The State of Disability in Nigeria:

How Society Responds to Persons with Cerebral Palsy

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Abstract

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This study looks at the problem of disability health care assistance in Nigeria. It argues that Nigeria does not have sufficient technical or political capabilities to address the health concerns of adults living with CP. It focuses on Cerebral Palsy (CP), a neuro-development condition caused by developmental brain injury, triggering adverse effects on an individual's posture, movement or muscle control and persists throughout such an individual's life. This research argues that a comprehensive approach intersecting the Social-Oppression and Capability Human-Rights models of disability is needed to better understand and bolster disability development in Nigeria. It further argues that such an approach encompasses the embodied experiences of an individuals' impairment in direct correlation with the development of a rights-based approach, thereby fostering improved quality of life and care provision to people living with CP in Lagos State, Nigeria. Study findings were collected during a three-month field research employing semi-structured interviews with participants from six established organisations.

May 21st, 2019

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Finally, after a gruesome sequence of ups and downs, *Today is the day!*

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CHAPTER ONE - INTRODUCTION

BACKGROUND OF STUDY

> Globally, people are talking about “inclusion”. Inclusion! Inclusion! and so basically it came to Nigeria, and we also started talking about inclusion. But while we were talking about inclusion, we had forgotten that the system doesn't support this concept of inclusion. We must, as Black people, as Africans, pursue our wellbeing and happiness rather than trying to escape. Not like the experience of a Black American or Canadian which is very different from us! The things that drive us are different; very different.
>
> I love my country I will not lie, but I don’t like my government most of the time. In the sense that, they do not wake up and make policies or make laws that protect those who are most vulnerable amongst us. When they do, they do it in such a way that it robs people of their dignity.
>
> (Disability Director, Participant).

This narration articulates the reality of the disability movement in most developing countries, particularly Nigeria. The prevalence of capitalism, a free-market economic system, propels higher rates of inequalities amongst people living and working within Nigeria (Barnes & Sheldon, 2010, p. 771). This system impinges mostly on vulnerable populations such as Persons living with disabilities (PWDs). While this study does not encompass all disabilities, it focuses on the experiences of adults living with Cerebral Palsy (CP) disability in Nigeria. CP often classified as an intellectual disability, is a key manifestation of the experiences and attitudes to disabilities in the country. Existing in Nigeria with a disability means being in a constant state of poverty, poor health, lack of adequate health or rehabilitative care and other daily struggles, exacerbated by structural violence, inequality and a lack of rights-based support (Lagunju, Oyinlade, & Famosaya, 2016). The narration of a university student living with CP in Nigeria depicts this experience.

> A major side effect of my CP is pain. Just daily pain. It also affects the way I talk. I am always shy because right from time, from secondary school, people use to make jest of me. I sometimes feel really bad because I cannot do some things, like playing instruments, which I am so interested in because I love music. I just know that I survive living (with my disability).
>
> Participant S.O, 2018.

Contemporary societies structured around privately-owned competitive market systems are the prevailing norm. A capitalist free-market system operates through, self-interest and competition are the motivators of economic well-being, but little is mentioned about how society can adapt to those with special needs within it. Someone earning money through their own labor benefits not only themselves, but ultimately the whole society as well. Modern development discourse also embraces this sentiment, with shocking little attention paid to those who are marginalized due to their disabilities. Such a system, if left unchecked, fails to provide support for persons with special needs. In Nigeria, people who do not fit within socially set standards, are widely perceived as unproductive or irrelevant, and often become marginalized. For those in Nigeria with disabilities like CP, marginalization is inevitable. There are often two spectrums of experiences available to people who find themselves labeled or categorised within this standard. This was expressed in a female participants' narrative,

> Knowing I had a disability didn't change anything. I know there are lots of people in Nigeria who have CP too, and realising that I had this disability, made me want to help them become accepted in the society. People with CP tend to have different upbringing. While growing-up, I was allowed to do a lot of things on my own because my parents were enlightened. I had a childhood friend who passed away, she also had CP. Her parents always left her at home, they never brought her out. I think they did this because they

> believed she could never achieve anything in life. She eventually died in a fire while at home alone. She died not because she was disabled, or because she had a disability. She died because of her parent’s negligence (of her disability).
>
> Participant O.A, 2018.

Despite a historical trend of development overlooking the needs of persons with disabilities, in recent years, subsequent changes in these trends are creating a shift towards long-term inclusive development agendas. An example is the 17 Sustainable Development Goals (SDGs, 2030) agenda, which moves beyond past trends and limitations of the Millennium Development Goals (MDGs, 2010). This new development agenda claims to include all persons within the society. It encompasses the most influential actors in the society, such as government officials, all the way down to the poorest member in every community, such as people living below the poverty line, and even PWDs. But is this broad claim achievable?

Studies suggests that personal, social, and economic benefits may be attained from addressing disability issues (Metts, 2004, p. 1). Some benefits of disability inclusion are, higher Gross Domestic Product (GDP) per capita resulting in higher monetary market values for the country, personal development of PWDs resulting in greater independence for them, higher rates of employment, less assistance concerns for the government, higher mortality rates, and better mental supports systems for families of PWDs (World Report, 2011; Metts, 2004). With greater attention to disability appearing within international development, issues related to PWDs are explicitly being referenced and identified (Metts, 2004). Nevertheless, concerns about the health and well-being of PWDs are still not adequately addressed within new development agendas. Development-oriented policies and strategies should seek to increase the capabilities of PWDs by reducing the economic costs of disability care and addressing barriers that impede access to personal, economic or social opportunities (Metts, 2004).

The impact of having a disability is fundamentally a constant struggle to delink the growing oppressive relationship between ones' health and poverty (Braddock & Parish, 2001, p. 53). According to the ILO Geneva (2007), one out of every ten people across the world has a disability. This is out of 650 million people worldwide, approximately 470 million of which are of working age (ILO Geneva, 2007). An estimated 80 percent of this population reside in rural areas of developing countries, with limited or a complete lack of access to services they need. What's more, many must survive on earning personal income through informal market mechanisms in the bottom economic rung of their societies (ILO Geneva, 2011). Disabilities, either physical, sensory, intellectual or psychological, are often excluded at all level of government policies and programmes in developing countries such as Nigeria. This is also the reality of anyone living with CP in Nigeria. When many patients try to visit health care facilities in Nigeria, the prohibitive cost of health services, combined with sporadic service provision creates a challenging health landscape. The ideal management of CP is unfortunately very expensive and rarely available to the average Nigerian (Ogunlesi, Ogundeyi, Ogunfowora & Olowu, 2008). In other situations where they are made accessible, patients still report the inadequate capability to sufficiently address their health needs.

> Medical facilities in Nigeria don't explain to people about CP. When they treat patients with CP, they just look at ones' symptom. CP is treated as a general disability without any classification, the same procedure is given to everyone and this should not be so.
>
> Participant D.A, 2018.

The exact population of PWDs in Nigeria is difficult to ascertain, largely due to the lack of accurate statistics. According to the World Development Indicators (WDI) report written by the World Bank (2016), Nigeria’s population as of 2016 was approximately 185 million. The 2011 World Bank Report notes that of this 185 million people, approximately 25 million live with some form of disability. Out of the 25 million people living with a disability, 3.5 million have very significant difficulties in social and physical functioning including physical and intellectual developmental conditions (World Report, 2011). These data help provide a background to the problem of disability in Nigeria. However, there are still some excluded communities and persons not included in this count, thereby obscuring the general statistics on disability in Nigeria. What’s more, no accurate data exists in Nigeria as to the number of persons with Cerebral Palsy (CP) which is important to the purpose of this study. However, this should not hinder us from attempting to understand the experiences of PWDs like CP in Nigeria. Given the right environment, PWDs can find fulfilling opportunities as active societal members, improve their human dignity and social cohesion in all spectrums of society (World Report, 2011).

STATEMENT OF THE PROBLEM

This thesis explores the problem of disability and health care, especially how it shapes developmental issues within a country such as Nigeria. The overall aim of the study is to understand the state of disability assistance for people living with CP in Nigeria, its limitations within the country’s social context and possible solutions through development practices. Indicating these problems to inclusion and improved services is a crucial step in analysing and addressing problems of disabilities in Nigeria.

CP is a form of disability referring to a well-recognised neurodevelopmental condition that begins in early childhood, due to brain injury, or a development defect which affects the individual’s posture, movement or muscle control, and persists through the individual’s lifetime (Rosenbaum *et al.*, 2007). Disabilities such as CP are a challenge that impacts specific dimensions of an individual’s functionality. Such challenges account for unequal access to life chances for people labelled as "disabled". Government interventions are limited as PWDs are highly vulnerable and restricted by physical and social limitations imposed by other members of the society. Developing countries, due to their limited resources for social programmes, usually find it difficult, if not impossible, to acquire access to expensive disability support systems that could alleviate some of their concerns. As a result, most PWDs in developing countries tend to either die prematurely, resort to begging to care for themselves, or be cared for by their families and friends (Metts, 2000, p. 23). Disability issues not only impact the people with disability, but ultimately the broader society.

Historically, disability services in developing countries tended to consist of low budget training programs for PWDs, small-scale rehabilitation centres and special-needs home (Metts, 2000, p. 23). These programs resulted in the building of overcrowded publicly-funded training centres. This publicly-funded training centres were built specifically to help in staffing shelters, centres and aid projects adopted directly from industrialised countries by churches, Non-Government organisations (NGOs) and Private Voluntary Organisations (PVOs) (Metts, 2000, p. 23). In recent years, this is still largely the norm in developing countries. Due to the high cost and strain on such programmes, developing countries fail to reach a significant proportion of their target population. The impact of such services and programmes are still restricted by the same conceptual complications that have long plagued social programs in the Global North. Government administrations of developing countries have attempted to reach a larger proportion of their citizens by initiating social programs and projects that better address their local context. However, most adopted approaches tend to consist of disjointed, and underfunded combinations of expensive, and inappropriate programmes previously established (Metts, 2000, p. 23).

Increasingly, PWDs are taking control of their lives through self-representation and advocacy. They are making a demand to be treated with equality, dignity, freedom and the right to be fully included within their communities (People's Health Movement, 2005). By actively increasing the economic contribution of PWDs, the present cost to other family members will be reduced. The present state of disability capacity forces family members of PWDs to limit their economic activities and undertake home-based treatments to contrast the overall cost of public or private health care assistance. However, excluding PWDs and their family members from the development agenda will be a significant barrier to their inclusion in development. The failure of developing countries such as Nigeria to meet the technical or political capability of disability issues, will have long-term consequences on affected citizens and the society at large.

STATEMENT OF PURPOSE

This thesis focuses on how the needs of PWDs are not met by health care services in Nigeria. The overall aim is to delve into the state of disability assistance, especially health-care provision, and its limitations within the system and avenues for improvements. According to the World Health Organisation report for Nigeria (WHO 2013), the 2006 census put figures of people living with disability at approximately 3 million. Of this figure, the total number of women and children with disabilities account for 1.5 million and 1 million, respectively. Going by these figures, the total number of PWDs is approximately 2.32% of the provided Nigerian census of 2009 population (140 million), with women and children with disabilities being 1.1 and 0.71%, respectively (Federal Republic of Nigeria Official Gazette 2009; National Population Commission, 2010). These figures greatly underestimate the actual number and prevalence of disability in Nigeria. Considering the WHO estimates that 15% of any given population has some form of disability, it becomes difficult to rely on available statistics for people currently living in Nigeria with disabilities (Abang, 1988). Considering Nigeria's difficulties in achieving a reliable census for those with disabilities, the total figure of PWDs could be much greater, given Nigeria's current population of 188 million.

During its military rule, Nigeria structured a Disability Decree law (1993) but following the country's shift to a democratic rule of government, the Act, although incorporated under the Nigerian Constitution of 1999, failed to be implemented within its framework. Therefore, this law, though present in the country's laws of the Federation, cannot be applied to any person or utilised in any legal proceeding. There are three major reasons why this Constitution failed to adequately provide for PWDs in Nigeria's society. The first major problem is that, disability was not a ground for discrimination within this constitution. Although the Constitution of Nigeria (1999) outlines general protection for every individual against discrimination under its Fundamental Rights (S. 42), it is nevertheless insufficient when manoeuvring the overall prejudice faced by its PWD population (Nigerian Constitution, 1999, S. 42). This implies that people discriminated against based on disability have not been protected by this constitution, making the inclusion of issues about disability irrelevant.

Secondly, regarding employment provision for PWDs, without the successful implementation of an Anti-Discriminatory Bill for disabled workers, the society leaves open an avenue for employers to exclude disabled people during their hiring processes. The Constitution (1999) mandated employers to provide benefits and remittance to hired employees with disabilities. Employers see this as a burden because they are not given incentives to include PWDs. There is an assumption that employing workers with disabilities increases the cost of production and reduces outputs resulting in less profit. This further aggravates the exclusion of PWDs.

Lastly, the Constitution provides a brief definition of a "disabled person” but fails to outline what is constituted as a disability. It states that:

> Disabled person means a person who has received preliminary or permanent certificate of disability to have condition which is expected to continue permanently or for a considerable length of time which can reasonably be expected to limit the person's functional ability substantially, but not limited to seeing, hearing, thinking, ambulating, climbing, descending, lifting, grasping, rising, any related function or any limitation due to weakness or significantly decreased endurance so that he cannot perform his everyday routine, work and living without significantly increased hardship and vulnerability to everyday obstacles and hazard.
>
> Nigerian Disability Decree, 1993, S. 3.

This definition of a disabled person, as provided in Section 3 of the Decree is very restrictive. It fails to classify different forms of disabilities, or account for other factors such as personal or health struggles faced by people with disability. This definition fails to account for the role that society, policies and medical frameworks play in the disablement and restricted provision of good care for PWDs.

The Ministry of Women's Affairs was the department previously responsible for all issues involving Women and Disability in Nigeria. This joint portfolio emphasises the importance that government places on these two groups. It also stresses the limitation of the *Aid Policy approach* and the resources currently in place, which are unproductive and unsustainable in addressing difficulties of PWDs. Disability needs to be considered a policy-worthy issue. Adverse economic conditions tend to exert considerably more pressure on families of PWDs than they can cope with (Ogwumike, Adeniyi, & Obidiegwu, 2012).

Some States in Nigeria are actively taking steps towards implementing policies, and administrative laws, geared towards sustainable health care development goals. Through these steps, they hope to foster the inclusion of previously excluded groups such as PWDs, amongst other target populations. For Lagos State, existing gaps resulted in the push towards creating a localized Disability Bill for its residents. On 24th June, 2011, the Lagos State Governor, Mr. Babatunde Raji Fashola signed into law, "The Special People's Law (SPL)", following the successful implementation of the Lagos State special people's Bill by Lagos State House of Assembly. This move made Lagos State the first in Nigeria to enact a law specifically aimed at demonstrating its ratification of similar international standards. The Special Peoples Law, (2011) incorporates many obligations such as non-discrimination, education, health and data collection provisions. More so, it takes steps to ensure that all levels of Lagos State government, provide PWDs with an adequate standard of living for themselves and their families, including the provision of food, clothing and housing (SPC, S. 23). The law also establishes the office of Disability Affairs in compliance with its provisions.

On a national level, a recent positive step for disability development came in the form of a bill put before the Nigerian Senate in June 2016, titled, "A Bill to Ensure Full Integration of Persons with Disabilities into the Society and to Establish a National Commission for Persons with Disabilities and Vest it with the Responsibilities for their Education, Health care, Social, Economic and Civil Rights (Establishment, etc.)", (Onogu, 2016). However, the Bill was not passed, resulting in its subsequent abortion along with two previously failed attempts. Nevertheless, this advancement raises hope for disability communities and their advocates, as it implies that more is being done to foster the development of the disability agenda within Nigeria. Nigeria is marked by tribal and State division, governed by different political laws, cultural ideas, societal practices and beliefs. The treatment and services provision for PWDs also vary geographically (from region to region). These differences also contribute to the lack of the development of, and adequate attention to disability problems in the country.

While Nigeria has signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2010), it still has a long way to go in implementing its provisions. In January 2019, after three rejections and 9 years of relentless advocacy for a disability law by rights groups and activists, Nigeria finally enacted the Discrimination Against Persons with Disabilities (Prohibition) Act (DAPDA 2018). It is hoped that this law will build on the strength of the CRPD (2010) ratified and signed by the government. By Article 4 (1)(a) of the CRPD, 2010, Nigeria undertook to adopt all legal and administrative measures to implement rights recognised in the Convention. Thus, finally enacting a Nigerian Disability Rights Act fulfils its responsibility under the Convention. This law should further align Nigeria with its local and international obligations, particularly the Conventions' provision which compels parties to fully realise the rights of PWDs through the adoption of appropriate legislative, administrative and other essential measures to implement the rights recognised within the Convention.

It is worthy to note that, other African countries are far ahead in their legislation on PWDs. Uganda, for instance, has no fewer than six different pieces of legislation covering different aspects of the lives of persons with disabilities. Kenya's legislation for PWDs was enacted as far back as 2003, while Ghana passed its "Persons with Disabilities Act" in 2006.

NIGERIA'S HEALTH AND DISABILITY AGENDA

Focusing on issues ranging from physical limitations, health-care, the day-to-day living of PWDs, to the fundamental issue of survival itself, the study examines the resources and facilities that are available for meeting the needs of PWDs, such as those with CP in Nigeria. It hopes to get responses on the various forms of care arising from the available resources and facilities.

Nigeria's economy adheres to an informal health care system. This economic system encourages the privatisation of health care services over publicly funded health services. In retrospect, it boosts the commodification of medicine and health care access, making it extremely difficult for people who cannot afford expensive services to access the care they need (Farmer, 2003; Pogges, 2008). Some of the contemporary literature on disability and discrimination against PWDs in Nigeria discuss specific forms of physical, visual, or sensory impairments like blindness. Contemporary scholars have attempted to venture into moral, social and psychological implication of different impairments on PWDs within Nigerian society. Authors, such as Abang (1988), Audu, Idris, Olisah, & Sheikh (2013), Ozoji (1991) Etieyibo and Omiegbe (2016), among others, explore ideas of disability, disablement, stigmatisation and attitudes of Nigerian society across the different States. Eleweke (2013) undertakes a review of the challenges encountered in the attempt to foster provision and advancement goals for PWDs in Nigeria. Badaru, Ogwumike, Adeniyi, and Kaka (2013) also research the psychosocial difficulties, as well as the issue of depression faced by mothers of children with disability in Nigeria. Several of Nigeria’s contextual disabilities studies on CP, focus on educational opportunities, or the lack thereof, for children (Obiakor & Eleweke, 2014; Lagunju, Oyinlade & Famosaya, 2016).

THEORETICAL RATIONALE

Due to the complicated and multidimensional nature of disabilities, there is a chronic difficulty in conceptualising it. "Because of the extensive variety in the nature of the problem, a global definition of disability that fits all circumstances, though very desirable, is in reality, nearly impossible" (Slater *et al.*, 1974 as cited by Altman, 2001, p. 97). In addition to the effect imposed by the impairment upon an individual's physical functioning, disability also shapes the economic functioning and emotional well-being of the person's family.

It is a constant challenge for researchers and advocates of disability to fully understand the process of disablement. Zola (1989) asserts that disability must be recognised as an ever-changing continuum with various facets of economic, social, physical and political interaction, rather than an absolute focus on a person's special needs. Altman (2001) and

Bickenback *et al.*, (1999) emphasise attempts by researchers to develop the nature of this continuum through conceptualisation, modelling, and operationalisation of disability management measures.

A research approach to disability combines relationships between multiple factors, such as health, functioning, context and the dynamics of conditions as they come together in shaping the disability process (Altman, 2001, p. 100). A surge in the number of people coming forward to recount their personal disability experience has transformed existing understanding of disability beyond personal limitations to social restrictions, moving beyond just the medical into social and political spheres (Oliver, 1998). As Thomas (1999) and Shakespeare (2007) explain, there has always been a dichotomy between the medical and the social models of disability because PWDs are not just faced with medical concerns, but also societal experiences.

A variety of theories and definitions contribute to ideas around disability and, in retrospect, the development of theories on disability. Some of the approach to understanding disability includes: The Medical model, The Social model, Human Rights model and the Critical Disability Studies model of disability. Some theories that contribute to these categories are those developed by Nagi (1965), Verbrugge and Jette (1993), WHO's ICIDH (1980) and ICIH-2 (1998, 1999), Abberley (1987), Oliver (1990), Shakespeare (2004), and the Convention on the Rights of Persons with Disabilities (2010), among others. While these models attempt to address most of the issues facing PWDs, they fall short when incorporated into Nigeria's societal context. Therefore, a balanced approach is needed. A critical disability model through the human rights capability and social construction frame of disability serve as a theoretical framework for this research and helps achieve this balance.

The theories allow for intersectionality of the social, economic, political and rights-based approaches to analysing issues of disabilities within different societies through the lens of capabilities. The Capability Approach and Human rights theory of Amartya Sen in comparison to the Social Model of disability alone, is better suited to addressing this problem, as it better analyses the limitations that hinder people from fully functioning and contributing to society. Nevertheless, to get the full representation of what it means to exist in Nigeria with a disability, the "Social model of disability" is also required.

