



THE SOCIAL MODEL OF DISABILITY: THE EXPERIENCES OF PEOPLE WITH A
SPINE INJURY IN THE ORGANIZATION OF EASTERN CARIBBEAN STATES (OECS)

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THE SOCIAL MODEL OF DISABILITY: THE EXPERIENCES OF PEOPLE WITH A SPINE INJURY IN THE ORGANIZATION OF EASTERN CARIBBEAN STATES (OECS)

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Doctor of Philosophy (PhD)

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Abstract

THE SOCIAL MODEL OF DISABILITY: A QUALITATIVE STUDY OF THE EXPERIENCES OF PEOPLE WITH A SPINE INJURY IN THE EASTERN CARIBBEAN STATES

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This qualitative study investigates the experiences of people living in the Organisation of Eastern Caribbean States (OECS) with spinal cord injuries (SCI). The OECS has seen a steady rise in SCI, mainly due to vehicular collisions and gunshot wounds. Despite ongoing global interest in the lived experience of persons with disabilities, little to no research has been done in the OECS to capture the experiences of people with SCI. The phenomenological framework was used to conduct this study, and the following questions guided the research procedures: (a) in what ways do people with SCI experience daily life? (b) what are the most commonly mentioned barriers to inclusion experienced by people with SCI? (c) how are the experiences of newly disabled people with SCI affected by different social backgrounds? and (d) how is this affected by overall care, cost, gender and sexual orientation? Sixteen participants with SCI were engaged in semi-structured interviews and photo-elicitation and the in-depth data analysis brought to light several themes: (a) family care and support; (b) being misunderstood; and (c) discrimination. Participants expressed that they were pleased for the opportunity to present their views on their experience while living with SCI and the study suggests they experience varied educational and societal forms of discrimination. The results highlight the importance of care and support for people with SCI and show the need for additional research into the mental impact of people caring for individuals with SCI experiences and the impact on the overall care of the person with SCI. The study offers

inimitable perspectives on the experiences of people with SCI and presents opportunities for further research to validate this study.

Key words: the social model of disability, lived experience, disability, ethics, independent living, Organisation of the Eastern Caribbean States, thematic analysis.

Declaration

I declare that this thesis has been composed solely by me and that it has not been submitted, in whole or in part, in any previous application for a degree. Except where it states otherwise, by reference or acknowledgment, the work presented is entirely my own.

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Dedication

This dissertation is dedicated to three beloved individuals who have and will continue to mean so much to me. Although two of them are no longer with me, their memories continue to be the driving force behind my determined spirit.

My maternal grandmother, Iola Roberts, a disabled person, managed to raise, nurture, and love me unconditionally even up to her last moment with me. I will always appreciate all you've done for me, even the simple things such as teaching me to plait coconut bows at a young age.

My paternal grandmother, Muriel Tonge, has been my silent motivator to work hard against all odds. I wish you were still around to hear your voice calling my name. I miss you, Mother.

Finally, I dedicate this dissertation to my mentor and former French teacher, Mr. Anthony Hampson, for being a fantastic role model, educator, and individual. You have been instrumental throughout my professional and academic achievements. I will continue to strive for and share my academic excellence so that I may be a role model and a mentor who will leave a lasting and positive impact on the lives of our young men in Antigua and Barbuda.

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CHAPTER 1: INTRODUCTION

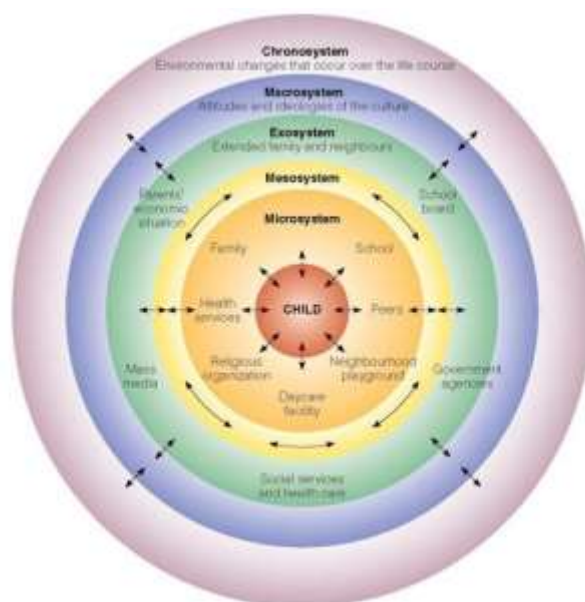
This dissertation is based on a qualitative study: an investigation into the experiences of people living with a spinal cord injury (SCI) in the Organisation of the Eastern Caribbean States (OECS) sub-region. The phenomenological and methodological study is used to capture the experiences lived by people with an impairment, (Vagle, 2018). This methodology in qualitative research highlights the social living conditions of individuals or groups under investigation. This research will highlight society's views of people living with disabilities. Informing an understanding of the history of disability and disability itself, Watson & Vehmas (2020) pointed out the ideology of how society saw individuals with impairment as being marginal. Research and detailed studies on people with SCI in the OECS have been minimal, and as a result, much interest has not been put into researching this area.

The social model of disability considers studies done by leading academics over the years, both in British and American institutions. The results of these studies can be of particular importance to the legislative arm of governments within the OECS, the business community in which individuals with impairments work and non-profit organisations. This study uses the phenomenological theoretical framework. The literature on phenomenological frameworks is explored to get a better reflective view of people living with an SCI from a qualitative standpoint.

According to Arslan and Yildirim (2015), the phenomenological framework in this research seeks to undertake the evolutionary process of exploring the lived experience of people afflicted with a spine injury while focusing on the social aspect of disability in the environment in which these individuals operate. The ecological framework by Bronfenbrenner (2009) investigates the external influences of the study and how they affect the research.

The phenomenological perspective is relevant to the systems outlined by Bronfenbrenner (2009, p. 25). These systems include the Microsystem, Mesosystem, Exosystem, Macrosystem and Chronosystem, and how they influence people with impairment and their lives (Bronfenbrenner). However, Bronfenbrenner's theory, Figure 1, is centred on a child's development and external influences. This ecological systems theory can also be aligned with individuals with a physical impairment. These systems are further examined in the upcoming chapter.

Figure 1 *Bronfenbrenner's Ecological Systems Theory*



Note. Bronfenbrenner (1977) suggested that a child's environment is a nested arrangement of structures, each contained within the next. From Bronfenbrenner's Ecological Systems Theory, by Oliver Guy-Evans, Published Nov 09, 2020.

People living in the OECS with some form of physical impairment, if otherwise not in a care home, usually are cared for by family members. If a society, in which infrastructure,

building codes, green spaces, signage, and technological advances are universally available, and adhere to universal design, the community is said to have catered to all its citizens. The rights of the impaired, the young and the elderly to universal access to public transportation for people with disabilities are widespread and is not just a right for non-disabled citizens, but a fundamental right for all citizens of any country.

There is little to no research within the OECS on the lived experiences of individuals with some form of disability. It is expected that the results of this research will inform the legislatures, disability associations, and, most importantly, societies in this sub region, about the importance of inclusivity and universal design. This can enable these groups of people to provide and facilitate an enabling environment for all. The main aim of this study is to understand the ecological environment of the lived experience of people living with a physical impairment.

The social model of disability (Twardowski, 2018) assists individuals with impairments in understanding the society in which they live. The model visualises people as not having a disability, but impairment. However, because of society's exclusive nature, individuals with impairments become disabled when they are not able or less able to operate, compared to non-disabled individuals. Looking deeper into the social model and its structure, we can identify the problems of segregation, inaccessibility (physical and institutional), social prejudice, and cultural and religious beliefs. Some of the issues people with impairment face from these social problems include over-protectiveness, inflexible employment, lack of quality education, inaccessible transportation, stigma, and fear (Purlrang, 2021).

Though there have been various studies on inclusivity and the social model of disability, and the medical model of disability, globally (Watermeyer, 2012), the Caribbean region,

specifically, OECS countries, has a dearth of such research relating to both the social and medical models of disability. Over the years, organisations such as the International Disability Alliance (IDA), Disabled People's International (DPI), and the International Disability and Development Consortium (IDDC) have been championing the cause of people living with impairment worldwide. Is it enough? Perhaps not.

Background

Characteristics of spinal cord injuries. The global incidence of spinal cord injuries (SCIs) is reported to be 10.5 cases per 100,000 people (Kumar et al., 2018). In the United States alone, over 17,000 people (Pukos et al., 2019) are affected by spinal cord injuries, annually. Road traffic accidents and falls are the leading causes of spinal cord injuries globally (Kumar et al., 2018) and in developing countries for example in Latin America and the Caribbean. Spinal cord injuries result in rapid loss of motor, sensory and sudden autonomic impairment, generally below the level of damage (Kumar et al., 2018; Pukos et al., 2019). Spinal cord injuries typically generate physical disability and, as a result, economic dependency (Kumar et al., 2018).

The prevalence of this dependency is usually seen in low and middle-income countries such as the OECS. Globally, the population age group that is mainly affected ranges from 15 to 35 years, with males most affected by this condition (Londoño et al., 2022). The WHO (2019) report indicated that global road vehicle injuries are estimated to be 1.7% of all persons living with disability – violence and conflict, accounts for an additional 1.4%. If these incidences of injuries continue to increase, then the economic outlook of developing countries such as the OECS will be bleak.

The experiences of people living with a spine injury come with many challenges, and one such challenge is the onset of complications related to the injury, including pulmonary

infections, urinary tract infections and bed sores (Kang et al., 2018). As it relates to the severity of these complications, Kang et al. concluded that the more complete the injuries are, the more severe the difficulties may be. Tetraplegia, the most common form of spinal cord injury in developing countries, derives from vehicular accidents (Kang et al., 2018; Kumar et al., 2018 and Londoño et al., 2022). The mortality rate of people with spine injuries is still very high (Londoño et al., 2022) when compared to individuals with for example, tetraplegia versus paraplegia. Individuals with tetraplegia have a shorter life span than those with paraplegia (Pukos et al., 2019). In developing countries, where there is limited research on the experiences, complications and mortality rate of people who have suffered a spine injury, it is challenging to tabulate data for academic research (Londoño et al., 2022).

Treatment of people with spinal cord injuries.

The severity of a spinal cord injury can determine the treatment of individuals with spinal cord injuries. Research conducted by Badhiwala et al. (2021) shows that people who underwent decompression surgery in the first 24 hours of their injury experienced significant recovery than those who had surgery more than 24 hours after their injury. This was evident when the research showed that a year after surgery, there were significant improvements in pinprick scores and lower-extremity motor and light touch sensitivity (Badhiwala et al., 2021) in individuals who had their surgeries in the first 24 hours versus the ones who had theirs after the first 24 hours. Though there have been advancements in medical science in the treatment of spinal cord injuries, (Karsy et al., 2019) approve the idea of supportive care, which is a critical element of rehabilitative therapy as a viable additional treatment for people with spinal cord injuries.

Reintegration of people with spinal cord injury

Life satisfaction and community integration of people with spine injuries after rehabilitative care are important to them (their quality of life) and the community they are integrating into (Ahmed et al., 2018). However, this reintegration depends on several factors: 1) the severity of the injury, 2) demographic characteristics, 3) the socio-economic profile of the individual and the secondary health condition of the community (Ahmed et al., 2018). Studies show that life satisfaction depends on how integrated an individual with spinal cord injury is within his community. This, therefore, hinges on the social model of disability and the removal of barriers so people with disability may live a comfortable integrated life. Other factors may affect an individual's integration into the community, these include the type of injury, the individual's gender, age, and educational attainment (Ahmed et al., 2018).

There is a social responsibility for governments and organisations to provide a reasonable living standard for people with spine injuries and other disabilities during their reintegration process. One such reasonable accommodation is access to transportation so individuals may involve themselves in social activities, including activities in educational facilities, if their loved ones cannot provide for them. Offering injury-appropriate employment is another recommendation by Ahmed et al. (2018) to achieve community integration and an all-inclusive society. The WHO defines quality of life (QOL) as:

Individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social

relationships, and their relationship to salient features of their environment

(Haraldstad, et al., 2019, para 7).

Qualitative studies of people with spine injuries have all suggested that their experiences of living with the injury depend on different factors. Factors such as continued care, family care and affection, independent living, assistive technology and addressing social barriers, determine whether the individual experiences of people with spine injuries are inclusive or exclusive (Ahmed et al., 2018; Badhiwala et al., 2021; Dwivedi, 2019).

There is a dearth of research on the experiences of people with spine injuries in the Caribbean, more so in the Organisation of Eastern Caribbean States (OECS). These experiences can inform future legislative changes to improve the lives of those with spinal injuries. Furthermore, the experience of people with spine injuries may be vastly different from people who experience other forms of disabilities.

Statement of Problem

It is imperative to develop further understanding concerning facilitating and constraining the factors that impact the participation of people with SCI in daily activities (Alve & Bontje, 2019). The range of factors includes social and human factors, which affect the opportunities to lead satisfying social lives (Berghs et al., 2019). People living in the OECS with a spine injury constantly fight for the right to access, fairness and inclusiveness (B. Warner, personal communication, October 26, 2019). The experience of people living with a spine injury has been an under-researched area in the OECS.

Access to international agencies and local government funding can be problematic in developing countries in the Caribbean. Though there are various types of research globally on SCI studies (New et al., 2019; Badhiwala et al., 2019), there have not been any within the OECS

on this level on the experiences of people living with a spine injury. Moreover, there has been little research exploring the social model of disability and the phenomenological aspect of people living with SCIs. Therefore, it has become necessary to research this problem in more detail so that this research gap may be filled. For a person in the OECS, living with a spinal cord injury is a life-changing condition that substantially affects their socioeconomic situations and those who provide care (Alizadeh et al., 2019). The approach taken in this phenomenological study should give a deeper understanding of the life of an individual with a disability in the Caribbean sub-region (the OECS).

Sole et al. (2020) suggest a direct association between physical disabilities and depression. If infrastructures such as proper disability pathways, ramps, and guard rails for the blind and assistive technologies for physically challenged individuals are not addressed, then according to Smith et al. (2020) the lack of these resources may lead to depression in people living with disabilities. The change in someone's quality of life living with a disability due to SCI is adaptive and problematic (Parmenter, 2021) affecting the individual's psychological and financial way of life. The derived depression sometimes comes as a result of the individual's inability to perform everyday tasks, which may lead to chronic dysfunctions, with some adapting to their environment and showing improvement over time (Khanjani et al., 2019).

There is continued interest in qualitative research into the experiences of people living with impairment on account of SCI and the acknowledgment that there is the need for more research (USAID, 2019). Several pieces of literature were found on the lived experiences of people living with a spine injury in the wider Caribbean specifically in Haiti, referring to the earthquake that ravished that island (Watson et al., 2023). Another study done by Mayol et al., (2019) looked at the effects of the timing of surgical intervention on persons affected by cervical

spinal cord injury. The study also noted that over eighty per cent of the participants in the study were males who mostly suffered vehicular accidents. There is undoubtedly a need for this type of research to most importantly address this gap. This area of research is needed as it has the potential to shed light on the overall context of the experiences of people living with SCI.

There has been a great deal of research on the lived experiences of persons with disabilities and some on spine-related injuries, their findings and implementation (Beatty et al., 2019; Bekmansurov et al., 2019). However, despite research from (Morris, 2018; Stephenson, 2019 & Parey 2022), who explored many aspects of the life of Caribbean people who are living with a disability, there have not been studies which examine the perspectives of people living with a spine injury, how it affects their daily lives, the relationship with caregivers and how to develop a multifaceted approach to understanding their lifestyle.

This new dimension of understanding the lifestyle of people living with spine injury and the influence of the social model of disability can allow for a multifaceted and multi-organisational approach to solving issues relating to people with a spine injury. Finally, people with spine injuries are expected to live as sheltered human beings (Retief & Letšosa, 2018). The authors reflect on the moral and or religious model of disability and how at times, people with disability are seen as less than human. This attitude towards people living with a spine injury and other disabilities may present circumstances in which the self-esteem and self-worth of such individuals may be negatively affected (Retief & Letšosa, 2018).

Purpose of the Study, Research Aims, and Objectives

The purpose of this study is to explore the lived experiences of people with a spinal cord injury living in the OECS and garner a more comprehensive understanding of their life experiences while exploring recommendations for social and policy change. Additionally, there

will be an examination into the implications of the findings on improving the lives of people living with spine injuries. According to Marshall (2009), the worldview of people living with a disability is usually derived from more developed countries such as Europe and North America. This is because most of the academic research on this study area comes from these More Developed Countries (MDCs). Therefore, most of the literature will likely reflect the small percentage of the world's disabled population. Marshall (2009) estimates that 80 per cent of the world's disabled population is from developing countries, for example, those in the Caribbean. With this figure, the view of the world's phenomenological disposition on disability is strictly focused on the MDCs.

Aims and Objectives

The aim of conducting this qualitative research is to add to the body of knowledge about the lives of people with a spine injury in the OECS region by understanding their individual daily experience. It is hoped that this research paper will close the gaps and continue to build on the already profound findings by (Jones, 2018; Guerrero-Garcia et al., 2017) and others, but more specifically, to provide in-depth insight into the OECS's social platform and any model, if any, that is related to disability. Further, it is hoped that the information garnered from this research can assist policymakers, caregivers, and any medical and rehabilitation personnel in ensuring that people with spine injuries live a more comfortable and rewarding life.

Main objectives of the project:

- To assess the experiences of people with a spine injury through semi-structured interviews.
- To identify barriers that people with spinal cord injuries face in their daily lives.
- To determine whether the experiences of people from various social backgrounds are different.

- To determine the effect of external factors on the lives of people with spine injuries.

Nature and Significance of the Study

The ability of an individual to maintain independent bodily functions is frequently considered a prerequisite for participation in social activities (e.g., employment, education, and leisure), though opinion on this subject is changing due to the influence of a global disability movement for independent living (Masakuni, 2015). According to Jones & Lubin (2018), about 250,000 people are living in the Caribbean with significant disabilities. There is an even smaller number living with significant disabilities in the OECS. There is no data, as a result of scientific inquiry, on the number of people living with spine injuries within the OECS. All numbers on SCIs are therefore estimated.

The research objectives outlined above will be filtered from the participants' responses, their experiences living with a spine injury, and how these experiences have affected their quality of life. There is a gap in research on the experiences of people living with a disability in the OECS. As a result of this gap, meaningful recommendations can be made to policymakers and non-governmental organisations to effect change. The qualitative research will serve as an impetus to explore the experience of people living with a spine injury in the OECS. It will foster a more in-depth understanding of participants and people with spinal impairment and how they perceive themselves.

Spinal cord injuries (SCI) affect an individual's normal bodily functions. Traffic accidents, gunshots and sports accidents are the leading causes of spinal cord injuries (Fernández Londoño et al., 2020). Permanent disability depends on the injury's severity (Fernández Londoño et al) and can further cause physical and economic dependency (citation).

It is expected that the findings could be used to enable decision-makers to understand better the needs of people living with spine injuries and impairments and inform civic society and legislators how to better structure and implement or strengthen laws pertinent to the protection of people living with impairments. Most importantly, it will allow participants the opportunity to share their perspectives on the marginalisation of the disabled in society. It also provides a voice to the often-voiceless individuals in the population and highlight everyone's value.

Legislative framework in the study

There are different legislative frameworks which govern different jurisdictions globally. The legislative frameworks in the OECS may bare similar characteristics to each other. This study will investigate the framework that governs the OECS islands in the Caribbean. It will look at the legal aspects of disability in the OECS and how it affects the experiences of people living with spine injuries and general disabilities. The different legislative frameworks form part of this qualitative research which will give a general picture of their composition.

Delimitation of the study

This study was delimited to a sample size of 16 participants who were at least eighteen 16-years-old and were all living with a spine injury for at least one year. For an average sample size and data saturation for qualitative studies (Hennink & Kaiser, 2021), suggest a sample size of (9-17). The participants were recruited from three OECS countries, Antigua and Barbuda, Saint Lucia, and Saint Kitts and Nevis; therefore, the sample was limited to the residents of these OECS countries. All participants were recruited using the referral method, where the participants were referred to me by each disability association and further referrals were made by subsequent participants. The narratives of this study came from a particular group of people, that is, people with spinal cord injury.

Research Questions

1. In what ways do people with spinal injuries experience daily life in the OECS?
2. What are the most commonly mentioned barriers to inclusion experienced by people with spinal injuries?
3. How are the experiences of newly disabled people with spinal injuries affected by membership in different social groups?
 - a) How is this affected by overall care, cost, gender, and sexual orientation?

Summary

This chapter provided a background of the study and a problem statement and further outlined the research questions that guided the study, an outline the significance of the study and identified gaps in the area of research and delimitation. The study was organised into the following chapters: Chapter 2 provides a review of literature related to the study. Chapter 3 is a detailed outline of the research methodology. Chapter 4 provides the study's findings and outlines the participants' profile, in addition to an evaluation of the conclusions of the participants' accounts of their experiences and results. Additionally, the chapter identifies where the findings were consistent or inconsistent with past research. Chapter 5 is the presentation of the implementation, recommendation and, finally, a comprehensive conclusion.

CHAPTER 2 LITERATURE REVIEW

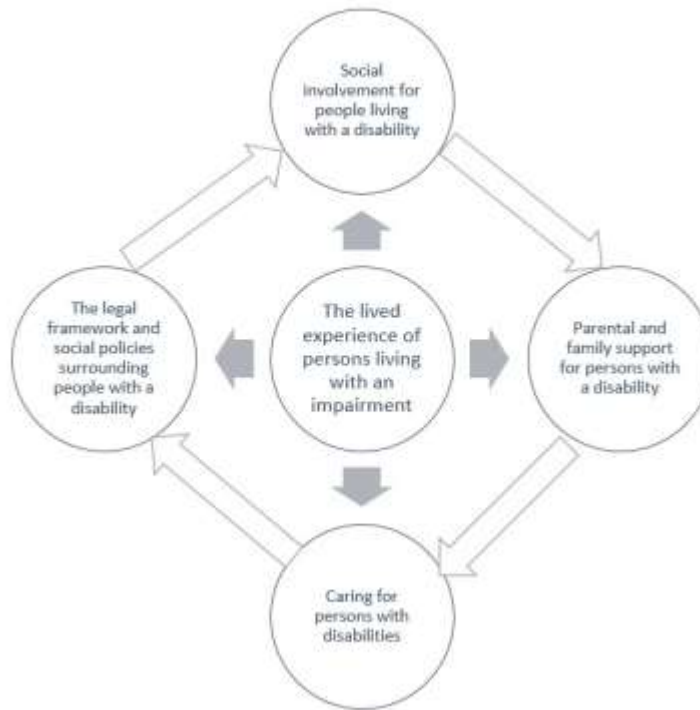
Theoretical Framework and Industry

This qualitative phenomenological study aims to investigate the individual experiences of people living with an impairment caused by a spine injury within the OECS while also looking at the legislative framework that governs disability in these islands. According to Marshall (2009), the world view of people living with a disability is derived from more developed countries in Europe and North America.

There are eight main aspects that will be examined in the review: (1) the history of the global disability movement, (2) the legislative framework for people with disabilities, (3) people with spinal cord injuries on their independence and sexuality, (4) sexual relationship and disability, (5) persons with disabilities and gender based violence, (6) persons with disabilities and the use of assistive technology, (7) discrimination and gender identity in people with disabilities, and (8) Disability Culture. Figure 2 illustrates this literature review's adopted principle.

Figure 2

Adaptable principle of the lived experience for people living with a disability



Note. Adaptable principle of the lived experience for people living with a disability.

Theoretical Framework and Theories

While there are several frameworks and existing theories that could provide insight into the existing issues of society's perception of people living with impairments, I used phenomenology as a theory to examine the lived experience of people living with an impairment, using its presupposition-less form of inquiry (Christias, 2018). To get a clearer understanding of theoretical frameworks, Anfara, & Mertz (2015) define the terms as quasi-empirical or empirical theory of social and/or psychological process of ones mind. These are then applied to

understanding a phenomenon by using muted group theory, described by (West & Turner, 2018) as a group that may have difficulty expressing themselves fluently in a dominant mode of expression and the critical disability theory provides insight into two perspectives of disability, power and context. West & Turner (2018) suggest that the lack of control of a person with a disability means a high possibility that that persons may be marginalised and thus left out of society's normal functions. This study hopes to capture experiences of people with disabilities, provide said insight such as the critical disability theory provides and compare to present literature the outcome of the findings.

The Phenomenological framework

Research methodology and philosophy are both aligned with phenomenology. Moustakas (2010) refers to phenomenology as knowledge as it appears in one's consciousness, it further known as the science of describing what one perceives. In many ways, phenomenology can be viewed as a way of looking at reality (Nesti, 2004), the way one lives, and an investigation into one's experience. It is this experience that this study wishes to highlight.

German researcher Husserl (1859-1938) founded phenomenology as a research method. Husserl's phenomenological idea stemmed from the thought that the focus should not primarily be on the individual's experience of an object but on a holistic experience. The philosophical framework of understanding phenomenology resides in considering that it is both descriptive and qualitative. Finally, Polkinghorn (1989) suggests that using phenomenology as a research methodology differs from other qualitative methods. This is mainly because its primary concern is about the experience of the person, group, or even an event.

Critical Disability Theory

Critical Disability Theory, or CDT, explores social and ontological issues encountered by present-day disabled people. The theory also analyses disability as a cultural, political and social phenomenon (Hall, 2019). The Critical Disability Theory, according to Hall (2019), focuses on four main diverse, interdisciplinary set of theoretical approaches which is explained below. These approaches tend to focus on the environment in which the individual lives. Critical Disability Theory is seen as a methodology and not a subject area of study (Schaik, 2017). The critical disability theory encompasses examining not physical or mental impairments but also looking into social norms that define particular attributes as impairments. Further the critical disability theory looks into the social conditions that concentrate stigmatised attributes in particular populations. CDT challenges ableist assumptions (Hosking, 2008), which somehow shapes the way society sees individuals with impairment. Hosking (2008) also suggests that CDT revolves around comparing liberal norms and actual values in the lived experience of people with an impairment.

Issues surrounding disabilities studies and theories about disabilities are not just about the physical impairment that an individual has but also the values and norms that society places on these people. Inherently the political sector will must be encouraged to make visible changes in legislation to support those individuals with impairment who will then more likely view themselves as more valuable citizens.

Through interviews, this research will investigate the experience of individuals living in the OECS with spine injuries. The study will not only extrapolate their experiences in living with the impairment, but also focus on the assessment of the disability climate, disability assistance, theoretical controversies, and discrimination and finally, identify how the social and political

constructs of disability in terms of persons with disability (Hall, 2019); then, determine the implications of the said constructs. The Critical Disability Theory advocates jurisprudence and the social, economic, and legal principles, all of which affect individuals with a disability.

Critique Surrounding the Critical Disability Theory

The Stanford Encyclopedia of Philosophy (2019) suggest that one of the tension points with the CDT is that of its political inclusion of individuals with a disability. There is a tendency by some researchers and health professionals to label their work as disability studies, just by using persons with disabilities as an object in their study (Stanford Encyclopedia of Philosophy, 2019). However, the theory is not as some researchers make it out to be. The theory focuses on the perspective of the disabled individual while investigating their social environment and experiences.

Language in the study of disabilities has always seemed to be aligned with the medical model, especially when referring to rehabilitated individuals and students with special needs. This, however, was never the case and has always been aligned with the rights movement (Stanford Encyclopedia of Philosophy, 2019) and always from the so-called correctional intervention (the medical model of disability).

Conclusions

The CDT is central and encompasses two main models addressed in the upcoming sections: the medical model of disability and the social model of disability. As we will find out, the medical model is based solely on a scientific approach and usually promotes medical intervention. On the other hand, the social model of disability is based solely on principles, such as the environment and society's perception of individuals with impairment.

Theory of Social Constructionism

Hirschberger (2018) expresses the meaning of this theoretical approach as aligned to meaning, belonging and self-esteem of the individual. Learning from the experience of people with a disability gives significant meaning to understanding disability in and of itself. The controversy surrounding this theoretical approach claims that disability is commercialised into a multimillion-dollar industry in industrialised countries such as the United States. “Disability becomes a commodity” (Oliver, 1998, p. 4) and a source of income for doctors, lawyers, rehabilitation professionals, and disability activists. This commodity ultimately demisnishes the professional service that persons with disabilities should at the end of it all receive. Oliver (1998) also highlights that an individual's consciousness is disrupted when people with disabilities are treated as abstract. Vinney (2019) defines social constructionism as a theory that supports the development of knowledge by individuals in a social context. As it relates to disability and disability studies, this context is created in cultures where knowledge and meaning are the basis of the theory. Social constructionism is concerned with meaning, and both ontological and epistemological aspects of disability (Vehmas and Riddle, 2019). Burr (2015, as cited in Gergen, 1985) explained that there are a few assumptions that should be made while considering the meaning and understanding of social constructionism:

A critical stance towards taken-for-granted knowledge: This assumption explains that individuals within a society or group need to take a more proactive approach in matters relating to themselves (Burr, 2015) towards understanding oneself or the world one lives in, where people with disabilities are often taken for granted. This study should bring to the fore the experience of individuals living with spine injuries in the OECS. The theory challenges

researchers to be over-suspicious of assumptions made by positivists and epistemologists. This group of individuals depends on hard science for their findings.

Knowledge is sustained by social process: The knowledge is sustained assumption suggests that knowledge of work is made possible through human interactions throughout their life (Burr, 2015). The knowledge of a particular impairment can come from interaction by or with the individual with that specific disability (Burr, 2015).

There is a direct link between social constructionism and the social model of disability where, according to (Vehmas & Riddle, 2019) the social model of disability is derived from social constructionism. There are also some societal contributors which add to social construct. One such contributor is the media. Anastasiou (2011) suggests that the media plays a part in portraying the difference between men and women as it relates to their impairments. The assessment made is that the man is seen as the dominant being and as such it highlights the view that is socially constructed of the woman to be the weaker being.

It can be concluded that similarities may be also drawn between non-disabled and persons with disabilities when it comes to the philosophical view of social constructionism and portrayal of people with disabilities. It is stereotypes like these that cause a separation in the way society view people with disabilities.

Conclusion

The theory of social constructionism relates to shared knowledge (Oreilly et al., 2018). The social constructionism theory is not concerned with the reality but rather how that knowledge is constructed and is knowledge-based. This theory fits well with this research as it is a phenomenological study, and the knowledge gained will be pure and based on language. (Oreilly et al., 2018).

Disability Models

Various models of disability exist in the field of disability and disability studies. Researchers such as Dembo, Wright, and Goffman from the 1960s have all examined the three main types of disability theories, sociological and psychological (Hoeman, 2008), as opposed to the medical model of disability. As put forward by Llewellyn, Ayers & McManus (2019), medical professionals see this model as a see it, fix it perspective (p. 80) for people living with a disability. These ideological concepts are based on earlier theories, including sociological and psychological theories of disability. On the other hand, the social model sets out to improve the lives of people with a disability.

Social Model

The social model of disability, as proposed by Barnes (2019), is derived from societal attitudes and not attributes possessed explicitly by the individual. Oliver (1996) opines that the social model of disability has been received more unreservedly by individuals with a disability. Because of this, individuals with a disability can make a more personal connection, hence the idea of a phenomenological study and individual consciousness (Hegel, 1977). Earlier pioneers like Mike Oliver, the first professor of disability studies out of the United Kingdom based the model of social disability on the environment in which the individual lives that fail to provide the appropriate services and not on the individual's limitations. Due to the clarity of the definition given by Barnes (2019), it will be used given the term societal attitudes. Oliver (1996) finalises the meaning of the social model of disability as all those factors that impose some restriction on people with a disability (Figure 3). These restrictions may range from individual prejudice to discrimination meted out by institutions and inaccessibility. The social model of disability is exceptionally vital to this study as revelations can be made as to how people living with a spine

injury use the social model framework in the OECS and conclusions drawn from the lived experience of people living with impairment in the OECS. Union of Physically Impaired against Segregation UPIAS (1976) cites the following:

It is a society that disables physically impaired people. Disability is imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are, therefore, an oppressed group in society. (p.14).

Table 1 shows a comparison of the social and individual models of disability.

Table 1

Comparative Disability Models.

<i>The individual model</i>	<i>The social model</i>
personal tragedy theory	social oppression theory
personal problem	social problem
individual treatment	social action
medicalisation	self-help
professional dominance	individual and collective responsibility
expertise	experience
adjustment	affirmation
individual identity	collective identity
prejudice	discrimination
attitudes	behaviour
care	rights
control	choice
policy	politics
individual adaptation	social change

Note. Reprinted from Understanding Disability: From Theory to Practice, (p. 34), by Oliver, M, 2012, Palgrave Macmillan Copyright 1996 by Michael Oliver.

Figure 3*The Social Model of Disability*

Note 'The Social Model of Disability.' From Inclusion London (2019)

(<https://www.inclusionlondon.org.uk/disability-in-london/social-model/the-social-model-of>

disability-and-the-cultural-model-of-deafness/) Copyright [2019]. Adopted with Permission.

Individual –Environmental Model of Disability

Oliver (1996) explains the individual model of disability as an issue of identifying the problem within the individual and then pinpointing the cause of that problem as a functional limitation of the individual's disability as being false. The genesis and cause of social disability lay squarely on the barriers that society produces Oliver (1996). The individual model of disability is the problem disabled individuals experience due to their individual impairments (Bjarnason, 2004). Unlike the social model of disability, the personal model sees diagnosis of impairment and its subsequent solutions in medical terms. Oliver (1998) noted that literature written by disabled people has over time transformed our understanding of the real nature of disability with individuals. These writings have moved from a personal limitation to a more

socially based ideology and imposed social restrictions on individuals with a disability (Oliver, 1998).

The environment model of disability adds a classification called societal limitations as expressed by (Retief, 2018). This classification or limitations on people with disabilities, somewhat limits the independent participation activities, roles and even tasks. The environmental model of disability gives an example of employers' unwillingness to construct suitable ramp access or the unwillingness of educational institutions to provide reasonable accommodations for their students. These may be seen as subset of the environmental model which falls under **the Physical Environment in which the disabled person lives which also includes the Psychological and Social Environments** (Retief, 2018).

The Human Rights Model

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was the first human rights treaty to be presented and developed for persons with disabilities (Series, 2019). The human rights model in its initial stage focused on a theme on *nothing about us without us* focusing on a social understanding of disability (Series, 2019). The human rights model of disability may also be considered to have similarities with the social model of disability (Degener, 2017) as it relates to their core values, where the social model focuses on the human being as not being the problem but in the society in which person with disabilities live. It further focuses on limited policies, attitudes, the environment and structural barriers that may affect the independence of people with disabilities. The human rights model of disability values the human being and includes policies that affect the livelihood of people who are disabled, and non-disabled concludes Degener. Degener (2017) also concludes that the social model of disability assists individuals in understanding society's social responsibility towards people with

disabilities and the underlying factors which affecting their lives. However, the human rights model not only allows individuals to understand but it shapes a framework for policies regarding people with disabilities that places specific emphasis on the human factor (Degener, 2017) and the rights to live as non-disabled human beings.

The human rights model is particularly applicable when considering older adults facing disability as a result of spinal injury since, in addition to focusing on the individual and their human dignity, it considers their ability to live independently. Factors such as one's civil rights, an individual right to be a part of society and not to be discriminated against because of one's physical or mental condition, are examined. One's political rights give individual independence and freedom (Degener, 2017). An individual's economic rights, whether that individual is disabled, gives him the autonomy and right to sufficient food, shelter, water, education, housing, adequate health care and employment. These factors contribute to an individual with a spine injury having reasonable independence as required by that individual (Retief, 2018).

Medical Model

Barnes (2019) expresses that disability interest in the 1970s was mainly focused on a more individualistic and medical interest. In centuries past, medical professionals had been in the business of strictly identifying and correcting functional and structural defects. This view has long criticised the lack of foresight of the **psychological and social dimensions of the personal illness of each disabled individual**. Watermeyer (2012) posits that individuals with a disability are socially and economically marginalised. Abberley (1996) points out that examining defective bodies rather than investigating how society treats these bodies will always be why such issues remain unaddressed. In critically looking at the medical model of disability, medical professionals are trained in biomedicine (Watermeyer, 2012) and never in social intervention.

Therefore, it would typically be difficult for them to make sense of the struggles of a physically impaired individual.

We can agree, to an extent, that the disabled community has been marginalised and sidestepped owing to the stereotype that all medical practitioners are alike, leading to the misconception of the term medical model of disability. It is argued that the medical model has neither focused on contextual factors (e.g., social or environmental factors) expressed (Marini & Stebnicki. 2018, p. 406) nor considered the experiences subjectively of individuals with a disability. The medical model of disability was coined directly, as it was seen as an individual or medical issue that required medical intervention or some sort of cure to curtail the problem. Figure 4 draws attention to society's views of the medical model. As illustrated, the medical model of disability suggests that an individual with a disability is 'unable to perform specific daily functions' because of their impairment and must depend on medical intervention to be able to fix the physical aspect of the impairment.

Figure 4

The Medical Model of Disability



Note. The diagram illustrates the medical model of disability. The Medical Model of Disability, [Inclusion London (2019)] Retrieved from <https://www.inclusionlondon.org.uk/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/>

Theoretical Controversies.

Disability is seen and conceptualised as a social and political issue rather than a medical one (Schaffernicht & Quendler, 2023).

Controversies with Critical Theory

The ideology of Critical Theory stems from the view of society and its cultural base, which in turn exposes its challenges. Geuss (2010) suggests that the ideology of social issues is manifested by social structure and cultural assumptions. If a society maintains said ideology, it will be the obstacle to human liberation. Critical Theory has been criticised for its inability to present a new pathway to political action. These political actions can often lead to legislative changes in society and the hope that the social conditions of the people in it can be improved. This also includes merging individuals' private lives versus their social life.

Finally, Critical Theory has come under criticism by many theorists. Most notable is Fraser (1985), who described Marx's definition (1843) of the critical theory as straightforwardly political character, which is essence saying he did not even make any sort of epistemological claim. The theorist has long said that the critical approach is standalone and makes no claim to other theories like epistemology.

Controversies in Social Constructionism Theory

The Constructionist Theory has sparked various debates even though the theory has produced a flurry of imperial studies (Martin, 2018). The more conventional theorists see the

objective reality of social problems. Holstein & Miller (2007) point out that this should be the topic of all sociological studies, which is stubbornly denied by constructionists. Two schools of thought appear to have caused a rift between constructionists. Firstly, an argument for maintaining a strict constitutive reading of constructing social problems, which suggest that social construction should be void of any influence of human biology on human behaviour and any influence on their culture. Secondly, others argue for a more contextual constructionism Holstein & Miller, (2007, p. 5, as cited by Best, 1989). Constructionist belief on contextual constructionism suggest that it is based on a community's fundamental and cultural beliefs.

Sokal & Bricmont (1999) argued that a more notable controversy with constructionism is its omission, or the lack thereof, of biology on behaviour and culture and society. In other words, society in and of itself cannot exist with just human relationships, as stated by Vinney (2020,) but with some element of biology and physics. This study provides an insight into the assertion of Olsen et al., (2022) on the disabled individual in that, all bodies, whether socially or otherwise, are inter-connected. Coming out of this study, it is hoped that the experiences of disables people will provide further insight that society's attitude, institutional policies, far outweigh that of the biological composition of the disabled individual which is thought to make up their reality. Not only does the Social Constructionism Theory promotes for the overall experience of the disabled individual, but it further focuses on the culture and self-awareness of the disabled individual (Olsen et al., 2022). This study hopes to amalgamate the constructionism paradigm outlined by (Olsen et al., 2022) which recognises this interplay between individuals interpretation and shared understandings.

The Global Disability Movement

Introduction

One of the most significant strides made over the life of the disability movement was the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Lohmann (2018). According to Retief & Letšosa, (2018) the disability movement gained political and academic traction when people with disabilities (PwDs) started to be more vocal about their issues. Issues such as poverty and residential incarceration are some of the plights people with disabilities have agitated for, so their voices can be heard both socially and politically. It was not until the 1970s when the Open University created a course focusing on disability whilst highlighting this vulnerable group's consciousness. The course was entitled "*The Handicapped Person in the Community*". The course began academic studies on disability in the United Kingdom. Other educational institutions followed suit.

It was not until the 1970s and 1980s that members of the general population began to see the importance of and garnered a deeper understanding of disability and its effect on people (Pfeiffer, 1995). The mere assumption was that individuals with a disability could not formalise and organise any political action or make any meaningful political move, as they were seen incapable of effecting change; thus, they were only seen as capable of being solved by way of medical intervention. This was later coined as the medical model of disability. Pfeiffer pointed out that in the 1990s, medical professionals could not take care of PwDs. However, Pfeiffer pointed out (as cited in Watson, 1993) that some members of society believe that certain individuals will need medical intervention from a professional.

Historical discrimination in Disability

After the passing of the Rehabilitation Act in the United States in 1948 (Parry, 2008), there were dispiriting views on two divided aspects of individuals with an impairment. The first was the initialisation of individuals with mental disabilities. This group of individuals saw most of the discrimination being meted out by an uninformed society. Society saw mental disability as a developmental disease, and these individuals became disadvantaged members of society. Another discriminatory idea was that individuals with a physical disability were, in most parts, represented a little more sympathetically in the public's eye. The level of discrimination in American society had practices that today are viewed as inhumane. Individuals with a disability were chased out of their towns, and frequent acts of violence were meted out to them, Albrecht et al., (2001). This treatment was a core reflection of the violence, poverty, and ignorance of an uninformed society about the nature of the disability and its sensitive nature.

Albrecht et al. (2001) made biblical and prehistoric references to specific disabilities and people with disabilities. The analogy was made with an example of an ape falling out of a tree and having a severe injury. The other apes will not forsake or abandon the seriously injured Ape and will make sure he moves with the pack until he gets better. In contrast to humans, specifically in the pre-World War II era, individuals were abandoned and treated less humanely than non-disabled individuals.

The changing tide of the acceptance of the disability movement in the eighteenth to the nineteenth century continued into the modern periods (Albrecht et al., 2001). The era saw the movements of individuals with a disability being thought of as demon-possessed or created by

Satan, and the treatment of individuals with a mental disability in the form of beating their heads as a means of some form of cure for sickness, such as depression, paralysis, and having an intellectual disability.

According to Parry (2008), one of the most vulnerable sets of individuals with a disability that faces discrimination and oppression are individuals with mental illnesses. This group of individuals has been labelled with many names, for example, insane, idiots, morons, and imbeciles. As a fundamental right, individuals with disabilities are deprived of the right to decide for themselves, primarily if standardized. Parry (2008) states this is because of fundamental valuation principles. This, according to Parry (2008), is institutional abuse.

The Native American beliefs about disability

Different cultures have varied ideologies of life and their individual beliefs of many things that affect life. The constitution of what disability is and its meaning to an individual will vary across cultures (Weaver, 2015). The Native American culture views life conceptually different from all other western cultures. Native American culture according to Leib-Neri (2015) accepts the idea that their social reality is inherently chaotic and further believes that their health comes from finding balance in chaos. The Native American cultural consciousness holds that there are different perspectives and interpretations to this existing chaos (Leib-Neri, 2015).

The idea of abnormality and normality in the culture of the Native American is non-existent. Their belief system surrounds that of an ever-changing reality (Leib-Neri, 2015), that is rooted in a fundamental reality that is ever changing. Research has over the years unearthed many Native American tribes. However, the research has also shown that their ideology of disability, health and wellness has consistently remained the same throughout the tribes. This

consistent ideology is their ability to accept differences in every fact of life with includes one's disability (Leib-Neri, 2015).

Nielsen (2012) cited in her book *A Disability History of the United States* stated that, the concept of disability in the Native American culture does not exist, such that there is no official native translation (Nielsen, 2012) for the word disability in the native culture. This overarching concept of disability and the Native American belief system stem directly from the connection of their spiritual of religion to tribal community social health and their medical care that is provided. The wholeness of one's existence is the Native Americans' guiding philosophy of their Tribal Medicine.

Finally, the Native American culture was systemically destroyed by war, diseases and systemic political interference. The belief of disability in the Native American culture surrounds that of a spiritual disharmony (Dwyer et al., 2000). Within the Native American disability traditional ceremonies, it is believed that a disabled individual can be cured (Nielsen, 2012) regardless of their physical or mental disability.

The Chinese cultural and historical beliefs on disability

In contrast to the beliefs and cultural views of the Native American Indians on disability, the Chinese cultural perspective is much different. Chiang & Hadadian (2007) point out that when it comes to disability, the Chinese focus on two terms, Chanji and Chanfei. The Chanji is understood to mean an individual having a disease that one will never recover from. The Chanji? implies that a person with a disability is considered worthless by family and society. If we conceptualise this in today's modern consciousness, it will be seen as harmful, insensitive, and even inhumane. **The historical culture of the Chinese regarding disabilities considers the child to be a disruption to nature and the natural order of the family and its society, which affect their**

cultural balance. This conform to the contextual constructivism, where understanding the fundamental cultural belief is critical to their overall existence.

It is a Chinese tradition that a child born with any form of physical or intellectual disability has always been seen as a negative reflection of some bad luck that has followed the parents. Traditionally, Chinese cultural beliefs would incorporate superstitious beliefs such as insinuating that a pregnant mother who consumes the wrong foods or even visits a cemetery will give birth to a disabled child. These strong traditional beliefs and the negative outlook are why families do not make public the birth of a child with some form of disability (Tsao, 1999) Punishment by ancestors is generally attributed to the birth of a child who is disabled. Moreover, Chan (1997) stated that these parents are usually left with great shame and humiliation with the upbringing of their children. The care and upbringing of a disabled child in Chinese culture are often seen as considered experiences. Therefore, seeking assistance is always withheld by the parent (the mother) in most instances, as she normally takes the blame for the child's disability on herself.

It is believed that in the American Chinese and traditional Chinese culture, the parents of children with developmental disabilities should be suitably equipped with the requisite training and skills in support systems. To conclude, Wong et al. (2004) suggest that parents of children with a disability should have some understanding of the child's disability.

Western history of disability

Albrecht et al. (2001), distinguish between a disability and an impairment. He explained that a disability exists as it is situated within the larger social context which includes barriers, while impairment is a biological condition, for example someone who is visual impaired. The legislative framework for identifying disability as a social category was not officially framed

until after the eighteenth century. Albrecht et al. (2001) suggested that the documented history of disability in the west was not well documented, so it is challenging to acquire literature on the field. The notion of ancient civilisation on impairment, specifically in Greek and Roman cultures, suggests that an individual born with a mental impairment should be eliminated from integrated into their society (Albrecht et al., 2000). They believed that being born with a disability was a curse from the gods. In contrast, if one developed impairment some years after birth one was socially accepted and was in-cooperated into society as regular workers and even soldier.

We see similarities in the Greek culture (Albrecht et al., 2001) as with the Oriental (Chiang & Hadadian, 2007) and American Indian cultures Lipson & Rogers (2000) that their beliefs of being born with an impairment are linked to some spiritual taboo of bad luck. This bad luck was thought to have come from the mother's actions. Impairment was always also related to an improvised society. After World War II, in the United States, soldiers coming home with impairment had issues finding employment in the civil service. Therefore, the US government enacted its first legislation recognising people with impairments and their smooth transition into the civil service Parry (2008). This legislation is today known as the Rehabilitation Act (p. 1).

Fuchs (1999) looked at the French culture as it pertained to the treatment of the disabled and how they were treated at birth and developing a disability after birth. The French culture's survival rate for children with a disability was meagre (Fuchs, 1999, p. 243). Those who survived were sent to the countryside rather institutionalised. The practice of foster parents caring for impaired children came into French culture around the 1850s. The French government offered extra funding to these foster parents to care for these impaired children and keep them in

school. The authorities made it mandatory for children aged six to attend school so society's expectations may morally guide them.

The French government, in its kindness, also offered clothing to abandoned children until their eighth birthday. Vocational training schools were frequently opened to facilitate children with disabilities; this vocational training included cabinetmaking, printing, and typography Fuchs (1999). The French society mainly addressed the needs of impaired children, who had to be at least fourteen to enter these institutions.

After joining these vocational schools, impaired children worked in return for lodging but were given an extra stipend for good work done. Fuchs (1999) indicated that for poor orphans and abandoned impaired children, it was mandatory for children after reaching the age of twelve to repay the state in military navy service as ship boys. When children were abandoned in the 18th century, Fuchs (1999) suggested that they were left out not because of any form of mental illness but rather a form of drastic actions due to economic and social pressure mothers and families faced in the era.

Age-old beliefs

Before the advent of the movements that brought about the advocacy of disability, the understanding of disability was more of a spiritual one in some ancient societies (Mackelprang & Salsgiver, 2016). Civilisations such as the Spartans who believed in abandoning their disabled Children once born with any form of disability at the side of the road or the Neolithic tribes thought that having a disability was a result of spirits (Munyi, 2012). Their practice was to have surgeries on these individuals to release the evil spirits that may be possessing the young child (Mackelprang & Salsgiver, 2016). People who lived with disabilities in Asian societies in the past were often seen as being somewhat less than humans, substandard, and beggars.

In more recent times, Mackelprang & Salsgiver (2016) explain that in western cultures, due to Christianity, people with a disability were not seen as a part of humankind and, in that light, were seen as being able to have some form of imperfection. At an early age, Tom Shakespeare was diagnosed with achondroplasia, which also influenced his work in the disability movement in the United Kingdom. His personal life also influenced his continued research in the LBGTQ community, which further gave rise to his book *The Sexual Politics of Disability* (1996). Shakespeare's disability was genetic, and he had children despite of his disability. Thus, this gave the natural thrust towards him researching disability in children. His disability later in life was complicated by severe back pains, which further led to his growing interest in genetics and bioethics.

Shakespeare's work over the years led him to rethink his ideology on the models of disability, as in his mind, it was too reliant on political rhetoric and ideology, which according to him, needed a rethink. His new ideology started to become increasingly critical to researchers of the social model of disability. His most profound statement was in his book *Disability Rights and Wrongs*, where he said, "I am among those who argue that it should be abandoned" (Shakespeare, 2014, p. 5); here, Shakespeare refers to the Social Model of Disability. Shakespeare's future works focused on the medical model of disability while focusing less on the social model. British society advocated strongly for the social model of disability (Shakespeare, 2014). A broader look at disability must be taken into context and not just an individualistic view of the topic (Shakespeare, 2014). Research should take a more comprehensive look at the varying models. Perhaps, instead of looking at one model and streamlining it to group people's disabilities with one such model, a holistic approach must be taken if disability studies are to be fully explored and understood.

In his research, Shakespeare (2014) claimed that historically, in British society, many of the problems and issues that persons with disabilities face were socially generated and not particularly that of their impairments. Additionally, over the past years, there have been claims that disability has only been entrenched in the social context. Researchers such as Tom Shakespeare pointed out the continued use of the terms disabled and impaired people and how they are used for physical disability. Founding disability groups in the United Kingdom, such as UPIAS's Union of Physically Impaired against Segregation, seemed to have only focused on the social aspects of persons with disabilities and not on the medical model. Michael Oliver dispels the notion that there is no such thing as the medical model. Still, there is the individual model of disability in which medicalisation is a significant component (Shakespeare, 2014).

Shakespeare (2014) explained that he did not entirely dispel the notion of a social model but rather urged researchers and organisations to have a broader view of different models instead of focusing solely on the social model. For this reason, exploring Bioethical questions relevant to disability was researched. The medical model of disability can be used to improve the lives of impaired individuals whose impairments may not be solved otherwise by social intervention.

Discrimination

Before the advent of the worldwide disability movement, the issue of discrimination, whether they were skilled or not, was deemed legal in the United States (Pelka, 2012). The unfortunate aspect was that, for example, the general population understood that people with a disability were seen as handicapped a word used in the early disability movement or, at other times seen as undesirables. In instances where a prospective house tenant may be refused occupancy because of his impairment (blindness) or an individual who might have dismemberment yet still be productive may be fired or dismissed.

Discrimination was militated against persons with disabilities before the movement started, even at places of business, seemingly one of the biggest obstacles to discrimination. Social justice activists neglected disability discrimination (2015) and in their journal commented that discrimination in disability is an issue that has not been given much attention. This attention consequently caught the consideration of the American legislature in the 1990s, which further led to the passing of the disability act. Though this act, when passed, was well-received, social justice activists neglected disability discrimination. (2015) highlighted the difficulty in enforcing this act, owing to the low percentage of qualified people with disabilities and people with disabilities hired compared to the high percentage of non-disabled.

