2018

Caregiver Support and Advocacy for Children with Disabilities in Guyana

Shiromanie Sharla Khargi
Walden University

Walden University

College of Social and Behavioral Sciences

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Shiromanie S. Khargi

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Review Committee
Dr. Michael Plasay, Committee Chairperson, Psychology Faculty
Dr. Karine Clay, Committee Member, Psychology Faculty
Dr. Rachel Piferi, University Reviewer, Psychology Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Abstract

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MA., Adelphi University 2004

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

Walden University

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Abstract

In Guyana, a developing country in South America, many parental caregivers of disabled people struggle to understand their children's disability as well as provide, and advocate for, educational resources and medical and psychological care for their children. The researchers have found that the needs of this population have been minimized placing disabled people at risk for neglect, abuse, and death. In 2006, the Convention on the Rights for People with Disabilities created a plan to help developing countries improve the care and advocacy for people with disabilities. The purpose of this evaluative study, which was guided by general systems theory, was to examine and assess whether the Community Based Rehabilitation Program serves caregivers of the disabled population in Guyana effectively, identify the positive and negative aspects of the program, and recommend improvements to the program. Qualitative research methods were used. Surveys and interviews were administered to 73 caregivers of disabled people. Data were analyzed using triangulation strategies for data verification to identify specific themes. The findings of this study indicated that caregivers of people with disabilities are in dire need of educational resources, support groups, and training. They also suggested that when provided relevant information, caregivers tend to feel more empowered to serve as agents of care for their disabled children. Results from the study may spur policy makers to implement relevant training for Guyanese caregivers and provide them with necessary resources, which may lead to improvements in the lives of disabled people in Guyana and the possibility for social justice.

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Dedication

This paper is dedicated to my children, Jessica and Joshua. Your numerous efforts to help me understand patience and tolerance in myself are priceless and worth a lifetime of thank yous. Your innocence and belief in me have made this research possible and future ones strong possibilities. You have left your mark within my soul. If I believe that I can do something, then I am certain that I can acquire the capacity to do it.

Acknowledgments

My sincere gratitude to my committee for their relentless guidance and support throughout this process. I thank Dr. Plasay and Dr. Clay tremendously for their faith in my ability to complete this project.

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Chapter 1: Introduction to the Study

At the Convention on the Rights of Persons with Disabilities (CRPD) in 2006, the United Nations stated that all children are entitled to equal human rights, freedom, and the same fundamental rights to an education and full involvement within their society (United Nations, 2006). A follow-up report by UNESCO (2006) estimated that, of the approximately 600 million people with disabilities worldwide, 80% are children living in developing countries. Children with disabilities are amongst the poorest of the world's youth population in developed or developing countries (UNESCO, 2006). UNESCO further estimated that 98% of children with disabilities in developing countries do not have access to a quality education and 99% of girls with disabilities are illiterate. This high rate of illiteracy reveals that some of the educational systems in developing countries may not be addressing the basic learning needs of their populations.

The lack of awareness and effective education reform based on the Rights of Persons with Disabilities may also be an influencing factor on illiteracy rates. After the expected improvements of decades of system-wide reform, caregivers of disabled children in developing countries are still struggling with access to the appropriate care for their children due to the lack of educational resources, caregiver skills training, caregiver support groups, and mental health care (UNICEF, 2000). The central focus of research discussions by the United Nations (2006) is primarily on improving societal awareness and quality of care and combating stereotypes concerning children with disabilities, as well as maintaining a higher accountability for caregivers, teachers, and administrators. Other influential factors were identified in areas regarding global economic and monetary concerns, such as wheelchair accessibility, employment, technology tools, and education devices (United Nations, 2006). Previous reform policies established by the CRPD to address these concerns included increasing educational resources, developing a universal design for education, developing awareness-training programs, and increasing caregiver involvement in policy and planning, among other measures (United Nations, 2006).

Developing countries within the Caribbean, such as Antigua and Barbados, are making great strides in their attempts to bridge the gap by developing programs and policies that would provide adequate care for children with disabilities (UNESCO, 2006). However, countries such as Guyana are still behind in the development and implementation of essential policies, laws, and practices regarding the care of children with disabilities (UNESCO, 2006). According to the National Commission on Disability (2005), Guyana has not yet developed or demonstrated an official definition of the term. Guyana is challenged with providing procedural resources for identifying children with disabilities and addressing the concerns of caregivers with special needs children. Although Guyana does maintain a National Policy on the Rights of People with Disabilities, the language within the written documents does not specifically address the rights of children with disabilities within this policy (International Disability Rights Monitor, 2004). That very issue was also raised in a 2005 Report on Human Rights Practices. The report further added that there continues to be a lack of services in developing countries like Guyana that are specifically designed to address the needs of children with special needs (U.S. Department of State, 2006). In this chapter, I will present the problem statement, outline the purpose of the study, and provide information on the context of the problem.

Background

According to the United Nations (2008), there are between 180 and 220 million children with disabilities worldwide, with nearly 80% living in developing countries. The prevailing culture of many developing countries such as Guyana includes certain traditional beliefs associated with the causes of disability. These include curses, spells, and contagion, and holding mothers responsible for their children's disability and at risk of being shunned and isolated from society (Pan American Health Organization, 2008). In Guyana, when a child is born with a disability, others perceive the birth as tragic and detrimental to the child's family and community (Pan American Health Organization, 2008). Issues that affect persons with disabilities (e.g., access to education, employment, health care, and social services) not only minimize their rights but compromise their receipt of appropriate care and immunizations, resulting in high infection rates and communicable diseases amongst this population (Pan American Health Organization, 2008).

In 2006, the CRPD presented a framework to developing countries stressing the importance of recognizing and adhering to the rights of persons with disabilities. This framework provided distinct goals that are critical for the disabled population. These goals included the following:

1. “The principles proclaimed in the charter of the United Nations recognize the inherent dignity, worth, and equal rights of all human beings as a foundation for freedom, justice, and peace in the world” (IDA, 2009, p.12-15).
2. “Everyone is entitled to freedom without distinction” (IDA, 2009, p.15).
3. Affirming the universality, indivisibility, interdependence, and interrelatedness of all human rights and freedom, as well as full enjoyment without discrimination to be guaranteed to persons with disabilities.
4. Recalling economic, social, and cultural rights, as well as eliminating all forms of racial discrimination against women, torture, cruelty, inhuman, degrading treatment or punishment, and protection of the rights of all migrant workers and their families.
5. Recognizing that disability continues to be an evolving concept and results from a lack of social interaction between people and their environment, which hinders equality.
6. Abiding by the principles and policies in the World Program of action concerning Disabled Persons, promoting equal employment opportunities, formulation and evaluation of policies, plans, programs, and actions at the national, regional, and international levels.
7. Acknowledging the importance of mainstreaming disability issues and integrating relevant strategies for sustainable development.
8. Acknowledging that discrimination against any person with a disability is a violation of dignity.

9. Recognizing the diversity of disabled people.
10. Promoting and protecting human rights of all persons with disability, including those who require intensive support.
11. Showing concerns that despite the various instruments and undertakings disabled persons continue to face barriers disallowing them to participate as equal members in society, which violates their rights in all parts of the world.
12. Recognizing that there must be international cooperation in every developing country for improving living conditions for persons with disabilities.
13. Recognizing that persons with disabilities can contribute tremendously to their society, culture, social, and economic conditions which can increase a sense of belonging and decrease poverty.
14. Acknowledging that persons with disability are independent and autonomous, especially when given the right of freedom to make their own choices.
15. Disabled persons should be actively involved in decision-making policies and programs that relate to their population.
16. Acknowledging the difficult conditions that disabled persons face (such as race, color, sex, language, religion, political, national, ethnic, indigenous, origin, property, birth, age, or other status).
17. Recognizing the high rates of female persons with disabilities who are at risk in or outside of their home of abuse, neglect, violence, injury, maltreatment, and exploitation.
18. All disabled children have the fundamental right to freedom on an equal basis.

19. All efforts must be made to incorporate gender perspective to promote enjoyment of human rights and freedom.
20. Recognizing the severity of poverty that disabled people experience and work towards changing that poverty.
21. Protecting all disabled people during armed conflicts and foreign occupation.
22. The importance of physical, social, economic, cultural access to health, education, and communication.
23. Striving to promote the rights of disabled people as recognized in the International Bill of Human Rights.
24. All disabled persons are entitled to receive protection and assistance to enable their families to continue to enjoy full life experiences.
25. Understand that the International Convention will continue to support and make significant contributions to address all barriers, allowing full participation in social, political, economic, cultural involvement by all disabled persons (IDA, 2009, p. 20-32).

Problem Statement

The 2006 CRPD program sought to raise global awareness regarding persons with disabilities, and to foster respect for the rights and dignity of all persons with disabilities (United Nations, 2006). This Convention is important to the successful inclusion of all children within the education system of Guyana (United Nations, 2006). As such, the Community Based Rehabilitation Program (or CBRP) was established in Georgetown Guyana to help disabled people and their families. The goals of the CBRP are to teach, encourage, and empower disabled people to become independent and self- reliant (United Nations, 2006)). In addition, the CBRP provides assistance to caregivers of disabled children in the form of caregiver education, through caregiver training skills classes, focus and support groups, and methods for attaining resources to effectively advocate and care for their disabled children(United Nations, 2006).

The goal of this evaluative case study was to examine and assess whether the CBR program serves caregivers of disabled children effectively, identify the positive and negative aspects of the program, and recommend measures that can be introduced to improve the program as well as caregivers' ability to advocate and care for their disabled children in Guyana. This program has never been evaluated, and the need for this evaluation study encompassing caregivers' perception is supported by data collected by the UNICEF (2006) indicating that 75% of Guyanese children with a developmental disability are neglected, and 15% of the overall disabled population have never attended school (Ministry of Health Guyana, 2008). According to this report, these children are not provided with adequate care, such as appropriate parenting and education, which leaves them vulnerable and at risk for abuse and death (World Health Organization[WHO], 2008).

The lack of medical professionals and facilities, widespread poverty, inadequate education, and cultural/social barriers are a few of the influential factors that have been identified as having a direct impact on the future of Guyanese children with a disability (WHO, 2008). This impact is pervasive and affects families and their community psychologically, economically, and emotionally (WHO, 2008). According to a study conducted by Ajodia and Frankel (2010), parents of disabled children reported feelings of hopelessness, depression, and helplessness. The lack of access to outside resources provided in schools and communities to support their families was also found to have had a direct affect on these parents' income and ability to financially support their families and address the special needs of their disabled children (Ajodia & Frankel, 2010).

I designed this study to assess the perceived effectiveness of the 2006 Convention on the Rights of Persons with Disabilities CBR program and its impact on caregivers' ability to advocate and care for their disabled children in Guyana. I will provide a brief analysis of past reform programs and propose changes for present and future reform initiatives likely to result in a more successful and inclusive educational system in Guyana. There has not been an official assessment of the achievement of the CBR program in Guyana since its inception. In this evaluative case study, I sought to provide a deep understanding of the perceived effectiveness of the CBR program to assist decision makers in finding resolutions that may improve the quality of, and access to, the educational system for children with disabilities in Guyana. Findings from the study may also lead to improvements in Guyana's economy with a better-educated and inclusive labor force and population. Children with disabilities are among the poorest in the world and experience negative attitudes and discrimination(United Nations, 2006) ; these conditions make it more difficult for people with disabilities to go to school, acquire employment, and participate in local social activities(United Nations, 2006(. In many countries, the environment, both rural and urban, poses immense challenges, including, but not limited to, gender, sexuality, ethnic, economic, physical, and communication barriers that make it hard for people with disabilities to participate in social life (WHO,2008). The results of this study are expected to add to the research on the prevalence, consequences, and challenges that caregivers of disabled children face in comparison to their typical nondisabled peers.

Purpose of the Study

The purpose of this evaluative case study was to assess the perceived effectiveness of the 2006 Convention on the Rights for People with Disabilities Community Based Rehabilitation program in providing resources to the parents of disabled children, and examine its impact on caregivers' ability to advocate and care for their disabled children in Georgetown, Guyana. This was accomplished by examining the Community Based Rehabilitation Program, which is one of the programs developed and implemented as a result of the 2006 convention. This program provides interdisciplinary and rehabilitative services (such as speech, audiology, occupational therapy, special education and vocational training to disabled children), as well as helping caregivers to improve the way they advocate and care for their disabled children. This study seeks to identify the positive and negative aspects of the Community Based Rehabilitation program that increase, and improve caregivers' involvement. Findings from this study will guide our recommendations for improvements likely to help in the development of effective education reform and policies for the disabled. In addition, the results derived from this study will be made available to the Ministry of Education and Public Health to use in improving the overall quality of care and access to resources for caregivers of disabled children in Guyana.