This theoretical approach considers post-colonial theories on the hegemony of the global north in disability discourse. With the dominance of the global north within disability research, literature remains detached from the global south, its histories, context, geopolitical spaces and culture (Meekosha, 2011; Grech & Soldatic, 2015). This frame of reference constructs the local obstacles within the social context into this discourse of disability development. It situates the research problem and purpose within the localised context, histories, geopolitical space and culture so as not to marginalise the experiences of PWDs within the global south (Grech & Soldatic, 2015). This is considered a major highlight of this thesis as it takes a step beyond Eurocentric perspectives of disability.

THESIS STATEMENT

Adults living with CP in Nigeria should be given better access to health care facilities and services such as disability assistance information, well-informed medical professionals, rehabilitative professionals such as counsellors, speech therapists, and other resources they require to fully function in their environment. The rights and needs of PWDs like CP in Nigeria are ignored and overlooked in development initiatives. This results in an endless cycle of suffering for PWDs and their families. PWDs are entitled to the “Right to development (RtD)” which should be supported by the provision of health, employment, community services and so much more that will assist them in attaining this right. The provision of better health care for CP is important because it fosters better opportunities for an improved quality of life and also promotes inclusive development for PWDs and their family members within their societies.

CP is the most common childhood neuro-disability in Nigeria (Lagunju, Oyinlade & Famosaya, 2016). Adults or children (and their families) living with CP are often hampered by poverty, lack of proper health or rehabilitative care, zero educational opportunities and stigma, among other daily struggles (Lagunju, Oyinlade & Famosaya, 2016). The prevalence of this impairment is oftentimes associated with a shortage of knowledgeable health-care professionals, access to information and the poor state of health development in the country (Ogunlesi, Ogundeyi, Ogunfowora & Olowu, 2008). The embodied experiences of a persons' impairment are linked directly to the individuals' social struggles and, reinforces the need for the development of a rights-based approach to disability. Without this, it is impossible to foster improved quality of life and care provision for PWDs, especially CP in Nigeria. This research contends that failing to adopt a better rights-based disability practice in Nigeria will only result in adverse ramifications to the functioning capabilities of already marginalized people living with CP in the country. It argues that a critical disability model that combines a human rights capability approach with the social construction of disability is more appropriate for addressing and advocating the development of disability movements within developing countries. Therefore, by examining this problem, feedback becomes obtainable on the various forms of care available to persons living with CP in Nigeria. The research will enrich local knowledge on existing organisations', their active input to health assistance, disability movement and societal development. This research is significant because it undertakes a contextual outlook to analyzing disability and development, explores barriers of prejudice and stereotypes, and addresses the general lack of commitment to disabilities to encourage and promote change.

CEREBRAL PALSY

Discussions on disability takes several turns, including the provision of health care, rights, community and national development initiatives. However, the main focus in this thesis is CP impairment, which creates physical or Intellectual Disability (ID) or a combination of both. Impairments affect people in various areas - physically, psychologically, mentally or developmentally. There has been a constant struggle globally to bring coherence to this aspect of childhood neurodevelopmental disability. CP has often been associated with rather imprecise or conflicting definition and classification. As Rosenbaum and Rosenbloom (2012) emphasise, clinical medicine adopts a tradition of labelling and categorising diseases and disorders to better separate their underlining conditions. “This process of diagnosis is important both to the physicians and patients because knowing what ‘it’ means helps us focus our attention on the ‘right’ conditions and also eliminate other factors” (Rosenbaum & Rosenbloom, 2012).

> Developmental disabilities refer to a number of different conditions with onset in childhood; intellectual disability (ID) is a nonspecific term that refers to mental

> capacity below normal, due to any condition that impairs development of the brain before birth, during birth, or in the childhood years.
>
> Van Schrojenstein Lantman-De Valk *et al.*, 2000

These discrepancies extend beyond not just disability classifications, but also the different health-care provisions available for person's with IDs. Patients with ID despite their increased chronic health problems, are less likely to receive adequate medical care than other members of the general population (US Public Health Service, 2002). Their medical concerns combined with limited preventive health interventions create additional complications for ID patients who already have a shortened life expectancy (ranging from 13 to 20 years shorter) (Rosenbaum *et al.,* 2007; Goldstein, Rosenbaum & Leviton, 2005).

CP is a group of disabilities that affect a person's posture, movement or muscle control due to development problems or brain injury. For the past 40 years, CP has typically been defined as 'a disorder of movement and posture due to defects or lesions in the immature brain' (Bax, 1964). Despite some useful enhancement of this definition by Mutch *et al.,* (1992), there are still discrepancies within CP's definition. They defined CP as "an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development" (Mutch *et al.*, 1992; Bax *et al.*, 2007; Morris, 2009). There remains uncertainty about the definition and the usefulness of the term "CP" itself (Bax *et al.*, 2007; Morris, 2009). The developmental disability known as CP remains prevalent across the developed world at a rate of 2 to 2.5 to every 1000 people, and with rates often much higher in developing countries like Nigeria (Nottidge & Okogbo, 1991).

CP can be referred to as a heterogeneous group of conditions involving permanent nonprogressive central motor dysfunction that affect muscle tone, posture, and movement due to abnormalities in a developing fetal or an infantile brain resulting from a variety of causes (Rosenbaum *et al.*, 2007). These motor impairments generally result in the limitations of functional abilities and activity ranging in severity (Rosenbaum *et al.,* 2007). "It often occurs just after birth and 63 percent of its causes are generally preventable" (Nottidge & Okogbo, 1991). In addition, multiple other symptoms often accompany the primary motor abnormalities, including altered sensation or perception, intellectual disability, communication and behavioural difficulties, seizure disorders, and musculoskeletal complications (Rosenbaum *et al.,* 2007). Although the underlying cause of the condition itself is not progressive, its clinical expression may change over time as the brain matures. This definition continuously gets revised as new findings are unearthed and explored. A new definition, published into its final version in 2007, reads as follows:

> Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that is attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by the secondary musculoskeletal problem.
>
> Rosenbaum *et al.,* 2007.

However, one question to be highlighted in this definition is the implicit use of the word "permanent" found in the first sentence of the new definition; that is the idea that CP is a life-long condition. Like virtually all 'neurodevelopmental' disorders, CP has traditionally been thought of as a "childhood" disease'. Discussion around what age CP patients should start and end their medical assessments is more of a social concern rather than a medical one. This problem will be further explored in subsequent chapters.

RESEARCH DESIGN AND METHOD

This research engages in a field research study and literature content analysis using secondary sources from the library. Semi-structured interviews were used for data collection during the fieldwork. By using semi-structured interviews, the personal meaning of CP and disability to individuals' experiences and actions in the context of their everyday social and cultural environment was extensively analysed. This technique allows for a thorough examination of the issues within the natural environment concerned. Fifteen participants were identified based on referrals from the contacted organisation and participants were interviewed using a chain-referral (Snowball) sample technique. Snowball sampling, also known as chain-referral sampling, is the process of selecting a sample using networks (Laws, 2013; Newman, 2006). This sampling technique was chosen because of the sensitive nature of the topic and difficulties finding potential study participants within the research setting.

SCOPE AND LIMITATIONS

There are certain limitations to this study. One is the short length of time in which the research was undertaken. The research was only undertaken in Lagos State, Nigeria, which is only one section of a vast country, thereby limiting the context and pool of people being observed. Due to the non-randomised selection of participants, the research could become open to bias, making it difficult for the researcher to generalise the findings beyond a similar small-scale setting such as Lagos, Nigeria. These limitations also make it difficult to prove anything beyond the accounts of the interviewed respondents.

Due to the differences in tribes and communities across Nigeria’s States, further research is necessary before the findings from this study can be applied to other states and groups within the country. However, this shortcoming could also strengthen the research by better capturing different local contextual perceptions, while allowing a close focus on cases and issues of interest. The use of a qualitative approach ensures the plausibility of the research topic by capturing different local contextual perspectives, making it easier to discover hidden meaning and issues that are relevant. It is an understanding approach that gives people an opportunity to fully discuss things they otherwise would not tell others, thereby creating an avenue for more issues and evidence to be accumulated. It also runs the risk of losing focus because it can become subjective to external analysis such as biases if not well managed.

SIGNIFICANCE OF THE STUDY

Research on disability is a pathway to creating a better understanding of issues faced by PWDs and identifying areas and types of disability that need further support. By exploring issues surrounding disability as it directly impacts development, it is possible to better understand which aspects are neglected across different sectors and actors. Research that focuses on or involves PWDs is critical in uncovering issues that could inform available policies and evaluate how the current programmes and services meet their objectives. By evaluating the issues raised in this study, it adds to the importance of upholding rights, like the universal rights to health, a good standard of living and development, in conjunction with exploring present laws, policies and national agendas on disability in Nigeria. The data collected through this research sheds light on some socio-political and development issues that can be further researched in the future.

The research is beneficial as information collected from it will contribute to a better understanding of how Nigeria’s health-care sector serves those with disabilities. By exploring issues around service access, provision and limitation for PWD like CP, some possible solutions to its limitations will be addressed. This avenue of discussion will help create platforms for discussion about disability issues across different sectors and actors such as NGOs, trade unions, and associations. This will also allow for additional exploration by advocates and researchers on issues concerning PWDs. Research that involves PWDs is vital in uncovering issues that could inform policies and help evaluate how current programmes and services meet their objectives. It could also help to suggest how things could improve for the PWDs and offer suggestions on potential policies to improve their individual development, and ultimately, that of the whole society.

This study is significant because evidence provided by the empirical data collected will show how PWDs are currently being treated. It will also provide information to communities about how disability is being discussed and how local partners currently contribute to disability movement in Nigeria. A summary of the research findings will be shared with interested local communities. By providing a guide to existing organisations that help people with CP, researchers can look forward to what more can be done.

DIVISION OF CHAPTERS

This study is sectioned into six chapters: An Introduction to the Study, Review of Literature and Theoretical Reasoning, Research Methodology, Research Findings, Discussion and Analysis, and lastly, Conclusion and Recommendations.

Chapter One: An Introduction to the Study

This chapter provides a general introduction to the study. It outlines an introduction to the fundamental challenges of disability in Nigeria and its surrounding issues. It comprises the statement of the problem, statement of the purpose, objective of the study, theoretical framework and the research design to be used. By explaining the realities and providing a peek into the goals of the study, the chapter outlines the gap this research is trying to fill.

Chapter Two: Review of Literature and Theoretical Reasoning

This chapter surveys and discusses existing literature on themes and theories relevant to the study. It provides a concise overview of what other studies have argued and established thematically to inform the research question. In this chapter, the theoretical framework of the study is explored: Amartya Sen's Capability Approach theory and The Right to Development. Other major themes, such as Sustainable Development, Disability Theories, Intellectual Disability, Disability laws and policies, Health care and Development, and Human rights are also thoroughly discussed.

Chapter Three: Research Methodology

This chapter describes how the field study was carried out, particularly how certain elements and appropriate techniques are used. The research elements implemented are the research method: Qualitative approach; the research setting: Lagos, Nigeria. Sample representation, data collection procedures and data analysis are also explained. The chapter also explains the steps taken to ensure consent, protection and confidentiality of all involved human subjects.

Chapter Four: Research Findings

This chapter primarily outlines the findings and outcomes of the field research. The realities of disability, examined through the experiences of people interviewed during the field research, are outlined and categorised into themes. Findings are presented in greater detail to emphasise the voice of the respondents.

Chapter Five: Discussion and Analysis

In this chapter, a description of the themes that emerged during the research are reiterated. Themes and sub-themes are analysed to help determine the importance of health-care and development to the "contribution" of PWDs to development in Nigeria. It also makes use of theoretical lenses examined in previous chapters to scrutinise the practical implications of disability health access and development within the research setting.

Chapter Six: Conclusion and Recommendations

This chapter provides a review and summary of previous chapters by linking them together to connect the findings. It also presents the conclusion, and the lessons learnt through the study. Those lessons are based on the overall research findings.

CHAPTER TWO – LITERATURE AND THEORETICAL REASONING

INTRODUCTION

While various scholars contribute to models, definitions, and theories on disability, very little is really understood about the experience of adults living with disability in Nigeria. This thesis intends to understand the problems adults living with disabilities (PWDs) in Nigeria live through. The main research question is whether Nigeria has sufficient and functional health care assistance and practises that will improve the societal experiences of people living with CP in Lagos State, Nigeria? By analyzing the societal and personal experiences of PWDs and health assistance providers, this chapter demonstrates how inclusion, equality, human rights and development are also affected.

This chapter will provide a survey and discussion of existing literature on relevant themes and theories to the study. It will provide a concise overview of what work has been done and established thematically to inform the research question. Ideas from Amartya Sen's Capability Approach theory, Paul Farmer’s take on Structural Violence, and also The Right to Development all contribute to the theoretical framework of the study will be explored. Major themes such as Sustainable Development, Disability Theories, Intellectual Disability, Disability laws and policies, Health care and Development, and Human rights will also be thoroughly discussed. The chapter will also examine the similarities and differences among disability theories like the Social Oppression Theory, the Bio-medical Model, the Capability and Human Rights theory, on issue of disability to provide an in-depth analysis of the major themes addressed in the research. Themes such as “othering” “accessibility” and “capabilities” will also be drawn from existing literature, policies and discussions that shape disability definitions, disability health care systems, types of disabilities and development agendas for Persons with Disability (PWD) amongst others. By exploring these themes, it is possible to theorise the embodied experiences of people living with CP impairment in direct relation to their unique physical and societal experiences and struggles.

HISTORY OF DISABILITY MOVEMENT

The initial global report on disability, published by the World Health Organisation (WHO, 2011) estimates that at least 1 billion people in the world, fifteen percent of the current population in 2011, are living with a disability. With the prevalence of disability advocacy, development in health care, expansions of disability theories and classifications, this number continues to rise yearly. As early as the 1970s to 80s, several scholars have attempted to further understand disability within the academic framework. One of such scholars, a medical sociologist, Zola (1982a; 1982b) explores how personal experiences of disability, especially physical experiences, can be analysed and understood within a social context using social science methods and concepts available for the study of disability.

Before the eighteenth century, disability was not viewed or categorised as a social problem within western societies. More so, there are very limited historical records of discussions on disability in developing societies such as Nigeria. Differences in social, cultural and environmental circumstances surrounding issues of disability among developed and developing countries, prevent an even playing field for comparison. For example, an individual’s cultural belief plays a huge role in shaping their identity and perceptions (Etieyibo & Omiegbe, 2016). A society that views disability as an abnormaility will always see a person living with disability as “different” rather than “normal”. Such society creates a space whereby “different” or “abnormal” persons are excluded from normalised social norms and activities. In turn, these imposed ideas shapes how the individual views their “self” and how the society interacts, perceives and relates with him or her.

An in-depth examination of the history of disability and dominant theories on disabilities, particularly what is currently being done is needed to adequately understand existing similarity or differences around disability issues in different countries. The segregation of PWDs became ingrained in societies as far back as the 1700s when country asylums were first proposed and enacted (Braddock & Parish, 2001, p. 25). Persons classified as “idiots, blinds and apples” were accepted and confined in institutions such as mental hospitals, asylums, residential schools, and orphanages, emphasising their status as special persons (Braddock & Parish, 2001, p. 25). It was thought that society’s main duty was to make impaired individuals conform to community norms through cures, treatment or rehabilitation (People's Health Movement, 2005, p. 180). Following up on this trend, the seventeenth to the nineteenth century saw a rapid expansion on the segregation and institutionalisation of persons with disability. This also represented the boom of the medical approach to disability, commonly referred to as “Medical Model”. Rotham (1990) contends that it was unavoidable for residential institutions (Asylums etc.) to develop in the United States, because they represented a ground-breaking solution to the persistent social problems that plagued the economic and social structure of Westerns societies at the time. This system was also built largely as a desire to manage anyone viewed or categorised as “different” amid the social order (Braddock & Parish, 2001).

The increase of custodial residential institutions in the past undermined the self-determination of PWDs during a period of rapid urbanisation and industrialisation in Western societies (Braddock & Parish, 2001; Rotham, 1990). Ideas developed and perpetrated during early urbanisation reinforced negative societal attitudes towards human differences, and this continues to be the norm in development today. Following the boom of industrialisation, the nineteenth century was characterised by schools, institutions and interventions geared towards persons with physical disabilities, deafness, blindness, mental illness and intellectual disabilities, as they took root throughout Europe and North America (Braddock and Parish, 2001). Professionals within this period developed differential diagnosis to specify medical conditions, formulated treatments interventions, and promoted educational schemes focused on specific impairments. Within this period, the medical model of defining and classifying disability became thoroughly ingrained within Western societies (Braddock & Parish, 2001, p. 36).

The steady exclusion of PWDs from their families, communities and the society at large is the current situation of PWDs in Nigeria today. Historically, health care services in Nigeria was segmented into three periods. First, the pre-colonial era predominated by localised and culturally based health such as bone-setting and traditional attendants. PWD were either never considered, viewed with suspicion and negativity or totally rejected because they did not fit into the cultural setting (Munyi, 2012). Second, the colonial era introduced formalized medical care set up by missionaries exclusively for the provision of health care services to staff of the colonial administration and their families. Lastly, the post-colonial era introduced National Development Plans aimed at the provision of Basic Health Services for all members of the society (Atulomah, 2017; Abang, 1988).

During these periods, disability was not incorporated into Nigeria's agenda because the majority of the country's population still adhered to beliefs that disability was a result of being "evil", "cursed" or a "punishment" by God for evil deeds done (Abang, 1988). After Nigeria hosted the Africa Regional Community-Based Rehabilitation Conference on October 7, 2010, disability issues became relevant on its policy agenda (Eleweke & Ebenso, 2016). Till then, the disability movement in Nigeria lacked appropriate laws and policies that should ensure the provision of economic, social, educational, emotional and psychological services which could foster societal integration and development for PWDs.

DEFINING DISABILITY

Diverse countries and organisations adapt varying definitions of disability, influenced by their political, social, historical and disability awareness contexts. Their cultural, medical and social beliefs shape ideological constructs of what it means to be "normal", be "functioning" or someone with "abilities" within society. A society that values individuals' personal connection to nature, over a free market governed by private ownership of goods for profit, will defer on societal priorities and agendas (Barnes & Mercer, 2005). These ideologies come together to shape the definitions of disability and vary based on what the enforcing administration considers its associating purpose.

When disability data is analysed, layers of nuance are revealed – how and to what level the environment plays a role, what the capacity to perform means for each individual and much more. These social and cultural variations represent the different concepts of what constitutes the definition of disability. The central differences across perspectives on disability can be reduced to three major features: (1.) Illness or impairment-based schemes

(2.) Limited function creating restricted life activity (3.) Ecological perspectives focusing on the interaction of personal characteristics with the physical and social environment. Disability data are typically constructed from an assessment of physical or mental anomalies within a population by assessing for any perceived limitation to an individual's "capacity to perform", or the "loss of function" in their everyday living (Fujiura & Rutkowski-kwitta, 2001). Does the patient have fully functioning physical, sensory or mental capabilities? This basic logic to disability is relatively straightforward, from a medical point of view. However, because of the different variations in definitions of impairments, disabilities and what it means to be, "normal" data collection becomes complicated (Fujiura & Rutkowski-kwitta, 2001).

Disabled People's International (1986) states that "impairment is the functional limitation within the individual caused by physical, mental or sensory impairment; disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others because of physical and social barriers" (Oliver, 1998, p. 1445). In contrast, the American with Disabilities Act (ADA) of 1990 states: "The term 'disability' means, with respect to an individual: (A) a physical or mental impairment that substantially limits one or more of the major life activities of an individual; (B) a record of such an impairment; or (C) being regarded as having an impairment" (U.S 1990, S. 504). The World Health Organisation's (980) universal definition makes a clearer distinction between impairment and disability:

> Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. This disability is a complex phenomenon,

> reflecting an interaction between features of a person’s body and features of the society in which he or she lives.
>
> WHO, 1980.

The World Health Organisations’ (WHO, 1980) definition distinguishes between impairment, disability, and handicap, as well as the socially constructed disadvantages confronted by persons with impairment in their physical realities (Lupton, 2000). These ideas were also grounded in the writings of early theorists and advocates on issues relating to disability (Lupton, 2000). The early 1950s witnessed friends and parents of PWDs organising far more extensively in many parts of the world (Braddock & Parish, 2001, p. 44). Schools and activity centres were established, and ultimately international associations comprising national organisations that had interests in the prevention of disability were founded (Braddock & Parish, 2001, p. 44). Such advances were not witnessed in the Nigerian society until the 1960’s with the establishment of Nongovernmental organisations to assist parents of children with disability. Professionals within this field such as neurologists, therapist and rehabilitation workers in Nigeria also adopt the WHO’s definition of disability, as no constitutional definition of disability exists within the country’s framework.

While the ADA’s (1990) definition emphasises the idea that PWDs are relegated to powerless positions based on stereotypical assumptions about their disabilities, it focuses on anti-discrimination agendas against PWDs in employment, public services, public accommodation and telecommunication (Braddock & Parish 2001, p. 50). In contrast, its counterpart, the British Disability Discrimination Act (DDA, 1995) mandates reasonable adjustments to accessibility in public transportation, policies and physical environments of employers with 20 or more workers that have disabilities. However, advocates of disability management have expressed disappointment in the law's inability to fully protect and facilitate the enforcement of the rights of PWDs in Britain's' society (Braddock & Parish, 2001, p. 50).

