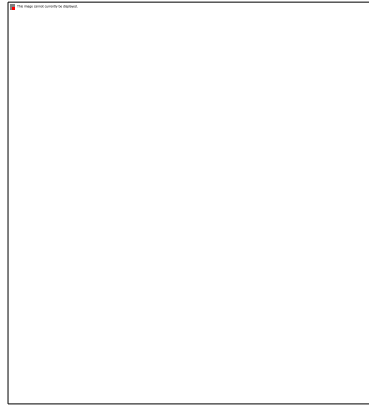


BINDURA UNIVERSITY OF SCIENCE EDUCATION
FACULTY OF SOCIAL SCIENCES AND HUMANITIES
DEPARTMENT OF SOCIAL WORK



**INVESTIGATING THE SOCIO-ECONOMIC CHALLENGES FACED BY
CAREGIVERS OF CHILDREN LIVING WITH DISABILITIES IN CHITUNGWIZA.**

BY

(B200726B)

**A dissertation submitted to Bindura University of Science Education, Faculty of Social
Sciences and Humanities, Department of Social Work, in partial fulfilment of the
requirements for the Bachelor of Science Honours Degree in Social Work.**

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ABSTRACT

The aim of this study was to investigate the socio-economic challenges faced by caregivers of children living with disabilities in Chitungwiza. The study was done using the case study research design. The study was done with 15 caregivers of children living with disabilities and was conducted at Mufudzi Wakanaka parental care for children with disabilities. Information was obtained through in-depth interviews, focus group discussions and key informant interviews. The study objectives included to establish the nature of care provided to children with disabilities by caregivers in Chitungwiza, to identify the socio-economic challenges faced by caregivers of children living with disabilities and to explore the strategies that can be used to support caregivers of children living with disabilities in Chitungwiza. The study established a number of socio-economic challenges faced by caregivers of children living with disabilities. Thus, these factors include financial challenges, lack of support services, accessibility barriers and stigma and discrimination. From the findings financial challenges was a key factor that the caregivers of children living with disabilities face. The study also revealed the global, national and African perspectives towards disability and from the study in Africa people who are living with disabilities are perceived as a curse or punishment from the Gods and as a result parents of children living with disabilities face discrimination when attempting to integrate their children with other people. The study's recommendations included the following, social connections and support, financial assistance, education and employment opportunities, healthcare and wellbeing and support and policy and advocacy for caregivers of children living with disabilities. The study also included the implications of social work practice to socio-economic challenges faced by caregivers of children living with disabilities. The implications of social work practice included advocating for more funding for disability and support services, financial assistance, access to educational opportunities and employment opportunities and also access to healthcare services for caregivers of children living with disabilities.

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I also want to extend my heartfelt gratitude to all the parents who participated in this study.

DEDICATION

I dedicate this dissertation to my loving family, whose unwavering support and encouragement have been the cornerstone of my academic pursuits. To my dear friends and mentors, your guidance and belief in me have been invaluable. Lastly, to the memory of Brain Makatite, whose wisdom continues to inspire me. This achievement is a testament to your enduring influence on my life.

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ACRONYMS AND ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
CHIP	Children's Health Insurance Program
CRPD	Convention Rights of Persons with Disability
DPO	Disabled Persons Organization
IEPs	Individualised Education Programs
SSI	Supplimental Security Insurance
SSDI	Social Security Disability Insurance
WHO	World Health Organization
UN	United Nations

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Table 4.1.2 Demographic Characteristic of Respondents(n=11)

CHAPTER I

INTRODUCTION AND BACKGROUND OF THE STUDY

1.0 Introduction

According to estimates, around 15% of children globally have a disability, and while the UN Convention on the Rights of Persons with Disabilities (2019) recognizes their right to a decent standard of living, including access to healthcare, social services, and education, caregivers of these children often face numerous socioeconomic challenges. As highlighted by Willis and Jacobs (2023), these challenges include financial struggles due to reduced work hours or time off to care for their child, increased healthcare costs, limited employment opportunities, lack of support services, social isolation, and emotional and mental health issues. Additionally, caregivers may struggle to balance their responsibilities with other aspects of their lives, such as maintaining relationships or engaging in social activities, making it difficult to provide adequate care and support to their children.

1.1 Background of the Study

Chitungwiza is a Zimbabwean town located approximately 30 kilometers south of the capital city of Harare. With over 250,000 residents, it is one of the country's most populous towns. Chitungwiza is a relatively new town, established in the mid-1970s, and it is still expanding rapidly. The town has faced significant challenges in recent years, including economic difficulties, high unemployment rates, and limited access to basic services such as water and sanitation. Caregivers of children with disabilities in Chitungwiza face challenges that are part of a larger social and economic context. The high levels of poverty in Chitungwiza exacerbate the socioeconomic challenges that caregivers of children with disabilities face.

A 2012 study revealed that over 70% of households in Chitungwiza lived in poverty, with a significant number headed by women, leading to caregivers struggling to meet their families' basic needs, let alone the additional needs of their children with disabilities. The lack of adequate social safety nets and government assistance for people with disabilities exacerbates this issue. Furthermore, people with disabilities in Chitungwiza face significant barriers to healthcare access due to limited awareness of their rights, scarce specialized services, and inaccessible facilities, resulting in unmet care and support needs. Additionally, children with disabilities face challenges in accessing education, as schools often lack the necessary resources, trained teachers, and specialized materials to accommodate their needs, creating significant obstacles to their educational development.

Children with disabilities have long been perceived as a burden on their families and communities, but Digby and Wright (2002) emphasize the importance of supporting both caregivers and the children in their care. Despite this, research has primarily focused on the emotional and physical aspects of caregiving, overlooking the significant socioeconomic challenges caregivers face. Moreover, there is a notable gap in research exploring the unique challenges specific to caregivers of children with different types of disabilities, highlighting the need for a more comprehensive understanding of the complex issues involved.

Caregivers of children with disabilities in Chitungwiza face numerous socioeconomic challenges, including financial struggles, limited resource access, and societal stigma, which can significantly impact their ability to provide quality care. These challenges can have a profound effect on their capacity to support the children's needs, making their role even more daunting. Moreover, the emotional and physical strain experienced by caregivers in managing the daily needs of children with disabilities has garnered significant research attention, highlighting the need for comprehensive support systems to alleviate their burden.

One study highlighted the practical difficulties encountered by caregivers in adhering to scheduled therapy sessions for children with disabilities, shedding light on the factors contributing to treatment defaulting. Another source emphasized the impact of socio-economic status on attitudes towards disability and the challenges faced by children with disabilities within their families. Furthermore, a study specifically explored the strain experienced by caregivers of children with cerebral palsy, providing valuable insights into the socio-economic and emotional burdens experienced by these caregivers.

A 2016 survey by the National Survey of Children's Health, as reported by Kurpur et al. (2019), found that approximately 17% of children in the United States had a disability, with the most prevalent being developmental delays, ADHD, and learning disabilities. The survey revealed that families with disabled children faced greater economic hardship, social isolation, and health issues compared to families with non-disabled children. Moreover, many families encountered difficulties accessing services and support for their children, with minority groups, such as Hispanic and non-English speaking families, being less likely to receive these essential services. These findings highlight the disparities and challenges faced by families with disabled children, emphasizing the need for improved support and access to resources.

In addition, many families reported difficulty obtaining services and supports for their children. The survey also discovered that certain minority groups, such as Hispanic and non-English speaking families, were less likely to receive services for their disabled children.

Caring for a child with a disability can impose a substantial economic burden on families and caregivers, necessitating specialized medical care, assistive devices, therapies, and support services that strain family finances. Caregivers, often mothers, may need to reduce work hours or leave the workforce, resulting in lost income and increased costs, pushing families into poverty and financial insecurity. Accessing affordable childcare, transportation, and respite

services can be challenging, limiting employment opportunities. The physical and emotional toll of caregiving can also harm the caregiver's health, leading to higher medical costs and reduced future earning potential. These interconnected socioeconomic barriers affect the entire family, creating a cycle of disadvantage that is difficult to overcome. Addressing these complex challenges is crucial to meeting the comprehensive needs of children with disabilities and their caregivers, requiring a holistic approach that considers the economic, social, and health impacts on the whole family.

The financial burden of caring for a disabled child can be overwhelming. Aside from medical expenses such as specialized therapies, assistive devices, and prescription medications, families may also be required to pay for home modifications, specialized childcare, transportation, and other support services. These additional financial burdens can quickly deplete household savings, pushing families into debt or poverty, particularly for those with low incomes or insufficient insurance coverage.

Many caregivers, particularly mothers, are forced to cut back on their work hours or leave the workforce entirely in order to provide the intensive, around-the-clock care their child requires. This loss of income can have long-term consequences, limiting the caregiver's ability to save for retirement and maintain their own financial independence. Caregivers may also face discrimination or difficulties re-entering the workforce after long absences, exacerbating the economic impact.

1.2 Aim

To gain a comprehensive understanding of the socioeconomic challenges and burdens that caregivers for children with disabilities face.

1.3 Statement of Problem

Caregivers of children with disabilities encounter substantial financial hardship and limited job opportunities, compromising their well-being and that of their children. The absence of robust social support systems and restricted access to educational and recreational resources further intensify their challenges, making it difficult to provide optimal care. Despite the growing acknowledgment of the need to support these caregivers, there is a significant knowledge gap regarding the specific socioeconomic obstacles they face. This lack of understanding hinders the development of effective policies and programs, leaving caregivers without the necessary support and potentially limiting their children's ability to reach their full potential. Addressing this knowledge gap is crucial to ensure caregivers receive the necessary assistance and children with disabilities receive the care and support they need to thrive.

1.4 Objectives.

1. To establish the nature of care provided to children with disabilities by caregivers in Chitungwiza.
2. To identify the socio-economic challenges faced by caregivers of children living with disabilities in Chitungwiza
3. To explore strategies that can be used to support caregivers of children living with disabilities in Chitungwiza.