When discrimination is built into an organisation's process, structure or system and that organisation fails to consider the needs of a group of people, Megson (2011) suggests that this is referred to as institutional discrimination. Studies by the National Health Service (HNS) in the United Kingdom and the Equality Rights Commission (2010) pointed out the many forms' disability can take. These forms can be unequal treatment by service providers, unfair treatment, or even cases where victimisation has been proven. Barber (2015) also links discrimination to employment in that an employer may show unequal treatment towards an individual who is disabled because that said individual is disabled. When the Disability Discrimination Act was passed in the United Kingdom in 1995, the emphasis was placed explicitly on healthcare workers to be provided adequate training to promote equality of service for persons with disabilities, and access to those provisions. Barber also suggests that healthcare workers should be aware of published guidelines to mitigate the effect of institutionalised discrimination. Finally, in addition to being aware of published guidelines, one should also be mindful of legislative policies.

Abandonment

There are many past discrimination examples; one such example is abandonment. Albrecht et al. (2001) speak to the many instances of abandonment, for example, he pointed out that children who were born deformed, or a very dependent elderly person would have normally been abandoned. It can be argued that these forms of discrimination still take place. However, we can agree that history has brought us a long way. Parents giving up their children to adoption agencies is not unique to ancient communities as they are still prevalent today in the form of anonymous delivery because of adoption. Grech and Soldatic (2016) indicated that abandonment might be coupled with loss, as it highlights the human nature of individuals. It was not uncommon for individuals to be abandoned by friends and family after a mobility impairment resulting from a spine injury or dismemberment.

In some instances, loss and abandonment result from families and friends who have accepted the past behaviour of the affected individual. For example, a woman in a violent relationship was dismembered by her partner and is now disabled. Such actions by family members to shun the affected member can cause a level of socio-spatial isolation, which will cause a significant case of abandonment and loss. Safford and Safford (1996) pointed out that in Greek culture, the culture trumped military training. If a baby was born with an impairment, that child would have been disposed of in a clay vessel and left by the wayside which will overtime be killed. This was a cruel form of abandonment. However, because of the Greek solid cultural belief, it was always thought that someone would pass and care for that disabled child. Ancient Roman law also instituted that if a child is born disabled, he is at times floated down or invoked what was then known as *abdication*, which indicated the child would have been driven from the house and sold into slavery. The rarest form of neglect, abandonment, or loss was the

killing of a deformed child in Roman culture. Notwithstanding, most families did not kill their newborns; instead, they were left at a roadside, hoping that the child would be picked up by someone to care for them Lowenfield (1975 (as cited in Safford & Safford, 1996). According to Stiker (2019), the historical, social construct of a society of difference is what marked individuals with a disability as alien. The medical model of disability has long been seen as the Middle Age answer to curing individuals with a disability. Disability is a social phenomenon, Stiker (2019) and the way a society treats a particular phenomenon reveals the depth of that society.

Culture

The disability culture and people with a disability have been looked upon and defined by their differences. The definition of disability outlined by Withers (2020) suggests it is a lack or limitation of competence to perform daily. Disability also refers to an individual with a limitation that might have resulted from dysfunction in the person's mind and body. Notwithstanding, we can view disability as a social setting, for example, social poverty and race. The cultural outlook on the disabled community internationally started taking shape when in 1981 with the inception of the International Year of Disabled People and then in 1983, the United Nations Decade for Disabled Persons. These two cultural events created a global multicultural shift which caused the consciousness of society to be more sensitive to the disabled community. Owing to the change in perception and the emphasis placed on disability awareness and culture, many studies have been done by psychologists and sociologists to have a firmer grasp on this evolving area of study. It must be highlighted that most cultural studies were concentrated in the more developed countries, for example, the United States and Europe, Ingstad & Whyte, (1995).

The American outlook toward the Lakota Disability Culture

Two of the most reported disability conditions in the American Indian or the Alaskan Native community are spinal injury and mobility disability (Pengra & Godfrey, 2001). Some of these disabilities are developed early in life and are even acquired at birth. The Sioux tribe believed that disability was never a problem with the person who has the disability but believed that disability is society's inability to assist all people. The principle is in line with the modern-day *Social Model of Disability* (Harley, 2018). The Lakota people believe that an individualistic methodology to social modification of one's attitude to disability can be the ultimate result of said individuals coming together to affect change for a common goal (Lipson & Rogers, 2000).

The medical model of disability is firmly rejected by the Native Americans, as it only suggests that only medical intervention may be used to correct the disability (Deloria, n.d). The native Indians disagree with the idea of capitalism as it emphasises the idea individualism (Westbrook, et al., 1993) which gives rise to the exclusion of individuals with a disability. Many activists in the disability culture argue that specific barriers that prohibit full inclusion in mainstream society are not the characteristics of the individual. Still, the way society itself is structured renders the individual disabled. The people of the Lakota, therefore, demanded equality and access to all people, and if an individual had a problem, then unique solutions should be provided. In other words, the Lakota people believe in an all-inclusive society for their people (the Native Indians) and all critics.

Bellemere et al, (2019) outlines that several factors may aid in the recognition and, subsequently, the improvements in the lives of the people with a disability in the Lakota settlements. Factors such as political actions, anti-racism initiatives, and poverty elimination are

a few that (Joe and Mallach, 1992) indicated can mitigate discrimination toward people with disabilities. There is a school of thought by Tripp-Reimer, et al. (2001) that the native Indians have possibly produced a barrier of exclusion rather than inclusion for themselves by sticking to their own cultural beliefs in instances where medical intervention may be necessary. Their refusal to allow their children to engage in what we deem as routine medical checkups and other services are what the Lakotas believe are the services that cause them to compromise their beliefs.

An activist view

The history of disability has seen many pioneers advocating for people with a disability. Gold (2011) highlighted Justin Dart Jr. as one of those pioneers who has made significant strides over the past decades and has campaigned repeatedly for persons with disabilities on the international stage. His advocacy began after contracting polio in 1930 at the ages of eighteen. Dart saw his first level of discrimination dished out to him after completing his masters degree in History. By the Second World War and certainly, before the first disability act was passed, persons with disabilities faced an uphill battle with exclusion and discrimination in the societies in which they lived. The College Board refused Dart his teaching certification because of his disability, and therefore he had to relocate to Japan to work in his family's Walgreens Drugstore. Dart became famous after his return to the United States and wrote numerous articles about hiring individuals with disabilities while in Japan. As a result of this, he served on the governor's committee representing and advocating for persons with disabilities (Gold, 2011) and further, in 1981, he served on the National Council for the handicapped under President Reagan. Dart's work propelled him to be the chair of the Congressional Task Force on the Rights and Empowerment of Americans with Disabilities.

Dart's work came after the introduction of the Disability Act following World War II. By then, society in general would have been sensitised and had a different level of consciousness and understanding of the plight of people with a disability. Due to the increasing awareness of individuals with disabilities, affected people across the United States started to be more vocal about discrimination and exclusion and issues they faced with housing, transportation, education, and employment. The work of Dart, supported by his wife Yoshiko Saji, paved the way for today's disability groups in America to have a voice moving from exclusion to inclusion, from full discrimination to none at all. Dart was presented with the Presidential Medal of Honor by President Bill Clinton.

Conclusion

The historical view of persons with disabilities has been a long one, due to the discrimination and exclusion in the social context. The cultures investigated had their own beliefs that were specific to their way of life. However, one aspect of their lives was how persons with disabilities were treated. This treatment was clearly because of the absence of activism and knowledge. However, the introduction of the Rehabilitation Act, the United Nations CRPD, and councils such as the National Council for the Handicapped have given voice to people with disabilities. On May 3, 2008, the United Nations Convention on the Rights of Persons with Disabilities entered into force. The Convention enumerates several rights that relate directly to sexuality, including the right to health, liberty and security; freedom from exploitation, violence, and abuse; and respect for home and the family. The formation of the congressional Task Force on the Rights and Empowerment of Americans with Disabilities by the United States Government led the way for influential activists such as Justin Dart Jr to be a driving force in the mobilisation of the disability movement in the Western World.

The Legislative Framework Surrounding Individuals with a Disability

Introduction

In the previous section, we looked at the historical perspective of disability and the disability movement, its genesis, cultural meaning, and its understanding of discrimination towards people with a disability. This section focuses on the legal aspects of disability from its inception, investigates what progress has been made over the decades and identifies legislative frameworks that are in place in different jurisdictions around the world.

Degener & Koster-Dreese (2021) looked back on the National-Socialism policy that existed in Germany, in which the judicial system aimed to eliminate those deemed Disabled, by killings and sterilisation programs. Throughout the centuries, up to modern times, persons with disabilities were always labelled as non-productive individuals in mainstream society. They were often not included in society's activities, resulting in either being institutionalised or sent to a nursing home. This action led to persons with disabilities being deprived of their liberty to choose, a safe society in which to live, a political life and their right to education and work.

A major shift happened after the United Nations hosted its International Conference on Disabled People in the early 1990s. This Vancouver conference proved to be a catalyst of change where a drastic policy shift was made from the Medical Welfare model towards a "concept of independent living" (Degener & Koster-Dreese, 2021, p. 11). This change meant that disabled people were no longer seen as objects of society but as a part of society itself. In essence, this was a thrust to show the entire world that disabled people demanded the very same rights as able-bodied people did and not just be seen as a group of individuals who only deserved handouts.

The perception of people with disabilities globally

Berger (2021) believes that knowing how society views people with disability, leads to understanding the phenomenon from a disabled person's viewpoint and sees the importance of development and support programs for people with disabilities. According to Berger (2021), there is a growing appreciation for people with disabilities. Different societies have varied views on the topic of disability, and that is due to cultural consciousness and their perception of the topic. For example, in the Oceanic region, including Australia and the Pacific Islands, there is a cultural belief that disability is not just a biological issue but a misdeed, or an act performed by someone. Consequently, this cultural belief often leads to isolation and rejection from the society in which disabled people reside.

The isolation of people with disabilities, according to Le Clair (2014), often leads to shame. It, therefore, suggests that one's cultural beliefs are directly hinged on how society views people with disabilities. This view ultimately forms the perception of society and consequently will have a lasting impact on able-bodied persons' overall involvement in development programs for people with a disability.

Americans and Europeans who are non-disabled generally believe that persons with disabilities are considered individual who are on the lower end of the social ladder and are usually poor (Marini & Stebnicki, 2018) and are seen to be fundamentally different from people without a disability. The average American perception of disabled people is that of helplessness, incapability, and inferiority. Marini & Stebnicki (2018) point out that societies such as the Native American and African societies do not share the ideology of the Americans. Moreover, in cultures such as Asian and Hispanic, people perceive that those persons with disabilities should be embraced and protected. As Pickett et al. (1993) suggest, this sort of overprotectiveness can,

in some way, rob a person with a disability of the opportunity to become independent. In the Asian culture, not only are they overprotective (Marini & Stebnicki, 2018), they also believe that persons with disabilities are societal failures. Marini & Stebnicki, 2018,) outlines that a society's attitude can hurt a perceived minority.

This review section focuses on selected cultures: China, the European Union, and CARICOM (Caribbean Community). These societies were mainly targeted for their varied views on persons with disabilities and the progress they have made with their legislative agenda. The European Union was explicitly chosen for its rigorous disability policies and legal framework for protecting people with disabilities. Additionally, it annually recognises the European city that facilitates the best access for people with disabilities. Furthermore, the OECS member states fashion some of their legislations from the United Kingdom. Since China is the most populated country on earth, the study gives us an idea of its legal framework and how it operates and deals with millions of disabled individuals in a single society and, consequently examines gaps in its legal framework. The focus of this research is the Caribbean, specifically the OECS. It looks into the OECS's legal framework, legislations and policies and will give a general picture of how adapting the United Nations Convention on the Rights of Persons with Disabilities, helped frame the region's legal guidelines.

The review also goes into three approaches to disability. Lejeune & Ringelheim (2019) outlines the academic argument to suggest that the law, the society, and disability fall along three lines: law and policy approach, which deal with legislative matters. The social movements approach includes aspects such as the social model of disabilities, removing barriers, and the conscienceless legal approach. These three approaches will be independently investigated to understand better the legality of the law and policy of disability. The rules governing the social

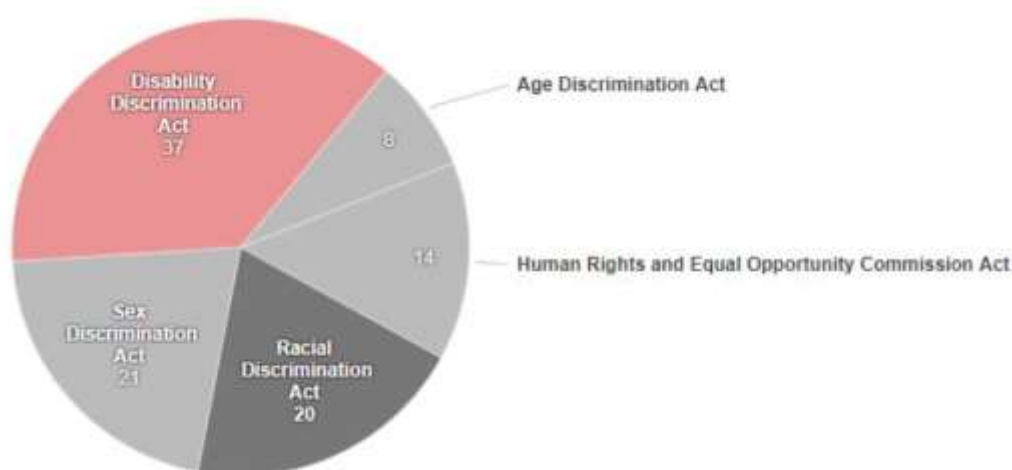
model of disability will be examined as the relationship between society and people with a disability.

Policy and perception of people with a disability

According to a report by Touchet et al. (2018), there is still a robust stereotypical perception of persons with disabilities regarding the care they need and how productive they are. The level of prejudice against the disabled community from Scope (2018) survey is show in figure 5.

Figure 5

Prejudice against people with disabilities.



Note. The chart shows the grave margin in Australia's discrimination against people with a disability. From *Disability discrimination in the Workplace*. By Sykesruby. (2019). Retrieved July 6, 2022, from <https://rubyanddisability.wordpress.com/2019/01/27/disability-discrimination-in-the-workplace/>

Perception and policy have, over time, informed public policy on people with disabilities. Hampton (2016) provided a historical perspective on the Poor Law Relief Act of 1662. The act provided for England's and Wales's poor and impoverished population. However, the public views on disability at the time were that of neglect and abandonment. The policy was not in any way formed because of care and love for persons with disabilities, but was created because the public perceived persons with disabilities as poor and disadvantaged. As the overall global number and the change in perception increased, both from persons with disabilities and people without, Kaur et al. (2015) explained that legislation and policies also changed to create an all-inclusive society. Accepting one's disability demonstrates enabling individual control and integrate disability so that a person may improve his quality of life. The upcoming section will examine the European Union's legal framework and how it shaped social policies for people with disabilities.

The legal framework in the European Union for people with disabilities

The foundation of an effective and well-functioning disability policy system is a well-established legal framework (Hao & Li, 2020). The re-emergence of unemployment and the exclusion of persons with disabilities in the European Union has caused several union members to institute measures in public legislation to incentivise economic activities for persons with disabilities (Korres et al., 2011). Providing these financial incentives, it is hoped, will give much-needed employment to workers who are discriminated against, including people with disabilities. This section will examine the legislative framework for people with disabilities.

One of the most discussed aspects of disability is its true definition. Korres et al. (2011) provide a legal description and outline that a person is disabled because of several physical, sensorial, and mental disabilities. These handicaps will result in a disability, usually resulting in

limitations to functioning optimally in society. Age, social and cultural issues, and sex affect people with disabilities.

The European Council for Employment and Social Affairs, (2011), adopted a framework directive for all member states which will ensure equal treatment and opportunity in employment and occupation (Korres et al., 2011). Protecting people with disabilities in the workplace has always been an essential aspect of the disability movement, and the directive was given to protect vulnerable people with disabilities from discrimination. This decision was made in part with an approach decided at the sitting of the Lisbon Council. Korres et al. (2011) outlined the main objectives of the directive as a national action plan which 1) Promotes the participation in employment and universal access to resources, rights, goods, and service for all persons with disabilities; 2) Prevent the risk of exclusion for persons with disabilities, 3) Action for the most vulnerable persons; and 4) Mobilize all the relevant actors which includes legislators and civil society. The foregoing objectives encompass several underlining factors when considering people with disabilities. They are employment, education, vocational training, housing, and health.

In addition to the overall directives, the framework must ensure that policies relating to job creation, employability, adaptability, and equal opportunity for men and women may contribute equally to increasing equality, diversity, and health and safety practices. Subsequently, because of this framework which came down as a directive, an employment fund was set up by the European Commission of the European Union to provide financial assistance to member states to create jobs and, most importantly, to develop job-friendly policies for person with disabilities (Degener et al., 2021).

Legislative structure for persons with disabilities in China

Laws protecting people with disability in the Peoples Republic of China were ratified in 2008. The Law on the Protection of Disabled Person 2008, was referred as the disability law (Lin, et al., 2012). This act provides the security for the provision of the state to ensure that disabled people are given the rights to gainful employment, and the proper conditions are put in place for persons with disabilities to feel just as comfortable as nondisabled individuals.

According to the United Nations, eighty-three million people in China have been classified as disabled; *United Nations Enable (2007)* which is just about six per cent of the republic's total population. This number, according to Hao and Li (2020), may be slightly higher as China employs a narrow medical definition of disability to that of the western world, which means that there is a possibility that there are more people in China living with a disability than previously thought. If China were to use the International Classification of Impairment, Disability, and Health (ICF), globally in 2011, it was 15 per cent and the figure would rise drastically. Hao and Li (2020) point out that of the eighty-five million people with disabilities, only 40 per cent of that amount were voluntarily registered up to 2019. While economic growth is prevalent in China Lv and Zhao's (2012), research shows that employees were only focused on economic consistencies, where the responsibilities to nationals, most importantly, people with disabilities, mainly, were nonexistent. Hao and Li (2020) explained the unavailability of adequate literature, both internationally and in the Chinese economy, to show that companies are interested in the legal framework for persons with disabilities in China. If a legal framework is created, there is the possibility that the social barriers that may exist can be broken down to make way for equality and inclusivity where persons with disabilities are concerned Jones & Marks (1999).

Within the context of change, researchers such as Lejeune & Ringelheim (2019) agree that there is a new legal and policy approach towards the ideology (para. 1) that has come about, giving rise to a new paradigm shift from society's protected model to an anti-discrimination model. Recently, there has been a significant focus on the consciousness of scholars in the study of disability, with particular emphasis on discrimination in the workplace. The perception in the workplace is that persons with disabilities are seen as mentally and physically impaired. However, according to Shakespeare (2006), the new model depicts disabled individuals as people with rights and entitlements (Lejeune & Ringelheim, 2019) as any other person. Heyer (2015), in his observation, suggests that this increased consciousness is a reflective move from the medical to the social concept and from social protection to an anti-discrimination model policy framework.

Lejeune and Ringelheim (2019) outline the academic argument to suggest that the law, the society, and disability fall along three lines: law and policy approach that aims to protect the rights of persons with disabilities, the social movements approach with aims to integrate and socialise persons with disabilities, and finally, the conscienceless legal approach. These three approaches will be independently investigated to understand better the legality of the law and policy of disability.

The Law and Policy Approach

The Americans with Disabilities Act (1990) (ADA), which was signed into law in 1990, was the premier comprehensive piece of legislation that changed the conscientiousness of the American society, and how it sees disablism as a sense of welfare towards antidiscrimination and laws driven to prove equality, Vanhala (2009). This shift reflected society's views of persons with disabilities and a view from a more medical to a social model. The introduction of

the Law and Policy approach sees disability as interaction amongst people with their disabilities, including their social, physical, and institutional environment, which had not been adapted to their needs (Barnes & Mercer, 2005). The legal international disability framework was based on the American Disabilities Act; Burk (2004) saw society's focus on equality, inclusion, and disability rights. As mentioned, the anti-discrimination framework aided in shaping the EU Directive of 2000. The requirements of the directive states, that all EU states should forbid all form of discrimination in employment and occupation (Lejeune & Ringelheim, 2019). It was directive like these that paved the way for the formation of discrimination laws to protects persons with disabilities. Quinn and Flynn (2012) assert that the new global discrimination approach identified earlier was the catalyst for the drafting of the UN Convention on the Right of Persons with disabilities (2007)

The Social movement approaches

The social approach focuses on social changes that social and legal scholars instigated. According to Shakespeare (2006), the social movement approach mainly focused on two main aspects after the focus was made on the legal policy approach. The first factor identified by (Shakespeare 2006; Vanhala, 2009) are groups and organisations that are run by persons with a disability, as opposed to individuals who had an interest, for example, a family member or a disability activist. Having disabled people heading these organisations helped change the focus on disability from the medical model's point of view to be more focused on disability rights, inclusion, and equality (Shakespeare). The second factor relates to the available legal opportunities that are and can be available to people with disabilities. Heyer (2015) suggests that the impact of these opportunities presents specific legal reforms, such as disabled person's rights

to reasonable accommodation in education, employment, rehabilitation, healthcare and housing (Lejeune & Ringelheim, 2019).

The Legal Conscienceless approach

Heyer (2007) believed disability is predominantly a social, cultural, and political phenomenon, which can lead to the exploration of the legal rights of people with disabilities. Persons with disabilities did not usually pay attention to legal norms or reference them when needed. The influences of the law on disabled individuals and policy change assisted in changing the perspective of disabled people and their consciousness toward equality and inclusion. Hence, the legal consciousness approach to disability, according to Ewick and Silbey (1998), deals with the consciousness of people with disabilities and their everyday life experience. However, most importantly, a disabled individual's consciousness should not only be asserted when an individual wants to make an explicit claim for inclusion or making claims for his or her basic rights (Engle & Munger, 1996).

Albrecht et al. (2001) pointed to the fact that the identification of the human rights approach to disability advocacy is the most significant development in the disability movement since the first set of legislation was passed. The political aspect of the consciousness of disability was born from political and global lobbying actions in the 1960s. According to Albrecht et al. (2001), social consciousness was a human rights approach to disability and social policy laws. These emerging disability laws and social policies focused and continue to focus on specific areas of disability. These areas include areas such as employment, education, transportation, rehabilitation, and health care. These needs came to the fore to provide good services to war veterans; a strong political will was needed to extend these social policies to society.

It must be noted that the disability drive got its genesis from the protest of people with disabilities. The driving force behind the global disability movement was not asking for more programs but specifically, what was needed was a closer look at the policies and laws governing persons with disabilities and, most importantly, the recognition of human rights for people with disability (Albrecht et al., 2001).

Understanding the law regarding persons with disabilities and the way it fits into the constructionist viewpoint, Jones and Ann (1999) suggest that even if there existed a perfect regime of human rights and the system or the rule of law promotes and empower people with disabilities, Jones and Ann explain that this will only be a small part of what will be necessary for complete equality to be recognised. Therefore, a deconstruction of the law will be needed for complete equality to be identified. There needs to be a dismantling of the law to uncover the barriers that exist toward people with disabilities.

The Caribbean perspective

In many parts of the world, people with disabilities face different challenges and barriers according to their geographic location, the severity of their disability and economic status, and other factors (Jones & Lubin, 2018). In the Caribbean region, according to a 2017 Economic Commission for Latin America and the Caribbean (ECLAC) report, there are about 1.3 million persons living with a disability, of which approximately 250,000 have a severe disability. Very few infrastructures, including offices, schools, and public or private transportation systems, offer suitable designs for persons with disabilities in the Caribbean, much less the OECS. The implementation of the United Nations Convention on the Rights of Persons with Disabilities saw 172 (Jones & Lubin, 2018) nations worldwide signing on to the treaty. Antigua and Barbuda and other members of the OECS were signatories.

The CARICOM community is a block of independent Caribbean states that worked together to formulate what is known today as the Kingston Accord (2004), which expresses that each Caribbean citizen has the same human, civil, political, cultural, and economic rights. Further, the CARICOM member states adopted the United Nations Convention on the Right for Persons with Disabilities (CRPD). The member states formulated another treaty, *the Declaration of Petion Ville* in the Island of Haiti on the 6th of December 2013. Proposals from the Petion Ville declaration were a framework to embrace the 2004 Kingston Accord and provide a legal framework to give the recommendations from the (CRPD) some legal backing.

Some governments of CARICOM, over recent years, have adopted local legislation focusing on people with disabilities. These governments instituted legislation, for example, employment laws, and in the case of Trinidad and Tobago, they introduced in 2008 an Equal Opportunity Commission and an Equal Opportunities Act (Jones & Lubin, 2018).

CARICOM governments sought to improve the lives of people with disabilities, specifically to formulate of a legal framework, looking at the laws of disabilities in three phases:

- Provide assessment for persons living with disabilities,
- Provide evaluation for present government legislation, policies, and programs and
- Provide evidence and policy recommendations to implement the agreed convention (Jones & Lubin (2018, p. 8)

Not all countries have ratified The Convention on the Rights of Persons with Disabilities (CRPD). Saint Lucia and Saint Kitts are the two countries that have not signed on to The Convention on the Rights of Persons with Disabilities (CRPD). The table below demonstrates the few CARICOM countries implementing the optional protocol aligned with The Convention

on the Rights of Persons with Disabilities (CRPD). Countries such as Antigua and Barbuda, St. Kitts and Nevis and Saint Lucia have yet to implement the protocols up to the time of the CRPD report's publication. Though Antigua and Barbuda have been signatories to the protocol since 2007 and have the potential to advance the legal and judicial framework of the country, the protocol is yet to be ratified (Jones & Lubin, 2018).

Table 2.

CRPD and Optional Protocol signatories and ratifying States in the Caribbean.

	CRPD		Optional Protocol	
	Signature	Ratification	Signature	Ratification
Antigua and Barbuda	30/03/2007	07/01/2016	30/03/2007	
Bahamas	24/09/2013	28/09/2015		
Barbados	19/07/2007	27/02/2013		
Belize	09/05/2011	02/06/2011		
Dominica	30/03/2007	01/10/2012		01/10/2012
Grenada	12/07/2010	27/08/2014		
Guyana	11/04/2007	10/09/2014		
Jamaica	30/03/2007	30/03/2007	30/03/2007	
Saint Kitts and Nevis				
Saint Lucia	22/09/2011			
Saint Vincent and the Grenadines		29/10/2010		29/10/2010
Suriname	30/03/2007	29/03/2017		
Trinidad and Tobago	27/09/2007	25/06/2015		

Note. From “Disability, human rights and public policy in the Caribbean: A situation analysis” by Jones, F., & Lubin, L. 2018, Report No. S.17-01279, p. 14. Copyright 2018 by the United Nations publication.

There is no doubt that the members of CARICOM have done considerable work in the area of disability; specifically, the countries of the OECS. However, can more be done? Absolutely! According to the Economic Commission for Latin America and the Caribbean (ECLAC) report on Disability, human rights, and public policy (2017), the larger countries of the

Caribbean, namely Guyana, Trinidad & Tobago, and Jamaica, have enacted legislation for the protection and promotion of persons with disability. The report further pointed out the broad initiative countries like the Bahamas and Guyana took to effect changes for persons with disabilities in education, employment, health, and Information Communication Technologies (ICT). In 2017, the legislative arm of government in Antigua and Barbuda passed the Disabilities and Equal Opportunities Act (2017), which follows the twin-track approach outlined by the ECLAC report on Disability, human rights and public policy (2017). The twin-track approach suggests that it addresses all issues in every sectors relating to persons with disabilities, see Figure 6. (Disability, human rights, and public policy, 2017). Therefore, the Disabilities and Equal Opportunities Act (2017) of Antigua and Barbuda covered areas such as Employment, Healthcare, and Accessibility, Access to Education and training and protection from discrimination, exploitation abuse, and violence.

Figure 6

Disability, human rights, and public policy in the Caribbean



Note: Twin-track approach. From “Disability, human rights and public policy in the Caribbean: A situation analysis” by Jones, F., & Lubin, L. 2018, Report No. S.17-01279, p.16. Copyright 2018 by the United Nations publication.

The enforcement of these laws is only partially adhered to. However, the Disability Association of Antigua and Barbuda mobilises its members and always strives for recognition and equality. In the case of Saint Lucia, this island passed an Equality of Opportunity and Treatment in Employment and Occupation Act (2001). The act covered areas such as protection against unlawful discrimination. Part two of the act was the only section that dealt with anything close to persons with disabilities. The act does not address areas such as education and housing.

The law and the Social Model of Disability

The social model of disability's function highlights the social relation between society and people with disabilities. This social relation is responsible for excluding people with disabilities, (Barnes, 2019). Various cultures, over time, have seen disability in a different light. Notwithstanding, it was always seen as an abnormality that could only be treated by medical intervention by repairing damaged or physically deformed persons. This was then referred to as the medical model of disability, which led to the institutionalisation of these individuals. Putting things into perspective, the term disability, according to Jones & Ann (1999), in the 20th century, referred to individuals who lacked legal competency or capacity. In other words, people deemed disabled by law, including women, children, and lunatics, were not recognised because of their incapacity to acquire property and display some level of independence. Due to this impairment, these indigent individuals were placed in institutions and deprived of their fundamental human rights.

The European Union policymakers, according to Blanck and Flynn (2017), have adopted the social construct as it pertains to people with disabilities. This construct focuses on social and environmental barriers, which, in part, prevent people with a disability from fully participating in the society in which they live. Because of the view that individuals with a disability are seen as

incapable of making decisions (cognitive or mental disability) or performing everyday tasks (physical disabilities), the natural approach is for law and policymakers to focus on cure, and having the view that persons with disabilities are of the consequence of embodied differences and which further focuses on medical cure and correction (Blanck & Flynn, 2017). The legislative clout in the social model lies in the reorientation from the viewpoint of the limitations of the individual's biological function to the renewed focus on the attitudes, processes, and way society is structured.

Blanck and Flynn (2017) explain that the laws specifically referring to people with a disability have deprived these individuals of their human rights. Some people with disabilities are under the guardianship of a friend or family or due to mental impairment are denied their right to marry, to vote, to refuse medical treatment and even contractual employment (p. 14). Adopting a social model of disability is very rare in any society. However, many policies have been informed due to the (CRPD). According to Blanck and Flynn, the legal system, within itself, contains barriers that may prevent full justice for people with disabilities. These barriers to justice may include people seeking legal advice or an inquiry for a claim made or even during an ongoing investigation or legal proceedings.

Inequality in the legislative agenda has always been a grey area concerning people with a disability. Disability inequality ranges from voting rights to educational exclusion because of an impairment of a child or the denial of formal education from learning, (Barnes, 2019). Notwithstanding the push for social justice, equality, and inclusiveness, the fight for all this must take a multipronged approach. Though the law cannot be excluded from the process of fixing this problem, there are apparent gaps in the legislative framework and must include scholars from other disciplines (Jones and Ann, 1999), to come to a workable all-inclusive framework.

The importance of the law in dealing with issues such as anti-discrimination should not be underestimated, as it provides a starting point for dismantling these existing barriers. Jones and Ann (1999) suggest anti-discrimination laws that have been passed for minority groups, which may include Blacks and Hispanics, can result in similar anti-discrimination laws for people with disabilities.

Conclusion

There is no question that the social model of disability over time has had a powerful influence on how countries have legislated their laws and policies on and for people with disabilities. The United Nations committee, responsible for overseeing international guidelines for the United Nations Convention on the Right for Persons with Disabilities (CRPD), has also taken on board the Social Model approach to disability. This chapter also looked at the perception of persons with disabilities and the perception that disabled individuals have of themselves, which have been slowly changing public policy worldwide.

The chapter looks at the three regions globally: the European Union, China, and the Caribbean. Their legal frameworks were examined, looking at individual societies and seeing how they integrate the consciousness and perceptions of persons with disabilities. This research section identified areas of these societies, for example, discrimination and exclusion, which are responsible for legislative change and improvement of social policies. The academic argument about the law and disability highlighted three approaches: law and policy, social movement, and legal consciousness. The law and policy approach focused on the mental shift from seeing disability as a welfare issue to that of discrimination. In contrast, the social approach looks at social changes, which include changing the mindset of the society in which persons with disability live.

We will agree that the purpose of the law is to offer some form of regulation, control, and discipline to society. Indeed, the law cannot control or curtail the problems that people with disability face. The basis of the law and the improvements of existing policies are grounded in the coming together of social constructionist views on disability and further to an overall commitment to the worth of people with a disability. In the upcoming chapter, we will look at the technological aspects of disability and the role technology play in the lives of people with disabilities.

People with SCIs on their independence and sexuality

The ability of an individual with a spinal cord injury to make choices (Federici et al., 2019) that affect his or her life, for example, the option to be romantically involved, have sex and have children, may be seen as independent living. Federici et al. (2019) express that no matter the injury or how severe that injury may be, one's ability to have a relationship, experience love or be attracted to another person who wants to share that love, should not be denied. The fight for social acceptance by people with spinal cord injuries resonates among themselves, focusing on whether they can function sexually, wondering if they can receive sexual pleasure and in other instances thinking whether their imperfections will be a deterrent to their desires (Federici et al., 2019).

The American Consortium for Spinal Cord Medicine (2011) suggests that one's physical condition should not limit one's ability to have a romantic relationship and experience love. According to Federici et al. (2019), the first barrier is the removal of self-doubt. People with spinal cord injuries must fight social oppression and the ideology that people with spinal cord injuries are not sexual beings. The social ideology of people with spine injuries and sexuality is based on the premise of two myths (Federici et al., 2019), one of perceived bodily perfection and

asexuality. Consequently, these two myths have apparent alignments with the medical model of disability (Bickenbach et al., 2012). The medical model of disability often sees an individual's disability as their inability to adapt to social standards, especially when change happens in an individual's life (Bickenbach et al., 2012). This change occurs when an individual has an unfortunate traumatic experience, for example, a vehicular accident or fall. An impairment that causes a spine injury affects one's ability to experience intimacy and some affection, entirely.

When an individual experiences a spine injury, it impairs his or her ability to experience genital stimulation (this depends on the severity of the spinal cord injury), which generally satisfies a non-disabled individual's sexual desires (Chhabra, 2015). The experience is different in both males and females. That is, in males, the ability to have an erection and or maintain one and ejaculate are some physical changes that may be possible (Chhabra, 2015). For females, their ability to reach self-lubrication and orgasm (Chhabra, 2015), is a biological function that causes sexual dysfunction. According to the medical model of disability, people with a spinal cord injury cannot perform a sexual act because of a lack of restriction in that individual's ability to perform sexually (Chhabra, 2015) in a manner that is to be considered normal or ideal. Buss (2016) highlights the social perception of an individual with a spinal cord injury mating or having a family as someone with a medical disease mating with a healthy individual. Socially this is looked upon as socially irresponsible. Likewise, for an individual with a spine injury to engage in sexual activity or think of starting a family is frowned upon in the same manner (Hirsch et al., 2015).

Sex after SCI for Disabled Women

The World Association of Sexual Health (WAS) (2015) is an international non-governmental organisation that promotes sexual health and sexual rights for all individuals. This

global organisation's declaration was decreed at their 13th congress in Valencia, Spain, in 1997. The organisation's final general assembly ratified their mandate in 2015: sexual rights and the independence of sexual rights are fundamental human rights (WAS, 2015). Due to this human right, people living with a spine injury should be able to make decisions independently and, therefore, have the right to sexual freedom. The recognition of this freedom (WAS, 2015) validates that sexual freedom is based on dignity and equality for all human beings.

The fundamental right to sexual freedom is a right that is entrenched in the United Nations Convention on the Rights of Persons with Disabilities (2006). Female sexuality has rarely been discussed, while the sexuality of men has been widely discussed (Federici et al., 2019). It is believed that the female in society is regarded as a function of male sexuality (Federici et al). Unfortunately, this function is seen in the same light as women with spinal cord injuries. Therefore, society's perception of attractiveness and beauty is the biggest problem for women with spinal cord injuries (Buss, 2016). Thrussell et al. (2018). However, a United Kingdom-based study, identified that women with a spinal cord injury had a different image of themselves than those post-injury. Some identifiable themes from the study included not feeling attractive after injury, lacking confidence, and feeling sexually unattractive. In other words, women with spinal injuries felt that having high self-esteem, a positive outlook on body image and competent social skills, seem to be essential for a woman with spinal cord injury and her sexual outlook.

Society is blamed for adding to the misconception of a male sexually dominated society, which sees women who are disabled, including those with spinal cord injuries, as oppressive (Santos & Santos, 2018) and are discriminated against because of their disability and gender.

Further, the desexualisation of women is seen negatively because of the impairment of the female's body and is therefore seen as dependent and unsociable. It, thus, presents a social construct that women with spinal cord injuries and other disabilities are inadequate and thus incapable of an (Santos and Santos) intimate life. Santos and Santos point to these misconceptions as unfortunate because society fails to accommodate and embrace diversity. The idea of disability and intimacy needs to be addressed (Santos and Santos) socially, and the conversation around independence among women with spinal injuries and their ability to be intimate. It is, however, the opinion of (Santos and Santos) that society's views on disabled women and sexuality are one of culture and modernisation. Further, for a complete understanding of sex, intimacy, and sexuality in disabled women, the ideology of gender studies and disability studies must be understood and appreciated from a feminist point of view.

Independence and Social Model of Disability

As life expectation increase, the risk and occurrences of spinal injuries increase among older adults (Browne et al., 2012). In addition to other identified causes of spinal injury that affect the general population, older adults face increased risks by deteriorating muscular and skeletal systems and reduced coordination resulting in decreased mobility (Leib-Neri, 2022). It is therefore, necessary to give additional consideration to the models that would best capture the circumstances experienced by this population.

One component of disability resulting from spinal injury among older adults is their ability to maintain independence. In this context, independence is defined as a range of residential options allowing older adults to live independently while taking advantage of various amenities and community offerings (Leib-Neri, 2022). The social model of disability addresses the vital role that independence plays for individuals affected by a spine injury. The independent

living model of disability runs almost parallel to the social model of disability in considering independence. The slight difference is that the independent living model of disability focuses on the specifics of advocacy for the independence of people with a disability, including spine injury.

The appreciation that pain and suffering hinge on the human right model of disability (Retief, 2018) and respects that these two factors are challenges that come with independent living, which the social model does not speak to (Degener, 2017; Retief, 2018 &). The issue of pain and suffering forms part of the framework alluded to earlier. The social model of disability does not always address human rights issues (Degener). However, independent living is a critical factor in the social model of disability. If social barriers are addressed, older individuals with spine injuries (depending on the severity) of the injury can live a reasonable independent life (Degener, 20017).

Older people with spine injuries are usually classified under the charity model of disability. This charity model exempts individuals with disabilities from most of all the independence (Degener, 2017). People with disabilities and spine injuries are seen as victims of their impairments which is a general view for all (Degener, 2017). This labelling of people with disabilities as victims ties in with the medical model and shares a similar view. Further, the charity model sees a person with disabilities as unable to function without assistance and, therefore, requires (special assistance) to live in a boarded institution.

A more robust social model for more independence?

When the social model of disability was introduced by its originator Mike Oliver, he coined himself as the father of the social model of disability (Berghs, 2019). The social model focuses on society's barriers and how these barriers may be dismantled. However, in recent times advocates and disabled people have noted the incremental removal of rights and entitlement of

people with disabilities (Berghs). Berghs (2019) suggests that there seem to be no appropriate alternatives to the social model of disability to fight for the social right of people with disabilities. The rights of persons with disabilities need to be strengthened by the social model to ensure their rights to live and live in an environment that is suitable for people with disabilities.

The genesis of the social model of disability was coupled with the formation of the Union of the Physically Impaired against Segregation (UPIAS) which was founded by Paul Hunt, and Ken and Maggie Davis, all disabled persons (Berghs, 2019). The Union of the Physically Impaired against Segregation initially argued that *“it is a society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way, we are unnecessarily isolated and excluded from full participation in society”* (1976, 4). One of the driving forces of the UPIAS was its argument for independence (Berghs) and independent living and their importance for people with disabilities. Two of the founders, Maggie and Ken Davis, defined independence as a linkage between disabled people having control over their lives and the ability to make personal decisions for themselves independently (WAS, 2015). The aim of the social model and the formation of UPIAS was to have full participatory involvement of people with an impairment in society (Berghs et al. 2017), improving their independence and independent living.

The social model of disability, according to (Berghs, 2019), helped with the formation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) legislation which to date is perhaps the most critical piece of legislation created for people with disabilities globally. The inception of the social model focused on barriers and their removal so that attitudes in society may be changed and people with disabilities are seen as normal human beings and receive the same social services and treatment as everyone else (Shakespeare, 2014). Berghs,

(2019) however, thinks that the social model of disability is much more than just that. The social model of disability, as with any other model, evolves as time evolves, and the model's perspective must also change.

The issue with the social model is that it was seen as a model with an end; that is, it had a narrow rights-based approach, and some points were a means to its future. (Berghs, 2019), noted, *The ideological problem facing the disability movement in the UK from the 1990s onwards, was whether the social model of disability was still relevant in guiding our struggle or whether social changes had advanced so far that the original model no longer reflected the social context in which it had been created? (Finkelstein, 2007, p. 14).*

These questions which arose are essential to ask as disabled individuals are still experiencing the same struggles that their disabled counterparts in the 1990s experienced.

The effect of society on independence and independent living

Research papers published since the global economic crisis in 2008 suggest that in more developed countries (MDC) where there has been a significant rollback for the funding of social services, disabled people have been negatively affected and, most importantly, impacted their independence, at least those who depend on social welfare (Levitt 2017). Due to these global cuts, less developed countries (LDC), such as the OECS, at times depend on international funding (Bleeker, 2019) to assist countries with their disability programs. All these changes over the years have caused people with disabilities to question where the social model of disability is still relevant in today's context of disability.

The United Nations CRPD set out guidelines for people with disabilities to be afforded reasonable access to amenities that non-disabled people also have access to (United Nations 2006). These reasonable accommodations also affect a disabled person's independence and

ability to live independently (Berghs, 2019). It is the opinion of Berghs that after the global crisis, people with disabilities who lived in the United Kingdom, a global leader in the disability movement, thought that their human rights were disrespected and sidelined and were therefore seeking a remodeled model of disability where their human rights could be intertwined with the social model. This social model of human rights would be in line with the (United Nations, 2006) charter, which speaks in (Article 9) about accessibility for persons with disabilities, (Article 20) personal mobility, (Article 13) access to justice, (Article 10) having the right to life, (Article 18) having the liberty of movement and nationality, (Article 30) which see the participation of disabled people in recreation, leisure, sport and cultural life and (Article 28) adequate standard of living and social protection.

The aforementioned affect the independence of a disabled individual and his ability to live an independent life. A more robust social model means the possibility of the model becoming legislation which will create a more inclusive environment (Berghs, 2019) for disabled individual, despite of their disability. In the mind of Berghs not only should the social model be legislated, but perhaps there may be a clause in the Human Rights Act in the United Kingdom to protect the rights of persons with disabilities who make up a community unto themselves. Since the rights of persons with disabilities have always been seen as non-important (Berghs), disabled people feel that they always need to defend their basic needs, even though their rights have been mandated by the (United Nations 2006) convention, which most developed and developing countries, including the OECS, have been signatories to and, in addition, have ratified.

Conclusion

The right to make decisions as a disabled individual is, firstly, a fundamental human right. It is then a right as mandated by the United Nations CRPD and its 50 articles. The right of

a disabled female with a spine injury to decide whether to have a child or a romantic relationship or engage in sexual activities is a fundamental right of that individual, and going against that is discrimination against that individual. Notwithstanding, there are factors which may affect the decision-making power of some disabled individuals. One such is the severity of the injury, which in turn affect one's ability to reproduce. Independent living is also a fundamental right of a disabled person in (Article 19) of the (United Nations, 2006). It gives the right to persons with disabilities to live independently and to live inclusively in their community of choice. Finally, the thoughts of (Berghs et al. 2017) in having a more powerful social model of disability or a new human rights model of disability will enforce what disabled people have been asking for many years. This new model will not only look deeply into the humanistic elements of the disabled individual but also the social aspect that affects their life.

Sexual relationships and disability

Introduction

Relationships are central to happiness but present some of life's most significant challenges. Some assume that persons with disabilities are not interested in dating or sexual relationships. There is no difference between the intimate needs of persons with disabilities and the non-disabled and their desire for healthy and happy intimate relationships. Evidence suggests that disability negatively affects people's propensity to find a partner. Persons with disabilities that eventually find a partner do so later in life compared to the average population. (Lotta et al., 2020). Mackelprang et al. (2022) state that the significant issue around disability continues to be unabated discrimination. They claim that this one issue has severe consequences in every aspect of a disabled person's life, from employment to housing to dating to raising a family.

Human Rights and Sexuality

The United Nations CRPD includes several sexuality-related rights. However, the sexuality-related rights in the adopted conventions are far less explicit and affirmative than those included in the initial draft text. The right to sexuality incorporates the right to express one's sexuality and be free from discrimination based on sexual orientation. The concept of the right to sexuality is difficult to define, as it comprises various rights within the framework of international human rights law. No right to sexuality exists explicitly in international human rights law; it is found in several international human rights instruments, including the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The United Nations adopted the Convention on the Rights of Persons with Disabilities, which gives individuals with intellectual disabilities the same rights to sexual and reproductive health (SRH) as people without disabilities. That includes the rights to retain fertility, relationships, family, and parenthood, to education on reproduction and family planning in an age- and development-appropriate manner (Wickström et al., 2020).

The United Nations CRPD states that people with disabilities have the same rights as everyone else. Article one of the Convention outlines the purpose of the Convention which is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and to promote respect for their inherent dignity. Dunja Mijatović, Commissioner for Human Rights of the Council of Europe, in her address to the Council of Europe Commission for Human Rights in Strasbourg, on 14th November 2022, detailed that societal stereotypes of people with disabilities as dependent individuals are at the basis of laws and policies which continue to allow institutionalisation,

deprivation of legal capacity and segregation in education, in violation of the United Nations CRPD and other human rights standards.

People with disabilities include people with long-term physical, mental, intellectual, or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

Importance of intimate relationships for people with disabilities

Reitsema and Mackenzie (2021) define intimacy as nurturing one another in various relationship contexts so that we feel known, seen, loved, and cared for. Intimacy is present when people tend and feel deeply about each other. Sometimes intimate relationships result in physical affection and sexuality. Intimacy is essential in a relationship because it forms a basis for connection and communication. It ensures that each person feels understood, allows them to be themselves, and ensures that each person gets the care and comfort that they need.

Research has found that disabled couples in long-term romantic relationships experience more emotional intimacy, which leads to an experience of higher levels of sexual desire and sexual activity. Friedman (2019) writes that despite the difficulties persons with disabilities may have garnering intimate relationships, intimate relationships may be particularly beneficial for persons with disabilities as they result in greater self-acceptance, less internalised stigma and more camaraderie.

The quality of life can be enhanced for disabled people through their intimate social relationships. Friedman (2019) writes that despite the difficulties persons with disabilities may have garnering personal relationships, close relationships may be particularly beneficial for persons with disabilities as they result in greater self-acceptance, less internalised stigma and more camaraderie. Intimate relationships can provide persons with disabilities the support

needed to thrive in the community. Despite the desire for personal friendships and romantic relationships, persons with disabilities face several social relationship disparities. One of the most significant reasons for these disparities is because of a lack of opportunity to form and maintain intimate relationships, even going so far as to describe people with developmental disability's social networks as impoverished because of the lack of opportunities they have.

As persons with disabilities face many barriers that negatively impact their intimate relationships, such as lack of opportunity or privacy, support professionals and provider organisations need to help promote the creation and maintenance of these relationships. The experiences of individuals with disabilities have shown that the basic human need to form close relationships is as relevant for individuals with disabilities as it is for humans without a disability. Furthermore, the social networks of persons with disabilities can be small, and this restricts the ability to form new relationships.

Dating the Disabled

Dating is an emotionally risky proposition for everyone, but it is particularly challenging for people with disabilities. People who rely on wheelchairs or have another form of physical impairment often begin to date much later in life, and the marriage rate is lower. The 1990s saw the reproductive rights of disabled people being addressed from a human-rights approach to safeguard their legal protection. With 50 binding articles, the United Nations CRPD (2006) was the first international treaty to afford disabled people full civil rights and fundamental freedoms in all aspects of life. Article 23 is particularly relevant to this collection, stating that disabled people should be afforded the right to participate in marriage, partnerships, and parenthood equally to their non-disabled contemporaries.

Dating someone with a disability is no different from dating a non-disabled person in that the same rules and boundaries that apply to non-disabled people, also apply to disabled persons. It is well established that the stereotyped perception characterises communication between the disabled and the non-disabled that having a disabled partner will negatively impact the relationship. According to Kroll and Klein (2022) the disabled are seldom seen as whole and complex, leading the same everyday lives as non-disabled people.

A disability may sometimes create an emotional or psychological burden for the individual with disabilities. People with disability may feel self-conscious about pursuing relationships, fearing rejection due to their disability. Their self-esteem may suffer as a result of disfigurement or lack of confidence.

The idea that the challenges people with disability experience when dating are rooted in broader societal attitudes, is not new. General attitudes towards people with disability position them as asexual, de-gendered, incapable of sexual relationships and lacking the capacity to have successful long-term intimate relationships (Namatovu et al., 2020). In his study, Paul van Trigt (2020) traces another macro-level development across time concerning disability and reproduction: the right to form a family as enshrined in United Nations policy. This right is stated in Article 23 of the UNCRPD (2006), which says: “*States Parties shall take effective and appropriate measures to eliminate discrimination against people with disabilities in all matters relating to marriage, family, parenthood and relationships.*”

Disability and Intimate Sex

As for sexual health, the WHO (2020) defines sexual health as a state of physical, emotional, mental and social well-being in relation to sexuality. Sexual health requires a positive and respectful approach to sexuality and sexual relationships and the possibility of having

pleasurable and safe sexual experiences free of coercion, discrimination, and violence.

Depending on their condition, people with disabilities are more likely to be perceived as powerless and physically helpless. People with disabilities usually have fewer opportunities to learn their sexual likes and dislikes or to set emotional boundaries with an intimate partner.

In recognition that sexual rights are essential for the achievement of the highest attainable sexual health, the World Association for Sexual Health (2022) states that equality and non-discrimination are foundational to all human rights protection and promotion and include the prohibition of any distinction, exclusion or restriction based on race, ethnicity, colour, sex, language, religion, political or another opinion, national or social origin, property, birth or another status, including disability, age, nationality, marital and family status, sexual orientation and gender identity, health status, place of residence, economic and social situation.

Sexuality and disability are topics regarding the sexual behaviour and practices of people with disabilities, who have a range of sexual desires and differ in how they choose to express their sexuality. People with disability may experience more difficulties finding partners and forming intimate relationships than people without disabilities. The sexual rights of people with disability are often ignored due to discomfort or a belief that sexuality is not essential to people with disability (McGrath et al., 2021).

Muise (2018) states that sexual and relationship satisfaction tend to be closely linked in the context of romantic relationships. Research suggests that people without a disability resist establishing intimate relationships with people with a disability (Hunt et al., 2018). For people without disabilities, dating a person with a disability is often seen as too much work, socially awkward and unlikely to be sexually satisfying. Conversely, Rainey notes that if people without

disability form intimate relationships with people with disability, they are either viewed with suspicion or as martyrs.

Human beings are inherently social, as are most animals, and it is the way of nature. However, our social relationships are much more complex and fulfilling as humans. They provide us with a sense of connection, purpose, support, better health, and longevity.

Mor (2019) states that over time, courts have adopted a more promising and dynamic approach to disabled persons' sexuality while remaining within an individual-medical framework. They suggest that these shifting trends can be linked to the slow diffusion of the social-affirmative approach to disability, the limits of tort law as a field, and the role of healthcare policy in shaping the landscape of tort claims.

Sexual Assistance for the Disabled

Sexual assistance services that persons with disabilities use for help with sexual activity must be specialised and adapted to the users' different conditions. Sexual assistance includes any person who provides sexual assistance to physically and intellectually disabled people. Sexual assistance is a subject that is still relatively unexplored, particularly regarding adapted services for people with disabilities.