After World War I, thousands of people became physically, emotionally and intellectually impaired. To separate them from those whose impairments were rooted in other causes such as birth defects or work accidents, they were labelled "War-maimed" (Toboso, 2011; Striker, 1999). To compensate veterans for their disabilities, legislation and laws were established to guarantee them social services such as disability pension plans, rehabilitative assistance and work allocations (Toboso, 2011). These services were later expanded in the 1970s, to include all PWDs irrespective of the root cause of impairment (Work Accidents or War).

The Society of Disability recognises disability as being a key aspect of human life which has important economic, social and political implications for the whole society. Boosting perceptions around disability across cultures promotes awareness of experiences in the disability community and raises advocacy for social change (Ferguson & Nusbaum, 2012, p. 71). Focusing on individualised disability without considering the social and environmental context that create additional burdens to existing approaches of disability ultimately reduces PWD's participation. The first problem with defining disability is separating concepts of "impairment" from "disability". The term "disability" applies to people with a diverse range of impairments, the majority of which are invisible to others. The second is that a lot of people who meet the legal definition of disability do not define themselves as disabled, however diverse it is, although others with an identical impairment may well do so. The third has to do with impairments that fluctuate or become progressively more incapacitating, in contrast to other impairments that are more constant in their effects but generally vary in their levels of severity (Sloarch, 2016). This means disability is both a medical and social construct influenced by environmental, social, political and many other contexts.

As Shakespeare (2008) argues, “Disability is a complex, scalar, multi-dimensional phenomenon”. He emphasises that because the “social exclusion and devaluation of disabled people are widespread and persistent, developing an adequate understanding of the disability phenomenon and improving the participation and quality of life of disabled people are linked and urgent concerns” (p. 13-14). The sociologist, Zola (1993) challenged the very notion of disability as a condition into which one can be reliably classified due to its complicated and multidimensional nature. In Zola’s analysis, the inflexibility of numbers is undermined by the inherent dynamism of disability status – the changing nature of temporary health status. Therefore, the surrounding context is important in manifesting any limitation and oddities of conflicting classification systems. Above all, Zola (1993) maintains that disability is not a “thing” possessed by some but rather “a set of characteristics everyone shares to varying degrees and in varying forms and combinations” (p. 30). This means, every person lives with one form of disability or the other: emotional, psychological, physical or mental.

In general, a society’s characterisations of impairment, illness, and disability ultimately say which areas of a disabled person’s life its members rationalise and accommodate. Examples of such accommodations are policies, buildings, laws, political action, even in some cases, radical alternatives when all else fails. These accommodations, in turn, shape policy development that help generate health advancements for PWDs, and in the long term the overall development of the society. For such advancements to take place, disability within research communities must be recognised as a continuum rather than an absolute, because it is unceasingly being shaped by our environment (Altman, 2001).

EVOLUTION OF DISABILITY POLICIES

Nigeria adopted and ratified the African Charter and Human Rights, as well as The African Charter on Human and People's Rights Act Chapter A9, No. 2 of 1983 (LFN, 1990), thereby preserving key international provisions that promote human and African people's rights, particularly the well-being of persons with disabilities. Nigeria is also a signatory on other international conventions like the ILO Convention (NO. 15a) concerning Vocational Rehabilitation and Employment of Disabled Persons (1983/1985), The World Programme of Action Concerning Disabled Person (1981), The Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1991), United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993), and The Declaration on the Rights of the Disabled (1995) with the intent to contribute to the protection of persons with disability among other incentives such as the provision of education. Nigeria also ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on the 24th of September 2010 (UN, 2011a, b) which placed disability on the country's agenda. This evolution of policies, including the United Nations' approach to disability, tend to reflect the progression of the country's various legislative expressions on disability. They embody some of the most critical debates within the field on issues such as physical accessibility, inclusion, empowerment of PWDs and the creation of better social and economic opportunities for people living with disabilities across the world.

In reaction to numerous international conventions Nigeria has enacted, the government approved a bill titled “Discrimination Against Persons with disabilities (Prohibition) Act 2018” in January 2019, the first and only legislation since 1993 aimed at addressing the needs of persons with disability. Before being approved by President Muhammadu Buhari, the bill had previously been rejected four times in the last eighteen years (Ope, 2019). Until it was enacted, Nigeria had no legal definition of what constituted a disability. This Discrimination Against Persons with Disabilities (Prohibition) Act (2018), outlines a “Person with disabilities” as:

> (a) A person who has received Temporary or Permanent Certificate of Disability to have condition which is expected to continue permanently or for a considerable length of time which can reasonably be expected to limit the person’s functional ability substantially, but not limited to seeing, hearing, thinking, ambulating, climbing, descending, lifting, grasping, rising, and includes any related functions or any limitation due to weakness or significantly decreased endurance so that he cannot perform his everyday routine, living and working without significantly increased hardship and vulnerability to everyday obstacles and hazards; and
>
> (b) A person with long term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on equal basis with others.

The Act is supposed to safeguard and protect PWDs from all forms of discrimination. It aims to provide PWDs with the right to better education, accessibility to buildings and transportation, employment opportunities, access to health-care, social, economic and civil rights. This legal protection hopes to advance and fully integrate PWDs into the society so they can be included on an equal basis with others (Nigeria, 2018). As can be inferred from these provisions, the act focuses on providing supports for PWDs by advocating the means through which they can engage in all aspects of the society, politically, socially, economically and independently. PWDs, just like other members of the society, require laws and policies, established through different avenues such as bills, that assist them in functioning effectively within their environment. They help remove conditions that become disabling factors due to individuals' impairments.

DISABILITY MEASUREMENTS

With regards to statistical representations of disability, identification is distorted by notions around definitions, culture, language, religion and environment among others, creating complexities during measurement processes. Data collection on disability at its basic level is usually constructed from an assessment of an individual's mental and physical anomalies; any limitation or loss of functionality in a persons' capacity to perform common daily activities within a society (Fujiura & Rutkowski-kwitta, 2001). As Metts (2000, p. 1) states, "The severity of the disability associated with any given impairment for any given person is a complex function of the impact of the impairment on the person's functional capabilities, and the combined impacts of many other social and environmental factors on the person's ability to gain access to his or her family, community and society".

There are two most influential approaches to disability measurement used in analysing disability. One is the "Disability Adjusted Life Years" (DALY) developed for World Health Organisation (WHO) and the World Bank by the Harvard School of Public Health, and the second, developed by the World Health Organisation (WHO), known as the "International Classification of Impairments, Disabilities and Handicaps" (ICIDH) (WHO, 1980) and its subsequent revision, the ICIDH-2 (WHO, 1999). These approaches to measurement are found in the International Classification of Diseases (ICD) (WHO, 1978-2018) and the Global Burden of Disease (GBD) (WHO, 1990-2013; Murray *et al.*, 2012).

The GBD uses metrics based on "disability" gaps such as Disability-adjusted life-years (DALYs). The DALY system of classification is popularly used in the World Bank's World Development Reports. DALY measures health lost because of mortality or non-fatal injuries or diseases and is calculated by adding years of life lived with disability. By the late 1990s, criticisms of the use of the DALYs had emerged (Berghs *et al.*, 2016; Murray *et al.*, 2012). These criticisms questioned the norms and values underpinning such a measure by emphasising the dangers of viewing health without its connections to broader social environments, especially its failure to capture disabling experiences (Berghs *et al.*, 2016). Its criticisms focused on attempts to understand the influence of self-reporting, cost-effectiveness and culture on disability studies.

Within developed countries, where resources could be allocated to PWD, the International Classification of Impairment, Disability and Handicap (ICIDH) embodies the society's' social, medical and individual attitudes to disability (People's Health Movement, 2005, p. 181). The ICIDH was created as an attempt to improve the accuracy of disability conceptualisation internationally, and after certain criticisms were raised in its usage, the ICIDH-2 was created. Among quantitative researchers, ICIDH-2 is revered as the most superior conceptual framework for disability research and policy development. This is because the ICIDH-2 classification system, unlike the DALY framework, is more encompassing as it incorporates into its analysis, the role environmental and social factors play within its conceptualisation of disability.

> As conceptualised in the ICIDH, an impairment (caused by a disease or disorder) may result in a disability which, in turn, may lead to a handicap, as is the case when polio (a disease) results in paralysis (an impairment) which limits a person's mobility (a disability), which, in turn, limits the person's ability to find employment (a handicap). "It is also possible for an impairment which does not result in a

> disability to still lead to a handicap, as is the case when a facial disfigurement (an impairment) limits a person's ability to socially interact (a handicap), even though it does not result in a functional limitation (a disability).
>
> Metts, 2000, p. 2.

Before ICIDH was introduced in 1980, there was virtually no existence of internationally comparable disability statistics because there were differences in the definition of disability being used. To overcome this problem, ICIDH and ICIDH-2 framework were created to provide a standard disability definition for systemic use in data collection strategies using the United Nations Framework for Integration of Social, Demographic, and Related Statistics. Despite this advancement, there are still inadequate data and statistics that can be used in the creation of disability policies. The United Nations Disability Statistics Data Base (DISTAT) was created in 1988 and became the first comprehensive attempt to identify and bring together, the world's existing national disability statistics and has now grown to contain national disability statistics from different countries (Metts, 2000, p. 4). Undergoing these changes created advancements in the fields of rehabilitation, health-care and legislative rights for PWDs across the world.

"Advances in Medicine in the last half-century have worked together with advances in rehabilitation to increase the lifespans and the quality of the lives of PWDs, leading to increase in the size, social and economic potentials of the world's disabled population" (Metts, 2000, p. 14). In response to these changes, there is a call for a human rights rather than an aid-based approach to disability, causing a shift in disability policy focus. This shift has occured from "the segregated rehabilitation and custodial-care systems of the past, towards strategies that couple rehabilitation with broader social policies and strategies designed to increase the physical accessibility of the built environment and foster the social and economic acceptance, inclusion and empowerment of PWDs" (Metts, 2000, p. 14). In addition, attempts have been made to improve accessibility of PWDs in all scopes of life, for example political involvement, economic opportunities, cultural recognition as well as social acceptance.

As previously stated, this study attempts to examine the resources and facilities available to meeting the needs of persons living with CP in Nigeria. It questions the dichotomy between an individual's impairment and their unique societal struggles and experiences. Analysing the problem of disability through the application of two different models, Social Oppression theory and Capability Human Rights theory, is necessary to get the full scope of Nigeria's disability agenda. While most developed countries have statistical frameworks such as DALYS and the ICIDH-2 to gauge their disability population size, Nigeria still lags. There is an overall lack of reliable statistics on the number of people living with disability, especially intellectual disabilities such as CP in Nigeria. This lack of knowledge restricts the creation of services and programmes geared towards alleviating the suffering of PWDs. Moving from approaches to measurements applied to disability theories, an engagement of the various models applied to the discussion around disability is also crucial. Different ideologies on the relationships of impairment and their limitations generate contrasting approaches to disability.

MODELS OF DISABILITY

There are different variations in approaches used in the analyses of disability agenda. The relevant models in the analysis of this study are the medical, social, critical and human right models of disability. The first model to be analysed is popularly referred to as the Medical

Model of disability. It was developed based on the premise that PWDs' was "the commodity of health professional" rather than persons with equal rights to participation, personal autonomy and life, just like everybody else (People's Health Movement, 2005, p. 180).

The medical model informs traditional approaches to disability. It emphasises the understanding that "disability" is solely about a physical or mental impairment afflicting an individual (Berghs *et al.*, 2016; Williams, 2001). Therefore, whatever limitation is faced by PWDs socially or physically is primarily a result of their medical condition or impairment. It argues that as an individual's feature is directly caused by a disease, trauma or health condition, the only solution is a medical treatment to "correct" the problem (Berghs *et al.*, 2016). Within this model, some scholars subscribe to the assumption that, measuring individual's impairments is an effective way to evaluate their needs (Persons living with Disabilities). Some other approaches and authors that contribute to this discourse of disability are; Nagi (1965), Verbrugge & Jette (1995), WHO's ICIDH (1980) and ICIDH-2 (1998, 1999). This model attempts to connect primarily with the public health interest in describing populations, measuring outcomes and developing interventions to improve people's well-being (Gross & Hahn, 2004; Üstün *et al.*, 2003). It is most often automatically adopted by health-care professions and philosophers.

The Medical model of disability was the initial approach adopted to "correct" impairments (William, 2001, p. 125). It formed the basis for disability definitions within fields of education, social welfare, and rehabilitation (William, 2001). Other models on disability, therefore, tend to be built as a response to how the medical field has viewed disability. Themes around body functionality or any deviation from the normalised perception which needs to be corrected are still debated and emphasised. The biggest critique of proponents of the medical model is their focus on disability as a deficit that needs to be fixed or rehabilitated, rather than analysing it through the lens of societal influences *(*Berghs *et al.*, 2016). Shakespeare (2008, p. 11-14) responds to reviews on disability rights and argues that, the "Medical Model" creates a suggestion that medicine is undesirable while the focus should be on medicalisation, which is the root of the problem. This means external factors, especially the environment, should be analysed as it surrounds the individuals and their bodies within which the illness is located. He concluded that the growth of disabled people's activism across the world has pushed for radical changes in disability studies, away from an over-medicalised thought process (Shakespeare, 2008, p. 11). As Oliver and Barnes (1998) reason, the recounting of people's disability experiences has opened and transformed the understanding of disability beyond personal limitations to social restrictions, beyond the medical to social and political spheres.

The second and most prominent model to be analysed is called the "Social Model" of disability. It is the most dominant theory when discussing disability from a non-medical viewpoint. This approach is used particularly amongst activists and its proponents within political and ideological sphere since its development in the UK from the early 1970's (Berghs *et al.*, 2016, 35). In 1967, Berger and Luckmann conducted a study that later fostered the intellectual basis around social and environmental factors as an essential problem of disabilities. Through this study, the interaction between disability and society are powerfully advanced. This approach grew as a result of disability movement leaders, analysing and understanding disabling factors within their societies and communities (People's Health Movement, 2005, p. 181). Their views on the social model of disability later emerged in the research works of Nagi (1970), disability studies and the independent living movement of the 1970s (Bowe, 1978; Davis, 1997; Linton, 1998; Oliver, 1983, 1990; Scott, 1968). As stated by Oliver (1998), the “Social Model of disability or Social Oppression Theory seeks to improve the quality of disabled people’s lives,” through processes like awareness raising, educational changes, barrier removal and legislation changes, among other initiatives. While the general title “Social Model” can be given to ideologies that have similar components or major themes in this theory, it still varies by scholars and activists. In the United States, it is most commonly referred to as the “minority group” model of disability (Berghs *et al.*, 2016, p. 134).

Through this viewpoint, political responses are emphasised as the direct response to unifying barriers and experiences of social oppression in the local context. Proponents of this theory are authors such as Abberley (1987), Oliver (1990, 1992, 1996), Finkelstein (1981), Barnes (1991), Goodley (2001), Shakespeare (2004). They assert that people are excluded from major domains of a social life because of certain physical and mental characteristics. Segregation for this theory is therefore built into the organised social environment of societies. Scholars such as Bickenbach (1993) and Altman (1981, 2001) maintain that a person’s environmental context is what plays a considerable role in the limitation of the individuals’ actions and activities. Barriers created within society such as inaccessible building, stigmatising attitudes, assumptions of competence or intellect, structural violence and lack of intrinsic right to health, contribute more of a disadvantage to having a disability. For Hahn (1997, p. 174), the main point of the social model is that, disabled men and women are constantly subjected to a marginalizing form of prejudice, discrimination and segregations imposed upon other opposed groups seen as different from regular members of the general population based on characteristics such as race or ethnicity, gender and ageing. Oliver (1990, p. 94) asserts that dependency is emphasised in the lives of disabled people, not because of the effects of their functional limitations, but rather because of a variety of economic, political and social forces. This means lack of independence for PWDs is a result of their social context.

Although the social model in all its varied forms is now the foremost framework for understanding disability, its British version has been critiqued. Authors such as Bichenback (1993) argue that impairments must be recognised as a foundational basis for classifying disability, as this helps distinguish discrimination because of impairment from other forms of discrimination. Critics of this model often argue that extreme versions of the social model implausibly deny or understate the role of impairment itself as a source of disadvantage to PWDs (Anastasiou & Kauffman, 2013; Terzi, 2004, 2009; Shakespeare, 2007). The social model has been critiqued for not paying attention to disability, but rather enhancing the medical model (instead of rejecting it) by placing emphasis on details of illness and impairments (Williams, 2001, p. 137). Shakespeare (2008) and Thomas (2007) both claim that the social model of disability is no longer helpful because it fails to capture the complexity of the life of a person living with disability. This is because the social as well as the medical models of disability both rest on a false dichotomy between biological impairments and social limitations. In the words of one critic, head counts of persons living with disability as the basis for policy have failed because, "they have focused on the wrong thing; they have tried to measure the number of disabled people rather than the effects of disabling environment" (Williams, 2001, p. 137). The social construct of disability in this model is a theoretical approach centrally concerned with showing the importance of learning from disabled people's experiences when attempting to understand disability. One of the shortcomings of this model is that persons classified under this theory are viewed as "separate" or the "others" that must be reassessed before their involvement in everyday society. This critique raises concerns about steps to be taken towards disability as a commodity, a way to collectively benefit PWDs without adding to their existing cost of care. How can this be achieved, while also producing doctors, rehabilitation professionals, and disability aid technology that would cater for the needs of PWDs despite the dominance of commodified health-care in Nigeria?

The third model to be analysed is referred to as the Critical Disability Studies (CDS). This approach is a more recent model that questions the dualism between impairment and disability. It is often blurred with the social model of disability. Contributions to the approach are informed by both postmodernist and post-structuralist perspectives which adopt a critical approach to linguistics, biological, psychological, and social worlds of disability (William, 2001, p. 137). It analyses disabilities from the scope of concepts such as culture, power and language. For these theoretical approaches, impairment is fully cultural, and the body is an outcome of social processes inscribed by power and language on individual's bodies (Foucault, 1979, 1980; Huges & Paterson, 1997, p. 332). As Foucault (1980, p. 39) states, "Power reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives". In this model, recent poststructuralist and neo-Foucauldian analyses attempt to bring the body back into theoretical discussions by conceptualising it as the object of knowledge and the target of power. In Hughes and Paterson's (1997, p. 333) terms, "post-structuralism can be useful in theorising impairment out with a medical frame of reference; if medical language produces impaired bodies, then it can be deconstructed". In this way it is argued, the embodied experience of different impairments and their relationship to identity can be part of a more inclusive disability politics.

This approach will allow for a near universalisation of disability to include voices that have previously been excluded from the movement. Post-structuralist, postmodernist and feminist analysts argue that, an all-encompassing theory of disability and oppression can never fully incorporate the diversity of lived experiences (Crow, 1996; Hughes & Paterson, p. 1997). As Radley (1995) argues, being disabled involves living with unique bodily experiences. This unique body experience symbolise characteristics of social constructions and struggles revealed through a person's body. One of the arguments against this approach is that, it attempts to bring impaired bodies back into the literature by going over the old arguments rather than building on them to make new theories. This for critics will ultimately blur the boundaries between impairment and disability as a social oppression. This approach covers many alternative ways of viewing disability by questioning existing assumptions about various sites of the body and it is also one of its greatest strengths.

The last approach is, the "Human Rights Model" of analysing disability. This model is embedded into the 1948 Declaration of Human Rights, the Disability Rights Commission, which became entrenched in the United States' legal policies, the United Kingdom's Human Rights and Equality Commission policies, and the Convention on the Human Rights of Persons with Disabilities. Arguments within this model are based on the proponent that, disability struggles are a product of an unequal society and therefore solution are found in social action and change (Oliver, 1998, p. 1447). It maintains that prejudice and discrimination disable and restrict people's lives much more than impairment do, largely because ideologies perpetuate practical barriers and exclusion. This approach provides a more appropriate societal framework for approaching the everyday living and health-care struggles of PWDs.

RIGHT TO DEVELOPMENT: DISABILITY AND HUMAN RIGHTS

Based on the findings of this research, this thesis argues that a critical disability model that combines a human rights capability approach with the social construction of disability is more appropriate for addressing and advocating the development of disability movement within Nigeria. To achieve this, strong advocacy for equality, inclusion, health-care resources and other facilities for PWDs needs to be endorsed with adequate government support.

Development initiatives were previously ignorant of the "human rights system" and the implication it has on development agendas (Uvin, 2007). Awareness of this system later introduced languages such as "Rights", "human rights", and "rights-based" within development initiatives (Uvin, 2007). The source of this human-rights system in development, is largely credited to the adoption of the Declaration on the Right to Development (RtD) introduced by the United Nations in 1986. This Declaration is, "an inalienable human right by virtue of which every human person and all people are entitled to participate in, contribute to and enjoy economic, social, cultural and political development, in which all human rights and fundamental freedoms can be fully realised" (UN, 1986, Article 1.1). Across national and international dimensions, this declaration hopes to integrate individual and collective human rights into development theories and practises. To achieve this goal, countries would have to implement national policies and agendas centered on RtD through its entire population, including vulnerable and excluded groups such as PWDs. Sengupta (2002), Indian economist and Independent expert on the RtD states, “the motivation of the human rights approach to development guides along the lines of protecting the worst-off, the poorest and the most vulnerable” (p. 884).