1. 5 Research questions

1. What are the main socio-economic challenges faced by caregivers of children with disabilities?
2. How do these challenges vary depending on the type of disability and the caregiver's socioeconomic status?

3. What are the main sources of support for these caregivers, and how effective are they in meeting their needs?
4. What are the barriers to accessing support and services for these caregivers?

1. 6 Assumptions

- Caregivers of children with disabilities encounter a distinct array of difficulties that are specific to their role, setting them apart from other caregivers.
- The challenges faced by caregivers of children with disabilities can substantially affect their economic stability and overall quality of life, leading to potential financial hardship and reduced well-being.
- The specific challenges encountered by caregivers of children with disabilities can vary significantly depending on the type of disability, with different disabilities presenting unique demands and requirements.
- Targeted policy and program interventions can help alleviate the challenges faced by caregivers of children with disabilities, leading to improved well-being and quality of life for both the caregivers and their families.

1. 7 Significance of study

This study will lead to the improved Support Systems and also understanding these challenges will help identify gaps in existing support systems and inform the development of targeted

interventions and policies to address the specific needs of caregivers. This will lead to improved access to financial assistance, healthcare, education, and social services, ultimately enhancing the overall well-being of both caregivers and children with disabilities.

1.8 Key definitions

1. Caregivers

According to the World Health Organization (2018), a caregiver is defined as an individual who provides assistance and support to someone with temporary or permanent limitations, such as those resulting from illness, injury, or disability, helping to address their various needs and concerns.

2. Disability

According to World Health Organization (2007), disability is an impairment in a person's body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss.

1.9 Chapter summary.

This chapter provided the background of the study, statement of the problem, justification of the study. The chapter also provided the aim of the study and the study objectives. Therefore, highlighting the main issues to be discussed.

CHAPTER II

LITERATURE REVIEW

2.0 Introduction

This chapter examined the literature on the socioeconomic challenges faced by caregivers of children with disabilities in Chitungwiza. Literature was reviewed in accordance with the study's objectives. It also provided the theory used in this study. The systems theory and social model of disability serve as the study's guiding theories. The chapter also examined existing research gaps and the global, African, and national perspectives on disability.

2.1 Theoretical Framework

The theoretical framework aims to make scientific findings more meaningful and generalizable. As a result, this section discusses the theoretical foundation that underpins the study. The research will be based on the social model of disability and systems theory. These two models have been found to be suiting to the current research.

2.1. 1 Social model of disability

According to Thomas (2013), the social model introduces a very different way of thinking, with disability being recognized as the result of an individual's interaction with an environment that does not accommodate that individual's differences. The Social model focuses on removing barriers so that people with disabilities have equal opportunities to participate as others. According to Shakespeare (2006), society must change in order to remove physical, social, and communication barriers that prevent community participation. According to the social model, disability is not a "mistake" of society, but rather an aspect of its diversity. According to Martin (2013), the social model emphasizes the importance of removing physical, social, and attitudinal barriers in order to create an inclusive society that allows individuals

with disabilities to participate fully and equally. It emphasized that disability is largely influenced by societal barriers and discrimination, rather than an individual's physical or mental condition.

The social model's central premise is that disability is a result of how society is structured and organized, rather than an inherent flaw or limitation within an individual. According to this viewpoint, disability is caused by physical, social, and attitudinal barriers in the environment, rather than the individual's medical condition or impairment. A wheelchair user, for example, is not disabled because of a physical mobility impairment, but because there are no ramps, elevators, or curb cuts to allow them to access the built environment. Similarly, a Deaf person's hearing loss does not render them disabled, but rather the lack of sign language interpreters, closed captioning, and other accessibility accommodations. The social model shifts the focus away from "fixing" the individual and instead emphasizes how society fails to accommodate diverse abilities and needs.

This viewpoint empowers people with disabilities because it reframes disability as a political and collective issue rather than a personal medical problem. People with disabilities are encouraged to recognize the systemic barriers that exclude them and advocate for the societal changes required to enable their full inclusion and participation, rather than seeing themselves as inherently limited. This has been a driving force in the disability rights movement, resulting in landmark legislation such as the Americans with Disabilities Act, which requires accessibility and nondiscrimination. The social model also promotes universal design principles, which hold that environments, products, and services should be designed to be as accessible to all people as possible, without the need for adaptation or specialized accommodations. This contrasts with the traditional approach of developing specialized

"disability-friendly" solutions, which can reinforce the stigma of disability as a deviation from the norm.

The social model, by focusing on the experiences and expertise of people with disabilities, has helped to shift public perception and policy responses to disability. It represents a fundamental rethinking of disability, shifting away from a medical/individual framework and toward a perspective that acknowledges the disabling impact of societal barriers, as well as the critical importance of inclusion and accessibility for everyone.

2.1.2 System Theory

The researcher used systems theory in this research project. The research was based on systems theory, an interdisciplinary study of interconnected, interdependent systems, which can be natural or man-made. According to Checkland (2022), each system is bounded by space and time, influenced by its environment, defined by its structure and purpose, and expressed through its functioning. A system can exhibit synergy or emergent behavior, which elevates it above its individual components. According to Lundan (2022), the theory proposes that people are the products of complex systems rather than individuals acting alone. The socioeconomic structure of a community as a complex system presupposes the nature of disability in communities.

2.2 Literature review

A literature review, as defined by Scott (2007:4), is a comprehensive paper that synthesizes current knowledge on a specific topic, including substantive findings, theoretical contributions, and methodological advancements. The concept of disability has been defined and approached by various stakeholders and organizations, including the World Health Organization (2017), which views disability as encompassing impairment, activity limitation, and participation restrictions. In Zimbabwe, while the Constitution does not provide an explicit definition of

disability, it ensures the rights and protection of persons with disabilities, indirectly benefiting caregivers, and addressing the socioeconomic challenges faced by disabled individuals.

According to Tederera and Hall (2017), children with disabilities require extensive care over an extended period, placing a significant burden on their caregivers and necessitating a higher level of responsibility compared to caring for typically developing children. Caregivers must adapt to the situation and employ effective coping strategies to manage the demands of caregiving. As noted by Zulfia and Allenedikania (2020), caregivers play a multifaceted role, serving as parents, facilitators, and navigators, while also mitigating stigma and ensuring the protection and well-being of their children.

Caring for a child with a disability can be emotionally draining, leading to feelings of hopelessness, guilt, and frustration, as noted by Makura (2018). Mazibuko (2019) concurs that caregiving for children with disabilities requires significantly more time, effort, and patience, which can lead to exhaustion. Moreover, Bahry et al. (2019) emphasize that caring for a child with a disability exceeds the scope of typical parenting, necessitating adaptability and resilience as caregivers navigate the complex and fluctuating needs of their child.

The challenges of caregiving for children with disabilities vary depending on the specific disability and the family's socioeconomic situation, as noted by Bahry et al. (2019). Moreover, the caregiver's understanding of their roles and responsibilities significantly impacts their emotional and physical ability to provide effective care, according to Ndadzungira (2016). This understanding plays a crucial role in determining the caregiver's capacity to manage the unique needs of disabled children and maintain their own well-being.

Raising a child with special needs can lead to crisis situations, and mothers' coping abilities are influenced by various factors, including their perception of family support, crisis events, family dynamics, and community resources, as noted by Elnabawy (2012). Caregivers employ diverse

coping strategies, including acceptance, social support, and seeking help from family and relatives, as highlighted by Diseko (2017). Social workers play a vital role in providing necessary support and resources to caregivers, including education, facilitation, and enablement, to alleviate their burden and enhance their capacity to care for children with disabilities. The reviewed literature underscores the significance of understanding the daily challenges faced by caregivers of children with disabilities.

2.3 Global view on disability

Children make up 10% of the over one billion people who are categorized as "persons with disabilities," and they are primarily found in developing nations. A limitation or incapacity to carry out a task in a manner deemed typical for a human being is what the United Nations defines as a disability. Because of misunderstandings and unfavorable social perceptions, children with disabilities are commonly perceived as different, dependent, and incapable. This perception leads to their exclusion through institutionalisation, abandonment, neglect, or marginalisation. A child's sense of exclusion is influenced by many factors, including class, culture, geography, the type of impairment, and the behavioral barriers that the child must overcome.

When looking at disability on a global scale, it is clear that parents of disabled children have difficulty engaging their children in social situations. When it comes to raising disabled children, parents face numerous challenges. Financial stress, lack of access to appropriate support services, and social isolation can all have an effect on children's cognitive development. Parents of disabled children face discrimination and stigma, as well as communication difficulties, high costs, scarcity of resources, limited access to social services, and marital and unemployment issues. These readings highlight the challenges that parents of disabled children face when integrating them into global social interactions.

Fathers of children with intellectual disabilities face a number of challenges, including social isolation and building stronger bonds with their children. It has also been observed that parents of children with disabilities want to engage more with their teachers in order to participate in their child's educational decision-making. As a result, they believe their teachers are dismissing their concerns and providing insufficient information about their child.

In recent decades, the global perspective on disability has shifted dramatically, from outdated medical and charity-based models to a more holistic, rights-based approach. Disability is increasingly recognized as a fundamental human rights issue on a global scale, with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) serving as a watershed moment, having been ratified by over 180 countries. The global perspective emphasizes that disability is caused by the interaction of an individual's impairment and the environmental, attitudinal, and institutional barriers they face in society. Rather than viewing disability as an individual deficiency, this social model locates the "problem" of disability in the failure of communities and systems to be inclusive and accessible. As a result, the global approach focuses on removing these disabling barriers through legislation, policies, and initiatives that promote accessibility, reasonable accommodations, and the full participation of people with disabilities in all aspects of society.

The global perspective recognizes the extraordinary diversity within the disability community, which is an important aspect. Disability encompasses a wide range of physical, sensory, intellectual, and psychosocial impairments, each with its own set of experiences, needs, and connections to other identity factors such as gender, race, age, and socioeconomic status. Effective global frameworks must be multifaceted, addressing the diverse experiences of people with disabilities around the world while also emphasizing shared struggles for equality, dignity, and self-determination.