Sexual assistance refers to the provision of one or more of these activities: sexual intercourse, oral sex, and massage therapy including erotic massage, masturbatory acts, discussion of sexuality, contraception, and the appropriate use of sex toys (Morales, 2020). Within this definition, very diverse possibilities exist with equally different limits.

Piatt (2022) says sexual wellness is an essential component of overall quality of life, which is often ignored or omitted from the scope of recreational therapy practices, primarily due to attitudes, beliefs, and lack of formalised training and education. For physical disabilities that

change a person's sexual functioning, such as spinal cord injury, some method of assistance is needed. Individuals with disabilities may enjoy sex with the help of sex toys and physical aids (such as bed modifications), by finding suitable sex positions, or through the services provided by a qualified sex worker. Some people with a spinal cord injury can transfer their orgasm using sexual energy to any part of the body that has a sensation. Sexuality for persons with disabilities is often linked to fetishes Gutiérrez-Bermejo (2022). Disabled people have a range of sexual desires and differ in how they choose to express their sexuality. Commonly, persons with disabilities lack comprehensive sex education to assist their sexual lives.

Gutiérrez-Bermejo (2022) refers to three models of sexual assistance delivery: (1) the Therapeutic Model, (2) the Auto-erotic Model, and (3) the Erotic Model. The Therapeutic Model is based on the idea that the person needs help or advice to solve difficulties in sexual matters. Its origins are in the 1970s in the United States, with the therapeutic techniques developed by Masters and Johnson for treating sexual dysfunctions. The Autoerotic Model consists of instrumental erotic accompaniment. According to this model, the sexual assistant supports the person with a disability in his or her sexual practices with others or with themselves. However, the sexual assistant does not have sexual relations with the person. The Erotic Model consists of erotic accompaniment. It is advocated by associations such as Sex Assistant, Tandem Team, and Touching Base. According to this model, the sexual assistant can have full sex with the people they assist.

Spinal Cord Injury

Federici et al. (2019) state that people with spinal cord injury must fight their societal attitudes and stereotypes that limit sexuality to the physiological functions of genitalia, phallocentric primacy of sexual pleasure, and sexual attractiveness of perfect bodies. The slogan

of the American Consortium for Spinal Cord Medicine explains that, no injury, no matter how serious that injury is, can take away an individual's ability to have a relationship, experience love, and experience the attraction between two people. The scope of spinal cord injury care encompasses acute care for the newly injured and rehabilitative care to restore function, maintenance, and support throughout the lifecycle. In addition to restoring function and managing secondary medical complications, optimal clinical care addresses other essential aspects of living with spinal cord injury, including preventive care and psychosocial issues (Murphy and Thomas, 2021).

Sexuality remains an important, valued aspect of female identity following SCI; sexual activity continues and though altered, remains enjoyable and rewarding. Sexuality rehabilitation should commence early, preparing women for altered sexual sensation, disclosing altered sexual function to partners, and encouraging early self-exploration (Thrussell et al., 2018). Sexual functioning and satisfaction are priority rehabilitation areas, yet they are persistently sidelined in multi-disciplinary team (MDT) rehabilitation agendas. Healthcare professionals do not feel supported to engage with their patients to improve and manage sexual functioning/satisfaction (Barrett et al., 2022).

According to Nevin and Melby (2021), personal conversations between spinal cord-injured patients and dedicated members of the interdisciplinary health team can enhance the quality of rehabilitation care and patients' satisfaction with rehabilitation care. They further declare that nurses are central clinicians in the rehabilitation programme of spinal cord-injured patients and should engage in individually designed conversations about post-injury sexual functioning. After a spinal cord injury, individuals must acquire maximum independence before returning to their previous social and working conditions. The education provided during

rehabilitation is one of the basic but complex aspects influencing the health perspectives of people with spinal cord injuries (Conti et al., 2020).

Spinal cord injury results in autonomic, motor, and sensory impairments that can compromise the mental health of the affected individual. Guidelines directing the management of mental health following SCI presently address clinical anxiety, depression, post-traumatic stress, substance use disorders, and suicide. However, evidence suggests that perhaps as many as 70 per cent of individuals with SCI do not develop a clinically diagnosable mental health disorder (Sandals, 2022). Spinal cord injury often represents a significant life change, yet most individuals with spinal cord injury show resilience and positive adjustment after injury. Social support, including support from health care providers, has been associated with increased stability among the spinal cord injury population (Schultz & Brindle, 2022).

Gender and Disability

The United Nations CRPD states that individuals with intellectual disabilities (ID) should have the same rights to positive sexual and reproductive health (SRH) as people without disabilities. Women with disabilities have been described as doubly marginalised on account of their disability and their gender. They may be more vulnerable to poverty and social exclusion and often have limited social, political, and economic opportunities and a lack of access to basic services. In addition, in her address to the Council of Europe, Dunja Mijatović, Commissioner for Human Rights of the Council of Europe Commission for Human Rights in Strasbourg, on 14th November 2022, stated that women with disabilities are affected by inequalities and discrimination in virtually all areas of their lives. They have lower employment rates and incomes, are less educated and have more unmet health needs than men with disabilities and women without disabilities.

Women with disabilities may also be at greater risk of sexual and physical violence and abuse. According to the Center for Reproductive Rights Universal Periodic Review Fact Sheet, women with disabilities are two to three times more likely than non-disabled women to experience violence, including but not limited to sexual violence. They also face numerous physical, informational, and economic barriers to accessing sexual and reproductive health services. Dunja Mijatović, Commissioner for Human Rights of the Council of Europe, in her address to the Council of Europe Commission for Human Rights in Strasbourg, on 14th November 2022, said it is estimated that women with disabilities are two to five times more likely to experience violence compared to other women. She, however, said that women with disabilities are often ignored by the police and other support services when they report such violence. She further stated that during her visits to various countries, women victims of gender-based violence have shared their difficulties in accessing shelters, which were not adapted to their needs, and in obtaining protection from courts.

The Council of Europe Commission for Human Rights, in addressing the invisibility of women and girls with disabilities, submitted evidence to an inquiry by the United Kingdom Parliament concerning violence against women and girls, Disabled Survivors Unite, a United Kingdom disability rights NGO, pointed out that women with disabilities were more than twice as likely to experience violence and abuse compared to women without disabilities in the United Kingdom. The Council of Europe Commission for Human Rights, in addressing the invisibility of women and girls with disabilities, declared that the exclusion of women with disabilities from decision-making spaces has long impoverished our societies. It masks the root causes of the discrimination they face, allows the perpetuation of harmful stereotypes concerning gender and disability, and leads to innumerable human rights violations.

The draft language of the United Nations CRPD (2006) stipulated that people with disabilities have an equal opportunity to have sexual and other intimate relationships. Through the process of establishing the Convention as it was adopted, the language changed to the right to marry and found a family. Rugohoand Maphosa (2020) wrote that following the adoption of the UNCRPD, adolescents with disabilities still commonly suffer from widespread violation of their rights, particularly concerning sexual and reproductive health, often being viewed as either asexual or hypersexual. Contemporary societies do not readily encourage the participation of these young people in conversations or decision-making processes concerning their own sexual and reproductive health.

Siri (2020) states that women and girls with disabilities, constantly, must deal with multiple intersectional discrimination, due to their gender and their disability, as well as social conditioning. Indeed, the intersection made up of factors such as race, ethnic origin, social background, cultural substrate, age, sexual orientation, nationality, religion, gender, disability, status as refugee or migrant, and others has a multiplying effect that increases discrimination yet further. Chigunwe (2021) writes that access to sanitary facilities is a global human right concern. Challenges faced by adolescent girls with physical disabilities to access sanitary facilities are not only an affront to their dignity but also endanger their rights to the highest attainable standards of health as well as that of access to education. (D'Agincourt-Canning et al., 2019) outline that numerous issues confront women's healthcare today, including the medicalisation of women's bodies, cosmetic genital surgery, violence against women, HIV, and perinatal mental health disorders.

Bantekas (2018) emphasises the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with

disabilities. Furthermore, Hobbs and Rice (2018) state that disabled women are likely to experience a deterioration in health care and are concerned that due to financial policies, the sexual and reproductive rights of women with disabilities would be negatively affected. Debarati and Brahmbhatt (2021) reference that the committee on eliminating discrimination against women did mention that the practice of non-consensual sterilisation of women with intellectual disabilities in India is prevalent. India's coercive family planning system is extremely detrimental, especially to disabled women. Sterilisation of disabled women is often non-consensual, forceful, and violate of bodily integrity, reproductive rights, and privacy of such women.

Hobbs and Rice (2018) suggest that sexual and reproductive rights are of critical importance to all women, yet among those with disabilities, the term acquires a new and broader meaning. They go on to state that historically, the reproductive abilities of disabled women, particularly those with learning disabilities, have been tightly controlled through institutionalisation, forced sterilisation and social control. Many have lost custody of their children in divorce, and others have had their children removed from their care by welfare agencies.

Katsui and Mesiäislehto (2020) reference the London Commitment document that ensures the inclusion of women and girls with disabilities in all programmes aimed at empowering people with disabilities, including social protection and sexual and reproductive health. Disabled women and girls benefit from more opportunities for empowerment in social protection and sexual and reproductive health programs, increasing their participation, involvement, and inclusion.

Spinal Cord Injury and Sexuality

A catastrophic injury such as a spinal cord injury strains marriages and other romantic relationships, which has important implications for quality of life (Stoffel et al., 2018). Partners of injured people often feel out of control, overwhelmed, angry, and guilty while having added work related to the injury, less help with responsibilities like parenting, and loss of wages. Although spinal cord injury often causes sexual dysfunction (Quadri et al., 2020), many people with spinal cord injuries can have satisfying sex lives. Physical limitations acquired from spinal cord injury affect sexual function and sexuality in broader areas, which in turn has important effects on quality of life (Quadri et al., 2020). Drugs, devices, surgery, and other interventions exist to help men achieve erection and ejaculation (Ko and Huh, 2021). Although male fertility is reduced, many men with spinal cord injuries can still father children, particularly with medical interventions (Anderson et al., 2019).

According to Ko and Huh (2021), after a traumatic injury, people usually experience a period of reduced sexual drive and activity. They further write that successful sexual adaptation is affected by many factors, such as time of injury, quality of social support, physical health, gender, and severity of the injury. In the acute rehabilitation phase, sensitive discussions about sexuality are appropriate. People with spinal cord injuries can learn about issues such as dating, efficiency, relationships, parenting, and physical appearance (Ko, 2019). It can help decrease one's sense of isolation and loneliness and increase social integration. A person with spinal cord injury is already struggling with feelings of low self-esteem and isolation (Lieberman, 2022).

Lieberman (2022) states that rehabilitation can play a huge role in recovering sexuality and sexual identity. A concern for sexual activity that is not dangerous but that can be upsetting for both partners is bladder or bowel leakage due to urinary or faecal incontinence. Couples can

prepare for sex by draining the bladder using intermittent catheterisation or placing towels down in advance. People with indwelling urinary catheters must take special care with them, removing them or taping them out of the way.

According to the Mayo Clinic (2022), spinal cord injury can impact control over the genitals and sexual structures. The ability to achieve and maintain an erection and ejaculation may be affected by spinal cord injury. Spinal cord injury may affect blood flow to the vagina and vaginal lubrication. There may also be notable changes in libido and the ability to experience an orgasm. Mayo Clinic (2022) outlines that support from friends and educational and support groups can provide knowledge and coping skills. Support and education for partners are also crucial in sexuality rehabilitation after SCI.

Sexual and Reproductive Rights

Mac-Seing et al. (2020) say that while access to sexual and reproductive health services has improved globally, persons with disabilities continue to face enormous barriers to sexual and reproductive health, infringing on their sexual and reproductive health rights. They further declare that despite these legal instruments, the sexual and reproductive health rights of persons with disabilities continue to be violated and denied and the disabled continue to encounter numerous physical, attitudinal, and communication accessibility barriers.

The need to improve the sexual and reproductive health and rights of women with disabilities is increasingly acknowledged. Unfortunately, women with disabilities in low- and middle-income settings face several barriers (including structural, financial, physical, social, and attitudinal) to accessing sexual and reproductive health services and care (Badu et al., 2018). For people with disabilities, article 25 of the UNCRPD entreats governments to make sexual and

reproductive health services and care accessible and inclusive, and on an equal basis to people without disabilities.

Badu et al. (2018) conclude that women with disabilities experience compounded vulnerabilities, including higher rates of violence, and lower rates of access to economic and social services, due to intersections of gender and disability. Poor access to sexual and reproductive health services and information can lead to many negative consequences, including poor sexual, reproductive, and maternal health outcomes; rights violations; and impacts on mental health and livelihoods. Disabled women, who are marginalised and stigmatised both by their gender and their disability, may face significant barriers to access (Soule and Sonko, 2022).

Soule and Sonko (2022) explain that one of the most common barriers cited to accessing sexual and reproductive health services was a lack of wheelchair ramps and elevators. They described people with disabilities as having difficulty getting into health facilities and then making it to consultation rooms, and they described consultation tables as being inaccessible. According to the United Nations Department of Economic and Social Affairs (2018) disability and development report, improved access to skilled health personnel for childbirth is crucial to improve maternal health and an essential component of sexual and reproductive health care. A skilled birth attendant is an accredited health professional such as a midwife, doctor or nurse who has been educated and trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the immediate postnatal period, and in the identification, management and referral of women and newborns with complications.

Persons with Disabilities and Gender-based violence

The United Nations defines disability as "a long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." The United Nations CRPD is a global treaty that affirms the rights and fundamental freedoms of persons with disabilities and describes how adaptations must be made for persons with disabilities to participate fully in society.

Although 166 countries signed the United Nations CRPD, its implementation varies and remains challenging in many settings. WHO defines it as an umbrella term for impairments, activity limitations, and participation restrictions for person affected, the negative aspects of the interaction between individuals with a health condition and personal and environmental factors.

The World Report on Disability (World Health Organization, 2011) estimated that more than a billion people live with some form of disability, representing about 15 per cent of the world's population. According to the Progress Report on the implementation of the European Disability Strategy (2010–20), it is expected that, by 2020, approximately 120 million Europeans will have a disability (European Commission, 2017). Disabled people are excluded from society by various barriers: social and cultural discrimination; negative attitudes; limited social support; inaccessible transportation, public buildings, information formats, products and built environments; inflexible organisational policies, procedures, and practices; lack of services; and problems with service delivery and a lack of involvement.

Progress is slowly being made to increase the visibility of the issues faced by women and girls with disabilities in the disability rights and gender equality movements. Studies have highlighted the common issues and shared experiences between women and girls with disabilities and women and girls without disabilities in areas such as gender-based violence,

access (or lack thereof) to sexual and reproductive health, lack of visibility in decision-making for a and lack of access to social and economic opportunities. Women and girls with disabilities may not be able to access the few available support services, such as hotlines or shelters, to recover and escape from violence. A study by the UNDP found that women with disabilities were less likely to access support, refuge, or legal redress than their peers without disabilities. Support services for men and boys with disabilities who are facing GBV are non-existent.

Attitude to people with disabilities

According to Wang et al. (2021), public attitude is crucial to disabled people concerning their daily lives, social participation, and their integration into the community. Dunn (2022) writes that the actual or perceived presence of a disability can lead non-disabled people to automatically categorise disabled people as members of an outgroup (i.e., a different group than nondisabled people inhabit). Improving attitudes toward persons with disabilities needs to become a key priority. The negative attitudes of persons with disabilities towards disabilities and other persons with disabilities is an area that requires attention, as such attitudes can slow progress towards equality.

Although negative attitudes to disability continue, there is evidence that such prevailing attitudes to disability are improving. Berghs et al. (2019) argue for a model of disability to change 'society to become more inclusive. Even though Berghs et al rightly identify how the human rights of persons with disabilities are being 'denied and eroded by society. What is at stake is the fundamental needs, which are 'very basic, [or] the right to live and have a dignified life as a human being'. They acknowledge that what they discuss is a matter of justice. Negative stereotypes about disabled people have caused many organisations to shy away from employing them, and if they do, they keep a keen eye out for them in case they mess up. The attitude of the

organisation's leader towards the person with a disability may cause climatic results that would last his or her lifetime.

Devine (2021) states that individuals with disabilities do not have the same avenues to experience social justice as the general public. Lack of opportunities and misinterpretation of living with disabilities are just a few obstacles this population experiences when attempting to engage in daily activities, including leisure. Contradictory to the WHO's position of all humans having the right to pursue a quality of life, individuals with disabilities often experience oppression rather than equal rights. Attitudes towards disability affect the way people think and behave towards disabled people. They also impact outcomes for disabled people in the way they are treated and able to participate in society. The attitudes disabled people experience inevitably affect the way disabled people interact with others.

Closer to home, in the Caribbean, Parey (2019) expressed that attitudes from teachers towards children with disabilities in primary and secondary schools are ambivalent, and more so to remedy the indecisiveness, Parey suggests that additional educational resources and advanced professional training may go a long way in the development and curbing of attitudes towards disabled children. Though the focus on educational disability has been on the inclusivity of children in the broader curriculum, it focuses not on the system itself but on the teachers. Though there have been improvements in the inclusion of children with disabilities in the classroom, there is still a lack of attitudinal change among the teachers in the classrooms (Parey, 2019).

The lack of change in attitude among teachers remains an issue in the classroom where children with disabilities are concerned. Students with disabilities remain socially and academically excluded within the classroom setting (Lord & Stein, 2018). The critical factor of attitudinal change is the understanding of disability (Parey, 2019) and its place in the educational

system. The main agents of change in attitude towards children with disabilities are teachers in the classroom. Though, for example, principals are responsible for the overall administration of the institution, teachers play a pivotal role in fostering an all-inclusive environment, and with that will come a change in attitude overall (Parey, 2019).

A review of twenty-six studies by Miroslav et al. (2022) revealed that teachers' attitudes in the primary school system were more favourable than those in the secondary school system. The positive attitudes towards students with disabilities in the secondary system were captured in the United Kingdom and Serbia. Parey (2019) suggests several factors that may affect teachers' attitudes towards classroom inclusion involving students with disabilities. One such variable is the size of the classroom teachers are placed in, that is, the student population. Having sufficient educational resources is another variable identified by Parey that may affect teachers' attitudes toward inclusion. Lastly, human resources, professional development and time are other critical factors that may be affecting teachers' overall attitude towards students with disabilities.

The knowledge of students lived experiences, and sufficient understanding of classroom inclusion are two key elements (Parey, 2019) suggest teachers must have for gradual change in attitude to take place in the classroom. Notwithstanding, the overall institutional disability policy, that drives a positive attitude towards students with a disability, must be in place and adhered to. High self-efficacy is critical to a successful inclusive classroom (Parey), an environment that is conducive to learning for disabled and non-disabled students. It is further essential for teachers to embrace and develop high efficacy levels as the potential for improved outcomes for students with disabilities is extremely high. Finally, the examination of teachers' perception of inclusive education should be encouraged in both primary and secondary schools

will assist in the breaking down of attitudinal barriers in the classroom and ensure an all-inclusive experience for teachers and students with disabilities.

Disability and employment

There are many challenges that disabled people must live with when employed and even as they seek employment. These may include employers' doubt, lack of education, stigma, inadequate transportation access, and facilities. There are many challenges that a person with disabilities must go through to secure employment and keep it. In some cases, disabled people are paid less than their coworkers. According to Shantz et al. (2018), a British government survey data analysis confirms pay dissatisfaction when (PwDs receive individual variable pay. This was especially true when disability related Human Resource Management (HRM) practices and formal organisational policies were not aligned or when people with disabilities perceived their management as unfair and biased (Shantz et al., 2018). No matter how persons with disabilities try to fit in, they do not fit in at work when they get employed as people with disabilities are given meagre roles, which the boss think is the only thing they can handle.

The successful employment of people with disabilities has become increasingly relevant for organisations worldwide. Some reasons include a shortage of skilled labour, the demographic change in the age comes with a rising disability prevalence in ageing workforces, as well as changes in societal perceptions and legislative frameworks to promote the workforce participation of PwDs (Baldrige et al., 2018).

People with learning disabilities can make hard-working and enthusiastic employees. They bring new skills, talents, and perspectives to their employers and with the proper support, they will remain loyal and longstanding employees. Pérez-Conesa et al. (2020) suggest that disability-focused practices would no longer be needed if companies aimed for inclusive

cultures, providing generic training, professional development, and internal communication systems for all employees.

According to the WHO (2011), fifteen per cent (15%) of the global population has some form of disability. There is underemployment of people with disabilities globally in the labour market (Colella & Bruyère, 2011). Countries that have regulated labour laws see their unemployment rate for people with disabilities double that of non-disabled people (Vornholt et al., 2017), consequently, for countries with unregulated employment laws, the figures are much higher. Many major European cities are signatories to the United Nations CRPD (UNCRPD, 2006). The adaptation of this convention was a mark of commitment towards people with disabilities and the many challenges they face in their lived experiences. The convention was resolute that people with disabilities have equal rights to employment and to make a living (United Nations on the Rights of Persons with Disabilities, 2006, art. 27). The article promotes the idea of self-employment and starting and maintaining a business venture (Vornholt et al., 2017). The moment an individual is employed in an organisation, it is that organisation's responsibility to ensure that reasonable accommodation is available for the individual with a disability (Vornholt et al., 2017).

Apart from the (United Nations CRPD, 2006), many countries in the European Union enacted their own individual anti-discrimination legislation to strengthen the one they are all signatories to. For example, in the United Kingdom, the Equal opportunity Act and in the Netherlands, the Disability Act and so forth (Vornholt et al., 2017). Similarly, in the Caribbean, OECS countries have also enacted legislation to protect the rights of persons with disabilities. In Antigua and Barbuda, there is the Disabilities and Equal Opportunities Act of 2017. In St Lucia, there is the Equality of Opportunity and Treatment in Employment and Occupation Act of 2000.

These acts go a long way in protecting people with disabilities from employment discrimination in the workplace.

Violence against children

There have been reports of violence against children with disabilities that are higher than among their non-disabled peers (Maclean et al., 2017). However, research has shown that little is known about the effect of domestic violence on children with disabilities and thus the information that can be used to develop or formulate a child-centred environment for young children suffering from domestic abuse is lacking (Hernon et al., 2015). The effect of domestic family violence on children with disabilities has often seen them being processed through different social services agencies only to be marginalised and discriminated against in a system that is supposed to protect them (Fawcett, 2016).

Hernon et al. (2015) point out that social services that offer disability care to domestic abused children are lacking in a holistic, collaborative approach to tackling family domestic abuse in disabled children. Apart from the lack of collaboration across agencies, a comprehensive understanding of what disability really is, awareness, education and funding, and resources are some of the attributes that are lacking to fully address the issues of child abuse in disabled children on the social services level (Flynn, 2020).

To comprehensively understand and manage effectively the social services aspect of child disability abuse (Octoman et al., 2022), suggest a two-prong approach: 1) Population-level identification which entails using all reported children born with a disability and then further identifying the status of that disability. This first approach exposes all registered or reported cases of disability in children. 2) The second approach is to conduct an analysis of the data

collected. The analysis conducted can drive policy changes across the disability spectrum, which will then improve the lives of children with disabilities.

The consideration of support for parents of children with disabilities, and the caregivers who offer their services to children with disabilities is vital to adequate access to services and support for parents of children with disabilities (Octoman et al., 2022). Octoman et al identify that child abuse is a shared global phenomenon. However, the issue is compounded by the child having a disability. Therefore, it is recommended that child protection services be implemented to be both preventative and responsive (Octoman et al., 2022) and further to ensure the availability of such services to families with disabled children.

The social model of disability speaks to the inclusion and eligibility of people with disability to have access to services that will allow people with disabilities to live a comfortable life. Exclusion of services for abused children with a disability should not occur at any stage of a disabled child's life. It is, however, understood that children with disabilities who are often abused are often from families with multiple resource needs explains Octoman et al. The training of individuals to handle cases of violence against children with disabilities is vital to the overall care of that child (Flynn, 2020). Therefore, first responders, special care hospital staff and social services personnel must undergo training to deal with children with disabilities who have been abused. The abuse of a disabled child by his parents is significant and is therefore considered important (Octoman et al., 2022) enough to separate the disabled child from that parent. Alternate housing arrangement is essential for protecting children with disabilities who have been abused by family members.

According to Deb (2022), children with disabilities are more vulnerable to all forms of abuse, be it mental, physical, or sexual, in all settings, including the family, schools, private and

public institutions, and the community. Research conducted by UNICEF indicates that violence against children with disabilities occurs at around rates 1.7 times higher than for their peers without disabilities. They are more likely to be victims of violence and sexual abuse (Deb 2022) Kauts (2021), states that research has shown that girl children with disabilities are more prone to abuse because of mobility issues, communication barriers and isolation.

ProChild (2020) asserted that children living with disabilities are more likely to experience violence, thereby necessitating a greater focus on developing legal and policy frameworks at national and international levels to prevent such abuse of human rights. (Hartley, and Tarvydas, 2022). According to Tarik Jasarevic's Pan American Health Organisation (PAHO) article, children with disabilities are almost four times more likely to experience violence than non-disabled children, according to a review commissioned by WHO and published today in the medical journal *The Lancet*. Children with disability associated with mental illness or intellectual impairments appear to be among the most vulnerable, with 4.6 times the risk of sexual violence compared with their non-disabled peers.

The United Nations CRPD affirms that all people with disabilities, including children, should enjoy all human rights and fundamental freedoms and should be protected from all forms of exploitation, violence and abuse, including their gender-based aspects (Article. 24, para. 3). Girls with disabilities, in particular, are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation. In an article in the Columbia University Mailman School of Public Health (2022) publication, children and adolescents with disabilities experience physical, sexual, and emotional violence and neglect at considerably higher rates than those without disabilities, despite advances in awareness and policy in recent years. This is according to a systematic review of research involving more than

16 million young people from 25 countries conducted between 1990 and 2020. Children who are blind or deaf or have an intellectual impairment are at significant risk of social exclusion (Falola and Hamel, 2021) and suffer more discrimination and significant abuse than those with other types of disabilities.

Types of Child Abuse against Children with Disabilities

Children with varied disabilities are at different levels of abuse, however, disabled children with conduct disorders have been shown to have a very high rate of abuse from both the community they reside in and family members (Maclean, 2017). It must be, however, noted that children with intellectual disabilities (ID) face an uphill challenge because of their inability to navigate decisions successfully. According to Wissink (2015), this inability creates a vulnerability for children diagnosed with intellectual disabilities to be both the victim of sexual abuse and the perpetrator.

The WHO (2014) cites the definition of an intellectual disability as a significantly reduced ability to understand new or complex information and to learn and apply new skills (Impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. However, despite ongoing research on intellectual disability, (Wissink, 2015) suggests that there needs to be more research done on the extent and the nature of the sexual abuse done to children with intellectual disabilities. The aspect of children with intellectual disabilities becoming perpetrators is essential to note as their inability to construe many social circumstances (Wissink, 2015). Their inability to understand emotions and intended consequences puts children with intellectual disabilities in a disadvantaged position when exposed to society's ills. Wissink (2015) suggest that children with intellectual disabilities usually take images literally, this means that images of

pornographic nature have the propensity to affect the mind of the children who are exposed to these images and perhaps videos. Therefore, if exposed, it creates a reference point of action for children with intellectual disabilities. Further, children with intellectual disabilities who have been identified as perpetrators may have been victims of previous sexual abuse (Hernon et al., 2015).

Victims' punishment is insufficient in dealing with child abuse in children with disabilities. A rigorous evaluation of child abuse, including children with disabilities, including prevention strategies, is essential to address this issue (Mendelson et al., 2015). Mendelson (2015) suggests that the first stage in addressing this issue is by looking at the strict involvement of parents with children with disabilities, but most importantly, children with intellectual disabilities. Parents have been a neglected factor in dealing with child abuse in disabled children. Mendelson (2015) indicates that parents of disabled children are the first line of defence in preventing and curtailing child abuse by increasing effective communication and constant monitoring of their children.

Gender and violence

Violence against women who are disabled as compared to men who are disabled is significantly higher, according to global studies (Bussieres et al., 2022). However, there is a marked difference in the incidences of sexual violence among adults with a disability than younger individuals with the same type of disability. According to Bussieres et al, individuals who are disabled because of some sensory impairments are at greater risk of some form of sexual victimisation. This increases if the individual is a female. The incidences of sexual violence against people with disabilities are more prevalent in African countries and other developing nations (Bussieres et al., 2022), however, the incidences are lower in European countries than in

the United States. Not only does sexual victimisation goes against the United Nations CRPD, but it is also a violation of an individual's human rights (WHO, 2013). What was clear also was the findings which showed that the incidences of sexual violence are less in non-disabled individuals as they enter adulthood but are entirely different for individuals who are disabled as they reach maturity (Bussieres et al., 2022). This may be because individuals who are disabled, particularly those with a sensory impairment, their condition do not change. Their ability to make decisions does not change over the years as they develop, so their capacity to consent remains nil.

The sexual needs and desires of people with disabilities are the same as people without a disability. Therefore, limiting sexual education, public awareness, and social attitudes about the sexual needs and rights of people with all types of disabilities may increase their risk of sexual victimisation (Bussieres et al., 2022). Overall, men with a physical disability are more likely to report acts of physical violence than women with the same or similar physical disability (Dammeyer& Chapman2018). However, women with a mental disability are significantly higher to be sexually violated than men with the same or similar mental disability.

From the above, it can be concluded that gender was significant in the level of violence that men and women with disabilities go through in their lived experiences. Women with disabilities seemingly experience more sexual type violence and humiliation throughout their lives than men with disabilities.

People with a physical disability, including spine injuries, are likely to report higher levels of discrimination and violence and to be threatened because of their impairment (Dammeyer& Chapman, 2018). The types of violence of visually impaired people usually differ from people with other types of disabilities. According to a study by Dammeyer and Chapman, individuals with visual impairments are generally victims of humiliation, financial violence,

physical violence, and significant sexual violence. Individuals with, for example, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and Schizophrenia are likely to be victims of significant physical violence (Dammeyer & Chapman). There is, in addition, one aspect of Dammeyer and Chapman's study that is most important: the incidences of reporting are much higher in females with mental or physical disabilities than those reported with men with disabilities in the same category.

Hughes et al. (2012) study supports the work done by (Dammeyer&Chapman, 2018). It highlights their similar findings in that females with various disabilities are at a higher risk of humiliation, discrimination, and sexual violence than disabled men in the same category. However, there were significant differences in the type of violence versus the type of disability the individual may have.

The inequality of disabled people of different sexual orientations and gender

An individual's disability, gender, and sexual orientation are all aspects in which one can be discriminated against. The stigma towards individuals who are disabled and are of the Lesbian, gay, bisexual, transgender questioning, intersex (LGBTQI) community (Nakkeeran & Nakkeeran, 2018) has serious health consequences for the affected individuals. From exclusion to inadequate medical resources, discrimination and other critical services are just some ways members of the LGBTQI community are marginalised. Nakkeeran and Nakkeeran (2018) suggests that the environment and society are key factors that contribute to the growing stigma and discrimination against people of the LGBTQI community. The individual's identity (a person with an impairment) and the disability community's lack of recognition are contributing factors to the growing inequality.

On the premise that the (United Nations Convention, 2006), which speaks to the rights of people with disabilities, are adhered to, social, environmental, and attitudinal barriers (Shakespeare et al., 2018) will start to erode from the minds of all who meet people with disabilities. Disability is about the body and one physical being and a direct connection to medicine (the medical model of disability); however, people with disabilities are also marginalised in their health (Nakkeeran & Nakkeeran, 2018). Due to the existence of health inequality, people with disabilities will normally have to navigate the system highlights Nakkeeran and Nakkeeran, to get some level of acceptable healthcare. This inequality results from existing health systems not organised with the necessities of people with disabilities in mind. Unfortunately, incorporating the needs of people with disabilities in the healthcare system is usually an afterthought (WHO, 2018), rather than an all-inclusive design process.

For a healthcare system to be seen as all-inclusive, that system must go past the usual non-discriminatory (Nakkeeran & Nakkeeran, 2018) expressions and appear to be more affirmative, engaging and promote a more disability-friendly environment. Coupled with an all-inclusive environment, other aspects, such as language (Shakespeare et al., 2019), infrastructure, and attitudes towards people with disabilities, must change. Further, Nakkeeran & Nakkeeran, (2018) points out that Discrimination in the form of rude behaviour, verbal abuse, bullying, delay in providing treatment to persons with disabilities. Importantly, respecting their privacy and dignity, negligence extending as far as physical violence and even sexual exploitation of disabled people are not infrequent in the health system context (Nakkeeran & Nakkeeran, 2018) This assertion points to the earlier discussion on general violence towards the person with disabilities.

Sexual orientation and health inequality

Placing individuals into categories and adding labels as normal and abnormal is a fundamental problem (Ketki et al., 2017) society faces today. Ketki et al. (2017) describes sexual orientation as a person's sexual and emotional attraction to another person whether male or female. This attraction forms associated behaviour and, thus, social affiliation (American Psychological Association, (2018). By that definition, an individual should not be identified by their physical appearance or by some sexual act but by their individual identities as being a part of the LGBTQI community. An individual's identity as part of the LGBTQI community comes with its own discrimination and humiliation (Parmenter et al., 2021). There is another layer of discrimination in the healthcare system against people in the LGBTQI community, whether disabled or non-disabled. One such example is the registration forms at medical institutions, which only provide a column for male or female (Parmenter et al., 2021).

Understanding health inequalities regarding people with and without disabilities and their experiences is essential to the individual and the healthcare sector. By understanding these experiences, people with disabilities who are of different sexual orientations can reduce the incidences of discrimination and marginalisation and become catalysts for an improvement of the overall healthcare experience for people with disabilities.

Conclusion

The overall attitude towards persons with disabilities, internationally, is still a growing problem despite increasing global advocacy and the growing educational thrust to inform and sensitise society to the experiences of people with disabilities. Attitudes towards employment towards people with disabilities should be a policy-driven endeavour, likewise for the educational system. For barriers such as discrimination and exclusivity to be eliminated from the disability

narrative, all attitudes must change. Notwithstanding, people who are disabled and are of the LGBTQI community face double discrimination (Ketki et al., 2017) which can lead to various social issues. Issues ranging from discrimination (educational, employment and health) are barriers to inclusion and reasonable accommodation for people with disabilities.

Abuse among children with disabilities is an ever-growing problem in disability studies and among families with children with disabilities. Focusing on close surveillance parenting to help prevent abuse from other family members is one step in preventing child abuse in disabled children. The proposal by (Mendelson, 2015), that parents should be targeted, is quite warranted as it harnesses the involvement of parents in the social and private lives of their disabled children, and most importantly those with intellectual disabilities.

Persons with Disabilities and the Use of Assistive Technology

Introduction

Poverty is often associated with disability, mainly in developing countries, (Borg, et al., 2009), where there are insufficient legislations and social policies to drive lawmakers to adopt or introduce new policies. As a result of poverty in these developing countries, education, employment, and health (para 1) are often negatively affected for people with disabilities. Studies have shown that in countries like the United States, and also in the United Kingdom, assistive technology (AT) has improved the lives of people with disabilities, thus increasing their chances of better work opportunities and education (Borg et al., 2009). Cook (2009) shared similar sentiments, too (Borg et al., 2009). It was pointed out that AT can significantly assist people with disabilities in performing and completing tasks to make their lives more comfortable.

Assistive technologies have seen advances parallel to Computer and Information Science (Cook, 2009). Further in this section, we will look closely at why assistive technologies are developing more slowly than traditional computer technologies. Phillips & Zhao (1993) explain that the development of assistive technologies to alleviate the issues faced by people with disabilities are not always universal, as there have been disuse and abandonment of such technologies.

In this section, we will look at the definition of, and a brief history of assistive technology and how its inception has changed the lives of people with disabilities. We will then look at various types of assistive technologies used in helping people with disabilities live better lives. Additionally, we will investigate whether there are any barriers to assistive technologies. Then finally, we will investigate and analyse assistive technologies in developing countries, specifically in African and Asia.

The Introduction of Assistive Technologies

According to Carlson, Ehrlich, Berland & Bailey (2001), assistive technology is a device that aids or assists people with a disability in performing daily tasks, which they would not have been able to do without these technologies. Lancioni (2014) outlines assistive technology as an intervention for individuals who use either commercialised or customised technological devices to assist people with disabilities to live a more comfortable and better quality of life. These ATs are most important in the reduction of the impact that their disability has on their daily lives while increasing their daily functions (Lancioni). The concept of AT arose from the general focus of well-being of people with disabilities, which may be physical, social, and emotional. Lancioni highlighted based on international consensus that as many as eight domains are core to quality of life. These include emotional well-being, interpersonal relationship, material

wellbeing, personal development, physical wellbeing, determination, social inclusion, and rights (Lancioni, 2014).

Assistive Technology (AT) must be looked at from a multidisciplinary approach, Ravneberg and Söderström (2017). This approach involves its effect on human relations amongst themselves, the technology itself and the society in which it is used. Ravneberg and Söderström, (2017)_suggest an approach to Science, Technology, and Society (STS). This approach is used to understand the importance of AT to grasp the complexity and fully understand assistive technology. Technology, over time, has evolved as an absolute necessity for non-disabled persons, hence its vital importance, Ravneberg and Söderström. Over time, the study of disability has been taken from several perspectives. The social science perspective and the medical perspective, are the two main views from which disability studies have been developed (Ravneberg & Söderström). However, the medical field has, from times past to recent, dominated the way society's ideas have been formed about people with disabilities.

The general view, according to Ravneberg & Söderström (2017), from the viewpoint of the study of disability, is that assistive technology has been at the forefront of the medical model of disability perspective. With that ideology in mind, the clinical or one-size-fits-all approach is widely applied to persons with disabilities. The opposing view, however, is that the social model of disability conforms to a different type of consciousness. It takes a more social and cultural perspective on assistive technology, adopting a more aesthetic and tailor-made design (Sapey et al., 2004).

Researchers such as Oliver and Shakespeare have always been champions of the social model of disability. This move, according to Ravneberg & Söderström (2017), has been from pathology to a more open view of social barriers and attitudes towards disability and persons

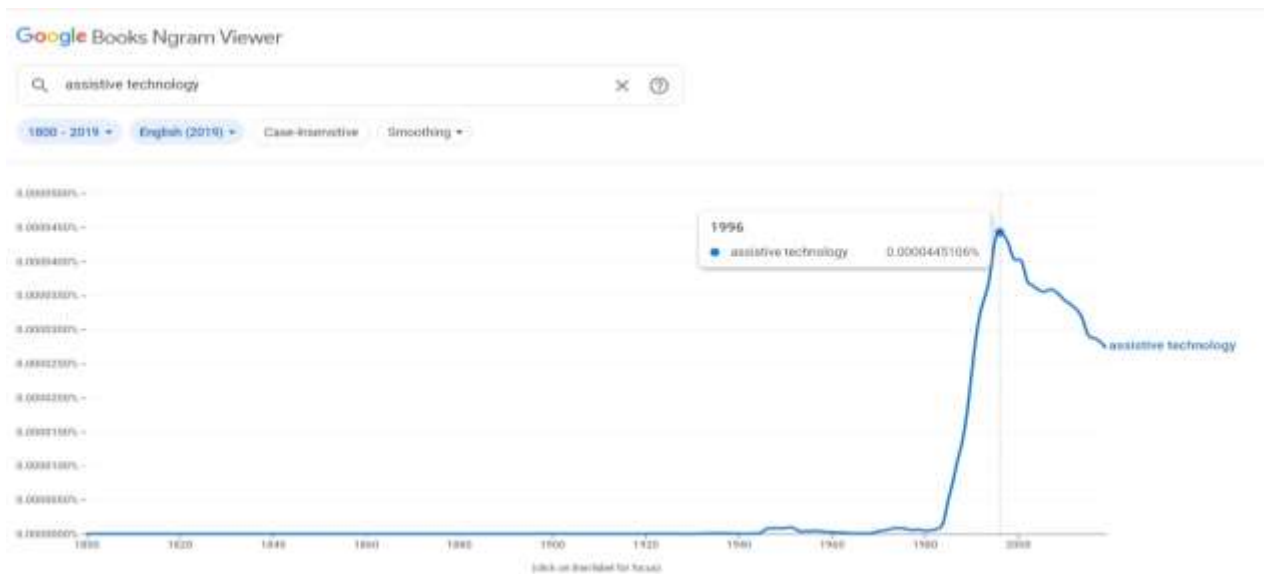
with disabilities. Assistive technology, the study of people with disabilities and the social model are intertwined and viewed as a social construct and conceptualisation of interpersonal relationships between humans, the environment, people, and society. Therefore, assistive technology is not governed by an individual's impairment. Instead, it is in the context and social practices in which said assistive technology has been used.

Assistive Technology uses

Many people have used assistive technology over the years to make life easier. Groups use these technologies, moreso people with disabilities. Assistive technologies help individuals who require assistance. Additionally, they are adaptive, allowing people with disabilities to use these technologies to lead better and more productive lives (Cook, 2009). Finally, they are also rehabilitative devices that are often aligned with people who are advanced in age with or without a disability. The search and widespread use of assistive technology started in 1944, Figure 7, and subsequently saw a spike in interest in 1995 (Edyburn, 2015). This increase in the interest in assistive technology (AT) was due to the passing of the *The Technology-related Assistance Act for Individuals with Disabilities, 2004* (Hussey et al., 2008). The use of assistive technology gained popularity in the United States when policymakers were confronted with case studies (Edyburn, 2015) which proved the value that assistive technology can have on people with disabilities by improving their daily output. The famous quote is always cited when Judy Heumann of the US Department of Education, Office of Special Education Program said: “for most of us, technology makes things easier. For a person with a disability, it makes things possible”. This statement expresses the importance of assistive technology but most importantly, the possibilities of it changing the lives of persons with disabilities.

Figure 7

The frequency of use of the term Assistive technology was revealed by Google "Ngram Viewer."



Note. The chart shows the frequency of use of assistive technology from the 1980s to the 2000s. From Google Ngram Viewer.

Considering what was previously mentioned, assistive technology siding with the social model of disability, we can look deeper into the quote by Heumann. Hussey et al. (2008) outline five variables that are aligned with AT. Edyburn (2015) indicates that interventionists are tasked with determining on an individual basis and analysing all the variables at play which in the end results in that person with a disability able to perform a task which was otherwise difficult or impossible. Therefore, interventionists conclude that assistive technology takes this cycle first: search, trail, select, implement, and finally evaluate these technologies that augment or compensate for disability (Edyburn, 2015).

Having several definitions of assistive technology, we will look at the legal terminology used by the United States after passing the Technology Act 2004. The definition states, *“Assistive technology devices mean any item or piece of equipment alternatively, product system, whether acquired commercially off the shelf, modified or customised, that is used to increase, maintain, or improve the functions capable of a child with a disability”* (S. 108-364 10/25/2004). There are six components that should be taken into consideration when considering assistive technology for people with disabilities.

- a) Evaluating the needs of the person with the disability includes the functional environment of the individual.
- b) Whether the technology will be purchased, leased, or otherwise provided.
- c) The selection and design ensure fitting, adapting, applying, maintaining, and repairing or replacing the said technology.
- d) The integration and use of other therapies and services to work alongside assistive technology.
- e) The training and assistance for persons with disabilities and their families and the individual caring for the person with the disability.
- f) The training of individuals proves the rehabilitation service for the person with the disability.

While legislations need to be tabled and passed to assist persons with disabilities to live full and productive lives, in the following section, we will investigate the ethical aspects of assistive technology while looking at the viewpoint of both sides; the engineering side and the medial aspect of assistive technology.

Ethics and Assistive Technology

The core nature of assistive technology is to facilitate a better standard of life for people with a disability so that their lives may be made more comfortable. Ethics in AT has two branches. According to Oishi, Mitchell, & Van der Loos (2010) those aspects are engineering ethics and medical ethics. The advances in engineering, medicine and technology have seen tremendous advancements. Traditionally, the engineering of technology has, over the years, developed without the involvement of its end users while considering capabilities and overall requirements and finally hinging those requirements to its end users (Perry & Beyer, 2012).

Ethical Engineering

Engineering, since its inception, has a social obligation and is held first and foremost to promote the public good and to advocate on behalf for persons with disabilities. (Oishi et al., 2010). This is unlike its medical counterpart, which focuses on patients as the most critical asset; biomedical engineers are responsible for the designing of assistive technology. The ethical issues surrounding bioengineers are two-fold: medical ethics and engineering ethics. The practice of engineers as professionals is engraved in social reality. Therefore, engineering ethics aims to protect the public from the danger of unhealthy engineering. Medical ethics seeks to protect individuals from ineffective practitioners.

One aspect of engineering and ethics is the aspect of human experimentation. Ezeiza et al. (2008) suggest that there should be more significant efforts to improve the ethical issues and standards in engineering. Reference has been made to the Ibero-American Association on Human-Computer Interaction (AIOP), where they have developed an Ethical Code for human

experimentation. In conducting human experimentation, more so in investigating people with disabilities, several factors are considered. Privacy, informed consent, and confidentiality are some factors that are adhered to when developing assistive technologies (Ezeiza et al.

Rehabilitation and Assistive Technologies

The use of a wheeled chair in the twentieth century has been seen as a medical failure, or the person using the wheeled chair has given up all hope (Ravneberg & Söderström, 2017). Similarly, individuals who used first-generation hearing aids were seen as having some form of mental deficiency and looked at strangely or associated with old age. With the advent of more advanced engineering in the field of disability studies, Clinical Rehabilitation Engineering (CRE) sits on three pillars of engineering (1) direct service delivery (e.g., rehabilitation and education), (2) design and development engineering, or Assistive Technology (AT) and (3) research engineering (where engineering scientist focuses on assistive technology research (Cooper, et al., 2007). The engineering factors must consider the AT devices' usability, however crucial they are. With that in mind, a trilogy of scholars, practitioners and consumers must work together to see the successful implementation of AT devices suitable for persons with disabilities. According to Cooper et al. the main factor in adopting an AT device for usage is its advantage or disadvantage. If the advantage outweighs the disadvantage, it may be perceived as suitable for use. If the burden outweighs the benefits, the device will significantly change usage.

According to (Cooper et al., 2007), the functional independence of the user to cope with the AT device must factor in the following: cooperation, and ability to adapt and learn (Figure 8). However, this may be different for people with disabilities who are advanced in age, which will therefore mean that the challenge to use and adapt to these assistive technologies will be greater.

The new challenge for rehabilitation engineers is adapting to a new paradigm of attitudinal features of the environment (Ravneberg & Söderström, 2017), in which people with disabilities reside in Figure 9. In this paradigm, AT engineers pay more attention to Universal Design (UD) and less to the limitation of an individual disability. So much so, according to Shakespeare (2006), the social model of disability in the United Kingdom has become more popular over time and moved away from the medical model aligned to the above statement of social inclusion and universal design. By this, the term disability described in a previous chapter has less to do with the individual (Shakespeare) as the medical model would indicate, but more to do with what is done to people with an impairment, which reduces their functionality and, in turn, causes them to be disabled.

Figure 8

Functional independence diagram for people with disabilities

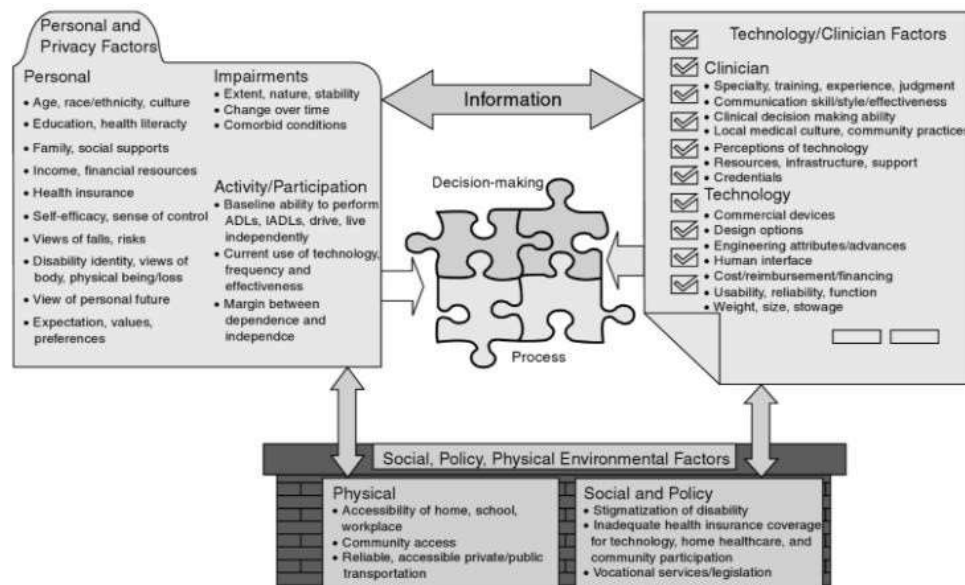
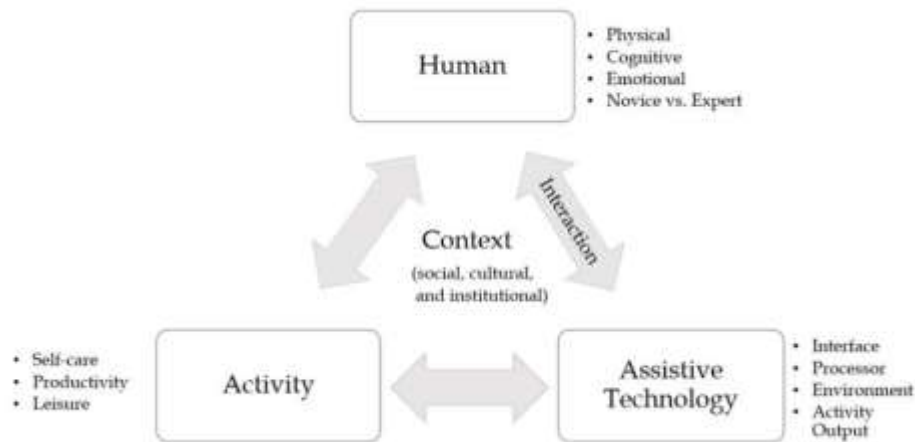


Figure 9

Interaction between different acceptance factors related to assistive technology (AT) devices.



Note. The four components of the Human Activity Assistive Technology (HAAT) model are presented in [4]. The interaction between human and assistive technology (AT) is emphasised to highlight the relationship between the needs of Augmentive and Alternative Communication (AAC) users and the elements of the development of high-tech solutions discussed in this review. From AAC advances: A review of configurations for individuals with a speech disability (Elsahar et al., 2019)

Issues in Assistive Technology

The grappling factor with assistive design and rehabilitating engineering stems from people with disabilities and older individuals having to deal with realities such as the individual, society, and social policy. (Cooper et al., 2007): design, research, and development. As was mentioned, this new paradigm that includes a country's policy agenda and environmental factors is emerging (Figure 10). Including all external factors makes this new paradigm important to

engineering and medical assistive technology. According to Bühler & Knops (1999), several key factors play in the issues related to assistive technologies.

Factors such as age, location, gender, and the failure to match the right AT to the correct customer, play a massive role in whether the said device will be used or if it will be abandoned by it user over a period of time. There are instances where, for example, clinical technologists will apply assistive technology as a medical solution when it is a technological issue.

Figure 10

A modern paradigm includes Functional, social, behavioural, economic, and regulatory policies for ageing and disability.



Note. A modern paradigm includes Functional, social, behavioural, economic, and regulatory policies on ageing and disability.

Disability only presents itself when there is an interaction between an individual with impairment and the environment in which they reside has barriers and prevents full participation in life's activities (Berman-Bieler et al., 2015). One of the issues in assistive technology is its barriers to the people who need it most; the impaired. The acquisition of these technologies has been somewhat of an issue due to product and service-related barriers. Barriers that are only a

big disadvantage to persons with disabilities. According to (Berman-Bieler et al., 2015), some of these barriers include the lack of a sound governance structure (legislation and policies), lack of awareness, lack of service, lack of products, and financial barriers.