The most applicable use of the RtD is found in Sen’s work on *Development of freedoms* (1999), where he explored the relationship between freedom and development. Sen’s (1933; 2005) work explores the relationship between freedom and development, especially how freedom is both a basic component of development itself and an enabling factor to other aspects of growth. For Sen (1933) development has to do with what people are actually able to do or be—which he called their ‘functionings’, and the opportunities they have to choose to allow them to live in any given way- this he refers to as ‘capabilities’. As Sen (1999) argues, the inability to achieve political freedom, economic facilities, social opportunities, transparency and security in any society should be seen as a violation of the people’s human right. Through this connection, emphasis is placed on individuals being denied equal rights and freedom, especially the opportunity to live life as they desire without being restricted by influencing limitations such as disabilities. This is because such limitations are based solely on their physical or mental capabilities and ultimately obligate the individuals to live the way they otherwise would not have chosen if given a choice. This approach closely aligns with the idea of capability with the International human rights movement (Sen, 1999, 2005). Sen’s work shows that, all people by virtue of their humanity have core entitlements that their society has the basic duty to respect and support.

As Sen’s rightly states, "An adequately broad view of development is sought in order to focus the evaluative scrutiny on things that really matter, and in particular to avoid the neglect of crucially important subjects" (Sen, 2000, p. 34). This means PWD should also have the freedom to live their lives achieving their desires unhindered by their disabilities (Functioning), fully supported by the provision of services like health care, employment and community services (Capabilities), which will assist them in achieving valuable dreams and goals in their everyday lives. This freedom cannot be achieved, however, if there are limitations in government policies, support services or a lack of understanding about the restrictions imposed on a person with a disability that actively affects their freedom daily. Disability right advocates and organisations are awakening to the realisation that, to better foster sustainable changes on disability agenda, human rights such as the right to health, right to an adequate standard of living and the rights to development must be equally upheld in development strategies (OHCHR, 1996-2017).

Sen (1999) argues that major factors like poverty, poor economic opportunities and social denial must be seen as a deprivation of basic capabilities instead of low incomes. To support this claim, Sen uses the “Capability Theory” (1933; 2005), which contrasts with most traditional indicators of economic growth when studying development. Sen (1999, 2005) connects the discipline of disability and development economics in his advancement of the “Capability Approach” theory. Sen’s (1933; 2005) capability theory approach emphasises the importance of living life unrestricted. Having the freedom to develop and live the way each person wants, irrespective of influencing limitations such as one’s disabilities. Most development initiatives and organisations, such as the World Health Organisation (WHO), use economic indicators and measurements to assess the effectiveness of growth and development goals, for example the United Nations Sustainable Development Goals (SDGs). The Capability approach focuses on human diversity by concentrating on each individuals’ “functioning” which represents what a person manages to achieve or become in life. Sen explains two forms of functioning. The first can be very basic, for example being properly nourished or having good health, while the second, is more complex, for example being well integrated socially (1993 p. 31). This functioning helps determine how a person lived. Capabilities are described as ‘the capacity to lead the kind of life he or she has reason to value’ (Sen, 1999, p. 87). It is the real possibility of choosing to function in life the way one desires. Thus, for example, a person with disability will require more resources or a more favorable social environment such as ramps, to be able to travel (a functioning). This is also very applicable in the case of health-care access, a resource which PWDs require to manage their everyday pain and “lifespan” itself.

This approach stresses that, providing individuals with an improved well-being, basic education and equal access to health care, all of which PWDs in Nigeria currently lack, is paramount to their inclusion and development. If given the same advantages as other members of society, they would have equal chances for development and survival. The development approach is people-centred, with the “human person” as its central subject, participant, and beneficiary of development. RtD provides an opportunity for vulnerable groups to extract themselves out of poverty, by giving them equal access to facilities such as health, education, work, housing, nutrition and other daily needs they require to survive. It entitles everyone to participate in, contribute to and enjoy development within economic, social, cultural and political dimensions. It is a human system approach whereby development strategies are planned in an active, free and meaningful way for every individual or group, by everyone.

Prejudice and discrimination also severely disable and restrict people’s lives much more than individual impairments do. This is because, these negative ideologies perpetuate practical barriers and exclusion. Disability struggles are a product of an unequal society; therefore, its solutions are also found in social action and change. Farmer (2003) builds on the importance of the right to development by emphasising that human rights are more valuable and enforceable when we truly believe that all humans are equal and valuable regardless of disabilities or health status. Farmers (2003) work portrays how the process of ‘Structural Violence’ eats into societies’ ability to enforce human rights. “Structural Violence” is a systemic way in which social structures or social institutions harm vulnerable people within its society (Farmer, 2003, p. xiii). It does this by preventing them from meeting their basic needs. Failing to provide basic health-care and services to PWDs, the most vulnerable population within Nigeria’s society falls into this description and has adverse effect on their development and well-being. PWDs have limited opportunities within their society. They have little or no access to advantages such as health care institutions or services. Their basic rights are not enforced due to labels of “difference” or “abnormality”. They lack access to development, and in worse cases higher mortality rates due to constantly deteriorating health. While the effects of structural violence are easy to pin-point, the process itself is hard to see (Farmer, 2005).

Farmer’s work places great importance on the rights to health care, which for him also translates to the right to life (2003, p. 218-219). Without life, all other rights count for nothing. This means that everyone has a right to live decently in good health rather than living in complete misery with poor health, and without the access or facilities to pursue a better life in good health, this cannot even be achieved. As Farmer (2003) mentions, the

Universal Declaration of Human Right (1948, Article. 25-27) outlines that everyone is entitled to the right to a certain standard of living, economic and social rights and adequate health and well-being for himself and his family. Interventions and the research evaluating them can be disempowering for PWDs. Particularly when individuals' experiences are scorned or when a population is regarded as "vulnerable" or "excluded". Their rights tend to be framed within able-bodied norms alone. Focusing on the determinants and maintenance of inequalities is specifically more valuable when discussing disability and connects with more rights-based and social model approaches. Not only does a rights-based approach connect well with a public health moral commitment to equality; it also considers individual factors, social participation and environment access, within a context of macro-structural factors.

Poverty, inequality and poor health are some of the negative effects and causes of underdevelopment in the global south (Huish, 2007). To address these issues, policy makers often focus only on increasing economic growth and democratic solutions in development initiatives (Huish, 2007). Pogge's work, *World poverty and human rights* (2003) argues that world poverty exists because of inequality which dates back to ancient times. Cockerham (2013) believes that inequality is often regarded as a negative side-effect of uneven resources, income or wealth. He suggests instead that poverty has more to do with class and hierarchy. Inequalities within societies creates a situation whereby people in higher classes have better access to support services, living conditions and health facilities which have positive impacts for their health (Cockerham, 2013). In contrast, members of lower classes are at the bottom rung of societies. They live much harsher lives exposed to daily challenges that have negative impacts on their health. Poverty and inequality have to be addressed from the local level rather than simply attempting to throw money at glaring problems (Pogge, 2008; Huish 2007). Pogge (2008) suggest that, the current foreign aid system perpetuates the assumption that world poverty is gradually being eradicated and because of this, people have better health and more money (Huish, 2007). However, this is not the reality for vulnerable population in developing countries like Nigeria. Nigeria's health care sector relies heavily on foreign aid, primarily because it is not seen as a priority by the government. However, without a reduced reliance on foreign aid and better management of domestic money, inequality and health-care will never improve. Low expectations of PWDs encourages their social, political and economic exclusions, creating another barrier to their equality. Disability reinforced by inequality and poor health aggravates other challenges such as mobility constraints, stigma and social isolation.

CONCLUSION

Too often, the rights and needs of PWDs have been ignored or overlooked in development initiatives. Turning a blind eye to the problems of people living with disabilities creates an endless cycle of suffering. PWDs are often hampered by poverty, lack of health and rehabilitative care, among other daily struggles reproduced by inequality and lack of rights within their societies. Without addressing these concerns, it is not possible to foster better opportunities for an improved quality of life. Development practitioners now have an opportunity to change Nigeria's negative situation with the help of right -based approaches such as the Right to Development, which embeds development and disability in every stage of planning. As the UN Working Group on the RtD rightly says, "Its realization observes the full observance of economic, social, cultural, civil, and political rights. It further embraces the different concepts of development of all development sectors, namely sustainable development, human development, and the concept of indivisibility, interdependence, and universality of all human rights" (UNDP 1998: 3; cited by Uvin 2007, p. 597). With this approach a inclusive community-based approach that empowers all involved can be strived for. It is in considering these theoretical approaches to disabilities and capabilities that the research explores how PWDs, notably those with CP, deal with the limitations of Nigeria's health care and support systems.

CHAPTER THREE – METHODOLOGY

INTRODUCTION

Having laid out the theoretical reasoning that informs the research question, this chapter provides a review of the research methods, tools, and techniques to be used throughout the study. This chapter begins by presenting a general assessment of the research approach implemented, its benefits to the study objective, a review of the field research process and lastly, a description of the research location in Lagos, Nigeria. This study examines the practical problem of health-care service accessibility for people living with disability in Nigeria. Due to the difficulties in accessing information about persons with CP, their health-service experiences, and its limitations in Nigeria, a study of these concerns is necessary. The highly urbanised context of Lagos State may result in disadvantages as well as disadvantages for PWDs. The study results provide a better understanding of obstacles to disability inclusion and service provision by taking into consideration limitations the context will impose on research findings.

METHODS OBJECTIVE

This research embarks on an assessment of the health-care resources, facilities, and services that shape the everyday experiences of individuals living with CP in Lagos State, Nigeria. Due to the exploratory nature of this research, a qualitative research strategy fit best. This methodological approach makes use of activities and techniques to collect, discover, and produce practical information on the resources and services available for persons with CP in Nigeria. It does this by actively engaging in a field research study and literature content analysis by means of secondary sources from the library, e- and virtual libraries (Scott &

Garner, 2013). Through the methods utilized by the researcher, data is produced for a selected number of cases in such a way that it can later be diffused to a larger sample size (Scott & Garber, 2013).

With qualitative methods, relationships between the variables are analysed using evidence provided from data accumulated in the field. Variables and themes will be drawn from contextualized accounts of events, relationships, and places with the use of investigative tools such as formal or informal interviews or participant observation. This approach fully explores how services currently offered in organisations and the personal experiences of individuals with these resources. This assessment provides a comprehensive understanding of those individuals' contextual experiences rather than merely gathering people’s opinions and behaviours.

The research technique employs face-to-face interaction with respondents, allowing for one-on-one contact with study participants, and also encourages additional evaluation of their reaction to study themes raised in conversations. This style allows for conversational and in-depth understanding of significant social issue being studied from the viewpoint of participants (Laws *et al.*, 2013; Newman, 2006). Furthermore, it takes a step towards the study objective by exploring the practical problem of health-care access for CP patients, contributing to existing knowledge and arriving at some possible solutions to existing limitations in the Nigerian context.

The first stage of the study involves an analysis of grey literature searches on critical concepts like disability theories, disability in developing countries, disability health care development, sustainable development, and development rights connected to the general themes of the research. Based on initial findings, CP was selected as the focus disability to be examined in Nigeria. The study focus was narrowed to CP after a review of the present disability issues in Nigeria. Apart from CP, other disability issues are autism, polio, sickle-cell anaemia, and others. Discussions on existing policies and laws were also done. Moreover, secondary source data in the form of Government organisations' publications and collected data such as the census, labour force surveys, health reports, economic forecasts and demographic information will be comprehensively analysed to get a wider view of the situation.

The second stage of the research involved building connections with local actors such as prominent advocates, researchers and organisations on the research focus. The first contact made was with Doctor Alero Ann Roberts, a professor at Lagos University Teaching Hospital who acted as the field research supervisor for this study. Her expertise in the research area created a direct connection between key respondents and partner organisations.

TIME FRAME OF STUDY

Based on preliminary literature search of the local contexts, available services and existing policies, Lagos State was chosen as the field research setting. The fieldwork was conducted in Lagos State from January 2018 to March 2018. All participant recruitment and interviews were collected during this three-month period.

PARTICIPANT RECRUITMENT

Respondents to the research were recruited to make use of the snowball sampling method (also referred to as Chain-Referral). Snowball sampling is the process of selecting a sample using networks due to difficulty in finding potential study participants in the environment of study (Laws, 2013; Newman, 2013; White *et al.*, 2015). This respondent-driven sampling (RDS) created access to hard-to-reach sub-groups otherwise tricky to investigate using other epidemiological methods due to the sensitive nature of the topic (White *et al.*, 2015). The field supervisor recommended the first set of participants. The second batch of participants was then identified based on referrals from the organisation and initial respondents interviewed.

RESEARCH TECHNIQUE: SEMI-STRUCTURED INTERVIEW

Data was collected in the field using a semi-structured interview technique which makes use of prepared open-ended questions to cover the primary study topic and themes for participants to answer (Scott & Garner, 2013; Lloyd-Evans, 2006). Potential participants were contacted and given information about the research study. They were also given time to consider participating. Potential participants were then contacted in person for the semi-structured interview.

Further referrals were received after the interview, compared to the study sampling frame, and contacted if they were found to fit the study criteria. Each interview lasted from thirty minutes to an hour, following a guideline to address all relevant issues to the research. Separate recordings and files were created for each respondent. Participants were given the option of answering questions in English or Yoruba, a popular native language in Lagos.

Semi-structured interviews ensured the expression of diverse perceptions by focusing on issues that are particularly meaningful to individual participants (Scott & Garner, 2013; Lloyd-Evans, 2006). This technique was most suited to the study. It was a good experience to study individuals' perceptions and opinions on sensitive and emotional issues present in this research topic. Using this technique, the personal meanings of CP and disability to people's experiences, actions and their everyday social and cultural environment within Lagos State, Nigeria were analysed. This analysis allowed for a thorough examination of the issues within its natural environment. The answers given reflected participants' personal feelings and perceptions about issues raised. By encouraging the introduction of new questions or discussion topics during the interview process new concepts, themes and ideas were raised. The conversational atmosphere also positively influenced the results of the study in such a way that other field techniques would not have. This technique encouraged participants to expand on the conversation as much as they wanted.

PARTICIPANTS

The semi-structured interviews covered samples from Lagos State, Nigeria. These study participants were recruited from six organisations in Lagos State, three of which are clinics and rehabilitation centres that provide services for Persons with Disabilities (PWD) such as CP: a teaching hospital, an advocacy organisation dedicated to fostering CP initiative in Nigeria, and the Lagos State Office for Disability Affairs (LASODA) that deals with all PWDs within the state. The sample pool consisted of fifteen people: eight females and seven males. Forty-two percent of the study pool were participants with CP, twenty-five percent were advocates and consultants, twenty-five percent were health care providers and eight percent worked in vocational services.

Participating Organisations

1. Lagos State Office for Disability Affairs (LASODA): The Secretariat, Alausa, Ikeja, Lagos, Nigeria.

2. Lagos University Teaching Hospital (LUTH): Department of Pediatric Neurology: Ishaga Road, Idi-Araba, Lagos, Nigeria.

3. Benola: A Cerebral Palsy Initiative: Praise Plaza, Ajah/Ado Road, Lekki, Lagos, Nigeria.

4. Children's Development Centre (CDC): 31, Modupe Cole Johnson Crescent, Adeniran Ogunsanya, Surulere, Lagos, Nigeria.

5. Cerebral Palsy Centre (CPC): 37b, Bode Thomas Street, Surulere, Lagos, Nigeria.

6. Modupe Cole Memorial Childcare and Treatment Home: No 1, St. Finbarr College Road, Akoka, Lagos, Nigeria.

NO	**INITIALS**	**GENDER**	**ROLE**
1.	O. A	Male	Doctor
2.	G. B	Female	Doctor
3.	F. G	Male	Consultant/Advocate
4.	N.N	Female	Caregiver
5.	Y. A	Female	Caregiver/Doctor/Advocate
6.	O. O	Male	Government Worker
7.	A. O	Female	Occupational -Therapist
8.	A. I	Male	Special Needs Teacher
9.	C. O	Female	Vocational Instructor
10.	R. G	Male	Advocacy Worker
11.	T. A	Female	CP Participant
12.	S. O	Male	CP Participant
13.	D. A	Male	CP Participant
14.	A. I	Female	CP Participant
15.	O. A	Female	CP Participant

Table: 1:1. List of Field Research Respondents Including Participants' Gender and Role in the Research Theme.

PRE-RESEARCH BIASES

This study explores the problems faced by adults living in Nigeria with CP. It examines available resources, their limitations, dysfunction or inability to give equal access to PWDs. Before undertaking this study, several assumptions based on the researcher's bias and personal experiences were made and this, in turn, shaped the hypothesis of the research objective and method.

The first assumption made was that a semi-structured interview technique would elicit the most reliable response from participants, as it creates a larger field of discussion by bringing in subject themes that have not been addressed in previous studies. The second assumption was that the methodology employed in this study is suitable for studying people's perceptions and opinions, especially on sensitive and emotional issues which are very much present in this research topic. The approach will also make it possible to express diverse perceptions by focusing on issues that are particularly meaningful to the participants. Therefore, the answers provided by participants will reflect their personal feelings and perceptions about issues being raised. This conjecture is based on the bias that by allowing the introduction of new questions during the interview process, new concepts and ideas that could influence the result of the study could become visible. More so, it encourages responders to expand on the conversation as much as they want in the process. Analyses of the data collected will assume that respondents will provide honest expressions of their opinions and experiences. The third study assumption is that feedback from the population sample is limited by their willingness to share personal or painful experiences to avoid further labelling as “others” within the society.

By evaluating these biases, the primary researcher is forced to re-evaluate their labels and opinions about how impairment and disability are framed and discussed. Awareness of these biases is needed to avoid them overhauling the focus themes during the discussion. These biases also create some background foundation for the comparison of the current changes that the disability agenda has undergone over the years in Nigeria.

STRENGTHS AND LIMITATION OF METHODOLOGY

Due to the flexibility of the qualitative approach, some possible strengths and limitations of the research approach were taken into consideration. The first strength of this approach is that it allows flexibility in the semi-structured interviews, ensuring more evidence and connections to the focus issues. It also helps capture unexpected or hidden meanings within the variables which increase “believability” of the data (Scott & Garner, 2013; Mayoux, 2016). While this is a strength of the approach, it runs the risk of lacking focus due to external factors like social connections if not carefully handled. This is particularly true for this research because, social networks and connections influenced who got referred to be a potential participant for the study.

The second strength of the methodology is its ability to capture different local contextual perceptions. This strength is important in the setting of Lagos State which has a higher degree of recognition and provision for PWDs when compared to other States within the country. The case sampling utilized will allow a close focus on cases and issues of interest within a smaller sample frame, but it can still be generalised into a broader contextual sample (Scott & Garner, 2013; Mayoux, 2006).

The third strength of the research design employed is its ability to capture in-depth knowledge about the subject. Interviews are conducted one-on-one, creating a safe space for participants to explore sensitive and personal themes. This design helps reduce the possibility of falsified information and is also very good for putting together information about processes and causality, which the researcher aims to establish in this study (Scott & Garner, 2013). The researcher also runs the risk of having difficulty proving anything beyond the account(s) being analysed. The research results could also be over-influenced by the researcher’s biases if these are not taken into consideration. The researcher biases have been explicitly expressed in the first section to reduce the effects of these limitations.

The fourth strength of the methodology is its reflexive nature. This means it engages in the constant questioning of the ethics, bias, and approach being applied to the study so that any debates or ethical issues surrounding morality and practicality of the research will be noted and addressed (Scott & Garner, 2013). All methodological tools used created a safe strategy, giving respondents opportunities to discuss issues they otherwise would not disclose to others.

The fifth strength of the research is the researcher's nativity to the study location, Nigeria. The principal investigator's familiarity with the culture, region, and language as well as the aspects of disability in the country better informs the research focus and removes any misinformation that could occur from the use of external factors such as an interpreter. It also improves trust between the principal investigator and the participants, preventing non-subjective information and misinterpretation during the research.

The final limitation of the study is that the recruitment process required assumptions about the sampling process as not all the referred target population members have the probability of selection. The selection of study members is based on assumptions and study data. Therefore, due to pre-existing relationships among respondents, the observations and information provided are not independent of others' opinions and participants' experiences.

ANALYSIS OF DATA

During interviews, along with a voice recording of each session, notes were taken using a diary to document additional observations. In addition, after each interview, notes were reviewed to ensure the inclusion of omitted information observations made later were included in the diary to ensure a well-informed interview session daily. After the interviews were completed, all collected audio-recorded interviews were transcribed to provide a visible reference for the collation and organisation of data. Compiled and transcribed data were analysed using the system of coding – a process whereby particular words and phrases were assigned to sections of the language so that essential themes or phrases in each session of the collected data were captured. This process helped the organisation and structuring of the collected data into abridged and concise forms.

ETHICAL CONSIDERATION

Certification

An ethics review application was submitted to the Saint Mary's University (SMU) Research Ethics Board (REB), Halifax, Canada and approved before the research commenced. Also, an ethics review application was submitted to the Lagos University Teaching Hospital, Health Research Ethics Committee (LUTHREC), Lagos State, Nigeria and approved before the research commenced at the study location. Collected data are stored on Encrypted Universal Serial Bus storage, and password-protected on the laptop for the period of the research. Data will be retained in the SMU Records Centre (not Archives) for five years after its last use on this thesis research project.