Furthermore, the global perspective emphasizes the importance of nothing about us without us, which means prioritizing the voices, leadership, and agency of people with disabilities in all matters that affect them. Disabled people's organisations (DPOs) and disability advocates play critical roles in shaping disability-inclusive policies, programmes, and narratives at the international, national, and local levels. This shift toward genuine inclusion and meaningful participation by the disability community is a key component of the evolving global perspective.

2.3.1 African Perspectives on Disability

The African perspective on disability is multifaceted, influenced by a wide range of cultural, social, and historical factors across the continent. In many traditional African societies, disability is frequently viewed through a spiritual or supernatural lens, with physical or mental impairments being attributed to curses, sins, or punishment from ancestors or deities. This belief system has the potential to socially stigmatize and marginalize people with disabilities, who may be viewed as burdens or sources of shame by their families and communities. Many African cultures, however, place a high value on community, interdependence, and the inclusion of all members, including those with disabilities. People with disabilities may be treated with respect and support in these settings, with their needs and contributions considered integral to the collective. Furthermore, in recent decades, disability rights movements throughout Africa have challenged harmful stereotypes and advocated for legal protections, accessibility, and equal opportunities for people with disabilities. Overall, the African perspective on disability is complex, with elements of discrimination and inclusion present in various regions and communities.

In Africa, disability is often perceived as a curse or divine punishment, leading to discrimination against individuals with disabilities and their families. As a result, parents of

children with disabilities face significant barriers when attempting to integrate their children into society. In Zimbabwe, parents of children with intellectual disabilities require additional support and resources to overcome these challenges. A case study in Kenya highlights the alarming vulnerability of individuals with disabilities to various forms of abuse, including violence, emotional, physical, and sexual abuse, which further exacerbates the need for support and inclusive services.

People living with disabilities in Uganda face social marginalization and exclusion. According to one cab, people with disabilities face challenges in accessing basic needs and resources such as healthcare, education, and employment. This demonstrates how people in Africa perceive disability as a personal characteristic, which may cause difficulties for parents of disabled children.

2.3.2 National perspective disability

Zimbabwe, like the majority of other countries, stigmatizes and discriminates against people with disabilities, making it difficult for parents of disabled children to integrate their children into society. People with disabilities are subjected to a variety of discriminatory and marginalizing practices, as well as other forms of inequality. People in Zimbabwe are more likely to discriminate against people with disabilities because they believe they are incapable. This makes it easier for Zimbabweans to discriminate against people with disabilities because they are viewed as incapable.

The national perspective on disability is heavily influenced by a country's historical, cultural, economic, and political contexts. Disability has been approached from a variety of perspectives across countries, ranging from medical models that pathologize impairment to social frameworks that situate disability within societal boundaries. In many countries, people with disabilities face systemic marginalization, with limited access to education, employment,

healthcare, and full civic participation. Disability is frequently viewed through the lens of charity or paternalistic welfare, denying disabled people their basic rights and agency. However, disability rights movements around the world have challenged these discriminatory attitudes and policies, calling for legislative reforms, accessibility standards, and the meaningful inclusion of disabled voices in national policymaking. Some countries have made significant progress in adopting a human rights-based approach to disability, recognizing it as a cross-cutting issue that must be addressed across all levels of government. However, progress is uneven, as deeply entrenched stigmas, resource constraints, and political will continue to impede the implementation of truly inclusive and empowering national frameworks.

2.4 Socio-economic challenges faced by caregivers of children living with disabilities.

Caregivers of children with disabilities often bear a significant financial burden, with expenses including medical care, equipment, therapy, and educational support, leading to increased poverty and debt. The cost of care can be exceedingly high, forcing caregivers to reduce their work hours or leave the workforce entirely, resulting in reduced income and exacerbated financial difficulties. This financial strain can be crippling, highlighting the need for adequate support and resources to alleviate the economic challenges faced by these caregivers.

Caregivers of children with disabilities encounter numerous barriers when seeking support services, including limited access to essential social and emotional support services like respite care and counseling, which can exacerbate stress and isolation. Additionally, they face significant accessibility barriers, struggling to access suitable services and facilities for their child, such as appropriate schools, housing, and transportation. Moreover, public spaces often lack accessibility features, making it challenging for caregivers to engage in community activities with their child, further complicating their caregiving journey.

Caregivers of children living with disabilities face additional challenges, including stigma and discrimination. Caregivers of disabled children may face stigma and discrimination from others, including family members, friends, and medical professionals. This can lead to feelings of isolation and make it difficult to get the help and services needed to care for their child. Caregivers of children with disabilities may experience social isolation due to the demands of caregiving and the societal stigma associated with disabilities. Families may face discrimination, prejudice, and a lack of understanding from their communities, further exacerbating their challenges. The limited availability of inclusive social activities and support networks can contribute to the isolation experienced by caregivers and their children.

Caregivers of children living with disabilities face educational and developmental challenges. Ensuring that a child with disabilities receives appropriate educational support and opportunities for development can be a significant challenge. Navigating the education system, advocating for necessary accommodations, and securing specialized services can be time-consuming and stressful. The lack of inclusive and accessible educational environments can limit the child's educational and social opportunities.

Caregivers of children living with disabilities also face challenges like lack of access to healthcare and support services. Navigating the healthcare system and securing appropriate medical care, therapies, and support services for a child with disabilities can be complex and time-consuming. Families may face barriers in accessing these services due to geographic location, lack of insurance coverage, or long waiting lists. The coordination of multiple healthcare providers and social services can be a significant burden on caregivers.

However, addressing these socioeconomic challenges requires a multifaceted approach, including increased access to financial assistance, healthcare resources, respite care, educational support, and community-based programs that provide holistic support for both the

child and the caregiver. Efforts to reduce stigma and promote inclusive policies and practices are also crucial in improving the well-being of caregivers and their children living with disabilities.

2.4.1 How the socio-economic challenges vary depending on the type of disability and the caregiver's socioeconomic status?

Caregivers of children with disabilities face a wide range of challenges, depending on the disability and the caregiver's socioeconomic status. Caregivers of children with physical disabilities, for example, may face accessibility and transportation challenges, whereas caregivers of children with intellectual disabilities may face challenges in education and behavioral supporting in terms of socioeconomic status, caregivers who have lower incomes may face additional challenges in terms of access to resources and support. Additionally, they may not have equal access to information and support networks as those with higher income. Caregivers from diverse racial and ethnic backgrounds may face unique challenges for example, they may face barriers in accessing services or navigating systems that are not designed with their needs in mind. Additionally, they may face cultural barriers or stigma that further complicate their caregiving experience. In general, it is important to consider the individual circumstances of each caregiver and child when determining what challenges, they may face and how best to support them. There is no one-size-fits-all approach to supporting caregivers, and it is essential to consider the unique needs of each individual.

2.4.2 What are the main sources of support for these caregivers, and how effective are they in meeting their needs.

Caregivers of children with disabilities can draw support from various sources, including family members, friends, and community networks, which can offer emotional support, practical assistance, and respite care. While some families may face challenges in providing

support due to distance or strained relationships, online support groups and forums can connect caregivers with peers who share similar experiences. Professional support services can also provide valuable information, referrals, and guidance, particularly for those without a strong support network or facing specific challenges related to their child's disability, helping caregivers navigate their journey.

Caregivers of children with disabilities can benefit from informal support networks, which offer a sense of community, emotional support, and practical help, but these sources may be unreliable and inconsistent. Therefore, formal support services are also essential, including government programs like Medicaid, CHIP, and state-based programs that provide financial assistance, healthcare coverage, and specialized services. Additionally, special education services, Individualized Education Programs (IEPs), disability-specific programs like SSI and SSDI, and respite care services provide crucial support, offering temporary relief and comprehensive care for caregivers and their children. These formal support services are critical in providing caregivers with the necessary resources and support to navigate the complex healthcare system and ensure their children receive the necessary care and services. While informal support networks can offer emotional support and practical help, formal support services provide a more comprehensive and reliable support system, addressing the unique needs of caregivers and their children. By combining both informal and formal support services, caregivers can receive the support they need to provide the best possible care for their children with disabilities.

However, Government-funded programs can be helpful in providing essential financial and service-related support, but they often have strict eligibility criteria, long waitlists, and limited funding, which can limit their effectiveness in fully meeting the diverse needs of caregivers.

Local and national non-profit organizations that offer support groups, educational resources, advocacy services, and direct assistance to families are also a main source of support for caregivers of children living with disabilities. Community-based support services, such as parent-to-parent networks, disability-specific organizations, and peer-led support groups. Charitable foundations and private donors that provide grants or funding for disability-related services and programs.

Community-based resources are often better equipped to address the unique needs of local families, offering tailored emotional and practical support. However, their availability and accessibility can differ greatly depending on the location, and they may not have the capacity to fully address the diverse needs of caregivers, leaving some needs unmet.

Healthcare professionals, including pediatricians, specialists, case managers, and therapists (physical, occupational, and speech), provide essential support to caregivers of children with disabilities. They offer guidance, referrals, and care coordination, as well as direct therapy and recommendations. While healthcare providers and therapists play a vital role in navigating the healthcare system and providing specialized expertise, their focus on medical care may limit their ability to fully address caregivers' emotional support and respite needs, highlighting the importance of complementary support services that can address the broader range of caregiver needs, including emotional support, respite care, and practical assistance. By acknowledging the limitations of healthcare providers' roles, caregivers can seek additional support from other sources, such as support groups, counseling services, and community organizations, to ensure they receive comprehensive support and care for themselves and their children. This integrated approach recognizes the interconnected needs of caregivers and their children, leading to better outcomes and improved well-being for both.

