# FACTORS AFFECTING PARTICIPATION IN ACTIVE LEISURE ACTIVITIES BY PEOPLE WITH PHYSICAL DISABILITIES

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A research report submitted to the Faculty of Health Sciences, School of Therapeutic Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy

# **DECLARATION**

I, Esther Keats, declare that this research report is my own work. It is being submitted for the degree of Masters of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not previously been submitted for any degree or examination at this or any other University.

Ders	
Esther Keats	

\_\_\_\_\_\_ day of \_\_\_\_\_\_\_, 2019

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# **DEDICATION**

# I dedicate this research to:

- My parents; through you I have learned curiosity, compassion, perseverance and the value of education.
- My husband; I am very grateful for your support and encouragement, for continuing to make me see the value of education and believing that I could do it.

# PRESENTATION ARISING FROM THIS STUDY

Oral presentation: School of Therapeutic Sciences Research Day September 2019. Title: Factors affecting participation in active leisure activities by people with physical disabilities.

#### Introduction

This research aimed to describe the lived experiences regarding active leisure participation of disabled persons with mobility impairments residing in Gauteng, South Africa, with the purpose of determining the factors affecting their participation. South Africa has enabling legislation, to understand if engagement in active leisure is a challenge. The research method used an explorative, descriptive, qualitative methodological approach. Participants were selected using purposive sampling. Focus groups and in-depth interviews were used for data collection, and thematic analysis was used to interpret the data.

## **Findings**

Three major themes emerged - i) "Meaning of leisure," ii) "I am a thinking feeling human being not a disability," and iii) "Participation in active leisure." The findings indicated that the participants differed in their perception of active leisure. Their choice of active leisure was influenced by factors such as their disability, what was accessible and within their financial means, and consequently some participants felt active leisure was not a priority due to these. All participants perceived their active leisure was constrained by public emphasis on what they could not do, rather than what they could do and they rejected this negative view. Barriers and facilitators that affected their access to active leisure participation were identified.

# Conclusion

Despite enabling legislation in South Africa, the findings of this study illustrated that PWPDs in this study faced discrimination and exclusion to active leisure participation.

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#### **NOMENCLATURE**

**Disability** is used in this study interchangeably to mean both impairment and disability. Impairment is described as "problems in body functions or structure as a significant deviation or loss" (1), and disability described as a "dynamic interaction between health condition (disease, disorders, injuries, and trauma) and contextual factors resulting in activity limitations and participation restrictions" (1).

**Environmental barriers** are external to the people with disabilities (PWDs). These include society's negative attitudes towards PWDs (stigma), architecturally inaccessibility of man-made physical environments, ecological barriers, lack of accessible transportation, and rules and regulatory barriers that are discriminative to PWDs (2).

**HandyDART** is a door-to-door transportation for PWDs operated in British Columbia, Canada. HandyDart operates 18 hours a day (3).

Interactive barriers include challenges posed by the active leisure participation that does not match participant's capacity to engage and complete the leisure activity presented, as well as communication barriers between the disabled and non-disabled person (2).

**Intrinsic barriers** relate to the PWD's own physical, psychological and cognitive functioning level, such as physical and psychological dependence on caregivers, lack of knowledge of available resources, social ineffectiveness resulting in the inability to communicate and interact with the targeted social environment and health-related problems (2).

**Leisure** is defined as a "non-obligatory activity that is intrinsically motivating and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care, or sleep" (p. S21) (4). This includes active and passive or quiet-leisure.

Active leisure consists of activities that are physically demanding such as wheelchair sports or travelling for pleasure (5). For the purpose of this research, active leisure includes the usage of public transport or own vehicle for travelling to and from facilities of active leisure. Participating in activities offered at places such as the Botanical Gardens or shopping malls for the purpose of leisure, for example, eating out, or watching a movie, recreational parks, the zoo, casinos, going to concerts, museums,

or any active leisure trip that may be done in a day, or involves sleeping away from home. **Passive or quiet leisure,** which is mostly performed at home, consists of reading, watching television and listening to music (5).

**Limb amputation,** is the unilateral or bilateral surgical removal of a limb due to disease, such as vascular disease, infection or injury. It can be acquired after birth or be congenital due to lack of limb development (6).

**Main-streaming** disability aims to achieve disability equality. It involves government and civil society taking into consideration the needs of people with disabilities in all planned actions. Such actions include the formulation of legislation, the creation of policies, and the establishment of programmes in any political, economic and social endeavour (7).

**Occupational adaptation** is described as the building of an individual's occupational identity and achieving occupational competence. These develop side by side over time through continuous participation in one's chosen occupation (8).

**Occupational alienation.** This situation arises when there is lack of occupational choices that are meaningful and enriching, therefore a PWPD is not able to achieve a positive self-identity in what he/she does (9).

**Occupational deprivation** arises when factors external to the individual cause limitations and deprivation of occupational participation in meaningful occupations causing the individual to be isolated or lack fulfilment in their lives (9).

**Occupational imbalance** is engaging in an occupation that does not meet or develop one's capabilities in physical, social and mental occupational needs and there is little time available to pursue an occupation he/she enjoys (9).

**Paraplegia** is the partial to total loss of sensation and movement of the lower limbs and lower trunk resulting in functional ambulation loss (10).

**Physical disability** is a physical impairment that affects the body's functions, and structure, which impairs a person's physical performance in major life areas, such as personal care, mobility, domestic and social life. Physical disability includes acquired physical disability, obtained after birth, and congenital disability, obtained in utero or through birth trauma (11).

**Quadriplegia** is the partial to total loss of function of the upper and lower limbs and the trunk (10).

**Social exclusion** is a "multidimensional process, which involves lack or denial of access to resources, goods and services, rights, and inability of individuals to participate in the normal social relationships and activities, available to the majority of people in a society. These may be in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole." (p9) (12).

#### LIST OF ABBREVIATIONS

ADA Americans with Disabilities Act

ADL Activity of daily living

ATM Automatic Teller Machine

CUD The Centre for Universal Design

ICF International Classification of Functioning Disability and Health

ID Identity Document

INDS Integrated National Disability Strategy

NPO Non-profit Organisation

OTPF3 Occupational Therapy Practice Framework 3<sup>rd</sup> edition

PAU Passenger Assistance Unit

PWDs People with Disabilities

PWPDs People with Physical Disabilities

UNCRPD United Nations Convention on the Rights of Persons with

Disabilities

WHO World Health Organization

# **CHAPTER 1**

# INTRODUCTION TO THE STUDY

#### 1.1 Introduction

It is estimated that 15% of the World's population lives with a disability which is higher than the previous estimation of 10% (13). Similarly, over the last two decades, there has been an increase in the reported number of people with disabilities (PWDs) in South Africa. The 2001 South African Census reported a 5% incidence of disability, of which 29% were physically disabled (14), while the 2011 Census reported an increase in the incidence of disability to 7.5% of the population (15).

The clinical experience of the researcher, as an occupational therapist, indicates that people with physical disabilities (PWPDs) have particular difficulty in re-establishing meaningful active leisure time activities as the final stage of rehabilitation. Additionally, there is little visibility of PWPDs participating in active leisure activities in main-stream society in South Africa. This is supported by literature, which suggests that physical disability imposes diminished capacity to carry out previous occupational roles, such as participating in active leisure, reduced social roles and relationships with others, which previously required no effort. The enjoyment and satisfaction a PWPD once derived from participating in active leisure may be changed by the physical disability (8). Inaddition, Wolbring and Leopatra (2015) stated that invisibility of PWDs in the physical and social environments negatively affects their well-being. They further attributed the invisibility of PWDs to being perceived as marginal, with little accommodation made for their inclusive participation in areas such as active leisure (16).

Rehabilitation, particularly at primary health care level, is an essential part of ensuring that PWPDs are integrated into their communities and are actively participating in all life areas including active leisure (17). South Africa has policies that guide and oversee the implementation of rehabilitation including at primary health care level: the National Rehabilitation Policy (2000), White Paper on the Rights of Persons with Disabilities (2016). The delivery of primary health care rehabilitation was identified by several authors to be impairment-based with little or no social integration or active participation of PWDs in their communities (17)(18)(19). The latest policy, The Framework and strategy for Disability and Rehabilitation (FSDRSA) (2015) was developed to correct

shortcomings of the previous policy in addressing community rehabilitation (17)(20). The effects of this current policy in ensuring social inclusion and full participation of PWDs in community life, including that of active leisure, are not yet evident (18).

Hanson (2008) suggested that leisure is a challenging concept to define as the same activity may be perceived differently by two people as being either a leisure or work activity (5). Despite this, leisure offers the opportunity to be actively or passively involved. Literature shows that challenges imposed by the physical disability, contextual factors in which active leisure is carried out, forces PWPDs to experience diminished active leisure enjoyment and satisfaction, and as a result, participate in passive leisure activities that are mainly home-based, solitary, or with a few to no social relationships (21)(22)(23).

Fenech (2008) revealed that lack of active leisure participation created an experience of poor sense of self-competence, diminished awareness of society and its shared values, boredom and withdrawal from participation. Fenech also stated that because leisure is freely chosen, it helps PWPDs to connect with their current and past active leisure roles enabling them to better adapt to living with a disability (24). Active leisure, as one of the components of leisure, is essential as it promotes the active participation of the PWPDs, their social involvement with others, helps them gain physical and psychological well-being and aids in building the altered self-identity (24)(25)(55). Understanding active leisure participation from the view of PWPDs may enhance their active participation, with added the benefits of enhanced self-efficacy, self-esteem, opportunities for better community integration through creating and maintaining social relationships, and belonging (5)(15)(25)(27).

Literature suggests that society's understanding of leisure and what it constitutes may be inconsistent with the experiences of PWPDs (21). Aitchison (2009) argued that leisure studies have not been inclusive of PWDs as leisure participants, thus their views and perceptions of the meaning of leisure and their experiences are not reflected in the presented definition. Moreover, models of leisure have largely been influenced by the dominant views derived from able-bodied individuals who fit the categories of "economically employed, independently mobile, physically able and have a conventionally aesthetic body." (p. 375) (21).

Active leisure participation is often viewed as social involvement. Wilcock (1998) argued that the doing of leisure tasks was important to health and well-being and it provided an outlet for social interaction with others (9). When people participate in their active leisure, they are being true to the essence of being, exercising their capabilities as human beings (28). Due to the nature of the disability PWPDs are often excluded from active leisure activities due to their physical limitations, as well as barriers in the physical and social environments consequently they tend to view active leisure related to the social encounters and interactions they experience during their leisure participation (21). This perception of meaningful social encounters experienced by PWPDs during their leisure participation led Aitchison (2009) to suggest that 'leisure interactions' should be included in the definition of leisure alongside other terms, such as 'leisure time,' 'leisure spaces,' 'leisure activities,' 'leisure function,' and 'leisure freedom.' This would make the concept of leisure more inclusive of PWDs by embracing their lived experiences (21).

According to the World Disability Report (2011), the environment is the determining factor in the experience of active leisure by PWPDs (13). Without prior knowledge of the usability of the environment, it is very challenging for PWPDs to embark on spontaneous active leisure because of perceived lack of confidence in completing the activity, and environmental barriers that may be encountered (29)(30). trustworthy information, active leisure is just an untested dream to many PWPDs. Kielhofner (2008) asserted that for any occupation to be carried out, such as PWPDs participating in active leisure, it requires volitional thoughts and feelings that motivate a person to take action (8). These volitional thoughts and feelings include personal causation, values, and interests, which the individual uses to identify important and meaningful leisure activities that may be enjoyable and satisfying (8). causation involves the awareness of one's capacity to take action, as well as selfefficacy, which is one's awareness of the ability to be in control of one's own decisions and capacity to the desired outcome (8). When PWPDs encounter barriers and are not able to experience personal causation, according to this affects their volitional thoughts and feelings, the nature of their engagement, as well as their feelings of competence (8). Previous research by Cole (2010) reported that active participants were able to effect change and be successful at active leisure, while the less active participants

reported decreased motivation to engage. The more active participants were found to have a positive awareness of personal capabilities to effect positive change and achieve success, experienced sustained motivation, were more resilient and set targets to achieve their goals (31). This is in line with what Kielhofner (2008) described as the perception of own capacity that develops over time through lived experiences. Furthermore, Kielhofner stated that people evaluate their sense of personal capacity through their physical, intellectual and social abilities for occupations executed in their social-cultural environments, through their lived experiences (8). The perceived sense of capacity motivates one to act on or avoid engagement if one anticipates failure in a desirable occupation (8). This is believed to be important for many PWPDs, as energy will only be expended where the results of active engagement are guaranteed, or felt not to be too challenging (8).

The desire to partake in an active leisure activity does not diminish because of a disability, and the motivations and expectations for active leisure are the same as for able-bodied individuals (32)(33). However, it has been reported that PWDs encounter barriers as they attempt to participate in active leisure activities (32). Smith (1987) identified three significant barriers to the participation of PWDs: i) intrinsic barriers within a PWD, ii) environmental barriers external to a PWD, and iii) interactive barriers (2). In a recent study on the effects of intrinsic, environmental and interactive constraints on a disabled person's intentions to participate in active leisure, the result showed that such constraints interfered with the PWD's intentions to participate. Their perception of constraints and lack of ability to overcome them was reported to be the main cause of their feelings of helplessness (30).

In South Africa, inaccessibility to active leisure environments has been reported to be a violation of PWPDs' human rights, which prevents them from achieving their desired active leisure goals and satisfaction. This inaccessibility stems, in part, from the current government's inability to address past apartheid segregation injustices adequately which were inherited from the previous apartheid government. These injustices were reported to have affected PWDs in their human right needs, and their integration into the greater South African society was not considered (34)(35). The 1997 South African White paper on an Integrated National Disability Strategy (INDS), updated in the White Paper on the Rights of Persons with Disabilities (2016) with no fundamental change,

aligned government policies on disability with the social model of disability, acknowledging disability as a human rights issue. The post-apartheid government acknowledged that within society, physical and attitudinal barriers can be disabling and exclude PWDs thus emphasising main-streaming disability from a human rights perspective to enable full participation (35)(37).

The South African Human Rights Commission also asserted that any barriers that prevented PWDs from participating in physical and socio-cultural environments, from accessing information, and participating in the civil, political and economic aspects of PWDs was a violation of their rights to equality, dignity and freedom (38). This is consistent with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), to which South African is a signatory. The UNCRPD mandates signatories to ensure PWDs can participate in "cultural life, leisure, recreation, and sports activities on an equal basis with others" (p. 22) (39). Furthermore, the UNCRPD emphasises participation, inclusion, accountability, non-discrimination, equality, freedom of movement, and access to public services as important human rights that everyone should enjoy on an equal basis (39).

Even though progress has been made by the introduction of policies that respect the human rights of PWPDs, and with the more recent Framework and Strategy for Disability and Rehabilitation and White Paper on the Rights of Persons with Disabilities (2016) (20)(37), as well as PWDs holding positions in government to advocate disability issues, PWPDs reportedly continue to face marginalisation, negative attitudes and are undervalued in mainstream South African society (35)(40)(41).

This study aims to explore the perceptions of the lived experiences of PWPDs living in Gauteng South Africa, regarding factors that facilitate or prevent participation in active leisure activities. Participation in active leisure appears to signify the last stage in which a PWPD claims back their personal freedom and self-esteem, which may have been lost due to the physical disability and attempts to regain their human rights.

# 1.2 Statement of the Problem

Active leisure activities are often difficult and complex for PWPDs to engage in (32)(42) as decisions have to be made not only on affordability, but on a range of other factors,

such as accessibility of the destination, accessible public transport for PWPDs to and from the destination, destination experience and the experience of the social environment (42)(43)(44). Although South Africa is attempting to advance equal access to participation in social active leisure and cultural activities for PWDs, there is limited research on the lived experiences of PWPDs. South Africa has ratified agreements such as the UNCRPD (2006) has an Integrated National Disability Strategy, updated with White Paper on the Rights of Persons with Disabilities (2016) and the Promotion of Equality and Prevention of Unfair Discrimination Act (30)(36)(37)(45), however, it is unknown whether these policies and strategies benefit PWPDs' rights by improving access to active leisure and other social or cultural activities.

# 1.3 Purpose of the study

The purpose of this study was to explore and describe the perspective of active leisure of PWPDs living in Gauteng, including their understanding of their active leisure and their perception of factors influencing their participation in active leisure activities, through the examination of their attitudes, experiences and views of active leisure participation.

#### 1.4 Research Question

The following two questions guided the study:

- What factors do PWPDs believe challenge or facilitate their choice of active leisure activities?
- What are their perceptions and experiences of their active leisure participation in Gauteng?

#### 1.5 Aim of Study

To determine the extent to which PWPDs in Gauteng, South Africa, participate in active leisure in their community and society, and, from their experiences understand if engagement in such activities is a challenge under enabling South African legislation.

## 1.6 Objectives of the Study

Three objectives were used to direct this study:

#### 1.6.1 Objective 1:

To explore and determine the views of PWPDs' understanding of active leisure participation.

# 1.6.2 Objective 2:

To explore the perceptions of PWPDs about their experiences of their active leisure participation.

# **1.6.3 Objective 3:**

To identify factors that challenge or facilitate the participation of active leisure of PWPDs.

# 1.7 Significance of the study

The study seeks to explore the lived experiences of active leisure by PWPDs and establish factors that affect their participation in such activities. Most research on active leisure of PWDs has been carried out in Australia, Europe, and the Americas; little research has investigated the active leisure participation of PWPDs in South Africa. Therefore, this research will contribute to The Occupational Therapy body of knowledge regarding lived active leisure experiences of PWPDs. Meaning and enrichment in one's life are derived from active leisure in social environments; this is important for health and well-being (25). Research suggests that most PWPDs experience social exclusion and marginalisation due to environmental barriers (13)(41)(42). Occupational therapists need to be aware of the lived experiences of PWPDs' participation in occupations in their social-cultural environments, but especially active leisure as an essential component of wellness. Occupational therapists are well-positioned to understand the importance of participation in valued and meaningful occupations (8)(46)(47). Understanding that many PWPDs are in forced into solitary environments or imprisoned in their homes due to occupational injustices caused by environmental circumstances, requires decisive action by occupational therapists to ensure occupational justice for PWPDs in social-cultural environments (42)(43)(46). Through full participation, people exercise their rights and attain health and well-being (9)(22).

#### 1.8 Conclusion

This chapter has highlighted an increase in the number of PWDs in South Africa. The chapter also reported that the desire to take part in active leisure does not diminish because of disability. However, what constitutes active leisure for PWPDs may be

different from that of able-bodied participants, as research has not considered their perspective. Further, the chapter highlighted lack of active leisure diminishes awareness of society and its shared values. South Africa has excellent disability rights legislation and regulations but the extent to which this allows PWPDs to access and participate in meaningful leisure activities is unknown. This research study will attempt to fill the gap in the knowledge through an appropriate research design, answer the two research questions: What factors do PWPDs believe challenge or facilitate their choice of active leisure activities? and what are their perceptions and experiences of their active leisure participation in Gauteng? Chapter 2 will report on the present international and local literature review on disability and active leisure for PWPDs.

# **CHAPTER 2**

#### LITERATURE REVIEW

#### 2.1 Introduction

This chapter includes a review of both national and international articles about this study topic during Apartheid years 1987 to 1993 to post independence 1994 to 2018. The following search engines were used to source literature concerning the research phenomenal: PubMed and Google Scholar. The following words and phrases were used to search for literature: disability, leisure, active leisure, disability and leisure studies, occupation, occupational participation, environmental, attitudinal, barriers, stigma, occupational identity, disability identity formation, disability identity integration, occupational justice, disability health and well-being, benefits of leisure activity, environment, physical, social, cultural, influence, transportation, stigma, human rights and South African legislation, disability and human rights, health calendar, occupational therapy primary health-care.

The chapter starts with the discussion on disability, and the different models of disability's views on disability. Active leisure participation is discussed and this is framed around human rights. The concept of identity construction and self-determination derived from being occupied meaningfully and purposefully, particularly in active leisure activities, is discussed. The three psychological human needs, which are the universal requirement for every human being for optimal functioning through the engagement in activities, are then discussed in consideration of the lives of PWPDs with regard to their health and well-being. Social participation, as an active leisure pursuit, aids in the development of occupational identity, and lack of engagement could potentially put PWPDs at occupational risk. Furthermore, barriers to active leisure participation, as identified by the ICF, are described. This is followed by a review of occupational justice and the idea that disability inclusion requires a shift in thinking from all stakeholders. Lastly, the whole-life approach to accessibility, and how this interlinks with universal design, and the utilisation of universal principles is highlighted.

## 2.2 Understanding Disability

Disability is a multi-dimensional construct, which is complicated to define. There is no consensus about its meaning among medical professionals, scholars, persons affected by it, other people with vested interests, as well as the public in the different social-cultural environments(13)(48). Active leisure participation for PWPDs cannot be understood without considering disability construct and the complex dynamics it brings into play.

Jaeger (2005) stated that disability has been part of human circumstances since the beginning of human existence. Despite this, there is a perceived belief that most societies possess a strong resistance to acknowledge it as a natural component of human life. For example, Jaeger reports that some people acquire a disability through accidents, injury, illness or birth, while others acquire it through the natural process of ageing (13)(48). There are different levels of disability each with a different impact on active participation, namely spinal cord injury with complete or incomplete injury to the spinal cord resulting in paraplegia or quadriplegia (10), cerebral palsy also resulting in quadriplegia or affecting lower half of the trunk (49), limb amputation - unilateral or bilateral amputation (6). Despite the common occurrence of disability, Jaeger draws attention to the fact that disability is not generally given the appropriate consideration it deserves as it affects society as a whole, therefore, requires a deeper understanding of its impact (48). This has been attributed to the different models of disability that emphasise opposing perspectives and theoretical understandings of disability (13)(48) (50).

## 2.2.1 Models of Disability

The political, social, and cultural lives of PWDs have been shaped by the model's of disability's theoretical viewpoint, which continues to have relevance today (50). Wendell (1996) and Smart (2009) highlighted the importance of accurately defining disability to inform legislation, which in turn affects how social policies are determined. The definition of disability accepted by society firstly influences a PWD's eligibility, which in turn influences how public programmes are delivered (50)(51). For example, Wendell reported that this affects the provision of mobility equipment, medical supplies, transportation, disability benefits and rehabilitation. Secondly, an acceptable definition

of disability in the social environment assists members of the community, friends, and family to recognise and acknowledge the disability and offer the necessary assistance where needed. Thirdly, for political purposes to highlight the rights of PWDs such as equitable access to social and physical environments, to access opportunities to work and to engage in active leisure and other rights that other members of society enjoy. Fourthly, it has an influence on an individual's self-identity in acknowledging and associating oneself as a person with a disability and associating oneself with and mirroring experiences with other PWDs. Wendell however cautions that disability-identity carries with it stigmatisation and stereotyping (51). Moreover, the author argued that society acknowledges and defines individuals as being disabled, defines society's expectations and attitudes towards disabled individuals, what is considered normal behaviour in terms of normal physical and mental performance, normal physical appearance, as well as who gets stigmatised (51). Jaeger (2005) shared the same sentiments, arguing that the legally recognised definition plays a big role in the civil rights of PWDs (48).

The models presented here are to guide the understanding of disability and make sense of what PWPDs' perception of barriers and facilitators to their participation in active leisure are in mainstream society.

## 2.2.1.1 The Medical Model of Disability

The medical model also known as the individualistic model of disability, views disability as a problem within the individual arising from adverse complications in the person's biological system. In turn, this results in a physical ineffectiveness causing the body not to function as well as that of a person without impairments. This results in functional limitations that cause disabilities (52).

Globle (2014) argued that this view has persisted since the shift from a pre-industrial to an industrialised society, which introduced capitalism. Capitalism brought changes in the pre-existing social interdependent systems of social cooperation on which many PWDs and their families depended (53). Industrialisation introduced a new set of norms related to work production, which saw many PWDs being alienated and marginalised socially and economically (53). People with disabilities were seen as unsuitable candidates for industrial production lines, thus unable to earn a living and forced to

become dependent on their families for sustenance and care, and as a result, became a burden (53). The international response was the introduction of segregated institutionalised care for PWDs (53).

Goble further reported that the World Health Organization (WHO), being the world authority on health at this time, emphasised disability as being an individual medical problem, which also helped to cement the medicalised perspective. The belief was that disability was an individual problem originating from one's biological system not performing typically and had to be managed from a medical perspective (53).

Thus, the medical model focused on curing and rehabilitating the impairments caused by biological deficits and or the abnormality, to restore what the individual had lost (54) (55). If the impairment was not correctable through medicalisation, the PWPD had to accept it as a 'personal tragedy' and accept they would not be able to participate in the typical roles expected by society (46)(47)(51).

This view of disability has been widely criticised for its narrow approach that disability originates from the individual alone and that the individual has to be restored to fit environmental demands, which only focuses on the measurable biological characteristics of the body, both physically and cognitively (54)(56)(57). The medical model does not consider the disabling environments and social exclusion to which PWDs are exposed (55). These criticisms have been highlighted in South Africa's Integrated National Disability Strategy (1997) (36) and by Schneider (2006) (58).

#### 2.2.1.2 The Social Model of Disability

The social model of disability took a different approach to define and understand the concepts surrounding disability (59). This model arose from the movement of PWDs who drew attention to the economic and social difficulties they were experiencing and demanded access to full participation in environments and equal enjoyment of human rights (56)(60). The social model views disability as being rooted in the social environments and not only created by a biological problem, as reflected in the medical model. Proponents of the social model argued that when one views disability in terms of the domains of the body, identity, social structure and culture, and how these domains overlap, the complexity of the disability in the social environments is

acknowledged (56)(57). Supporters of the social model argued that disability was a form of social oppression and had nothing to do with the body, rather, was a burden forced on a person's impairment through inaccessibly built and social environments (59) (61). The inaccessibility of these environments constitute discrimination and forced social exclusion, which prevents PWDs from participating in mainstream society, and not the impairment, as suggested by the medical model (60)(62). Shakespeare (2013) argued that impairment is located within a person and is a private matter, but public infrastructure and social environments are for public use (60). The duty therefore lies with society to remove barriers and create inclusive environments (52)(60)(63). There is a separation between impairment and disability from a social model perspective. Disability is seen as the experience that is caused by inaccessible physical and social environmental structures located in the public domain (51), therefore disability is created by society as people with impairments try to access the disabling physical, social and economic environments within society (62).

In general, PWDs may find themselves socially disadvantaged or excluded from social environments that others take for granted, such as access to goods and services like transport and active leisure environments. These exclusions extend to political participation, cultural activities, employment and education (52)(56)(64). The social model of disability, as a human-rights-based approach, called for the human rights of persons with impairments to be acknowledged within the public environment, instead of focusing on charitable interventions and pity (57).

The social model of disability is seen to have made a political impact in many countries by mobilising PWDs to fight for their civil rights, identify environmental barriers to be removed and helping them to build positive self-esteem and collective identity, in the process liberating PWDs (52). However, the social model has been equally criticised for not considering the role of impairments in contributing to the disability experience of PWDs. By taking a strong stance in rejecting the medical model, the supporters of the social model of disability rejected the medical prevention, rehabilitation or cure of impairments even though this was not their original intention (52). Oliver (2013) accused critics of the social model of disability of just talking and criticising without suggesting meaningful alternatives. He pointed out the divisions in PWDs has left them vulnerable to neglect with no defence except big charities with vested interests. In his

views, this has taken PWPDs back to the role of 'tragic victims of impairment' (57). In response Levitt (2017) concurred that the social model would benefit from re-evaluation. Levitt argued that the social model was an outcome of the social conditions when it was introduced therefore its present emphasis embeds this context. If its application reflected the challenges reported in other countries, the model being applied would be beneficial (61).