Research Questions

I sought to answer the following research questions:

RQ1. What is the caregivers of children with disabilities’ understanding of the extent to which the 2006 Convention on the Rights for People with Disabilities Community Based Rehabilitation Program promotes caregiver education and ability to care for and advocate for the overall well-being of their disabled children?

RQ2. What follow-up resources can be implemented to assist caregivers in being able to advocate and sustain successful change in Guyana for disabled children?

Conceptual Framework

The conceptual framework guiding this research study is systems approach because it offers unique opportunities to reach a better understanding of disability reform likely to be helpful for our target population (Johnson & Christenson, 2004). Historically, Guyana has implemented nonsystemic, piecemeal disability reform approaches to solve problems within the macro learning systems for the disabled with little success (UNESCO, 2006). For example, permitting disabled students to attend regular education schools without also considering and implementing other necessary components in that decision to insure its success and that the challenges are managed from a systems approach. The word *system* and phrase *systems approach* have become an acceptable part of the language of administrators and policy makers (Hanson, 1994). Describing and analyzing how programs for the disabled are organized as well as how the subparts interact in the program are ways to explain a system. In addition to looking at one program for disabled persons system, the local, city-wide, county, or state systems also avail themselves of systems analysis to enhance the learning opportunity being offered to disabled students (Hansen, 1994). Reform and modification of state and city programs are expected to improve local programs and promote independence as well as growth within the disabled population.

This study was also framed following the general systems theory created by biologist Ludwig Von Bertalanffy in 1936 (Paquette & Ryan, 2001). General systems theory allows the examination of complex interpersonal, intrapersonal, inter-group, and human nature interactions without reducing the phenomenon to individual stimuli. It capitalizes on real interpretations and provides a platform for integration of complexity and human experiences. The view is that each element has an effect on the functioning as a whole, and is affected by at least one other element in the system. The advantage of using general systems theory is that the theory itself has the potential to provide trans-disciplinary framework for simultaneous exploration of relationships as they purport to represent. We find that this theory helps to understand the extent to which complex factors affect the care of disabled children in Guyana (Skyttner, 1996). In addition, we also find that this theory helped to provide meaningful information on the effects of having children with a disability and its impact on caregivers' ability to care for their disabled children (Laszlo & Krippner, 1998).

This study is also influenced by Rotter's social learning theory in that it provides additional understanding and conceptualization of attitude, behaviors, reactions, and perception in a specific culture. Social learning theory places emphasis on the observation and modeling of various factors such as attitude, behaviors, perception, and emotional reactions (Rotter, 1966) This theory methodically expands and changes over time and is rooted within the reality of social action and interactions (Rotter, 1966). This theoretical framework allows individuals to freely adopt behavior that is modeled with favorable outcomes and results, organize, and rehearse modeled behavior symbolically. It also allows for the enacting of the behavior overtly as well as the functional value of the behavior (Rotter, 1966). The general framework of the theory is likely to help caregivers learn and understand resources to improve the overall well-being of their disabled children and their overall outlook.

Nature of the Study

This evaluative case study examines the perceived effectiveness of the Community Based Rehabilitation program that was implemented as a result of the 2006 Convention on the Rights for People with disabilities in Guyana to determine the positive and negative attributes of education reform and disability awareness initiatives, as well as to make recommendation that can improve the access to quality resources for the caregivers of disabled children in Guyana. Methodology used in evaluative research has been found to be extremely effective in determining whether programs are attaining their intended goals and services are being administered and managed appropriately (Singleton & Straits, 2005).

This evaluative case study approach was conducted over a four – six week period and utilized structured surveys, interviews, caregiver focus groups, analysis of archival data, and facility observations.

The population selected for the research study only included caregivers of disabled children selected through snowball and convenience sampling methods. No persons with a disability were used for the research study. Letters were sent to inform and invite caregivers with disabled children who are involved with the Community Based Rehabilitation program to participate in the study.

During the initial process, selected caregivers were provided with a general information about the scope and intention of this research project and the articles and goals of 2006 Convention of Rights for People with Disabilities. Interviews were conducted in order to gain a better understanding of the most significant factors that are impeding on caregivers' ability to care for and advocate for their disabled children. This researcher also examined whether there was a change in their understanding and overall outlook in their ability to care and advocate for their disabled children upon completion of the program.

Assumptions

Upon review of the goals and articles that were put in place by the rights on the 2006 Convention for People with Disabilities, it has become abundantly clear that these goals cannot be appropriately implemented in Guyana without adequate training and education of caregivers and professionals. To examine the extent of implementation of these goals, Guyanese caregivers with disabled children will be asked to provide their individual experiences (e.g., success stories, challenges) and how these experiences impact their ability to care for and advocate for their disabled children. It is expected that training and education will result in a change in the overall outlook of Guyanese caregivers' ability to care for their disabled children with an increased understanding of their disabled child after being exposed to focus groups, caregiver education, and support groups.

Significance

This qualitative case study is expected to add to scholarly research and literature on a regional, national, and international level in areas such as education, social work, psychology, and public health policies. Creating and implementing programs, focus groups, caregiver support groups, and protocols to accommodate disabled children in school and community settings are expected to provide a framework for an integrated programmatic approach for this population, which also includes educating caregivers on the rights and needs of the disabled. The results of this study are expected to highlight factors that impede on caregivers ability to care for and advocate for their disabled children. This study also explores and identifies factors that affect the care of children with disabilities within Guyana, assesses the effectiveness of The Community Based Rehabilitation program that was put in place by the 2006 Convention on the Rights for People with Disability, and raises awareness meant to reduce stereotypes that minimize the care, advocacy, and rights of disabled children. The data and information gathered from this study is expected to assist in understanding specific barriers in need of modification and change to improve communication skills between teachers, professionals, and caregivers of disabled children as well as policy makers. The findings of this study are also expected to help in understanding disability, improve the psychosocial well-being of disabled children, and create frameworks that can be generalized to similar immigrant populations in the Caribbean (e.g., Trinidad, Jamaica, and Grenada) that share similar characteristics.

Summary

The 2006 Convention on the Rights for People with Disabilities called for recognition, implementation of proper care and reform for disabled people; however, Guyana has not fully adhered to the needs of this population as reflected by the fact that even the term "disability" is yet to be defined. There are many challenges that caregivers of disabled children face within Guyana. Some of these challenges include a lack of resources to facilitate appropriate school and community involvement, medical professionals and facilities to promote caregiver education, caregiver support, focus groups and advocacy, as well as a lack of teacher and professional training. This study sought to explore and identify positive and negative factors that affect the care of disabled children, examine the effectiveness of the of the CBR program, and assist caregivers in improving their ability to care for and advocate for their disabled children in Guyana.

Chapter 2: Literature Review

The primary focus of this evaluative case study was to examine the perceived effectiveness, strengths, and weaknesses of the CBR program that was put in place by the 2006 Convention on the Rights for People with Disability in Guyana and assess its impact on caregivers' ability to care and advocate for their disabled children. The secondary focus was on identifying program areas in need of improvement to effect positive change. The tertiary focus was to contribute to research and literature as well as raise awareness about disability in Guyana.

To provide a context for this study's purpose, in this chapter I provide a concise review of the current literature in relation to the challenges that children with disabilities experience, the understanding and ability of parental caregivers to care for their disabled children, and resources that have been identified as being effective in improving care and raising awareness and advocacy for the disabled population. First, the historical overview section in this chapter expands on Chapter 1's discussion of the theoretical foundation for this research study. This section includes discussion of general systems theory (Paquette & Ryan, 2001), and its relation to organizations and organizational structures that provide resources for the disabled population and caregivers with disabled children. It also includes a discussion of the social learning theory (Paquette & Ryan, 2001), and its relation to organizational culture and the care of disabled children and strategies to raise awareness and educate caregivers and professionals who are involved in addressing the needs of children with disabilities. This theoretical overview is followed by a review of studies of programs and initiatives implemented for the disabled population in Guyana. The chapter concludes with a summary of the available research and support for awareness and education for the caregivers of disabled children. I also provide information on local and state professionals and facilities that are involved in the care and education of disabled children. I also explore the international issue of large-scale reform of disability programs in developing countries and specifically in Guyana that could be helpful to advocates seeking to make programs for disabled populations more effective and sustainable.

Theoretical Foundation

I concluded that systems theory Paquette & Ryan, 2001), was the most appropriate theory for this research study to allow for a full understanding of the challenges that parents of disabled children face. Systems theory provides a framework for understanding complex entities that are created by multiple interactions that are abstracted from the structure and components, while also concentrating on the dynamics that define the characteristic functions, properties, and relationships that are internal and external to a system (Paquette & Ryan, 2001). Systems theory provides a trans-disciplinary framework to explore and understand individuals' perception and conceptions of the world Paquette & Ryan, 2001). It encompasses the multiplicity of interrelations of human beings and processes that are specific to culture, society, and nature.

Systems theory capitalizes on interpersonal, intrapersonal, and intergroup interactions without reducing perceptual phenomena to individual stimuli, while at the same time allowing the interpretation of the reality of human experience Paquette &

Ryan, 2001). The theory was advantageous for this study because it allows for a consideration and examination of the effect of each element in a system and how it functions as a whole Paquette & Ryan, 2001), created by Von Bertalanffy in 1937 (Paquette & Ryan, 2001), systems theory focuses on human development and how it influences an individual's developmental process (Paquette & Ryan, 2001). It is in keeping with Paquette and Ryan's (2001) ecological systems theory which identifies five environmental systems (microsystem, mesosystem, exosystem, macrosystem, and chronosystem) that influence an individual's development, with each system considered to be interrelated and each layer affecting one another.

Microsystem refers to the individual's own biology, environment, and structure Paquette & Ryan, 2001). It includes relationships and interactions with caregivers, school, teachers, and community. *Mesosystem* includes the experiences in the microsystem and how they influence each other Paquette & Ryan, 2001), the extent to which an individual's experiences at home affects his or her experiences at school). *Exosystem* consists of the larger layer of a social system with which the individual does not have direct contact but is nevertheless positively or negatively affected by Paquette & Ryan, 2001) . For example, if a child is left unsupervised for long periods of time with a sibling due to the demands of the parent's job, his or her development will be influenced as a result. *Macrosystem* is the outermost layer that consists of state and culture in which the individual lives; it includes values, customs, traditions and socioeconomic status Paquette & Ryan, 2001). For example, strict cultural expectations and practices can influence the development of individuals living in developing countries. Finally, c*hronosystem* is the timing of one’s physiological or events that occur during an individual’s development Paquette & Ryan, 2001) . An example of this system effect is the influence on a person’s development of losing a parent.

I expected that systems theory would provide me with valuable information related to data about parents’ backgrounds, culture, medical and psychological history, education, society, previous experiences, socioeconomic status, and parenting styles, which I could use to examine the challenges caregivers of disabled people face in caring for disabled children. My ultimate goal was to provide recommendations that could benefit caregivers of disabled children, improve the psychosocial well-being of these children, and provide the necessary conditions for professionals in the field, teachers, and policy makers on the local, regional, and international levels to engage in the struggle to combat negative societal effects of disability.

Literature Review Related to Key Variables and/or Concepts

Historical Overview

The overall picture that emerged from this review suggests that the education system for the disabled population in Guyana is in dire need of improvement and change. The literature in the review supports the importance of educating administrators, policy makers, teachers, and caregivers to understand disabled children and their needs (Ministry of Education, 2005). I used general systems theory Paquette & Ryan, 2001), to guide my analysis because this model allowed for a more careful examination of the unique need of my target population and its relation to changes within systems and organizational structures. Using this theory, I was able to illustrate that the quality of care for the disabled population in countries like Guyana is not equal to developed countries and argue that the concepts and strategies employed in the delivery of education for the disabled population need to be further examined. In general, caregivers of disabled children experience many challenges in caring for and advocating for their disabled children. Some of these challenges are due to limited access to effective schools, resources for community involvement, socioeconomic status, transportation, and appropriate housing(United Nations, 2006).

The output of the 2006 Convention on the Rights of Persons with Disabilities resulted in 50 articles, which depicted in detail the plan for change to address the needs of disabled persons in developing countries (see Appendix G). Guyana signed the Convention on the Rights for Disabled Persons with Disabilities on April 11, 2007 agreeing to afford appropriate treatment and care of persons with disabilities regardless of their race, place of origin, political opinion, color, creed, age, disability, marital status, sex, gender, language, birth, social class, pregnancy, religion, conscience belief, or culture (United Nations, 2006). Although the 50 Articles delineated by the United Nation are meant to address issues likely to affect the welfare of all individuals with disabilities, this study will be focusing on areas articulated in Articles 1,2,4,8,9,14 and 20, which are summarizing below. Since this study will also assess Guyana's implementation of areas articulated in Articles 23 and 24 related to the educational needs of children with disabilities, we are also summarizing them below(United Nations, 2006):

- Article 1 stressed the need for appropriate communication to include languages, text, braille, tactile, large print, written, audio, multimedia, human reader and technology. Language includes spoken, signed, and other non-spoken languages. Article 1 also stated that there would be no discrimination against persons with disability, including any distinction, exclusion, restriction, and denial of reasonable accommodations. By reasonable accommodations is meant any necessary and appropriate modification or adjustments that does not pose a burden, to ensure that all persons with disabilities can enjoy their fundamental human rights and freedom on an equal basis.