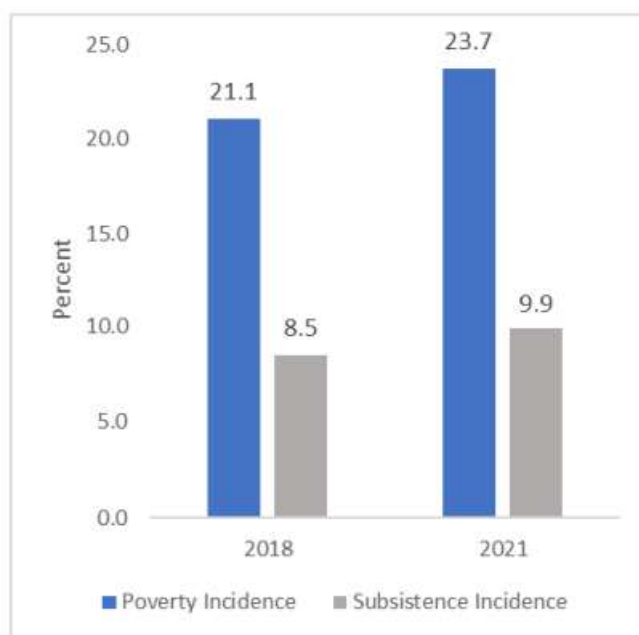
In rural areas in Oceanic countries like the Pacific, some families with limited resources may need more awareness (Eide & Kamaleri, 2009). This includes the ability of families to know what technologies that are out there may improve the lives of their loved ones. The legislature, whose job is the implementation of social and public policies, which ultimately affects people with disabilities, is required to ensure that people with disabilities are allowed to ensure that the suitable products meet the needs of people with disabilities to include woman and children. This need must be socially, physically, and environmentally met (Eide & Kamaleri) If not, there will always be a diminishing need for assistive technology products that can ultimately meet the needs of people with disability

The inaccessibility to assistive design services is another barrier that people with a disability deal with daily. When children, people with disabilities, and the elderly are deprived of accessing their services, their chances of living more productively are less due to an inaccessible environment. In addition to inaccessibility to services, people with disabilities face an uphill human resource issues due to a small number of qualified personnel in the manufacturing of assistive technology (Berman-Bieler et al., 2015). The lack of rehabilitation personnel is posing a problem relating to assistive technology. Berman-Bieler et al. suggest ongoing training programs for professionals in the field of rehabilitation coupled with technical training to enhance the cadre of trained personnel to deal with people with disabilities and assistive technology. Doing so will begin to break down the human resource barrier. The financial barrier plagues many persons and families in the disabled community.

Mori, Reyes & Yamagata (2015) suggests that one of the most important barriers to living a productive life as a disabled person is poverty. A person with a disability who falls into the poverty bracket is affected by two external factors: their average income and their distribution of income. A disabled person has a higher chance of making a low income. Figure 11, though not a global representation, shows a Third-World populated metro city like Manila and the income and expenditure of respondents. It shows that most respondents earn less than 100,000 pesos annually which translates to \$2,060.80 pesos or \$171.70 USD monthly. Mori et al. (2015) suggest that finance can be a contributing factor that denies people with disabilities access to assistive technologies. People with disabilities also face the barrier of accessibility. In an analysis of interviews done by Dwivedi (2019), Figure 12 identified lack of awareness, high cost, lack of training, and repair and maintenance are the top barriers/hindrances to assistive technology. Attitudes towards people with disabilities usually have unintentional negative consequences, which ultimately promotes discrimination, which in turn highlights pity and sympathy towards a person with a disability. This environment of compassion and empathy causes people with disabilities to develop a negative self-consciousness towards themselves, resulting in creating a negative attitude towards assistive technology. Therefore, it is safe to conclude that attribute relating to socio-psychological behaviour greatly hinders the adoption of assistive technology.

Figure 11

Despondence in manila in a personal income survey



Note.: The First Semester 2018 estimates were updated due to the adoption of the 2015 Census of Population (POPCEN 2015) results for the weights used in the Family Income and Expenditure Survey (FIES) and the urban-rural classification of barangays. These were incorporated to ensure comparability with the 2021 estimates.

Figure 12*Assistive Technology, analysis of interviews in India*

S. No.	Question Related To	Categories	Percentage
1.	Age	0–3 years old	None
		4–22 years old	45%
		23–59 years old	55%
		60 years old +	None
2.	Disability	Physical Disability	65%
		Intellectual Disability	30%
		Learning Disability	30%
		Hearing Impairment	5%
3.	Work Status	Full time	63%
		Part time	29%
		Non-working	8%
4.	Contribution of AT to improve life-style	Strongly Agree	80%
		Agree	20%
		Disagree	None
5.	Barriers faced in getting/ using right AT	Lack of funding	38%
		Lack of knowledge on what AT devices are available	5%
		Lack of skilled professionals to make good recommendation	37%
		Frustration using AT	20%
		Incompatibility with higher tech AT	10%
		Transport problems due to lack of user-friendly environment	12%
		Lack of awareness	48%
		High cost	40%
		Lack of training	30%
		Repair and maintenance	80%
6.	Perception of Family members/ Society	Normal behavior	58%
		Show Sympathy	26%
		Avoid Interaction	11%
		Treat badly	5%

Note. Assistive Technology, analysis of interviews in India. From Exploring barriers to the use of assistive technology for PWDS in India. By Dwivedi, A. K. (2019).

Assistive technology for people with chronic spine injuries

Damage to the spinal cord can be devastating and traumatic, leaving individuals with severe impairments and, sometimes, complete paralysis (Badhiwala et al., 2019). The incidences of spinal cord injuries vary from country to country and region to region. These incidences have increased due to population expansion (Badhiwala et al.) and a growing ageing population. Men are increasingly more likely to be affected by spinal injuries than women, due to risky activities such as high-impact sports and other activities (Sayenko et al., 2019). The cervical area of the spine is the area that is most affected during a traumatic spine injury. According to Badhiwala et al. (2019), electrolyte disturbances, pulmonary infections, urinary tract infections and bedsores were the four most common complications that individuals with spine injuries live with throughout their lives.

Assistive technology is used to assist patients with traumatic spine injuries to lead a comfortable life (Sayenko et al., 2019) and support them in their everyday experiences. However, there is perceived isolation among people with spinal cord injuries (Cimino et al., 2020) and the use and integration of assistive technology. Though assistive technology is required to facilitate affected individuals with chronic spinal cord injuries and to promote inclusion and independence, only five to per cent (Daryl et al., 2020) of individuals in developing countries with spinal cord injuries has some form of access to assistive technologies. People face multiple hindrances with spine injuries. Limitation in mobility and the performance of simple bodily functions, hinders individuals from living a normal everyday life.

Assistive technologies are not just device technology, they also include strategies, services, and practices (Daryl et al., 2020) implemented to ensure problem alleviation for people with spine injuries and other impairments that cause a disability. Due to the common use of

assistive technology in developing countries, employment and productivity are typically very low among individuals with spine injuries. In contrast, there is a significantly high healthcare cost (Daryl et al.) including the social exclusion for individuals who are unable to access suitable assistive technology. In developing countries such as the Philippines and the member states of the OECS for example, the environment and public transportation remain inaccessible for people with spinal cord injuries. This is a stark contrast to their counterparts in more developed countries (Daryl et al.). The developed countries have legislation which legislates accessibility access (Barclay et al., 2016) for motor scooter and wheelchair users. In many developing countries, the use of motor scooters and an electric wheelchair is limited because of the poor infrastructure to accommodate their service, and when there is some access, it is typically an afterthought (Barclay et al., 2016) and is usually not constructed to international standards.

Robotics to Assist People with SCI

After being in a motor accident or a fall which causes an individual to have an impairment which causes a disability, mobility is the one aspect of that individual's life that is perhaps most important to him or her (Mekki et al., 2018). Individuals who have lost all mobility in their entire body (tetraplegia) must rely on assistive technology to access the environment in which they reside. Mekki et al. suggest that, though there is still an almost complete reliance on human intervention (caretaker intervention), some form of assistive technology is still used to communicate with that caretaker or the outside world.

The use of robotics in the past decade has significantly improved the lives of people with spine injuries, specifically those who are paraplegic or partially paraplegic. According to Mekki et al., (2018) the use of robotics as an assistive technology serves two purposes in the rehabilitation of individuals with spinal cord injuries. Firstly, recovery through repetitive

functional movements, and secondly to act as a mobility aid beyond orthoses and wheelchairs.

Assistive technology in robotics may help individuals who may have partial or complete tetraplegia, this means the lower the damage to the cervical spinal cord the less the damage to the arms, fingers, and wrist (Lo et al., 2016). This type of assistance may go a long way in improving the lives and independence of people with SCI and their overall interaction with society and their environment. This type of technology normally starts with rehabilitation, with the aim of improving body strength and the motor pathways to the hand and arm which controls upper bodily functions for person with spine injuries (Lo et al., 2016).

When using assistive technology in robotics with individuals who are tetraplegia, technicians focus on neuro rehabilitation, that is, the focus on either the shoulder and elbow (an exoskeleton that deals with alignment and support) (Lo et al., 2016) or the wrist and fingers (robotic end-effectors which supports articulations), (Mekki et al., 2018). The use of these assistive technologies has the capacity to improve over time independence and the promotion of functional recovery. Due to the high cost of these types of assistive technology, affording them in developing countries is always a challenge (Narayan et al., 2021). Considerably more studies are needed in robotics and individuals' upper spinal injuries to close the knowledge gap and increase the possibilities of fuller and more groundbreaking research outcomes.

Individuals, whose impairments are caused by a spine injury and are paraplegia or what is sometimes called thoracic SCI can, at times, result in partial or complete paralysis (Mekki et al, 2018) on the affected individual's lower extremities with the outcome of limited recovery. The use of a wheelchair is normally a priority for people with lower body impairments from some form of injury which causes either partial or complete paralysis. However, the use of assistive technology (Narayan et al, 2021), such as an exoskeleton, can assist people with spinal injuries in

standing upright and improving mobility. There are various other technologies, such as bracing, that are used besides an exoskeleton. The disadvantage of bracing is that it has a very high physical demand on the individual (Mekki et al). Another bit of assistive mobility technology that may also be considered is the Even Body Weight Support Treadmill Training (BWSTT). This machine has two main disadvantages, its in-portability and its inability to be used as mobility technology. Mekki et al. (2018) suggest that the even body weight support treadmill training machine is very useful for rehabilitation purposes.

Conclusion

One of the topics missing from the discourse on people with disabilities is the care of this vulnerable group in the matter of assistive technology. It was identified that the importance of AT in the lives of people with disabilities could not be overlooked because its significance in improving their lives. While we recognise the broad definition of assistive technology as the technology that enhances the lives of people with a disability, several factors must be considered. One such factor is that of ethics. Medical and engineering ethics are the primary aspects of assistive technology while considering the rights of people with disabilities. Ethical engineering has a social obligation to the public, guiding the engineering process to prove safe and usable products. Ethical engineering, unlike ethical medicine, whose responsibility is to the individual patient, must consider both the patient and the environment. Therefore, while considering assistive technology for people with disabilities, medical and engineering ethics play a vital role.

Barriers to the use of AT are many, and obstacles include accessibility, availability, finance, social attitudes, and qualified personnel. These barriers are often unmet because of the inability of people with disabilities to access services because of their financial status. The existence of these barriers requires an urgent need for government and organisations to play a

greater role in making sure that people with disabilities are afforded the opportunity of assistive technologies. When these technologies become available, individuals must be in place who are trained in the use of assistive technologies to act as therapists and repair and maintenance technicians for the administration of assistive services. To conclude, assistive technology must be a part of the lives of persons with disabilities so that they can be productive and perform daily functions as non-disabled people do.

Discrimination and Gender Identity in People with Disabilities

Introduction

The term disability may be seen as an umbrella term for people with a long-term impairment that limits their participation in daily activities and their interaction with their environment (Hackett et al., 2020). This lack of interaction among persons with disabilities has increased difficulties in their everyday lives (Hackett et al.). According to Stephenson (2019), the incidences of disability in the Caribbean are more prevalent in males than females. In the over-sixty age bracket, the prevalence of disability in females is much higher. On a global scale (Bunbury, 2020), people with disabilities are likely to have fewer educational opportunities, which translates to little or no employment and are therefore exposed to a higher level of poverty than non-disabled individuals (Hackett et al., 2020).

As a result of the barriers faced by people living with spine injuries and other disabilities, experiencing discrimination is one additional obstacle faced by people living with a disability (Equality and Human Rights Commission, 2017). In defining discrimination against disability, (Hackett et al., 2020) explained it as unwanted exploitation or abusive conduct or behaviour against people living with a disability, which intrudes upon their security and dignity. Further,

The Equality and Human Rights Commission (2017) adds that discrimination against people with disability also includes the creation of an environment that is offensive or intimidating. According to Hackett et al., though there are many legislations against disability discrimination, it is perceived to be very common.

Stephenson et al. (2020) highlight several anti-discrimination legislations in the Caribbean that protects the rights of people with disabilities. The Guyana, St. Lucia, Trinidad, and Tobago legislations all have similar prohibitions, including protection from race, sex, and religion. colour, ethnic origin, social origin, political opinion, disability, based on pregnancy, one's age and marital status. These prohibitions are also enacted in other Caribbean islands that have signed on to the United Nations Convention for People with Disabilities. They are Antigua and Barbuda, Jamacia, the Bahamas, and Barbados. Despite this legislation to protect this vulnerable group, persons with disabilities often find it difficult to secure employment because of stereotypes (Stephenson, 2020). The exclusion of people with disabilities from mainstream society is seen as a prohibition of inclusivity (Stephenson, 2020). Stephenson argues that as compared to other aspects of discrimination, such as age and race, there is an argument that these groups of marginalised individuals have been associated with advantages to society and employment unlike individuals with various types of disabilities.

On the issue of gender and gender identification, is that (Jackman, 2017) identifies that members of the LGBTQI community face discrimination out of fear of the unknown and religious beliefs. The perception of society that by association, you are known, further compounds the discrimination barrier amongst people of the LGBTQI community. However, Stephenson (2020) explains that this perception of association assumes acceptance of the

lifestyle or that the individual may be a member of such. These perceptions are thwarted by aggression and ridicule towards individuals of the LGBTQI community.

There have been studies which show various incidences of discrimination against a person with disabilities. Field experiments have shown that fake applications were used to secure interviews on actual job postings, resulting in differentiated employment outcomes for persons with disabilities (Baert, 2018). One such study was carried out by (Ameri et al., 2018).

Educational discrimination

The United Nations CRPD protects the rights of persons with disabilities and their right to education (Stewart & Dean, 2021). Education is not only a right for persons with disabilities (UNESCO, 2019) but it is also a human right. With this, access to education becomes a right of all humans, not a privilege (Stewart & Dean, 2021). This access to education can only be guaranteed if the appropriate legislation is enacted as part of the overall disability act of individual countries.

Access to education for people with a disability becomes a social issue and is therefore aligned with the social model of disability. The social model states that an individual's disability is related to the individual and the environment (Wasserman et al., 2016). A study conducted by the University of the West Indies Mona Campus Centre of Disability Studies generally found that students who are disabled in the 84 schools assessed had considerably less access to education than their non-disabled counterparts. The same study conducted indicated that 63.1 per cent of the schools had registered students who had some form of disability. However, many schools had no accommodations for these students with impairments.

The United Nations CRPD provided a critical framework encompassing all signatories to the convention to adopt said framework relating to inclusivity in education for persons with

disabilities. Article 24 of the convention was created with the aim to legislate and develop policies to reduce the incidences of discrimination amongst persons with disabilities. The United Nations convention framework identifies that though different countries may set up different legislative frameworks, the overarching goal is to develop policies to protect students and other people with disabilities who are seeking an education. However, Byrne (2022) suggests that a voice must be given to the individuals affected by discrimination to be deemed all-inclusive. However, there is continued focus on an all-inclusive educational system addressing the root cause of discrimination, as highlighted by (Wibowo & Muin, 2018), is one step toward eliminating educational discrimination. One such root cause is poverty.

The United Nations Millennium Development Goals (MDGs) led the charge first in overcoming the challenge of poverty in developing countries. Wibowo and Muin (2018) see disability as a bidirectional issue, in that he thinks disability may increase the risk of poverty and poverty may increase the risk of disability. This bidirectional link has both a direct and indirect effect on the lives of disabled young people seeking an education. In poverty-stricken communities, the incidences of disability are more significant than in middle-income communities. These incidences of poverty give rise to marginalisation and exclusivity, usually caused by a rise in stigmatic behaviours towards people with disabilities. The educational sector is one area that is heavily discriminated against. According to a United Nations report, 90 per cent of children globally with disabilities in developing countries, including the OECS, do not attend school (Wibowo and Muin), and the literacy rate in disabled adults in developing countries is one per cent. There are also limited employment opportunities for people living with a disability because of the inequality regarding educational opportunities, which increase the incidences of poverty

Further discrimination can be seen in developing countries such as the member states of the OECS (Wibowo and Muin, 2018), by setting up special schools for people with disabilities. Additionally, institutions sometimes discriminate against individuals with disabilities, but research shows that teachers also discriminate against students with a disability (Karwono et al., 2021). This rejection forms part of a knowledge gap among teachers and how they should deal with students with special needs. Within the OECS, with the adaptation of the United Nations article 24, which protects the rights of persons with disabilities, there has been the passing of various legislations throughout which seek to protect the rights and privileges of persons with disabilities. These rights and privileges include the right of young children and people seeking education to be afforded the same benefits (Karwono et al.) that non-disabled students are afforded.

Implementing an all-inclusive learning environment, while incorporating students with disabilities is one way of eliminating marginalisation and discrimination (Wibowo & Muin, 2018) in educational systems in low and middle-income countries. However, Lord & Stein (2018) suggest that inclusive education is elusive to individuals with a disability, especially in developing countries. Lord & Stein further point to attitudinal, physical, and communication-based barriers that all play in the limitation and exclusion of people with a disability in wholesome inclusive educational systems. These barriers go on to form a myriad of social issues in the long run (Lord & Stein, 2018), whose consequences can be grave to society. The barring of the advancement of people with disabilities from further academic training.

How do Disabled Students Face Discrimination?

A student is said to be discriminated against if the institution fails to provide adequate means related to admission, the provision of their education and denial of any services the

institution offers (Mifsud, 2019). An educational institution accommodating students with disabilities should ensure that measures are put in place to accommodate instances of examination, for example, the availability of a scribe, providing additional time and the availability of assistive technology. The topic was previously examined in this chapter (Mifsud).

We first must look at inclusion in education to understand what is lacking and identify what may be determined as discrimination. For an educational system to be deemed inclusive, all institutions under its remit must become better at “educating all children in their communities” (Imaniah and Fitria, 2018, p 19, p.3). Imaniah and Fitria, therefore, explain educational inclusion as a process of addressing the entire child whether the child is disabled or non-disabled and regardless of gender and status. Inclusive education aims to reach that point of social and educational equality for all learners, regardless of their physical or mental impairment.

An indirect form of discrimination against people with disabilities, including those living with a spine injury, is poverty. Disability is seen as a bidirectional facet of life. That is, disability may increase an individual’s risk of poverty in their lives, and the existence of poverty may increase an individual’s risk of developing a disability (Wibowo & Muin, 2018). Poverty created by individuals living with a disability has a consequence of exclusion and marginalisation caused by stigma and social misunderstanding of the disabled community. Wibowo and Muin suggest that inclusive education for individuals with a disability is one of the prominent growing stigmas. The inequitable educational opportunities for people with a disability creates an unbalanced society where employment opportunities are concerned. With limited access to education, an individual with a disability may experience inadequate employment opportunities, leading to societal poverty.

Curriculum accommodation and participation in higher education institutions is another source of educational discrimination (Podzo & Chipika, 2019), which feeds into what is termed reasonable curriculum accommodation which forms part of the United Nations Convention of the Rights for Person with Disabilities . It is argued that the curriculum should be the central focus for education to be seen as all-inclusive. In contrast, full participation, including people with disabilities, is made. Podzo and Chipika suggest that a general and successful curriculum entails placing students who are disabled in the general classroom environment so appropriate accommodation may occur. The following guidelines are presented as appropriate for a suitable all-inclusive curriculum in education which may reduce the incidences of discrimination:

- It has broad common goals, including acquiring knowledge, skills, and values.
- It has a flexible structure to facilitate responding to diversity and providing diverse opportunities for practice and performance in terms of content, methods, and level of participation.
- It contains learning assessments based on students' progress.
- It acknowledges the cultural, religious, and linguistic diversity of learners.
- It is based on content, knowledge, and skills relevant to the learners' context. (p. 59)

Gebrehiwot (2015) defines curriculum as a total learning experience of individuals who are not only learning in the school setting but also in society. Gebrehiwot, (2015) defines curriculum as the plans made for guiding learning in the schools, usually represented in retrievable documents of several levels of generality. He further states, that actualisation of those

plans in the classroom, as experienced by the learners and recorded by an observer, take place in a learning environment that also influences what is learned.

The Social Model and Inclusive Education

Through the lens of curriculum and access to education, the social model focuses primarily on learners' physical and environmental rights (Gebrehiwot, 2015). Mike Oliver introduced the social model of disability in the mid-1970s and viewed disability as a social construct rather than an individual problem. These individuals have no control over such environmental, social, and organizational factors. It is argued that the social model of disability is better suited for individuals with a physical impairment and thus will be more aligned with students with a physical disability. Therefore, I have varied issues, such as classroom access and other material amenities. The use of and access to assistive technologies will fall under this model. Gebrehiwot (2015) points out that though the social model of disability does solve other aspects of disability, such as learning disabilities, it remains the superior model for now.

One of the main aspects of eliminating educational discrimination is addressing the inclusion issue (Podzo & Dzviti, 2017). As defined by UNESCO (2019) as a process, inclusion in education addresses the needs of all learners mainly by increasing the learner's participation in the learning process, culture, and communities in which they live. It further involves the need for modifying and changing to approach to curriculum structures and strategies. Podzo & Dzviti (2017) looks at inclusive education as one that promotes adapting the social model. Instead of only looking at the challenges of an individual student, inclusive education should look at the entire community in which the learner and the institution are located, working together to overcome the difficulties of education inclusiveness (Makanya, 2015).

Education Discrimination as a Human Factor

Considering educational institutions making changes to facilitate inclusiveness in their overall curriculum and reduce discrimination incidences (Podzo & Dzviti, 2017), the human factor still needs addressing. Bunbury (2020) indicates that the institution's staff members still struggle with inclusiveness and how to accommodate students with impairments. This struggle is due to several factors, including the lack of training, knowledge of the phenomenon and lack of knowledge. The recommendation for training for staff members and awareness training is paramount for educational institutions to facilitate inclusiveness.

Barriers to Inclusive Education

An all-inclusive educational environment can be achieved if barriers such: as 1) environmental; 2) physical and transportation; 3) admission and program choice offered, and 4) attitudinal (Lord & Stein, 2018) are improved to foster an environment envisaged by the United Nations when it implemented the United Nations CRPD. Lord and Stein (2018) suggest that these barriers go against the grain of the provisions of the United Nations CRPD. They further suggest that it is time that frameworks be implemented that move beyond would not it be nice, to a more, let us legislate what is right so all can benefit from a more inclusive educational system.

Examination barriers

In a study by Lord (2017), various types of examination barriers were faced by the sample of disabled students who were all enrolled at a higher institution of learning. Issues such as poor readers and those who were provided to write for students with visual and physical disabilities were pointed out in the study. This indicates the need for institutions to suitably train their faculty about the needs of all students, including those with disabilities. Moreover, it is the institution's responsibility to provide reasonable accommodation related to the conduct of all

examination periods offered by the learning institution, according to the United Nations CRPD provisions (Lord & Stein, 2018).

In cases where students feel as if they have not been treated fairly, (Lord & Stein, 2018) pointed out that they would often turn to assistive technology away from the human element. It is often the case that educational administrators are unaware of the institution's duty to provide reasonable accommodation for all students. The awareness, however, that must be taken into consideration, is that all types of accommodations are not possible, and reasonableness must prevail in assessing all circumstances.

Physical Barriers to Inclusive Education

The idea of the physical environment and its effect on an individual with a disability encompasses several variables. These variables include overall access to the school or campus (entry and exit), how students with disabilities are able to move around the campus, and access to school and campus facilities (CRPD, 2006, art. 9). In the same study, (Lord, 2017) indicated that there was evidence of physical, infrastructure and transportation barriers on the schools and higher educational institutions he visited. The lack of these basic amenities to facilitate people with disabilities can lead to critically disabling the already impaired individuals.

The blind and physically disabled students, especially wheelchair users, are most disadvantaged in reaching facilities such as lecture halls and library facilities (Lord & Stein, 2018). The impact of physical barriers affects the holistic educational experience of a single disabled student, notwithstanding the primary purpose for them attending the institution in the first place. Lord (2017) points out that physical barriers affect not only the learning capacity of a disabled individual but also recreational and extra-curricular activities. It is these kinds of barriers that affect disabled students' social interaction with other students overall.

One aspect indicated that just over 40 per cent of institutions visited in the (Lord, 2017) study had accessibility and planning issues. Though there were strategies for implementation, these implementation never happened. The reliance on other students, parents and faculty members helped some students overcome many physical barriers. There can, at times in higher education, be the absence of some written policies which should lay out the guidelines regarding accommodations for students with disabilities and, notably, how they access facilities and services on their respective campuses. Higher learning institutions with insufficient provisions to decrease the incidences of physical and environmental must deal with many complaints from students with disabilities. These barriers limit the overall learning experience of students with disabilities. These environmental and physical barriers are often seen in developing countries (Karwono et al., 2021), such as the OECS. Lord and Stein (2018) suggest that the inclusion of students with disabilities should be a precondition when tackling physical and environmental barriers at learning institutions. This recommendation is in keeping with article 4(3) of the United Nations CRPD.

Attitudinal Barriers

Attitude towards people with disabilities comes from all sections of the education system (Lord, 2017). The attitude emanates from faculty, administration staff members, non-disabled students, and students with disabilities (Karwono et al., 2021). The attitude towards people with disabilities, including students, continues to be an issue in schools and higher educational institutions. The United Nations CRPD was responsible for introducing guidelines, specifically, Article 24, which ensures the inclusiveness of the education system at all levels (Buchner et al., 2021). The interpretation of all levels means primary, secondary, college, and university

institutions falls under these guidelines. Article 24 explicitly states that all “persons with disabilities are not excluded from the general education system based on disability”.

The inclusion of people with disabilities, including those with intellectual disabilities, is still the remit of the charter of the United Nations (Buchner et al.), and it is expected that signatories to this convention continue to build an all-inclusive educational environment, including those with intellectual disabilities. A comparative study showed that senior management in higher educational institutions had very little knowledge of the rights of students with disabilities (Lord), including their rights to higher education. The findings also concluded that senior management, including Chancellors, Vice Chancellors, and Deans of departments, had little knowledge of the social or medical models, but they were not surprisingly more familiar with the latter. This may explain the unawareness of students’ rights, inclusivity, and the lack of knowledge to facilitate reasonable accommodation for all students, specifically those with disabilities (Reiko & May 2011). Understanding these matters will produce a better and clearer picture for administrators, faculty members, non-disabled students, and disabled students. Therefore, the attitudinal culture of educational institutions towards students with developmental and intellectual disabilities will take on a more positive trajectory and will therefore be in line with Article 8 (awareness-raisin), Article 9 (Accessibility), and Article 24 (education) of the United Nations CRPD.

Admissions and Choosing Programs

Attitudes towards people with disabilities applying to and getting admitted into higher education have always been an issue that people with disabilities constantly must grapple with. Studies (Buchner et al., 2021; Lord, 2017) showed that the requirements for entry into higher education in some developing counties are sometimes unclear to disabled applicants. Further,

their study finds that the admissions process is usually left up to the head of the faculty as opposed to the broader university body (Lord). This practice highlights a point made previously, that there is a lack of disability policies at many learning institutions which govern the treatment of people with disabilities.

In addition to the inadequacies and difficulties faced by students with disabilities accessing grade-entry secondary school or higher education institutions, provisions are not made for students with certain types of impairments. For example, students who may apply to a particular program of study are sometimes convinced that the program they are applying for is not suitable for them (Lord & Stein, 2018). The barrier to admission and choice of a program for students with disabilities is seen as educational discrimination. Also, some learning institutions' reasonable accommodations are not implemented as they should.

Apart from students with visible physical impairments, deaf and hearing-impaired students face the most significant barriers to admission into higher learning institutions (Lord & Stein, 2018). Similarly, students who are visually impaired face an uphill battle when choosing their desired program of study. Not only is this going against the United Nations CRPD, but students are also forced to leave a particular university or forgo their dream of becoming a university graduate altogether (Buchner et al., 2021). In place of a comprehensive written disability policy, some universities in Egypt and Northern Africa have explicitly written policies for prospective or existing students who are visually impaired, barring them from enrolling on certain faculties at these universities (Lord & Stein).

Achieving inclusiveness

There is a need to eliminate discrimination amongst people living with a disability in the educational system. Moreover, a close inspection of the institution's overall curriculum and the

implementation of an inclusive curriculum suggests that two models may be used to achieve inclusion (Gebrehiwot, 2015). The flexible way in which information is presented, how teachers give information to students and how learners demonstrate or respond to knowledge can still be called universal learning design (UDL) (Gebrehiwot). Further, its main aim is to reduce barriers in pedagogy while providing appropriate accommodation, support and any challenges that may present themselves to all learners, including learners with disabilities. In using universal learning design, educational institutions employ this approach in creating course material and instructions to benefit all who will be beneficiaries of these instructions. According to Gebrehiwot, Universal Design Learning has three main concepts. Though there are several criticisms about its use and implementation, namely its time limitation for implementation and its financial implications:

- Flexible ways of presenting lesson content;
- Flexible options for student engagement; and
- Flexible methods of expression and assessment

According to Gebrehiwot (2015), the Accommodation Model speaks to the adjustment of, and the alteration of arrangements made in the learning environment to reduce barriers to learning and further promote accessibility for all. In articles United Nations CRPD 2006; Gebrehiwot, 2015; Stephenson et al., 2020) dealing with students and persons with disabilities, the term reasonable accommodation is used to identify accommodations suitable for the learning experiences of people with disabilities as somewhat appropriate. Notwithstanding, Gebrehiwot points out that the word reasonable specifies that any modification and adjustments made for individuals with a disability should not be intended to treat unfairly or cause any malice against those who are non-disabled.

Recommendation to facilitate and reduce the incidences of educational discrimination

The number of students with a disability entering the education sphere at all levels is increasing annually (Podzo & Dzviti, 2017, as cited in Gebrehiwot, 2015). In ensuring that an educational institution does as much as possible to curb discrimination against students with disabilities, Makanya (2015) suggests that alternate curriculum materials and teaching practices are necessary to meet the requirements of students with disabilities. The learning environment and curriculum revision are recommended changes to facilitate educational inclusion and reduce incidences of discrimination. Consideration should be given to all students in the areas of academic support, emotional support, and social support.

Conclusion

Curriculum inclusion forms the core of an inclusive educational structure. Further, having an inclusive educational system will only be possible if all levels of the academic ladder adopt and implement an inclusive agenda. That means being prepared to accept and educate all types of students, including those with disabilities. The definition of inclusion speaks to the process of addressing and responding to the various needs of all children, and adults in the learning, social, and cultural needs while reducing and eliminating exclusion in the education system.

Podzo & Dzviti (2017) suggest that curriculum reform should focus on three pillars of participation and accessibility: epistemological, structural, and systematic. These three pillars cover the holistic learner and their needs; therefore, they will reduce discrimination incidences if they are looked after. It is, therefore, critical that a curriculum be seen as inclusive. It should provide some level of flexibility for adjustment and alteration to facilitate the needs of students with disabilities.

Disability Culture

An intellectual disability, or an intellectual development disorder, is defined by the WHO as a significant impairment affecting the general cognitive functions, severely affecting an individual's social and adaptive skills and behaviour. A physical disability is described as a physical condition that limits an individual's ability to function normally and perform everyday activities (Patal et al., 2018). To fully understand the meaning of disability, we must investigate the various types.

According to the Australian National University (2018), there are varied ranges of disabilities. These include vision impairments and mental health conditions, deaf or hearing-impairment, acquired brain injury, intellectual disability, autism spectrum disorder, and physical disability. These varied forms of disabilities affect all aspects of society, leading to our definition of culture, its tie-in to a disability, and how the two are interrelated. According to LaMorte (2016), culture is one way of life that includes arts, beliefs, perceptions and attitudes. Hofstede (1997) defines culture as a system of knowledge shared by a large group of individuals or people. Hofstede describes one of his six levels of culture as the gender level, which represents the relationship between females versus males. However, within the level emanates a group of individuals, persons with disabilities, who have, over time, formed their own culture either knowingly or unknowingly.

However, there is a difficulty when looking at the word disability. In different cultural settings, it will have different meanings. The meaning of culture and disability globally will have many different connotations depending on which part of the world people live in (Brown, 2022). If we are to look at the meaning of both definitions combined, Brown puts it best when he said disability culture is mainly about self-value and visibility. This definition expresses the coming

together of different views from persons with disabilities and their living expressions no matter where they live. These expressions are globally common and therefore give rise to a culture- the disability culture. Brown expresses that the idea of disability culture is new and consequently resisted and contested, mainly because persons with disabilities are often looked at and referred to as in-valid, limited, crippled, and deformed.

There is, however, an element of change, as with any community. This change is relevant because if there is no change, the community becomes irrelevant and stagnates (Pulrang, 2022). The difference in a cultural mind set starts with an individual. People with an impairment come from different social backgrounds, so they will think differently even if they are of the same grouping. The commonality, however, in having one common experience is the disability itself (Pulrang, 2022). Disagreements over a common goal or a strategy are some differences that disability groups commonly face.

Disability is a culture, an expression, of a group of people. Therefore, if this group is to be recognised, they must consider a few things (Brown, 2002,), such as encouraging and educating the public. To achieve this, Brown suggests including someone disabled on an organisation's interview panels. This inclusion shows the diversity and an unbiased system of employment regardless of ability. 2) Ensuring the rights of persons with disabilities are promoted and upheld. This may be achieved by persons with disabilities familiarising themselves with complaint processes. These complaint processes ensure that an equal platform is available for persons with any form of disability. 3) Creating a well-cultured disability environment includes the provision of employment for persons with disabilities. This may be possible by ensuring the criteria for employment are the same across the board and not disadvantaging persons with disabilities. 4) Another way of promoting disability culture is by nurturing

leadership amongst disabled people. This can be done by including disabled staff in training and educational courses for self-upliftment and improvement. 5), There must be a promotion of full participation in the legislative process. Brown explains that including persons with disabilities in policy decisions, decisions that will ultimately affect their lives, is paramount in promoting a thriving disability culture.

Promoting Disability Culture

Waldschmidt (2018) suggests that in understanding culture relating to persons with disabilities, a look at the cultural model of disability may give some more perspective. To appreciate and accept culture as a category and part of the lives of persons with disabilities, a look at the cultural model of disability may help to put things into perspective. It was sociologists like Tom Shakespeare who called for a more heightened sense of awareness of the cultural outlook involving persons with disabilities. Shakespeare's ideals were also echoed by other activists and sociologists (Devlieger, 2005; Garland-Thomson, 2002), who argued that understanding disability as a category of society adds to its cultural reality and historical community. Though the cultural model focuses on an artistic outlook, Brown, et al., (2016) indicated that the model is incomplete and will need constant updates. As explained by (Joshua & Aschillmeier, 2010), the cultural model seeks to represent persons with disabilities in the cultural sphere, including arts, media, and literature. Joshua and Aschillmeier (2010) further mentioned the need for a cultural shift in how academics approach disability studies.

In summary, the cultural approach to disability and disability studies has some ways to go (Waldschmidt, 2018). Though it has made significant gains in the past decade, comprehensive explanations and definitions still need to be provided.

Disability and Cultural Honesty

A cultural breakthrough in the disability culture has to do with the notion that an individual with a disability is not sick but suffers from social oppression (Purlrang, 2021). With this philosophical turn, the focus has moved from the cure of the individual living with a disability towards expanding disability rights, legislative changes and accessibility. This shift, according to (Purlrang, has now become a personal acceptance of the change and has now seen many people with disability moving from the prospect of constant medical care (the medical model of disability) towards having a more socially enjoyable life that society has to offer (the social model of disability).

The cultural shift from the medical model (depressive state) to the social model (being productive and not depressed) was helpful in every way (Purlrang, 2021). The cultural shift also exposed how persons with disabilities see themselves. The social discourse amongst persons with disabilities is no longer about talking about their actual conditions and even admitting that sometimes being disabled is awful, but it is more about inclusion into society. However, it was not the conversation that was tabooed, but the content of the discussions. Purlrang explained that it was satisfactory to lament social oppression and injustices against persons with disabilities, but not to talk about the debilitating pains, depression and illnesses. The social model of disability triggered a cultural shift in how persons with disability see themselves and appreciate the environment in which they live. What has not changed, however, is the resilience of persons with disabilities to make their continued advocacy commonplace and publicly start that they are not ok (Purlrang, 2021).

A General View of Disability Culture

The critical function of identifying and embracing disability culture is celebrating the uniqueness of disability itself (Brown, 2002). Persons with a disability should embrace each other, identify who they are as individuals and express themselves as persons with disabilities. "Through the arts, we can make discoveries about what we have in common and emphasise those things rather than on our differences", this quote by (Vasey, 1989, cited in Brown, 2002) emphasises the spirit of community amongst while countering the thought of the traditional charitable model of disability that has historically kept persons with disabilities separated from each other

Persons with disabilities have forged group identities. They share a history of oppression and a common bond of resilience. They create art, music, literature and other expressions of their lives and cultures infused with their disability experiences. More importantly, people with disabilities pride themselves on being disabled. They are proud to affirm their disability as part of their identity. They are who they are. They are people with disabilities. (Published in 1996 by Mainstream magazine).

The Cultural Model of Disability

The cultural model of disability values disability as a factor of human diversity. According to the cultural model, ableism, a lack of accessibility and personal feelings exacerbate problems and will constantly be a barrier for persons with disabilities (Twardowski, 2022). The cultural model of disability, like the social model, sees the ideology of ableists and social institutions as the source of the problem. According to this viewpoint, those who can effect change are society, disability culture, and social movements. The cultural model aims to change institutions' perceptions of disability as a problem that must be solved or ignored. The goal of the

change is to reframe disability as a valuable and necessary component of human diversity and the community in which people with disabilities reside.

Twardowski (2022) points out that there must not be any differentiation between persons with disabilities and non-disabled individuals. Twardowski argues that every individual at some point in life goes through some declined efficiency, which hampers their ability to function optimally. Developing a disability is characteristic of human development. Twardowski (2022) further assumes that the experience of how persons with disability are understood and treated should be by persons with disabilities themselves. Matters relating to disabilities and disability rights should be respected by non-disabled individuals and be left up to persons with disabilities to decide. This decision often is commonly known as independence.

The Genesis of the Cultural Model

Until the mid-1960s, the dominant model of disability was the medical model. This model focused on the impairment as being of the body (Twardowski, 2022). Waldschmidt (2017) expresses the sentiments of Lennard J. Davis, where he explains society's approach to disability and human rights:

When it comes to disability, 'normal' people are quite willing to volunteer solutions, present anecdotes, recall from a vast array of films instances they take for fact. No one would dare to leap into Heideggerian philosophy, for example, or the art of the Renaissance. However, disability seems obvious – a missing limb, blindness, deafness. What could be simpler to understand? One has to imagine the loss of the limb, the absent sense, and one is halfway there (p.2)

The cultural model of disability took some time to develop as it was not understood by disability practitioners and, at times, by some academic scholars (Waldschmidt, 2017). This misunderstanding has caused a delay in the development of this naturally occurring model

Though the social model and the study of culture and disability were undertaken simultaneously (Waldschmidt, 2017), many scholars considered the social model too strict. However, the cultural model in its infancy stage was still too underdeveloped to be regarded as a complete model, such as the medical and social models. In other words, there was still much work to be done to develop this model further.

The arguments by Tom Shakespeare for the further development of culture as it relates to persons with disabilities gained traction from his feminist debates (Waldschmidt, 2017), arguing that persons with disabilities are objectified through cultural representation. This artistic representation was also echoed by other educators (Browne, 2002; Twardowski, 2022). This movement of cultural expression started, however, from the beginning of the emancipation of the disability movement which officially began in the United States (Twardowski, 2022). The development of this movement happened simultaneously in the United States and the United Kingdom. They protested mainly in the United States where the right of the person with disability was enacted into law (Twardowski), hence giving rise to the social model of disability. It was there shortly after that researchers began to understand the cultural value of people with disabilities.

Understanding the Cultural Model of Disability

Understanding the cultural model means having an appreciation of the previous model. The medical model speaks to the focus on the human body (Shakespeare, 2014). The medical model sees the disability as something internal to the individual and believes that the problem

can be fixed by fixing what it considers to be internal. The social model, on the other hand, sees the problem of disability as stemming from barriers, discrimination and social prejudices. (Twardowski, 2022). Therefore, the social model sees the solution for adjusting the environment to the needs of persons with disabilities. What is evident is that in both models, the cause is zeroed into one group of issues. This means the bigger picture of what disability means is overlooked. If this were the continued attitude of disability and disability studies, it would have had much more practically and theoretically consequences. According to (Wilinski, 2010), these consequences can lead to ignoring certain aspects of the disability phenomenon that are critical to comprehending the concept of disability and explaining its causes and effects. The missing element of these models is the element of culture, self, and identity. The imperfection in medical and social models makes the cultural model quite fitting. Though there has been a void in theoretical research coming from Tom Shakespeare's utterances of the culture of persons with disabilities only works by (Synder and Mitchel, 2005) on the cultural model of disability which highlights the aspects such as arts and identity were published.

There have been publications after that by others; for example (Brown, 2002; Twardowski, 2022; Waldschmidt, 2017; Waldschmidt et al., 2017). However, there is still an ongoing gathering of strengths in developing the cultural model of disability. The ideas surrounding the cultural model of disability, fall on three pillars, Waldschmidt (2017). Firstly, the cultural model sees disability, not as a given entity or a fact but as a description of a process, the experience of persons with disabilities, their lived experiences, their situations, or events. It is an all-encompassing model. Secondly, the cultural model of disability is seen as a model of differentiation of an embodied category, and the cultural model is identified as a natural difference giving its own identity and meaning. Thirdly, the cultural model sees disability as

connected socially to issues addressing all relevant parties, including support experts and rehabilitation and, on the other hand, the average person, whether non-disabled or disabled. Both have the desire to or difference of to comply with social and cultural normal expectations.

Conclusion

To conclude, the cultural model of disability suggests a fundamental change in the perspective on how disability is generally seen and hopes that it will be more holistic. Culture is the centre of society, and the disability movement is one such society, and culture provides an identity for the group it represents. To fully understand the subject of disability and disability studies, one must first understand the culture of disability (Waldschmidt (2017)). Persons with disabilities constitute their own culture. Further, all aspects of disabilities are considered part of the disability culture. Whether it is health, accessibility, assistive design, the arts, accommodation, or independence, it is all part of it. The disability culture is an amalgamation of beliefs and artistic expressions created by persons with disabilities which describe their way of life. The social model of disability allowed persons with disabilities to focus on self-awareness, and the betterment of self, rather than focusing on their impairments. The cultural model of disability, though not as established as the medical and social models, is responsible for fostering and bringing together the artistic pieces that make the disabled community a cultural one.

CHAPTER 3: RESEARCH METHOD AND DATA COLLECTION

Introduction

This chapter is presented with the following aims: To (i) identify and present the research methodology; (ii) explain the goal of the study; (iii) analyse the theoretical framework, research methodology and the research questions which guided the research and data collection. I first investigated the phenomenology of the research paradigm. The study focused on people with spine injuries while using a phenomenological approach to get a first-hand experience of their lived experience. Semi-structured questions and photo-elicitation were used as the instruments of choice to extract the required data. The nature of the study requires that ethical issues be considered to guide the research process. I then investigated the research data collection and analysis of the data to be presented.

Statement of the Problem

People with a disability in the OECS are often marginalised. Increasingly there has been a need for the voices of this vulnerable group to be heard. People with a disability in the OECS constantly fight for recognition and to be treated like any other citizen with fairness and inclusiveness. The lived experience of people with impairments has never been researched in the OECS. In developing countries in the Caribbean, access to local government funding can be a problem. However, passing legislation can be a definite way for people with impairment to live better lives, conforming to the social model of disability. Though there is global research on general disability studies, there has not been any within the OECS on this level. Moreover, there has been little exploring of the social model of disability and the phenomenological aspect of people with impairments.

Social exclusion of individuals with disabilities is a growing problem in the Caribbean and the smaller islands in the OECS. Turner & Nor (1998) suggest a direct correlation between physical disabilities and mental illness. This finding may be expounded if the support base is lacking in the demographic in which these individuals reside. If infrastructure such as proper disability pathways, ramps, guard rails for the blind, and assistive technologies for physically challenging individuals, are unaddressed Turner & Nor (1998) suggest that these issues may lead to depression. If these issues are addressed in an all-inclusive manner, it may create a society where people with disabilities can have the minimum living standards as none-disabled people.

Purpose of the Study

This qualitative study aimed to explore the lived experiences of people with a spinal cord injury living in the OECS and garner a more comprehensive understanding of their life experiences while exploring recommendations for social and policy change. Additionally, this study examined the implications of the findings on improving the lives of people living with spine injuries. According to Marshall (2009), the worldview of people living with a disability is usually derived from more developed countries such as Europe and North America. This is because most of the academic research on this study area comes from these More Developed Countries (MDCs). Therefore, most of the literature will likely reflect the small percentage of the world's disability population. Marshall (2009) estimates that 80 per cent of the world's disabled population is from developing countries like the Caribbean. With this figure, the view of the world's phenomenological disposition on disability is strictly focused on the MDCs.

Conceptual Framework: Streamlining the Analytical Process for Data Elicitation in Qualitative Research Using Data Extraction.

Thematic analysis and extraction

The introduction of this conceptual framework and its intended use evaluated the process of analysing qualitative data using thematic analysis as described by (Sundler et al., 2019) in phenomenological research and data extraction (Bandara Et al., 2020). Combining these two principles, I formulated a powerful concept of sorting data from its most complex state to understanding the data in its simplest form. The idea of data extraction saw the execution of three processes: extract, transform and load. Data extraction is a process of getting and processing raw data of varied forms and types to improve the outcome and meaning of the data (Gopal, 2022).

Data Extraction

Extraction, in the extract, transform, and load (ETL) process was central to the idea of this conceptual framework. The process included the identification of three main components used in data extraction; data was extracted/transformed and loaded from an Information technology perspective. According to Gopal (2022), the ETL process enabled data consolidation, analysis and refinement; a similar concept used in thematic analysis. The class of the data in the ETL process is necessary to convert meaningful information.

Though the ETL process is automated, similar to using Nvivo in the thematic analysis process, there is also a manual or physical aspect. This manual process is what I used, identical to the one used in the ETL process. With the adaptation of this model, I first aim to identify the raw data from the transcripts, which were then put into categories. This grouping into categories is similar to the ETL section of extracting data from its source and enforcing data type and

validity (Ralph & Kimball, 2004). The data cleaning process was paramount in the extraction phase (Gopal, 2022) as it allowed for data sorting and, as with thematic analysis, creating codes by noting repeating words and phrases. I used this phrase to capture expressions that emerged from the transcripts. I then reviewed the transcripts of each of the participants in an iterative process.

ETL process

According to Hughes (2002), data extraction in qualitative analysis, while using the ETL process, consists of five (5) main processes. These are: extract, clean, transform, load, and analyse. As explained above, the primary focus these steps were to extract, transform, and load. Hughes explains that extraction should be the first phase of a clean and successful analysis process. In this phase, I collected raw unstructured data from its source and move it into a repository for later use. This repository can be physical data storage, for example, cloud storage or a secure hard drive.

Actual process

The raw data was collected using semi-structured questions as the participants are interviewed. The interview was voice recorded and stored securely for later retrieval. There is a direct connection between this first phase of the thematic process and the ETL, as in both cases one retrieves unstructured data.

Clean

In the ETL process, the cleaning of the data took place as unwanted and unrelated bits of data were separated and discarded from the relevant data, a process we called segmentation.

Actual Process

After the recorded interview scripts were collected, they were transcribed one transcript at a time, and then prepared for the first phase of a complete review, ensuring the text corresponds with the audio recording.

Transform

The data in this phase was then structured into a usable format that was used to form part of the analysis phase.

Actual Process

After data transcription, each script was read line by line while phrases and words, primarily repeating ones, were circled. This was where the coding process took place and was aligned with the transformation process of ETL after the coding process, which entailed labelling and organising the data. Here, I then identified themes and the relationship between each of them. This process was repeated for each transcript.

Load and Analysis

The structured data at this point was prepared for analysis and usage.

Actual Process

At this stage, the data was coded, and labels were created, and represented themes by identifying repeated words or phrases in the transcripts. After that, these themes were grouped into categories where the analysis phase took place.

Concept

Using an idea formed from information science gave rise to the notion that qualitative analysis can be used not only with the framework of thematic analysis but can also be joined with information science from a comprehensive analytical framework. Table 2. shows the makeup of the framework.

Table 3*A working example of an Experimental Model*

Step 1	Data familiarisation/ Raw Data	<p>Being disabled and in a wheelchair, and the perception of falling in love with someone non-disabled. I questioned him a lot to see if he was sincere and what was his intentions. I don't know; I felt Ok. I was more worried about him than me. Because then, when we started going out, people would ask him why he was with me. Why is he taking advantage of me? Doesn't he see that he's taking advantage one time? He stopped and told them. Why are you so sure She's not taking advantage of me, or am I? And then he realized that the negative questions, the hostile stares. Everybody always had something negative to say towards him, like what is he doing to the young girl in a wheelchair. If you know that young lady cannot have children that you only, they cannot go out and do what he wants to do with the young lady, and that used to **** him off. But I was okay because I was used to those stairs and those stupid comments. It's like I must protect myself from society's image or persons with disabilities. I am not, oh my God, this is like. You can live your life; I'm not supposed to live my life the way I choose to. What makes you better than me? So, when he realized he had an alley cat there. He became aggressive and very protective. He's very protective. So, he got used to it. He has his days where he doesn't understand. But then he comes around. He's all right.</p>
Step 2	Code generation	<p>Needing surety</p> <p>Being disabled and in a wheelchair, and the perception of falling in love with someone non-disabled. I questioned him a lot to see if he was sincere and what was his intentions. I don't</p>

		<p>know. I felt Ok, and I was more worried about him than me.</p> <p>Questions about relationship</p> <p>Then, when we started going out, people would ask him why he was with me. Why is he taking advantage of me? Doesn't he see that he's taking advantage one time? He stopped and told them? Why are you so sure She's not taking advantage of me, or am I?</p> <p>Public Perception</p> <p>Doesn't he see that he's taking advantage? One time, he stopped and told them, why are you so sure? She's not taking advantage of me, or am I? And then he realized that the negative questions, the hostile stares. Everybody always had something negative to say towards him, like what is he doing to the young girl in a wheelchair. If you know that young lady cannot have children that you only, they cannot go out and do what he wants to do with the young lady and that used to ***** him off.</p> <p>Feeling frustration</p> <p>Because then, when we started going out, people would ask him why he was with me. Why is he taking advantage of me? Doesn't he see that he's taking advantage one time? He stopped and told them?</p> <p>Questioning oneself</p> <p>But I was fine because I was used to those steers and those stupid comments. It's like I must protect myself from society's image or person's disabilities. I am not, oh my God, this is like. You can live your life; I'm not supposed to live my life the way I choose to.</p>
Step 3	Improve data quality/Identify themes	<p>Public perception towards the participants appeared to be because of the public lack of understanding of how persons with impairments live their lives. This lack of knowledge brings on</p>

		<p>discrimination. Not all participants reported incidences of discrimination.</p> <p>Questions about relationships appeared three times because this only affected three participants in relationships, post their injuries. Though not a prevalent occurrence, it was important enough as it is hoped to bring out some interesting findings.</p>
Step 4	Themes review	<p>A holistic view of the entire script is undertaken in an iterative process. Here additional themes were identified. Themes such as social education and discrimination were also identified. Participants experienced many levels of discrimination throughout their lives. Therefore, it was necessary to subdivide workplace, educational, and social discrimination.</p>
Step 5	Cleaning up the data	<p>Identifying themes at this point is essential. Looking at codes such as feeling frustrated and questions about relationships can fall under the central theme of discrimination. I then again looked at the coding done in a previous stage and repeated the actions done to public perception. It is here that segmentation took place</p>
Step 6	Final report or analysis	<p>The analysis in this stage looked at the overarching themes which were created. For this example, the core questions about the relationship and feeling frustrated were looked at thematically to produce discrimination, further subdivided into types of discrimination.</p>

New Conceptual framework: My experience of its implementation.