## 2.2.1.3 The Biopsychosocial Model of Disability

The WHO (2001) acknowledged disability was part of the human challenge and that anyone could be disabled during his or her lifetime, and held the view that disability should not be viewed as either a medical or a social problem (1). The WHO (2001) proposed a biopsychosocial model of disability associated with their International Classification of Function and Disability (ICF), which addressed the views of both the medical and the social models (1)(13). The ICF framework, which distinguishes human functioning, disability and health condition, states there is a complex interaction between a person's health condition, and contextual factors, which comprised both environmental and personal factors. The ICF identified three levels at which human functioning can occur: i) at the whole person's body level, ii) body structure level, and iii) the whole person engaging with one's activities, participating with one's environmental factors in one's life situation. Moreover, impairment was described as a loss of function in a body structure or whole body due to problems in a person's health condition (1). Therefore, the ICF states that disability is generated because of engagement between the health condition, environmental and personal factors resulting in activity limitation or participation restriction in one's life domain. Thus, the ICF views disability as encompassing different factors represented by impairments at the biological level, activity limitations at the activity level and participation restriction, such as the inability to participate in one's life events (1)(65). Figure 2.1 illustrates the multidimensional interactions of the ICF components, in other words any functioning in one's life domain such as active leisure induces multidimensional interactions between a person's health condition, environmental factors and personal factors.

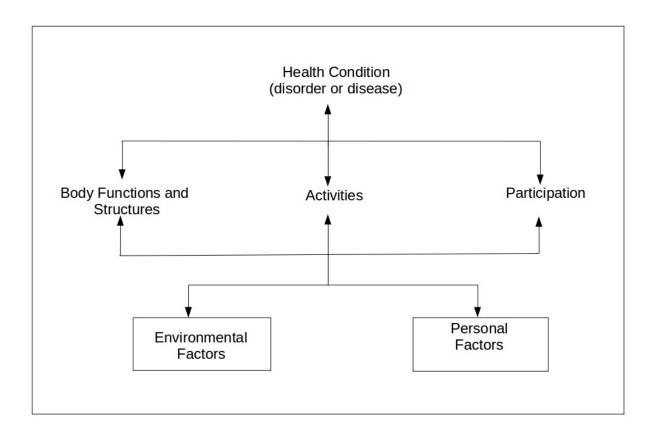


Figure 2.1: Multidimensional interactions of the ICF components.

Sourced from: World Health Organization (2001), International Classification of Functioning Disability and Health, p18.

Accordingly, problems of disability result from interconnected areas, namely health conditions such as impairment (described as abnormality in body function and body structure), activity limitations identifying difficulty in performing a desired activity and participation restrictions (described as problems encountered while participation in areas of one's life, such as active leisure trying to access inaccessible transportation) and stigma encountered in the social environment (1). Consistent with this, UNCRPD advocated for a human rights-based approach to disability, supporting the sentiments that "disability results from interactions between person with impairment, attitudinal and environmental barriers that prevent the full and effective participation in society on an equal basis with others" (p1) (39). Schneider (2006) concurred that disability is a dynamic changing experience and is influenced by the changing environments at an individual and national level, which also change the experience of disability (58).

Mitra (2006) argued that social-economical and other non-health related factors that play a role in disabling PWPDs, are not covered by the ICF. The scope of its consideration in the activity and participation domain does not consider whether PWDs have jobs and how sufficient they are (66). Galvaan, Mdloko, and Joubert (2010) also argued that, although the ICF aligns itself with the UNCRPD, the use of the ICF in advocacy, promotion of social change and occupational justice for PWDs is limited. The authors propose that the UNCRPD framework is better for advocacy and building partnerships that challenge environmental barriers faced by PWPDs to achieve occupational justice (46). Nonetheless, the ICF gives a clear indication of the contextual factors, such as environmental and personal factors, that influence functioning and disability and can be understood as ranging from a PWPD's immediate environment to the community and society's environment (1).

The shift in the understanding of disability from an individually based problem to being inclusive of contextual factors, advocates that corrective interventions should be socially orientated, and national policies should target social environments so that they are accommodating of people with impairments, facilitating inclusion and independence (58).

#### 2.2.1.4 Conclusion of the Models of Disability

Models of disability endeavour to define disability and tend to emphasise different views of what constitutes a disability and how it is caused. The model that is adopted by state and society therefore influences the lives of PWDs (50)(51) how social policies are formulated, and how services for PWDs are determined and delivered. Moreover, how society acknowledges and defines disability shows society's expectations, attitudes towards PWDs, their perceived normal behaviour, and performance. In addition, it also shows society's harboured stereotypes, misconceptions and the social relevance of PWDs (48)(51). It has also been highlighted how models of disability play a role in how PWDs identify themselves and make sense of their experiences of all activities, including active leisure (48)(51).

#### 2.3 Active Leisure and People with Physical Disabilities

Leisure is a fundamental non-obligatory occupation, as stated by the Occupational Therapy Practice Framework, 3rd edition (2014) (OTPF III), and is an important

construct in enabling and maintaining occupational balance and promoting health and well-being (4)(5)(9). Literature suggests that leisure is a subjective experience and there is no consistency in its' meaning as the same activity may be experienced differently by two individuals (5)(67). Cultural beliefs also play a significant role in determining what constitutes leisure activity, when and where these leisure activities can take place (68). Nonetheless, the perception within literature appears to suggest three focal points of understanding the leisure concept: leisure as time, leisure as an activity and leisure as an experience (67)(68).

Leisure as time relates to the time spent when one is not engaged with work activities. The time is discretionary and the activities are freely chosen by the individual. Leisure as an activity refers to the actual activities chosen during this discretionary time. Lastly, leisure as an experience involves the individuals' subjective perception of the meanings attached and experienced from the engagement with the activity. The most important aspect of the experience is that it encompasses the individual's sense of freedom in the choice. Active leisure activity choices should be based on preferences, nature of the activity, meaning derived from engagement, and how, when and where the activity will be performed. Another important factor should be that the process of the active leisure experience is intrinsically valued, rewarding and pleasurable to the PWPD (67)(68).

#### 2.3.1 Active Leisure as a Construct

Active leisure was reported to enable PWPDs to be active citizens and take control of their lives (26). Participation, as a construct of human occupation, is described as taking part in life situations, such as active leisure, which is predominantly socially dependent and has a positive effect on health and well-being (1)(15)(35). Law (2002) suggested that active participation is an important aspect of human development, through which a person attains lived experiences and fosters social inclusion. Consequently, through social inclusion participants acquire skills, and enhance social skills by connecting with the community, and find purpose, meaning and satisfaction in one's life (22).

Several studies have reported the benefits PWPDs can derive from participating in leisure activities. Leisure was found to be therapeutic, with a range of health benefits because it played a role in achieving mental, physical, social, emotional, health and

well-being (69). Disability is understood to have undesirable negative effects on active leisure participation (8)(58). Many PWPDs experience considerable stress due to barriers associated with their disability while negotiating disability unfriendly environments associated with active leisure (5)(58). Active leisure participation has reportedly enabled PWPDs to disengage from stressful situations, and build resilience to cope with stress and their physical impairments (67)(69)(70).

Iwasaki and Mannell (2000) proposed that leisure coping strategies and beliefs help to ease the effects of stress. The authors described leisure coping beliefs as an individual's psychological belief that participating in active leisure would help ease the effects of stressful challenges; these beliefs develop over time through socialisation in active leisure. Leisure coping strategies were described as taking coping-action to counteract the effects of stressful events. Iwasaki and Mannell suggested three components to leisure coping strategies, namely i) 'leisure companionship,' the action of seeking out companionship for social support to cope with stress; ii) 'leisure palliative coping,' as escaping stressful challenges temporarily though active leisure to refocus and re-energise; iii) 'leisure mood enhancement' to counteract negative mood. According to Iwasaki and Mannell engaging in these actions, counteracts the effect of stress, thus promoting health and well-being (71).

Further studies found that leisure provided participants with an escape from their illness or disability (72) and from their families and others, as this enabled them to challenge their abilities, achieve their goals and develop independence (26). Participants reported that active leisure provided an environment where they did not have to think about or experience the limitations imposed by their disability, gave them the opportunity to connect with others with similar interests and was a source of motivation for maintaining coping efforts (72). Through active leisure, participants were able to develop friendships, build competence and self-efficacy (67)(69), connect with others in similar circumstances (62) and gain social support in their communities (67)(70). The community participation and social support they received from friends, family and others through active leisure, allowed participants integrate with their communities and feel content with their lives (63), gain a sense of acceptance and belonging and be motivated to maintain coping efforts (72).

Belonging and being accepted through active leisure appears to be important in the lives of PWPDs, as this was emphasised by Iwasaki, Mackay, Mactavish, and Ristock (2006), as well as having the opportunity to participate in meaningful active leisure activities in the community (70). A Canadian study reported that despite experiences of discrimination, the youth with disabilities had a strong sense of belonging to their community, felt supported, did not experience stigma and felt satisfied with their lives (74). Therefore, belonging implied PWPDs felt respected and valued with their attributes, they felt connected to the wider community without being judged, stereotyped, or stigmatised. They had equal access, could participate in whatever they wished and were motivated to capitalise on accessing resources to build their potential (75).

# 2.3.2 Meaningful life through Active leisure and Effects of Disability

Active leisure has been found to assist people's understanding of the meaning of life. This is achieved through purposeful, successful and challenging leisure pursuits, as opposed to inhibiting non-pleasurable encounters (25)(76). Iwasaki (2015) reported that active leisure provides space for living a life of meaning, motivation to participate to achieve active leisure goals and feel joyful at achievements. Iwasaki stated that human beings are biologically programmed to seek a life of meaningful participation. He suggested a link between active leisure, meaning-making, and engagement due to active leisure encompassing all the elements required to participate actively and live a meaningful life. Iwasaki argued that meaningful participation is reached and strengthened through leading a happy life, staying focused and in control of your life in the social, cultural, spiritual environments within one's community. This creates a positive self-identity, help staying inspired and living an empowered life (25).

Similarly, Bruner (1995) and Christiansen (1999) reported that meaning in life is derived from what has been exchanged with social relationships, and further action is taken based on what has been derived from that interpretation, be it typical or deviation from the expected norm (77)(78). Disability creates a deviation in occupational behaviour from what would be typically expected (34)(58)(79). Disability has been reported to have an adverse effect on participation in an individuals desired active leisure occupation, with consequences to the development of one's identity (8)(22)(77).

# 2.4 Disability and Identity construction and Self-determination

Literature shows that identity plays an important role in living a happy life filled with a purpose (25)(77)(80). The effects of disability on identity construction are presented next.

# 2.4.1 Disability and Occupational Identity

Literature suggests that when a person experiences loss through illness, impairment or disability, it becomes a loss to their identity and this may interfere with the competent performance of their desired occupations from which they derive meaning (8)(77). However, it is also suggested that with congenital disability, the disability is not viewed as a loss, as the person born with such a disability has no pre-morbid views of their identity other than that of being disabled (81)(82). Consequently, a person with a congenital disability cannot express what they have not experienced or developed (8). Bogart (2014) reported that participants with a congenital onset of disability exhibited high levels of self-concept and a greater positive disability identity (82).

According to Shakespeare (1996) people with acquired physical disabilities struggle to develop a positive sense of identity due to several obstacles. Firstly, disability is seen as a negative in the social environment because of society viewing PWPDs as impaired bodies. Secondly, PWPDs perceive themselves as inferior and inadequate based on the constant highlighting of their impairments from the marginalisation, they experience. Moreover, a lack of visible, positive, PWD role models exacerbates the problem, forcing PWPDs to gravitate towards medical professionals. Medical professionals usually offer assistance consistent with the medical model of disability, which then reinforces the negative disability identity (79). Literature suggests that all human beings, disabled or not, strive to express a positive identity, to be seen in a positive light and avoid projecting a negative view of themselves (8)(77).

Christiansen (1999) reported human beings possess an innate need to express their identity, which reflects a positive and meaningful life. Human engagement in an occupation such as active leisure plays an important role in identity formation and is, therefore, a catalyst for one's social life and meaningful experiences. In addition, a positive identity allows an individual to experience life as their own, maintain a motivated state of being, be goal-directed and take action towards their desired goal

(77). This view is supported by the Self-determination theory described by Ryan (2002), which proposes that three universal psychological needs must be satisfied to sustain human motivation for optimal physical and psychological needs for health and well-being, whether one is disabled or not. These needs are competence, relatedness, and autonomy (83).

'Competence' involves a feeling of triumph or satisfaction due to engagement. Feelings of competence and being successful instil confidence and propel human beings to seek challenges that exercise and improve their capabilities (83). 'Relatedness' involves being connected to others, belonging and being accepted by a social group, being cared for or caring for others (83). 'Autonomy' is one's experiencing one's decisions and behaviour as originating from oneself; having the freedom to choose and being able to make independent decisions before and during the engagement (83).

According to the Self-determination theory, social environments can both nurture and challenge these psychological needs. Nurturing social environments will therefore facilitate a well-integrated self-identity with enhanced motivation, whilst a challenging social environment will produce a fragmented passive self-identity or self-alienation from others and society at large (83).

Christiansen (1999) suggested that when identities are built around successful engagement in a variety of human occupations, including active leisure, this moulds a person's sense of purpose, acquired competencies, self-concept and feelings of occupational adaptation. This adds to living a life of meaning and well-being (77). Kielhofner (2008) described this as occupational identity, which develops over time through awareness of interests and capabilities to carry out a variety of occupations successfully including active leisure, and perception of one's future possibilities (8). Both Christiansen and Kielhofner stated that identity includes both self-concept and self-esteem that are created in the social environments, where one receives positive feedback and social approval for self-worth and acceptance as a person. While these two concepts are used synonymously, there are differences. Self-concept is described as an individual's interpretation of self, the roles played in the social environment and the social relationships one maintains (8)(77). Self-esteem is demonstrating

confidence in the positive outcome of one's ability to effect change to reach the desired goal and gain social approval (8)(77).

Christiansen (1999) suggested that because identity is closely linked to an individual's actions, competent awareness and presentation of the self, any disruption to these factors may create a disturbance to self-identity, self-esteem, and self-concept, ability to have free choice and take control of one's life in active leisure participation (77). Freedom of choice is central to the development of occupational identity. Physical disability by nature may limit free choice to access occupational opportunities for PWPDs, thus influencing their ability to develop their occupational identity (77)(79), which leaves them vulnerable to poor health and well-being (8)(77). Literature also reports that the loss of identity that occurs with acquired disability, results in changes in a PWPD's social standing, perception of self, as well as being perceived by others as 'being different' (84)(85)(86)(87). Moreover, persons with acquired disabilities often struggle to come to terms with their loss due to the social messages that they are impaired; this is frequently interpreted as PWPDs having less value. This situation poses a challenge for PWPDs to regain an altered-self identity (66)(67)(79)(85).

The literature further suggests that when PWPDs are bombarded with exclusionary messages, the social problems they experience are personalised and they tend to carry the burden of disability, and society rarely addresses or challenges the physical and socio-cultural disabling structures (54)(57)(79). Carrying this social burden may facilitate feelings of hopelessness and despair, and an inaccessible social environment may force PWPDs into voluntary isolation (75).

According to Gill (1997), the process of recovering a lost identity and redefining one's capabilities is through integration into society. Gill described four types of integration that PWPDs would go through to reacquire their lost identity whether the disability was from birth or acquired later in life.

The first disability integration involves claiming the right to integration into mainstream society as deserving citizens, "coming to feel we belong" (p. 42). This includes the right to equal access to active leisure resources, transportation, and to be accommodated as PWDs. They reject the blame of disability on their bodies but rather place the blame on the environment and lack of access.

The second disability integration, according to Gill, entails identifying and connecting with the disabled community, namely "coming home" (p. 42). In this integration, Gill reported that certain PWDs feel at ease associating and socialising with other PWDs, while others reject being associated with or contacting other PWDs, particularly in activities arranged for only PWDs. Gill suggested that some PWDs avoid such contact because it reminds them of experiences of previous segregation, of accepting society's resistance to provide equal access, of avoiding the stigma, and group stereotypes of being devalued, of being incompetent, charitable, shameful and pitiful. However, PWDs eventually make contact with one another through the various information seeking or services offered to them or other PWD's support. Gill stated that when PWDs established contact with one another, they discovered a unique connection and enjoyment in the company of others with disabilities.

The third disability integration described by Gill was internal integration of sameness and differentness, namely "coming together" (p. 43). This integration is framed by the perceptions of professionals, family members and others on how they perceive the effects of disability on the PWD. The notion is for the PWD to work hard at matching normalcy as close as possible, and to avoid the effects of their disability. Gill suggests that framing around integration in this way puts the PWDs a path of exhaustion, as striving to match abled individual's performance is demanding and strenuous. The person with a disability may give up altogether, therefore building one's identity is fruitless. To build a sound identity and integrate a PWD must reclaim their disability, their emotions and reject the normal values imposed on them by mainstream society. The fourth disability integration is integrating one's feelings, how you project yourself to others, namely "coming out" (p. 45). In this final step to rebuilding a positive disability identity, a PWD integrates a positive perception of self, with a comfortable view of self to be projected to others in main-stream society. Gill suggested that in this integration, a PWD is comfortable with who they are and how they present themselves, despite their circumstances (89).

# 2.5 Active Leisure as a Human Right

Participating in active leisure activities by PWPDs in social-cultural environments is a fundamental human right, affirmed in the UNCRPD (39)(90). This is specifically stressed in Article 30 of the Convention, which states that PWDs should be able to

participate in "cultural life, recreation, leisure and sport" (p22). This article acknowledged the right for PWDs to participate in active leisure just like other citizens on an equal basis. The Convention also makes it clear that governments should take appropriate steps to allow the PWDs to exercise their rights in accessing areas of active leisure resources such as museums, theatres, tourism services, cinemas, or monument sites (39). Coupled with this, the Convention affirmed the process of participation is made easier when PWPDs accept their disability (91).

Murugami (2009) asserted that by PWPDs' acknowledging and accepting their impairment as a human condition, they can re-construct their lost self-identity that is independent of impairment. Hence, when one has a clear understanding of self through participation in meaningful active leisure and other activities, one's capabilities and limitations become clearer. This author reported that rebuilding one's identity can only be facilitated by recognising PWPDs' human rights through creating and reinforcing legislation that would enable the active self to be enhanced through main-streaming (91).

People with physical disabilities often suffer violations of their human rights due to a lack of main-streaming (34). Darcy and Taylor (2009) asserted that to achieve main-streaming accessibility to community and country resources, systems and services are required, as well as inclusion into the social-cultural life of the community and the broader society. Thus, when PWPDs are main-streamed they possess the freedom to choose what activities to participate in, which is the basis and enjoyment of citizenship (92). An analysis of court cases lodged by PWDs in Australia, considered a first world country, supported that PWDs were discriminated against daily in their social-cultural lives, specifically in areas of access to services, access to goods, access to physical environments (92). In a third world country such as South Africa, PWPDs were reported not to capitalise fully on their capabilities due to their human rights are being violated, and they are prevented from living a dignified life due to social injustices (93)(94). These injustices have been particularly reported to be in social-cultural rights, economic rights, political rights and civil rights (95).

When social injustices prevail such as the denial of the right to access social resources that would enable PWPDs to participate in active leisure activities that others take for

granted, this leads to social exclusion. These social injustices are identified as the leading cause of social exclusion facing vulnerable populations among them, PWPDs (96). Townsend and Wilcock (2004) argued that society can only be seen to be just for all citizens, abled and disabled, when the capabilities of all its citizens are addressed and they can participate in diverse occupations to build their potential health and well-being (97). According to Nussbaum (2012) capabilities are attributes of basic social justice. They bring to light the understanding of human rights by linking capabilities with material and social aspects of human rights (98). When members of a community encounter barriers to access community resources and opportunities such as denial of access, marginalisation, imbalance, or segregated conditions, occupational injustices prevail eventually lead to social exclusion (84).

# 2.6 Barriers to Active Leisure Participation

Several authors have highlighted that PWPDs encounter various barriers to participation in physical and social environments needed for active leisure daily (42)(43)(58)(94).

According to the ICF, these barriers can be attributed firstly to personal factors located within a PWPD. For example, in a person with acquired impairments, these include past and present experiences of participation, levels of motivation and perception of self-esteem, coping styles to encountered barriers, overall behaviour patterns and age (1). In other studies, lack of motivation was identified as a barrier to active leisure participation. This was reported to stem from disappointment in previous active leisure participation as participants did not find their experiences enjoyable (99)(100). Secondly, environmental factors external to a PWPD play a considerable role in limiting or denying inclusion in main-stream active leisure activities in society due to inaccessible physical environments, unaccommodating public transportation systems, poor communication strategies, stigma and discrimination (42)(43)(63)(101). Literature also showed that a lack of physical and social support creates poor motivation to participate and renders an individual socially excluded (100).

Jaeger (2005) stressed that social exclusion predominates when PWDs are viewed by society as having little value and as a result, minimal effort is made to accommodate equal access to society's resources for active leisure participation (48). Wilcock (1998) asserted that when people experience a lack of opportunities or are unable to

participate in meaningful occupations such as active leisure, or have no control of what they do, they may be at risk of occupational risk factors (9). Wilcock identified these risk factors as being an occupational imbalance, occupational deprivation and occupational alienation (9). Barriers caused by external factors, such as cultural values, social services, political and environmental factor and attitudes of others, facilitates the development of occupational deprivation (102). PWPDs may find themselves experiencing occupational imbalance, devoid of meaning and enjoyment, due to external environmental factors (9).

The ICF clusters these external environmental factors into five different domains namely; product and technology, natural environment and human-made environment, support and relationships, attitudes of people towards PWPDs as they interact with one another and socialise, as well as within services and systems and policies (1).

# 2.6.1 Product and technology

This includes the transportation designed to enable PWPDs to move around outdoors and indoors for recreational, active leisure, sport, and cultural activities. Other aspects described as the products and technologies include assistive technologies, assets described as product of economic exchange, construction of a building to enable easy access, at entrances and exits, for example, entry and exists to shops, theatres, ramps, door's handles, toilet facilities, lifts and walkways, access to land developments such as parks, conservation and wildlife areas, and financial facilities for the exchange of services and goods (1). Various studies have highlighted that products and technologies can be a barrier or facilitator to active leisure participation. As an example, in a study conducted in the USA, the authors reported that even though the participants had access within their immediate micro-environment, lack of appropriate assistive technology for personal mobility was a barrier to their community participation, particularly in active leisure and work (103). Similarly, assistive devices for mobility and financial assets were the most common barriers identified by a study conducted in the Western Cape (42).

### 2.6.2 Natural environment and human-made changes to the environment

Human-made environmental changes and the natural environment according to the ICF can cause barriers to active leisure participation for PWPDs. For example, the built

architectural infra-structure, poorly designed ramps, steps and walkways as well as inaccessible terrain around the beaches and poor mobility on sand with an ordinary wheelchair. Steep inclines on the natural terrain can be challenging for a wheelchair, crutch or lower limb prosthetic user (1), however this can be overcome by specialised assistive technology, for example, wheelchair tyres that can ride on the sand.

Eichhhorn and Buhalis (2011) reported that accessibility to the physical environment is one of the key components that enable participation and inclusion, but most often widespread barriers are reported that exclude PWPDs from participating (104). Australian research, by Darcy and Daruwalla (1999), reported on the inaccessibility to physical environments and inaccessible destination attractions for PWDs. Participants in a study by Newman (2010), in the USA, reported about inaccessible exterior environments, such as sidewalks, ramps, curbs, parking lots and uneven terrain. Similar findings were identified in a South African study by Maart (2007), which identified curbs, stairs, elevators and uneven terrain as the most common barriers to participation by PWPDs (101). In more recent research in South Africa, Cawood and Visagie (2015) and Visagie, Dyrstad, Mannan, and Swartz (2017) highlighted the fact that inaccessibility prevents PWPDs from achieving their active leisure goals and satisfaction and consequently they become dissatisfied and disengage from active The most common barriers to active participation were steps and participation. inaccessible public buildings (42)(43). In Hammel, Magasi, Heinemann and Gray's (2015) study, participants reported restaurants, restrooms and doorways as being inaccessible (103).

In a study by Carpenter, Forwell, Lyn and Jongbloed (2007), participants with spinal cord injuries highlighted barriers in accessing hotels, motels and swimming pools. The participants further, indicated areas they would change to improve access to public social-cultural spaces including the availability of parking spaces for PWDs, beaches, trails, wash rooms, lower elevator buttons, swimming pools, public marinas, ramps, and wider shop aisles (73).

### 2.6.3 Support and relationships

This category included physical and emotional support from other people, from immediate to extended family, personal care providers, neighbours, friends, colleagues,

community members, people in a position of authority and strangers, to facilitate accessibility (1). Inadequate physical and emotional support have been reported to create barriers for PWPDs in active leisure engagement. For example in a study by Cawood and Visage (2015), the majority of participants reported their immediate family and acquaintances were supportive and were facilitators to leisure participation (42). However, in a community study by Carpenter, Forwell, Lyn and Jongberg (2007), the majority of participants who lived alone reported having no one for support, and this was a barrier to their community and active leisure participation (73).

### 2.6.4 Attitudes

This refer to observable attitudes of others in the social environments where PWPDs participate. The attitudes play a role in how PWPDs are perceived and treated in the social and cultural environments, while they partake in active leisure, creating either barriers or enablers for them (1).

The social-cultural environment is understood to play a very important role in engaging with an activity, as it is also believed to be the aspect of the environment where meaning is assigned to the different activities undertaken (1)(25)(105). Negative attitudes towards PWPDs may be exhibited by individuals resulting in stigmatisation, stereotyping and marginalisation (48). Hammel, Magasi, Heinemann and Gray (2015) reported that participants with a more visible disability experienced more frequent negative attitudes. These negative attitudes often took the form of the PWPD being perceived as incapable, and unable to think and decide for themselves (103). Other exclusionary social behaviour displayed by the public included showing feelings of discomfort when around PWPDs, ignoring them, stereotyping and pitying them (such as 'ag shame'), resulting in PWPDs feeling inadequate, sub-human and not belonging (40) (48). Jaeger (2005) stressed that stigmatisation affects every facet of PWPDs' life and is the most challenging to overcome (48). Stigma is a social problem where negative feelings of disgrace, pity, misfit, dependence, fear, and discrimination are projected onto another person due to undesirable differences (40)(106).

According to Coleman Brown (2013) stigmatisation is a form of social control, which is forced onto PWPDs by others due to their perceived differences (107). Hamilton (2004) reported that in general society is obsessed with the normal physical body and

expectations of normal behaviour, therefore any deviation from this creates negative attitudes (106). Coleman Brown asserted that physical abnormalities are the most severely stigmatised due to the visible appearance, and as the people affected are not able to disguise their affliction they attract stigmatisation. Coleman Brown describes this as a "social death" (p.156), arising from the behaviour of non-disabled members of society by socially rejecting and avoiding PWPDs and acting as if they were invisible or lifeless in front of them. Consequently the only social interactions that PWPDs find open to them are other stigmatised victims or their family members (107).

In South Africa, stigma and prejudice is reported to plague the social environment, leaving PWPDs and other vulnerable groups socially excluded, unable to access social support, services, transport systems and infrastructure that other citizens take for granted (40)(42)(94)(108). In a 2015 study in the Western Cape, with fifty stroke survivors living in the community, it was reported that 47% of the participants perceived the community's attitudes as negative, 53% perceived societal attitudes as a barrier to their active participation, while 72% of participants felt their immediate family exhibited positive attitude towards them (42). Two participants reported the attitudes of other people towards them as social rejection; one described that members of her community viewed her as incompetent and mad, while the other described how people showed feelings of fear of being contaminated by wiping their hands after shaking hands with him (42). According to Kielhofner (2008), most social environments display deep-rooted mixed feelings towards PWDs and the majority of PWDs narrate experiences of unwarranted negative attitudes, inappropriate social reactions and rejection towards them from able-bodied members of society (8).

#### 2.6.5 Services, systems and policies

This refers to services, systems and policies offered by the government or private sector and includes the people that administer these services for all persons, including PWPDs. It also includes adopted conventions that govern standards of service delivery by the government. However, many of these 'services, systems and policies' have been reported to be more disabling than enabling to PWPDs (1). Among areas involved are architectural design and construction of public, private residential and commercial buildings, open spaces including recreational, conservation and development of public

land for parks, meeting and commercial activities, plazas, open-air markets and pedestrian routes (1).