- Article 2 stressed that the universal design of all products and environments must meet the needs of disabled people without the need of adaptation or specialized design.
- Article 4 stated that all efforts must be made to undertake, ensure, and promote full realization of all human rights and freedom without discrimination for persons with disabilities. This includes adopting all legislative, administrative, and other necessary measures for the implementation of appropriate customs and practices, policies and programs, and promoting research and development to meet the needs of all disabled people. In addition, Article 4 supported the training of professionals and staff working with disabled people to provide better services to this population.
- Article 8 stressed the importance of raising awareness and promoting awareness-training programs throughout society at the family level, to foster their full capabilities, respect and rights, education, positive perception, and

greater social awareness to combat stereotypes, prejudice, and harmful practices.

- Article 9 maintained that all disabled people have a right to live independently and be provided with a physical means to transportation, information, and communication technologies and systems in public urban or rural areas. This includes building roads, transportation, indoor and outdoor facilities, such as schools, housing, medical facilities, emergency services and workplaces.
- Article 14 specified that all disabled persons have a right to liberty and security on an equal basis.
- According to article 20, effective measures must be taken to facilitate personal mobility, mobility skills, and quality mobility aids and devices for persons with disabilities.
- Article 23 focused on respect for the home and family. It described that the home and families of all persons with disabilities will be respected and supported in regards to marriage with free and full consent, deciding on the number of children they want to have, and the right to procreate, retaining fertility, child rearing and family skills education.
- Article 24 maintained that appropriate and effective education would be provided to all disabled people regardless of their level of disability to enhance a sense of dignity, self-worth and freedom. This includes education on the nursery, primary, and secondary level by trained professionals who can

> facilitate education in all forms including language, mobility skills, peer support, mentoring, and social development.

In the United States, caregivers of disabled people benefit from many services and resources provided by the state they reside in as mandated and articulated in the 1973 Committee on Special Education Act. For example, caregivers in the United States can receive one-to-one assistance in school, counseling, and educational services for their children, community involvement, and respite care. Caregivers are also encouraged to advocate through schools and community programs to better the lives of their disabled children.

In some other parts of world, however, children with disabilities and their caregivers do not fare that well. For instance, according to Boberiene and Yazykova (2014), children who are born with a disability in Russia are considered defective and socially segregated. These children tend to be placed in large institutions that are inadequate and poorly managed. When these children become adults they are sent to a larger mental institution and ostracized from society. As a result, these adults tend to suffer from profound socio-emotional, cognitive, and behavioral difficulties. In addition, they suffer retarded physical growth, diminished intellectual aptitude, and depressed language development. Similar to many developing countries, Russia did sign the Convention on the Rights for Persons with Disability; however, implementing changes, securing adequate resources, education, and awareness have yet to be done effectively.

In Guyana, South America, we witness similar response in that caregivers struggle to access appropriate services to help improve the lives of their disabled children. There are no CSEA committees or state programs to help facilitate appropriate education, advocacy, and community involvement. Thus, leaving the disabled population and their families to face their challenges on their own. Caregivers are in need of skills training, additional programs, access to advocacy resources and services to improve their ability to understand and advocate for appropriate services for their disabled children (United Nations, 2006).

A very different response to the need of disabled children is found in countries like the USA and Canada that have made significant gains in supporting disabled children and their families by keeping them with their families instead of resorting to institutionalization (National Institute of Mental Health, 2013). There are more than half of a million children in Canada with some form of disability (National Institute of Mental Health, 2013). One hundred and fifty thousand children are between the ages of 5 to 14 (National Institute of Mental Health, 2013). Most relevant for our project is the fact that these countries have developed a clear definition and criteria to identify various forms of disability (for example, cognitive and physical). Such a development is helpful in being able to create and implement the kind of resources and programs to support disabled children and their families available in these countries. This is particularly the case with regard to programs for caregivers of disabled children to assist them in caring for and advocating for their disabled children. There are also more readily available programs with caregiver support and focus groups to assist caregivers in learning about their children's disability and effective ways to help them in school and integrate into the community (U.S. Department of Education, 2015).

Several states in the U.S. provide day and interdisciplinary programs, which include educational, vocational, and adaptive training to teach and increase independence in disabled children. Some of these programs are made possible with the active involvement of the Office for People with Developmental Disabilities as well as the Office of Mental Health. These offices provide the necessary oversight to assist caregivers in building and sustaining skills to help their children at home, school, and the community. Through these offices, caregivers are also afforded an opportunity to build and participate in support groups, which are helpful in keeping caregivers informed of new research, skills, and strategies to help their disabled children. In addition, these programs provide psychological assessments for disabled children that are instrumental in identifying specific disabilities and provide a clearer understanding of caregiver needs once identified (U.S. Department of Education, 2015). Supports for the benefit of these types of intervention are found in a report by The Families and Advocates Partnership for Education Program (2015) indicating that caregiver training skills classes and support groups reduce stress levels and empower families.

Challenges for Developing Countries

Implementing education and raising disability awareness are challenging for developing countries at various levels. For instance, research conducted by Eleweke and Rodda (2002) found that the facilities to accommodate children with disabilities are often inadequate or non-existent. Additionally, many developing countries lack basic educational materials and equipment to provide appropriate education for disabled children, educators, and caregivers. Facilities for the disabled population are quite rare and often only can be found in urban areas of developing countries. As a result, many children with disabilities who live in rural areas do not receive any form of education due to transportation and financial challenges (Eleweke & Rodda, 2002).

We recognize that maintaining suitable funding structure to support programs for the disabled or reforming of the education system would be a challenge for developing countries. Chaikind, Danielson, and Brauen (2009) estimated that providing educational services for children with disability would cost 2.3 times more than providing education for non-disabled children. As a result, education for children with disabilities tends not to be a priority for governments. In addition, there is often a lack of compulsory laws, policies, and legislation within developing countries to ensure the provision of inclusion and services for the disabled population (Eleweke & Rodda, 2002).

These challenges are particularly evident in various developing countries in the Caribbean. For example, Jamaica, Trinidad and Tobago have not yet implemented adequate policies and programs to promote awareness and education for disabled children (Bergsma, 2000). Neither country has yet developed policies to support the restructuring of the school system, caregiver programs and education, and training for teachers (Hall & Figueroa, 1998).

Although we found that there are some appropriate policies in place in Caribbean countries, their implementation remains in infancy for the most part. Armstrong (2005) examined eastern Caribbean countries of the Organization of Eastern Caribbean States [OECS] and found that there are some indications of reform for disabled children.

However, serious challenges still exist for being able to secure long term funding, adequate teacher training, and caregiver support and education.

There are other countries, such as Mongolia, that have been able to successfully implement and sustain some programs for disabled people by establishing a new inclusive education curriculum for their preschool teachers. These teachers are able to understand the level of disability of their students, create goals and plans to teach based on their level of learning, as well as including caregivers as part of the educational process (Jigjidsuren & Sodnompil, 2005). We also see positive movement in Costa Rica where the Ministry of Education was able to establish within the last decade, educational services to support children with disabilities, with laws to support their caregivers (Stough, 2003).

The Education System in Guyana

The Ministry of Education in Guyana consists of schools on three levels: nursery, primary, and secondary. This system was put in place after Guyana gained its independence from the United Kingdom (Britain) in 1966. Each level is responsible for the education of specific age groups. Nursery is from the ages of 2 to 5. Primary is from ages 6-10, and secondary is from ages 10-15. Upon completion of secondary school, students are encouraged to study at the University of Guyana, attend vocational school or study abroad (e.g., in the West Indies, England, Canada, United States, and Cuba). The education that is offered through this system is mainly for general education. This system does not cater to the education for disabled children. There is also a limited amount of services in terms of education that is available for disabled children. The few programs that are available have limited resources and trained professionals to teach disabled people (Ministry of Education, 2005).

One educational program that is available for disabled children in Guyana is The Community Based Rehabilitation Program [GCBRP]. The basic tenets of this program is to provide effective education to disabled children and their families, increase caregivers' involvement, raise awareness, and provide sustainable change to improve the care and advocacy of disabled children. This program also focuses on educating the disabled population academically and socially to foster independence and self-reliance, as well as providing assistance to caregivers of disabled children so that they are able to care for and advocate effectively for their disabled children (Ministry of Education, 2005).

Although this program provides education services to disabled children, there is still a need for teacher education and for caregiver education. One of the greatest challenges is that the program is not logistically available for the majority of the disabled population living in Guyana (Ministry of Education, 2005).

Attitudes Toward Disabled Children in Guyana

Oskamp (1991) suggested that attitudes and perspectives are learned traits that are influenced by physiological and genetic factors, personal experiences, caregiver and group experiences, the media, lack of awareness and education. Once established in the individuals, traits become part of the personal repertoire that guides the individual's interaction with his/her environment. The Ministry of Education and Cultural Development in Guyana (2005) stated that negative societal attitudes are the main barrier preventing children with disabilities from equal education access. Guyanese communities continue to stigmatize children with disabilities and perceive them to be a burden to society. Groenewegen (2004) also stated that, in addition to stigma, disabled persons are rarely presented with opportunities for self-development and employment. This view is supported in responses to a survey conducted by Mitchell (2005) on the perspectives and experiences of 1485 people with disabilities across Guyana. Mitchell (2005) also found that roughly 44% of disabled children experienced negative attitudes from Guyanese society due to their disability. Specific factors that were reported included typical areas amply discussed in the literature on bullying (Mitchell, 2005): name calling, staring, resentment, and exclusion. According to Mitchell, this led to feelings of hopelessness and contributed to low self-esteem and hindrance from being involved in society. The incessant discrimination also contributed to feelings of shame and disrespect for the caregivers of disabled children, leading to isolation.

Guyana has established and implemented a Community Based Rehabilitation program as a grass roots approach to include and integrate disabled children and their caregivers into neighborhood schools, raise awareness, and provide focus and support for caregivers. At this point, however, we are not clear whether the project resulted in additional development, sustainability, and reform for policies within Guyana. What we know is that Guyanese caregivers are still lacking resources to aid in their understanding and education of their disabled children.

The 2006 Convention of the Rights for People with Disabilities outlined a detailed proposal to provide appropriate assistance to caregivers to help with their disabled children. Despite the institutionalization of this program, caregivers of disabled children in Guyana continue to experience many challenges in caring for their children. The greatest challenges are the lack of education resources, medical and psychological guidance, caregiver support and education groups.

Caregivers are in need of support groups and education to help teach them to cope and manage their children's disability. They are in need of resources that will support their children in school and at home. These resources include communication, training in activities of daily living, and socialization skills building that can be generalized in school and community settings. According to Groenewegen (2004), the problem becomes more complicated because teachers in Guyana are unwilling or unable to embrace and teach a child with a disability in their classroom, and those few who are willing are not adequately trained to understand the specific disability needs of these children and teach based on the adequate understanding of their needs.

Caregiver Understanding and Awareness

Findings from Lindsey and McPherson (2011) suggest that raising awareness is expected to improve caregivers overall self-efficacy and their ability to care, interact, and advocate for their disabled children. In addition, a positive effect on caregiver-child relationship and caregiver-child attachment is also expected. Lindsay and McPherson (2011) conducted a qualitative study that examined parental reactions and understanding of their children's disability before and after support groups and awareness. Findings from this study suggest that initial common factors experienced by caregivers of disabled children were denial, anger, grief, loss, fear, guilt, confusion, disappointment, rejection, and powerlessness. Caregivers reported that their initial response in learning about their children’s disability was a tremendous blow to their immediate family’s self-esteem and confidence. They reported that they immediately internalized the news to be their fault. These caregivers engaged in self-blame shame, guilt and heartbreak. Some caregivers reported that they felt as though a sack was pulled over their faces and felt as though they were suffocating.

Caregivers reported that parent’s education classes and focus groups were extremely helpful in their understanding of their children’s disability. They also felt confident to advocate and seek help for their children within their society and environment when there was an open disclosure about disability and social inclusion.