The amalgamation of these two traditional concepts see figure 13 of analysing data brought to this study a unique perspective. The idea of getting the rigours of information science and the seamlessness of the thematic process created a solid framework for thematic extraction.

Coming out of this newly minted framework figure 14, are processes ensuring data correctness and accuracy, both of which were essential elements in qualitative analysis (Akinyode & Khan, 2018). The traditional way of data collection was used in this new framework, using semi-structured questions to elicit the raw data from the participants. This new framework ensures both correctness and accuracy and a rigid process that includes an iterative process of checking and rechecking, ensuring that the study's themes were aligned with the study's aim and objectives.

This flexible framework may be adopted into other disciplines requiring thematic analysis and coding. The framework is one of structure, and with the influence of the ETL process from information science, the framework may also be used in the computing discipline, whether it is used for data extraction from a large pool of data or it is used in a data mining process (Diba et al., 2020).

There is much flexibility in using this particular framework. It brings together all the necessary variables for successful data capture (interviews), refinement of the data (extraction/coding), and analysis of the refined data. Because of these defined relationships, this concept model could produce detailed results for this study. Robson & McCartan (2016) explain that a carefully constructed conceptual framework of one's study, expectations, and theories that supports and informs the research is paramount to a detailed outcome and carefully collected results.

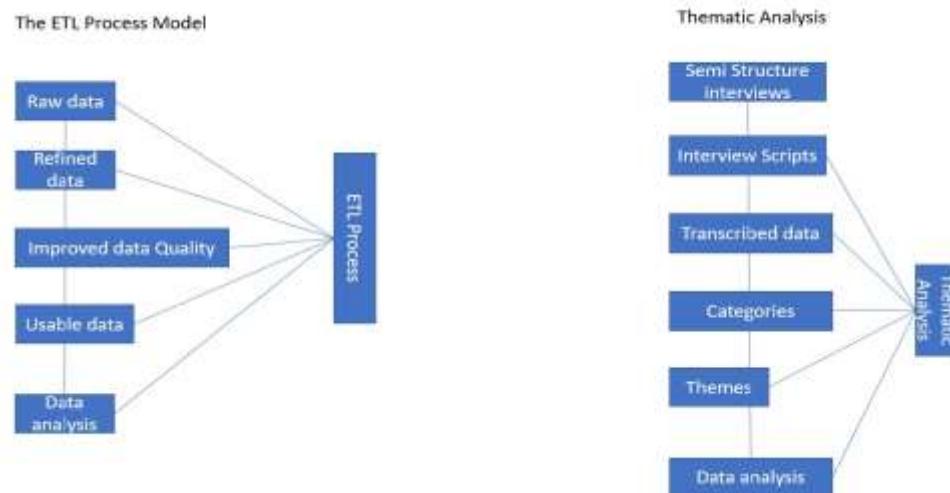
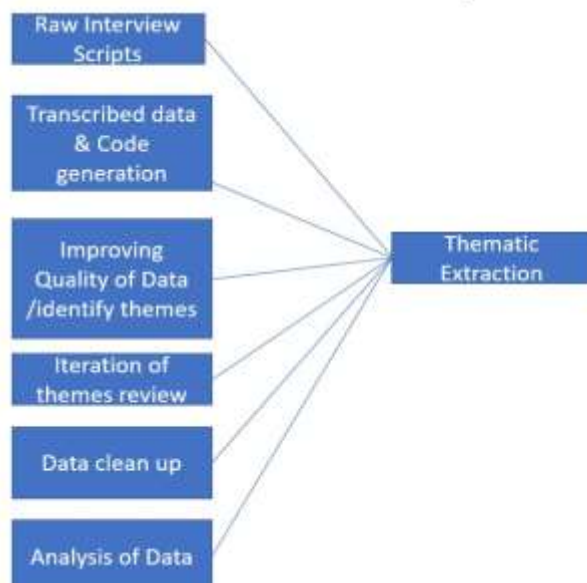
Future Research

It is important to note that there is still much to conceptualise related to this new framework. For example, can this new framework be generalised, and can it be used in other disciplines? Can it be used in the different existing methodologies? Namely quantitative and

mixed method methodologies? Further research will be able to answer these questions. Not only is the use of other methods, but the combination of computing and social science a good fit for qualitative research. The detailed analysis outcome and the processes involved highlighted the framework's robustness. Future research can also be considered in contexts such as the size of the sample, other groups in society (victims of rape), or even as it relates to culture. While it is accepted that this conceptual framework is an amalgamation of two existing models, more research can be done to test its validity further to ensure data correctness.

Conclusion

The conceptual design presented in this section explored a combination of two different models from two other disciplines, which provided a critical approach to data elicitation, processing/coding, and, finally, analysing the data. The crucial component of this conceptual framework included the refinement of data (an iterative process), rigidity, and data correctness. Though not a traditional model, this model can be used in the three more popular research methods: qualitative, quantitative and mixed-methods. Lastly, in alignment with the conceptual design, coding levels were introduced so I had an uidea on how the different levels of iterative codoing procedures were done.

Figure 13.*ETL Model and Thematic Analysis Diagram***Figure 14***Experimental Model*

Coding Levels

Preliminary Appraisal

After the interviews, each transcript was given a thorough first reading to have a general overview of the content of the interview transcript. Individual tables were created for each participant and analysed with the themes during this process. This initial reading was also for the researcher to check for any errors in the transcript. During this reading, preliminary notes of exciting words and phrases were jotted down and jumped out. This reading was also a chance for the researcher to immerse himself in the participants' individual experiences.

Coding Descriptively or Level 1

In this stage or level, the researcher focuses on the large chunk of extracted data from the initial or open coding data. The researcher focused on those words or phrases that stood out in the initial reading and underlined and highlighted them in Appendix A. This method helps the researcher identify words and phrases that eventually develop into themes. This initial phase or step is called initial or open coding (Richards & Hemphill, 2018).

Level 2

On this level, themes are redefined that were previously identified in level 2. On this level, a deeper focus was placed on words identified to be used to develop themes. Most importantly, the frequency of repeating words and phrases was highlighted and noted, and this was particularly important for identifying themes and interpretative purposes.

Conceptual Coding or Level 3

At this level, a conceptual interpretation of the meaning of themes and a wholesome understanding of the participants' experiences are undertaken. Here, the researcher received an overall understanding of the experience from a micro level.

Analysing Themes

The analysis was done by identifying themes from single transcripts and then further comparing these themes across different ones. Table 4 displays the three-level of coding employed, and the emerging themes created in a sample transcript.

Research Approach and Design

Design

The chosen research design that was undertaken in this study was be the qualitative design. The exploratory design methodology is instrumental in uncovering the phenomenon's general nature that is not fully understood (Hunter et al., 2019). Exploratory research answers questions such as why and how (Stebbins, 2001). This design's flexibility is exceptionally suited for this type of study. To fully capture the experience of people with impairment caused by spine injury, I use episodic narrative interviews to capture and better understand the phenomenon by generating individual stories and capturing individual experiences as explained by (Mueller, 2019). The episodic narrative interview approach, therefore, gives each participant the ability to provide a personal narrative account of their lived experience.

A well-rounded depiction of the participant's study experience is expected to be developed throughout the study. It is further anticipated that using the experimental method will formulate the foundation for more investigation to be carried out with people with disabilities and their varied lived experiences. Using the exploratory approach raises more research questions and, ultimately, a future study in disability.

The qualitative design aligns with many different approaches, including grounded theory, which deals with the enabling design of the discovery of inductive theory (Wiesche, et al., 2017). Another approach to qualitative design focuses on anthropology, which according to (Rashid et

al., 2015), is concerned with the study of foreign people. As the focus of this research is based on the experience of people with impairment caused by a spinal injury, phenomenology, as explained by (Neubauer et al., 2019), is a qualitative research approach that focuses on an individual's or group of individuals' lived experiences. Husserl's descriptive point of view of phenomenology as described by (Jackson, 2018) considers the individual's extracted meaning of their lived experiences.

Phenomenology in research

The Research methodology and philosophy are both aligned with phenomenology. Moustakas (2010) refers to phenomenology as knowledge as it appears from the individual's experience, and consciousness, the science of describing what one perceives. Phenomenology, in many ways, can be viewed as a way of looking at reality (Nesti, 2004), the way one lives, and an investigation into one's experience.

Husserl's phenomenological idea stemmed from the thought that the focus should not primarily be on the individual's experience of an object but on a holistic experience (Vagle, 2014). The idea of phenomenology as a research methodology divorces an object's experience but holistically encompasses the individual's memory, their imagination, and feeling as it is experienced (Moustakas, 2010). The philosophical framework for understanding the true meaning of phenomenology is that it is both descriptive and qualitative. Creswell (2005) explains that phenomenological methodology is a subclass of qualitative research, making it suitable for dealing with complex phenomena such as cultural and social needs, family dynamics, and disability issues. In the previous chapter, which dealt with the literature review, specifically in the Organisation of Eastern Caribbean States, the evidence showed a lack of

qualitative research and study in phenomenology exploring the lived experience of people with disabilities.

Research Question

This study is an examination into the lived experiences of people with a disability caused by a spine injury. Using the Phenomenological approach allows research participants to immerse themselves in the study, directly, and to have further opportunity to tell of their experience. The questions below guided the study:

1. In what ways do people with spinal injuries experience daily life in the OECS?
2. What are the most significant new barriers to inclusion experienced by people with spinal injuries since their injuries?
3. How are the experiences of newly disabled people with spinal injuries affected by membership of different social backgrounds?
 - a) How is this affected by overall care, cost, and gender? And sexual orientation?

These questions, which guided the research, are in line with the principles of phenomenology because they are also concerned with gaining insight into the participants' lived experience in the study. Husserl's descriptive point of view of Phenomenology considers the participant's exact gist of their lived experiences. This is also true when the wholistic experiences of the participants are expressed and documented (Vagle, 2014). Therefore, I chose Husserl's descriptive phenomenological method as it suited this phenomenological study. The recruitment of the participants is explained in the upcoming chapter.

Population and Sample of the Research Study

Introduction

Heidegger's general philosophy points to studying the lived experience of people (Paley, 2014). In capturing that lived experience, the participant engages in meaningful dialogue with the researcher using interviews. The meaning of a lived experience expressed by Heidegger is that time can only be represented by the person who experiences it (Paley). Thus, if assumptions were to be drawn; the primary assumption would be that the experience of people living with a spine injury can only be expressed by those living with a spine injury.

Snowball Sampling

Qualitative sampling differs from quantitative sampling. Conducting qualitative research is not limited to the approach of knowing according to (Qutoshi, 2018) but rather an intelligent conversation regarding the interpretation and meaning of an experience lived by that person. The snowballing technique, qualitative method and small sample size are the three elements used in this phenomenological study of a person's lived experience with an impairment caused by a spine injury. Another difference may come from the sampling itself. Qualitative sampling is concerned with the richness of the data collected. It is also concerned with all participants sharing a common experience but at the same time these experiences vary in characteristics (Moser & Korstjens, 2018).

The snowball sampling strategy used the researcher's social network or the social network of others to make a sampling momentum (Parker Scott & Geddes, 2019) which captured as many participants as the researcher needs. Snowball sampling usually ends when data saturation is reached. The pool of participants came from a very diverse demographic, including age, location and incident type. This meant, the data from the participants varied vastly. However, there was a point during the interview process, specifically for the participants in

Antigua, I noticed there were repeating themes when I approached participant 9 to 10. I then proceeded to interview the other participants from the other two islands, their experience were different as were their injuries, and so different themes emerged from those interviews. Mwita, (2022) states that literatures are not very clear on how data saturation is reached in practice. However, Mwita, (2022) suggest that data saturation is normally reached when the researcher finds out that all his needed data have been collected and no further relevant can be collected from any other respondents or participants of a study. It was at that point after about 10 participants in Antigua I decided that I reached data saturation.

Participants' Selection

The selection of participants was made according to several inclusion and exclusion criteria. Due to ethical concerns, participants under 18 were not allowed to participate in the study. In addition to being a vulnerable group, acquiring informed consent on behalf of children can be post-reissued for researchers. Because of the varying needs of children and their diverse backgrounds (Crane & Broome, 2017), individuals in this group are vulnerable to issues such as informed consent, adhering to legal requirements, parental permission and the assent of the child or adolescence (Field & Behrman, 2004).

All participants were over 16 years; anyone younger than 16 was excluded. The selected age range for the study was 18 to 70. Participants were excluded if they were more than seventy years of age or had any memory loss due to age or injury. All participants included in the study who met the criteria should also have had spine-related damage that caused their disability. The participant, in addition, should be residents of the OECS, specifically residing in St. Lucia, St. Kitts, and Antigua and Barbuda. The breakdown of the participants in the study totalled 16. Three participants were from St. Lucia, which includes all females; three are from St. Kitts,

including one female and two males and ten participants from Antigua including sis males and four females.

The participants in the study were chosen using a referral method (snowball) where one referral let to another, on each participating island from their respective disability associations.

The Rationale for Inclusion and Exclusion Criteria.

Inclusion Criteria.

The study included both inclusion and exclusion criteria. Therefore, it was important that if participants were a part of the study, they had met the inclusion criteria. The inclusion criteria used in this study will define critical features of the population that will be targeted. The inclusion criteria must first be met demographic; all participants must be between 16 and 70 The core rationale for this criterion is that, though a spine injury can occur in young individuals, such as a congenital disability, there are several causes of spine injuries. According to Chen et al. (2013), causes include automobile accidents, falls, motorcycles accidents, sports, diving incidents and medical and surgical mishaps. These incidences typically occur in young adults between the ages of 16 to 30, though fall accounts for a higher percentage in older individuals fifty-five and older.

The second inclusion criterion to be considered as a participant must be diagnosed with a spinal cord injury. This rationale is based on the premise that only individuals diagnosed with an SCI will be considered and included in this study. Thirdly, all prospective participants should be residents of Antigua & Barbuda, St. Lucia, and St. Kitts. The study needed to be conducted within the Organisation of Eastern Caribbean States (OECS). Moreover, because of the present Covid-19 pandemic and the proximity of these islands to Antigua, the researcher's home base, it was best to have participants from these islands. Another critical criterion of the study is the

ability of participants to communicate in English, both written and spoken. Unfortunately, the study was not sufficiently resourced to accommodate residents of these islands who were not speakers of the English language.

The final criterion for inclusion has clinical characteristics. The study required participants to be diagnosed with a spinal cord injury for at least one year. Because this study is phenomenological; having an SCI for less than a year would not glean sufficient data to suitably justify the lived experience of the participants.

Exclusion Criteria

Patino and Ferreira (2018) suggest that including inclusion and exclusion criteria for participants is a standard a practice that is required when designing quality research protocols. The first exclusion criterion is based on the participant's age. An older person over 70 with a spinal cord injury may find it very difficult to participate in the study. Mody et al. (2008) suggest significant barriers that may hinder the recruitment of older participants. Barriers include substantial failing health in person with disabilities, cultural and social barriers, and the capacity to provide and agree to informed consent. Additionally, suppose these prospective participants are boarded in institution and are abandoned by their family members. In that case, cooperation from the boarding institution may provide an added layer of complexity.

Clinical reasons or co-morbidities may exclude a person from participating in the study, for example, mental illness or memory loss. Suppose a person at the time of the study experiences pain and discomfort. In that case, they will be advised to take intervals, or the interview length will be shortened, and finally, for adjustments to be more comfortable during the interview. Considering the interview duration carries a maximum time of 90 minutes, it may not be feasible to have an SCI and be in pain to be subjected to 90 minutes of discomfort. Having

an individual in distress may cause considerable harm to that individual and may not be advised (Herrera et al., 2010). More so, it will go against the ethical guidelines of the study.

For this study, I used snowball sampling or chain-referral-sampling (Etikan et al., 2016) method, a form of purposeful method of sampling (Ghaljaie et al., 2017). The participants were chosen from a broad cross-section of society and socio-economic levels, and participants were selected using the criteria outlined in Table 1. Therefore, I recruited participants with office jobs, some who were limited to their homes, and those with limited mobility.

The snowball method of participant recruitment is most effective for this qualitative phenomenological study, as suggested by (Ghaljaie et al., 2017). The snowball method also indicates that it is best used when research participants are not easily accessible. It was difficult to locate research participants with an impairment caused by a spine injury for this qualitative study. So it was, therefore, necessary to contact the head of both disability associations to search within their respective associations to identify the most suitable participants who met the research criteria.

In selecting this group of sixteen participants and with the snowball sample method, it was intended that a rich and greater understanding of living with a spine injury would be had from those living with a spine injury than those in the broader population. This small sample size is in line and is consistent with phenomenological qualitative research guidelines (Vagal, 2014). Various literature suggests that a robust phenomenological study should have 6 – 20 participants (Ellis, 2016). Factors such as time, finances and ready access to participants are some factors that can affect the sample size of a phenomenological study. Consequently, at the time of this research, I executed the data gathering with the population that was available to me.

The data gleaned from this study will provide information on this vulnerable group of individuals and how people with disabilities caused by a spine injury are viewed by society, how they think, and how they are treated. Participation in this study was voluntary.

Materials/Instrumentation of Research Tools

Semi-structured interviews are regularly used in qualitative phenomenological research (DeJonckheere & Vaughn, 2019). This data collection method involves dialogues and opens conversational discourse between the researcher and the research participant. This method of data elicitation relies on its fundamental philosophy of using in-depth interviewing to understand a lived experience fully. Additionally, the process allows for the collection of open-ended data with drills into the thoughts, feelings, and often the research participant's beliefs. These thoughts, feelings, and ideas, such as this phenomenological study, typically surround the researched topic. This method was most suited for this phenomenological study. It represents the investigative nature of semi-structured interviews while finding out about the lived experience of people with a disability caused by a spine injury.

The open conversation between myself and the research participants allowed me to gain as much insight into their lived experiences and meaning. The decision was made to conduct interviews in the comfort of the participants' residences as it provided them with ease and allowed them to converse comfortably during the study. Newcomer et al. (2018) suggest that semi-structured interviews (SSI) combine structured and unstructured interview techniques. Semi-structured interviews are most suited for studies where the researcher seeks to get participants independent thoughts on a particular research topic. The SSI method uses a system of asking open-ended questions, often followed by a backup/probing question. Semi-structured Interviews are among the most used methods in qualitative studies (Petrescu et al., 2017). One

main advantage of using semi-structured interviews (SSI) is that they allow for open dialogue between the researcher and the interviewee, reducing the close-ended responses and briefness of answers typically found in structured surveys.

The semi-structured interview method was chosen for this phenomenological study because it involves the total inclusion of the interviewee/participant. The introduction of a warm-up question to the research participant was a welcome start, as it allows the participant to be relaxed and not too tense too early in the interview stage. This strategy was employed for my research phase because the research was done with a vulnerable group. In addition to a warm-up question, base questions were used, followed by follow-up questions in Appendix C. Another advantage of Semi-structured questions is that it contains a set of structured questions, which may be altered as the interview matures and allows the researcher to openly ask questions that are not formally in the interview research guide (Appendix C).

Though there were some structured questions, participants were given the latitude to express themselves and provide as many details as possible about their individual experiences. The interview research guide was well structured and flowed to the end. Ayres (2008) suggests that semi-structured interviews transition from unstructured interviews to more structured data collection methods. This method and structure are consistent with the phenomenological traditions used by researchers to capture the lived experience of research participants experiencing a particular phenomenon (Stenfors-Hayes, 2015).

As suggested by (Longhurst, 2012), the interviews began with an icebreaker conversation that ranged from how hot the day was to how plentiful the mango season was. This method allowed for comfort between the researcher and the research participant. When that comfort level

was reached, the participants were more willing to open and discuss their lived experiences more meaningfully.

The photo-elicitation started with me asking prompted questions to the participant to capture as much details as possible about the photograph. These leading questions encouraged the participants to elaborate on the questions asked. Qualitative interviews in phenomenological research are an effort by the researcher to understand the world or a particular phenomenon from the participant's point of view. This effort precisely understands the true meaning of peoples' experiences (DeJonckheere & Vaughn2019).

Limitations of the interview methodology

The study had some rules while using semi-structured interviews as the data collection method. The use of semi-structured interviews caused the interview session to be time-consuming, which led to my seeking participants to meet the study's inclusion criteria. The duration of the interviews was between 60 to 90 minutes. There was one male participant who appeared as if he was getting emotional. I immediately asked him if he needed to take a break or if he wanted to reschedule the interview. However, he was determined to have his experience told.

There was always the potential risk of participants' vulnerability after disclosing personal information during the interview, and this disclosure may leave them feeling exposed. As the interview process was in session, participants were asked at intervals if they were doing ok and were reminded that they could take a break at any point in the interview session. The photo-elicitation method was used to glean a different perspective from the participants at this interview stage. Most participants related positive feelings towards the photo-elicitation elicitation process. Two participants expressed sadness and depression during this process. There

was no report of participants feeling in anyways vulnerable during any of the interviews. For the two participants who expressed sadness and depression, a counselor was suggested to them so a conversation between than can be held.

The study was also limited to a specific population. This phenomenological study focused on people living with a disability that was caused by a spine injury. Therefore, this study excluded all other forms of disabilities not related to spine injuries. The sample size was limited to three small Caribbean islands, a part of the OECS. The lack of financial support and the global pandemic hindered me from exploring the other OECS islands to seek interest in the study coupled with a few none responses.

The researcher in this phenomenological study must have highlighted a person who would have suffered an acute spine injury and gone through therapy and surgery to correct a disc degenerated/bulging disc disease. Therefore, it was paramount that I did not allow my personal feelings or opinions to be inserted into the interview process or the data analysis that may sway the interview in any way. Any reactions I may have had were kept strictly outside the interview time frame. Another limitation identified using semi-structured interviews was that the interviewer presented his information that may be subjected to bias. Kiraly et al. (2020) Indicated that asking different questions to different research participants is one way of introducing bias into one's research. Additionally, a researcher may pose questions to male participants that he would not otherwise pose to a female participant (Kiraly et al., 2020), calling this gender bias. Data validity is affected by a researcher's attitude, prejudice, and preconceptions.

All the participants indicated that their interviews went as they expected and expressed gratitude to have been able to participate in the research study and to be able to contribute in

some meaningful way. They each reported that they were extremely comfortable throughout the process. The participants were briefed before each interview, and during the interview process, I exercised respect by listening actively to them (Yin, 2014).

Recording the interviews

After each interview, after each participant had had their consent forms for at least a week, I perused the form, ensuring they were properly signed and dated. All participants were informed that the interview would be recorded. The recordings were done using (Otter, a software that automatically transcribed the voice into text. After the discussions, participants were reminded that I, as the researcher, would be the only one with access to their data and that their real names would not be used in the transcripts. They were also reminded that the transcripts might be made available on request.

Study Procedures and Ethical Assurances

Before initiating any data collection, approval had to be sorted and approved by the UNICAF University's ethical approval committee. This approval was only given if all ethical concerns were addressed and satisfied the university's ethical standards. After all ethical considerations were addressed, the participants were contacted at least a week before their scheduled interviews. It was agreed that all discussions would take place in the comfort of their homes. One participant, however, invited me to his workplace as it was more comfortable than his home. The consent forms were first reviewed and checked for correct spelling and name to ensure that their signatures were in the right place (Appendix D). After a brief reintroduction of myself and rehashing the aim and purpose of the study, I alerted the participant that the recording would commence. My interview questions were used to guide the process.

All participants were assured that I was bound to maintain the confidentiality and privacy of the data they presented during the interview. The consent forms were read and signed by each participant, assuring them of the high standard of confidentiality. All participants were also informed that the recordings would be stored confidently, with access restricted to me. Similarly, the participants were told that the Photographs used in the elicitation process would have their faces obscured for privacy and confidentiality. The right to withdraw during the research process was communicated to each participant.

When the participants and I got settled in the process, we had a meaningful exchange and open conversations about their lived experiences. In the middle of the dialogue, I introduced photo-elicitation into the process. These photographs were previously requested so that they were ready before the interview. Participants were asked, for instance to describe to me the person in the photograph. The participant's response would determine how deep we go into the conversation about a specific picture. There were instances where photos were shown using mobile phones and, in the example where the interviews were done using zoom, the photographs were sent before the interview or shared onscreen.

A further explanation was given to the participants that photographs are to be used as a means for them, as an alternative, to express themselves, which the semi-structured questions were unable to do. The lived experience of people with a disability caused by a spine injury may be represented through photos. According to Bookman et al. (2018), the qualitative interview method allows the interviewer to get responses, reactions, and possible insights from photographs presented to the interviewee. It was also explained that using the photos can bring back memories that regular interviews would not bring out. Some pointing questions or prompts were used to stimulate the participants.

1. Choose a photograph and tell me about it.
2. Select a photograph and tell me about the individuals in it.
3. Choose the photograph that resonates with you more and tell me why it resonates with you.
4. By looking at the photo, what emotions do you feel while looking at it?

As was previously highlighted, screenshots were taken where applicable, and I took images of the photographs after the face-to-face interviews. At the end of each interview, participants were reminded that the information they presented and disseminated during the discussion would be kept in the strictest confidence governed by the University's ethical rules. I thanked each participant for taking the time out to sit and have such a meaningful dialogue with me and, most importantly, for agreeing to be a part of the study in the first place. The participant's images were stored in individualised electronic folders, on an external hard disc, and in a combination lock file cabinet in my home office. All other research materials were stored similarly.

According to Dodgson (2019), reflexivity is essential to research-gathering. The period of reflection by the researcher increased the credibility of the research findings but, most importantly, gave me a deeper understanding of the work. According to Palaganas et al. (2017), when using reflexivity in the research process, it mainly pertains to the analytic attention to the researcher's role in qualitative research (Goulding, 2006, p. 16 cited in Dowling, 2006). The concept of reflexivity refers to the researcher's consciousness and, additionally, their self-awareness (Palaganas et al., 2017). Combining the researcher's consciousness and self-awareness

allows him to be actively involved in the research process. Overall, Palaganas et al. (2017) describe reflexivity as a process of reflection and introspection while looking at the research study as subjective as possible. This reflection primarily involves the values of the researcher and how it is affected by their social background. It affects the researcher's ability to examine, recognise and understand the background from which the researcher immerses himself.

In the research process, I employed reflexivity on the participant's experience during the study. During this reflective process, I created a research journal that contained my thoughts on the activities of the study. I included the process bracketing with the research journal. I started to focus on any potential biases and assumptions. I used bracketing as it was vital to look into any assumptions and biases during the research process. I continuously and consistently analysed the photographs and audio recordings helped me in the reflective process, which is consistent with the phenomenological research method. Bracketing was also used with the notes taken during the study process about my research findings and any perceptions made. After the initial interviews with most participants, we had open discussions about my personal experiences, including my perceptions of their lived experiences and the data provided.

In the continuous reflection on the research data, I found that it was necessary to revisit one of the participants, age 16, as we did not get a chance to discuss his photos in any detail. Therefore, we both felt that it was necessary to return with a fresh interview, specifically to have a look at the photographs so I may learn some more about his experience. The participants' photographs added much more value to the research as they presented the participants as happy, spirited, family-oriented individuals.

Ethical Assurances

Compliance with standards for conducting research was followed. The procedures that were performed in this study which involved human participants followed the guidelines set out by the UNICAF University's ethical guidelines in addition to the 1964 Helsinki Declaration. Informed consent was obtained from all individuals participating in the study (Appendix D). Additional informed consent was also obtained from all individuals participating in the study for identifying information included in the section that uses photographs. However, the faces of the participants were obscured.

Maintaining the confidentiality of all participants was an absolute priority for me as the researcher in this study. To reduce any psychological, financial, or social harm that might have caused embarrassment, distress and possible loss of employment, all participants were reassured that their information would be kept and stored with the strictest confidence. Participants were informed that the findings would be published. However, to protect their identities, I will not use their real names. A few participants had no issues with their real name being used in the study, as they thought it would bring more meaning and realism to the findings.

Formal approval for this study was given after two iterations. The first iteration needed improvement in addressing ethical issues with the participants. The ethics form was then resubmitted to be returned because of a problem with an inclusion criterion Appendix E.

Role of the researcher

The researcher is an associated member of the disability association in Antigua and Barbuda. He is also a person who has had spine surgery for an acute spine injury (degenerative disc disease). For the past six years, I have been actively involved in disability awareness in my country of Antigua and Barbuda. I am also a member of the University of the West Indies

Disability Committee, responsible for formulating the universities' disability policy. I have always been sensitive to the needs and plight of people with disabilities, especially those who have suffered an acute or traumatic spine injury. I am also fully committed to research and research ethics, particularly phenomenological research. I was susceptible to the needs of all the participants I interviewed, especially since they all had different experiences.

I also acknowledge the biased nature of qualitative research (Galdas, 2017). I am a strong advocate for people with disabilities. As an individual who has endured years of suffering from degenerating disc diseases and several sessions of expensive therapy, I think my lived experience has positioned me as a suitable candidate to conduct this phenomenological research. Though I come from a background of having a first degree in Business Information Technology, a Masters degree in Computer Science and a Post Graduate Diploma in Business Studies, my interest and experience in disability and disability studies have ballooned.

My own lived experience fits right in with the principles of phenomenology and its desired outcome. Giving voice to people with a disability has made this phenomenological research most suited for me as a researcher and given my personal experience. Given that there has been little to no research in the OECS on the lived experience of people with disabilities, I thought it is necessary to pioneer this research within the OECS and my home country of Antigua and Barbuda.

By using reflexivity in the research study, I gained a deeper understanding of the participant's lived experiences. The use of phenomenology in this research has allowed me to maintain several core principles, including capturing data free from preconceptions, assumptions, and presuppositions of a particular phenomenon. I aimed to be as fair and bias-free as possible to maintain the research's validity and credibility.

Data Collection and Analysis

Data description. The methods to collect data were photo-elicitation for data analysis from the photos used in the interview process, and semi-structured questions, for data analysis of the interview responses. Both analytical methods were combined to evaluate a person's lived experience with disabilities caused by a spine injury. After the data was collected, I engaged in two iterative processes of reading the scripts in the first instance and rereading them to gain a wholesome understanding of the collected data. Along with the photo, which many meaningful insights were gained from this process; I was able to use the following steps outlined by (Bhandari 2020).

1. I first prepared the interview scripts for transcribing, and in addition, using my interview journal assisted me in nullifying the instances of bias and preconception.
2. I constantly reviewed using an iterative process described earlier. This was further helped by identifying the pattern and any ideas or images from the iterative process.
3. The coding of the collected data was the third process. Though NVivo and Atlas are highly recommended analytical software, I manually coded my data because of the richness of the information it can produce, allowing me to be more steeped in the collection process. I also chose this method as it allowed me to select the relevant data from the study that aligns with the research questions. Doing this reduces the amount of data in the final analysis. I also chose inductive coding (Bodine, 2021), where I created a list of codes from the beginning. These codes were created from the data coming out of the research data, and it is from this data

that the themes, theories and categories are created. The decision was made to use inductive coding as, according to Thomas (2006), the analysis process can produce reliable findings and increase the study's validity.

4. Using the inductive methods of qualitative coding, I went through each participant's interview script and assigned the codes to the responses as I went through them. The data after transcribing was coded, then themes were identified, and the finding was written up.
5. I finally incorporated a validating process of returning to the participants and comparing their original transcripts to the coded version.

Photographic analysis. A photographic study is a part of a methodological construct of visual methodologies (Glaw et al., 2017) and comprises two components auto-photography and photo-elicitation. While conducting the photo analysis of the photographs that were used in the research study, I used the steps below:

1. Collecting all pictures that were used in the study.
2. All photographs were then sorted and aligned to the associated participant.
3. Each photo was then grouped and numbered according to its associated participants.
4. After grouping the pictures, the transcripts were used to assign meaning to each grouped photograph.
5. Finally, each picture was analysed for its importance to its given participant.

Validity of Research

In qualitative research, credibility, consistency applicability, and triangulation are philosophical concepts used to give overall reliability to the research study (Golafshani, 2003). Reliability in qualitative research is the ability of a researcher to have consistent results Overtime during the research process, and an accurate representation of the total population under examination. Lincoln & Guba (1985) highlighted dependability and conformability as two other concepts researchers should consider before considering their research can be regarded as valid.

I used the concept of dependability as used by (Lincoln & Guba 1985) to emphasise reliability and consistency when the steps of the research process were followed as outlined by (Bhandari 2020) and (Glaw et al., 2017), both in the data analysis and photo-elicitation, respectively. Close examination of my research and “process notes” (Golafshani, 2003, p. 3) assisted in the study's dependability concept.

Dependability. According to (Lincoln & Guba 1985), dependability in qualitative research is aligned with reliability as in quantitative analysis, where the credibility of a researcher’s study is validated against its reliability. I adopted this philosophy of dependability as Lincoln & Guba further insisted that having an inquiry audit strengthens the dependability of one’s research study. During my research, an internal auditor assisted me in each phase of the study to ensure the consistency of processes and activities.

Generalisation. Generalizability is another critical concept of research validity. The meaning of generalizability extends to the broader population in which the study is conducted (Myers, 2000). According to the principles generalisation and of Myers the finding on people with disabilities with a spine injury should be generalised to the wider disabled community. The

results from a small sample size may be more useful in examining a phenomenon as it focuses on concentrating the date, making it richer for deeper analysis. This phenomenological study examines the lived experience of people with a disability caused by a spine injury living in the OECS. However, there is a limitation to generalisation. The replication of some qualitative studies (Stake, 1980) suggests that new and existing researchers may not access the study participants.

Triangulation. Triangulation is a method used in qualitative research studies to check or validate the robustness of their research (Guion et al., 2011). Data triangulation, theory triangulation and methodological triangulation are methods researchers use to achieve data triangulation. I employed data triangulation in my study, described as using different sources. My data was captured from the research participants, and photo-elicitation was used to triangulate the data.

Environmental Triangulation. This method involves using various environmental settings (Ndanu & Syombua, 2015) where participants are engaged in multiple locations. In my study, participants were interviewed at different locations, including their workplaces and homes, in the comfort of their backyard, and using zoom technology. This method was used to ascertain the validity of the data gathered (Guion et al., 2011). Coupled with the environment, the inclusion criterion explained in an earlier chapter may also be used. It captures the various age ranges of the participants, most with similar causes of their spine injuries.

Qualitative Design Support. Qualitative design uses analytical approaches to highlight cultural descriptions and provide an interpretational view of a social phenomenon (Vaismoradi & Snelgrove, 2019). I choose to use thematic analysis over qualitative content analysis though it offers an iterative process of data and code checking to verify and validate data (Vaismoradi &

Snelgrove). The thematic approach is used for data analysis identifying themes and reporting them as they appear in the research study (Braun and Clarke, 2006). The thematic analysis provides a rich account of the data collected in the phenomenological research and a higher level of interpretation (Vaismoradi & Snelgrove). When using the thematic approach, the content of the participant's data is manifested in a more meaningful way while capturing the true meaning of the phenomenon. My main idea was to create categories from the predefined codes.

The analytical process provides meaningful data aligned with the aim, purpose, objectives, and research questions through the analytical process. Connelly et al. (2016) suggest that using a thematic approach to focus on theme development will provide a profound, rich, complex interpretation and understanding of the identified themes.

Summary

The lived experience of people with a disability caused by a spine injury was studied using phenomenological methodology. Photo-elicitation and semi-structured were used to gather data from the research participants to represent their lived experiences better. The steps used in the photo-elicitation methods were suggested by (Glaw et al., 2017), while iterative methods presented (Bhandari, 2020) was employed using a semi-structured method. During the research process, to establish validity, consistency, and dependability of data, I ensured that the research participants were well briefed while ensuring the consent forms were sight before the commencement of the interview. Bracketing was used to eliminate bias incidences, as Fischer (2009) suggested. Finally, the thematic analysis provides a richer account of the data collected in this phenomenological study and a higher level of interpretation.

CHAPTER 4: FINDINGS

Introduction

As mentioned in sections of the other chapters of this dissertation, this study aimed to understand the lived experiences of people living with a disability caused by a spine injury within the Organization of Eastern Caribbean States (OECS). To grasp an understanding of the lived experience of people living with a spine injury, interpretive phenomenological analysis and thematic analysis were used to assist me in answering the following research questions:

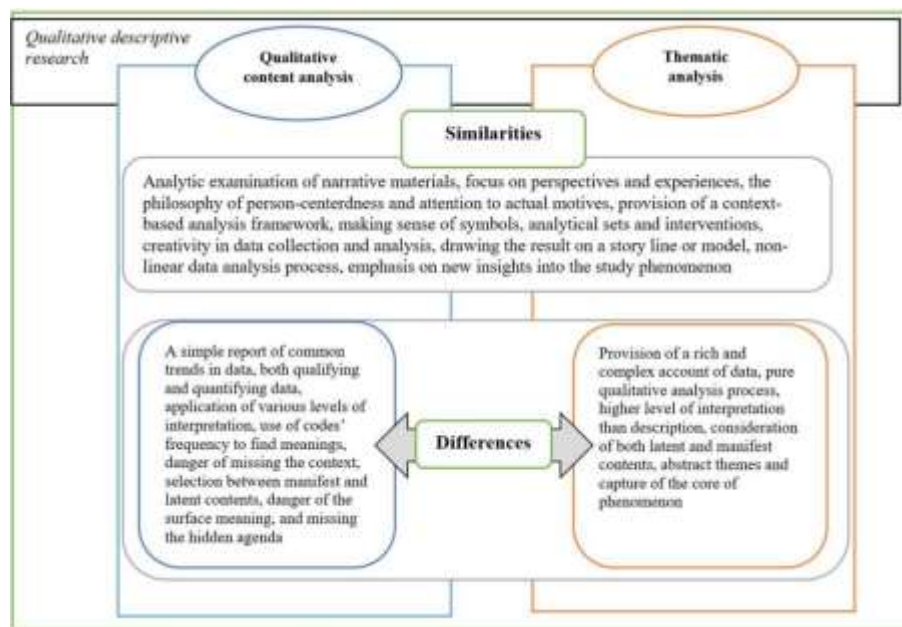
1. In what ways do people with spinal injuries experience daily life in the OECS?
2. What are the most commonly mentioned barriers to inclusion experienced by people with spinal injuries since their injuries?
3. How are the experiences of newly disabled people with spinal injuries affected by membership of different social backgrounds?
 - a) How is this affected by overall care, cost, gender, and sexual orientation?

The chapter further explains how the research participants expressed their experience while living with a spine injury. The research questions above, alongside the literature review, revealed the difficulties that people with disabilities face, either being born with or having suffered an injury that caused them to be disabled. The research questions assisted me in shaping the interview questions see Appendix C. Based on Vaismoradi et al. (2016), work was used to help shape the analysis for this study. The analysis process suggested by (Vaismoradi et al) uses thematic analysis, which produces rich data and employs pure analysed data as opposed to qualitative content analysis (QUA).

Thematic analysis used in my qualitative study captures the core of the phenomenon under investigation, see Figure 13. Further, the guidance by Vaismoradi et al. (2016) assisted in formulating the coding and emerging themes. When these themes were developed, a careful examination of the interview scripts (Vaismoradi & Snelgrove. 2019) was done by breaking down each script into manageable pieces to grasp a more meaningful understanding of the phenomenon under investigation. The process of breaking down the individual scripts into pieces assisted me in exploring the true meaning of the study while making a linkage to the research questions.

Figure 15

Comparative diagram between Qualitative Analysis and Thematic Analysis



Notes. Comparative diagram between QA and TA. From *Theme in qualitative content analysis and thematic analysis*. (Vaismoradi & Snelgrove 2019, p 4).

The literature review outlined the many difficulties that people with spinal injuries undergo. As the chosen research methodology, Phenomenology works perfectly with Thematic analysis as it ensures a more reliable and rigorous line of reasoning explains (Vaismoradi & Snelgrove, 2019) aligns with collecting rich, meaningful data. Thematic analysis was used to analyse the data, which led to identifying themes related to the lived experience of a person with a spine injury (Braun and Clarke, 2006). The themes generated from the interviews do not generalise; instead, they come together from a bigger picture of the phenomenon under investigation.

Trustworthiness, auditability, credibility, and transferability were explored and will be further examined in this chapter to form the basis of the appropriateness and validity of the research (Daniel, 2019, para. 5). It also gives an overarching picture of the process undertaken to analyse the research data. Specifically, chapter 4 is divided into five sections, closely looking at each research question, the themes coming out of those questions and how these themes relate specifically to the lived experience of the study participants. Section One is an investigation into the trustworthiness of the research process and how this was achieved. Section two is an outline of how the reliability and validity of the study were conducted. Section three is a discussion of comprehensive research and details the participants' demographics involved in the study. This section is a presentation of the essential themes that came out of the research study. The findings coming out of this phenomenological study are examined in Section Four.

Trustworthiness of Data

When conducting phenomenological research, its focus is on the reliability and validity of the data collected. Further, for a study to be considered rigorous; triangulation, transferability, dependability, and confirmability are vital (Pierce, 2008). For this Qualitative research, I

employed the model Lincoln & Guba (1985) used, who identified triangulation, transferability, dependability, and confirmability as the pillar of trustworthiness in sound qualitative research.

In qualitative research, transferability refers to how the result of a qualitative study is transferable to other contexts with other respondents (Lincoln & Guba 1985). Establishing transferability aims to describe the participant's behaviours and experiences completely. However, to an outsider, reading the study, this context ties back to their behaviour and knowledge to become meaningful (Korstjens & Moser, 2018). Additionally, transferability aims to reach a somewhat universal structure of the phenomenon under investigation. It is expected that the findings of this study will be transferable in other situations. Transferability in quantitative research is usually compared to reliability in more qualitative research (Lincoln & Guba 1985). Transferability in qualitative research does not confirm generalisation as in quantitative analysis (Smith & McGannon, 2017). However, transferability points out that the research finding in the framework offers in-depth insight into other settings that may be similar.

When establishing transferability, it is not the researcher's duty to prove that the research findings will apply to others. The interpretive nature of qualitative research does not allow a researcher to replicate the researcher's findings (Tong & Dew, 2016). The dependability process includes various aspects of the study under investigation, including the research findings, methods, methodology, data collection, and auditability. During the research process, I ensured that an audit trail was in place from selecting participants, preparing the research tool, data collection, data analysis, and interpretation (Guba, 1985). The participants were carefully selected, ensuring they met the research criteria. I confirmed that consistency was maintained throughout the interview process.

However, because semi-structured questions were used, several interview questions may vary depending on the flow and direction of the interview.

Confirmability in phenomenological research concerns the findings of a researcher's study that could be confirmed or corroborated by other researchers (Anney, 2014). Further, confirmability is concerned with establishing that data and interpretations of the findings are not figments of the researcher's imagination (Tobin & Begley, 2004) but from the data collected from the participant's involvement in the study. Audit trails and reflexive journals were kept for confirmability (Guba, 1985).

As for the study, bias and assumptions would always have a way of creeping into the study. I was transparent with that. I could identify myself with the participant's position of having a spine injury and going through surgery and rehabilitation, leading to research bias (Hammarberg et al., 2016). It will always be challenging to eliminate research bias in qualitative research. However, it can be assured that all the participant's data and experiences were accurately represented and documented. Having the participants express themselves openly using semi-structured questions was one sure way to introduce confirmability.

Reliability and validity of data

Evaluating a good research paper depends on its validity and reliability, primarily if used in practice and comparative study. Though validity and reliability are generally associated with quantitative research, this section hopes to align both measurements with qualitative. research specifically to phenomenological methodology (Noble & Smith, 2015). Reliability and validity are research concepts used primarily in quantitative analysis based on a positivist epistemology (Winter, 2000). However, I aim to highlight the naturalistic approach to reliability and validity.

A research study is considered reliable if the results are accurate over time. A good representation of the total population is studied (Noble & Smith, 2015). The study can be reliable if the results can be reproduced under similar conditions. In my research study, the participants' responses to some test items were identical, given that the circumstance and environments were almost identical. The instrument's characteristic is stability (Bashir et al., 2008). Bashir et al. indicated that the quality of the study itself is the necessary quality test in qualitative research. By using well-structured semi-structured questions, each participant was given sufficient time to interact with me as the researcher to improve the quality of the research findings (Noble & Smith). However, it must be stated that the concept of reliability in the qualitative research paradigm is not usually a criterion used to measure reliability.

On the other hand, Lincoln and Guba (1985) relate reliability in quantitative research to dependability. Dependability in qualitative research is how organised and rigorous on research piece is. Each stage of the research process was clearly defined and outlined. Additionally, a review was conducted independently of the research process of the research methods and instruments used.

Data validity comes from two schools of thought in qualitative research, but most importantly, when dealing with phenomenological study. The first school of thought is from the school of Smith et al. (2004), who primarily think that good qualitative research is hinged on the methodology used. While on the other hand, (Lincoln et al. (2011) emphasise that rigour of interpretation of results gives the best possible result of research validity. Leung (2015) suggests that validity in quantitative research refers to the appropriateness of the research tools used to inform the study and the quality of data collected. In this study, semi-structured

interview questions were used as a research tool. The participant identification and selection process included the snowball method, while data collection was done using both face-to-face and virtual interviews. These interviews were recorded. The validity of the research questions was formulated to get the desired outcome of the research (Leung).

Phenomenology was the chosen methodology, as the research aimed to capture the experience of people living with an impairment caused by a disability. A well-documented audit trail (Leung 2015; Tenny et al. 2017) was done in addition to the participant's verification of the analysis of the findings (Leung, 2015) to increase the study's validity.

Results

Participants Details

Sixteen (16) participants from their OECS territories enrolled in the study. Approval was received from each participant using the approved University of UNICAF's ethical consent form, see Appendix D. Participants were informed that their participation was entirely voluntary. They had the choice to opt out of the study at any point that they wished to do so. For this study, participants were assigned pseudonyms to help in ensuring anonymity. The table below represents the participants and their details.

Table 4

Participant's demographics

Participant Pseudonyms	Gender	Age	Country	Cause of Spine Injury	Present situation
Shawn	Male	43	Antigua	Fall from a roof	Bed Ridden
O'Neil	Male	26	Antigua	Car Accident	Working
Franklyn	Male	31	Antigua	Motorcycle accident	Wheelchair & Unemployed
Jeffery	Male	29	Antigua	Car Accident	Wheelchair & Self employed
Antoine	Male	34	Antigua	Car Accident	Wheelchair & employed
Leroy	Male	56	Antigua	Car Accident	Bedridden
Katty	Female	40	St. Lucia	Hit by Motorcycle	Wheelchair & employed
Jessica	Female	41	St. Lucia	Gunshot	Wheelchair & employed
Natalie	Female	44	St. Lucia	Fall from loft	Wheelchair & employed
John	Male	55	Antigua	Motorcycle accident	Wheelchair & Welder
Amington	Male	48	St. Kitts	Gunshot	Wheelchair & employed

Rudith	Female	69	Antigua	Gunshot	Bedridden
Shorne	Male	28	Antigua	Gunshot	Wheelchair and Welder
Ambrose	Male	49	Antigua	Gunshot	Wheelchair & football coach
Keroy	Male	33	Antigua	Developmental spinal injury	Wheelchair & unemployed
Travlynn	Female	35	St. Kitts	Car Accident	Wheelchair secretary

It was essential to highlight a more detailed demographic representation of all the participants in a tabulated format to understand their lives better; Figure 14 shows a breakdown. A piece of essential information from the figure below is the high number of participants who have experienced discrimination. Further, all participants think that the government can do more to assist people with disabilities, from social assistance to improving the legislative agenda for people living with a disability in the OECS. Also of significance is the number of employed or self-employed participants. Their employment underpins their independence and self-sufficiency as a person living with a disability.

Figure 16

Detail representation of participant's lives.

Association to Participants	Shawn	O'neil	Franklyn	Jeffery	Antoine	Leroy	Katty	Jessica	Natalie	John	Amington	Rudith	Shorne	Ambrose	Kemoye	Travlynn
Discrimination		X	X	X		X	X	X	X	X	X		X	X	X	X
Assistance from government		X	X	X		X	X	X	X	X	X	X		X	X	X
assistance from association	X	X	X			X					X	X	X	X	X	X
Attended Rehab	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Had Surgery	X	X	X	X	X	X	X	X	X	X	X				X	X
Vehicular accident		X	X	X	X	X	X			X						X
Gun shot								X			X	X	X	X		
Fall	X								X							
Other															X	
walk assisted											X					
Wheelchair user		X	X	X	X		X	X	X	X			X	X		X
Bed ridden	X					X						X				
Employed		X			X		X	X	X		X				X	X
Self Employed			X	X						X			X			
Unemployed	X					X						X		X		
Things the govt can do more	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Is aware of the CRPD					X	X			X							
Is aware of Govt legislations		X	X		X	X	X	X	X	X	X			X	X	X

Note. Represents the themes that all participants interact with throughout their lives.

The general overview for research question one (1) is presented below.

This research question aimed to find out. In what ways do people with spinal injuries experience daily life while living in the OECS? Most participants described their daily lives as being challenging, difficult, depressing, and at times discriminatory at first, especially after the injury/accident. However, as the interview progressed, I noticed that some described their daily lives as accepting, routine, and in some instances, optimistic. In contrast, others maintained a somewhat negative tone throughout the interview and used words such as difficult, unacceptable, and disrespecting to describe their experiences while living with a spinal cord injury.

It is essential to thoroughly analyse any phenomenon to select a standardised IPA group (Larkin et al., 2019). In this phenomenological study, the perspective of all sixteen (16) participants was established, considering the specific criteria met to participate in this study. The study had limitations; however, it did not limit the full participation of the participants. The

participants had comparable responses to the research question as their impairments were very similar and from similar circumstances and backgrounds.

The participants in this study have all expressed emotions of first gratitude to be alive, which forms part of the positive aspects of the study. However, the lived experiences are of some variety. These variations stem from the severity of the injury, first responders' care, hospital treatment, and how the surgical intervention was administered. A few participants said they received surgical intervention within days of their incident, while others took a few months. Finance seems to have played a part in introducing the soon surgical intervention. The most important aspect was the participant's aftercare or habitation. A few participants reported receiving excellent rehab services outside their home country. In contrast, the others who received rehabilitation in the country of the incident pointed out that their rehab services were minimal. One participant said, *the Service offered was very limited and routine, so I found it pointless after a while.*

For the participants who have closely bonded families, their lived experiences are somewhat different. Those who have a good family bond used words such as very supportive, loving, and incredible to describe the support they received from family members. However, some reported that the support they received from friends and family was lacking in many way, whereas some mentioned it was insufficient according to their needs. This lack of inadequacy and insufficiency added to other negative aspects of some participants' lived experiences, such as depression and loneliness. According to Tarvainen (2021), there is a direct correlation between loneliness and disability. It involves excluding an individual, which includes unwanted emotions and social isolation. According to some participants, this social isolation from friends and family is not wanted. The feeling of depression and loneliness often leads to a social disconnect.

What are the most commonly mentioned barriers to inclusion experienced by people with spinal injuries since their injuries?

For most participants, having an all-inclusive society will break down any existing barriers that may prevent them from operating or functioning to their maximum potential. Some participants expressed the disgust about society's level of visible ignorance towards a person with a disability. In the OECS, a person with a disability goes through social neglect. Their families may be ignorant of their loved one's condition, and society includes governmental organisations. Some participants believe that these government organisations have not implemented sufficient programs and social policies so they may live more inclusive lives and integrate themselves into society. Some participants expressed disappointment over the lack of basic infrastructure that adheres to the social model. These include essential ramps on public buildings, proper signage for parking, and even the availability of adequate public transportation for persons with disabilities to have access to. While others indicated that they have been some improvements over the years.

Understanding the participant's lived experience is determined by the environment where they live or spend most of their time. The value of the social model of disability, according to (Hope College, 2017), focuses on impairment, function limitation and disability itself. The experiences of most of the participants vary. Most participants expressed that their main issue surrounds two main aspects, (1) people in society and (2) the physical infrastructure of buildings and sidewalks being inaccessible. Some participants expressed their feelings of persistent marginalized because the government seem not taking the issue of Disability seriously. Finally, according to (Sudiatmaka et al., 2020), these general factors still affect people with disabilities,

such as weak social policies, cultural norms, and little to no law enforcement to protect people with disabilities.