Literature shows that PWDs in many parts of the world are at a disadvantage when it comes to accessing these resources compared to their able-bodied counterparts (1)(35) (109). In South Africa, many PWDs continue to be socially excluded from societal resources that enable active leisure participation, leisure and recreation and transportation (93), as an example, Cawood (2015) reported transport services as a major barrier to participation by 88% of participants in this study. In addition, services, systems and policies around architectural design and construction, communication and general social support were identified as barriers to participants' active leisure participation (42). A study by Maart (2007) had similar findings. Maart pointed out that for PWPDs to access services they require access to transport as a facilitator, therefore, a lack of suitable transport made it impossible for PWPDs to access any available service including active leisure opportunities. Maart reported that this was mainly due to poor policy implementation, ignoring the recommendations in the INDS (101).

A USA study by Hammel, Magasi, Heinmann, and Gray (2015) reported that PWDs experienced barriers at all levels of participation. Participants in this study reported inaccessible restaurants as well as people in society and business owners not being aware of what to do, or how and what type of assistance to afford PWDs. It was also reported that PWPDs are further compromised due to a lack of information to assist in identifying accessible resources (103).

Transportation is one of the key resources that enable PWPDs to participate in active leisure occupations located in different places. This lack of accessible public transport can impose social participation restrictions on desired active leisure occupations by PWPDs (106)(110)(111). Swartz and Schneider (2006) reported that PWPDs in South Africa are restricted from participating in their desired active leisure in their communities not because of their inability to do so, but due to lack of an accessible, affordable and safe public transport system. An inadequate and unsafe transport system is commonplace for the majority of South Africans therefore, the authors stress that equitable access to public transport that caters for PWPDs would not be a priority given the enormity of the public transport problems affecting all South Africans (110).

Chikuta (2015) also reported that accessible transport is a key factor denying PWDs access South African National Parks (112).

In the USA, in a recent study by Bezyak, Sabella and Gattis (2017), participants with mobility problems were reported to experience many barriers due to the transport services. The barriers stemmed from drivers exhibiting negative attitude, refusing to stop or not calling out stops; steps or gaps when entering the vehicle, and the operating system of the lifting system into the transport vehicle also created difficulties (113). A study carried out in Ethiopia found PWDs experience inaccessible public transport systems, as public transport vehicles are not designed to carry PWPDs (114). The Western Cape study in South Africa also identified a lack of access to public transportation as a barrier to community participation and integration for 80% of the participants (42). In the South African National Household Travel Survey (2013), access to transport was recognised as the means for economic and social transformation for all citizens (115). Therefore, South Africa has the mandate to provide accessible transport to PWDs as outlined in the National Development Plan 2030 (116). According to the South African National Travel Survey (2013) minibus taxis are the most popular mode of public transport because they can be found in most streets, areas and do not have specific operating times (94)(114), followed by buses (115).

However, Coulson, Napier and Matsebe (2006) reported that PWDs are viewed negatively by taxi drivers as they take longer to load into taxis, especially those with mobility problems (94), occupy extra space and are seen to offer little economic value (42)(108). Participants in that study reported that most of the time, taxi drivers do not stop for them (94). In a further study examining factors affecting public transport provision for PWDs carried out in eThekwini municipality, in KwaZulu-Natal Province, Lister and Dhunpath (2016) identified insufficient policy dialogue among stakeholders as well as lack of reaching consensus as contributing problems. Furthermore, the control the taxi industry has on public transport undermines government initiatives on providing equitable transport to PWDs, such as the Integrated Rapid Public Transport System (108).

In the Carpenter, Forwell, Jongbloed, and Backman (2007) study, participants who owned vehicles indicated that owning a vehicle enhanced their active leisure

participation. However, they also indicated that convenient and monitoring of parking spaces for PWDs would enable more participation. Those who did not own vehicles reported needing increased transport schedules for PWDs, such as 'HandyDART' (door to door transportation for PWDs operated in British Columbia, Canada) (3), availability and monitoring of parking for PWDs, and more bus stops and routes (73).

### 2.7 Occupational Justice and Disability Inclusion

According to Townsend and Wilcock (2004), occupational justice is based on the belief that all human beings including PWPDs, are occupational and social beings with an innate urgency to engage in diverse occupations as autonomous participants to satisfy the need for health and well-being (86). The authors stated that participating in an occupation of choice is interdependent and contextual, and is carried out in diverse physical, social environments, which, as described above, can enhance or restrict occupational opportunities and participation (86). Moreover, when members of a community encounter inaccessibility, marginalisation, imbalance, or segregated conditions, this eventually leads to occupational injustices and social exclusion (84).

Whiteford and Townsend (2011) stressed that occupational justice highlights the many factors that result in certain members of a population being socially excluded and restricted from exercising their rights to accessing societal resources, opportunities, and privileges for occupational participation (117). When access to occupations is framed around justice, PWPDs rights to access a variety of occupations and the liberty of enablement to develop their potential are affirmed (86). Whiteford and Townsend stated that the desired long-term aim of occupational justice is to see social transformation where all members of society are socially included, empowered and participate in their desired occupations in mainstream society. This requires a collaborative effort from all stakeholders to address and eradicate all perceived occupational injustices, because equal access and social inclusion are a collective responsibility (117)(118).

The South African 20-year review report on disability emphasised the lack of significant changes in main-streaming PWDs into societal structures. This was attributed to limited capacity on part of the government to implement the policies aligned with the UNCRPD and poor co-ordination of the disability sector with government structures (109).

According to Van der Veen (2011), this situation is the result of a poor co-ordinated understanding of the disability action plans and disability organisational structures, lack of formulation of clear targets and monitoring indicators at government and disability organisation level (118). Carpenter (2007) argued that PWPDs' participation of active leisure in society should be viewed from a perspective of community integration, using whole life approach, as opposed to addressing rehabilitation goals and community integration following injury (73).

### 2.8 The Whole-life Approach

Darcy and Dickson (2009) argued that disability and ageing are part of the human natural life cycle. The authors indicated the connection between disability, ageing, tourism, and access, and they stressed the need for strategically using the concept of a Whole-life approach to plan and develop accessible active leisure and tourist environments (119). The Whole-life approach uses the same sentiments as the WHO (2007), acknowledging the acquired loss of function throughout the different stages of life. (120). According to Darcy and Dickson, the Whole-life approach addresses the access requirements that may be present throughout life using universal design principles. Darcy and Dickson concur that this approach aligns with UNCRPD which ensures that all citizens are always able to access societal resources without hindrance in exercising their rights and citizenship to participate (119).

### 2.8.1 Universal Design

The universal design embraces the idea that the design of infrastructure can be structured to accommodate the needs of all citizens, and according to Eichhorn and Buhalis (2011) this goes beyond access and inclusion of PWPDs (104). Mace, Hardie, and Place (1991) stated that universal design takes into consideration the natural continuum of changes that occur over a life-span (121). The universal design considers the design of environments and products for use by everyone without requiring adaptation or a special design as an afterthought (122). This strategy allows equitable use to maximise social participation, by designing environments that exclude all foreseeable barriers that may prevent participation. According to Mace, Hardie, Graeme, and Pace (1991) propose that designing the built environment, communication systems, services, and products from the beginning with universal access in mind, is

more cost-effective than alterations (121). Similarly, Ndaba (2003) argued that designing for individuals or specific group needs is impractical and costly due to a variety of usability needs that may change with age. Furthermore, universal design is an equitable concept and should not just be seen as something designed to accommodate PWPDs, but rather the same features that are used by all citizens including older citizens, and mothers with their children in prams (123).

Other authors have reported that universal design supports self-reliance, with social engagement by all and reduces levels of stigma and stereotypes that most PWPDs suffer from by considering them as part of the normal social system (119)(124). Darcy, Cameron and Pegg (2010) have also argued that by designing infrastructure and delivering services and products that are aligned with the principles of universal design, assists people who utilise these services (44).

# 2.8.2 Universal Design Principles

According to the Centre for Universal Design (1997) (CUD), the seven universal design principles were developed by architects, engineers, environmental and product research designers under the leadership of Mace, a disabled architect. These principles guide the design of environments, communication systems, and products so that they can be utilised by everybody regardless of circumstances, age and ability. Moreover, these principles can be used to evaluate existing infrastructure, services, and products (125). The seven principles are listed below, followed by an explanation of their practical utilisation.

- Principle One: Equitable use. The design is useful appealing and marketable to people with diverse abilities and avoids segregating or stigmatizing any user.
   Provisions for privacy, security, and safety should be equally available to all users.
- Principle Two: Flexibility in use: The design should accommodate a wide range
  of individual preferences and abilities. Accommodate right and left-handed
  access and enable user's accuracy, precision and adaptability to the user's pace.
- Principle Three: Simple and intuitive use. The design should be easy to understand and use, regardless of the user's experience, knowledge, language

skills, or current concentration levels. Unnecessary complexity should be eliminated, and the design should be consistent with user expectations and intuition. Information should be arranged consistent with its importance and effective prompting and feedback should be provided during and after task completion.

- Principle Four: Perceptible information. The design communicates necessary
  information effectively to the user, regardless of ambient conditions or the user's
  sensory abilities. The use of different modes (pictorial, verbal, tactile)
  presentation of essential information is essential.
- Principle Five: Tolerance for error. The design minimizes hazards and the
  adverse consequences of accidental or unintended actions. Elements within the
  design should minimise hazards and errors, hazardous or inaccessible elements
  eliminated, isolated, or shielded. Warnings of possible hazards, and errors
  should be provided and unconscious action discourage in tasks that require
  vigilance.
- Principle Six: Low physical effort. The design should be used efficiently and comfortably with a minimum of fatigue and allow the user to maintain a neutral body position using and sustaining the physical effort.
- Principle Seven: Size and space for approach and use. Appropriate size and space should be provided for approach, reach, manipulation, and use regardless of the user's body size, posture, or mobility. A clear line of sight and reach should be provided to all components, comfortable for any seated or standing user. Variations in hand and grip size should be accommodated and adequate space provided for the use of assistive devices or personal assistance.

Legislation has been identified as a vehicle to enabling PWPDs to exercise their human rights and their capabilities in an environment for active leisure with a supportive universal design. Thus, the slow implementing of policies for social change and integration of PWDs has been identified as a driver to PWDs' slow integration in to main-stream society (43)(126). Matsebula, Schneider and Watermeyer (2006) highlighted the implementation had not matched up to the legislation due to poor

coordination and monitoring processes at three levels of government (national, provincial and local), as a result, the legislative strategies are not filtering down so that the accessibility so desperately needed by PWDs, such as public transport, is not forthcoming (127). McClain, Nhlapo, Watermeyer and Schneider (2006) stated that legislation by itself does not guarantee that human rights will be enabled, as the law only provides a framework to guide a process of redressing the injustices (34).

#### 2.9 Conclusion

Living with a disability is a reality facing many people in South Africa. Active leisure in its broadest sense has been identified as an essential aspect of human occupation to promote social integration, health and wellness; it is also a vehicle for developing and re-establishment personal identity, self-esteem competence and capacity following an acquired disability or being born with a disability. However, there are many challenges PWDs have to navigate regarding access to different environments to participate in active leisure.

This chapter introduced and discussed the different models of disability, as well as how the proponents of each model view PWPDs. The biopsychosocial model was identified as the most suitable to inform the study, as it encompassed the ideals of both the medical model and the social model. Environmental barriers to access active leisure resources, as identified by the ICF, were introduced and discussed. Consequently, the chapter has framed access to active leisure resources as a human rights issue. Barriers within society's environments represent a violation of PWPDs' human rights (39)(90), that denies them the opportunities to build or rebuild their potential and express their identities, which leads to health and well-being (9)(79)(102).

Being active and engaging in the occupation of choice and self-determining one's own goals is crucial to an individuals social cohesion and development of self-identity and the competent self. It is through these identities that a person can formulate their abilities and to be effective at what they do, how they can develop and how they can use this to express themselves with others (80)(83).

The concept of occupational justice and disability inclusion in main-stream society was discussed, which emphasised that individuals have unique occupational needs that

need to be fulfilled to maximise potential. Disability inclusion, to be effective, requires a different way of thinking to enable equal access of PWPDs to society's diverse occupations (86).

Within this chapter, the South African's legislation and signatories to international instruments that enable the creation of an inclusive climate in the physical and social-cultural environments for PWPDs have been noted. However, even with the political will and the legal framework in place, many PWPDs have yet to see an inclusive society in South Africa (43)(101). This is an international problem and while first world countries have made good progress by enforcing the whole person and disability inclusion approaches, South Africa is reported to have made little progress in spite of having good legislation but poor implementation and monitoring (109)(118).

Moreover, policymakers and service providers adopt the Whole-life concept, with the use of universal design with its principles to design and deliver environments and products and services that are in line with a whole-life approach using universal designs so that everyone's access needs are addressed throughout a human lifespan (119) (121).

There is little visibility of PWPDs participating in active leisure activities in main-stream society and according to Coulson, Napier and Matsebe (2006) are trapped in isolation and socially excluded from main-stream society (94). Active leisure participation at community and society level symbolises the last stage of PWPDs rehabilitation in which PWPDs can reclaim or rebuild their lost independence and social networks and create meaningful lives for themselves through active leisure. Therefore their lived experiences need to be explored, to uncover the dynamics behind this phenomenon.

The following chapter discusses the qualitative methodology used to collect data for this research.

# **CHAPTER 3**

### **METHODOLOGY**

### 3.1 Introduction

This chapter describes the qualitative research methodology that was used to answer the following research questions:

- What factors do PWPDs believe challenge or facilitate their choice of active leisure activities?
- What are their perceptions and experiences of their active leisure participation in Gauteng?

The chapter describes the sampling procedure, and the inclusion criteria used to select the sample, and discusses the data collection process, data analysis and ethical considerations that were followed. The components of trustworthiness employed in the study will also be discussed.

# 3.2 Study Sites

The data collection for the study was carried at five non-profit organisations (NPOs), located in different areas of Johannesburg, Gauteng Province, South Africa. Disabled People South Africa (DPSA) is an NPO run by PWDs in South Africa. The organisation aims to create a voice for PWDs through their mobilisation, to represent and advocate for their economic empowerment and human rights. People Awareness of Disability Issues (PADI) is run by PWDs and aims to create awareness of disability issues through educating the public, at schools or places of employment. Gauteng Provincial Association of South Africa for People with Physical Disabilities (GPAPD) coordinates the work of 22 member organisations providing services to people with physical disabilities. The GPAPD services include training and organisational development, sensitisation training on disability, employment placement of persons with a disability, application for disability parking discs, motor vehicle rebates and beach permits, advocacy and lobbying of the rights of PWDs, social work services, and community development services. The Quadriplegic Association of South Africa, Ry-Ma-In, is a home for persons with quadriplegia and run by them. The residents are expected to manage housekeeping, transport maintenance, staff and run the thrift shop on the property. Lastly, Ann Harding Cheshire Home is an assisted living for people with physical disabilities. The accommodation is single rooms with 24-hour care from nurses and caregivers. The facility also offers the services of occupational and physical therapists, and a social worker.

### 3.3 Study Design

This study used an explorative, descriptive, qualitative methodology to explore and describe the perceptions and views of PWPDs understanding of active leisure engagement, and their lived experience of factors that influence their participation in active leisure. This methodology was chosen as the research method most likely to assist in uncovering and understanding the individuals and groups that were studied, in this case, a sample of South African PWPDs residing in Gauteng (128). Some authors have suggested that qualitative research aims to create and understand the narrative of those living and participating in the story, through their subjective experiences, the assumption being that human behaviour can only be analysed and understood in the context in which the behaviour was created. This was also the view of Creswell (2018), who argued that participants cannot be separated from the context in which they are Thus, qualitative research empowers the experiencing the problem or issue. participants to share their stories and allows the researcher to understand the context in which these stories were created. Furthermore, by exploring the subjective experiences of PWPDs we, as occupational therapists, can begin to understand the meanings that PWPDs attached to their experiences of their active leisure as participants of their own story (126)(128).

An explorative descriptive approach was selected to understand the complexity of active leisure participation for PWPDs living within their communities (131). According to Van Wyk (2012), an explorative approach is utilised when there is scarce knowledge of the problem in the area being studied, in this case, active leisure participation of South African PWPDs residing in Gauteng. Moreover, explorative research aims to uncover the salient factors and how they affect the problem being studied (132). Qualitative descriptive design analyses the rich descriptions of the experiences of the participants regarding the phenomenon being studied. Furthermore, according to Sandelowski (2000) and Neergaard, Olesen, Andersen and Sondergaard (2009), qualitative

descriptive research used open-ended questions to induce rich data from participants, such as what, where who and why. In addition, a qualitative descriptive research design, as described by Sandelowski (2000) and Neergaard, Olesen, Andersen and Sondergaard (2009), the researcher does not stray far from the data in analysing the findings and a comprehensive descriptive summary was derived from the data (131) (133).

The researcher collected data in the natural setting of the participants. This was done with individuals or groups of participants through in-depth interviews and focus groups at a place and time convenient to the participants (128).

# 3.4 Sample and Sampling Process

Purposive sampling was used to select the participants for this study from the population of PWPDs in Gauteng, South Africa. Patton (2015) stated that purposive sampling allows the researcher to select participants as rich cases with knowledge and purpose for in-depth understanding, to uncover the issues pertinent to the study at hand This purposively selected participants inform the researcher regarding the research questions (128). Qualitative research requires a small sample, and a number of participants that it recommends range from one to fifty (128). Guided by Bryman's (2016) and Creswell and Poth (2018)'s view, the researcher selected the sample consisting of a variety of key characteristics best suited for an in-depth understanding of their active leisure (128)(130). The participants were selected by engaging with five registered non-profit organisations (NPO) dealing with PWPDs around Gauteng. Five participants lived in their communities, one had a carer and eight participants resided in the assisted living at the two NPOs. It was convenient to select participants from the five organisations and to collect the data at these organisations' premises because this was their natural context. This sampling procedure was relevant to the study and with beneficial elements to answer the research questions (129).

### 3.4.1 Inclusion Criteria

Both male and female adult South African PWPDs, between the ages of 18 and 65, with a variety of physical disabilities that affected mobility, were invited to participate. Participants with either acquired physical disabilities of more than one year, or congenital physical disability, who had active leisure experiences were included. Other

inclusion criteria were that participants had to have full-time employment, do voluntary work or be on disability grant and earning from R1000 and R20 000, and able to manage their finances. Lastly, they had to have experience of engaging in active leisure activities for one-year post acquiring a disability and from 18 years of age if congenital.

### 3.4.2 Exclusion Criteria

Any persons with stroke, head injury or cognitive deficits, mental illness, problemsolving, decision making and judgement deficits.

### 3.5 Data Collection Process

# 3.5.1 Demographic questionnaire

The researcher developed a demographic questionnaire. The information gathered by the demographic questionnaire included age, gender, marital status, type of disability mobility aids, employment status, and income distribution (see Appendix A).

# 3.5.2 Questions and prompts for focus groups

Open ended questions and prompts were used to initiate the focus groups and in-depth interviews to collect data from the participants (see Appendix B). The researcher developed these from the research questions, objectives and from the literature that had been reviewed in preparation for this study.

### 3.5.3 Data Collection (focus group and in-depth interviews)

The five NPOs referred to above were approached for permission for their members to participate in the research (see Appendix C). A letter explaining the research was sent to the manager of each NPO. When permission was granted, the approved information sheet explaining the research and nature of participant involvement in the research was handed to the potential participants who met the inclusion criteria (see Appendix D). The information sheet explained the nature and purpose of the research, that participation was voluntary, and they were free to leave at any time if they wished to do so. It also stated that due to the nature of the focus group, absolute confidentiality could not be assured, however, what the participants shared would be treated with confidentiality and not be attributed to them in the final report. The researcher and supervisor's numbers were on the information sheet for participants if they wanted to

ask further information. When the participants volunteered to participate, a date for data collection was set.

It was planned that all the data would be collected in focus groups as these would allow the researcher to explore the groups' opinions, feelings, experiences, perceptions, and issues about the topic of active leisure, which was being discussed (130). The advantage of focus groups was that it afforded the researcher the opportunity of listening to how a group of participants constructed meaning and made sense of the phenomenon of active leisure as it affected them (135). Patton (2015) asserted that in a focus group, participants present their views while being exposed to the views of other participants (134). Thus, participants are afforded the opportunity to reflect on their own experiences and opinions and gain an enhanced insight from what they have heard (136). Patton further reported that focus groups can generate rich group discussions around the issues related to active leisure affecting the participants and generate thick rich data as it provides a broad range of information about social issues, ideas and feelings a targeted group has, and how social issues are affecting them (134).

Both focus groups and in-depth interviews were used to collect the data for this study. This was necessary because it was not feasible for all the participants with PWPDs, some with specialised adapted wheelchairs who agreed to participate, to come together for several focus groups at a set date due to transportation and venue problems, some participants were not able to commit to a specific time. Lewis and Nicholls (2013) reported that in-depth interviews generate a deeper personal point of view of participants' experiences than from a focus group. Additionally, in-depth interviews can be used with participants who are not able to travel or are geographically dispersed (136).

In-depth interviews were carried out with single participants who were unable to attend the focus group at the specified venue because of other commitments and transport issues. Organising focus groups for participants with physical disabilities proved to be a challenge as most participants used specialised adapted wheelchairs, thus structuring a group of 8 participants together in the available venues proved difficult. Two organisations could not provide an appropriate venue for a focus group, therefore appointments were made for individual in-depth interviews with participants from these

NPOs. The same questions and prompts were used for both focus groups and in-depth interviews (see Appendix B), however, the social context of the two data collection procedures was different. Two focus groups and all in-depth interviews were conducted in English and one focus group was conducted in Zulu. The researcher facilitated all focus groups and in-depth interviews.

Two focus groups were carried out at the organisations at which the participants worked, in one of the available offices; the third focus group was carried at a social worker's house as she felt this was a convenient location for everyone involved. The five in-depth interviews were carried out at the participants' organisations and one was carried out at a restaurant at Clear Water Mall, as this was a preferred venue by the participant. The duration of the focus groups and in-depth interviews varied, lasting between 20 minutes and 1h 38 minutes.

Before the commencement of each focus group and in-depth interview, the researcher explained the research using the approved information sheet (see Appendix D) and answered any questions the participants had. The researcher further informed the participants that participation was voluntary and that they were free to leave if they desired. The researcher informed the participants that confidentiality within a focus group could not guaranteed, however, whatever they shared in the groups would be anonymous and not attributed to a specific person. The participants were then asked to sign a consent form to participate in the focus group and in-depth interviews (see Appendix E). The researcher also explained the need to audiotape the section so that nothing of what they shared in the focus group and interviews would be missed. For this, they were asked to fill in a form consenting to being audiotaped (see Appendix F). The participants were then required to complete a demographic form that was designed by the researcher for this research (see appendix A).

The focus groups and in-depth interviews were recorded with a Zoom handy recorder H4n, and downloaded and stored on a password-protected laptop. The word for word transcriptions were done by the researcher, and cross-section were checked for accuracy by the supervisor. Data collection continued until the data was saturated and no new perceptions or experiences were evident.

### 3.6 Data Analysis

Data from the demographic forms were transcribed on to an EXCEL spreadsheet and analysed descriptively. The data from the audio recordings of the focus groups and indepth interviews were transcribed word for word by the researcher, the transcriptions checked for correctness and the transcripts anonymised before interpretation. Transcription of the recordings enabled the researcher to immerse herself in the data to assist with interpretation, as supported by Patton (2015) (128).

Patton (2015) stated a qualitative inquiry produced a large amount of data and the researcher had to identify patterns to explain what the data was communicating (134). While Patton stated there was no prescribed way of analysing qualitative data, there are guidelines and principles that assist the researcher in the analysis (134). Creswell and Poth (2018) suggested the data be prepared by sieving through it, through coding and creating of themes (128). The data from the focus groups and in-depth interviews were analysed using inductive coding to identify codes, subcategories and themes (130). Initially, the transcripts were read to try to understand, gain insight and reflect on what meanings the participants were trying to disclose about their active leisure experiences. The transcripts were then re-read, this time writing key concepts in the margins of the page (137). Patton (2015) reinforced that the initial reading allows the researcher to familiarise themselves with the data and identify coding categories and look for emerging themes, which is believed to be the core aspect of qualitative data analysis (128).

The coding reduced the data into patterns of meaningful components, identifying supporting evidence to the generated codes from the presented data. Themes were identified and these were grouped with similar groups of information in categories, subcategories and their corresponding codes, which represent the participants' experiences (134). This process of thematic analysis and coding was checked and verified by the research supervisor.

#### 3.7 Trustworthiness

Literature suggests that ensuring trustworthiness is an important characteristic of good qualitative research, as it is essential to establish the credibility of the process and the outcome of the research so that others have confidence in the findings (128)(130).

Creswell and Poth (2018) recommended the researcher should carry out two of the trustworthiness strategies to establish credibility and transferability of the research (128). The researcher employed the following strategies to determine the trustworthiness of the research:

### 3.7.1 Credibility

According to Bryman (2016), credibility is the authenticity of the research findings (130). To ensure the congruency of the findings to the research, the researcher used data triangulation, data saturation, reflexivity, and member checking.

### 3.7.1.1 Data Triangulation

Creswell and Poth (2018) reported that data triangulation involves the process of substantiating the data from different multiple sources (128). The researcher carried out the methodological triangulation of the data by using different sources for the data. Focus groups and in-depth interviews were used to obtain data from the participants. These methods of data collection complemented one another and produced relevant data from a different perspective of the participants' perceptions of the active leisure phenomenon. Thus, the in-depth interviews provided participants' perspective that was not influenced by group dynamics and interactions (128)(138).

### 3.7.1.2 Data Saturation

Saturation instils confidence and credibility in the content of the research and its findings (130)(139). Data saturation is the collection of data to the point of redundancy, where no new information or themes emerge from the sampled participants (140). Brod, Tesler and Christiansen (2009) suggested formulating a saturation matrix to aid in identifying saturation. Inaddition, these authors recommended both saturation matrix and coding of the data should be used to determine the final presentation of saturation (128)(139).

The researcher constructed a saturation grid, which was populated with emerging concepts from the focus groups and in-depth interviews. Data saturation was reached when no new concepts were forthcoming from the focus groups and in-depth interviews. However, the final data saturation was reached when the researcher immersed herself

in the data by analysing it to determine patterns of emerging themes, categories and subcategories. This was done through constant comparison of the data, emerging themes and saturation matrix table. As the themes emerged and the categories and sub-categories were refined, repeated patterns of information shared by the participants were noted until no new themes emerged. This indicated the point of saturation had been reached (138)(139).

### 3.7.1.3 Reflexivity

Creswell and Poth (2018), Bryman (2016), and Ormston, Spencer, and Barnard (2013) have stated that reflectivity enables a researcher to disclose, highlight and clarify their role, values, and beliefs as well as influence and implications they hold in the context and throughout the research process (128)(130)(138). Reflexivity was very important as it assisted the researcher to understand and analyse the phenomenon from the participants' perspective, as well as understand and manage her perspective on the shared issues and the experiences of the participants. The researcher kept a reflective research diary which allowed her to reflect on the participants' experiences, and as well as her own emotions and reactions to their stories and context. participants' contextual environment allowed the researcher to experience some of the active leisure participation problems that participants experienced. The researcher was affected by one of the core problems that lead PWPDs to feeling socially excluded, a lack of accessible public transport while trying to organise focus groups. It was difficult and costly to get six to eight PWPDs together in one place for a focus group, which raised the question, how can one participate in active leisure activities with a lack of accessible public transport, and when the available transport service will not accommodate the basic performance of routine daily life demands for PWPDs?(128).