2.4.3 What are the barriers to accessing support and services for these caregivers?

Caregivers face various barriers in accessing support and services, including lack of awareness about available resources or how to access them, financial constraints, and work commitments that leave no time for support groups or activities. Additionally, rural caregivers may encounter difficulties due to limited transportation options or scarce local services, further isolating them from the help they need. These obstacles hinder caregivers from receiving essential support, underscoring the need for increased awareness, accessibility, and flexible support options.

Financial constraints pose a significant barrier for caregivers, as the high costs of medical care, therapies, specialized equipment, and other disability-related expenses can lead to financial hardship, exacerbated by inadequate insurance coverage or lack of resources for low-income families, making it difficult for them to access necessary support services, afford private care, or even travel to reach available resources, further compounding their caregiving challenges.

Caregivers face navigational barriers when trying to access support services, due to the complex and fragmented healthcare and social service systems, which can be difficult to navigate and understand. This complexity can lead to confusion about eligibility criteria, application processes, and availability of support programs, making it hard for caregivers to identify and access the resources they need. The absence of centralized information and coordination between service providers further exacerbates this issue, hindering caregivers' ability to find and receive the necessary support.

Caregivers in rural or underserved areas face significant barriers in accessing support services due to limited availability and accessibility. Long distances to travel, unreliable transportation, and unaffordable travel costs can prevent caregivers from receiving necessary support. Moreover, families in remote or isolated areas have limited local options and may rely on

virtual or telehealth services, which may not be readily available or accessible, further exacerbating the challenges they face in accessing support services.

Caregivers from diverse cultural backgrounds encounter unique challenges, including language barriers that hinder their understanding and navigation of healthcare and social services. Cultural differences in beliefs, values, and practices also shape their views on disability and support-seeking, potentially leading to underutilization of resources. Furthermore, the absence of culturally sensitive and linguistically appropriate services exacerbates these challenges, creating additional obstacles for diverse families to access and utilize the support they need.

Societal stigma and negative attitudes towards individuals with disabilities and their families can hinder access to support, as caregivers may encounter discrimination and lack of understanding from service providers, making them hesitant to seek help or feel unwelcome when trying to access resources. Additionally, the fear of being stigmatized or socially isolated can prevent caregivers from reaching out for support, further exacerbating their isolation and difficulties in caring for their loved ones.

Addressing the barriers to caregiver support necessitates a thorough and multifaceted strategy that involves increasing funding for support services, enhancing coordination and integration of healthcare and social services, expanding transportation options, and developing resources that are culturally and linguistically tailored to diverse needs. Additionally, efforts to combat stigma and promote inclusive policies and practices are essential to ensure caregivers can access the support they require, ultimately fostering a more supportive and inclusive environment for caregivers and their loved ones.

2.5 Research Gaps

2.5.1 Financial burden and economic impact

A major research gap in the larger field of socio-economic challenges studies the financial burden and economic impact experienced by caregivers of children with disabilities. Even though there has been some research done in this field, there are still a number of issues that need to be further explored and comprehended. Studies have brought to light the out-of-pocket expenses that come with raising a child with a disability, such as medical bills, therapy costs, and assistive technology. More thorough research that measures and examines the total cost of care is still required, though. This entails looking at costs for ongoing support services, home modifications, transportation, and specialized education. Policymakers and support organizations can create effective strategies to reduce the financial burden by having a complete understanding of it.

Taking care of a child living with disabilities frequently means that caregivers have to cut back on work hours, take time off, or quit their jobs altogether. In turn, caregivers may experience a reduction in income and unstable finances. The extent of income inequality and job disruptions among parents of disabled children requires more investigation. Long-term financial effects like lower retirement savings or fewer opportunities for career advancement should be looked into as they might provide important insights.

Financial assistance programs for parents of children living with disabilities are available in certain nations, but more research is needed to determine how accessible and successful these programs are. Furthermore, learning from the experiences of caregivers without access to financial support programs can help clarify the unique difficulties they face and guide policy suggestions. Additionally, studying the experiences of caregivers who do not have access to

financial support programs can shed light on their specific challenges and inform policy recommendations.

2.5.2 Mental health and emotional wellbeing

Even though this topic has been studied, there are still a lot of unanswered questions about the mental and emotional health of those who care for children with disabilities. Longitudinal studies are needed to monitor the emotional and mental health of caregivers over a prolonged period of time. This can shed light on the ways in which these variables develop and alter over time as well as the long-term consequences of caregiving for mental health results. Studies with a longitudinal design can also be used to find protective variables or coping mechanisms that improve the mental health of caregivers.

While there is evidence that caregivers of children with disabilities are more likely to face mental health difficulties, more research is required to fully understand the mental health problems that this population faces. This includes researching the frequency and effects of illnesses like anxiety, depression, stress-related disorders, and burnout in caregivers. Support services and interventions can be more specifically tailored if caregivers' particular mental health issues are recognized.

The components of resilience and good mental outcomes in caregivers should be the subject of future research. This may entail assessing the function of coping strategies, self-care routines, social support, and accessibility to mental health services. By promoting resilience and well-being among caregivers, protective factors can help mitigate the negative effects of stress related to caregiving.

2.5.3 Lack of focus on rural areas

A significant research gap exists in understanding the socioeconomic challenges faced by caregivers of children with disabilities in rural areas, as most studies have focused on urban

areas. However, it is crucial to investigate the distinct challenges faced by rural caregivers, who often have limited access to resources and services. Additionally, rural communities may harbor more pronounced stigma and shame associated with disability, exacerbating the difficulties experienced by caregivers in these areas. Addressing this gap in research can help tailor support and interventions to meet the unique needs of rural caregivers and their families.

2.5.4 Lack of focus on specific types of disabilities

Research on the socioeconomic challenges faced by caregivers of children with disabilities has a significant gap in that it largely focuses on intellectual disabilities, neglecting other types of disabilities such as physical or developmental disabilities. This oversight is significant, as each disability type presents distinct challenges for caregivers, and the lack of research in this area hinders the development of effective support services. By exploring the specific challenges associated with various disability types, researchers can gain a more comprehensive understanding of caregiver experiences and develop targeted support interventions to address their unique needs.

2.6 Chapter Summary

This chapter revealed literature that was in line with the study objectives. The chapter also explained the socio-economic challenges faced by caregivers of children living with disabilities in Chitungwiza and also reviewed the existing research gaps on the socio-economic challenges faced by caregivers of children living with disabilities and also mentioned the global, African and national perspectives towards disability.

CHAPTER III

RESEARCH METHODOLOGY

3.0 Introduction

This chapter outlines the research design and methodology employed in the study, detailing the research approach, design, sampling methods, data collection instruments, data analysis techniques, and ethical considerations. Specifically, the study will utilize a qualitative case study design, which enables an in-depth exploration of the research topic. The case study design allows for a detailed examination of the phenomena under investigation, providing rich insights and contextual understanding.

3.1 Research design

A research design is the overarching strategy that guides the research process, serving as the blueprint for the entire study (Denzin and Lincoln, 1998). It plays a vital role in ensuring the research achieves its objectives and informs methodological choices (Bless et al., 2006). In this study, a case study design was chosen for its ability to examine a phenomenon through multiple data sources (Yin, 2003), providing a rich and nuanced understanding of the research topic (Baxter and Jack, 2008). This design enables an in-depth exploration of various aspects of the phenomenon, yielding a comprehensive understanding of the issue under investigation.

A case study design acknowledges the subjective aspect of research, where researchers and participants collaboratively construct meaning from their experiences, while aiming for objectivity (Zucker, 2009). This approach allows participants to share their stories and experiences, enabling the researcher to gain a deeper understanding of their perspectives and the meaning they assign to their actions (Baxter and Jack, 2008). To ensure accurate data collection, the researcher must possess knowledge of the phenomenon, strong listening and

questioning skills, and employ an in-depth approach to explore the issue in its real-life context (Baxter and Jack, 2008). This design was chosen to gain a comprehensive understanding of the socioeconomic challenges faced by caregivers of children with disabilities in Chitungwiza, enabling the researcher to explore and elucidate participants' perceptions in this specific context.

3.3 Data collection methods

This research employed key informant interviews as the primary data collection method, utilizing in-depth interviews to gather most of the required information. Additionally, focus group discussions were conducted to specifically explore the socio-economic challenges experienced by caregivers of children with disabilities in Chitungwiza, providing a comprehensive understanding of their experiences and perspectives.

3.3.1 Key informant interviews.

Key informants, as defined by Walliman (2005), are individuals possessing valuable insights and knowledge relevant to a specific study, which they share with researchers through key informant interviews, a data collection method. According to Kvale (1996), interviews are interactive face-to-face conversations aimed at gathering rich and productive information. In this study, key informant interviews were employed to collect data from group mentors, gaining valuable insights into the challenges faced by caregivers of children with disabilities, providing a deeper understanding of their experiences.

3.3.2 In-depth interviews

This research employed in-depth interviews as a data collection method, which involves conducting comprehensive, face-to-face conversations with a small number of participants to gain insight into their thoughts and experiences on a specific topic (Babbie, 2001). In-depth interviews are particularly useful for exploring individuals' beliefs, opinions, attitudes, values,

and experiences, making them an ideal choice for this study (Creswell, 2013). Guided by an interview guide, three participants were interviewed to collect data, providing rich and detailed information on their perspectives and experiences related to the research topic.

3.3.3 Focus group discussions

According to Walliman (2005), focus group discussions are a data collection method that harnesses the collective knowledge and experiences of a group of individuals with shared interests and expertise, gathered to share ideas, information, and solutions related to the study topic. In this study, a focus group discussion will be conducted with 10 participants who are caregivers of children with disabilities, providing a platform for them to share their experiences, challenges, and insights on the socio-economic difficulties they face in caring for their children, thereby generating valuable data for the research.

