, LaJoy Johnson-Law, Walden University Doctoral student, at lajoy.johnson-law@waldenu.edu to schedule their interview.



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* Indicates required question

Thank You and Contact Information

Thank you so much for agreeing to be a part of this study. I am looking forward to meeting you for our interview and cannot wait to hear more about you and your family. If you have any additional questions or concerns, you may contact me at lajoy.johnson-law@waldenu.edu.


Name and Email Address *

Your answer

Back

Next

Clear form



Caring for Children w/ Intellectual Disabilities: A Caregiver's Perspective Study

ljohnsonlaw22@gmail.com [Switch account](#)

Not shared

Thank You So Much! Looking forward to working together.

Please make sure you select the SUBMIT button below. Thanks.

Appendix B: Interview Guide Protocol

Interview Guide (Protocol)

Checklist

- Check Zoom for all updates and ensure recording is set to record to the cloud and ensure transcribe option is turned on
- Change Zoom Name to LaJoy Johnson-Law (Walden Doctoral Student)
- Arrive 15 mins before scheduled interview
- Have Questionnaire results open in browser
- Check to make sure informed consent is signed and contact information is up to date
- Good lighting
- Remember to establish Rapport with the participant and have warm welcome
- Review confidentiality with participants to ensure privacy and confidentiality
- Review purpose of the interview, questions, and concerns with the participant to ensure comfortability
- Review the \$25 gift card compensation
- THANK the participant and ensure the participant has time to ask questions

Zoom Script

Hello ____,

Welcome. Thank you so much for joining me today to help me with this important research surrounding caregivers. I am so grateful for your participation. This research will help stakeholders and policy researchers understand your experience as a caregiver and understand caregivers' perspectives. Also, I want you to know that this interview is a celebration for our caregivers and their child(ren) with intellectual disabilities. If you have more than one child with an intellectual disability, we can celebrate and discuss them all in this interview. Before we begin the interview, I want to review some quick reminders for us.

This interview will take about 35-40 minutes and will be recorded. If you ever feel uncomfortable or overwhelmed, we can **stop** the recording anytime. I will let you know when we are about to record, and give us a countdown. Also, in the questionnaire, you should have received the informed consent. Do you have any questions or concerns about the consent? Also, I want to ensure your privacy is protected. You will receive your \$25 VISA gift card at the end of the interview once the interview is complete. The gift card will be emailed to you. Can you confirm your email?

Do you have any questions for me, before we begin the audio only-recording?

Once the participant is ready, Countdown.... 3, 2, 1 (recording on)

INTERVIEW QUESTIONS

Note: Questions are open-ended to allow participants to answer in a way they feel is best and for comfort.

Questions:

1. Tell me a little about yourself and the child we will be discussing the most today. I especially would love to hear something amazing about your child and/or family.
2. Describe how you first found out about your child's intellectual disability.
3. Describe how caring for your child has affected your family?
 - ⇒ Probe: Tell me about a typical day with your child? Tell me about a typical doctors appointment or school day (maybe?)
4. Tell me about your social experience raising a child with an intellectual disability? Tell me about your financial experiences...? If any, tell me about your coping strategies?
 - (*This question is asked because of the literature and social model of disability theory)
5. What have been great positive experiences raising your child with an intellectual disability?
6. What have been your challenges raising a child with an intellectual disability?
 - ⇒ Probe: Tell me about your child's educational experience and how this affected you?
 - ⇒ Probe: Tell me about your child's medial experience/journey and how has this affected you.
7. Do you feel your family or other families could benefit from a public program targeted to help caregivers of children with disabilities? If yes, what policies and programs would you recommend? If no, tell me why.
8. Describe how involved you feel in the policymaking process in DC.
 - ⇒ Probe: What programs do you use or are you aware of that helps caregivers of children with disabilities?
 - ⇒ Probe: What programs or policies would you like to see implemented? or if you were a policymaker, what policy would you create?
 - ⇒ Probe: What would make you feel more involved or more engaged in the policy-making process?
9. How important is it to you to be involved in the policy-making process?
10. What advice would you give to other caregivers raising children with intellectual disabilities?

11. Is there anything else you would like to share?

Thank you, email \$25 gift card at the end of completed interview.

Appendix C: Emails: Invitation for Potential Participants Email and Interview

Confirmation Email

Subject line: Interviewing Caregivers of Children w/ Intellectual Disabilities (\$25 thank-you gift card)

Email message:

There is a new study about the experiences and perspectives of caregivers of children with intellectual disabilities that could help policymakers better understand their experiences to help create programs and policies to assist caregivers. For this study, you are invited to describe your experiences as a caregiver of a child(ren) with intellectual disabilities and navigating programs and policies to provide recommendations to policymakers.