Some focus groups and in-depth interviews proved very emotional for the researcher, as it felt that she had opened up a Pandora's box of suppressed lived experiences. The researcher observed emotions ranging from sadness to anger that had been bottled up for years with no outlet. She was aware of her presence and controlled her questioning and reactions in order to across as

someone who was listening empathetically and acknowledging, but not judging what they were sharing.

Patton (2015) suggested that researchers should exercise 'empathetic neutrality.' He suggested that being neutral does not mean you are distancing yourself from the situation being studied, but rather acknowledging and being conscious of any pre-existing bias the researcher may hold which may influence the data collection and analysis. The researcher reflected on the participants' shared narratives and how they understood and made sense of their shared experiences. The researcher also reflected on how to best capture the participants' experiences and report them without any distortions of what was being shared through audio taping (134).

### 3.7.1.4 Member Checking

Member checking involves obtaining participants' feedback to establish the credibility of the interpretation of the research finding (128). Creswell and Poth (2018) and Anney (2014) suggested only analysis, results, themes, and conclusions should be communicated back to the participants for their verification that the interpretations and findings represented their experiences (128)(142). Participants' feedback was obtained from the two focus group participants regarding respondent validation of the credibility of the interpreted findings. Feedback sessions were carried out with two focus group members at their NPO offices. The themes were presented to members of both focus groups and discussed; both focus group members concurred with the findings. One participant responded "The results are spot on. I always tell people I am differently-abled." The second focus group participants responded "The results show more barriers to PWPDs participation in active leisure participation, which shows that we are still suffering. We need to see more facilitators to active leisure participation for PWPDs in mainstream society. For that to happen, we need people from different organisations representing us in government so that we can push for changes that reflect more facilitators to our participation" (128).

### 3.7.2 Transferability

Bryman (2016) suggest that qualitative research involves in-depth study of individuals or small group with similar characteristics, therefore, the findings tend to be unique to the context and the participants involved (130). Therefore, transferability involves the extent to which the research findings can be transferred to other context or individuals with similar characteristics. Thus the researcher provides a detailed description of the research process and findings for others to determine the transferability (128)(130). To determine transferability the researcher used the following:

# 3.7.2.1 Purposive Sampling

Creswell and Poth (2018) and Bryman (2016) reported that purposive sampling involves sampling participants strategically in selecting the sample that is suited to best inform the study of the topic under study. Thirteen participants with physical and mobility disabilities were selected (128)(130). The researcher used purposeful sampling of participants that shared similar characteristics and held experiences of rich accounts of the phenomenon under study (128)(130).

#### 3.7.2.2 Thick description

Creswell and Poth (2018) and Bryman (2016) stated that in the thick description, the researcher provides the in-depth, detailed report of the process of research, context and its findings (128)(130).

The researcher used a detailed thick description of the experiences of the participants. This was achieved by using open-ended questions in the focus groups and in-depth interviews to stimulate participants' discussion of their lived experiences of active leisure participation. Thick description is also reflected in the context of this thesis, data collection, analysis, interpretation and conclusion which enables other readers to determine the transferability of the results (128) (130). Furthermore, the researcher created an audit trail by describing and documenting the research process from permissions to conduct research, from the university's ethics and the organisations, data collection, recording and analysing the transcripts, data analysis and interpretation of the findings and conclusion (128)(130).

#### 3.8 Ethical Consideration

The protocol for this study was approved by the Graduates Study Committee of the Faculty of Health Sciences at the University of the Witwatersrand. Ethical clearance to conduct the study was granted by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (see Appendix G). Thereafter, permission to conduct the study was sought from the five organisations involved in the study (see Appendix C). Once these organisations approved the study, the researcher began the recruitment of potential participants as described above. All potential participants were given the approved information sheet outlining the nature and purpose of the research, the expectations of them as participants and that their identity would be protected by participating in the focus group (Appendix D). The participants were also briefed on the difficulty of ensuring the confidentiality in focus groups, however they were assured of confidentiality of their responses, which would be anonymised (see Appendix D) (135).

The participants were also asked for consent to audiotape the focus group and in-depth interviews discussions. Once approved they were required to sign a consent form for participating in the focus groups (see Appendix E) and audio taping the interview (see Appendix F). The derived data and audio transcripts will be placed in locked storage for six years as recommended by the Health Professionals Council of South Africa (HPCSA).

### 3.9 Conclusion

The purpose of this chapter was to describe the methodology used in addressing the presented research questions. Qualitative research inquiry was selected to allow the researcher, a window into the lives of the participants. This enabled the researcher to understand how the phenomenon under study affected their lives and how they constructed meanings from their interaction with this phenomenon, based on their understandings. The sampling process was discussed and how purposive sampling was relevant, as the participants who volunteered held a rich account of their experiences of the phenomenon under study. The data collection process used was also discussed, as well as the decision to use both focus groups and in-depth interviews to collect the data.

Chapter 4 will describe the findings of this study.

### **CHAPTER 4**

# **RESULTS**

### 4.1 Introduction

This chapter presents the results of the data gathered from the participants through focus groups and in-depth interviews. The research aimed to answer the following two questions: What factors do PWPDs believe challenge or facilitate their choice of active leisure activities? What are their perceptions and experiences of their active leisure participation in Gauteng? Thus, this chapter reports on the findings of participants' perception of the factors they perceive to influence their participation in active leisure through the emerging themes, categories, subcategories, and codes from the data collected from.

# 4.2 Participants

Thirteen participants contributed to this study in three focus groups and six in-depth interviews. The demographic profile of the participants is reported in Table 4.1.

Table 4.1: Demographic Characteristics of Participants

Participants (n=13	Age	Gender	Marital Status	Disability	Employment	Mobility
Participant 1	56	Male	Separated	Spinal cord injury Paraplegia	Yes	Manual Wheelchair
Participant 2	55	Female	Single	Spinal cord injury Quadriplegia	Disability Grant	Motorised wheelchair
Participant 3	23	Female	Single	Cerebral Palsy Quadriplegia	Disability grant Voluntary work	Motorised wheelchair
Participant 4	60	Female	Single	Cerebral Palsy Quadriplegia	Yes	Manual Wheelchair
Participant 5	49	Male	Single	Spinal cord injury Paraplegia	Yes	Manual Wheelchair
Participant 6	50	Male	Divorced	Spinal cord injury Paraplegia	Yes	Motorised wheelchair
Participant 7	28	Male	Single	Spinal cord Injury	Internship Disability grant	Motorised wheelchair

				Quadriplegia		
Participant 8	60	Male	Divorced	Spinal cord Injury Quadriplegia	Pension Voluntary work	Motorised wheelchair
Participant 9	27	Female	Single	Genetic disorder Quadriplegia	Voluntary Disability grant	Motorised wheelchair
Participant 10	60	Male	Single	Cerebral Palsy Quadriplegia	Voluntary work Disability grant	Motorised wheelchair
Participant 11	59	Female	Single	Cerebral Palsy Quadriplegia	Voluntary work Disability grant	Motorised wheelchair
Participant 12	42	Female	Widowed	Right below knee amputation	Disability grant	Prosthetic right leg uses crutches
Participant 13	42	Male	Single	Right below knee amputation	Disability grant	Prosthetic right leg Uses crutches

As can be seen from Table 4.1, the gender distribution was almost equal with seven (n=7) males and six (n=6) females. The disability of participant consisted of eight (n=8) participants had acquired disabilities for more than one year previously and five (n=5) had disabilities from birth. Most participants (n=11) were wheelchair-bound, while two (n=2) had a prosthetic leg and used crutches to aid walking. Only five (n=5) participants had full-time employment, while the remaining eight received a disability grant or pension. Four did voluntary work and one was busy with an internship. All participants engaged in active leisure activities before the research.

As active leisure usually has a cost involved, participants were asked to estimate the monthly expenditure of their available financial resources. Figure 4.1 shows on average, the funds available for active leisure entertainment by the participants was 8.2% and that of going on holiday 0.3%.

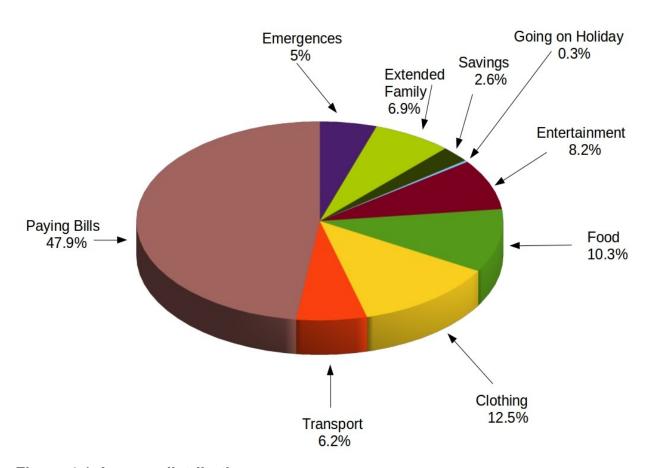


Figure 4.1: Income distribution:

Even though the average monthly spending income was 8.2% as shown in Figure 4.1, above only 46% of participants indicated having entertainment income, as shown in Figure 4.2 and 7.7% indicated having holiday income, as shown in Figure 4.3 below.

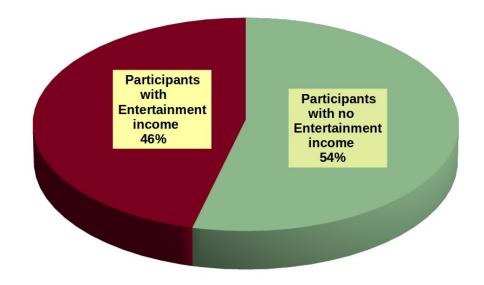


Figure 4.2: Percentage of participants with entertainment income

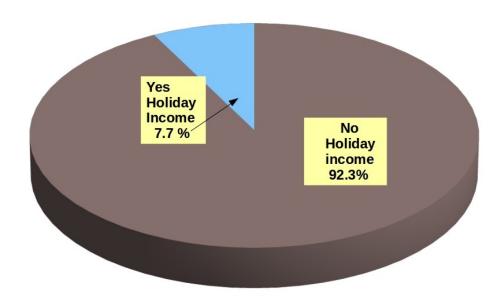


Figure 4.3: Percentage of participants with holiday income

# 4.3 Emerging Themes

All themes that emerged from the qualitative data from the focus groups and in-depth interviews emphasised that active leisure was a challenge all the participants faced. This was despite South Africa having a legislative framework that aimed to support the social inclusion of PWPDs in all aspects of their life, including active leisure.

The three themes that emerged were:

- Theme 1: Meaning of leisure.
- Theme 2: I am a thinking feeling human being, not a disability.
- Theme 3: Participation in active leisure.

These themes, categories, subcategories and their codes are listed in Tables 4.2, 4.3 and 4.4.

Table 4.2: Theme 1, Categories, sub-categories, and codes

Theme	Categories	Subcategories	Codes		
Meaning of	Getting out and	Leaving the house	A change of scenery		
Leisure	about		Being out in the open		
			Going to the mall		
			Options when		
			constrained by funds		
			Going abroad		
		Meeting others	Good company		
			<ul> <li>Friendships with</li> </ul>		
			non-disabled		
			<ul> <li>Inclusion in activities such as tours</li> </ul>		
	Family time	Active leisure with	Family's consideration of		
		family members	activity		
			<ul> <li>Family consideration of</li> </ul>		
			choice of place		
	Active leisure is	Few resources	<ul> <li>Cost burden of active</li> </ul>		
	pointless and not		leisure for PWDs		
	a priority		Limited finance - Grants		
			Limited inclusive access to		
			active leisure		

• Enjoymer access	t spoilt by lack of
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#### 4.3.1 Theme 1: MEANING OF LEISURE

Many of the participants spoke passionately about what active leisure meant to them. Just like everyone else, they perceived active leisure as providing a very meaningful human experience. However, what constituted meaningful active leisure experience and its' personal human value varied between the participants; they differed in their understanding and meaning attached to active leisure and activities associated with it. Table 4.2 records the perceived differences in the meaning and value of activities participants associated with active leisure; these are elaborated upon in the description below. As can be seen from Table 4.2 the first category of this theme was getting out and about.

#### 4.3.1.1 Getting Out and About

Participants stated that for them active leisure was important as it meant they could be out and about from their usual places, they did not want to be stuck in one place. They shared that it was important for them to be out with other people and socialise. This made them feel they belonged with other people and were part of their community. All participants spoke of doing different types of active leisure activities, which they liked to do, were perceived to be meaningful and brought joy and satisfaction to them (5)(25). As can be seen from Table 4.2, two sub-categories emerged from this category: leaving the house and meeting with others.

#### 4.3.1.1.1 Leaving the house

Participants reported several factors that confined them to their homes, which resulted in them being socially excluded; these factors included inaccessible physical environments and hostile social environments. Participants viewed leaving the house as expressing one's freedom and being part of the greater main-stream society. The participants narrated that being able to leave the house expressed their freedom of movement which they experienced as exhilarating, liberating and empowering. The meaning and nature of these active leisure activities were expressed as a **change of scenery** from the mundane everyday environment to which they were confined because of their disability. The following participants expressed their views of the purpose and

meaning of active leisure in the quotes below, which reflect the codes listed in Table 4.2.

**Participant 2:** "For relaxing, it's about being in a different environment, to recharge your batteries."

Participant 3 stated: "It also takes you out of your own environment and gives you a fresh set of mind. You've got other things to think about, than the normal things at home that are just boring. When you go out you tend to remember gees, there is an outside world out there, it's not just these four walls that I am in. That's why it's nice to be reminded that [there are other exciting things to do out there] even like for me I think this is a luxury to even walk to SPAR, like literary in my wheelchair driving to Spar. I actually love it because it's such a [liberating feeling] although it's the same path we take every day but it's something different. You see the birds walking on the ground. You see the general things. It's not about what I am going to do when I get there. It's the journey you take getting there in the first place, that's the most exciting."

Other participants expressed that active leisure involved going away from the stresses of life in general and from confined spaces to being out in the open, where one can feel the greatness of open spaces. This rejuvenated their spirits and allowed them to destress, as expressed by the following participant:

Participant 6: "[...], I am going to answer in a very personal way for me travelling [as an active leisure activity] is like medicine, travelling is like this injection of fresh air into my system, into my emotions, into my mind. Once I am in a very tight space with a lot of problems, a lot of things to deal with, having worked hard, having done a lot of things, all I need for me to unwind is if I can go on a long road trip. I become refreshed and truly, truly I become refreshed. I don't need a drug to refresh myself, I don't need alcohol, [...]. Just travelling being in an open space, it's so rejuvenating the fresh air, the scenery. [...], the views that I admire. Those are the things that I am yearning for. It's what I wanted to see."

Others felt going to the mall and socialising with friends and good company while out and about was active leisure and very meaningful to them, as expressed by this

## participant:

Participant 11: [...], "I go for a meal with a friend. My friend and I go out for instance and spend a most enjoyable morning. When she invited me and some of the staff, we went to Cresta [mall]. We had a meal and then we went shopping. We broke up in groups and yeah we just enjoy being together, laughing and you know all that kind of thing. Quality time is my lifeline. One or two friends and you know just chit-chat, you know seriously, not joking, you know, meet together socially."

Another participant indicated that to him active leisure was being adventurous and going abroad was a very meaningful active leisure activity. This he felt allowed him greater freedom than what he was able to access here in South Africa, as a person living with a disability. He perceived South African environments for partaking active leisure to be stressful and disability unfriendly. This participant shared the following:

Participant 7: "Going abroad and seeing things. Locally its difficult because South Africa isn't the most wheelchair friendly place and for these big chairs to climb upstairs [it's difficult], if you are in a push chair then it's fine [but] you have got to have someone the whole time that's pushing you and helping you. Whereas with these [motorised wheelchairs] we are mobile, we can do what we want. We have been to the Walter Sisulu gardens, we have been to Monte Casino, we do everything, but we don't, how can I say "sleep out" we don't. Like you were mentioning earlier that you going to stay out-and-about in Gauteng. It's kinda difficult because it's not a lot of places that are wheelchair friendly."

Most participants felt that facilities that cater for active leisure activities were not inclusive due to accessibility challenges or did not communicate their accessibility effectively, which lead PWPDs to embark on frustrating journeys laden with anxiety. Consistently PWPDs were socially excluded from outside leisure activities and restricted to their homes. The apparent enjoyment of active leisure by those participants who were able to partake was noted in their facial and verbal expressions, compared to those who were not able to participate, due to the severity of impairments and compounded by barriers to access. One participant expressed:

Participant 7: "To get out and about, to see things, you don't want to be stuck in one place the whole time. I mean most of the guys here are stuck here [at home] the whole time because they don't want to get to a place, then you can't get out and you can't get into the place or you gonna struggle. They don't wanna go through that. Whereas me and participant 8 we [are] still able, we go about, we do our thing, so it's easier for us."

#### 4.3.1.1.2 Meeting others

Meeting other people was viewed as being more important than getting out and about for most participants. They felt that active leisure was more important to them when they were spending time with good company and doing things such as going to eat out or shopping in the mall. To them, it was very important to socialise with friends and doing active leisure activities together. For example, one participant when describing her active leisure outing with her friends, stressed that:

**Participant 9:** "[...], we went with good company, we were good combinations of company. We all enjoyed it."

One participant reported that most of his friends were non-disabled and it was important for him to be able to participate in active leisure that his group of friends decided to do rather than the decision on where to go being based on his disability. He reported that:

Participant 5: "Whenever I go somewhere, people assume I am going to come with friends that are disabled. Most of my friends are people with no disabilities. That's why if they say "No, we want to go fishing", I want to go with them to a place that's for fishing. I don't say "No I can't go" because I am in a wheelchair, stuff like that."

Another participant stated that to her active leisure was more enjoyable when PWPDs were **included in activities such as tours**, and where they are treated like anyone else on a tour. She found active leisure experiences to be meaningful and enjoyable when environments were inclusive of everybody who needed to use and participate in them. For example, the participant stated:

Participant 4: "The only thing is that for me and [I] am talking from my own opinion is that when I travel [for active leisure], I don't necessarily want to travel with people with disabilities, I want to be included in any tours. Like when I've been to Mauritius, I didn't go out in a tour with [people with] disabilities. I just went on a tour that I booked."

### 4.3.1.2 Family Time

As can be seen from Table 4.2 'family time' was the second category in the theme Meaning of leisure. Spending time with family was perceived to be an important and special active leisure activity as this allowed participants to have meaningful social interactions with family members in a relaxed manner compared to when they were alone at home. One sub-category emerged from this category, as seen in Table 4.2.

#### 4.3.1.2.1 Active leisure with family members

Some participants stressed the importance of doing active leisure with family members. They had a positive experience when the family's consideration of the activity took their disability into account. They reported this strengthened family bonds and created lasting treasured memories. However, participants shared that when the family's activities were not accommodating of their disability, it became a source of exclusion and they missed out. For example, participant 3 stated:

"Yes, I have been to Durban. [...] It was nice, [at first and] I enjoyed it very much then after a while you start feeling a bit off because as [participant 2] said, you have to make cancellations as to where they [family] were planning to go, [as] they [aren't] equipped [accommodate for] you to go there. We were there for [...] seven days. The first and second day, I loved the first day because the first day we were travelling there by bus, so I loved just looking out of the window. Second day we went to Shaka Marine World, I loved it there. But the next four days, I was stuck in the house because the others could go to the beach, but I couldn't go there. All I did was sit and watch TV and maybe go to the pool, but of course, my brother in law and my brother had to get me out of the chair."

Withdrawing from family planned holidays or outings was highlighted as being emotionally difficult, especially when the family's consideration of an active leisure

activity did not take the disability into account. These negative experiences created negative feelings, particularly when participants declined participation and when the family had to cancel or restrict themselves on their planned activities because the member with a disability could not participate. This was evident, as stated by the following participant:

Participant 2: "Our families they say to us, let's go on holiday. You know, [it will be a problem] you say no. You're hurting them, at the same time they don't understand that when you are on [family] holiday, lets say we've gone through all of this. They've got to restrict themselves, as well, in [doing] the things that they [want to] do. They want to go horse riding, [but] you can't get onto a horse and now they've got to change activities that they are going to be involved in and you feel very bad. Even though they say "No! no! no! it's okay", but you don't feel okay about it."

Participants also reported they were subjected to exclusion in some outing activities when **family consideration of the choice** of venue did not take into consideration the accessibility needs of a family member with a physical disability. The emotional effects were apparent when the participant described the ordeal.

Participant 3: "That is the most degrading thing that can happen to you. You feel like such an 'invalid' seeing your family doing all the exciting things and all you do is just sit there. I don't know if you ever experienced this. But when you go to somebody's house and there is a party, the party is outside because there are stairs to the outside, you [are] stuck in inside looking at them through the window and they have to come to you every five minutes and say: "Do you want something to eat? Do you want something to drink"? You can't go down there yourself. It's horrible, knowing you actually feel like "what the hell am I doing here?" "Why am I not at home in my bubble, where I know everything is there for me and everybody who is there knows what I need?" You don't feel like an 'issue' when you are at home than when you are out some where."

#### 4.3.1.3 Active Leisure is Pointless not a Priority

This was the final category in the first theme. Some participants emphasised that active leisure was pointless and not a priority at this point because there were just so many pressing issues and life demands to consider before they could successfully participate in such activities. One sub-category emerged from this category, as seen in Table 4.2

#### 4.3.1.3.1 Few resources

Most participants reported that although they had the desire to participate in active leisure the **cost burden of active leisure for people with disabilities** prevented them. All participants felt they had to deal with extra expenses for their disability first, which able-bodied people do not need to do, as well as other living expenses before entertaining active leisure intentions. The participants had the following to say:

Participant 6 reported: [...] "Disability in itself is expensive. Firstly, there are certain things that I have to cater for [first for disability], that are a must that you don't buy, you don't need. Now, how are [PWPDs] going to be able to afford [active leisure] when they are at the lowest, lowest level of income [with extra expenses]. [...] When we are working in one firm together, occupying the same position, the same level of grading, we both get the same salary [...] R8000. Yours is R8000. Mine is no longer R8000. I need tyres for my wheelchair, I need a battery, batteries they die any time. A set of these batteries is about [R]3000, tyres you're talking R700. The caster in front, you talking R400. The cushion itself, for you to have a good cushion, you will spend well into R15000. You understand my point. Now [where] do you get that [money]."

Participant 8 agreed: "Definitely, because of the cost. Where do we put the cost? They got Rea Vaya, but Rea Vaya doesn't come here. They've got certain routes, so how must I get to that route? There is no taxi that can take my wheelchair you see. So, where do we put [the cost], so now we [are]stuck. Luckily, I have my own vehicle but these people are living off a grant of R1600. You must spend to go to Walter Sisulu [gardens] say R800, [this] is half of your grant. You can't afford it. That's why the people are sleeping, staying in bed. The life is like over, you see."

Participant 6 elaborated further to include poverty: "And remember poverty and disability are friends. You are more likely to find a person with a disability at poor levels [...] with a disability causing poverty to them, one way or the other they feed on each other. There is no ways about it. So, you do not have money, you can't afford [active] leisure that's the sad part. We [...] don't have that money, but for those that can be able to scrape around and get something for themselves, then the obstacle will be infrastructure, and transportation."

Participant 2 added the extra cost of a care giver: [...] "We are coming up to Christmas, I mean there is anxiety, I think in all of us. The family is going to come and say we are going to Knysna what's your ID number we need to make bookings. I say "no, I am okay guys, please go, it's okay" because otherwise they have to pay for a care-giver to go with me, that's another thing. You've got to pay for an extra person. If my flight is going to cost R5000, they must find another R5000 for this person who is going to look after me. Then, there is the hotel. The whole cost of that whole holiday is [...] for me alone, it's going to be R20 000, double by the [extra] person they have to take."

Some participants reported the only money they had was their disability grant which they received from the government every month. The **limited finance/disability grant** was not enough to service one's disability needs, purchase sustenance for the family for the month and on top of this enable participation in active leisure activities. Active leisure for many of the participants was perceived to be a luxury that had to be relinquished as the grant money was insufficient to accommodate associated costs.

Participant 13 reported: "I also have the wish to go to the game reserve, just like mama [Participant 12] but once I go to the game reserve or Johannesburg city or Johannesburg Zoo, all my grant money is going to finish for that. That's why am not able to go and see the animals. I'd love to go, but once my money is finished, what would I use for other things. [...], the work of this money is a lot, and things are expensive and for you to take it and spend it all on active leisure, what are you going to buy food with? Because even this money is not enough to buy food for the month."

Participant 12: "I can't afford to go to these places. To go to these places, you require money and you require a car and I can't afford that. [...] even when you want to buy a jersey for your child, you first have to buy small food items and then [if there is money left] you can be able to buy a jersey for your child. Next month is the same thing, you don't buy certain food items so that you can be able to buy clothes for your child. This money [disability grant] is not enough. [...] like you buy mealie meal, you buy rice, you buy soap, you buy sugar, and leave milk, we don't know what to do."

One participant reported that even when they wanted to supplement their grant, the opportunities for work were minimal and the effects of physical impairments prevented them from competing with able-bodied people. Therefore, they felt they were at the mercy of the disability grant they received to service all their living needs.

**Participant 13:** "Even when you want to work and do garden work, the legs are painful, we are not able to make extra money quick like abled people. We want to make extra money but it's difficult."

Some participants reported experiencing challenges due to **limited inclusive access to active leisure**. Those participants who were able to partake in active leisure with their friends, tended to frequent places they perceived to be aware of their needs and could accommodate them without interfering with the enjoyment of such activity.

Participant 7, "I know I have been everywhere, all the casinos in the area, I've got friends that live around here, we always meet at pubs and stuff, because we've been here a while. We know where we can go and where we can't."

Another issue that was highlighted included the amount of effort involved in getting ready to engage in active leisure, and then when reaching a facility being confronted with poor access. Participants felt overwhelming that they had to consistently explain their accommodation needs to participate in simple active leisure activities. According to the participants, when their accommodation needs are not known, this resulted in their **enjoyment spoilt by lack of access**, as stated by the following participant:

Participant 7: "Aggrrr, you know it's one of those things that happen so often. But it depends who you go out with. My friends they all know where to sit, where we going, what we gonna do. If I have to go out, say me and my girlfriend go out, she can't do all that stuff. So now I must explain to everybody and its difficult because it's not that you don't want to do it, it's just you've done it so many times that you, in your head, are expecting people should know this by now."

#### 4.3.1.4 Summary

In conclusion of theme 1, 'meaning of leisure' active leisure activities meant different things to different participants. The participants selected different kinds of active leisure activities which they found to be meaningful in their lives (Table 4.2). What was highlighted was that when circumstances were constraining, the participants sought to exit their stressful environments to experience something different and meaningful in Socialising with others appeared paramount (Table 4.2). Participants their lives. enjoyed socialising and sharing their active leisure activities with other people. It was also noted that when participants were struggling due to a lack of financial resources, active leisure was the least of their interests. Being aware of active leisure facilities was also important as this meant participants could frequent these facilities and enjoy such activities without disruption. Overall, all participants agreed that active leisure was important in their lives and that it was good to experience different things instead of being stuck in one place. Furthermore, to cope with a disability was reported to be costly, and required physical disability to be addressed first to maintain optimal function. As reported by participant 6, they are caught in a vicious cycle of disability and poverty, this left most participants unable to engage in active leisure, and stayed home.