How are the experiences of newly disabled people with spinal injuries affected by membership of different social backgrounds? How is this affected by overall care, cost and gender? The lived experience of newly disabled people with a spine injury in the OECS and its effect on membership of different social backgrounds can be complex. Each participant's experiences with individuals of diverse backgrounds vary very much. However, some common themes include rejection, lack of support, disrespect, and acceptance. Some participants came up with other themes, such as empowerment or the lack thereof. Those who encounter empowerment have strong family or friendship support. Some participants indicated that they sometimes feel awkward while going out in public for the first time. This awkwardness stemmed from the unknown, not knowing how societies would see them. This feeling brought about the feeling of wanting to be alone. However, a few participants identified that they mixed well with people of their age group who were mainly from the same village or area.

A few participants were from well-off backgrounds, so dedicated care and after-injury care were something other participants could only dream of. One participant had constant care from the moment he was released from the hospital after surgery up to the time of this study. That spanned six years of rehabilitation surgery, while other participants had only one year or two of government-sponsored therapy. The cost of care can be prohibitive. In the early stages of one participant's injury, he struggled to have the basic needs as only his sister, who had to quit her job, could assist in his daily care. Few participants were lucky to have gainful employment, so the pressure of dependence was less. Out of the 16 participants, five were females, and all were working except for one gunshot victim. The females showed a very high motivated spirit,

possibly because of the high prevalence of Christianity, their faith providing some level of hope and comfort.

The injuries of the male participants in the study varied; therefore, some were able to work in established businesses and organisations. Others used their skills before the injury to continue providing for themselves. Although many factors may be explored concerning the experience of people with disabilities caused by a spine injury, some participants indicated that it affected their families in many ways. Some participants expressed hurt from their partners, leaving them shortly after their injury. According to Smith et al. (2016), the cost of caring for someone with a spine injury can be very prohibitive. This cost ranges from personal caregivers to rehabilitation, medications, equipment, and services.

Although all participants went through varied experiences, some common positive themes emerged from the study. Themes such as *close relationship* expressed some participants' familiarity with their caregivers (usually a family member) or friends who stuck with them throughout their experience. Another theme coming out from some participants was *life-changing*. Some participants expressed having to undergo drastic adjustments in their lives. These adjustments typically come with consequences, so much so that one participant had to adjust to doing most things for himself, even while living in a household with family members. In addition, the mental grief of losing his other half and not seeing his son as much as he wants adds to his loneliness. His experience is essential as it highlights the loss that people living with a spine injury can go through and the emotional anguish associated with living with a spine injury.

The experience of people with a spine injury in the Organisation of Eastern Caribbean States is primarily about what can be learned about those experiences, highlighting everyone's

perspectives. By understanding everyone's experience, a more profound and precise picture is had to society can be more sensitive and understand people with disabilities. Most importantly, it highlights how the Caribbean culture views people with spine injuries. Finally, their experiences further bring to light the need for legislative change to existing laws governing the social aspect of a person with a disability. All the study participants also highlighted the need for a more socially inclusive society.

Analysing Themes

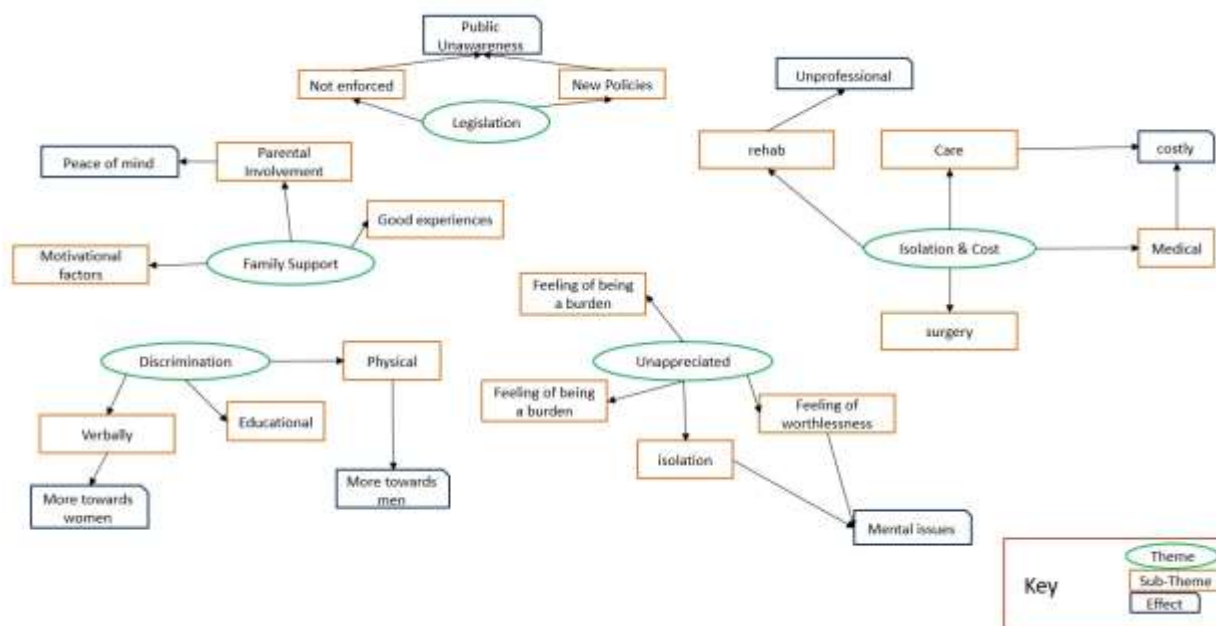
The analysis was done by identifying themes from single transcripts and then further comparing these themes across different ones. Table 4 displays the three-level of coding employed, and the emerging themes created in a sample transcript. The figures and tables below display each research questions and their emerging themes with quotations from different participants as they came out of the study. The relevant discussion expresses the issues that came out of interactions with each participant. In addition to the major themes, there were some subthemes that also emerged which created a deeper dive into the understanding of the participant's findings.

Research Question 1

The diagram below illustrates the emerging theses coming out of research question one. The oval shaped green objects denoted the main emerging themes coming out of research question one.

Figure 17

Themes and sub-themes emerging from research question one (1)



The interaction between myself and the participants saw me using semi-structured interviews: The first research question explored, *in what ways do people with spinal injuries experience daily life in the OECS?* A series of semi-structured questions examined this question see Figure 17 and Appendix A, highlighting several salient themes that highlighted their lived experiences living in the OECS. Themes such as family support, isolation, resilience, taking control of difficult situations, discrimination, accessibility, and reality are a few that dominated the transcripts. There were also some sub-themes which were aligned to the major themes. Sub-themes such as: costly, mental issues, peace of mind, unprofessional service in the regions rehabilitation centers, and public awareness were essential to the participants' experience.

There were notably different themes from various participants, mainly because they had different experiences with their spine injuries. With each participant having a different experience, we will examine the themes that came into focus and highlight their experiences.

Family Support

After one participant's car accident, his outlook on life changed. As he reflected on his lived experiences, he indicated that his family has always been good to him, reflecting his close-knit relationship with his family. This good experience led to an overall good mental health and overall accepting his impairment. Further, he also added, he thinks that they are even more loving now after his injury. His support from his family has given him a positive outlook on life, pointing out that his family has always been there for him. A quotation of the participant's family experience is follows.

“Well, I think my family has changed well. To be honest. I think that they were way more loving. No. I think that we're ever more loving now. And my family has always been there for me. Wish me luck. I don't think I would be where I am today without the support of my family.”

Most participants pointed out that they are not sure where they would be today without their family support. This family support has been with him from the time of his injury to this day. He describes himself as being loved and luck to have them. O'Neil often spoke of an aunt who always assisted him in getting ready for work each morning. The theme of motivation emerged here, where he used his aunt's daily encouragements to motivate him attend work and have a pleasant outlook in life.

Natalie's Incident occurred in a family home with her uncle present. She indicated that her experience from the start has been pleasant. She explained that her family gave her the

encouragement to go forward. Natalie, throughout her experience, has always been a fighter. This experience and encouragement gave Natalie the drive to stay motivated, while after recovery, my family helped me, she indicated in finding employment and love. In all this, her father became very protective. Natalie believed that her relationship with her mother, father, and siblings made her experience more comfortable since her injury. She further indicated she found them more supportive and more understanding, which was the most crucial aspect of Natalie's overall experience.

Many participants indicated that their families mainly supported them through their experiences. One participant from one of the other islands said that she believed she got closer to the family, and it is thought that the Injury made the relationship with her mother much better. She also describes her family's relationship as Encouragement to push forward, very supportive and protected by her family. This encouragement has been a big part of her professional growth. Most of the other participants described their experiences as being very similar.

The Past

A few participants described their past as regretful and for others they described it as depressing. One participant described his past as having regrets this regret was based on his inability to have children due to his injuries. As part of the data-gathering process, photo-elicitation was used. Most participants recounted that looking back on their photos caused them some level of depression, while others used them as motivation to continue living. The past has caused some participants to describe their experience as, having to move past it, even though it is tough to move past.

Independence

Most participants described independence, though few were bedridden and had limited independence. Some participants describe their autonomy as having the ability to do morning chores for themselves, giving them the independence to make sure physical decisions. I transfer from bed to the wheelchair unassisted was one level of independence explained one participant. Though there was no complete physical independence in all instances, most participants described their independence as still having some level of dependency. A few participants described their independence as an accomplishment. The few who described themselves as accomplished can do many things unassisted; in their view, they had come a long way from where they were when they had to seek assistance from others. The ability to make their own choices was another way independence was articulated by a few participants. One participant explained that her choice to take the bus in the mornings to work was a decision she made because he wanted to do things on her own.

Most participants accept that they will need assistance to complete some tasks. However, few participants describe their independence as little to none, with one participant being dependent on help to get things done due to the severity of his injury. Today, I see myself as confident, beautiful, and hardworking. I see myself as an intelligent young woman who can do anything and make my own decisions, is one way one participant describes her feeling of independence.

Unappreciated

The main reason participants expressed their nonappreciation is related to several factors. In one participant's experience, she described her experience as nonappreciation and felt

abandoned by friends and family on return to St. Lucia because the thinking was that I was a burden.

The subtheme of burden emerged several times throughout the study, which made it important enough to highlight. She further said that the relationship between her and her dad was not always good. This may be seen as some level of isolation *which was one emerging subtheme* by either family members or friends. She, however, mentioned that he provided transportation to and from her workplace. One participant described her therapy session as always depressing. She explained she stopped going to therapy because the therapist would just leave her there and say, and leave arbitrary instructions unattended.

Several participants expressed feelings of worthlessness. This emerging theme was important as it highlighted the importance of the previously described theme of family support. One participant stated he was so affected by the feeling that he had to seek permission to see his son more as a means of comfort for him.

How I am seen

The public's perception of the participants was essential as it formed how they viewed themselves as having a disability caused by a spine injury. Those participants who can go out in public expressed varied views on how they are seen. A few participants described their experience as a feeling abandonment when they are out in public. One participant shared an experience of being stalked and robbed in his community one evening, although he was well known. He described the feeling as being low and disappointing. There was also the occasional expression from the public that they should even stay home. One participant described society's view as being stereotypical, explaining that they see the participants as the problem. Other participants expressed the feeling of feeling less than a human being when out in public.

Participants' views of their experiences are multi-dimensional. I coach a youth football team from my wheelchair said one participant. The participants further expressed that he has lost some meaningful friendships since the accident. This loss has caused him to conclude that he is seen differently because of his spine injury. One participant views himself as a good father despite his physical condition. One participant believes that disabled people do not need a person's pity; we need people's respect, he expressed. This participant indicated, that he felt comfortable around non-disabled people in the same light.

There were varied views of how different participants felt about themselves, thus shaping self-perception. One participant said, that at first, when he got his injury, he was very uncomfortable going out, and when he did, people will just stare at him. When the participant started working at an international bank, she said, People would also look at her when she started to work. It took some time for the uncomfortable feeling to fade, she said. Respondents believe that the following statement reflects the mindset of people in the society: "I guess it is too much trouble to deal with the disabled," which in turn fuels their feelings of neglect. However, one participant expressed that her family and friends sees her as a non-disabled person, and they do not see her as a disabled person. She said, she was treated like an ordinary child, and her siblings treated her like an ordinary child, which in turn improved her level of independence. Though her injury was sustained from age five, she explained she got the normal treatment that everybody person got.

Legislation

An essential aspect of the social model of disability and the lived experiences described by the participants of this study is legislative change, the improvement of existing ones, and the enforcement of all disability laws. Inaccessible summarizes the social interactions of most

participants. One participant described his social experiences as the disgusts of inaccessibility of certain buildings as they are not wheelchair accessible. There are not enough emphasis been placed on making the public building accessible for people with disability he explained. He further express that he is not aware of any government policies, which might be a lack of public education and advocacy. He speaks about protecting the rights of people with disabilities. When asked if the government and society are doing enough for people with disabilities, he replied, no! He indicated that he gets government get support at times, and do not think they consider people with a wheelchair when constructing buildings. His wishes for legislation to include building codes that will consider access for wheelchair users. That's how I feel, he further expressed. He explained that he feels like all of the new buildings that they build should be mandatory that they are wheelchair accessible and accessibility to all form of small transportation. The government needs to create more awareness to protect people with a disability and spine injuries from discrimination and public misunderstandings he expressed.

A few participants expressed the need for public awareness, an emerging subtheme which of the theme new policies. The need of new policies to protect and promote the disabled community, was important to many of the participants.

According to one participant, there are instances where the government never really took the law seriously. The subtheme of un-enforcement of legislation governing the right of persons with disabilities, was common. This lack of enforcement influences the disabled community which leaves the members at a disadvantage. A few participants think that there is not enough to assist them. One participant said, that the disability laws are to be ratified, but he doesn't know about the law as he never read it as it is too much to read. I need to make time to go through it he said. The government never really took the law seriously, and I know that I can use the law as a

weapon. The government needs to create more awareness he further explained. Overall, the participants thought that much more can be done to educate, enforce and implement new policies that will socially improve the lives of persons with disabilities.

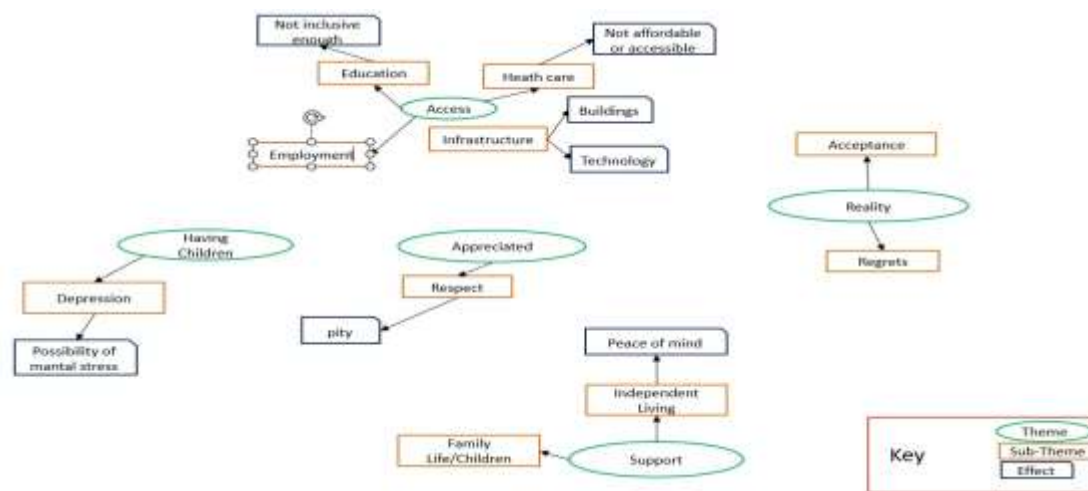
Research Question 2

The second research question explored, *what are the most commonly mentioned barriers to inclusion experienced by people with spinal injuries since their injury?*

Like question one, semi-structured questions were used in discussion with the participants. See Figure 18 and Appendix C, which revealed several salient themes highlighting the participant's new barriers to inclusion in the social model of disability and their understanding of it. Themes such as appreciation, respect, value, employment, accessibility, support, and love and reality, are a few that dominated the transcripts. Several themes emerged from the participant's responses, mainly because they had different lived experiences. With each participant having different experiences, I examined the themes that came into focus during the study.

Figure 18

Themes and sub-themes emerging from research question two (2)



Appreciation

While gathering information, the theme of appreciation emerged several times from a few participants. Having gone through their experiences, some participants described their appreciation as having the chance to be out with their friends. A few participants find comfort in their friends, families, and other people who are also disabled from a spine injury. One participant described this as going out a lot with the other girls who are also living with a spine injury. This appreciation helps form long-lasting and closer relationships among friends and family. One participant shares that he bonds with a family member when his aunt comes for two hours to assist him on weekdays to prepare for work. The disability association helps when they can, explained one participant. However, a few participants described their appreciation in a different form. “I could no longer do things to help them and lost most of my friends who could not deal with someone in a wheelchair, and I understand” said one participant.

The sentiments of appreciation resonated throughout the participant's experience. Though it was not a popular theme, it was important enough to be highlighted. Additionally, although it was not out rightly expressed, it created a sense of being alive even though they faced many barriers in their experiences.

Respect

Most participants described their new experience as being treated with both respect and disrespect, explained one participant, despite the fact that wheelchair use is a very common occurrence. Some members of the public are very respectful. "If you come to work and the door is closed, and you need to come in, someone will open the door for you" said one female participant. In living these new experiences, most participants indicated that they had been treated more as disabled than non-disabled individuals. The same participant explained that she has never been discriminated at work. However, some participants insisted that disabled people do not need pity, it is respect that they need.

This general theme of pity can be married to respect. Most participants described their new experience as disrespected by individuals who have no idea of, is not educated about people with disability. Due to this behaviour, people with disability have to demand to be seen, heard, and respected as human beings. This feeling of being, adds to the comfort that people with disability feel when they socialise within their communities. A few participants described their experiences as not feeling recognised or valued in the community they live in. Some articulate this feeling for these participants as community support.

Employment/Work

The social model of disability suggests that individuals are disabled by the barriers they face and not specifically by their impairment. If these barriers are removed, people with a

disability, especially the most critical people with a spine injury, can live a more independent and inclusive life. The participants in the study who worked described their employment environment as a pleasant one. I love my work, and I hardly ever take breaks described one participant. Two participants worked in the same office coincidentally. Though they have different roles, one in a senior position and the other junior, they both were happy that they were employed to have that level of independence. A few participants described that their jobs has made them develop some level independence. Employment has somewhat been a motivating factor in the lived experience of these participants' lives.

My injury killed my dream for my dream employment expressed one participant. As described by one participant, this feeling of nothingness explains that the general sense of unemployment amongst people with disabilities has been depressing. This refers to one participant's dream of being a speech therapist. One participant explained she was happy to be working, so she is not dependent on others. Having a job that most participants spoke of can be coupled with independence. All the participants explained that they gained a sense of independence since working. One participant explained that he was unable to send daughter to college. He eventually got around to do some welding. He explained that he would have someone bring welding jobs for him to work on. He expressed his love for welding, this participants' drive and love for his work keeps him going. He would spend most of his time on the road now, and is working with contractors building a house. He is very skilled in metal building rails, and gates.

One other participant also worked in welding at the oil refinery before his present job in maintenance. "Actually, I am a mechanic, and still do a little mechanic, as we speak" explained another participant. He explained that his love for cars sparked his interest in mechanical work.

The determination in this participant shows the independent nature of people living with a spine injury to as much as possible decrease the dependency on others for both financial and general help.

One participant described her work experience.

“OK, I am a local supplier with Massey stores and Lucia. I deal with all our local manufacturers and local distributors. I'm here on the island before they get onto the shelf. Before getting onto the Massey shelves, I must get the product to do quality control. And everything else, like pricing everything else before it gets onto the market. So, I do more clerical work, so I'm working from home due to COVID-19. They make I'm working from home. I've been home for, like, maybe nine months now.”

Her work experience demonstrates her employer's confidence in her despite her impairment.

Access

Several participants described accessibility as one of the most spoken-about barriers throughout the interview. A few participants described their experience at their workplace as very accommodating. One participant explained that certain arrangements were made for her in her work place. She said they erected a ramp in front of the building for her to get up into the office building. This accommodation from her workplace made her feel comfortable in addition, they also made provisions for her to access her electric wheelchair. Her experience at her workplace was pleasant, but she then described going out in public as having to access places that are not wheelchair friendly. She expressed she would love to see the introduction of legislations that mandates all public places has to be wheelchair friendly. This assertion suggests that she is not pleased with the state of the buildings in her country. Another participant

expressed the inaccessibility to certain buildings makes wheelchair use impossible. Access to most businesses and the public came up as a much-talked-about issue from the participants. One participant summed it up by saying, “Antigua is not wheelchair friendly” and further said he cannot get into the banks and most public buildings. He also expressed his disappointment when he cannot get out of his car without falling. There is an awareness amongst the participants that much work is still to be done to improve both the public and private buildings.

Though the theme of educational barriers was not featured a lot, it was necessary to note it as a sub theme as it brought out the importance of universal access to education. One participant suffered significantly in her early year because she was not able to access early childhood education because of the absence of wheelchair ramp at her primary school. The participant explained, her shock when she was told that there is no provision for disabled students at the school wanted to attend after her injury, which is a clear indication of education discrimination inclusive of physical barriers in society. Another subtheme that emerged under the main theme access, was that of access to proper health care and rehab services. A few participants explained their dissatisfaction with the rehabilitation services in their respective countries. One participant explained they were of the opinion that rehab technicians were disinteresting in having them at the centers. “They are never pleasant to me,” said another participant. This sort of behavior has caused some participants to stay away from therapy, which could cause further damage to their already fragile conditions.

Children

Having a child or wanting to have a child while living with an impairment such as a spinal injury can be a challenging and even nervous experience. In other instances, having a child before a spine injury can be a fulfilling experience. A few participants had children before

their spinal injury and one after her spinal injury. They blamed my husband, she said. They here means the society who blamed the husband for having a romantic relationship with this participant. The same participant explained that her lover was accused of injustice because she got pregnant. This reaction was in line with society's views and treatment of a person with an impairment caused by a spine injury.

The participant described that her lover was verbally abused and bashed because they said he didn't have to get her pregnant. In an uninformed society, people with an impairment caused by a spine injury are often looked upon differently, especially if they are usually not public. This participants has always wanted a child, and she finally got one. She explained that she was so afraid because the doctor said that there was a fifty-fifty chance is either she or the child could die. In her first trimester, she was in constant tears because she did not know what would happen. Throughout this new experience, she often asked, what would happen to her baby. She explained, she did not know what would happen.

A few participants described their new experience as a disabled person as difficult. One participant described his experience as having two children, one girl and one boy and the difficulty he would face not being a father to them as he would like to. The other participant explained that he has an excellent relationship with his wife and daughter and also having a good relationship with his only child. He described her education as affected as he could not afford to send her to college because of the accident. A few participants had injuries when their children were young. I have a son and a daughter, "My son is 19, and my daughter will be 12 on November 1", he explained. He further explained how having a new child as a disabled individual changed his life.

One participant explained that when he got injured, his son was about three years old, and shared a lot of Father-Son moments during his formative years. He further explained when he got injured, he was sure things changed, because he could not have been the father he wanted to be. He explained he got married in 2008 and had a perfect lasting relationship for about ten years with his family. He further explained that he got married sometime after his injury, then his daughter was born. The relationship with his children was not as he hoped. Sometime after his family fell apart and he eventually got divorced.

The first participant I interviewed had a different view of children and their perceptions. He suffered a traumatic spine injury. As such, he described his situation as impossible to have children. He explained that he tries not to think of those kinds of things as they can make him depressed. The subtheme of depression emerged when some participants spoke of the general theme children. The onset of depression can cause individuals who are in these vulnerable groups, to develop some form of mental stress which may affect their overall health. Some participants had children before their injury and became depressed at times because of the thought of not being able to either provide for or be that able-bodied parent they could have been. One participant also considered not being able to have children a barrier, then indicated that he understands that he will never have a family, which was a big part of his dream growing up. Something that he accepted over time.

Support

Living with a spine injury in the OECS can be a debilitating experience without friends, family, and governmental organisations (for individuals are less able to have that family support). Caribbean governments are often cash-strapped to fund disability originations and social programs fully. Therefore, people suffering from an impairment caused by a spine injury

are usually left up to the support of loved ones. Most participants described their experience as loving. May family has always been there for me, explained one participant who, throughout the interview, constantly made mentioned the overwhelming support from his family, especially his mother from his workplace. The support he received from his co-workers, he describes as a lovely work experience. He further describes the support from his job as a supportive work environment.

Support for people with a spine injury goes a long way in improving their mental state. Most participants said they did not know where they would be without the support of their families. One participant described his situation as society having no idea of what is going on in the world of disability *they* refer to the society in which they live, and without the support from friends and family, he would not know how he would have made it this far. The support of one participant's family brought her closer to her mother. That support caused her to feel loved and accepted. The support that most participants spoke of has somewhat improved their independence which contributes to some level of peace of mind. Most participants expressed their love and gratitude for the support they received.

For a few participants, the support from civic organisations and the government was very much welcomed but, in a few instances, was not forthcoming. One participant welcomed the disability assistance offered by the government. In this instance, the support from the government was more financial. He would normally receive \$150 every month to purchase food. This assistance came from the government's social transformation program. One participant revealed that government assistance is \$500.00 a month through social security and the PDV Cab, a utility program in Antigua and Barbuda that offers relief to senior citizens and person

with disabilities on their utility bills. One participant said in Saint Lucia, the Government has not assisted her with anything.

Reality

The new experiences of an individual with an impairment caused by a spine injury created a new reality. Most participants described this new reality as something to live with. One participant expressed his experience as having regrets and having to live a new life now. This new life concerns this participant's inability to have children. I will not be able to have children he told me. I try not to think of those kinds of things as they can make me depressed, he confessed. His reality was even more profound when he expressed he have regrets about not being able to walk. Still, I can't dwell on those things he expressed. He had to move past those thoughts, even though it is tough to move past them the participant said.

A few participants describe their new life as accepting. This theme of acceptance emerged from a few participants' responses on reality. Some participants accepted their present reality as a disabled person, more so with their new reality and living with what cannot be changed. Some expressed dismay at misunderstanding society's views of people with disabilities, specifically those with spine injuries. A few participants think that there is much more to be done regarding the comfort and experiences people living with spine injuries undergo daily. One participant insists, that people with spine injuries and other disabilities must demand to be seen, heard, and demanded to be quoted as a human being. She further expressed that things should not be done for the disabled because society feel sorry for them but should be done to recognise that they are also human beings. This expresses the vulnerability of the social model of disability for a person who is newly experiencing life with a spine injury.

The core reality for most participants is that if society does not fix itself and allow for inclusivity and promotes an environment where discrimination, unfairness, accessibility, and exclusion are tackled, there will always be inequality between them and society.

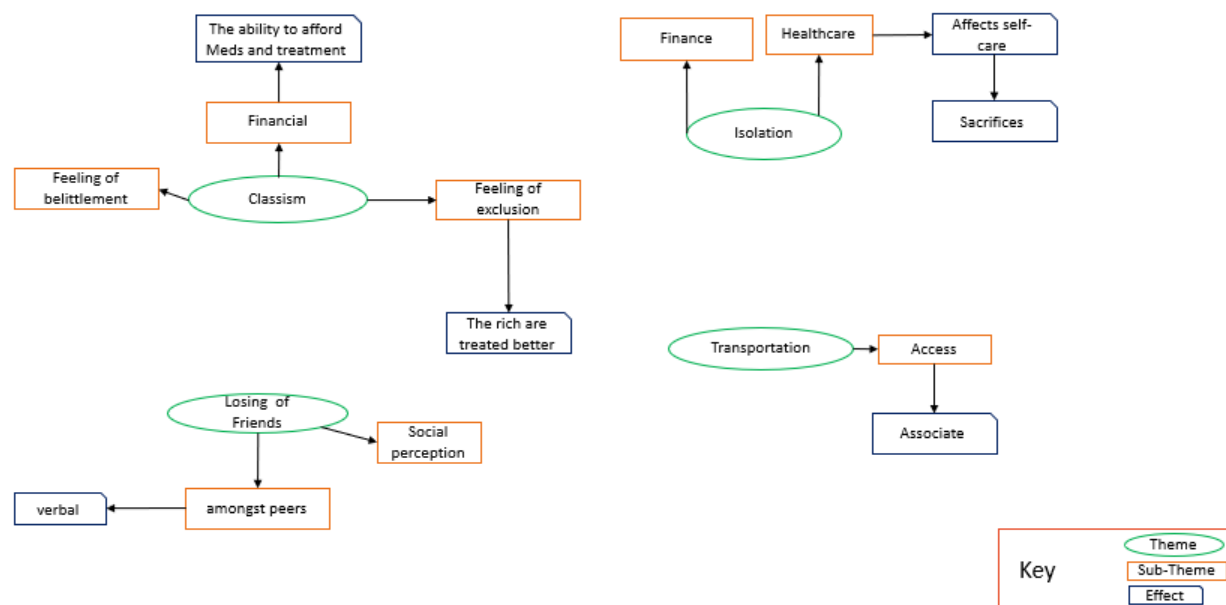
Research Question 3

Being a disabled individual can be a physically, mentally, and intellectually challenging experience, depending on the individual's type of impairment. There is even a more socially challenging experience that people living with a spine injury or other disabilities face, which is social class discrimination or classism. Siordia (2015) identifies that disability is related to social class.

The third research question explored, how valuable is the social model of disability for people with spinal injuries to understand their new experiences? This research question, like questions (1) and (2), used semi-structured questions to investigate the question. People suffering from an impairment caused by a spine injury stand to be influenced by and can contribute to the production and reproduction of social inequality. This social inequality can potentially affect the care and cost of people with disabilities depending on the gender of these individuals. Gender parity is one aspect that is also affected. See Figure 19 and Appendix C, which brought out several salient themes highlighting the most significant new barriers to inclusion experienced by people with spinal injuries since their injuries. Themes such as isolation, transportation, classism, loss of friends, accessibility, care and cost, and reality are a few that dominated the transcripts. The themes coming out of the responses from participants in the study as it pertains to question three will be examined further below.

Figure 19

Themes and sub-themes emerging from research question three (3)



Isolation

The isolation experienced by people with disabilities leaves individuals lonely, with very little social support and social isolation (Emerson, Fortune, Llewellyn & Stancliffe, 2021). A few participants described their experiences as being alone, a feeling expressed in the literature review on the topic of abandonment. Factors that affect isolation in people living with an impairment caused by a spine injury were highlighted by a few participants from lower social and financial backgrounds. One participant described his situation as having financial shortage. This financial shortage caused many issues for this participant as his sister was the only one caring for him, and she had to quit her job. Therefore, he savings started to dwindle. There were not many isolation issues concerning his social life. He said he have an excellent relationship with my sister. He said, looking at my old pictures, he felt joy and wish he can be there again.

His experience of isolation also affected his health, as he cannot get the medical supplies to assist him in his daily care mainly because of cost.

Another participant's circumstances and experiences are somewhat different. He revealed he do not look at his past photos. His experience of isolation is overshadowed by the kindness of his family. This new life he speaks of is possible because of his caring friends, supporting the relationship between the themes of support and isolation. Having consistent support limits the incidences of isolation of a person living with a spine injury. This participant's ability to work reduces his financial dependency, thus reducing the possibility of isolation.

One participant described his experience as losing some meaningful friendships since his accident. Isolation and loneliness creep in at times because this participant does not work, so financially, he struggles. He did several surgeries and spent months in hospital, and the accident had caused a discord between him and his child's mother. This discord affected his son's ability to see, and he lost a treasured part of his life. However, he described feeling lonely but expressed the support and love from his family.

A few participants characterised their social interactions by admitting, that they feel very comfortable around nondisabled persons. The incidences of isolation decrease significantly when there is interaction with persons with similar impairments in a support group. Due to his family's support, one participant suffered little to no incidence of isolation. He explained that he have not had many changes in his family life he further explained his family is still basically the same way and is still very supportive, especially his mom and dad. The incidences of isolation vary amongst people with spine injuries from different social backgrounds. Family and finance seem to be the most prevalent factor in reducing these incidences of isolation.

Loss of Friends

The emerging theme loss of friends emerged with a few participants expressing that they believe they lost friends because they were not able to fully function as they used to and could not provide for them. Some participants believed if they had been of a different class on the social ladder, they would have been able to provide for themselves more and would perhaps maintain the friends they had before their injuries.

Care and Cost

All participants indicated that they received rehabilitation services after their injuries. Whether short-lived or continuous, rehabilitation can be a costly undertaking. Some participants noted that rehabilitation was prohibitive, and it was challenging to sustain paying a daily fee for service.

He said the rehabilitation was costly. He further expressed his financial experience with the cost of surgeries. The cost of best surgery in Trinidad was prohibitive, so he opted for a more affordable one in Jamaica. His rehab experience was not what he hoped for. He explained the hospital had no space to accommodate me for rehabilitation, so he had to do it privately. He explained that the cost of rehabilitation is high. “Covid has caused me to stop going to rehab” he said, which affected the quality of his recovery. Not having sufficient resources for aftercare can force persons with a spine injury into depression, exacerbate the injury, and cause more harm to the individual. For these participants, their limitations were finances, and they could only afford the essential aftercare.

Some participants were socially and financially better off than others. For instance, one participant described her aftercare as caring. Before she worked, she mostly stayed home to recover. She expressed that the government has not assisted her in anyway. This lack of

assistance meant that the participant could, with the help of their family, do her surgery and pay for rehabilitation services.

Transportation

Transportation is a barrier sometimes when some participants want to go out. In most instances calling a taxi is a bit expensive most times. This puts an extra financial burden on people with spine injuries without adequate public transport. I stopped going to therapy because it was very depressing one participant said. She explained she stopped doing it because it wasn't helping her. Though the service was free at her country's hospital, it affected her negatively mentally rather than financially.

Emergency and Aftercare Rehabilitation

The unavailability of appropriate emergency and aftercare rehabilitation services within the OECS has a cost factor. Most of the participants travelled to other territories for emergency care surgery. One participant even travelled internationally. He travelled to Miami a few days after his incident via air ambulance to undergo surgery. Not all individuals are fortunate enough to afford international air travel for surgery. One participant explained that he had to travel to Trinidad to do surgery, which is a considerable cost for anyone without medical insurance, which was the case for most participants in this study. The participants were further forced to travel for rehabilitation services. The rehab centers here are not fully equipped, so one participant travelled to the United States at times for therapy sessions. He explained it was costly, \$200usd per session. This somewhat indicates the availability of sufficient funds for travel and aftercare. A luxury that most other participants cannot afford.

A few participants could not afford the surgery to help them at least live a life of some normalcy. Close family members carry the cost of care for some participants. One participant

said, that it is expensive to constantly buying pampers, medication, and catheters. A few participants said they did not get any help from the government. One participant used to go to therapy at a private centre, but he had to stop on the count that it was too expensive. One participant described his situation as lucky to have a good family. He had to revert to having a personal therapist for two years. Even when it is much more costly to attend the private session, he explains that the private therapy session is much better than the government offers. He, however, admitted that the ongoing cost of Rehabilitation, supplies and medication can be hard.

Classism

According to a United Nations (2003) report, people with disabilities are at a higher risk of developing conditions such as depression. This depression surfaces when individuals are at the lower of the economic scale. Some participants however, though they did not express or experience any form of negative classism, did however mention that it was evident amongst their disabled peers, that persons who were of a higher social class were more likely to receive better, social acceptance because of their financial status and perhaps family name. More so, it further offers them the chance of better chances of continued employment said one participant. One participant said he does not feel any sort of segregation when he is with other disabled individuals, however, you do not see disabled people from rich or well to do families, whenever they meet up he explained.

The theme of exclusion did not only come up when participants spoke about social barriers, but also as a feeling when asked about people of a higher social class. One participant suggested perhaps they do not want to mingle with them. The effect of this assumption could have increased negative feeling of exclusion.

Themes Identification with research questions

Evans & Lewis (2018) explain that themes aim to, as much as possible, to capture some form of data that is relatable to the research question that has a patterned meaning. Identifying themes that emerged across the dataset from participants' responses was essential. This is particularly important as these emerging themes are related to the research questions. (Table 4) captures a sample of the participants and the related themes and is also used to analyse the various themes across the associated participants and themes. These themes were identified as phrases and words appearing more than once across the transcripts (Evans & Lewis 2018). Therefore, in Table 4, each column represents a participant and the theme relating to the three research questions. In contrast, the row represents the association of the theme to the interview question. In order to exemplify the themes and to understand them more, Table 5 was created, Further, Figure 17 represents a thematic map that represents additional sub-themes coming out of the study. This has also been qualitatively discussed in further detail within the body of the results section.

Table 5

Comparison of Cross Themes of sample participants

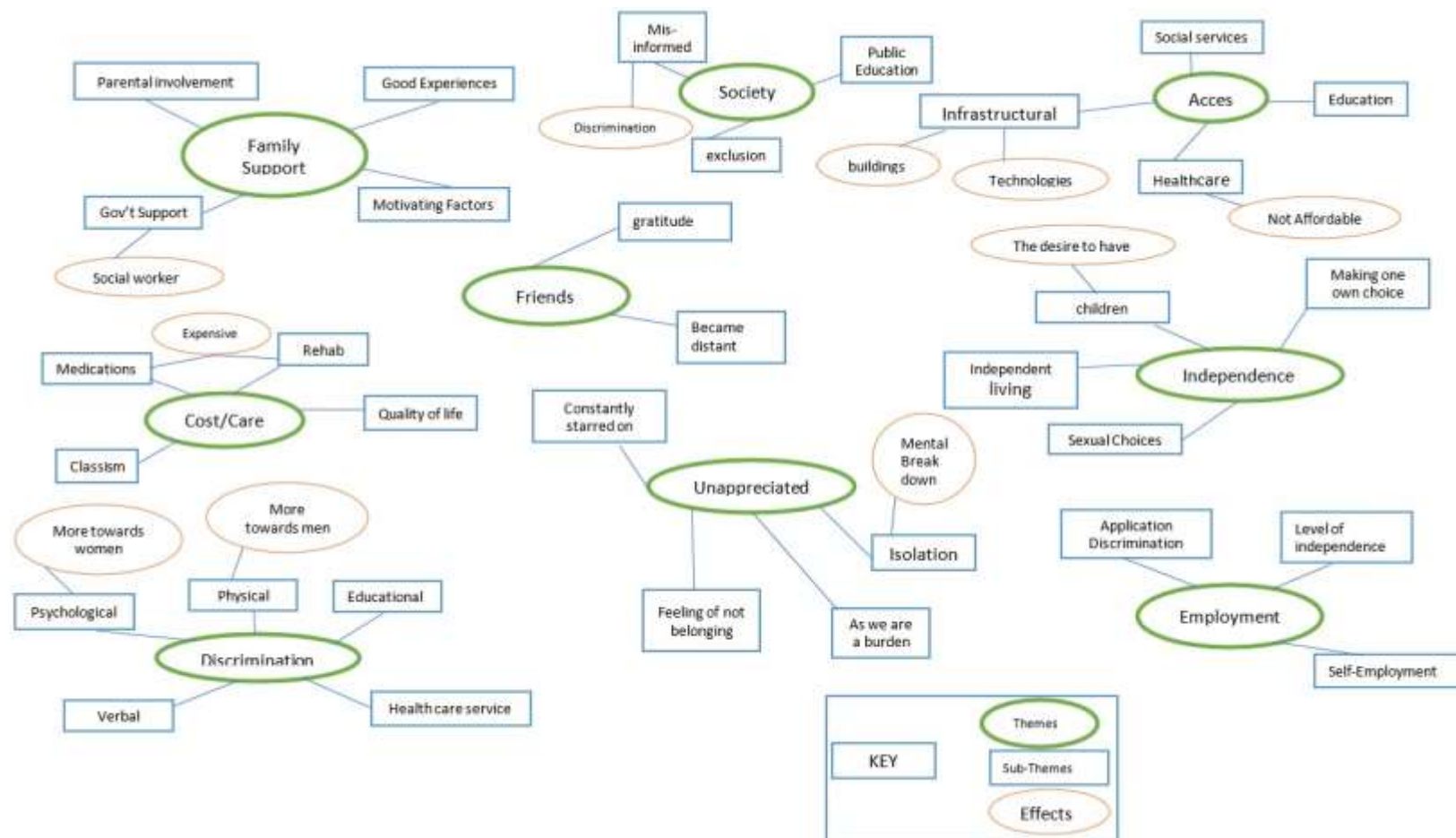
Interview Questions	Natalie	O'Neil	Jessica	Antoine	Trevlynn
Experience living with a spine injury	<p>Looked at as being different</p> <p>Difficult to adjust to life at first</p> <p>Found love and in a</p>	<p>Traumatised by accident.</p> <p>I love the feeling of independence</p> <p>Accepted that I will</p>	<p>Not feeling recognised and valued.</p> <p>Dependent on others for support</p>	<p>I did therapy every day</p> <p>My home was not accessible.</p> <p>I made independent choices.</p>	<p>Feeling dependent on people for basic needs</p> <p>Difficulty of independency</p> <p>Gotten closer to family</p>

	romantic relationship Needed to accept her Disability	never walk again. Bathroom at home not Disability friendly Affected social life	Job after made me independent. Brought on a state of depression and loneliness.	Felt vulnerable because of Covid, it caused me not to see my physio.	independence Society is not inclusive
How do they see themselves after the injury	Taken for granted Misunderstood Gratitude Valued [referring to friends and family]	Independent Acceptance of injury Regret [referring to him not being able to have children]	Very independent [though some dependency on mother] Acceptance of life for what it is Very thankful for life	Productive member of society government. He accepts his impairment and is happy to be alive.	Lucky Outgoing Thankful [referring to friends and family] I see myself as normal.
How did their family/close friends treat them after the injury	Encouragement to push forward Very supportive Protected by her family	Treated well by family Increase love and affect by the family since the injury	Has full support of mom Have very few friends Treated very well by work friends	was treated well by his family and friends His family members treated him well.	Got closer to family Injury made the relationship with mother better. Social activities with friends
Participants views on society	Should stay at home looks at her relationship in a negative way Stereotype [they see you as a problem]	Mixed perception Seen as less of a human being. Seen as dependent individuals	Church family more receptive to her as an individual [assisted her in building a ramp at home]	I want to be treated like a regular human instead of feeling sorry for. Disability issues are	They have always been watched when out. Uncomfortable Fair of the unknown

	they, means people she worked with	Should not be out	I believe people think we should stay at home. Discriminated against.	not taken seriously.	Stigma, Locked away and Unawareness
Important words coming out	Family Friends Policy Inclusion Not enough	Depression Children Accessibility Family Friends Disability	Independence Sadness Depression Family Government Access Discrimination	Friends Accessibilit y Family Barriers Therapy	Family/Friend s Discriminatio n Emotions Different Not Sufficient access

Figure 20

Thematic map showing themes and sub-them



Summary

This qualitative study relied on semi-structured interviews to capture rich, meaningful information from the participants. Further, qualitative research is considered ethical, the study of a phenomenon, especially when human beings are involved (Busetto et al., 2020). The aim was to present the findings on the experiences of people in the OECS living with a spine injury without misrepresenting them. Though the participants were similar in the type of injuries, their experiences living with a spine injury made them remarkably different. Some participants had the opportunity of private rehab services, while others had to rely on state-run rehabilitation services. Few participants had families before their incident, and two had families after it. The significance of the findings is their similarities in the results amongst all participants.

Recurring themes in the findings suggest a need to improve rehabilitation services and remove social barriers such as infrastructural barriers. Therefore, there are implications for practice for the findings mentioned above. Secondly, though not a popular theme expressed, a few participants reported discrimination as a negative experience. This has further implications for research as verbal discrimination turned into violence for one participant. The experience of all the participants living with a spine injury provided deep insights into the phenomenon and how people with spine injuries and other disabilities experience their lives living the OECS.

Evaluation of Findings

Purpose of the Study, Research Aims, and Objectives

As stated in the previous chapter, this qualitative phenomenological research aims to examine the daily lived experiences of people with an impairment caused by a spine injury and, at the same time, look at the legislative framework that governs disability in the OECS. This chapter explores the overarching importance of a person's experience living in the OECS with a spine injury.

The research questions listed below are a reminder that they are used to understanding the lived experience of people with spine injuries.

1. In what ways do people with spinal injuries experience daily life in the OECS?
2. What are the most commonly mentioned barriers to inclusion experienced by people with spinal injuries since their injuries?
3. How are the experiences of newly disabled people with spinal injuries affected by membership of different social backgrounds?
 - a) How is this affected by overall care, cost, gender analysis, and sexual orientation?

Research Question 1

The first research question asked participants to examine their daily experiences living with a spine injury in the OECS. They were then asked to consider the changes to their routine that have evolved since the injury. These changes were compiled and sorted according to themes. Seven major themes were identified from among the responses of the participants.

Family Support

One of the most prevalent themes emerging from this research question was family support. All participants described their experiences of support from their families as something that brought them closer together. One participant explained the overwhelming support in preparing her meals, bed, and many other daily chores that she is otherwise unable to carry out. Most participants explained that their mothers were close to them during their care up to the interviews. Only two participants mentioned their fathers as support figures during the interview sessions. Most participants underlined how vital family support is.

The study revealed that the most common theme for most participants was support. Over the past decades, there have been many changes and improvements in the care of people with disabilities (Carnemolla & Bridge, 2019). In one participant's case, individuals with spinal cord injuries have improved home care facilitated by family or a redesigned home donated by the government (Carnemolla & Bridge, p. 2). One example is assistive technology, where the participant uses voice-to-text technology to communicate on his laptop and uses Facebook to communicate. One other participant was gifted with a unique motorised wheelchair by the rotary club of his country. He was also privileged to have the ability to communicate online because he owned a laptop that had speech recognition. However, this improvement in care comes with an additional financial burden on the families caring for people living with a spine injury. Family support heavily depends on practical and emotional support for people with a spinal cord injury (Huang, 2021).

O'Neil and Natalie experienced very similar levels of high family support. Their support was a motivating factor and positively impacted their lives. Natalie said her mother always encourages her to have a positive outlook on life. O'Neil indicated that he noticed his family

members getting closer to him since his impairment. For example, he said his aunt would come each morning to get him ready and transport him to the office daily. All participants, except for Shawn (who lived with his sister), Leroy (who had a live-in carer), John (who lived with his wife) and Rudith (who depended on a government social service assistance program), had immediate family support where their mothers were the primary individuals involved in their care. Only Natalie mentioned her father, who offered transportation services early after her injury. All the participants indicated that their families often provided emotional and financial support throughout their incidents. Natalie's situation is unique as she is in a romantic relationship with her live-in partner, and had a child by caesarean section. The quality of family support for people living with a spine injury depends on the emotional and financial support they offer. The support has assisted many of the participants to overcome periods of depression, as expressed by two participants. One participant's narrative showed this financial superiority when he explained that his family could get him surgical intervention just 48 hours after his incident via a private air ambulance. This was not the same for the other participants.

A few participants indicated that members of their family and a few friends provided valuable support to them throughout their life since living with a spine injury. All participants except three lived with close family members, for instance, their mothers, aunts, or wives. The support from those participants who lived with immediate family members and in the cases where the family was large had substantially more support than those living with one or two members. This type of support was seen in the case of one participant who lived alone primarily and depended on government care workers for daily visits so that she may be fed and washed daily. Another participant who relied on his sister for care is not receiving as much financial and

family support as others. Many participants developed their injuries early, so their help was always from that household.

The past

A few participants compared their current situation to their lives before their impairment. These discussions were often related to dynamics and changes in emotions, love, and support. Though some participants indicated that they had lost support from friends sometime after their incident, the family support continued from the time of their injury, leading to them living somewhat comfortable life. Some participants said their families have stepped up financially to support them because they cannot work. Another way the support continued for one participant was the social support she got from her mother by taking her out to social and other sporting events. O'Neil explained that he found his greatest regret was that he did not have children before his injury. This is painful for him. However, he indicated that his present situation had given him a new meaning in life, and he appreciates that he is alive and plans to continue contributing to society in any way possible. O'Neil mentioned that he takes life more seriously now since his injury, and his work at his organisation takes top priority.

Independence

Independent living is an essential aspect of the lives of people with disabilities, as is their autonomy and freedom, and it is not always viewed as living alone. Furthermore, it should not be interpreted solely as an individual's ability to perform daily tasks independently but rather as the freedom of choice and control related to respect for one's dignity and individual atonement (Lawson & Waddington, 2018). Independence amongst people with an impairment who were aware of a social model and their right to autonomy helped them live better lives, have fuller freedom, and make independent decisions (Berghs et al., 2019).

The discussions found that participants faced several social barriers, inadequate medical support, and limited trained and qualified individuals in spine rehabilitation (Zahari et al., 2020). Most participants described their independence as an accomplishment. One participant explained that assistive technology aided her independence at work, while another had his entire home renovated to help him in his everyday living. However, the participants saw this independence accomplishment as their ability to make independent choices independently. Not all participants who were interviewed had that level of independence. A few participants are still bedridden, which minimises their ability to make political or economic decisions or participate in social events. However, as previously mentioned, one participant uses assistive technology to communicate on social media.

In O'Neil's case, his injury was due to a vehicular collision, and because of ongoing and continuous rehabilitation, he increased his mobility over the years. In the case of Curt, he was a victim of a shooting incident during which his spinal cord was damaged, and he, too, was able to have some form of mobility due to rehabilitation. Most participants have experienced similar experiences in some form of rehabilitation service. However, the data collected suggest that for a person with a spine injury to have consistent and meaningful repair, it takes substantial finance for the rehabilitation treatment. In addition to finance, the family's support for the individual suffering from impairment is another critical element. According to Kang et al. (2018), family support in the care of people with spine injuries helps decrease the incidences of depression, which is the most common psychological complication in SCI patients. Mackie et al. (2018) suggest that having good family support can improve the overall care of the spine patient.

Feeling unappreciated

This lack of appreciation for disabled people's needs often leads to low self-esteem and depression (Trani et al., 2020). One participant expressed the feeling of being a burden during the initial stages of her injury. She explained that the thought of being unable to work again and being dependent on others has always been on her mind. This feeling of being a burden to others affected relations between her family, more so her father. The participant's relationship with her father was strained. He had been her source of transportation (taxi) for many years. The participant said she did not live with her father, making it slightly more complex and inconvenient. The participant's description showed that she was forced to fight feelings of depression with the possibility of losing her future ambitions as a professional. There were not many instances of feeling unappreciated. However, one participant expressed that he had that feeling of nonappreciation from his immediate family members at one point in the early stages of his injuries. This feeling came from doing most of this for himself domestically at home.

Treating people with an impairment with respect can positively affect people living with an impairment (Abes & Wallace, 2018). The participants' descriptions indicated that they are generally treated as individuals who should not be in public view and are constantly being disrespected and belittled by non-disabled individuals because of their physical appearance and inability to function as they can. One example of such disrespect stems from the educational system refusing to provide accommodations for teaching, learning and access to one participant in her early years.

The social model of disability, when it was first identified as such, focuses on removing barriers to ensure equality and inclusivity and supports that society has the responsibility to people living with an impairment. This supports the literature in Chapter 2, which indicates that

the social approach to disability focuses on societal changes. The feeling of uneasiness in society was described by a few participants when they were out in public. Collectively, the participants expressed being labelled as not belonging or you're not able to do it and stereotyped in public. For example, one participant said, "I was constantly steered at in public and called names". The stereotype can significantly impact how people with an impairment view themselves, and a few participants expressed feelings of depression. According to Clément-Guillotin et al. (2018), people with disabilities were implicitly and overtly associated with reduced positivity and more kindness but lower competence than people without disabilities. Rohwerder (2018) explains that globally, stigma, prejudices and stereotypes are significant contributors to the discrimination and exclusion that people with impairments face. According to (Rohwerder, 2018), several factors may contribute to how a person with spine injuries is seen. One such factor is the misconception that people with spine injuries cannot contribute to society because of their physical condition. A lack of understanding and educational awareness about the causes of impairment and its effects are critical factors influencing experiences of stigma in people living with a spine injury. For instance, if there had been widespread public awareness and education, the pregnant participant and her partner would not have gone through that unpleasant experience of public ridicule.

Positive outcomes were also reported. Participants expressed some of their experiences as being integrated. As a football coach, Ambrose's integration came from his involvement with coaching a youth football team of young males in his village. He is seen as making a positive difference in society regardless of his impairment and uses his knowledge to help make a difference. Ambrose sees himself as a role model to the children he coaches. Rohwerder (2018) describes Ambrose's situation as one where one might experience less stigma. This is because of

active participation with the children in the community. Natalie is one participant who has the imposition of stigma.