3. 4 Target population and sample

According to Shokane, Makhubele, and Blitz (2018), the target population refers to the specific group of individuals or elements to which a researcher aims to apply their findings and make inferences. In this study, the target population consisted of caregivers and parents of children with disabilities at Mufudzi Wakanaka Parental Care. A sample of 15 participants was selected from this population, with 3 participants engaged in in-depth interviews, 2 in key informant interviews, and 10 in focus group discussions, divided into two groups of 5 participants each, to gather a range of perspectives and experiences.

3.5 sampling techniques

Sampling techniques are methods used to select a subset of individuals from a target population, and the chosen technique significantly impacts the study's credibility and validity. According to Creswell and Poth (2018), sampling techniques describe the process of selecting specific data sources to participate in the study. In this research, the researcher will employ

purposive sampling, a technique that involves intentionally selecting participants who possess specific characteristics, experiences, or knowledge relevant to the study's objectives, ensuring that the sample is rich in information and insights.

3.5.1 Purposive sampling

Purposive sampling was employed to select two key informants from the staff at Mufudzi Wakanaka Parental Care for Children with Disabilities, based on their expertise and experience in disability programming and working with caregivers of children with disabilities. According to Goldstein et al. (2019), purposive sampling involves selecting participants based on their characteristics and relevance to the research objectives, rather than representing a larger population. This method allows researchers to intentionally choose individuals with specialized knowledge and experiences, providing valuable insights into the research area, and was utilized in this study to select key informants who could offer in-depth perspectives on the topic.

3.5.2 Convenience Sampling

The researcher employed convenience sampling to select 10 caregivers of children with disabilities in Chitungwiza for the focus group discussion, relying on readily available and easily accessible participants. According to Etikan et al. (2016), convenience sampling is a non-probability method that involves selecting individuals from the target population based on practical criteria such as proximity, availability, and willingness to participate. This approach prioritizes ease of access and availability, allowing the researcher to focus on participants who were readily reachable and willing to participate at the time of the study, making it a practical and efficient sampling method for this research.

3.6 Data presentation and analysis procedures

i. Data collection

The researcher employed a multi-faceted approach to data collection, utilizing a range of methods including surveys, interviews, and focus groups to gather information. Standardized questionnaires or specially designed instruments were used to capture relevant socio-economic data, while also leveraging existing databases and records related to caregivers and their socio-economic situations, providing a comprehensive understanding of the research topic. This diverse data collection strategy enabled the researcher to triangulate findings and increase the validity of the results.

ii. Data cleaning and preparation

The researcher meticulously cleaned and organized the collected data to ensure precision and reliability, scrutinizing it for any missing values, outliers, and inconsistencies. This process involved a thorough quality control check, followed by the transformation and recoding of variables to prepare the data for analysis, thereby enhancing the accuracy and coherence of the findings. By doing so, the researcher ensured that the data was in a suitable state for meaningful analysis and interpretation.

iii. Descriptive analysis

The researcher initiated the analysis by performing descriptive statistics to summarize the socio-economic challenges experienced by caregivers of children with disabilities in Chitungwiza. This involved calculating statistical measures such as means, medians, frequencies, and percentages to describe the distribution of relevant variables, providing a comprehensive overview of the data and helping to identify emerging patterns and trends. This initial analysis laid the foundation for further investigation, enabling the researcher to better understand the characteristics of the data and inform subsequent analytical steps.

3.7 Ethical issues

According to Durrheim and Wassenaar (1999:65), the primary objective of ethical considerations in research is to safeguard the well-being and rights of study participants. In this study, the researcher adhered to essential ethical principles, including obtaining informed consent from participants, ensuring confidentiality of their personal information, and respecting their right to voluntary participation, thereby prioritizing their welfare and upholding their autonomy and privacy.

3.7.1 Informed consent

According to Rose et al. (2013), informed consent is a voluntary agreement to participate in a study, which involves ensuring that participants comprehend the research purpose, risks, and benefits. The researcher obtained informed consent by clearly explaining the study's objectives, procedures, and potential risks and benefits to participants, providing them with sufficient information to make an informed decision about their participation. This process also involves being truthful and transparent about the research goals, avoiding false expectations, and informing participants about how their data will be used, who will have access to it, and who to contact with questions, as emphasized by Mack et al. (2005).

3.7.2 Confidentiality

According to Kaiser (2009), confidentiality is the duty to protect information shared by individuals or organizations, ensuring it remains secure from unauthorized access, use, disclosure, or modification. Upholding this ethical principle is crucial for establishing trust between researchers and participants, as well as maintaining the integrity of the study. To achieve this, researchers often employ methods like using pseudonyms and disguising locations, as noted by Christian (2005) and cited in Mtetwa (2016:123), to safeguard

participants' identities and prevent individual identification, thereby ensuring the confidentiality of their personal information.

3.7.3 Voluntary participation

Participants were fully informed that their involvement in the study was entirely voluntary, and they had the right to decline answering any questions that made them uncomfortable or withdraw from the study at any time without facing any negative consequences. Additionally, the researcher clearly stated that there would be no rewards, financial or otherwise, for participating in the study. By providing participants with a clear understanding of the study's purpose and their rights, they were empowered to make informed decisions about their participation, ensuring a transparent and ethical research process.

3.8 Feasibility

Feasibility assessment determines the practicality and viability of a project, considering factors like resources, time, and technology. It evaluates whether a project is possible, achievable, and realistic, identifying potential challenges and successes before investing significant resources. In this study, feasibility is evaluated by examining the availability of data, the potential for qualitative research, and ethical considerations, ensuring that the project is viable and worth pursuing. By conducting a feasibility study, researchers can make informed decisions and avoid investing time and resources in a project that may not be successful.

3.8.1 Availability of data

There is existing literature and data available on the socio-economic challenges faced by caregivers of children living with disabilities. This provides a foundation for further research and allows for a comprehensive review of the topic. Additionally, various organizations and institutions may have collected data on this subject, making it accessible for analysis.

3.8.2 Potential for qualitative research

This study utilized qualitative research methods, including interviews and focus groups, to collect rich and detailed data on the experiences and challenges of caregivers. These methods enabled the researcher to gain a nuanced understanding of the complex socio-economic factors affecting caregivers, providing a platform for caregivers to share their stories, perspectives, and personal experiences, and offering a deeper insight into their lives and challenges.

3.8.3 Policy implications

Investigating the socio-economic challenges faced by caregivers of children with disabilities can have a profound impact on policy development, as the findings can shape the creation of supportive programs, policies, and interventions tailored to alleviate these challenges and enhance the well-being of caregivers and their families. By informing policy decisions with research-based evidence, it is possible to develop effective solutions that address the unique needs of this population, ultimately improving their quality of life.

3.9 Study possible limitations

3.9.1 Sample representativeness

Recruiting a representative sample of caregivers can be a difficult task, as this group encompasses a wide range of individuals with diverse socio-economic backgrounds, cultural contexts, and access to resources. This diversity can make it challenging to capture the comprehensive range of experiences and challenges faced by caregivers, which may result in potential biases in the research findings, if not adequately addressed. This highlights the importance of employing strategic sampling strategies to ensure a diverse and representative sample, thereby enhancing the validity and generalizability of the research.

3.9.2 Self-reporting bias

Studies relying on self-reporting methods, such as surveys or interviews, may be subject to response bias. Caregivers may underreport or overreport certain challenges or experiences due to social desirability bias or memory recall issues. This can impact the accuracy and reliability of the data collected.

3.9.3 Limited scope of variables

Research on socio-economic challenges may focus on specific aspects, such as financial burden, employment opportunities, or access to healthcare. While these variables are important, they may not capture the full range of challenges faced by caregivers, such as emotional well-being, social support, or educational resources.

3.9.4 Chapter Summary

This chapter revealed literature that was in line with the study objectives. The chapter also explained the socio-economic challenges faced by caregivers of children living with disabilities sampling techniques, sample size, data collection tools, limitations of the study, feasibility of the study, data analysis and the ethical considerations.

CHAPTER IV

DATA PRESENTATION, ANALYSIS AND DISCUSSION OF FINDINGS

4.0 INTRODUCTION

This chapter provides the presentation, analysis and discussion of the findings of this study. This study made use of data collection tools which includes, key informants, focus group discussions and in-depth interviews. Since it is a qualitative study verbatim statements from discussions with participants were utilized to promote the authenticity of the data which was collected from the participants. The data which was collected from the participants was analyzed through the thematic content analysis which is mainly used in carrying out qualitative research. Therefore, data or information was organized in line with the objectives of this study.

4.1 Demographic information of participants

The researcher interviewed 9 caregivers of children living with disabilities and 2 Key informants from Mufudziwakanaka ranging from 23 - 37 years. Participation in the study

required being a parent or guardian of a child living with disabilities or disability. The researcher collected information on the participants namely their age, sex and level of education. The demographic information of participants will be shown in the table below.

Table 4.1.2 Demographic Characteristic of Respondents(n=11).

Name	Age	Sex	Level of education
Care giver1	23	Female	Secondary
Caregiver 2	30	Female	Secondary
Caregiver 3	28	Male	Secondary
Caregiver 4	25	Female	Tertiary
Caregiver 6	26	Male	Tertiary
Caregiver 7	24	Female	Secondary
Caregiver 8	30	Female	Secondary
Caregiver 9	28	Male	Secondary
Caregiver 10	30	Male	Secondary

Key informant 1	35	Female	Tertiary
Key informant 2	37	Female	Tertiary

4.2 Roles and responsibilities of caregivers of children living with disabilities

4.2.1 Nurturing and creating supportive environment

One important aspect of providing a nurturing environment for children with disabilities is to instill a sense of acceptance and inclusion. Caregivers can accomplish this by openly discussing the child's disability, informing others about it, and cultivating an environment of understanding and empathy. This may help the child feel more accepted and understood by those around them. The first participant said,

As a caregiver for a child living with disability, my role is to provide a nurturing and supportive environment that promotes their overall health. I ensure my child's safety, help with daily tasks like feeding, bathing, and dressing, and administer any necessary medications or therapies. (Female participant 23 years).