Table 4.3: Theme 2, categories, sub-categories and codes

Theme	Categories	Subcategories	Codes
I am a thinking, feeling human being not a disability	I have needs that require consideration	I am not my disability	<ul><li>I want to belong</li><li>Mutual respect from public</li></ul>

		Participants can participate in what they choose	Capable of choosing my active leisure
		I can take control of my life like other people	<ul> <li>Can participate in what I chose</li> <li>Enjoy solving issues myself</li> </ul>
	My enjoyment and experience of active leisure is enhanced when my needs are considered	Positive emotions due to easy access to active leisure is important to me	<ul> <li>Happy and satisfied, when my participation is enabled</li> <li>Fulfils me as an individual</li> </ul>
	Reinforcement of my disability spoils my active leisure experience	Negative emotions due to inaccessibility	<ul> <li>Angry and rejected</li> <li>Frustrated</li> <li>Loss of motivation to participate</li> <li>Anxious that it will go wrong</li> </ul>
		Others not understanding their actions result in exclusion	<ul> <li>Feeling     abandoned and     a burden to     family</li> <li>Not part of a     human race</li> <li>Ignored and not     acknowledged</li> <li>Don't appreciate     unsolicited help</li> </ul>
		Lack of opportunity to engage	<ul> <li>Lack of accessible transport</li> <li>Lack of reliable information</li> </ul>
		Unrealistic expectations	<ul> <li>Needs are not anticipated</li> <li>Assistance is not up to expectations</li> <li>Public lack of understanding</li> </ul>
		Reflection on own disability	Previous lack of empathy for those with disabilities

#### 4.3.2 Theme 2: I AM A THINKING FEELING HUMAN BEING NOT A DISABILITY

In this second theme, the participants perceived that others considered them as a disability rather than a person, which they felt was a factor that deterred them from experiencing pleasure in active leisure activities. Conversely, the participants expressed they identified themselves as human beings first, possessing feelings of enjoyment and dissatisfaction, just like every other human being. Thus, they strongly rejected the disability identity with its implied incapacity and dependence imposed on them by society, but rather affirming the identity of belonging to the human race with different desires, feelings and capabilities. Three categories emerged from this theme as seen in Table 4.3.

## 4.3.2.1 I Have Needs that Require Consideration

All participants reported they have needs that require access to active leisure activities in social-cultural, and physical environments and transportation service. Their experiences indicated a systematic lack of access. They could not understand why their needs were not considered as PWPDs when they were just like other citizens with similar expectations. This made them feel marginalised, unimportant and victims of unabated stress. Three sub-categories emerged from this category as can be seen from Table 4.3.

#### 4.3.2.1.1 I am not my disability

All participants stressed they were human beings first and that they deserve respect and recognition, but particularly concerning active leisure, which contributes to their health and well-being. Judging from their shared experiences the participants described their disability as just one aspect of their identity, which they had to live with but was not the sole representation of who they were. They had many needs, desires, capabilities, and limitations just like others. They want to belong to their communities and society as human beings through being accommodated and being able to exercise their capabilities with everyone else. This would be the most satisfying feeling.

Participant 12: "I would want the [people with disabilities], whether they walk slowly, and they want to get into my bus or by taxi. I will wait until the person gets in and sits down nicely, because I can see that the person is not able to walk properly. I will wait and help, I will hold and help the person walk, help them sit

properly and love the person so that the disabled person can see that she is also the same as other people in the bus. There is no difference [but] they treat us like we are different."

Other participants felt there should be mutual respect from the public, instead of staring, ignoring, speaking and asking about them to someone else, rather the public should engage with a PWPD as a form of recognition and respect. One participant described how showing mutual respect could transpire.

**Participant 9:** "I would greet you. I would introduce myself, and kind of like talk to you, speak to you. Find out what's wrong, and if I can help you."

## 4.3.2.1.2 Participants can participate in what they chose

Self-Determination and personal choice about what active leisure to participate in came out as a strong enabling factor from the participants. They felt having an independent choice and engaging in an active leisure activity that they had personally chosen was part of being an independent human being, included in your community. It is a way of exercising one's independence as an individual. All participants described they were capable of choosing their active leisure activities in supportive environments.

**Participant 5:** "I don't just go to places that are accessible for me. I want to go anywhere." I want to go to a place that is going to be accessible [for active leisure]."

Participants desired to be independent in their active leisure participation as reported by participant 6:

"You either need somebody who is going to push you, assist you, and some of us we want to live our lives independently. Now, if I am going to go to a lodge or to a game reserve and when I am there, I have to keep on bringing somebody to come and assist me, that is quite discouraging."

## 4.3.2.1.3. I can take control of my life like other people

Some participants reported that they were aware of the continuous challenges in the physical infrastructure and social attitudes, and the need to be resilient and **enjoy** 

**problem-solving challenges on their own** to actively participate in a meaningful way. This assisted in developing self-protective mechanisms, which helped to be independent of others. Participant 6, reported:

"You know, I don't know whether it is me being me, because some of these challenges I think I already know them. Especially challenges of infrastructure, challenges of transportation being not disability friendly, challenges of people's attitudes. I already know that. So somehow I have developed a protective layer for myself. When I travel anywhere when [...] alone, I make sure my wheelchair is right behind me so that I don't ask anybody to assist me with my wheelchair. I don't beg anybody to assist me with anything. I [...] do that in order to avoid asking anybody, in order to avoid finding myself under anybody's favour, you understand. So, even the attitudes of the people I am going to meet on the road, I already deal with them in a way that, "I don't care". I don't even beg you, [so] what the hell should I care about you? I have already built that layer. But believe you me, there is always the permanent feature, infrastructure disturbances, transportation that is not disability friendly."

# 4.3.2.2 My Enjoyment and Experience of Active leisure is Enhanced when my Needs are Considered

The participants expressed that when their abilities are enabled and they can participate fully like everyone else without encountering barriers, the quality of their enjoyment and experience of active leisure is enhanced; they feel satisfied with the results of their participation. One sub-category emerged from this category, as can be seen in Table 4.3.

**4.3.2.2.1** Positive emotions due to easy access to active leisure is important to me Most participants felt happy and satisfied when their participation was enabled in inclusive environments, resulting in their chosen active leisure activities being accomplished and promoting positive emotional responses.

**Participant 7** stated: "We do all the garden stuff, the botanical gardens because its accessible. Those places are perfect, ash wheelchair friendly, they've got paths and you can get anywhere, like Walter Sisulu Gardens."

Others reported feeling **fulfilled as an individual** when they could participate when visiting game reserves, where their ability and not their disability was emphasised. Participant 6 had this to say:

"No, not at all, instead those are the views [in nature] that I admire, those are the things that I am yearning for. It's what I wanted to see. Even, sometimes when I see there is a big python [which I am frightened of] crossing the road, I stop and marvel at it, until it crosses over and disappears into the bushes. I go wow!! That's exactly what refreshes me."

#### 4.3.2.3 Reinforcement of my Disability Spoils my Active leisure Experience

The participants expressed that when they are denied access to participate in active leisure, it reinforced their disability and thus, interfered with their sense of belonging and engagement with others. They viewed denial as a blow to their existence as an occupied active human being and found this to be very frustrating. Five sub-categories emerged from this category, as seen in Table 4.3.

## 4.3.2.3.1 Negative emotions due to inaccessibility

All participants felt angry and rejected when inaccessibility limited their engagement and when told by others they could not do what they desired. They stressed they are human beings like everybody else in the community and resent when they are not able to access their desired active leisure activities. This was demonstrated in the following participants expressions.

Participant 9: "I hate it when people say no you can't. I will show them that I can do it. [...] Sometimes, it makes me feel like inadequate. I feel bad."

**Participant 13:** "The transport that you are using, but the complaints are too much and makes us angry."

All participants expressed frustration when access to active leisure activities was denied due to inaccessibility issues in the physical and social environments, which have long been identified as human rights problems against PWDs. One would have thought that these issues would have been addressed and the public more aware.

Participant 8 reported: "It's frustrating, it's frustrating, you know the bank, Ah! the shopping, parking, it's terrible, especially in raining weather. The old people [are] parking there. Now he [the driver] must stop on top there for me to offload and then I must drive [in my wheelchair] in the rain, by the time I get to the mall I am soaking wet and am disabled. Then you speak to the car guard, he says "it's a magogo, it's a magogo." Old people that's stopping [parking] there. So, you don't want to fight all your life, you just [leave] old people to use it."

Participant 7 concurred: "I mean there [are] so many [people with disabilities] around, how can you not know that, and that's the frustrating [part]."

Most participants expressed a **loss of motivation to participate** due to countless inaccessible humiliating attempts at active leisure. They felt that active leisure was supposed to be fun, enabling you to unwind with your friends, and if it was something that was not accessible and caused anxiety, it was something that must be given up. This was evident with the following participant's stated experience:

Participant 1 reported: "I have reached that stage where I don't want to travel [for active leisure] any-more because you book places, and in the first place you are uncomfortable the whole time while travelling there and [when] you get there, the place is not equipped for [people with disabilities]. There are steps to get into the building in the first place or the cottage you renting, you can't get into the bathroom. A big place like that should be equipped with showers for us [...] one for the whole complex because 99% of the people are going to be abled-people, just make [provision] for the one person, just think of that one person that's going to come."

#### 4.3.2.3.2 Their actions cause exclusion

Another issue highlighted by some participants was family members as well as people in social environments that were unaware of the impact of their behaviour and actions in excluding those with physical disabilities. For example, when the family selects active leisure activities and venues with no consideration of the disabled member's ability to engage, it left the disabled person feeling abandoned and a burden to the family, or

ignored and not acknowledged by members of the public/service providers, as narrated by the following participants:

**Participant 3** reported: "You feel like an issue or a burden [...]. Or sometimes before they even take you to that place, they have to check whether that place is suitable for you. You feel inhuman, you feel cheap. Do I really have to put my family through that? Uhh."

Participant 4: "You must also understand that people don't believe that people with disabilities have got power in terms of finance. So, they just ignore you basically. And it's been [like that] for a long time. [...], the nicest thing for me if I go out with students for example. I never get the bill, because am in a wheelchair (she laughs)."

Other participants perceived that the public, as well as authorities, do not acknowledge the challenges which PWPDs experience, including the lack of appropriate concrete political will to address these issues, which left them feeling they were **not part of the human race**; they feel side-lined. This was expressed by the following participants:

**Participant 1:** "Sometimes, this is a bit extreme now, sometimes you feel [like] you no longer part of the human race."

Participants 2 and 3 concurred with this.

**Participant 12:** "We complain because they don't treat us nicely. Every person treats us like we are not the same as them. Like if you are disabled they think you have no brain. When you are disabled, they think that you don't feel [emotional] pain."

One participant reported members of the public assist him without asking if he needed help. He found this to be offensive and demeaning. He believed that this assistance was not coming as a genuine offer of help, but rather from feelings of pity for him. He reinforced that PWPDs don't **appreciate unsolicited help**.

Participant 5: "[...] a lot of people's attitudes is still 'oh shame syndrome', "oh shame I must help this poor guy," or "shame, he is struggling, let me go and do

this for him." Ah ah, just ask me, if I say no, just accept it. It's not your duty to be around and help me. If I need help, I will ask. If you offer it and if I say no then [accept it]."

#### 4.3.2.3.3 Lack of opportunity to engage

All participants perceived the lack of opportunities to engage in active leisure as one of the main challenges they face. In instances where they could engage, the experience was marred by incomplete frustrating access, or a denied access. This was attributed to the lack of accessible transport service accessible to them. For example:

Participant 1: "We had a guy [...] he came from America. He had his accident in America. He stayed here for about four months while they made his house wheelchair friendly. He said there [in America], there is a bus that come around once a week, a bus to pick up people with disabilities in the States. They stop there and they wait for you and it's free of charge. The town council pays for the transport and they take you to the shopping centre and they pick you up at 12 o'clock again. We [have] got nothing like that [here] because buses here are, I am not talking about Rea Vaya, I am talking about normal buses are not accessible and taxis are not."

Participants stated that information is key to enabling active leisure participation, especially with regards to accessibility. A lack of reliable information caused PWPDs to waste time and embark on a journey for active leisure, only to be denied access due to inadequate communication of the accessibility of the place. There is no reliable communication about what is accessible, how accessible it is to people with a variety of disabilities. This is what participants 5 and 4 reported:

**Participant 5:** "I don't know any buses and stuff that I could get on. That's why also a lot of people don't travel [for active leisure], they don't know what is accessible for them."

**Participant 4:** " [...] if you look at the local B & B's, they don't, [they] should advertise in the magazines for travelling. They should be saying "we are people orientated and you can use our B&B [for] what-ever it is." Not just say 'we are wheelchair friendly'. Wheelchair friendly doesn't mean anything."

#### 4.3.2.3.4 Unrealistic expectations

Some participants had unrealistic expectations of the public, such as full public awareness of their special needs and the public's willingness to assist them when required. The participants felt their needs are not anticipated timeously by the public and this created a frustrating situation for them. This was evident in the participants' shared experiences. For example:

Participant 6: "You go to a hotel. You are alone. I just roll my wheelchair inside there. Let's start with the entrance of the gate. You come by the gate, that's okay they open the gate for you. You [go] inside, you park there in the disability parking bay. The security [guard] will stand there and look at you, not thinking that you may be needing some assistance to get out of the car or anything else. They will just look at you until you honk and say come and assist me. Now to me, that mentality is forever keeping me [like] a beggar because now I have to beg for assistance. For in essence, you are put there for a purpose, which one of the purposes is for you to assist me. If I have to hoot and beg you to come and assist me then why were you hired in the first place?"

In situations where the public offered the needed assistance, the assistance was not up to expectations, as narrated by the following participant:

Participant 3: "Yes, we don't have muscle strength to lift it [foot] up and you know what I hate for me? I hate it for me, when it happens to me at Northgate mall. You know how uncomfortable it is to ask a stranger to pick up my foot. Someone who has no idea what am talking about. They look at you and they are like "pick up your foot" You literary have to say "please lift my foot and put it on the foot rest" and only then does it click, but you have to explain to them word for word. That is the most annoying thing for me because that's the one thing I hate. I do not like explaining to somebody. If I tell you something once, listen to me. If you make me say something twice, you make me feel as if I've got a speech difficulty. Really you do, because I think I didn't pronounce this properly or something."

#### 4.3.2.3.5 Reflection on own disability

Two participants shared their reflective experiences of life before and after their disability. One participant felt ashamed of her **previous lack of empathy for those with disabilities** and wondered whether she treated PWDs in the same way as how the general public were treating her and other PWDs. The following was what the participant reported:

Participant 2: "The other thing is I am sure participant 1 will attest to this. Some of us [...] it's been an interesting thing [about disability] because we became disabled when we were much older. We were not born disabled therefore, we lived a lot of our lives [without disability]. I was 45 years old when I became disabled. So I know what ability is [ in it's] absolute form. Now it becomes a little depressing [to my self] I think when I think about how I treated people with disability. Did I do these things that I am talking about and I am expecting out of people? You know, because now you are looking at it from a different perspective. I am the one in a chair now. So it is hard. Very, very hard."

## 4.3.2.4 Summary

In this second theme, participants reject the disabled identity imposed on them by society and claimed back their human identity and its attributes. They asserted they were capable human beings who could take control of their lives, including their active leisure participation. However, they reported that lack of opportunities to engage created negative emotions, which left them susceptible to withdraw. What was also of interest was the 'offer for help' from members of the public and how different participants viewed this. From one participant the perception was that help came from pitiful feelings therefore it was rejected. The perspective of another participant was the offer was welcomed, but members of the public had to anticipate the need. A third perspective was the offer of help was not up to satisfaction. There was also the reflection on disability by two of the participants who acquired a disability in their adult years that brought out feelings of remorse for not showing empathy towards PWDs before they acquire their disability. Further participants felt grateful for the few facilitators to active leisure participation as these enabled their access and inclusion to opportunities.

Table 4.4: Theme 3, categories, sub-categories and codes

Themes	Categories	Subcategories	Codes
Participation in active leisure	Barriers to active leisure participation	Barriers to active leisure access: Policies and legislation	<ul> <li>Inadequate implementation of legislation policies</li> <li>Policies not-enforced</li> </ul>
		Barriers to active leisure access: Social environment	<ul> <li>Stigma – public perception of disability</li> <li>Lack of understanding</li> <li>Miss representation of accessibility</li> </ul>
		Barriers to active leisure access: Physical environment	<ul> <li>Poor accessibility for disabled in facilities for active leisure</li> <li>Poor accessibility for disabled in holiday accommodation</li> </ul>
		Barriers to active leisure access: Transport	Inaccessible planes, public transport
	Facilitator to active leisure participation	If you want to support participation consult with us	We are the experts
		Disability friendly facilities	<ul> <li>Knowing what leisure facilities are accessible</li> <li>Accessible transport</li> </ul>

#### 4.3.3 Theme 3: PARTICIPATION IN ACTIVE LEISURE

The categories, subcategories, and codes of this third theme are listed in Table 4.4.

From Table 4.4, it can be seen that 'participation in active leisure' was the final theme to emerge from the collected data. All the participants spoke of the importance of participating in active leisure, and the need to be socially included in the wider community and its opportunities, even though for some it was not a priority. Active leisure participation was being involved in the community, just like everyone else. Participants felt that being included in the wider community allowed them to develop their abilities, to be happy and to develop relationships with others.

## 4.3.3.1 Barriers to Active Leisure Participation

Barriers to participation in the physical, social-cultural, political environments and transportation service were the main obstacles participants identified that prevented them from engaging in their different active leisure activities in their local community and the wider Gauteng and South African society. Discussion of these barriers was often accompanied by strong emotions reflected in their body language and the nature of their communication. Participants stated that it was difficult to participate in active leisure in their communities and main-stream society due to several barriers that limited access. These barriers were the main cause of participants feeling socially excluded from their communities. The participants identified both barriers and facilitators to active leisure participation and these are presented as the categories, subcategories, and codes as recorded in Table 4.4. Four sub-categories emerged from this category as seen in Table 4.4.

## 4.3.3.1.1 Barriers to active leisure access: Policies and Legislation

Most participants felt the inadequate implementation of the legislation and policies was discriminatory. They perceived the lack of proper procedures for application and monitoring of building regulations created barriers that excluded them from the physical, social-cultural environments where active leisure activities take place.

Participant 6 noted: [...] "Remember the National Development Plan is the bible of the government, the bible of the country. Now the gospel that the government should be preaching is the gospel that is inside their bible. Now they need to be supporting us in order to spread the message that says 'accept people with disabilities.' You as a business [...] in South Africa, [...] there is a Building Regulation Act, it was last [amended], I think in 1978 by the apartheid government itself. When they revised that Act it was also put in that all building erected after 1978 should be disability friendly. Now inspectors should do that, engineers who are responsible for the infrastructure, all those people, should be familiar with that. You don't pass a plan of a building that is not accessible. Now do they care? [...], That is why I said the problem lies with the managers, the Head of [different government] Departments, [...]. Those are [...] the gate keepers, who are making sure that [people with disabilities] do not [have access]. That's my problem! Because if as a manager, I've got people working under [me

in] my department and they know that they must pass plans that are disability friendly and they pass plans without considering the element of disability then who should be blamed? It is me who is the Head of Department. I must carry that blame, I must see to it that I get punished for that blame."

Other participants talked of being inconvenienced when service providers of places of active leisure applied Inconsistent policies, or when there are policies put in place but are not en-enforced. Some participants had to personally confront the managers of the facilities that offered active leisure activities complaining of non-enforcement of the adopted policy. One participant reported that a typical example is that of disabled parking. Even though the regulation is written down and openly displayed, nothing was being done about cases of violations.

Participant 8: "They don't care about [the approved disability parking] disc, they stop without the disc. They don't care because no one is clamping their wheels, no one is issuing the fine. [...] if you put a law up, you must see, that law is reinforced. It's you [who] must reinforce the law. It doesn't help you to put out signs there, that say "you will be fined" and they will do this and no one is doing nothing."

## 4.3.3.1.2 Barriers to active leisure access: Social Environments

All the participants reported having experienced exclusion from social environments in which active leisure took place due to their disability. The participants perceived that for one to function optimally, you need social contacts in your community. These contacts need to be accessible and accepting of you as a person living with a disability. Most of the time the participants in this study perceived they experienced factors, which they felt excluded them from the social environment such as stigma and poor public perceptions of their disability. This stigmatisation they described being presented in a number of different ways, such as being ignored by the public, speaking to the person next to them about them, and being viewed as of less value. This was narrated by the following participants:

**Participant 9:** "Sometimes it's like the people around us, they don't really think about people in wheelchairs [and] what they go through and [their] difficulties. It's

hard for abled [people] to understand that because where I lived in Durban like people, abled body people, will be inconsiderate. They used to look at you, but they won't speak to you or anything, they treat you totally different. They ignore you; they won't speak to a disabled person directly, they would rather speak to a person who is helping a disabled person. Like me and my parents were always with me, so people they won't talk to me but speak about me to my mother, they never speak to me. [...] Sometimes, it's not like a good feeling, you not sure whether people are ignoring you on purpose. They treat you like you are deaf, dumb or mute whatever. That's really not a good feeling."

The effects of stigmatisation caused participant 12 to feel alienated and withdraw from all active leisure and social contacts:

Participant 12: "You feel like you don't want to go into the streets and walk because you will meet them [the public]. [...] I like to stay at home. When I go out, I go to get my grant and I come back and just stay at my house and lock myself in."

Similarly, other participants narrated that they experienced stigmatisation in places where they engage in their active leisure activities, such as in shops, restaurants and during an outing with their friends. For example, the participants reported that waiters would ignore them, but ask the able-bodied person next to them what they would like to eat, as explained by the following participant:

**Participant 5** reported: "When I say attitudes, I mean I go to Wimpy with my friends. The waiter will come and give everybody a menu. He will come and take everybody's orders and then ask my friend "what would he like" [pointing to me]. Then I say, hey! I am here, I can speak. I can tell you what I like. Just give me a menu."

Other participants stated they experienced stigmatisation in the form of being pitied by able-bodied people saying 'ag shame' and being assumed to be a 'charity case' where members of the public gave them unsolicited donations of money. Participants 2 and 3 supported this:

"If I am standing at a corner and am waiting for the traffic light to turn green so I can cross, I am not asking you to come and put R10 in my lap, because I am not begging. Not everybody in a wheelchair is carrying a cup waiting for money. I don't know about you? The number of times that people come and just throw money in my lap. They don't even ask! They just come. I am waiting there for the bus and the next thing somebody comes and they just put R10 here. I am like "What is going on?" It also happened to me at the beach, I was sitting at the beach and looking at the sea and this group of young tourists dropped R10 in my lap. I say, "Hey please I am here enjoying the beach just like you." [participant 2].

"Even a R100. I am sure when they give us money, they must think we are some sort of charity case and we go to Northgate [mall] to [beg for] money. That's what they think." [participant3].

When out and about participating in active leisure in the mall, participant 2 also highlighted the refusal of charity organisation in receiving donations from a person with a disability. In her eyes, she felt this was an odd scenario and perpetuates that PWDs are charitable receivers and should not be giving; rather a PWD should keep their money and use it when they need to. This was felt to be demeaning and stigmatising that a PWD should not contribute to the good of others.

Participant 2: "Exactly, You know, the other thing that happens in holiday times, you find that in the malls they've got the Salvation Army, you know, and you want to go an put something in the tin. Even those people from the Salvation Army [are] almost like [they are saying] "No! no! no! We're collecting this for you." You want to go and put something in the tin and help. It's like you should not give, you must just receive. You are a recipient (Group laughs). Yours is to just receive not to give. You know it's an odd thing."

All participants expressed dismay at the general public's lack of understanding through their displayed impatient behaviour towards those with disabilities. The participants felt marginalised by these actions and it affected every facet of their existence, especially their active leisure. The participants expressed a view that in general, able-bodied people deny the possibility that disability could happen to them. From that view, they

have difficulty accepting disability and lack interest in and awareness of the challenges the PWPDs may face. For example, some of the participants expressed extreme frustration at having to attempt to engage in active leisure under such socially excluding and marginalising conditions. This is expressed below:

Participant 3 reported: "You know how often when I go to pay for something and there may be somebody behind me. You know, they can get so agitated when they see me struggling to take out my money that they actually say "No! No! No! Don't worry, we will pay for it". I say, but I've got my own money, you just have to be patient and I will pay for it."

**Participant 1:** concurred: "You see also, the thing is that, [...] when they see you in a wheelchair, they think you brain dead as well. I broke my back, I didn't break my brain. They think you [are] stupid."

**Participant 5** added: "Because people think it can't happen to them. Anybody, with the crime and the violence and the muggings in South Africa at the moment, anybody can become a disabled person. It's not going to change you as a person. You going to be the same person, [...] it's just going to make life so much more difficult for you."

Misrepresentation of accessibility by service providers was another issue participants in this study perceived as compromising their engagement in active leisure. Participants felt that when service providers advertise their services and service environments as 'disability friendly,' this was often misleading and did not necessarily mean accessibility for all PWDs. In many cases, participants have found that when service providers use the term 'disabled friendly,' they basically mean a ramp was provided, but in some instances these ramps were not constructed to the satisfaction and safety of the PWDs using them. The following participants described examples:

Participant 4: "You see the misconception [of] people who cater for travellers [as an active leisure] with disabilities is that, they think that if they create a ramp that's all that's necessary. So, when you book a facility, for example, they will say the facility is accessible. "Yes, of course, we've got a ramp" and it stops there. It doesn't go further to the bathroom facilities and what the bedrooms are like and

can I get into the dining room and put my feet underneath the table to be able to eat."

Participant 7 concurred [...] "When people think of 'accessibility' they mean a ramp and the room [that] is spacious. They don't think about, out-and-around the place like, someone in a pushchair can't go and ride on grass, it's impossible, not impossible, [but] it's difficult unless you [have] got your helper with you, but you don't wanna [want to] take a helper with you, you just want to spend maybe time with your friends, maybe family."

#### 4.3.3.1.3 Barriers to access active leisure: Physical Environments

The participants also shared issues relating to the physical environment that they perceived prevented them from participating in their desired active leisure. The participants expressed the view that they were marginalised and that the physical environment mostly allows others to partake in their desired active leisure activities but denies PWPDs the opportunity to engage due to its inaccessibility. Among the issues they described were the lack of appropriate equipment. One participant narrated that he loves going to the beach, but is unable to access it because having on proper wheelchair to manoeuvre on the sand.

Participant 5 stated: "We love all these [active leisure] like everybody else, so we would like to go on holidays. I can't go there at the beach with my wheelchair because of the sand. But there [are] wheelchairs that 'participant 4' told me about with broad wheels and stuff. Once again to hire a wheelchair like that cost an arm and a leg [it's expensive]."

Poor accessibility for the disabled in facilities of active leisure was another issue participants described as being debilitating and frustrating. They perceived that an active leisure environment should allow all people to relax and unwind but the participants in this study found most active leisure environments to be a source of stress as they were unaccommodating. The following areas were discussed by the participants:

Poor accommodation of independent access and exploration.

Participant 7: "Like you mentioned there, at Gold Reef City, we struggle to drive there [in our wheelchairs] there because they've got those little bricks. So when you [are] driving [motorised wheelchair] you hop and your feet fall off, your stuff falls off your chair, so it's difficult. People don't think about stuff like that."

Participant 6 added: "You look at the hiking trails that are there, you look at the entertainment areas that are there in these facilities for a person in a wheelchair it's a problem. They are not accessible, easily accessible. You need somebody who is going to push you and assist you. Some of us we want to live our lives independently. Now if I am going to go to a lodge or to a game reserve [...] I have to keep bringing somebody to come and assist me. That is quite discouraging. Now that is the infrastructure problem before we even further go to the mindset [and] the social aspect of it."

Staff clueless on how to service customers with disabilities.

Participant 3: [...], "You going out with somebody who is normal, and you are in a wheelchair, and you [are] paying for something or whatever, that person at the till asks the person behind [me] "What's wrong with them? Why are [you] in a wheelchair?" ASK me, don't ask the person behind me. I've got a brain not a glass bottle on my head. Do not say "ohh shame" to me, that is not nice. [...] They get to a point where they even ask the person who is with you, "How do they want their eggs made". I hear you, you heard me talking to this person but you still ask that person next to me, "How do I want my things made", but you heard me talking to him before you asked that question."

Restaurant chairs wrong height and spacing.

**Participant 4:** "The other thing is if you go into restaurants, you can't always get your wheelchair under the table, because the legs are wrong. You can't fit your wheelchair in."

Restaurant toilets inaccessible.

Participant 2: "Just normal restaurants as well, to get into the toilets is also difficult."