The importance of education intervention was also endorsed by Mennen and Trickett (2011) who found that mothers of disabled children were in the 98th percentile for exhibiting high levels of anxiety and depression due to the lack of education, resources and assistance in understanding and advocating for their disabled children.

An important issue to consider when developing educational interventions in Guyana is the fact that caregiving style in Guyana is embedded in a dependent culture where there are unwritten rules and understanding of the way children should be raised. Within the Guyanese culture, every family has a hand in raising a child, whether it’s a grandparent, aunt, or teacher. Guyanese caregivers mostly resonate with an authoritarian style of parent, which is described by Baumrind (1964) as very rigid and unquestionable obedience. Our challenge is that, while we recognize that this parenting style (which emphasized control and rigid adherence to expectations) is not the most effective when it comes to understanding and caring for disabled children, we will need to consider its history when introducing a different style for this population. . Effective parenting for disabled children is found to require warm and openness so as to foster independence and resilience.

Chapter 3: Research Method

The purpose of this qualitative case study was to evaluate the CBR program in Guyana. I collected and performed a descriptive analysis of qualitative data consisting of surveys, interviews, caregiver focus support groups, program observations, and archival data. The data collection was instrumental in helping to (a) explore and identify factors that affect caregivers' ability to advocate and care for their disabled children within Guyana, (b) assess the perceived effectiveness of the CBR program; and (c) provide parental education in the form of focus and support groups that were expected to improve the ability of parents to care for and advocate for their disabled children within Guyana.

In an attempt to examine how different factors impact Guyanese caregivers' ability to care for their disabled children, I undertook an evaluative case study. This evaluative case study included qualitative components, which enabled a broad understanding of what resources would be most beneficial to improve caregivers' ability to care for and advocate for their disabled children in Guyana. In addition, collecting and analyzing qualitative data allowed me to assess change as well as better understand the research problem. Creswell (1998) asserted that this research method was effective in similar studies for direct interpretation, pattern recognition, categorical aggregation, and naturalistic generalizations. I concluded that this method was most appropriate for this research study because of the likelihood that it would provide results that were helpful to caregivers, teachers, administrators, and all professionals involved in caring for disabled children.

This chapter provides a description of the methodology for conducting an evaluative structured research study. It also includes sections that provide detailed information on the relevance and viability of the design, location, instruments, data collection process, and analysis, as well as the validity of the research.

Research Design and Rationale

I reviewed other research designs proposed in the literature but did not consider these to be appropriate for the present study. Examples of these designs are phenomenology and ethnology studies. With regard to phenomenological study**,** Creswell (1998) posited that such a study model is useful for explaining the day-to-day experiences of a group or society and examining the structures of consciousness in human experiences for various individuals about a particular phenomenon, as compared to a biography, which only examines the experiences of one individual. In analyzing data for a phenomenological study, a researcher uses the method of reduction and searches for all possible meanings and themes (Creswell 1998). This approach was not suitable for this study because it would have minimized or discredited the day-to-day experiences of participants, as well as the positive and negative impact of the CBR program.

With regard to ethnological study, Singleton and Straits (2005) described the model as focusing on a detailed description of a culture collected during field research. Creswell (1998) added that, in addition to a detailed description, it is an interpretation of the culture, social group, or system. In contrast, I collected data from existing documentation, surveys, observations of participants, and interviews. I surmised that the ethnology method was more suitable for a longitudinal study and was not appropriate for this research study with its limited 4-6 week time frame for data collection.

I determined the evaluative case study model to be the best fit for my investigation because it includes a clear and concise objective and it allows for the examination of expression of higher learning and critical thinking through the use of nondirectional verbs of the participants, for the clear identification of the participants, and an open and creative collaboration between the researcher and participants. It permits the exploration of a bounded system or case over a period of time through the assessment of detailed in-depth data that includes multiple sources of information (Creswell, 2005). Finally, it allowed for an evaluation of the positive and negative impact of the CBR program and its impact on caregivers of disabled children in Guyana. For example, it allowed me to examine the quality and nature of the academic and educational resources that are currently being provided to parents (e.g., parent workshops in specific subjects, homework sheets, reading materials, etc.).

Additionally, researchers have found this evaluative method to be effective in qualitative educational research, especially with respect to public policy and public programs. As suggested by Weiss's (1998), "the systematic assessment of the operation and/or the outcomes of a program or policy, compared to a set of explicit or implicit standards, as a means of contributing to the improvement of the program or policy" (pp. 13-25).

Role of the Researcher

In this evaluative research study, I served as the primary instrument for the collection and analyzing of all data. Hatch and Yin (2003) posited that conducting an exceptional case study requires the researcher to have exemplary skills and training to facilitate the necessary steps in a research study. I believe that I have the qualities described by Hatch and Yin in that I have extensive experience as an adjunct lecturer, program and facility administrator, researcher, and parent educator required for this role. In addition, I have extensive and recognized knowledge about the culture, population, and organizational systems. These skills helped me to create a strong therapeutic alliance with the participants.

Methodology

Five key elements of evaluation research were employed in this case study: (a) evaluation procedures was conducted by systematically employing formal and rigorous processes, (b) an in-depth analysis of the internal functions and implementation procedures of programs was used to assess efficacy and success, (c) the focus was mainly on the effects of program outcome on the intended target population, (d) there was a comparative assessment of program expectations, and (e) the purpose for conducting the evaluation was clearly stated at the outset (Weiss, 1998). Weiss (1998) further noted that "[e]valuation is a practical craft, designed to help make programs work better and to allocate resources to better programs" (pp. 31-47). This statement describes how the goals of the kind of evaluative study I performed should be carried out so as to ensure its effectiveness. I gathered detailed information from various sources in order to increase the effective evaluation of the efficacy and impact of educational reform initiatives in Guyana and consider their applicability. This approach enriched not only the quality of the pertinent data but also strengthened the validity of the study, I believe.

Participant Selection Logic

I invited 60-100 caregivers of disabled children who were receiving resources and services from the CBR program in Guyana for at least a year to be part of this project. Of those, only 73 became part of the project. Participation was voluntary. None of the caregivers reporting having a disability.

I used a convenience sampling method and snowball techniques to select the participants. Convenience sampling is a method that is used by researchers who have eager volunteers willing to engage and contribute to a study (Creswell, 2003). The snowball sampling method has been found to be effective in acquiring additional participants for a study.

The site and sample population for the study were selected based on their involvement and experience in caring for and advocating for disabled children in Guyana. This site is The Community Based Rehabilitation Program [GCBRP], located in Georgetown, Guyana, and is readily accessible and convenient to the participants. This program services approximately 1000 disabled children and employs about 500 professionals.

The participating caregivers were asked by the researcher to help in identifying additional individuals who would be willing to participate in this research study. Caregivers selected for this case evaluative study had at least one child with a disability.

All caregivers who wished to participate in the study were used throughout the entire duration of the study.

Instrumentation

All obtained data and information were gathered through the use of survey questions, parent observation, interviews, follow up phone calls and caregiver focus support groups. A modified version of a quality of education survey created in 2006 by Clay was used for this qualitative case study with permission from the author (see appendix H). One-to-one interview questions focused on the self-assessment and experiences with raising disabled children. The survey data was collected from the structured 22-item survey that was hand delivered to the participants (see appendix C).

These complex and innovative instruments of data collection allowed the researcher to collect information with depth and breadth. According to Singleton and Straits (2005), conducting systematic and structured interviews, observations, and questionnaires enhance the reliability of the data. This strategy of utilizing systematic and structured interviews, parent observations, and questionnaires was designed to ensure the researcher's interactions were consistent with the participants and facilities involved in the study.

Procedures for Recruitment, Participation, and Data Collection

Data collection included a survey, observation of parent interaction, interviews, and a review of documents. Initially, letters were sent to caregivers of the program inviting them to participate in the research study. Caregivers were informed about the process including the one- on-one interviews, filling out the survey, and post interviews.

Before conducting the survey, the researcher was introduced as a doctoral candidate who is studying in the United States at Walden University. The participants completed the survey in the presence of the researcher at the selected facilities in an area selected and confirmed by the researcher and CBRP administrator. The surveys took each participant approximately 5-10 minutes to complete, and all completed surveys were collected and analyzed by the researcher immediately after completion.

The survey was initially tested through a pilot study. The purpose of the survey was to assist this researcher in determining the effectiveness of the CBR program, specific areas of the Program for improvement, as well as determining specific needs of caregivers to help enhance their ability to improve the lives of their disabled children. The Survey consisted of two sections with a total of 22 questions. The first section was designed to help to examine what resources and services are being provided to caregivers and the effectiveness of these services and resources. The second section was designed to help to examine what measures are being taken to ensure that caregivers are able to advocate appropriately for appropriate education, health, and safety services for their disabled children at school, home, and in the community. Each survey took approximately 20 minutes in length.

The survey questions focused on quality of caregiver support and experiences with the Community Based Rehabilitation program, health, safety, and security of the CBR facility. This was to examine the safety of their disabled children within the CBR program as well as at home. One-on-one classroom observations were conducted onsite at the Community Based Rehabilitation Program to observe caregiver's skills learned through the CBR program while interacting with their disabled children. This was helpful in determining the extent of the caregivers' needs. The questions in each part of the survey were designed to assess whether the CBR program is adhering to the articles of the 2006 convention on the rights for people with disabilities in providing appropriate resources, skills to assist with their disabled children at home, and strategies to improve their overall lives.

Individual interviews were conducted with participating caregivers on a one-to-one basis to gain an understanding of caregiver overall outlook, the challenges they face in caring for and advocating for their disabled children. Thus, questions pertaining to their ability to communicate effectively to understand the basic needs of their disabled child, attend to and teach daily living (such as facilitating independence with eating, brushing their teeth, bathing etc. and social interaction with peers) were explored. Also, documents related to functional behavior analysis, behavior intervention plans, ABC data forms etc. were examined for reoccurring behaviors and trends that are challenging for caregivers; example of data gathered in this regard included information about intensity, duration, and frequency of maladaptive behaviors, along with how many times these behaviors occur; it also included information about their severity, how long they last, specific triggers (such as where, when, and with whom does these behaviors occur), effective/non effective strategies, and goals that were put in place to address maladaptive behaviors. This process was designed to assist in identifying specific needs for caregivers which could, in turn, help in creating specific goals to assist caregivers with improving the way they communicate, teach, and foster independence in their disabled children.

Information gathered through the initial interview was then utilized to design and implement caregivers skills classes, and caregivers focus support groups to assist caregivers with some of the challenges reported. Caregivers were interviewed both in person and follow up phone calls following the intervention period (i.e., the administration of the caregivers skills classes and focus and support groups) to assess the outcome of the intervention related to any changes in their overall outlook in their ability to care for and advocate for their disabled children. This information provided important feedback regarding the effectiveness of the CBR program and what is needed to improve the services and resources provided to caregivers.

All allowed recordings, notes, and documents gathered were transcribed. Participants were read the researcher's observational notes to validate and verify responses for accuracy and clarity. Comparison of transcripts, observational field notes and government documents were cross-referenced with different resources to establish validity. The administration and assessment were conducted in private offices, boardrooms, or classrooms.

Data Analysis Plan

This study employs Creswell's (1998) most powerful strategies of triangulation and member checks for its data analysis. Triangulation allows the collection of data from additional sources to support the study and a member check means taking research findings and interpretations back to the participants for their authentication and viewpoints. Cresswell (1998) supported triangulation and member checks as a way to verify data analysis. The procedures for these strategies are considered more simple to conduct popular and most cost effective than other strategies.

These strategies were also found to be beneficial for this study because it assisted in the data analysis process through validation and verification. The data analysis process included examination of collected information and determining the common threads among all participants' responses The common threads were summarized and organized in quantified terms according to the number of participants who selected each major thread. All responses were presented in a variety of formats, which included tables, figures, and text. Interpretative analysis was used to assess and evaluate caregivers understanding of the effectiveness of the Community Based Rehabilitation Program.

Issues of Trustworthiness

Reliability and Validity of Data

Various strategies were incorporated to ensure the reliability and validity of the study. NVIVO Qualitative software, that was found to show good validity and reliability values in a previous qualitative study (Zamane, 2015), and Cronbach alpha were used to analyze the qualitative components of this study. These strategies were important to strengthen and increase the validity of the study (Creswell, 1998).

Ethical Procedures

Caregivers were informed that their names and identities will not be revealed. Caregivers were given a synopsis of the intention of the study and were then invited to sign up to participate in the study on a voluntary basis. A consent form was also distributed to each participant and organization as part of the confidentiality procedure. Generic labels were used to protect any and all identity. All research documents were stored at the residence of this researcher.

To conduct a study in Guyana, the Community Based Rehabilitation Program requires permission from the Indian Diaspora Council. Written permission was obtained from the Indian Diaspora Council’s president. A total of 73 consents were signed by caregivers of disabled children who attend the Community Based Rehabilitation Program and who completed the surveys.