Informed consent

The decision for participants to participate in the research was voluntary, informed, and ongoing to ensure full disclosure of all research processes. Participants were provided with an informed consent form, designed in a simple language before their involvement in the study. Any refusal to participate was respected. Ongoing updates were provided to participants during the study process. Organisations were also asked for their approval before any of their employees were approached to ensure no breach of ethics and to avoid harm to potential participants. The researcher also checked to ensure that recruiting caregivers in clinics, and government officials required no additional approval or permission such as from the administration before potential participants were approached.

Confidentiality

During the study process, participants’ wellbeing and integrity was a priority. All personal data was made anonymous to ensure the confidentiality of all participants. Only the investigators of the research will be privy to participants’ identities. Information was not disclosed to anyone else. In the case of participants with cognitive impairments, participants themselves were involved in the consent process to ensure the full understanding of the research purpose and to help them understand why their consent is needed. All information given was stored in an encrypted and password-protected storage to protect the anonymity and confidentiality of participants. Participants' confidential forms and personal information given on paper or audio-recorded form was stored in encrypted and password protected to ensure confidentiality. In subsequent use or presentation of data, the study participants' identities will be sufficiently protected. During the release or presentation of findings, participants’ data was assigned codes to ensure that participants are kept anonymous, and their details are secure. Only the research team (supervisors and student investigator) will have access to the information before they are coded accordingly.

Risks and Harms

All participants’ physical needs, including comfort, refreshments and breaks were accommodated during the interview process. All participants involved in this study were protected to ensure the avoidance of any undue risk or harm. In the case of this research, participants faced the risk of distressing or uncomfortable emotions. This was minimised by giving participants the choice of not answering any questions they find uncomfortable.

The difference in the conditions of PWDs and other participants was taken into consideration by ensuring that interview venues were accessible and comfortable. For participants with intellectual disabilities, informed consent and feedback letters were provided in easy-to-read formats and carefully explained to ensure full understanding.

Inclusion Criteria

All consenting adults with CP identified in the organisations specified in this research work were between the age range of 20 and 70 years.

Exclusion Criteria:

This research work did not include children with CP because the study aims specifically to understand the experiences of adults living with CP.

Study Location

This study was carried out in Lagos State, Nigeria. The formal name of the country is the Federal Republic of Nigeria. Its territorial extent and political jurisdiction encompass the city of Lagos and the four administrative divisions of Ikeja, Ikorodu, Epe and Badagry collectively referred to as "IBILE" (Lagos State Government 2018). The choice of Lagos State was necessary because of the various policies that Lagos State has for the development and inclusion of people living with disabilities in various facets of life. Lagos State has a Ministry that takes care of disability affairs. There are also more Non-Governmental Organisations that identify with and care for PWDs such as CP. While Lagos State is the smallest state in Nigeria, it has the highest urban population which is 27.4% of the national estimate (Lagos State Government, 2018).

CHAPTER 4 - RESEARCH FINDINGS

INTRODUCTION

Using field research methods mentioned in Chapter 3, data were gathered from respondents about their experience living with a disability, accessing, or providing health-care resources and facilities to people with CP in Nigeria. This chapter presents the findings of details and themes discussed by participants during the interviews. Some of themes highlighted from participants' narratives includes: identity, social acceptance, inequality, societal stigma, access to services, capability, and structural violence. Findings are presented in such a way that the voices of the respondents in the data collected are emphasised. The overall question this study aims to answer is; Are Nigeria's disability health assistance practises functional enough to understand and improve the societal experiences of people living with disabilities such as CP?

The following questions also informed this study: (a) To what extent does Lagos State have services and resources that adequately address the needs of people living with CP in Nigeria, if any? (b) What are the political and economic limitations that shape the capabilities of these facilities and hinder CP patients from accessing these services and resources, if any? (c) What steps can be taken to improve the effectiveness of available services and resources to better improve life for people with CP and enforce their "Right to development", especially health and personal development? By exploring each participant's response, the research demonstrates the embodied experiences of each person's impairment in direct connection to their unique physical and societal struggles.

During each semi-structured interview, while some respondents narrated their personal experiences with CP, the professionals amongst them narrated their experiences providing services to people with disabilities such as CP. Attempts were made during the study process to determine how these experiences and functioning contribute to the alleviation of burdens for people living with CP in Lagos State. This chapter outlines findings collected from semi-structured interviews and the researcher's observations in the field.

PARTICIPANTS’ BACKGROUND

Participants in the interview comprised of 15 people. Of these, five individuals reported living with CP. Three of the participants were identified as doctors in the field of Paediatric Neurology. The remaining seven participants are either founders of non-governmental organisations (NGOs) or work within these organisations to provide assistive services and resources to persons with disabilities, not necessarily CP alone. Participants were between the age range of 24 to 80 years. Seven of them are male, and eight are female. Eleven of the fifteen participants reported having between 3 to 26 years of personal life experience with their impairment or professional experience working with PWDs. Only one participant reported having spent less than three years within the disability service sector. All other participants had at least five years of personal or professional experience with disabilities. Two of the participants have children presently living with CP, both described as completely dependent and non-verbal. Four of the five participants living with CP had completed a university degree or other higher national diploma qualifications despite difficulties. One of the four participants attained his degree outside Nigeria. All others completed their post-secondary education within the country. The fifth participant is currently undertaking a university degree. All participants with CP involved in the research can be classified on the mild spectrum. All 15 participants described themselves as being disability advocates.

CHARACTERISTICS OF ORGANISATION

Data collected was retrieved from six different organisations that contribute to disability health assistance practise within the country. The first organisation the study engages with during the field research is the Lagos State Office for Disability Affairs (LASODA). A government department in Lagos State, Nigeria which advocates for the inclusion of rights and equalisation of opportunities for PWDs within the region. This department was established after the implementation of the Lagos State People's Disability bill in June, 2011. The office officially took off in 2012 and has been in operation since. The aim is to uphold the rights of people living with all forms of disabilities and help bridge the gap between PWDs and able-bodied counterpart through awareness and empowerment planning. The office is empowered by law to protect and safeguard PWDs from abuse, discrimination or intimidation by equalising their potentials within the larger society. This department works directly in collaboration with local and international stakeholders in the execution of its agenda. Lagos State government is also currently taking steps to expand this agenda by breaking the office into smaller branch offices that would better reach people in rural communities. This department is also directly responsible for the management of 31 publicly-funded primary schools, seven publicly funded secondary school and five publicly funded vocational and trade schools dedicated to the provision of education to persons with special needs. It operates in place of the Ministry of Women's Affairs and Social Development which previously managed these services.

The second organisation engaged with was the Lagos State Teaching Hospital (LUTH), one of the major publicly owned and funded teaching hospitals within the State. This research engaged explicitly with the Neuro-developmental pediatrics departments. The government subsidises its fees for services provided to the public within these organisations. However, there are still wide misconceptions among members of the public on how entirely free the services provided in these organisations really are. This concern was one of the plights raised by all participants in this study.

The third organisation engaged with is called "Benola", a non-profit initiative that focuses on fostering information, raising awareness and capacity building on CP within the society. Their services aim at connecting with parents, caregivers, practitioners and the public to educate and bring significant changes to perceptions on CP disability. They hope to shape how CP is viewed and managed on long-term basis in Lagos State and in Nigeria as a country. This organisation has been operating for the last five years. It continues to advocate the welfare of CP patients. In conjunction with ambassadors, volunteers and advocates who themselves live with a disability, Benola runs conferences, roundtable sessions and forums for any interested parties. These events create an avenue for people living with CP, stakeholders, partners, clients, government parties and the members of the public to get hands-on information from experts on concerning issues.

The fourth organisation visited was the Children's Development Centre (CDC), a non-governmental organisation that adopts a multidisciplinary system of operation. Within this organisation, there are doctors, special educators, occupational therapists, physiotherapists, communication therapists and a speech therapist, one of the rarest professions in Nigeria. They work together to manage children registered within the organisation. The organisation is run by workers and volunteers to help the children manage a sustainable lifestyle with their disability. The organisation started by providing support to children with Autism specifically. Further awareness of the broader concern of disability experienced by children with other impairments such as CP led to a module change. Becoming aware of the complete lack of support and care for PWDs and their families lead to this expansion. Children with CP, Down Syndrome, severe learning difficulties, multiple disabilities amongst others were accommodated into its framework. This organisation has been in operation for 20 years and has projects in other parts of the country such as Ogun State.

The fifth organisation visited was the Cerebral Palsy Centre (CPC), a privately-owned non-profit –making organisation for children with CP. The founder of this organisation established it after failing to find appropriate services or resources that could provide care to her biological child living with CP while she went to work. Realising she was just one of several parents, especially single mothers, facing this difficulty, the organisation was established in 2010. It has been in operation since then, creating a pillar of respite for parents and caregivers struggling to manage children with disabilities.

The last organisation assessed was Modupe Cole, a publicly-funded organisation run solely on government funds and donations. This centre was one of the first public homes to be set up for people with "special needs" in Lagos State. The different sections of the school: primary classes, vocational classes, clinic, therapy and others work together and provide for children registered in the school. Teachers trained in special needs education work together with the school management to educate the children and encourage independence.

All the organisations visited reported an initial intake assessment as a prerequisite before a new client can be accepted. This helps them better gauge what needs the individual has. This is very important because of the diversity in the spectrum of disabilities like CP. However, this process differs based on the organisation and type of services being offered. One of the participants, a member of the management board within the special-schools described what this entailed:

> If they should bring any child to this place for admission what we normally try to do is a kind of assessment for them and through the assessment, we know how we are going to place them. There are some that we put in a classroom and some in stimulation. Those in stimulation, we don't consider their age, it depends on their ability, and if we notice their ability is more than stimulation, we place them in TMC, which is Training Mental Challenges. After, we have EMC, Equitable Mental Challenges. If they cannot cope in the classes, we refer them to vocational to see what they can do over there.

CEREBRAL PALSY IN NIGERIA

Understanding of disability differs among participants based on factors such as their education, level of awareness or personal experience. Some people, for example Pediatric Neurologists, would choose to focus on the medical aspect of an individual’s disability leaving out the social experiences associated with that individual. Other people live their whole lives never knowing what CP is, while others seek out understanding due to family members, friends or acquaintances who have such conditions. Therefore, professional differences, personal levels of awareness, educational and personal experiences on disability issues, tend to create different approaches to interpreting and engagement with people on disability discussions. One of the participants, a worker within one of the organisations, expressed disability as:

> something that can delay someone. I don't know the definition very well... we have different types of disability

Another participant, a professional within the field of neurology, aptly described the distinction between the medical and social model of disability. She stated it as:

> Disability in children has to do with a child who is not able to do what we expect that child to do at a given age, and because of that, it impacts on his/her interaction with the environment or with the people in the community. So, once you have any structural impairment, these days, we talk about the bio-psychosocial profile, and that means it's not just biological alone, which is actually where the disability starts from. But you can have a sociological impairment and not be disabled. But if you have a structural or functionally impairment, something is wrong, and then it affects your ability to interact with the environment, and you need to now get somebody else supporting you, or you need another intervention for you to function within the society. For me, that's what disability is all about.

However, as this research is set within the African culture influenced by varying cultural beliefs, myths and superstitions, there are certain assumptions that come with having an impairment within the different societies. This is no different in Nigeria. One of the participants living with CP describes her struggle when trying to explain her disability to people:

> I try to tell people that disability is not a disease. It is just a condition that can happen to anybody. In Africa, the disability mindset is that disability is a disease, a lot of people move away from us. We are still trying to eradicate that belief among the Nigerian setting as a whole.

Due to its complexity and a lack of extensive information about CP as a disability in Nigeria, there is no consensus on its definition or classification. Even among participants, there is a lack of agreement about classifying CP as a physical or intellectual disability. One of the respondents working within the medical field expressed this dichotomy accurately:

> CP by definition is a physical disability. However, somebody with CP can also have associated impairment. So, you can't say somebody has CP without having the physical motor impairment. Somebody can have intellectual disability without having CP. Someone who has CP can however also have in addition, intellectual disability. Actually, for us in developmental pediatrics, CP is a norm rather than the exception.

Describing CP as a norm is understandable in so far as CP, and other related neurodevelopmental conditions present within the very early years of an individual's life can also be recognised and managed within the health services available for children. This will be a null point if such sectors do not exist as is the case in most developing countries. Nigeria has a unique situation whereby some medical conditions such as Autism and Sickle-cell have greater levels of awareness and capability in the country than other impairments. This is seen with the establishment of a certified Autism Centre and Sickle-Cell foundation. In contrast, CP often confronted with the added dilemma of classification is much less talked about. People familiar with the disability often have difficulty deciding how it should be categorised: either as an intellectual or as a physical disability. This lack of understanding further encourages its continuous stigmatisation and lack of interest.

The reality, according to Strauss *et al.* (2007) is that the mortality levels associated with neurodevelopmental conditions are very low. Most children with CP eventually become adults. Rosenbaum and Rosenbloom (2012) report that there are more adults living with CP than children. However, little is explored or understood about their experiences. Therefore, this challenging fact has important implications for individuals, their families, professionals and the public who have traditionally thought of CP as exclusively a "childhood" disability (Peter Rosenbaum & Rosenbloom, 2012). One of the participants stated the following:

> You see when you talk about people with CP or people who are disabled, because of the figures, people talk of children. When using statistics, the World Health Organisation's figure is 14, 14 years old then you have to use world figures to interpret it. Part of what people should understand is that CP is so complex, has a face of its own and needs a lot more care and attention. In terms of being sick, people above 18 years are not like children but are like adults, and so they have come to an adult management system cognisance to their background. It took a while for us living here (Nigeria) to understand this. It is really difficult because nobody is talking about the adults, all the emphasis is on children. All the literature you get are on children and even treating the health issues as children is even a problem, talk less of when they now become adults.

CP is often superficially similar in symptoms to having a stroke, an acquired brain injury or other neuromotor disorders experienced by older people. Individuals with CP bring to adulthood, a life-long experience of developmental struggles fundamentally different from that of a person who has lived a conventional lifestyle until adulthood, without having a medical condition that interfered with their daily functioning. One implication of this difference is that people working in adult health services may have little or no appreciation of such unusual life trajectories and "cultures", making them ill-equipped to help adults with CP fit into the "adult world **(**Rosenbaum & Rosenbloom, 2012). The medical aspect of living with CP is often presented as less important than the social, vocational, and community-living dimensions for which adults with CP also need support. When asked what "having a disability" means, participants automatically equated it to having low intellect and high mortality levels. Participants of the study expressed their constant struggle to overcome the dominant assumption of "early" death and low intellect as a motivating factor in maneuvering everyday living. This is one of the leading assumptions of people with CP. One of the participants living with CP expressed this in their narrative saying:

> Yes, I found out in fact, that people are always surprised when I tell them I am a graduate that I have BSC in International Law and Diplomacy. They shouldn't give

> up. CP is not a disease, it is just a condition and it is not their fault. It has nothing to do with mental illness even though it affects a portion of the brain, but the portion of the brain is not the part that conveys human intellect it is just a part that controls our mobility. So, they shouldn’t mix it up that is a brain damage.

CP is commonly defined as an intellectual developmental disability. The least addressed of the disability sections that people within developing countries such as Nigeria choose to focus on. This is because it is believed nothing can be changed. This mentality creates a reality whereby anxieties faced by persons living with these types of disabilities go unattended. A medical professional participant stated that:

> Then again, developmental disability is the last thing that gets on the agenda. When you talk about physical and sensory disabilities, that is not a problem. But developmental disability, because it is an intellectual disability as well and you do not always have self-advocates apart from those who have Down syndrome or a mild form of disability, then the others are stuck. So, they have to rely on their parents or their caregivers to advocate for them.

STUDY FINDINGS

Through interviews with study participants, this study examined the effectiveness and functionality of Nigeria’s health assistance practises for people with disability in reference to understanding and improving the societal experiences of people living with disabilities such as CP. The following themes were uncovered from the answers provided to this question.

Lack of Normality, Low Intellectual Proficiency and Societal Stigma

Through the interviews, respondents demonstrated a strong concession to the fact that persons with CP are often assumed to be intellectually deficient and predisposed to dying early. Participants reported that CP within the African context is often synonymous with having low intellectual capabilities, creating a powerful stigma against anyone labelled as a CP patient. Participants living with CP conveyed a strong desire to freely express themselves as “normal” and “able-bodied” members of the community. They deplored any stigma of complete dependency for care and support. They also worry about the constant anxieties that association with this term brings: low employability and more dependency. One of the female participants living with CP narrated her experience in school:

> I gained admission to Lagos State Polytechnic at Ikosi Campus. I studied Food Science and technology. I liked it, but due to my physical challenge problem, I cannot practise it, you know this our country they use to discriminate. They use to say, "this one is an handicap; she cannot hold herself; how can she hold paper." They are supposed to test someone, the ability of the person before judging the person.

The “Ceiling” age for discussion around CP within medical or health assistance sectors is 14 years of age. This module has been preserved by the assumption of early death as a result of the impairment(s). Individuals with disabilities constantly fear being turned away or judged solely on associating CP challenges such as impaired motor or speech condition for example. One of the participants with CP said:

> Let people know that what a normal person can do, the physically challenged can do too.
> I cannot go and meet them because I’m afraid they will not help me but if I still have the opportunity to work in a Food Company with my intelligence, I can do it. My condition doesn’t affect my brain, I can work, I can write, and I can speak.

People with CP show a willingness to educate others on their medical conditions. Participants with CP shared a strong desire to become contributing members of their family and the society at large. CP as a disability is about management rather than cure. This lack of cure drives up the cost of care and expenses for patients and their family members because it is a long-term need. A daily treatment plan is necessary to manage impairment(s). The attitude upheld by PWDs was revealed in the response of one of the participants working with people with CP as stated below:

> They don’t have a problem, and they don't see themselves as if they have a problem. We the normal one are the ones looking at them as if they have a problem. They are looking at themselves as if they are like us. If you want to pity them, they will ask you why you are doing it; and the moment you show love to them they are ready to go to any extent with you. Maybe they are eating, and you want to eat with them, you have gained their heart, they don’t have a problem.

Lack of Early Intervention and Diagnosis Services

The majority of families, children and adults that have disabilities are the poorest of the poor within the society. Due to this, clients often experience difficulties in covering the cost associated with medical, rehabilitation or educational services incurred. This, in turn, creates disagreement between the disability office and the health-care services on issues of "free service". The lack of access to health assistance becomes most detrimental when issues around “free services” delay care delivery, leading to morbidity in a worst-case scenario. Respondents expressed unmet needs for diagnosis and better health information needs. Reasons for dissatisfaction were further elaborated to include limitation of freedom, living choices, and facilities. One of the participants that had some experience with this explained that:

> Even if you took your child to a public school, they will say, oh but there is a special unit, take your child to the special unit. They will just tell you where the nearest special unit is. When you get to those special units, there is no education going on there because they have not even separated the children by diagnosis. So, if you get into the classroom, there’s everybody from down syndrome, to CP, polio, to visual impairment to hearing impairment all in the same classroom. Some with no serious impairment and no trained teachers so obviously nobody to prepare these children for life.

There is also a lack of technical capabilities to diagnose impairments. Parents have limited knowledge of whatever constitutes a disability. A lack of proper diagnosis creates a situation whereby a significant number of CP patients, though classified as mild, become categorised as "non-cerebral palsy" just because their conditions does not fit the classification of extreme motor movements impairments (twitching). This inadequate diagnosis hinders early intervention services and creates a delayed treatment of CP conditions. A great proposition of severely disabled children and adults who could get access to better management are excluded. A participant living with CP expressed her experience:

> I get people calling me and saying, "the video we watched says that you have a Masters' degree and recently went to graduates and you still have CP, how did you grow up with that?" and I'm like I did it the way everybody else does it, you know school, graduate. My brain works; its not that hard! And then I realised that the management of CP was almost non-existence in this country. Cause things that I assume that parent will diagnose because their doctors would have told them, they didn't know. I was shocked. I was like this sounds really weird.

Lack of Information and Information access

There is a general lack of in-depth knowledge about CP as a disability. Several respondents reported not being knowledgeable about the condition until people with similar conditions emphasised their similarities. One of the participants stated as follows:

> Yes, so first the central assumption is these children will soon die. Seriously, it's the first assumptions. Two, the second assumption... No! Let me even start again; The first assumption is "this is the devil" (African mentality). Yes, therefore, that this child will soon die. And then, of course, "This child cannot amount to anything." "This child cannot learn so let's not waste money." So, of course, that includes they cannot learn anything, so there's no point paying school fees. Then there is an assumption that you have to do everything for them so there will always be care-ers and they always be cared for and they will never become care-ers, so independence is never factored.