The above response aligns with the principles of systems theory, particularly in the context of family caregiving and support for children with disabilities. Systems theory emphasizes the interconnectedness of various elements within a system and how they influence one another. In this case, the caregiver's role in providing a nurturing and supportive environment, ensuring the child's safety, assisting with daily tasks, and administering necessary medications or therapies reflects the systemic approach to caregiving within the family unit.

This approach recognizes the dynamic interactions between the caregiver, the child with disabilities, and the broader family system, as well as the impact of these interactions on the

overall health and well-being of the child. It also acknowledges the interconnectedness of various caregiving tasks and the need for a holistic approach to support the child's development and health.

However, it is critical to advocate for their rights and access to necessary educational and healthcare services. In addition, we should promote their independence by developing their skills and abilities while providing emotional support and understanding.

4.2.2 Understanding the specific needs and challenges of the child

Caregivers' responsibilities for children with disabilities are multifaceted. We must have a thorough understanding of each child's unique needs and challenges, and tailor our care accordingly. This includes assisting with movement, communication, and social interactions.

During the discussion, the participant said:

I have noticed that each child has distinct needs and reacts differently to various situations. Caregivers must recognize and address these individual needs in order to support their holistic development. **(Male participant 26 years).**

The above response aligns with the principles of the social model of disability. The social model of disability emphasizes the importance of understanding and accommodating the unique needs and experiences of individuals with disabilities within the broader social and environmental context.

This model recognizes that disability is not solely an individual's impairment but is also shaped by societal attitudes, physical barriers, and other forms of discrimination.

Another participant said,

Technology has become such an important part of children's lives. We must strike a balance and guide them to use technology responsibly while prioritizing real-world interactions and activities.(Male participant 28 years).

Another participant also said,

Emotional well-being is an important concern. We must provide safe spaces for children to express their emotions and develop resilience as they navigate challenges.(Female participant 25 years).

Caregivers must also work with healthcare professionals and educators to develop individualized care plans that consider physical, cognitive, and emotional development. We must be patient and compassionate, empowering children to reach their full potential while also ensuring their safety and well-being at all times.

4.2.3 Advocating for the children's rights

Caregivers for children with disabilities play an important role in creating a supportive and inclusive environment. Caregivers must advocate for their clients' rights, ensuring that they have access to appropriate education, healthcare, and social opportunities. Caregivers should actively participate in their child's therapy sessions, assist them with daily routines, and offer emotional support. It is critical to foster a sense of belonging and self-esteem while also encouraging the development of life skills and self-reliance. Collaboration with other caregivers and support networks is critical for sharing experiences, resources, and strategies for effective caregiving. During the discussion the participant said,

I believe that children have the right to be heard and that their best interests should be taken into account in all decisions affecting them. It is our responsibility as caregivers

to advocate for their rights and provide a safe and nurturing environment in which they can grow and thrive.(**Male participant 28 years**).

Another participant said,

I believe that advocating for children's rights entails fighting for their access to quality education, healthcare, and protection from harm. It is about fostering a supportive community in which every child feels valued and safe.(**Female participant 30 years**).

Another participant also said,

As a caregiver, I consider it my primary responsibility to advocate for children's rights. It entails allowing children to express themselves freely, protecting them from all forms of violence, and ensuring they have access to basic necessities for healthy development.
(Male participant 26 years).

Caregivers' advocacy for children's rights is critical to ensuring their well-being and development. Mueller and Buckley (2012), provides important insights into caregivers' roles and responsibilities in advocating for children's rights. The International Literacy Association (ILA) has long recognized the right to read as fundamental and inalienable, emphasizing the role of literacy in improving children's lives. This emphasizes the importance of caregivers in promoting literacy and education as fundamental rights for children.

4.3 Socio-economic challenges faced by caregivers of children living with disabilities.

4.3.1 Financial burden

One of the major socio-economic challenges faced by caregivers of children with disabilities is the financial burden. The costs associated with specialized medical care, therapies, assistive devices, and educational support can be overwhelming. Many caregivers may have to reduce their work hours or give up their jobs entirely to provide full-time care, resulting in a loss of

income and financial strain. In addition, the lack of adequate insurance coverage for disability-related expenses adds to the financial challenges, making it difficult to meet the needs of the child and the family as a whole. During an in-depth interview the participant said

It has been incredibly challenging to manage the financial burden of caregiving. The cost of medical treatments, medications and specialized equipment adds up quickly. On top of that, there are additional expenses like transportation for doctor visits and home modifications to accommodate the are recipient's needs. It feels like a never-ending cycle of expenses, and it has definitely put a strain on my finances.(**Female participant 30 years**).

Another participant said,

I never anticipated the financial impact of caregiving. I have to reduce my working hours to provide care, which means a significant loss of income. In addition, there are unexpected costs that arise such as hiring additional help or paying for respite care when I needs a break. (**Female participant 25years**).

The responses mentioned earlier align with Makura's (2019) assertion that caring for children with disabilities is a more challenging and time-consuming endeavor, requiring greater effort and patience from caregivers. This perspective highlights the added difficulties and demands that caregivers face when supporting children with disabilities, emphasizing the need for understanding and support.

The financial burden experienced by caregivers of children living with disabilities is a significant challenge that they often face. It refers to the financial strain or hardship resulting from the additional costs associated with caring for a child with disability as children with disabilities often require specialised medical care, therapy sessions medication, assistive

devices and frequent doctor visits postulates Stabile and Allin (2012). These expenses can quickly accumulate and place a significant financial burden on caregivers especially if they are not fully covered by insurance or government assistance programs.

4.3.2 Lack of affordable and accessible childcare services

The socio-economic challenges faced by caregivers of children with disabilities go beyond financial constraints. The caregiving responsibilities can be demanding and time-consuming, often requiring round-the-clock care. This can limit the caregivers' ability to pursue employment or educational opportunities, leading to reduced career prospects and professional growth. Additionally, the lack of affordable and accessible childcare services specifically tailored for children with disabilities further exacerbates the socio-economic challenges, as caregivers may struggle to find suitable care options that meet their child's unique needs. During the discussion the participant said,

Finding affordable child care services for my child living with disabilities has been a constant struggle. Many centers either don't have the resources or the expertise to accommodate my child's needs. Those that do offer specialized services come with exorbitant fees that are simply not feasible for my family. (**Female participant 24 years**).

Another participant said,

I have spent countless hours searching for accessible child care options, but it feels like a never-ending battle. Even when I do find a center that claims to be inclusive, they often lack the necessary accommodations or properly trained staff to support my child. It's disheartening and makes it incredibly challenging for me to work or pursue other responsibilities. (**Male participant 28 years**).

Research indicates that there is a significant shortage of accessible child care services for children living with disabilities. According to Rosenthal, Cashman and Viste (2019), many child care centres lack the resources, training and accommodation necessary to meet the diverse needs of children with disabilities resulting in limited options for caregivers. Studies have also shown that accessible child care services for children living with disabilities often come with higher costs compared to traditional child care. The need for specialised staff, adaptive equipment and additional support services contribute to the increased expenses making it financially challenging for caregivers to access these services.

4.3.3 Social isolation

Caregivers of children with disabilities often face social isolation and limited support networks, which can have a significant socio-economic impact. The demands of caregiving can strain relationships and lead to reduced social interactions, making it challenging to find emotional support and practical assistance. This isolation can also affect the caregivers' mental health and well-being. Furthermore, the lack of community resources, inclusive recreational activities, and respite care options can further compound the socio-economic challenges faced by caregivers, as they may struggle to find opportunities for self care rejuvenation. During this discussion, the participant said,

My social circle has dwindled as friends and family struggle to understand the complexities of my situation. It's isolating to not have a network of people who truly comprehend the daily struggles and triumphs we experience. **(Female participant 23 years).**

Another participant said,

It's not just the lack of understanding from others, but also the limitations in participating in social activities and events. Finding inclusive environments for my

child can be difficult, and this often means we have to miss out on social gatherings.

It's a lonely journey at times. **(Female participant 30 years).**

Another participant also said,

It's not just about feeling disconnected from our friends and community; it's also the emotional toll of not being able to relate to others who don't understand the unique challenges we face. The lack of meaningful social interactions takes a significant toll on our well-being. **(Female participant 24 years).**

The findings mentioned earlier are consistent with Makura's (2018) observation that being the primary caregiver for a child with a disability can be emotionally draining, leading to feelings of hopelessness, guilt, and frustration. This suggests that caregivers may experience intense emotional challenges, including negative emotions and a sense of despair, which can impact their well-being and ability to provide care.

4.4 Roles of the community in providing care for children living with disabilities

4.4.1 Creating an inclusive and supportive environment

The community plays a crucial role in providing care for children living with disabilities. One important role is creating an inclusive and supportive environment. The community can promote awareness, understanding, and acceptance of children with disabilities, which helps reduce stigma and isolation. This can be done through educational campaigns, organizing inclusive events and activities, and fostering inclusive spaces such as accessible playgrounds or community centers. By creating an inclusive community, children with disabilities can feel a sense of belonging and have opportunities for social interaction and integration. During the discussion the key informant said,

*I believe the community plays a pivotal role in creating an inclusive and supportive environment for all. By fostering a sense of belonging and acceptance, the community can empower individuals to thrive and contribute positively to society.***(Female participant 35 years).**

Another key informant said,

*In my view, the community serves as a foundation for support and collaboration. When community members come together to celebrate diversity and provide resources for those in need, they lay the groundwork for an inclusive and supportive environment where everyone can feel valued and respected.***(Key informant 37 years).**

The key informant also said,

*From my experience, the community acts as a catalyst for change and progress. By promoting equity, understanding, and empathy, the community can break down barriers and ensure that every individual, regardless of background, has the opportunity to flourish within a nurturing and inclusive environment.***(Key informant 35 years).**

The community plays a crucial role in providing support and resources for children with disabilities. King, Gurries and Petersen (2014), indicates that inclusive educational settings within the community are essential for the well-being and development of children with disabilities. It emphasizes the need for adequate support services and accommodations to ensure that these children have equal access to education and opportunities for growth.