Summary

This evaluative case study sought to examine the effectiveness of The Community Based Rehabilitation program that was established as a result of the 2006 Convention on the Rights for People with Disability. Previous findings suggest that caregivers of disabled children are not being afforded appropriate educational, medical, psychological resources, or community and school involvement to assist in caring for their disabled children (Ajodia-Andrews & Frankel, 2010). The current investigation seeks to evaluate the extent to which this neglect is present among caregivers of disabled children in Guyana. The data and information gathered from this study are expected to assist in creating the necessary condition to improve the care for disabled children and support for caregivers of disabled children locally and globally.

The Community Based rehabilitation Program in Guyana has the potential of effecting social change on a local and global level regardless of its success. At a local level, it is expected that disabled children enrolled in the program would benefit from resources to education, community, and vocational training offered in this program. If found successful, these programs are expected to aide in developing skilled professionals at a global level, with the resulting benefit of increase in their socioeconomic status. If unsuccessful, Guyana would be considered noncompliant with the 2006 Convention in that it will be violating the rights of disabled children, as well as hindering the positive development of education and positive social change for this population.

Chapter 4: Results

The overall picture that emerged from the analysis of all available data is that the program provided to disabled children and their caregivers is in dire need of improvement if Guyana is to be in compliant on the 2006 Convention on Rights of People with Disabilities. I will now present each of the components in support of this finding.

Setting

The building that houses the CBR program was found to be inadequate and ill-equipped to serve the need of the disabled population. For instance, there was no bridge over the trench that separated the building from the road, which thus created a dangerous situation for users who were disabled. Caregivers and their disabled children had to walk through mud patches and go around the building in order to enter the facility. The building consisted of one office, a library, a bathroom, and two classrooms. The library had only a few books which, according to the teachers, were not appropriate for the children they serve. The furniture in classrooms was found to be broken and disheveled, and the bathroom was barely functional and with no running water. Commenting on that issue, those interviewed reported that they collect water in a bucket at the beginning of the school day and store for later use. Another finding is that there were no functional windows in this building, which created a major problem with ventilation. I observed that the building has grids that are imbedded within the concrete walls to permit fresh air. However, sand was found to seep through these grids, creating unsanitary conditions for children to learn. Finally, the lighting was found to be poor and no safety plans in place for emergencies were evident. Taking all these components together, it is abundantly clear that the condition of the environment dedicated to provide services to one of the most vulnerable populations in the Guyana society raises serious questions regarding the implementation of the 2006 Convention.

Data Collection

Archival Data

When I assessed the availability of archival data, I found limited data sets I could use in my research. The teachers at the CBR program took attendance manually in a book they referred to as their “student’s register.” The main form of communication was found to be verbal, which does not provide the necessary structure for adequate follow-up regarding the implementation of the information provided. For instance, teachers reported being able to speak with caregivers who are able to pick their children up from school to provide feedback on performance and upcoming events. Caregivers who are unable to pick their children are sent messages via other caregivers.

Technology and Other Resources

Regarding technological tools that could be used in the storage and access to relevant information that could assist teachers in performing their educational duties, I found that the CBR program had only one computer that was also barely functional. In addition, in my conversation with the teachers, I found that the textbooks that were used to create lesson plans were not appropriate for the children who attended the program. Finally, I found that there were no formal assessments to create or collect baseline data and hence no clear structure that would allow for the development of appropriate and verifiable plans to address behaviors or reinforce learning.

Results

Quality of Caregiver Survey Results

I analyzed the results of Questions 1,6,7,20 and 22 from the survey and Questions 1-4 from the interviews to address RQ1. As suggested by Creswell (2005), I organized the group results by questions and coded responses. Table 1 presents the code key for analyzing participants' responses to the survey.

Table 1.

Code Key for Survey Responses

Survey response	Code
Strongly disagree	SD (1) Series 1
Disagree	D (2) Series 2
Neutral	N (3) Series 3
Agree	A (4) Series 4
Strongly Agree	SA (5) Series 5

The analysis of each question and responses appear in Figure 1 and Table 2.

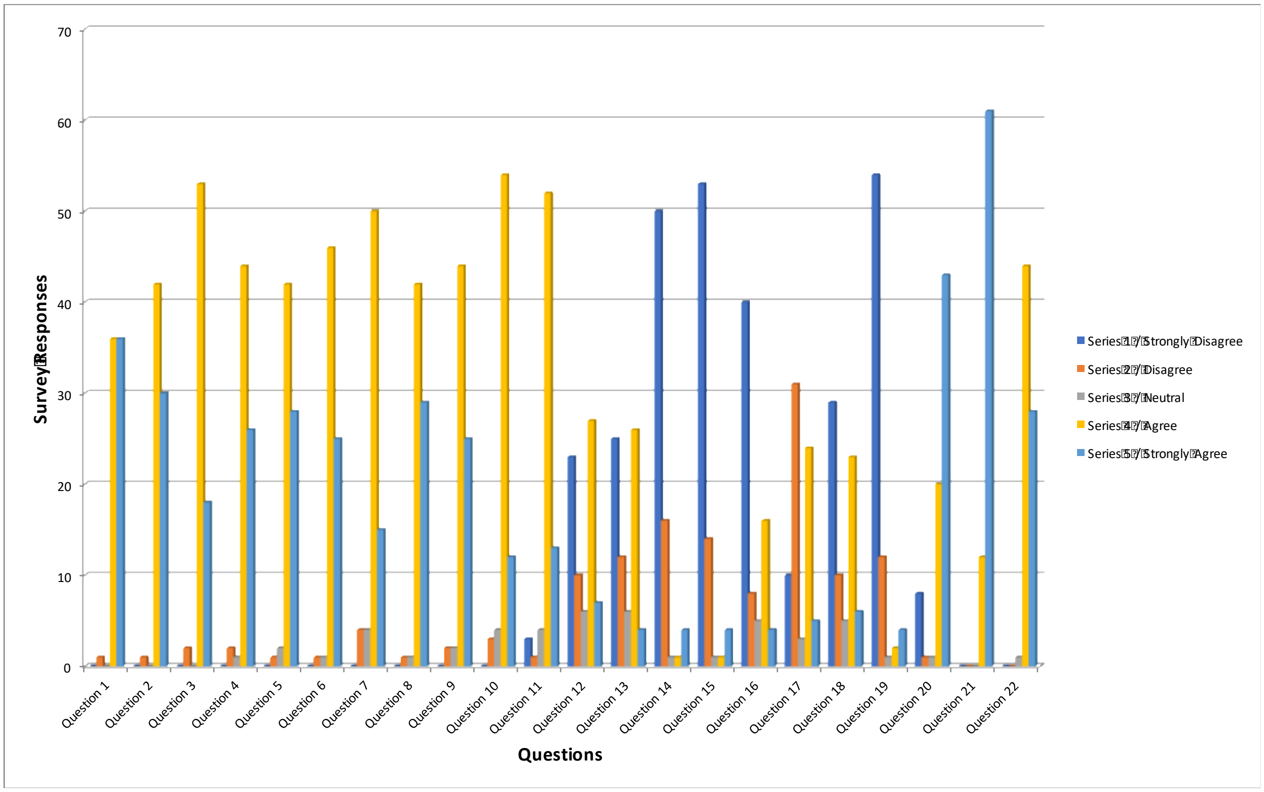


Figure 1. Bar graph showing the survey responses of the caregivers who participated in the Community Based Rehabilitation Program.

Table 2

Results for Quality of Caregiver Survey

Question	Strongly disagree (%)	Disagree (%)	Neutral (%)	Agree (%)	Strongly agree (%)
Q15. The CBR	72	19.2	1.4	1.4	5.5

program has sufficient technology resources for research and instruction					
Q19. All educators have been adequately trained to effectively implement the curriculum of the Community Based Rehabilitation Program.	74	16.4	1.4	2.7	5.5
Q20. There are insufficient resources to effectively implement the CBR program’s curriculum.	11	1.4	1.4	27.4	58.9

For Questions 15 and 19, more than 50% (*n* = 73) of the participants strongly disagreed that the educators of the Community Rehabilitation Program were adequately trained and that there were sufficient technology resources for research and instruction. For question 20, more than 50% of the participants strongly agreed that there are insufficient resources to effectively support caregivers of the Community Based Rehabilitation Program.

Results for Caregiver Interviews

Face-to- face structured interviews were conducted with 5 caregivers of disabled children who participate in the Community Based Rehabilitation Program. The interview data were collected from the following five open-ended questions:

- Question 1: What types of resources has the Community Based Rehabilitation Program provided to you?
- Question 2: What is the most and least beneficial resources you have received from the CBR program?
- Question 3: In what ways has these resources helped in improving your ability to care for and advocate for your disabled children? Please explain why or why not?
- Question 4: Are there resources that you are in need of that has not been provided by the CBR program?
- Question 5: What are your hopes for the future of your disabled children in CBR program?

The following are the caregivers' responses to the five open-ended questions used for the face to face interviews:

- The CBR program give us whatever little they have.
- They don't have much but they try their best to help us.
- The teachers are really nice but their hands are tied.
- The most beneficial resources we have received are the relationships with the other caregivers and the teachers.

- The least beneficial resource is when they ask us to come and listen to the government people talk about how they going to help us but they do nothing.
- We feel good when the teachers help us, but overall we don’t feel that we getting what we need for our children.

The responses collected from the interview questions were coded and arranged into three categories: not effective, effective, and neutral (see Table 2). Most of the responses from the interview questions reflected caregivers’ dissatisfaction with the resources and services provided by the Community Based Rehabilitation Program. Caregivers reported in this regard that the teachers are working to the best of their ability to aid caregivers of disabled children despite the financial constraints and lack of support from the government. Caregivers reported that teachers need more education and training to be able to provide the necessary supports to the disabled community. Caregivers reported being overwhelmed due to the lack of resources and support. The resources such as textbooks and curriculum were reported not to be appropriate for the disabled children who are served by the CBR program. In addition, caregivers reported feelings of hopelessness for the Community Based Rehabilitation Program due to the lack of advocacy, education, and general support from the government (see Table 3 and Figure 2).

Table 3

Code Key for Interview, Focus Group, and Observation Responses

Survey response	Code

Not effective	NE	Series 1
Effective	E	Series 2
Neutral	N	Series 3

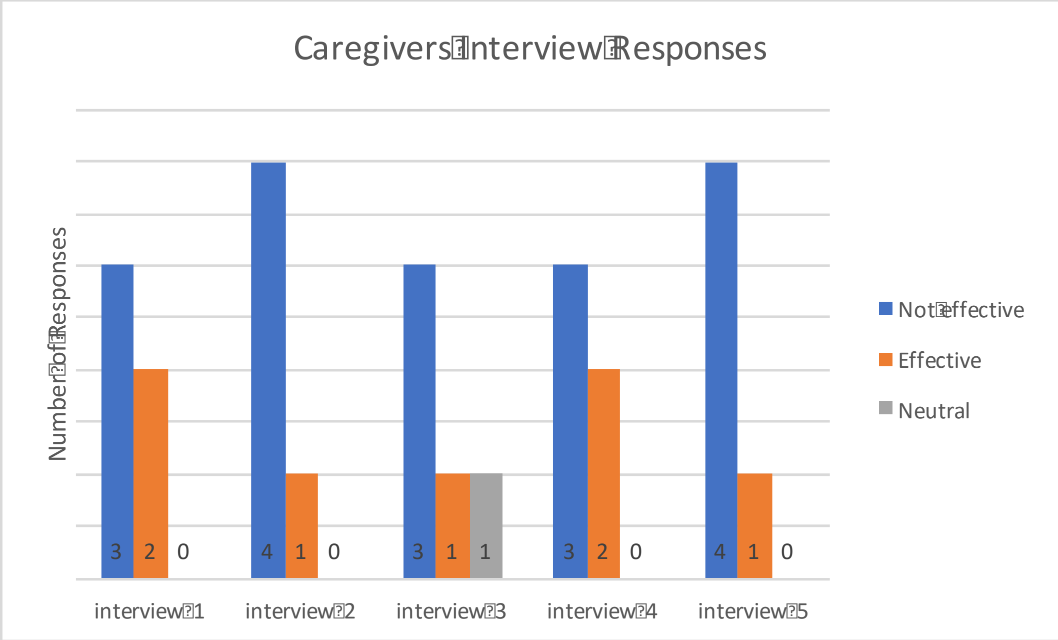


Figure 2. Interview responses of the caregivers who participated in the Community Based Rehabilitation Program.