Several participants reported the Internet as their primary source of information. Others reported getting information about CP from friends, families or homes. Very few got an explanation of the condition themselves and neither did their other family members when visiting hospitals or related health-care organisations. Due to this lack of knowledge and access to information on CP, there is a delay in their capability to manage their lives better while taking appropriate care of their children. The field narratives emphasised the absence of a male figure within families that have children with intellectual disabilities. Several experiences showed abandonment by fathers, leaving the mothers to fend for the family alone while also nursing the child with disability themselves. They often complain about not having the time to adequately care for their children, much less sitting and educating them about their disabilities. This was most common among low-income families within the context. An apt description of this was made by one of the female respondents:

> It was when I joined Benola that I discovered CP management, the occupational therapy, food and nutrition or that there are some particular diets. Before they just told me to take lots of protein, apart from joining the team they never told me about occupational therapy, emotional therapy, speech therapy and all the therapy, and a lot of protein that's all. Judging from what I can say CP management in Nigeria is very low, nobody is giving accurate information about how to go about it.

There is no specific style for the management of information, research or health-care provisions for CP; however there are some approaches been implemented in different countries. Three examples of these practises are, one, the International Cerebral Palsy Society (ICPS), founded in the United Kingdom, 1969 with its headquarters in Great Britain. This society of 140 members from 49 countries, comprises of national disability organisations, parent organisations, institutions and professional organisations that provide services to the CP community (ICPS, 2017). This society provides a network for people with CP by encouraging prevention and research in all areas affecting CP to better understand and exchange information worldwide. The second, is the CP International Research Foundation (CPIRF), a non-profit founded in 1955, located in New Jersey, United States. This foundation focuses solely on funding research, advocating for federal support and educational initiatives on behalf of people with CP, to help generate initiatives within the medical community by preventing the causes, discovering potential cures and improving evidence-based care for CP. The last is Surveillance systems used to create Registries for people with CP. There are over 40 functioning registers and population-based surveillance systems for CP existing across the world (Goldsmith, Shona, et al., 2016). In North America, this registry is called the Canadian CP Registry, located in Montreal, Canada and implemented in 2003. It is the first national registry for CP created in North America for the purpose of collecting medical and social information about children with CP.

There are also very limited medical experts who are genuinely knowledgeable about CP in Nigeria, making the development or management of the disability more difficult. Several participants emphasised this problem in their narrative:

> If we have the manpower, the centre might work, but we do not have the manpower. So even if we have the centre, it'll have to be a training one. We'll have … the first thing you'll have to do is to train. So, I always say when everybody dawns on they want to start a centre, and I'm like, how are you going to staff it?
>
> It’s not because we don’t train. It is because we don’t re-train (yeah, we don’t retain the good ones, yeah) because our services are terrible. So, I am like, unless our health sector is funded properly, so that we can retain good doctors, we will continue to have these problems.

Lack of Health Care Accessibility or Capability

Through this study, it has become evident that professionals need to implement improvised treatment options that take into consideration, patients’ inability to gain access to expensive training equipment within local communities. This is important to ensure that some services are available to relieve the burden of disability for persons living in local communities who do not have easy access to urban centres. Health-care professionals reported having robust services geared towards clients with disability, ranging from the initial assessment provided to the diagnosis, to consultations with the psychiatric department for a more rounded disability management. However, patients with disabilities and parents that have children with disabilities disagree with this report. A female participant living with CP evaluated the services offered and stated the following:

> Out of 1 – 10, it is kind of like a 2. It is pretty horrible. One problem is that we have inadequate manpower because of brain drain. Two is because there is inadequate manpower, so there are a lot of quacks. That is what happens again because there are a lot of (Quacks) there is inadequate manpower. The physiotherapist also don't give the required attention and amount of time required to do the right things. So, they also get away with just doing nothing.

This experience implies that available resources are not useful when dealing with the population size as required. Most of the other respondents agreed with this rating which implied that they were also not satisfied with the health care system or government support for persons with disabilities. The current service levels are poor and almost non-existent when issues around CP is raised. Lack of adequate services as well as the stigma associated with being disabled guarantees majority of children with CP end up being "hidden". They are prevented from socialising or interacting with other members of society and kept at home. In addition, high treatment cost combined with the stigma of disability influences parents' perceptions and ultimately, they lock their children at home every day. Most children with CP reach adulthood in such situations never being able to gain independence. A participant reported the example of her acquaintance:

> While growing up, she was somebody they used to leave at home, and they didn't bring her out. I think the parents thought she couldn't achieve anything in life". "Some families don't even allow their children to go out. They are too ashamed of them. They feel that people would talk to them about their child and they don't take them out. We need to know that these children also need love and care. As my director would always say, a child is first a person before disability came and that's

> why they call us people living with disabilities. It's like we are people first before you talk about our disability.

This encourages long-term dependency on caregivers and family members alone. The lack of basic care levels within organisations is because of the poor availability of medical professionals. Medical experts, caregivers and teachers with experience and expertise in managing CP are not enough. One participant explained her experience as a person living with CP: She gives a recount of her conversation at the hospital:

> I told them, I'm in pain, and they were like, that is CP. You should be experiencing pain. I told them, I know the pain that is normal for CP, I'm telling you I'm in pain. I know that I'm in pain.

She goes further by explaining that:

> First of all, the amount of time it takes to access health care, unless, you're accessing private health care, cost an arm and a leg. It's ridiculous, and then because nobody really takes you seriously, everybody kinda ties everything to your disability. You don't access the right level of care, and so, you're dismissed because everything is a result of you having a disability. So for instance, in 2008, I was diagnosed with clinical depression, and for a very long time, it was always associated with the fact that I have a disability**.** Until I spoke up and fought for better assessment.

Other patients might not have had the time, resources or ability to fight and gain better assessment for themselves. There is the lack of available interventions such as diagnostic testing, physiotherapy and occupational therapy that would otherwise assist in the management of CP There is an in-proportionate ratio of doctors to clients to address the need. Interview reports showed a complete lack of mental health personnel such as counsellors and psychologists in the provision of services to PWDs including CP:

> Somebody needs to begin to even get people who probably don’t even have a health background…..to actually now go in to like short course or whatever to kinda get them into the health sector, people that are smart and that are interested, we need to begin to train people, because like our gap is crazy…in….because of my experience with errm metal health….. I started to read a lot of research, and I realise that our mental health, one psychiatry's to 1.2million Nigerians, I say there is approximately

> one psychiatrist 1.2 million, so we have…it's not even just CP, we have a major problem with the health sector, every day, so, it's not building a centre that will solve the problems, it's, fixing our manpower problem, our current hospitals are under-staffed.

Lack of Adaptive facilities or External Health-Care Services

The lack of adaptive equipment such as wheelchairs, accessible transportation, and accessible buildings contributed to people choosing not to seek out existing care services. This widens the treatment gap for children and adults with CP in the long run. There are two public teaching hospitals in Lagos that have dedicated Pediatrics (children) neurology departments. They provide affordable services to patients, but these services are not sustainable for the population size. There is a need for medical practitioners to plan for the management of CP upon early recognition. This will foster better disability management approaches suited to Nigeria's environment. A female participant living with CP emphasised the importance of independence. She advised as follows:

> Make those provision, prepare your child in such a way that without you they can function, I said look, it doesn't matter how much money you leave in your trust fund, if your child doesn't have basic numeracy and literacy skills it's useless.

Astronomical Cost of Care

Caregivers and families found the financial cost associated with medical care, rehabilitation, assisted devices and transportation as a significant barrier to seeking care. Participants described their access to health-related information, accessible transportation, the condition of the family and access to employment as factors that influence living with disability in Nigeria. When participants were asked why they have not accessed available health care services, they reported being burdened by the cost associated with the management of their disability. A participant responded that:

> I cannot stand well but now my condition I am improving but if I have the opportunity of going to the health centre, is it, someone that has eaten properly that will go to the hospital, you supposed to understand what I'm saying.

Sustainable Home-Grown Initiatives

Participants reported some community and parent-support groups as being useful in reducing the mental and emotional stresses associated with the care of children with CP. However, the effectiveness of this services has not been thoroughly evaluated. Participants reported needing a vital support system from their families to live from day-to-day. There was emphasis on home-based therapy, improvised treatment and collaboration to further reduce inquired cost. These changes can help reduce the cost of expensive medical equipment that adds to treatment costs, transportation fees, the cost to parents' professional life and much more. A disability advocacy participant asserts that:

> We need to fill it on our own (gap in professionals). The only way I see that we can do this is to begin training parents to do these things themselves at home. Medical professionals, especially therapists, need to get over themselves and stop over thinking. If we……parents, then cannot come to them …..cause the truth is that they cannot meet the need. So, can we begin to actually train parents, so that parents can begin to do these things at home and only come to the hospital for things like reviews or maybe for quality or some other purpose. It would save a lot of work… exactly. Save you professionals work and also save the parent's costs. For me, that's kind of like a solution to that bit.

Lack of Stakeholders Cooperation or Service Exchange

While government departments and health-care services collaborated, they each voiced significant dissatisfaction about the others respective technical and political capabilities. Workers within these departments and clients who received services from them expressed dissatisfaction about the capability levels of personnel, service options, service levels and costs associated with services offered. Organisations that work in collaboration with external parties also expressed difficulties in partnership operations due to imposed restrictions, lack of available personnel and equipment. A worker within the governments' disability departments expressed the following:

> Disability! You can't do it alone, you use stakeholders in the police, with the Lagos State Traffic Management Authority (LASTMA), do you know the meaning of LASTMA? It has to be compliance, the building code for disability has to be there. Not only that, we work with other agencies. Education! how is the education in Lagos State. What kind of disability education are we practising in Lagos State? We collaborate with so many agencies like WOPA women above poverty alleviation. We have a lot of private organisations; a lot that collaborate with us.

Government Services Accessibility

Privately-owned service organisations that reported being run mainly by donations, limited public funds, and out of pocket payments present a great difficulty in acquiring funds for services. This also influences the level of care being offered. There were also concerns about the capability levels of publicly-funded services. To improve disability movement in Nigeria, Lagos State implemented a "Special People's Law" in 2010. From this law, the State government established the Lagos State Office for Disability Affairs (LASODA) in 2012 to better monitor and enforce the law within the society. This office works in collaboration with the local and international organisations to foster its goals. LASODA supervises 31 inclusive public Primary Schools, seven public Secondary Schools and five Special Schools dedicated to the educational training of PWD's.

Despite being established for five years or more, there are no proper regulations on services provided by these schools. There is also little, or no funding allocated for the development of these educational institutions to assist in further capability improvement. At the state and local levels, there are no monitoring or evaluative frameworks in place to assess the effectiveness of these public disability service providers. Without improving or expanding services provided, a full range of the target population size and their needs will not be met. Study finding revealed that low priority is given to disability issues within government agendas as reflected in the insufficient budgetary resource allocation for the public. Members of the public assume that services provided by these government-funded organisations are "free." Several, PWD service workers and members of the public interviewed hoped this assumption was true. One of the health-service workers laments this situation;

> When the government says the services are free, where are the free services? That's the question you should have asked. Where can I get the free service? They told me they have only five schools. Do you know how many children we see who have these disabilities? How many of them can they cope with in their schools? How many children go to the government schools? Even the government schools, how many of them do they have?

According to several participants who are professionals within the field, this concept of "free" health-care tends to create conflicts among different stakeholders such as government departments, health consultants and other external partners. A statement made by one of the participants adequately describes the situation:

> They are not doing anything. To be honest with you, there's no free lunch, and I can tell you that categorically. I can speak about federal government services. It may be a ridiculous amount of money may be as low as five hundred naira, but it is not free. There's nothing completely free.

Another participant expressed the following:

> Well, maybe it's supposed to be free, but it is not free because I know there is a lot of equipment that would go into the work. Even in government hospitals, it is not free.

There is a need to raise better awareness about private and publicly owned organisations and facilities that address the needs of PWDs and meet the right level of assistance they require.

Sustainable Disability Management

Coming to terms with Nigeria's limited circumstance and services is another crucial milestone for long-term management and dependency issues faced by adults with CP. The overall aim in treating an individuals' disabilities is to produce "Independent Adults" living everyday life with a disability**.** A disability service providers' narrative contributes better to this reality:

> Usually what happens in Nigeria is that they look for residential homes so the problem is off the parents, but this is a very poor choice. We don't have the money to support that kind of system and these things that are our problem. Mainly, we're integrating the system; if it works for the parents, it works for everybody and it is cost-effective. However, it is costly to the customer and the parents; it's costly to service providers like me because I'm having to do everything I can. I provide everything but obviously, I can't, and the parents they get put in between.

As several participants expressed during the interviews, "there is ability in disability" and as another participant stated, *"*the person first before the disability". These are important paradigms that should govern disability management within any country. To better ensure long-term sustainable capabilities, disabilities such as CP need to be addressed in adults as well as in children. Adulthood itself brings its different forms of struggles, discrimination and perceptions that individuals fight with every day. An example is the state of one's mental health. Support groups, caregivers and psychiatrists who can better provide this mental support and increase advocacy for persons with CP are needed to keep disability management in optimal condition. There is a general lack of neurological services, nutritional or mental health support because it is not viewed as an essential part of the disability agenda in Nigeria. This circumstance is seen not only in the mental health management of disability, but in the overall approach to disability issues within the country. The constant struggle experienced by vulnerable persons is captured in a statement made by one of the medical practitioners:

> I love my country I will not lie, but I don't like my government most of the time in the sense that they don't wake up and make policies, make laws that protect those who are most vulnerable amongst us, when they do, they do it in such a way that it robs people of their dignity.

CONCLUSION

This chapter presents the findings of the fieldwork based on the primary analysis of the interview transcripts. The results were sectioned based on emerging themes from the data collected. The first section outlined a description of organisations and participants involved in the study. Health care practices, facilities and services are commodified, and they vary across the different States in Nigeria. This makes it difficult to fully generalise the study findings and assessment across the different States. To that end, the next chapter analyse themes emerging during this study from the scope of literature and recommends future practise and research to be undertaken.

CHAPTER 5 - DISCUSSION AND ANALYSIS

INTRODUCTION

The previous chapter outlined themes that emerged from interview transcripts, while ensuring respondents' voices were reiterated. The focus of this chapter is to provide a breakdown of the major themes and sub-themes discovered within the data collected. Analysed themes will then be related to literature reviewed in chapter 2. Using the theoretical lenses previously examined, the practical implication of disability health-care development is further explored. Building on the interviews collected in Nigeria, and presented in chapter 4, this chapter will undertake an analysis of the different facilities and capability levels available for the provision of care to persons with CP in Lagos State. The analysis will range from the perspectives of individuals with CP, to the experiences of caregivers, professionals and organisations working together to alleviate their health and daily needs.

ANALYSIS OF FINDINGS: BROADER SIGNIFICANCE

There are no credible or robust statistics in Nigeria about CP disability. In addition, very little has been researched or reported about what people living with CP require to live a meaningful life in Lagos State. Past attempts have been made in Nigeria to put the advancement of disability on the country's agenda. However, it has not yielded the expected results. This is a knowledge gap that needs to be filled. This study reveals that despite the availability of services geared towards people with CP, services remain inadequate when meeting their daily needs. More facilities and capacity building are required to provide long-term planning for sustainable disability health-care management.

Service provision for persons with disabilities (PWDs) needs to be incorporated into the public health care system, especially at the local community level for individuals and their families. Such an approach will better accommodate the needs of all involved. This is especially true given that disability affects not only the individual, but also the family, community members, and the broader society.

Fears expressed by interviewed participants living with CP ranged broadly from, their health conditions, environmental factors, accessibility, social integration, to sustainable management difficulties (Participant, A.I, 2018; Participant, T.A, 2018). In contrast, the interviewed participants who are health care professionals and consultants, expressed the various advancements taking place within their respective fields and workplace (Participant, O.O, 2018; Participant, G.B, 2018). They also emphasised steps being taken to improve the services being provided (Participant, O.O, 2018; Participant, G.B, 2018). This difference in opinions of patients and professionals emphasised the disconnect between parties involved in disability management within Lagos State. The expectations about what professionals such as Pediatric Neurologists, can and should provide differs based on a patient’s knowledge and experience. Some patients expected that the pediatric department should not only provide diagnosis for children, but also cover the duties of the Speech pathologists, Physiotherapists and Psychologist (Participant G.B, 2018). In contrast, some Doctors choose not to fully explain CP during diagnosis; instead they just prescribe treatment. Their belief seemed to be that explaining to mothers that their children have CP, a disability that can only be managed due to its lack of cure, would only encourage them to abandon treatment or the children themselves (Participant N.N, 2018). Similar miscommunication and assumptions also exist around issues of treatment cost when visiting available public hospitals. This disconnect emphasises the need to piece together confusions about service requirements for PWDs and health care providers. Achieving this will get the appropriate consciousness of the work presently being done and improvements for the future.

Accessibility of care services is essential to the goal of independent functioning of individuals with disabilities. In low-income countries such as Nigeria, public health status is weakening because of the wide inequality between health provision and health-care consumption. The uncontrolled rise in health-care needs, profit-driven inefficiency, and the deterioration of trust between citizens and providers are all factors contributing to these disparities. For better management of CP, various health service providers such as speech pathologists, psychologists, physical and occupational therapists, recreational and medical practitioners and counsellors should be made available in Nigeria (Participant, F.G, 2018; Participant, Y.A, 2018; Participant, T.A, 2018). Each of these primary care providers play a significant role in the development and management of services for children and adults living with CP. This approach to treatment is considered to be the best form of practise for CP care within the Global North. Health providers are required to improve the planning and implementation of treatment strategies for CP patients based on need assessments and evaluations. However, this reality of care is not available or expected in Nigeria. This lack of strategies or improvement emphasises how structural violence is embedded within Nigeria’s health care context. Despite the availability of services geared towards people with CP, the institutional and social structure of care in the country harms vulnerable persons by ensuring that services remain inadequate when meeting PWDs daily needs.

The level and type of treatment an individual with CP gets during their early age influences the nature of adulthood experience they progress into (Participant, O.A, 2018). From discussions with some of the respondents, it can be understood that providing early intervention impacts the level of treatment provided to persons with CP. Treatment options guide the progression of an individual's fine and gross motor movement, muscle strengthening, joint mobility, neurodevelopment, speech and vocational techniques, among other impairments (Participant, O.A, 2018). Available and accessible treatment options affect each child's future ability to improve or develop impaired functions affected by CP disability, and, ultimately, it influences their ability to perform tasks independently. The provision of successful treatment options for some of these impairments not only elevates independence, but also creates a better body image. Improved body image and presentation is also a significant factor in physical and social integration. It plays a significant role in "qualifying" persons as socially acceptable contributing members of the society.

Reliable access to expert help assists persons with CP and their family members effectively plan short and long-term management strategies. However, as reported in the data collected, accessibility to such rehabilitation services is currently very poor in Nigeria. This also shows the importance placed on disability management (Participant, Y.A, 2018). Participants living with CP expressed that their main priority were getting food and money for themselves and their family's day-to-day provisions, rather than their own health concerns (Participant, T.A, 2018). Despite their personal pain and health difficulties, the participants choose not to focus on their health but rather basic survival each day. The lack of health as a priority coupled with low expectations for change, encourages the acceptance of poor health provisions.

Concerns were further raised during discussions evaluating services delivered by the public health providers. The first problem expressed by participants was the high cost associated with access to these services (Participant, N.N, 2018). The second problem mentioned by workers in these health-service organisations was the sheer number of patients they had to see each day (Participant, G.B, 2018). The number of patients that they had to provide services to when compared to the level of equipment and time they could provide, were greatly disproportionate. During the field research, evidence of limited space available for organisations providing homes and services to children with disabilities was stressed. Public and privately funded homes for children with disability are currently running at full capacity (Participant, C.O, 2018). This contributes to the frustration of the personnel and affects the number of future referrals they can accept. The third concern was expressed by professional participants working in health care organisations. They expressed the lack of consolidated partnership between the different health service providers and organisations such as homes, clinics and hospitals for PWDs like CP (Participant, O.O, 2018). Greater communication and exchange of information was expressed as a key factor for inclusion and advancement. Participants also reported that health care professionals were not able to fully satisfy their needs. Respondents indicated that doctors, therapists, and counsellors are not readily available near the people who needed them.

Findings in the research also emphasised the importance of self-help and community support groups. Such groups were usually formed because of the patients’ and their family members’ dissatisfaction with the assistance professionals provided. There was a realisation that such assistance was limited and incurred a higher cost than they could afford. Many of the people with disability do not have the funds to pay for available health care services (Participant, T.A, 2018). These community support groups play a significant role understanding and sharing the needs of children with CP than the limited services public health could (Participant, N.N, 2018). It also created an avenue for single parents or caregivers to talk about the emotional, mental and physical strain that came with being caregivers. Respondents in this study were mainly concerned about the level of care being given, and how health-care facilities could be of better help to them and their families (Participant, T.A, 2018). They expressed a strong desire for more home and community-based approaches to care provision as the only other option, since private health-care was too expensive (Participant, T.A, 2018). This support system reaches a broader percentage of the population than professionals within health-care services could access. Consultants and service providers outside the public health system expressed their concerns about the lack of advancement in publicly provided care for PWDs (Participant, F.G, 2018; Participant, T.A, 2018). Given the opportunity, early stage capacity building would foster a more improved and sustainable approach to disability management.