Society's primary concerns revolved around the marriage of women with disabilities and their ability to conceive, give birth, and safely raise a child. Natalie's pregnancy was seen as abnormal in her society, and she described the constant verbal discrimination against her and her partner, blaming him for her pregnancy. This experience for Natalie debunks the ideology in society that people with physical disabilities, more so, with spine injuries are not able to raise a child while living with a spine injury. According to Devkota et al., 2019, society views a woman with an impairment such as a spine injury as having no control over her pregnancy, the childbirth and motherhood. This stigma limits women's rights with impairments to their sexual and reproductive rights Fawcett (2018). On the other hand, a male participant who got married and had a child did not describe any stereotype or discrimination toward him.

Legislation

The participants' responses to their lived experiences are mixed concerning their thoughts on existing legislation. The issue of legislation is a recurring theme in this study, and most participants said they think the present laws do not go far enough to protect people with disabilities. Moreover, few participants said they were unaware of legislation protecting people with disabilities. O'Neil explained that the inaccessibility of public buildings has made them increasingly difficult to access, making it almost impossible to conduct business. John explained that being a businessman, he cannot go into the city expecting it will be hassle-free to do the basics transactions that non-disabled individuals can do. Inaccessibility is a critical theme and most social models of disability are orientated toward developing new legislation to improve inclusion.

Legislation across the world dealing with people with disabilities has improved since the introduction of the United Nations CRPD. However, in the OECS there is still much to be done on legislation explicitly dealing with how buildings are currently constructed. Persona with disabilities are confronted with infrastructure, public buildings with no ramp access, commercial buildings with little to no or no ramp access and private dwellings (Jackson, 2018).

All participants expressed that their governments need to do more work in creating better cultural awareness and stronger laws protecting people with impairments. Jackson (2018) questions whether people with impairments significant difficulties have been exercising their rights within existing legislation because of the lack of finances to bring legal actions and enforce these laws or, in some instances, make stronger ones.

The matter of reasonable accommodation states the need for Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to people with impairments the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms (Beco, 2019). This section of the act speaks of an equal basis for all human rights and fundamental freedoms. However, participants have clearly expressed isolation and marginalisation experiences because their access rights are not enforced.

Research Question 2

This question asked participants to describe, what are the most significant new barriers to inclusion experienced by people with spinal injuries since their injuries? A few themes came out of the study relating to this research question: employment, respect, procreation, support and reality.

Access

The description of access relates to access to proper health care, education, and access to buildings (United Nations CRPD, 2007). Most participants mainly commented on access to proper infrastructure. One participant said it was difficult to do business in his country's capital as a wheelchair user, as access to buildings was inadequate or there was none.

Accessibility plays a vital role in the lives of people with physical or mental impairments (Gharebaghi 2019). Most participants saw access to proper infrastructure as a barrier to living a comfortable life. Most of the participants in this study expressed dissatisfaction with the physical accessibility measures that presently plague the three participating countries. Access was related to physical infrastructure, but participants mentioned that access to proper health care, mainly rehabilitation services, was inadequate and unaffordable. A few participants indicated that they had to sort private access to rehabilitation services from those provided by participating countries. These services, however, come at a very high cost to most participants. For those who could afford the high rehabilitation cost, some participants indicated that the services offered were not to the standard that they thought they deserved. The participants and or their families had to find scarce resources to fund the private rehabilitation services on individual islands or travel overseas, which was usually very costly.

For participants, not having access can also affect their financial lives by not being able to access their banks when they need financial services in the city centre, as one participant pointed out. It can also affect an individual who uses a wheelchair and constantly asks for assistance from strangers when trying to enter a place of business, which can be a frustrating issue for people who use a wheelchair.

Children

A few of the participants had children before or after their injuries. The focus, however, will be on three participants who (1) cannot have children because of the extent of their injury, the other (2) conceived a child after her injury by Caesarean section, and the final participant (3) had also fathered a child with his non-disabled partner after his spine injury.

The first participant's narrative indicated his frustration and depression about his inability to father children and that he is still very young (not yet 30). This participant's inability has not affected his view on life after his injury, as he has accepted that he will not be able to produce children. This acceptance may be due to the participant's way of life (Aaby et al. 2020), his support system and job satisfaction. He explained that his job keeps him focused, despite the respect and independence of working at the office.

The description of the female participant of being a mother seemed hindered by the negative remarks and discriminatory comments made at her and her partner while out in society. She said, Why did he do that to you, or how will you take care of the child? These and other words were uttered to her while out with her partner. The participant described being bedridden in the hospital because of being at high risk during her pregnancy. The availability of care and advice for women suffering from a spine injury is vital and a right of the participating countries in this study under their disability act legislation. The other two participants of childbearing age did not discuss the possibility of having children. This may be due to insufficient education or inability to attract a partner who would consider having a child with them.

In contrast to the female participants, the male participant's social outlook differed, and he did not describe any social pushback or discriminatory comments. Generally, the view on gender treatment for a person with an impairment caused by a spine injury was somewhat

evident when a comparison was made between the two participants who had children after their injury. The female participant explained she experienced discrimination while pregnant, while the male participant did not express any discrimination. The United Nations Department of Economic and Social Affairs (UNDESA) highlighted that women and girls with disabilities face double discrimination, increasing their vulnerability to gender-based violence, sexual abuse, neglect, maltreatment, and exploitation.

Employment/Work

Employment was one of the most common themes coming out of the study. This theme highlighted and explained the experiences of some participants since their injuries. O'Neill & Dyson-Hudson (2020) have outlined employment benefits for people with spine injuries, such as improved quality of life (QOL) and increased independence. However, a few factors must be considered, for instance, the individual's level of education, transportation, and any other social barriers that may present themselves (O'Neill & Dyson-Hudson, 2020). For example, consideration should be given to wheelchair users qualified to fill an advertised position. Therefore, employers should see qualified impaired individuals as capable individuals. Inge et al. (2018) also suggests that difficulties with accommodation affect employment for a person with an SCI. In one participant's experience, the employer had to invest heavily in a special parallel motorised wheelchair and specialized work area to accommodate her.

The participants' experience of maintaining or gaining employment suggests pleasant or positive experiences. In describing his experience, one participant narrated his love for his job, which could be explained as job satisfaction. The theme of independence was emphasized while speaking about job satisfaction. Not all participants sought employment, as there was at least one self-employed participant. While offering equal employment opportunities, these experiences of

independence and accommodations will be rendered useless if the person who is being hired uses a wheelchair and there is no ramp access to the main entrance (Blanck, 2020). The ability to work as self-employed was prominent among the two participants. One participant worked exclusively as a welder from home and drove to do outside jobs after his vehicle was specially modified for his purpose. The other participant, who works from home, bakes pastries and sells them in the community. Both experiences were very similar as a result of their entrepreneurial endeavours. However, they differed concerning the type of job for these two male participants. According to a study by Ashley & Graf (2018), self-employment suggests that it comes with its difficulties of negativity and unhelpfulness, as individuals may stereotype the business operated by the impaired individual and not support it.

Respect

The participants' responses suggest that because of a lack of awareness in the public domain, individuals who are non-disabled are ignorant of barriers facing people living with a spine injury. Concerning the participant who got pregnant, if the individuals who made remarks toward her knew that people with disabilities could have children, the comments toward her and her partner would not have been made. The experience of some participants suggested that people living with a spinal injury do not seek pity or empathy, but that society respects them as ordinary human beings so they can live comfortably in society just as non-disabled individuals do. Considering this, people with spinal cord injuries should be treated no less than any other human being. Munthali et al. (2009) suggest that this attitudinal barrier will continue to be a significant cause for concern for a person with a spinal cord injury.

Research Question 3

As outlined previously, research question three focused on disabled people and members of different social backgrounds. How are the experiences of newly disabled people with spinal injuries affected by membership of different social backgrounds? How is this affected by overall care, cost, and gender and sexual orientation? Brown and Moloney (2019) found that compared to men with disabilities and men and women without disabilities, women with disabilities are more psychologically impacted by inequitable workplace conditions. The inequity is partly because they earn less, are subjected to more workplace stress, and are less likely to have autonomous working conditions. Though these findings were not a theme coming out of this study, it shows the gender bias created in an environment produced by our society.

Another aspect of social gender bias is the ability of women with disabilities to secure employment. Brown and Moloney (2019) further explain that though women with disabilities may find work, they are always likely to be in part-time or low-skills positions. Though the treatment of women in the workplace did not feature in the study, the treatment of women who are disabled is a social barrier to women with disabilities and shows gender bias. The findings of Brown & Moloney contradict this study's results, stating that women are less likely to be hired in a position of self-directed work. However, two female participants in this study had self-directed functions and were respected. One participant was an experienced product sales representative and was even trusted to work from home self-directed. The other participant was a professional front desk customer representative at a globally respected bank.

Due to society's attitudes towards disabled people, having an impairment puts that individual at a disadvantage socially and financially and affects health, education, and work prospects. Matin et al. (2021) study on disabled women and healthcare suggests that women with

disabilities face various sociocultural (erroneous assumptions, negative attitudes, being judged, insulted, impoliteness), financial (poverty, unemployment, high transportation costs) and structural (inaccessible equipment and transportation facilities,) factors that impacted their lives. The findings of their study are consistent with the results of this research as it pertains to the treatment of women with disabilities, particularly the participant who was pregnant and faced similar ridicule.

The participants in the study were from varied socioeconomic backgrounds, and therefore, their experiences varied. One of the few factors that affect isolation in people living with an impairment and a feature of classism is the issue of finance. Many participants described their inability to maintain their rehabilitation services as too costly. However, on the other hand, a few were able to fully fund and even travel to continue their rehabilitation during this study. According to a few participants' narratives, isolation stems from friends and family not fully understanding the circumstance surrounding the cause of their impairments. Emerson et al. (2021) points out that the prevalence of isolation is among adults with an impairment who are younger and economically inactive.

Care and Cost

The cost and care of people with a spine injury is a mammoth undertaking, and it is not only for the individuals with the impairment but also for their families and carers. Since having an impairment, in general, is considered a cause and a consequence, it separates individuals with said impairment. Socioeconomic status (SES) includes income and educational attainment, financial security, subjective social status, and social class perceptions. Socioeconomic status can consist of quality of life and the opportunities and privileges available to people in society.

The quality of life of people with disability should not differ from non-disabled individuals. However, this changes if the affected person is not cared for sufficiently. Poverty is not a single factor but rather a collection of physical and psychosocial stressors. Shogren et al. (2018) suggest that the socioeconomic status of an impaired individual, such as living in a low-income neighbourhood, can increase their cost of care. Factors such as unemployment, underemployment and the unavailability of appropriate healthcare can affect the socioeconomic status of individuals with disabilities.

Some participants said that they often face difficulties financially, while others who are employed face little to no challenge caring for themselves and meeting their medical needs. One participant also remarked that her perseverance and attitude towards education helped her be where she is today, with regard to her employment. Groce (2018) indicated that restrictions to education and jobs for people with disability, including people with a spine injury, continue to keep them at the bottom of the socioeconomic ladder. The growing number of people with disability increases each year. With this increase, so is the number of people unable to access primary affordable healthcare and education if the individual is of school age (Groce, 2018).

A few participants said their rehabilitation services were too expensive to continue. During this study, the Covid-19 pandemic was at its peak, preventing people from accessing their services. Khoo et al. (2021) indicated that the global pandemic presented untold challenges for people with impairments, including people with a spine injury. One such challenge was accessing rehabilitation services. This lack of services, if they are dependent on the government, has the potential to exacerbate the mental and physical health of individuals who rely on such services. Only a few participants were able to access rehabilitation services by private

technicians. This situation shows the financial disparity between those who can afford proper health care and those who cannot.

Summary

The study yielded some significant and intriguing research themes, such as care and cost, with the potential to show the vulnerability of impaired individuals if they or their families cannot financially care for them. Family support is an important theme in the study, because it can minimise depression and increase the chances of a healthy lifestyle. The evaluation of the findings highlighted the many difficulties disabled people face in the OECS. There is much knowledge to be gained from the lived experiences of people with spine injuries. Their pleas for reasonable accommodation, including access to public buildings and infrastructure, public understanding, and education, are compelling.

The aim and goal of this study were to have an in-depth understanding of the participant's experience living with a spine injury. As was narrated in most of the participant's experiences, family support, isolation, rehabilitation, cost, and care were the most prevalent themes identified. Two participants stood out from the group as they had children after their traumatic spinal injuries, which made their experiences quite different from most participants in the study.

Much insight was drawn from all participants due to their varied experiences. Previously, I mentioned the more common merging themes. However, if these issues were fed through to policymakers, substantial changes could be made to the existing policy, affecting societal change. Chapter 5 of this study will provide my assessment of the implications and recommendations of the study while giving my conclusions.

CHAPTER 5 IMPLICATIONS, RECOMMENDATIONS, AND CONCLUSIONS

Implications

Over the years, people living with spine injuries have faced many barriers in their experiences. The qualitative study has scholastic, legislative and pragmatic implications for disability reform in the OECS and, likely the wider Caribbean. There is a certainty that there is an absolute need for more qualitative research on the experiences of people living with a spine injury in the OECS. Coming out of the literature, there are calls both globally and regionally for more research on the experiences of people living with a disability and, more importantly, people living with a spine injury. The results of this qualitative study apply to and are supported by existing literature on the experiences of people living with spine injuries in the OECS. Given the rich and detailed stories captured by the study, there are opportunities to disseminate how people with spine injuries have lived. Caregivers, families, and legislators may find the information helpful through published journals and articles.

Question 1

Question one set out to answer: How do people with spinal injuries experience daily life in the OECS? The findings of this study concerning the affairs of people living with a spine injury in the OECS highlight society's inadequacies and its existing barriers. The inadequate enforcement of existing legislation to protect the rights of people living with a spine injury also came out as a finding. It is found that people living with a spine injury in the OECS face overwhelming barriers; these include discrimination, limited governmental specialist rehabilitative care and accessibility issues, which prevents several participants from performing simple daily tasks.

Family Support

The emphasis was placed on family support throughout the study by all participants. The findings of the qualitative research relating to family support allow other families who have people with disabilities to see first-hand through the eyes of the participants the importance of family support. This care offered to the participants by their families might inform other families' general practices and procedures. This close-knit family support can expose the valuable service otherwise offered to people with spine injuries, the need for affordable rehabilitation services and transportation services, and further promote advocacy for the better overall benefit for a person with a spine injury. The study's findings relating to the care and affection from family are consistent with the literature reviewed in Chapter 2.

Independence

A person's experiences with a spine injury have specific implications for independence, and the participants' stories could impact general discussion on a person's life with a spine injury. The literature suggests that independent living entails living independently and making decisions with full autonomy that affect the lives of people with disabilities. The implication is that it can further investigate and discuss the rights of people living with a spine injury to make their own decisions on matters relating to them. Further on the issue of independent living, the findings may be necessary for conversations on affordable housing for suitable qualified disabled individuals who may need to live alone.

How am I seen

The way people living with a spine injury see themselves has many implications. Firstly, the implication of how people with disabilities is a practical one, that is, it has far-reaching benefits and implications for social intervention and inclusion with individuals on the primary

and secondary levels of their lives. The implications for policymakers are that they may see it fit to introduce policies for early exposure to people with disabilities. This, then, will have a more far-reaching effect on the social plane of society. The findings suggest that people with disabilities are often disrespected. With that in mind, the stories from the participants have the potential to bring about social change if these stories are shared and reverberated so socially that a possible change may be brought about in the treatment of people with disabilities. This research is very timely as one of the participating countries has yet to develop legislation for the protection and rights of people living with a disability. This is significant as it can potentially guide legislative change regarding the public's view of people with disabilities. The findings call on people to be more sensitive towards people with disabilities. If the plight of people with disabilities is left unattended, severe mental issues may grow into health problems in years to come.

Question 2

Question two looked at the most significant new barriers to inclusion experienced by people with spinal injuries since their injuries. The implications of this research question derive from the findings pointing to issues of discrimination, employment and entrepreneurship and accessibility. The results of this study highlighted several forms of discrimination against participants reported against participants ranging from verbal, physical and educational discrimination. The findings further suggest that we need to be more involved with people with disabilities regarding respect and awareness. As highlighted by the results, people with disabilities who are victims of discrimination are likely to keep to themselves after such incidents. These incidences have the potential for people with disabilities who are discriminated against to seek counselling and improve on the support system available to them, which will

build self-esteem. There is a further implication for current and future individuals who may become disabled and the experience they may have to undergo. If the insights of this study discussed in the chapter are taken into onboard, people living with a disability stand a chance of living and benefiting from a more inclusive life in the OECS. The study's findings further suggest that the males received fewer levels of discrimination than the females. Efforts should be made on a community and inward level to denounce and reduce bias in the OECS against people living with spine injuries.

Employment and entrepreneurship

Across the study's spectrum of participants, this research's findings show that a few participants could secure employment after their injury. However, two were employed before and continued to work sometime after. This finding was consistent with current literature, which suggests employment is possible even after a spine injury. However, a few branched off into creating their businesses. The implication is that efforts should be made to social agencies within the private and public sectors in the OECS to provide avenues for employment, whether long-term or short-term.

Question 3

The findings from this study suggest financial classism among the people living with a spine injury within the OECS. Question three looked at how the experiences of newly disabled people with spinal injuries are affected by membership of different social backgrounds and how this is affected by overall care, cost, and gender analysis. Other factors that may have a cost implication may affect the livelihood of people with a spine injury. For example, a person with a recent spine injury who may have adequate financial resources may receive that added support and may be able to get the best medical treatment in the shortest possible time. Conversely, a

person with limited financial aid may have a negative perspective, which delays the commencement of surgery and even treatment. Some participants' narratives evidenced the lack of finance to cover care and cost. Therefore, this implies that having adequate financial support will give the best services, from surgery to aftercare. Those without will be at the mercy of friends, family, and the respective governments. One participant explained that she tried to get her government's support to assist her with her surgical cost and rehabilitation aftercare, but that assistance was not forthcoming. The participant further explained that her medical expenses were all funded by her family's fundraisers.

This disparity among people with a spine injury shows the financial hardship and the mental agony that the person with the injury and the family caring for that person may experience. For instance, one participant could undergo surgery overseas via a private airline within three days. It was more than a month before another participant could seek surgical intervention after his incident. Again, this gap shows how financial support can be a huge advantage to one's quality of life QOL. This financial classism among people with disabilities affects their ability to seek and maintain adequate rehabilitative care. Several participants explained that they could not afford to bear the cost of private rehabilitative care. In contrast, others could afford rehabilitative care even up to the point of this study.

The current findings support the assertions of Badhiwala et al. (2018) regarding the very high cost of initial spine surgery for patients. Only a few participants could afford surgery immediately after their injury. There are many ways the findings of this study can improve the lives of people living in the OECS with spine injuries. These include disseminating or sharing the stories shared by the participants so individuals and service groups may be informed and the implication for training service providers for people with disabilities. Additionally,

nongovernmental organisations like disability groups and associations have the potential for advocacy support.

The findings of this research are consistent with the review of the literature found in Chapter 2 concerning several aspects, including independence, independent living, discrimination against people with disabilities, employment, family support and rehabilitation. The contribution to knowledge can be seen as a continuum to disability studies and the methodology used to capture the information needed to ascertain the study's findings. Data elicitation was employed by using semi-structured interviews and photo-elicitation. Combining these two data-gathering tools, it may contribute to knowledge. Secondly, critical reflection relates to the experiences of people with spine injuries while having insights into the social model and the barriers people living with spine injuries face in the OECS.

Recommendations for application

The recommendation for application will be related to the principles enshrined in the United Nations CRPD, adopted in December 2006. Antigua and Barbuda was the first of the three participating OECS countries in this study to ratify this convention in January 2016, followed by St. Kitts and Nevis in October 2019, and St. Lucia in June 2020. The convention's ratification in these countries signalled the consistency in their respective constitutions and is central to my enquiries. Apart from the United Nations CRPD framework, the recommendations for application will be framed using the research findings, the literature review found in Chapter 2 and the Disabilities and Equal Opportunities Act (2017) of Antigua and Barbuda.

The social model of disability will be my starting point. The social model refers to the idea that social barriers render physically impaired people disabled (Berghs et al., 2019). It is barriers such as society's attitude, the environment, and architecture that hinder people living

with a spine injury from experiencing productivity daily. My research found that government policy for people with disabilities rarely considers the needs of people with spine injuries. Further, it can be argued that existing disability policies do not go far enough to ensure the comfort of people with spine injuries. A critical point that arose from the participants' narratives is that few identified any existing policies relating to people with disabilities. If some legislations are not revised and enforced, such as local building codes, employment policies for people with disabilities and the existing disability tribunal people living with disabilities in the OECS will continue to receive substandard health care and marginal educational service. The disability association of the participating countries has an essential role in promoting disability reform. Without advocacy and an improved policy-driven agenda, disability associations will not have the drive and will not be taken seriously on legislative change.

Recommendation A

To fill this gap, it is recommended that the policymakers and the disability associations in the represented territories first embark on a massive educational campaign. This campaign will assist in advocacy and allow public sensitisation of disability issues. It will also have the potential to create an open dialogue with policymakers.

Recommendation B

It is vital that people who have sustained an injury and are diagnosed with traumatic or acute spine injury be offered rehabilitation services as soon as practical, as this is central to the individual's development care. This quality of care at rehabilitation centres owned by the state has been reported to be of a low standard. One participant in the study explained that she was dissatisfied with her service. The state-run rehabilitation generally does not meet the standard of care given to a person suffering from a spine injury. Therefore, it is recommended that the

government rehabilitation centres be suitably fitted with the appropriate equipment and trained staff to deal with people who have suffered a spine injury specifically.

Recommendation C

The continued training for rehabilitation staff is aligned with Article 26, which speaks of promoting and continuing the activity of staff members who work at the rehabilitation centres. These recommendations adhere to the United Nations CRPD article guidelines of providing reasonable health care and rehabilitation to all people with disabilities. The reasonableness of this recommendation will provide the minimum standard required when providing service to people with impairments. As it related to the participants in the study, most had access to reasonable health care. A few participants had access to excellent health care because of their socioeconomic background and the sound financial support from their families. Additionally, those participants who can afford better health care are the ones who were employed at the time of this study.

Participants who were employed could provide for themselves more than those who were unemployed. Though education played a central role in one participant's experience and eventual employment, other participants narrated that getting assistance to start a new venture from the governments, was challenging. Being self-employed, he disabled can create viable options for overcoming employment inequalities for people with spine injuries and various disabilities (Ashley, 2018). Therefore, it is recommended that employment opportunities be made available for people with spine injuries (in addition to employment assistance) who can work and be given the necessary support. The United Nations CRPD further obligates signatories to the convention to support persons with disabilities in their entrepreneurial endeavours (Bekmansurov & Kovalenko et al., 2019). Incentives may be given to people with

disabilities who wish to engage in entrepreneurship to lessen the unfavourable disparity or discrimination between self-employed and employed individuals, which seems higher amongst people with some form of disability (Cieřlik & Dvouletý, 2019).

Breaking social barriers amongst people with disabilities has always been at the forefront of the fight for the social model of disability. Mike Oliver, since the 1980s, has always contended that a person is disabled not by physical impairments but by the daily barriers, whether social, attitudinal, infrastructural, or technological. Many participants have expressed similar views on the treatment and views of the societies in which they live. Their philosophical standpoint is that society sees them as individuals who should be kept away from the public's eyes. Moreover, people with an impairment have argued that if society does not change its attitude, these barriers will still negatively affect the lived experiences of people with a disability.

Considerable importance is placed on the independence and the way of life of people living with an impairment caused by a spine injury. Williams et al. (2018) suggests that people with a spine cord injury (SCI) must live an active and, as much as a possible, independent lifestyle to promote longevity and well-being. Moreover, the findings determined that many feel a loss of independence, which is probably a significant contributor to adverse feelings such as isolation and low self-esteem. Independent living amongst people with SCI is linked to the social model of disability as it involves the inclusion of people with disabilities into the broader society, including making decisions that directly affect their lives. Further, the ability to live independently is to participate in legislative decision-making and open discussions that will affect their social and sexual lives.

Recommendation D

Most of the participants in this qualitative study displayed very high levels of independent living in some areas. One of the participants, Natalie, uses public transportation to get to work each day, and another participant explained that he bakes at home. The ability of these two participants to make choices for themselves indicates some level of independence. Further, I think the most significant example of independence from this study relates to the decision-making of the participants who chose to have children. As Williams et al. (2018) explained, this level of autonomy from a 2016 study promotes perceived importance to individuals with an impairment caused by an SCI. Therefore, promoting independent living is recommended for individuals diagnosed with SCI. This promotion must come from or be encouraged by the caregivers of individuals with an SCI.

Recommendation E

Further, the rehabilitation process should include physical activity directed by a trained and qualified physiotherapist. A further recommendation is that governments must be prepared to invest in the quality of care (QOC) for people with spinal cord injury to improve their perspective on quality living and the quality of the rehabilitation staff and facilities offered. The latter is expressed by Williams et al. (2018), reinforcing that staff who provide rehabilitation services lack specific education and skills training for people with SCI, thus failing to promote overall independence in a person with a spine injury.

Recommendation F

The findings from this qualitative research relating to the participants' views suggest that public opinion is based on an ingrained perception of people with disabilities. The public's perception of a spine injury can be cruel and unforgiving. The findings highlighted this as most

participants felt unwanted, abandoned, and unwelcome in society. Therefore, it is recommended that disability legislation such as the one in Antigua and Barbuda, the Disabilities and Equal Opportunities Act (2017), be revised.

Though most of the employed participants did not have negative experiences in the workplace or finding a job, a participant from St. Lucia indicated that her injury significantly reduced her employment prospects. Such traumatic experiences have caused people with spine injuries to become dependent. This finding supports the literature in Chapter 2, where a spinal injury can affect an individual's employment and education, which is viewed as discrimination.

Recommendation G

Therefore, it is recommended that employers, when advertising job openings, clearly indicate an all-inclusive workplace and policies and encourage application by suitably qualified persons, including people who are impaired due to a spine injury. This policy, however, must be driven by legislative involvement. It is further recommended that legislation be introduced or that it becomes mandatory for financial institutions and places of business to have access to ramps at the main entrance (which can encourage people with spine injuries to do business). Improving the internal infrastructure of all public offices and places of business to accommodate and facilitate people with spine injuries and many other ranges of impairments is of absolute importance to the overall care of people with impairments.

Recommendation H

Many participants indicated significant exposure when asked about assistive technology, some due to cost and availability. This reality is consistent with the literature research in Chapter 2, as detailed by Ravneberg and Söderström (2017), who further explain the importance of assistive technology concerning the social model of disability as significant towards various

types of impairment. Therefore, I would recommend that governments in the participating territories seriously consider the provisions of assistive technology in public buildings. Further, creating social environments such as parks will improve the lives of people with disabilities, foster a more inclusive society, and further promote broader participation.

The current legislation in Antigua and Barbuda, St. Kitts and Nevis and St. Lucia supports people with disabilities, including people with spine injuries. Most participants did not know about legislation that protects the rights of people with disabilities. The individuals who were aware of these legislations are those that are in some way connected to that country's disability association.

Recommendation I

Therefore, it is recommended that people with spine injuries and other disabilities, whether formally or informally, be made aware of any legislation that protects them and offers rights as non-disabled people do. The awareness of these legislations can add to the knowledge of people with disabilities related to discrimination in society. A theme emerging and worthy of mention for recommendation is concerned with parenting. As an impaired woman, having children can positively affect one's QOL, as covered in Chapter 2 of this study. Tefera et al. (2017), in a study done on motherhood and disability, suggest that women with disabilities who desired to become pregnant and have children expressed sentiments of joy and lived their lives of motherhood in good spirits.

Recommendation J

Therefore, it is recommended that after a female's spinal cord injury, the appropriate medical checks be done, and helpful advice is given on whether she can conceive. The

participant did not narrate any negative experience during the process and therefore found the experience quite normal.

Further, she expressed that having the child brought joy to her experience as an impaired woman. Support for people who have suffered a spinal injury comes in many forms. These may include but are not limited to ongoing rehabilitation, spousal or familial support, and organisational and government support. The general consent of all participants in the study supports Alireza et al. (2019) work on care and support. It was suggested that participants need support and training through well-trained teams and social support to increase their independence. However, according to Alireza et al., (2019) early discharge from the hospital and rehabilitative care put pressure on the support that may be given by society and the government, as access to reasonable accommodation and adequate support from organisations and families is significantly reduced when they settle at home. Therefore, it is recommended that suitable supervision be given during the rehabilitation process by an experienced physiotherapist.

Recommendation K

Further support can be provided at home to strengthen the overall care for the affected individual. Another recommendation is to make provisions that ensure that the premises to which the patient is returning are reasonably accommodative, where suitable supervision and the appropriate mechanisms are in place to support the individual with a spine injury. Moreover, the preferred recommendation would be to have a state-funded three to six-week midway house that will facilitate families and patients and act as a transition period for the patients to become accustomed to life with their impairment. The midway house will encourage the impaired individual to mentally adjust and transition from a hospital to a home environment.

Recommendation L

Cost is one of the most challenging aspects of the experience for a person with a spinal cord injury. The initial cost of surgery in the Caribbean can be extremely high if not state-funded. As described by most participants, public rehabilitation services in the OECS do not offer the required services for someone in their physical condition. The cost of assistive technology to aid patients with a spine injury can be more than tens of thousands of dollars and often requires further costly maintenance while increasing the homeowner's energy (utility) cost (Smith et al., 2018). It is recommended that the publicly-owned rehabilitation centres are appropriately outfitted with suitable equipment and supervised by highly qualified and trained individuals. Few participants said their experiences at the publicly owned rehabilitation centres were unhelpful and off-putting. It is further recommended that all staff members be trained in the social model. Therefore, rehabilitation workers can offer patients social rehabilitation and widen their views on autonomy and interdependence (Blanck, 2020).

Recommendation M

People with disabilities have always been and constantly been mistreated. The negative attitudes that have been demonstrated toward people with disabilities, and societal beliefs, are all associated with unfair treatment of people with disabilities, which further increase the incidences of depression and very low self-esteem (Trani et al., 2020). Some participants described being mistreated and discriminated against in some way. There are no avenues for people with disabilities to report acts of unfair treatment in the local setting. It is recommended that a disability rights tribunal board be formed to hear these complaints against individuals, business, and the state. One of the primary purposes of the board will be to reinforce while promoting the recognition of basic human rights principles concerning people living with a disability who have

the same rights as any other person living within the OECS. This tribunal board is recommended to hear grievances from disabled people or the caregivers of disabled individuals.

Recommendations for future research

There is still much to be researched on the experiences of people with a spinal injury in the OECS. This study may create awareness and interest and encourage further research on the lived experiences of people living with a spine injury in the origin of the OECS.

This research has possibilities for adding new knowledge to the existing societal gaps for people with spinal cord injuries. For example, the lived experience of people with spinal cord injuries in the OECS highlights the intense efforts that are needed to improve the livelihood of all individuals with an SCI. Depending on the severity of economic inequality, the individual's life may be considerably affected by limited participation in routine activities promoting independence, financial stability, and accomplishment. Therefore, creating enabling environments for adults and children living with a spinal cord injury may add to the depth of this research; this may allow for the examination of new and existing policies and standards that consider the economic needs of people with spinal cord injuries.

Recommendation A

Additionally, the present study had a majority male demographic. Thus, making adequate gender experiential comparisons was somewhat challenging. Further studies can be gender inclusive, allowing for comparisons between the experiences of males and females living with a spinal cord injury. It would be informative to ascertain if women with disabilities experience more significant discrimination and disabling barriers. Gender-based experiences may add further insight into society's attitudes towards males and females living with SCI. For

example, this study revealed an incident where one of the female participants fell in love after her injury and had a child. However, a substantially larger female sample size from countries within the OECS would be needed to understand better the females' lived experiences and to ascertain and compare the factors that influence experiences, outcomes, and perceptions.

Recommendation B

Further, sexual health in people with disabilities in the OECS is another possible area of research. People with spine injuries and other disabilities are sexual beings. They deserve equal rights and opportunities and, more so, full autonomy over their lives which will increase their independence Shah (2017). The freedom over their rights to choose on matters of sexual autonomy is critical to their overall emotional and physical health. Loeser, (2018) indicates that missing from literature is investigating disability and sexuality as both an aspect of pleasure and sexual desire in people with a disability. Further studies in this area will not only broaden the public discourse but also lead to a better understanding of the sexual experiences of people with impairments to determine how such people are impacted or restricted by physical and psychological barriers.

Recommendation C

Another area for potential future research would be the experience of caregivers who give long-term care to people with spine injuries living in the OECS. Pullin & McKenzie (2020) suggest that most of the studies done to understand the viewpoint of caregivers have been for about five years after the injury. Future research on the effects of long-term care may be conducted to examine how long-term care has impacted caregivers, partners and family members of people living with a spinal cord injury in the OECS. These research areas may also address

comparison between long-term care and patient satisfaction, thus addressing an all-encompassing impact of long-term care on the lives of careers of people with a spinal cord injury.

Recommendation D

Further studies may be conducted on the survival rate of people with various spinal injuries. This qualitative study identified two classes of spinal injuries: traumatic tetraplegia and paraplegia participants. This study may examine the life experiences of individuals with both classes of injuries and their experiences in the first three years after their injuries. This may be important as it can inform medical science for appropriate care and treatment and caregivers so they may be educated about the processes and procedures in caring for people with spine injuries.

Recommendation E

A few participants indicated that during their experience, they developed mild to severe urinary tract infections that were sometimes unbearable. Research could be conducted to investigate the incidences of urinary tract infections (UTI) in people with spine injuries in developing countries, and a comparative analysis drawn between developing countries and more developed countries. This study may be necessary, as it may inform caregivers of appropriate care to be given to while attending to people with spine injuries. Another potential area of research could be the influence of early surgical intervention. The study's results can significantly impact the developmental and financial implications for the person with spine injuries. According to Badhiwala et al. (2021), the sooner an individual accesses surgical intervention after his injury, the better the chances of reducing future complications and overall prognosis.

Future case study research***Recommendation F***

During the research process, one prominent aspect of the participants' experience was that most participants admitted not knowing the United Nations CRPD and their local legislation governing the rights of people with disabilities. Given this phenomenon and how it may affect how the person with disabilities are seen and how they see each other, it could add to the body of research to investigate whether knowing disability legislation could change the perspective and the experiences of people living with spine injuries and other disabilities. This research could be based on a case study with several advantages. Gaille (2018) suggests that the data obtained from case studies can provide valuable information in replicating results for use in similar studies. The information provided by case studies is factual, as they represent the real-life experiences of the participants involved. One of its most versatile assets is the ability of the researcher to use a combination of research methodologies (Gaille) in the study. Using a case study, the researcher will have the opportunity to delve deeper into the participants' experiences to ascertain their understanding of the legislation governing them. I chose not to use case studies in my research because of two main issues: 1) Because of the in-depth analysis that would have been undertaken, transferability would not have been possible, and 2) the high rate of bias that is usually associated with case studies as the researcher's opinion may impact the research.

Recommendation G

A case study may be further used to examine the various circumstances in which the participants were affected by their impairment. For instance, some participants were injured by vehicular accidents, some by gun shots and others by falls. It would be helpful to ascertain how the various types of injuries affect each group's experiences in life.

Recommendation H

Finally, additional research can be conducted on the mental health of people with disabilities within the OECS. Peterson et al. (2020) suggest that living with a spine injury increases the individual's chances of developing various mental disorders, such as depression and anxiety, compared to those without spine injuries. Hughes et al. (2019) also highlighted that persons with disabilities are more likely to be abused than those who are not disabled. It is further indicated that mental health and its consequences on people with a disability are little known. Research in this area would qualitatively examine mental health's psychological and physical outcomes on people with disabilities. The findings of this study will have the capacity for an extended-reaching effect on groups, associations, and policymakers across the OECS and further in the wider Caribbean Community (CARICOM). The number of people with disabilities is growing, and almost everyone will experience some form of disability in their lifetime.

Replication for study in other populations

Research on the experiences of caregivers in developing countries has achieved traction within the past decades. While looking at the intersection between the role of the caregiver and their mental health during the administration of care to the individual with a spine injury, these areas of research have become more critical in disability research. Keihanian et al. (2022) explain that caregivers for people with spine injuries encounter high financial, physical, and psychosocial burdens while providing long-life care and assistance. Depression in family caregivers is a growing phenomenon and needs to be explored especially to granularly investigate the root causes of overall depression in caregivers (Lee et al., 2022). Studies done by Lee et al. indicate that the economic situation of a spine patient affects the caregiver either negatively or positively. The more financially strained the patient was, the higher the level of

depression in the caregiver versus the more economically independent the patient was, the study showed that the level of depression for the latter was very low.

The injury's severity also affected the caregiver's psychosocial aspect. That is to say the more active the patient was (Lee et al., 2022) the more the caregiver was able to participate in more social activities. My study explored the phenomenon of understanding the experiences of people with spine injuries in the OECS. The participants in my study understood and appreciated their impairment and the environment in which they lived. However, if examined closely, the themes might be very different for people with spine injuries in more developed countries where regulations and legislation are more strictly adhered to ensure a more inclusive environment for people with spine injuries. For instance, regarding the provision of caregivers the state provides ensures an even playing field for providing quality care for all.

Further, there is a need for continued public social education to keep society sensitised to matters of disability. Sensitisation, therefore, may reduce the incidences of discrimination, which increases public awareness. Generalisation was somewhat limited in this qualitative study. Consequently, it can become significant when research is done and when inferring the experiences of other populations and cultures.

Longitudinal replication with the participants of this study

When other populations are introduced to an existing study, emerging themes will change across that population. Therefore, emerging themes are subjected to time, as the participants were at different stages of their experiences. Participants will likely face new challenges as time progresses to varying stages of their experiences. Various participants expressed growing close to their families which increased their level of comfortability.

Notwithstanding, the participants looked at the possibility of increasing independence. Extending

the study longitudinally may add insights into participants' independence, family care, and caregivers' health assessments.

The independence of people with spine injuries is a developmental process. This developmental process comes with dedicated rehabilitation service over the affected individual's life. Moreso, introducing assistive technology can be an incremental process towards achieving independence for people with spine injuries. The increased level of autonomy will assist in community participation and mental stability. A longitudinal study will capture the lived experiences of individuals from the time of injury to the time of death. However, it may be interesting to capture the experiences of people with spine injuries in the first two years of injury.

Researchers Reflexiveness

The idea of reflexivity in qualitative is not a new phenomenon in research. However, as qualitative research becomes increasingly popular in social science, researchers have seen the need for reflexivity to be more prominent in their work. The depth of a researcher's reflexiveness depends on their epistemological and ontological assumptions (Haynes, 2012). Dodgson (2019) suggests that if researchers outline the intersecting relationship between themselves and their research participants, it increases credibility and further develops the understanding of the research. Shacklock and Smyth (1998) further describe reflexivity as one's conscious revelation of the core beliefs and values of the researcher in choosing his or her methodology and then justifying its approach. Through this approach, research transparency on the researcher's bias, position, and assumptions is vital to the judgement of the quality of the research (Reid et al., 2018).

The first section of this reflexive piece focuses on the ethical aspect of the paper. While conducting this research, I considered (Somers, 2020) advice that the study calls for excellence

and integrity throughout its duration. As an upcoming researcher, personal motivation and competing interests must be investigated. As a full-time employee at a regional university, I wondered if my selection process and methods for participants were done fairly and competently. Though I used an inclusive approach throughout, my full-time job sometimes creates a heavy workload, and I might have put a little less effort into the entire participant selection process. Reid et al. (2018) refers to this as a biased blind spot.

One positive aspect of the ethical aspect of the participants' selection is that I did not have any prior relationship with any of the chosen participants. This non-relationship reduced or nullified any bias during the data-gathering phase. An aspect of delimitation occurs when we rely on the truthfulness of the participants and my motivation.

In this study, I investigated the experiences of people living with a spinal cord injury in the OECS. The study was qualitative and used semi-structured questions. With the supervisor's support, I completed the dissertation on time, notwithstanding the pandemic and its many challenges. The dissertation's success hinged on the successful selection and participation of the research participants. All the participants provided valuable and detailed accounts of their lives with a spine injury. Having access to all the data from the participants allowed me to dedicate my time to creating categories and themes which formed the basis of the study's analysis. It was from the analysis that the findings were extrapolated.

Reflection on background

The background for this qualitative study stemmed from the need to understand the experiences of people with spine injuries in the OECS. Having experienced the fieldwork in interviewing the participants in their natural environment, I have gained some valuable lessons, but admittedly, I have also made some mistakes during the research process. My interest in spine

injury research and the experience of people living with spine injuries stemmed from a personal experience where I developed a condition called bulging disc and disc degenerating disease while I was a fitness instructor. This condition caused the affected disc to protrude out of alignment and compress the spinal cord, causing excruciating pain almost constantly.

This experience has opened my eyes to many things, from care and treatment, rehabilitation services, cost, discrimination, and the many barriers faced by people living with an impairment. After teaching my A-level class one evening while incapacitated, I decided to change my idea of investigating a PhD topic of integrating mobile app development and disability to thoroughly investigating the experiences of a person with spine injuries in the Caribbean. Another factor that led me to go entirely to social science was my experiences in the United Kingdom doing therapy sessions compared to those I experienced in my home country, and the experience were miles apart in terms of professionalism, care, and equipment.

Results and their interpretation

After the analysis, one of the first things was to interpret the data and identify possible biases from the researcher's perspective. Writing the dissertation and analysing the data provided me with sufficient evidence to conclude that living with a disability in the OECS was a serious enough issue that needs immediate attention, not only on a social but also on a legal level. I acknowledged that since using thematic analysis, which was new to me and using manual coding, I would have been challenged regarding time and competence. However, I wrote these lines in my research journal:

“I need some help with transcription, as this is getting overwhelming.

Make sure to contact my work colleague for assistance, as he has experience in

this area and can act as a second eye and add accountability, reliability, and validity to the process."

Due to the volume of work relating to transcribing and coding, I often found myself overwhelmed and had to take some time off to regain composure and restart. One of the main challenges I encountered was identifying portions of the transcripts that did not relate to the study. This was particularly challenging because the information was so rich and relevant, in my view. I believe the interpretation and findings of this study add value to the area of study and contribute to the already limited amount of research done in the OECS on the experience of a person with spine injuries. The relationship and the advantage of using manual coding made me research the data deeply, which caused me to be vested in the entire coding process. The primary outcome of rich and untainted data was the relationship between the participants, the data and me as the researcher. The data was explicitly placed between the participant and the researcher to illustrate that, without the participants, there would be no data. Moreso, the data produced affects the findings of the analysis undertaken by the researcher.

Research significance

I needed to undertake this research by adding to an existing body of knowledge highlighting the lived experience of people with spine injuries and general disabilities. Most importantly, the conceptual framework marrying phenomenology and the principles of extraction, and the process involved also adds to a body of knowledge as a novel process in data analysis. However, having completed the dissertation, I think the analysis of the data and description of the findings could have been a bit more detailed. I would have been a bit clearer if given a second chance to rewrite the analysis chapter. However, the use of thematic analysis brought out some perfect themes. After fully acknowledging the need and receiving advice on

my proposed research, I was convinced that this research area needs further study, especially in the OECS, where I reside. Having examined my island of Antigua and Barbuda and knowing the similarities in demographic in the other islands, I requested information on the incidences of spine injuries in the other OECS countries. I decided to concentrate on my study with the OECS rather than just in Antigua and Barbuda. One of the biggest hurdles was finding current literature on the phenomenon facing the OECS region.

With that, I was further convinced that this was an untapped area which required investigation. I understood that the study needed to be done. I also understood that studies about minority groups would be a sensitive topic. I further understood the importance of the study and was determined that my efforts would not be wasted. Significantly, the goal was to produce findings that could add to the regional literature. Understanding all this motivated me throughout my study. Some of the general things we know about people in the OECS living with spine injuries are: 1) They are mainly in a wheelchair or bedridden, 2) They are poorly cared for if not in the home of loving relatives. What we do not know is their stories through their lenses. So, questions such as 1) In what ways do people with spinal injuries daily experience life in the OECS, and 2) What are the most significant new barriers to inclusion experienced by people with spinal injuries? And 3) how are the experiences of newly disabled people with spinal injuries affected by membership in different social groups? This includes how this is affected by overall care, cost, gender, and sexual orientation were the three main questions which drove the research process and the choice of an appropriate research design to get the desired outcome. However, these were not the initial research questions. Still, as I got to the point where I was formulating my research instrument, I realised I needed to tweak the questions to get a better outcome.

Methodology

There were rich benefits from using the qualitative method for this study. Since I wanted to fully understand the experiences of the lives of people living with a spine injury, the primary data from the participants served that very purpose. Secondary to that, photo-elicitation was used as a means of further drilling down into understanding the participants' lives. If I were to identify any drawbacks in this process, it would be the time it took to transcribe the raw data. As a researcher having a solid literature base is necessary as it shows the investigative capability of the researcher. Second it gives the researcher the ability to identify theories and concepts which may be used in his or her research.

Reflecting on the data collection

Semi-structured questions were used as the interview tools to elicit information from the participants. The richness of data was a testament to the close relationship between the participants and I. The very first few interviews set the tone for the others which followed. In my interviews, I indicated that I had experienced spinal impairment. In my view, that revelation caused me to feel a part of the process and allowed the participants some level of evident comfort to express themselves freely and confidently. I will acknowledge that on reflection perhaps identifying myself as part of the disabled community, whether temporary or permanent, was not the best approach. My reason is that maybe by working with a researcher who has no connection to the community, their responses may not be questioned or queried.

I found myself looking back on my personal experience and where I am now, doing academic research to improve local and regional advocacy on behalf of people with a disability. I further find myself acting as that local literary voice, producing research findings that may improve the quality and frequency of conversation in disability.

The community of people with spine injuries and, by extension, people with disabilities living in the OECS needs a voice. This voice will speak and advocate on their behalf, representing findings like the ones in this study. This research brought out the need for me as an upcoming academic to look at the importance of continuous academic research, which may affect social and legislative change. I saw myself as an insider researcher in this study.

As an insider, I see myself as impaired and part of the community of people with a spine injury. However, this insider relationship is seen as a conflict or being biased toward the community (Dyer & Burckle, 2009). This conflict was resolved by gathering data with my eyes open while assuming that I knew nothing about the phenomenon under investigation. Dyer and Burckle suggest that which I found to be accurate, not because I was a part of the community culture does not mean I understand the subculture. I understood on reflection, looking at the data, that there is no neutrality in bias, and there is where the difficulty lies. Though I consider myself an insider, my experiences were nowhere near to what all the participants experienced, which is complete paralysis or partial paralysis and dependency in some cases. So, the question may be, does it give me full legitimacy? The answer is no. That is so because I do not fully experience the impact of an SCI. The study's findings gave me a different level of consciousness of how I viewed myself before the research and how I see myself now. I am now enlightened about my experience compared to that of the participants.

I must mention that according to Al-Natour (2012), there are complexities in the research that may arise from the researcher and the research. My experiences in this research paper have filled a void of knowledge, awareness and understanding of a phenomenon I came to be a part of. I want to reflect on my initial topic proposal to the one I just completed. In the beginning, I proposed integrating mobile app technology to improve the lives of people with disabilities. At

that point in my life, I had no issues with my health. So, I was always interested in improving the lives of people with disabilities. Then during my first year, I got injured. From that moment, while undergoing extensive treatment, I decided to complete/USE social science to investigate the experiences of people with spine injuries like mine. At this point, I am more conscious about my desire to learn more, so I can contribute more.

To this end, I think that having qualities such as being compassionate, and an active listener can aid a researcher in capturing a large volume of deep-quality quantitative data. As an educator for twelve years and an advocate for the past five, I have developed qualities such as the ability to gain someone's trust and honesty, which in my view, is integral to a suitable data collection process.

Data authenticity in qualitative research has always been a topic of discussion because it has always been said it is challenging to prove the reliability and trustworthiness of qualitative data. Reviewing my data by a seasoned researcher was the first step in ensuring data authenticity and validity. I made sure to choose someone who had qualitative research experience, was trustworthy and had an open mind towards the topics under investigation. In addition, it was important to ensure this researcher learn as much as possible about the participants and their experiences. A second step was to ensure that the interpretation of the data was still authentic to the original data given to me by the participants in the form of a recording. Taking samples of the findings to the participants for review added another level of validation to the process. The third level of validation in ensuring data authenticity is ensuring that chosen participants were all qualified and met the criteria for the study. By selecting the participants using snowball sampling, I ensured that all participants completed the requirements to be a part of this critical study. Finally, the consistency of the results across the participants assisted in the validity of the

findings. Several questions, when asked, produced very similar responses, thus indicating some level of data validity, which leads me to the point of data interpretation.

The interpretation of the data suggests several things to me as the researcher of spine injuries in the OECS. (1) People with spine injuries are not only concerned about access and accessibility but also about the aspect of independence, having the ability to make their own choices. One female participant suggested in her interview that they (females with disabilities) should have the choice to choose whether they want to have a child or not and not have to depend on someone or a group of people to decide how they live their lives. This brings me to point (2), regarding the discrimination against women with spine injuries and their decision to enter romantic relationships. Two female participants experienced discrimination and were ridiculed for the choice they made. Additionally, I must stress that one male participant made a similar choice and was not ridiculed or discriminated against for his choice. Discrimination against females with spine injuries is far more prevalent than their male peers. Lastly, (3), most participants stressed the importance of care. According to some participants, care played a significant role in maintaining a healthy mental balance. This healthy mental balance made me realise that happiness in people with disabilities comes from showing them that they are loved and cared for.

General reflection

Overall, the entire process was a challenging one. Coming from a strictly technical background, I first found difficulty in comprehending the central philosophical concepts used in social science. Further, my most challenging aspect was analysing the data using a new thematic analysis concept. As difficult as it was, I pledged to maintain a professional stance at the risk of not compromising data integrity that may affect the rigour and validity of the study. My

confidence in using manual coding and thematic analysis came from my audit process, which helped maintain the integrity of the process and the data produced.

Notwithstanding, I went through many iterative methods to ensure trustworthiness and validity of the data. When I introduced data extraction, I was skeptical at first about how I would be able to marry extraction, a concept primarily used in data science, with phenomenological ideas that would produce data fitting for a qualitative experience. Interpreting certain aspects of the data was necessary as, colloquially, it might have been passed over as a simple expression. Expressions such as *yeah*, *man* may be interpreted as yes in an everyday context. However, depending on the context and the questions asked, it can also mean yes in a negative sense.

Getting too emotionally attached to participants during interviews should always be avoided to reduce compromising the validity of the research. As the researcher, my role in the process was vulnerable and powerful (Vince, 2020). It has always been a concern whether my personal experience and interest in going into the research would prejudice it. I was aware that I would not only be a researcher in this study but could also be a participant. I anticipated that doing this research would mean reliving my own experience through the lenses of the participants. Therefore, there were periods when I experienced emotional and psychological feelings. Due to my firm beliefs and conviction for the need to do this research, I thought my own experience could add significant value to the entire research experience. It would be an excellent idea to have more extensive research examining the benefits of emotional attachments in phenomenological study.

Research Impact

Statly (2017) suggests the impacts of researcher involvement are often looked at with regard to differences made to the research, the participants involved and the researchers

themselves. A research impact from a researcher's reflexive point of view considers personal and emotional attachment to the study and the research participants.

Personal Impact

There are some personal impacts that I wish to highlight and how the outcome of the research affected me on a personally. My identity as a person with an impairment used this research as an opportunity to understand the world around me and better understand that world from someone else's perspective. It allowed me to build research skills as a budding researcher and, most importantly, to build personal character, which I now see as strength. This personal character-building came from my interaction with research participants face-to-face and on the zoom platform. The ability to control one's emotions on reflection was essential to this research.

In the early stages of the data-gathering process, I became emotionally attached to the stories and reflections of participants. This emotional attachment was caused by the fact that I could relate to the participant's accounts. I soon found myself able to control those emotions and considered it to be building my professional status as a researcher. Sometimes, I thought I knew what the responses to some of the questions [should] be. However, after doing a few interviews, I realised I had some conscious expectations, which, according to Al-Natour (2011), is not effective research practice.

The fact that gaining new knowledge in the area of the participants' lived experiences and new skills in communication had a profound impact on me as the researcher. Meeting participants for the first time face-to-face changed my perspective, personally and professionally, on people with spine injuries.