**Participant 1:** "We don't go there [to the toilet], we travel with coca-cola bottles so that we can urinate into that and somebody must carry it to the toilet."

Disability unfriendly ATM (Automatic Teller Machines)
 Some active leisure required participants to withdraw money from the ATM.
 Some participants perceived the disability unfriendly ATMs were a limitation to their active leisure as well as to their safety.

**Participant 8:** "And another thing is to draw money, it's terrible, you must always ask the security guard. The ATM is on top there, I can't do it, it's too high. You must give your pin number to the security guard, he pushes it in and he is giving you money. Otherwise, you can never draw money by yourself, it's too high or you must go inside the bank."

### Or paying with your card,

Participant 3: "Lack of understanding for the wheelchair life. [...its] the same thing when you pay for something with your card. They don't make the punching thing long enough so you can punch in your numbers. Then you [have] got to give someone else your pin and [ask them] like "please can you punch in my pin," you know. It's degrading. You can see, even by the way, when they help you, they go 'ag shame."

#### No disabled check out point.

Many active leisure opportunities require some kind of check-in or check-out point to pay and to gain access. Participants perceived they were seldom wheelchair friendly

Participant 1: "You are expected to squeeze your way through this little [narrow] passage [by the till] and then as she said, if you are paying with a card, that little thing [speed point-machine] the cord is too short, you can't see the numbers, and then you have to give your numbers [pin] to a total stranger. South Africa is not built for disability. That's just the long and short [story] of it. We've got the best legislation, but its not being implemented."

Most participants talked about having an interest in taking a local holiday somewhere. However, **poor accessibility for disabled in holiday accommodation that** they **had previously** encountered affected their wanting to continue participation. One participant reported that it's easier to be accommodated in Dubai than Johannesburg:

Participant 7: "When I was that side [Dubai], like the hotel that I stayed in, they had rooms that accommodate just wheelchair people. So the bathrooms have been modified, the rooms [were] bigger, the hallway [was] more spacious, the elevator to that room was more spacious. You've got all your needs and stuff met, which makes it so much easier. Now [here in Johannesburg] you must get there, you can't get to the bed, you can't get to the toilet or you can't get into the shower. Now what do you do, you booked this whole holiday and now you stuck. So that's why [...] we don't travel around that much in Johannesburg. But even if you go onto Google, and do a Google search of wheelchair accessible places in Johannesburg, if you get three you would be lucky."

Participants reported that nearly all accommodation facilities have one room designated for PWDs which were mostly booked, and poses a challenge when you want to participate in your active leisure.

**Participant 8:** [...], "For instance now you want to go [...] for holiday in Durban okay, they've got one room, one room that's wheelchair [accessible]. There are so many people in wheelchairs, so [when] you wanna book, its booked for three years in advance."

Participant 6 concurred: [...] "When you look at our lodges and our number one hotels all around Gauteng, it's only Birchwood Hotel that has more than 10 rooms that can accommodate people with different disabilities. Only Birchwood. There is no [other] hotel that has got more than three rooms that are disability friendly. Now you ask yourself are we considered? No, we are not. So is that going to encourage them [PWPDs] to embark on [active] leisure travelling when even the facilities that they should be travelling to are not accommodating. That's the infrastructure problem."

In addition, no provision is made to accommodate a carer in holiday accommodation when travelling for active leisure. You, as a PWPD, are expected to sleep in the same bed with your carer, or the carer [must] sleep on the floor on a mat.

Participant 4: "But the thing that really annoys me is that, I've got a carer and they don't have enough beds to be able to put [another bed] into the room for the carer. And then they say, "Oh she can sleep on a mattress." But that's discriminatory or else they say "She can share your bed". I always make a joke and say "She's not my lover she is my carer."

Those participants that enjoyed sleeping over felt that most facilities have only one accessible room available and this room tends to be mostly used by smokers and the facilities had no other alternatives for non-smokers.

Participant 4: [...], "You know they normally [have] got what they call the paraplegic room [...] but its always being used by people who are smokers and I've got chest hassles and there's no [other] designated room for non-smokers. So I normally use an ordinary room, which I then move the furniture around to suit my purposes."

#### 4.3.3.1.4 Barriers to access active leisure: Transport

The participants reported that transportation was one of the major barriers, they experienced daily and excluded them from participating in many activities including active leisure activities in their communities. The participants expressed that without transportation they were unable to participate in active leisure activities. Among the issues they described were **inaccessible airplanes and public transport**. When it comes to air travel, some participants felt the airlines were inconsistent with their rule application. One such rule is the insistence by some airlines of a passenger with a disability travelling with a carer, when that passenger is capable of travelling alone. This scenario participants perceived added extra travel expenses to the journey, resulting in high costs, thus excluding them from air travel due to finances. One participant however had a different experience, as he reported being allowed to travel alone without a carer. The following is what the participants shared:

Participant 9: [...] "If I want to fly out to Jo'burg. They tell me I can't [fly alone], someone has to [fly] with me. Apparently, that's like a new rule for the airlines. So, that means that, although I am able to fly alone, and I don't really need help because all they will basically [be] doing is sitting not helping you. So I would be okay for the whole two hours, but they told me if I want to fly someone has to come with me. So that means that, I must pay a ticket for me and for the person who comes. My mother was supposed to come with me and [then] she has to go back to Durban [on the] same day because she has to be at work on Monday. So most of the time it's hard for you to get someone to be with you and to come with you. So you have to think about that person, then you have to worry about yourself as well. So it is too costly to fly."

**Participant 6** stated of other airline in support: "Well for now they do allow for you to travel alone. I do, I don't have a problem. [...] There is now this [people with disabilities'] assistance' they call it PAU (passenger assistance unit), that is in each and every airport. When you get to the airport, there will be people assisting you out of the plane until the exit of the airport. When you come in until you enter into the plane. There is that assistance for people with disabilities."

All participants that utilised the airlines for transportation complained of experiencing extreme anxiety, as well as being handled by untrained personnel who assist with boarding and disembarking from the aircraft.

Participant 2: "They are not trained, [they treat us] like we are about to break. You know, [yet they have] got the tools like your skyjack, vehicles and all of that to take you to the actual aircraft. You get in this car in your wheelchair, at that point you are still in your wheelchair, so you are in your comfort zone. As soon as you leave that comfort zone, you get onto that sleeper chair [aisle chair] its now a problem. You've got to be talking constantly, "Pick me up this way." They are not trained on how to pick you up [...]. "Hold me here, don't touch this side," and then you've got levels of people who are, how do I put it, who are nicer than others and there are those who are just very impatient. They just want to get a job done quickly."

Participants also perceived that the co-ordination of travelling information was poor between the travel agent and the airline concerned. This scenario caused unnecessary anxiety, frustrations and lack of enjoyment for the journey.

Participant 2: "Even [when] we make the bookings, I don't know with other people, you make a booking through a travel agent for instance, you got to fill up what is called a medical form. You tell them what your disability is and you expect that this information is going to the airport. So that when you get to the airport they are prepared for you, with things like a sleeper chair [aisle chair]. [When] you get there at the check-in desk, you find they have not ordered a sleeper chair [aisle chair]. When there is no sleeper chair [aisle chair], then the anxiety begins."

There are no disability-friendly check-in points at airports. The participants perceived that the lack of disability check-in point dis-empowers them and they feel inferior due to the way the check-in process is staged.

Participant 2: "Airports, and I'm sure you guys [have] had the same thing with the airports. When you go in and check-in at the airport, the desk is that high, I'm down here. This woman is trying to deal with me, and I can't see her and she can't see me. She wants [me] to give her my ID [Identity document] so she can give me a ticket [boarding pass]. There is no disability desk for checking in, which is low enough [so] I can see her and [she] can take my ID with dignity. I just don't feel like I'm [being] treated with dignity. I am now forced to give my ID, if am travelling alone to a stranger, "can you please give the lady over there, up there." She does not take the time to come out from behind her desk, which she could do by the way, and come and stand next to me, deal with everything that I've got and go back to behind the desk and come back to me with my ticket [boarding pass]. She is going to talk to me from there. It doesn't make sense."

Participants acknowledged that accessible transport was the key to active leisure participation, and they all perceived **inaccessible public transport** to exclude them from such participation. Participants perceived that there was no safe, effective and efficient provision of public transport for PWPDs. There was no thought given to what

happens to PWPDs in the communities that need to use public transport for whatever reason, including active leisure. Participants perceived that the authorities do not care about PWPDs because if they did, they would make public transport accessible for them.

**Participant 1:** "Public transport, they don't make provision for [people with disabilities]. It's so easy for anybody else to catch a taxi or a bus, but for us, it's a job. You must beg that guy [taxi/bus driver], you must pay him extra just to get you in an out of the vehicle."

Other participants reported that minibus taxis were not accommodating of people in wheelchairs, and sometimes they don't stop for a passenger in wheelchair. Taxi drivers, as well as passengers, were perceived as being impatient, rude, unaccommodating and uncaring. Another participant thought it was not only the taxis drivers who were to blame for not stopping for PWDs.

Participant 12: "One day I was going to the hall, I was walking with crutches. I stopped the taxi, he didn't stop he just passed me. Ohh I just turned, went back home and stayed [...]. We don't have money to hire a private car to take us where we are going and take us back home. When they see us, they think that we are wasting their time. They don't care about us. We are the same as other people catching taxis because we also have nothing [like them]."

Participant 6: "You know the sad part is that right now we [...] blame taxis [not accommodating PWPDs] it on the taxis and the taxi drivers, but in essence, it is not the taxis. It is the society that we live in. Sometimes you find that the driver would really, really want to stop but just as soon as they [passengers] see the person [taxi driver] stopping the taxi in front of the wheelchair you will find people [passengers] starting to complain inside the [taxi] and saying "But we are late, eee but we are late." Then what do you expect the driver to do? Obviously, these people are already inside the [taxi]. Once you stop, waste your time loading that [PWPD], to them you are like wasting their time and remember you are there to service them [passengers already in the taxi], they are your bosses you

understand. So sometimes, the drivers are caught in a very, very dangerous situation."

#### 4.3.3.2 Summary

As noted in this section on barriers to active leisure, even though participants had the desire to participate in active leisure, and acknowledged that this was important for their health and wellness, the barriers described above created challenges for them to participate in their active leisure. These barriers limited opportunities, thus excluded the participants from active participation in their active leisure in their communities.

## 4.3.3.3 Facilitators to Active Leisure Participation

The participants identified several key facilitators to participation in active leisure.

These were described as being consulted on accessibility issues by service providers, disability-friendly facilities and accessible transport.

#### 4.3.3.3.1 If you want to support participation consult with us

Most participants felt that 'we are the experts.' If service providers of active leisure in the social-cultural environments consulted and discussed accessibility issues with PWPDs, this would alleviate most of the inconvenience and exclusion they experience. They also acknowledged that while it's difficult to be cognisant of all PWPDs needs, if consulted this could help start to address the physical and attitudinal barriers in these environments. This is what participant 5 and 8 reported:

**Participant 5:** "A lot of times when they do say the place is accessible [it is not], they don't consult the people [PWPDs] that are in the position of accessibility."

Participant 8: "Like what I say, you can't expect a normal person to know all your needs and stuff, but they can always invite us for a day and then we can show them what is a problem, because now they, think that, "there it's paved, but why are these people complaining?" I can show you, if I drive [electric wheelchair] booboobooboo like that it's like you [are] driving on a bad gravel road. It's the same for me, these are my legs [indicate the wheelchair]. If it's paved, I don't want to go back there. It's the same with speed bumps in the road, you know you must go over and stop and some times you feel like you want to

fall backward. They must invite us or when they build from now on, [...] I can't see any building that's built from now that is wheelchair accessible 100%, 100%, there [are] no excuses. I mean there [are] mothers who have push-chairs, you know baby chairs, your trolleys, all that kind of stuff."

## 4.3.3.2 Disability-friendly facilities

All participants felt that disability-friendly facilities were a life-line; they respected your humanity and your right to social participation and inclusion. Knowing what leisure facilities were accessible was crucial as it eliminated potential stress and anxiety that PWPDs may experience when encountering barriers and to foster enjoyable active leisure experiences. Knowing what leisure facilities were accessible made participants feel that they belonged, were accepted; this enabled PWPDs to plan active leisure activities with confidence, knowing they could participate without hindrance. It also enabled them to have a positive active leisure experience and enjoyment with their friends. In reply to what made knowing the accessible places an enjoyable experience, this is what one participant stated:

Participant 7: [...] "I think it's because the people [service providers] know us already because we mainly drive on the road with our chairs. [...]. So everyone gets to know you and the community around you also. So when they see us coming, they start moving the tables already, they move the chairs. [...] They know what your needs are. Whereas, if I now go to Pretoria to go drink, let's just say at 'Rocco Mamas' when I get there, they're gonna stand and look at you [and] ask you for a table for how many. They don't think to just take the table out of the way. Most people put you in the aisle. This chair is big, you can see it, if I am sitting in the aisle [it is] covering the whole aisle. So its small stuff that [like that] people don't think about [what] changes your whole perception of going out and doing things because you don't wanna struggle. You don't wanna now explain to the people and... I am not saying its common sense for everybody, but it's just a little bit of sense."

When a facility was accommodating, it was an enjoyable experience, you do not struggle.

Participant 6: "Birchwood Hotel, even when you get into the gate, [...] the place is level, the whole yard is level you don't struggle. The hotel room space is so big. The toilets and bathrooms are so big inside, you don't have a problem. If you look at the eight pillars of the universal accessibility document, the eight pillars, you will find them all encompassed there and at the end of the day [this is] what you do for [people with disabilities]. You don't only do [this] for [people with disabilities] remember that. [...]. Its inclusive access, even the old people they come there, their knees are tired you don't want to start [struggling] they also want to enjoy the fruits of their labour. You understand my point. Sometimes a person is young, or recently injured, he had accident at work but he just wants to go and unwind. When you have a space like that, [that] is accessible, even that person with a cast on his leg is able to utilise the place fully. You understand. So at the moment it's only Birchwood that I know of, and all the others have only one or two rooms".

All participants perceived that accessible transport was key to inclusive participation inactive leisure. A limited number of accessible transportation vehicles facilitated inclusive participation in active leisure. These are vehicles and buses that belong to NPOs at which some participants work or reside that had been modified to carry PWPDs specifically.

Participant 1: "For us here to go to the botanical gardens, or to Walter Sisulu whatever, we [are] fortunate that we've got two buses that are equipped with sky jacks so that the wheelchairs can go in. But for people that haven't got that privilege, that facility, they're going to struggle, because just getting in and out of a car, it's difficult."

**Participant 4:** [...], "I am very fortunate that I have the use of a vehicle which is the organisation's that both of us work for."

The second mode of accessible and convenient transport that some participants talked of, was having their own vehicle. This eliminated a lot of worries about transportation and was easily accessible when needed.

Participant 5: "I am fortunate when I go places I have my own motor vehicle so I drive myself."

Participant 6: [...] "I end up using my own car, because in my car, I find my car as my palace. In my car, you will find things that I think I might need in-order to make me comfortable. Even when I am pressed [and] I [...] go to the loo in my car I am comfortable. I already even have methods of how to relieve myself without having to go and trouble anybody."

The third mode of transportation as a facilitator to active leisure was identified as a motorised wheelchair:

**Participant 11:** "The wheelchair of course is actually the first, the motorised wheel chair and [...], also the fact that Cresta is quite accessible, yeah."

Participant 1, thought Uber was accessible and was very happy with their service:

"Also one thing for Uber. Uber comes and they take us. They don't complain nothing. They put you in the vehicle and they put the wheelchair in the boot, obviously that is push chairs like mine, electric wheelchairs are just about impossible."

Participants argued as to whether the Rea Vaya was accessible for PWPDs.

Participant 7 stated, "QASA did a thing with Rea Vaya, so I know that it is accessible... [...] I think I have [rode on] it twice in the last two years, that I actually used public transport and that was the Gautrain and Rea Vaya."

Participant 6 argued: "When you look at the Rea Vaya buses as a means of accessible transport that is government sponsored, government approved and the fact that the government itself are saying that this bus system is going to improve [the] travelling needs for people with disabilities. It does not meet our needs. You find the bus can only accommodate two people with disabilities."

# 4.3.3.3.4 **Summary**

Facilitators enabled active leisure participation of PWPDs to accomplish their goals and feel good about themselves. Participants placed value on being consulted on accessible usage of a facility, having prior knowledge of disability-friendly facilities and accessible transport.

#### 4.4 Conclusion

The chapter presented the findings that emerged from the data collected from the participants through focus groups and in-depth interviews. The collected data sought to address the three objectives of the study, namely to explore and determine the views of PWPDs' understanding of active leisure participation, to explore the perceptions of PWPDs about their experiences of their active leisure participation, and to identify factors that challenge or facilitate participation of active leisure of PWPDs. The first theme 'Meaning of leisure' (Table 4.2) addressed Objective one, the second theme, 'I am a thinking feeling human being' (Table 4.3) addressed Objective two; the third theme 'Participation in active leisure' (Table 4.4), in which participants identified both barriers and facilitators addressed Objective three. The participants also perceived being treated as sub-human because of the multiple levels of disability they experienced when accessing these environments, suggesting that no one cared about their right to access and well-being. Yet, they are just like anybody else, they have thinking capacity, feelings and the desire to be active in the process of developing one's self through active leisure.

In the following chapter, the underlying factors that emerged from the themes are analysed and presented.

# **CHAPTER 5**

# **DISCUSSION OF STUDY FINDINGS**

## **5.1 Introduction**

This study aimed to determine the extent to which PWPDs in Gauteng, South Africa, are participating in active leisure in their community and society, and to understand from their experiences if engagement in such activities is a challenge under enabling South African legislation. This chapter will discuss the study participants and the qualitative data obtained from the focus groups and in-depth interviews, which yielded three major themes: 1) "Meaning of leisure" - participants' perceptions of the meaning of active leisure; 2) "I am a thinking, feeling human being not a disability" - participants' perceived identity. 3) "Participation in active leisure" - participants' perceptions and views of barriers and facilitators to their active leisure participation; Finally, the limitation of the study will be discussed.

# 5.2 The study participants

# 5.2.1 Number of study participants

Thirteen participants with physical disabilities took part in the study, and although this number is small, it is typical of a qualitative study (134). Patton (2015) argued that detailed data gathered from a small number of participants can have significant value, particularly where a rich detail is provided by participants who have personal experience of the topic at hand (134). The researcher had initially planned to include only participants that worked, some difficulties were experienced in locating people with physical disabilities that had open labour market employment and so the sample was extended to include participants who were engaged in productive unremunerated work.

According to Mitra (2008), there has been a decrease in the employment rate of PWDs in South Africa over the period 1996 to 2006. This has been attributed to a growth in the disability grants for PWDs (143). This was similar to the findings reported by Mizunoya and Mitra (2012), where employment of PWDs was found to be decreasing in nine of the 15 developing countries (144). Although active leisure is influenced by the availability of finance (145), it is a basic need of all people (4), so considering it across the financial spectrum had clinical merit.

# **5.2.2 Nature of Disability**

All participants in this study had a physical disability that impaired mobility. As can be seen from Table 4.1, the nature of disability varied in type and severity, which enabled discussion of active leisure from different perspectives. There were six participants with spinal cord injuries, three paraplegics (complete injury), three quadriplegics (incomplete injury), four participants had a cerebral palsy with quadriplegia, one participant had congenital disorder with quadriplegia and lastly, two participants has acquired right knee amputation (Table 4.1).

#### 5.2.3 Assistive Devices

Eight participants used powered wheelchairs, three used manual wheelchairs and two used lower limb prostheses, (as can be seen in Table 4.1). The participants who used electric wheelchairs reported finding it easier to navigate independently through the terrain during their active leisure at the Botanical Gardens, Johannesburg Zoo and their communities with their electric wheelchairs. The participants who pushed manual wheel chairs found it difficult to navigate through these environments and often required the service of an assistance to push the manual chair. Similar findings are reported in a previous study, where the use of a powered wheelchair was reported to enhance activity and participation in leisure and recreation activities (146). Participants in these study reported having greater freedom and independence in activity engagement (146). Powered wheelchairs were also found to enhance happiness and improve participants self-esteem in mobility (146)(147), as also noted in this current study.

One of the problems reported with a motorised wheelchair by participants in this study was it was too big and could not be collapsed and put in a boot of normal motor vehicle. Thus, they required specialised transport with equipment to load a motorised chair into the vehicle. Other problems that were reported by the participants using wheelchairs in this study were difficulties in negotiating around poorly designed ramps and kerbs on the roads; this finding was reported in a previous British study Frank, Neophytou, Frank and De Souza (2010) (148).

The participants in this study who used lower limb prosthesis complained of stump pain in cold weather; one complained of loss of balance when using lower limb prosthesis and required the additional use of crutches while the other complained of pain and slow walking. Both participants experienced participation restriction in active leisure due to terrain, walking to catch public transport and climbing up bus steps. In an Irish study, Gallagher, O'Donovan, Doyle and Desmond (2011) reported that 54.1% of participants with lower limb amputations and using a prosthesis experienced participation restriction in leisure and cultural activities and community participation. Active leisure and cultural activities amongst others were the most areas where participation was restricted. The authors indicated this may be attributed to environmental barriers that a person with lower limb prosthesis was likely to experience (149).

# 5.2.4 Summary

Thirteen participants with physical disabilities participated in the study. The sample was appropriate for this study and only a sample with active leisure experiences was selected which ensured rich data of such experiences was acquired. Focus groups and in-depth interviews were used with participants who had lived experiences of active leisure, and thick data was acquired. The sample was also a diverse group of people with physical conditions, almost equally represented across the gender line which added to the depth of experiences. Patton (2015) suggested that a small number of participants could yield information rich in detailed, in-depth understanding of a phenomenon under study (134).

## 5.3 Discussion of the Qualitative Data

In addressing Objective 1, this discussion aligns with theme 1, in Table 4.3, in which the participants identified the value of active leisure to them.

The participants with physical disabilities in this study stated variety of perceptions of what active leisure was and meant to them, however they held a common view that active leisure involved leaving the house and 'being out and about.' Where they differed, was the type of active leisure activities they engaged in whilst 'out and about.' Most participants reported participating in various active leisure activities which they perceived were important for them to get away from confinement of their homes, debilitating or stressful spaces at work, to go and experience something different and 'recharge their energies.' More importantly, the participants in this study perceived there was enjoyment and renewal in 'being out and about,' experiencing rejuvenation, and this was seen to be valuable to them. According to Hanson (2008), the variation in

the leisure activities was based on an individual's attitude and perception towards his/her chosen activity (5). Similarly, Sellar and Stanley (2010) stated that leisure can be performed and experienced anywhere, at any time, so long as the participant interprets the activity as leisure (67).

According to Kielhofner (2008), a number of factors influence the choice of an occupation, such as active leisure, as demonstrated by the participants in this study. These active leisure choices were based on the participants' perceived own competence to carry out the activity the participant having an interest in that particular activity, because it was perceived to be valuable, enjoyable and satisfying to him/her. Kielhofner further elaborated that these personal choices have a much greater impact on a participant's life (8), in that it has an effect on a participant's health and well-being (9).

These findings in this study are also in line with literature's view, which suggests leisure as a 'time,' as an 'activity,' and as an 'experience' (67)(68). Leisure as a 'time' was noted with 69% of the participants use of their discretionary time to participate in their active leisure. Although 31% had discretionary time at their disposal, they could not utilise it for active leisure due to lack of environmental accessibility, declining health and lack of resources, such as finance and accessible public transport. Leisure as an 'activity' was noted in the various meaningful activities that participants chose to participate in while they were 'out and about.' Leisure as an 'experience' was noted with 39% of the participants' perceiving experiencing enjoyment, freedom of choice and control in their active leisure only through participating with their active leisure in a context and facilities they knew to be accessible and accommodating of their needs. Overall, with the exception of known context and facilities, all participants generally experienced dissatisfaction, lack of control of choice and demotivated with their active leisure experiences.

The finding of getting away from confinement, and debilitating and stressful spaces is consistent with previous research of Iwasaki and Mannell (2000) (71), and Hutchinson, Loy, Kleiber, and Dattilo (2003) (72). The participants in this study reported that when they found themselves in challenging, stressful and constraining environments they got away from the situation by utilising their personal choice of active leisure activities in

search of enjoyable encounters, something new and refreshing. This is in line with Iwasaki and Mannell's view of 'Leisure palliative coping,' which is described as temporary escaping from stressful environments to rediscover yourself and refocus. Similar findings were identified by Hutchinson, Loy, Kleiber and Dattilo (2003), as participants in this study reported escaping stressful confining environments in search of enjoyable and meaningful pursuits for coping (72).

#### 5.3.1 Competence, accessibility and affordability of active leisure

Furthermore, this study has highlighted other factors that influenced the participants' choice of active leisure, which were based on what participants were able to do as PWPDs, what was accessible to them and what they could financially afford. While in some ways this was not different to able-bodied people (150), the participants' physical limitations, accessibility of the environments in which they needed to partake their active leisure activities, the cost of active leisure plus the extra costs that living with a disability incurred were important perceptions that influenced their choices.

# 5.3.2 Social interaction during active leisure

Participants in this study placed high value on social interactions during their active leisure with family and friends, and both able-bodied and PWDs. In the process of getting away and being 'out and about,' the participants sought the company of friends and family to share their active leisure experiences. Most participants in this study expressed a strong need to meet people (friends and family) and socialise with them while engaging in their active leisure. These participants only perceived their active leisure to be meaningful if others were involved in sharing the experiences with them. This was in keeping with the view of Iwasaki and Mannell (2000), who reported that as a leisure coping belief, when people experience stress or challenges in their lives they seek friendships for support, and to share their gratifying experiences of active leisure (71). This finding also supports that of Aitchson (2009), of PWDs valuing social encounters and interactions during their leisure participation (21).

Furthermore, Sears (1988) described human beings as having a strong biological desire to belong to a group and interact with other people through socialisation. In this way, one does not isolated or feel alone without support of other people (151). Additionally, this need to belong, as demonstrated by PWPDs in this study, was important in the

understanding and developing of self-concept and their future goals (8)(77)(147). The pull to spend active leisure time with friends socialising was based on participants' perceptions that they share similar interests, goals and values with good friends and they feel socially connected and satisfied interacting with them during their active leisure (151).

Socialising and bonding with family members while engaging in active leisure away from home environment was another factor that participants felt was meaningful and important. It was evident in this study that some participants enjoyed family time while engaging in active leisure. This finding is in line with Condie (2016), who described similar sentiments about participants enjoying socialising and feeling socially connected with friends and family during their leisure time (152). However, participants in this study, also expressed that spending this active leisure time, socialising and being out and about with family was perceived to be a source of pain, anxiety provoking and stressful. Participants felt that instead of socialising and enjoying active leisure together as a family, their time was spent searching and solving issues of accessibility to the leisure activity to accommodate the disabled participants in the planed family active leisure. The lack of inclusion in the family active leisure activities due to inaccessibility caused one participant to withdraw from the activity to avoid being a burden to the family. The family had to participate without her, and by family members enjoying their holiday undisrupted without disabling issues, she vicariously enjoyed this through them by the mere fact that the family had a good time. Feeling a burden to their family, and society, was also reported by other participants. They felt abandoned by family when they were not able to join with other family active leisure activities due to access issues. This left them being spectators, while their family was engaging in fun active leisure activities without them.

Agate, Zabriskie, Agate and Poff (2009) examined satisfaction with family leisure participation and with family life, and found that satisfaction with family active leisure experiences is determined by the whole family participating in the activity together and is a predictor for family life satisfaction (153). This suggests that because some participants in this study were not able to participate in certain family active leisure activities due to lack of inclusive access, the burden of care and costs, this broke the purpose of the family togetherness and socialisation through active leisure, and

rendered the family active leisure unsatisfying and having no meaning. Even though the Agate, Zabriskie, Agate and Poff (2009) study was conducted with able-bodied family members, the findings are relevant to this study (153). Moreover, the participants in this study consistently highlighted that for active leisure to be meaningful and enjoyable for them, it was important to have unhindered access to physical, social-cultural and transportation environments with their families. This is supported by Eichhorn and Buhalis (2011), who stated that barriers to access remains a major obstacle to PWDs' to inclusion and participation (104), as well as their connection to their broader community interacting and belonging with others, which was not the case for some participants in this study.