Having access to health and rehabilitation services is a precondition to equal opportunities as outlined in the United Nations (UN) Standard Rules for Equal Opportunities (United Nations, 1993). It is also an essential component of being a valued and productive member of the society. As mentioned in the study findings, Lagos State established a disability office (LASODA) in 2012, to foster the development of equal opportunities for PWDs within the state. This department works alongside other departments and organisations such as The Down Syndrome Centre, State planning department and publicly funded teaching hospitals, to improve health care services and accessibility for PWDs. They also collaborate with international organisations which work to provide funding to smaller non-governmental establishments. To access the services provided in this office, PWDs get a medical assessment of their condition from one of the publicly funded hospitals within the state. After this assessment, they are given a registration form (attached as Appendix E) which is then submitted to the disability office to get access to the services and provision enforceable by the office. However, to qualify for these provisions, a PWD must be registered as a resident of Lagos State. One of the participants working within this department reported that they currently do not work with any CP-focused organisations (Participant, O.O, 2018). This means there are no services offered to persons with this specific disability. Current workers within the department also expressed the strain the work has on them due to the need for more workers and branches of the office to better meet the needs of the population.

Health professionals within the health-care sectors reported that their clients complained about cost and accessibility to transportation when travelling to service locations (Participant, G.B, 2018; Participant, Y.A, 2018). Due to the nature of CP disability, patients need to travel daily for physio, speech and occupational therapy to help improve patients' chance for some degree of independent living as adults. In an attempt to address this shortcoming, Lagos State government is currently working towards establishing five branches of the disability office, across five different sections of the state, known as "IBILE" (Participant, O.O, 2018). These branches will be opened in Ikeja, Badagry, Ikorodu, Lagos Island, and Epe, (IBILE: an acronym for the original regions which constitute the administrative zones of Lagos) central communities within the state and thereby reduce the burden and cost of long-distance trips for rehabilitative services such as physiotherapy.

As expressed previously, bringing disability into the development mainstream will have a significant effect on plans to reduce poverty for developing countries. However, ideas of "disability" constantly interfere with ideas of being contributing "humans" within societies. Societal attitudes towards disability need to be addressed before progress can be made, especially the assumption that "disability" means needing charity. PWDs are often excluded from the mainstream society and hence, cannot be perceived as contributors to the development of a society. Due to the UN's standard rules on the equalisation of opportunities for people with disability, some countries have tried to develop strategies to address disability amid overall processes for development strategies. An example is the South African Integrated National Disability (SAIND), notable in South Africa as a key policy area that includes the advancement of prevention, health care, rehabilitation and research on people with disabilities (White Paper, 1997). However, even where government's commitment and the policy environment are favourable, most PWDs may not experience significant changes in quality of life due to unequal access to rights and varied levels of community integration.

SUSTAINABLE CEREBRAL PALSY MANAGEMENT

CP is a disorder of movement and posture resulting from a permanent non-progressive defect or lesion of the immature brain; it is reported to be the most common cause of motor deficiency in childhood both in developing countries and developed countries" (Adejoke, Ibeabuchi & Lesi, 2016, p. 96). Among the fundamental realities is that in most parts of the world, adult-focused services are unfamiliar with these 'childhood conditions' of CP. At the same time, there are important aspects in the process of ageing with CP disability that need to be better understood, to avoid making assumptions about the living experience of an adult with CP simply because of their underlying “childhood” neuromotor conditions (O'Brien & Rosenbloom, 2009). Unemployment and social isolation are often identified as key challenges for adults with CP and other neurodevelopmental disabilities (Participant, F.G, 2018). In addition, the social and counselling services available to adults with CP in Nigeria are grossly inadequate in helping them (Participant, N.N 2018).

While there are classic neurodegenerative disorders in early childhood that are clearly “progressive”, meaning they get worse over time, it could also be the case that some of the traditional “static” brain damage or malfunction in infants and children are slowly advancing in ways that have not been previously recognised (Evenhuis *et al.*, 2001). Also, it seems likely that adults with CP age differently from other adults, related at least in part to factors such as “wear and tear” on their systems and also the development of minor conditions of muscles and joints (Evenhuis *et al.*, 2001). An interviewed participant explains how an accident aggravated his underlying CP impairment and further complicated his motor skills (Participant, S.O, 2018). These enhanced changes in body functioning and structure can also be linked to the availability of programmes and services to such adults (Mudge *et al.*, 2016). As Rosenbaum & Rosenbloom (2012) argue, if this is true, then there may be significant and yet unrecognised opportunities for secondary prevention of the consequences of CP on adults well-being.

Health and disability need to be reconceptualised by examining gaps in determinants of health, especially social circumstances, health-care access, individual behaviours, environment and types of health conditions (Krahn, Hammond & Turner, 2006). Inequalities experienced by people with CP have a higher prevalence of adverse consequence because of inadequate access or attention to care, lack of health promotion on

CP, and insufficient care services (Krahn, Hammond & Turner, 2006). The perspectives of people living with this disability, providers of care or services, and policies that influence their systems of care all need to be re-evaluated.

To balance out problems of service accessibility, most clinics and centres for PWD offer a boarding house model (Participant F.G, 2018; Participant, N.N, 2018). This approach reduces the burden of cost on individuals, but raises the cost incurred by these organisations. Cost of daily living, care, services and equipment for each PWD are now incurred in the organisation's day-to-day finance. These self start-ups run solely on fundraising, donations or the personal funds of the founder, creating additional anxieties when funds are needed (Participant, N.N, 2018). To worsen the situation, publicly-run centres in Lagos lack the capacity and space to meet the State's PWDs population size (Participant, F.G, 2018).

Participants expressed their dissatisfaction with currently poor services and an apparent lack of resources for smaller establishments (Participant, T.A, 2018; Participant, T.A; Participant S.O, 2018). In the organisations visited, the lack of appropriate equipment required to sufficiently provide services to clients was noted. Personnel have been trained in such a way that expensive equipment, unavailable to low-funded establishments are still required to meet the needs of their patients. Influenced by factors such as finance, religion, ignorance, distance from home communities and attitudes towards PWDs, many individuals with CP are discouraged from exploring the services being offered by available centres and organisations.

Developing a robust monitoring and evaluation mechanism in order to supervise the activities of government, health care departments and private agencies is necessary for a proper demonstration of their effectiveness. Without this approach, it becomes difficult to evaluate how well they meet their goals of disability care and inclusion for persons with CP towards whom these services are continuously geared.

STRUCTURAL VIOLENCE

Themes emphasised in the interviews depicted Farmers' (2005) ideas around structural violence and the need for a “right to health.” The poor, according to Farmer (2003) are those with the enormous task of "trying to survive". Farmer (2003) maintains that this "right to health" is the right to life. As Farmer (2003) argues, treatment is important for the sick despite its cost, and any society that fails to honour the experiences and views of the poor in designing strategies to respond to those with diseases, is in error. This means without a right to health, individuals have a lower chance of surviving in their environments. Everyone has a right to live in decency, and this can only be achieved with the enforcement of a right to health for people in poor health. Such rights are more valuable and enforceable when we believe that all humans are equally valuable within society (Farmer, 2003). Doing this will ensure individuals reject second-rate interventions or health care access, and instead remediate the inequalities that are becoming clear in globalised economies.

Equity of care is the central challenge for the future of medicine and public health (Farmer, 2003, p. 20). Focusing on the equality of health-care service and access is necessary when analysing the level of care and services provided to people with CP in Nigeria. The promotion of equity, social and economic rights is the central ingredient for respecting human rights in health care. The poor, who lack access to health-care and knowledge of health problems because of poverty, lack of access and inequality, most often have short life expectancies due to easily preventable or treatable diseases and accidents.

Farmer (2005) describes structural violence as a form of violence in which some social structures or social institutions may harm people by preventing them from meeting their basic needs. Farmer (2005) contends that many of the concepts currently in vogue in public health such as “cost-effectiveness”, “sustainability”, and “replicability” are likely to be prevented unless social justice becomes central to public health and medicine. Nigeria’ society epitomises structural violence within the health care institution, the result of which is systemic poverty, suffering, and in the worse case, death. This public health module being used in Nigeria will only contribute to the deterioration of its advancement. These effects of structural violence are also the typical experiences faced by PWDs in Nigeria. Inequality is the reality of disability health care within Nigeria’s framework.

RECONCEPTUALISING DISABILITY DEVELOPMENT

When traditional measures such as GDP, are used as the only indicator for development rather than also measuring human freedom and development, economic growth becomes the only sector assessed (Sen, 2015). This creates negative effects because the development assessment lacks a full perception of the society’s accurate level of development (Sen, 2015). Development, according to Sen (2015), should be a comprehensive output of the economic, social, cultural and political process and should aim at constantly improving human well-being. Falola and Achberger maintain that “when development programmes are preoccupied with economic development, there is a greater danger of losing the concept of development that fosters real humanity, humanness, fellow feeling and concern for others" (2013, p. 333). This implies that development is not just about economic growth, but also personal development as they tie in with the state of the society as a whole. To achieve this comprehensive output, the personal, social and economic development of PWDs in any society must be included. The well-being of all members of society, especially its vulnerable population, is significant to development. The creation of equal opportunity for all members within the state is required for development to be truly achieved. This study findings shows that, this is not the case in Nigeria. This responsibility to create equal opportunities for development, enable growth of the local community, and the removal of obstacles to these agenda, lies with the state and its individual members.

In addition, disabilities cannot be boxed into a binary category of disabled or non-disabled because they can be rendered irrelevant with the use of assisted devices (Slorach, 2016, p. 18). The stigma of PWDs being dependent on care or support by others, and the constant fear associated with those seen as less employable and more dependent becomes created by society. This means, disability should not be seen as a restriction to a person's abilities, because advancements and access to opportunities within the society, such as access to wheelchairs and health-care, shape the disablement of disability.

FREEDOM WITH DISABILITY

From the findings presented in the previous chapter, the role culture and society play in the discriminatory practices against PWDs is consistent with Oliver's variant of the social model of disability (Oliver, 1998; 2012). In his seminal work, Oliver seeks to provide conclusive evidence that disability "as a category can only be understood within a framework which suggests that it is culturally produced and socially structured" (Oliver, 1998, p. 22). This means discriminatory practices against PWDs are sustained by culture, which also reinforces dominant perspectives regarding disability. This argument highlights the fact that, religion and culture within societies promote certain beliefs and attitudes about disability and PWDs, leading to discrimination and inequality. Beliefs, assumptions and attitudes are sustaining factors to the inequality and discrimination of PWDs. These practices should be denounced as they result in the invasion of dignity, personhood and life of PWDs.

While the social oppression and human rights capability approaches are both valid and relevant, they become irrelevant when applied separately within Nigerian society. A synthesis of models is needed to create a more useful approach. Development in any society is an all-round process, beginning at the level of the individual and accounting for all facet of a person's life (Andrew, 2013; Falola & Achberger, 2013)**.** This process of development should involve the growth of individuals' well-being, skills, and capacity advancements, greater freedom, better and more opportunities to create, self-development and individual accountability (Falola & Achberger, 2013). The Capability and Human-Rights approach provides the opportunity to better access this growth by achieving valuable functioning such as dreams, goals, interest and actions (Sen, 2015). These approach helps differentiate between (1), value in being able to make choices and (2), opportunities being given to make these choices of one's own volition. This perspective helps in asking questions such as:

1. Does difference in capability function due to disability affect the difference in people even with the same personal means (primary goods such as wealth)?
2. Is there a different capability function of public health care and contribution to society between PWDs, and others?

3. Does capability to function affect access to goods that help persons live daily such as employment, income, access to transport, and food for PWDs?

PWDs should have the freedom and choice to access health care, employment, and other services. The lack of access to such provisions and services makes this freedom null, while a non-disabled person has full access to such services and more. Exclusion from such rights implies social injustice which trespasses on the inalienability of human rights, in general, and the rights of persons with disabilities, as recognised by human rights conventions and laws (UN, CRPD 2010). Denial of the medical treatment or the opportunity to live without being restricted by one's influencing disability is a violation of ones' rights. Individuals are then being forced to live life a certain way. This is an additional problem resulting from social and cultural labels and ideas, leaving PWDs with no freedom to make other choices. More so, being forced to live "minimally" because limited health care or capabilities obligates them to do so, restricts their opportunities for development personally, socially or economically. To ensure that PWDs are treated fairly, overcome stereotypes and prejudices, and harmful practices relating to PWDs, the Nigerian society must implement legislations targeting cultural and religious practices discriminating against PWDs. In addition, it must undertake effective and appropriate measures aimed at raising better awareness about PWDs and obstacles to greater inclusion and improved services throughout the society (Etieyibo & Omiegbe, 2016).

CONCLUSION

This chapter presented an in-depth analysis of the literature presented in the literature review in connection with the result findings outlined in the findings. Themes around identity, accessibility, capability, rights and sustainable development were explored. In conclusion, it can be inferred that obstacles to disability inclusion are further aggravated by unequal access to care, structurally harmful institutions and the lack of relevance given to disability. They are disabling factors to the advancement of health care for adults living with CP in Nigeria. Interventions strategies that promote the personal, social and health-care development of PWDs, with the collaboration of individual, private and public sectors in the country are needed to improve Nigeria’s situation. The next chapter provides a summary of the study's purpose, methodology, literature review, and the theoretical and conceptual framework. It also provides some possible solutions to the realities of disability in Nigeria and proffers recommendations for future research.

CHAPTER 6 - CONCLUSION AND RECOMMENDATIONS

INTRODUCTION

This research explored the experience of CP within Nigeria. It studied the problem of disability and health care, especially how they shape other issues in the society. The overall aim of the study was to understand the condition of disability assistance in Nigeria for adults living with CP. The research demonstrates that the false dichotomy between an individual's impairment, their unique societal experience, and personal struggles contributes to the lack of understanding around their embodied experiences as persons living with disabilities (PWDs). To better understand this, the thesis asked the question: Are Nigeria's disability assistance practises functional enough to understand and improve the societal experiences of people living with disabilities such as CP? Answered simply, under current conditions in Nigeria, they are not.

The study concludes that obstacles to disability inclusion are further aggravated by unequal access to care, structurally harmful institutions and the lack of relevance given to disability. They are disabling factors to the advancement of health care for adults living with CP in Nigeria. In addition, Nigeria fails to consider the active role society, policies and the medical framework plays on the continuous disablement of adults with CP. To better understand why, a critical model of disability from the human rights capability approach combined with the social construction of disability is applied. This approach is more appropriate for addressing and advocating the development of disability movement within Nigeria. This encompassing approach will also enrich local knowledge on existing organizations' active input to the individual's development, disability movement and societal development. Without addressing this concern, better opportunities for an improved quality of life for people with CP cannot be adopted. Therefore, by examining this problem, it is possible to understand the various forms of care available to persons living with CP in Nigeria. The research can also deepen local knowledge on existing organizations' active input to health assistance, disability movement and societal development. This research is significant because it breaks the barriers of prejudice, stereotype and a general lack of commitment to disabilities by promoting change.

This chapter provides a review, summary and discussion on the implications of the study findings for its practical application in society. It also outlines possible recommendations for further research on disability in Nigeria, while illustrating the potential impact neglect will have on the society at large

SUMMARY OF STUDY

CP, a form of disability, is defined as a well-recognised neurodevelopmental condition that begins in early childhood due to brain injury or development defect that affects the individual's posture, movement or muscle control and persists through his or her lifetime (Rosenbaum *et al.*, 2007). CP, expressed in simple terms, refers to a group of impairments that affects a persons' posture, movement, or muscle control due to development problems, or brain injury often occurring after birth. The field research examines the resources and facilities geared towards alleviating burdens faced by people living with impairments such as CP. It illuminates the problem of disability in Nigeria by assessing the extent to which these resources are limited in their qualities, abilities, and development. It analyzed the experience of adults living or working with patients that have CP, the most common childhood neuro-disability in Nigeria. Persons living with CP are often hampered by poverty, lack of adequate health or rehabilitative care and other daily societal struggles, propagated by inequality and lack of human rights.

Disability is a challenge affecting specific dimensions of an individuals’ functionality. For example, the inability to engage in social practises such as employment or the inability to performing daily actions such as walking, talking or accessing buildings. It accounts for unequal access to chances for people labelled as "disabled" within the society. Government interventions are not substantive, as people with disabilities are highly vulnerable, and restricted by physical and social limitations imposed by their society. By analysing the problem of disability and health care access for people with CP, especially the degree to which it shapes advancement within Nigeria, advocacy for possible solutions, policies and agendas that foster a rights-based approach to disability is possible. Disability issues not only affect PWDs but also the overall development of society. The overall advancement of everyone in the society, including vulnerable population like PWDs, comes together to foster the development of the whole society.

Due to the complicated and multidimensional nature of disabilities, there is great difficulty conceptualising disability. Each person’s impairments uniquely shape their physical and economic functioning, emotional well-being and those of their family members. While different scholars address disadvantages facing people living with disabilities, for example, their daily responsibilities and activities, their analysis falls short when these are incorporated into Nigeria’s social and cultural contexts. In the case of CP, there are misleading assumptions about peoples’ individualized impairment and their unique societal experience and struggles which contributes to a lack of understanding about their living experiences. Without separating and understanding these experiences we cannot foster improved quality of life and care provisions for adults with CP. Attempts are always made to separate people's health condition, CP, autism or sickle cell, from how they live the rest of their daily lives. This separation is perpetrated by the lack of access to rights or adequate health-care, discouraging individuals from engaging in their larger society. Their skills or passions are viewed as irrelevant. The embodied experiences of a person's impairment must be related directly, to help understand and develop a rights-based approach, fostering an improved quality of life and care provision for people with CP in Nigeria. As argued, failing to adopt a rights-based approach will have adverse ramification on the functioning capabilities of people living with CP. Nigeria currently practices a charity-based outlook to disability, thereby reinforcing the exclusion and segregation of PWDs from societal activities. A balanced approach incorporating the Capability and Human Rights Approach with the Social Oppression model of disability is necessary to overcome disability inequality and limitations. This approach analyses the experiences of PWDs from their daily social concerns in connection to rights provided and enforced within the country. This allows for a comprehensive intersectionality of the civic, social, economic, political and rights-based approach to analysing the issues and rights of PWDs within different societies through the framework of capabilities.

Very little is known about the experience of adults with CP in Nigeria. Most of the available facts and figures focuses exclusively on children with CP. The literature does not include studies that involve interviews of people with CP. The current society also makes it difficult to implement technical or sustainable health-care capabilities required by adults with CP in several areas. The resources currently available in the country are dysfunctional and inadequately managed to achieve its present goal. Therefore, they fail to provide PWDs with equal access to life chances. As Farmer (2003) emphasises, equity is the central challenge to the future of medicine and public health-care. This study takes a human rights-based approach towards a more rounded understanding of the social, political and environmental needs for CP. Through the study finding, it is emphasised that an individual's full potential is supported through the realisation of Human rights such as "the right to development" and "the right to adequate health-care" among others. Rights such as this, give people equal access to life chances that can extract them from poverty and reduce some of their daily burden. It enables everyone participate in, contribute to and enjoy development in an active, free and meaningful way.

The methodology employed in this study includes, a literature review of existing "grey" and published literature on disabilities, specifically CP in Lagos State, Nigeria. Three-months of fieldwork was undertaken in Lagos State, with visits to key organisations and stakeholders that work on CP. Employing the use of snowball sample, fifteen participants were recruited from six organisations in Lagos State, who deal with CP disability programmes and services. Data was collected from these participants using semi-structured interviews. These disability advocates were engaged in discussions on their personal and professional experiences of CP, using open-ended question during the interviews.

The research question raised by the study problem was answered with the help of themes emerging from data collected in the field. Themes such as structural violence, inequality, human rights system and disability misconceptions were analysed in chapters four and five. As emphasised in previous chapters, developing countries such as Nigeria, often find it difficult if not impossible to implement health-care systems that actively includes PWDs due to limited resource and programme funding. It is up to the state government to set a solid foundation in the public socio-economic sector and fulfil its obligations to its people. There is a connection between social development, environment development, public sector growth and economic advancements within any country. Neglecting one or more of these sectors will draw back the advancement of the others. A lack of funds from the government to aid the implementation of more comprehensive assistance due to poverty and the high cost of privately-run services, creates a situation whereby the life of PWDs are relegated to the backburner, contributing to a short lifespan.

FINDINGS AND RESULTS

There are negative implications of having limited care and technical capabilities to better manage the care of PWDs in Nigeria. Findings from this study emphasise the need for early and affordable health care delivery, because it is essential to preserving human life. The data collected revealed that there are limited health care services and structures available to cater for these necessities. This, therefore, creates a negative aftermath for persons with CP within Lagos State, Nigeria. Despite the fact that Lagos State is the most active on disability advancement and issues, it still falls short of the assistance required by PWDs like CP. While Lagos State government has taken steps towards facilitating agendas, making provisions for persons with CP within the state, these provisions are limited in their enforcement, political and technical capabilities. Current government department, LASODA, delegated to the equalisation of rights for PWDs, is very limited in its capability to reach a large portion of the focus population. Response given by participants on discussions about disability, its definition or their understanding of CP emphasised the lack of knowledge and access to information available on these topics. This lack of understanding reinforced society members' fear of the unknown and a continuous "othering" of anything seen as unfamiliar or abnormal (Participant, T.A, 2018). Persons perceived as “different” or “abnormal” are frequently excluded from social activities because of the assumption that they can only be dependants and not contributors (Participant, F.G, 2018, Participant, T.A, 2018).