About the study:

- One 45-60 minute Zoom interview that will be audio recorded only
- You would receive a \$25 Visa gift card as a thank-you
- To protect your privacy, the published study will not share any names or details that identify you

Volunteers must meet these requirements:

- 18 years old or older
- Caregiver of a child (3-21) with an intellectual disability
- Be a current DC resident

This interview is part of the doctoral study for LaJoy Johnson-Law, a Ph.D. student at Walden University. Interviews will take place during [the month here](#). To confidentially volunteer and begin the screening process, click [here](#). For more information, please contact researcher LaJoy Johnson-Law at lajoy.johnson-law@waldenu.edu. The flyer for this study is also attached to this email. You are welcome to forward it to others who might be interested. Thank you.

Potential Organizations that will be receiving this email: Advocates for Justice and Education, Quality Trust, Children's Law Center, Children's National Hospital, Health Services Children with Special Needs - Nadine /Amanda, DC Department of Developmental Disabilities, Friendship Public Charter School, KIPP Public Charter School, Hart Middle School, E.L Haynes Public Charter School, Parents Amplifying Voices in Education, DC Deputy Mayor for Education Office, DC Public Charter School Board, DC State Board of Education, DC Public Schools Division of Specialized Instruction, and the Special Education Co-op.

*This study contacted various government agencies, nonprofit organizations, and schools across the District of Columbia to assist with participant recruitment.

Interview Confirmation Email

Hello,

Thank You so much for completing the Caring for Children with Intellectual Disabilities: A Caregivers' Perspective questionnaire. Below are your interview confirmation details. Please note, you will also receive this information in a formal calendar invite.

Interview Information:

Title: **J.Doe Caregiver Interview**

Date:

Time:

Location: [REDACTED]

This interview is part of the doctoral study for LaJoy Johnson-Law, a Ph.D. student at Walden University. If you have any additional questions or concerns please contact me at [REDACTED]

Appendix D: Invitation Flyer

INTERVIEW STUDY SEEKS CAREGIVERS

OF CHILDREN W/ INTELLECTUAL DISABILITIES

There is a new study about the experiences and perspectives of caregivers of children (ages 3-22) with intellectual disabilities that could help better understand their experiences and help create programs and policies to assist caregivers. For this study, you are invited to describe your experiences as a caregiver of a child(ren) with intellectual disabilities.

- 45-60 minute zoom audio recording
- You would receive a \$25 gift card as a thank-you
- To protect your privacy, the published study will not share any names or details that identify you



Volunteers must meet these requirements:

- 18 years old or older
- Caregiver of a child with an Intellectual Disability
- Current DC Resident

This interview is part of the doctoral study for LaJoy Johnson-Law, a Ph.D. student at Walden University.

Interviews will take place during Month, Year.

To confidentially volunteer, click [here](#) and begin screening process

For more information:

 lajoy.johnson-law@waldenu.edu

Appendix E: Social Media Invitation



*This is a copy of the flier in Appendix D.

Caption: There is a new study about the experiences and perspectives of caregivers of children with intellectual disabilities that could help better understand their experiences and perspectives to help create programs and policies to assist caregivers. For this study, you are invited to describe your experiences as a caregiver of a child(ren) with intellectual disabilities. For more information on the study, please click [here](https://forms.gle/ZqXKKmc6L1g2bem79). **Link:** <https://forms.gle/ZqXKKmc6L1g2bem79>

About the study:

- One 45–60-minute Zoom call that will be audio recorded only
- You would receive a \$25 Visa gift card as a thank-you once the interview is completed
- To protect your privacy, the published study will not share any names or details that identify you

Volunteers must meet these requirements:

- 18 years old or older
- A caregiver of a child with an intellectual disability
- Current DC Resident

To confidentiality volunteer and begin the screening process, visit:

<https://forms.gle/ZqXKKmc6L1g2bem79>

Please message [REDACTED] with questions and to let them know of your interest.

Appendix F: Literature Review Pre-Codes

Policy Pre-Codes

IDEA- IEP, 504, transportation caregiver burden and/or stress, child's education, school

DC Grandparent Program/Policy- caregiver burden and/or stress, managing daily activities, Caregivers managing finances, behavior, other children, doctors and therapeutic visits

Scholarly Literature Review Pre-Codes

Literature Review Pre-Codes - caregivers experienced caregiving burdens and burnout as social, emotional, and mental challenges. families struggled with their children in school, increased physical and mental caregiver burden, economic instability and strain, and dysfunctionality

Conceptual Framework Pre-Codes

Critical Disability Theory- interactions with policy/programs; ableism; inclusion
Social Model of Disability Theory – social impact on caregiver on child with disability; managing daily activities; friendships, familial relationships