4.4.2 Practical assistance

The community can provide valuable support to caregivers of children living with disabilities. One role is offering practical assistance. This can include providing respite care services, where

community members volunteer to care for the child temporarily, giving the caregiver a break. The community can also organize support groups or peer networks that allow caregivers to connect, share experiences, and exchange information and resources. Additionally, community members can offer help with everyday tasks such as grocery shopping, transportation, or running errands, easing the burden on caregivers and providing them with much-needed support. During a key informant interview the key informant said,

I believe the community plays a vital role in providing practical assistance to those in need. By offering tangible support such as access to essential resources, mentorship, and skill-building programs, the community can empower individuals to overcome challenges and thrive. (Key informant 37 years).

Another key informant said,

In my experience, the community serves as a valuable network for practical assistance. Through collaborative efforts and community-based initiatives, individuals can receive hands-on support, guidance, and opportunities for skill development, ultimately fostering self-sufficiency and resilience. (Key informant 35 years).

The key informant also said,

From my perspective, the community acts as a source of practical assistance through its collective efforts to address the diverse needs of individuals. By offering practical resources, mentorship, and tailored support, the community can contribute to the overall well-being and success of its members. (Key informant 35 years).

The above responses shows that community engagement is recognized as an essential component in improving prevention, treatment, and recovery support services for individuals with mental illnesses and substance use disorders says Roghavan, Pawson and Small (2013).

This underscores the community's role in providing comprehensive support services that address the diverse needs of children with disabilities, particularly in the context of mental health and well-being

4.5 Financial costs associated with caring for a child with disability

4.5.1 Financial implications

Being a parent of a child living with disabilities has significant financial implications. Besides the regular expenses of raising a child, there are additional costs related to medical care, therapy sessions, specialized equipment, and modifications to the living environment. These expenses can quickly add up and put a strain on the family's budget. In some cases, families may need to hire caregivers or pay for respite services to ensure their child's well-being. Overall, the financial costs of caring for a child with disabilities can be substantial and require careful financial planning. During the discussion the key informant said

The financial implications of caring for a child living with a disability are immense. From medical expenses and specialized equipment to the costs of therapies and caregiving support, our family faces a constant financial strain. It's not just about the direct costs; it's also about the impact on our ability to work and the sacrifices we make to ensure our child's well-being. (**Key informant 35 years**).

Another participant said,

The financial burden is significant, and it extends beyond medical expenses. We often have to navigate complex insurance processes and face non-reimbursed costs for essential disability-related supports. Balancing these financial implications while ensuring our child receives the necessary care is a constant challenge. (**Male participant 30 years**).

Another participant also said,

Caring for a child living with a disability has substantial financial implications. It's not just about the direct costs; it's about the sacrifices we make, the impact on our careers, and the additional expenses for specialized care and equipment. (Female participant 25 years).

The above responses correspond to what Bahry et al (2019) stated. He said that the challenges of providing care differs depending on the child's disability and family economic status.

The review highlights the significant economic burden associated with caring for a child with a disability. According to Coda, Marcus and Mandell (2012), it addresses the challenges faced by families in managing the financial impact and the potential consequences it can have on their lives.

4.5.2 Medical expenses

The financial costs of caring for a child living with disabilities can vary depending on the specific needs of the child. Medical expenses, such as doctor visits, medications, and surgeries, can be a significant part of the overall costs. Additionally, there may be costs associated with therapy services, including physical, occupational, or speech therapy. Specialized equipment like wheelchairs, hearing aids, or communication devices can be expensive. The participant said,

The medical expenses associated with caring for my child living with a disability are overwhelming. We have to juggle copays, deductibles, and the costs of various therapies and medications. It's a constant worry, and we often find ourselves making tough choices to ensure our child receives the care they need. (Female participants 25 years).

Another participant said,

The financial impact of medical expenses is significant. From mobility aids to specialized medical equipment, the costs add up quickly. It's not just about the direct expenses; it's also about the time and effort spent navigating insurance coverage and seeking financial assistance. It's a constant source of stress for my family. (Female participant 30 years).

Another participant also said,

The medical expenses for our child's care place a heavy burden on my family. I often find myself having to delay or forgo other essential expenses to cover the costs of therapies, doctor's appointments, and medical supplies. It's a constant struggle to ensure my child's well-being while managing the financial implications of their care. (Male participant 30 years)

However, caring for a child living with disabilities involves various financial costs that can impact a family's financial stability. Families may need to modify their homes to make them more accessible, which can be costly states Shimabukuro, Grosse and Rice (2008). Ongoing medical expenses, including doctor visits, medications, and assistive devices, can also strain the family's budget. In addition, there may be indirect costs related to lost income if parents need to reduce their work hours or leave their jobs to provide care. It's crucial for families to consider long-term financial planning, explore disability benefits and grants, and seek support from community organizations to mitigate the financial challenges associated with caring for a child with disabilities."

4.6 Training or education that would be beneficial for caregivers of children with disabilities

4.6.1 Specialized training programmes

Caregivers should have access to educational opportunities that can enhance their understanding of their child's condition and provide them with the tools to support their child's development. They can greatly benefit from training that focuses on understanding the specific disabilities their child has. This can include learning about the medical aspects of the condition, its potential impact on the child's development, and strategies for managing associated challenges. Practical training in caregiving skills such as administering medications, handling medical equipment, and assisting with daily activities like feeding, bathing, and mobility can also be invaluable. The participant said

I think a comprehensive training program for caregivers of children living with disabilities should encompass a wide range of areas. Firstly, education on the specific disability and its impact on the child's development and daily life would be crucial.

(Female participant 25 years).

Another Participant said:

*As a caregiver of a child living with disabilities, I believe that training programs focused on specific disabilities and their associated challenges would be highly beneficial.***(Male participant 28 years).**

This would help caregivers gain a deeper understanding of their child's needs. Practical training in areas such as feeding techniques, hygiene care, and managing behaviors would also be beneficial. Moreover, training that focuses on advocating for the child's rights, navigating the

healthcare system, and accessing support services and resources would empower caregivers to effectively meet their child's needs and ensure they receive the best possible care.

4.6.2 Access to educational opportunities

Caregivers should have access to educational opportunities that can enhance their understanding of their child's condition and provide them with the tools to support their child's development. Caregivers should receive training in various domains, including medical, therapeutic, and educational aspects. Understanding the medical condition, its potential complications, and how to manage them would be essential. Additionally, training in therapies such as occupational, physical, and speech therapy would equip caregivers with techniques to support their child's development. During an indepth interview the participant said,

*In my experience, access to educational opportunities for my child with disability in Chitungwiza has been challenging. There is a need for more specialized educational support tailored to the unique needs of these children. I believe that inclusive education practices and targeted resources can make a significant difference in ensuring that our children have equal access to quality education.***(Female participant 25 years).**

Another participant also said,

*I have encountered disparities in access to educational resources for my child with disability. It is important for the education system to recognize and address the specific needs of these children. Caregivers would greatly benefit from more educational support and training to effectively support the educational development of our children living with disabilities.***(Female participant 30 years).**

However, inclusive education is seen as a key aspect of providing equal opportunities for students with disabilities. The literature suggests that inclusive education can lead to positive outcomes for students with disabilities, including improved academic and social development.

4.7 Chapter summary

This chapter provided an illustration on the presentation, analysis and discussion of findings that were attained during this study. It also presented the findings on the socio-economic challenges faced by caregivers of children living with disabilities. This chapter also mentioned training or education that would be beneficial for caregivers of children living with disabilities.

CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction.

This chapter offers a thorough summary, conclusion, and recommendations based on the study's findings regarding the socioeconomic challenges encountered by caregivers of children with disabilities. It synthesizes the key points, reiterates the main conclusions, and provides actionable recommendations to address the challenges faced by these caregivers, with the aim of improving their situation and enhancing their ability to provide care.

5.1 Summary

Caregivers of children living with disabilities face a myriad of socio-economic challenges that significantly impact their well-being and ability to provide care. These challenges include loneliness and isolation, economic adversity, education inequalities, and adverse socioeconomic outcomes for both the caregivers and the children. The impact of these challenges is exacerbated by children with disabilities' unique needs, which can result in increased financial strain, fewer employment opportunities, and less access to social and emotional supports.

The study aimed at investigating the socio-economic challenges faced by caregivers of children living with disabilities in Chitungwiza. The study involved 15 caregivers of disabled children and was carried out at Mufudzi Wakanaka parental care for disabled children. In-depth

interviews, focus groups, and key informant interviews were used to collect information. The study's objectives included determining the nature of care provided to children with disabilities by caregivers in Chitungwiza, identifying the socio-economic challenges faced by caregivers of children living with disabilities, and investigating strategies for assisting caregivers of children living with disabilities in Chitungwiza.

The study identified several socio-economic challenges that caregivers of children with disabilities face. Thus, these factors include financial difficulties, a lack of support services, accessibility barriers, and stigma and discrimination. According to the findings, financial challenges are a major concern for caregivers of children with disabilities.

The study also revealed global, national, and African perspectives on disability. According to the study, people with disabilities are perceived as a curse or punishment from the Gods, and as a result, parents of disabled children face discrimination when attempting to integrate their children into society.

5.2 Conclusion

Caregivers of disabled children face a wide range of socio-economic challenges. These challenges have a significant impact not only on the caregivers' ability to provide adequate care and support, but also on the children's overall well-being. To address these challenges, a comprehensive approach that includes social, economic, and healthcare interventions for both caregivers and children with disabilities is required.

The study used the social model of disability and systems theory to look into the socio-economic challenges that caregivers of children with disabilities face. The social model of disability emphasizes the importance of removing physical, social, and attitudinal barriers in order to create an inclusive society in which people with disabilities can participate fully and have equal rights. The study also identified the primary sources of support required by

caregivers and how they effectively meet their needs. According to the findings of this study, family members, friends, and the community can provide important emotional support, as well as professional support services such as support groups, online forums, and respite care.