Ideas about disability impose a limitation on the involvement of PWDs within the society. By their label of “disabled,” PWD's are most commonly the poorest members of society because of societal constraints and views on their capabilities. They are often viewed as non-active members of the society. The study articulates the openness of PWDs to talk about their experiences, impairments, health concerns and any accompany plight with people who show interest. As emphasised by several respondents in the study, expressing interest in their condition validates them as "human" rather than a norm of society (Participant, D.A, 2018). Respondents with CP also expressed being subjected to anxiety and the fear of being outcasts, restricted in their choices and excluded from actively contributing to the society (Participants, D.A, 2018; Participant, S.O, 2018). For these problems to be addressed, access to education and information on disability to all members of the society, is a necessary component to evolve disability management in Nigeria. Following feedbacks from participants, further research is required to fully analyse the limitations “disability” imposes on PWDs. While this study cannot propose specific policy solutions for these issues, it creates an avenue for further discussion about these topics.

A better information network scheme between services and organisations in similar fields is also compulsory, to enhance the information pool to which members of the public have access. The current society lacks a comprehensive collection of related knowledge organised for convenient access or training exchange for people who might be interested. This knowledge could include stories, reports, experiences, statistics, figures and so much more, that help showcase the reality of locals. This lack of network creates a situation where each newly formed private or public organisation must undergo a learning curve of trial and error rather than working off successful modules with higher chances of success. Learning from each other through experiences, success and exchange is a crucial element to the building of a full module suitable in the local environment. To achieve this goal, national policies and agendas centered on Right to Development (RtD) would have to be implemented in the entire population, including vulnerable and excluded groups. If equal opportunities are given to PWD, they would have access to better, if not equal chances for development and survival.

This thesis shows the lack of proper diagnosis capability within the local community which is a compulsory foundation for early intervention. A very limited number of professionals within the field are fully equipped to meet the need in urban community areas and are almost non-existent in local areas. Lack of diagnostic capability fosters lack of awareness and information reinforcing the inadequate understanding of disability struggles, situations and their impact on society. One of the adverse effects of not having enough access to information is that, parents and caregivers of PWDs lack accurate comprehension about their kids' conditions to effectively manage them into adulthood or independence. To make up for this lack of knowledge, parent often avoid discussing the child’s disability to them or others.

To improve disability movement in Nigeria, Lagos State government implemented a "Special People's Law" in 2010, from which the Lagos State Office for Disability Affair

(LASODA) was carved in 2012. This law was the first policy-worthy step taken within Nigeria to foster the protection and equalisation of PWD's rights within the society. Work within this department is done in collaboration with other governmental departments, external community organisations and international agencies. Despite these changes, there still exists a lack of proper support system for persons with CP, separate from immediate family members. A scarcity of mental or counselling structure to support clients, patients or family members, also exists. These mental support avenues could include medical experts, social workers, therapists, patient or family support groups. The lack of mental-health support multiplies emotional pressure experienced by personnel, family members and individuals with disabilities because of their struggles. Individuals are burdened by navigating their everyday lives, management and cost of impairments causing burden to their families. In contrast, professionals within this field are burdened by the population target size they are required to assist. The limited resources available, accessibility concern, high cost of services, high cost of accessible transportation, and availability of qualified personnel come together to create a higher cost of care among persons with CP and their family members. This system portrays structural violence outlined in Farmer’s (2003) work. It takes away from a society’s ability to enforce human right, harms vulnerable persons (PWDs), and prevents PWDs from meeting their basic needs (Health-care).

SIGNIFICANCE

The availability of locally relevant information in an avenue that is readily accessible to the people that truly need them is crucial. Available trained personnel are so limited, when compared to the overwhelming workload that must be addressed. This research encourages the promotion of human dignity and social cohesion for vulnerable persons with a disability such as CP. It also emphasises the need to make available, early interventions to facilitate better management of CP, foster independence and allow the advancement of their overlooked talents and capabilities. It encourages active participation of PWDs as contributors to the affairs of the society.

Involving members of the local community, such as Disabled People’s Organisations (DPOs) and other adults directly connected with CP and their relatives, creates an affirmation to vulnerable and marginalised agencies. They become better able to chart their destiny and empower all individuals to claim their rights, rather than being treated as passive recipients of aid and charity. Current neo-liberal policies favour commercial profit-oriented services and goods within the public sector, which tends to dominate development strategies. Human rights obligations become downplayed, or, in some cases, denied. Voluntary assistance for global health continues to root the logic of charity rather than shared responsibility in a global community.

RECOMMENDATION FROM PROBLEM

Parents and adults living with CP need to create and support localised community and family-based support services to better improve and include PWDs. Patients and family members should be encouraged to join such support services or create these groups to substitute for the lack of social workers, counsellors and mental services provisions. Home-based or community approaches to rehabilitation are well suited for low-resource settings, as it often requires minimal infrastructure and resource to implement in comparison to alternative models such as centre-based interventions. Rather than focusing on hospital-based services, which are costly and rare, Nigeria needs to embrace a community-based approach to health care that fosters accessible options that can reach the local levels faster and more effectively. This is also one of the gaps within the study findings that would benefit from additional research. Further research exploring the benefits or dangers of localised community services and how it can influence PWDs and their families is needed.

There is a need to introduce standardised and relevant training for workers in the neuro-developmental department of health-care centres. The early recognition of CP by medical practitioners will foster and improve the capabilities of personnel to provide a basic management plan for CP patients. This expansion needs to be undertaken within urban and rural communities for a greater effect within the society. Current steps undertaken by the government such as the “IBILE” project will help enhance this expansion and improve accessibility which was a major concern in the research finding. This approach will bring informative access points closer to the community level, especially for people in rural communities. A collaboration between information, services, facilities and centres, that can assist persons with CP and members of their family to get better access to available resources is very crucial.

Better advocacy for education and information about disability is needed to produce an improved and sustainable health management of CP. The first step to achieving this is the creation of community and family-focused support groups to aid in the management and mental support of people living with CP at the local level, particularly in rural communities. The second step is the provision of better funding and management to already established publicly funded organizations assisting PWDs within the State. To achieve this, capacity building and training of more personnel is a necessity. The third step is the expansion of current services and resources available to people with disability in local communities and other parts of the country. This is also a requirement for improved disability management. Higher quality of monitoring and evaluative framework is needed to assess the effectiveness of publicly-funded services. Lastly, further improvement on the Lagos States' current disability law and the adoption of such law by the Nigerian government to encompass other parts of the country is necessary to better provide and enforce disability agenda in Nigeria. Health care advancement with a disability agenda focus needs to be put on the country's sustainable development agenda. Disability in Nigeria needs to become a rights-based agenda rather than "charity-based". The education of PWDs, their families and the society on disability as a health care concern, is vital to eradicating assumptions perpetuated by cultural beliefs. For example, the cultural supposition that disability is spiritual or "evil", and therefore arises because of a "curse or punishment from God for wrongdoing.

The government needs to draw upon the experience of PWDs around the country, to better assist in the development of existing disability services, and better manage core activities that will make for better service development. However, the disability agenda needs to be diversified to encompass other disability groups such as persons with visual impairment, mental health concerns, and physical impairments and others. It will account for any discrepancies in living experiences influenced by local conditions. There is a continuous need for a flexible and sustainable ideological framework that addresses the needs of a larger population.

NEXT STEP: FUTURE RESEARCH

There is no relevant information available on home-based approaches being implemented by the parents of children or adults with CP to manage their disability. Disability agenda needs to be placed on the country's political plan. Current agendas within Nigeria lack this implementation. For example, in the "Economic Recovery and Growth Plan” (2017-2020), there is no mention of persons with disabilities in programmes involving either employment or health care services advancements. Making the issue of disability a compulsory feature in the plan would create a sustainable approach that can be better adjusted and developed over a long-term period. Furthermore, the misinformation and disregard for disabilities in Nigeria does not support its education. Further research is needed on the condition and capability of Disabled People’s Organisation (DPOs) in the country and their proficiency for self-representation.

Lagos State is also the only major pioneer for disability development in the whole country. Further research into adults living with disability, especially CP in Nigeria, rather than in just one State, is also needed to fully understand the issue. Current literature on persons living with CP fails to account for the experiences of adults in Nigeria. Available services and provisions presently end when children get to the age range of 12 to 14 years old. A better analysis of how adults with CP cope within the society will assist in compiling better comprehension of their experiences and health management. This will help get accurate statistics of children and adults with CP. Future research also needs to assess existing or the complete lack of rehabilitative and medical services available within the country. A build-up of mental health, psychological and counselling services is very much necessary to foster support for PWD and their families.

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APPENDIX A:

INFORMED CONSENT FORM

The State of Disability in Nigeria: How Society Responds To Persons With Cerebral Palsy
SMU REB # 17-528 (SMU REB File Number)
NREC #ADM/DCST/HREC/APP/2018 (LUTH HREC No)

Anuoluwapo Oduwole, Professor Robert Huish
Saint Mary's University
Faculty of Graduate Studies and Research
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T: 0813-827-2678 E: a_oduwole5@yahoo.com T: 1 (902) 494-2979 E: huish@dal.ca

You will participate in a semi-structured interview in an evaluation of disability health care and other services for people with Cerebral Palsy (CP) in Nigeria being conducted by Anuoluwapo Oduwole of Saint Mary's University in pursuit of her Masters' Thesis completion. This study is being done under the supervision of Professor Robert Huish. As a participant in the research, you will be invited to conduct a semi-structured interview which will last 40-60 minutes long. Your participation in this study is voluntary. In addition, participation in this study will not affect work status or your daily life.

This study has been designed to determine which resources and facilities do the best job of meeting the disability needs of persons with CP in Nigeria. The aim is to get feedback and a better understanding of the implications of having limited technical and political capabilities that deal with people with CP in Nigeria. Through this research, we will come to know how the practical needs, equal opportunities, and the right to development of persons with CP are being upheld. The research is beneficial as information collected from this study will contribute to a better understanding of the state of health care access for people with Intellectual disabilities such as CP and some possible solutions to its limitations will be addressed. It will also contribute to the knowledge on the extent existing organisations help people with CP contribute to the society

This study is interested in inviting patients with CP disability and those who contribute to their health care access and provision such as consultants, doctors, nurses and government employees in efforts to aid their daily living.

There is minimal risk associated with this study, and your confidentiality will be assured. Although you are greatly encouraged to answer all the interview questions as frankly as possible, you are not obligated to answer any questions that make you feel uncomfortable or are unwilling to answer. You can withdraw from this study at any point in the research without any consequence. If you withdraw before the research is completed and submitted, your information collected will be permanently removed. Your identity will not be recorded, and your anonymity will be protected.

By volunteering to participate in an interview your information will be kept confidential but no longer anonymous. Only the researchers will know the identities of interview participants and will keep this information confidential. The results of this research may be published in professional journals, presented at conferences or used in articles but any presentation of data will ensure that there will be no breach of individual confidentiality.

If you would like to discuss the study or would like a copy of the study findings you can contact me by email, **Anuoluwapo.Oduwole@smu.ca** or phone at (1) 613-869-6203 and (+234) 813-827-2678 while I am in Nigeria or my supervisor Prof. Robert Huish at **huish@dal.ca**.

Certification:

The Saint Mary's University Research Ethics Board has reviewed this research. If you have any questions or concerns about ethical matters or would like to discuss your rights as a research participant, you may contact the Chair of the Research Ethics Board at ethics@smu.ca or (1) 902-420-5728.

Signature of Agreement:

The State of Disability in Nigeria: How Society Responds to Persons with Cerebral Palsy

I understand what this study is about, appreciate the risks and benefits, and that by consenting I agree to take part in this research study and do not waive any rights to legal recourse in the event of research-related harm.

I understand that my participation is voluntary and that I can end my participation at any time without penalty.

I have had adequate time to think about the research study and have had the opportunity to ask questions.

Participant

Signature : ____________________________ Name (Printed) :_______________________________
Date :___________________

(Day/Month/Year)
Principal Investigator

Signature : ____________________________ Name (Printed) :_______________________________
Date :___________________

(Day/Month/Year)

Please keep one copy of this form for your own records.

APPENDIX B:
SEMI-STRUCTURED INTERVIEW QUESTIONS

Focus should be on the research problem which is the capability of the disability organisations.

Members, Consultants and Doctors in organisation

1. What kind of organisation do you work for or are you a member of?
2. When did you start working here?
3. How did you come to work with this particular organisation?
4. What is the history of the organisation?
5. What are some of the visions and objectives of the organisation?
6. What does disability mean to you?
7. What does CP mean to you?
8. What has been your experience working with CP patients?
9. What has been your most difficult experience either mentally or emotionally so far?
10. How are programs structured and for who is it supposed to help?
11. What kind of activities/services are carried out in the organisation to support people with CP?
12. How easy would you say it is to access the organisations' services?
13. What are some of the difficulties you feel people will experience in accessing this service?

Cerebral Palsy Participants/Actual Clients

14. Tell me a little about yourself? What kinds of things do you enjoy doing?
15. How old were you when you were diagnosed with CP?
16. What were your parents told about your condition (if applicable)?
17. How did/has your condition (disability) affected your everyday life? Your family?
18. What is/was your dream? How has your situation (disability) affected this dream?
19. What organisations have you received services from in the course of your treatment?

20. What are your experiences of those services?
21. What you personally think of those services?
22. Did you have to pay for the service?
23. How were you able to afford the services?
24. What were some difficulties you had in accessing the services (clinic, rehabilitation centre etc.)?
25. Are you getting any service/assistance at the moment?
26. How satisfied are you with the care and assistance that you are getting at the moment?
27. How well do the services meet your needs?
28. What has been the greatest challenge for you?

Nurses and Doctors in organisation (Additional questions)

29. How long have you treated patients with CP?
30. What has been you experience in the process of offering assistance to people with CP?
31. What has been your greatest challenge working with CP patients so far?

Conclusion

32. Thank you for your time. Do you have any questions that you would like to ask of me? Do you have any further comments?

APPENDIX C:
FEEDBACK LETTER

The State of Disability in Nigeria: How Society Responds to Persons with Cerebral Palsy
SMU REB # 17-528 (SMU REB File Number)
NREC #ADM/DCST/HREC/APP/2018 (LUTH HREC No)

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January 16th, 2018.

Dear Participant,

I would like to thank you for your participation in this study.

As a reminder, the purpose of this study is to better comprehend which resources and facilities do the best job of meeting the disability needs of persons with Cerebral Palsy in Nigeria. The aim is to get feedback and a better understanding of the implications of having limited technical and political capabilities that deal with people with Cerebral Palsy (CP) in Nigeria

The data collected during interviews will contribute to a better understanding of the state of health care access for people with Intellectual disabilities such as Cerebral Palsy and some possible solutions to its limitations will be addressed. It will also contribute to the knowledge on the extent existing organisations help people with CP contribute to the society.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analysed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations and journal articles.

If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact me at either the phone number or email address listed at the bottom/top of the page.

If you would like a summary of the results, please let me know by providing me with your email address. When the study is completed, I will send it to you. The study is expected to be completed by March 30th, 2018. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted above.

As with all Saint Mary's University projects involving human participants, this project was reviewed by the Saint Mary's University Research Ethics Board. Should you have any comments or concerns about ethical matters or would like to discuss your rights as a research participant, please contact the Chair of the Research Ethics Board at 902-420-5728 or ethics@smu.ca.

LAGOS STATE (FIVE SPECIAL SCHOOLS)

S/N	NAME OF SCHOOL	LGEA
1	NATIONAL ORTHOPAEDIC SPECIAL SCHOOL, IGBOBI-YABA	SOMOLU
2	ATUNDA-OLU SCHOOL FOR THE PHYSICALLY CHALLENGED, SURULERE	SURULERE
3	MODUPE COLE MEMORIAL CHILDCARE AND TREATMENT HOME/SCHOOL, AKOKA	MAINLAND
4	WESLEY SCHOOL I FOR CHILDREN WITH HEARING IMPAIRMENT, SURULERE	SURULERE
5	WESLEY SCHOOL II FOR CHILDREN WITH HEARING IMPAIRMENT, SURULERE	SURULERE

LAGOS STATE (THIRTY ONE INCLUSIVE UNITS)

S/N	NAME OF SCHOOL	LGEA
1	OLISA PRIMARY SCHOOL, PAPA AJAO	MUSHIN
2	OJUWOYE COMMUNITY PRIMARY SCHOOL, MUSHIN	MUSHIN
3	COMM PRY SCHL, AFROMEDIA AJANGBANDI	OJO
4	AGANJU AKA PRY SCHOOL	OJO
5	COMM. PRY SCHL,	APAPA
6	METHODIST PRY SCHL, APAPA	APAPA
7	SARI IGANMU PRY SCHL, APAPA	AJEROMI IFELODUN
8	EREKO METHODIST PRY SCHL L/ISLAND	L/ISLAND
9	ST. JOSEPH'S CATH. SCHL. ELEGBATA	L/ISLAND
10	AMOSUN PRY SCHL, AGEGE	AGEGE
11	OORE OFE PRY SCHL DOPEMU	AGEGE
12	ESTATE PRY SCHL, OGBA	Ikeja
13	AMUWO ODOFIN PRY SCHL, MILE 2	AMUWO ODOFIN
14	CENTRA PRY SCHL, FESTAC	AMUWO ODOFIN
15	ROMAN CATHOLIC MISSION PRY SCHL, OKUNRAYE	IBEJU LEKKI
16	ST. JOHN'S R.C.M. PRY SCHL, AYETEJU	IBEJU-LEKKI
17	CENTRAL PRY SCHL, OSHODI	OSHODI ISOLO
18	BOLA MEM. PRY SCHL, IKEJA	IKEJA
19	METH. PRY SCHL, AGBOWA-IKOSI	EPE
20	ANSA UD DEEN PRY SCHOOL, EPE	EPE
21	ANGLICAN PRY SCHL, ARAROMI	AJEROMI IFELODUN
22	ARMY CHILDREN'S SCHL, BONNY CAMP	VICTORIA ISLAND
23	LGA PRY SCHL IPAKODO	IKORODU
24	OKI PRY school	ALIMOSHO
25	L.G. PRY SCHL, IGANDO	ALIMOSHO
26	MUSLIM PRY SCHL, BADAGRY	BADAGRY
27	MARLAND PRY SCHL,	KOSOFE
28	G.R.A. PRY SCH, OGUDU	KOSOFE
29	ADO PRY school	ETI OSA
30	ALL SAINT, PRY SCHL, IFAKO	IFAKO IJAYE
31	NEW OKO OBA PRY SCHL,	IFAKO-IJAYE

LASRRAIDNO [redacted]	
SECTION A. PERSONAL INFORMATION	
First Name	
Middle Name	
Last Name	
Date of Birth	Gender

Passport Photograph

O

SECTION B. CONTACT INFORMATION

Residential Address

Email	**Phone No.**
SECTION C. **NEXT OF KIN**	
Surname	**First Name**

Residential Address

Phone No.	**Relationship**
SECTION D. **DISABILITY INFORMATION**	

1. DISABILITY TYPES
   - ○ Sensory
   - ○ Physical
   - ○ Intellectual
   - ○ Psychiatric / Psychosocial
   - ○ Others

2 . CAUSES OF DISABILITY
   - ○ Diseases / illness
   - ○ Birth
   - ○ Aging process
   - ○ Accident or injury
   - ○ Genetic condition
   - ○ Congenital malformation
   - ○ Other causes

3. DURATION OF DISABILITY
   - ○ Below 6 months
   - o6 month - 1 year
   - 01 - 5 years
   - ○ Above 5 years
   - ○ Unknown

4. SEVERITY OF DISABILITY
   - ○ Mild
   - ○ Moderate
   - ○ Severe
   - ○ Very severe

5. ONSET OF DISABILITY
   - ○ Before birth
   - QAt birth
   - ○ After birth
   - ○ Unknown

6. BODY PARTS THAT IMPAIR MOVEMENT
   - ○ Right arm
   - ○ Left arm
   - ○ Right leg
   - ○ Left leg
   - ○ All body including the trunk

7. VISUAL IMPAIRMENTS
   - ○ Right eye low vision
   - ○ Left eye low vision
   - ○ Both eyes low vision
   - ○ Right eye blind
   - ○ Left eye blind
   - ○ Both eyes blind

8. HEARING IMPAIRMENTS
   - ○ Right ear low hearing
   - ○ Left ear low hearing
   - ○ Both ears low hearing
   - ○ Right ear deaf
   - ○ Left ear deaf
   - ○ Both ear deaf

9. INTELLECTUAL / NEURODEVELOPMENTAL DISABILITY
   - ○ Down syndrome
   - ○ Asperger syndrome
   - ○ Autism
   - ○ Cerebral palsy
   - ○ Epilepsy
   - ○ Communication disorder
   - ○ Phenylketonuria
   - ○ Klinefelter syndrome
   - ○ Others

10. PSYCHIATRIC / PSYCHOSOCIAL DISABILITY
   - ○ Alzheimer disease
   - ○ Anxiety disorder
   - ○ Depression
   - ○ Bipolar disorder
   - ○ Obsessive-compulsive disorder
   - ○ Schizophrenia
   - ○ Memory loss
   - ○ Others

Name of Medical Practitioner ____

Medical Council of Nigeria Membership No. ________________________________ _

Practice Address ____ _

Signature & Stamp

LASSRAIDNo

Surname

First Name