# 5.3.3 Inclusive versus segregated tours

Two participants reported they did not want to participate in segregated tours or activities organised only for PWDs, they enjoyed being part of the broader community with able-bodied people. These participants were only satisfied with their active leisure if it was perceived not to be segregated, but inclusive of their abilities. However, the opportunities for inclusive active leisure were reported to be minimal in Gauteng.

According to other authors Pegg and Stumbo (2008), inclusive access enables all participants, abled and disabled, to have unhindered access to the physical, social-cultural environment. Thus, by enabling access everyone experienced the enjoyment of the active leisure activities, and felt they were supported and could make independent choices (154). Miller and Katz (2009) suggested that PWPDs want to feel valued, respected not stigmatised and to have a variety of opportunities to access active leisure activities and tours. In their opinion, social inclusion is a collective responsibility and requires enabling social inclusion policies, and change of attitudes and practices from the general public and service providers (75). The participants' views in this study were also echoed by the UNCRPD, which calls for the enabling and inclusive environments for PWPDs through inclusive social policies and programmes. The UNCRPD forbids discrimination based on disability, encourages respect of the dignity of PWPDs, their individual autonomy, ability to make free choices and their full participation in society. The UNCRPD further calls out for reasonable accommodation of PWPDs in all active leisure activities, as well as the universal design of products and the environment,

using universal principles, so programmes and services can be utilised by everyone without the need for special design or adaptation (39).

# 5.3.4 Unsolicited help from public

One participant reported he did not like accepting unsolicited help from the public as he perceived this offer for help to come from pitiful, 'oh shame' feelings for him. The same participant reported that he enjoyed hanging around and participating in active leisure with his able-bodied friends and wanted to participate in what-ever these friends desired to engage in. Wendell (1996) suggested that society defines disability, and it carries stigmatisation and stereotyping as well as expectations of what qualifies as typical and atypical body performance. This participant, by rejecting unsolicited offers of help, was psychologically avoiding the stigma and stereotyping, associated with his physical disability, as having a negatively perceived body. Participant perceived by not being able to do certain active leisure activities, implies the need of help and charity (51). Similarly, by socialising mostly with able-bodied friends and performing what they do without accommodation was proving the participant could perform like his friends. This was also in line with the view of Gill's (1997) disability identity integration of 'coming home.' In this integration, as can be noted in the participants' views of only wanting to do activities with his able-bodied friends, Gill suggested that PWPDs could reject other PWDs to avoid group stereotypes associated with disability. Moreover, by accepting segregated activities, they perceive it as accepting segregation imposed on them by society and its reluctance to provide equal access for everyone, therefore, they do not see value in associating with other PWPDs (89). Both Gill and Wendell suggest that PWPDs would work harder than non-disabled people to prove they are capable, attributing this to their poor body image and lack of acceptance of their disability (51) (89). Gill suggested that in this way, PWPDs are exhausting themselves in trying to match up to the society's normal standards, which appears to be the case for the participant who wanted to prove his capability. Others may give up completely accepting invisibility, which was the case for two participants who reported they used to partake in active leisure but no more, as it was too uncomfortable due to numerous barriers, therefore they gave it up. The other participant reported that she did not feel supported, she felt shunned and talked about by her community, therefore she gave up active interactions at all levels except for collecting her grant money, going back home

and locking herself in (89). This was also the view of Kielhofner (2008), who stated that when PWPDs experience constant failure in accessing active leisure activities, they lack confidence in their personal causation, therefore when one senses a lack of personal capacity to complete the active leisure activity, he/she would avoid it (8).

# 5.3.5 Expecting help from public

In contrast to not accepting help from strangers, one participant reported expecting to be assisted by the public during his active leisure activities. If this assistance was not forthcoming or not to his satisfaction, he perceived this as an orchestration to marginalise him. Shakespeare (1996) suggested that PWPDs have been conditioned to view themselves as incapable, weak, charitable, and requiring professional assistance. It can be suggested that based on this view of Shakespeare, the participant in this study had projected the negative experience of disability back to the able-bodied members of society. He sought assistance from those who were able-bodied and capable of assisting him, since these internalised feelings of being incapable were being orchestrated by them (79). Kielhofner (2008) further suggests that this participant had an awareness of his poor personal causation and poor control through own self efficacy, however he channelled his motivation to complete the task by seeking the assistance of able-bodied individuals. Kielhofner further suggested that poor personal causation may affect the integration of occupational identity and loss of ones, self-esteem (8).

# 5.3.6 Active leisure is not a priority

Four participants reported that active leisure to them was a desire but not a priority. The stresses of living with a disability, coupled with few resources, made it impossible to think about participating in active leisure activities. With reference to Figure 4.1 on participants' income distribution, 8.2% was the average entertainment income. This was indicated by 46% of the participants who were able to save money for active leisure entertainment, as shown in Figure 4.2. Only one participant (7.7%) indicated was able to save money for a holiday. The other participants (54%) in the study were not able to save money for active leisure activities as most of their available income was used for paying bills and buying sustenance. Others reported that they could barely survive on the grant money. Three participants reported failing health as a barrier to active leisure participation. The ICF stresses that impairment and personal factors can cause limitations in the body and the body structure level, causing a PWPDs' activity limitation,

partial to complete lack of activity performance and participation restrictions, as a difficulty in performing active leisure. The participation restriction was worsened when coupled with experiences of lack of social support, which was the case in this study. This lack of ability to participate caused the participants in this study to experience stress, some to withdraw from participation and be socially excluded (39). This was also the view of Smith (1987) and Darcy and Daruwalla (1997), who reported that the intrinsic factors, such as psychological, physical capacity, caregiver dependency and lack of knowledge and access to this knowledge, can be a barrier to active leisure participation (2)(150).

## 5.3.7 Few resources to enable active leisure

Lack of resources was reported to be a barrier to active leisure by participants in this study. Firstly, this was mostly attributed to participants' personal factors, such as poor economic status, as suggested by the ICF. This disadvantage was exacerbated by their disability, activity limitations and participation restrictions in their community to be able to generate an income sufficient to cover active leisure. Secondly, the financial resources available were not enough to cover active leisure expenses; all participants in this study complained of high costs involved in participating in active leisure. As can be noted in Figure 4.1, the funds available for active leisure and holiday were low compared to other expenses. For example, one participant wished to go to the beach but could not afford the specialised wheelchair to ride on sand.

Mitra (2006) suggested that disability may impose an economic burden on PWPDs by restricting their capacity to earn an income and sufficient income to support the needs of their disability. Thus, a person with a physical disability may not be able to capitalise on his/her strengths to access resources for active leisure (66). This situation was compounded by a lack of tangible support at community and societal level. Sen (2005) argued that a PWD having the same income as a non-disabled person can only manage to do less in capitalising on opportunities than a non-disabled, therefore a PWD cannot be judged to have the same financial opportunities as a non-disabled person (155). Inaddition, Palmer (2011) reported that disability generates extra expenses for a PWPDs than a non-disabled persons. A PWPD will have higher minimum costs needed to service their disability first, in order to be able capitalise on opportunities such as active leisure (156). Most of the participants in this study were caught in this vicious

cycle of high disability expenses first, paying bills, buying sustenance, leaving them with no extra income for active leisure. This was also exacerbated by their in-ability to make extra income to supplement their wages or disability grant for active leisure and, as a result, lived in constant non-abating economic hardships (156).

There was not much significant difference between participants who worked and those on disability grant in terms of their perception of costs of active leisure. The only noted difference was that three participants with employment owned their own vehicles, thus found moving around for active leisure less expensive than did those on a disability grant. The fourth participant who owned a vehicle acquired it before his spinal cord The other noted difference was that the extra money they had through injury. employment was used up by servicing their disability and other costs of living. The participants that managed to save money for active leisure tended to do their leisure participation in drivable distances with their motorised-wheel chairs to the near by malls or hiring their organisation's vehicle as a group to go for an active leisure outing. Those who owned vehicles tended to go to other areas for active leisure. Participants on disability grants with families who could afford to cover active leisure expenses could participate because their families tended to cover expenses locally or on holiday. There were participants on disability grants who perceived active leisure not to be a priority as their money was used to cover living expenses. Financially-related barriers to active leisure participation have been reported in literature (2)(157).

In Wilcock's (1998) view, this lack of opportunity to participate in meaningful active leisure occupations, as well as having lack of choice to active leisure, puts the PWPDs in this study in a state of occupational deprivation and imbalance (9). When viewing this with an occupational justice lens, the rights of PWPDs to access available opportunities and resources for active leisure were not available to them due to lack of resources. This social exclusion was based on their disability, which left participants in this study marginalised, socially excluded with a disintegrated sense of self and limited purpose in life. In the absence of the enabling social, economic climate, the participants in this study could not develop their potential and participate fully in active leisure occupations (158).

# 5.3.8 Summary

Participants in this study had varied perceptions of what constituted active leisure activities, however, they agreed it involved leaving the house, as they perceived there was enjoyment and renewal in being 'out and about.' Different perceived factors played a role in influencing choice of active leisure for the participants, namely their ability to engage with an activity, accessibility and affordability. Furthermore, participants placed value in social interactions with family and friends while 'out and about' with their active leisure. Some participants were not happy with the few resources available for family active leisure activities, as the time meant for enjoying the leisure activity as a family was spent on solving access issues for the disabled member. Conversely, the disabled member of family felt abandoned when not included in other family activities. One participant disliked unsolicited help from the public, as it was perceived as pity, therefore it was demeaning to him. In contrast, another participant expected help from the public, when this was not forth-coming it was perceived as an orchestration to segregate him. Lastly, some participants felt active leisure was not a priority in their lives due to lack of financial resources and extra expenses they incur to service their disability and day to day living.

## **5.4 Perceptions of Active Leisure Experiences**

In addressing Objective two, this discussion aligns with theme two, in Table 4.3, in which the participants perceived themselves as capable human beings and rejected the negative identity of disability placed on them by society. Participants in this study perceived their engagement in active leisure was influenced by the public's emphasis on their disability and what they could not do rather than on what they were able to do and enjoy. This, they felt was related to their experiences of stigma, discrimination, multiple barriers, lack of accommodation and support from the wider community in their quest to engage in active leisure. They reported that in general, others do not see pass their disability, which made them feel they were perceived to be a 'disability,' rather than human beings with capabilities and needs despite their apparent physical limitation. All participants in this study rejected the 'negative disabled identity' placed on them by society, a finding consistent with the Cook and Shinew (2014) study, in which the participants also distanced themselves from a discriminatory identity that only focused on their disability. Participants in the Cook and Shinew study reported they possessed

different identities in their different life domains, with disability being just one attribute of who they were as PWPDs, therefore it was not an attribute that solely defined who they were as people (159).

Shakespeare (1996) reported that PWPDs struggle to develop a positive sense of identity amongst the negative perceptions of being physically different from others, and being categorised as impaired or unable. Thus, the negative view of disability tends to result in discrimination, which originates in and is perpetuated by the public in the social environment, creating resistance to changing views and approaches to PWPDs (79). Priestley (2008) argued that these socially constructed barriers deny PWPDs the opportunities for active leisure participation, preventing them from exercising their autonomy, choice and human rights as citizens, as well as accessing social networks to develop positive and valued identities for themselves gained through participation in meaningful active leisure (55). The participants in this study, by rejecting the negative view of disability, affirm their human identity and human rights.

This finding is also in line with Gill's (1997) final stage of disability identity integration, of 'coming out.' Gill stated that this stage is when the PWPDs accept themselves as persons with a disability and with nothing to hide. This process relieves a PWPD of the internal tension of the split perceptions of self, such as the disabled self, the capable self, and the shame and discomfort experienced in the public. According to Gill, by truly accepting themselves, PWPDs are able to present their true self in the public domain (89). Swain and Cameron (1999) stated that once PWDs realise that ability and disability are separate entities, they experience a strong pull towards 'coming out,' creating a new positive self-identity for themselves. Once out, the positive self-identity and internal tension about being disabled are resolved, they are able to view their disability as a limitation, but not something of which to be ashamed (160).

Additionally, participants in this study placed strong emphasis and value on being able to be in control of their active leisure activities and their lives, as can be noted in Table 4.3. Participants reported they wanted to choose what active leisure activities to participate in and take control, if given the opportunity, with supportive environments. Participants perceived themselves as being capable and enjoyed solving challenges. Moreover, having opportunities to participate and achieving goals was important to them

and a good motivator to engage, as they did not want to struggle all the time to have full participation. This was consistent with the Self-determination theory, which stated that the need for 'autonomy' requires satisfying to maintain one's motivation for optimal functioning as a human being (83). The participants placed value on autonomous actions to participate and achieve their active leisure goals.

# **5.4.1 Summary**

Participants in this study rejected the negative disability identity placed on them by society. They affirmed and embraced the positive human being identity with their human rights. This section also highlighted participants' need to be self-determined, by being able to make decisions and being in control of their actions pertaining to active leisure and their lives.

# 5.5 Challenges to Active Leisure Participation

Discussion of Objective three, aligns with theme three, in Table 4.4, in which the participants identified factors that challenge and facilitate their active leisure participation. The participants in this study identified a number of factors, which, from their experiences, they perceived to be barriers and facilitators to their engagement in active leisure. However, the participants perceived the barriers to exceed the facilitators.

## 5.5.1 Barriers to active leisure engagement

All participants described a variety of personal and environmental barriers that restricted their participation in active leisure activities of their choice. The barriers they perceived to be most limiting to their active leisure participation were in the ICF's environmental factors of 'services, systems and policies,' which included inadequate implementation of legislation and policies, 'attitudes' of others in the social environment, human made changes to the physical environment, lack of transportation services and inadequate financial support.

# 5.5.1.1 Barriers due to inadequate implementation and enforcement of legislation and policies

The participants stated they experienced participation restriction in this area through inaccessible public physical facilities. This they attributed to the inadequate

implementation and enforcement of legislation and policies, such as the building regulation, which should ensure that all buildings for participating in active leisure were accessible to everyone. Participants noted that South Africa has some of the most progressive disability related legislation. They felt this legislation was supposed to create a climate where full participation was possible for all citizens, including those with disabilities, and should enable their self-determination in active leisure (45)(90)(127).

The South African Constitution (1996) and The Promotion of Equality and Prevention of Unfair Discrimination Act (2000), as reported in Chapter Two, forbids unfair discrimination on the grounds of disability (45)(90). However, participants in this study perceived they were being discriminated against because of their disability due to inaccessible facilities they experienced. They described this as being excluded from main-stream society due to lack of access and lack of being accommodated and, as a result, they felt they were not able to exercise their enjoyment of their human rights as PWPDs. This perceived discrimination included undermining of their dignity due to behaviour or practices that humiliated them, such as treating them as if they did not exist and denying them the freedom to participate in active leisure under enabling conditions. They perceived these limitations as a violation of the Promotion of Equality and Prevention of Unfair Discrimination Act (2000) (45). This Act clearly states that promotion of equality is the responsibility of all individuals offering services in the public or private environment. The legislative framework exists but participants explained that no one was monitoring that the relevant authorities were ensuring legislation was being implemented and nobody was being held accountable when it was not. The participants felt abandoned, even in light of the Office on the Status of Disabled Persons which appointed PWDs to represent them in parliament to oversee government implementation of policies and programmes that are designed for their benefit (127).

Reports by Sen (2005) supported the view that PWPDs perceived they were marginalised by serious barriers in both physical and social environments and their potential to develop and live a fulfilling happy life that promotes good health and well-being was limited. Although enabling policies and systems exist, when services to develop a PWPD potential are lacking or inadequate they are not able to build a life of value and effective social cohesion (155). In addition, Sen (2005) reported that when PWPDs are marginalised and forced into social isolation, firstly their rights to autonomy

are violated by limiting choice, goals and access to meaningful occupations such as active leisure. Secondly, by limiting opportunities to develop their potential to influence their life in a positive way is violated (155). These violations leave PWPDs with limited or no goals to work towards and compromises their health and well-being. Having a goal such as that of active leisure has been identified as an important predictor of leading a happy life and maintaining a subjective well-being (161).

#### 5.5.1.2 Barriers to social environment

All participants in this study identified the attitudes of the public towards them in the social environment as being negative and as a major participation restriction in their pursuit for active leisure participation. They stated a lack of understanding and sensitivity to the needs and experiences of PWPDs was a problematic barrier in the social environment, which had implications for their acceptance and belonging in the social setting as well as active leisure of a social nature. The attitudes took the form of being stigmatised, stereotyping such as ignored, pitied, ag shame, poor accommodation of their needs and talking about them with other persons in their presence.

Social classification and socially negative reactions to disability, such as stigmatisation and stereotypes was identified as one of the major restrictions to active leisure participation by participants in this study. The negative reactions from abled-people in social environments led to concerns about their social acceptance and social identity. These negative reactions resulted in the restriction of participants' active leisure. Participants in this study complained of being subjected to discriminatory and negative attitudes, which they perceived dis-empowered and marginalised them which led to them feeling socially isolated and not belonging to the broader community. They were disillusioned about the extent of their marginalisation and the lack of access to active leisure that other fellow citizens enjoy and take for granted. The social exclusion they experienced led participants to feel invisible due to their lack of opportunities for active leisure in the physical and social environments, as well as interacting with others, as reported by Lawson (2008) (162). The stigma and stereotypes which participants experience in the social environment is believed to have been created by both the medical model's view of disability (48) and cultural views of disability as being dependant, unproductive, victims or villains (8). These beliefs and myths influence how people in society perceive disability as negative and react to it (8)(48). This has cemented a negative view of disability and the idea that PWDs are incapable, pitiful and charitable (48).

Vash (2004) suggested that the stereotyped perception and belief that disability is a loss and that PWPDs are in continuous mourning of their loss, for example of their physical prowess, and therefore deserve to be pitied perpetuates negative behaviour towards them (163). These stereotypes resulted in the 'ag shame' behaviour that participants described as making them feel devalued as people, and encourages the view of them as being a burden to society, requiring constant care and charity. This public view only acknowledges the disability and what they have lost, ignoring the other attributes of PWPDs (40). The social stereotyping that participants experienced from the public behaviour assumed they were mute, incapable of comprehending or speaking for themselves, as has been described in the literature. McDougall (2006) described this stereotypical behaviour takes the form of being, excluded from the social conversation, their presence not being acknowledged, and the PWD becoming a bystander to their own narrative by default of being disabled (40). McDougall suggested that others assume a PWD is physically and mentally incapable of self-representation. process of ignoring the PWPD, the able-bodied people also lack awareness of the effects of their actions on the PWPD (40). Even though others may not be aware of their unintentionally prejudicial behaviour, their actions were felt to be discriminatory and restricted the rights of participants to participate in active leisure and lowered their selfesteem (48).

This finding of stigma and stereotyping in this study is consistent with that reported by McDougall (2006) who described the same "ag shame" stereotype (40). Coleman-Brown (2013) suggested that stigma and stereotyping was related to social categorisation in the mind of the stigmatiser and were based on the fear of acquiring a disability. This fear of disability, then leads some abled people to isolate, ignore and avoid PWPDs, assuming the problem of disability will disappear with them. This social discrimination results in PWPDs being invisible, socially excluded and denied opportunities for their personal growth and well-being (107).

# 5.5.1.3 Barriers to physical environment

Participants in this study identified access to the natural environment and human made changes to the environment particularly human made changes among the major barriers that restricted their active leisure participation. All participants complained about the inaccessible physical environment. Inaccessible physical environments interfered with the participants' free choice and enjoyment of their active leisure They reported inaccessible pathways leading to the facilities, lack of activities. opportunities for independent exploration at facilities and steps as common physical barriers. Inaccessible restaurant lay out for wheelchair users, wheelchairs not fitting under restaurant tables, narrow toilet cubicles and often toilets meant for disabled users were frequently locked resulting in frustrations. Furthermore, staff at facilities of active leisure, were unaware of how to provide an inclusive experience for customers with physical disabilities. Automatic teller machines (ATMs) with easy access to disabled customer were lacking, as were disabled checkout points. Participants that enjoyed sleep-overs as a form of active leisure found holiday accommodation inaccessible; this is consistent with published literature (103). It can be noted that the experiences of multiple concurrent barriers while attempting to participate in active leisure was not unique to the study participants, who described feeling overwhelmed at the level of inaccessibility they experienced. Some of the participants preferred to withdraw from active leisure participation to spare themselves the frustrations and difficulties in attempting to engage in their chosen activities.

Viewing these barriers from the ICF perspective, the participants were restricted in their right to access to activities situated in the physical environment. This meant participants had little or no meaningful participation in their leisure pursuits, being denied their right to access and social participation to active leisure activities situated in the physical environment (1). These results support other research, for example, Hammel, Magasi, Heinemann and Gray (2015) reported inaccessible restaurants, arguing that, lack of compliance of businesses to non-discrimination and social inclusion laws acts as barriers to active leisure participation (103). Cawood and Visagie (2015) highlighted the inaccessible public buildings and steps as a barrier to participation (42), and Carpenter, Forwell, Lyn and Jongbloed (2007) reported on inaccessible hotels and motels (73).

Mafhala (2009) identified weaknesses in the implementation of regulations to ensure that the design and construction of buildings complied with the National Building Regulations Part S, which requires that building accessibility be ensured. The weaknesses were attributed to non-legal enforcement of National Building Regulations Part S, and poor internal monitoring and cross-checking exacerbated the exploitation of the legislation meant for enabling equal access for all citizens in South Africa. This has negative consequences for the disabled users of these buildings. The participants, as in this study, perceived that this lack of access to the built environment emphasised their disabilities, which indirectly, communicated to them that they were not welcome (164).

Jaeger (2005) argued that access to the physical environment should ensure PWPDs are included in the utilisation of the physical environment. They should have equal unhindered opportunities as others citizens, and this requires the removal of discriminatory practices that hinder inclusive experiences of access to the built environments (48); inaccessibility to these physical environments for active leisure was a violation of PWPDs rights to participate in their desired active leisure activities. According to UNCRPD, of which South Africa is a signatory, Article 2 states that member states must take appropriate and reasonable measure to accommodate PWPDs. The state should take reasonable action to ensure that public authorities, businesses and facilities offering services for public use, such as those for active leisure, identify and remove barriers that interfere with PWPDs enjoying the same human rights as other citizens. Moreover, Article 2, recommends universal design obligation to enable accessibility of products, services and built environments, as well as requiring that information is accessible to everyone on an equal basis (39)(162).

The Convention's Article 2, provides that reasonable accommodation is subject to a defence of undue burden, suggesting that the burden of introducing reasonable accommodation will be greater in developing countries than in developed ones. This is a confusing situation where the UNCRPD mandates for reasonable accommodation but relieves some member states and businesses in terms of financial support for implementation, because they put forward the hardship of accommodating PWPDs in mainstream society (39)(162).

When access needs are addressed from a perspective of Whole-life approach, access needs of all citizens are considered. This approach is interlinked with universal design and utilises the universal design principles in designing products, systems and services for the usage of citizens who are in need of access throughout their life-span; it encourages social interactions of everyone who has access. The Whole-life approach allows parents pushing prams, shoppers pushing trolleys, senior citizens, PWPDs, occupational health to access with the reduction in stigma and stereotypes (119). South Africa ratified the UNCRPD in 2007, thereby committing to the utilisation of universal design principles as mandated by the convention (39).

# **5.5.1.4 Barriers to transportation**

Lack of affordable disability-friendly public transport was highlighted as one of the major problem that limited access and participation in active leisure by all participants. Although transport is covered under the 'product and technology,' the transportation barrier is discussed under 'services, systems and policy.' Participants using wheelchairs highlighted the problem as lack of accessible loading of both push and motorised wheelchairs within the public transport services; exceptions to this were the four participants who owned their own vehicles, Rea Vaya and Gautrain. However participants identified Reya Vaya pick up points and routes as being far from where they resided. Distance of pick up points was highlighted as a barrier to the utilisation of Rea Vaya for PWPDs in the Check Point (2019) show (165).

A commonly reported problem was taxis. Some participants shared that taxi drivers do not stop when they notice their disabilities. Both drivers and other passengers complain that they take long to board the taxis, which creates discomfort for PWPDs. This finding is consistent with Cawood and Visagie (2015), Lister and Dhunpath (2016) and Coulson, Napier and Matsebe (2006) who described taxi operators as profit driven, therefore PWPDs are avoided because of the extra time required to board a taxi, which compromises their profit margins for the day (42)(94)(108). Lister and Dhunpath reported that it may take 15 to 20 minutes for a PWPD to board a taxi, depending on the level of assistance required (108). In the absence of reliable accessible transport for PWPDs, hiring a private vehicle as a transport option was also reported to be expensive and beyond the means of all the participants. This finding was consistent with that of

Cawood and Visage (2015), who reported on the burden of high private transportation costs for PWDs (42).

The inaccessible public transport service left most participants feeling distressed and disillusioned at this lack of inclusion in main-stream society. They felt marginalised and isolated resulting in restricted active leisure participation, with the exception of those with own vehicles. The domain of systems, services and policy is overarching and supports participation in active leisure in other environmental domains with an inclusive transportation system, which would allow PWPDs to move from one area to another to to perform their active leisure. However, in-adequate implementation and monitoring of legislative mandate and policies disadvantages PWPDs, in that adequate inclusive public transport system was not in place for all to use (103). This finding is in line with other studies by Maart, Eide, Jelsma and Loeb (2007), who all found transportation for PWDs to be a barrier in urban areas (101). Similarly, Carpenter, Forwell, Jongbloed and Backman (2007), Cawood and Visage (2015) and Visage, Eide, Drystad and Manna (2017) found transport services to be a major barrier to participation by PWDs (42)(43)(73).

Some participants identified the accessibility of aeroplanes as a barrier to their active leisure participation. This was reported as a problem, especially during boarding of the aircraft, as sleeper/aisle chairs were frequently used. Once transferred from their wheelchair into a sleeper/aisle chair, the participants reported feeling loss of control, anxiety and discomfort. On board the aircraft, the seat allocation was also identified as a humiliating experience, especially when placed in the middle or aisle seat, as other passengers had to climb over them to get to the toilets. Two participants reported that some airlines have regulations that require a PWD to fly with a care-giver, which participants perceived as a barrier to their active leisure participation. In contrast, one participant reported being allowed to travel alone by the airline he uses, and is assisted by the PAU from the time he checks in, to disembarking the aircraft. inconvenience he reported was that sometimes he would find at check-in that the PAU had not been booked to assist him. However, the participants who were required to travel with a carer felt that airlines should be consistent with similar rules for everyone who is disabled. Most participants who travel by air felt this rule imposed extra costs on their already constrained financial resources. In most cases, they had to abandon their active leisure air travel plans, as they could not afford it, resulting in participation restriction. This finding was supported by the Darcy (2007) study in which he highlighted the airline boarding practices as discriminatory, leading to loss of independence of the participants once transferred into a sleeper/aisle chair. When participants were also separated from their wheelchairs, this made them loose dignity and confidence and was a disembodied experience (166).

The lack of reliable affordable and accessible public road transport services and airline practices were perceived to be discriminatory against PWPDs and contravened the UNCRPD, the South African Constitution and the Promotion of Equality and Prevention of Unfair Discrimination Act (2000). Fredman (2008) argued that these patterns of ineffectiveness and discrimination in the application of legislation and policies promote inequality in service delivery, which lead to unchanged discrimination and social exclusion of PWPDs (167). Participants in this study wanted to use an accessible public taxi or bus, just like other citizens, and be allowed to fly alone if capable to do so.

There is a perceived political will to create an inclusive environment in South Africa (94)(168), however according to the participants of this study, the benefits of this political will were not filtering down to the physical and social environments where PWPDs need to participate in their chosen active leisure activities. The study highlighted that participants in this study who participated in active leisure in Gauteng faced marginalisation and appears to be expected to deal with the challenges on their own.