Emotional impact

To most people, the nature of the research and the stories recalled by the participants can almost be emotional. I remembered one participant, Natalie, whom I interviewed, recalled her experience visiting the doctor and being in so much pain. At that moment, I related to my experience in the United Kingdom. I became emotional after going to the doctor, the chiropractor, and laser treatment. Though not visible, I had to pause for a moment, move away from the camera and wipe my tears. I also noted that a few participants appreciated that I suffered a spine injury and was very happy that I had the opportunity to have corrective surgery soonest.

The acknowledgement of their concern suggested that they still exhibited the distinctive human trait of love and compassion in spite of their struggles and uncertainty in life. I also became conscious of the participants' determination, tenacity, drive, and spirit of care. The data showed that most participants who could work were employed in some way, either full-time or owned their small businesses. I attributed that to independence and self-sufficiency.

Reflective consciousness

Keromnes et al.'s (2019) idea of self-consciousness is derived from the idea that an individual's awareness of their own body in a time continuum and the interaction with the environment and others and that individual's body is significant. Further, this consciousness includes the individual's awareness of their identity, having interacted or lived with that identity for some time while interacting with others. Additionally, one's self-consciousness allows one to be aware of others and differentiate from them, including their perspective and emotional experience.

Philosophically, Gallagher and Zahavi (2019) relate one's consciousness to an *object* of one's self. Well, known philosopher Hegel suggests that for one to experience self-consciousness, one must have the capacity to be conscious of some form of an external object separate and apart from oneself. This consciousness, according to Hegel, required self-awareness of oneself as an *object*.

If I am to relate to Hegel's philosophical stance of consciousness in this reflective piece, I must first connect to my unconscious state coming into this study. As a budding researcher, I did not fully understand the depth of phenomenology and the lived experience of other individuals with spine injuries, and I initially took for granted the meaning of my consciousness and the effect it may have on the outcome of this study. According to Hegel's phenomenology of consciousness, an individual can only be conscious of an object (this object can be external or internal, of the mind or without the sense) when three phases are considered: general consciousness, self-consciousness and reason. These three phases, according to Hegel, are necessary for consciousness to be achieved.

General consciousness

In alignment with this study and this section on reflexiveness, the object of understanding bears much importance in consciousness's character. Hegel believes that understanding an object (the phenomenon under study) is the beginning of a general understanding of consciousness. From the character, a phenomenon is understood as the internal of things. Before this study, I saw disability as a way of life for impaired people, but never understood my consciousness of the object (the phenomenon) having somewhat similar experiences as the research participants. This new understanding of my general consciousness provided a unique perspective of how I see myself, 1) as a researcher and 2) as part of the research itself. In other words, consciousness is

internal to an object, which causes a reflection of that same object. To understand general consciousness and be genuinely reflective, one must understand one's self-consciousness.

Self-Consciousness

Hegel's idea of self-consciousness surrounds not an object but the individual self and understanding of its true nature. This true nature must become the individual itself in all aspects. An individual's self-consciousness is achieved when the otherness (refers to anything outside of the object) is cancelled. This cancelling of everything else allows the individual to focus on self and become an object unto him or herself. This newly formed object becomes the individual's focus, whether in existence or still existing. It is that self-awareness of the individual where self-consciousness is possible.

There is more to self-consciousness than just the individual seeing him or herself as an object. Hegel expresses that true self-consciousness is the product of culture and society, which he further explains cannot be achieved through an individual's experience. This explains the contradiction earlier, where it was explained that self-consciousness surrounds one, self-creating an object unto oneself. However, in later literature, Hegel explains that through mutual recognition, we are self-aware, creating the avenue for self-consciousness.

Hegel's self-consciousness is said to be centred on three stages: 1) desire, which relates to other things other than the one as an object, 2) the master-slave relationship, which relates to another self-consciousness that is not related to itself, 3) universality of self-consciousness, which relates to one intuition and is additionally related to all virtues, example (love, understanding, caring, and compassion).

Reason

He explains that Hegel's *reason* of phenomenology is the highest level of consciousness and self-consciousness. The reason is explained by (Lugosch, 2021) as valid new assertions even when new ones are given.

Application to study

Hegel's theory of consciousness and self-consciousness described one's dialectic perspective on the self. Further, coming out of the ideology of understanding consciousness in this study was *desire*. So then, the question can be asked, how did consciousness relate to me as the researcher in this study? Was I self-conscious at any time during the research process? Lastly, was this reached according to Hegel's theory of *reason*?

In the initial stages of conceptualising this study, I knew I was always interested in people living with a disability and their well-being. However, more particularly, my interest initially was an investigation of mobile applications to assist people with a disability to live more comfortably. The *knowing* in this instance was a consciousness of my environment, particularly my emphatic feeling towards the need to help advance the need for technology in the lives of people with disabilities. According to Hegel's theory of consciousness, this consciousness is an absolute consciousness of an external object (people with disabilities). My passion for further advancement in the academic study of a person with disabilities soon changed to what I refer to as a personal consciousness.

Into the first few months of my academic courses of study, my life changed completely, and so did my perspective. My perspective on the study focused more on how people with spine injuries lived their daily lives. After being diagnosed with disc degenerated disease and a severe bulging disc in the L4/L5 region of my spine, I was left unable to move from my bed for more

than eight months, with severe pain before seeking therapy and sometime after spine surgery. This personal experience then caused me to understand Hegel's second phase of consciousness called self-consciousness. I then realised that I had to change my view of what I now acknowledge as consciousness, realising an object person with disabilities to a more concentrated focus, which is now looking at the social model of disability and the experience of people living with a disability. This experience then triggered self-consciousness in me. At this point in the study, I started interacting with the participants and their environment. I was aware of myself as the object, aware of who I was and my role in the study as the researcher, but not far removed because of the shared experience with the participants. Hegel made mention of a struggle between two individuals while describing self-consciousness as master and slave. This aspect of self-consciousness was not explored as only one entity/object existed. However, after acknowledging self-consciousness, there was one final stage in Hegel's three phases of Phenomenological consciousness, reason. This self-sufficient factor of reason is a powerful element in Hegel's three phases of consciousness. Hegel equates reason to a rational process that guides history, which includes the idea of knowing. The acknowledgement of the certainty of knowing is the certainty of one's consciousness (Lugosch, 2021). That is, knowing that something exists exclusively in reality. This applies to me as a researcher as it gives me more scope to investigate my inner self and more reasons to do further academic queries into the phenomenon called reason.

Conclusion

A researcher is his best critic and his loudest cheerleader. It was a lonely road but perhaps the most rewarding journey ever. Many other research projects can potentially come out of this dissertation, looking into the lives of the caregivers of people with disabilities and the legislative

framework that governs people them. Additionally, looking at the whole aspect of disability from a social transformation standpoint, schooling, healthcare, and accessibility are just some areas I will endeavour to look further into as a budding researcher. All this is possible because of the motivation and drive I was determined to maintain from the start of this four-year journey.

CONCLUSION

Adding to the existing body of knowledge regarding the lived experience of people living with a spine injury within the OECS was one of the primary goals of this study. It was envisaged that a deeper understanding of people's experiences with spinal injury might contribute to social changes that better meet their social needs. This study has found that people with spine injuries suffer significantly from barriers caused by cultural stereotypes, which pose numerous challenges to people with spine injuries. Challenges include employment discrimination, educational discrimination, rehabilitative care, cost of treatment, infrastructure, and technological, social, and individual attitudes. It was considered that an examination of spinal cord injuries seen through the social model would provide a much-needed perspective of life with these conditions in the OECS.

The main aim of this study was to examine the lived experience of a person living with a spine injury in the OECS. This study allowed for a view of the lived experience of all the participants in the study. Phenomenology as a research methodology was chosen to understand their experiences better. The sampling method of selecting participants from the three participating countries brought many important issues facing individuals living in the OECS who are affected by a spine injury. Essential topics such as independence and the autonomy of individuals living with a spine injury to make their own choices are important matters relating to people with spine injuries. The point of discrimination is a problem amongst people with

disabilities. Though it was not a significant theme coming out of the study, it highlights other researchers' work consistency. Further, a lack of public education needs to be sensitised to matters related to individuals living with disabilities.

The social model of disability as pointed out in this study comes with several components which were aligned to this research. The social model since the 1980s has garnered a wealth of literature and knowledge for the academic world (Lawson et al., 2021). The model was created by disabled people for disabled people, which explains that disability is created by the society in which they live (Lawson et al., 2021). With that, the social model of disability focuses on three main components or barriers. 1) These are physical barriers which, for example, include factors such as inaccessible buildings, which came out in the study where several participants expressed not having proper wheelchair access to places of business and school. 2) The second component relates to social barriers. This barrier relates to the attitude of individuals in society which translates into many forms of discrimination (Lawson et al., 2021). This was highlighted when some of the participants mostly females, expressed how they were discriminated on various levels. These levels included discrimination in education and independence, where her decision to make a family was looked upon as been unnatural. 3) Lastly, attitudinal barriers. This according to Lawson et al., (2021) is the inability of individuals to understand aspects of the lives of disabled people without being educated about the lives of disabled people. In my study, many instances of the lack of education about the lives of disabled people came out strongly. In some instances, participants often expressed being stared at harshly and at times are often heard saying things like *“why don't they stay home”*, or *“they better off be on their verandahs.”* The social model makes a mark distinction between what is an impairment and a disability.

The genesis of this education journey should start in the schools: Attitudes to disability and other facets of identity are formed in primary and secondary forms of socialisation (Moss et al., 2020). I have also highlighted the need for legislative enforcement and change in dealing with the building code of public and private buildings. The improvement of accessibility for people living with a disability featured prominently in the study. Further, it highlights the need for public and private institutions to have a work policy that deals with policies surrounding people with disabilities. One example is that a few participants said that doing business in the city areas is very difficult, as access to buildings and public road infrastructure.

This research further supports existing literature (Borg Larsson & Östergren, 2011) on the need for medical and rehabilitation staff training. A few participants described some unpleasant encounters at the rehabilitation centres, and the quality of service offered. This additional training will also assist rehabilitation workers in acquiring new skills appropriate for helping people with an SCI. Ghosh et al. (2021) point out that most additional training for rehabilitation workers is done in the private sector, which indicates that insufficient is not in the public rehab facilities. The research also highlights the importance of care and family support to individuals with spine injuries, particularly in the early stages of the damage. One participant explained this support from family was always been good and also thought they are even more loving now. It highlights the importance of family support and the positive effect on an individual with a spine injury. The findings from this study highlight and support current literature on the need for dedicated support from family members and caregivers of people with spine injuries.

The lack of support for people with disabilities, according to Baker (2021), can harm the individual educational journey. Not only can support aid in the education journey of people with

disabilities but also, with adequate support, people with disabilities can go on to find employment and contribute to society. As suggested, this support is vital for the physical and mental recovery of people with spine injuries and the mental and emotional challenges ahead. This research may help guide further legislation on ensuring that businesses adopt disability policy changes, begin meaningful discussions on society's involvement in how people with disability are treated and seen and strengthen and enforce existing ones by reviewing existing legislation. The review will ensure that all laws and policies are up to date and in line with international standards set by the United Nations CRPD.

Most importantly, this study allowed participants to talk about their experiences, concerns, and struggles while living with a spine injury. Interpretations based on participant narratives have been made, which has helped to highlight the importance of the participants' perspectives in this research. People living with a spinal cord injury in the OECS have frequently felt marginalised and misunderstood; this study has thus served to validate their experience and give a voice to this often-voiceless group in the OECS.

Women with spine injuries face more stigma and discrimination with social and infrastructural barriers than men with the same or similar impairments. Most of the women in this study expressed the desire to function in society by appealing to recognise their abilities to perform daily activities for their well-being. Most participants said they experienced discrimination about their impairments because of their physical appearance. In this light, the participants believe that disability carries a negative connotation. Generally, the females did not receive discrimination which was different from the males. However, one participant experienced open discrimination because pregnancy can be a significant issue for all females who may have a child despite their impairment. Women's overall experience in the study were

generally more of overcoming societal norms by going beyond the norm and seeking employment despite their impairments. Most women in the study sought and gained employment after their injury, which shows their abilities (United Nations CRPD, 2006). According to the study, this ability to work independently depended on family members being supportive and allowing participants to make decisions that affect them (Chan, 2018).

The findings of this OECS study are essential to understanding the experiences of people with spine injuries, as they brought to light the experience of a female participant who conceived a child well after her injury. The significance of her accounts lies in the discrimination she recounted, which was directly associated with her status as a disabled, pregnant woman. This experience further indicates the need for broader public consultation and for the voices of associations and groups to minimise discrimination against women living with spine injuries. Though this was a one-off incident from the pool of participants, (Beleza, 2003) suggest perhaps that women with disabilities generally feel that the medical profession discourages them from engaging in sexual relations. This ideology comes from the perception that women with disabilities are unfit to be parents, unlike the assumptions made of males who are disabled. This finding brings to light the need for further dialogue with trained medical professionals who can advise women with spine injuries who are thinking of becoming pregnant. The participant faced discrimination during her pregnancy, as outlined in the findings section of this study. Still, initially, the uncertainty of whether it was possible to get pregnant was a knowledge barrier within itself.

Generally, all participants lacked social inclusion, making this issue the most prevalent one raised in the study. Many participants shared varied forms of exclusion, from inadequate infrastructure to proper access to buildings to being excluded or barred from attending school, a

form of educational discrimination. The participants spoke of unfriendly environments, discrimination on the streets, and lack of access to public and other buildings when they go out, in school and even when trying to have a child. However, despite the protection against disability discrimination offered within the legislation of (Antigua and Barbuda's Disabilities and Equal Opportunities Bill 2017 and St. Lucia's Equality of Opportunity and Treatment in Employment and Occupation Act, 2001), there is still substantial evidence that this is now working to better many social and economic outcomes faced by individuals living with an impairment (Temple et al., 2018). A negative attitude from society toward people living with an impairment can isolate them, where people living with impairments may be forced to stay inside from public view.

Thus, they are significant to the government institutions whose responsibility is to ensure infrastructural safety, social inclusion, and development to ensure that people with impairments live comfortable and inclusive life. For example, the Social Transformation Ministry in the three islands in which this study was undertaken can agitate for structural changes in policies for a more inclusive society for people living with an impairment (UNCRPD, article 8, 2006). All findings from this study could initiate meaningful discussion among interest groups (friends, family, government institutions, legislators, government organisations and people with disabilities alike). If stakeholders participate in meaningful and open discussions, the results can benefit everyone, resulting in a more all-inclusive society.

Overall, the study demonstrated the many barriers presented to people with spine injuries living in the OECS. The participants' narratives of depression, exclusion, discrimination (education, high cost of healthcare) and infrastructural obstacles can only be eliminated if a concerted effort is made to remove the stigma aligned with people living with a spine injury outlined in the recommendation section of this report. All participants in the study expressed a

need to be seen as valuable individuals. Therefore, they wish to be seen as people of worth who can contribute to society despite their impairment. Rembis (2019) suggests that we can only advance disabled people's positions and promote their inclusion and full participation in society by deconstructing these social barriers. Shakespeare and Watson (2018) further iterate that social and public policy changes will be visible throughout societies through global transformation. This global transformation will start in local communities, organisations and groups through persistent activism and education.

One of the most critical aspects of this study is raising awareness. Most participants felt that enough is not done to raise awareness about people living with an impairment. While interviewing one participant, it was supposed that they do not care. This non-caring perception stems from the overall treatment and the public's perception of people with an impairment. With public awareness comes empathy, which creates understanding, and this awareness fosters an all-inclusive society where all are seen as one and treated as equals. Improving public awareness from the primary level of people living with an impairment is vital to breaking down social barriers like discrimination. Discrimination is hinged on verbal discrimination, the educational system, employment opportunities, and even the judicial system.

Beckett and Lawson (2018) suggest that further study on disabilities concerning discrimination against people with impairment is needed to raise awareness. Ableism promotes value for certain forms of personhood and psychological health more than others, organise social environments around normative citizens, and creates an institutional bias (Beckett & Lawson, 2018). Therefore, one should believe people when they disclose their disability and listen to people when they request reasonable accommodation (Eisenmenger, 2021). According to Beckett and Lawson this discrimination brings to focus the issue of disablism. Eisenmenger

(2021) describes ableism as rooted in the assumption that people with an impairment are defined by their disability and are classified as less than people with little worth. Professional practices that privilege normative ways of living and our other values must be investigated.

Qualitative content matters were addressed in the study. Most importantly, the data coming out of this qualitative study illustrates that the participants believe that society's perception of impairment and disability presently offers few interpretative positions. The accounts from the study suggest that issues of impairments and living with impairment will continue to be misunderstood by society. The discrimination faced by the participants and having no consideration for suitable building access to facilitate all types of impairments are just some of the barriers participants face daily.

The social model assists us in identifying barriers that make life more difficult for disabled people. This should underline future research, policy, and practice in these areas if lives are to be improved. Eliminating these barriers promotes equality and provides disabled people with greater independence, choice, and control (Lawson & Beckett, 2021). Lawson & Beckett's (2021) assertions of political repurposing are consistent with the findings of this research as far as the necessity to improve existing legislation and introduced new ones that may tackle existing barriers that previous legislation failed to undertake. Finally, the social model of disability was created by disabled people to protect disabled people from socially constructed marginalised and disadvantaged experiences by individuals with an impairment. The social model of disability can be essential for disability policy in the OECS, and it may provide policymakers with valuable insight into developing policies that will improve the lives of people with disabilities.

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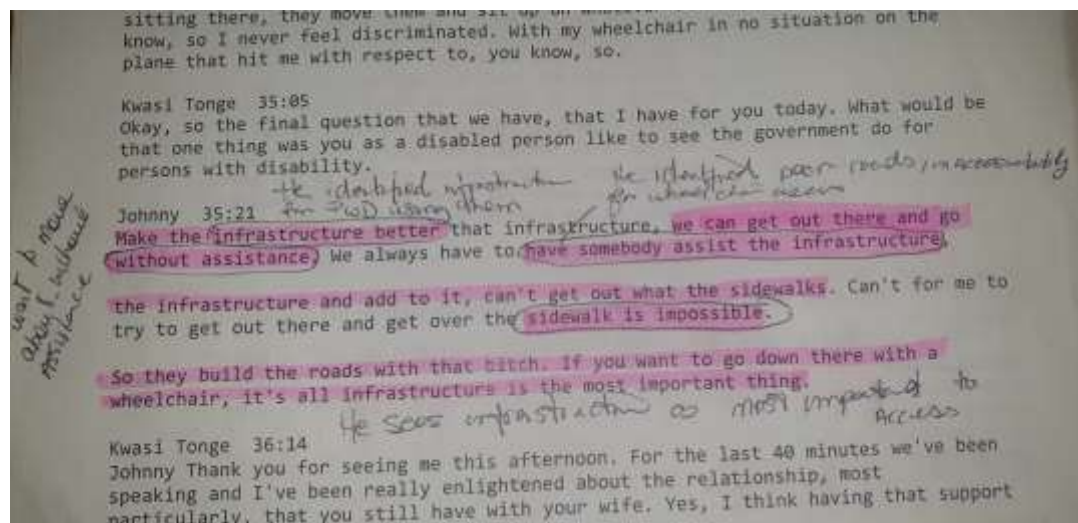
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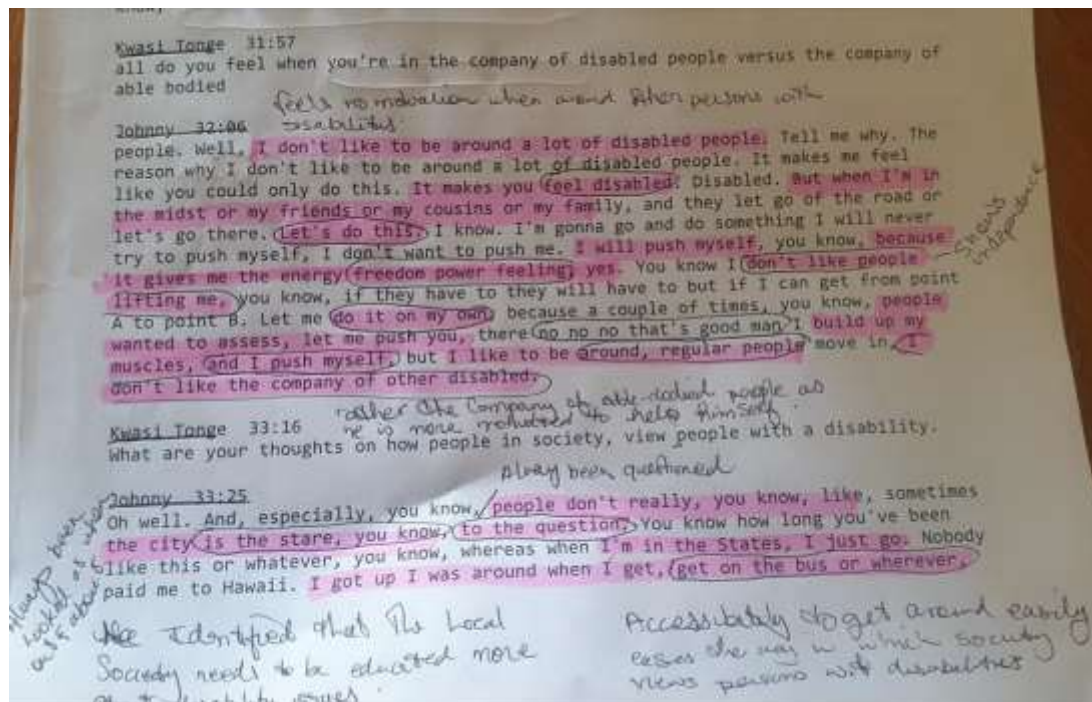
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APPENDICES

Appendix A: A Sample Level of Coding with the Transcript from a Participant





Appendix B: Sample Themes Emerging from Naomi

Name	Descriptive/ Frequently Used	Linguistic/Key Word	Conceptual Comments	Emergent Themes	Superordinate Themes
Naomi: St. Lucia 1. In what ways do people with spinal injuries experience daily life in the OECS?	Family / Siblings / Friends Supported	“They encouraged me to go forward. Do not give up.” “My family helped” “So, you find them more supportive and more understanding.” Committed relationship with her partner	Close to mother Closer to my brother than my sisters. Father assists He's very protective.	Feeling loved and accepted	Love
	Unappreciative	“Then you see persons who don't appreciate their life.” “They have mobility, and they don't appreciate it and you who want it cannot have it.”	Taken for granted	Feelings of ingratitude	Unappreciated
	Sensitisation / Awareness	“Because I think they still look at persons with disability as a problem.” “I don't think they understand.” “Why don't you just stay home?”	Misunderstood	Lack of awareness that disabled people are still “able.”	Misconceptions

Descriptive/ Frequently Used	Linguistic/Key Word	Conceptual Comments	Emergent Themes	Superordinate Themes
Depressed	<p>"They tend to put you down."</p> <p>"Why you're doing certain things."</p> <p>"So, they turn their backs on you and just leave you to fend for yourself."</p> <p>"Because when we started going out, a person said to him why he was with me. Why is he taking advantage of me?"</p>	Ostracised by individuals	Feelings of being unwanted / left out / excluded	Exclusion
Emotional	<p>"I just wanted to cope with me having my Disability. I needed to accept me."</p> <p>"I wish I could turn back the hands of time."</p> <p>"I wish I could have gone back to when I could walk."</p>	Life outlook is dynamic	Constant reminiscing of what was has caused her to be in a state of "what if I was not disabled."	Regret

Name	Descriptive/ Frequently Used	Linguistic/Key Word	Conceptual Comments	Emergent Themes	Superordinate Themes
2. What are the most significant new barriers to inclusion experienced by persons with spinal injuries since their injuries?	Appreciated	“I am always out with my friends.” “I go out a lot with the other girls in a similar position as I.”	She finds comfort in the presence of both her friends and close family members		Relationship
	Respected	“Despite the fact they were not used to it as we forced ourselves onto society”. “If you come and the door is closed, and you need to come in, they will come open the door for you and stuff.” “I don't understand why society feels that way to persons with disability at the end of the day, and they're human beings with needs and dreams and desires and wants.”	Some individuals have made her feel welcome, When she goes out for drinks or a regular time with friends. I talked about little assistance that people would give	Gratitude towards individuals	Appreciations

Name	Descriptive/ Frequently Used	Linguistic/Key Word	Conceptual Comments	Emergent Themes	Superordinate Themes
2. What are the most significant new barriers to inclusion experienced by persons with spinal injuries since their injuries?	Valued	<p>“They were very accommodating at work.”</p> <p>“They have a right to live their lives the way they choose not to do with society.”</p>	They here mean that my co-workers and supervisors go all out to ensure I am comfortable, knowing that I can produce	So long as the environment is conducive to work, persons with disabilities can produce just as much as non-disabled individuals	Accommodative
	Employed	<p>There are three of us ladies who are used to seeing Jelena me. I work with the government, and there's Krishna who works. In the supermarket chain, so they're seeing us.</p> <p>Persons with disabilities have the right to work and the right to education.</p>	She expresses the right to employment. The environment in which she works is comfortable	Public's view on employment and persons with disabilities	<p>Empowerment</p> <p>Disability rights</p>

Name	Descriptive/ Frequently Used	Linguistic/Key Word	Conceptual Comments	Emergent Themes	Superordinate Themes
2. What are the most significant new barriers to inclusion experienced by persons with spinal injuries since their injuries?	Accessibility	<p>"They had to make certain arrangements, like putting a ramp in front of the building for me to get up."</p> <p>Then they have to put another one somewhere in the building so I can get around. My electric wheelchair.</p> <p>"Business places they're not wheelchair friendly. I would love to see some bill being active that says. Your place has to be wheelchair friendly."</p> <p>The right to transportation.</p>	She indicated the willingness of her employer to assist her in any way		Barriers

Name	Descriptive/ Frequently Used	Linguistic/Key Word	Conceptual Comments	Emergent Themes	Superordinate Themes
3. How are the experiences of newly disabled people with spinal injuries affected by membership of different social backgrounds? a) How is this affected by overall care, cost, gender analysis	Isolation	"One of the nurses that were close to me. She had chickenpox, so I had to be isolated."			Abandonment
	Transportation	"Transportation moving from one point to another, it wasn't as easy as I was used to. I needed to get a special taxi to take me from point A to point B". while in the UK "I was faced with transportation barriers, but my dad was around. Before buying a license, my dad stepped in, so I was my chauffeur. He would take me to doctor therapy, and then when I started working, he was my transport for more than five years to and from work."			Accessibility / Availability

3. How are the experiences of newly disabled people with spinal injuries affected by membership of different social backgrounds? a) How is this affected by overall care, cost, gender analysis	Descriptive/ Frequently Used	Linguistic/Key Word	Conceptual Comments	Emergent Themes	Superordinate Themes
	Stereotype	<p>“The business places we had problems hiring persons with disabilities because they saw you as a problem.”</p> <p>“They saw you as a problem because they do not cater to persons with disabilities in other business places.”</p>	<p>She is unable to do things because of her Disability</p> <p>She sees another business has been a follower of the crowd</p>	Ignorant of the social responsibility toward the person with disabilities.	Discrimination
	Disregarded	<p>“When it's time for you to get a promotion, they look down on you because it's like you're not able to move around like the able-bodied persons.”</p>			Equal Opportunity; Bias
		<p>“Everything from the one where they put the needles in your back like the Chinese does acupuncture.”</p> <p>“Rehab in Saint Lucia was worse off than</p>			

		<p>England.” It was a lot less than what they did in the UK.</p> <p>“You would come, and they would stretch your leg and cast it until you stand. Stand for half an hour, then massage and send you home.”</p> <p>My assistant governmental signature. I got assistance when I was going to Martinique, and I got some money from NIS.</p>			
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Appendix C: Research Interview Guide

Introduction:

1. Introduction of the researcher (**I will introduce myself to the participant**), I would like to thank the participants for speaking with me today.
2. The purpose of the study will be explained to the participants, and a brief history of the institution will follow. (**UNICAF University**)
3. The duration of this interview will be between **60-90 minutes**.
4. Participants will be informed that their participation in today's interview is optional, and they have the right not to answer any questions posed to them and have the right to withdraw at any time.

Consent and confidentiality:

1. The study's findings will be compiled in a thesis and reviewed by my supervisor and me.
2. During this data-gathering phase, your name or the organisation you are associated with **will not** be included in the study.
3. Participants will be informed that their real names will be substituted with pseudonyms
4. I will be recording this interview using recording software. This way, all the interview details will be captured electronically, and no data collected will be lost. For the interviews sessions that will be conducted online, zoom will be the preferred platform as it provides a secure means of voice and video recording and an add-on that atomically transcribes the voice into text,
5. Please confirm that you understand the purpose of the study and that they are happy to be a part of it.
6. Do you have any questions at this point?

Personality

- 1 Can you please tell me a little about yourself and your social life
 - I. Like where you grew up?
 - II. Activities you engaged in?
 - III. Do you have any siblings?
 - IV. What is your relationship with them?
- 2 Please tell me about your work. Do you work, or have you ever worked? If you have worked, can you please tell me about it?
 - I. Please tell me where you have worked.
 - II. What position you held, and for how long?
 - III. Did you enjoy working there?

Life Experience

- 1 Do you mind telling me a little about your life before your injury (impairment)
- 2 Would you mind telling me about the changes in your life since the injury that caused you to become disabled?
 - I. Has your impairment caused any other ailments (comorbidities)

Family Life

- 1 Has your family changed much since your injury? If so, please tell me to what extent.
- 2 Do you have children? If so, how has your injury affected your relationship with them?
- 3 Please tell me what the photo you have chosen means to you and why? How does it relate to your current life?

Present and future care

1. Please can you tell me about your daily routine
2. Tell me about support and your perception of it?
3. Please tell me of any barriers you face because of your impairment.
4. Please tell me about any assistance, whether (in assistive technologies or rehabilitative therapy) you receive from the local association or the government.

Work Experience

1. Please tell me about your current work environment, if you work, and your other activities if you still need to.
2. How do you see yourself in terms of the wider team and relationships with senior and junior colleagues?

Technologies

1. Please can you tell me about any technologies you use to assist you in your daily living
2. Was this state-funded or personal (family-assisted)?
 - I. Please can you tell me about any rehabilitation therapy you are presently undergoing?

Society's views

1. I know few of us have had social lives as such since the pandemic, but please, can you tell me about your social life in the past, currently and how you see this in the future?
 - I. Do you ever go out?
2. Please, can you tell me about your self-identity?
 - II. How do you see yourself in the company of disabled people and non-disabled people?
3. What are your thoughts on how society sees a person with impairments?
 - I. Are there any stereotypes or discrimination that you face when you go out?
4. Are you aware of government policies protecting the rights of persons with impairment?
5. Do you think society and the government are doing enough for persons such as yourself living with an impairment?

6. Final Question

1. What would you like to see the government/policymakers do to improve the lives of persons living with an impairment?

Conclusion

Thank you for the time you spent with me today. I want to reassure you that all information gathered will be treated with the strictest confidence, following the University of UNICAF's ethical guidelines.

Are there any questions you wish to ask at this time?

Appendix D: Consent Forms



UU_IC - Version 2.1



Informed Consent Form

Part 1: Debriefing of Participants

Student's Name: Kwasi Kefentse Tonge
Students Email: Kwasi.tonge@gmail.com
Student ID #: R1805D5173731
Supervisor's Name: Dr. Alison Wilde
University Campus: Unicaf University Zambia (UUZ) UUZ: PhD
Program of Study: Doctorate of Philosophy
Research Project Title: Social Model of Disability: A phenomenological study of the lived Experiences of persons living with an Impairment caused by a Spinal Injury in the Organization of Eastern Caribbean States (OECS).

Date: 16-Apr-2021

Provide a short description (purpose, aim and significance) of the research project, and explain why and how you have chosen this person to participate in this research (maximum

The purpose of this qualitative phenomenological research is to capture the many difficulties that people living with an impairment caused by a spinal injury go through on a day-to-day basis and to gain in-depth understanding of the lived experiences of these persons. The aim of this study is to fully understand from the view point of person living with an impairment caused by a spine injury and the meaning of living with this impairment. The significance of this study will bring light to persons with this specific impairment, specifically for those persons living in the OECS. Granted that there has been research conducted in more developed countries like the United States, The United Kingdom and the European Union, very little study have been carried out within the Caribbean more the Organization of the Eastern Caribbean States (OECS)

150 words).

The above-named Student is committed in ensuring participant's voluntarily participation in the research project and guaranteeing there are no potential risks and/or harms to the participants.

Participants have the right to withdraw at any stage (prior or post the completion) of the research without any consequences and without providing any explanation. In these cases, data collected will be deleted.

All data and information collected will be coded and will not be accessible to anyone outside this research. Data described and included in dissemination activities will only refer to coded information ensuring beyond the bounds of possibility participant identification.

I, Kwasi Kefentse Tonge, ensure that all information stated above is true and that all conditions have been met.

Student's Signature: Kwasi Tonge



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Informed Consent Form

Part 2: Certificate of Consent

This section is mandatory and should to be signed by the participant(s)

Student's Name: Kwasi Kefentse Tonge

Student's E-mail Address: kwasi.tonge@gmail.com

Student ID #: R1805D5173731

Supervisor's Name: Alison Wilde

University Campus: Unicaf University Zambia (UUZ)

Program of Study: UUZ: PhD Doctorate of Philosophy

Research Project Title: Social Model of Disability: A phenomenological study of the lived experiences of persons living with a Impairment caused by a Spinal Injury in the Organization of Eastern Caribbean States (OECS).

I have read the foregoing information about this study, or it has been read to me. I have had the opportunity to ask questions and discuss about it. I have received satisfactory answers to all my questions and I have received enough information about this study. I understand that I am free to withdraw from this study at any time without giving a reason for withdrawing and without negative consequences. I consent to the use of multimedia (e.g audio recordings, video recordings) for the purposes of my participation to this study. I understand that my data will remain anonymous and confidential, unless stated otherwise. I consent voluntarily to be a participant in this study.

Participant's Print name:

Participant's Signature:

Date:

If the Participant is illiterate:


I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had an opportunity to ask questions. I confirm that the aforementioned individual has given consent freely.

Witness's Print name:

Witness's Signature:

Date:

Appendix E: UNICAF Ethics Approval Form



REAF_DS - Version 3.1
☐

UNICAF UNIVERSITY RESEARCH ETHICS APPLICATION FORM DOCTORAL STUDIES		UREC USE ONLY: Application No: _____ Date Received: _____
Student's Name:	Kwasi Tonge	
Student's E-mail Address:	kwasi.tonge@gmail.com	
Student's ID #:	R1805D5173731	
Supervisor's Name:	Alison Wilde	
University Campus:	Unicaf University Zambia (UUZ) ▼	
Program of Study:	UUZ: PhD Doctorate of Philosophy ▼	
Research Project Title:	Social Model of Disability: A phenomenological study of the lived experiences of persons living with a Impairment caused by a Spinal Injury in the Organization of Eastern Caribbean States (OECS)	

1. Please state the timelines involved in the proposed research project:

Estimated Start Date: _____ Estimated End Date: _____

2. External Research Funding (if applicable):

2.a. Do you have any external funding for your research?

☐ YES ☒ NO

If YES, please answer questions 2b and 2c.

2.b. List any external (third party) sources of funding you plan to utilise for your project. You need to include full details on the source of funds (e.g. state, private or individual sponsor), any prior / existing or future relationships between the funding body / sponsor and any of the principal investigator(s) or co-investigator(s) or student researcher(s), status and timeline of the application and any conditions attached.

2.c. If there are any perceived ethical issues or potential conflicts of interest arising from applying or and receiving external funding for the proposed research then these need to be fully disclosed below and also further elaborated on, in the relevant sections on ethical considerations later on in this form.



REAF_DS - Version 3.1

3. The research project

3.a. Project Summary:

In this section fully describe the purpose and underlying rationale for the proposed research project. Ensure that you pose the research questions to be examined, state the hypotheses, and discuss the expected results of your research and their potential.

It is important in your description to use plain language so it can be understood by all members of the UREC, especially those who are not necessarily experts in the particular discipline. To that effect ensure that you fully explain / define any technical terms or discipline-specific terminology (use the space provided in the box).

This research will investigate individuals living with impairment caused by spinal injury. An investigation of people with a physical impairment in the OECS is an untapped area of research, focusing on their integration into society as per the social model of disability. Many studies have been done in developed countries but fewer in less developed countries like the Caribbean. Researchers such as Shakespeare (2015) have identified gaps in disability research which may answer questions such as "what impact does disability have on family life" (p. 2.) Unstructured interviews and photo-elicitation will be used to collect their detailed life story, looking into their social stance and their point of view on how living with an impairment has affected their way of life and any use of technology that enhances it. The research will focus on the following questions. a) What are the most significant aspects concerning the quality of life of persons living with a spinal injury-related impairment in the OECS? b) How can data collected from people with Impairments be used to model a better legislative agenda? c) In what ways are people with impairment living using the social model as a framework in Antigua & Barbuda and St. Lucia?



REAF_DS - Version 3.1

3.b. Significance of the Proposed Research Study and Potential Benefits:

Outline the potential significance and/or benefits of the research (use the space provided in the box).

Disability research is as essential as any other research. "Disability research is universally becoming more and more important" (Bolt, 2016, p. 11). As early as the 1970s, the Open University offered its first course in Disability Studies, and the University of Leeds opened its center for disability studies. In the industrial world, there have been steady advances in disability studies in the UK and Australia, Tokyo, and the United States. Unlike in less developed countries like Antigua and other countries, the OECS, research on disability studies has been few. Apart from the United Nations Convention on the Rights of People Living with Disabilities to protect them, there are no other mechanisms to indicate how people with impairments are included in society. Another critical aspect of the research is providing valuable information on the needs and barriers of this particular group of disabled people in order that lawmakers, policy-makers and the public may become better-informed. Further, to have a deeper understanding and appreciation of an individual's social challenges living with an impairment and the importance of having an all-inclusive society.

4. Project execution:**4.a. The following study is an:**

- ☐ experimental study (primary research)
- ☐ desktop study (secondary research)
- ☐ desktop study using existing databases involving information of human/animal subjects
- ☒ Other

If you have chosen 'Other' please Explain:

The proposed study is a phenomenological study which is exploratory in nature, using semi-structured questions and photo-elicitation to elicit data from participants.



REAF_DS - Version 3.1

4.b. Methods. The following study will involve the use of:

Method	Materials / Tools
Qualitative:	<input type="checkbox"/> Face to Face Interviews
	<input type="checkbox"/> Phone Interviews
	<input type="checkbox"/> Face to Face Focus Groups
	<input type="checkbox"/> Online Focus Groups
	<input type="checkbox"/> Other *
Quantitative:	<input type="checkbox"/> Face to Face Questionnaires
	<input type="checkbox"/> Online Questionnaires
	<input type="checkbox"/> Experiments
	<input type="checkbox"/> Tests
	<input type="checkbox"/> Other *

*If you have chosen 'Other' please Explain:

The instruments that will be used in this study will be narrative interviews and photo-elicitation.

5. Participants:

5 a. Does the Project involve the recruitment and participation of additional persons other than the researcher(s) themselves?

- ☒ YES If YES, please complete all following sections.
- ☐ NO If NO, please directly proceed to Question 7.



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5 b. Relevant Details of the Participants of the Proposed Research

State the number of participants you plan to recruit, and explain in the box below how the total number was calculated.

Number of participants

According to Creswell (1998, p.64) five to 25 is an acceptable number Morse (1994, p.225) suggest at least six in phenomenological studies. Therefore, I will be using a sample size of eight on both islands. Therefore, as it's a phenomenological study i will be using the suggested quota from Creswell.

Describe important characteristics such as: demographics (e.g. age, gender, location, affiliation, level of fitness, intellectual ability etc). It is also important that you specify any inclusion and exclusion criteria that will be applied (e.g. eligibility criteria for participants).

Age range From To

Gender ☒ Female
☒ Male

Eligibility Criteria:

- Inclusion criteria
- Exclusion criteria

Disabilities

Other relevant information (use the space provided in the box):

It is important to note that the on-going pandemic (Covid-19) may affect one or two interview session. I intend to adhere to all protocols set out by both countries Ministries of Health. If a participant cannot meet face-to-face, the association has agreed to make available conferencing technology to facilitate the interviews.



REAF_D5 - Version 3.1

5 c. Participation & Research setting:

Clearly describe which group of participants is completing/participating in the material(s)/ tool(s) described in 5b above (use the space provided in the box).

5 d. Recruitment Process for Human Research Participants:

Clearly describe how the potential participants will be identified, approached and recruited (use the space provided in the box).

The recruitment for this study will be from two OECS countries, Antigua and St. Lucia. I will work with the disability association in Antigua and Barbuda to disseminate and publicize the study specific to members with back and Spinal Injuries. (these participants have already been identified but the president). If there are any drop-outs, the president has assured that sufficient candidates meet the criteria to complete the vacant slots. For the interested participants, I will provide an information sheet (in various formats) and a consent form to ensure informed consent is gained before I proceed to interviews. Therefore, I will be choosing a minimum of eight (8) participants from the association in Antigua and Barbuda. For the island of St. Lucia, I have consequently made contact with the Head of the disability association on the island, and a similar arrangement was made to that of Antigua, that is, recruitment of eight (participants), presented with an information

5 e. Research Participants Informed Consent.

Select below which categories of participants will participate in the study. Complete the relevant Informed Consent form and submit it along with the REAF form.

Yes	No	Categories of participants	Form to be completed
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Typically Developing population(s) above the maturity age *	Informed Consent Form
<input type="checkbox"/>	<input type="checkbox"/>	Typically Developing population(s) under the maturity age *	Guardian Informed Consent Form

* Maturity age is defined by national regulations in laws of the country in which the research is being conducted.



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5 f. Relationship between the principal investigator and participants.

Is there any relationship between the principal investigator (student), co-investigators(s), (supervisor) and participant(s)? For example, if you are conducting research in a school environment on students in your classroom (e.g. instructor-student).

☐ YES ☒ NO

If YES, specify (use the space provided in the box).

6. Potential Risks of the Proposed Research Study.

6 a. i. Are there any potential risks, psychological harm and/or ethical issues associated with the proposed research study, other than risks pertaining to everyday life events (such as the risk of an accident when travelling to a remote location for data collection)?

☒ YES ☐ NO

If YES, specify below and answer the question 6 a.ii.

According to Good (2005), in her paper "Ethics in disability research", she sets out several ethical guidelines while conducting ethical research involving person with impairments. To include: The respect of Human rights, equality and dignity. Social justice advancement, well-being and complex avoidance are just some of the guideline a researcher should look out for. I do not foresee any potential risk being physical or psychological to the research participants. Participants will be in the know of what is happening from the inception, during the research and after (debriefing). I hope to follow guidelines such as the United Nations Equalization of Opportunities for Persons with impairments. All participants will be informed of the study before and after the study. Thi

6 a.ii Provide information on what measures will be taken in order to exclude or minimise risks described in 6.a.i.



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6 b. Choose the appropriate option

		Yes	No
i.	Will you obtain written informed consent form from all participants?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
ii.	Does the research involve as participants, people whose ability to give free and informed consent is in question?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
iii.	Does this research involve participants who are children under maturity age? If you answered YES to question iii, complete all following questions. If you answered NO to question iii, do not answer Questions iv, v, vi and proceed to Questions vii, viii, ix and x.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
iv.	Will the research tools be implemented in a professional educational setting in the presence of other adults (i.e. classroom in the presence of a teacher)?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
v.	Will informed consent be obtained from the legal guardians (i.e. parents) of children?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
vi.	Will verbal assent be obtained from children?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
vii.	Will all data be treated as confidential? If NO, explain why confidentiality of the collected data is not appropriate for this proposed research project, providing details of how all participants will be informed of the fact that any data which they will provide will not be confidential.	<input checked="" type="checkbox"/>	<input type="checkbox"/>
viii.	Will all participants /data collected be anonymous? If NO, explain why and describe the procedures to be used to ensure the anonymity of participants and/or confidentiality of the collected data both during the conduct of the research and in the subsequent release of its findings.	<input checked="" type="checkbox"/>	<input type="checkbox"/>



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	Yes	No
ix. Have you ensured that personal data and research data collected from participants will be securely stored for five years?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
x. Does this research involve the deception of participants? If YES, describe the nature and extent of the deception involved. Explain how and when the deception will be revealed, and who will administer this debrief to the participants:	<input type="checkbox"/>	<input checked="" type="checkbox"/>

6 c. i. Are there any other ethical issues associated with the proposed research study that are not already adequately covered in the preceding sections?

☐ Yes ☒ No

If YES, specify (maximum 150 words).

6.c.ii Provide information on what measures will be taken in order to exclude or minimise ethical issues described in 6.c.i.

6 d. Indicate the Risk Rating.

☐ High ☒ Low



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7. Further Approvals

Are there any other approvals required (in addition to ethics clearance from UREC) in order to carry out the proposed research study?

☐ YES ☒ NO

If YES, specify (maximum 100 words).

8. Application Checklist

Mark ✓ if the study involves any of the following:

- ☒ Children and young people under 18 years of age, vulnerable population such as children with special educational needs (SEN), racial or ethnic minorities, socioeconomically disadvantaged, pregnant women, elderly, malnourished people, and ill people.
- ☐ Research that foresees risks and disadvantages that would affect any participant of the study such as anxiety, stress, pain or physical discomfort, harm risk (which is more than is expected from everyday life) or any other act that participants might believe is detrimental to their wellbeing and / or has the potential to / will infringe on their human rights / fundamental rights.
- ☐ Risk to the well-being and personal safety of the researcher.
- ☐ Administration of any substance (food / drink / chemicals / pharmaceuticals / supplements / chemical agent or vaccines or other substances (including vitamins or food substances) to human participants.
- ☐ Results that may have an adverse impact on the natural or built environment.

9. Further documents

Check that the following documents are attached to your application:

		ATTACHED	NOT APPLICABLE
1	Recruitment advertisement (if any)	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2	Informed Consent Form / Guardian Informed Consent Form	<input type="checkbox"/>	<input type="checkbox"/>
3	Research Tool(s)	<input type="checkbox"/>	<input type="checkbox"/>
4	Gatekeeper Letter	<input type="checkbox"/>	<input type="checkbox"/>
5	Any other approvals required in order to carry out the proposed research study, e.g., institutional permission (e.g. school principal or company director) or approval from a local ethics or professional regulatory body.	<input type="checkbox"/>	<input type="checkbox"/>



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10. Final Declaration by Applicants:

- (a) I declare that this application is submitted on the basis that the information it contains is confidential and will only be used by Unicaf University for the explicit purpose of ethical review and monitoring of the conduct of the research proposed project as described in the preceding pages.
- (b) I understand that this information will not be used for any other purpose without my prior consent, excluding use intended to satisfy reporting requirements to relevant regulatory bodies.
- (c) The information in this form, together with any accompanying information, is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- (d) I undertake to abide by the highest possible international ethical standards governing the Code of Practice for Research Involving Human Participants, as published by the UN WHO Research Ethics Review Committee (ERC) on <http://www.who.int/ethics/research/en/> and to which Unicaf University aspires to.
- (e) In addition to respect any and all relevant professional bodies' codes of conduct and/or ethical guidelines, where applicable, while in pursuit of this research project.



I agree with all points listed under Question 10

Student's Name: Kwasi Tonge


Supervisor's Name: Alison Wilde

Date of Application: 08-Apr-2021

Important Note:

Save your completed form (we suggest you also print a copy for your records) and then submit it to your UU Dissertation/project supervisor (tutor). **In the case of student projects, the responsibility lies with the Faculty Dissertation/Project Supervisor.** If this is a student application, then it should be submitted via the relevant link in the VLE. Please submit only electronically filled in copies; **do not** hand fill and submit scanned paper copies of this application.

Appendix F. Unicaf University Research Ethics Committee Decision


UREC Decision, Version 2.0

Unicaf University Research Ethics Committee Decision	
Student's Name:	Kwasi Tonge
Student's ID #:	R1805D5173731
Supervisor's Name:	Dr Alison Wilde
Program of Study:	UUZ: PhD Doctorate of Philosophy
Offer ID /Group ID:	O24681G25017
Dissertation Stage:	3
Research Project Title:	Social Model of Disability: A phenomenological study of the lived experiences of persons living with a Impairment caused by a Spinal Injury in the Organization of Eastern Caribbean States (OECS)
Comments:	No comments
Decision*:	A. Approved without revision or comments
Date:	10-Jun-2021

*Provisional approval provided at the Dissertation Stage 1, whereas the final approval is provided at the Dissertation stage 3. The student is allowed to proceed to data collection following the final approval.

Appendix G. Non-completed consent form

UNICAF
UNIVERSITY

UU_IC - Version 2.1

Informed Consent Form

Part 1: Debriefing of Participants

Student's Name:

Student's E-mail Address:

Student ID #:

Supervisor's Name:

University Campus:

Program of Study:

Research Project Title:

Date:

Provide a short description (purpose, aim and significance) of the research project, and explain why and how you have chosen this person to participate in this research (maximum 150 words).

The above named Student is committed in ensuring participant's voluntarily participation in the research project and guaranteeing there are no potential risks and/or harms to the participants.

Participants have the right to withdraw at any stage (prior or post the completion) of the research without any consequences and without providing any explanation. In these cases, data collected will be deleted.

All data and information collected will be coded and will not be accessible to anyone outside this research. Data described and included in dissemination activities will only refer to coded information ensuring beyond the bounds of possibility participant identification.

I, , ensure that all information stated above is true and that all conditions have been met.

Student's Signature:



UU_IC - Version 2.1

Informed Consent Form**Part 2: Certificate of Consent**

This section is mandatory and should to be signed by the participant(s)

Student's Name:

Student's E-mail Address:

Student ID #:

Supervisor's Name:

University Campus:

Program of Study:

Research Project Title:

I have read the foregoing information about this study, or it has been read to me. I have had the opportunity to ask questions and discuss about it. I have received satisfactory answers to all my questions and I have received enough information about this study. I understand that I am free to withdraw from this study at any time without giving a reason for withdrawing and without negative consequences. I consent to the use of multimedia (e.g. audio recordings, video recordings) for the purposes of my participation to this study. I understand that my data will remain anonymous and confidential, unless stated otherwise. I consent voluntarily to be a participant in this study.

Participant's Print name:

Participant's Signature:

Date:

If the Participant is illiterate:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had an opportunity to ask questions. I confirm that the aforementioned individual has given consent freely.

Witness's Print name:

Witness's Signature:

Date:

Appendix H. Gatekeeper Letter



UU_GL - Version 2.0



Gatekeeper letter

Address: Yorks Hermitage, Jennings, Antigua

Date: 12-Apr-2021

Subject: Assistance for recruitment

Dear Major Wilkin,

I am an/a doctoral student at Unicaf University Zambia.

As part of my degree I am carrying out a study on Social Model of Disability: A phenomenological study of the lived experiences of persons living with an Impairment caused by a Spinal Injury in the Organization of Eastern Caribbean States (OECS).

I am writing to inquire whether you would be interested in/willing to assist me in recruiting participants for this research.

Subject to approval by Unicaf Research Ethics Committee (UREC) this study will be using Phenomenological qualitative study with persons who have an impairment caused by a spin injury or spine birth defect. The study hopes to capture their lived experiences. The study will involve semi-structured interviews and the used of photo-elicitation to capture as much data as possible. The age group will be between eighteen (18) and sixty-five (65) and at least one year with the spine issue.

This qualitative phenomenological research aims to capture the many difficulties that people living with an impairment caused by a spinal injury experience daily and to further gain in-depth understanding of their lived experiences. Research topic: (The Social Model of Disability: A phenomenological study of the lived experiences of persons living with a Impairment caused by a Spinal Injury in the OECS). Alison Wilde is supervising this PhD research project.

Your roll in this process is to identify suitable participants by contacting them with details of the study. They will then be presented with a consent form with further details of the study for their approval.

Thank you in advance for your time and for your consideration of this project. Kindly please let me know if you require any further information or need any further clarifications.

Yours Sincerely,

Kwasi Tonge

Student's Name: Kwasi K Tonge

Student's E-mail: kwasi.tonge@gmail.com

Student's Address and Telephone: Hermitage Jennings Antigua, Tele: 268-780-6332

Supervisor's Title and Name: Dr. Alison Wilde

Supervisor's Position: Tutor

Supervisor's E-mail: a.wilde@unicaf.org