	Not Effective	Effective	Neutral
Q 1. What types of resources has the Community Based Rehabilitation Program provided to you?	3	2	0

Q 2. What is the most and least beneficial resources you have received from the CBR program?	4	1	0
Q 3. In what ways has these resources helped in improving your ability to care for and advocate for your disabled children? Please explain why or why not?	3	1	1
Q 4. Are there resources that you are in need of that has not been provided by the CBR program?	3	2	0
Q 5. What are your hopes for the future of your disabled children in CBR program?	4	1	0

Results for Caregiver Support Groups

For question 1, 4 caregivers reported that the focus groups were not effective because they won’t be able to remember and realistically maintain the skills that were taught. They reported that the focus groups would be more beneficial if they were more frequent and ongoing. The 5 caregivers, who reported that the focus groups were effective, reported that they would be able to retain some the skills taught because they had some support from family members. Three (3) caregivers reported neutral feelings due to their level of education and general understanding of disability. In addition, one particular caregiver reported there has been too many broken promises and there is no use in building hope (see Table 4 and Figures 3 and 4).

Question 1. Based on the information that you received from the parent skills/focus groups classes, do you feel that you are better equipped to work with your disabled child?

Figure 3. Focus groups responses of the caregivers who participate in the Community Based Rehabilitation Program (Question1).

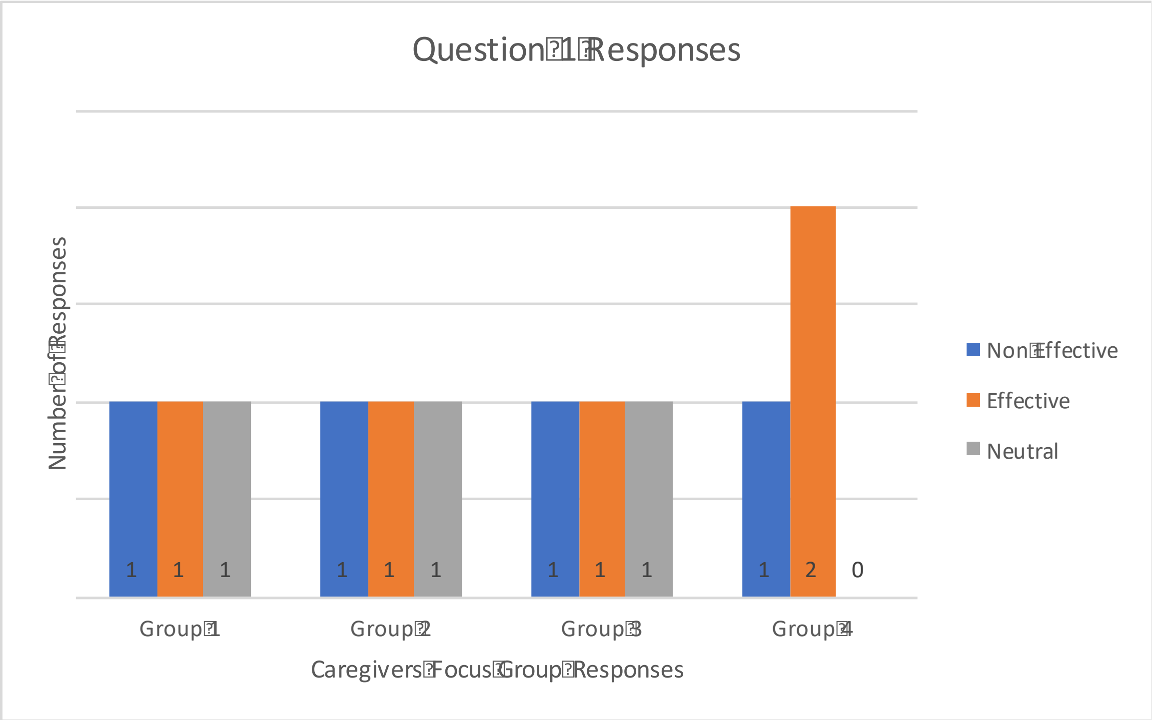
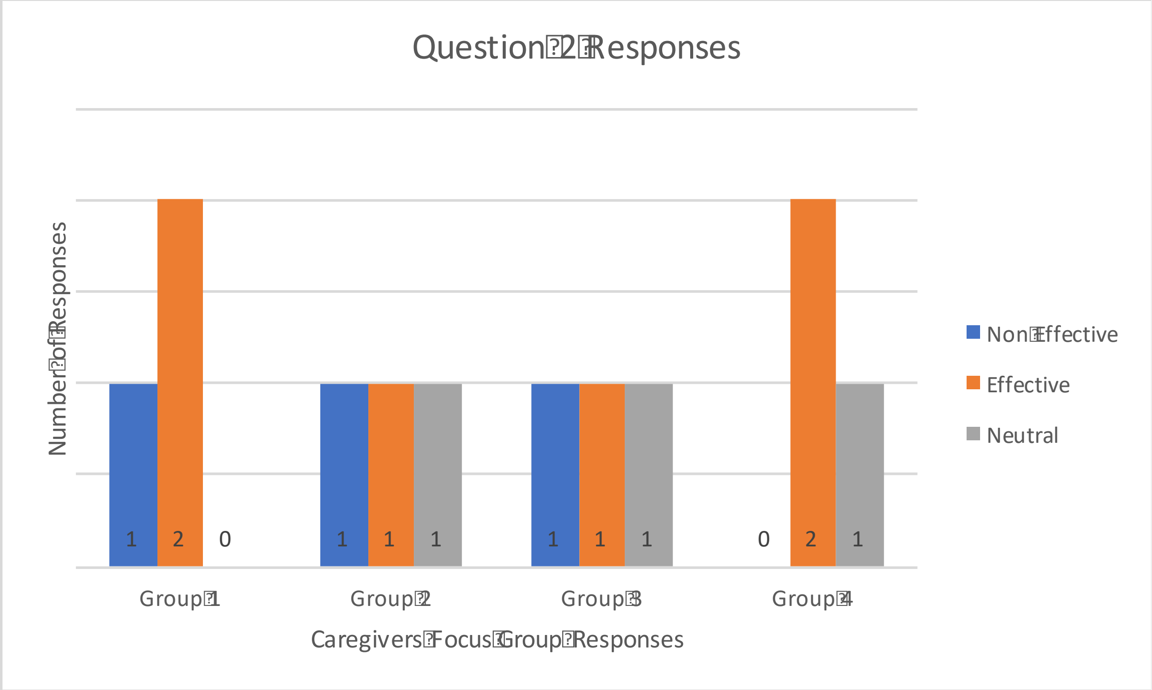


Figure 4. Focus groups responses of the caregivers who participated in the Community Based Rehabilitation Program (Question 2).

For questions 2 and 6, caregivers reported feelings of hope and were motivated to ask questions and to seek out assistance from the various resources provided. Some of these resources included referrals to community resources, the Commission for Disability in Guyana, and the Ministry of Public Health and Education. Four (4) caregivers reported that they felt that the focus groups was non-effective because of the limited time they had to retain the information taught. These caregivers stated that the groups or support won't be consistent so why bother. Two (2) caregivers reported that their feelings were neutral. Although the information was helpful, they felt that it wouldn't last and they didn't want to get their hopes up that there will be a chance for a long term change (see table 3 and figures 3 and 4).



Question 2. Are there any changes in your overall outlook about your ability to advocate and work with your disabled chid?

These questions permitted the caregivers an opportunity to naturally answer and express their perceptions.

Table 3: Results of Caregiver Focus Group

	Not effective	Effective	Neutral
Q1. Based on the information that you received from the parent skills/focus groups classes, do you feel that you are better equipped to work with your disabled child?	4	5	3
Q 2. Are there any changes in your overall outlook about your ability to advocate and work with your disabled child?	4	6	2

Chapter 5: Discussion, Conclusions, and Recommendations

The purposes of this study were to examine the perceived effectiveness and impact of the CBR program on caregivers' ability to care for and advocate for their disabled children in Guyana. I sought to answer two research questions. The first question asked to what extent does the 2006 Convention on the rights for People with Disabilities Community Based Rehabilitation Program promote caregivers' education and ability to care for and advocate for the overall well-being. Findings from the responses given by the caregivers in the study revealed that the Community Based Program is ineffective in responding to their needs. The Quality of Education Survey data results revealed that more that 50% of the caregivers who participated in the study reported that the resources that are provided by the CBR program are inconsistent and inappropriate for the level of education of the caregivers and their disabled children. Caregivers also reported that there were no community integration programs facilitated by the CBR program to provide respite or relief. In addition, caregivers reported that there is an extensive lack of support from the government, specifically the Ministry of Public Health and Education, to support and sustain the CBR program.

The focus of the second research question was on what follow-up resources can be implemented to assist caregivers in advocating and caring for their disabled children to sustain successful change in Guyana. The data obtained through one-on-one interviews and caregiver support groups provided overwhelming evidence of the need for education, resources, and advocacy for caregivers. At least 50 % of caregivers who participated in the focus group sessions reported that once they received some education, however little, they were able retain some level of confidence to face some of the challenges because they knew what resources to inquire about. An important finding is that caregivers in the study were completely unaware of the existence of the 50 amendments.

Taken together, these findings illustrate why it is important for staff of the CBR program to address the needs of all caregivers of disabled children who participate in their program. In addition, findings illustrate the need for the entire culture of the disabled community to be changed and accepted as an integral part of society.

Limitations of the Study

One of the greatest limitations in the study was that the instructors at the CBR program were not fully trained and capable of providing education and resources to caregivers of disabled children and that not all caregivers had a child or children with a disability. That is, I encountered a situation where students with special needs were generally not placed in programs that are specifically designed to address their educational needs and the teachers were primarily trained to work only with children without a disability. That situation complicated the data gathering process in that I had to dedicate additional resources to identify and expand my definition of caregivers to include aunts, uncles, brothers, sisters, and grandparents, in addition to parents.

The other complication was created by the limited time frame for data collection of 4 weeks for locating and interviewing participants and only being able to rely on one site for the study. The limited time frame and use of one research site stemmed from the limited financial resources available to successfully conduct the study and from there being only one fully functional program available in Guyana that fit the study focus.

Using the resources of the CBR program limited the number of participants to be interviewed. This notwithstanding, I was able to gather relevant information about the operation and effect of the program that provided a good indication, I believe, of the state of affairs and the kinds of services available to disabled children in Guyana. An unintended consequence in this regard was that the main focus became a specific population from a specific country. Thus, the information and factors derived from the analysis may not contribute to the understanding of disability in other immigrant populations. Findings may also contribute to creating a bias that all immigrant population are uneducated and lacks appropriate tools to address and understand disability.

One of the most important findings is that our study provides information that may impact policy modifications, and changes for lawmakers on a regional, national, and international level; the findings could also be used as guide to affect positive social change by creating a forum for future research in the field of education, social work, psychology, and public health. In the end, our study hopes to help to improve the psychosocial well-being of disabled children in Guyana, including caregivers' support, changes in classroom models, and community integration and involvement.

Recommendations for Action

Through the process of this study, the researcher was able to corroborate the data from the in-depth interview results and surveys that the Community Based Rehabilitation Program was designed to provide holistic and challenging learning opportunities to all caregivers so they were equipped with the necessary knowledge, skills, and aptitudes for caregivers to advocate for their disabled children. The Ministry of Public Health in Guyana sought to ensure achievement of the 2006 Convention on the Rights for People with Disabilities' goals and objectives, by creating its strategic plan that commits to achieving four major objectives over the 2006 - 2020 period:

1. Accessibility to educational opportunities for all.
2. Delivery of quality education to caregivers at all levels of the education system.
3. Sustainable policy development for caregivers and their disabled children.
4. Continuous alignment of the strategic direction in the education system for the disabled population with objectives set for national development.

While we found in our study that these objectives have not been implemented effectively, they are laudable goals that should be pursued more actively. The findings also suggest that the Community Based Rehabilitation Program needs to genuinely encourage caregivers and community involvement as vehicle for promoting advocacy. The few attempts at bridging the gap between the Community Based Rehabilitation Program and caregivers of disabled people that have been implemented, have left a number of areas of concern between/among caregivers, teachers, and administrators. This is particularly the case around the issue of *accountability, and of diversity, collaboration, partnership, and innovation* among community partners, the government, and the Community Based Rehabilitation Program, *both of which were found to be very underdeveloped and in need of attention.* The results of the study suggest that a tri-model concept of implementing change simultaneously among the three levels of the educational system is necessary to establish sustainable large-scale reform in developing countries, such as Guyana (Ajodia-Andrews & Frankel, 2010).

The implications for the required social change are twofold: On a local level, in Guyana all students regardless of socio-economic status, age, experience, level, or education are entitled to resources and advocacy that will improve their standard of living. In addition, Guyana now has access to learning opportunities at every education level. However, there are still many areas in grave need of improvement, such as caregiver education and empowerment, disability awareness, medical and psychiatric assessments, and community integration.