## 5.5.2 Facilitators of active leisure participation

Participants in this study identified some facilitators, which they perceived facilitated their meaningful engagement in active leisure.

## 5.5.2.1 Consultation to support active leisure engagement

Participants in this study valued being consulted about assessment of accessibility of facilities for active leisure, and being able to provide input. They felt it was important that the accessibility to facilities and product delivery of active leisure during the planning, development or alterations stages were guided by their experience of the usage of the particular facilities. They perceived being consulted as a sign of being

included in mainstream society for their active leisure participation. In the Kadir and Jamaludin (2012) study, access audits and accessible usage of a facilities was determined by PWDs according to their satisfaction and enjoyment in the utility of the facilities (169).

# 5.5.2.2 Disability friendly facilities

Participants in this study reported there were some disability-friendly active leisure facilities that were accessible to them. The staff within these facilities were aware of their needs and could anticipate and remove barriers before the participants encountered them. The participants reported that these were their preferred facilities which enabled their active leisure participation. The participants described preference for undisturbed flow of active leisure enjoyment, and for being in control without barriers or negative feelings and attitudes robbing them of enjoyment. This is in line with Hutchison, Abrams and Christian (2007), who suggested that PWPDs shield themselves from being disappointed, devalued and from feelings of low self-esteem by avoiding facilities or situations that were not accessible to them (170).

# 5.5.2.3 Personal transportation

Owning and being able to drive their own vehicle or motorised wheelchair were perceived to be facilitators to their active leisure engagement. The few participants who owned vehicles described greater independence in performing their active leisure, as they were able to drive themselves to their desired destination. They stated that this eliminated the transportation problems that most PWPDs face in Gauteng. Participants acknowledged they were very grateful for this facilitator for their independent participation. This finding is supported by Carpenter, Forwell, Jongbloed and Backman (2007), where satisfaction with transportation and greater social activity participation were correlated with owning your own vehicle (73). Participants who drove their vehicles or were able to hire a vehicle from the organisations in which they worked, mostly complained of violations of disabled parking spaces at the active leisure facilities. Those who did not own a vehicle, mostly complained of lack of transportation services for PWPDs, and appeared to be stuck and isolated. The non-vehicle owners in the Carpenter, Forwell, Jongbloed and Backman wanted increased accessible bus schedule, and convenient stops and routes (73). Nine participants in this study reported they were able to hire or make use of disability-friendly transport provided by their employers or the facility in which they worked or stayed, however some indicated they could not afford to hire it alone, only when there was a planned group active leisure. They valued this as it provided transportation access to their active leisure facilities.

# 5.5.2.4 Company of good friends and family

The company of good friends and family was also seen to be important and a good facilitator to active leisure. Participants perceived that it was important to be among their friends and family and other people, as this gave them a sense of belonging with them during their active leisure participation, thus satisfying the need for relatedness. This is consistent with the Self-determination theory, which states that the need for relatedness is required to be satisfied in maintaining one's motivation for optimal functioning as a human being (160). Iwasaki and Mannell (2000), through their leisure belief, found that to cope with stress PWPDs would seek the company of good friends for support and to share their experiences (71).

## 5.5.2.5 **Summary**

Participants identified environmental barriers in natural 'product and technology,' 'environment and human made changes to the environment,' attitudes of others and services, systems and policies to their active leisure participation. Inconsistency in the application of 'services, systems and policies was perceived to make them stuck, restricted in their participation and limited in their activity choice. Participants perceived that even with the presence of enabling legislation they were being discriminated against through the barriers they were experiencing in their pursuit of the active leisure. Their perception of inadequate implementation of legislation meant they were unable to find enjoyment in their active leisure participation in areas they identified as containing major barriers to their participation. These areas included deeply entrenched negative views of disability in society, which acted as a barrier to their enjoyment of their active leisure activities. These negative views of disability, coupled with inaccessible physical environments, reinforced their disability and the perception of persons to be pitied by 'ag shame.' This 'ag shame' stereotype left participants feeling dis-empowered and socially unaccepted. Inaccessibility to the physical environment was perceived as a major barrier. Participant saw this as a discriminatory sign that said to them, they were not welcome. For some participants this created feelings of anger, frustration, feelings of being rejected by society, anxiety of not being in control of their actions and the idea of not being considered part of the greater human race. Others felt a loss of motivation and saw no point in attempting to participate in active leisure due the number of barriers they had to negotiate, which made active leisure just too hard.

Reeve (2002) stated that negative feelings are the typical psychological emotional responses to physical and social environmental exclusions experienced by participants in this study (171). The inaccessibility made the participants feel devalued, not welcomed and not belonging with others in public or private environments (171). This resulted in participants having low self-esteem and caused some to withdraw from participation (170). Participants reported not being able to feel positive about themselves and what they were able to achieve, their ability to choose and be in control of their actions were all denied by the physical and social barriers they encountered.

Transport was also identified as one of the major barriers that marginalised, isolated and restricted participants from their active leisure participation. Even with the presence of reasonable accommodation in some areas of transportation services, such as Reya Vaya and Gautrain, these were not accessible to the majority of PWPDs in this study, leaving them profoundly under-serviced in the public transport sector. This was echoed by other published research in the Southern African region by Visagie, Eide, Drystad and Mannan (2017) and Banda-Chalwe, Nitz and deJonge (2014) (43)(162). Finance was also identified as a barrier by the participants as it played a major role in what active leisure activities the participants could participate.

This study revealed that some participants utilised facilitators to active leisure participation, which enabled them to obtain meaningful engagement with some of their participation. These meaningful engagements were facilitated by their ability to own and drive their vehicles, or owning a motorised wheelchair. Participants also placed value in their awareness of accessible facilities for active leisure as well as socialising with their good friends while doing their active leisure participation. Lastly being consulted to give input on experienced audit of accessibility of active leisure activities and facilities was perceived as valuable to the participants' inclusion.

# **5.6 Limitation of Study**

Though the population consisted of a wide range of participants with different physical disabilities, the drawn sample was small which is typical of qualitative research. Additionally, the inclusion criteria for this study excluded other forms of disabilities, thereby limiting the understanding of how the challenges and facilitators of active leisure participation affected them. Furthermore, 54% of the sample were from assisted living organisational environments, therefore, may not represent the majority South Africans with physical disabilities living in their own homes in their communities. In light of these limitations, caution should be exercised in the interpretation of the results.

#### 5.7 Conclusion

This chapter has discussed the findings of the data collected from the focus groups and in-depth interviews. The data highlighted that for active leisure to be meaningful, it had to be achieved by participants leaving confined, isolating and stressful spaces, such as the house or work environments, to get 'out and about' in search for changes of scenery, open spaces or being adventurous and going abroad. However, from escaping confinement, the data demonstrated that participants encountered multiple barriers to their active leisure participation, thus having their human right to equal access and participation violated. The barriers were expressed as experiences of prejudice, stigma, stereotypes, lack of understanding of disability and discrimination emanating from the social-cultural environment and lack of opportunities to participate in active leisure in the physical environment. This was compounded by lack of adequate policy and services application. The data revealed that in the context of impairment and disability, the participants felt they were not the disability they were perceived to be, they were human beings with same needs as the broader society and these needed to be addressed. They ascribed value to being consulted to give input on barriers to their active leisure participation. Participants also identified facilitators to active leisure participation which included owning your own vehicle, motorised wheelchair, having access to some participants' organisation's accessible vehicle, known accessible facilities for active leisure and the company of good friends and family.

Some of these barriers are not unique to this study or to the South African situation, such as discrimination, social and physical barriers and social exclusion. This research

is, however, the first to enquire on the lived experiences of active leisure of adult PWPDs in South Africa. The findings indicated that participants' rights to access were not upheld, they were, socially excluded and their active leisure was marred with multiple barriers despite the presence of enabling legislation.

## **CHAPTER 6**

# **CONCLUSION OF STUDY**

#### 6.1 Introduction

This chapter reports conclusion of the main findings of this study. The two research questions that were explored were: What factors do PWPDs believe challenge or facilitate their choice of active leisure activities? What are the perceptions and experience of their active leisure in Gauteng? The main findings that address these two questions will be summarised according to the three objectives set to guide the study.

# 6.2 Objective One

# To explore and determine the views of PWPDs understanding of active leisure participation

The qualitative data showed that participants in this study viewed active leisure as desirable and beneficial to their health and well-being. However, for some participants active leisure was just a 'pipe dream,' because although desirable, it had a financial demand beyond their personal resources. Even so, most participants valued getting away from mundane, confining living and work spaces to go and experience something that was meaningful and rewarding to them. The act of escaping to their chosen active leisure activity enabled them to re-discover their depleted meanings in the mundane routine of daily life, to de-stress, thus allowing them to re-focus and cope better with their daily challenges. Most participants valued social companionship of active leisure with friends (disabled or abled) and family for social interaction in the broader community. The range of activities varied based on resources and personal interests, and capabilities which is in keeping with literature.

## 6.3 Objective Two

# To explore the perceptions of PWPDs about their experiences of their active leisure participation

The qualitative data showed that all participants perceived their active leisure participation to be impacted by their disability which they could not hide from the environment. A negative disability identity was a constant companion gained from the physical barriers, stigma and stereotyping they experienced. Participants reported struggling to build a positive active leisure identities for themselves as capable

individuals. In view of this, participants strongly rejected being perceived as a 'disability,' preferred to be embraced in a collective human being identity with different capabilities, identities and needs. In this way, participants in this study wanted to be viewed in a positive light and participate in their communities and society with a positive identity and image with which they were happy. This highlighted that they had the same needs and desires for active leisure as other citizens, and their needs were of equal importance, and was part of their human rights.

This perception of their human identity also revealed that the experiences of participants were multidimensional, involving experiences with their own disabilities which required servicing first. The experiences of active leisure required access facilitators to enable full participation, and the experiences of meaningful engagement enabled the development of an active leisure identity to maintain health, well-being and a joyful life. Thus, for PWPDs as human beings possessing emotions, positive engagement with their active leisure activities facilitated positive happy emotions and satisfaction, suggesting having an effect on their health and well-being. Conversely, lack of, or intermittent access to their active leisure caused participants to experience negative emotions of anger and rejection, constant anxiety that something will go wrong and loss of motivation to participate. Participants perceived that South Africa has a good legislation, but their rights as PWPDs were not realised because of inadequate implementation and monitoring which eventually affected them in their pursuit to access active leisure resources. The state, PWPDs, businesses and facilities that offer active leisure activities need to address problems encountered by PWPDs, as illustrated in this study, in a multidimensional and co-operatively manner, if ideals of UNCRPD of full participation of PWPDs in society are to be realised (39).

# 6.4 Objective Three

# To identify factors that challenge or facilitate participation of active leisure participation on PWPDs

The findings from the qualitative data yielded both challenges and facilitators to active leisure participation. The challenges experienced by the participants pertaining to active leisure showed participants struggled to obtain access to active leisure activities located in certain physical environments. Negative attitudes and stigma located in the

social environments caused some participants to be isolated and dis-empowered. The challenges are indicated below.

# 6.4.1 Barriers to active leisure participation

Participants perceived that even though there are legislation and policies to enable their inclusion in active leisure participation, these were not adequately implemented nor monitored to their advantage.

All participants reported experiencing negative social altitudes in the form of stigma, stereotyping, being objects of pity 'ag shame,' and being perceived as charity cases. These attitudes were shown by the general public, service providers, bus drivers, taxi drivers and staff at facilities of active leisure. These attitudes stemmed from the influence of the medical model, the human need to categorise and cultural beliefs of disability. Such attitudes persist because there is no visible investment in co-ordinated disability awareness campaign strategies carried out by the state, disability organisations and the media at provincial or national level, to make the public aware of the rights of citizens with disabilities. More importantly, media needs to portray a positive image of PWPDs or the consequences when these rights are not being upheld.

The lived experiences of PWPDs in this study revealed participants experienced challenges in physical environments, such as encountering steps, cobbled pathways, poorly designed ramps, poorly designed restaurant layouts and furniture, locked disabled toilets and lack of disabled service points. Furthermore, mis-representation of accessibility of accommodation facilities was a common experience. To the participants these were a constant reinforcement of their disabilities and a sign they were not welcome. The physical barriers often interrupted their enjoyment of the active leisure, resulting in restricted, incomplete participation or total exclusion of active leisure participation. This treatment isolated and dis-empowered them.

Lack of affordable, accessible public road and air transport were other areas the participants found to be a major barrier that marginalised them from achieving their active leisure participation. The lack of reasonable accessible public transport that could load wheelchairs made them feel they were not considered as valuable citizens. They acknowledged Rea Vaya and Gautrain, but perceived the distance for the pick-up

routes to be inaccessible to them. Airlines were identified as inconsistent with their rule application, inaccessible in the handling of some disabled passengers and some passengers with disabilities were required to fly with a carer which made air travel expensive for them.

Finance was another area which all the participants perceived to be a barrier to their active leisure participation. Participants with employment perceived that living with a disability was expensive, thus they had to service their disability first, pay bills and buy the necessary sustenance before they could think of active leisure. Participants on a disability grant felt the grant money was too little to cover their sustenance and active leisure whilst others who had families that could afford it, had some of their active leisure expenses covered. The participants who could afford to save, tended to undertake their active leisure in the nearby malls, zoo and botanical gardens.

This study was framed on the rights-based approach. The right to full access for PWPDs is protected by the South African Constitution (1996), the Promotion of Equality and Prevention of Unfair Discrimination act, the National Building Regulations and Building standards Act (1977) Part S and the UNCRPD. Article 30 of the UNCRPD affirms that signatories state responsibility to ensure PWDs access to "participation in cultural life, recreation, leisure and sport" p 22 (39). The UN convention also calls for universal design of environments and products. Products and environments that are poorly designed disable all citizens and marginalise them (172), hence the need to address challenges faced by PWPDs from a Whole-life approach and design for all, so that anyone who needs access benefits.

## 6.4.2 Facilitators to active leisure participation

Participants also identified facilitators to active leisure participation including owning and driving your own vehicle, motorised wheelchair or hiring the NPO's accessible vehicle for which some participants worked. These modes of transportation gave them greater freedom to move around and reach active leisure activities located in other areas. The company of good friends and family were also identified as a valued facilitator for active leisure for most of the participants. This was important for them for sharing the enjoyment of the activities with others and supported by them. Another important facilitator, was participants' awareness of accessible facilities, as well as staff at these

facilities being aware of the needs of PWPDs. This was identified as an important facilitator to full active leisure participation, so participants did not have to struggle with access to their chosen active leisure activity. It also enabled participants to just concentrate on the engagement with the active leisure without being anxious or worried that something will go wrong or they will not be able to finish their active leisure activity. Lastly participants valued being being consulted by relevant stakeholders, they saw this as a facilitator to their full participation in their active leisure participation.

#### 6.5 Recommendations

The study has indicated that participants with physical disabilities in this study struggled to access and engage in inclusive active leisure participation because of the encountered violations of their human rights to access in the social-cultural and physical environments. Even though some of these barriers are known in literature, they were perceived to being addressed inadequately.

- The nature of environmental barriers encountered in different environmental domains by the participants in this study, suggest that research should be carried out to develop an intra-sectoral strategy to address these barriers.
- 2. This study only targeted PWPDs, therefore further research is needed with other types of disabilities to understand how challenges and facilitators to active leisure participation affects their active leisure participation.
- 3. This study was carried out in the urban areas of Gauteng, therefore it would be interesting to compare the findings with research of PWPDs or other disabilities in rural areas, where their challenges and facilitators to active leisure participation may be different.
- 4. In addition there seemed to be a misconception between facilities that offer active leisure activities and PWPDs on what constitutes to be a disability friendly environment, or what PWPDs perceive acceptable reasonable accommodation for them in the domains they encounter barriers, hence further research pertaining to this needs to be conducted.

5. The data showed that participants experienced barriers due to people in mainstream society lacking disability awareness. Even though there is a dedicated time allocated once a year for disability awareness, activities are mainly carried out by individual organisations representing PWDs once a year. Raising awareness is in line with the mandate of the UNCRPD. Article 8 of the Convention calls for raising awareness within the broader society's mainstream to assist in combating prejudice and negative attitudes.

This study recommends that the disability stakeholders, the South African Disability Alliance, DPSA, Gauteng Provincial Association of Persons with Disabilities, PADI and government form a panel to deal with disability awareness in a co-ordinated manner. Disability awareness campaigns should be delivered through print, television and social media and promote inclusion of PWDs and their positive aspects, to change the perception, stereotypes and prejudicial beliefs against PWDs, encourage celebration of our humanity and diversity as human beings and preserve the dignity of PWDs. Others to be targeted should be businesses and facilities, that offer active leisure services for public and private use, travel agents, airlines and airport companies, government departments such as the city council building regulations and transportation services on the rights of PWPDs as citizens requiring access and on how to offer an inclusive participation experience.

6. Lastly, a disability discount scheme should be introduced, similar to pensioner's discount, to alleviate the burden of extra costs incurred by disability thus enabling PWPDs access active leisure activities. For example, these could involve free entry on certain days to National Botanical Gardens, as offered to pensioners, and other facilities of active leisure or a discounted fee on any given day. Another example would be to offer a clustered discounted active leisure product that offer PWPDs quintessential active leisure experience, such as a discounted cinema ticket and a meal at a restaurant. These discounts need to be advertised and PWDs should be aware of them without having to ask for them. The process of asking and waiting for discounts to be approved, can be a source of barrier to active leisure participation. For example, most businesses in South Africa have membership cards used to attract customers to their businesses with discounts,

disability discounts could be embedded in these customer discount cards. It is hoped that providing discounts for PWDs will stimulate inclusive participation for them to engage in active leisure more often and be visible in mainstream.

#### **6.6 Practice Implications**

Full participation in occupations, including active leisure is what Occupational Therapy strives to achieve (173). Thus, active leisure enables PWPDs to develop competence, necessary social skills, social networks, social support for inclusion and belonging to their community, maintaining health and well being (160), as well as leading a life of meaning (22). Literature has shown that, the largest share of therapy time is dedicated to addressing competent performance of activities of daily living (ADL) because of the constraints of rehabilitation time in hospital and this may not be adequate to address the needs of PWPDs to participate fully in their communities or society after rehabilitation has been terminated (18)(21)(174).

Hammel, Magasi, Heinemann and Gray (2015) reported that environmental factors influence participation at all levels, the personal level (micro), community level (mesa), and societal level (macro), not just the individual level (micro) of which ADLs (activities of daily living) are targeted by the bulk of rehabilitation. This current study has highlighted that the participants with physical disabilities struggled to participate fully in their active leisure, in their communities, to rebuild their previous or establish new active leisure activities. Most participants were overwhelmed and unaware of how to navigate and deal with the environmental barriers they were encountering.

In view of this, there needs to be a strong continuation of rehabilitation from tertiary to primary health-care rehabilitation. The Occupational Therapy goals at primary health-care level need should align with The Framework and strategy for disability and Rehabilitation in South Africa (20), to include community and societal engagements for active leisure and problem solving, as it is in these areas that meaningful occupations are carried out and PWPDs can exercise their human rights as productive citizens. The current Occupational Therapy focus at primary health-care level in South Africa needs to be researched to determine its impact in community inclusion and active participation of PWPDs.

If the active leisure participation of PWPDs is to be realised, Occupational Therapists need to embrace active leisure fully, as meaningful is derived through participation and leading a joyful life from active leisure participation in an individual's community and creating an active positive self-identity. It is through social environments that a person truly discovers who they are and their capabilities. Through that, they are able to develop their social potential by exercising their right to accessing meaningful and enriching diverse occupations in their communities as well as the larger mainstream South African society (25)(158).

#### 6.7 Policy implications

The results of this study have shown that participants with physical disabilities in this study are yet to see the benefits of full participation in active leisure in their communities and society. The lived experiences of all participants in this study showed they experienced participation restrictions, were marginalised and socially excluded due to lack of services, such as accessible public transport and opportunities, and barriers to social and physical environments to participate in their active leisure. Participants perceived that legislation was not making it easier for them to participate to the extent that it should, as narrated by Participant 8, "So if the laws are making it easier for us it would be just so much nicer." Neille (2013) suggested that the social-cultural and political environments determine the lived experience of all citizens (175). This study recommends that the South African government should:

- Re-assess implementation and monitoring strategies of service provision policies that impact the lives of PWPDs.
- Implement accessible public transportation system that is accessible to the majority of PWPDs and closer to where they live, as this is their right and is in line with UNCRPD.

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### APPENDIX A: DEMOGRAPHIC QUESTIONNAIRE

1.5 widowed

<b>DEMOGRA</b> before focu				(to	be	filled	in	after	signing	consent	letter	and
1. Gender:												
	Female	Male										
2. Age:												
3. Type of	Disabilit	:y				Тур	e c	of Mo	bility aid	i		
4. What is		arital stat	us;									
1.1 Marrie	ed											
1.2 Separa	ated											
1.3 Single												
1.4 Divorc	ed											

5.	Curre	nt en	ıploy	/ment
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8000 - 10000 11 000 - 15 000 15 000 - 20 000

1.1 Full time Job			
1.2 Part time job			
1.3 On disability Grant			
1.3 On disability Grant  6. How much do you earn per mo	onth?		
<u> </u>	onth?		
6. How much do you earn per mo	onth?		

7. Hov	<i>m</i> anv	people	do	vou	support	on	vour	salarv	/?
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### 8. What percentage of your earnings do you spend on?

1.1 Food	
1.2 Transport	
1.3 Clothing	
1.4 Paying Bills	
1.5 Entertainment	

1.6 Going on Holiday	
1.7 Savings	
1.8 Extended Family	
1.9 Emergencies	

### **APPENDIX B: FOCUS GROUP QUESTIONS AND PROMPS**

- 1. When you think about active leisure activities, what is the first thing that comes to mind?
- 2. Why is it important to you to perform active leisure activities?
- 3 Have you done any active leisure in the last 24 months in Gauteng?

#### Promps

Gold Reef City	Johannesburg Botanical Garden
Ceasers Palace	Pretoria Botanical Garden
Monte Casino	Wild Waters Park - Boksburg
Union Building - Pretoria	Zoo Lake
Soccer City Stadium	Dinokeng
Ellis Park	Craddle of Human kind
Johannesburg Zoo	Walter Sisulu National Botanical
	Garden
Pretoria Zoo	Hartbeespoort dam
Parks: Suikebosrand	Museum - Johannesburg
Rietvlei	Museum - Pretoria
Krugersdorp Game Reserve	Apartheid Museum
Private Game reserves	Constitution Hill

**APPENDIX C: PERMISSION LETTER TO NPOs** 

Dear Manager,

Re: Permission to access your database for people with physical disabilities for

their participation in a research study through focus group to identify their

experiences and opinions regarding active leisure.

Greetings to you. I am a post-graduate student registered for MSc degree at the

University of Witwatersrand, in the Faculty of Health Science, School of Therapeutic

sciences, Occupational Therapy Department. My supervisor is Prof. P. De Witt

The title of my research is: "Factors affecting participation in active leisure

activities by people with physical disabilities"

The aim of the focus group is to better understand why only a limited number of people

with physical disabilities participate in active leisure. Participation in focus group

discussion is voluntary and anonymous and information obtained is confidential and

none of their personal information will be passed on to a third party or used in the final

report. Participants will be required to sign an informed consent sheet before each focus

group discussion.

There are no risks involved in participation and their participation, opinion and views in

the focus group is very important to the research success. All focus group discussions

will be grouped together to get the answers to the research question.

For further information contact my supervisor Prof. P. De Witt 011 717 3701

Thanking you in advance for your valuable assistance.

Your Sincerely,

**Esther Keats** 

Occupational Therapist

MSc. Student,

School of Therapeutic Sciences, Faculty of Health Sciences,

University of the Witwatersrand, Johannesburg

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APPENDIX D: LETTER TO POTENTIAL PARTICIPANTS WHO MET THE CRITERIA

Greetings to you

I would like to invite you to participating in a focus group about active leisure activities. I

am Esther Keats, a post-graduate student registered for a master's degree in

Occupational Therapy at the University of the Witwatersrand, Faculty of Health

Sciences. As part of the masters study;

The title of my research is: "Factors affecting participation in active leisure

activities by people with physical disabilities"

The aim of the research through focus group is to better understand why only limited

number of people with physical disabilities participate in active leisure.

Participant in focus group discussion is voluntary and anonymous. Confidentiality within

the focus group cannot be ensured. However, what is shared with the researcher will

be treated with confidentiality and none of your personal information will be passed on

to a third party or used in the final report. Participants will be required to sign an

informed consent before each focus group discussion.

There are no risks involved in participating and your participation, opinion and views in

the focus group is very important to the success of the research. All focus group

discussions will be grouped together to get the answers to the research question.

Feedback on the results of the research will be provided if requested.

If you agree to participate, please send me an sms / whatsapp on: 072 313 9095.

If you require further information, contact my supervisor Pro. P. De Witt on 011 717

3701.

Yours Sincerely,

**Esther Keats** 

Occupational Therapist

MSc. Student

School of Therapeutic Sciences, Faculty of Health Sciences,

University of the Witwatersrand, Johannesburg

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### APPENDIX E: CONSENT FORM TO PARTICIPATE IN FOCUS GROUPS

### **INFORMED CONSENT FORM**

I the undersigned hereby
agree to participate to in a focus group discussions about "Factors affecting
participation in active leisure activities by people with physical disabilities" My
participation is voluntary and I am free to withdraw at any time.
I confirm that,
<ul> <li>I have been informed that confidentiality in a focus group discussions cannot be</li> </ul>
ensured.
<ul> <li>The aim of the research has been explained to me</li> </ul>
Signature: Date

### **APPENDIX F: CONSENT FOR AUDIO TAPING**

### **CONSENT FOR AUDIO RECORDING**

l	the undersigned hereby
agree focus group discussions about "Fa	ctors affecting participation in active
leisure activities by people with physic	cal disabilities" and my contribution being
audio taped.	
Signature:	Date

### **APPENDIX G: ETHICAL CLEARANCE CERTIFICATE**



R14/49 Mrs Esther Keats

# HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE NO. M131035

NAME: (Principal Investigator)	Mrs Esther Keats
DEPARTMENT:	Occupational Therapy Medical School
PROJECT TITLE:	Factors Affecting Participation in Tourist Leisure Activities by People with Physical Disabilities
DATE CONSIDERED:	25/10/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Patricia de Witt
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	06/12/2013
This clearance certificate is va	alid for 5 years from date of approval. Extension may be applied for.
DECLARATION OF INVESTIGA	ATORS
Senate House, University.  I/we fully understand the condition  research and I/we undertake to econtemplated, from the research	ons under which I am/we are authorized to carry out the above-mentioned ensure compliance with these conditions. Should any departure be a protocol as approved, I/we undertake to resubmit the agree to submit a yearly progress report.
Principal Investigator Signature	Date
PLEAS	E QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES



## HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

26 September 2019

Ms E Keats School of Clinical Medicine Department of Occupational Therapy Medical School University

Sent by email to: 501581@students.wits.ac.za

Dear Ms Keats

Re:

Protocol Ref No: M131035

Protocol Title: Factors affecting participation in active leisure activities by people with physical

disabilities

Principal Investigator: Ms E Keats

I note that on 16 May 2019 the Faculty of Health Sciences approved an amendment to your study title, as reflected above.

Your ethics clearance expired on 5 December 2018.

Thank you for keeping us informed.

Yours Sincerely

Mr I Burns

For the Human Research Ethics Committee (Medical)

Research Office Secretariat:

Physical address: Phillip Tobias Building, 3<sup>rd</sup> Floor, Office 302, Corner York Road and Princess of Wales Terrace, Parktown, Johannesburg 2193.

Postal address: Private Bag 3, Wits 2050 Tel Nos. +27 (0)11-717-1234/2656/2700/1252

Office E-mail: HREC-Medical ResearchOffice@wits.ac.za.

Website: http://www.wits.ac.za/research/about-our-research/ethics-and-research-integrity/

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