5.3 Implications to social work practice

The socio-economic challenges that caregivers of children with disabilities face have important implications for social work. These challenges can result in financial hardship, psychological stress, and limited access to social supports and services for both caregivers and the children they care for. Social workers can provide vital support services to caregivers, such as access to financial assistance programs, respite care, education and support, access to healthcare, employment opportunities and counseling services to address the psychological effects of caregiving. Social workers can help develop policies and programs to address the specific socio-economic challenges that caregivers of disabled children face. This could include advocating for more funding for disability support services and promoting inclusive policies that help these families with their financial security. Social workers can help caregivers, disability support organizations, and community resources work together to build a support network that addresses both the caregivers' and children's economic and psychological needs. However, by addressing these challenges, social workers can play an important role in supporting and empowering caregivers while also improving the overall well-being of disabled families.

5.4 Recommendations

- ★ Social connections and support. To reduce feelings of loneliness and isolation, implement programs and initiatives that promote social connection and support for caregivers of children with disabilities.

- ★ Financial Assistance. Provide financial assistance and resources to help caregivers cope with economic hardship and reduce financial strain.
- ★ Education and Employment Opportunities. To address educational disparities and negative socio-economic outcomes, create inclusive education and employment opportunities for both caregivers and children with disabilities.
- ★ Healthcare and well-being support. Create comprehensive healthcare and wellness support systems that are tailored to the specific needs of caregivers and disabled children.
- ★ Policy and advocacy. Advocate for policies that address the specific socioeconomic challenges that caregivers of children with disabilities face, and work to create a more inclusive and supportive community.

5.5 Chapter summary

This chapter provided an overview, conclusions, and recommendations for strategies that can be implemented to improve the socio-economic challenges faced by caregivers of children with disabilities. It also unveiled the overall summary, conclusions, and recommendations on the strategies that can be adopted to improve the socio-economic challenges faced by caregivers of children living with disabilities.

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RESEARCH TOOLS

APPENDIX 1

INDEPTH INTERVIEW GUIDE

INTRODUCTION

My name is Wayne Tafadzwa Makatare. I am currently studying a Bachelor of Social Work Honors Degree at the Bindura University of Science Education and I am doing my undergraduate dissertation. I am conducting a research study on the socio-economic challenges faced by caregivers of children living with disabilities in Chitungwiza. The information collected will be used for academic purposes only. Your participation will be greatly appreciated.

Demographic information of participants

NAME.....

AGE.....

SECTION A: Establishing the nature of care provided to children with disabilities by caregivers.

What are your roles and responsibilities in providing care for children with disabilities.

What do you think is needed to improve the care and support for children with disabilities

What are some interventions you use to support children with disabilities.

SECTION B: Identifying the socio-economic challenges faced by caregivers of children living with disabilities.

4.How does caring for a child with disability affect your ability to work outside the home.

5.Do you feel like you have enough support in your role as a caregiver of a child living with disability.

6.What are the financial challenges you face as a caregiver of a child with disability.

SECTION C: Exploring strategies that can be used to support caregivers of children living with disabilities.

7.What are some strategies you found helpful in supporting your child with disability.

8.What has been the most difficult aspect of being a caregiver.

9. How have you been able to find support for yourself as a caregiver.

THANK YOU.

APPENDIX 2

KEY INFORMANT INTERVIEW GUIDE

INTRODUCTION

My name is Wayne Tafadzwa Makatare. I am currently studying a Bachelor of Social Work Honors Degree at the Bindura University of Science Education and I am doing my undergraduate dissertation. I am conducting a research study on the socio-economic challenges faced by caregivers of children living with disabilities in Chitungwiza. The information collected will be used for academic purposes only. Your participation will be greatly appreciated.

AGENCY.....

GENDER.....

SIGNATURE.....

SECTION A: Establishing the nature of care provided to children with disabilities by caregivers.

1. How do you define care for the children with disabilities.
2. What do you see as the role of the community in providing care for children with disabilities.

3. What are some of the barriers to providing care for children with disabilities.

SECTION B: Identifying the socio-economic challenges faced by caregivers of children living with disabilities.

4. What are financial costs associated with caring for a child with disability.
5. What kind of social support is available to caregivers of children living with disability.
6. What are societal perceptions of children with disabilities and their families.

SECTION C: Exploring strategies that can be used to support caregivers of children living with disabilities.

7. What kinds of strategies have you seen or heard about that have been helpful for caregivers.
8. What types of services or resources do you think are lacking for caregivers.
9. What kind of emotional support is available and how can it be improved.

THANK YOU.

APPENDIX 3

FOCUS GROUP DISCUSSION

INTRODUCTION

My name is Wayne Tafadzwa Makatare. I am currently studying a Bachelor of Social Work Honors Degree at the Bindura University of Science Education and I am doing my undergraduate dissertation. I am conducting a research study on the socio-economic challenges faced by caregivers of children living with disabilities in Chitungwiza. The information collected will be used for academic purposes only. Your participation will be greatly appreciated.

Demographic information of participants

NAME.....

Gender.....

Age.....

SECTION A: Establishing the nature of care provided to children with disabilities.

1. What improvements do you think is missing from the care that is currently available.
2. How do you feel about the care that is available.

3. What kind of care is typically provided to children with disabilities in your community.

SECTION B: Identifying the socio-economic challenges faced by caregivers of children living with disabilities.

4. What are the financial challenges you face as a caregiver.

5. What social support is available to you as a caregiver.

6. How does being a caregiver impact your social life.

SECTION C: Exploring strategies that can be used to support caregivers of children living with disabilities.

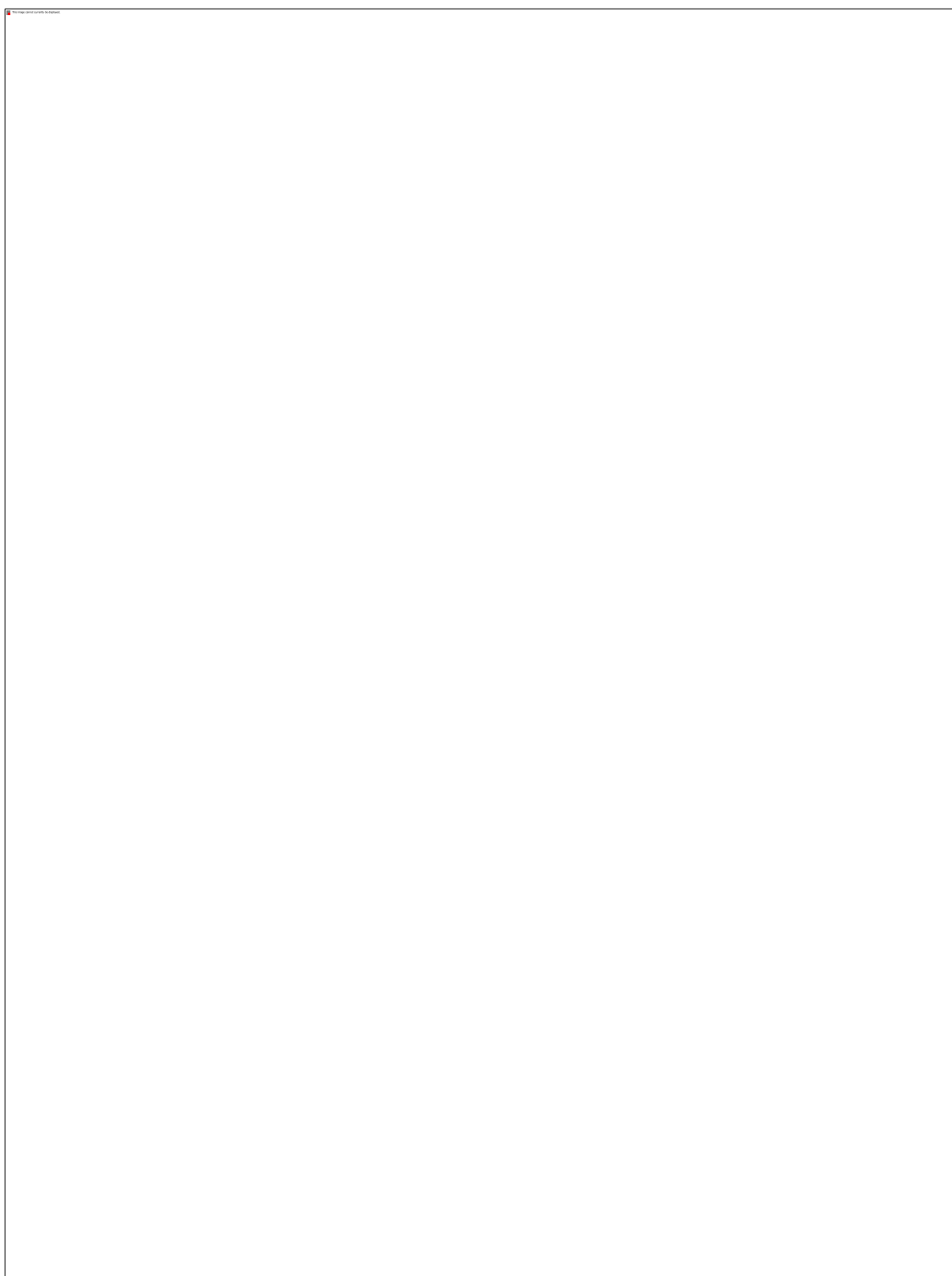
7. What are some ways that communities can work together to support caregivers.

8. What kind of training or education do you think would be beneficial for caregivers.

9. What kinds of support would be most helpful to you as a caregiver.

THANK YOU.

APPENDIX 4: APPROVAL LETTER 1 FOR DATA COLLECTION



APPENDIX 5: APPROVAL LETTER 2 FOR DATA COLLECTION