One of our concerns was clearly articulated by Stough (2003) who indicated that if the Community Based Rehabilitation Program continue to perform poorly would result in a decrease in funding opportunities for disabled people due to a lack of resources and advocacy. The resulting internal and external challenges for Guyana are likely to impact negatively on the growth and development of the society. Guyana has already encountered developmental challenges, such as poor economic health and educational and social inequalities, which has hindered its pursuit of developed country status.

For an effective response to these challenges it will require unlearning prior values and political bureaucracy from prior reform initiatives (Paquette, 2001) and the establishment of different systems thinking. We remain hopeful with Mitchell (2005), that Guyana and other developing countries are committed to investing the resources and time at all levels of the educational system to create a culture of continuous assessment and improvement. In the short-run, the achievement of the Community Based Rehabilitation Program is minimal. However, with a high degree of committed assistance from local and international organizations, more collaboration with parental groups, and sufficient amount of resources, combined with the logistics noted in this study, the task is surmountable for this developing country and others.

Implications

The information gathered in this research project include both the positive and negative aspects of the Community Based Rehabilitation Program and the recommendations for improving, reorganizing, and influencing disability reform policy to effect positive social change. It also include recommendation to improve the quality of service and resources provided to caregivers of disabled children in Guyana. Indeed, our study tried to provide important information regarding the extent to which Guyana is fulfilling its goals to meet the overall educational challenges and needs of the disabled population in Guyana as developed and established at the 2006 Convention on the Rights for People with Disability and delineated in its 50 amendments. One intent of these amendments includes transforming Guyana into a developed country by 2020 with updated, revised, organized, and strategically identifiable steps to improve the lives of disabled people.

This study focused on the challenges that caregivers of disabled children are facing in Guyana and we were able to identify important issues in that regard. The challenges in providing access to learning opportunities for the disabled population regardless of gender, age, experience, or socioeconomic background and also improving the standard of living for the disabled population through education and advocacy are as enormous as they are crucial. We believe that our findings add to the discussion on disability reform with the hope that will also add to the literature and encourage additional research on the impact and effectiveness of the 2006 Convention on the Rights for People with Disability in developing countries similar to Guyana. In the end, the study seeks to promote positive social change.

This case evaluative study was guided by organizational change theory and its relation to organizational culture, as well as the foundation for sustaining disability reform. That perspective allowed us to make clear disability issues nationally and internationally and suggest recommendations to ensure effective and sustainable change. These recommendations are meant to assist caregivers, teachers, and administrators in fostering a more positive and sustainable culture that are likely to lead to a better quality of life for caregivers and their disabled children. Our findings suggest that caregivers of disabled people are in dire need for high-quality educational resources, technology, employment opportunities, and advocacy. They also suggest that Guyana is in need of large scale reform to create a new system that will serve to establish and retain sustainable change. This type of reform will require to employ a bottom-up ownership, an important ingredient to assist in building morale and a sense of autonomy, resilience and strength of the program. This approach was endorsed by Trickett (2011) who concluded that effective large-scale reform can accomplish long-term sustainable change with bottom-up ownership. In keeping with that sentiment, it is also our contention that for Guyana to progress a disability program forward would require all parties involved (e.g., caregivers, policy makers, educators, etc.) to understand the complexity of the system.

The basic goal of large-scale reform is to create a new system which serves the purpose of the globally competitive society that developing countries, such as Guyana, need to build for the future (Mitra, Posarac & Brandon, 2012) Therefore, moving a disability program or organization forward in developing countries, such as Guyana, would require caregivers and governmental agencies to understand that these programs are complex interdependent social systems (Mitra et al., 2012); that the interconnections of these systems allow for the strength and resilience of the entire program; and that disability programs are composed of subsystems that interact, collect data, and process information to better the entire system. According to Paquette (2001), systems thinking is optimal for promoting learning and growth of the system when an organization faces complex issues or when there is a situation where many people are involved. The majority of the caregivers surveyed and interviewed supported Paquette's theory and considered the Community Based Rehabilitation Program to be partially effective in this context.

Conclusion

The conclusions of this evaluative case study could add to the understanding of large-scale systemic reform on a global, national, and local level within Guyana. The emphasis here is that we need to see the poor treatment of disabled children and caregivers as systemic problem that requires a systematic solution. That recommendation is also endorsed by Mitchell (2005) who stressed that if any problem situations arise due to a lack of communication within the system, the situations should be treated as a whole and not broken into parts that are treated independently of one another. According to Mitchel (2005), in order for this systemic transformation to occur, there must be professional learning communities at all levels within the disabled population and across the programs. The programs must be supportive and provide good leadership.

Miles (2001) also concurred that all levels of a system must be involved in planning and implementing change in a systematic way to allow disabled people, the most important resource of a developing society, such as Guyana, to have an optimal opportunity for overall success. According to Weiss (1998), there needs to be a focus on making changes to the system in developing countries, such as Guyana, by identifying areas of improvement and aligning feedback mechanisms with learning goals for caregivers of disabled children. After these changes are implemented, the achievements of caregivers of disabled children are expected to be significant (Weiss, 1998). The majority of the caregivers surveyed and interviewed, who participated in the focus group, supported making changes to the Community Based Rehabilitation Program in Guyana and considered the Community Based Rehabilitation Program in its current condition to be ineffective and unable to address the needs of caregivers with disabled children.

We could see this sentiment clearly expressed by the c*aregiver interview responses listed below:*

- The CBR Program and teachers try their best to get us involved, but it takes too long. The information and resources we get is not always consistent. Sometimes they give us lessons on how to talk to our kids.
- The most beneficial we received so far is when the teachers ask us to come and sit with them to do arts and crafts.

- The least beneficial was when they told us to go to the Ministry of Public Health, the people at the Ministry of Public Health make us feel as though we are stupid. We just come back home more frustrated than when we went there.
- This government never told us about any help from the United Nations or anybody else.
- This school (the CBR Program) doesn't have a single computer or books on their level. How are our children supposed to learn and keep up with technology? The teachers feel that they are in need of more training and resources to help us.
- We need books, we need to know where to go for help. We need doctors to help our disabled children. We need a better building with books and computers. We want more training for our teachers so that our program can stay here with us.

The need to identify issues and incorporate change continues to be a challenge facing Guyana and other developing countries. In all levels of a disability program, caregivers must be involved in planning and implementing change in a systematic way to allow their disabled children, the most important resource of a developing society such as Guyana, to have an optimal opportunity for success (Miles, 2001). This was evident in the most overwhelming response in this study from the caregiver survey which revealed that caregiver involvement and communication between the home and the Community Based Rehabilitation Program were extremely low.

Successfully developed monitoring systems are needed to evaluate programs such as the Community Based Rehabilitation Program in Guyana and other developing countries. The results of these assessments are expected to contribute to the research in large-scale reform in developing countries. They are also expected to assist policy makers in determining the effects, including teaching standards put forth by globally competitive nations, that allow the educational system to be successful by offering caregivers of disabled people quality education (Eleweke & Rodda, 2002).

Important Ingredients for a Successful and Efficient Program

Based on our review of the literature and findings, we can now identify a number of important factors that should be considered when developing educational programs for disabled children: Such programs should have,

1. a clear moral purpose or a commitment to high standards and the equal worth and success of every caregiver and their disabled children;
2. an emphasis on developing a system that is coherent at every level;
3. a mechanism to allow the program to acquire resources and autonomy at the local level to build capacity to innovate and transform the Community Based Rehabilitation Program, regardless of the challenges;
4. a nimble and structured schema for community integration;
5. an emphasis on diversity, collaboration, partnership, and innovation toward the goal of raising overall standards; and finally,
6. an emphasis on working with community partners, non-governmental organizations, and the government to create local and regional capacity for professional support and challenge, to strengthen informed professionalism and build capacity for continuous improvement.

These core principles are in keeping with the ones designed by the United Nation (2006) to assist Guyana and other developing countries to develop and create a learning culture of high performance. Our study supports the United Nations' (2006) conclusion that these core principles should be utilized as a guide and strategy to systematically organize a system transformation at the school, local, and national level in developing societies such as Guyana.

References

Ajodia-Andrews, A. & Frankel, A. (2010). Inclusive education in Guyana: A call for change. *International Journal of Special Education, 25*(1), 5-17.www.ERIC.ed.gov

Armstrong, A. C., Armstrong, D., Lynch, C., & Severin, S. (2005). Special and inclusive education in the Eastern Caribbean: Policy and provision. *International Journal of Inclusive Education, 9*(1), 71-87. Doi. 10.1080/1360311042000302905.

Belsky, J. (1996). The determinants of parenting: A parenting model. *Journal of Child Development, 55*, 7-12. Doi. 10.2397/1129836.

Bergsma, S. (2000). *The regular classroom as a battleground for inclusive special needs education: An assessment of options of special needs education in the Commonwealth Caribbean* (Report No. 26). Retrieved from the United Nations website: http://www.unitednations.org

Boberiene, L. V., & Yazykova, E. (2014). Children with disabilities in Russian institutions: Can the West help protect the most vulnerable? *American Journal of Orthopsychiatry, 84*(3), 266-272. Doi. 10.1037/hoo00913.

Chaikind, S., Danielson, L., & Brauen, M. (2009). What do we know about the costs of special education? A selected review, Part 1a, Part1b, Part 2. *Journal of Special Education, 26*(4), 344-370. Doi. 10.1177/002246699302600402.

Clay, K. R. (2006). Quality of Education Survey. *Mental measurements yearbook*. Retrieved from EBSCOhost.

Creswell, J. W. (1998). *Research design: Qualitative, quantitative, and mixed methods approaches* (1st ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2005). *Educational research. Planning, conducting and evaluating quantitative and qualitative research*. Upper Saddle River, NJ: Pearson/Merrill/Prentice Hall.

Del Balso, M., & Lewis, A. (2001). *First steps: A guide to social research*. Toronto, ON: Thomas Nelson Learning.

Eleweke, C. J., & Rodda, M. (2002). The challenge of enhancing inclusive education in developing countries. *International Journal of Inclusive Education, 6*(2), 113-126. Doi. 10.10801136031101100067190.

Frankel, E. B. (2004). Supporting inclusive care and education for young children with special needs and their families: An international perspective. *Childhood Education, 80*(6), 310-317. Doi. 10.1080/00094056.2004.10521277.

Frankel, E. B. (2006). The knowledge, skills and personal qualities of early childhood resource consultants as agents of change. Exceptionality Education Canada, 16(2), 35-58.

Frankel, E. B., & McKay, D. (1997). Embarking on integration of preschool programs: Creating positive change. Early Child Development and Care, 138, 57-70.

Fullan, M. (2001). The new meaning of educational change (3rd ed.). New York, Teacher College Press.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago, IL: Aldine Publishing Company.

Government of Guyana (2003). Ministry of Education: Strategic plan 2003-2007. Georgetown, GY: Inter-American Development Bank.

Groenewegen, I. (2004). Sharing skills, changing lives: Addressing disadvantage within disability in Guyana. GY: Voluntary Services Overseas.

Hall, W. M., & Figueroa, M. (1998). Jamaican children with special needs: Concerns, realities and possibilities. Disability & Society, 13(2), 269-278.

Hatch, J.A., Lin, M.(2003). Doing Qualitative Research in education Settings. New York: Guilford.

International Disability Rights Monitor (2004). International Disability Rights Monitor (IDRM) Publications-IDRM-Guyana 2004 IDRM country report. International Journal of Special Education, (25)1, 143. Retrieved February 09, 2007, from http://www.ideanet.org/content.cfm?id=5B5D70.

Jigjidsuren, D., & Sodnopil, N. (2005). Inclusive Education at the Pre School Education College in Mongolia. In C. Sternhill (Ed.). Inclusion: Children with Disabilities. Latvia

Mongolia and Ukraine. Step by step case study project (pp. 13-17). Retrieved on February 09, 2007 from www.ibe.unesco.org.

Johnson B., Christensen, L.B., (2004). Educational Research (2nd ed.). Allyn & Bacon Publisher 2004.

Laslo,A., Krippner, A. (1998). Systems Theories. Amsterdam: Elsevier Science. http://dx.doi.org/10.1016/S0166-4115(98)80017-4.

Lindsay, S., McPherson, A.C. (2011). Strategies for Improving disability awareness and social inclusion of children and young people. Child Care Health Dev. 2015 Nov;38(6):809-16. doi: 10.1111/j.1365-2214.2011.01308.x. Retrieved December 2011.

Miles, S. (2001). Enabling inclusive education: Challenges and dilemmas. Retrieved February 10, 2007, from http:// www.eenet.org.uk/theory_practice/bonn_2.shtm

Ministry of Education and Cultural Development.shtml

Ministry of Education and Cultural Development Guyana (2005). An education policy and five-year development plan for Guyana: Providing education in an environment of economic crisis and political change. Georgetown, GY: Guyana National Printers Limited.

Ministry of Mental Health Guyana (2008). Comprehensive report (2008). Retrieved from University of Guyana September 2009.

Mitchell, H. (2005). Raising the profile of disability in Guyana: An agenda for action. Georgetown, GY: National Commission on Disability.

Mitra, S., Posarac, A. (2012). Disability and Poverty in Developing Countries: A Snapshot form the World Helath Survey. Retrieved January 2014 from www.worldhealthorg.org.

National Commission of Disability 2005. Annual Report (2005). Retrieved February 2003.

Oskamp, S. (1991). Attitudes and opinions (2nd ed.). Englewood Cliffs, NJ: Prentice Hall.

O'Toole, B., & Stout, S. (1998). Hopeful steps in the Rupununi: Our response to meeting the challenge of special needs in the interior of Guyana. In J. L. Evan, E.M. Ilfeld, & E. Hanssen (Eds.), Inclusion. Inclusive ECCD: A fair start for all children (pp. 28-35). Haydenville, MA:

Pan America Health Organization 2008 (PAHO, 2008).

Paquette, R., & Ryan, T (2001). Systems Theory Von Bertalamnffy. Ghana: Science and Education publishing.

Singleton, R. & Straits, B.C. (2005). Approaches to Social Research. California: Oxford University Press.

Skyttner, L., (1996). General Systems Theory. McMillan Press.

Stough, L. M. (2003). Special education and severe disabilities in Costa Rica: Developing inclusion in a developing country. Research and Practice for Persons with Severe Disabilities, 28(1), 7-15.

Strauss, A., & Corbin, J. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Trickett, P.K., (2011). Child Maltreatment and Adolescent Development. https://doi.org/10.1111/j.1532-7795.2010.00711. Retrieved January 2014.

UNESCO 2006. Annual Report (2006). www.unecso .org. Retrieved April 2007.

UNICEF 2000. Annual Report (2006). www.unicef.org. Retrieved February 2006.

United Nations (2006). Convention on the rights of persons with disabilities. Retrieved September 06, 2007, from http://www.un.org/esa/socdev/enable/rights/convtexte.htm#convtext.

United Nations (2008). Convention on the rights of persons with disabilities. Retrieved November 06, 2010, from http://www.un.org/esa/socdev/enable/rights/convtexte.htm#convtext.

United States Department of Education (2015). https://www.ed.gov.

Retrieved from ebscohost, January 16, 2015.

United Department of States (2006). National Report (2006). Retrieved January 2008.

Weiss, C.H. (1998). Methods for studying programs and policies. Prentice Hall.

World Health Organization (WHO) (2006). Annual Report 2006 .https://worldhealthorganization.org. Retrieved on

April 2015.

World Health Organization (WHO) (2008). Annual Report 2008 .https://worldhealthorganization.org. Retrieved on

November 2015.

Yin, R.K. (2003). The Art of Case Study Research. Design and Method (3rd ed.). Thousand Oaks CA: Sage

Zamawe, F.C. (2015). The Implication of using NVIVO software in qualitative data analysis: Evidence- Based Reflections. Malawi Medical Journal, VOL 2 (1) 13-

15. Retrieved on February 11, 2017 from

https://www.ncbi.nim.nih.gov/pmc/articles/PMC4478399/

Appendix A: Quality of Caregiver Support Survey

Name _________________No. of children in the CBR program __________

No. of Years in the CBR program ___________

DIRECTIONS: Please circle ONLY ONE response per question.

1.The CBR program promotes mutual respect among all students and caregivers.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

2.The CBR program promotes understanding among all students and caregivers.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

3.The CBR program's learning environment encourages group interaction among all caregivers.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

4.The CBR's program learning environment encourages group collaboration among all students.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

5.The CBR program has established clear expectations of caregivers and student participation during instruction.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

6. The CBR program works collaboratively to further develop all student and caregivers' critical thinking skills.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

7.Caregiver's class Instruction is well organized and logically sequenced.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

1.All caregivers are encouraged to think creatively.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

9. All caregivers receive detailed and comprehensive feedback from instructors.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

10.Grading policies are clearly established and communicated to all students and caregivers.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

11. All caregivers and students are periodically informed of academic progress through grades and feedback.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

12. The CBR curriculum is easy-to-follow, accurate, and provides a clear understanding to caregivers of student assignments, course objectives and responsibilities.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

13. Curriculum assignments are meaningful and extend the knowledge for all caregivers and students.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

14. The textbook provides relevant information and contributes to all caregivers and students' understanding of the subject matter.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

15. The CBR program has sufficient technology resources for research and instruction.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

16. Instruction is academically appropriate and evenly paced for all caregivers and students.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

17. The CBR program utilizes various forms of assessments to routinely evaluate the understanding of all caregivers and students.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

18. The classrooms are interactive and its features are well organized and easy to use for all caregivers and students.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

19. All educators have been adequately trained to effectively implement the curriculum of the CBR program.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

20. There are insufficient resources to effectively implement the CBR program's curriculum.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

21. More caregivers involvement is needed in the CBR program.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

22. The CBR program encourages staff collaboration with caregivers.

Strongly Disagree Disagree Neutral Agree Strongly Agree No Opinion

Appendix B: Caregiver Interview Questions

1. What types of resources has the CBR program provided to you?
2. What is the most and least beneficial resources you have received from the CBR program?
3. In what ways has these resources helped in improving your ability to care for and advocate for your disabled children? Please explain why or why not?
4. Are there resources that you are in need of that has not been provided by the CBR program?
5. What are your hopes for the future of your disabled children in CBR program?

Appendix C: Caregiver Focus Group Discussion Questions

1. Based on the information that you received from the parent skills/focus groups classes, do you feel that you are better equipped to work with your disabled child?
2. Are there any changes in your overall outlook about your ability to advocate and work with your disabled child?

Appendix D: 2006 United Nations Convention on the Rights of Persons with Disabilities

- Article 1 stressed the need for appropriate communication to include languages, text, braille, tactile, large print, written, audio, multimedia, human reader and technology. Language includes spoken, signed, and other non-spoken languages. Article 1 also stated that there would be no discrimination against persons with disability, including any distinction, exclusion, restriction, and denial of reasonable accommodations. By reasonable accommodations is meant any necessary and appropriate modification or adjustments that does not pose a burden, to ensure that all persons with disabilities can enjoy their fundamental human rights and freedom on an equal basis.
- Article 2 stressed that the universal design of all products and environments must meet the needs of disabled people without the need of adaptation or specialized design.
- Article 3 of the convention focused on the general principles to respect the dignity, individual autonomy, freedom to make independent choices, non-discrimination, full participation and inclusion in society, acceptance of persons with disabilities as a part of human diversity and humanity while also respecting the differences of disabled people. In addition, disabled people must be allowed equality of opportunity, accessibility, equality between men and women as well as respecting the capacities, identities and rights of children with disability.
- Article 4 stated that all efforts must be made to undertake, ensure, and promote full realization of all human rights and freedom without discrimination for persons with

disabilities. This includes adopting all legislative, administrative, and other necessary measures for the implementation of appropriate customs and practices, policies and programs, and promoting research and development to meet the needs of all disabled people. In addition, Article 4 supported the training of professionals and staff working with disabled people to provide better services to this population.

- Article 5 stated that all disabled people would be afforded equality and non-discrimination with effective legal protection.
- Article 6 recognized the discrimination that disabled women face and stressed the importance of creating measures for the development, advancement, and empowerment of disabled women.
- Article 7 assured that disabled children will be allowed to express themselves freely on all matters, which pertain to them on an equal basis.
- Article 8 stressed the importance of raising awareness and promoting awareness-training programs throughout society at the family level, to foster their full capabilities, respect and rights, education, positive perception, and greater social awareness to combat stereotypes, prejudice, and harmful practices.
- Article 9 maintained that all disabled people have a right to live independently and be provided with a physical means to transportation, information, and communication technologies and systems in public urban or rural areas. This includes building roads, transportation, indoor and outdoor facilities, such as schools, housing, medical facilities, emergency services and workplaces.

- Article 10 stated that all disabled persons have a right to life and will be protected on an equal basis.
- Article 11 dictated that all measures will be taken to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies, and the occurrence of natural disasters.
- Equal legal rights and representation for all disabled people is covered in Article 13. This may include appropriate and effective safeguards to prevent abuse. All efforts will be made to ensure equal rights to own or inherit property and control their individual finances.
- All disabled persons, according to article 13, will have effective access to justice. Appropriate training will be provided to staff in the field of justice administration to ensure that disabled people have effective access to justice.
- Article 14 specified that all disabled persons have a right to liberty and security on an equal basis.
- Article 15 assured that all disabled persons will not be subjected to torture, cruelty, inhumane degrading treatment, experiment or punishment.
- Article 16 aimed to protect disabled persons from exploitation, violence, and abuse within their homes or outside by educating families, staff and effectively monitoring facilities and programs independently. In the event of any form of abuse or exploitation, measures will be put in place for full intervention via physical, cognitive, psychological, rehabilitation, and social interaction.

- Article 17 indicated that all disabled persons would be respected physically and mentally despite their disability.
- Article 18 protected the rights of persons with disabilities to liberty of movement, to freedom of choosing their residence, and to a nationality, on an equal basis with others. It recognized as well a right to a birth name, cared for by a parent, change of nationality, and to enter or leave their country without discrimination.
- Article 19 ensured that persons with disabilities have a right to full inclusion in their community, choose a residence, access to in home, residential and community support.
- According to article 20, effective measures must be taken to facilitate personal mobility, mobility skills, and quality mobility aids and devices for persons with disabilities.
- Article 21 indicated that all appropriate measures will be taken to ensure that persons with disabilities can freely exercise the right of expression and opinion, including the freedom to seek, receive, and impart information and ideas on an equal basis, as well as access information through current technology and modes of communication including sign language Braille, augmentive, and alternate communication.
- Article 22 covered the respect for privacy. It stated that the personal privacy of all disabled persons would be protected including personal health and rehabilitation.
- Article 23 focused on respect for the home and family. It described that the home and families of all persons with disabilities will be respected and supported in regards to marriage with free and full consent, deciding on the number of children they want to

have, and the right to procreate, retaining fertility, child rearing and family skills education.

- Article 24 maintained that appropriate and effective education would be provided to all disabled people regardless of their level of disability to enhance a sense of dignity, self-worth and freedom. This includes education on the nursery, primary, and secondary level by trained professionals who can facilitate education in all forms including language, mobility skills, peer support, mentoring, and social development.
- Article 25 specified that affordable health care must be provided to all disabled persons including sexual, reproductive health, intervention services and public health services as well as raising awareness in all communities.
- Article 26 detailed the effective and appropriate measures that will be taken through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, full inclusion and participation in all aspects of life beginning at the earliest possible stage and are based on the multidisciplinary assessments of individual needs and strengths. Support participation and inclusion in the community and all aspects of society are voluntary and are available to persons with disabilities as close as possible to their own communities including rural areas. In addition, all efforts will be made to promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services as well as promote the availability, knowledge, and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

- Article 27 focused on work and employment of persons with disabilities. It stated that work would be recognized on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in the labor market and an environment that is open, inclusive, and accessible to persons with disabilities. State's parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation to prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment hiring, employment, continuance of employment, career advancement and safe and healthy working conditions, protecting the rights of persons with disabilities, on an equal basis with others, to just and favorable conditions of work, including equal opportunities, and equal work and protection from harassment. Ensuring that persons with disabilities are able to exercise their labor and trade union rights, access to effective general technical, vocational guidance programs, placement services and continued training. Promotion of employment opportunities, career advancement, assistance in obtaining, maintaining and returning to work, self-employment, appropriate accommodation, and job retention.
- Article 28 addressed the need for adequate standard of living and social protection for persons with disabilities, including taking appropriate steps to safeguard and promote the realization of their rights without discrimination on the basis of disability.

- Article 29 guaranteed that persons with disabilities have political rights and the opportunity to enjoy these rights on an equal basis with others.
- Article 30 recognized that persons with disabilities have the right to take part on an equal basis with others in cultural life. All appropriate measures to ensure that persons with disabilities enjoy access to cultural materials, such as access to television programs, films, theatre and other cultural activities in accessible formats. Additionally, all appropriate measures will be taken to ensure access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.
- Articles 31 through 50 – focused on regional, national, and international cooperation to implement, monitor, build healthy relationships with similar programs and institutions, gather data and report statistics about the effectiveness and monitoring of these articles (United Nations, 2006).